University Library

MINERVA ACCESS

A gateway to Melbourne's research publications

Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:
Heffernan, Margaret Ellen

Title:
Human papillomavirus (HPV) vaccines: the attitudes and intentions of Australian health providers and parents from three diverse cultural groups toward HPV vaccination of pre-adolescent children

Date:
2011

Citation:
Heffernan, M. E. (2011). Human papillomavirus (HPV) vaccines: the attitudes and intentions of Australian health providers and parents from three diverse cultural groups toward HPV vaccination of pre-adolescent children. PhD thesis, Department of Paediatrics (RCH), The University of Melbourne.

Publication Status:
Unpublished

Persistent Link:
https://hdl.handle.net/11343/36306

Terms and Conditions:
Terms and Conditions: Copyright in works deposited in Minerva Access is retained by the copyright owner. The work may not be altered without permission from the copyright owner. Readers may only download, print and save electronic copies of whole works for their own personal non-commercial use. Any use that exceeds these limits requires permission from the copyright owner. Attribution is essential when quoting or paraphrasing from these works.

Title of the Thesis

Human Papillomavirus (HPV) vaccines: the attitudes and intentions of Australian health providers and parents from three diverse cultural groups toward HPV vaccination of pre-adolescent children.

Margaret Ellen Heffernan, OAM

Submitted in total fulfillment of the requirements of the degree of Doctor of Philosophy

August 2011

Department of Paediatrics

The University of Melbourne

Produced on archival quality paper

ABSTRACT

Australia has one of the lowest incidences of cervical cancer globally, but its disproportionate rate among Aboriginal women, the underscreening cervical practices of some cultural groups, and the high incidence of other HPV-related morbidities in the general population makes a compelling need for HPV vaccination. High coverage of prophylactic HPV vaccines in sexually naïve adolescents will substantially reduce their risk of oncogenic HPV infection, and subsequent related disease; but as the hepatitis B vaccine experience demonstrated vaccinating this cohort presents challenges for public health providers. The delivery model of HPV immunisation into Australia, which commenced as an organised national program in 2007, mirrored that of other adolescent vaccination programs and its uptake has met forecast expectations.

Prior to the introduction of the HPV vaccines the lay public globally had little awareness of genital HPV infection and its sexual characteristics and concerns were held that once this factor was known it may impact on parental consent. Very little behavioural research had been undertaken to identify determinants of acceptance for HPV vaccination in pre-adolescents among Australian parents with diverse cultural norms for a new vaccine that has potentially controversial and some unique characteristics. This thesis argued that in order for there to be widespread uptake of the HPV vaccine among targeted female adolescents in a mixed-culture nation culturally appropriate implementation strategies are needed. The research examines the attitudes of General Practitioners (GPs) and parents from three distinct cultural groups towards HPV vaccination among preadolescent children, and in particular the influence of cultural norms on parental attitudes and intentions.

Applying qualitative methods through a systematic framework approach, this thesis aimed to (i) explore the determinants that influence parental and health provider attitudes; (ii) examine those elements through a multiple perspectives lens; and (iii) identify key factors and approaches for the successful uptake to the delivery of HPV vaccines into diverse cultural

populations. To achieve these aims, a mixed-method purposive sampling strategy was applied with GPs practicing in Victoria, and Aboriginal, Anglo and Chinese-Australian parents residing in Victoria or Central Australia. The method and semi-structured interview guide explored knowledge and attitudes toward cervical cancer prevention from biomedical, structural, psychosocial and cultural perspectives.

A key finding is that socio-cultural and environmental factors do provide challenges for parents and health providers in accepting HPV vaccines in pre-adolescents. Participants demonstrated a positive attitude toward adolescent vaccination, but their attitudes reflected their normative values toward health prevention and sexuality. Their experiences were shown to influence their education resource and infrastructure needs indicating that implementation strategies for HPV vaccines cannot be generalised to cross-cultural populations. Findings from this study can begin to provide a socio-ecological basis for the development of culturally sensitive approaches to encourage HPV vaccination in the Australian adolescent cohort. The empirical findings also have significant implications for guiding its diverse population to a new cervical cancer prevention paradigm.

DECLARATION

This is to certify that:

i. With certain exceptions, this thesis comprises only my original work towards the PhD. The exceptions include:

   a) Professor Suzanne Garland contributed biomedical and epidemiological information to Chapter 2 to ensure accuracy;

   b) Field work in Victoria and Central Australia, during the preparation and conduct of which I was assisted by members of the Aboriginal Advisory Group and Aboriginal Health Workers in the modification of resources I had designed: the interview protocols and interview consent form; data collection in both regions from the Aboriginal participants; and the Memorandum of Understanding (MOU) for the Aboriginal communities which was based on a MOU designed by Peter Waples-Crowe and Priscilla Pyett of VACCHO, Victoria;

   c) The transcription of interviews. Whilst these were entirely undertaken by me (with the exception of the Aboriginal focus groups in Central Australia and Victoria) and interpreted by me, the transcription was conducted by a professional transcription service, DB Conference Services, Carlton, Victoria.

ii. Due acknowledgement has been made in the text of all other materials used.

iii. The thesis is less than 100,000 words in length, exclusive of figures, tables, bibliographies, appendices and footnotes.

Margaret Ellen Heffernan OAM

ACKNOWLEDGEMENTS

'We are as one'

The first trimester of this PhD study presented the ongoing need to justify, refine and validate one's approach to analysis and construction that at times felt like personal destruction, and a transition to 'nothingness' (Silverman, 2005:68). The implementation and completion of such a body of work demands the effort and resources of a vast number of people, often inadequately acknowledged, and thus the riches to be enjoyed at completion are equally theirs.

SUPERVISORS I am deeply indebted to my academic and field supervisors who have guided and shaped this research offering wisdom, expert guidance and support, and who have inspired me in ways that will endure. I do not underestimate the privilege I have had of working with such eminent contributors to the domain of science, medicine and public health, and who had belief in me as a researcher.

Academic Supervisors: Professor Suzanne Garland, Department of Microbiology and Infectious Diseases, University of Melbourne, Australia

Doctor Kirsten McCaffery, School of Public Health, University of Sydney, Australia

Professor Susan Sawyer, Centre for Adolescent Health, University of Melbourne, Australia

Professor Michael Quinn, Department of Obstetrics and Gynaecology, University of Melbourne, Australia

In particular, *Professor Suzanne Garland* and *Dr. Kirsten McCaffery* who have modelled what excellence in research requires, and for their wisdom, patience and forbearance;

Dr Susan Sawyer for her insights in adolescent health, securing my PhD scholarship through MCRI / CRCEH, and being a wise mentor at critical times;

Professor Michael Quinn who provoked much contemplation in me on the shape of life after a gynaecological malignancy, ‘negotiating the swamp’ (Silverman, 2005:68); for thoughtful and insightful guidance and collaboration with my women’s health projects that has been fundamental to my achievements over the past twenty years, and his introducing me to Professor Suzanne Garland that made the thesis a reality.

Aboriginal Advisory Group members and field supervisors Collectively we share the vision of contributing to the well being of women in Australia challenged by geography and scarce resources. I am indebted to them for their wisdom and guidance in good cultural and Indigenous research. I acknowledge with gratitude the assistance of the Aboriginal Advisory Group members in collecting the data.

Central Australia: Kirsty Smith, Tristate STI/HIV Project Co-ordinator; Leshay Maidment, Alukura Congress Aboriginal Medical Service; Sandra McElligott, DCHS Women's Health Educator; Tania Passey, clinic 34, Alice Springs; Julie Wright, AHW & DCHS Women's Health Educator.

Victoria: Marika Kalargyros, Senior Aboriginal Women’s Support and Education Worker, Aboriginal Women's Health Business Unit, Royal Women's Hospital, Melbourne; Kellie Loughron, Koori Maternity Services Coordinator, VACCHO; Peta Reynolds Aboriginal Programs Coordinator, Cancer Council Victoria; Papscreen Victoria.

Aboriginal Health Workers and their communities in Central Australia and Victoria

Study Participants: General Practitioners and the Divisions of General Practice, Melbourne, Victoria; and **Parents,** for their willingness to participate and freely give opinions.

Advice and Support: Centre for Adolescent Health, Parkville, Melbourne; CRCAH: Arwen Pratt, Jenny Brands, Johanna Monk, Alistair Harris; Chinese Women’s Association [Box Hill]; Dr. Monica Cooper; Ellen Margaret Daly, Florida USA; Department of Microbiology and Infectious Diseases, Royal Women’s Hospital, Melbourne , Professor Sepehr Tabrizi and Staff; Department of Paediatrics, Royal Children’s Hospital especially

Kate Bride; DHCS Northern Territory Government; Dr. Maria Pirotta; Mark Van Asten; Onemda, Prof. Ian Anderson; PapScreen Victoria; Victorian Cytology Service (Stella Healey and Dr. Happy Tang); Dr. Jeffrey Tan and Mrs Felicia Tan, Dysplasia Unit RWH, Melbourne; Kenneth Leung and Sally Mak, for Chinese community recruitment; VACCHO, especially Peter Waples-Crowe, Priscilla Pyett and Anke van Sterren.

Financial support: CRCAH: In-kind and financial support; CSL and GSK for conference travel; MCRI CCRE Immunisation Scholarship 2006, 2007; PHERT PHAA Student Researcher Scholarship 2007; Royal Women's Hospital Melbourne: Study Grant 2005, 2006, 2007.

HREC staff: Central Australian HREC; Royal Children's Hospital HREC Melbourne; Royal Women's Hospital HREC Melbourne; University of Melbourne HREC.

RMIT University, Melbourne, School of Management: Professor Lyn Bennington, Dr Keith Toh, Dr. Malcolm MacIntosh, and colleagues

Personal support: friends and family, especially the legacy of my father Jim Heffernan who died prematurely and in the midst of his prime, but who instilled in me curiosity and an enduring belief of the infinite possibilities in life, and the importance of 'carpe diem'.

…and most profoundly, John and Caity Dunne
'Raison d'etre'

for unconditional love and enduring support.

RESEARCH AND PROFESSIONAL OUTCOMES

A. PhD research funding grants:

2007	PHERT PHAA Post Graduate Research Scholarship	$ 8,000
2007-2005	MCRI Fulltime Postgraduate Scholarship per year	$23,400
2007-2005	RWH PhD Study Scholarship per year	$ 5,000
2007	CRCAH Study Grant 2007	$10,000
	CRCAH 2007, 2006	In-kind
2009	Travel Grants for IPV conference	$10,000
	PHAA Researcher Postgraduate Scholarship Award	$ 8,000
2007	Travel Grants for IPV conference	
	CSL Pharmaceuticals	$ 5,000
2006	Travel Grants for IPV conference	
	GSK Pharmaceuticals	$ 5,000

B. Publications arising from the research

Heffernan ME, Garland SM, Kane MA. Global reduction of cervical cancer with human papillomavirus vaccines: insights from the hepatitis B virus vaccine experience. *Sexual Health* 2010; **7**:383-390

Kent J, **Heffernan ME**, Silvers J, Moore E, Garland SM. The role of the nurse immuniser in implementing and maintaining the national human papillomavirus 'cervical cancer' vaccine rollout through a school-based program in Victoria. Letter *Sexual Health* 2010; **7**:391-393

Laycock, A. with Walker, D., Harrison, N. & Brands, J. 2009, Supporting Indigenous Researchers: a practical guide for supervisors, Cooperative Research Centre for Aboriginal Health, Darwin
ISBN 978-0-7340-4062-6
http://www.crcah.org.au/publications/downloads/supervisors_guide1.pdf
(Contributor and reviewer by invitation from CRCAH)

Laycock, A. with Walker, D., Harrison, N. & Brands, J. 2010, Researching Indigenous Health: a practical guide for researchers, Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (for release January 2011)
(Contributor and reviewer by invitation from CRCAH)

C. Conference papers arising from the research

1. Theme: Research approaches in vulnerable communities
Heffernan ME, Reynolds P, Smith K, Kalargyros M, Loughron K, McElligott S, Wright J, Passi T, Maidment L, Quinn MA, Sawyer S, McCaffery K, Garland SM. *Ignorance is not bliss! The importance of 'knowing' for cross cultural health researchers and advisory groups when researching vulnerable communities.* Poster presentation: Aboriginal Health Research Conference, April 29 – 30 2008, Dockside at Cockle Bay Wharf, Sydney

2. Theme: Cross cultural communication of HPV vaccines
(i) Heffernan ME, McCaffery K, Quinn MA, Sawyer S, Garland SM. *Overcoming the challenges of educating mixed culture communities about HPV vaccines.* Oral presentation: 2010 PHAA 12th National Immunisation Conference Adelaide South Australia: August 17 -19 2010

(ii) Heffernan ME, McCaffery K, Quinn MA, Sawyer S, Garland SM *Why the current communication of HPV vaccination as a cancer prevention strategy is not sufficiently educating cross cultural communities. Global strategies for successful HPV education programs*
Oral presentation at: RMIT@Asia Seminar Series, August 11 2010

(iii) Heffernan ME, McCaffery K, Quinn MA, Sawyer S, Garland SM. *Communicating HPV and vaccination to Indigenous and cross cultural communities.*
Invited speaker: '*Cervical Cancer Not Yet Beaten':* AOGIN Australia, Melbourne, Bio21 Institute Parkville, Friday July 24 2009. HPV Vaccine Forum

3. Theme: Implementation strategies for HPV vaccines in cross-cultural communities
(i) Heffernan ME, McCaffery K, Quinn MA, Sawyer S, Garland SM. *Critical Issues for HPV Vaccination in mixed culture communities.*
Oral presentation*:* PHAA 2008 11th National Immunisation Conference, Oct 8 -10 2008, Gold Coast Queensland

(ii) Heffernan ME, McCaffery K, Quinn MA, Sawyer S, Garland SM. *Issues for mass immunisation of HPV vaccine in mixed culture communities.*
Oral presentation: EUROGIN 7th International Multidisciplinary Congress, Monaco, October 4 -11 2007

(iii) Heffernan ME, McCaffery K, Quinn MA, Sawyer S, Garland SM. *Difference does matter with HPV vaccine mass immunisation programs. Critical issues in mixed culture communities.*
Oral presentation: IFCPC XIII World Congress, Auckland New Zealand October 19 -23, 2008

4. Theme: Implementation strategies for HPV vaccines in Indigenous communities
(i) Heffernan ME, Reynolds P, Smith K, Kalargyros M, Loughron K, McElligott S, Wright J, Passi T, Maidment L, Quinn MA, Sawyer S, McCaffery K, Garland SM. *HPV vaccine introduction in Indigenous communities require different approaches.*
Poster presentation: HPV2009 25th International Papillomavirus Conference, Malmo, Sweden, May 8-14 2009

(ii) Heffernan ME, Reynolds P, Smith K, Kalargyros M, Loughron K, McElligott S, Wright J, Passi T, Maidment L, Quinn MA, Sawyer S, McCaffery K, Garland SM. *Introducing sensitive vaccines requires different approaches. Lessons for international Indigenous communities.*
Oral presentation: IFCPC XIII World Congress, Auckland New Zealand October 19-23, 2008

(iii) Heffernan ME, Reynolds P, Smith K, Kalargyros M, Loughron K, McElligott S, Wright J, Passi T, Maidment L, Quinn MA, Sawyer S, McCaffery K, Garland SM.
Mass immunisation programs of HPV vaccine: how understanding the perspective of Indigenous communities will lead to optimum uptake.
(i) Oral presentation: PCC2009 Conference '*Preventing Cervical Cancer: Integrating Screening and Vaccination*' March 18 -20th 2009. Sofitel Melbourne.
(ii) Poster presentation: HPV2009 25th International Papillomavirus Conference, Malmo, Sweden, May 8-14 2009

(iv) Heffernan ME, Reynolds P, Smith K, Kalargyros M, Loughron K, McElligott S, Wright J, Passi T, Maidment L, Quinn MA, Sawyer S, McCaffery K, Garland SM. *Issues for mass immunisation of HPV vaccine in two Australian Aboriginal Communities.*
(i) Oral presentation: RANZCOG 2008 Australian Indigenous Women's Health Meeting, August 14 -16, 2008; Darwin Convention Centre, NT '*Healthy Women, Healthy Future*'.
(ii) Oral presentation: The Cancer Council Victoria Seminar Series, Tuesday May 6 2008. Co-presented with Peta Reynolds: member of the Victorian Aboriginal Advisory Group
(iii) Oral presentation: PHAA 2007 38th Public Health Association of Australia Annual Conference, Reality Check: Inequities & Health, September 23-26 2007, Alice Springs NT.

5. Theme: Psychosocial issues and gynaecological cancers
Heffernan ME, Quinn MA*. The psychosocial and psychosexual implications of gynaecological cancers*
Invited speaker: New Zealand Cancer Council, Christchurch and Greymouth NZ, September 6 - 9 2007

D. KEY COMMUNITY- BASED OUTCOMES AS A RESULT OF THE RESEARCH
Reciprocity: Central Australia:
(i) I initiated and secured $6,000 funding from the Northern Territory Department of Health and Community Services (NTDHCS) for the development of radio advertisements about HPV vaccines in five Central Australian Aboriginal languages that are broadcast to communities on CAAMA radio during the implementation of the HPV vaccine program.

(ii) Due to the strength of the relationship between Margaret Heffernan and the Advisory Group members, two AHWs (Sandra McElligott and Julie Wright) asked Margaret to secure funding for their 'Woman Health On Wheels' (WHOW) bus initiative. Funding for one bus was secured from the Federal Government Department of Health and Ageing, and $130,000 for operational costs from the NTDHCS. The WHOW bus was launched in October 2009 in Alice Springs and provides health services to women across Central Australia.

Central Australia and Victoria:
(i) Community awareness of HPV, HPV vaccine and cervical cancer issues
(ii) Education of AHWs about HPV and HPV vaccine

Research engagement:
2008 CRCAH Aboriginal Research Showcase, Parliament House, Canberra, 13 March. This PhD research was selected for the Showcase as an exemplar of Indigenous and non-Indigenous collaborative research outcomes. Co-attended with CAAAG member Julie Wright.

Chinese- Australian population During the study interviews the Australian Government HPV education resources were identified as being in Chinese traditional script by Chinese-Australian participants, whereas the majority of Chinese peoples use simplified script. After this finding was shared at the 2008 PHAA conference, the information on the Australian Government HPV website was changed.

E. Professional engagements as a result of the research

2010 PHAA member of the newly formed Vaccine Special Interest Group

2010 Chair of the HPV Educators sub-community - a WHO sponsored HPV virtual community of practice, chaired by Dr Jessica Kahn USA. (Role to resume in 2011)

Preface

My interest in public women's health issues was stimulated when, in the prime of life in 1992, I was diagnosed with a gynaecological pregnancy-related malignancy. This cancer experience had compromised any opportunity to achieve professional status in the corporate business world, my original domain of interest and expectation, and resulted in pervading and unresolved sense of grief at this loss. My energies were then transferred into contributing to women's health, and in particular gynaecological cancer, at community level with practical resource based initiatives that endeavoured to improve quality of life for women. However I instinctively knew that the only way to counter cancer morbidity and mortality incidence was through medical research. As my awareness of the enormity of the knowledge gaps increased I became specifically interested in exploring measures to help reduce the burden of gynaecological cancers in vulnerable and young populations.

It is not surprising then that these undertakings would escalate to the scientific domain as an extension of inquiry. This may be seen as an atypical progression, but as the following discussion demonstrates, is a culmination of skills and experiences over considerable time. This research is also an extension and melding of my postgraduate studies specialising in communication and diverse cultures. These merge with my academic involvement in the delivery of management theory and practice at university environments in Australia and South East Asia; and my personal interest in women's health.

In developing the research I grappled with a range of intersubjective elements. First, the issue of researching in a discipline for which there had been no formal scientific training; research outcomes which had secondary impact on my professional career in academic management; but most significantly the outcomes of this study may have a direct impact on my daughter and her (then) late adolescent age peers, and their future gynaecological health. I was cognisant that each of these conflicting

elements and other unconscious motivations could potentially impact on the study unless one endeavoured to remain an impartial researcher. Moreover my prior research with Aboriginal populations was peripheral and in which little understanding was held of their research practices; and the experience with Chinese populations was based in a South East Asian business context.

Initially, and in fleeting episodes, these endeavours mirrored Finlay and Ballinger's reference (2006) to the preliminary research process of "'negotiating the swamp', of interminable deconstructions, self analysis and self disclosure" that evolves from problem to opportunity." I was determined to use these primal experiences as the basis of exploration and broadening of knowledge. And then try and understand what diverse cultures within nation states want in health prevention as self-determination rather than the current politically-determined approach. This thesis represents the culmination of inquiry and the opportunities that arose and were fulfilled.

Table of Contents

ABSTRACT **1**
DECLARATION **3**
ACKNOWLEDGEMENTS **4**
RESEARCH AND PROFESSIONAL OUTCOMES **7**
PREFACE **11**
TABLE OF CONTENTS **13**
TABLE OF FIGURES **20**
TABLE OF TABLES **21**
A. ABBREVIATIONS **23**
B. CLASSIFICATIONS, DEFINITIONS AND IDENTIFIERS **25**
C. THE THESIS STRUCTURE **29**
PART 1: BACKGROUND TO THE STUDY **31**
CHAPTER 1: THE STUDY OBJECTIVES AND SCOPE OF THE STUDY **31**
1 INTRODUCTION **31**
1.1 Background to the study 32
1.1.1 Lessons from hepatitis B virus (HBV) vaccination and human immunodeficiency virus (HIV) vaccine studies 32
1.2 Aims 34
1.3 Australia: An overview of key characteristics 35
1.3.1 Australia's geographical and regional diversity 36
1.3.2 Australia's population diversity 36
1.3.3 Australia's age diversity and life expectancy 37
1.3.4 Australia's cultural diversity 37
1.3.5 Language diversity in Australia and impact on health information 40
1.4 Profile of Australian General Practice (GP) medical services 41
1.4.1 Aboriginal people and health service use 42
1.4.2 Selected Australian health promotion strategies 43
1.5 Australia's sexual health strategies 44
1.5.1 Adolescent sexual health in Australia 44
1.6 Background to the immunisation of Australian adolescents 45
1.6.1 Australian adolescents and school based immunisation 45
1.6.2 The attitudes of Australian Aboriginal people to immunisation 46
CHAPTER 2: LITERATURE REVIEW: BIOMEDICAL PERSPECTIVES OF CERVICAL CANCER PREVENTION **47**
2 INTRODUCTION **47**
2.1 HPV epidemiology and impact of HPV infection 47
2.1.1 Heterogeneity in HPV Type distribution 50
2.2 HPV prevalence 52
2.2.1 HPV prevalence in Australian women 53
2.2.2 HPV prevalence in North-East Asian women 56
2.3 Determinants of HPV infection 57
2.4 Invasive cervical cancer (ICC) and global incidence 58
2.4.1 Incidence of ICC in China 59
2.4.2 Incidence of ICC in Australia 60
2.5 The first generation of prophylactic HPV vaccines 63
2.5.1 HPV vaccines and genital warts (GW) 65
2.5.2 HPV vaccine safety and efficacy 66
2.5.3 Age for HPV vaccination 69
2.5.4 Impact of cervical screening on the HPV vaccinated cohort in Australia 71
2.5.5 The implementation of HPV immunisation in Australia 71
2.5.6 HPV immunisation of adolescents through Australian schools 73
2.5.7 HPV immunisation of adolescents through Australian medical clinics 76

CHAPTER 3: LITERATURE REVIEW: ATTITUDES TOWARD CERVICAL SCREENING AS CERVICAL CANCER PREVENTION 77
3 INTRODUCTION TO CERVICAL CANCER SCREENING 77
3.1 Australia's cervical screening program 77
3.1.1 Cervical screening and Australian Aboriginal women 78
3.1.2 Cervical screening in China 79
3.2 Barriers to cervical screening in Developed Countries 80
3.2.1 Barriers to cervical cancer screening among Australian women 81
3.2.2 Barriers to cervical screening for Chinese women 83
3.3 Women's knowledge and perceptions of risk of HPV and ICC 83
3.3.1 Knowledge levels of cervical screening among Chinese women 86
3.3.2 Men's knowledge of HPV 86
3.4 The impact of women's understandings of HPV as a STI on screening behaviours 87
3.4.1 The influence of 'shame' and 'stigma' on cervical screening 88
3.4.2 'Shame' and 'stigma' in Aboriginal communities 91
3.5 Influence of doctors on screening practices and knowledge 91
3.5.1 Australian GPs and cervical screening 94
CHAPTER 4: LITERATURE REVIEW: ATTITUDES OF PARENTS AND DOCTORS TOWARD ADOLESCENT HPV VACCINATION 96
4 INTRODUCTION 96
4.1 Background to parent attitudes: understanding adolescents as the target population for HPV immunisation 96
4.1.1 Adolescents' knowledge levels of HPV vaccines 97
4.1.2 Supporting adolescent HPV knowledge needs through sexual health education 98
4.2 Parents' knowledge levels of HPV vaccines 99
4.2.1 Misconceptions about HPV vaccines in the general population in Developed Country (DC) nations 100
4.2.2 The influence of HPV vaccine knowledge on parental consent 100
4.3 Factors that contribute to parent acceptance of adolescent HPV vaccination . 101
4.4 Parent attitudes toward HPV vaccines and STI factors 103
4.4.1 Role of the school and sexuality education with adolescent HPV immunisation programs 106
4.5 Parents attitudes toward age for adolescent HPV immunisation 107
4.5.1 Attitudes of Australian parents 108
4.6 Parent perceptions of barriers to adolescent HPV vaccination 109
4.6.1 Specific factors for immigrant parents 112
4.6.2 Chinese women's attitudes to HPV vaccines 114
4.7 Attitudes toward vaccinating males with HPV vaccines 115
4.8 The influence of the media on parental attitudes toward HPV vaccines 117
4.9 Strategies for increasing parental acceptance of adolescent HPV vaccination 119
4.10 GPs: The attitudes of health professionals toward HPV vaccination 120
4.10.1 Attitudes of GPs toward age for adolescent HPV immunisation 121
4.11 GPs attitudes toward their educative role in HPV vaccine delivery 124
4.11.1 GPs and sexuality issues 125
4.12 Experiences of Australian GPs with HPV immunisation 127
CHAPTER 5: UNDERSTANDING 'CULTURE' AND HEALTH INTERVENTIONS 128
5 INTRODUCTION: SOCIO-CULTURAL DERIVATIONS OF HEALTH PRACTICES 128
5.1 A culture paradigm 128
5.1.1 'Culture', 'ethnicity' and 'race' 129
5.2 'Culture' as a social determinant of health 130
5.2.1 Influence of Aboriginal cultural paradigms on women's health beliefs: '*women's business'* 130
5.2.2 Chinese cultural attitudes toward health and sexuality 131
5.3 Increasing support for HPV vaccines through a socio-ecological approach 134
5.4 Summary of the literature 136

5.4.1 Limitations of the literature 140
5.4.2 Significance of the research topic 142
5.4.3 The research questions 142
PART 2: THE RESEARCH METHODS 144
CHAPTER 6: BACKGROUND TO THE RESEARCH DESIGN 144
6 THE RESEARCH PLAN: THEORY OR IDEOLOGY 144
6.1 Selecting an approach 144
6.1.1 The quantitative versus qualitative debate 145
6.1.2 Polarising views 147
6.1.3 Defining qualitative research 147
6.1.4 The complexities of a qualitative approach 148
6.2 Selection of the research methodology 148
6.3 The researcher as a bricoleur 149
6.3.1 The interpretive bricoleur 149
6.3.2 Contextual contingency and triangulation 150
6.4 Ontological position 150
6.5 Epistemological position 150
6.6 Interpretivism 151
6.7 Pragmatism 151
6.7.1 Pragmatism and knowledge claims 152
6.8 Reliability 152
6.8.1 Reflexivity 152
6.8.2 Limitations of reflexivity 153
6.8.3 The strength of reflexivity 153
6.9 Framing the research question 154
6.10 Evolution of the research plan 154
6.11 Informing the methodology: related studies 155
6.12 A ‘Framework’ approach 156
6.12.1 Selecting a ‘Framework’ approach 156
6.13 Data management: Ritchie and Lewis (2003) ‘Framework’ approach 157
6.13.1 Data analysis 158
6.14 Sampling in qualitative research 159
6.14.1 Purposive sampling 160
6.14.2 Range of approaches 160
6.14.3 Approximation of size and sampling 160
6.14.4 Saturation 161
6.15 Representativeness and sampling 161
6.16 Obtaining generalisability and transferability 161
6.17 Summary 162
CHAPTER 7: AIM AND METHODOLOGY 163
7 THE RESEARCH PROPOSITION 163
7.1 Obtaining ethics approval 163
7.1.1 The Memorandum of Understanding 163
7.1.2 Ethical challenges 164
7.2 Research population: the role of comparisons 164
7.2.1 Populations of interest 165
7.2.2 Population diversity 165
7.3 Sampling criteria 166
7.3.1 Australian studies 167
7.3.2 Recruitment of samples from vulnerable communities 167
7.3.3 Participant recruitment sites 169
7.4 ‘Mixed methods’ qualitative approach to data gathering 170
7.4.1 Semi-structured face to face interviews versus focus groups 170
7.5 The final methodological framework 172
7.6 Implementing the Framework: development of the topic guide 172
7.6.1 The ‘parent’ topic guide 173

7.6.2 Piloting the topic guide ... 174
7.6.3 Topic guide: Aboriginal communities ... 174
7.6.4 The 'GP' topic guide ... 175
7.7 Informed consent ... 175
7.8 Data collection 2005 – 2006 ... 176
7.8.1 The interviews ... 176
7.8.2 Recording and transcribing interviews ... 177
7.8.3 Unanticipated events ... 177
7.9 Summary ... 178
CHAPTER 8: RECONSTRUCTING THE METHODOLOGY ... 179
8 UNPACKING IGNORANCE: THE INTRICACIES OF CROSS-CULTURAL RESEARCH ... 179
8.1 Evolution of the methodology: cultural considerations ... 179
8.2 Power relations in cross-cultural research ... 180
8.3 The Aboriginal population ... 180
8.3.1 Conducting ethical research in Aboriginal communities ... 181
8.3.2 The influence of prior research experiences ... 181
8.3.3 Study protocols ... 182
8.3.4 Co-researcher recruitment ... 182
8.3.5 Capacity building and reciprocity ... 182
8.3.6 Engaging Aboriginal Health Workers (AHWs) ... 183
8.3.7 The role of the AHW ... 183
8.3.8 Variations to informed consent ... 185
8.3.9 Moderating the focus group discussions ... 186
8.4 The Chinese population: divergent views and methodological challenges ... 186
8.4.1 Snowball sampling ... 187
8.5 GPs: Remuneration and reimbursement ... 188
8.6 Summary ... 188
PART 3: RESULTS ... 189
CHAPTER 9: INTRODUCTION AND ANGLO PARTICIPANT RESULTS ... 189
9 INTRODUCTION TO RESULTS ... 189
9.1 Profile summary: Anglo, Aboriginal and Chinese parents ... 189
9.1.1 Presentation of results ... 191
9.2 Results: Anglo parents: Theme1: Individual beliefs and experiences of cervical cancer prevention ... 192
9.2.1 Cervical screening: attitudes toward ICC ... 193
9.2.2 Attitude toward cervical screening ... 194
9.2.3 Psychosocial experiences of cervical screening ... 194
9.3 HPV vaccines: General responses to HPV information ... 195
9.3.1 Attitudes toward HPV as an STI ... 196
9.3.2 Attitudes toward males and HPV infection ... 197
9.3.3 Attitudes toward HPV vaccines ... 199
9.3.4 Attitudes toward the need for parallel Pap screening ... 200
9.4 Theme 2: Anglo parent perceptions of factors for HPV immunisation success 201
9.4.1 System factors: the role of Government: attitudes toward an Australian HPV immunisation program ... 202
9.4.2 The role of schools and GPs: attitudes toward schools and clinics for HPV immunisation ... 205
9.4.3 Attitudes toward consent to adolescent HPV immunisation ... 207
9.5 Theme 3: The influence of Anglo cultural beliefs on ICC prevention ... 210
9.5.1 HPV information needs: attitudes toward key HPV messages for adolescents 210
9.5.2 Normative values: the influence of upbringing on attitudes toward adolescent sexuality ... 212
9.6 Summary of Anglo parent results ... 218
CHAPTER 10: RESULTS FROM CHINESE-AUSTRALIAN PARENTS ... 222
10 INTRODUCTION TO RESULTS: ... 222
10.1 Theme 1: Individual beliefs and experiences of ICC prevention ... 222

10.2 Cervical screening: attitudes toward ICC 222
10.2.1 Attitudes toward cervical screening 223
10.2.2 Psychosocial experiences of cervical screening 224
10.3 HPV vaccination: General responses toward HPV information 224
10.3.1 Attitudes toward HPV as an STI 225
10.3.2 Attitudes toward males and HPV infection 225
10.3.3 Attitudes toward HPV vaccines 227
10.3.4 Attitudes toward the need for parallel Pap screening 229
10.4 Theme 2: Chinese-Australian parent perceptions for HPV immunisation success 229
10.4.1 System factors: the role of government: attitudes toward an Australian HPV immunisation program 230
10.4.2 System factors: The role of schools: attitudes toward school and clinics for HPV immunisation 233
10.5 Socio-political factors: attitudes toward consent for adolescent HPV immunisation 236
10.5.1 Potential barriers to consent 237
10.5.2 Attitudes toward vaccinating males with HPV vaccine 238
10.6 Theme 3: The influence of Chinese cultural beliefs on ICC prevention 239
10.6.1 HPV information needs: attitudes toward key HPV education messages for adolescents 239
10.6.2 Normative values: the influence on upbringing on attitudes toward adolescent sexuality 241
10.7 Summary of Chinese-Australian parent results 246
CHAPTER 11: RESULTS FROM ABORIGINAL PARENTS 249
11 INTRODUCTION TO RESULTS: THEME 1- INDIVIDUAL BELIEFS AND EXPERIENCES OF ICC PREVENTION 249
11.1 Cervical screening: Attitudes toward ICC 249
11.1.1 Women's psychosocial experiences of cervical screening 250
11.2 HPV vaccines: General responses toward HPV information 251
11.2.1 General responses to the HPV vaccines 252
11.2.2 Concerns with HPV vaccine characteristics 253
11.2.3 Attitudes toward side effects and safety of HPV vaccines 254
11.2.4 Specific concerns for Aboriginal communities 254
11.2.5 Attitudes toward parallel Pap screening with HPV vaccination 255
11.2.6 Influence of attitudes on HPV vaccine information resources 256
11.3 Theme 2: Aboriginal parent perceptions of factors for HPV immunisation success 257
11.3.1 System factors: the role of Government: Attitudes toward Government health programs 258
11.3.2 Attitude toward Government HPV education resources 258
11.3.3 Educating health providers 261
11.3.4 Government consent processes 262
11.4 System factors: The role of schools: Attitudes toward schools and HPV education 262
11.4.1 Attitudes towards school for a HPV immunisation program 263
11.4.2 Attitudes towards compliance of the 3 dose schedule through schools 264
11.5 Socio-political factors: Attitudes toward age for HPV immunisation 265
11.5.1 Attitudes toward consent for HPV immunisation of young adolescents 266
11.5.2 Attitudes toward potential barriers to consent 266
11.5.3 Influence of stigma of HPV on consent 267
11.5.4 Males and consent to HPV vaccination 268
11.5.5 Foster children and consent 268
11.5.6 Intentions to recommend HPV immunisation 268
11.6 Theme 3: The influence of Aboriginal cultural beliefs on ICC prevention 269
11.6.1 Aboriginal cultural beliefs and health: 'Women's business' 269
11.6.2 *'Men's Business'* and educating males about HPV 271
11.6.3 Educating Aboriginal communities about HPV and as an STI 272

11.7 The impact of cultural and social values on HPV immunisation: Sexual mores and social implications 273
11.7.1 Concerns about HPV immunisation and adolescent sexual behaviour 274
11.7.2 Influence of sexual behaviours on attitude toward age for HPV vaccination 274
11.8 HPV Information needs for two Aboriginal regions: Impact of cultural beliefs on HPV education strategies 276
11.8.1 Attitudes toward two HPV resources reflecting Aboriginal cultural beliefs 278
11.8.2 Attitudes toward sexuality issues in HPV information for adolescents 279
11.9 Summary of Aboriginal parent results 281
CHAPTER 12: RESULTS FROM GENERAL PRACTITIONERS (GPS) 284
12 INTRODUCTION TO RESULTS: GPS: PERSONAL CHARACTERISTICS 284
12.1 GPs: characteristics of clinical practice 285
12.1.1 Presentation of results: Thematic categories 287
12.2 Theme 1: GPs beliefs and experiences of ICC prevention 287
12.2.1 Cervical screening: GPs experiences of cervical screening and educating patients about the Pap test 288
12.2.2 GPs management of patients' reactions to an abnormal Pap test result 290
12.2.3 Managing patients' responses to a genital wart diagnosis 293
12.3 HPV vaccines: General response toward GPs knowledge levels of HPV and HPV vaccine 293
12.3.1 Attitudes toward HPV vaccine characteristics 297
12.3.2 Attitudes toward parallel Pap screening with HPV vaccination 298
12.3.3 Attitudes toward adolescents' gender and age for HPV immunisation 298
12.4 Theme 2: GP perceptions of factors for HPV immunisation success 301
12.4.1 System factors: the role of Government 301
12.4.2 The role of medical clinics: attitudes toward managing adolescent HPV immunisation 302
12.4.3 Schools: Attitudes toward the role of schools in HPV immunisation programs 304
12.5 Knowledge Factors: Role of GPs as HPV vaccine educators 305
12.5.1 GPs attitudes toward their role of educating patients from diverse cultures about HPV vaccines 306
12.5.2 Factors that influence GPs recommending HPV vaccines 309
12.6 Summary of GP results 315
PART 4: OUTCOMES OF THE RESEARCH 318
CHAPTER 13: DISCUSSIONS, CONCLUSIONS AND IMPLICATIONS 318
13 SECTION A: DISCUSSION 318
13.1 Overview of the thesis 318
13.2 Summary of key findings 318
13.2.1 The influence of biomedical factors on parental and GP attitudes 318
13.3 The influence of system and environmental factors on acceptance 320
13.3.1 Attitudes toward school-based HPV vaccination programs 324
13.4 The influence of psychosocial factors on parental acceptance 325
13.4.1 Knowledge factors and parental attitudes 325
13.4.2 Normative values and attitudes toward age for adolescent HPV vaccination .. 327
13.4.3 Sexuality norms and attitudes toward HPV vaccination 328
13.4.4 Religious factors 332
13.5 Unique factors relating to the attitudes of two specific participant groups 333
13.5.1 Aboriginal participants 333
13.5.2 Chinese participants 337
13.6 Strengths and limitations of the research 340
13.6.1 Methodological considerations of the qualitative approach 340
13.6.2 Ontological position 341
13.6.3 Epistemological position 341
13.6.4 Generalisability 342
13.6.5 Role of the Aboriginal and Chinese advisory groups 345
13.6.6 Timing of the study 346
13.6.7 Data management 347

13.6.8 Issues encountered with researching 'culture' 349
13.7 SECTION B: CONCLUSION 351
13.7.1 Overall conclusions 351
13.8 SECTION C: PRACTICAL IMPLICATIONS 356
13.8.1 Assisting diverse cultural groups to make an informed choice about adolescent vaccination 356
13.8.2 Planning HPV vaccine programs that engender parental acceptance 356
13.8.3 A socio-ecological framework for HPV immunisation in cross-cultural populations 359
13.8.4 Contributions of this study to knowledge of ICC prevention in Australia 363
13.9 Future research on HPV vaccines 366
REFERENCES 367
APPENDICES 425
Appendix 1 : Regional distribution of Aboriginal, Anglo and Chinese-Australian people within Australia at 30 June 2006 (ABS, 2008, 2010a) 425
Appendix 2 : Australian population Profiles of Aboriginal, Anglo and Chinese-Australian People (ABS 2010b) 426
Appendix 3 : Age profile of three Australian population groups (ABS 2010b) 427
Appendix 4 : Language profile of Australia for Aboriginal (Indigenous) languages, English language, and Chinese languages (ABS 2008a) 428
Appendix 5 : Australia's sexual health 429
Appendix 6 : Timeline of the development and implementation of the first generation HPV Vaccines. Focus: Australia 431
Appendix 7 : Related HPV studies 1995 - 2005 435
Appendix 8 : Thematic Chart Summary: (Parents and GPs) 444
Appendix 9 : HREC Application, University of Melbourne (Victoria) 447
Appendix 10 : The Royal Children's Hospital Melbourne HREC (Victoria) 448
Appendix 11 : The Royal Women's Hospital Melbourne HREC (Victoria) 449
Appendix 12 : Central Australian HREC for Indigenous Research in Northern Territory. 452
Appendix 13 : Memorandum of Understanding, Aboriginal Communities 453
Appendix 14 : Recruitment posters: Anglo and Chinese Parents 460
Appendix 15 : Anglo and Chinese Parent Topic Interview Guide 461
Appendix 15.1 : Topic Interview Guide: Aboriginal communities in Central Australia and Victoria 468
Appendix 16 : HPV Education Intervention 472
Appendix 17 : Australian Government HPV Information (English) 473
Appendix 18 : GP topic guide 477
Appendix 18.1 : GP Information Statement and Consent Form 478
Appendix 19 : Consent Form – Central Australian Aboriginal Participants 491
Appendix 19.1 : Consent Form - Victorian Aboriginal Participants 492
Appendix 19.2 : Consent Form – Release of Data (Aboriginal Participants) 493
Appendix 20 : Anglo and Chinese Parent Consent Form 494
Appendix 21 : Personal Details Anglo and Chinese Participants 500
Appendix 22 : Victorian Aboriginal Health Worker Recruitment Poster 501
Appendix 23 : Chinese Fact Sheet 502
Appendix 24 : Government HPV advertisement – Aboriginal people 503
Appendix 25 : Northern Territory Government 'Top End' Brochure 504
Appendix 26 : Central Australian HPV vaccine brochure 505
Appendix 27 : Summary of key factors for parental acceptance of HPV vaccines 507
Appendix 28 : Central Australian HPV Vaccine Radio Advertisements 508

Table of Figures

Figure 1: HPV related cancers: Annual cases worldwide (GLOBOCAN 2010; HPV PREV 2010). 49
Figure 2: A multifactoral model of cervical carcinogenesis (Adapted from Spence et al. 2005 in Frazer et al. 2006:S72; PATHa 2010)..... 58
Figure 3: Global incidence of ICC. (Garland et al. 2008)..... 59
Figure 4: A socio- ecological model for understanding HPV vaccine acceptance136
Figure 5: Scope of the Literature review 137
Figure 6: The methodological framework..... 173
Figure 7: Thematic categories 192
Figure 8: Theme1: Individual beliefs and experiences of ICC prevention among Anglo parents 193
Figure 9: Theme 2: Perceptions of factors for HPV immunisation success 202
Figure 10: Theme 3: Influence of Anglo cultural beliefs and practices on cervical cancer prevention..... 210
Figure 11: Theme 1: Individual beliefs and experiences of cervical cancer prevention among Chinese-Australian women..... 222
Figure 12: Theme 2: Perceptions of factors for HPV immunisation success 230
Figure 13: Theme 3: Influence of Chinese cultural beliefs and practices on ICC prevention..... 239
Figure 14: Theme: Individual beliefs and experiences of cervical cancer prevention among Aboriginal women..... 249
Figure 15: Theme 2: Perceptions of factors for HPV immunisation success 257
Figure 16: Theme 3: Influence of Aboriginal cultural beliefs and practices on ICC prevention..... 269
Figure 17: Thematic categories: GPs..... 287
Figure 18: Theme1: Individual beliefs and experiences of cervical cancer prevention among GPs..... 288
Figure 19: Theme 2: Perceptions of factors for HPV immunisation success 301
Figure 20: A socio-ecological model for HPV vaccine acceptance in cross-cultural populations..... 361

Table of Tables

Table 1: GP headcount by gender and broad geographic region (Aust. Govt. Dept Health & Ageing December 2009) 42
Table 2: Australian and Victorian adolescent immunisation schedule: 2010 and ongoing (DHS 2008a; DHA 2010b) 45
Table 3: Epidemiologic classification of genital HPV types associated with clinical disease (Walboomers et al. 1999 in Frazer et al. 2006:S72; Garland et al. 2009; Schiffman et al. 2009; WHO 2010) 48
Table 4: Profile of HPV related diseases in Caucasian and Asian Australian women (Summarised from Pirotta et al. 2009:6 Table 1) 61
Table 5: Cervical cancer incidence in Australian regions (Source: Australian Bureau Statistics, 2008 62
Table 6: Quadrivalent human papillomavirus vaccine coverage (doses administered to enrolled population) in school-based programs, 2007,* by state or territory (Brotherton et al. 2008a) 74
Table 7: Correlates of parental acceptance toward HPV vaccination summarised from the literature 103
Table 8: Parental perceptions of barriers to adolescent HPV vaccination (summarised from the literature) 111
Table 9: Determinants of vaccine recommendations by physicians (Summarised from Kahn et al. 2007: 369 Table 1; Wong 2009; Askelson et al. 2010; McCave 2010) 123
Table 10: Barriers to counselling patients (summarised from Verhoeven et al. 2003; Sussman et al. 2007) 127
Table 11: The five stages of the iterative process throughout data analysis in a 'Framework' approach (Ritchie and Lewis 2003:212) 158
Table 12: Recruitment and data collection summary 169
Table 13: Summary profile: Anglo and Chinese parents 190
Table 14: Identifiers for the verbatim quotations from interview data 191
Table 15: Summary of key biomedical factors on attitudes toward adolescent HPV vaccination: Anglo parents 218
Table 16: Summary of system factors on attitudes toward adolescent HPV vaccination: Anglo parents 220
Table 17: Summary of key cultural and normative factors on attitudes toward adolescent HPV vaccination: Anglo parents 220
Table 18: Summary of key biomedical factors on attitudes toward adolescent HPV vaccines: Chinese-Australian parents 246
Table 19: Summary of key system and socio-political factors on attitudes toward adolescent HPV vaccination: Chinese-Australian parents 247
Table 20: Summary of key cultural and normative factors on attitudes toward adolescent HPV vaccination: Chinese-Australian parents 248
Table 21: Summary of key biomedical factors on attitudes toward adolescent HPV vaccination: Aboriginal parents 281
Table 22: Summary of key system factors on attitudes toward adolescent HPV vaccination: Aboriginal parents 282
Table 23: Summary of key cultural and normative factors on attitudes toward adolescent HPV vaccination: Aboriginal parents 283
Table 24: Personal characteristics: GPs, Victoria 284
Table 25: Profiles of GPs clinical practice 286
Table 26: GPs: Self-assessed levels of knowledge: HPV and HPV vaccines 294
Table 27: HPV vaccination – GPs preferences for age for adolescent HPV vaccination 298
Table 28: Barriers to GP's recommendations for HPV vaccines 310

Table 29: Factors contributing to GPs recommendation of HPV vaccination..... 311
Table 30: HPV vaccine recommendation..... 311
Table 31: Summary of key biomedical factors on attitudes toward adolescent HPV vaccination: GPs 315
Table 32: Summary of key system factors on attitudes toward adolescent HPV vaccination: GPs..... 316
Table 33: Summary of key knowledge factors on attitudes toward adolescent HPV vaccination: GPs 317
Table 34: Key findings from the research about attitudes toward adolescent HPV vaccination 364

A. ABBREVIATIONS

All abbreviations are expanded when first used in a chapter.

AAG	Aboriginal Advisory Group
ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community-controlled Health Services
ACIR	Australian Childhood Immunisation Program and Register
ACT	Australian Capital Territory, Australia
AHW	Aboriginal Health Workers
AIHW	Australian Institute of Health and Welfare
AIN	Anal intraepithelial neoplasia
ALLS	Adult Literary and Life Skills (Australia)
ASHR	Australian Study of Health and Relationships
CAAAG	Central Australia Aboriginal Advisory Group
CAAMA	Central Australia Aboriginal Media Association
CALD	Cultural and Linguistic Diversity
CAus	Central Australia
China	The People's Republic of China (excluding Hong Kong and Taiwan)
CDC	Centers for Disease Control and Prevention (USA)
CIN	Cervical intraepithelial neoplasia
CRCAH	Co-operative Research Centre for Aboriginal Health
DC	Developed Country
EHRC	Ethics in Human Research Committee
EGW	External genital warts
GP	General Practitioner
GW	Genital warts
HBV	Hepatitis B virus
Hib	Haemophilus influenzae type B
HIV	Human immunodeficiency virus (that can lead to acquired immunodeficiency syndrome (AIDS)
HPV	Human papillomavirus
2vHPV	Bivalent human papillomavirus vaccine
4vHPV	Quadrivalent human papillomavirus vaccine
HR	High risk
HREC	Human Resource Ethics Committee
HSV	Herpes simplex virus
ICC	Invasive cervical carcinoma
LDC	Least Developed Country
LR	Low risk
MOU	Memorandum of Understanding
NATSISS	National Aboriginal and Torres Strait Islander Social Survey 2002
NCSP	National Cervical Screening Program (Australia)
NE Asia	North East Asia
NHMRC	National Health and Medical Research Council
NHPVP	National Human Papillomavirus Vaccination Program (Australia)

NIPS	National Immunisation Program Schedule (Australia)
NSW	New South Wales, Australia
NT	Northern Territory, Australia
NTDHCS	Northern Territory Department Health and Community Services (now Department of Health and Families: DHF)
NTPSR	Northern Territory Pap Smear Registry (Australia)
NTWCPP	Northern Territory Women's Cancer Prevention Program (Australia)
ONEMDA	VicHealth Koori Health Unit (Victoria, Australia)
Pap test	The Papanicolaou test, also called Pap smear
PHAA	Public Health Association Australia
QU	Queensland, Australia
RAN	Remote Area Nurse
RCH	Royal Children's Hospital (Melbourne, Australia)
RWH	Royal Women's Hospital (Melbourne, Australia)
SA	South Australia
SHP	Selected health promotion
SIL	Squamous intraepithelial lesions
SMR	Standard mortality rate
STI	Sexually transmitted infection
TAS	Tasmania, Australia
UK	United Kingdom
UN	United Nations
USA	United States of America
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VIC	Victoria, Australia
VIS	Victorian Immunisation Strategy (Australia)
WA	Western Australia
WHO	World Health Organisation
WWSP	'Well Women's' Screening Program (NT: Australia)

SYMBOLS

~	Approximately
$	Australian dollars, unless another currency is specified
=	Equals
>	Greater than
<	Less than
n	Number
%	Percent
'000	Thousands

B. CLASSIFICATIONS, DEFINITIONS and IDENTIFIERS

(a) CLASSIFICATIONS

Classification of 'developed' (DC) and 'developing' (LDC) countries

There is no established criterion for the designation of 'developed' and 'developing' countries, or areas, in the United Nations (UN) system (United Nations 2002 - 2005). The following classifications are applied in the thesis, although they are considered controversial because they are based on notions of 'Western' capitalism (Reed 2002).

i. '*Developed Country'* (DC) classifies nations with a high standard of living such as Australia;
ii. 'Developing' or '*Least Developed Country'* (LDC) classifies nations with common features: low-income; human resource weakness based on indicators of nutrition, health, education, and adult literacy; and economic vulnerability (United Nations 2002 - 2005). These features are regularly applied to resource-poor countries such as Africa or South America. Many remote regions within Australia, and where Aboriginal peoples reside, meet the criterion of a LDC.

(b) DEFINITIONS

These definitions relate to key terms used in the thesis.

'Acculturation'

Acculturation is an important factor with immigrants in their sociocultural adaptation (Senghaas 1998). The definition of 'acculturation' for this study is the extent to which immigrants have adopted the culture of their host population (Palmer et al. 2007). Marlow and colleagues (2009) claim that generational status is also an important indicator of acculturation, whilst LaFromboise and colleagues (1993) noted that, whilst 'second culture acquisition' encouraged belongingness in the new culture, it did not compromise one's sense of original cultural identity.

'Culture'

Whilst no definite conclusion can be drawn as to what constitutes an ideal definition of *culture* (and appreciating the heterogeneous factors within population groups), this study will apply the UNESCO definition (UNESCO

2002) that '... culture should be regarded as the set of distinctive spiritual, material, intellectual and emotional features of society or a social group'.

'Health literacy'

Health literacy in the Adult Literary and Life Skills survey, Australia (ALLS), is defined as 'the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy' (ABS 2006a).

'Health promotion'

The definition for *health promotion* as defined by the Ottawa Charter, and applied by the Australian National Health and Medical Research Council, is 'the process of enabling people to increase control over, and to improve their own health'. Health promotion, in addition to disease prevention and behavioural programs, addresses the environmental and sociological determinants of health and disease (Raupach et al. 2003:353).

'Shame'

In the context of this thesis, *shame* refers to situations in which a person perceives they have been singled out for any purpose [such as cervical screening] and in which they have lost the security and anonymity that they would have in a group situation (Maher 1999). Therefore any contravention of normative values is perceived as contributing to the anguish and 'shame' in individuals and groups.

'Stigma'

The concept of *stigma,* as a 'dynamic process of devaluation' (Wood and Aggleton 1999: 5), is hard to define and much variability exists in its definition that can be culturally bound (Link and Phelan 2001:364; Major and O'Brien 2005:395; Yang 2007), and constructed and reinforced in language (Wood and Aggleton 1999:5; Yang 2007). The seminal work of Goffman (1963:3 in Link and Phelan 2001:363; Weiss and Ramakrishna 2004; Yang 2007) defined stigma as an 'attribute that is deeply discrediting' but later research elaborated with variations on this. In the context of this thesis, the notion of health-related 'stigma' adopts a social psychological perspective on stigma (Link and Phelan 2001:367; Weiss and Ramakrishna 2004), conceptualising 'stigma' as existing when there

is a deviation from the interrelated components of human differences, dominant cultural beliefs, leading to the construction of stereotypes and subsequent 'disapproval, rejection, exclusion, and discrimination'. Furthermore stigmatisation is deemed to be contingent on 'social, economic and political power'.

(c) IDENTIFIERS

Participant cultural identifiers

The data was collected from participants in Central Australia and Melbourne, Victoria, Australia. This thesis applies the following terms to identify their cultural origin:

i. '*Aboriginal*' refers to Aboriginal people, Australia's original inhabitants, as distinct from '*Indigenous*' that classifies both Aboriginal and Torres Strait Islander people (NSW 2004:9);
ii. '*Anglo*' refers to residents of Australia who were born in the United Kingdom (UK);
iii. '*Chinese-Australian'* refers to residents of Australia who were born in North East (NE) Asia, particularly mainland China and Hong Kong, and as classified in the 1998 Australian Standard Classification of Countries for Social Statistics (cat. no. 1269.0) (ABS 2008).

International research applies the following terms to describe cross-cultural populations:

i. '*African-American'* , for example, refers to residents of the United States of America (USA) of African descendency;
ii. '*ethnic minority'* describes population groups by the number of people represented in a nation who are not the dominant cultural group;
iii. '*people of colour'*, '*black*', '*white*' describes population groups by their skin colour, and who are not necessarily the dominant cultural group in a nation;
iv. '*Asian*', '*Malaysian*', for example, are people or culture classified by the continent or country in which the population resides;

v. ‘*Western*’ refers to the ideologies and practices of people in countries dominated by the values and paradigms of ‘Anglo’ or predominantly English language populations.

Report identifier

The terms ‘study’ and ‘research’ are applied to the findings referred to in the literature, and as determined by the author’s style preference in the literature review. The term ‘study’ is used in reference to the research undertaken for this PhD thesis.

C. THE THESIS STRUCTURE

The thesis is structured in four sections.

PART 1 sets the scope and background to the study; examines relevant literature and identifies the gaps in knowledge that form the study questions.

Chapter 1 introduces the study and describes its background and aims. The overview of relevant characteristics of Australia's diversity is to help place the study in context.

The next four chapters examine cervical cancer (ICC) prevention approaches, and the influence that culture has on parental and health provider attitudes toward human papillomavirus (HPV) vaccination for adolescents.

Chapter 2 examines the biomedical and epidemiological factors of ICC that will inform our understanding of the key characteristics of the two licensed first generation prophylactic HPV vaccines.

Chapter 3 examines ICC screening, and the factors that underpin screening practices globally, and within Australia. The knowledge, attitude and behaviours of women, and specifically Aboriginal and Chinese-Australian women; and of family health providers toward cervical screening, and their clinical management by GPs, will be reviewed.

Chapter 4 reviews HPV vaccination in adolescents, and the attitudes of parents and GPs toward the psychosocial and sexual factors of HPV vaccines for this cohort.

Chapter 5 defines 'culture', and places 'culture' in the context of this study to enable analysis of results in Part 3, and summarises key findings from the literature.

PART 2 describes the methodology, and justifies the approach undertaken for this study in Chapters 6 to 8.

Chapter 6 describes the study purpose and significance of the study, and places the methods in a broad research context. This chapter debates the merits of quantitative versus qualitative approaches in a socio-behavioural

research paradigm, and examines key philosophical and methodological issues.

Chapter 7 focuses on the study aims and methodology and describes the specific research processes engaged for this study.

Chapter 8 reconstructs the methods approach within a specific cultural paradigm.

PART 3 discusses the results from the four population samples, which are reported by discrete cultural groups (Anglo, Aboriginal and Chinese Australians), and functional role (parents; GPs) in Chapters 9 to 12. The results focus on data relating specifically to participants' attitudes to both cervical screening and HPV vaccination which emerged from the thematic analysis.

Chapter 9 presents the results from participants in the Anglo population sample.

Chapter 10 presents the results from participants in the two Aboriginal population sample groups.

Chapter 11 presents the results from participants in the Chinese-Australian population sample.

Chapter 12 presents the results from GP participants. Summaries of results are at the end of each Chapter.

PART 4 discusses the results and proposes insights for HPV immunisation in cross-cultural communities in light of previous behavioural and attitudinal research.

Chapter 13 discusses the study findings and defines its major limitations and strengths, forms conclusions and implications for theory and practice, and proposes future research.

PART 1: BACKGROUND TO THE STUDY

Chapter 1: The Study Objectives and Scope of the Study

1 Introduction

The licensure and hence availability of two first-generation prophylactic human papillomavirus (HPV) vaccines offers a new paradigm for invasive cervical cancer (ICC) prevention globally. Its success will depend on acceptance by parents of adolescents (the targeted population for prophylactic HPV immunisation) and health professionals, and as the key findings from this study reveal Australian parents have specific needs. Adolescents, if sexually active, are at high risk of acquiring HPV infection and potential development of cervical dysplasia, and if unchecked and treated, a small proportion will progress to ICC (Mulhall et al. 1995; Kahn 2005; Moscicki 2005).

The prevention of oncogenic genital HPV infection, as a precursor to ICC, through high uptake of the prophylactic HPV vaccines is a global public health need of the highest priority, and essential to significantly reduce cervical morbidity. It is desirable that any HPV vaccine strategies avoid the implementation and uptake challenges that faced the vaccine for hepatitis B virus (HBV). For example, when first introduced in Australia in 1973, the HBV vaccine subsequently took over a decade for widespread community acceptance (NCIRS 2005; Shaw 2005), because the target population for HBV vaccination was narrowly defined to those perceived as high risk (Rothman and Rothman 2009; Heffernan et al. 2010).

Limited research has been undertaken in Australia on critical issues relating to the implementation of HPV immunisation programs prior to the commencement of the current program in 2006. One significant challenge facing the delivery of the Australian HPV vaccine program is the cultural diversity within the population, including Aboriginal Australians, and its influence on parental acceptance for HPV vaccination in pre-adolescents. Equally, little is known about the attitudes of one group of Australian health providers, general practitioners (GPs), who are the main providers of HPV vaccination outside the national school-based immunisation

program. The key findings from this study reveal some groups of Australian parents have specific needs with the adolescent HPV vaccination program (Table 34) and highlight the critical implementation factors that need to be considered if the adolescent Australian population is to benefit from HPV vaccination.

1.1 Background to the study

When this study proposition was developed in late 2005, there was an absence of empirical research that addressed what understanding the general public had of HPV infection and its aetiological role in ICC and other disease related associations. The need for health professionals to better understand cross-cultural factors is seen as important to enable an improvement the quality of health outcomes for marginalised population groups (Chu 1998; Morgan et al. 1997; Durie 2003). Biomedical and structural factors which are necessary for HPV immunisation success have been widely reported, whereas behavioural and socio-cultural factors had been less well examined (Frazer et al. 2006; Siddiqui and Perry 2006; Garland, Brotherton et al. 2008).

1.1.1 Lessons from hepatitis B virus (HBV) vaccination and human immunodeficiency virus (HIV) vaccine studies

There has been a plethora of research on HBV vaccination strategies that have direct relevance for HPV mass immunisation programs. The experiences of the introduction of the HBV vaccine demonstrates that, in order to obtain the maximum health benefit and reduction in disease, a public sector broad-based immunisation strategy, rather than a targeted approach, was important (Heffernan et al. 2010; Kane 2010). Within the corpus of HBV vaccine research, critical psychosocial and cross cultural factors were not examined and consequently could not guide HPV immunisation strategies. The experience of HBV immunisation highlights the need to consider these factors to ensure higher uptake of HPV vaccines at the population level, and a successful HPV public health program.

Why are these study objectives important? The history of the delayed integration of HBV immunisation into the general community (Van Damme et al 1997; Heffernan et al. 2010; Kane 2010) revealed that, although confusion and ignorance about the vaccine's characteristics among the general population led to poor outcomes in its first decade, vaccine implementation strategies can be strengthened after initial, ineffective attempts (Cassidy and Mahoney 1995; Lawrence and Goldstein 1995; Lister et al. 1999; Skinner et al. 2000; Hinds and Cameron 2004; Shaw 2005; Heffernan et al. 2010; Kane 2010). The initial HBV vaccine strategy targeted immunisation to 'high-risk' groups which, initially, did not significantly impact on HBV carriage or its disease related sequelae. Once the expanded childhood immunisation program was established globally (with World Health Organisation (WHO) and local government support, and with recommendations for newborn - infant vaccination), an increase in uptake, with concomitant reductions in cases of acute HBV hepatitis as well as chronic carriage and ultimately liver cancer associated with HBV, resulted.

Inadequate public education about the HBV vaccine characteristics, its efficacy, and existing prevailing sexual and cultural practices, were secondary factors that also contributed to low levels of HBV vaccine uptake for the first decade (Freed et al. 1994; Brookman et al. 1995; Woodruff et al. 1996; Lam and McLaws 1998; Chen et al. 2000; Zimet et al. 2000; Chen et al. 2001; Freed et al. 2004; Wallace et al. 2004; Zimet, Perkins et al. 2005; Heffernan et al. 2010; Kane 2010). Later strategies that maximised vaccine uptake in pre-adolescents with HBV vaccination were parent education, co-operation of schools and the pro-active role of GPs (Lawrence and Goldstein 1995; Skinner et al. 2000; Hinds and Cameron 2004; Heffernan et al. 2010; Kane 2010), and government support and involvement. The HBV experience demonstrated the need for a supportive environment for the vaccine through coordinated and culturally appropriate media campaigns involving key agencies (Lam 1998; Sherris et al. 2006; Heffernan et al. 2010; Kane 2010).

Streefland (2003), who explored cross cultural issues toward a Human Immunodeficiency Virus (HIV) vaccine, posited that culture would influence the success of [HIV] vaccination programs in vulnerable populations. Furthermore, he posited that the process of the introduction of vaccines into a cross-cultural environment could not be generalised, because these environments are now known to be not static, as a result of the infiltration of social and cultural influences.

1.2 Aims

Health interventions must be acceptable to all subcultural groups within diverse populations, if they are to be implemented successfully. In order to achieve that, an understanding of key characteristics of each subcultural group is necessary when drawing conclusions about their needs to minimise transubstantive error. The phenomenon of transubstantive error (Wells 1985; Robinson 1997) occurs when conclusions about one social group are drawn that uses the criteria and standards that belong to a different group. Therefore inappropriate ascription of beliefs or standards by the dominant culture over the sub-culture could lead to the development of inappropriate prescriptions for change, and non-compliance with the required action could result (Bronfenbrenner 1979; Wells 1985; Robinson 1997; Biellik et al. 2009). This presupposes a central theme that sensitivity and customisation of HPV vaccine communication to diverse culture groups is critical to the success of the reduction of HPV infection and related diseases, especially the subsequent reduction of ICC (Stevens and Walker 1999; Tjalma and van Damme 2005).

This study will examine the variation in attitudes of Australian parents from different cultural groups toward adolescent HPV vaccination, to inform the development of differentiated messages and intervention approaches for the delivery of HPV vaccination in Australia. Research on cross-cultural and parent attitudes toward HPV vaccines emerged primarily from the UK and USA, and has partial relevance for Australia in determining diverse population concerns. Most of these studies conclude that parents are

supportive of vaccines that prevent disease for their children, but new vaccines provoke concerns about aspects of vaccine technology, especially their constituents and their safety features (Brabin et al. 2006; Dempsey et al. 2006, 2009; Noakes et al. 2006; Sherris et al. 2006; Waller et al. 2006; Zimet et al. 2006; Agosti et al. 2007; Marlow et al. 2007a, 2007b, 2008; Vallely et al. 2008; Leader et al. 2009; Mortensen 2010), which are discussed further in this review.

More recently, several HPV-related studies have emerged from countries with limited access to cervical screening, such as The People's Republic of China (China) and Malaysia (Lee et al. 2007; Wong and Sam 2007; Shi et al. 2008; Wong 2008), revealing the attitudes of those populations toward the HPV vaccines, and which contribute to our understanding of the needs of these immigrant groups for the Australian population. With the [then imminent] introduction of HPV vaccines into Australia in 2005 and 2006, little was known about the attitudes of Australian parents, or guardians, of adolescents toward HPV vaccination; or those of the attitudes of primary Australian health providers.

This study aims to contribute to the knowledge of attitudes, perceptions and understandings of HPV vaccination in diverse populations that are critical for HPV vaccine uptake in adolescents, and the complexities and challenges involved in educating those population groups about a new cervical cancer health initiative. By understanding these attitudes, key factors for the successful introduction of STI vaccines into multicultural communities, such as Australia, can be identified.

1.3 Australia: An overview of key characteristics

Australia is a diverse country in terms of its population and geographic profiles, and heterogeneity exists in key characteristics. The following overview of its key characteristics will help our understanding of the context that aspects of the literature review, the sample population, and the analysis are placed in.

1.3.1 Australia's geographical and regional diversity

Australia's population reside in five distinct regions, which are classified according to the Australian Standard Geographical Classifications, the primary classification used by the Australian Bureau of Statistics (ABS) (ABS: 2009, 2010b):

i. Major Cities (MC) [DC] (68.4% of total population)
ii. Inner Regional (IR) [DC] (19.7% of total population)
iii. Outer Regional (OR) [DC] (9.5% of total population)
iv. Remote (R) [LDC] (1.5% of total population)
v. Very Remote (VR) [LDC] (0.8% of total population)

The regions where Aboriginal, Anglo and Chinese-Australian people live, within Victoria (Vic), and the Northern Territory (NT) and relative to the Australian population as a whole, are shown in Appendix 1. The proportion of the Aboriginal population residing in urban areas [DC] and remote areas [LDC] varies considerably between the NT and Victoria, and in the NT the majority (56%) of Aboriginal people live in VR regions, and none in IR or MC regions [Darwin, the major city in the NT, is classified as being Outer Region]. With Chinese-Australian residents, over 90% live in MC regions, compared to 68.4% of the total Australian population (ABS 2008) (Appendix 1).

1.3.2 Australia's population diversity

At December 20, 2009, there were 22.15 million people living in Australia (ABS 2010b). The diversity of Australian population profiles of Aboriginal, Anglo and Chinese-Australian people are shown in Appendix 2. Australian people of **Anglo** descendency comprise the dominant population group (n= 14.072 million), representing 70.9% of the total Australian population (ABS 2010b). A similar proportion of Anglo descendants represent the total populations of Victoria (69.6% of the Victorian population) and the NT (76.8% of the NT population). **Aboriginal** people comprise the least proportion of the total population nationally (2.5%, n = 517,000 people) (ABS 2010a) and are disproportionately distributed across Australia.

Chinese-Australian people comprise 3.2% of Australia's population (5.6 million people) (ABS 2010b), and are the sixth most common ancestral group (and dominant Asian cultural group) in Australia (ABS 2010b), with the majority being first generation in Australia. Australian census data (ABS 2010b) shows that migrations of people of Chinese ancestry originated from China and Hong Kong (36%), Malaysia (10%), and Vietnam (8%).

1.3.3 Australia's age diversity and life expectancy

The median age of the general population in Australia was reported at 36.9 years in 2008 (AIHW 2009c:8, 9), and the age structure for females is anticipated at 83.3 years, and males at 78.5 years. The life expectancy is 'among the highest in the world, but disparities exist within the Aboriginal population' (AIHW 2009c: 8) where the life expectancy at birth for Aboriginal Australian females (mean of 72.9 years: 69.2 for females in the NT, and 75.0 in NSW) was 9.7 years lower than the Australian average for non-Aboriginal females (82.6 years) (ABS 2010a,b). No data is available for Victorian Aboriginal females due to their low death rates proportionally. The substantial diversity in the age differentials between the Aboriginal and non- Aboriginal populations is highlighted in Appendix 3, although Anderson and colleagues (2006:1776) maintain that only 60% of mortality data are of 'reportable quality' for the Aboriginal population.

1.3.4 Australia's cultural diversity

Australia has a high number of immigrants, with 24% of the current population (5 million residents) born outside Australia (ABS 2010b) with the 'most common' countries of birth for immigrants being England, New Zealand, China, Italy and Vietnam (AIHW 2009c; ABS 2010 b). Although Aboriginal Australians are its original occupants with sustained cultural traditions (Anderson 2006), Australia is now an Anglo-dominated immigrant country, and its assimilation ideology developed a multiculturalism policy in 1986, which resulted in an influx of immigrants (DIMA 2001), many who arrived from the NE Asian region.

The Chinese diaspora maintain their cultural and linguistic distinctiveness, and provide an important Asian cultural imprint in Australian society. This thesis does not have the scope to make heterogeneous distinctions between the different regions in China that Chinese-Australians may have emigrated from. The following summary of dominant cultural characteristics is common to the Aboriginal and Chinese population groups in Australia.

1.3.4.1 Cultural traditions of the Aboriginal population

In Australia, cultural diversity within Aboriginal groups across Australia was found to be as great as the diversity in non-Aboriginal groups. The persistence and strength of Aboriginal identity, as a complex, dynamic and fluid entity (seen to extend into the land one's 'country' or 'place', has prevailed for 200 years and is claimed as central to Aboriginal people's commitment to their community (Bond and Brough 2004). Aboriginal Australians comprise many different communities, each with diverse cultural characteristics such as kinship, language, or the belonging to a particular place or 'country'. Sullivan and Oliver (2004) observed that Aboriginal communities do not exist in a vacuum, but rather in a pre-existing system of (informal) governance that influences people's lives and relationships with non-Aboriginal people and organisations.

Much of the literature on Australian Aboriginal culture focuses on Aboriginal people's beliefs within OR, R and VR regions, but this can not be generalised for those people living in MC and IR regions. Whilst the traditional beliefs of Aboriginal people have adapted to changing circumstances, their placing a specific meaning on health-related events provides them with a coping mechanism for serious illness and death. The manner in which the biomedically constructed services are delivered to Aboriginal people suggests that there had been an absence of conceptualisation of culture as a 'way of life' within some approaches to managing Aboriginal people's health and well-being (Brady 1995; Bond and Brough 2004), and these factors are discussed in Chapter 5.

1.3.4.2 Background to the traditions of Chinese-Australian residents

Demographic and economic changes in China started in the 1990s and have influenced Chinese people's upbringing and created the emergence of a new social psychology (Stockwell and Youyi 2004) although the influence of Confucian values prevails and coexists with emerging social norms. These changes were wrought through a tripartite framework of moral education (Yuan and Shen 1998), described as 'institution-centred' rather than 'person-centred' (Ping 2009), and was considered the weapon of ideological-political indoctrination (Meyer 1990). Furthermore, the integration of both sociological and psychological phenomenon has shaped the basic ideologies of the Chinese population.

1.3.4.3 Shaping Chinese normative values

In the contemporary cultural sphere of the Chinese diaspora familial values (the parent-child relation and child education is the core), familial piety, and a patrilineal family system with male dominance (Cho and Yada 1994; Waters 2005; Palmer et al. 2007) continue to be fundamental to its society's foundation. These normative values are in contrast to Cho and Yada's study (1994) that noted Western families emphasise spousal relations and an erosion of parental authority.

Chinese people place importance on social and instrumental values of stability, relationships and the 'collective' good (Hofstede 1983 in Yuan and Shen 1998) .This factor was supported by later studies (Feather 1986; Domino and Hannah 1987; Senghaas 1998) that also concluded that moral-ethical factors were given high value, reflecting differences in the socio-political environment between 'Western' and 'Asian' cultures.

Studies which compare moral values between China and 'Western' nations identified key differences (Yuan and Shen 1998), but their generalisations need to be treated with caution as the focus on most studies has been undertaken in urban areas [and not in rural China] (Parish et al. 2007). Senghaas (1998) contributed to the proposition that generalisations could not be made about 'Asian values' because they

were especially propagated in East Asia and NE Asia as a political asset, and to specifically differentiate it from 'Western individualism', as a form of governmental social and economic control.

1.3.5 Language diversity in Australia and impact on health information

English is Australia's 'de facto' national language (Gordon 2005) despite 430 language categories being identified. Immigration has resulted in a permeation of the original language within social and domestic networks within cultural groups, and 16% of Australia's population are registered as speaking a language other than English at home, and ~7% of those (aged 15 to 74) have English as their second language causing concerns within the Australian Government that understanding English-based health information may be difficult for these people whose first language is not English' (ABS 2008a, b) (Appendix 4).

1.3.5.1 Aboriginal languages

The retention and strength of local Aboriginal languages prevails with 250 spoken languages and 75% of the Aboriginal population nationally speaking one of 20 languages domestically in their primary communication (ABS 2009a:4714). The 2002 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) (ABS 2009: 4714) reported that over 50% of Aboriginal people (aged 15 years or more) identified with a language group or clan. Appendix 4 identifies the seven main Aboriginal languages spoken in the Central Australian region.

English language capability has impacted on Aboriginal Australians experiences with health services (Lowenthal et al. 2005; Valery et al. 2006). For example,19% of Aboriginal people who live in OR, R, and VR regions reported in the 2002 NATSISS study (National Aboriginal and Torres Strait Islander Social Survey) that they had difficulty in being understood by mainstream service providers compared to 8% of people in MC and IR regions) (ABS 2008b). One urban Sydney study (Koori Elders et al. 1999) demonstrated that story-telling, an oral tradition of the

Aboriginal peoples of Australia is an effective vehicle for disseminating health promotion messages in urban Aboriginal communities.

1.3.5.2 Chinese languages

The majority of Chinese-Australians (64%) people speak either Mandarin or Cantonese languages at home (Appendix 4). With Chinese written language, Mandarin script is in both Traditional and Simplified forms, and these differences in script are critical distinctions for translation. The majority of Chinese-Australians use Simplified script form with Traditional script form mainly used by Taiwanese people and some elderly Chinese-Australians. Among Chinese Australians, a high proportion of people [who will potentially give informed consent for HPV vaccines] rated their English language proficiency as 'not well', or 'not at all' (ABS 2008a), and rely on English literate family members [often a school-child] for language interpretation and translation.

This reliance on a third-party creates tensions with censorship, and the inappropriate need for child involvement in health decisions (Naish et al.1994; Yeo et al. 2005) was reinforced in a small Australian ethnographic study of 15 Chinese-Australian participants that explored associations of cultural meaning and service access (Askell-Williams 2004). Its findings are consistent with Naish and colleagues' study (1994) that explored barriers to access of cancer services that were explained by the impact of acculturation and a need to maintain traditional Chinese beliefs, with the alignment of western biomedical explanations.

1.4 Profile of Australian General Practice (GP) medical services

In Australia GPs are integral to primary health provision (McMurray and Param 2008), and the majority (~85%) of the population, predominantly to females' age 15 years and over (Britt et al. 2009), visit a GP annually, and place high value and trust in them (Harris and Mercer 2001; Raupach et al. 2001; AGPN 2010). The average Australian GP consultation, which uses a fee-for-service structure (an Australian Government health initiative and rebated by Medicare) (Raupach et al. 2001), lasts 14.6 minutes, and

more than 40% of these encounters involve dealing with two or more presenting problems.

GPs deliver primary health services through a cluster of 123 local networks (referred to as Divisions of General Practice that manage GPs needs) that vary in their profiles within defined geographical areas throughout Australia (DHA 2008). There is variation between the ratios of gender of GPs within the geographic regions, as illustrated in Table 1.

Table 1: GP headcount by gender and broad geographic region (Aust. Govt. Dept Health & Ageing December 2009)

Year	**Major City**		**Regional**		**Remote**	
	Female	Male	Female	Male	Female	Male
2008-09	7,500	10,891	2,429	4,289	239	378
% change on 2000-01						
2008-09	20.10%	-0.60%	47.30%	12.30%	85.30%	31.70

More male GPs than females practice within each region. Significant increases in the ratio of females practicing since 2001 is evident in the Regional and Remote regions (47.30% and 85.30% respectively), which is three to four times that of the increase in male GPs (12.30 and 31.70% respectively). Despite this increase, there is still an increase of 150 male GPs practicing in remote regions, which has implications for Aboriginal women's health.

1.4.1 Aboriginal people and health service use

By world standards, Australia is classified as a healthy nation, although Aboriginal people have a different health profile with reduced access to health services based on historical, cultural, linguistic, and socio-economic factors (Trees 2008), especially in rural and remote areas (Ring and Brown 2002; Stephens et al. 2005; McMurray and Param 2008; Smith Humphreys et al. 2008; ABS 2010a), and 'unique to Aboriginal communities' (Lowenthal et al. 2005:106). This has resulted in higher mortality and morbidity rates than non-Aboriginal people across all age groups (ABS 2010a), and especially with infectious diseases in Aboriginal people (Ring and Brown 2002; McDonald 2004; Zhao et al. 2004; Lowenthal et al. 2005; McIntyre and Menzies 2005; Peachey et al. 2006).

Aboriginal ‘identity’ is perceived as a determinant of Aboriginal people’s disconnectedness with mainstream medical clinics due to the clinic being seen as ‘someone else’s country’ (Morgan et al 1997; Maher 1999). To over come this, Aboriginal Health Workers (AHW) play an integral role in the health and well being of Aboriginal peoples (Willis et al. 2005; Mitchell and Hussey 2006; Hooper et al. 2007), especially through Aboriginal Community-Controlled Health Service (ACCHS) where women have confidence and trust in the staff (Reath 1999; McCave 2009). This has resulted in an increase in clinical health services (Maher 1999; Budd 2007) for women’s health programs (84%), screening services (79%) (O'Brien et al. 2000; Couzos 2008), and sexual health services (Kelly 2005). In contrast, Aboriginal adolescents were reported (Blair et al. 2005) to have had less contact with all types of health providers and services compared with non-Aboriginal children.

1.4.2 Selected Australian health promotion strategies

In Australia, health promotion is a ‘core function for all public health’, with selected health promotion (SHP) activities that target specific health matters (AIHW 2009c: 35). For example, with cervical screening in Victoria, a *‘Don’t Just Sit There*’ media campaign (television and radio) resulted in a 13% increase in screening during the campaign period. For Victorian Aboriginal women in 2007-2008, a *Protecting Our Mob* program provided culturally relevant cervical screening education resources and a comprehensive guide on cervical cancer prevention (AIHW 2009c: 75).

1.4.2.1 GPs and sexual health issues

Health promotion is an emerging aspect of GPs clinical practice (Raupach et al. 2001:363) as a way of them increasing ‘social capital’ and connections with the communities they serve (Zwi and Henry 2005). Many GPs consider health promotion to be ‘difficult and lengthy’ (Sherris et al. 2006: S3 / 210) playing only a minor role in the health care they offer, and their participation in it is voluntary, and mostly ambivalent (Raupach et al. 2001). An Australian study (Smith et al. 2007) with adults 16 to 64 years of age that analysed GPs activity in 2005 and 2006 determined that 1 in 15

consultations with a GP concerned sexual and reproductive health. The management of diagnosed sexually transmitted infections (STIs) forms only a small part of a GP's workload in Australia with viral STIs (genital herpes at 0.08 per 100 encounters; genital warts at 0.07 per 100 encounters) reported as the most commonly managed conditions. Sexual health data from the BEACH program is described in Appendix 5.

1.5 Australia's sexual health strategies

Young Australians under age 25 years are reported to have higher rates of STIs than other Australians, and as found elsewhere in the world and are attributed to behavioural factors (Jordan et al. 2004). To address this incidence, several sexual health strategies have been developed in Australia (Appendix 5), but they do not sufficiently address the full range of STIs, including HPV, and there is little parallel formalised national sexuality education.

1.5.1 Adolescent sexual health in Australia

Social changes in Australia over the past four decades have resulted in a change of attitudes towards sexuality, marriage and other sexual conditions. Since 1997, more young people are reported as being sexually active (Boyle et al. 2003; Rissel 2003; Agius et al. 2006; Garland et al. 2008), with the median age for first vaginal intercourse for both males and females identified as 16 years [Year 10 of Australian secondary school] (Garland et al. 2008), with 10 to 20 years of sexual activity before committing to a life partner (Jordan et al. 2004; AAP 2005; Smith et al. 2007). First vaginal sexual intercourse before age 16, in 13% of women and 22% of men, was also reported (Rissel et al. 2003; Garland et al. 2008), and this is consistent with findings of genital HPV infection evident in adolescents, and an indicator of sexual debut (Agius et al. 2006; Burchell et al. 2006; Manhart et al. 2006; Dunne et al. 2007). Australian adolescents were also found to have inconsistent safe-sex practices and varied low levels of knowledge about STIs, and this raises concerns about the challenges that health educators face with adolescent sexual activity before the age of 17 years (Agius et al. 2006).

1.6 Background to the immunisation of Australian adolescents

In Australia, the responsibility to achieve high immunisation coverage (*National Immunisation Program Schedule* (NIPS)) is shared between the Federal Government and State and Territory Governments (DHS 2008a:3). The Australian Government initiated the *Immunise Australia* program in 1997 (as part of the NIPS and developed the *General Practice Immunisation Incentive* (GPII) scheme, to maintain high coverage rates (AGPN 2010) of immunisation through GP clinics. The expenditure for the *National HPV Vaccination Program* (NHPVP) in 2007 was $235.8 million (AIHW 2009c: 47) across Australia.

1.6.1 Australian adolescents and school based immunisation

In Australia, local government agencies deliver the vast majority of the NIPS adolescent immunisation through a well established school-based program (DHS 2008a:8) (Table 2).

Table 2: Australian and Victorian adolescent immunisation schedule: 2010 and ongoing (DHS 2008a; DHA 2010b)

AGE	VACCINE
#10 -13 years	*Hepatitis B*: Two doses for students not previously vaccinated, with an interval of four to six months. *Chickenpox*: Varicella-zoster (VZV) One dose for Year 8 students not previously infected or vaccinated, given at the same time as hepatitis B.
#12 -13 years	*HPV*: One cohort only in this age range. will form part of the ongoing school based vaccination program delivered to female students in the first year of secondary school in conjunction with hepatitis B and varicella
15 -17 years	*Diphtheria tetanus-pertussis* (DTPa): Diphtheria, tetanus and whooping cough (acellular pertussis). One dose for Year 10 students with no previous booster who have had a previous primary course.
15 – 49 years	*Influenza* (Aboriginal and Torres Strait Islander people medically at-risk *Pneumococcal polysaccharide* (23vPPV) (Aboriginal and Torres Strait Islander people)

Key: # Immunisation given in Year 7 secondary school Victoria ~age 12-13

These voluntary programs are proven to be successful, cost effective, and an efficient strategy (as shown with the HBV and rubella vaccine programs), and achieve high population coverage (Buttery et al. 2008; Reeve et al. 2008; Skinner and Cooper Robbins 2010). For example,

in 2001 in Victoria 78.3% of adolescents were reported as having completed their third dose of hepatitis B vaccine through a school based program (NPHP 2001:7); and data for the first cohort uptake of 4vHPV vaccine is discussed in Chapter 2.

1.6.2 The attitudes of Australian Aboriginal people to immunisation

Universal vaccination programs are accepted by Aboriginal people and have achieved excellent disease control, comparable or higher to that in non-Aboriginal people (Hull et al. 2004; McIntyre and Menzies 2004, 2005; Menzies et al. 2008), but this can not be generalised across all regions of Australia, where the reverse was found in northern NSW (Menzies et al. 2004). The success of immunisation programs is determined by several factors, including an awareness of the need for immunisation (PPHP 2001: 10), culturally appropriate services such as an ACCHS, and accessible vaccination schedules (Couzos 2008).

1.6.2.1 Aboriginal adolescents and school based immunisation

The effectiveness of school based programs for Aboriginal adolescents is not consistent across Australia, and particularly in the NT, where they are not regular school attendees due to less access to secondary school in rural and remote communities, and other social factors. For example, in 2004 it was estimated that 36% of Aboriginal children living in OR, R, and VR regions of Australia reach Year 12 at school compared with a national average of 73% attendance (Tsey 1997; Ring and Brown 2002; Askell-Williams et al. 2004).

Chapter 2: Literature Review: Biomedical perspectives of cervical cancer prevention

2 Introduction

This chapter examines the literature regarding the basic elements of HPV epidemiology; its global and Australian prevalence, and differences in HPV genotypes across Australia and South East (SE) Asian populations. The key characteristics of the bivalent (2vHPV) and quadrivalent (4vHPV) HPV vaccines, and the introduction of HPV vaccination into Australia, conclude the chapter.

2.1 HPV epidemiology and impact of HPV infection

Over 200 types of HPV have been identified, of which 40 have a specific genotype in the genital tract, the latter of which were only relatively recently conceptualised as an STI. These genotypes that specifically infect mucosal surfaces have been classified into high and low risk types, according to their oncogenic potential (as shown in Table 3).

The twelve high-risk (HR) HPV genotypes are capable of causing progression to cancer of the uterine cervix. HPV-16 (54.4%) and HPV-18 (15.9%) combined consistently cause 70% of cervical cancers worldwide (de Sanjosé et al. 2010; WHO 2010:1) and seem to be the most virulent of all oncogenic types, causing disease earlier in women than other types. Two further types, (HPV-68 and HPV-73), are probable oncogenic types, i.e. very suggestive of carcinogenic tropism (zur Hausen 1976,1996; de Villiers 1994,2004; Bosch et al. 1995; Walboomers et al. 1999; Schlecht et al. 2000; Bosch and de Sanjosé 2002; Bosch et al. 2002; Bosch and Munoz 2002; Cuzick 2002**;** Goldie 2002; Munger 2002; Gillison and Shah 2003; Munoz et al. 2003; Frazer et al. 2006; Stanley 2008; Castellsague 2008; Schiffman et al. 2009). Whilst HR HPV DNA contributes to 100% of cervical cancers worldwide (Bosch et al. 1995,2002; Schlecht et al. 2000; Munger 2002; Schiffman et al. 2007,2009; Garland and Smith 2010), ICC is considered a rare outcome of very common HPV infection, most of

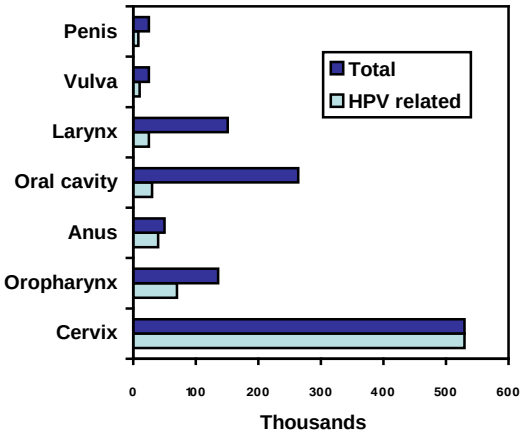
which are transient (Elfregen et al. 2000; NHMRC 2005; Garland et al. 2007; Porta 2008; Allen 2009).

Table 3: Epidemiologic classification of genital HPV types associated with clinical disease (Walboomers et al. 1999 in Frazer et al. 2006:S72; Garland et al. 2009; Schiffman et al. 2009; WHO 2010)

	HPV types	Manifestations
High Risk (HR) types	16, 18, 31, 33, 35, 39, 45,51 52, 56, 58, 59,66, 68,73,82 # 16: 'uniquely powerful' (Schiffman et al. 2009:6) # 18: common in adenocarcinoma (Schiffman et al. 2009:4) #16 (54.4%) + #18 (15.9%) = 70% of cervical cancers worldwide (Munoz 2004;WHO 2010) #16+18+45+31+33 = 83% of cervical cancers worldwide (WHO 2010) # 45,31,33,35,52,58: important globally with regional variations # 51,56,39,59: each causes a few percent of cervical cases worldwide #68: 'probably' carcinogenic (Schiffman et al. 2009:6) #73: possibly' carcinogenic (Schiffman et al. 2009:6) #82: originally classified by Walboomers et al. 1999 #66: found as a single infection in cancers; extreme rarity (Schiffman et al. 2009:6)	Low grade genital lesions High grade genital lesions Cervical cancer Other anogenital cancers: # in women: vulvar, vaginal and anal cytological abnormalities, and the later development of anal, oral and oropharyngeal cancers (Franceschi et al. 1996; Brotherton and McIntyre 2004; Kreimer et al. 2005; Parkin 2006; Dai et al. 2007; D'Souza et al. 2007; Clifford et al. 2006) # in men: penile, anal, scrotal, tonsillar and conjunctival cancers (Giuliano 2007; Palefsky 2007; Garland 2010)
Low Risk (LR) types	6, 11, 40, 42, 43, 44, 54, 61, 70, 72, 81, CP6108 # 6,11 associated with 90% genital warts (Garland et al. 2009)	Low grade genital lesions Condylomata acuminata (genital warts) Recurrent respiratory papillomatosis

The incidence of annual cases of HPV-related cancers worldwide is shown in Figure 1, with cervical cancer the most common (GLOBOCAN 2010; HPV PREV 2010).

Figure 1: HPV related cancers: Annual cases worldwide (GLOBOCAN 2010; HPV PREV 2010).



Some HR genotypes of HPV, especially HPV-16 (which if remains persistent is a 'uniquely powerful human carcinogen' (Schiffman et al. 2009:6), are recognised as a necessary cause of some vulval, vaginal and anal cytological abnormalities, and the later development of anal, oral and oropharyngeal cancers in women (Franceschi et al. 1996; Brotherton and McIntyre 2004; Kreimer et al. 2005; Parkin 2006; Dai et al. 2007; D'Souza et al. 2007; Clifford et al. 2006; Schiffman et al. 2009). Emerging data indicates that penile, anal, scrotal, tonsillar and conjunctival cancers in males are also attributable to HPV infection (Giuliano 2007; Palefsky 2007; Garland 2010).

Twelve of the HPV genotypes designated as low-risk (LR) (Table 3) rarely, if ever, lead to cancer, and research is still being undertaken to determine the oncogenicity status of some other subtypes (Nindl et al. 1999; Meyer et al. 2001; Munoz et al. 2003; Schiffman et al. 2009; WHO 2010). HPV-6 and 11, which are covered by the 4vHPV vaccine, have been identified as the cause in ~90% of cases of genital warts (GW) which are benign, but a major cause of physical and psychologic morbidity, and have a high treatment related cost (Persson et al.1993; Greer et al. 1995; Birley 2001; Aguilar et al. 2006; Frazer et al. 2006; Garland et al. 2007, 2009; Giuliano 2007; Palefsky 2007; Pirotta 2009a, 2009b, 2010; Garland and Smith 2010; Mortensen and Larsen 2010).

2.1.1 Heterogeneity in HPV Type distribution

Whilst HPV-16 causes 50% of cervical cancers worldwide (Manos et al. 1999; Konya 2000; Frazer 2002; Koutsky et al. 2002;Plummer and Franceschi 2002; Villa et al. 2002; Brestovac et al. 2005; Clifford et al. 2005; de Sanjosé et al. 2007; Garland et al. 2008; Kim et al. 2009; Li et al. 2010) it is as a species consists of a number of variants, each with different geographic distributions and carcinogenic potential (Franceschi et al. 2006; Bao et al. 2008; Schiffman et al. 2009; Li et al. 2010). Whilst there has been some variability in percentages contributed to HPV16 and/or 18, some of this may relate to numbers of cancers within studies. In the most recent study of a very large number of cancers, 10,575 in toto worldwide (de Sanjosé et al. 2010), HPV-16 and 18 predominated, being present in 70.8% of cancers from 38 countries.

Globally, the most commonly acquired HR HPV types evident in women with cervical cytology screening results is HPV-16 (De Sanjosé et al. 2007; Li et al. 2010), with HPV acquisition decreasing with age, and other social factors. However caution must be applied in generalising HPV typing for all populations. For example, the prevalence of HPV-18, 31 and 58 was not as common in a Hawaiian cohort (Goodman et al. 2008) as it was for women in North America and in the SE Asian region (Hoover et al. 2008) and this may have direct relevance for HPV vaccination strategies. These differences could also be attributed to the environmental features of sites where samples were collected; differences in collection methods; and the sensitivity of the assay used in the test.

Other HPV subtypes have epidemiological links across and within nations where the distribution of HPV types and proportion of women infected vary greatly across populations (Manos et al. 1999; Berumen et al. 2001; Clifford et al. 2005a,b; Franceschi et al. 2006; Li et al. 2010) and heterogeneity in HPV type distribution exists in women worldwide aged between 15 and 74 years (Clifford et al. 2005a) including multiethnic groups (Franceschi 2006; Manhart et al. 2006; Dunne et al. 2007; Goodman et al. 2008).

HPV-type distribution (after HPV-16) in ICC in the Asia Oceania region has been reported as having different distribution of HPV types than that found in other regions (Bao et al. 2008; Garland, Cuzick et al. 2008; Li et al. 2010). For example, HPV-58 has been detected as the most common type in women in this region, and second only to HPV-16 prevalence in HR types, with HPV-18 more dominant in the Asian region than other areas.

The findings from a cluster of studies (Bao et al. 2008; Shi et al. 2008; Hong et al. 2008; Dai et al. 2008; Lin et al. 2008) undertaken in China with women with ICC were consistent with the findings of major reviews (De Sanjosé et al. 2007;Smith et al. 2008a). Bao and colleagues (2008:4) found that HPV-16 and 18 were the most common genotypes in women with ICC in central China (69.5%), with 67% overall in all Asian geographic regions, with the exception of Japan (51.3 %). HPV-58, 33, 52, 45 and 31 were identified as the next most common genotypes. Whilst there was variation in studies (Bao et al. 2008; Shi et al. 2008) of HPV-18, which was reported as the second prevailing subtype (especially in adenocarcinoma and adenosquamous carcinoma), this may be due to the use of PCR detection techniques with lower sensitivity.

Other studies (Hong et al. 2008; Dai et al. 2008; Lin et al. 2008) reported that, whilst HPV-16 was commonest, HPV-18 was not as common as the aforementioned HPV sub-types. Bao and colleagues (2008:77) concluded that the first generation prophylactic 2vHPV vaccine had the ‘potential to provide protection against 67% of ICC [cases] in Asia’, and that this was consistent with earlier estimates for western nations. Hong and colleagues (2008) also reported that, in addition to HPV-16, HPV-58 was identified as a predominant genotype in Chinese women with ICC, and because of this they raised doubts that the first generation HPV prophylactic vaccines might not offer women in China, and other Asian areas, the same benefit as women in Western regions.

2.2 HPV prevalence

It is estimated that over a lifetime there is a 70 to 80% risk of HPV infection in sexually active men and women. For women, peak prevalence is in those with an average age <25 years when there is a higher probability of acquiring new infections (Pagliusi 2001; Schiffman and Kjaer 2003; AIHW 2004; Brotherton and McIntyre 2004; Stevens and Walker 2004; WHO 2005; Franceschi et al. 2006; Frazer et al. 2006; Da Ros and da Silva Schmitt 2008). Moreover, there is substantial difference in prevalence patterns by age over geographical areas (Franceschi et al. 2006). For example, 'steady declines in HPV prevalence were observed with increasing age in the highest income countries'; U-shaped curves were noted in Latin America (Franceschi et al. 2006:2681); and flat age curves in Asia. In another analysis (Smith et al. 2008a), variations were found to be between 20% (in North, Central and South America, and Africa) and 15% (in Asia and Australia).

A systematic review by Smith and colleagues (2008a) of world-wide genital HPV-DNA prevalence in women (n = 346,160 women from 70 countries over 375 studies), and de Sanjosé's meta-analysis (2007), were consistent in their findings that HPV prevalence is strongly associated with age, although there was difference in prevalence by age across regions. Importantly for HPV immunisation programs, both HPV-16 and HPV-18 show similar age related prevalence across major regions with HPV-18 being less prevalent, and its prevalence differed across regions. However we must be cautious in accepting this conclusion as Smith and colleagues (2008a), and Porta (2009), noted the limitation of current data from some countries, such as lack of available data; selection bias (e.g., only sexually active women); lack of generalisations for large geographic regions (such as isolated rural communities for China and India); or viral prevalence (Franceschi et al. 2006).

In males, HPV DNA prevalence ranges from less than 10% to 72% among predominantly heterosexual men overall (Giuliano 2007; Garland 2010), with the most common oncogenic subtype being HPV-16 (Garland 2010),

and GW being the most common clinical presentation. This is consistent with a cross cultural study (n = 136, mean age 28.5 years) of unmarried males (Hernandez et al. 2006) that found concurrent HPV infection in multiple sites, with GW being the most common. Although males were found to be at equal risk to women of HPV infection (Giuliano 2007; Garland 2010) male prevalence patterns were found to be different to women (as flat line with age).

2.2.1 HPV prevalence in Australian women

An age-specific HPV global prevalence review (Smith et al. 2008a) noted that for Australian women the HPV prevalence, in four Australian studies (undertaken in the 1990s: Fairley et al. 1992, 1994 a b, 1995), ranged from 6% (women aged 13 to 44 years, a mean age of 19 years) to 41% (women aged 18 to 20 years) utilising the polymerase chain reaction (PCR) with the L1 consensus primers method for detection. The large cohort (n = 2,461) WHINURS study (Garland et al. 2008) of Australian women also showed a high risk prevalence (overall 23.6%), with the highest rate in young women. When age stratified to age bands, for women between ages 15 to 19 years, HPV prevalence was at 44%; for women aged 20 to 24 years, at 42%; and with ages 25 to 29, at 34%; and decreasing after the 30s. An earlier study (O'Keefe et al. 2006) reported variations in HPV prevalence among a cohort of 16 to 19 year old schoolgirls in Canberra, Australia, which was slightly lower than in similar age females overseas, and lower than in older Australian women. However it was also found that very young women have fewer partners, who were also young and sexually inexperienced; even then, in this cross sectional study partners of the young girls were also inexperienced and may have explained the low prevalence described.

The first Australian study (Bowden et al. 1998) to determine HPV DNA genotypes (in both sexually active adult Aboriginal and non-Aboriginal women (n=646) living in the 'Top End 'of the NT noted that HPV was a common infection to both groups. A total of 360 HPV types were identified in 311 females, who used a self-administered tampon technique for

specimen collection during their attendance at STD clinics or Family Planning Clinics [in Major City and Inner-Outer Regional areas], and community health centers [in Remote areas]. There was a marginally higher prevalence of HPV in age-matched non-Aboriginal women than Aboriginal women (56.1% versus 41.8 % respectively, with a mean age of 26.1 years), and those without HPV had a mean age of 29.8 years. Non-Aboriginal women were reported to be 'more likely to have more than one HPV type present (30/161; 18.6%) than Aboriginal women (10/150; 6.7%)'. HPV oncogenic genotypes (HPV-16, 18, 31, 33, 35, 39, 45, 51, and 52) accounted for 54.7% of all HPV types detected, with an overall HPV detection in 48.1% of the sample population. This prevalence of HPV (41.8%) in the Aboriginal women was considered to be 'representative of the prevalence for all Aboriginal women' (Bowden et al. 1998:474) as it was a similar finding to results found in three other Australian studies (Borg et al. 1995; Fairley et al. 1994a, 1995) using the same methodology. The difference between the results for Aboriginal and non-Aboriginal women may relate to the curves of acquisition and peak prevalence being more to the left in the Aboriginal population as a result of their earlier age of sexual debut.

In other HPV studies, with Aboriginal women in the 'Top End' of the NT (Reath et al. 1991; Mak and Straton 1993; Fairley et al. 1997, 1998; Bowden et al. 1998, 1999; Cunningham et al. 2008) in similar age groups, prevalence of HPV infection ranged between 2% and 45% in other Aboriginal populations. This phenomenon of increased prevalence is believed to manifest because Aboriginal women acquire detectable HPV DNA early, but its prevalence slowly decreases with age (Bowden et al. 1999; Brestovac et al. 2005), or is a combination of epidemiological and behavioural factors (Condon et al. 2009:72).

An Australian study, (Kattampallil et al. 2002; Zardawi et al. 2004; Condon et al. 2009) of women (n=71) in the Top End of the NT, noted evidence, in a remote community, of a geographic cluster of vulvar cancer (n=32) or high-grade vulvar intraepithelial neoplasia (VIN) (n=39), and limited to

women < 50 years. This incidence (with the age-adjusted incidence rate) was considered to be ‘over 50 times higher (31.1 per 100,000) than the national Australian rate (0.4 per 100,000) for vulvar cancer; and for VIN, the age-adjusted incidence rate was higher (34.7 per 100,000), compared with Aboriginal women living elsewhere (6.7 per 100,000) in the ‘Top End’ of the NT’ (Condon et al. 2009:70). Condon and colleagues (2009:72) surmise that this variation in vulvar cancer incidence may be due to the HPV-16 variant being ‘more virulent at causing vulvar malignancy’ or due to a ‘heritable genetic risk factors’ or possibly an environmental factor (2009:73) in this community, rather than behavioural (smoking) or immunosuppression (diabetes or HIV) factors.

In a study undertaken with Western Australian women (Brestovac et al. 2005), HPV-16, 53, 52 and 58, that are more commonly associated with HPV genotypes in the Asian region, were found to be more common than HPV18. However as only 30% of women tested had HPV16 or 18, the protection that the licensed HPV vaccines would give this group was questioned. This HPV type association suggests a possible epidemiological link between Western Australia and SE Asia. However, the study only looked at genotyping of HPV carriage, not specifically at cancers in Aboriginal women, which may well not correlate.

A high incidence of GW was found in Australian women. Pirotta and colleagues (2009:182) reported on data from a national survey of GP consultations (n= 6,460 GPs / 646,000 consultations: 59% female / 41% male), that ‘GW incidence peaked in women aged 20 to 24 years (at 8.61 cases per 1,000), and in men aged 25 to 29 years (at 7.40 cases per 1,000). These data were consistent with an earlier study by Brotherton and colleagues (2009) who also reported that young Australian women have a high incidence of GW, peaking at age 20 to 24 years, with 26 per 100,000 being hospitalised for treatment. These figures are also consistent with worldwide figures, whereby GW are common and found to be increasing in young women (Kjaer et al. 2007). All women in these categories were of an eligible age to receive the first generation

prophylactic HPV vaccines. It is noteworthy, with implications for 4vHPV vaccination, that GW is 'rarely' seen in Aboriginal women' (Bowden et al. 1998:474), but are a common reason for attendance at STI clinics by non-Aboriginal women (Bowden et al. 1998:474, 1999; Pirotta et al. 2010).

2.2.1.1 HPV serosurveillance

Serosurveillance is a much less sensitive marker of past HPV DNA infection, as only around 50% of those who are DNA positive will make a measurable type-specific serological response (Carter et al. 2001). A study (Newall et al. 2008:1650) on the population seroprevalence of HPV-6, 11, 16 and 18 in Australian women, men, and children, reported that in women, seroprevalence peaked in the 30 to 39 years age group and then decreased with age; and that HPV-6 and 16 was higher among women than in men. In females, the seroprevalence for HPV types 6, 11, 16 and 18 differed across ages, but that 'there was higher seropositivity for HPV-6 and 16 across the whole population' (Newall et al. 2008:1648). For example seropositivity for HPV-6, 16, and 18 (22%, 22%, and 10.5% respectively) occurred in women age 30 to 39 years, and HPV-11 (11.8%) in women 40 to 49 years. This was in contrast to males, where peak HPV seropositivity occurred in men aged 40 to 49 years for HPV-6 and 11 (15.4% and 9.1% respectively); and in the 50 to 59 year age group for HPV-16 and 18 (14.3% and 8.2% respectively). No seropositivity was found in Australian children <10 years of age, which suggests that the modes of HPV transmission (persistent maternal IgG, sexual transmission) are rare for this cohort and do not produce seroconversion. In older children, the presence of HPV antibody positivity was attributed to vertical or horizontal buccal transmission, or sexual abuse (Newall et al. 2009:1651).

2.2.2 HPV prevalence in North-East Asian women

HPV prevalence data, from 10 studies on Chinese women (Smith et al. 2008a), was found to range from 5.5% (women aged 30 to 60 years) to 53% (women aged 22 to 36 years), and this could be explained by the heterogeneity in the Chinese population as well as age. Despite the

consistent reporting of the prevalence of HPV-16 as the dominant subtype, the study of Lin and colleagues (2008) in the eastern area of the Guangdong region of China found similar rates of HPV prevalence to other global studies, but there were two novel findings. Firstly that HPV prevalence increases then plateaus with age, and secondly, that the predominant HPV genotypes were HPV-52 and 58; which correlates with HPV-52 and 58 detected in ICC cases. Lin and colleagues (2008) reported on similar findings in two other studies of subtypes HPV-52 and 58 in women from Hong Kong and Taiwan. The difference in prevalence curves in these populations may relate to the lack of any organised cervical cytology program and therefore treatment of precursor lesions.

2.3 Determinants of HPV infection

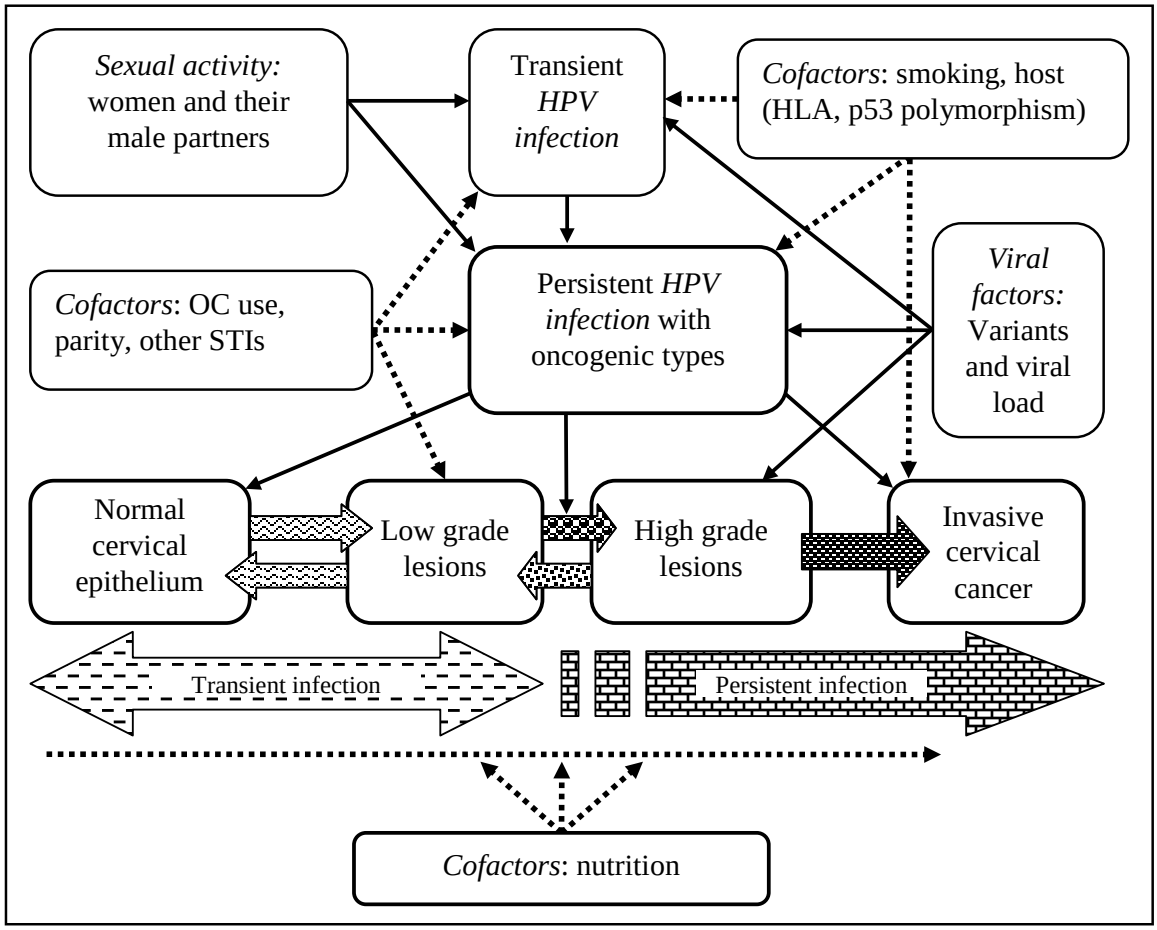
HPV has been classified as a common viral sexually transmitted and asymptomatic infection which is highly contagious (de Sanjosé et al. 2007). The term *infection* is a critical distinction as it is often misrepresented as a *disease* (Porta 2008, 2009). Determinants of HPV infection, as shown in Figure 2 (Frazer et al. 2006: S72), have been identified as young age and behavioural factors (such as a greater lifetime number of sexual partners, nuliparity, marital status (Burk et al. 1996; Vaccarella et al. 2006; Dawar et al. 2007); education (Franceschi et al. 2009); and often compounded by high risk behaviours such as drinking alcohol, using oral contraceptive medication and smoking (Burk et al. 1996; Vaccarella et al. 2006; Dawar et al. 2007; Goodman et al. 2008; Garland et al. 2008).

Tobacco smoking, the link between long-term oral contraceptive use and greater number of sexual partners, are thought to be co-factors in the risk of initial HPV infection, especially in Australia (Garland et al. 2008). Other global studies noted inconsistent findings (Baseman and Koutsky 2005; Moscicki et al. 2006; Trottier et al. 2006; Goodman et al. 2008).

Because of the asymptomatic nature of HPV, studies have shown there is a high rate and relatively fast transmission between an HPV infected partner to a non-infected partner for both men and women (Hippelainen et

al.1991; Agarwal et al. 1993; Verhoeven et al. 2006). Men who have sex with men, and those who are immunocompromised, are also considered to be high risk of HPV infection (Frazer et al. 2006; Giuliano 2007; Kim et al. 2007; Sharma 2008; Huh and Roden 2008).

Figure 2: A multifactoral model of cervical carcinogenesis (Adapted from Spence et al. 2005 in Frazer et al. 2006:S72; PATHa 2010)



Key: OC oral contraceptive

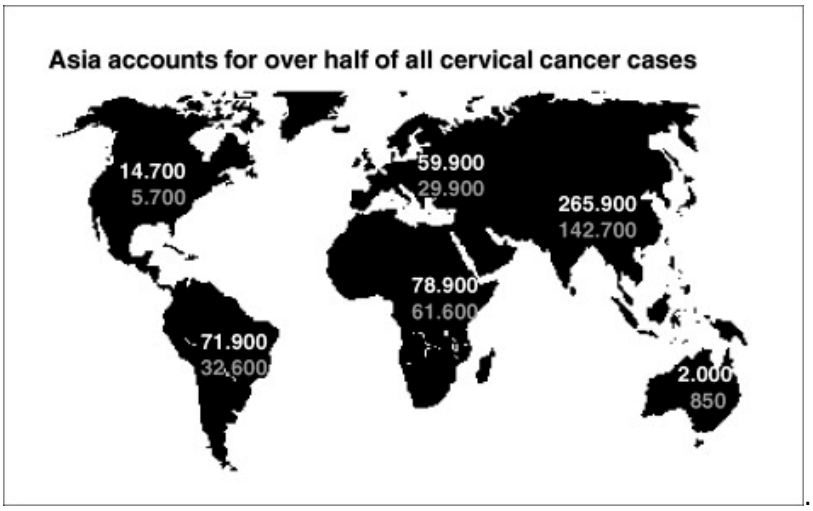
2.4 Invasive cervical cancer (ICC) and global incidence

Invasive cervical cancer continues to be a global problem affecting women, and with approximately 529,000 new cases identified each year (and 274,000 deaths) it is the second most common cancer globally, been second to breast cancer (GLOBOCAN 2008). The greatest burden from ICC is borne by women in developing countries, with 452,000 cases

diagnosed annually and high mortality rates of nearly 241,000 deaths annually (88% of the global incidence) (GLOBOCAN 2008).

Major risk factors for the development of ICC, in the absence of cervical screening, include persistent oncogenic type HPV infection, higher number of sexual partners, cigarette smoking, and long-term use of oral contraceptives (Beral 1974; Jelfs 1995; Bowden et al. 1998; Walboomers et al. 1999; Garland and Smith 2010). Studies by Garland and colleagues (Garland, Brotherton et al. 2008; Garland, Park et al. 2008) reported that half of all world cases of ICC occurred in the Asia-Pacific region (Figure 3). Hence HPV vaccination has critical importance to Chinese-Australian women who may not have been regular participants in Pap screening.

Figure 3: Global incidence of ICC. (Garland et al. 2008)



2.4.1 Incidence of ICC in China

Invasive cervical cancer is an important health problem for women in China, particularly in rural settings, but its incidence is difficult to determine. Women in China were perceived as being at relatively low risk for ICC (Parkin et al. 2002; Bao et al. 2008), and its incidence and mortality rate relatively low, but more recent studies refute this. It is estimated that new ICC cases in China account for 29% of the world's annual total (GLOBOCAN 2008; LAN 2009).

Kim and associates (2009) assert that the incidence and mortality rates have increased in young women in some areas, and elderly women have sustained high HPV prevalence rates. Other data from the Chinese mortality surveys support this, and show variable patterns of risk across the country, and especially in young women in urban settings (Dai et al. 2008; Yang et al. 2003), and women in some rural settings (Yang et al. 2003; Dai et al. 2006) with nearly 200,000 cases reported annually and 20,000 deaths in 2001 (Yang et al. 2003).

The perception of 'low risk' (Jelfs 1995; Bao et al. 2008) of ICC in Chinese women was also refuted by the study of Yang and colleagues (2003), who estimated that ICC had increasing incidence rates (e.g. an increase of 13.8% between 2000 and 2005) and that the incidence would continue to increase due to an ageing population. Shi and colleagues (2008) noted that, despite the increases in the incidence of ICC in China, the overall mortality rate has declined (from 10.7 to 3.1 per 100,000 women) between the 1970s and year 2000. However these data cannot be generalised to all geographic regions within China, as the data was from hospital based registries in the four largest cities, and therefore could be perceived as inexact, and not representative of the country as a whole.

2.4.2 Incidence of ICC in Australia

In Australia, the incidence of ICC is reported as the thirteenth most common cancer, and the nineteenth most common cause of mortality, affecting Australian women, who to age 74 were found to have a 1 in 183 lifetime probability of getting ICC. Since 1991, when a well organised national cytology screening program together with treatment for those with dysplasia (Taira et al. 2004; Garland, Brotherton et al. 2008) was introduced, the age-standardised (world) incidence in Australia of ICC has decreased. In 2005, 5.9 new cases per 1000,000 women, (aged 20 to 69 years) were reported; with 1.5 deaths per 100,000 women in 2006 (AIHW 2009). Despite the low incidence of ICC in Australia there is a relatively high incidence of HPV infection with 100,000 abnormal smears detected

annually, and 15,000 women undergoing colposcopy treatment (Wain 2006).

In Australia, the age standardised mortality rate (SMR) for ICC in non-European immigrants ranged between 1.19-1.23, which indicated that women from these regions experience a relatively greater mortality for ICC than the Australian-born population (AIHW 2004). An Australian study (Pirotta et al. 2009) (n =331), on the psychosocial burden of HPV related diseases noted the significant difference in HPV related diseases between Caucasian and Asian women, as shown in Table 4.

Table 4: Profile of HPV related diseases in Caucasian and Asian Australian women (Summarised from Pirotta et al. 2009:6 Table 1)

	Caucasian	**Asian**
Normal Pap smear	n = 76 (75 %)	n = 20 (20%)
Abnormal Pap smear		
LSIL	n = 51 (88%)	n = 6 (10%)
HSIL	n = 47 (90%)	n = 3 (6%)
Biopsy confirmed CIN		n = 0 (0%)
CIN 1	n = 35 (97%)	
CIN 2+	n = 41 (93%)	n = 2 (5%)
External genital warts	n = 34 (85%)	n = 2 (5%)
Total population	n = 281 (86%)	n = 33 (10%)

On these data the prophylactic HPV vaccines should also reduce the need for colposcopy and other procedures and may have more relevance for older Asian women (Reeve et al. 2008).

2.4.2.1 Incidence of ICC in Australian Aboriginal women

In Australia, there is a disproportionate burden of ICC among Australian Aboriginal women and no specific national data for this cohort exists due to ‘poor quality data in several jurisdictions’ (Cunningham et al. 2008: 586). However studies (Binns and Condon 2006; Cunningham et al. 2008: 587) and Australian Government cancer reports (AIHW 2009b:41) show that the mortality rate from ICC in Aboriginal women is ‘generally significantly higher’ and commonly reported as being four times higher

than for other Australian women (O'Brien et al. 2000; Condon et al. 2006; Garland, Brotherton et al. 2008). The Australian Institute of Health and Welfare (AIHW 2009b:41,51) report that for 'Aboriginal [and Torres Strait Islander] women, ICC incidence was 16.9 new cases per 100,000 women for New South Wales, Victoria, Queensland, Western Australia and the NT combined, more than double the non-Aboriginal [and Torres Strait Islander] rate of 7.1 new cases per 100,000 women. Mortality from ICC in women aged 20 to 69 years for the period 2003 to 2006 was 10.3 per 100,000 women for Aboriginal [and Torres Strait Islander] women, 5.15 times as high as the mortality rate of 2.0 per 100,000 women for other Australian women'.

The proportional increase of ICC incidence in Outer Regional, Remote and Very Remote regions relative to the rest of the Australian population is shown in Table 5. Women in metropolitan areas have a 4 fold risk compared with nearly 10 times the risk for rural women and 18 times the risk for women in remote areas (O'Brien et al. 2000; Binns and Condon 2006).

Table 5: Cervical cancer incidence in Australian regions (Source: Australian Bureau Statistics, 2008

Region (Australia)	Major Cities n = cases	Inner Regional n = cases	Outer Regional n = cases	Remote n = cases	Very Remote n = cases
Cervical Cancer Incidence	468	145	84 *(20%)	13 *(35%)	6 *(26%)

KEY: ***** percentage increase on national average

Whilst caution is needed in analysing explanatory factors for this disparity of disease in Aboriginal women (Baillie et al. 1998; O'Brien et al. 2000; Binns and Condon 2006; Cunningham et al. 2008), contributing historical, social, economic and political forces, such as poor access to and utilization of screening services, and delayed diagnosis for Aboriginal women in rural and remote areas, are deemed to be significant factors (O'Donoghue 1999; Ring 2002; Zhao et al. 2004; Binns and Condon 2006; Cunningham et al. 2008).

Although these disparities portray a grim picture, the incidence of ICC in the NT has declined. For example, between 1991 and 2005 a 68% decrease was reported (Cunningham et al. 2008:587), and mortality from Aboriginal ICC decreased by 92% between 1991 and 2003 (NTDHF 2005; Cunningham et al. 2008:587), and explained by the high level of participation in the population-based cervical screening programs in that region (Binns and Condon 2006; Cunningham et al. 2008). Despite this success, the rates are still higher than for non- Aboriginal women, who experienced a 64% decline in ICC incidence. The screening behaviours of women in Australia are discussed more fully in Chapter 3.

2.5 The first generation of prophylactic HPV vaccines

The first generation prophylactic HPV vaccines, in part developed in Australia, are the second vaccine against a major human cancer, the other being the HBV vaccine which prevented primary liver cancer associated with HBV (Van Damme et al. 1997), and have been introduced into immunisation programs globally. Both HPV vaccines, which use the same technology as HBV, require a 3 dose schedule (1, 2 and 6 month) to be injected intramuscularly and ideally administered within 6 months, and have shown to be well tolerated (Koutsky et al. 2002; Ault et al. 2004; Brown et al. 2004; Harper et al. 2004; Pagliusi and Aguado 2004; Poland et al. 2005; Villa et al. 2005, 2006; Block et al. 2006; Bosch and Harper 2006; Schmiedeskamp and Kockler 2006; Pedersen et al. 2007; Reisinger et al. 2007; Moscicki 2008; Schwarz et al. 2009; WER 2009; Garland and Smith 2010; WHO 2010).

The science that underpins the HPV vaccines was the discovery of virus like particles (VLP) (Zhou et al. 1991; Frazer 2002; Frazer et al. 2006) which mimic the native virus and basically ‘trick’ the immune system. They are the outer shell of the virus, containing no DNA and hence not ‘live’ vaccines (Ault 2007; GSK 2007; WER 2009; Garland and Smith 2010), but maintain the shape of the native virus. The Phase lll clinical trials of both vaccines showed that they were efficacious in preventing persistent HPV infection and related (HPV-16, 18) cervical dysplasia, have achieved

100 % protection against persistent oncogenic HPV-16 and 18 infection in females who were sexually naïve to these types (The FUTURE II Study Group 2007; Garland et al. 2007; Paavonen et al. 2009; Garland and Smith 2010), with high coverage of the target population to date (Paavonen 2009; Garland and Smith 2010). As a result, it is anticipated that with high acceptance and with high coverage of the target population of sexually naive uninfected, young girls, that over time HPV vaccination should achieve its targets for reduction of ICC and its precursors worldwide (BMJ 2005; Garland and Smith 2010).

The aim of the HPV prophylactic vaccination program is to prevent HPV infection and eventually ICC in women by at least 80% (Harper et al. 2006; Ault 2007; The FUTURE II Study Group 2007; Paavonen et al. 2007; Moscicki 2008). HPV vaccines were licensed and introduced into Australia's public health program (Koulova et al. 2008) relatively quickly after the Phase lll trials (as shown in the Timeline, Appendix 6) and then followed by the UK and Canada. In Australia, predictions that the impact of the 4vHPV immunisation program from 2007 on the number of new vaccine related HPV infections would halve (56% decrease) by 2010, with an overall 90% reduction in HPV infections by the year 2050 (Smith et al. 2008a) has started to show results. The impact on GW has shown a 60% reduction in women younger than 27 years of age, and a reduction in young males just from herd immunity (if a high level of females are vaccinated it will have a herd immunity effect on the population) is anticipated (Donovan et al. 2010).

In summary, the 4vHPV vaccine Gardasil ^{TM} (Siddiqui and Perry 2006) protects against HPV-16 and18 (combined, is estimated to give up to 70% protection against ICC) and HPV-6 and 11 (combined, is estimated to give up to 90% protection against GW). It was first licensed in Gabon in March, 2006; and by March 2008 was licensed in 98 countries, and to May 2010 licensed in 120 countries worldwide (Garland and Smith 2010:1089).

The 2vHPV vaccine, Cervarix, protects against HPV-16 and 18 and is estimated to give up to 80% protection against ICC (GSK 2007; Aus Govt

Health 2007; Garland et al. 2007; Garland and Smith 2010). First licensed in Australia in April 2007, by January 2008 a total of 15 countries (2 in North America, 12 in Western Europe, and Australia) had issued formal recommendations or delivery and finance plans about 2vHPV vaccines (Koulova et al. 2008); by March 2008 it was licensed in 44 countries; and by 21 April 2010 it was licensed in 110 countries worldwide (Garland and Smith 2010:1089).

2.5.1 HPV vaccines and genital warts (GW)

Although some countries, including Australia and Mexico, have licensed the 4vHPV vaccine for males as well as females (Twombley 2006; Giuliano 2007), their Governments currently only fund female vaccination (Giuliano 2007). Data from ongoing studies in males have determined the benefit of prophylactic 4vHPV vaccination for men in preventing persistent infection with HPV16,18, 6 and 11 (Giuliano 2007; Koulova et al. 2008; Palmer 2009), and for external genital lesions and anal intraepithelial neoplasia (AIN) (Giuliano and Palefsky 2009), based on immunobridging studies. Acceptability of HPV vaccines for males is based on cost-benefit analysis, the perceived benefit for men, and how the vaccine message is framed (Kim and Goldie 2009; Garland 2010; Liddon et al. 2010).

An Australian national surveillance study, (Fairley et al. 2009; Donovan et al. 2010) on genital warts reported the considerable reduction in the presentation of new cases of genital warts in heterosexual men and women presenting at a sexual health clinic in Melbourne (Australia) after assessment of 4vHPV vaccination though a schoolgirl-based program. For example, in 2008, for women under the age of 28 years, a 25% decrease per quarter was shown; and in men, a 5% decrease each quarter. These reductions are attributed to the impact of herd immunity as very few males had been vaccinated (Donovan et al. 2010; Garland 2010), and these findings are consistent with results reported in a study of GW in geographically dispersed clinics across Australia (Kmietowicz 2009; Fairley et al. 2009; Garland 2010:S25). However, Donovan and

colleagues (2010:4) anticipate that ‘some genital warts will occur unless 4vHPV vaccination is universal’.

2.5.2 HPV vaccine safety and efficacy

Vaccination in general has proven to be a safe, well accepted intervention which has offered an opportunity to maximise disease reduction in diverse communities (McIntyre and Menzies 2005; WER 2009; WHO 2010). With the HPV vaccines for adolescents, the initial prevailing themes around parental concerns were vaccine safety and whether a booster would be needed (Zimet et al. 1997,2005,2006; Davis et al. 2004; Frederickson et al. 2004; Hinds and Cameron 2004; Mays et al. 2004; Hak et al. 2005*;* Olshen et al. 2005; Keane et al. 2005; Rosenthal and Stanberry 2005; Brabin et al. 2006; Dempsey et al. 2006*;* Brewer and Fazekas 2007; Carinci et al. 2007; Constantine and Jerman 2007; Wong and Sam 2007; Hausdorf et al. 2007; Kahn 2007; Lee et al. 2007; Marlow et al. 2007, 2008; Marshall et al. 2007; Ogilvie et al. 2007; Rosenthal et al. 2007; Fazekas et al. 2008; Herzog et al. 2008; Garland, Brotherton et al. 2008; Rosenthal et al. 2008; Breitkopf 2009; Cates 2009; Conroy et al. 2009; Gulati et al. 2009; Marlow et al. 2009; Sam et al. 2009; Robbins et al. 2010).

HPV vaccine safety data were derived from Phase I, II and III clinical trials which are a typical process for all newly introduced vaccines (Brotherton and Gold 2008; Paavonen et al. 2009; Garland and Smith 2010). A ‘head to head’ study of both HPV vaccines, one month after completion of the third dose (Einstein et al. 2009:710-711) reported that, whilst the incidence of ‘unsolicited adverse events’ was comparable for both vaccines, ‘solicited’ symptoms were generally higher in the 2vHPV vaccine group than the 4vHPV vaccine group (95.1% versus 85.1% respectively), but these symptoms were localised at the injection site (localised pain; redness; and swelling), and thought to be related to the use of AS04. The findings (based on the judgment of the investigator) of ‘solicited’ symptoms in the 2vHPV vaccine were consistent with the findings in a pooled analysis of the safety of the 2vHPV vaccine, seven

days after each dose compared with a control group (Descamps et al 2009). Other studies reported the 4vHPV vaccine having only minor side effects at the time of vaccination (Agorastos et al. 2009).

Full protective effect against ICC is not possible with the first generation prophylactic HPV vaccines because immunity is largely type-specific and 16 and 18, which in both vaccines contribute to around 70% of cancers worldwide. The HPV vaccine studies have demonstrated that the HPV vaccines prevent HPV acquisition, persistence and HPV associated pre-malignant disease as surrogates of ICC (Moscicki 2008; Kahn 2009; Gerhardus and Razum 2010). Kahn (2009) noted that the framing of key outcomes, and the complexity of vaccine efficacy, is rarely disseminated in public domains.

Furthermore, because other HPV types (other than HPV-16 and 18) cause abnormal cytology, both the 2vHPV and 4vHPV vaccines have demonstrated *no* therapeutic effect for CIN 2/3 for all HPV types in women who were already infected with HPV types 16 and 18.There was consensus that this might have been compounded by another misconception that results have reported on 100% vaccine efficacy against *infection* with HPV-16 and 18 and on rates of precancerous lesions, specifically CIN and adenocarcinoma in situ (AIS) (Moscicki 2008). Again, this was considered to be not achievable given that HPV status was not known at the time of vaccination in a large ratio of the vaccinated cohort who was sexually active.

Skinner and colleagues (2008: 240) advised that, with past exposure to the vaccine types, the HPV vaccines will have ‘no effect on current disease or recurrence of previous disease’ with the same HPV type, as the vaccines are prophylactic, not therapeutic. The vaccines may offer future protection to those vaccine types for which a female is naïve, due to different and vaccine-related types, and this was shown in the Phase lll trials of sexually active young females. For example, for those HPV types to which they were not previously infected, there was complete protection from HPV infection. The WHO Global Advisory Committee on Vaccine

Safety (GACVS) reported in June 2007 that both the 2vHPV and 4vHPV vaccines had good safety and efficacy profiles, and they reinforced this again, in December 2008 and November 2009, for the 4vHPV vaccine after a series of adverse events were reported (WER 2009; WHO 2010).

2.5.2.1 Adverse events from HPV immunisation programs

No severe adverse events were reported globally during the Phase III trials (Agorastos et al. 2009; Haas et al. 2009), and WHO (2010:12) reported that 'the most common adverse reactions to HPV vaccination have been injection site and muscle pain'. However in Australia, being the first nation to implement an immunisation program with the 4vHPV vaccine, several potential vaccine related events occurred. For example, an episode of fainting of young girls at one Melbourne (Australia) school, which required short term hospitalisation, resulted in widespread media exposure. On investigation, this was considered to be not a 4vHPV vaccine problem but rather a mass psychogenic episode. This event did not result in a loss of confidence in the general community toward the vaccine, partly due to a well organised and responsive risk communication strategy by the Victorian Department of Health (Buttery et al. 2008; Brotherton and Gold 2008; Kang et al. 2008). This is in contrast to the recent suspension of demonstration projects for the 2vHPV vaccine in two regions of India due to lack of public confidence in it for adolescent girls (Larson et al. 2010:572).

Other adverse events were recorded in Australia and globally. In Australia, anaphylactoid responses beyond the normal ratio of responses to vaccines, were also noted in other girls in NSW (Brotherton and Gold 2008), and, despite three related cases of Guillain Barre Syndrome being reported (Australia Cancer Council 2008; Haas et al. 2009), these are not considered to be cause for concern. One case of pancreatitis, in a 26 year old woman, was reported 3 days after 4vHPV vaccination (Agorastos et al. 2009); and five cases of multiple sclerosis were reported between one and three weeks post 4vHPV vaccination. Internationally, one case of a rare condition, brachial plexus neuritis, was reported; two case reports relating

to reactions at the site of vaccination (Agorastos et al. 2009); and a 'possible increase in thrombeolic events in girls taking OC' is being investigated in the USA (Slade et al. 2009; WHO 2010:12) However it is important to differentiate between causality from coincidence and various baseline disease rates of this age group.

Despite these events the global immunisation experts and groups concluded that the incidence [of adverse events] was not higher than 'would be expected by chance' (Agorastos et al. 2009: 7278) in view of the 5 million doses of HPV vaccines administered in Australia as of March 2009, and 23 million doses in the USA at December 2009 (Brotherton and Gold 2008; TGA 2008). Furthermore WHO and other expert groups (WER 2009; WHO 2010) have concluded that, as HPV vaccines seem to be 'safe, effective, and of great importance to women's health' (Agorastos et al. 2009:7279), they are recommended for inclusion into broad-based immunisation programs. The postlicensure safety data is reported as 'broadly consistent' with that of the prelicensure trials, and ongoing and careful monitoring, using 'epidemiologic observational studies', will continue (Slade et al. 2005:756-757).

2.5.3 Age for HPV vaccination

As HPV vaccination will become the primary prevention tool for ICC (Vetter and Geller 2007), for prophylactic HPV vaccines to be most immunologically effective against ICC they are recommended to be given to sexually naïve females (Adams et al. 2007; Cutts et al. 2007; Moscicki and Smith 2008; Smith McCune 2008). Tay and colleagues (2008) propose that given the diversity of the population at risk from HPV infection, and to ensure global relevance, it is essential that the vaccine trials include all representative populations.

The sample population in the vaccine trials has raised doubts about the vaccine's efficacy in the sexually active population, and explains why HPV vaccination is preferential in sexually naïve adolescents (Skinner et al. 2008), although there is some benefit for sexually active adult women between age 24 to 45 years via protection against vaccine HPV types

which they have not been infected with (The FUTURE II Study Group 2007; Munoz 2009:1956). Smith McCune (2008) reported that only a small proportion of participants in the Phase III trials of the 4vHPV vaccine were virgins, and therefore the reduction in cervical intraepithelial neoplasia (CIN) was less than 25%. Only 0.1% of females in the trial had all four HPV-related infections prior to vaccination. However in those naïve to a particular vaccine HPV type there was 100% efficacy for that type. As previously referred to, in those women who are noninfected but have had past HPV infection (that is, those who were DNA negative but antibody positive to one of the HPV vaccine-related genotypes) there is evidence that in this group, when vaccinated, there is a reduction in disease related to these types (Olsson et al. 2007).

Due to the ethics of conducting disease-related studies in young people, the only HPV vaccine trials conducted in preadolescent girls were immuno-bridging studies which gave evidence of higher antibody titres following vaccination in girls 12 to 16 years than that which occurred in older women (Wright et al. 2008; Di Giuseppe et al. 2008; Tay et al. 2008; Castle et al. 2009), and is further justification for vaccinating young school age adolescents. Other studies with clinical end points (i.e., CIN 2/3) involved 16 to 24 year old women (Haug 2008).

HPV vaccination programs targeted only to females are considered to have less impact (Herzog et al. 2008) than a universal program for both females and males, but a female-only approach is considered cost-effective, particularly in populations where cervical screening programs are limited. Several studies (Pagliusi 2001; Monk and Wiley 2006; Adams et al. 2007; Regan et al. 2009; Garland 2010) concluded that the higher burden of cervical disease in some population sectors requires a herd immunity approach, and this would also destigmatise the emphasis on HPV infection as a women's disease (Twinn 2000; Polzer and Knabe 2009; Garland 2010). Psychosocial factors of HPV infection are discussed more fully in Chapter 3.

2.5.4 Impact of cervical screening on the HPV vaccinated cohort in Australia

Australian HPV vaccine experts anticipate that when the [Australian] HPV vaccinated cohort enter the national cervical screening program the impact of vaccination will result in a decline in low-grade squamous intraepithelial lesions (SIL) by around 20%; high-grade SIL by 40% for those vaccinated against HPV-16, 18; and 50% for those vaccinated against HPV-6, 11, 16, 18 (ACC 2008; Kharbanda et al. 2010). A rapid reduction in 'the age-standardised incidence of HPV-16 by 56% (from current levels) in 2010 and by 92% in 2050' is predicted (Smith et al. 2008a:1857-9). However, this will not equate to similar reductions in ICC due to the 'relatively slow development time from HPV infection to ICC' (Smith et al. 2008c:1860). These data may vary across Australian states depending on the uptake through the school-based delivery system (Smith et al. 2008a), and are dependent on ongoing high coverage rates (Smith et al 2008a, c; Garland and Smith 2010). For women aged 27 to 45 years (who were vaccinated through GP clinics) a small incremental benefit (up to 5%) is anticipated in the short term, due to the lower (and elective) numbers vaccinated in this cohort (Smith et al. 2008c).

Despite the HPV immunisation program, ongoing ICC screening is still necessary for women since the vaccine does not offer complete protection against ICC, and maternal encouragement may be important to encourage the vaccinated cohort to participate in cervical screening. Chao and colleagues (2009) noted that the behaviours of mothers (across all cultural and socioeconomic strata) toward their own Pap screening practices was positively associated with consent for their daughter having HPV vaccination.

2.5.5 The implementation of HPV immunisation in Australia

Australia, the UK, and Canada are three of the first countries that have complied with WHO (2005) recommendations and introduced the HPV vaccines into their national immunisation schedules (Koulova et al. 2008; Kmietowicz 2009). The Australian NHVP which offers the 4vHPV vaccine,

was aimed at females with an objective to create 'broad based' immunity for all girls before the onset of sexual activity (DHA 2007b). Australia also established a dedicated *National HPV Vaccination Program Register* (Koulova et al. 2008; Shefer et al. 2008; NHPVVPR 2009) to track completion of the three dose 4vHPV vaccine schedule and monitor the impact of the vaccine on HPV related diseases.

The 4vHPV vaccine, Gardasil ™ was registered by the Therapeutic Goods Association (TGA) (Smith-McCune 2008) in Australia in June 2006, for use in females aged 9 to 25 years (and through a dual approach: an ongoing Government program for 12 to 13 year old schoolgirls; and a 'time-limited' 2-year catch-up program for females aged 13 to 26 years between July 2007 and December 2009); and males 10 to 15 years (Frazer et al. 2006; Siddiqui and Perry 2006; Garland Brotherton et al. 2008). This immunisation strategy had been previously, and successfully, applied for other Australian school-based public health programs, such as rubella and hepatitis B (Skinner et al. 1998). Twelve to thirteen year old females (first year of Australian secondary school) continue to be immunised in an ongoing schedule (DHANHVP 2007; Garland et al. 2008; Koulova et al. 2008; Shefer et al. 2008; DHA 2010b).

Australia was the first country to licence the 2vHPV vaccine, Cervarix, and in May 2007 its use for females, aged between 10 and 45 years on an elective basis (GSK, 2007), was registered; and in 2008 it was recommended for funding by the Australian Government for women between 10 and 26 years of age. The course initially required self-funding of AUD$450 plus the doctor's consulting fee and this created challenges for GPs in advising sexually active patients about the vaccine's benefit due to the limited availability of efficacy data (Harper 2008; Skinner et al. 2008) and its cost. The 2vHPV vaccine was not licensed at the time of the Australia government decision and thus was ineligible for inclusion in the school-based NHPVP program.

2.5.6 HPV immunisation of adolescents through Australian schools

Organised vaccine programs through a school-based approach were implemented on the assumption that the majority of adolescents attended school. However this is not always the case particularly for girls in many countries globally, including Australia, and concerns were raised that HPV vaccination and HPV education may be denied for them (Tjalma and Van Damme 2005).

An Australian study (Smith et al. 2008b) estimated that the initial 4vHPV vaccination coverage rates through the school-based program in 2007 to 2008 would reach 86% (feasible range 67 to 90%) for 12 to 13 year-old girls. However, despite the challenges of introducing a new vaccine into Australia, with its geographic and cultural diversity, the first year of the 4vHPV immunisation program was considered successful, and largely attributed to the success of previous broad-based immunisation programs. The coverage rates for 4vHPV vaccine between states in Australia, and within each state, as well as differences between age groups by school year in the first year cohort is shown in Table 6. These data show that the uptake rate across the age cohorts varies across several states, with an achievement of 80% to 70% uptake rate in populated areas (Rumbold and Nickels 2008; Senior 2008). The NT (a ‘Very Remote’ region) had uptake rates comparable to ‘Urban Region’ populations, such as the ACT and NSW, and a better rate than QU, SA and TAS. Tasmania had the lowest rate of uptake particularly among females in the last two years of secondary school, and for reasons yet unexplained.

Despite these the effectiveness of the vaccination model, in VR regions of Australia the uptake rate was reported as between 10% and 30% in some areas (Rumbold and Nickels 2008). This uptake rate was consistent with data from the 1980s on the sub-optimal uptake in the 5 to14 year age group in the NT, Australia with a HBV vaccine program (Menzies et al. 2004), which suggests that a targeted HPV vaccination approach is needed for the adolescent cohort.

Table 6: Quadrivalent human papillomavirus vaccine coverage (doses administered to enrolled population) in school-based programs, 2007,* by state or territory (Brotherton et al. 2008a)

Dose	Year 6	Year 7	Year 8	Year 9	Year 10	Year 11	Year 12
Australian Capital Territory (ACT): From 30 April 2007					**(Years 10 to 12 combined)**		
Dose 1	NA	82%	NA	NA	79%		
Dose 2	NA	79%	NA	NA	74%		
Dose 3	NA	68%	NA	NA	61%		
New South Wales (NSW): Metro from 17 May***							
Dose 1	NA	NA	NA	NA	84%	82%	84%
Dose 2	NA	NA	NA	NA	81%	79%	81%
Dose 3	NA	NA	NA	NA	75%	72%	75%
Northern Territory (NT): ** From 16 April 2007					**(Years 10 to 12 combined)**		
Dose 1	NA	NA	NA	NA	80%		
Dose 2	NA	NA	NA	NA	71%		
Dose 3	NA	NA	NA	NA	64%		
Queensland (QU): From 17 April 2007					**(Years 10 to 12 combined)**		
Dose 1	NA	NA	NA	NA	74%		
Dose 2	NA	NA	NA	NA	69%		
Dose 3	NA	NA	NA	NA	62%		
South Australia (SA): From 2 April 2007							
Dose 1	NA	NA	83%	69%	70%	64%	66%
Dose 2	NA	NA	78%	64%	64%	57%	60%
Dose 3	NA	NA	77%	65%	64%	57%	55%
Tasmania (TAS): From 11 April 2007							
Dose 1	76%	72%	70%	67%	73%	64%	57%
Dose 2	71%	67%	65%	63%	67%	58%	52%
Dose 3	64%	61%	58%	55%	57%	50%	44%
Victoria (VIC): From 16 April 2007							
Dose 1	NA	85%	NA	NA	82%	81%	82%
Dose 2	NA	81%	NA	NA	76%	76%	78%
Dose 3	NA	75%	NA	NA	69%	70%	71%
Western Australia (WA) ** From 1 May 2007					**(Years 10 to 12 combined)**		
Dose 1	NA	NA	NA	NA	71%		
Dose 2	NA	NA	NA	NA	67%		
Dose 3	NA	NA	NA	NA	60%		

KEY: ***** Does not include catch-up doses delivered in general practice/community health settings, except in South Australia where these are partially recorded.
**In some (smaller) areas the whole school will be vaccinated
*** Country and remote schools may be earlier.
NA Not applicable as this year cohort was not targeted in 2007

2.5.6.1 Comparison with uptake of HPV vaccine in the Netherlands, UK and USA

In the Netherlands (Rondy et al. 2010:2071) the uptake of the first dose of 2vHPV vaccine, through a ‘catch-up’ program, ranged from 31% to 61%, lower than the anticipated 70% uptake. Differences in the Netherlands data were evident across regions, and partly attributed to socio-cultural and structural factors. Younger and older girls were ‘slightly less vaccinated’, and religion and prior experiences with MMR vaccination were reported as influences on intentions to consent. Higher coverage was attributed to cultural (girls whose parents were both Dutch nationals) and socio-economic factors, and endorsement of professional entities (doctors and schools).

The 2vHPV vaccine was introduced into the UK through its childhood immunisation schedule in September 2008, and targeted adolescent girls aged 12 to 13 years, and from August 2009 targeted 14 to 18 year olds in a two-year ‘catch-up’ program (Forster et al. 2010). HPV vaccine uptake ranged between 69% (Brabin et al. 2007) and 85% (Forster et al. 2010) of the first cohort who received the first two doses of the HPV vaccine, compared to 54% of the first cohort in the ‘catch-up’ group.

In the USA, the national HPV vaccination program for women (that required full funding) was introduced in 2008 (Appendix 6), and early uptake data reported that, in the two to five month period after introduction, 10% of 18 to 26 year old women had been vaccinated, most of who were from higher socioeconomic demographic backgrounds (Jain et al. 2009). In 2009 there was a slight increase in uptake, with the USA Centers for Disease Control and Prevention (CDC) reporting that 44% of teenage girls had at least one dose of HPV vaccine, and 27% of them had received the recommended three doses, well short of the government goal of reaching 90% vaccine coverage (Kaiser 2010).

2.5.7 HPV immunisation of adolescents through Australian medical clinics

In Australia, a dual approach through schools and GP clinics was considered essential for optimal HPV immunisation coverage in the adolescent cohort (Reeve et al. 2008; Smith et al. 2008b). Vaccination coverage in previous adolescent immunisation programs had been less than 25%, if administered through health clinics alone, despite GPs undertaking opportunistic vaccination. Despite parent concerns that the pain of immunisation would be a deterrent, students were compliant with the dosage schedule they reported increased pain with each dose (Reeve et al. 2008).

In Australia the two-year 4vHPV vaccine ‘catch up’ program proved to be successful although data is still incomplete. By 2008, a NSW family planning clinic survey (Weisberg et al. 2009) found that 58% of females (n = 294) aged 15 to 26 years had received at least one dose 10 months into the HPV ‘catch-up’ program, and 53.6% (n = 59) of those women made a specific vaccine-purpose visit. A study (Reeve et al. 2008) in rural north Queensland noted that the uptake of HPV vaccines through GP clinics (89%) was higher than that predicted in other states, and partly attributed to those students (7%) who were absent on the day of immunisation and later engaged with the catch-up program through GPs. In other states, a 77% uptake was anticipated in South Australia (Marshall et al. 2007); and a 54% uptake was anticipated in Queensland (Hausdorf et al. 2007).

Chapter 3: Literature Review: Attitudes toward cervical screening as cervical cancer prevention

3 Introduction to cervical cancer screening

Before the introduction of HPV vaccination, worldwide efforts of ICC prevention were achieved through comprehensive population screening programs and the treatment of precancerous lesions (GLOBOCAN 2008), but these services are not available to all women globally (Bingham et al. 2009a; Garland and Smith 2010), and especially in LDC countries (Shah 2008). This disparity in access to screening services has resulted in little effect on reducing the morbidity and mortality from HPV-related disease (HRDOP 1995; Bingham et al. 2009a). HPV vaccination for populations in LDC countries will be most beneficial although HPV vaccination will not replace the need for cervical screening, which is an ongoing necessity for all women globally to age 69 years, including the vaccinated cohort (Franco et al. 2006; PATHa 2010). The cervical screening practices and knowledge of women relevant to this study, and the role of GPs in screening practices, are reviewed.

3.1 Australia's cervical screening program

In Australia, the *National Cervical Screening Program* (NCSP) [originally titled 'The Organised Approach to Preventing Cancer of the Cervix' (AIHW 2009c: 67)] was implemented in 1991, and targeted at women aged 20 to 69 years (Dickinson 1999, 2002; Stevens et al. 2006; Brotherton 2008; AIHW 2009c), with screening services provided as part of mainstream health services. The majority of Pap tests are performed by GPs, with the cost being rebated and often free of charge through specialist clinics (AIHW 2009c: 67). The NCSP has significantly reduced the incidence of ICC (Farnsworth and Mitchell 2003; Taira et al. 2004; Canfell et al. 2006) by more than 50% between 1991 and 2005 (from 1,092 new cases of ICC in 1991 to 734 cases in 2005: 7.27/100,000 to 6.9 / 100,000 respectively) (AIHW 2009b).

Total participation of Australian women in the NCSP is comparable to rates of international cervical screening programs (Budd 2007), and their participation is shown to increase with a longer screening interval. For example, in 2006 and 2007 in the target age group, with a two-year screening interval the participation rate for the NCSP was 61.5% of women; with a three-year screening interval participation increased to 74.0% of women; and with a five-year screening interval participation further increased to 86.4% of women (AIHW 2009a,b; DHA 2010). Among younger women (aged 20 to 24 years) eligible for cervical screening during 2005 to 2006, 47% of women participated (AIHW 2009a, b). Despite these participation rates, 39.5% of Australian women did not comply with the recommended screening interval of two years, and especially women who reside in R and VR locations where access to screening services is difficult (Lowenthal et al. 2005; DHA 2010).

Participation rates by geographic region between 2006 and 2007 reported 62.5% participation for MC regions; 61.2% participation for IR regions; 58.9% participation for OR regions; 53.6% participation for R Regions; and 54.0% participation for VR regions. The differences between the geographic regions were considered to be significant (apart from R and VR regions, which are not significantly different from each other), and this trend reflects the challenges in providing cervical screening to women in those areas (AIHW 2009).

3.1.1 Cervical screening and Australian Aboriginal women

Programs that support gynaecological health have been established specifically for Australian Aboriginal women, such as the *Northern Territory Women's Cancer Prevention Program* (NTWCPP); the *Remote Areas Well Women's Screening Program* 1994 (WWSP); the *Northern Territory Pap Smear Register* 1996 (NTPSR); and the *Gynaecology Outreach Service* 1997 (Binns and Condon 2006). Reliable data on specific screening participation rates for Aboriginal [and Chinese-Australian women] is not available due to the lack of cultural identifiers

(Binns and Condon 2006; Cunningham et al. 2008), but several studies reported varying rates of participation.

The pattern of screening participation among Aboriginal women varies over time and with the geographic data reported earlier, indicating the difficulties in obtaining a reliable picture. For example, data from 1996 and 2001 (Hunt 1998; Coory et al. 2002) showed that 20% to 64% of the Aboriginal female population had never screened, but increases are evident in recent years. The 2001 *National Health Survey* reported that 50% of Aboriginal women aged 18 years and over had regular Pap smears (ABS 2010a); and in the NT rates remained static (about 44.0%) after 2001.

Whilst the rates are reported to be lower for Aboriginal women in rural and remote areas (O'Brien et al. 2000; Lowenthal et al. 2005; Binns and Condon 2006; Couzos 2008; Cunningham et al. 2008), including three R and VR regions in the Top End, and Apatula in Central Australia (Binns and Condon 2006), these data cannot be generalised for all rural and remote regions. For example, recent data shows participation rates for women in the NT and remote Queensland to be two-thirds of the national average (Binns and Condon 2006; Cunningham et al. 2008), with some areas having higher participation than the national average (in Darwin from year 1997; Alice Springs from year 2000; and Area 'D' in the Top End) (Binns and Condon 2006:493; Cunningham et al. 2008). The successful rates of participation in VR regions Australia are attributed to the efforts of the allied health staff and organisational program factors (Binns and Condon 2006; Mak and Stratton 2008), especially the NTWCPP (Binns and Condon 2006). This is translating into a reduction in the gap in the incidence of ICC between Aboriginal and non-Aboriginal women.

3.1.2 Cervical screening in China

In mainland China the majority of women have never been screened, and opportunistic cervical screening was previously only offered within national health plans, and only in some regions (Tay Ngan et al. 2008). This

situation changed with the introduction in July 6 2009 of a Chinese government-sponsored program of free cervical cancer screening examinations for women between 35 years and 59 years (Shi et al. 2008). This initiative is supported by a parallel project that aims to increase the awareness of ICC among health professionals in each province.

3.2 Barriers to cervical screening in Developed Countries

In countries where screening opportunities are available underscreening practices continue (Kuitto et al. 2010), especially among immigrant women (Ponce et al. 2006; Downs et al. 2008; Fiebig et al. 2009). The differences in the screening practices of 'minority ethnic groups' (Elkan et al. 2007:109), and Indigenous women in New Zealand (Lovell et al. 2007), was found to be not due to apathy, but more to factors such as language and knowledge barriers (Ponce et al. 2006; Elkan et al. 2007; Lovell et al. 2007; McCave 2009), cost, and access to services (Elkan et al. 2007; McCave 2009).

A lack of cultural competence and health literacy, such as language difficulties and a lack of understanding of health-service processes were found to be a major obstruction for some cultural groups in availing themselves of health care services (Breitkopf et al. 2005: 82; Ponce et al. 2006; Harmsen et al. 2008). Language barriers for Asian-American women were found to be a 'major contributor' to cervical screening disparities in the USA (Ponce et al. 2006:1002).

Cultural norms, especially modesty, influenced American-Vietnamese women's participation in cervical screening, which compromised their cultural beliefs about sacredness. Additionally for them, preventative health care is perceived as a 'Western' concept, which is contrary to the Vietnamese community's concept of health management which is through the application of herbal medicine (Chilton et al. 2005). These findings are consistent with an earlier review of population groups who were at risk of underscreening (Siahpush and Singh 2002; Ponce et al. 2006). Women also have concerns about the Pap test procedure, finding it 'embarrassing' or 'troublesome' (Yu and Rymer 1998); and in the UK women perceive that

the test induces pain and discomfort (Breitkopf et al. 2005). However these findings should not be generalised to all under-screened women as the studies were not representative of the total population.

3.2.1 Barriers to cervical cancer screening among Australian women

In Australia, barriers to cervical screening for some women are reported as systemic, economic and psychosocial factors, including access to health services, domestic and economic factors, poor knowledge, and stigma around Pap screening (Morgan et al. 1997; O'Brien et al. 2000; Binns and Condon 2006; Cunningham et al. 2008; Fiebig et al. 2009); and socio-cultural factors especially holistic perceptions of health, and especially of cancer (Thurecht 2000; Cunningham et al. 2008), and women's need for privacy (Morgan et al. 1997). Australian [and UK studies] (AIHW 2004; NCSR 2010) found that some immigrant groups have lower rates of participation in cancer screening programs are due to socio-cultural factors relating to beliefs, attitudes and knowledge, differences in religious and philosophical beliefs (Wray 2004; Ross and Fernández-Esquer 2005; Sinha et al. 2005; Lui et al. 2009), as well as acculturation, and length of Australian residency (Cheek et al. 2008; Lesjak et al. 2008).

A review of qualitative studies (Taylor et al. 2001) noted that immigrant women in Australia and New Zealand were not averse to cervical screening, and that participation was enhanced by the provision of culturally appropriate and targeted services. This fundamental need of women to believe in, and understand, the value of cervical screening was supported in other studies (Shelley et al. 1994; Mandelblatt et al. 1999; Jennings-Dozier 1999; Taylor et al. 2001; Gao et al. 2008). Yeo and colleague's study (2005), on the attitudes of Chinese-Australian women to cervical screening, found two important but contrasting insights. Firstly, that the women believed that benign tumours had the capacity to evolve into malignant tumours, which may explain their reluctance to attend for Pap screening; and secondly, that their verbal exchanges with the health

professional were culturally bounded and interdependent, and this need for social congruence was often not understood.

3.2.1.1 Barriers to cervical screening for Australian Aboriginal women

Key factors in Australian Aboriginal women's engagement with mainstream health services are culturally and attitudinally bound. For example, women's perceptions of the health care provider; lack of confidentiality; lack of trust; and lack of understanding of traditional and contemporary Aboriginal culture and gender in the health care provider (Morgan et al. 1997; Toussaint et al. 1998*;* Kirk et al. 1999; Koori Elders et al. 1999; Kahn et al. 2001; Trees 2008; Mooney-Somers et al. 2009). Furthermore, these barriers can intensify when the purpose of the visit is gynaecological or sexually related (Trees 2008; Mooney-Somers et al. 2009); or if the health provider is a male, or non-Aboriginal (Koori Elders et al. 1999). The perception of cancer risk among Aboriginal people from the NT and Queensland was found to relate to psycho-social factors of disadvantage, rather than biomedical explanations, and fear of cancer, as a 'death sentence' that could not be fixed medically, was a persistent finding (Cunningham et al. 2008).

Carefully structured and culturally relevant communication strategies were recommended as a way to impact on cervical morbidity in Aboriginal women (Cunningham et al. 2008; Garland et al. 2008). For example, the number of Aboriginal women having cervical screening increased after AHWs (who had participated in a related education project) educated women in their communities about Pap tests and ICC factors (Mitchell and Hussey 2006). Whilst this reinforces the preference of Aboriginal women for women to treat 'women's business', this approach does not guarantee an uptake of health services, especially if women in the community feel uncomfortable with one of their community (such as a local AHW), examining them, especially for Pap tests (Reath 1999). Finn and colleagues (2008) posited that barriers to screening that were described for the Aboriginal Australian population (knowledge and communication

difficulties, fear, cultural alienation within a westernised model, and 'stigma') were not exclusive to Australia, but common to Indigenous populations globally.

3.2.2 Barriers to cervical screening for Chinese women

The influence on Chinese people's health behaviours that emerged from the literature, is both explanatory and conceptual, and partially explains women's attitudes toward cervical screening. Chinese women's beliefs about cervical screening are conceptualised from biological, psychological, environmental, lifestyle and sexual factors (Dickinson and Chan 2001; Kwong 2006; Lee et al. 2007; Kwan et al. 2009), and may be also attributed to Chinese women being uncomfortable in discussing sexual issues (Kahn et al. 2005: in Brumder 2009; Chow et al. 2010), or having their 'genital areas examined by a male doctor' (Dickinson and Chan 2001:285).

Women's reluctance to accessing mainstream western health services are described as a sense of invulnerability; fatalism; reticence and a preference for Confucian medical practices (Naish et al. 1994; Askell-Williams 2004; Yeo et al. 2005; Ponce et al. 2006; Howlett et al. 2009; Lui et al. 2009; Mast et al. 2009), and confusion about foreign health systems (Kwong 2006). Among Asian (Chow et al. 2010) and German women (Kuitto et al. 2010) knowledge did not impact on screening attendance but attitudinal factors, such as their subjective risk of ICC, was a major deterrent to screening participation.

3.3 Women's knowledge and perceptions of risk of HPV and ICC

Informed consumers are considered to be in a better position to manage their health and well-being (Lewis et al. 2001; Reed 2002; Cuzick et al. 2006; Wetzel et al. 2007; Armstrong and Murphy 2008; Deveraux et al. 2008; Harmsen et al. 2008; Robbins et al. 2010). Knowledge levels of HPV and cervical cancer vary among women globally and in Australia (Breitkopf et al. 2005; Anderson 2006a; Klug et al. 2008), and without certain levels of knowledge women were found to improvise their own

interpretations of causal associations of ICC risk factors in complex and sophisticated ways (Armstrong and Murphy 2008:1080). Furthermore, knowledge levels, education, and information dissemination of HPV vaccines and ICC among the population, are considered integral to women participating in ICC prevention strategies (Davis et al. 2004; Washam 2005; Mosavel and El-Shaarawi 2007; Brumder 2009).

Low levels of knowledge and misconceptions, especially among women about the function and benefit of cervical screening, HPV, and risk factors was shown in most studies (Baer et al. 2000 [adolescents]; Blake Weber and Fletcher 2004 [adolescents]; McCaffery and Irwig 2005; Breitkopf et al. 2005; Giles and Garland 2006; McClelland and Liamputtong 2006; Moreira et al. 2006; Hausdorf et al. 2007; Marshall et al. 2007; Rosenthal et al. 2007; Domingo et al. 2008; Konno et al. 2008; Garland et al. 2008a; Kollar and Kahn 2008; Sankaranarayanan et al. 2008; Shi et al. 2008; Tay et al. 2008; Stark et al. 2008; Vanslyke et al. 2008; Robbins et al. 2010 [especially among adolescents]). With Australian Aboriginal women, more than 80% of women underwent ‘well women’s health checks’ women generally remained ignorant about genital symptoms (Bowden et al. 1999; Binns and Condon 2006; Cunningham et al. 2008).

In Australia, some women displayed good knowledge of HPV factors (Pitts et al. 2007); and knowledge levels showed varying rates of improvement after HPV vaccination (Kollar and Kahn 2008; Jain 2009). An Australian study (Pitts et al. 2010) (men n=2556; women n=2634) on the impact of HPV vaccine implementation on knowledge levels of HPV and ICC found there were marked increases in knowledge of HPV (62.8% women; 38.3 % men), and ICC (66% women and 38.3% men).

In studies on knowledge levels of cervical screening, a qualitative mixed-culture study of women in the UK (Armstrong and Murphy 2008:1080) found that, although some biomedical explanations were applied when the women articulated their experiences and risk factors for ICC, their overall understanding of cervical screening was incomplete. Their knowledge was derived from cultural-contextual factors, especially around sexuality

issues, and this resulted in a complex and intricate way of them weaving meaning about ICC issues. Acculturation and religion were found to be important factors on knowledge levels among other UK women, and whilst the HPV information did not have an effect on their perceived risk of ICC, it did make women understand the importance of attending for screening (Marlow et al. 2009).

A study, with African-American and Latina participants (n=78; aged 12 to 17 years) (Mosavel and El-Shaarawi 2007), found that women's knowledge was gained informally through personal experiences and social networks; and the term 'cancer' was stigmatised, and evoked negative associations and emotionally-laden language (such as 'death', 'fear', and 'helplessness': 715). Based on these reactions, studies (Breitkopf et al. 2005; Mosavel and El-Shaarawi 2007; Cain et al. 2009) have recommended that health literacy interventions need to consider the way health knowledge is constructed in informal networks.

Among Australian women, knowledge and education attributed to screening participation. A community action intervention had a positive impact in twenty rural Australian towns and encouraged underscreened women to commence Pap screening practices (Hancock et al. 2001). A study (Jackson and Ward 2000) of twelve cervical screening information resources that medical clinics in NSW distributed to Aboriginal women found that, although four of the resources were specifically developed for Aboriginal women, most resources lacked cultural sensitivity and differed in the information.

Another Australian study (Hall et al. 2008) that examined to what extent HPV issues were addressed in Australian cervical cancer screening patient information leaflets, found that the information focused on biomedical rather than psychosocial issues. The study did not analyse the sufficiency of information relating to sexual associations of genital HPV infection, and, whilst culturally relevant resources had been developed, the HPV information was found to be inconsistent and lacking adequate detail about important information.

3.3.1 Knowledge levels of cervical screening among Chinese women

In the NE and SE Asian region [where Chinese-Australian women originate from], knowledge and beliefs on cervical cancer and HPV infection varied among several studies (Hoover 2008). Good awareness of cervical screening in the NE Asian region has been reported on (Dickinson and Chan 2001; Hoover et al. 2008; Shi et al. 2008), but women were found to have low understanding of the role that HPV infection plays in cervical disease (Shi et al. 2008). Variations in education levels and knowledge were evident, especially in women in rural China who had significantly lower rates than Chinese women living in urban areas (Dickinson and Chan 2001). Shi and colleagues (2008) report that in a population based-survey across four regions in China (n=5023; women aged between 15 and 54 years) their knowledge levels were extremely low (15.8%), and of that group, less than half (49%) understood HPV was associated with ICC.

For SE Asian women a population-based survey of Chinese mainland women (Li et al. 2009) demonstrated similar levels of HPV awareness to Singaporean Chinese women (15 and 20% respectively) (Pitts et al. 2009), but Malaysian women (Wong et al. 2009) displayed a lack of knowledge on cervical cancer and the Pap smear test, believing that symptoms were a precursor to screening need. Embarrassment and fear of pain were also expressed as deterrents for Pap screening participation. Paradoxically whilst the study noted considerable awareness of sexual associations with cervical cancer, as a result of public education resources, all were ignorant about HPV.

3.3.2 Men's knowledge of HPV

Studies of perception and knowledge levels of HPV in adult males (predominantly heterosexual in a review of related studies (Zimet and Rosenthal 2010); and university students aged 18 to 25 years, predominantly 'white' (80.5%) in a small sample (n=166) (McPartland et al. 2005)) in industrialised countries showed men have low to moderate

levels of knowledge and misconceptions about HPV infection, morbidity, transmission and prevention (Zimet and Rosenthal 2010:S27, 29). In particular, men demonstrated a limited understanding of their susceptibility to HPV infection, and the severity of disease for males, although they understood HPV infection to be severe for females (McPartland et al. 2005; Pitts et al. 2010). However, adolescent and adult males are shown to have 'moderate to high interest' in receiving vaccines for prevention of STIs, including 4vHPV vaccine (Zimet and Rosenthal 2010:S28). Singaporean men were found to have moderate knowledge of cervical cancer but poor knowledge and awareness of HPV, but they were supportive of HPV vaccination (Pitts et al. 2009).

3.4 The impact of women's understandings of HPV as a STI on screening behaviours

The complexity of educating diverse populations about the sexual transmission of genital HPV infection has raised concerns that this knowledge may negatively impact on women's screening behaviours, and their perceived risk of ICC (Armstrong and Murphy 2008; Marlow et al. 2009). Furthermore, Klug and colleagues (2008:95) review of knowledge studies between 1992 and 2006 reported on the 'substantial' confusion between HPV, HIV, and herpes simplex virus in the general public. Armstrong and Murphy (2008: 1081) refer to evidence of women's mediated responses to screening out of 'concern to preserve their sexual reputation and to avoid inviting the charge of promiscuity'.

International studies (McCaffery et al. 2003; Waller et al. 2005; Garcia et al. 2007) found that women from contrasting ethnic and socioeconomic backgrounds were found to have inconsistent and low causal conceptions about HPV, and its sexual associations with ICC. Furthermore, that sensitivity is required in HPV messaging to minimise its negative psychological impact among people. For example, in a study (Wang et al. 2010:19) of Taiwanese women (n=263), women with genital warts experienced 'the worst psychological outcomes' (sexual impact, self

image and worries) due to their perception of a STI diagnosis equating to promiscuity.

3.4.1 The influence of ‘shame’ and ‘stigma’ on cervical screening

The invasive nature of the Pap screening test is a deterrent for some women who reported that the procedure requires psychological discipline (Bush 2000; McCaffery et al. 2003; Maissi et al. 2004; Waller et al. 2005; Pirotta et al. 2009), or HPV testing with cervical screening (McCaffery et al. 2003). This response presents a challenge for health providers in managing trust with women who undergo Pap tests and feel stigmatised and perceive the test as shameful (Fiebig et al. 2009); or women who experience pain, embarrassment, fear and inconvenience (Cullen et al. 2004 in Pirotta et al. 2009; Cunningham et al. 2008).

The concept of ‘shame’ and ‘stigma’, widely associated with STI factors, is prevalent in women, and particularly with immigrants and cervical screening. For example, the perception of stigma was found to impact on the responses of a group of African-Americans to screening, treatment, and partner services. Cervical cancer was explained to women using both traditional beliefs and medical knowledge, but the participants stigmatised their responses to the information when they described their female genitalia as ‘dirty’ (Lichtenstein 2003).

3.4.1.1 ‘Shame’, ‘stigma’, and women’s responses to screening results

Knowledge is a key influence on attitudes to screening results and HPV issues (or HPV acquisition, Franceschi et al. 2009), and variations in the level of impact on emotional responses were found (Maissi et al.2004; McCaffery et al. 2004,2006; Denny-Smith et al. 2005; Waller et al. 2007, 2009; Wetzel et al. 2007; Pirotta et al. 2009b; Robbins et al. 2010). For example, increased knowledge about HPV was found to increase Pap screen participation, and reduce the ‘stigma’ of HPV as a STI (McCaffery et al. 2006). However in a study (Wetzel et al. 2007) on adolescent knowledge of HPV and Pap tests, adolescent’s low knowledge levels were seen as a contributor to potential psychosocial distress with a HPV

diagnosis or abnormal test result, and concern that this may influence their intentions to follow treatment protocols.

Delivering HPV information objectively was found to promote positive attitudes toward healthy sexual behaviours and the need for regular cervical screening (Kahn et al. 2005, 2007; Sherris et al. 2006; Lloyd et al. 2009) in all age groups including young adolescents. Several studies (Bailey et al. 2000; Lannin et al. 2002; McPhee et al. 2003; Dein 2004; Giordano et al. 2008) argued that the way forward with health prevention programs is to engage in intercultural consultations and community mobilization strategies, which reflects the process undertaken in a socio-ecological approach (Bingham et al. 2009).

In a cross-cultural study (McCaffery et al. 2003), responses to cervical screening results by women from four diverse cultural groups in the UK (Indian, Pakistani, African-Caribbean, and 'white' British) were found to be exacerbated by their concerns at the lack of prior community education by health professionals, and the new information had a differing influences (a positive influence mainly in 'white' British and African-Caribbean women; and a negative influence mainly in Indian and Pakistani women) on their future participation with cervical screening and HPV testing.

Doctor's communication of results by mail was a key contributor of anxiety in women (McCaffery and Irwig 2005), and women's anxiety, distress and confusion from the diagnosis was further exacerbated when self-education activities revealed to them that HPV was located in STI information portals, and was linked to controversial sexual behaviours (McCaffery and Irwig 2005).

Women's depth of emotional responses can not be generalised to all women. For example, Waller and colleagues (2009) hypothetical study of women in the UK demonstrated that an abnormal cervical screening result would create 'worry' in 90% of women. However, the feeling of 'shame' was expressed in only a small proportion (5%) of women, especially among women from a 'non-white ethnic groups' (Waller et al. 2009:418),

of lower education status, and who also displayed confusion and worry especially after learning that their condition was sexually transmitted. These findings were not consistent with McCaffery and colleagues' earlier study (2006) that found that 'shame' was a key factor for some women. The depth of women's psychosocial response to the sexually transmitted nature of HPV infection was determined by several factors, including relationship status, normative and cultural values, and sexual behaviour.

Misunderstanding among women about HPV transmission (Wang et al. 2010) was found to potentially prompt relationship tensions, including accusations of infidelity. Women reported that they felt 'shame' and 'stigma' and were concerned about disclosure to others and the impact of the diagnosis on their personal relationships, especially for women in long-term monogamous relationships (McCaffery et al. 2004, 2006). Clear HPV communication strategies (with salient information presented in a 'phased way' (Waller et al. 2009:418) was found to minimise distress and shame.

The complexity of discussing sensitive issues with young women was noted in a study on the personal meaning of HPV and Pap test results in sexually active adolescent and young adult women in the USA (Kahn et al. 2005, 2007a). A key finding was that in order to minimise adverse psychosocial outcomes in the patient, especially stigma and shame, it was important to deliver HPV information in an objective manner, whilst considering the individual psychological and normative values that the adolescent held toward sexual issues. Although information was found to allay psychosocial responses, high education levels in patients did not immediately correlate with a high understanding of the important factors that HPV is common, asymptomatic and transient (Waller et al. 2005) especially among young women (Vanslyke et al. 2008; Verhoeven et al. 2009). Studies (Kahn et al. 2007a; Armstrong and Murphy 2008) have shown there is a need to increase public health literacy in all aspects of HPV infection and its relation to ICC to support informed decision making about HPV vaccines and cervical cancer screening.

3.4.2 'Shame' and 'stigma' in Aboriginal communities

For Aboriginal Australians, 'shame' is viewed as an intricate and elusive issue, and exacerbated when a health intervention is in disharmony with their cultural and philosophical beliefs, and this is consistent with the experiences of African-American patients (Jacobs et al. 2006). Aboriginal women's sense of 'shame' is manifested through their sense of cultural isolation in a Western health setting, as well as language differences, and their different cultural constructions of medical knowledge (Morgan and Morgan 1997; Morrissey et al. 2004; Lowenthal et al. 2005). These experiences was evident in other studies (Plummer and Forrest 1999; Cunningham et al. 2008) where stigma, which was associated with STIs and the associated shame and embarrassment of Pap screening, was a major deterrent for Aboriginal women using screening services.

Additionally, Aboriginal women are very private and modest, and generally do not publicly disclose personal or intimate issues. Whilst Gracey and Spargo (2008) maintain that many Aboriginal people are more comfortable in talking about sexual issues than other Australians, Walpole (2008) contends that STIs are normally viewed as a culturally 'taboo' subject among those at risk and their families. Reporting of Aboriginal health issues in mainstream media (where there is an emphasis on reporting sexual issues to a readership that is largely middle-class and non-Aboriginal (Thompson et al. 2007), is also considered to have contributed to the stigma and taboo associated with STIs in Aboriginal communities.

3.5 Influence of doctors on screening practices and knowledge

Women's low knowledge levels of HPV and ICC are attributed to the attitudes of health providers toward patient education about ICC. The GP's ability to educate the patient is determined not only by the patient's capacity to retain information given by physicians (Breitkopf et al. 2005; Boyce et al. 2010), but by system issues (Boyce et al. 2010); the GPs knowledge levels (Klug et al. 2008; Brumder 2009); and their communication style (Giordano et al. 2008). Many GPs both globally, including Australia (Raupach et al. 2001), are considered to be

inadequately prepared to educate their patients about HPV (Klug et al. 2008; Brumder 2009), and some (in LDC nations) were found to confuse critical clinical matters such as HBV, HPV, HIV and HSV (Sherris et al. 2006).

Doctors' normative beliefs about their role (Boyce et al. 2010) can be a barrier to patient communication, with role-tension between curative (or biomedical) medical care versus preventive (or holistic) health care (Raupach et al. 2001:362; Sherris et al. 2006), or as the tension between 'principle' and 'pragmatism' (Armstrong and Murphy 2008:1081) and this impacts on 'informed choice in relation to screening initiatives' (Armstrong and Murphy 2008:1081). The quality and style of the doctor's communication, as well as their uncertainty about the patient's level of HPV knowledge, has been attributed to women's psychological responses to HPV issues, and especially abnormal test results (Gath et al. 1995; Posner Vessey 1988; Karasz et al. 2003; McCaffery and Irwig 2005; Giordano et al. 2008; Waller et al. 2009), and women's sense of stigma and confusion (Maissi et al. 2004; McCaffery et al. 2004, 2006; McCaffery and Irwig 2005; Waller et al. 2007, 2009; Wang et al. 2010). Some doctors display a reticence for public discussion on the consequences around sexual behaviours and its association with ICC due to the pervasive sexuality discourses in the media, such as 'good girl / bad girl' and 'promiscuity'.

Physicians are perceived to adopt a `protectionist' [biomedical] rather than a `right to know' [holistic] discourse (Braun and Gavey 1999a, 1999b) with patients, but this ignores the 'heterogeneity of the screening target population' (Karasz et al. 2003; Giordano et al. 2008:131). Braun and Gavey (1999a, 1999b) also argue that a 'protectionist' discourse, as a health policy, compromises women's well being, and suppresses sexual risk factor information. In contrast, Armstrong and Murphy (2008:1074) suggest that a 'right to know' discourse is important as it increases awareness about risk factors among [UK] women, and that 'restricting information may lead people to misinterpret their own vulnerability'.

Australian women, with an abnormal cervical screening result, were found to want to participate in decisions about their care, but several factors in the clinical conditions were a deterrent. Time constraints and medical jargon (such as ‘pre-cancer’, and ‘wart virus’) which may ‘encourage confusion and exacerbate stigma’ (McCaffery et al. 2003:45) in women, and intruded on their ability to get the information required from doctors (Kavanagh and Broom 1997; Karasz et al. 2003; McCaffery et al. 2003; McCaffery and Irwig 2005). The perceived imbalance of power-relations, and lack of doctor-patient communication, not only compromised the amount of detail and the reassurance that doctors could give, but contributed to women’s psychological distress.

Racial and cultural concordance is found to impact on the perceived quality of care (Kwong 2006; Harmsen et al. 2008). Ethnicity of both the doctor and patient was found to be a key factor on the doctor-patient intercultural communication (Arredondo et al. 2003; Harmsen et al. 2008) in a hypothetical study of USA health providers’ (n=100) likelihood to discuss cervical screening with a ‘white’ female patient (age early 20s) (Arredondo et al. 2003). Whilst spontaneous discussion of Pap tests would occur (with 53% of providers), ‘black’ [African-American] health providers speculated they would spend more time discussing cervical cancer (6.00 minutes) with patients than ‘Asian’[-American] and ‘white’ providers (3.63 and 3.77 minutes respectively), who were considered to be the least likely to spend time in detailed discussion; Asian-American doctors were more likely to endorse women’s barriers to cervical screening behaviours because of perceptions about women’s risk and lifestyle factors. However caution must be applied in generalizing these findings as the study was hypothetical and the results may not transfer to actual practice.

Whilst GPs are described (McMurray and Param 2008; Brown et al. 2009) as being in genuine partnerships with their patients, several studies have found that trust in the physician is a key influence in women’s health care behaviour and adherence to medical treatments. Key determinants of

behaviour were the interpersonal, cultural (Ponce et al. 2006; Harmsen et al. 2008; Fiebig et al. 2009) and technical competence of the physician, including a perception of racism toward patients, and a lack of trust in the information provider's recommendations (Thom 1997; Ward and Sanson-Fisher 1997; Ward et al. 1998; Doescher et al. 2000; Jacobs et al. 2006; Marlow et al. 2007; Pitts et al. 2007; Rosenthal et al. 2007; Giordano et al. 2008; McKee and Coker 2009; Tozzi et al. 2009). Studies of African-American people's view of physicians (Jacobs et al. 2006: 646; Ponce et al. 2006) revealed the key factor was 'racial concordance', and the physician's ability to communicate across language and cultural barriers, rather than trust.

A survey of Hong Kong doctors about their practices with cervical screening (Dickinson and Chan 2001: 287) noted that women's poor understanding about cervical screening, and their resistance and 'social' sensitivity to male doctors examining them, were inhibiting factors for doctors; and women were regularly referred to a 'wide range of providers' for screening. The need for cultural competency in the health provider to minimise shame was reported in two British studies (South Asian women from India, Pakistan and Bangladesh in Elkan et al. 2007; and Bengali, Kurdish, Turkish, Punjabi, and Chinese and Vietnamese women in east London (Naish et al. 1994) that focused on cultural constructs and service usage. They concluded that, in order to reduce morbidity of ICC in population groups most at risk, the biomedical paradigms, beliefs and attitudes about 'cancer' need to be modified.

3.5.1 Australian GPs and cervical screening

Several Australian cross-cultural studies (Kelaher et al.1999; Taylor et al. 2007; Cheek et al. 2008; Lesjak et al. 2008) on self-reported intentions to undertake cervical screening found that knowledge was integral to women's decisions, and that the GP was considered to be their primary information provider, with familial and social networks a secondary source. GPs frequently provide opportunistic taking of Pap smears, but health promotion by GPs about cervical and STI issues does not always occur

within the same consultation. Vietnamese-Australian women in Sydney (Lesjak et al. 2008) recalled that opportunistic advice about Pap screening from the GP was low, and they were found to have lower levels of Pap screening knowledge compared to that of the Anglo population (Cheek et al. 2008; Lesjak et al. 2008). Gender and the cultural background of the practitioner were other important factors for Vietnamese-Australian women new to Pap screening procedures, and who lack confidence with the medical environment (Cheek et al. 2008).

Chapter 4: Literature Review: Attitudes of Parents and Doctors toward Adolescent HPV Vaccination

4 Introduction

The reduction of HPV related diseases is dependent on widespread acceptance and agreement to HPV vaccination for pre-adolescents, especially among parents and guardians (hereafter collectively referred to as parents), and for many adolescents themselves. Although several studies had been undertaken between 1995 and 2000 on parent and adolescent acceptance of STI-related and HPV vaccines (Rosenthal et al. 1995; Zimet et al. 1999, 2000), it was not until 2000 that the first studies [the USA study of Zimet and colleagues (2000); and the Mexican study of Lazcano-Ponce and colleagues (2001)] examined, at an in-depth level, the attitudes of women (adolescents and adults) toward HPV immunisation, and findings of these studies will be reported through this chapter.

4.1 Background to parent attitudes: understanding adolescents as the target population for HPV immunisation

A substantial review of adolescent immunisation factors is beyond the scope of this thesis, but a brief review of some of the challenges confronting their positioning in HPV vaccination programs is warranted to aid our understanding of parental and GP attitudes toward adolescent HPV vaccination. Young people (aged 10 to 24 years) comprise nearly half the global population (Bearinger et al. 2007: 1220), and their vulnerability to poor sexual health outcomes is heightened in diverse social contexts. The delivery of STI [HPV] vaccines in the (sexually naive) adolescent age group is an integral strategic component of the control of STI diseases (Lewis et al. 2000; Streefland 2001; Hinds and Cameron 2004; Kahn et al. 2004; Gust et al. 2005; Shaw 2005; Shew et al. 2005; Forster et al. 2010), and universal HPV vaccination is discussed in several studies (Goldstein et al. 2001; Berlioz-Arthaud et al. 2003; Middleman 2004; Garland et al. 2008b; Forster et al. 2010). As adolescents are generally infrequent users of medical clinics compared with other age

groups (Skinner et al. 1998, 2000, 2001; Correll et al. 2003; Rand et al. 2007; Skinner and Cooper Robbins 2010: 216), the universal vaccination of the adolescent cohort is deemed to be a challenge (Moore-Caldwell et al. 1997; ASHR 2003; Hinds and Cameron 2004; Humiston and Rosenthal 2005; Slonim et al. 2005; Forster et al. 2010). Benin and colleagues (2010:378) speculate an effective approach with adolescents is through administering 'the [HPV] vaccine as part of a routine package of adolescent care', integrating other preventive health matters in general.

In Australia the adolescent NHPVP school-based program showed relatively high levels overall of HPV vaccine coverage in its first year cohort, as described in Chapter 2 (Skinner and Cooper Robbins 2010), and mirrored the results anticipated in pre-licensure modelling studies (Smith et al. 2008b), demonstrating that acceptable rates of adolescent HPV vaccination is achievable through well organised programs. This was in contrast with two experiences of adolescent 'catch-up' HPV vaccination, where in Paris (Rouzier and Giordanella 2010) data reveals a low proportion (32%) of 16 years olds received the HPV vaccine , and within that group 42% of them complied with the three 'HPV vaccine' doses, and in 2008 where 18% of 14 year old had received one dose; and in the UK (Brabin et al. 2010; Forster et al. 2010) with the 2vHPV vaccine where 54% of adolescents (age 16+) received the vaccine. Lehmann and Benson's review (2009:807) of adolescent immunisation suggests that immunisation in non-traditional settings and the establishment of adolescent vaccine registers, with direct marketing approaches, may facilitate an increase in vaccine uptake.

4.1.1 Adolescents' knowledge levels of HPV vaccines

Adolescents both younger and older (~18 years) have consistently shown poor knowledge and confusion about vaccination and its risks and benefits (Slonim et al. 2005; Lehmann and Benson 2009; Agius et al. 2010; Benin et al. 2010; Pitts et al. 2010). The concern about the eventual misconceptions by adolescents toward HPV vaccines and complacency toward cervical screening, or changes in sexual behaviour in the

population, was reported in several studies (Adams et al. 2007; Markowitz et al. 2007; Saslow et al. 2007; Haug 2008; Agius et al. 2010). Adolescent girls in the USA who had been vaccinated with HPV vaccines believed that it was now not as important to practice safer sexual behaviours (Mullins et al. 2010).

Australian adolescents who had been immunised through the NHPVP school-based program had low knowledge of HPV, which was exacerbated by an absence of appropriate educational resources targeted at adolescents (Robbins et al. 2010). These data were supported in a large-scale study (Agius et al. 2010) of Australian secondary school students (n=2926 from 105 Government, independent and Catholic schools) that found that HPV and ICC knowledge was poor, especially among young males. Female students (43%) were more knowledgeable about HPV vaccination than the males (19%), and the relationship between HPV and ICC. These responses were partially attributed to the females being vaccinated, and it was found that sexual activity did not influence their HPV knowledge, indicating that Australian parents and schools are not generally discussing key factors of HPV and HPV vaccines with adolescents.

4.1.2 Supporting adolescent HPV knowledge needs through sexual health education

As a group adolescents have been perceived as engaging in high-risk behaviours including sexual activity and, because they lack substantive knowledge about disease and vaccines, they have distorted perceptions of the risk of these behaviours on their health. Global studies were consistent in their findings that the effectiveness of community STI education strategies to adolescents was found to have often been compromised by subcultural norms (such as familial duty and child-parent relationships) and societal attitudes to sex and the reticence of some parents (Romo et al. 2004; Klein et al. 2005; Bearinger et al. 2007; Schouten 2007; Eisenberg et al. 2008; Guilamo-Ramos et al. 2008; Rosenthal et al. 2008; Rawson and Liamputtong 2010), and health

professionals to discuss sexuality issues with adolescents. Compounding these barriers are complex and socially determined issues of morality, privacy, stigma, shame and discrimination, which were notable issues for Australian people in small communities (DHA 2005a; Bowden and Fethers 2008).

The outcome of ineffective sexuality education was apparent in Zimet's studies (2000, 2005) that reported that sexually experienced and inexperienced adolescents in the USA failed to correctly identify their STI risk, and they also had low levels of HPV knowledge (but greater knowledge about HIV) and most did not (29% and 85% respectively) discuss their sexual health during medical visits. Whilst adolescent girls of mixed race (age 15 to 23) had knowledge of most factors relating to HPV, most did not know HPV was asymptomatic.

4.2 Parents' knowledge levels of HPV vaccines

Levels of parent knowledge (Dempsey et al. 2006; Kimmel 2006; Klug et al. 2008) and willingness of key stakeholders (individuals, parents, adolescents, health professionals and the broader community) to accept vaccination in adolescents will contribute to the long-term success of the HPV immunisation programs but not all mothers universally believe the vaccine is necessary for their daughters (Askelson et al. 2010) and, despite their acceptance in principle, not all parents understood the HPV vaccines. There were consistent findings (Kimmel 2006; Brewer and Fazekas 2007; Marshall et al. 2007; Dearnley et al. 2010; Read et al. 2010; Robbins et al. 2010) that globally, parents and adolescent had low understanding of the HPV vaccines and misconceptions existed (McLelland and Liamputtong 2007; Klug et al. 2008; Shi et al. 2008; Marlow et al. 2009; Ragin et al. 2009; Chow et al. 2010; Das et al. 2010; Kuitto et al. 2010).

Although early studies suggested that knowledge does increase acceptance for the HPV vaccines in some women (Kahn et al. 2003; Davis et al. 2004), a small USA study (Ragin et al. 2009:6) that compared knowledge and attitudes between cultural groups (n =220: Blacks n = 89;

Whites n=128; other ethnic including one Australian n =3) and geographic location, found that 'White' participants were more aware of HPV vaccine factors than 'Blacks', although knowledge for all groups was incomplete and unaware of 'important information' about HPV infection, and the vaccines including protective factors for ICC and GW.

4.2.1 Misconceptions about HPV vaccines in the general population in Developed Country (DC) nations

Misconceptions are considered 'frequent' when a 'new [health] technology is introduced (Sherris et al. 2006:S3/210) in the general population, and this is reflected in the introduction of the HPV vaccines. Despite the high acceptability for HPV vaccines where message framing emphasised HPV vaccines as prevention of ICC (Leader et al. 2009), several authors (Smith-McCune 2008; Herzog et al. 2008; Moscicki 2008; Kahn 2009; Kwan et al. 2009; Deanley 2010; Mortensen, 2010) have raised concerns that the general population might misperceive this information as meaning full protection against all STIs and ICC with HPV vaccination, and thereby stop the necessary regular cervical screening because the risk factors are not sufficiently understood (Askelson et al. 2010). Furthermore, among Chinese women, misconceptions about vaccine efficacy for sexually active women were found.

4.2.2 The influence of HPV vaccine knowledge on parental consent

Consent processes for adolescent vaccination vary globally (Mays et al. 2004; Brown 2008; Reeve et al. 2008; Brabin et al. 2009; Finn et al. 2010; Skinner and Cooper Robbins 2010), and findings from Zimet and colleague's studies (2000, 2005) noted that parents, rather than adolescents, were the key decision makers about adolescent vaccine acceptance, particularly in younger adolescents. Although a qualitative study with adolescents (n=25, aged 10 -14 years) reported adolescents have conflicted views about vaccine decision making (Benin et al. 2010), it is considered unlikely that an STI vaccine would be administered to them without parental consent. Issues with parental consent and the return of consent forms through a school-based program, where required, are key

challenges that compromise adolescent vaccine coverage in the general population (Plaitano et al. 1993; Pritchard 1997), and are a common barrier to dosage completion (Plaitano et al. 1993; Zimet et al. 2000). These findings mirror similar challenges that were found with HBV vaccination for adolescents in Hawaii (Dilraj et al. 2003).

In Australia, adolescent immunisation through schools requires written parental consent, and the older adolescent, or 'mature minors' (Skinner and Cooper Robbins 2010:216) can access vaccines through a medical clinic without parental consent. This presents ethical challenges for GPs in complying with adolescent's need for privacy, and non-parental involvement (Atkinson et al. 2003), and vaccinating mature adolescents without parental consent (Sanci et al. 2005; Lo 2006; Brabin et al. 2007; McNaughton et al. 2008; Brown et al. 2009) due to the principles of Gillick competence (Brown et al. 2008, 2009). In these circumstances, the long term benefits for the adolescent are considered to override parental consent (Sanci et al. 2005).

The notion of 'regret' with vaccination decisions was raised in a UK study (Marlow et al. 2007), and 'anticipated regret' in Ziarnowski and colleagues' study (2009) (n = 889) was raised as a key factor in 'white' and 'African American' care-giver decisions for adolescent HPV vaccination within a risk (ICC versus sexual disinhibition) context. Whilst the study did not examine whether intentions translated into behaviour, it suggested that whilst the action of vaccination lowered their perception of risk for their children, it did not necessarily lower 'anticipated regret'. Additionally for those care-givers who were still to vaccinate their daughters, 'higher anticipated inaction regret (especially for cervical cancer) was associated with higher vaccination intentions' (Ziarnowski et al. 2009: 413).

4.3 Factors that contribute to parent acceptance of adolescent HPV vaccination

Correlates of parent acceptance toward HPV vaccination for adolescents were summarised from the literature (Brabin et al. 2006; Dempsey et al. 2006; Noakes et al. 2006; Sherris et al. 2006; Waller et al. 2006; Zimet et

al. 2006; Agosti et al. 2007; Marlow et al. 2007a, 2007b, 2008; Pallecaros and Vonau 2007; Vallely et al. 2008; Kwan et al. 2009; Leader et al. 2009; Chow et al. 2010; Kuitto et al. 2010; Mortensen 2010; Taki et al. 2010) (Table 7). Since there was an under-representation of mixed culture populations in all papers, these findings are predominantly the opinions of Anglo or Euro-centric and resource-rich populations, with some data from the Asia region. Biomedical, information, psychosocial and structural correlates of health prevention were key factors. These influences on parental attitudes were consistent with studies on the HBV vaccination experience which had low levels of uptake for the first decade (Etzioni 1968; Streefland 2001; Freed et al. 2004; Ryan et al. 2005; Zimet et al. 2000, 2005; Cameron et al. 2007), although the positive reception for a HBV immunisation program was attributed to direct engagement with key stakeholders prior to implementation (Cameron et al. 2007).

Parent concerns about adolescent HPV vaccination and its unique and sensitive characteristic were raised. In particular, that the vaccine's efficacy was best suited to sexually naïve people and its effectiveness and long term safety which remained unanswered for the immediate term (Goldie et al. 2004; Harper et al. 2006; Mao et al. 2006; Garland et al. 2007; Haug 2008) although there have been no serious adverse events recorded to date that are directly attributed to the HPV vaccines (Reisinger et al. 2007; Descamps et al. 2009; Munoz et al. 2009; Garland and Smith 2010; WHO 2010).

Table 7: Correlates of parental acceptance toward HPV vaccination summarised from the literature

Biomedical	Desire to prevent ICC Desire to prevent GW Risk perception for ICC and / or HPV infection for their child Pro-vaccination Age-appropriate (older adolescent) Belief in vaccine efficacy Belief in vaccine benefit Belief in vaccine safety Access to alternative preventives (cervical screening)
Information	Endorsement by the medical profession Recommendation by doctor, parent ,friend, sibling, partner If information framing was pro-cancer prevention Sufficient knowledge of HPV vaccines HPV integrated into the child's sex education
Psychological	Family history of cancer Family and parental attitudes toward vaccines in general Personal experience with HPV infection Control over health-related decisions Parental responsibility to protect their child Cultural values toward health prevention Sexuality norms and adolescents Religious values and adolescent sexuality Trust in doctor Importance of significant others in vaccine decision Anticipated inaction regret
Structural	Subsidised cost of the vaccine Convenient access to immuniser to ensure compliance with dosage schedule Options for vaccine delivery: School-based and clinic-based Perception that HPV vaccination is compulsory

4.4 Parent attitudes toward HPV vaccines and STI factors

Positive parental attitudes towards vaccines that impact on STIs to protect their children were supported in early studies (Davis et al. 2004; Mays et al. 2004; Liddon et al. 2005; Olshen et al. 2005; Zimet et al. 2005,2005a; Waller et al. 2006; Marlow et al. 2007), but moral imperatives such as sexuality and promiscuity were found to be key factors for parents with the HPV vaccines (Goldie et al. 2004; Lo 2006; Monk and Wiley 2006; Stanley et al. 2006; Ault 2007; Garland et al. 2007; Paavonen et al. 2007; The FUTURE II 2007; Basu et al. 2008; Polzer and Knabe 2009; Benin et al.

2010; Dearnley et al. 2010; Robbins et al. 2010). There was initial opposition to the HPV vaccines from conservative political and religious groups (especially in Canada and USA) based on a fear that it would lead to increased sexual activity and promiscuity (Davis et al. 2004; Brabin et al. 2006; Zimet 2006; Chan et al. 2007; Marlow et al. 2007; Marshall et al. 2007; Ogilvie et al. 2007; Scarinci et al. 2007; Woodhall et al. 2007; Brewer and Fazekas 2008; Hoffner 2008; Lenselink et al. 2008; Wong 2008; Benítez-Bribiesca 2009; Haas et al. 2009).

Very few concerns about HPV vaccination influencing promiscuity were evident in other USA studies (Mays et al. 2004; Monk and Wiley 2006; Zimet 2005a, 2006; Rosenthal et al. 2008), and those concerns were overridden by normative values such as perceived vulnerability and protection factors. Some findings from USA studies suggested that parents might delay HPV vaccination until their child is sexually experienced, but due to HPV transmission occurring commonly and relatively quickly after sexual debut, this is not considered an ideal decision (Zimet et al. 2000a, 2000b, 2005; McPhee et al. 2003).The low levels of awareness among parents about the association between STIs and cancer (and subsequent vaccines) are not unique to HPV as similar findings were found with HBV immunisation (Gull et al. 1997; Merle and Trepo 1998; Goldstein et al. 2001; Hinds and Cameron 2004; Mays et al. 2004; Chen 2005; Olshen et al. 2005; CDC 2006; Meheus 2000; Rosenthal et al. 2007).

A key difference between the HBV and HPV vaccines is that the HBV vaccine was not primarily considered to be an anti-STI vaccine as a result of its message-framing (Meheus 2000; Monk and Wiley 2006), therefore the issue of sexual transmission had little impact on its uptake, and there was no evidence in the literature that it promoted earlier sexual activity as some initially feared (Lawrence and Goldstein 1995; Papaevangelou 1998; Lewis et al. 2000; Skinner and Nolan 2001; Middleman et al. 2002; Berlioz-Arthaud et al. 2003; Burke et al. 2003; Dilraj et al. 2003; McPhee

et al. 2003; Middleman 2004; Slonim et al. 2005; Tung and Middleman 2005; Benin et al. 2010).

Major concerns for parents in early studies were that an adolescent might interpret a parent's approval of an STI vaccine as condoning sexual behaviour (Zimet et al. 2000a, 2000b, 2005; McPhee et al. 2003; Mays et al. 2004), and how a parent would explain the vaccine to a young person (Rosenthal 2005; Zimet et al. 2005), but these concerns were refuted in studies that found that parents will accept STI vaccines if it protects their child from disease (Davis et al. 2004; Mays et al. 2004; Liddon et al. 2005; Olshen et al. 2005; Zimet et al. 2005, 2005a; Waller et al. 2006; Marlow et al. 2007; Crosbie and Brabin 2009; Askelson et al. 2010; Benin et al. 2010). Hoffner (2008) also maintained that such a supposition was unreasonable due to evidence that sex education for adolescents decreases STIs and pregnancies, more so than promoting abstinence. Lo (2006) also concluded that concerns about HPV vaccine related promiscuity were unfounded due to the multiple factors associated with initiation of sexual activity.

A 'significant minority' (Forster et al. 2010:206) of parents continue to display concerns about sexuality issues with HPV vaccination, despite this not being the reality (Basu 2008:19021; Crosbie and Brabin 2009). The systematic review by Brewer and Fazekas (2008) also concluded that a minority of parents were concerned that HPV vaccination would promote sexual behaviour (Chow et al. 2010). Because there were limitations on population samples (mainly Caucasian, and a few Hispanic women) in the studies, caution must be applied with this finding, and the beliefs may not be widespread among mixed-culture populations.

Mothers from the Da Nang region in Vietnam displayed positive attitudes toward HPV vaccination for their daughters and did not perceive promiscuity as a risk, although only 11% of them were aware of the HPV vaccine 12 months after international licensure (Dinh et al. 2007). However negative social consequences influenced their beliefs about premarital sex, but this factor was not associated with their support for

HPV vaccination for their daughters. Parents were more supportive of vaccines for which there was a behavioural strategy for prevention available, because of the lack of parental control over their adolescent's future exposure to HPV. However this was compromised by a belief in some parts of the Da Nang community that STIs were an appropriate punishment of premarital sexual activity (Dinh et al. 2007).

4.4.1 Role of the school and sexuality education with adolescent HPV immunisation programs

Although studies (Kirkman et al. 2005; Nguyen et al. 2006) have suggested that parents should undertake the role of primary sex-educator with their children, parents frequently look to school professionals to undertake that role in parental and child sexual health education (Kirby 2002; Meschke et al. 2002; Schouten et al. 2007; Eisenberg 2008; Vavrus 2009). The challenges faced by sexual health educators are exacerbated by the uncontrolled exposure of increasingly explicit (Brown et al. 1990) programming through mass media that influences the socialisation of youth (Braun-Courville and Rojas 2009).

Parents, from Asia in particular, hold school teachers and their authority in high esteem and generally accept their education of their children unequivocally, but some held concerns about cultural dissonance factors. For example, the [Australian] school curriculum is usually focused on the characteristics of the dominant culture [the Anglo population] (Phelan et al. 1991; Yao 1988, 1993; Rawson and Liamputtong 2010), some students and parents from less dominant cultures [such as China or NE Asia] perceive their cultural norms are not fully understood, and they feel their needs are excluded in sex education programs which have more open views than their own (Rawson and Liamputtong 2010).

The importance of acknowledging cultural factors with sexuality issues emerged in other studies. Chung and colleagues (2007) identified that acculturation in Filipino-Americans does influence sensitive sexuality communications and the development of public health interventions. In contrast, an Indonesian study on sex education for adolescents (Holzner

and Oetomo 2004) found agreement from parents and authority figures for the suppression of youth sexuality. However, and counter intuitively, youth were sourcing their own information independent of government and religious authorities.

4.5 Parents attitudes toward age for adolescent HPV immunisation

Despite concerns, and data on HPV vaccine uptake in Australia and the UK as described earlier, the majority of parents have supported HPV immunisation (McClelland and Liamputtong 2007; Bernat et al. 2009; Madhivanan et al. 2009), and especially for older adolescents (Mays et al. 2004; Olshen et al. 2005; Hopenhayn et al. 2007; Marshall et al. 2007; Woodhall et al. 2007; Fazekas et al. 2008). In determining the age for HPV vaccination parents considered the risk factors for HPV infection for their daughters (Mays et al. 2004; Olshen et al. 2005; Zimet et al. 2005; Brabin et al. 2006; Dempsey et al. 2006; Dunne et al. 2007; Askelson et al. 2010). However parents in studies in the Netherlands (Korfage et al. 2008; Lenselink et al. 2008) showed high intentions to vaccinate pre-adolescents (age 10 to 12 years) especially if it were at no cost to parents, and this attitude was also maintained among Canadian parents (Ogilvie et al. 2008).

A comprehensive review of the evidence from eleven studies on adolescent HPV vaccination in the UK (Tuckerman et al. 2008) found diverse views across the population, although the agreement for cancer protection was a consistent theme, and in girls aged 11 to 14 years. One early study (Brabin et al. 2006) showed differences between agreement and intent. High agreement for HPV vaccination was shown by 81% of parents in Manchester, but only 38% of them definitely intended to vaccinate their daughters and these ratios were supported by findings in later studies (Marlow et al. 2007b, 2008). In the UK, parent's acceptability of HPV vaccination for their 12 to 13 year old daughters was much lower in cross cultural populations than in the Anglo 'white' population (Marlow et al. 2009).

Support for vaccinating young adolescents against an STI had varying support in UK studies (Brabin et al. 2006; Noakes et al. 2006; Waller et al. 2006; Marlow et al. 2007a, 2008) and the South East Asian region where different social norms toward sexuality prevail (Lo 2006; Chan et al. 2007; Dinh et al. 2007; Wong and Sam 2007; Sam et al. 2009; Wong 2009; Chow et al. 2010) and where there was a preference for immunising older girls in late secondary school. These findings were consistent with a small qualitative study of 40 Malaysian women aged between 13 and 27 years (Wong 2008). Whilst there was high acceptance for the HPV vaccine, the need for socially and culturally acceptable HPV education was needed.

4.5.1 Attitudes of Australian parents

In Australia, very few studies had been undertaken at the time of the 4vHPV licensure, and found varied results. An early small scale qualitative study undertaken in 2005 of Victorian women from diverse sociodemographic characteristics and Iraq (n= 34, aged 22 to 71) (Rosenthal et al. 2007) found mixed acceptance for pre-adolescent HPV vaccination, and especially among women from Iraq, when based on the women's normative values towards adolescent sexuality and their perceived necessity for their daughters when cervical screening was available to them as an alternative. In contrast, due to their trust in doctors and the health system, the women showed high acceptance if the vaccine was professionally recommended and politically supported.

A Queensland study in (n = 2,165) (Hausdorf et al. 2007), undertaken during the Phase II trials, and before public awareness, found that parents had high levels of uncertainty (47%) about HPV vaccination for their children due to the lack of information of key factors. With more scientific certainty and public awareness, studies undertaken closer to the licensure period (Marshall et al. 2007; Pitts et al. 2007) found high acceptance among parents in two states for adolescent HPV vaccination, although these attitudes were based on limited knowledge of the vaccine characteristics.

The South Australian cross-sectional survey (n = 2,000 adults who were predominantly Anglo-Australian (89.3%), Indigenous Australians (0.6% n=13) and 'other' (10.0%) (Marshall et al. 2007) undertaken in early 2006 showed high agreement among both male and female parents (80%), and especially those from lower socioeconomic profiles, to vaccinate both girls and boys (mean age 13 years), and 77% of parents supporting vaccination for their child. Some parents rejected (5%) the idea of adolescent vaccination due to their perceived low risk of HPV infection. Indigenous people supported the vaccine for both men and women and had a preference for the 4vHPV vaccine.

The Victorian random CATI survey (Pitts et al. 2007: 179) (n = 1,100 women, mean age 42 years, predominantly Anglo-Australian(83.7%), Asian (4.9%), Southern European (5.1%), other European (4.9%), Middle Eastern (0.4%) and other (2.5%) backgrounds) found that women from an Anglo-Australian background (mean score = 6.4/8) had the most positive attitudes toward HPV vaccination, and the least positive attitudes were from women with Asian and/or Middle Eastern backgrounds (mean=5.7/8), although this cannot be generalised to the whole immigrant population because of the small sample size. Attitudes were driven by parent's desire to prevent disease (98.9%) and the majority of women (90.6%) did not think that the vaccine would promote adolescent sexual activity. There was a high indication (84%) that more information was needed before vaccinating their child.

4.6 Parent perceptions of barriers to adolescent HPV vaccination

Despite the general acceptance of HPV vaccination in principle, a variety of factors as potential barriers to HPV immunisation in adolescents were identified (Table 8) (Davis et al. 2004; Hamilton 2004; Raley et al. 2004; Olshen et al. 2005; Reidesel 2005; Baay et al. 2006; Sherris et al. 2006; Zimet et al. 2006; Agosti et al. 2007; Brewer and Fazekas 2007; Black et al. 2009; Dempsey et al. 2009; McCave 2009; Wong 2009; Mortensen 2010).

These include

i. Lack of data on vaccine risk factors, especially safety, and side effects (Noakes et al.2006; Marlow et al. 2007a; Reisinger et al. 2007; Munoz et al. 2009);
ii. lack of trust in the medical professionals (Marlow et al. 2007a; Lloyd et al. 2008);
iii. lack of necessity for vaccinating sexually naïve and young girls (Noakes et al. 2006; Waller et al. 2006);
iv. fear of promiscuity after vaccination (Marlow et al. 2007a; Lloyd et al. 2008);
v. sexuality factors of HPV (Waller et al. 2006; Vallely et al. 2008);
vi. religious values and sexuality factors, especially among Muslim parents (Brabin et al. 2007; Marlow et al. 2007a; Vallely et al. 2008).

These barriers are not immutable as many parents implied they would reconsider their decision when more vaccine information became available, or when their daughters were older (Pitts et al. 2007; Daley et al. 2010; Mortensen 2010).

Barriers to uptake in the UK were identified, where the third dose of the 2vHPV vaccine in UK schoolgirls was found to be lower among girls from ‘minority’ groups and lower socioeconomic backgrounds. Factors for the older cohort centered on differences in the intention-behaviour rate (70% and 54% respectively) (Kim 2008), as well as perceptions of risk and information factors (Kim 2008; Forster et al. 2010), fear and anxiety about vaccination (Forster et al. 2010). Religion and cultural background were also seen as potential barriers. For example, being ‘Christian’ and ‘white’ was associated with an increased acceptance of the vaccine; and girls in the UK from Asian, Hindu and Muslim backgrounds were less likely to accept vaccination (Forster et al. 2010).

Table 8: Parental perceptions of barriers to adolescent HPV vaccination (summarised from the literature)

Factors: General population	Specific factors: immigrants
Information Low knowledge levels	
HPV risk and age profile	Low knowledge levels of ICC and HPV vaccines
Low knowledge levels of ICC and HPV vaccines	Misconceptions about ICC and HPV vaccines
If HPV vaccine information framing was 'pro' STI prevention	
Biomedical: Lack of data	
Side effects & long-term safety	Side effects & long-term safety
Vaccine efficacy, and lack of efficacy trials for girls (9 to 15 years)	Vaccine efficacy, Impact on fertility
Anti-vaccine	Young age of child for vaccination
Young age of child for vaccination	Confusion about age of child for vaccination
Perceived low risk of ICC or HPV infection for their child	Perceived low risk of ICC or HPV infection for their child
Impact of the vaccine on the child's immune system & 'natural' immunity from HPV infection	
Cultural factors: Influence on values	
Race, ethnicity	Race, ethnicity
Socioeconomic and health insurance status	Linguistic barriers to understanding HPV information and consent forms
Education level and ability to understand HPV information	Normative values toward adolescent sexuality
Anti-vaccination beliefs	Religious values toward adolescent sexuality
Holistic health beliefs	
Lack of trust in medical provider	
Religious values toward adolescent sexuality	
Psychological	
Perceived risk for ICC &STIs	Age of parent
STI prevention	Sexuality issues and stigma with HPV
lack of relevance for vaccinating sexually naïve girls	Potential for the vaccine to promote promiscuity among adolescents
Potential for the vaccine to promote promiscuity among adolescents	Familial disapproval for STI vaccination
Lack of trust in HPV vaccine information	
Gender of doctor provider	
Fear of adverse events	
Structural	
High cost of vaccine	Political & economic sponsorship of the vaccine
Inability to comply with the dose schedule	Infrastructure: access to health services
Lack of trust in Government policies	Lack of culturally related HPV information resources
Inability, inconvenience, and time to access the clinic	Health provider recommendation
Lack of privacy with school based immunisation	Need for child to be involved in school based HPV sex education
Need for child to be involved in school based HPV sex education	

4.6.1 Specific factors for immigrant parents

Studies that incorporated racial differences in HPV vaccine acceptability (Lazcano-Ponce et al. 2001; Agurto et al. 2005; Chilton et al. 2005; Dinh et al. 2007; Lovell et al. 2007; Scarinci et al. 2007; Tissot et al. 2007; Armstrong and Murphy 2008; Bair et al. 2008; Hoover 2008; Kwan et al. 2008; Wong 2008; Breitkopf et al. 2009; Cates et al. 2009; Madhivanan et al. 2009; Marlow et al. 2009; Wong et al. 2009; Chow et al. 2010) noted that culture and race (including religion and moral issues (Kwan et al. 2009; Chow et al. 2010), and common misconceptions of their risk for ICC do impact on HPV vaccine uptake.

HPV vaccines were acceptable to immigrants but with some reservations (Table 8). Stanton (2004) suggested that vaccine-implementation controversies could be avoided if there was a focus on cultural issues regarding perceptions of disease, vaccination, and health services. Cultural and linguistic barriers in primary health care in the Netherlands (Harmsen et al. 2008), and a USA study (Herzog et al. 2008) on lessons from the first phase of HPV immunisation programs, found that patients' cultural views, language proficiency, and age were important factors in their attitudes toward standard of health care and HPV awareness.

There were consistent findings in other international studies. In a USA study of immigrants (Scarinci et al. 2007), African Americans cited factors similar to the general population (efficacy and side effects; promiscuity or unprotected sex). Influences on vaccine acceptance were knowledge about the vaccine, cost, and outcome of vaccine trials, and experiences of other HPV immunisation programs. HPV vaccines as an ICC preventative were important for mothers of Mexican and Latino origin, despite their low levels of awareness of HPV and the role that knowledge played with informed consent (Lazcano-Ponce et al. 2001; Bair et al. 2008). However despite this acceptance, Latino mothers raised concerns about the lack of overall information, and their confusion about the young age for vaccination (Lazcano-Ponce et al. 2001; Bair et al. 2008).

Cultural variations were found in the way parents make decisions about child vaccination, with ethnicity a key factor in vaccination uptake (Stanton 2004; Cheng 2006; Rosenthal Dyson et al. 2007). In studies of Vietnamese parents high concordance between spouses and between parents and daughters was important for HPV vaccination decisions for their daughters (Bingham et al. 2009; Breitkopf et al. 2009). Among Vietnamese people, vaccine decision making is parent based but some input is made by children depending on the child's maturity. Despite their low HPV knowledge levels, the Vietnamese people were keen to be educated about HPV vaccines but political and economic sponsorship were important determinants of their final acceptance. In contrast, barriers to acceptance were based on infrastructure, vaccine characteristics, safety and the perceived negative effect of the HPV vaccines on fertility (Bingham et al. 2009).

With Vietnamese-Australians moral imperatives and reputation is paramount in a bi-cultural and disparate environment, and where sexual expression can create cultural and family dissonance (Rawson and Liamputtong 2010). Agurto et al (2005) noted the importance of developing community partnerships to generate culturally appropriate messages and educational materials to increase demand, ensure follow-through for treatment, and ultimately reduce disease burden.

An international study, on Hispanic parent's willingness to engage their children in a low-income urban school-based HPV immunisation program (Middleman and Tung 2010), found that parents who had consented to prior vaccines through school were more likely to allow their child to be immunised with HPV vaccine, but overall fewer parents (29%) were willing to consent to the 4vHPV vaccine through a school-based program because of its newness in the vaccine schedule, and unknown reactions of vaccinees. In contrast greater willingness was shown toward Influenza and Hep B vaccines (57% and 37% respectively) through schools as these had been part of the immunisation schedule for some time.

Among Malay women, resistance to parental uptake were due to the vaccine's newness, lack of perceived HPV risk, and cost factors. Potential barriers to consent included sexual stigmatisation after immunisation and religious factors (Wong 2008).

4.6.2 Chinese women's attitudes to HPV vaccines

Support for HPV vaccination in China was found among women despite low knowledge levels, and where perceptions around sexuality as 'culpable behaviour', 'moral stigmatisation' and 'responsibility attribution' are prevalent (Kwan et al. 2009: 508). A population-based study (Shi et al. 2008) of Chinese women (n= 5023, aged between 15 to 54 years) from various regions (Shanxi, Shenzhen, and Shenyang) noted that among the 15.8% of women who had ever heard of HPV, 49% understood HPV was related to cancer; 87% of them expressed willingness to be vaccinated; and among rural secondary school students (n=292) (Wang et al. 2007 in Shi et al. 2008), 98.6% of them expressed interest, with 88% of mothers supporting HPV vaccination for their daughters. Potential barriers to vaccination for women in rural China (Shanxi region) were cited as lack of perceived risk of HPV infection (67% of women); quality and safety of the vaccine (~50%); low understanding of HPV and ICC (36%); and the majority (98%) preferred to receive vaccine information from their health provider rather than their family. Women expected the Government to subsidise the cost (Shi et al. 2008).

In Hong Kong the HPV vaccines have been available since 2007 (2vHPV: females 10 to 25 years; 4vHPV females 9 to 26 years) and initially by individual choice and cost, and marketed as ICC prevention (Kwan et al. 2009). Among Chinese adolescent girls in Hong Kong favourable attitudes were held toward HPV vaccination but potential barriers were on economic and safety grounds; lack of perceived need, and familial disapproval (Kwan et al. 2008). Chinese parents gave limited support for vaccinating young girls in a subsequent study (Kwan et al. 2009), where 27% of Chinese women opposed vaccinating sexually naive women, although the majority endorsed vaccinating sexually experienced women.

Concerns were expressed about the HPV vaccine's prophylactic characteristics and the value for sexually experienced women. The study concluded that because these degrees of acceptance indicated women's misconception about key factors and that they were fully protected against ICC, the HPV education approach needs to be culturally sensitive and targeted to the public, including men.

A UK study (Marlow et al. 2009), among a sample of ethnically diverse women, was the first large scale study to consider the impact of generational difference on attitudes that raised critical insights of HPV vaccine acceptability for mixed-culture nations, found that in Chinese households mothers were key decision makers and the least likely to make a joint decision within the family unit. Conversely, 17% of Chinese mothers stated they would allow the father to influence vaccination decisions. The study found lower HPV knowledge factors among Chinese women, not explained by generational status or language spoken at home, but through stigma associated with sexual discussions, and lack of culturally related media. Among mothers within the sample, ethnicity and religion (with fewer 'acceptors' among Hindus (34%) and Muslims (18%) (Marlow et al. 2009:1012) were strongly associated with acceptability of HPV vaccination. With ethnicity, highest acceptance was shown by 'white' women (63%) followed by African, Caribbean and Chinese women (51%, 49% and 40%), and much lower among Indian, Bangladeshi and Pakistani women (25%, 18% and 11%)' (Marlow et al. 2009:1012). Barriers to consenting to HPV vaccination were knowledge, sexuality and safety concerns (Marlow et al. 2009).

4.7 Attitudes toward vaccinating males with HPV vaccines

Very little research had been undertaken on attitudes towards HPV immunisation in males, despite the scientific evidence on their risk of HPV infection. Liddon and colleagues' (2010) reviewed the literature published between 2000 and June 2009 on the acceptability of HPV vaccines for males among parents, health care providers, and young males mainly from USA, Australia, Canada, the Netherlands, Turkey, and the UK. The

role of policies and healthcare systems in shaping the acceptability of HPV vaccination was considered, and culture to a lesser degree.

Overall there was general acceptance by adults, parents and health professionals for vaccinating both males and females (Noakes et al. 2006; Sauvageau et al. 2007; de Visser et al. 2008; Lenehan et al. 2008; Lenselink et al. 2008; Ogilvie et al. 2008; Dursun et al. 2009), but their preference was to vaccinate older adolescent females (Liddon et al. 2010; Zimet and Rosenthal 2010). Education, social values, perceived benefit (especially for protection against GW), and female siblings were key influences on agreement for vaccinating males (Ogilvie et al. 2008).

Waller and colleagues (2004) recommended that it was time to incorporate the role of males into ICC issues given the impact of males' sexual behaviour on HPV risk, and this paradigm shift was reinforced in a later studies (Sherris et al. 2006; Monk and Wiley 2006; Wong 2010). Educating fathers in diverse cultural groups about HPV vaccination was considered important to assist decision making. The need for destigmatisation through including males in key messages and approaches (Crosbie and Brabin 2009), particularly in a cross-cultural context (Wong 2010), was consistent with findings from a study on tetanus vaccination in Bolivia (Bastien 1995). However in Wong's study (2010) men showed high support for females to be protected from ICC, held concerns for long-term HPV vaccine safety, and favoured male vaccination.

In the USA literature (Zimet and Rosenthal 2010), the attitudes of mothers of sons toward HPV immunisation for males varied (between 12% and 100%), and culture and health benefits were influential factors. Zimet and Rosenthal's review (2010:4) concluded that, whilst there was evidence of parental intention, there were unknown factors about translating intention into behaviour, and the intentions for males in Developed Country nations, and a need for more comprehensive education of males about HPV.

Differences in acceptance rates of the HPV vaccines for males between parents from ethnic groups were apparent (Liddon et al. 2010). Overall, Latina mothers (Watts et al. 2009) were significantly more willing (92% to 100%) to vaccinate their sons with the 4vHPV vaccine, compared to non-Latina mothers (77% to 89% respectively) (Slomovitz et al. 2006), and this 'considerably lower' acceptance of an ICC vaccine for males was consistent with the findings that were influenced by perceived benefit for them.

4.8 The influence of the media on parental attitudes toward HPV vaccines

The advocacy role of the media as a behavioural-change model through its message framing (Leader et al. 2009; Connell and Hunt 2010; Forster et al. 2010) is considered to be a powerful influence on public [and parental] attitudes toward vaccine programs (Gainforth 2010). Whilst it incorporates risk communication, shapes community expectations, defines cultural attitudes towards health, and influences health policy agendas (Ponce et al. 2006; Thompson et al. 2007; Giordano et al. 2008; Neuhauser and Kreps 2008; Forster et al. 2010; Hilton et al. 2010), it also assumes that media dissemination is apposite.

The media has an integral role in the introduction of HPV vaccination and the way the message positioned influences public acceptance (Pitts et al. 2007; Hughes et al. 2009; Forster et al. 2010). The public HPV education programs could not commence in some countries until full licensure of the HPV vaccine had been approved (Sherris et al. 2006), and this led to early debate through the media. Whilst most coverage initially was neutral (Forster et al. 2010) there has been increasing counter- arguments on gender [female-centric] (Eisenberg 2009), and culturally exclusive (rather than inclusive) themes that have resulted in inappropriate and confusing messages in the media such as emotive (care for daughter); fear (prevent cancer); or misleading (increase promiscuity) (Anhang et al. 2004; Calloway et al. 2006; Haas 2009; Porta 2009; Forster et al. 2010; Hilton et

al. 2010) that were found to confuse the general public, and lack empirical evidence (Forster et al. 2010).

In nations with populations of diverse cultural values and ethical norms, normative principles toward advertising and promotion might be required to give the HPV vaccines legitimacy in some population groups (Reed 2002:184,186). For example, among Mexican women, the 'cervical cancer' message for HPV vaccines (rather than the message of 'HPV as an STI') elicited acceptance for the vaccine, and especially if it was Government sanctioned (Garcia et al. 2007). Haas and colleagues (2009) suggest that the dual public health message of the need for HPV vaccination *and* continuing Pap tests may be less effective in ICC prevention than the previous single message of regular screening, and may subsequently impact negatively on ICC incidence. This premise was reinforced by the conclusion in studies (Forster et al. 2010; Hilton et al. 2010) on media reporting of HPV vaccines in the UK where positive media coverage was found to influence uptake, but that the lack of balance, through reporting on HPV and women and promiscuity issues, was unhelpful for public health groups introducing the HPV vaccine agenda.

In contrast a USA study (Hughes et al. 2009: 367) (n=889; of caregivers of adolescent girls aged 10-18 years), showed large effects of media advertising on HPV awareness that was rated double to the levels reported in studies on awareness in 2005. This increase is attributed to the marketing efforts during the introduction of the 4vHPV vaccine, making 'drug companies de facto public health educators' although their information was considered to be biased toward positive messages about the vaccine (Wilyman 2010). However, although awareness had increased, vaccine uptake was reported as higher among those adolescents whose information was from brochures obtained through medical clinics or schools.

In Australia widespread media penetration (Roughead 2008; Haas et al. 2009) was evident, with 236 articles on the HPV vaccines published prior to the announcement of the PBAC funding decision in November 2006

(Roughead 2008). The societal impact from this awareness through public media streams led to a public push by the dominant population groups to make the vaccine immediately available in a desire to reduce the ICC risk, especially in Australia, Canada and the UK. The criticism of the hastily made HPV vaccine policy decisions by Governments in these countries in their response to public pressure (and further inflamed through the media) was widely reported (Sherris et al. 2006; Colucci et al. 2008; Lippman 2008; Roughead et al. 2008; Haas et al. 2009).

Most mainstream media reporting health issues and HPV lacks cultural relevance and ignores the normative values of mixed-culture populations (Reed 2002; Neuhauser and Kreps 2008; Hilton et al. 2010). For Australian Aboriginal people, McMurray and Param (2008) suggest that subtle racism exists in contemporary media, and especially against Aboriginal Australians living in Remote and Very Remote regions who are inappropriately compared with unrelated groups. Furthermore, this distortion engenders bias toward Aboriginal people in some health providers who characterise Aboriginal people by Western normative values, rather than by Aboriginal norms.

4.9 Strategies for increasing parental acceptance of adolescent HPV vaccination

Where vaccination uptake has been sub-optimal at the initial implementation phase (e.g. with small-pox and HBV vaccines) these disparities have successfully been overturned by involving cultural [or targeted] groups in the development phase of sensitive and appropriately targeted health promotion strategies (Woodruff et al.1996; Lam and McLaws 1998; Papaevangelou 2008; Chen 2000; McPhee et al. 2003; Burke et al. 2003; Middleman 2004; Stanton 2004). Marlow and colleagues (2009: 29) noted that the HPV information needs of women related to six dimensions that need to be placed in a context that is scientifically accurate and enables stigma associated with HPV to be minimised: identity; cause; timeline, consequences; cure-control; and procedural aspects of vaccination and testing.

The HPV vaccines are perceived as different to other vaccines, by their controversial sexuality characteristics and partial protection factors, and therefore broad based community education (a persistent theme in the HPV behavioural literature) is required to encourage vaccine uptake. As Koulova and colleagues (2008) report there was no universal strategy globally in the way the HPV vaccines were promoted to the community and it is not within the scope of this thesis to fully explore the different approaches that nations applied.

The wide-spread acceptability of the HPV vaccines dependent on unique and culturally relevant educational strategies was consistent with Tissot and colleagues USA study (2007), and Marlow and colleague's UK study (2009). Tissot noted that, in addition to higher education levels in parents, cultural congruence between the provider and patient (especially for those cultures where the open discussions of sexuality are not condoned) would aid acceptance of the HPV vaccines. Di Clemente and colleagues (2005) noted that STI prevention and control programs generally focus on individual behavioural change, and suggest that a strategy that encompasses a socio-ecological framework might be a more effective approach.

4.10 GPs: The attitudes of health professionals toward HPV vaccination

The studies that were reviewed about the attitudes of health providers both before and after HPV vaccine licensure (Aldrich et al. 2005; Riedesel et al. 2005; Kahn et al. 2005, 2007; Baay et al. 2006; Daley et al. 2006; Moorthy 2006; Duval 2007; Esposito et al. 2007; Tissot 2007; Feemster 2008; Ishibashi et al. 2008; Torne et al. 2008; de Carvalho et al. 2009; Henninger 2009; Katz et al. 2009; Lehmann and Benson 2009; Askelson et al. 2010; McCave 2010; Naki et al. 2010) showed the majority of doctors were consistent in their intentions to recommend HPV vaccination for males and females, with a preference for vaccinating older adolescent patients with the 4vHPV vaccine, and especially females (Daley et al. 2006; Esposito et al. 2007; Henninger 2009; Lehmann and Benson 2009;

Askelson et al. 2010; Lowry 2010; Naki et al. 2010). Some health professionals felt that because the vaccine was promoted as an ICC vaccine it would be less attractive as health prevention for males (Daley et al. 2006).

With physicians, concern for the HPV vaccine as a STI prevention negatively influenced some doctors' recommendations for males (Kollar and Kahn 2008). A review of the study of Italian paediatricians (Esposito et al. 2007: 6444) found results that were inconsistent with other studies, [although these views were given prior to a detailed HPV information campaign]. The high level of acceptance for vaccinating both males and females (56% to 69%) was lower than the studies conducted in the USA, and there was much lower acceptance for vaccinating females only (36% to 18% respectively). In India, health professionals (Dabade et al. 2010) recently indicated their significant concerns (about efficacy, side-effects, cost and marketing) about the 4vHPV vaccine and asked that all implementation strategies be disbanded until there was more certainty.

Religious beliefs of doctors (Buddhist) did not influence the attitudes of healthcare providers in Bangkok, Thailand, (n=100 doctors: 55% female, 45% male, 96% practicing Buddhist religious beliefs) (Songthapetal et al. 2009: 1053, 1055) who had 'moderate' knowledge on HPV and ICC. Collectively, they held positive attitudes toward HPV vaccination for adolescents, with high agreement (71% of doctors) that vaccination 'might not lead to an increase in exposure in risky sexual behaviour'. These data are consistent with other results (de Visser et al. 2007: 9) that showed 'more religious Buddhists were less conservative' indicating that assumptions cannot be made about religious affiliations and attitudes.

4.10.1 Attitudes of GPs toward age for adolescent HPV immunisation

Variations in the attitudes of primary care providers (GPs, paediatricians) toward the age for HPV vaccination were found. For example, Herzog and colleagues (2008) found that the majority of paediatricians (89.1%) thought the ideal age be 16 to 18 years, 65% of paediatricians preferred

age 9 to 13 years, and 18% of paediatricians preferred the target age to be younger than 9, or older than 13 years. Koulova and colleague's study (2008) found that Canadian health authorities recommended age 9, and in Germany, age 17 was recommended (Vetter and Geller 2007). These findings were consistent with parent preferences for age of vaccination in those countries. The low acceptance by health care providers to recommend HPV vaccination for younger adolescents was consistent with findings from the prelicensure data on females (Esposito et al. 2007).

4.10.1.1 Factors that contribute to doctors' recommendations

Key factors in GPs recommendations for HPV vaccines (Moorthy 2006) were structural and clinical barriers, interpersonal and patient factors, and lack of perceived benefit by GPs clinically and to the community. Despite their recommendations for HPV vaccine for females, over 90% of paediatricians and primary-care providers reported they lacked sufficient knowledge to adequately educate patients about the rationale for HPV vaccination (Daley et al. 2006; Sherris et al. 2006; Esposito et al. 2007; Brumder 2009; Lehmann and Benson 2009) and some doubted the vaccine's efficacy (Esposito et al. 2007; Herzog et al. 2008). Insufficient knowledge was a key barrier to HPV vaccine recommendation for GPs in Asia and Turkey (Chow et al. 2010; Naki et al. 2010).

One USA study (Kahn et al. 2005) (n= 1,000 USA family physicians, of whom 59% were male) noted that a family doctor's intention to recommend HPV vaccination varied and was dependent on several factors such as the vaccine type (2vHPV versus 4vHPV); patient age and gender; the extent of their HPV knowledge as knowledge provider; and gender of the doctor. A later qualitative study on the attitudes of USA paediatricians (n= 31) toward HPV vaccination prior to FDA approval (Kahn et al. 2007) showed three categories of vaccine determinants of adolescent vaccination (Table 9) that physicians took into account.

Table 9: Determinants of vaccine recommendations by physicians (Summarised from Kahn et al. 2007: 369 Table 1; Wong 2009; Askelson et al. 2010; McCave 2010)

New vaccines	Adolescent vaccines	HPV vaccines
Efficacy Safety Health impact Parental beliefs	Attending clinic Opportunistic vaccination Dosage compliance Developmental issues Safety, if pregnant	Efficacy Safety and risk Health impact & risk factors Adolescent susceptibility to HPV Sociodemographic, sexual, cultural & religious factors of patient HPV disease (cervical morbidity and mortality GW; cost savings) Opportunistic prevention Education Parental barriers (knowledge, relevance, denial) Cost Potential booster Patient-doctor relationship Cultural sensitivity and message framing

In particular, the doctor's normative values toward sexuality and vaccines; adolescent susceptibility to HPV infection; sociodemographic factors especially gender; perception of safety and risk; mistrust towards doctors and vaccine manufacturers; and misinformation from secondary sources (Kahn et al. 2007). Recent USA studies (Askelson et al. 2010; McCave 2010) on their behavioural and subjective norms of physicians toward barriers and support for adolescent HPV vaccination showed high intentions to vaccinate girls, and their high levels of activity were based on the recommendations of referent professional groups, and this was consistent with the physician populations in Germany (Vetter and Geller 2007) and Italy (Esposito et al. 2007). However a broader range of key factors (biomedical, information, psychological and structural) was

identified for HPV vaccines compared to other new and adolescent vaccines.

Studies of Malay physicians (Wong 2009; Chow et al. 2010) raised cultural sensitivity as a significant issue in patient-doctor discussions, which was absent in Kahn's profile. Among Malay physicians (Wong 2009) there was greater acceptance for HPV vaccines to be recommended to prevent ICC than to prevent a STI. Significantly, Malaysian patients were reported as preferring to delay adolescent HPV vaccination due to differing cultural beliefs and cost factors.

4.11 GPs attitudes toward their educative role in HPV vaccine delivery

People place high importance and trust in the information relayed by health professionals, about vaccination (Klein and Wilson 2002; Atkinson et al. 2003; Mays and Zimet 2004; Casiday et al. 2006; Daley 2006; Garland and Quinn 2006; Kimmel 2006; Dinh et al. 2007; Esposito et al. 2007; May 2007; Pitts et al. 2007; Rosenthal et al. 2007; Leask 2009; Lehmann and Benson 2009; Tozzi et al. 2009; Benin et al. 2010; Chow et al. 2010; Naki et al. 2010), but it can not be generalised that the doctor will be the primary source of information about HPV vaccines in all populations (Mosavel and El-Shaarawi 2007; Chow et al. 2010).

Key issues for GPs involvement in the HPV vaccination program, especially with 'opportunistic' vaccinations (Skinner et al. 2007) was the need to educate family physicians about HPV and using HPV vaccination as the primary ICC prevention in young women. These findings were consistent with findings from other studies (Streefland 2001; CCDP 2004; Raley et al. 2004; Gust et al. 2005; Kahn et al. 2005; Reidesel et al. 2005; Rupp et al. 2005; Tjalma and Van Damme 2005; Esposito et al. 2007; Tissot et al. 2007; Brown et al. 2009; Henninger 2009; Lehmann and Benson 2009). Studies on primary health care showed that physicians should have ongoing training in cultural awareness and linguistic diversity (Harmsen et al. 2008; Herzog et al. 2008) to better support patients' needs about HPV vaccines.

4.11.1 GPs and sexuality issues

The experiences of Australian GPs with patient sexuality issues varied. Patients want health providers to undertake the role of sexual health educator (Denny-Smith et al. 2006), but in Australia GPs cited time and funding, their perceived lack of influence on their patients and patients' education levels, as major barriers to sexual-health promotion with their patients (Raupach et al. 2001). Inconsistencies in practice on the prevention of STIs through GP clinics in NSW [Australia] were found in the study by Khan and colleagues (2008). For example, 67% of GPs provided STI-specific resources to patients diagnosed with a STI; 49% of GPs reported having STI take-home resources in their clinic, and 21% of GPs had posters on STI displayed in their waiting room.

A Victorian [Australia] survey of GPs' attitudes towards taking a sexual history (Temple et al. 1999) found varying attitudes among the profession. Most GPs commonly asked patients about mainstream sexuality issues. For example, 79% discussed safe sex practices, 63% discussed the number of sex partners, and 60% discussed injecting drug use. However issues such as using sex workers and sexual activity whilst travelling were not commonly discussed (31% and 50% respectively). Opportunistic discussion was found to be low with only 28% of GPs linking sexuality discussions to requests for the contraceptive pill, or Pap smear (30% of GPs). Female GPs who were younger, Australian trained and practicing in urban clinics were found to more frequently take a sexual history with a female patient and perceived less embarrassment among female patients (Temple et al. 1999). The proactive stance of female GPs was consistent with the findings of other Australian studies (Johnston et al. 2004; Freedman et al. 2006b; Khan et al. 2008).

The sexuality aspects of HPV vaccines influence GPs recommendations for adolescent HPV vaccination, their clinical practice and education of patients (Kahn et al. 2007; Sussman et al. 2007). The majority of physicians surveyed in the USA before licensure of HPV vaccines thought that parents would not support HPV vaccine (as an STI vaccine) offered to

young adolescents (Kahn et al. 2005; Riedesel et al. 2005; Daley et al. 2009). However, whilst patients do raise sexuality issues during a consultation, there are barriers to these discussions (Sussman et al. 2007; Verhoeven et al. 2010).

International studies (Arredondo et al. 2003; Verhoeven et al. 2003; Espositos et al. 2007; Herzog et al. 2008) noted that some pediatricians do not broker sexuality issues with their patients unless the patient does, although it has been found that discussions with patients on HPV vaccines provides an opportunity to open up broader discussions on sexual issues (Kimmel 2006; Kahn et al. 2007; Sussman et al. 2007; Benin et al. 2010). Other studies found that patients do not always support the notion of physicians talking about sexuality openly and honestly with them (Croft and Asmussen 1993; Thomas et al. 2004; Denny-Smith et al. 2006; Monk and Wiley 2006; Esposito et al. 2007). In contrast, although doctors in Christchurch, New Zealand 'are quite comfortable with these discussions' about STI vaccinations (Henninger 2009:283) doctors were 'less comfortable' in addressing adolescent sexual behaviour, and their perceptions of sexual risk-taking behaviour after HPV vaccination.

Significant barriers to counselling patients about sexuality issues reported in the literature (Verhoeven et al. 2003; Sussman et al. 2007) (Table 10) were centred on confidentiality issues if a third party was present, language and knowledge factors, and relevance of the topic to the complaint, culture barriers, system factors, and patient relationship history. Concerns about confidentiality and insurance in reporting STIs were identified as barriers to counselling patients in a UK study (Cassell, 2006) despite primary care managing most of STIs. Although UK physicians showed low concern around patient embarrassment, a study of Asian physicians (Chow et al. 2010) found that 56% of the physicians surveyed (n= 480: 120 each from Korea, Malaysia, Taiwan and Thailand) initiated sexuality conversations, but one in three of them were not comfortable doing so.

Table 10: Barriers to counselling patients (summarised from Verhoeven et al. 2003; Sussman et al. 2007)

Situational-related	Confidentiality: presence of the patient's mother Confidentiality: presence of the patient's partner Relationship: first contact with a patient Relationship: close professional
Patient-related	Language and comprehension factors Culture: ethnic differences Age difference between GP and patient Level of rapport and trust with patient Caution: fear of embarrassing the patient Presumption of patient's risky sexual behaviour Perception of patient receptivity
Doctor-related	Knowledge: insufficient training Management: lack of time Relevance: patient without genital complaints Complexity of HPV factors

4.12 Experiences of Australian GPs with HPV immunisation

Australian GPs' experiences, in a study of delivery of HPV vaccines to women aged 18 to 26 years (n =298) between 2007 and 2009 (Brotherton et al. 2010), expressed concerns about the NHPVP implementation strategy with short time lines, poor education, and impact on cervical screening rates. GPs self-reported their HPV knowledge as 'adequate', but a standardised survey found GPs knowledge to be actually 'moderate' (3.41 / 6), and GPs had unrealistic expectations about the impact of HPV vaccines on HPV infection.

GPs promotion of HPV vaccines to female patients (n=294; age 15-26 years: median age 22 years, attending a Family Panning health clinic in NSW, Australia) (Weisberg et al. 2009) varied. The study raised concerns that opportunistic promotion of HPV vaccines to eligible women is not occurring at optimal rates (n=84, 39.4% of women were offered the vaccine) but not all women (n =76, 42.5%) knew that the HPV vaccine was no cost during the 'catch-up' period.

Chapter 5: Understanding ‘culture’ and health interventions

5 Introduction: Socio-cultural derivations of health practices

The literature revealed there were few studies that specifically focused on population-based cultural factors and attitudes toward adolescent HPV immunisation. However, although cultural differences emerged in findings, the absence of a consistent definition of ‘culture’ across the HPV attitudinal and behavioural literature creates difficulties in drawing conclusions.

5.1 A culture paradigm

The conceptualisation of a culture paradigm, that incorporates the foundations of inter and intra- population differences within diverse cultures and nations, is an important factor in order to understand cross-cultural attitudes toward HPV vaccination. Anthropologists have been grappling with a definition for ‘culture’ since the mid-nineteenth century and their more recent stance has been in which the collective human capacity define their experiences symbolically. Context driven, its focus has evolved from Geertz’s humanistic perspective through to Foucault’s power and hegemony, and more recently to Szczelkun’s political and ethical processes of invention (McDonald 2004:256).These shifts in theoretical focus require caution when applying ‘culture’ as a comparative construct in cross-cultural population research.

Whilst the literature emphasises the term ‘culture’ (within the context of race and ethnicity), consideration of the complexities within a ‘culture’ paradigm emerged. Ladson-Billings (in Boulton 1994) suggests that the categories used to describe culture, also delimit. In defining ‘culture’ in the context of this study I also needed to consider where it sat within the construct of ‘ethnicity’ which is a complex discussion, and cannot be fully explored within the scope of this thesis.

5.1.1 ‘Culture’, ‘ethnicity’ and ‘race’

The complexity of defining ‘culture’ in health research (given its multidimensional nature and the differing views and emphasis of stakeholders) has resulted in differences in how population groups are classified. In recent literature on behavioural factors and HPV, ‘culture’ remains a ‘core theoretical concept’ (McDonald 2004:256), albeit a ubiquitous term. ‘Culture’ per se is not a universally accepted concept, and despite its inherent contradictions in health research (Tissot et al. 2007), it is a concept that researchers in this domain continue to engage with (McDonald 2004:256) because of the cultural heterogeneity of most countries globally in which research is conducted.

Michaud and colleagues (2001) maintain that the terms ‘culture’ ,‘ethnicity’ and ‘race’ are loosely applied in health research population surveys; thus the development of a definition for mixed culture populations for this study posed a semantic dilemma. Dein’s sociological perspective (2004) of ‘culture’ in health literacy referred to normative values; ‘race’ referred to ‘biological differences’; and ‘ethnicity’ was perceived as shared origins and philosophies.

Creswell (2003) adopted an anthropological view and posited that ‘culture’ was something that was attributed to a group when looking for patterns of a social world. Although the impact of entrenched ‘culture’ within the individual lessens with acculturation, these broad and racially bounded classifications in explaining health behaviours attribute to the ‘stereotyping’ and ‘victim blaming’ of vulnerable populations (as is evident with Aboriginal Australians), or dismiss groups as ‘ethnic minorities’ when it is often social and structural elements that are the causal factors of the behaviour (Naish et al. 1994; Pfeffer 2004; Tissot et al. 2007).

‘Ethnicity’ can be viewed as a broader term that defines transnational migration and is influenced by social processes. For example, Denzin & Lincoln (1998) maintain that, although ‘ethnicity’ is a critical attribute of ‘race’, it is a basis of the diversity within and between racial categories. Klessig’s behavioural perspective (1992) maintained it was not ‘ethnicity’

per se, but the social experiences of different groups that help shape particular cultural organization and value systems. Furthermore, Klessig (1992) proposed that the intracultural (or heterogeneous) variation within groups could be as great as, or sometimes even greater than, intercultural (or homogenous) variation.

5.2 'Culture' as a social determinant of health

The literature reports on the belief that 'culture' (as a lived experience) needs to be understood more cogently within the public health sector to reduce the burden of disease. Because 'lived experiences' are considered to be socially derived and dynamic, culture can not be self contained, (Bhopal 1997; Bond and Brough 2004) or a static concept (Donovan and Spark 1997; Morrissey et al. 2004; Bond 2005).

This proposition is examined in relation to Australian studies where McDonald (2004) claims that 'culture' as a way of being and knowing is a Western presumption of life as a category, and ignores the impact of socio-political practices and trends particularly on health and illness. Because 'culture' is often applied as a descriptor of broad similarities it does not always acknowledge the differences and customs within a specific cultural group. In particular, Australian [and USA, UK] health services and programs are viewed as being derived from Eurocentric, or 'westernised', forms and practices (McDonald 2004; Chilton et al. 2005), and in some situations this is perceived as creating information barriers and engendering racist approaches and negative stereotypes toward Aboriginal and immigrant health status (Brough 2000; Chilton et al. 2005).

5.2.1 Influence of Aboriginal cultural paradigms on women's health beliefs: '*women's business*'

Literature on the sociological aspects of Aboriginal society has identified that culturally, there are distinct separations between the roles of Aboriginal men and women. The reinforcement of cultural beliefs and practices were reinforced through generational oral narratives of 'the dreamtime'. A significant factor in the utilisation of women's health services, especially gynaecological and sexual health issues is the tension

between mainstream medicine practices versus ‘women’s business’ (de Ishtar 2005; Koori Elders et al. 1999).

Elder Aboriginal women often manage the cultural practices (‘women’s business’), and this role is a powerful influence on the well being of women’s health beliefs as well as their sexual and reproductive roles and practices (Warburton and Chambers 2007). ‘Women’s business’ is the foundation of both traditional and contemporary Aboriginal society and attendance by a female health provider is considered important to women’s well being (Maher 1999; Koori Elders et al. 1999).

In Victoria, Aboriginal women, and particularly the Elders, are described as the lifeline of their communities ensuring equitable outcomes for and within their communities (Victorian Government 2007) and are afforded considerable respect for this role. Koori elders and colleagues (1999) noted the strength of the normative and societal values within each community, in particular the negative impact on women’s health, if the elders had a biased view of the health intervention (Reath 1999) and do not recommend it for others.

5.2.2 Chinese cultural attitudes toward health and sexuality

In order to understand the attitudes of Chinese people toward sexuality, it first needs to be placed within the cultural framework of Chinese normative values toward health and well-being that survive with the Chinese diaspora (Lui et al. 2009). The elements of balance and harmony, described as ‘yin’ and ‘yang’, are the fundamental principle of their attitudes toward health, and illness is equated with a lack of self-discipline and neglecting filial duties (Lui et al. 2009). It is common within Chinese families to have matriarchic control over health decisions, and illness is not publicly discussed. Care for the ill is commonly, and firstly, sought from the immediate and extended family before seeking professional advice. Because Chinese people’s notion of health service operates within a ‘family centred model’, an illness such as cancer brings ‘family oriented stigma’ and represents a significant moral defect and social ostracisation for the extended family.

Creating a description of values and sexual norms in Chinese people from the literature was complex due to the heterogeneity of the Chinese population, and contrasting findings emerged. Despite some evolution in both public and Government attitudes China maintains a conservative sexual culture (Higgins et al. 2002; Jeffreys 2006). Sexual norms in China are influenced by ancient Chinese philosophies of harmony, with the universe and a biological epistemology of reproduction and sexual desire for the collective good (Zhang and Beck 1999). The general reluctance to publicly discuss sexuality issues, and the stigmatisation of people with sexually transmitted infections, arises from the emphasis on the ideology of 'sex for procreation'.

High regard is placed on the maintenance of moral values and generational authority-obedience values (Stockwell and Youyi 2004; Waters 2005), and as a result, expressions of sexual behaviour have been perceived as being manipulated by the needs of biology, culture, and the state (Parish et al. 2007). Recent changes in Chinese people's values has occurred with their exposure to Western cultural norms and values, where individualism and increasing diversity of sexual behaviour is respected, and sexual activity is considered a private matter, [rather than a state matter] (Boudville and Wong 1998; Liu 1999 in Zhang and Beck 1999; Tang and Parish 2000 in Parish et al. 2007; Higgins et al. 2002; Farrer 2002, 2008), and an individual's responsibility (Zhang and Beck 1999).

Women, who are considered 'asexual' and 'passive' beings (Zhang and Beck 1999) were integral to China's social engineering policy (Parish et al. 2007), which until recently included the need to undergo a premarital physical examination for marriage registration. These factors influenced women's sexual attitudes, and as a result traditional 'Chinese' cultural values places great emphasis on educational success, virginity, and therefore dating and physical intimacy is not encouraged prior to marriage.

The evolution of sexual norms in China has not been matched by an increase in reproductive-health education, although widely promoted since the late 1980s, in deference to the prevailing conservatism largely

dominated by an ‘abstinence only’ approach. Because sex education is not well taught, misconceptions about reproduction prevail (Gong et al. 1998; Aresu 2009). Moreover, the Internet and pornography are often a key source of information for young people despite it being heavily censored (Parish et al. 2007; Braun-Courville and Rojas 2009).

Several international studies reported varying degrees of sexual behaviours among expatriate ‘Asian’ people including sexual inhibition, later age of sexual debut, lower sexual and STI knowledge (Upchurch et al. 1998; Song et al. 2005; Meneses et al. 2006), are explained by factors in the family structure. Differences in parental attitudes toward adolescent sexuality emerged in the literature. Chinese parents who display contradictory emotions of ambivalence and care towards adolescent sexuality (Cui et al. 2001) were reported to recognise the importance of formal sex education for their unmarried children, and support the Government’s facilitation of this. For example, Chinese parents condone dating, as long as the child’s education achievements were not disrupted (Lau et al. 2005, 2009).

Despite the future-oriented moral progress, moral values are in transition and are perceived to be increasingly challenged by alternative ‘Western’ norms that are accepted in the younger population but still considered a corrupting influence by older people. Farrer (2008), and Parish and colleagues (2007) argue that the transformation in attitudes to sexuality can not be attributed solely to China but reflect a global trend.

5.2.2.1 Chinese adolescents’ attitudes to sexuality

In contrast to their traditional values toward familial piety and sexuality, the attitudes of older Chinese people are not necessarily held by the younger generation. Studies show that although premarital sex has become widely accepted among young people in urban China (Gong et al. 1998; Pan 1999; Wang and Zhang 1999; Cui et al. 2001; Zhang et al. 2002; Stockwell and Youyi 2004), sexual activity remains stigmatised for those whose socio-political upbringing deems premarital virginity a virtue (Parish et al. 2007). Moreover, a liberal attitude and increased tolerance toward

‘extramarital sex’ has resulted in an increase in STIs (Liu 1992; Gong et al.1998; Wang and Zhang 1999; Zhang and Beck 1999; Zhang et al. 2002; Parish et al. 2007).

5.3 Increasing support for HPV vaccines through a socio-ecological approach

There is one proposition in the literature that the cultural and environmental contexts of health interventions need to consider the diverse societal, demographic and psychographic domains in which the population resides (Bingham et al. 2009). In studies where socio-ecological approaches were applied, this multi-dimensional context clearly influenced health behaviours (Bailey et al 2000; Lannin et al. 2002; McPhee et al. 2003; Dein 2004; Di Clemente et al. 2005; Giordano et al. 2008) , and it showed that the influence of ‘culture’ is socially derived.

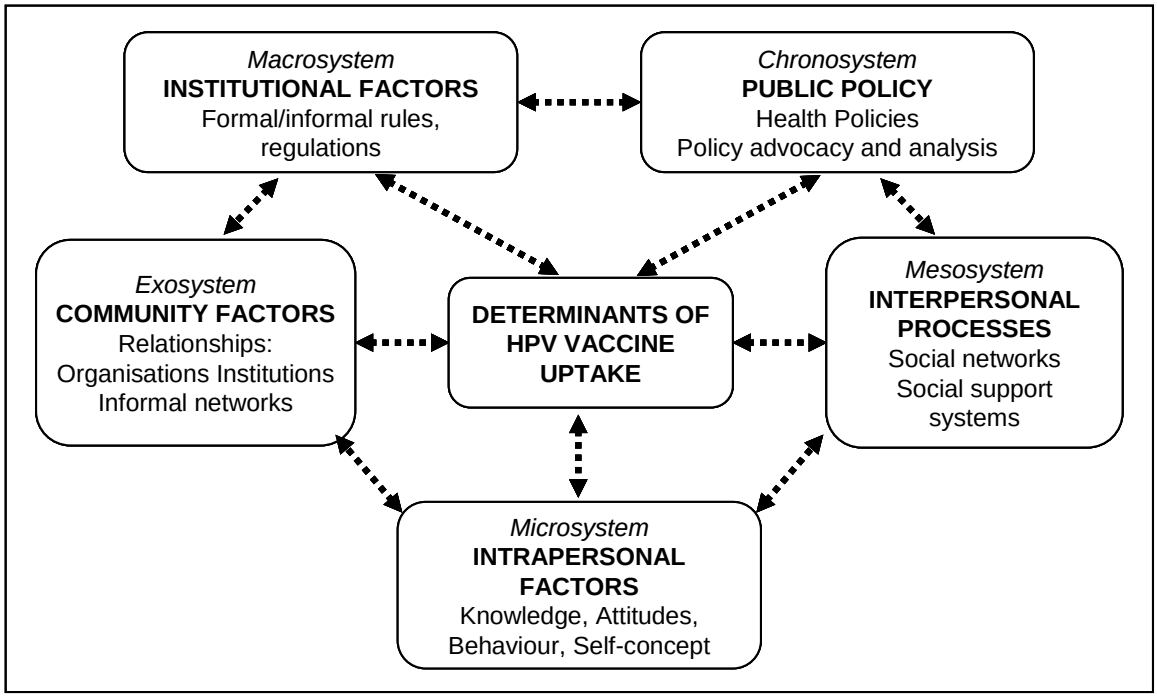
A large scale sociocultural study by the Program for Appropriate Technology in Health (PATH) (Bingham et al. 2009) of the implementation of HPV vaccines in four diverse and LDC nations (India, Peru, Uganda, and Vietnam) applied an adapted model of Bronfenbrenner’s (1979) socio-ecological perspective. The study demonstrated that the planning of immunisation programs is complex, but that a socio-ecological conceptual framework for HPV vaccine delivery can engender community and parental support for HPV vaccination. It highlights the ‘complex sociocultural factors influencing vaccine acceptance’ in diverse communities (Bingham et al. 2009: 459) such as distinctive interpersonal and social processes; intrapersonal factors such as knowledge, attitudes, and behaviour, as well as community and stakeholder relationships.

The benefits of this approach is consistent with the outcomes of a study of beliefs of cancer for Aboriginal people in Western Australia that applied a social constructivism approach (Shahid et al. 2009: 64), and that recognised the needs of the individual across multiple social domains. There was a greater acceptance for this approach among the Aboriginal community when gaining their engagement and rich insights.

An important element of applying a socio-ecological framework (Figure 4) when planning immunisation strategies is that it considers the micro and macro elements in the environment of key stakeholders: children, parents, and communities. Furthermore the model explains the interactions within complex social and environmental systems, and the specific social adaptations that relate to human activity and it's mutually influencing processes on individuals (Moos 1979; Streefland 2003; DiClemente 2005). The model integrates five key systems that shape an individual's behaviour and attitudes:

i. the context of their immediate environment (the individual or *microsystem*);
ii. the relationship between the microsystem and the immediate external world that the individual is active in (the interpersonal factors in the *mesosystem*).
iii. These systems then integrate with the passive influences which indirectly impact on the mesosystem (such as community examples or the *exosystem*);
iv. the broader cultural context of the immediate existence (the institution or the *macrosystem*);
v. the traditions that pattern environmental events and transitions (policy level or the *chronosystem*) (DiClemente 2005; Bingham et al. 2009).

Figure 4: A socio- ecological model for understanding HPV vaccine acceptance



(Adapted from (i) Bronfenbrenner et al. in McLeroy et al. 1988 (ii) Bingham et al. 2009)

5.4 Summary of the literature

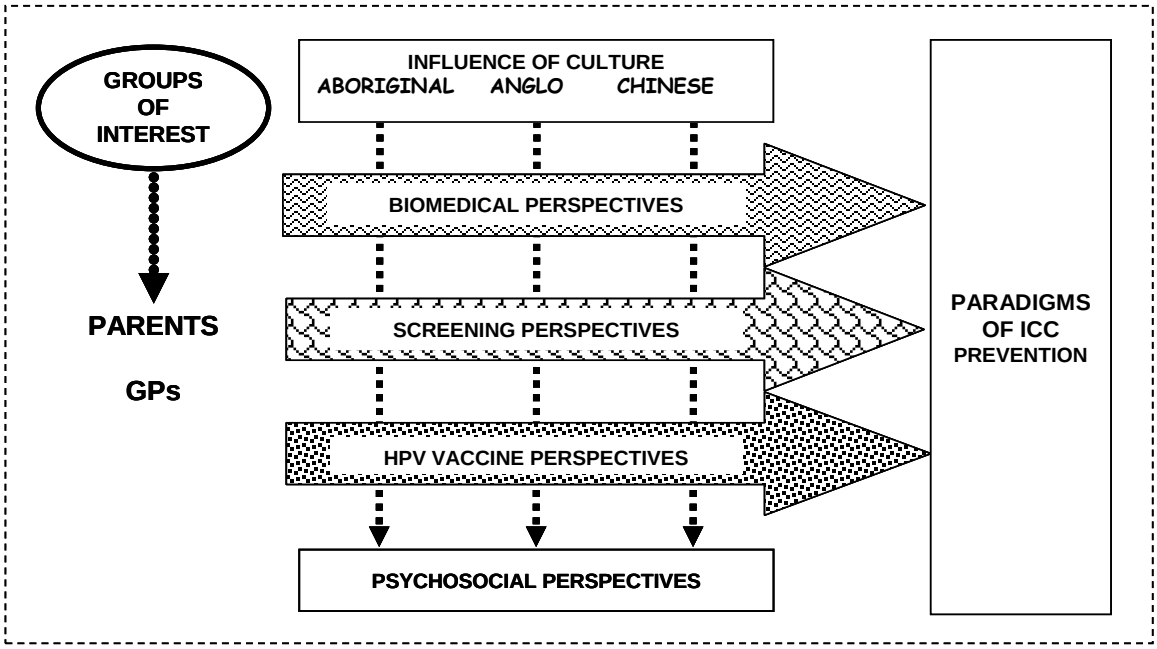
Studies cited in the literature review focused on three major dimensions of variables relevant to ICC prevention:

i. biomedical paradigms of cancer prevention through western models of screening and immunisation;
ii. structural paradigms and the delivery of cervical screening and HPV immunisation;
iii. psychosocial responses to cervical screening and immunisation interventions.

Underpinning these variables were cultural constructs and especially the notion of health prevention from Aboriginal and Chinese perspectives. Determining the influence of these variables on ICC strategies was complex because of the knowledge gaps in the literature, and in particular for the Australian population. The variables are interrelated and to

examine them as isolated entities is inadequate when trying to examine them through a cultural lens (Figure 5).

Figure 5: Scope of the Literature review



The sequence of perspectives under review has provided me with a fundamental understanding of the specific factors that impact on parental and health provider attitudes, responses and challenges to the introductory trajectory of HPV vaccines (Streefland 2003; Bingham et al. 2009). The introduction of prophylactic HPV vaccines has required a paradigm shift among health professionals and the general population and its impact will remain unknown for at least two decades. The absence of contextual consistency with the 'socio-cultural' perspectives of ICC prevention indicated there was a significant knowledge gap in this corpus of research on the role of culture and diversity of attitudes, social norms and experiences as they related to health interventions in multicultural contexts.

This reading of the literature revealed that the HPV vaccines are likely to be effective, and therefore will have a substantial impact on cervical morbidity globally. Whilst there has been consistent evolution in the development of knowledge relating to the biomedical perspectives of ICC

prevention, the literature on parental attitudes toward the HPV vaccines is not so well defined, and mainly from a Western-centric perspective. It is only in very recent years that literature has emerged from the Asian and sub-continent regions that examines critical HPV behavioural issues, and within discrete sub-population groups. When the behavioural literature was reviewed, the contextual approaches to ICC prevention did not sufficiently address the needs of diverse cultural groups, and especially in Australia.

The literature on cervical screening demonstrates the diversity of influences on participation, toward this form of ICC prevention, especially in Aboriginal and immigrant women. The perceived absence of cultural and social congruence between health providers and patients in some societies was reported to inhibit screening participation, hence the need for acceptance and uptake of HPV vaccines in those population groups. The literature also revealed that the psychosocial responses toward cervical screening, including ‘shame’ and ‘stigma’, and subsequent diagnosis pertaining to HPV infection and sexuality issues do impact on preventative health behaviours, and are culturally derived. For this thesis, the specific needs of Australian Aboriginal and Chinese women in ICC prevention are poorly understood.

Globally, the low awareness of HPV and HPV factors among adolescents and parents indicated the misconceptions that abound in societies globally about sexually transmitted infections and risk susceptibility. Although awareness levels varied across cultural groups, with higher awareness reported in ‘White’ populations than ‘Blacks’ or ‘Asians’, knowledge for all groups was incomplete. This low awareness was partially attributed to the absence of consistent sexuality education through schools, and with patients by health providers, and the reticence among family physicians for this was based on cultural factors both for themselves and their patients. The literature showed that family physicians from the Asian region in particular were reluctant to discuss sexuality issues, and doctors generally considered the sexual profile including the cultural background

of their patients when deliberating about sexuality information. Knowledge was found to increase acceptance by parents and health providers for HPV vaccination in adolescents, and if the message framing of the vaccines emphasised ICC prevention, although diverse opinions for the age of adolescent vaccination emerged based on sexual, physical maturation, and risk factors.

Biomedical, structural, knowledge and psychosocial factors all influenced parental acceptance for adolescent HPV vaccination in Developed Country nations primarily based on the vaccine being new, and its efficacy linked to sexuality factors. The strength of cultural, normative, and religious values in parental groups toward HPV vaccines being associated with risk perception of a sexually transmitted infection, and with their preference for vaccinating late adolescent females, was posed as a future challenge for sustainable HPV vaccination programs in some countries, particularly in the Asia region, and parents from the Middle East. Promiscuity after HPV vaccination was proven to be only a concern among a minority of parents in the studies, and was outweighed by parental desires to protect their children from disease.

Studies were consistent in finding that acceptance for the HPV vaccines could be enhanced through consideration for cultural and gender norms when planning strategies for implementation and parental consent, and promotion through mainstream media. The disparities in vaccine uptake in the first year cohorts in Australia and the UK indicate the need for a revision of HPV vaccine implementation approaches to avoid the HBV vaccine experience. The literature on cultural issues in health research described the fundamental challenges in the absence of a consistent classification when applying culture as a research construct, and therefore any comparisons from cross-cultural research cannot be generalised to populations within cultural categories because of the inherent heterogeneity in intra-cultural populations.

5.4.1 Limitations of the literature

The literature has shown that ICC prevention is complex and challenging globally. A review of HPV literature before the licensing of the HPV vaccines in 2006 indicated that there was a limited collection of research on both HPV awareness and psychosocial implications of HPV, and attitudes toward HPV vaccines. There was an important gap in the research on parental attitudes in mixed-culture populations and their intentions to vaccinate adolescent children with HPV vaccines. Findings in the literature review offer a possible explanation for the lack of conceptual consistency regarding what influence culture had in cancer prevention strategies in health care, and the broad variation in implementation strategies adopted by health professionals.

With the general Australian population much is unknown and generalisations cannot be made from international studies. Little is known about structural and psychosocial factors with Australian GPs especially their attitudes and the challenges they face in delivery of HPV vaccines, and if their beliefs are biomedically or culturally derived, or a combination. Government immunisation policies have imposed recommendations for age of vaccination but its uptake continues to be voluntary. The introduction of HPV vaccines has been sub-optimal and parents and primary health providers remain confused.

Because the HPV vaccines offer partial protection only against ICC, their role is misunderstood and controversial. Critical findings from the literature exposed low HPV vaccine knowledge levels in the general Australian population that may influence parental attitudes toward adolescent HPV immunisation. Knowledge levels about HPV and HPV vaccines for the population other than for specialist professionals' remains low and misconceptions prevail. One important finding was that HPV infection, as being very common in both sexually active men and women, has been well understood by health professionals for over twenty years, but the knowledge has not been adequately, nor consistently shared with the community, and especially with women who undergo cervical screening.

Normative and cultural values were shown to underpin attitudes and beliefs of parents in international domains and, whilst some cultural distinctions were significant, the studies related to discrete populations outside Australia. Although immunisation and cervical screening health research has been undertaken with discrete communities in the Aboriginal population, this research cannot be generalised for the national Aboriginal population. The literature showed that we know very little about Aboriginal and Chinese-Australian parents understanding of HPV, its association with cervical cancer or their views on HPV vaccines.

The majority of the studies on male HPV vaccination had limitations in their reporting or methodology and relied on convenience samples, and the findings could neither be generalized to the broader population nor vulnerable subpopulations. Culture was not defined as a factor in attitudes and intentions, other than reporting on the distinctions between Latino and Non-Latino mothers (Liddon et al. 2010). The knowledge deficit is further apparent in the recent body of evidence that is focusing more on cross – cultural needs through a broader socio-ecological approach.

Understanding factors that influence parental attitudes toward adolescent HPV vaccination from the literature is critical, but a recent study (Allen et al. 2010) reports that the findings from this specific corpus of HPV literature are not based on a standardised measure, and this limitation may distort the conceptual underpinnings of any comparisons, especially with research based in mixed-culture nations. The recent review by Fernandez and colleagues (2010: 239) also emphasises the absence of consistency, and in the ‘parental acceptability’ literature only five of the studies have been population based, and few studies ‘systematically examined the association between sociodemographic characteristics and acceptability’.

Furthermore, the normative values of Australian people toward health prevention and in particular Aboriginal and Chinese peoples are unknown. The Chinese-Australian group also represents a significant migrant population with divergent norms and cultural beliefs and values around

sexuality (Lau et al. 2005; Ross and Fernández-Esquer 2005; Sinha et al. 2005; Song et al. 2005).

5.4.2 Significance of the research topic

This research will provide evidence for health policy makers and health providers on how to better understand and have better implementation of HPV immunisation programs among Australia's culturally diverse population. The sample of populations of interest, Aboriginal, Anglo, and Chinese-Australian parents, have been specifically targeted as dominant and culturally and linguistically diverse groups within Australia, or are known to have a risk of poor outcomes from HPV infection and higher incidence of ICC incidence than other groups within the Australian population (Aboriginal women) (ABS 2001; AIHW 2001, 2007; AIHW 2003; Condon et al. 2004; Petoussis-Harris et al. 2004), and GPs (Prislin et al. 1999; Petoussis-Harris et al. 2004). This potential for disease reduction in vulnerable populations could be very valuable should researchers in the future be successful in developing an effective HIV vaccine.

5.4.3 The research questions

The literature published prior to the licensure of the HPV vaccines demonstrated that we do not really know what will assist Australian parents or guardians of adolescents in making informed choices about HPV vaccination; or what the attitudes of primary health providers will be toward the HPV vaccine. In order to maximise HPV vaccine uptake among the Australian adolescent population we need to better understand a range of phenomena around the attitudes and perspectives of two groups that influence vaccine uptake.

In particular, Melbourne based parents and guardians from the dominant Anglo population and two vulnerable and culturally diverse population groups, Aboriginal Australians residing in Victoria and Central Australia, and Chinese-Australians residing in Melbourne, Australia. HPV vaccine implementation will also be dependent on GPs for both patient information

needs about the HPV vaccines and vaccination, In particular, the perspectives of GPs practicing in metropolitan Melbourne, Victoria, and their intentions to participate in an adolescent HPV immunisation program.

This study will aim to contribute to the HPV and immunisation literature by investigating four research questions.

i. What do we need to know about the attitudes of Australian parents or guardians of adolescents, and GPs toward cervical cancer prevention through prophylactic HPV vaccines?

ii. What factors in the attitudes of Australian parents or guardians of adolescent prophylactic HPV vaccination will maximise uptake in the Australian population (Zimet et al. 2000a, 2000b, 2005; Waller et al. 2004; Kahn et al. 2005; Reidesel et al. 2005; Rosenthal 2005; Tjalma and Van Damme 2005; Zimet 2005)?

iii. What factors are associated with GPs attitude and willingness to recommend adolescent prophylactic HPV vaccination and what are the barriers to them recommending it (Cassidy and Mahoney1995; Waller et al. 2004; Kahn et al. 2005; Reidesel et al. 2005; Rosenthal 2005; Tjalma and Van Damme 2005; Zimet 2005; Zimet et al. 2000a,2000b,2005)?

iv. What influence do the ‘cultural’ norms of Anglo, Aboriginal, and Chinese-Australian parents and guardians have on their attitudes toward adolescent prophylactic HPV vaccination?

PART 2: THE RESEARCH METHODS

Chapter 6: Background to the Research Design

6 The research plan: theory or ideology

While ideologies are difficult to empirically challenge, theories are at the behest of evidence although ideology and theory are interlinked. Hoskins and Mariano (2004) maintain that when designing research, there are distinct differences between ideology and theory; that ideology is complex and resistant to change on the basis of empirical evidence.

6.1 Selecting an approach

There are a range of quantitative and qualitative approaches that can be used and a key challenge for any researcher is to apply an approach that best fits with the research question and demonstrates quality and rigour. Literature on behavioural factors and HPV vaccines has increasingly applied qualitative approaches but also exposes that there is no singular approach within the qualitative method.

In order to meet the research objectives this research needed an approach that would allow the discovery of how people are influenced by experiences from mixed culture social groups that are framed within a specific cultural context. An important element of the research focused on describing the phenomenon, ‘culture’ from an *emic* perspective, the perspective of the problem from the ‘native’s’ point of view where the cultural explanations and patterns are ‘inductively’ discovered within the cultural context rather than analysed from the researcher’s perspective; and in contrast to an *etic,* or ‘world view’, perspective that signifies quantitative research (Vidich and Lyman in Denzin and Lincoln 2003:61).

Although the selection of a qualitative method was particularly justified for this study it is worth briefly examining the historical basis from which tensions between quantitative and qualitative approaches arose.

6.1.1 The quantitative versus qualitative debate

If we support the basic tenet that any research method has to be considered against a set of assumptions about the nature of phenomena to be investigated, and the interrelated sets of assumptions regarding ontology, human nature and epistemology (Burrell and Morgan 1979 in Morgan and Smircich 2003; Denzin and Lincoln 2003; Kincheloe 2005), we are then compelled as researchers to have a clear view about our own understanding, and are therefore inherently open to challenge. But, as Morgan and Smircich (2003) further contend, the prevailing issue is whether researchers as human beings can ever achieve knowledge independent of subjective construction.

Quantitative approaches were dominated by an abstract empiricism toward organisational research throughout the 1960s and 1970s. Its research philosophy considered methods as ‘ends in themselves’ (Morgan and Smircich 1980: 492) and ignored the core assumptions. In contrast, the qualitative research paradigm emanated from cultural anthropology and American sociology, and its key influences arose from the United Kingdom and Europe (Kirk and Miller 1986 in Creswell 2003:179). A review of the historical strategies of inquiry shows the development of perspectives ranging initially with the development of empiricism and positivism with Descartes in 1637, Newton, Bacon, Hume and Comte in the 1700s (Ritchie and Lewis 2003:6).

Interpretivism followed in the 1800s with key contributions from Dilthey and his seminal work on ‘verstehen’ (Jureidini and Poole 2003:247) and people’s lived experiences; and the subsequent influence on Weber who attempted to link the work of the previous century with the emerging social contextualisation and understanding. These schools of thought underpinned the widespread adoption of qualitative research methods from the late nineteenth and through the twentieth century (Ritchie and Lewis 2003: 5-8).

Sociology saw the influence of positivism and its relation to the natural sciences as the dominant paradigm. The ‘modernist’ phase emerged as a

response to the need for justification of rigour and, diluting the criticism of qualitative approaches as ‘unscientific’, leads to the beginning of rigorous debate about the legitimacy of qualitative research as a scientific method. Qualitative methods were developed and applied to a range of theories especially in the psychology domain, and by the 1980s they were systematically being applied in psychology research. Throughout this evolution qualitative research was constantly challenged.

Creswell (1998:179) also noted the perspectives of other qualitative traditions and their contribution to current research practices, all with their distinct and contrasting knowledge claims, strategies of inquiry and methods of data collection and analysis. Early theoretical positions centered on grounded theory (Glaser and Strauss 1967 in Creswell 1998:179) and socially constructed models of reality (Berger and Luckmann 1966 in Creswell 1998:179). Following that, and as a result of the influence of the general critical theoretical notion espoused by Habermas in 1972, Shank (1995) describes the inclusion of interpretive areas including critical theory (e.g. McLaren in 1989); feminism (e.g. Lather 1991); action research (e.g. Argyris et al. 1985; Friere 1970); cultural studies (e.g. Giroux 1993); and postmodernism in general (e.g. Cherryholmes 1988).

Other important contributions to the qualitative research debate that have shaped the qualitative paradigm include post-modern thinking (Denzin and Lincoln 2003 in Creswell 1998:179); ideological perspectives (Lather 1991 in Creswell 1998:179); philosophical stances (Schwandt 2000 in Creswell 1998:179); and systematic procedural guidelines (Creswell 1998; Strauss and Corbin 1998 in Creswell 1998:179). Shank (1995) refers to this evolution of the qualitative inquiry as the ‘crossroads’ of qualitative research, noting that despite criticism of Lincoln and Guba's *naturalistic inquiry* (1985) it remains the basic philosophical statement in the current era of qualitative research.

As we examine the qualitative paradigm through time, it is apparent that the technique and methods espoused at particular points by social

scientists were shaped by contextual assumptions relevant to phenomena existing in that period. So rather than qualitative or quantitative research being seen as a particular set of techniques we are better embracing either as a product of recent influences.

6.1.2 Polarising views

All inquiry is laden with values (Mertens 2003 in Creswell 1998:179) and qualitative inquiry is no different. The selection of appropriate research methods in the social sciences as a scientific discipline has been a source of ongoing and polarising debate driven by varying assumptions about ontology, epistemology, and human nature. Traditionalists, advocating quantitative methods drawn from a reductionist research tradition have tended to devalue the potential contribution of more interpretive research methods, and those espousing qualitative methods have often criticised quantitative techniques.

These debates mask more fundamental differences in epistemology and approaches compatible with the philosophy of public health (Baum 1995; Pope and Mays 2006). Baum (1995: 460) argues that research methods are ‘simply tools that are used to further knowledge’. That neither a quantitative nor qualitative approach has an inherent advantage and further suggests that ‘public health researchers are most effective when they are eclectic in their choice of methods’.

6.1.3 Defining qualitative research

Many critiques of social research (Morgan and Smircich 1980; Baum 1995; Pope and Mays 2006; Denzin and Lincoln 2003; Burgess 1986; Silverman 1993; Hammersley 1989; Ritchie and Lewis 2003) argue that attempting to develop a definition or set of indicators for either quantitative or qualitative research methods is oversimplifying the inherent complex traits of each, both being ‘crude and oversimplified dichotomizations’ (Morgan and Smircich 1980: 491). For instance Creswell (1998: 181) and Denzin and Lincoln (2003: 9) claim the exclusive characteristics of the qualitative approach is its emergent investigative process in a natural

setting applying interactive, multiple methods attempting to better understand social phenomenon.

Morgan and Smircich (1980) also purport that qualitative research is an *approach* rather than a particular set of techniques, and its appropriateness derives from the nature of the social phenomena to be explored. Pope and Mays (2006: 8) and Morse and Field (1995) remind us that the ranges of approaches are mechanisms to assist us in solving research problems. They support the use of qualitative research with its emphasis on the *construction* of theory, a flexible design that does not seek to control, unlike quantitative approaches which specifically *test* a theory. At this point it is worth examining the historical underpinnings that have engendered so much debate and concern over qualitative approaches as an adequate research approach.

6.1.4 The complexities of a qualitative approach

In the absence of an agreed definition, the process of determining a qualitative research design to answer a research question is relatively complex given the different traditions within the 'school' of qualitative research (Ritchie and Lewis 2003). As Hoskins and Mariano (2004) noted, the design should fulfil a number of variables from answering the research question to issues of reliability and validity. Despite both quantitative (positivist philosophy) and qualitative (interpretive philosophy) (Jureidini and Poole 2003: 247) paradigms having unique assumptions, it was not until the 1990s that qualitative studies started to become accepted as a legitimate intellectual method of inquiry in clinical and biomedical domains. It is now accepted as a useful approach for studies that explore information and communication issues (Borreani et al. 2004).

6.2 Selection of the research methodology

A qualitative methods approach was selected for this research as its primary concern is attempting to understand how social phenomena occur. For example, because of the lack of published research in understanding what parents of adolescents from mixed culture

backgrounds and health professionals think of the HPV vaccine, in this study I am firstly seeking to understand what are the influences that underpin the attitudes and perspectives of parents and GPs toward the HPV vaccines, and if cultural determinants are a key influence in those attitudes. Secondly, I am seeking to understand what factors lead to informed consent in parents, and hence participation, in a HPV immunisation program for adolescent children.

6.3 The researcher as a bricoleur

If we accept that qualitative techniques are therefore linked to underlying assumptions, as discussed earlier, the researcher becomes a *bricoleur* (Denzin and Lincoln 2003: 5; Kincheloe 2005: 323) employing a range of methodological strategies as needed as the research situation unfolds.

The 'researcher as bricoleur' is a construct that emerged in the mid twentieth century. *Bricoleur* as a French term describes 'one who makes the use of tools available to complete a task' (Kincheloe 2008). The terms bricoleur and *bricolage* were first defined as a 'maker of quilts' (Levi Strauss 1966:17; Nelson Treichler and Grossberg 1992; Weinstein and Einstein 1991 in Denzin and Lincoln, 2003:5); and later, in a research context, as undertaking multiple and gendered images in various forms: interpretive, narrative, theoretical and political (Kincheloe 2008).

Kincheloe (2005: 324,325) maintains that if the researcher embraces multidisciplinarity and therefore that of the *bricoleur*, then the *bricolage* is grounded on an epistemology of complexity. Therefore a key task of the researcher is to attack the complexity and view the research method as far more than procedure.

6.3.1 The interpretive bricoleur

Denzin and Lincoln (2003: 9) maintain that the *interpretive bricoleur*, which mirrors the critical consciousness as a researcher, understands that 'research is an interactive process shaped by personal history, biography, race and ethnicity, and by those of the people in the setting', resulting in a reflexive collage and sequence of representations. Furthermore, it

disengages the researcher from passive acceptance of externally imposed research methods and the avoidance of monological knowledge from a 'lived' world that is impermanent (Kincheloe 2005).

6.3.2 Contextual contingency and triangulation

Two factors of a sociological approach to research impact on the quality of the research findings. The first factor, contextual contingency, occurs when the object of inquiry is ontologically complex and the interpretive process cannot be confined to a singular entity because it is part of 'many contexts and processes that are culturally inscribed and historically situated' (Kincheloe 2005: 333). The second factor, triangulation, is an integration of methods aimed at validation, or precision, of a research finding (Ritchie and Lewis 2003) and can give greater insights through multiple views to the phenomena being studied (Denzin and Lincoln 2003).

6.4 Ontological position

The ontological position adopted in this study is that of the '*critical realist*' (sometimes referred to as *subtle realism* (Hamersley 1992; Seale 1999 in Ritchie and Lewis 2003:13).That there is a presupposition of a pre-existing external reality, but that this reality is socially situated and therefore fluid. This is developed from a foundational construct that, whilst there is a social world within research that exists independently to my own, the only means of access to that world is by another's interpretations of that social reality. Those interpretations are then reinterpreted by me, the researcher, understanding that the research approach is dynamic, complex and not easily initially well understood.

6.5 Epistemological position

Epistemology refers to the researcher's perspective of nature and acquisition of knowledge which is socially, culturally, historically and linguistically produced (Finlay and Ballinger 2006). Ritchie and Lewis (2003: 13) maintain that there are three main issues that are debated in social research: the relationship between the researcher and the

researched and its impact on objectivity; the 'truth' and representation of socially constructed reality; and thirdly, pragmatic truth that produce predicted results. Their 'Framework' approach (Ritchie and Lewis 2003) is the primary approach applied in this research partially because of its epistemological stance of *interpretivism* and *pragmatism*.

6.6 Interpretivism

Creswell (1998, 2007: 15,101) elucidates that *interpretive* positions are pervasive perspectives within qualitative research because the participants represent underrepresented or marginalised groups. That the interpretative stance of the issues being researched seeks to respect the participants through reciprocity and most importantly acknowledge that 'the co-construction of the account between the researchers and the participants are the true owners of the information collected' (Creswell 2007:101).

6.7 Pragmatism

Pragmatism is interested in applying the right approach to ensure a 'fit' between the method and research question (Ritchie and Lewis 2003: 21) and that this may require multiple methods (a 'bricolage') of data collection. Pragmatic assumptions have governed claims about how knowledge arises; out of actions situations and consequences (Creswell 2003). Therefore *pragmatism* challenges the traditional notion of the absolute truth of knowledge (such as *postpositivism* with its 'scientific method' approach which imposes structural laws that do not fit marginalised individuals; or *constructivism* where individuals seek understanding and subjective meanings of their world) and is more concerned with applications and solutions to problems. Whilst the methods applied to pragmatist studies are important, the *problem* or 'practical reality' (Ritchie and Lewis 2003:15) is paramount, rather than the 'underlying philosophical debate' (Seale 1999 in Ritchie and Lewis 2003:15) that can limit the researcher to 'philosophically consistent' research methods (Ritchie and Lewis 2003:21).

6.7.1 Pragmatism and knowledge claims

Cherryholmes, Murphy and Cassell (in Creswell 2003: 12) suggest pragmatism forms the basis for several knowledge claims and is driven by anticipated consequences. This study adopts a *pragmatist* approach in that it

i. provides me with 'freedom of choice' in the selection of methods, techniques and procedures that best meet the study requirements. This is particularly apt for meeting the needs of the Aboriginal and Chinese population samples;
ii. seeks mixed ways to gather data rather than adopt a stance of 'absolute unity';
iii. recognises that research always operates within a range of social contexts.

6.8 Reliability

Although reliability is a construct that fits more readily within a quantitative research approach, qualitative researchers (LeCompte and Goetz 1982; Silverman 2000a; Seale 1999 [all in Ritchie and Lewis 2003:271]) contend that reliability and replication 'have direct relevance to qualitative research'. Seale (1999 in Ritchie and Lewis 2003: 271) in particular argues that reliability and replication can be achieved through reflexivity. In addition to the relationship between the researcher and the researched, it is important to consider the place of the researcher in the interpretation of the evidence (Ritchie and Lewis 2003: 205) in terms of reliability.

6.8.1 Reflexivity

Drawing on what May (2002: 332, 341) calls the 'politics of reflexivity' it is important to appreciate the politics of relations between the 'knower' and the 'known'; that the 'knower', in terms of their identity, is underpinned by the assumption that they are able to move across boundaries. If we view reflexivity as *mutual collaboration* and *social critique* (Finlay 2002: 218, 220) it enables the representation of multiple voices and management of the social construction of power balance and broader political dimensions.

This study intends to achieve this through enlisting participants as co-researchers especially with the Aboriginal communities where mutual collaboration is essential for data gathering.

6.8.2 Limitations of reflexivity

Paradoxically, Finlay (2002: 226) concludes that whatever one's stance, reflexivity has limitations with 'rhetorical functions' and 'infinite regress' and its 'preoccupations with collaboration and egalitarianism'. Therefore there is a need to emphasise contingent, partial, tentative and emergent qualities' of the research. In preparing for the participant interviews, I was mindful of this notion of reflexivity, and, in particular, that the knowledge I was seeking to gather was situated within the research participant.

There are varying frames of reference that situate the interview. For instance the social derivative construct of Mason (2002: 64) who views it as 'a social situation simultaneously orchestrating the intellectual and social dynamics of the situation'; and the systemic process within Denzin & Lincoln's (1998) description as a process of transforming ignorance and misapprehensions into more informed consciousness. Because of this epistemological assumption about the *interaction* in the interview, and my reflexivity, it was accepted that neutrality is impossible and that bias cannot be 'eradicated'.

6.8.3 The strength of reflexivity

Latimer (2003), Pope and Mays (1995, 2006) and Creswell (2007) support the previous merits of reflexivity as an important contribution to the qualitative paradigm. In their discussions of qualitative research they assert that all writing is positioned and within a stance and because of that the writer needs to be conscious of the biases, values and experiences that are brought to a qualitative research study. Qualitative inquiry draws its analytic and exploratory strength from reflexivity and goes as far to suggest that the omission of theory is an advantage; and that *essentia*l reflexivity and *derived* or *ideological* reflexivity (Denzin and Lincoln 2003: 471) are givens. Therefore the initial challenge ranged through the

positioning of self within the research process and, as importantly, to what degree of verisimilitude, or the appearance of truth, would be produced.

6.9 Framing the research question

Morse and Field (1995) and Pope and Mays (2006) posit that researchers are often limited in their approach to the research question by the knowledge of their mentor and by their own knowledge. Boulton (1994) argues that before we can ask *why* a social phenomenon is occurring or *how* we can influence it, we need to understand the phenomenon itself rather than being defined by the social problem. Whilst I accede that my initial knowledge of the research field was minimal this research was fortunate to have within the four academic supervisors (mentors) extensive experience with quantitative and qualitative, behavioural, clinical and scientific research approaches.

Silverman (2001) illustrates the value of framing research questions in terms of analytic issues, which in turn can lead to unexpected practical policy recommendations (an unanticipated outcome of this research in Central Australia) confirming the power of sociological analysis. The importance of understanding the acceptability of HPV vaccination among parents, given that HPV is a STI, was highlighted by an editorial in the British Medical Journal (2005: 915) which listed questions that should be addressed before communities start HPV vaccination programs.

6.10 Evolution of the research plan

The development of the research plan evolved from a wide reading of literature along the parameters of Strauss and Corban's purposes (1998: 73, 215):

(a) ***Stimulation of theoretical activity*** where concepts, relationships and research trends in a relatively new field of endeavour have been formulated and refined commensurate with knowledge acquisition;

(b) ***Secondary data sources*** that now provide valid underpinnings to assist this research in having purpose;

(c) ***Directing theoretical sampling*** that identifies international work that will support the formulation of hypotheses and theory;

(d) As ***supplementary validation*** that forms the scope (and eventual findings) of this research;

(e) ***Theoretical sensitivity*** in that the researcher is passionate about the research being undertaken; has familiarity with the research area and is skilled enough to cultivate the insights gained from previous experiences that are likely to occur.

6.11 Informing the methodology: related studies

In order to inform the methodology of this research, a review of methodological approaches in relevant literature was undertaken. An analysis of thirty seven related studies between 1995 and 2005 (Appendix 7) focused either on parent attitudes to adolescent or childhood immunisation, and STIs in general or HPV. It is surprising that despite the reported progress in HPV vaccine development to 2005, and especially from 2001 (see Timeline: Appendix 6), there were very few studies that specifically examined attitudes towards an adolescent HPV vaccine. This may indicate that few researchers were expecting the final rapid advance beyond 2005 that led to the quadrivalent HPV vaccine licensure in 2006.

The methodology within the selected studies revealed that a qualitative approach had been applied in twenty seven of the studies either in entirety (eight) or as part of a mixed methods approach (nineteen studies). This approach enabled a full exploration of the study participants' beliefs and attitudes from a diversity of backgrounds. Although none of the thirty seven studies was suitable to emulate completely, aspects of several studies had methodological elements that were either adapted or adopted to enable me to understand the attitudes of parents and the contexts in which those attitudes were formed.

A study by Zimet and colleagues (2004) (sample size n=40) reinforced the use of face to face interviews and recruitment though an adolescent primary-care clinic waiting room. Mays and colleagues (2004a) adopted a similar approach in the exploratory phase of their ongoing study on determinants of parental acceptance on STI immunisation for adolescent children. Prior studies had focused on young children.

6.12 A 'Framework' approach

A 'Framework' approach has both inductive and deductive elements, but is considered a more deductive form (or *a priori* reasoning) of analysis, with a more structured form of data collection that is increasingly used in health research (Pope and Mays 2006; Creswell 1998: 15). It uses a matrix-based method of analysis that was originally generated by Cobb and Hagemaster in 1987 (Spencer et al. 2003) and further developed in Britain specifically for qualitative research and particularly in the health sector (McDonnell et al. 2001; Pope et al. 2000; Ritchie and Lewis 2003).

The matrix provides a 'visual template' and summary of the data (Bates Averill 2002) which allows for the generation of meaning and knowledge, resulting in the dissemination of findings that benefit groups, especially vulnerable populations targeted for health interventions (London 2002), and this was an important consideration for me. Two approaches in particular (Miles and Huberman 1994; Ritchie and Lewis 2003) were considered as potential appropriate frameworks.

6.12.1 Selecting a 'Framework' approach

Miles and Huberman's 'Framework' approach (1994) was initially considered as a preferred model for this research, not only for its applicability to health research, but because 'matrix analysis as an analytic strategy appeals to the notion of pragmatism' (Bates Averill 2002: 864), and that the respondent accounts are central to deductive analysis. Whilst a benefit of this approach for other researchers is that its systematic processes are transparent, a British case study research noted

that with matrix analysis it is possible for the analyst to lose a holistic sense of individual cases (McDonnell et al. 2001).

The method of analysis that was finally selected was Ritchie and Lewis' 'Framework' Analysis (Ritchie and Lewis 2003) because of its philosophical approach, which takes a pragmatist perspective drawn from principles of rigour and accessibility that does not restrict or confine it (Ritchie and Lewis 2003:19). It also fits with the interpretivist epistemological stance chosen for this research. This approach has proven effective for health research, but a limitation is that the approach is quite procedural and because a 'Framework' approach is guided by abstract principles, the essence of the central underlying meaning of the experience could be restricted.

If one accepts this 'procedural' limitation, then Ritchie and Lewis's epistemological position on interpretivism does not fully allow for the complexity of the researcher – researched relationship inherent in cross-cultural research. Although there were parallel characteristics in both Framework' approaches, Ritchie and Lewis's (2003) epistemological and ontological stance sat better with my philosophy, and despite its limitation, was selected as a more contemporary and better fit for the outcomes of this research.

6.13 Data management: Ritchie and Lewis (2003) 'Framework' approach

Whilst every stage of the research process is critical for success, the analysis stage needs to be robust and therefore can be the most challenging. In essence, it is described as the culmination of interpretation of data 'rich in descriptive detail' (Ritchie and Lewis 2003: 209). A thematic framework analysis has been prescribed as the analytical approach, as justified in the previous chapter. Simplistically, and to mimic Ritchie and Lewis's (2003: 209) description, it is primarily a process 'concerned with understanding and interpreting substantive meanings.'

Furthermore Ritchie and Lewis (2003) thematic 'Framework' is a more formal systematic approach to data collection and analysis than other qualitative approaches (Pope et al. 2000). In addition its iterative approach to analysis (Ritchie and Lewis 2003: 212) depicts the five stages of framework data analysis (Table 11) enabling it to adhere to sound qualitative research principles of rigour, validity, defensibility, and accessible findings that would enable tangible outcomes from this study.

Table 11: The five stages of the iterative process throughout data analysis in a 'Framework' approach (Ritchie and Lewis 2003:212)

a. Assigning data to refined concepts to portray meaning
b. Refining and distilling more abstract concepts
c. Assigning data to themes / concepts to portray meaning
d. Assigning meaning
e. Generating themes and concepts

6.13.1 Data analysis

Ritchie and Lewis (2003) thematic 'Framework' manages data according to central themes and sub-categories. Although the thematic charts developed for each sample group (Appendix 8) had subtle variations the thematic coding was consistent between groups to enable patterns of association to emerge. The building of a thematic 'Framework', (described in Ritchie and Lewis 2003: 222 - 253) involves the following steps:

i. ***Identify (recurring) themes and concepts within individual contributions*** from a thorough review of the range and depth of the data;

ii. ***Construct an index*** by identifying links between categories, grouping and sorting them according to their levels of generality;

iii. ***Label the data*** so that it accurately portrays the status of the categories and its 'fit' with the data;

iv. ***Sort the data by theme or concept*** so that material with similar content or properties are located together;

v. ***Synthesise the data*** through summarising and distilling the essence of the evidence for later representation through thematic charting;

vi. ***Define elements and dimensions*** by refining categories and classifying data in a way that is conceptually pure and has meaningful distinctions;

vii. ***Establish typologies*** by identifying the relevant dimension of a typology involving cross-case analysis, testing on the data set and combining to form a typological category;

viii. ***Explanatory accounts – link phenomena*** through 'matched-set linkages' (pg 248) where connections occur between phenomena in the data within particular sub-groups;

ix. ***Associative analysis*** where links between two or more phenomena are identified and their existence explored;

x. ***Develop explanations*** through 'interrogation' (pg 252) of the data in multiple ways to determine what is underlying the occurrence of the data.

6.14 Sampling in qualitative research

The logic underlying sampling strategies for qualitative research is often different to quantitative research, which seeks generalisation via a random and statistically representative sample. The features of qualitative sampling are based on seeking information-rich cases for detailed study that will best illuminate the research questions. The sampling strategy and size is based on flexibility and evolvement; is serially selected; continuing to saturation or 'redundancy'; and thus an approximation of sampling size is initially set (Creswell 2003).

The key principles that guided the qualitative sampling strategy in this research were appropriateness and adequacy (Morse and Field 1995). Having defined the appropriate population another critical component of the research design was the determination of sample size, and confidence that the recruitment strategies would satisfy an adequate sample of participants. Qualitative samples are usually small for practical reasons to do with costs of time, money, and of generating and analysing data in depth. It is not possible to achieve this depth of analysis with large data sets in a qualitative approach.

6.14.1 Purposive sampling

Because purposive sampling is not based on a notion of empirical representativeness some critics dismiss it as *ad hoc* or vague if not employed systematically (Mason 2002). Ritchie and Lewis (2003: 79) provide a succinct definition of purposive sampling: ‘members of a sample are chosen with a ‘purpose’ to represent a location or type in relation to a key criterion’. This ensures all relevant and key constituencies are covered; and that diversity is included to enable full exploration of the phenomenon. The attraction of purposive sampling as a suitable strategy for this research was its fundamental premise that the processes of sampling are viewed dynamically and interactively, and that it had been used in previous similarly themed studies as described earlier.

6.14.2 Range of approaches

Ritchie and Lewis (2003: 79) further describe a range of approaches to purposive sampling: homogenous; heterogeneous; extreme or deviant; intensity; typical case; stratified purposive sampling and critical case sampling. The *stratified purposive sampling strategy* (Blaikie 2000: 205; Creswell 1998:119; Ritchie and Lewis 2003; Miles and Gilbert 2005:168) that was applied in this study is described as a ‘hybrid approach in which the aim is to select groups that display variation on a particular phenomena but each of which is fairly homogenous’ to allow for sub-group comparison (Ritchie and Lewis 2003: 79).

6.14.3 Approximation of size and sampling

Approximation of size and sampling populations for this study was facilitated by a review of relevant qualitative studies (refer Appendix 6: Rosenthal et al. 1995; Mays et al. 2000; Zimet et al. 2000; Lazcano-Ponce et al. 2001; McCaffery et al. 2003; Waller et al. 2003; Davis et al. 2004; Mays et al. 2004; Bair et al. 2005; Olshen et al. 2005; Short et al. 2005; Timmermans et al. 2005; Zimet, Perkins et al. 2005; Zimet, Mays et al. 2005) in which the average sample size was less than twenty participants. These studies also provided a methodological framework for the parent sampling of this research, as well as validating the choice to draw on

institutional settings and medical agencies as the most appropriate sites for recruitment.

6.14.4 Saturation

Strauss and Corban (1998:136, 212) uses the criterion of *saturation* (adding new cases to the point of diminishing returns, when no new information emerges) to determine sample size. In order to satisfy the saturation criterion the most commonly applied sample strategy was deemed to be *stratified purposive sampling strategy* (Blaikie 2000: 205; Creswell 1998:119; Miles and Gilbert 2005:168). Throughout the recruitment and interviewing phase it was necessary to question whether the sample provided access to enough data to address the research question, although 'saturation' had been reached (Betaux and Betaux-Wiame 1981 in Mason 2002:134; Pope and Mays 2006: 66).

6.15 Representativeness and sampling

If the purpose of a sampling strategy is to provide useful meaningful empirical contexts (Mason 2002), I also had to consider to what extent the qualitative approach could give adequate access to rich data that would allow me to develop an empirically and theoretically grounded argument about mixed culture attitudes. Although classifications are developed as a gauge of 'measuring representativeness' (Mason 2002:135), the characteristics of the participant groups in this study that were selected (specific and diverse cultures, parent status, gender; and GPs) could not be seen as characteristic of the wider population of each cultural group. Furthermore, as 'culture' is a key element of my ontological perspective (where the culturally derived attitudes and behaviours of people are meaningful to the research) then 'culture' per se *is* a relevant ontological property of the social world and cannot, in this context, be construed as measuring representativeness for the particular cultural group.

6.16 Obtaining generalisability and transferability

The issue of *generalisability* of data from qualitative analysis is questionable among some research sectors (Silverman 2005). Whilst my

study is Australian context specific I do not expect that the findings from this qualitative research will be representative of the communities within the sample, nor statistically representative. However, it is expected that the research will identify the kind of relationship the data may have to the broader population and make inferences that can be applied to the development of 'conceptual generalisability' (Green and Thorogood 2004) that has validity in informing a broader and subsequent study. Given the issue of generalisability is a qualitative research paradigm (Ritchie and Lewis 2003; 264) the findings will

i. not have ***representational generalisation*** with the Australian cultural groups studied, but will generate hypotheses to inform further research; it will be *representational* in terms of the accuracy of data gathering and interpretation, but with limitations for the 'parent population,' because the sample is drawn from limited geographical sections of Australia (Victoria and Central Australia);
ii. have some ***inferential* (or *empirical) generalisation*** (transferability) to countries with mixed culture populations;
iii. have ***theoretical generalisation*** for the GP component of the study (Ritchie and Lewis 2003: 264).

It is anticipated that the recommendations made for the communication of HPV vaccines in cross-cultural populations may also inform health communications in other similar cultural settings.

6.17 Summary

Designing a research study requires careful thinking, recognition of complexity, systematic planning and patience. Central to the design process is an understanding of key research approaches, the courage to be creative, and the responsible application of knowledge. However the 'knowing' requires insights gleaned from informed literature and undertaken to inform the research question. In embracing social research through a qualitative paradigm in a systematic manner a valid contribution to health research practice and appraisal can ultimately be made.

Chapter 7: Aim and Methodology

7 The research proposition

My primary objective was to understand cultural diversity and difference in the health domain and if this diversity, in fact, influences parent attitudes in uptake of adolescent vaccines. The research proposition described in Part 1 speculated that ideal health interventions can be implemented successfully in diverse cultural groups as long as they operate within a readily identifiable subculture (Wells 1985: 51, 55; Robinson 1997: 5). However, if the dominant culture ignores the needs of the subculture, some people in the sub-culture group may feel helpless and therefore not comply with the health intervention, in this case HPV vaccination of their adolescent children.

7.1 Obtaining ethics approval

Ethics procedures were first submitted to the Human Research Ethics Committee (HREC) of the University of Melbourne (Victoria) (Appendix 9) as this was the host University of the study. Later, after the sample selection was agreed upon, further ethics applications were submitted for approval with the medical centres and communities with which this study engaged: the Royal Children's Hospital Melbourne HREC (Victoria) (Appendix 10); Royal Women's Hospital Melbourne HREC (Victoria) (Appendix 11); and the Central Australian HREC for Indigenous Research in Alice Springs, (Northern Territory) (Appendix 12).

7.1.1 The Memorandum of Understanding

On the advice of the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) a Memorandum of Understanding (MOU) (Appendix 13) for both Aboriginal Advisory Groups (AAG) in Central Australia and Victoria was formulated. The MOU for both AAGs were prepared based on a framework developed by VACCHO, and with the fundamental role of protecting the cultural values of communities and the participants, and ensuring joint understanding and respect. The

philosophy and principles of research practice within Aboriginal communities in Australia will be discussed in detail in Chapter 8.

7.1.2 Ethical challenges

This study presented ethical issues in two groups that needed to be resolved. I required access to 'gatekeepers' who would introduce me to their Aboriginal and Chinese communities; and mentoring in appropriate and culturally respectful recruitment methods for the qualitative interviews. This included consideration of several factors for the Aboriginal participants who are historically perceived as 'vulnerable minorities' (Smith1999:18; London 2002; Liamputtong 2007:2) and recipients of historical structural injustice (Reed 2002); the ability of participants to give 'informed consent' where they do not give consent in writing; patient anonymity and de-identification; transcription of audiotapes; and interviewer bias and sensitivities around engagement with the personal life of the respondent.

7.2 Research population: the role of comparisons

At the time of the study design there was no existing Australian population study on parents' attitudes towards the HPV vaccine. International studies had focused on HPV awareness and STI vaccines in general, and furthermore the population samples in the studies did not really characterise Australia's diverse population. Ritchie and Lewis (2003: 49) highlight the 'role of comparisons' on the research setting and populations of interest.

The role of comparisons is an important feature in the current research design (Bryman 2001 in Ritchie and Lewis 2003: 50), and the value of comparisons in qualitative inquiry has the following advantages inherent in the management of phenomena between groups by:

i. identifying the absence or presence of particular phenomena between groups;
ii. exploring how manifestations of phenomena vary, and how they impact between groups;

iii. exploring the interaction of phenomena in different settings and the broader context in which they arise (Ritchie and Lewis 2003: 50).

This understanding of comparisons influences the sample size in order that it can be large enough, without being overly large, to 'reflect the diversity of the parent population, as well as the approach to data collection' (Ritchie and Lewis 2003: 51).

7.2.1 Populations of interest

The sample populations of interest,

i. parents of Aboriginal (urban and remote), Anglo and Chinese descendency living in Australia who have been specifically targeted as prominent cultural groups within Australia (ABS 2010) and
ii. General Practitioners (Prislin et al.1999; Petousis-Harris 2004),

relate to the Australian population groups most at risk of poor outcomes from HPV infection as described earlier. The sample selection was based on the dominant groups within Australia who were large in number of population (ABS 2010); culturally diverse (Aboriginal, Anglo and Chinese); or had a higher incidence of ICC incidence than other groups within the Australian population (Aboriginal women); or within their home country (women from mainland China). The Australian-Chinese population also represents a significant migrant population with divergent norms, cultural beliefs and values around sexual relationships (Lau et al. 2005; Ross et al. 2005; Sinha et al. 2005; Song et al. 2005).

7.2.2 Population diversity

Combined, the sample population groups represent three sufficiently diverse cultural groups to explore the influence of culture on parents' knowledge, attitudes and intentions to vaccinate their preadolescent children with HPV vaccine. This implication of diversity presupposes a central theme that sensitivity and customisation of HPV vaccine

communication to diverse culture groups is critical to the success of the reduction of HPV infection and subsequent reduction of cervical cancer (Stevens and Walker 1999; Tjalma and Van Damme 2004).

7.3 Sampling criteria

The study sampled two groups (a) parents, and (b) GPs with specific inclusion criteria:

(a) *Parent* participants:

i. cultural representation: Aboriginal, Anglo or Chinese descendency residing in Melbourne, Victoria, or Central Australia (Aboriginal participants only);
ii. a parent or guardian of a male or female child who was up to 16 years of age. Parents of children > 16 years of age were excluded;
iii. either male or female (Aboriginal parents were female only due to the research theme being 'women's business');
iv. those of Anglo and Chinese descendency had to be sufficiently English literate to understand the study information and consent;
v. participants had to be in attendance at one of the recruitment sites.

Some of the Aboriginal participants were also AHWs in the community, and the AAG advised me that the research outcomes cannot generalise across different Aboriginal groups due to their inherent heterogeneity. The sampling strategy therefore incorporated 'geography' as a key characteristic within the Aboriginal sample only.

(b) *GP* participants:

i. a practising full time member of the Division of General Practice in Melbourne, Victoria;
ii. male or female.

7.3.1 Australian studies

Two studies conducted in Australia (Bond et al. 1998; Marshall and Swerissen 1999) were important in demonstrating that vaccine behavioural research involving parent participants was acceptable to be undertaken in Australia and Melbourne in particular, and that parents were willing to participate in potentially controversial research topics. Despite a limitation being that both studies focused on parent attitudes to childhood, rather than adolescent, vaccination, they were useful in informing the parent sample of this study. Different approaches were utilised in the sampling strategies.

Bond and colleagues (1998) applied a purposive sampling strategy, and Marshall and Swerissen (1999) applied a snowball sampling approach, both of which were eventually applied to this study's parent population sample. Other factors from their studies were applied in the methodology of this research. In particular, 'gatekeepers' in the recruitment process; semi-structured interviews and interview structure including interview themes and influences on, risk perception; and the decisions, experience and outcomes regarding immunisation and consent protocols.

7.3.2 Recruitment of samples from vulnerable communities

Several studies have demonstrated the difficulty in conducting population surveys on risk behaviours among vulnerable communities (Liamputtong 2007) because of general resistance to invasion of privacy issues and sensitivity toward personal and sensitive topics (Boulton 1994; Pyett 2002; Smith 1999; Stewart et al. 2006). If the premise that some populations are 'vulnerable' is accepted then that presupposes the dominance of one group over another as originally proposed by Wells (1985) and Robinson (1997).

I understood from the outset of the study that a high level of participant trust and engagement within each community in the sample was critical for success. Trust was a pervading construct because of the sensitive nature of themes we intended to discuss with the communities. The

importance of gathering opinions from community members, confidentiality, and the sense that it was a ‘collective’ rather than ‘individual’ opinion was paramount.

As no research occurs in isolation, the relationship with other key stakeholders is vital to research outcomes. In the study design, consideration had to be given to not only building relationships, but making them sustainable for the longer term. Inherent in this process are fundamental principles such as reciprocity, participant and researcher characteristics, especially sensitivity and respect, transparency, consistency, authenticity, flexibility and integrity. From this understanding the ‘champions’ and ‘gatekeepers’ (Ritchie and Lewis 2003) for the Aboriginal and Chinese communities was formed, and this is discussed in more detail in Chapter 8.

The recruitment of the required minimum number of participants (ten) for each sample group to achieve the research outcomes posed considerable challenges which resulted in the development of a variety of sampling strategies designed for the unique characteristics of the target population. For instance, the sampling frames (which inform the inclusion and exclusion criteria) proposed for the Anglo, Chinese and GP populations (face-to-face semi structured interview with 10 to 15 male and female participants) were not suitable for the Aboriginal populations.

The recruitment strategy (as summarised in Table 12) had to be modified for the Aboriginal (and eventually the Chinese populations) due to difficulties of access to the sample population.

Table 12: Recruitment and data collection summary

CULTURAL GROUP	SITE	SAMPLE SIZE	METHOD
ABORIGINAL	Central Australia AHWs region wide	4 communities 19 participants Female only some of who were also AHWs	HPV education session Purposive sampling Focus Group Semi-structured topic interview guide
ABORIGINAL	Victoria AHWs region wide	6 communities 66 participants Female only some of who were also AHWs	HPV education session Purposive sampling Focus Group Semi-structured topic interview guide
ANGLO	Victoria: Metropolitan Melbourne	15 participants 9 Females 6 males	Purposive sampling Face-to-face interview Semi-structured topic interview guide
CHINESE	Victoria: Metropolitan Melbourne	11 participants Female only	Purposive sampling Snowball sampling Face-to-face interview Semi-structured topic interview guide
GPs	Victoria Metropolitan Melbourne	15 participants 8 Females 7 males	Purposive sampling Face-to-face interview Semi-structured topic interview guide

7.3.3 Participant recruitment sites

Clinics in two major tertiary referral hospitals in Melbourne were selected for the recruitment sites for Anglo and Chinese parent participants because of the volume of patient traffic through them on a regular basis. In early 2005, recruitment posters advertising for participants (Appendix 14) were placed in the waiting rooms, and prior to my personal recruitment approach to people waiting in those areas. The female and male Anglo parent quota was fulfilled through a specialist general gynaecologist clinic of the Royal Women's Hospital, Melbourne (Victoria); and the Adolescent Clinic at the Centre for Adolescent Health, Department of Paediatrics, Royal Children's Hospital, Melbourne (Victoria).

7.4 'Mixed methods' qualitative approach to data gathering

Dew (2007: 434) posits that 'the way we collect data creates or constructs a particular version of reality'. There are a variety of different approaches to collecting qualitative data, and which in turn inform the method applied. Ritchie and Lewis (2003: 34-36) bisect the categories and it is worth noting the differences at this point before we progress to the final preference for collection.

Ritchie and Lewis (2003) describe the principles and value of a 'mixed methods' approach between qualitative methods, not just in the traditional qualitative - quantitative combination. The use of qualitative methods is influenced by the aims of the research and the specific questions that need to be answered. Given the cultural and professional diversity of the sample selection, it was appropriate that a mixed-methods approach within the qualitative paradigm be applied. And thus a combination of data collection approaches (face-to-face interviews and focus groups) was generated (Table 12) so relevant issues could be adequately explored within cultural structures and the diverse needs of each cultural group.

7.4.1 Semi-structured face to face interviews versus focus groups

Initially semi-structured face to face interviews were proposed as the singular method for gathering data because it is considered to be well suited to the exploration of attitudes and beliefs of complex and sensitive issues, and facilitates comparability among a varied sample group (Barriball and While 1994). In semi-structured interviews, the focus is on the individual and the perspectives and context in which they derive the research phenomena, especially where complex issues need to be explored (Ritchie and Lewis 2003). Hence a list of themes to be discussed is generated, which also allows participants some element of control over the answer and in raising themes not initially identified (Dew 2007).

While this process may be considered costly, it enables the building of rapport with the individual (although this can lead to *interviewer effect* (Boulton 1994) and control of the context of the interview through

exploration of issues with the participant to gain a deeper understanding of the research question (Ritchie and Lewis 2003).

There are some limitations to the semi-structured interview method. It can be a cumbersome approach in terms of research time frames requiring much planning and preparation, including theoretical analysis and pre-testing to guide the selection of sample via a thorough review and analysis of literature to inform the interview schedule and thus determining the purposive sampling frame (Boulton 1994; Hoyle et al. 2002; Mays 2002; Miles and Gilbert 2005).

The semi-structured interview method was dismissed as the best approach for the Aboriginal sample cohort due to my lack of relationship with the Aboriginal communities; geographic accessibility, language issues and sensitivity of the topic. A focus group method (or organised group discussion, and another legitimate way for gathering data) was proposed instead for the Aboriginal participants. This method has been successfully used in market research techniques since the 1920s (Boulton 1004: 160) and more recently in attitudinal and health behavioural research (Ritchie and Lewis 2003).

Recent studies (Boulton 1994:13; Twinn 1998; Webb and Kevern 2001) support the application of focus groups in health research where it is not possible to investigate the research question through more traditional forms of data collection. Kitzinger's study (in Boulton 1994: Ch.10) demonstrates how focus groups are ideally situated for research exploring communication issues and cultural constructions. This is further supported in Twinn's study (1998) with Chinese women demonstrating how rich data from culturally sensitive samples can be obtained.

Focus group methodology employs an interviewing technique (Robinson 1999) and, as Boulton (1994:169) noted, an important element of focus group discussion is the variety of communication engendered, and that 'sometimes the group process itself generates ideas which the individuals alone might not have articulated'. As some of the characteristics of the

vaccine could be perceived as potentially controversial by the participants it was important that they were given the opportunity to give their opinions through direct contact with the researcher, rather than through a written survey.

The inherent challenges with both in-depth interview and focus group method, including accessibility to participants, and the potential for different results (Dew 2007) is discussed in Part 4. Furthermore, the Aboriginal groups that were interviewed involved members from community social groups that regularly interact, and are thus vulnerable to group dynamics and the inherent potential for bias (Hoyle et al. 2002: 408).

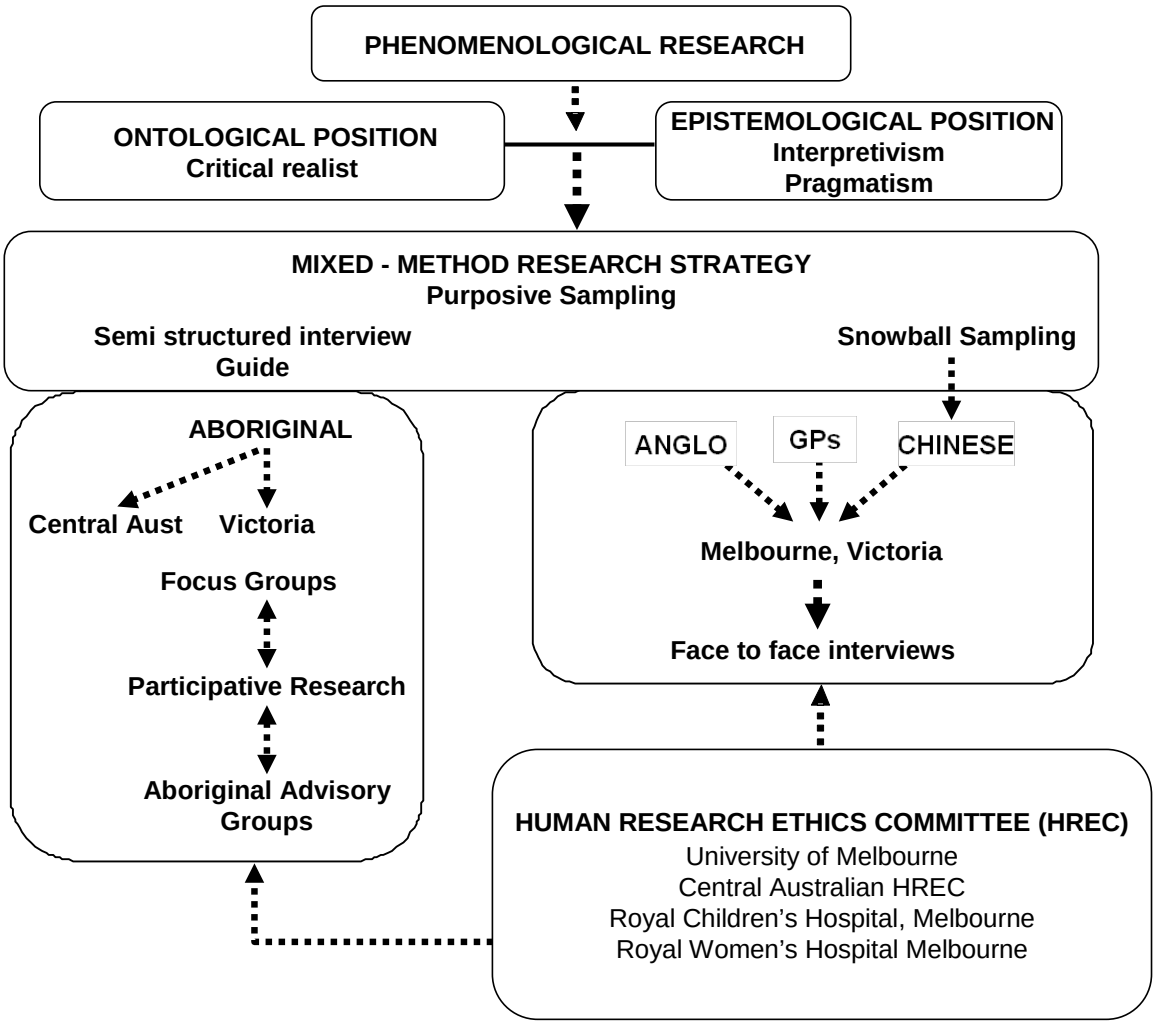
7.5 The final methodological framework

With the principles of good qualitative research study design in mind, (Figure 6) summarises the methodological framework that was applied in the study. It is important to note that as the understanding of researching mixed cultures evolved, and in the pursuit of pragmatism, that the Aboriginal and Chinese population groups prescribed a mixed methods approach.

7.6 Implementing the Framework: development of the topic guide

Topic guides, or interview schedules (Ritchie and Lewis 2003), are the central tool in the interview phase of the data collection. Given the sensitive nature of the research theme, it was essential that the topics discussed did not deter participants in the early phase of the interview. The structure of the topic guide was developed applying the Ritchie and Lewis (2003:115) model, which applies structure with flexibility, a ‘mechanism for steering discussion rather than an exact prescription of coverage’. The guide’s opening theme is designed to be a ‘soft’ entry into the greater body of work; then building to unknown territory with dramatic interludes; progressing to a climax; and then subsiding into completion.

Figure 6: The methodological framework



Both topic guides were preceded with assurances of confidentiality and the interview process, and collection of demographic data. It closed with follow up contact details, reporting and use of the data, and acknowledgement of participation.

7.6.1 The 'parent' topic guide

Key themes included in the parent topic guide were derived from the literature and developed from the study research question. Lazcano-Ponce and colleagues (2001) applied a quantitative population survey approach (n=880), but the key themes that were investigated were most useful in informing the cross cultural aspects of my parent interview schedule. Timmerman's study (2005), although on meningococcal C vaccination, further justified the purposive sampling size for cross cultural

studies and, with Zimet (2000), reinforced the vaccination themes for the parent topic guide (Appendix 15).

In summary, the key themes were:

i. Prior vaccine experiences
ii. HPV knowledge
iii. HPV vaccine knowledge
iv. Emotional impact of HPV knowledge
v. HPV vaccine target groups
vi. Adolescent relationships, STIs and the influence of culture on beliefs
vii. Attitudes to HPV vaccine messages
viii. HPV vaccine delivery
ix. Intention to consent.

Although cultural variations to the interview approach are discussed in the next chapter, the themes remained consistent for all parent population groups. In addition to the topic guide several other resources were developed for the interviews with parents: an HPV education intervention (Appendix 16); and HPV fact sheet derived from the Australian Government cervical cancer web site (Appendix 17). It was assumed that the parent participants would have similar low levels of HPV awareness of other populations (as described in the Literature review) and therefore education resources, given at particular points, would aid the interview.

7.6.2 Piloting the topic guide

The parent topic guide and resources were piloted with a ‘convenience’ sample of four parents to ensure relevance and flow of themes; semantics; readability; and ordering of topics, especially those potentially sensitive such as adolescent sexual practices; intimacy; and HPV as a STI. The topic guide was refined based on the pilot interviews.

7.6.3 Topic guide: Aboriginal communities

The topic guide for the Aboriginal communities (Appendix 15.1) was refined from the topic guide used for Anglo and Chinese parents. Feedback was invited from members of the AAG for each region on the applicability of the topics, discussion length and transcription of data. The AAG advised that the central themes be maintained in plain language; that

a transcription booklet be prepared for each focus group discussion; and that AHWs, as facilitators, would be the key representatives for informed consent.

Central issues included in the topic guides for both Aboriginal communities were:

i. HPV vaccine messages – males and females
ii. HPV information provider
iii. HPV vaccine education needs
iv. Gender and cultural issues: education of males
v. HPV vaccine target groups and age
vi. HPV vaccine implementation and dosage
vii. Parallel Pap screening

7.6.4 The 'GP' topic guide

The validated survey instrument used in Kahn and colleagues' study (2005) that examined paediatricians' intentions toward HPV vaccines informed my GP topic guide (Appendix 18).The GP topic guide focused only on key HPV and HPV vaccine issues to encourage GP participation. Central issues included in the GP topic guide were:

i. HPV knowledge
ii. HPV vaccine knowledge
iii. HPV vaccine target groups
iv. HPV vaccine delivery
v. HPV vaccine education needs
vi. Intention to recommend

The GP guide was piloted with five GPs and, due to financial constraints, the GP sample was confined to metropolitan Melbourne.

7.7 Informed consent

Boulton (1994: 229) asserts 'researchers can never be entirely confident they are proceeding on the basis of informed consent, especially when their respondents have little or no knowledge of the business of research'. It was on this premise with the Aboriginal participants, that the role and trust was paramount in the AAG and the AHWs who were gathering data and obtaining informed consent verbally from participants (Appendix 19 and Appendix 19.1).

Furthermore, it is common research practise that informed consent is given at the commencement phase of the research. Miles and Gilbert, (2005: 28) however suggest that informed consent should be considered as a process 'rather than a one-off event' in case the interview surfaces insights and information that the participant does not want to engage in. One of the advantages of qualitative research is that the interviewee can have periods during the interview where the participant can be advised of any forthcoming sensitive issues, and can therefore withdraw consent.

7.8 Data collection 2005 – 2006

The approaches to data collection reflected my epistemological and ontological positions (Dew 2007; Ritchie and Lewis 2003) as discussed in the previous chapter. The data was collected using in-depth semi-structured face-to-face interviews with a mean length of 75 minutes (range: 55 to 115 minutes) from fifteen Anglo, eleven Chinese and fifteen GP participants (Table 12), before the licensure of the 4vHPV vaccine.

Data was also collected by semi-structured focus group discussions from the 66 Aboriginal participants from Victoria and Central Australia, and which occurred after the international licensure and Australian registration of the quadrivalent vaccine, but prior to the government funded school based immunisation program commenced. Although a variation in time occurred, because of the time taken for relationship building and protocols within the Aboriginal populations, this time difference did not significantly impact on the outcomes.

7.8.1 The interviews

The Anglo and Chinese parent participants chose to be interviewed in their homes, other than one male Anglo parent, who chose to come to my research office where a secure and private space was available; one female Anglo parent; and one Chinese female parent who chose their respective secure office. Fourteen GPs chose to be interviewed in their clinics, during working hours and one GP elected to be interviewed after

working hours at his home. I ensured that one of my supervisors was aware of my whereabouts for my safety.

Prior to the interview each Anglo, Chinese and GP participant gave their informed consent (Appendix 20 and Appendix 18.1). Personal and identifying socioeconomic details and participant code were entered on a separate sheet signed by the participant (Appendix 21), for access by the PhD candidate only. Data was stored in accordance with the requirements of the respective HREC committees.

All participants were advised of their rights including privacy and de-identification. It was emphasised that during the interview sensitive topics relating to intimacy and relationships would be raised; that participation was voluntary; and they could withdraw from the interview at any time, including after the interview was completed. All participants responded to all topics, and none withdrew consent at any time.

7.8.2 Recording and transcribing interviews

All interviews with the Anglo, Chinese and GP participants were digitally audio-recorded and were later transcribed verbatim by a professional secretarial group. Participants were described on the audiotape only by self-reported cultural group, date of birth, gender and date of interview. This process ensured that at the time of transcription that the person undertaking the task would not be ably to identify the participant. In reporting extracts from interviews within this report, and to ensure that the meaning was not lost in the representation, word repetitions and speech hesitations (i.e. terms such as ‘um’ or ‘ah’) are omitted unless the entry was deemed integral to the analysis. The accuracy of the content of the transcription was proof-read by me, by comparing the audio recording with the written transcription provided by the secretarial group.

7.8.3 Unanticipated events

As the timeline (Appendix 6) illustrates, the approval for HPV vaccine licensure fell just after data collection with the Anglo and GP sample had been completed, but during the data collection phase with the Aboriginal

community and toward the end of the last of the Chinese sample interviews. Unanticipated timing of the development of relationships and subsequent entry into the Aboriginal and Chinese populations was a competing factor. Compounding this was the parallel initial public media campaign building awareness of the ‘cervical cancer’ vaccine in the later stages of data collection. However, as the discussion of results in Part 3 indicates, this activity had minimal impact on the data about the HPV vaccines given by the participants in these two sample groups, partly due to their lack of access to mainstream media.

7.9 Summary

In the absence of empirical research that addresses community understanding of a critical health issue (acceptability of HPV vaccination in adolescents), it was critical that the methodological approach was rigorous enough to enable the research achieving its key objectives. The development of the research aims and methods requires meticulous understanding of the implications of particular approaches to the research aim.

This study drew on a qualitative mixed-methods approach with systematic purposive sampling guided by time and resources. The design of the research, whilst drawing on prior research in the field, was specifically aligned to the research questions. This was further supported in the management of data by the application of a thematic framework approach. Awareness and sensitivity to the specific needs of the diverse cultures was mandatory at every stage of the methodology development to ensure maximum outcomes.

Chapter 8: Reconstructing the Methodology

8 Unpacking ignorance: the intricacies of cross-cultural research

A major challenge in selection of the sample for a cross-cultural study was to identify who, in the mixed culture nation of Australia, was the population group/s of most interest and determining what characteristics they should embrace. As my research journey began, I grappled with the dilemma that if the methodology was adapted for a subset of the sample population it could potentially impact on the research's methodological congruence (Morse and Field 1995), although congruence was maintained through the application of central themes across all interview guides. This ensured that the basic philosophy underpinning the methodology was interrelated and maintained.

8.1 Evolution of the methodology: cultural considerations

There are several important perspectives in understanding the fundamental requirements for this research. Importantly, in developing appropriate methodology frameworks for people from Aboriginal cultures and to a lesser extent those from Chinese descendency, both of whom could be classified within the construct of 'vulnerable minorities' (Liamputtong 2007). Denzin and Lincoln (2003: 422) highlight the need for generalisable qualitative methods 'for people of colour' structured around verbal communication. Whilst one could argue this is true for all populations regardless of 'colour' characteristics, it does in essence connote those whose primary means of communication media is orally derived.

Within the Aboriginal population oral-based cultures are derived from empirical evidence of experiences of colonisation and exclusionary practices through politicisation, sociological traditions and the imported cultural baggage (Denzin and Lincoln 2003). Significantly, in the design of the methodological approach for them, it was important to understand that one Aboriginal community cannot speak for another, and females cannot speak on behalf of males. In addition, people from Chinese cultures often

find it difficult to openly discuss personal issues centred on intimacy and relationships. It is therefore from this paradigm that the methodology for the Aboriginal and Chinese communities evolved.

8.2 Power relations in cross-cultural research

The research methodology literature has a prevailing central theme of 'power relations' which is a contradiction to my professional and personal ethos of 'equals' in partnerships…'we are as one'. May (2002) suggests that a reflexive understanding of power relations between the researcher and research participant in social research is inextricably linked to societal ideology where dominant groups conduct research, often on groups and individuals who are less privileged. Richards and Schwartz (2002) contend that power imbalance in the research relationship is inevitable. This notion is represented in recent cases with Aboriginal research (Smith 1999; Pyett 2002; Stewart et al.2006), and especially in non -Aboriginal researchers in mixed culture communities, where such ideology intersects and directly impacts on research relationships (May 2002).

Boutlon's study (1994: 229) with the HIV / AIDS sector discussed the potential for the 'exploitation and objectification of respondents' inherent in the research process, and what means would minimise the likeliness of this occurring. Boutlon's (1994) solution, and one that was adopted, was to know that one way in which these communities would have better outcomes in the future was to treat respondents with respect, and take the information they give as useful and important. Drawing on this, I assumed responsibility within the delivery of the research plan to ensure that power imbalances were addressed and avoided. By acknowledging the complexity and sensitivity of the subject to be researched (and with the 'gatekeepers' support) the potential imbalance of power between the AHWs gathering data and their communities was able to be diffused.

8.3 The Aboriginal population

Because of their feelings of social marginalisation within the Australian social context, Aboriginal populations are generally wary of outsiders and

suspicious of research, especially health related research (Pyett 2002). Smith (1999), Pyett (2001) and Liamputtong (2007) discuss the merits of collaborative, participatory approaches informed by Aboriginal research methodologies, and it was on this basis, and a willingness to be flexible to limit the effects within the communities I wished to engage with, that the original methodology was reconstructed for the Aboriginal sample.

8.3.1 Conducting ethical research in Aboriginal communities

The awareness of the challenges in conducting ethical research in Aboriginal communities (Smith 1999; Pyett 2002; Dunbar et al. 2007) made me seek the expertise of the AAGs and NHMRC National guidelines (2003) for research involving Aboriginal Australians. The importance of the stated values such as integrity, reciprocity, respect, equality, and responsibility, were complementary to my values but at the stage of the research there was little practical guidance other than that provided by the expert advisory groups in how to achieve these.

Complementary to Dunbar's experience (2007), this created a challenge for the research initially, due to a limited (and with me, non existent) relationship with both Aboriginal communities. Apart from shared values and determination, progress was reliant on the prior research relationship one academic supervisor had in Central Australia, and on the formidable reputations in the HPV sector of all four supervisors.

8.3.2 The influence of prior research experiences

Due to imperfect research experiences in Aboriginal communities, a legacy of community suspicion or mistrust of research prevailed (Menzies et al. 2007) and because of this, research involving Aboriginal communities now pursues a model that involves community participation at every step of the research process resulting in outcomes that are relevant and beneficial (NHMRC 2003).

As a non-Aboriginal researcher it was important that I maintain respectful engagement, ongoing consultation, and negotiation with communities by understanding that the models of collaborative, participatory, and action

research can present specific challenges to conventional research methods (Pyett 2002). A strategic outcome of the research was to provide opportunities for capacity-building and empowerment in the communities who were to be immediately targeted for HPV immunisation, and who were involved in the research.

8.3.3 Study protocols

After the Victorian AAG had endorsed the MOU (Appendix 13) it was sent to the Central Australian AAG for review, adaptation and modification for the specific characteristics of their communities, and subsequently submitted as part of the Central Australian HREC submission. Simultaneously, to ensure the content and approach was culturally appropriate, a plain English study proposal, participant information sheet, and interview schedule (modified from the original version developed for the Anglo population) was developed to enable informed consent (Appendix 19, Appendix 19.1 and Appendix 19.2).

8.3.4 Co-researcher recruitment

The role of ‘gatekeepers’ as key stakeholders in the Aboriginal community were instrumental in directing appropriate research protocols. Three leading research advocates in VACCHO, who were experienced anthropological researchers, guided me the appropriate approach to research with an Aboriginal community. Since the initial phase of HPV vaccine mass immunisation is targeted at women, and therefore considered ‘women’s business’ among Aboriginal communities, the project team members who led the Aboriginal community consultation comprised females who worked in Aboriginal Health in Central Australia, and regions across Victoria. All were AHWs except for two who are project leaders in women’s and sexual health.

8.3.5 Capacity building and reciprocity

On advice from the AAG, AHWs workers in Central Australia were engaged as temporary research staff to work with those in remote communities, because at that time the study lacked requisite capacity

building capabilities and avenues for reciprocity (NHMRC 2003). At the time of data gathering the HPV vaccine was not available for school-based immunisation, and therefore it would have been insensitive and irresponsible to accept information from the community without reciprocity.

Ethics requirements and the practicality of engaging with AHWs resulted in confidence that they, the AHWs, had local knowledge and access to individuals which would taken me, the researcher as an outsider, a considerable time to acquire; as well as immediate acceptance and trust by the community they work in. Although the AHWs had the benefit of familiarity with the local community culture the risk of misunderstandings in data collection and interpretation was possible due to them not being formal researchers, their reliance on external members for HPV information, and their variations in English language literacy levels.

8.3.6 Engaging Aboriginal Health Workers (AHWs)

During my first field visit to Alice Springs and attendance at an Aboriginal women's health forum in Melbourne (Appendix 22) I and the two AAG leaders set out to explain the HPV vaccine study in a manner that was understandable to all participants. The intention was to inspire participation and enable AHWs, as now appointed 'research team' members, to undertake important preliminary steps in bringing the data collection phase to fruition. This required them to be able to explain the study to their communities, invite feedback on the interview schedule, and gain expressions of interest from their peers for their involvement in recruiting other women within their communities who fulfilled the criteria for our purposive sampling strategy.

8.3.7 The role of the AHW

The AAG teams were women with extensive experience in women's health and / or trained Pap screen technicians. They advised me that the AHWs level of understanding of cervical cancer, Pap screening, and HPV was at a nurse practitioner level, and that most AHWs were experienced in explaining Pap tests to women. Therefore the information about HPV

and the vaccine we wanted to share with study participants had to be in a form that was factual, and immediately understandable (plain English), without being condescending or alarming.

The AHW teams needed to be able to adequately convey the HPV information and purpose of the study to their communities where colloquial terms are often used to explain women's health matters. For example, in Victoria, where English is a common language to all Aboriginal communities, the AAG engaged the expertise of a respected HPV educator (a non-Aboriginal doctor) to explain the medical aspects of HPV infection and the HPV vaccines to the AHWs.

In Central Australia where English is not the primary language used, the vaccine syringe is referred to as 'the needle'; the uterus as the 'baby bag'. The information was successfully conveyed through story telling and visual representation (with culturally relevant flip charts that explain Pap screening) of HPV infection; its sexual transmission and impact on women's health; and the role of HPV immunisation to communities.

8.3.7.1 Ambiguous roles

The roles of the AAG and AHW in gathering data within communities, with whom they had a prior and ongoing relationship, were important because of the ethical issues that can arise out of such relationships. As Boulton (1994) recognises, any position of privilege to personal and sensitive information and confidentiality may have multiple repercussions, especially in power relationships and rights of the researched. Although we imposed boundaries on the AHWs research role, it was important that each AHW identified with the community they were to gather data from, because of the need for trust.

We knew from the AAGs that among the Aboriginal population there was a sense of prior 'helplessness' with combating cervical cancer disease because of its prevalence. However the AHWs sensed that the introduction of the 4vHPV vaccine presented an opportunity (with appropriate community engagement) for them to effect change and they

were therefore keen to be involved in this study. Their unanimous feedback indicated it was a very important issue for their communities, (given the lack of accessible cervical screening and other preventative measures for many women, and lack of awareness about HPV), and one they wanted active involvement in, and that required them having full knowledge about all aspects of the HPV vaccines.

8.3.7.2 AHW training and empowerment

The AAGs in both regions invited AHWs who practiced in women's health and other key stakeholders to a women's health forum, and after a HPV / HPV vaccine education session the study was discussed. As part of the AHW empowerment strategy, issues around burden of HPV disease and impact of immunisation processes on the community were raised, as well as the benefits of communities informing health policy makers on their views about HPV immunisation implementation.

The agreement by AHWs to participate in the study was very positive, although they understood their involvement was going to create additional work load for them with no remuneration for their efforts. The training of AHWs in interviewing and data recording requirements was limited due to resource constraints but 'safety nets', especially through continual access to AAG members, were provided at every stage of their field work.

8.3.8 Variations to informed consent

Traditionally, informed consent is given in writing. However as understanding emerges about particular distinctions within cultures, there are circumstances, especially with those who are deemed to be impacted by social inequalities in health, or who feel vulnerable, where it may be more appropriate to give oral consent (Smith 1999; Liamputtong 2007). This was the case with our Aboriginal participants where cultural considerations combined with a sensitive research topic determined oral consent.

Written consent was initially obtained from each of the AHW facilitators (Appendix 19), and they subsequently gathered oral consent from the

women participants in their communities that they conducted a focus group discussion with. After advisement by the AAG that this process was acceptable, and preferred, approval was given by the Central Australian HREC (Appendix 12).

8.3.9 Moderating the focus group discussions

Data collection through focus groups was successfully applied using members of the AAG as moderators, all of whom had experience in facilitating similar group discussions on health related matters. Facilitation of these discussions was beyond my control, and transcription of oral data was undertaken by an AAG member or AHW supporting the moderator.

Tape recording of the discussion was not permitted due to their need to ensure anonymity and generate trust in the research. The participants (as AHWs and parents in the communities), were asked to share their opinions on a range of issues developed in the topic guide. This process allowed us to capture data without having constrained categories within a social context that was respectful and known to participants.

In one Victorian community I was invited to moderate the group. Without the support of audio recording, there were key differences in the level of detail transcribed against what was actually said. Realizing this, I knew it was important to make a follow-up telephone call to each AHW collecting data in her community to elicit more detail from the transcripts. This reflects Twinn's experience (1998) with Chinese participants and acknowledges the extent to which the translated data accurately reflects the feelings and experiences of the participants.

8.4 The Chinese population: divergent views and methodological challenges

Chinese communities can also be exclusive, engendering practical difficulties in identifying potential participants through a purposive sampling frame, and thus presenting difficulties in gaining their co-operation in research. Similarly, this group also represented a significant migrant population with divergent norms and cultural beliefs and values

around sexual relationships (Lau et al. 2005; Ross et al. 2005; Sinha et al. 2005; Song et al. 2005), as described earlier, adding the need for sensitivity when developing the topic guide and interview approach.

I came to realise that those Chinese-Australians who engage with targeted health clinics at a specific site are only a proportion of their population who attend health clinics, and that not every one in this targeted cultural group had access to such facilities. It was evident after three visits to the tertiary hospital clinics, where only one Chinese woman attended, that the recruitment strategy for Chinese parents would have to be modified and expanded beyond the clinical setting.

After the initial recruitment of three participants through the clinics I used a 'snowballing' technique to recruit an additional eight parents. Given it is the domain of the wife and mother to manage the health and well being of the family, no male parent of Chinese descendency participated in the research. I was aware that this would impact on the gender composition of the Chinese sample.

8.4.1 Snowball sampling

Snowball sampling as a multistage sampling procedure (Hoyle et al. 2002: 188) is effective when researching 'hard to reach' populations as in the case of the Chinese sample. The minimum quota of ten participants was filled after a two pronged recruitment drive. The data collection from the Chinese sample was subsequently reliant on two individuals who were respected health professionals within the Chinese community to act as 'gatekeepers' (Miles and Gilbert 2005).

To stimulate their interest in the research, Dr. Happy Tang [of the Victorian Cytology Service, Melbourne, and member of the Chinese Medical Practitioner's Association, Melbourne] agreed to act as primary 'gatekeeper' for the Chinese Community and, with one of the research supervisors, conducted a preliminary information session about the research during a Chinese Women's Association health forum in Melbourne. This recruitment approach resulted in five (of the minimum

ten) participants. Several women who were later approached to participate in the study declined on the grounds that their English was not of a sufficient standard.

In order to fill the recruitment quota a second ‘gatekeeper’, Dr. Jeffrey Tan [of Chinese descendency and a well known and respected dysplasia specialist at the Royal Women’s Hospital, Melbourne] was engaged. I understood that the subsequent sample would not be representative of the total population, and that the list of potential participants supplied by him was therefore limited by the recruitment strategy. Hoyle and colleagues (2002: 188) advise that ‘inferences drawn from information provided by samples obtained using the snowball method must be drawn with caution’ given the unknown association between the sample and the population.

8.5 GPs: Remuneration and reimbursement

Remuneration for participation in the research was not considered for any participant other than reimbursement for travel costs to parent participants. Whilst it is accepted that reimbursement for participation and travel time do not significantly influence research participation, our initial invitations to GPs (via targeted clinics within the Melbourne metropolitan region) that offered no reimbursement for time generated very little response. After this ambivalence from GPs toward participation we had to modify our value position on payment and offer reimbursement for GP interview time of half an hour.

8.6 Summary

Effective cross-cultural research requires diversity in methodological approaches, acknowledges the complexity and sensitivity inherent in culturally appropriate practices and processes, and enhances the researcher-participant relationship. A key insight from this is that by understanding appropriate approaches for research with mixed cultural communities, and adapting the core methodology accordingly, research outcomes can far exceed those initially anticipated.

PART 3: RESULTS

Chapter 9: Introduction and Anglo Participant Results

9 Introduction to results

This section presents the qualitative findings reported by discrete cultural groups (Anglo, Aboriginal and Chinese Australians) and by participants' functional role (parents; GPs). Data was collected from a total of 111 parent participants from Victoria and Central Australia and 15 GPs from Victoria. Some data emerged from the parent participants in relation to attitudes to vaccination in general that is not reported here. I have chosen to focus on data relating specifically to cervical cancer (ICC) prevention which emerged from the thematic analysis, and therefore only the results relating to participants' attitudes to cervical screening and HPV vaccination is reported.

9.1 Profile summary: Anglo, Aboriginal and Chinese parents

The characteristics of the Anglo and Chinese population are summarised in Table 13. Most participants were between 40 and 60 years of age, with 10% of the sample under age 40 years. Most were married (74% Anglo and 91% Chinese) with four Anglo parents either separated (n=2) or divorced (n=2), and one Chinese parent who was a 'single parent'. Parallel data is not available for the Aboriginal participants due to confidentiality agreements.

Among Anglo and Chinese-Australian parents there were varying educational qualifications, with a high proportion of Anglo participants with a tertiary qualification (80%, n=12) and fewer in the Chinese group in this category (27%, n=3). With secondary school education, two Anglo parents (13%) had less than secondary school education and one Anglo parent (7%) had completed secondary school. The Chinese parents had equal representation (36 %, n=4) of TAFE or secondary school levels of education.

Table 13: Summary profile: Anglo and Chinese parents

	ANGLO		CHINESE	
DEMOGRAPHIC	**n**	**% of the sample**	**n**	**% of the sample**
Female	9	60	11	100
Male	6	40	0	0
Overall aged 18+	15	100	11	100
Age, years				
30-39	2	10	1	9
40-49	6	60	5	45
50-59	7	30	5	45
Marital status				
Married	11	74	10	90
Single	0	0	1	9
Divorced	2	13	0	0
Separated	2	13	0	0
Widowed	0	0	0	0
Education				
<High School	2	13	0	0
High School	1	7	4	36
TAFE	0	0	4	36
Tertiary	12	80	3	27
Children				
Male	11		9	
Female	26		15	
Overall	37		24	
Vaccination status of children				
Yes	14	93	11	100
No	1	7	0	0
Vaccine decision maker				
Mother	2	13	5	46
Father			0	0
Both parents	13	87	6	54
Years residing in Australia				
1 - 5	NA	NA	0	0
5 - 7	NA	NA	2	18
7 - 10	NA	NA	2	18
10+	NA	NA	7	63

Anglo Australian parents had 37 children in total, 11 boys and 26 girls whose mean age was 13.5 years. Chinese parents had 24 children in total, 9 boys and 15 girls with a mean age of 14.4 years.

There were variations with the vaccination status of children (with the routine Government immunisation recommendations) and vaccine decision maker. Fourteen Anglo parents had their children routinely

vaccinated and one parent did not, whilst all Chinese parents had their children vaccinated. Among the Anglo parents there was a higher proportion of both parents making decisions about childhood vaccination (87%, n=13) versus mother only (13%, n=2). For Chinese parents there was more equal representation between both parents (54%, n=6) and mother only (45%, n=5) in making vaccine decisions.

With length of residency in Australia, all Anglo parents had resided in Australia for the duration of their life, and among the Chinese participants, who were all immigrants to Australia, there were variations. The majority (63%, n=7) had resided in Australia for more than 10 years, with two (20%, n=18) parents resident between 7 and 10 years, and two (20%, n=18) parents resident between 5 and 7 years.

9.1.1 Presentation of results

The results will be presented and discussed with the verbatim quotations from the interviews cited by specific identifiers (Table 14).

Table 14: Identifiers for the verbatim quotations from interview data

GROUP	IDENTIFIER	EXPLANATION
Aboriginal CA	(1CA)	Community group number + location
Aboriginal V	(2V)	Community group number + location +
Anglo	(4A: F, age 46)	Participant number + cultural identifier + gender + age
Chinese	(5CH: F, age 43, 14 Aus)	Participant number + cultural identifier + gender + age + years in Australia
GPs	(4GP:M, 30 years GP)	Participant number + gender + years in profession

Key: A: Anglo; CA: Central Australia; CH: Chinese; F: Female; GP: General Practitioner; M: Male; V: Victoria

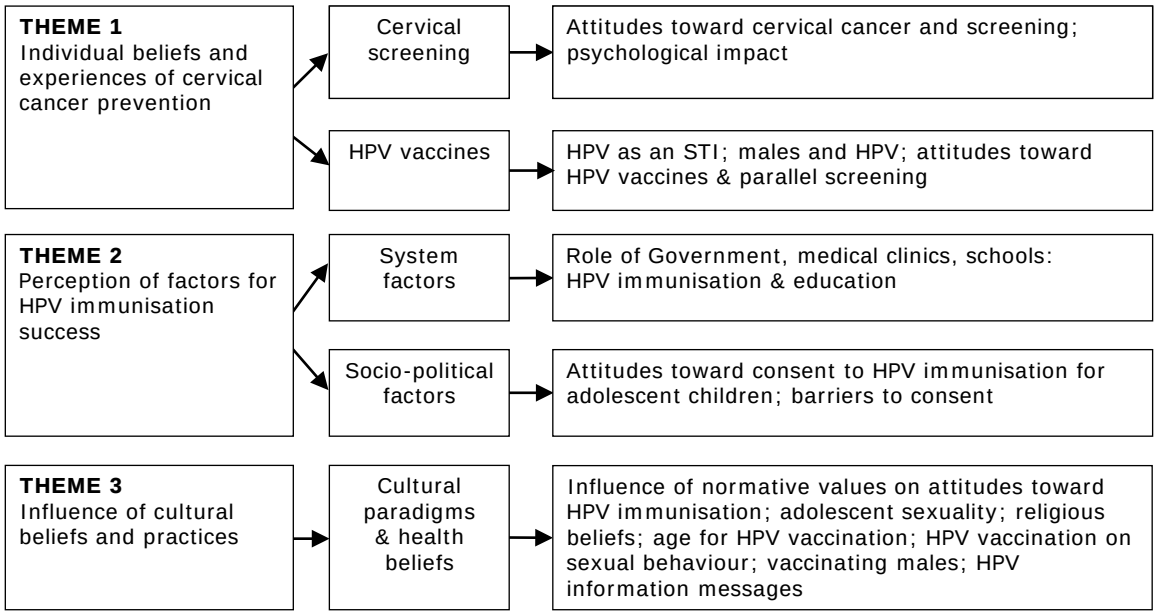
As a key hypothesis of this study was the influence of ‘culture’ on parental attitudes, the results are reported by cultural groupings. As the dominant population group in Australia, the Anglo parent results will be reported first, in this chapter. The reporting of the data from Chinese participants follows in Chapter 10; and the results from the two Aboriginal population

groups is reported in Chapter 11. Finally Chapter 12 presents the results from the GP participants.

Three main categories emerged from the analysis of the Anglo, Chinese and Aboriginal data representing recurrent themes across all groups (Figure 7), and form the basis of reporting of the parent results. These categories are associated with

i. individual beliefs and experiences of ICC prevention;
ii. perception of factors for immunisation success;
iii. the influence of cultural beliefs and practices on attitudes.

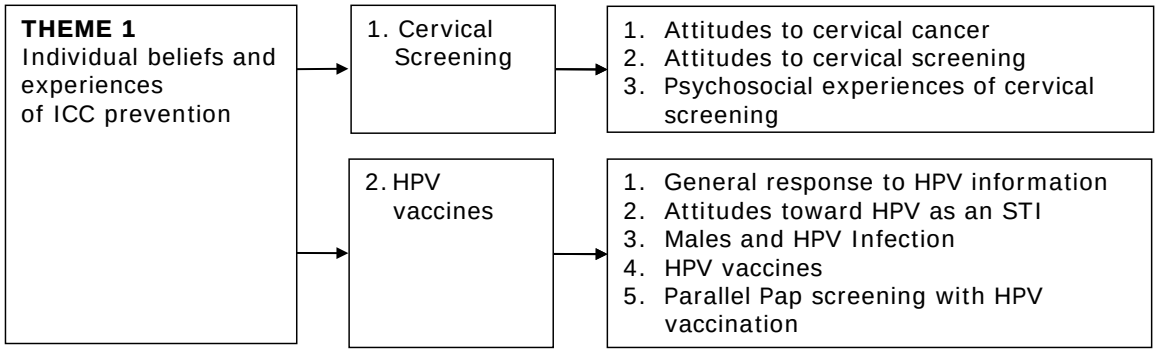
Figure 7: Thematic categories



9.2 Results: Anglo parents: Theme1: Individual beliefs and experiences of cervical cancer prevention

This thematic sub-category (Figure 8) captures participants' own beliefs of cervical cancer prevention through their attitudes and experiences of cervical cancer screening and HPV vaccination.

Figure 8: Theme1: Individual beliefs and experiences of ICC prevention among Anglo parents



9.2.1 Cervical screening: attitudes toward ICC

Anglo parents demonstrated a general awareness of '*cancer*' and '*cervical cancer*', and their attitudes towards preventative health behaviour were influenced by their prior experiences. Emotional responses to '*cancer*' were voiced, and several participants held a fearful attitude toward the term '*cancer*', and its increasing prevalence in the population, especially breast cancer, was described as '*frightening*' as a result of their awareness through public media. One male participant believed that cancer in women generated '*sympathy*' in the general public.

Awareness and attitudes toward '*cervical cancer*' varied. One participant with a nursing background had good knowledge of all aspects of ICC and made comment on its seriousness, and the impact of its burden on the health budget.

> *"I think at a certain stage it's an invasive horrible cancer, and I think it can take someone's life and it's terrible, but I also look at it as being one of the preventable cancers"* (6A: F, age 42[1])*.*

In contrast, knowledge levels among others varied, and ranged from no awareness of ICC, to misunderstanding risk factors, cause and symptoms. Several participants perceived ICC negatively, and several understood ICC to be genetically inherited or for older women, "*around sixty*". The

[1] The Anglo parent verbatim quotations are cited in parenthesis: Participant number + cultural identifier (A = Anglo) + gender (F = female; M = male) + age. For example (4A: F, age 46)

prevalence of ICC in Australia was mostly not known. It was variously rated between '*quite high'* and "*fairly common for women*". One male participant believed that men were at risk of ICC but "*not in the same proportion, but I could be wrong there*" (7A: M, age 33).

9.2.2 Attitude toward cervical screening

Most of the female participants generally had regular Pap tests and, despite understanding its general importance, some of the female participants were ambivalent about attending for regular screening. Most participants lacked precise knowledge of why a Pap test was performed, with one participant unsure about what part of the anatomy Pap screening related to, "*I can't think of the word*" (4A: F, age 46), whilst others held concerns for the safety of the Pap test procedure. Another participant was confused about what the term 'Pap' in 'Pap' screening referred to.

> *"I didn't even make the connection between Pap smear and if that's a papilloma. I don't know, I've got no idea what Pap means*" (3A: F, age 55).

Many participants were cynical about the need for cervical screening, and criticisms were made of the medical profession's insufficient education about it with women, and their lack of explanation about the Pap test.

> "*I didn't know that Pap smear results are caused by HPV…The doctors … just say 'it's time for your annual Pap smear' but they don't go into all the details about why, they don't use it as a time for education...There's certainly no published information around, brochures and things to give to people, that I've ever seen"* (3A: F, age 55).

9.2.3 Psychosocial experiences of cervical screening

Most female participants described the Pap procedure in disparaging terms. One male participant noted his wife who undertook regular screening did not look forward to the procedure. "*She grins and bears it and finds it fairly unpleasant*" (7A: M, age 33) and this view was shared by other female participants.

> "*It's a rotten thing to have I would have thought after three kids* [sic] *it would be easy to be examined. But it's just one of those things… you get your Pap smear… it's a maintenance thing*" (4A: F, age 46).

Pap screening was discussed by women with their husbands, except for those who considered their husband 'conservative'. The male participants indicated that their wives shared female health information and as a result this generated mutual support and encouragement for routine screening behaviours. Another male participant questioned if Pap smear information was generally available to the community. Conversely female participants did not consider seeking an explanation from their doctor.

Their abnormal Pap test results concerned some participants, and none could recall having any symptoms indicating an abnormality, and after the diagnosis they immediately assumed it was a '*cancer*'. Furthermore from women's accounts it appeared that the abnormality was not explained by the doctor other than being advised to present for another test at a shorter interval.

> "*You just go and have a Pap smear and they say 'see you later', and if you don't hear, you don't really know what they're looking for. I've never really known, I just know I've had to go since I was a late teenager … when you go and have one* [Pap test] *there's never any explanation of what they're actually doing"* (11A: F, age 45).

When another participant understood that an abnormal test result did not immediately mean she had a cancer diagnosis her fear was also reduced.

> *"I just think that peace of mind that it's nice to know what is happening to your body. Just to know that you know what's happening and what they're looking for and why you're having a Pap smear"* (11A: F, age 45).

9.3 HPV vaccines: General responses to HPV information

The participant who was a nurse was the only participant with reasonable knowledge of HPV characteristics. She was aware that HPV was

extremely common and you were '*lucky*' not to acquire it. Most other participants associated it with being a female condition, but generally they had no knowledge of HPV or its prevalence, and had not connected it with ICC, or were unsure. Among their responses, an association was made with HPV being a 'virus' because of its name, and there was minimal recall from recent mainstream media reports about the HPV vaccines. One male participant perceived that HPV caused infertility.

> "*You do hear about HPV a bit, but I guess I never connected it with cervical cancer so I just thought it was something you want to prevent because it's a nasty virus that makes you infertile or something. I didn't know that you should prevent it because it could lead to cancer*" (1A: M, age 48).

After the provision of HPV information (Appendix 16 and Appendix 17) during the interview several participants considered it to be complex information for a public awareness campaign.

> *"It's overload. It's a big one. I can't see a clear path for it, as a campaign it's complex*" (2A: F, age 54).

Awareness of genital warts was higher among participants but the difference between common and genital types of warts was not known. One participant queried its relationship to herpes. Overall, participants found the new information '*enlightening*' and '*comforting*', especially among the male parents.

> *"I'm* [now] *more aware of a lot of things….. if my wife in her next Pap smear test came home and said I've got a negative test, I wouldn't be panicking, as I possibly would have in the past…..... in terms of it* [HPV] *not being a sexually transmitted disease, but a virus…we've all got the virus… it's comforting more than anything*" (9A: M, age 59).

9.3.1 Attitudes toward HPV as an STI

Awareness levels of general STIs varied. One participant had no awareness of what current infections were classified as STIs; some participants were not sure of what the common STIs were; another

questioned if AIDS was an STI; one participant thought contracting a STI was due to '*bad luck*.'

> "'*Bloody' unlucky! Some people are very careful and still get it* [STIs]*, so I see it as being unlucky*" (4A: F, age 46).

When participants heard about the classification of HPV as an STI mixed opinions arose, and the realisation they had limited knowledge about STIs.

> "*It's unbelievable that it is caused by sexual activity - trying to understand how it goes from that to potentially cancer*" (7A: M, age 33).

However, the need for education on the health risks of STIs was strongly reinforced, as the majority of participants were surprised at the risk factors for HPV and ICC, and for any one who was sexually active regardless of their behaviour.

> *"Well the frequency of it,* [HPV infection] *it's unbelievable. People don't know they've got it. I don't think it's ever going to be out in the open, because I think* [of]… *the nature of people's private lives. You're going to have the element of secrecy at times."* (2A: F, age 54).

In contrast another participant knew of HPV's sexual transmission from a radio broadcast but was not concerned with the fact. Another male participant, whose parents were doctors, had knowledge about 'cervical cancer' being related to an outcome of sexual activity.

9.3.2 Attitudes toward males and HPV infection

Once participants understood that HPV was common to both males and females and transmitted through sexual activity, there was concern among some participants that current public information on HPV and HPV vaccines lacked gender balance, and was perceived as a female issue.

> *"It* [HPV vaccination of females] *sort of annoys me because it gets back to this, everything seems to be the female responsibility all the*

time whether it be pregnancy or what, it's all that the boys aren't supposed to feel any sense of responsibility, it's just a sexual action it's not their problem … even so for a vaccine" (14A: F, age 40).

There was a persistent theme among several participants, both male and female, of issues around shared responsibility, and the need for adolescent awareness of the impact of their sexual activity. Participants with sons and daughters viewed their daughters as being more susceptible to the risks of HPV infection, and believed that because Australian society had conflicting values toward gender and premarital sex the responsibility for outcomes of sexual behaviour was usually on women.

"You worry about them [daughters] *getting pregnant… and the sons, it's a bit like 'You beauty''...There's different cultural norms around sexual activity for males and females… it's about the fact that it impacts them both, having safe sex or both being vaccinated, it's about personal and joint responsibility, and the* [HPV] *information doesn't do that"* (12A: F, age 45).

The focus on females and HPV infection raised concerns that this bias would impact on men's understanding of their potential risk of HPV infection and genital warts, as well as their role as co-infectors and the subsequent impact on males' sexual responsibilities.

"*It* [the HPV education and vaccination program] *misses out on anything that the boys may have to do….girls are likely to take this and say I need this protection, but boys need to have it as well so they don't pass it on* " (10A: M, age 52).

Challenges with public perceptions of gender and educating males were raised.

"I'm a little surprised because it's [Australian Government HPV advertisement] *very strongly targeted at women, to the point where a man or a boy would just flip over the page, they wouldn't read it, they*

wouldn't be interested in it, they would think it's not their problem." (14A: F, age 40).

9.3.3 Attitudes toward HPV vaccines

Positive beliefs were held about the benefit of routine vaccination for a child's long term health, with all but one participant whose daughter had experienced an extreme adverse event after an infant vaccination. Participants had low to moderate levels of awareness of the 4vHPV vaccine from the general media despite their acknowledged ignorance about HPV. Some participants had heard about the imminent licensing of a 'cervical cancer vaccine' but stated that the media reports lacked detail.

> *"It didn't enter my mind that what he* [Prof. Ian Frazer] *was developing was something against HPV. The media side of it was for the cancer but not really mentioning the virus*" (1A: M, age 48).

Moreover concerns were expressed about the limited time between research and the HPV vaccine's public availability.

There was uncertainty about the vaccines being introduced into a broad HPV immunisation program because of its newness. Vaccine safety, risk, side effects, vaccine composition and long term benefits were important factors for parents. Most participants accepted that by the time a vaccine was licensed it had been well tested and proven, and that there was greater awareness among the community about manufacturing processes and liability.

> "*I just feel that there's not enough* [information about the vaccine]*… I'd have to know what's in the drug; I want to know what the side effects are… I just think I wouldn't get it done…. it's not something that's life threatening at that stage, and I feel that it's a personal thing for the children when they're a bit older. It's so hard because this is something that's so new…and it's a bit like* [we are] *a guinea pig and I feel that, 'God, am I doing the right thing'"* (11A: F, age 45)?

Reassurance was sought on the vaccines' research processes, especially with time frames, data findings and testing of the vaccines and Australia was administering it first globally.

> "*Years ago, anything in Australia was always 10 years behind Europe or America, and that 10 years was the safety blanket. … I always thought that was wonderful to be behind because the worst problems* [adverse reactions] *could come up and get sorted* [beforehand]" (2A: F, age 54).

There was concern about there being '*live*' or '*manufactured'* virus in the HPV vaccines due to one participant's concerns that some people would be *"terrified about introducing something into their system*" (6A: F, age 42). However, after an explanation by me of the vaccine's components her fears were allayed.

> *"Well that makes me feel happier about it, and I know that vaccines that are made now are a lot better and more friendly to the system … that it's not an invasion on their bodies"* (6A: F, age 42).

Whilst there was a positive attitude toward the vaccine, and feelings that it was a "*great medical breakthrough for females"* (8A: M, age 49), some other participants had reservations about the vaccine fulfilling its claims of ICC prevention, and that people would not link the vaccine's intent to managing a range of diseases caused by a sexually transmitted virus.

9.3.4 Attitudes toward the need for parallel Pap screening

Participants were mostly pragmatic about the partial coverage provided by the HPV vaccines and saw it as a way of helping to reduce the risk of ICC. For one participant 70% protection was considered to be a low percentage of cover.

> *"For my children I would possibly do it,* [but] *if it's only 70% protection it's a low percentage really. But I've always thought with* [children's] *medicine… I tend to go for it rather than not"* (14A: F, age 40).

One participant displayed confusion about the vaccine's characteristics when she considered that HPV vaccination would be helpful after an abnormal Pap test result.

> *"When you've been vaccinated, you feel you've got pretty much 100%, and I feel that 70% is… I wouldn't get my girls done, no, I'd rather they all have the Pap smears…we haven't had cancer in the family,… but if you went and had an abnormal Pap smear, of course you'd go, 'oh quick, can we have the vaccine'"* (11A: F, age 45)?

Concerns were raised that this vaccine lacked the effectiveness in disease prevention that their understanding of other vaccines had.

> *"It feels that it's not as effective as smallpox vaccine that totally eradicates smallpox, and as long as HPV is around and people are being sexually active you're still going to have to screen for cancer"* (1A: M, age 48).

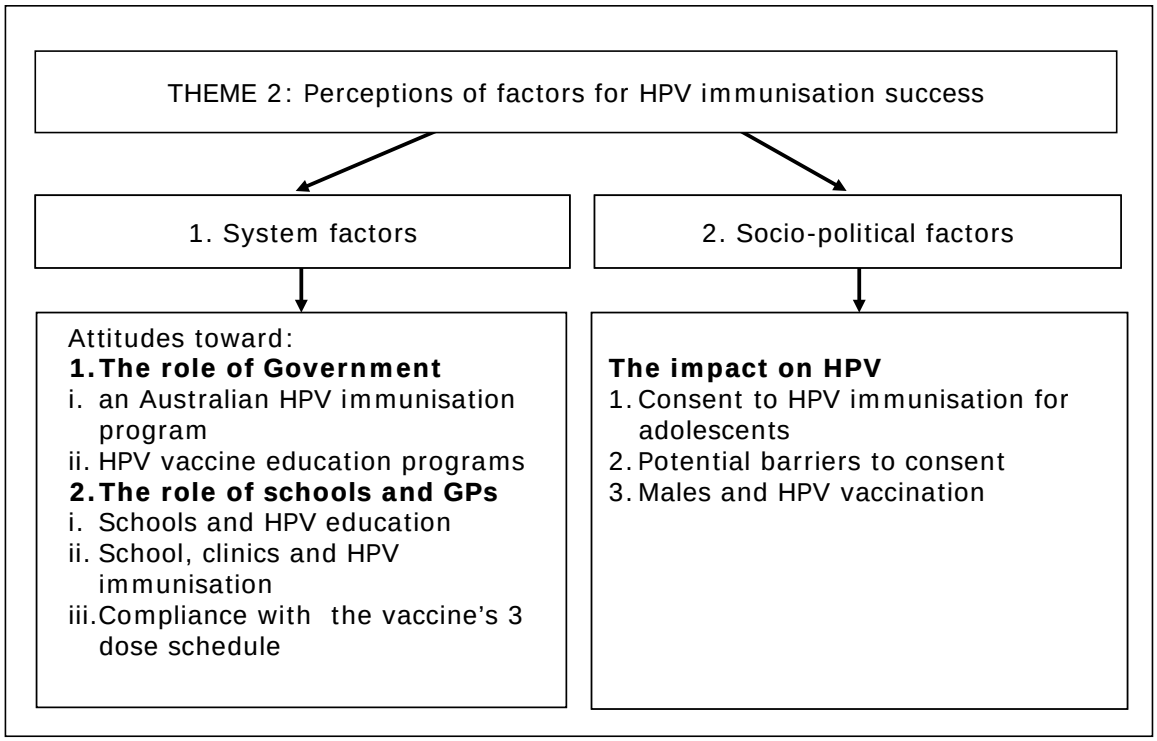
Two male participants held concerns that after vaccination young females might become complacent toward regular Pap screening, believing they were fully protected and invincible.

> *"Because I think people would say 'well I've had my vaccine so I'm good to go and I don't have to worry about a Pap smear'… In fact, if we hadn't had this discussion, I'm sure that's the type of thing I'd think"* (7A: M, age 33).

9.4 Theme 2: Anglo parent perceptions of factors for HPV immunisation success

The sub-categories in this theme (Figure 9) capture participants' perceptions of system and socio-political factors for HPV immunisation to be successful, in particular the role of Government and schools in the delivery of HPV immunisation programs, and factors that would contribute to parental and guardian consent of adolescents being immunised.

Figure 9: Theme 2: Perceptions of factors for HPV immunisation success



9.4.1 System factors: the role of Government: attitudes toward an Australian HPV immunisation program

Attitudes toward a national HPV immunisation program generated mixed responses. Whilst the vaccines were considered important for the reduction of ICC, participants had complementary but varying support for Government involvement in a HPV immunisation program, and most believe the management of cervical cancer to be the Government's responsibility. All but one participant placed confidence in the Government implementing an HPV immunisation program.

> *"They* [the Government] *haven't exactly endeared themselves… they tend to have a scatter gun approach to what they fund and what they don't fund* [in health]…*I think you'd have to have some hard evidence that it's* [HPV immunisation] *going to save a lot of lives before they would actually fund it"* (3A: F, age 55).

Additionally, one participant was more circumspect about a national immunisation program because of the newness of the vaccine and incomplete information regarding long term safety.

"If it's related to general immunisation…like Rubella etc, yes I would have trust, so probably around 7 out of 10 [support for the HPV vaccine program]*. However, if the government said 'well now we're going to do this new thing', then I'd have to be a bit more circumspect about it and assess* [it] *in terms of side effect implications, and so on"* (9A: M, age 59).

The current low incidence of ICC in the Australian population was raised as an example of why a broad-based immunisation program was not warranted, and that its introduction would not benefit women.

"You *might be hitting the hypochondria people, fear tactics. Its private enterprise isn't it, its money making at work; they'll use every marketing tactic they can*" (2A: F, age 54).

9.4.1.1 Attitudes toward Government HPV education resources

There were several views relating to the Government's responsibility in ensuring the public were adequately educated about the HPV vaccines before an immunisation program.

"If all that's [a HPV immunisation program] *going to happen then I don't know what to ask* [about the vaccine]… *if they're* [the public] *not aware they're not going to know to ask, so there has to be some sort of awareness campaign"* (10A: M, age 52).

One participant commented on the past introduction of new vaccine programs, such as HBV and meningococcal, where the initial publicity was not followed through sufficiently with detailed information, and many people undertook vaccination based on fear and without really understanding what they were doing.

"I think parents are going to be very apprehensive [because of their lack of knowledge] *… these will be the first generation of children that are going to be vaccinated and I think a lot of people are going to be wary, it is a bit like meningococcal, you think "oh my God it would be the worst thing* [if my child caught the disease] *and I should do it"* (11A: F, age 45).

Participants indicated support for media saturation in different ways including health providers, mainstream media and the Internet, brochures and resources in multiple languages, television documentaries and adolescent-related magazines. HPV vaccine information through newspapers and radio was considered to be effective in raising public awareness but was perceived to be limited in the amount of detail, and the potential for bias in its content. Health-related brochures with detailed information were highly regarded and regularly read by parents.

> *"I think brochures are probably the best way. The stuff in newspapers or on TV tends to get a bit sensationalised. People only read little bit of information in newspapers …..* [The brochures] *should be distributed through medical practices, or sent to families via a mail out, or something like that"* (3A: F, age 55).

There were two general approaches to how participants sought information about vaccines. One cluster of participants sought information first from their GP or health nurse, then the Internet or media and lastly assurance from their social networks ('*mothers groups, friends* (13A: M, age 41). The second cluster of participants obtained information in the reverse sequence.

> *"I'll be asking a lot of questions… I'd probably discuss it with friends, other mothers, who I value their opinion. I've always found it a good way to make a decision actually. And I will be asking a couple of doctors"* (4A: F, age 46).

There were differing attitudes toward the Internet and a free-call [1800 telephone number] as a source of HPV information with many not using either because of inefficiencies in connection to the resource or quality of information. Other participants discussed the limitations of mainstream information resources for citizens with low English competencies.

> *"In Australia we've got a huge number of people who just don't understand because of the language barrier…people don't send back their acceptances* [for school functions] *…because they don't read or write"* (6A: F, age 42).

There was support for explicit HPV messages because of other health campaigns with graphic images such as lung cancer. The importance of credible advocates promoting the benefits of HPV vaccination was raised.

> *"I believe if we get the right people in front… you've got to look at who you're trying to focus on, then you've got to look at people who can communicate that message appropriately"* (8A: M, age 49).

9.4.2 The role of schools and GPs: attitudes toward schools and clinics for HPV immunisation

There were mixed opinions about the HPV vaccine provider, and schools and GPs were both perceived as having dual roles in the delivery of health information and vaccines. Some participants were ambivalent and saw benefit in either school or the GP as vaccine provider as long as they were legally qualified. Overall support was shown for a national subsidised school-based immunisation program to ensure equity of vaccine access, and HPV education. However participants conceded that public commitment to the program would require government involvement in terms of education, resources and equitable access to the vaccine.

> "*We need to take whatever necessary actions are needed* [to eradicate ICC]. *I think the cost should be subsidised by the government… it is a necessity… if we want to get a high level of protection, and it should be run through the schools so they make sure adolescents get their three doses*" (8A: M, age 49).

In contrast, two participants believed school-based immunisation removed parental choice for when the vaccine should be administered, and ignored the child's stage of maturation.

> *"I think the government will come out and say 'this is going to happen', but as a parent I'd just say 'well it will be my choice for when my daughter has it'. Secondary school…that's very difficult…because you've got some kids* [who] *aren't sexually active until later on… That's why it's hard to put a blanket rule on it, it's got to be an individual thing for an individual case"* (4A: F, age 46).

9.4.2.1 Attitudes toward compliance with the HPV vaccine three-dose schedule

With vaccine dosage compliance, all participants had prior experience with three-dose schedules with HBV immunisation and were confident that immunisation through a school-based program would support compliance. Some participants preferred HPV vaccination through the medical clinic to reduce the 'trauma' on their child but this approach raised concerns about the challenges of compliance, especially among employed participants having to take leave from work for a 'non-urgent' medical visit.

9.4.2.2 Attitudes towards schools and GPs delivering HPV education

Parents were comfortable with schools delivering sexual health programs, but they did not consider it as the overall responsibility of schools. Concerns were raised about the quality of sexuality and HPV information given through schools, and especially about school-ground word-of-mouth as a common source of adolescent sexual information, and the peer pressure this placed on adolescents to conform to sexual activities.

> *"I think it would depend on what information was given in schools. I would prefer to talk to my children about this* [vaccine] *and take my children to my doctor individually…because there's a lot of misinformation in the school grounds already about all sorts of things… They're certainly influenced more by their peers than anyone else"* (3A: F, age 55).

High trust was placed on the GPs expert knowledge and vaccine recommendations, and especially as the HPV vaccine was new. Some parents who had a preference for their GP to be the HPV information and vaccine provider had an expectation that GPs would have full knowledge about HPV vaccines at the time of it being publicly introduced, and be able to discuss it with parents.

> *"I'd be happy to go to a local GP. The school vaccinations, you've got to make sure that the information is out there for all concerned, and it probably does put parents off who need to know all the facts. So they'd* [parents] *have to have all the information"* (4A: F, age 46).

This view was not shared by all participants, especially where people might not have a regular doctor.

> *"It's a different scene today to when you had a family doctor … these days, they* [GPs] *may not have a full history, and it's harder for them, but it doesn't take away the*[ir] *responsibility to be able to keep families, parents, children informed of* what [health interventions] *might help them"* (10A:M, age 52).

9.4.3 Attitudes toward consent to adolescent HPV immunisation

Consent issues generated varying opinions among participants and were influenced by several factors. Endorsement of the HPV vaccines by Government, doctors and schools was important to parents, especially as they had limited information. There was general support for consenting to a vaccine that protected against ICC but concerns were raised about the impact of the general lack of critical information and parent's ability to consent.

Although participants accepted that the short term side effects at vaccination were commonplace, the HPV vaccines' unknown safety and risk factors, and the potential for other viruses or cancers to emerge after HPV vaccination, were other key concerns. One participant who perceived her child had experienced a severe and lifelong adverse reaction with another routine childhood vaccine with a "*one in a thousand risk*" conceded the experience to be a "*powerful' influence*" (2A: F, age 54) on consent for subsequent vaccinations. The lack of evidence of serious risk factors in the long term from the vaccine versus the current low risk of ICC in Australia was also raised.

> *"The cervix is a very sensitive area of the body, how it affects antibiotics when you get thrush and all that, they'll be knocking out one thing to raise the head of some other ghastly thing. The current risk* [in Australia] *isn't great enough for me to be convinced this vaccine is worthwhile"* (2A: F, age 54).

In contrast one participant was unperturbed about the lack of long term safety data and considered current data reassuring because of her trust in scientific processes. Decision making about child immunisation was shared between both parents in most of their households, and this practice differed from their upbringing where that responsibility was delegated to their mothers.

The cost of the course of HPV vaccines (AUD$450.00) was not seen as a major deterrent to consent issue for those participants in full time employment. The opportunity to protect their children from cancer was viewed as more important and "[A] *bit like an insurance policy*" (8A: M, age 49). One participant remained uncertain that the vaccines were relevant for her child, and remained unsure about consent.

> *"I think if it's only working on 2 strains that she may never be exposed to, and given that she will have to continue to have Pap smears anyway. It sounds a bit like a 'braces and belt' approach. I'd need more information I think"* (3A: F, age 55).

Several participants stated that because of the lack of urgency to vaccinate their daughters with the vaccine they would wait for a Government subsidy, and they commented that the full cost of vaccination would discriminate against many families. Furthermore, the mixed levels of English literacy among Australian people were perceived as a barrier to consent for some parents in the general community. There were mixed views about recommending the vaccine to others, as consent was considered to be on an individual basis, and because of the lack of critical information and the vaccine's controversial characteristics.

Issues about the adolescent's age and their role in the consent process were raised. It was perceived that, because of their being more informed at an earlier age than they had been, many adolescents would feel more empowered to make decisions.

> *"Normally your children have been so much younger having vaccinations, these girls are older now and seem to be more*

informed, more exposed to information and feel more empowered to make decisions themselves" (12A: F, age 45).

9.4.3.1 Attitudes toward vaccinating males with HPV vaccine

Not all participants were aware that boys were also licensed for HPV vaccination in Australia, and there were mixed opinions about giving consent to vaccinating boys. Once participants understood that boys were eligible, there was more agreement for HPV vaccination for males among those participants who had sons.

> *"I didn't know they did get it* [HPV] *to the same extent. If they are, yes I think it should be available for them the same way it is for the girls"* (15A: F, age 51).

Cautious support was given by two participants for vaccinating boys due to the unknown risks for boys, the vaccine's lack of relevance for boys as an ICC preventative, including the signing of consent forms by fathers.

> *"I thought why you would bother a male about it, thinking cervical cancer, but …knowing that it's sexually transmitted, it can be picked up. So that was sort of interesting, I thought it* [HPV infection] *would be only a female thing"* (11A: F, age 45).

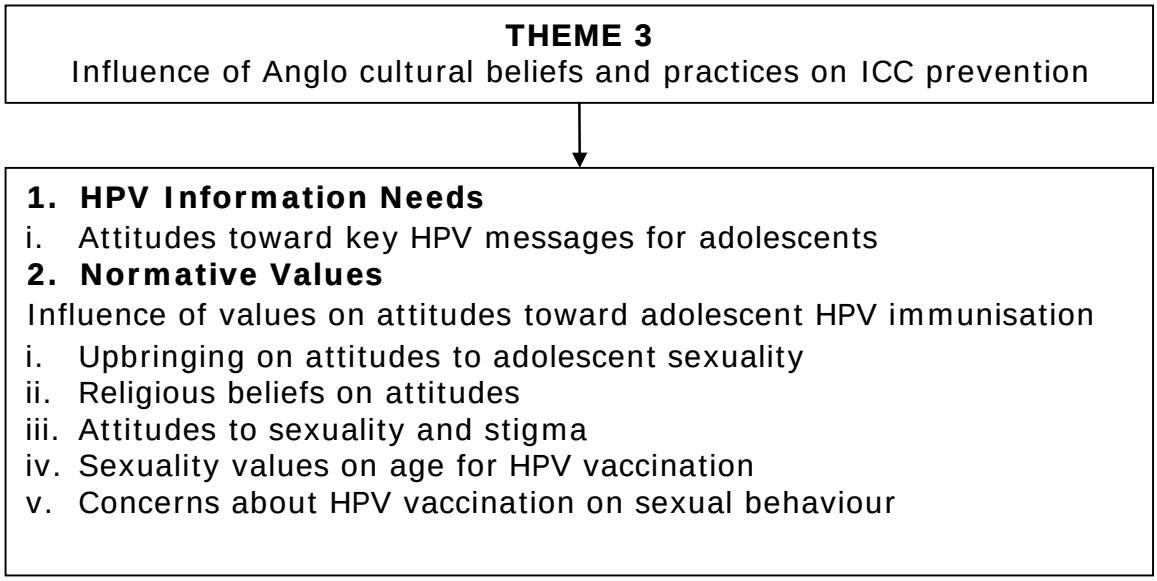
One male participant held reservations about consent for his son if there '*was even the smallest risk of serious illness or death*' (7A: M, age 33) from HPV immunisation, although he did not hold the same reservation for his daughter because of its potential ICC prevention factors. Participants commented on the uncertain risk to their children of contracting HPV or genital warts.

> *"Having a son, it's important that they know they are impacted by this as well… It gets more complex, that there's* [sic] *2 types* [of HPV vaccines]*…you would want to be protected against that* [genital warts]*. And that's just a lottery, whether you have sex with someone…and they transmit* [HPV], *that's a lottery"* (12A: F, age 45).

9.5 Theme 3: The influence of Anglo cultural beliefs on ICC prevention

The sub-categories in this theme (Figure 10) capture the cultural paradigms that participants believe influence their attitudes toward HPV vaccination in adolescents. In particular, appropriate community messages for HPV vaccines, and the influence of normative values and religious beliefs toward adolescent sexuality and HPV immunisation of adolescents.

Figure 10: Theme 3: Influence of Anglo cultural beliefs and practices on cervical cancer prevention



9.5.1 HPV information needs: attitudes toward key HPV messages for adolescents

The challenges for educating children about HPV were raised. There were mixed views about the best age for introducing HPV related sexuality and cancer themes to adolescents. These discussions were considered difficult with adolescents unless it was prevalent in their life, and the responsibility of parents who should initiate the discussion at home. Many participants thought that explicit HPV education was warranted to ensure that adolescents had a detailed understanding about all aspects of why they were being vaccinated, although the differing rates of maturation in

the adolescent cohort presented difficulties in generalising what information should be delivered to them.

> *"I always think it starts and finishes at home to be honest….You* [school] *can't talk on behalf of parents….. There's* [sic] *parents out there that would go, 'look, I like to have control over the sexual activities of my children. And I certainly wouldn't want my 13 year old yet to know about that* [HPV and sexuality] *because I know she isn't sexually active'. … I'm pretty old fashioned. I think the information …should be treated on individual cases. That's what concerns me about lining them up at school for it"* (4A: F, age 46).

A range of views surfaced about how they, as uninformed parents, would educate young adolescents and children about HPV issues. There was low support for the HPV vaccines being promoted solely as preventing a STI, and it was considered "*not tremendously compelling*" (7A: M, age 33). Some participants were uncertain, and believed that most young people under age twelve are not ready for a message about STI protection as it may lead to longer term negative attitudes toward sexual activity, and worry them unnecessarily.

> *"When you're talking to 10 year olds you have to be very careful because you don't want them to think that sexual activity is a terrible thing and put all these nightmares in their heads…at that age they're way too young to understand any of the implications of that. …. And giving children huge misconceptions and maybe worrying them unnecessarily"* (3A: F, age 55).

Most participants preferred age 14 years as a time to begin explicit sex education due to adolescents' emerging sexual awareness by that stage. Participants considered that after age 15 years adolescents were generally informed about sex, and that at age 16 years many adolescents were sexually active which made discussions with them easier. The advent of sexual debut was suggested as the best time to raise ICC and STI issues with young females.

> *"I'd talk about sexual activity. I would say that that this* [the message of HPV risk factors and STIs]*was more of an emotional* [sic] *loaded statement because it implies that there is going to be a level of sexual activity, especially say with multiple partners. I don't think they've got any particular attitude* [to ICC] *other than they know it as a disease"* (1A: M, age 48).

Importance was placed on HPV messages that focused the risks and benefits for ICC prevention but not all participants supported this level of detail in the vaccine messages. There was a sentiment that with vaccinations most children accepted that the 'needle' was to stop them getting ill in the future.

> *"With 12 year olds… it's like the HepB injection, they don't really like it but it's going to stop them getting sick"* (6A: F, age 42).

Furthermore, participants did not feel sufficiently well educated in cancer related issues to be able to discuss the vaccine as a cancer preventative with adolescents under age 16 years who were considered to find 'cancer' issues too abstract and complex a concept to fully understand..

> *"To them it only becomes an issue when it's* [the disease] *prevalent in some shape or form… I've spoken to* [an adolescent] *who's 15,* [and] *whose mother had breast cancer, and the first thing she said was 'I didn't understand it, I didn't know what it meant'... Now that's a 15 year old"* (9A: M, age 59).

9.5.2 Normative values: the influence of upbringing on attitudes toward adolescent sexuality

There was a common trend among participants' that their upbringing, in an era where study and hard work were the prevailing norms, has a strong influence on their attitude toward their adolescent's sexual behaviour. The majority rated highly the influence of their '*conservative*' parents' reluctance to discuss sexual issues with them at a young age, and subsequently their own attitudes as '*conservative*', although they perceived they were more liberal than their parents. Their upbringing

resulted in an adhoc approach to their sexual education usually learnt from school, siblings or friends.

> *"I just believe that I'm a creation of my environment... My family's probably conservative in relation to sexual issues. No, we didn't have that talk, but I was the youngest of 3 boys, they probably assumed that I was getting the information from them* [my brothers]*"* (7A: M, age 33).

This approach to sexual education influenced a '*prudish*' (8A: M, age 49) attitude toward sexual issues and HPV vaccination in sexually naïve children in one male participant. One participant described the confused messages that her parents behaviours gave her, of them being publicly overtly affectionate but *"terribly inhibited…shockingly inhibited* '(2A: F, age 54) in discussing sexual and puberty issues with their children, "*like we weren't prepared for periods"* (2A: F, age 54).

The adoption of parental family values by children was a persistent theme with participants, although they, as parents, were pragmatic about adolescent sexual behaviours and HPV immunisation, and differences in their attitudes toward sexual behaviours of sons and daughters emerged.

> *"My daughter I don't think would intentionally* [engage in sexual activity] *outside of marriage, she's so strong in those things, but I would still want her to be vaccinated... there's the possibility of circumstances being beyond her control, for example rape. My son, he's not quite as firm, and may be distracted from what he knows is right, and so it's that sort of a precautionary thing. Then to say that we have them vaccinated doesn't give them permission to* [have sexual relations] *either, so it doesn't take away the values that we would uphold"* (10A: M, age 52).

9.5.2.1 Attitudes toward sexuality, HPV and stigma

Persistent reference was made by participants to the differences in generational perceptions of stigma with intimacy and relationships in contemporary Australia versus the previous generation, and the influence

of this on their parental roles. Pejorative terms, such as '*dirty', 'shame'* and *'tainted*' (2A: F, age 54), were used to describe STIs , and another participant suggested that STIs are taboo, shrouded in secrecy and privacy and still similar to the attitude of previous generations.

> "*There is a stigma that you're unclean, that there's an unhealthiness, that you may no longer be attractive to others because you've got something that's contagious and is easily passed on, and therefore you'll be discarded by society or by those you might have a relationship with*" (10A: M, age 52).

Contrasting opinions were held by other parents. The notion of '*stigma*' and '*shame*' as an '*archaic notion'* and old fashioned concept, *"a lot of rot"* (4A: F age 46) was aired, and concerns were held that current issues of STIs and premarital sexual activity stigmatised women only. One female participant who experienced the stigmatisation of sexual activity among unmarried people during her upbringing stated that this influenced her to be more open in sexual discussions with her daughters.

> *"We have an open relationship and I just make sure that she's using condoms and that sort of thing. I grew up where we were supposed to wait until we got married… Society has changed so much now that sex isn't a special thing like it was for our generation, … like a privilege to some people"* (11A: F, age 45).

A male participant felt that because HPV was very common to the general population, whom he perceived to be more open minded than previous generations, HPV would be therefore destigmatised as an STI. Furthermore that because genital warts are prevalent with a high risk of occurrence people would naturally associate HPV infection in a similar way to other common viruses, such as the common cold, and this in turn would destigmatise HPV infections.

> "*I don't think there's much of a stigma these days; I think that the majority of people are much more 'open minded' and aware. And that HPV is very, very common from what I understand. We all get warts at sometime…and we're quite comfortable when we've got a cold,*

and you think if HPV is a virus that's got a sexual connotation, then I am very likely to get it at sometime" (8A: M, age 49).

Further attempts at destigmatisation of HPV infection were made. The distinction between HPV and STIs was considered to be more relative to a common [sexual] *activity* than sexually transmitted *diseases*. One participant considered HPV as not being a sexually transmitted *infection*, but a *virus* that was common to women. Another participant believed that HPV has no stigma because people have not yet made the connection of it as a STI, and the HPV vaccines' connection with ICC would over ride any stigma.

"I wouldn't have thought so at this stage [that HPV carried the same stigmas as other STIs]*, especially given that there isn't the connection there in people's minds"* (1A: M, age 48).

In contrast, when questioned, one participant immediately likened HPV to acquiring a range of STIs akin to '*herpes*' and '*Chlamydia*'.

9.5.2.2 The influence of sexuality attitudes on age and consent for HPV vaccination

The issue of age for HPV vaccination raised contrasting views. Most participants had a pragmatic view about contemporary adolescent sexual behaviours and perceived adolescents to be maturing faster and engaging in more risk taking than they did.

"I think my God, she [my daughter] *actually is young, she's at the age where she should be having the vaccine…I think in their world things are very different and are more maybe one night stands and risk taking with the younger kids"* (11A: F, age 45).

Participants who preferred age of vaccination at age 11 or 12 were influenced by adolescent sexuality issues

"When they're 11, … they're heading towards puberty …and mentally you're starting to prepare yourself for the sort of issues that you're

going to be facing over the next 6 to 8 years, and that's [sexual debut] *one of them along with a whole bunch of others"* (14A: F, age 40).

Concerns were raised about the impact on consent if parents thought it was a vaccine to prevent a STI. In contrast, one participant said a STI message would not alter her support for the vaccine, as adolescents sexual debut was considered inevitable and that its onset presented a risk for them contracting STIs.

"I guess it's a sad reality the increasing incidence of sexually transmitted diseases… and it's got a real risk of happening anytime, whereas the cervical cancer is something that could happen later. STDs don't discriminate, and … this [HPV infection] *is the next wave …. this is actually a far greater lottery than even HIV was"* (12A: F, age 45).

9.5.2.3 Concerns about HPV vaccination on adolescent sexual behaviour

Issues arose around the HPV vaccines giving protection against STIs, which was perceived as a concern to adolescents. Most participants displayed open - mindedness and were aware of the earlier age of sexual debut being influenced by societal pressures on adolescents to conform to their peers, in spite of the family values in which they had been raised.

"You see a lot of younger people under a lot more [peer] *pressure* [for sexual activity] *than we were at their age… there appears to be more traps surrounding the younger generation, so you become protective and we can discuss them with our children in this day and age"* (9A: M, age 59).

Parents accepted that sexuality education and HPV vaccination with adolescents would not be seen as a license to become sexually active or '*ignore family values*' (10A: M age 52), but that it was an important part of the process of making adolescents aware of the consequences of sexual activity. One participant, who thought young adolescents were physically too underdeveloped to be commencing sexual activity at a young age, and

that is why they were at greater risk of STIs, used this as a behavioural message to her children.

> *"What happens when it starts too young because your body's not ready, and you can get infections…, so I've used that* [information] *as a bit of a reason for* [my children] *not doing any of these things. I think with this generation it's important to get through that the concern is the diseases you can get, and what you're doing to your body"* (6A: F, age 42).

Issues of promiscuity as a consequence of HPV immunisation arose. One participant thought that promoting HPV as an STI would misinform adolescents about safe sexual practices despite them knowing there was a lot of sexuality information in youth magazines [such as *Dolly* and *Cleo*] which one participant described as "*shocking*" (10A: M, age 52). Moreover, concerns were raised about the HPV vaccines emphasising a STI message as it may lead to an assumption of promiscuity when there may be none.

> *"If they* [young adolescents*] saw that message* [HPV as an STI], *they'd say 'hang on, that's saying that I'm being sexually active', and …they may not want their parents to know about that, and they would see this* [being immunised with a HPV vaccine] *as consenting to the fact.*" (9A: M, age 59).

In contrast, another participant thought relating the HPV vaccine to promiscuity was "*nonsense*" (8A: M age 49), because promiscuity did not eventuate with HBV vaccine which was also STI related. Some participants were not offended by the intention of the STI message.

> *"My children at 14, they are acutely aware* [of] *sexual things already"* (10A: M, age 52).

9.5.2.4 The influence of religious beliefs on parental attitudes

Participants noted that extra-marital pregnancy and STIs generated stigma and shame, especially among females whose lives were impacted detrimentally. Some participants believed their religious upbringing and

"*society at that time with high moral values*" (4A: F age 46) strongly influenced their attitudes toward adolescent sexual behaviour, which they stigmatised.

> "*It's* [the influence of Catholic religion] *got to rub off, one of eight* [children], *a good Catholic family, you don't sleep around, you're not the town bike* [promiscuous] *or whatever"* (4A: F, age 46).

Adolescent sexual behaviours were the antithesis to one parent's moral values but he was pragmatic about it, despite his beliefs.

> "*I hold a Christian view that sexual relationship is God's intended design for couples, it's a wonderful thing and it's intended for marriage. So the fact that children are doing it* [engaging in sexual activity] in *their teens … I don't believe it's what should be happening"* (10A: M, age 52).

9.6 Summary of Anglo parent results

Anglo parents had a high acceptance toward a HPV vaccine to prevent ICC, although there were variations due to biomedical factors (Table 15). Female participants undertook Pap screening motivated by their fear of 'cancer', with some women being ambivalent toward its need. Male participants were also concerned about the possibility of cancer in their wives with an abnormal Pap test result.

Table 15: Summary of key biomedical factors on attitudes toward adolescent HPV vaccination: Anglo parents

BIOMEDICAL FACTORS	**Anglo**
Pap screen participation	H
Understanding of ICC risk factors	L -M
Vaccine safety	L
Vaccine efficacy	L
Medical contraindications	L
HPV type specificity -bivalent	M
HPV type specificity -quadrivalent	M -H
Natural immunity	H
Need for parallel Pap screening	L -M

Key: H: High acceptance M: Moderate acceptance
L: Low acceptance U: Unknown NA: Not applicable

Whilst Pap screening was considered to be an unpleasant procedure psychosocial distress or stigma was not evident in their responses. Knowledge levels of ICC risk factors were low to moderate across both male and females. Participants had nil to low levels of knowledge of HPV, and women were critical of GPs who generally did not provide information unless an abnormal Pap test result was diagnosed. Participants revealed they felt relieved and comforted by the knowledge that HPV is a common condition to men and women, and many associated it with a 'virus' rather than an 'infection' to distinguish it from other STIs.

Although questions arose about the need for HPV vaccination when the Australian incidence of ICC is low, parents showed a preference for the 4vHPV because of its broader coverage for ICC and genital warts, and moderate acceptance for the 2vHPV vaccine because of its protection being only for ICC. Concerns were widely held toward the lack of information regarding the long term safety and efficacy of the 4vHPV vaccines, and Australia being the first nation to offer it through a broad-based immunisation program. Parents accepted the need for parallel screening to give more complete protection against ICC among the vaccinated cohort.

System factors influenced parental attitudes. Moderate to high trust was held in the Australian Government immunisation programs and Australia's vaccine licensing processes, with the exception of one parent who had experienced adverse events with her child's vaccination and remained circumspect about the benefit of the HPV vaccines. Although parents had limited information about the vaccines, they displayed moderate to high intentions to consent to adolescent HPV immunisation because of the trust placed in Government. Parents indicated they routinely immunised their children due to their obligation to protect their children's health, but felt that the vaccines should be Government subsidised as the high cost was a potential barrier to uptake.

Table 16). Although parents had limited information about the vaccines, they displayed moderate to high intentions to consent to adolescent HPV

immunisation because of the trust placed in Government. Parents indicated they routinely immunised their children due to their obligation to protect their children's health, but felt that the vaccines should be Government subsidised as the high cost was a potential barrier to uptake.

Table 16: Summary of system factors on attitudes toward adolescent HPV vaccination: Anglo parents

SYSTEM & SOCIO-POLITICAL FACTORS	Anglo
Trust of Government and health agencies	M -H
Trust in Govt. immunisation programs	H
Access & availability of HPV vaccines: schools	H
Access to adolescent HPV vaccines: GP clinics	M
Cost (if not subsidised)	M-H
Cues to action	M -H
Dosage schedule compliance	M-L
Perceived pain of vaccines: adolescents	H
Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable	

The pain of vaccination was considered to be an inconsequential factor to consent. Cultural and normative factors were found to influence parental acceptance for the vaccines (Table 17).

Table 17: Summary of key cultural and normative factors on attitudes toward adolescent HPV vaccination: Anglo parents

CULTURAL & NORMATIVE FACTORS	Anglo
Normative values: vaccination	M-H
Parental responsibility and level of control	H
Knowledge levels of HPV	L
Knowledge levels of HPV vaccines	L
Perceived benefits from HPV vaccination	M-H
Perceived susceptibility and risk	M-H
Perceived severity (cancer)	H
Perceived severity (STI risk)	M-H
HPV vaccines & promiscuity	L -M
Protect daughter's health	H
Protect son's health	L - M
Parent's personal experience of STIs	M
Cultural influences on HPV / STI vaccines	H
Religious beliefs	M
Acculturation	NA
Age for vaccination*	12 -14
Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable *Age for vaccination varied. These are the general majority views.	

Parents indicated there was benefit to redressing ICC for their daughters through HPV vaccination, and a moderate benefit for their son's health. HPV as an STI was not a significant factor in attitudes toward the vaccine, and their children's perceived risk for HPV acquisition and subsequent cancer risk were key factors. Parents held differing opinions as to the ideal age for vaccination of girls, varying between age 12 to 14, at the onset of puberty.

There was overall agreement that the key vaccine message should emphasise 'cancer' rather than 'STI' prevention, although some parents expressed annoyance at the female-centric approach taken. Whilst there was support for school-based education, including males, of the sexuality factors of HPV vaccines some parents maintained that this information should be delivered by them because of the differing degrees of maturation in their children.

Whilst participants held conservative views and expectations for their children, most were pragmatic in their view toward STIs and adolescent sexual behaviour. A small number of parents held strong religious principles toward adolescent sexuality, but the potential for promiscuity in adolescents after vaccination was not a broadly held concern.

Chapter 10: Results from Chinese-Australian parents

10 Introduction to results:

Data from the interviews were categorised into three main themes:

(i) individual beliefs and experiences of cervical cancer (ICC) prevention;

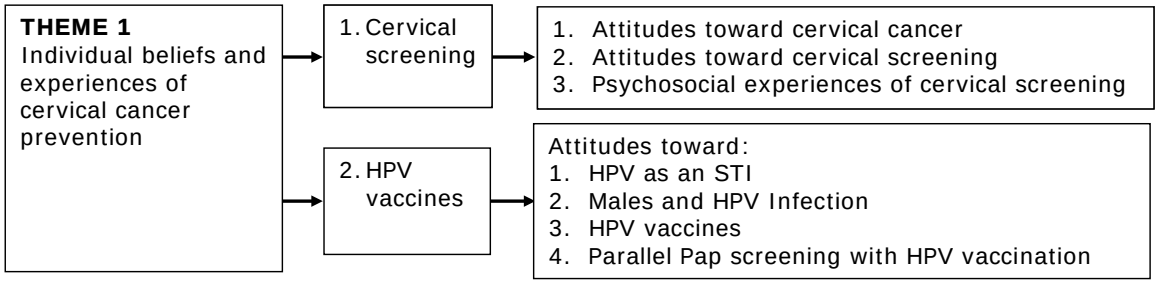
(ii) [Chinese-Australian] parent perceptions of factors for immunisation success;

(iii) cultural influences on [Chinese-Australian] parent attitudes toward HPV immunisation.

10.1 Theme 1: Individual beliefs and experiences of ICC prevention

The sub-categories in Theme 1 (Figure 11) capture participants' own beliefs of ICC prevention through their attitudes and experiences of cervical cancer screening and HPV vaccination.

Figure 11: Theme 1: Individual beliefs and experiences of cervical cancer prevention among Chinese-Australian women



10.2 Cervical screening: attitudes toward ICC

Participants had various degrees of understanding of ICC, and their knowledge was gained from various sources including Chinese news media about the related death of a Hong Kong celebrity, social networks and direct experience. The term '*cancer*' generated a strong psychological response in many. Several participants considered cancer to be a

"*horrible*" (2CH: age 52; 18 Aus[2]) and '*scary*' (11CH: age 37; 6.5 Aus) condition, and related it to a general cluster of untreatable diseases.

Despite most participants understanding ICC as a 'female' disease, their knowledge was incomplete, and it was difficult for participants to articulate their knowledge in English language.

> "*Is it something like cancer with any part of the body? I'm not really sure. Is it the vagina…Ladies? I can't remember the name… we know the name in Chinese"* (5CH: age 43; 14 Aus).

Cervical cancer was thought to be hereditary, and women were confused about risk factors and women's vulnerability. Most participants understood that older women, over 60 years, were most at risk. However, in contrast, one woman who had had direct familial experience had more complete understanding.

10.2.1 Attitudes toward cervical screening

Generally, participants had low levels of understanding about cervical screening, and some women were curious about Pap screening characteristics. Another participant, who understood the screening interval to be biannual, questioned how long the procedure took and only for 'old' women. Furthermore she and others shared negative views about the lack of education about Pap screening they had received both within the community and their doctors, and women commented on the Government and medical profession's lack of encouragement of younger women to attend Pap screening.

> "*At least if I know, I might be able to prevent cancer. Even Government is not really encouraging women; they do not inform them until they're old. The Chinese doctors, they just give you some herbs"* (4CH: age 46; 19 Aus).

[2] The Chinese-Australian parent verbatim quotations are cited in parenthesis: Participant number + cultural identifier (CH = Chinese-Australian) + gender (F = female; M = male) + age + years in Australia. For example (5CH: F, age 43, 14 Aus)

Participation in cervical screening varied, and the majority of participants indicated they did not attend for regular Pap screening, with several women never being screened. One participant had started routine Pap screening in Hong Kong immediately after screening became more accessible to women as a result of public demand from intensive media reporting of a celebrity's death from ICC. Prior to that, she had no understanding of Pap screening, nor its purpose. Two other women had occasional Pap screening, the remainder did not. One woman understood the need for and routinely undertook Pap screening but this was solely because of her trust in the doctor's recommendations, and not because of what she knew about ICC.

> *"I have not been told about this, I have just been told I must go for a Pap smear. I think it would be very helpful, every time when I go for a Pap smear, they just educate me on this"* (9CH: age 54; 6.5 Aus).

10.2.2 Psychosocial experiences of cervical screening

Because so few women participated in Pap screening there was limited information on their experiences. One woman who occasionally presented for Pap screening indicated her general apprehension and nervousness at the possibility of receiving a negative test result. After I shared HPV information during the interview and women became aware of the association of HPV with abnormal Pap test results and ICC, they placed importance on the term '*virus*' rather than '*cancer*' to manage their attitudes toward Pap screening. There was relief from one participant (who had described the information as '*scary*') when she interpreted ICC as a manageable '*virus.*'

> *"For me to keep doing the Pap smear…and not to… don't have to be so scared. Because it's not a cancer…it's just a virus that if you find early, it's not a problem"* (11CH: age 37; 6.5 Aus).

10.3 HPV vaccination: General responses toward HPV information

All women initially had no understanding of HPV transmission, and after my explanation their comments showed their confusion about the

progression of HPV infection, and some queried about whether the male or female was the primary transmitter of HPV. Whilst three participants had no comment to make about their level of HPV knowledge, with other women fearful emotions surfaced when they realised the risk factors. After the HPV information intervention most participants found the information helpful in increasing their understanding of HPV.

> *"To me its new information… it's educating me. I have to be very frank that I seldom have sexual activities, so it couldn't cause many alarm on me* [sic]*. I think everyone should know this information. That would make them think twice before starting to have sexual activity* [and] *…not many partners"* (9CH: age 54; 6.5 Aus)*.*

There was confusion between HPV and HIV, and one participant surmised on the relationship of HPV with a prior health issue; another showed her awareness of the Truescreen ^{TM} test but she was confused as to its capacity to detect HPV. Despite this perplexity, women revealed that their new understanding of HPV information prompted a change in their attitude toward regular cervical screening.

10.3.1 Attitudes toward HPV as an STI

The association of HPV with STIs was considered a sensitive topic and nine respondents had no comment on their feelings about HPV as a STI. There was shock and surprise among other participants when they realised the impact of sexual activity and ease of HPV infection, and the necessity now for them to discuss such intimate issues with their children. Participants stated they would need to seek more information about it from medical and education sources. All participants were surprised that the information had not been commonly known, and they considered this to be important information for the general community, and significant for the next generation.

10.3.2 Attitudes toward males and HPV infection

The risk of HPV infection for males was new information and it surfaced confusion and surprise among the women, and queries arose. Queries

arose about the role of condoms in the prevention of HPV infection, and they perceived that men would be surprised at the information.

Furthermore, that both the knowledge and HPV vaccination was important for men's health. Another participant, who indicated the sensitivity of discussing HPV infection with males, revealed that recently there been tacit resistance by a male relative to explain to her why men were at risk of HPV.

The impact of infidelity and the risk of acquisition of HPV and other STIs generated discussion. As participants revealed they were monogamous they rated the risk of sexual infection as not an issue for them, but they recognised the risk for younger people. One participant cited the impact of travel - acquired STIs among businessmen, and the general acceptance that a wife would not question her husband's conduct.

> *"People travel so much and can pick up these diseases. And with a man, you never ask who he has been with. So it's pretty scary thing to have for the rest of your life. You don't ask people to show you whether you've got a virus"* (7CH:4.2; unknown Aus).

Others who were also circumspect about male behaviour supported HPV vaccination for males, and maintained that HPV education may act as behaviour modification for them. Specifically, that in addition to HPV protection, the awareness of HPV factors could also act as a deterrent to early sexual debut in adolescent males. There was agreement among several women that males should be educated due to their role as co-infectors and particularly as a shared partnership with protecting female health. 'Warts' were mentioned by some women, but they presumed them to be the non-genital types, therefore the information on genital warts in males, and that they could be acquired by females, was new and daunting information for all women. Several participants further questioned whether females were susceptible to genital warts, showing their need for clarification of sensitive information.

10.3.3 Attitudes toward HPV vaccines

Despite the women's low awareness of 'HPV' infection, many women had general knowledge about 'a HPV vaccine' and its general importance to women and female children from several sources, including a prior HPV vaccine information day at their local cultural association; and through general media (a Chinese newspaper and a mainstream Victorian English language newspaper).

Their need to acquire information about the HPV vaccine characteristics was very important to them, with participants placing their main trust in authoritative sources such as Government and doctors. The quality of Australian scientific research was highly regarded and further contributed to their trust in Government vaccine programs. Moreover the Australian Government's recommendation for the 4vHPV vaccine implied to them that it was beneficial for the population's health.

> *"We trust Australian scientists…that's important* [to us] *that the research is of* [a] *very high standard…The Government does all the investigating ….We trust the government not to trick us, I don't think the government would just agree to something if it wasn't well researched. We trust the government's decision about vaccines"* (5CH: age 43; 14 Aus).

Although the 4HPV vaccine's high cost was recalled by some participants, some misunderstanding about key factors emerged. There were concerns about the newness of the vaccine, risk of HPV infection, the target age for vaccination, efficacy, cancer types that were protected through vaccination, and its impact on senior women and males. Reliability of the manufacturer was another consideration. Safety, and the long-term impacts with routine immunisations were not a concern, but it was a concern with the HPV vaccines.

There were mixed responses to the protective characteristics of the vaccine.

> *"I sort of wondered whether it actually works and how well it actually protects … with it being a new product that's been introduced. There's always a worry …in the back of my mind whether 10 years down the track… they'll find out… more information about the vaccine"* (8CH: age 36; 12 Aus).

Whilst some participants questioned the relevance of the vaccine if it only gave partial protection against ICC, most were pragmatic. Two participants had concerns about scientific issues, especially the risk of replacement of other viruses if the vaccine's HPV types were eradicated. Questions about it being compulsory for their children were a consistent matter, and one participant, who sought protection for herself at 50 years of age, raised the issue of HPV vaccination for older women.

Concern about distinctive ethnic characteristics and vaccine research investigations arose. One participant questioned 'proof of success' in the trial populations; the relevance to 'ethnic' groups due to her perception that there were variations in the genetic composition among cultures; and HPV immunisation policies in other nations.

> *"When they do the research, do they do it on all the ethnic groups? Because I think some groups all have different genes and reactions."* (7CH: age 48; unknown Aus).

One participant who had previously heard a media broadcast confused the HPV vaccine with preventing breast cancer. Another reported on her friend's uncertainty when she equated the 'cervical vaccine' with vaccination directly into the cervix. Her response indicated her own confusion despite her working in a medical clinic.

> *"One of the patients asked what part of the body they would get the jab in… She has no idea, she is so scared about it…she thought it was up in her bottom, but I quickly tell her that 'I don't think so - it's only for protection in your bottom, it [the vaccine] should be on your hand'.* [She replied] *'Ooh, what a relief…it's going to be 3 doses into the arm'. Because when she asked me is I said 'no, I don't think so,*

should be on the arm'. And she asked me, 'why are you so sure'; I said 'I'm pretty sure'. I had that impression that it's on the arm" (5CH: age 43; 14 Aus).

Participants were surprised with the possibility of having a choice with two HPV vaccines. One indicated she had not considered either vaccine because they had not yet been registered as a public immunisation program. The 4vHPV vaccine was preferred by some because of the increased protection it gave against more HPV types. Moreover participants accepted that young people were at greater risk of HPV infection and genital warts because of common sexual activity among male and female adolescents. Conversely, one participant, who supposed that genital warts were able to be clinically controlled, preferred the 2vHPV vaccine as a stronger 'cancer' preventative.

10.3.4 Attitudes toward the need for parallel Pap screening

There were mixed responses to the need for parallel Pap screening with HPV vaccination.

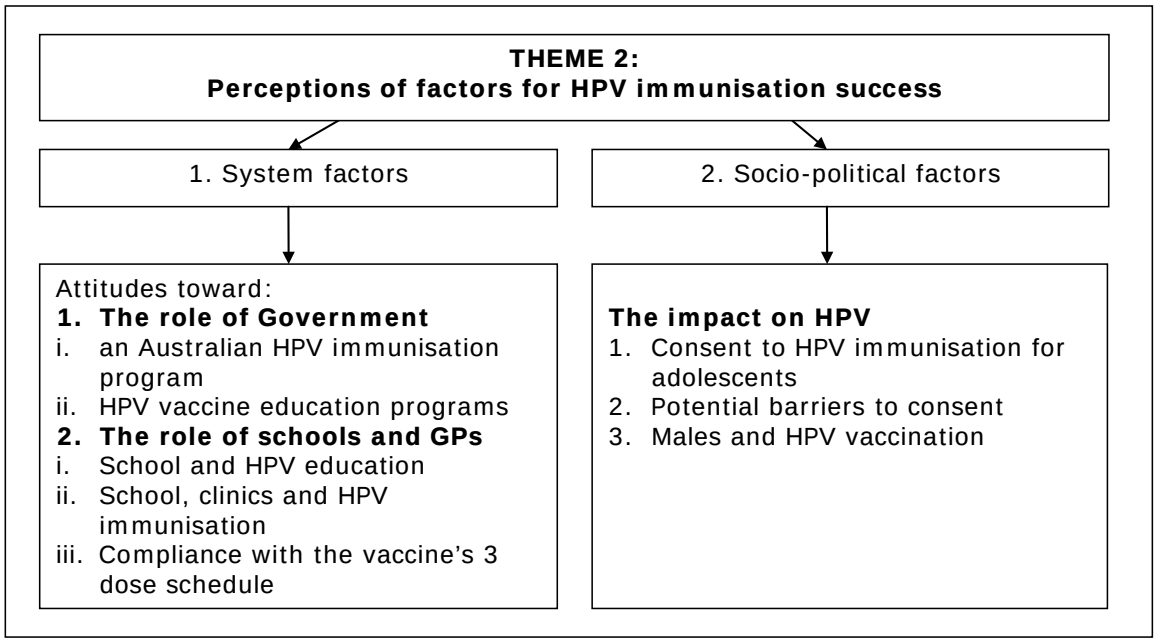
"I think from speaking with a lot of my friends, some of them actually think that if you get the vaccine that you're protected for life. Then they probably wouldn't bother with Pap smears" (8CH: age 36; 12 Aus).

Many women supported the importance of the Pap screen message for adolescents, to reinforce '*double insurance'* (9CH: age 54; 6.5 Aus) against ICC. However in contrast, some attitudes were framed by perception that cervical screening messages would not be understood nor heeded by adolescents.

10.4 Theme 2: Chinese-Australian parent perceptions for HPV immunisation success

This thematic category (Figure 12) captures participants' own beliefs of the role and expectations of both system and socio-political factors for a successful HPV immunisation program.

Figure 12: Theme 2: Perceptions of factors for HPV immunisation success



10.4.1 System factors: the role of government: attitudes toward an Australian HPV immunisation program

In order to ascertain the attitudes of Chinese-Australian parents toward a national HPV immunisation program, an understanding of their general beliefs toward prior immunisation programs was first sought. Whilst many participants had difficulty with recall of specific vaccines they had received, endorsement by Government, medical profession or school entities were important factors in their immunisation decisions. Participants placed confidence in established global immunisation programs, and supported routine Government childhood vaccination programs which were viewed as compulsory.

High value was placed on routine prevention for a child's long term health, and the women relied on advice within their social network about the consequences of non-vaccination. Women had learned (from the 'grapevine' in their social networks) that the Government would withhold financial incentives for non-compliance with HPV immunisation, but the incentive referred to only applied to infant immunisation, not adolescent immunisation.

"And I heard from my friends that if you do not have the childhood vaccinations, they're not being paid for the family benefits. Yes, because they have to get the vaccinations and send it to the government… they're not being paid the family benefits" (5CH: age 43; 14 Aus).

Despite these attitudes, participants held positive beliefs about a national HPV immunisation program.

10.4.1.1 Attitudes toward Government HPV education resources

During the interview women were shown the Government HPV vaccine advertisements in mainstream media (Appendix 17) and they generally thought they were useful as a first source of information. The majority of women commented on the importance of the inclusion of the Australian Government logo in the advertisement as confirmation of the vaccine's importance, and that it had been formally legislated for. Conversely, one participant did not totally trust information produced by the Government, perceiving the Australian Government had control of all mainstream media, and she criticised the content of the Government advertisements in the Chinese newspaper, especially the female images and misleading statements.

Some women positively viewed the Chinese HPV information advertisements produced by the Government (Appendix 23) but felt they lacked appropriate Chinese language translation. Several participants commented on the Government's error of applying 'traditional' Chinese script as it is read by only a small proportion of people of Chinese background from Taiwan and Hong Kong. They advised the majority read 'simplified' Chinese script, and the lack of relevance for them could deter some from receiving the information.

"Actually I don't want to criticise because some translation [in the Chinese translated HPV information brochure] *is not very good, it's not exactly the right words"* (2CH: age 52; 18 Aus).

Other criticisms were targeted at the image of an Anglo mother and daughter which was construed as the Government's endorsement of mothers supporting early sexual debut; equally that the vaccine was being targeted at the Anglo (not Chinese) population group. Furthermore the term '*cure for cancer*' was considered to be misleading when the HPV vaccines give partial prevention only. Combined, many participants thought these inaccuracies had the potential to send a wrong message to the Chinese community, especially those with lower standards of education. Another participant thought that Chinese women may perceive it as not relevant for them and therefore ignore the advertisements.

The banner header "*At last there is good news about cancer*" was viewed as grabbing the reader's attention, and women agreed that within brief advertisements messages about ICC prevention and ongoing Pap screening necessity were critical information, but most would have preferred a short statement assuring vaccine safety. In contrast, women did not support public advertising for promoting the vaccine as an STI protective.

Participants understood why Government HPV vaccine advertisements in newspapers have incomplete information, and they intended to seek detailed information elsewhere. Brochures were considered to be an acceptable information source, but only if they were from official sources such as the health department, and in plain language. Some participants considered brochures either at home or in the clinic to be useful as a prompt to take action.

Many participants were conscious of their English language difficulties and articulated the need for culturally specific and bilingual resources.

> *"I think* [information] *would help in both English and Chinese. Because of the different background of people some of them may not be able to understand* [English] *100% … you can get the idea but it's not professional information* [in the Chinese translated newspaper advertisement] *this is medical, it's not like gossip…and maybe people will have a stronger opinion toward it"* (3CH: age 50; unknown Aus).

As a solution participants suggested that images of Asian women or mixed races be used to indicate that HPV vaccination was not exclusive to a certain race. Furthermore, Chinese people would explain the vaccine in complete but simple terms in advertisements, but were unlikely to use a telephone hotline for further information because of language challenges, time and convenience factors. In contrast, some women indicated they would seek the hotline for detailed information.

10.4.2 System factors: The role of schools: attitudes toward school and clinics for HPV immunisation

Despite some concern and fear about the potential risk for their children to contract disease from other school children, schools were viewed as a major influence on a child's health and behavioural attitudes by most participants. Schools were perceived as having a legitimate role in the delivery of immunisation programs, with a dual role as a health educator for both students and parents.

There were mixed views on HPV immunisation for young children at school especially as the HPV vaccine was new. Some women wrongly viewed a connection between school delivery and compulsory immunisation, and peer pressure, convenience, dosage compliance, and economic factors influenced those who were supportive. However, another participant anticipated the importance social acceptability for their child by being immunised at school.

> "*I think she will probably want to suffer with her friends, so they can all compare the experience. I think she will probably feel comfortable with all her friends around her, but in the past we do tend to go to the GP because I like to be there"* (6CH: age 50; 25 Aus).

There were queries if there was an option in who administered the vaccine. Two women, who resided in Australia less than seven years, maintained the services of a Chinese traditional doctor. In contrast longer residing participants utilised a 'family' doctor in mainstream western clinics and preferred the clinic as preferred immunisation setting. In particular because the HPV vaccine is new, they wanted the reassurance of

immediate medical support in case of an adverse reaction. Beliefs that vaccinations were '*scary'* and '*hurt'* influenced some participants' preference for clinics for immunisation. Additionally one parent associated HPV vaccine with stigma and considered a clinic to offer her family more privacy, and for another it was her trust in the child-doctor relationship.

10.4.2.1 Attitudes toward compliance with the HPV vaccine three-dose schedule

Although participants had limited recall of specific dosage intervals with other adolescent vaccinations, the compliance with three-doses was not a concern for them when it was through a school-based immunisation program. Nonetheless, concerns about dosage compliance through a medical clinic were raised, and dosage completion and recall were factors with one participant who had a perception of her GP having a laissez-fair attitude toward incomplete vaccination schedules. A HPV reminder-recall system was considered important to overcome this.

One participant, who preferred the HPV vaccine to be a single dose because of her daughter's dislike of multiple vaccinations, saw the value of educating children about the benefits of HPV vaccines as a way of meeting dosage compliance. She considered that if HPV education stipulated the long term benefit of ICC prevention this would outweigh any short term vaccination discomfort, and ultimately support compliance.

10.4.2.2 Attitudes toward schools delivering HPV education

There was general agreement that schools were fundamental in facilitating parental sexual education with children, providing standardised and accurate information, rather than informal and incorrect information their children gleaned from external sources.

> *"They have sex education in schools anyway* [so] *tell them, 'okay you have this but it's not going to prevent you to stop the HPV as well, you still have to have these safe precautions about sex'. For us born in Hong Kong, in our school we never have sex education"* (7CH: age 48; unknown Aus).

Women indicated they would delay HPV education within the family until school had broached the issue first, as it was considered to be easier for the parent to later discuss the issue with the child.

> *"Even though we wouldn't discuss sex with the children, it's very important* [for the school] *to let their parents know that* [it has been discussed at school]*, because they should tell her*" (5CH: age 43; 14 Aus).

Whilst some participants considered teachers to be an appropriate source of HPV information others had negative views about information through schools. They placed blame on the influence of schools and the media for their teenagers having liberal perspectives on sexual issues, and being problematic.

> *"In our culture its* [forming sexual relationships] *a little bit later than the 'Western'* [people] *because it's a different culture; later, until they're married. Because they go to school here and they have the Western culture, they all change"* (1CH: age 48; 19 Aus).

Participants were realistic about the need to educate themselves about the HPV vaccines, but they recognised the limitations of the availability of information for parents through schools. Health information was sought from a variety of public sources including general media and Chinese television programs and the internet. Radio was considered to be useful for a general overview, but its information was incomplete. Some women with low levels of English literacy relied on their English literate children to inform them. Whilst friends were preferred, by most women, as an information source there was awareness that the information could be unreliable. There was overall preference for community HPV information sessions based at their local Chinese community centre with a Chinese speaking nurse.

Because of their preference for face-to-face conversations and their need for explanation of medical terms, the doctor was nominated as an important and reliable information source, and preferable to a telephone

'hotline' service interpreter services for which they were uncertain about privacy.

> *"They seldom call …the 1800 number* [because it] *takes …maybe half an hour, to know more about that* [the vaccine] *… I prefer to go on the website, I think it's much more* [sic] *easier. If I needed more information…I trust what my doctor tells me but not from the telephone…you can discuss face to face"* (5CH: age 43; 14 Aus).

10.5 Socio-political factors: attitudes toward consent for adolescent HPV immunisation

Whilst participants agreed in principle with the HPV vaccine as an ICC preventative, willingness to consent to HPV vaccination for their children was not unanimous, and the lack of detailed information was vital to their confidence in giving consent. Whilst it was not important that vaccines were developed in Australia for one participant, Government endorsement combined with trust in the school's recommendation were a key factor for others. Furthermore, the 4vHPV vaccine with broader protective potential was an influence for consent to participate in the HPV immunisation program.

Whilst participants indicated that vaccination issues were discussed with their husbands, their daughter's agreement to be vaccinated was important for some women. One participant (who was interviewed in early 2007 just prior to the national HPV immunisation program) stated she openly discussed the 4vHPV vaccine with her older adolescent daughter to facilitate her awareness of what she was receiving; and another participant indicated she was going to give the final choice of HPV vaccination to her 16 year old daughter.

The age of the child influenced consent and it was strongly intimated that children place their acceptance of vaccination on parent authority.

> "*Like all the Chinese families, they* [parents] *say* [to their children] *'you need to do this', and then they accept it. They won't say 'why do I have to do it'"* (4CH: age 46; 19 Aus)?

Vaccine decision making within families was influenced by several factors. For married participants, decision making was a shared responsibility. Their decisions were influenced by the child's risk factors for the disease and age of their child. Whilst there was resistance to their children knowing about HPV as a STI, all perceived young people to be irrational and vulnerable.

> *"You never know when your child will be sexually active…hopefully it's not before 12…* [this] is probably more the age when girls would become active sexually. *I don't want to give them a false sense of security to think they can do anything, now that they're vaccinated … Many Asian parents have come to realise that they're not immune no matter how much you drum into your child about your own values and things… although the parents may still have traditional values, they would be quite happy to let the children have this vaccination"* (6CH: age 50; 25 Aus).

For one participant, compliance with her social group was the primary motivator with HPV vaccination.

> "*Because normally everybody does it, I just follow the whole group of people… just normal practice*" (4CH: age 46; 19 Aus).

10.5.1 Potential barriers to consent

One parent was intending to consent to the vaccine for her daughter, but others were considering delaying consent for a variety of reasons including incomplete information; the need for more long-term safety data because of is newness; and the maturation and sexual development in their children. Additionally there was concern that the vaccine offered only partial protection against ICC.

> *"I heard about some of the medicine… can treat this kind of disease…and then after a few years they find out it causes cancer. That's why I'm concerned. Some of the things I think we need time to make sure if it's safe to your family. I think more people having this kind of treatment need time"* (4CH: age 46; 19 Aus).

Many women intended to make a final decision after considering advice from their husband and social networks. One noted that she would reconsider her consent if there was a proliferation of adverse media. The potential for adverse events after vaccination influenced some women's attitudes, but the long-term health benefit overrode most concerns, and many women were either complacent or pragmatic about adverse events, or did not contemplate the possibility of occurrence.

The high cost of $450 for the course was considered to be prohibitive, and would reduce people's access to being immunised, despite its importance.

> *"Not* [pay that much money] *for a new vaccine, because I don't have proof of its safety. I don't know what the market react* [ion] *to this one and you don't have any proven success. I would not spend $450 for that"* (7CH: age 48; unknown Aus).

Whilst the cost of the vaccines was not a major factor for another participant, she maintained that equity of access to the vaccine for disadvantaged sectors of the population was important if the Government considered eradication of HPV infection to be such a vital health policy.

10.5.2 Attitudes toward vaccinating males with HPV vaccine

Gender was also a determinant for participants with sons who were in the vaccination target age. HPV vaccination for males had not been previously considered by some women, and one parent had less urgency for her son to be immunised, because the vaccine had been promoted for 'cervical cancer'. Nevertheless, equity issues were strongly viewed, and several participants advised it was important that both sexes were considered in access to the HPV vaccine to diminish their perception that the health of one group was more important than another.

> *"Boys cannot get cancer of the cervix. But still they got the chance* [to get HPV]*… so I think it's unfair. I think they are both important …Everyone's lives are equal, you can't say that the girls are more important than males or men are more important than women"* (2CH: age 52; 18 Aus).

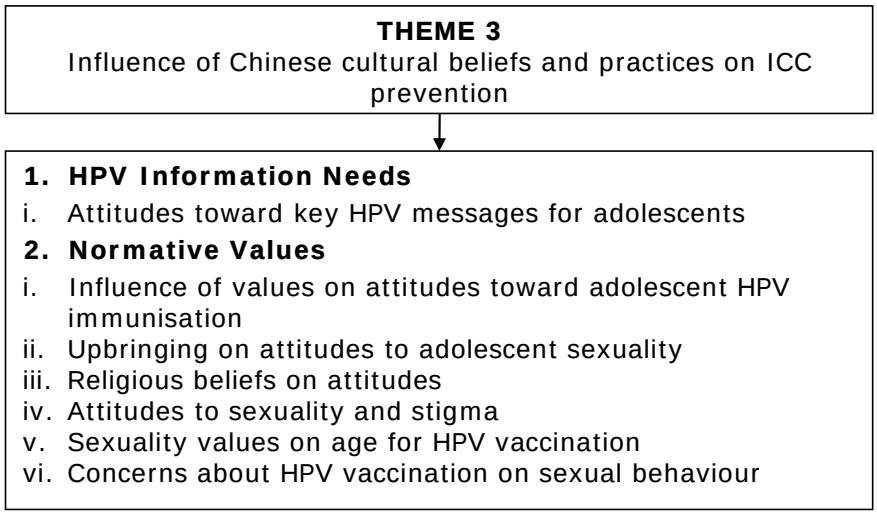
Some participants raised the issue that boys should be vaccinated because of their role in society, the risk and consequences of them acquiring HPV infection; and in anticipation of early sexual debut. Another participant's support for early protection in males was bounded by the impact on her daughter after marriage if the husband was HPV infected. In contrast one participant could not accept the relevance of HPV vaccination for her son.

> *"I don't think I would want to give him this vaccine. Because I am very sure that my son is under our family values. I know him very well, he will not need this. Not ever"* (9CH: age 54; 6.5 Aus).

10.6 Theme 3: The influence of Chinese cultural beliefs on ICC prevention

The subcategories in Theme 3 (Figure 13) captures the cultural beliefs and practices that participants believed influenced their attitudes toward ICC prevention

Figure 13: Theme 3: Influence of Chinese cultural beliefs and practices on ICC prevention



10.6.1 HPV information needs: attitudes toward key HPV education messages for adolescents

Definite views were held about what HPV information should be shared with children, and sexuality issues in the information resources were at the forefront of discussions. Because of its perceived influence on their

children, participants advised that parents routinely censored exposure to sexual media. In relation to HPV information most thought that immaturity created the inability of their children to cope with messages about cancer and sexuality.

> *"I think the sexually transmitted infection is important for the girls to know, but not until they are much older and independent. Cancer is the main message. It probably should be given in year 7 when the girls have the body changes and are more mature to understand"* (10 CH: age 48; 19 Aus).

Other participants expressed how daunted they felt at the task of discussing that HPV is sexually transmitted with their young adolescents. One participant with low levels of English language expressed relief (after the HPV education intervention) that she did not now have to rely on her daughter for information.

> *"Before I didn't know, it's good* [that the vaccine prevents cancer]*. Make them* [daughters] *more healthy* [sic]*. I didn't know that it [is] sexually transmitted. It's good for them but it gives them protection. Not need to open too early to have sex… It's important for me to know this. I can better understand it now. Not have to ask my daughters so much"* (11CH: age 37; 6.5 Aus).

Many participants felt that too much vaccine information would confuse young people who give little thought to their vaccines, and there were mixed views about key messages for adolescents at age 12 to 14 years. Some participants thought adolescents would be ambivalent toward messages about the risk of cancer and sexual issues. The understanding of cancer by adolescents was perceived to be inconsequential for this age group, and that adolescents would disregard parental and media opinions on the vaccine's necessity. Conversely some participants thought that whilst it needed to be considered on an individual basis, children aged 9 to 10 years were mature enough to cope with cancer information.

Some participants felt children at age 12 to14 were mature enough to give full information especially with the onset of puberty, and it was generally accepted that by the stage of late secondary school sexual awareness was commencing, and school would manage related discussions. Participants generally preferred their child's sexual education to be relevant to the child's level of maturity, and that ideally HPV vaccine information should be delayed until the onset of relationships at age 15 or 16 when the vaccine had more relevance.

10.6.2 Normative values: the influence on upbringing on attitudes toward adolescent sexuality

Participants advised that Chinese women do not openly discuss sexuality issues, and find it difficult to do so with their children, as emphasis is placed on physical, not sexual, development and well-being. They revealed there was no sexual education for them in their home country prior to marriage or immigration. There was a strong perception among this group that whilst adults were able to influence their adolescent children, this did not necessarily translate into actual obedience when it came to relationships and intimacy, and they held fears their children would engage in early sexual activity.

Women held a common belief that the 'Asian' values towards sexuality they held for their children were being eroded by the peer pressure of Western values, where information about sex is given to children at a young age.

> "*I wouldn't explain about the sex... With Chinese, we talk about the growing but not about sex now. Its difference in our traditional culture, we seldom talk about really personal things. It's really like you have to open heart to say to somebody else"* (5CH: age 43; 14 Aus).

All participants intimated that several factors influenced their sexual values. In particular, cultural traditions, religion and media were cited.

Despite the women's attempts to influence their children through their and cultural values, many participants of adolescents felt generally uninformed

about their child's sexual behaviour. There were varying beliefs about sexual practices aligned with the difficulties of discussing sensitive sexual information.

> *"I'm a bit old fashioned like that… they need to wait until they're older, until they're married… In our tradition, I can't accept one more partner after the first I can't accept the Western idea of thinking…having sex too young"* (4CH: age 46; 19 Aus).

There was a shared sense of 'sadness' for young children that sexual activity was even considered before marriage, and especially with multiple sex partners, although many participants who accepted that young Australian people may have different sexual practices. One participant was pragmatic about her 14 year old adolescent who had formed a relationship and she accepted it because her daughter was chaperoned. One participant was overwhelmed that her child might on embark in such a significant behaviour.

> *"Oh, that's shocking, it's shocking. I'm very sad, I'm very sad. How can such young children prepare for such a big thing? The culture has changed and people who are living here and my children have a lot of Australian friends. Definitely that would have some impact"* (2CH: age 52; 18 Aus).

10.6.2.1 The influence of religious beliefs on attitudes

Women's religious beliefs influenced their attitudes to sexual relationships and monogamy. Some participants, who were avowed Christians, had difficulty in accepting 'Western' values in relation to adolescent sexual practices. Several participants asserted that their religious beliefs (*"the will of God"* (9CH: age 54; 6.5 Aus), rather than 'Asian' values were a strong factor with their principles. "*Keep yourself clean*" and resisting "*temptation*" (9CH: age 54; 6.5 Aus) were commonly applied terms when describing sexuality issues, and to ensure their children would be virginal at marriage. Furthermore, it was considered to be the parent's responsibility to enforce this.

"I will teach my children you shouldn't be having sex before marriage… keep yourself clean … Sometimes its temptation and it's very difficult….A lot of [television] *programs they have free sex… I don't think I would allow my children to watch that. So far my youngest boy is really disciplining himself, and my other daughter also, she's a Christian…young people are very irrational, therefore they need the guidance of the family values"* (9CH: age 54; 6.5 Aus).

Participants were hopeful of the strong influence of religion in role modelling for the next generation, especially with their age of sexual debut.

"Our religion says you do not have sex until you are married, so I think the girls would take care not to…I think in this sense it's more of our Christian values than our Asian background. We teach the children about the Bible... Its [sexual activity] *not something that everybody has to be in it, its something that you have a choice"* (10CH: age 45; 19 Aus).

10.6.2.2 Attitudes toward HPV, sexuality, and stigma

The women revealed that stigma is associated with sexual diseases and pre-marital pregnancy, and the terms '*shame*', '*embarrassment*' and being '*fast*' '*disgraceful*' and '*bad*' were peppered through discussions. They were fearful of the consequences of early sexual behaviour in their children, and although many participants accepted 'sex' as a natural activity, others were ambivalent. One woman indicated that, because the Chinese people avoid sexuality discussions to avoid stigma and shame, illness, especially those linked to sexual issues, was couched in general terms.

"In case I have HPV I won't tell you, our Chinese culture, we don't tell anybody. ... if I'm sick I'm sick, I will just tell that I'm sick, I won't tell you I have an STI. You get embarrassed, because you don't want to tell friends who are from our traditional culture. Yes, they would be ashamed" (5CH: age 43; 14 Aus).

Many women felt that being immunised with a HPV vaccine would create stigma in the vaccinated cohort who would be perceived as sexually active and "*a bad boy or you're* [sic] *a bad girl*" (4CH: age 46; 19 Aus).

> *"If it's a sexually transmitted infection that will make some people think that you are a fast woman or your sexual behaviour could cause problems for you. When someone talks about the sexual relations, they're* [Chinese people] *going to think it's a disgraceful thing"* (5CH; age 43; 14 Aus).

One women disbelieved the information about HPV being sexually transmitted, and thought it a conspiracy when she heard it through a media broadcast explaining the cause of a Hong Kong celebrity death from ICC. She was disturbed at the way the media stigmatised the celebrity, through associating her death with her personal sex life.

10.6.2.3 The influence of sexuality attitudes on age for HPV vaccination

The age of vaccination generated mixed responses and lack of agreement. Cultural values toward early adult sexual debut, education expectations, and the negative impact on the child's health were seen as important determinants, and some questioned the need for vaccination in sexually naive and young girls was questioned.

Opinions on the ideal age for adolescent HPV immunisation varied between ages 12 to 20 years, depending on their beliefs around adolescent sexual behaviours. Some understood Western relationships commencing at age 12, others at age 15 or 16, and in contrast to Asian relationships which generally commenced at age 18 to 20. This awareness influenced some participants who considered early secondary schooling (age 12 to 13) the best age for HPV immunisation if it gave better protection against ICC.

Participants had agreement for HPV vaccination at a younger age because of the strength of the immune system, rather than the vaccine's efficacy with sexual naivety. Two participants accepted age 12 as a

realistic age for vaccination for pragmatic reasons equating to efficacy and sexuality, and that the age of sexual debut could not be anticipated. Moreover, although some were cognisant of peer influence on consent, most participants conceded that the lack of necessity for their daughter influenced their belief that there was no haste to vaccinate at a young age.

An appropriate age for HPV vaccination was considered to ideally correspond to parental beliefs. Accordingly, some agreed to their daughters being immunised with HPV vaccine when she was in late adolescent stage (age 18), because of the potential disruption to schooling if the vaccine stimulated sexual debut; and another participant considered an even later age as more appropriate. Participants claimed that sexual debut ideally occurred at early adult or at marriage and this greatly influenced their non-consent to HPV immunisation in the sexually naïve.

> *"At age 21 I think. The kids are still virgins. Maybe some at a young age have sex... Maybe at university they will have some relationship, but high school they shouldn't, it's too young for them to have some kind of relationship"* (2CH: age 52; 18 Aus).

10.6.2.4 Concerns about HPV vaccination on adolescent sexual behaviour

Some participants perceived the vaccine as promoting promiscuity and false beliefs of STI protection. Caution around immediate consent for HPV vaccination was driven by a perception that their children would see it as a license to commence sexual activity.

> *"It might do that* [increase promiscuity]*... If I have the vaccine, does it mean that I can have sex more regularly with all different men, all different people"* (7CH: age 48; unknown Aus).

Another participant held negative views toward the Government supporting vaccination in young girls, as she considered it to be Government mandating promiscuity. Whilst she recognised she would be branded a '*goody goody type'* for this view she insisted that ICC was

preventable through education about sexual abstinence and self-discipline, and it was the Government's responsibility to ensure this.

> *"If the government has licensed this* [HPV vaccine], *it's a burden to the taxpayer because this is to encourage to have free sex. Instead of subsidising this, why are the government not educating young people"* (9CH: age 54; 6.5 Aus)?

10.7 Summary of Chinese-Australian parent results

High acceptance was shown toward the vaccine preventing ICC in their daughters but less so for a sexually transmitted infection, although there were variations in the level of their acceptance (Table 18) due to biomedical factors.

Table 18: Summary of key biomedical factors on attitudes toward adolescent HPV vaccines: Chinese-Australian parents

BIOMEDICAL FACTORS	**Chinese**
Pap screen participation	L-M
Vaccine safety	L
Vaccine efficacy	L
Medical contraindications	M
HPV type specificity -bivalent	M -H
HPV type specificity -quadrivalent	H
Natural immunity	H
Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable	

Although 'cervical cancer' was known to most women Pap screening was not regularly undertaken, and some women had never been screened. Their low knowledge levels of ICC and the Pap test held misconceptions that it was for 'old women' and fear that 'cancer' might be identified, and HPV acquisition was confused with HIV. After the education intervention participants acknowledged their need to undertake regular Pap screening.

Parents had some knowledge of the HPV vaccines but misunderstood key factors. Parents had a higher preference for the 4vHPV vaccine because of its perceived broader coverage of HPV infection, and moderate to high acceptance for the 2vHPV vaccine because of its perceived stronger ICC protection. Concerns were widely held toward the lack of information

regarding the long term safety and efficacy of the 4vHPV vaccine, the potential emergence of other HPV types after vaccination, and its relevance for Chinese people.

Parent's attitudes encompassed system and socio-political factors (Table 19). They routinely immunised their children, and generally held high trust in Australia's scientific processes, and moderate to high trust in the Government immunisation programs which were viewed as compulsory.

Table 19: Summary of key system and socio-political factors on attitudes toward adolescent HPV vaccination: Chinese-Australian parents

SYSTEM & SOCIO-POLITICAL FACTORS	Chinese
Trust of Government and health agencies	H
Trust in Govt. immunisation programs	M -H
Access & availability of HPV vaccines: schools	M -H
Access to adolescent HPV vaccines: GP clinics	H
Cost (if not subsidised)	M-H
Cues to action	H
Dosage schedule compliance	H
Perceived pain of vaccines: adolescents	H

Key: H: High acceptance M: Moderate acceptance
L: Low acceptance U: Unknown NA: Not applicable

HPV vaccination was preferred through schools for compliance with the three-dose schedule, and through medical clinics to vaccinate at a later age. The cost of the vaccines was a barrier to uptake and Government subsidy was seen as an incentive.

Cultural and normative factors were found to influence parental acceptance for the vaccines (Table 20). HPV as an STI was a significant factor in their attitudes toward the vaccine, and the information was considered important to be shared with parents, and to be a potential deterrent to sexual debut among adolescent males. Parents held concerns about discussing the HPV vaccine with their children due to the fear of 'cancer' among Chinese people and because of the stigma around STIs. Parents relied on school to conduct sexuality education, believing that later adolescence was an appropriate age for information. For parents who held strong religious views toward adolescent sexuality, and who were relatively new residents (< seven years), the acculturation through

school was blamed as the influence on the changing sexual norms in their children.

Table 20: Summary of key cultural and normative factors on attitudes toward adolescent HPV vaccination: Chinese-Australian parents

CULTURAL & NORMATIVE FACTORS	Chinese
Normative values: vaccination	H
Knowledge levels of HPV	L
Knowledge levels of HPV vaccines	L
Perceived benefits from HPV vaccination	H
Perceived susceptibility and risk	L -M
Perceived severity (cancer)	L
Perceived severity (STI risk)	L
HPV vaccines & promiscuity	L
Protect daughter's health	H
Protect son's health	L -M
Parental responsibility and level of control	H
Parent's personal experience of STIs	L
Cultural influences on HPV / STI vaccines	H
Religious beliefs	H
Acculturation	H
Age for vaccination*	16 -18

Key: H: High acceptance M: Moderate acceptance
L: Low acceptance U: Unknown NA: Not applicable
*Age for vaccination varied. These are the general majority views.

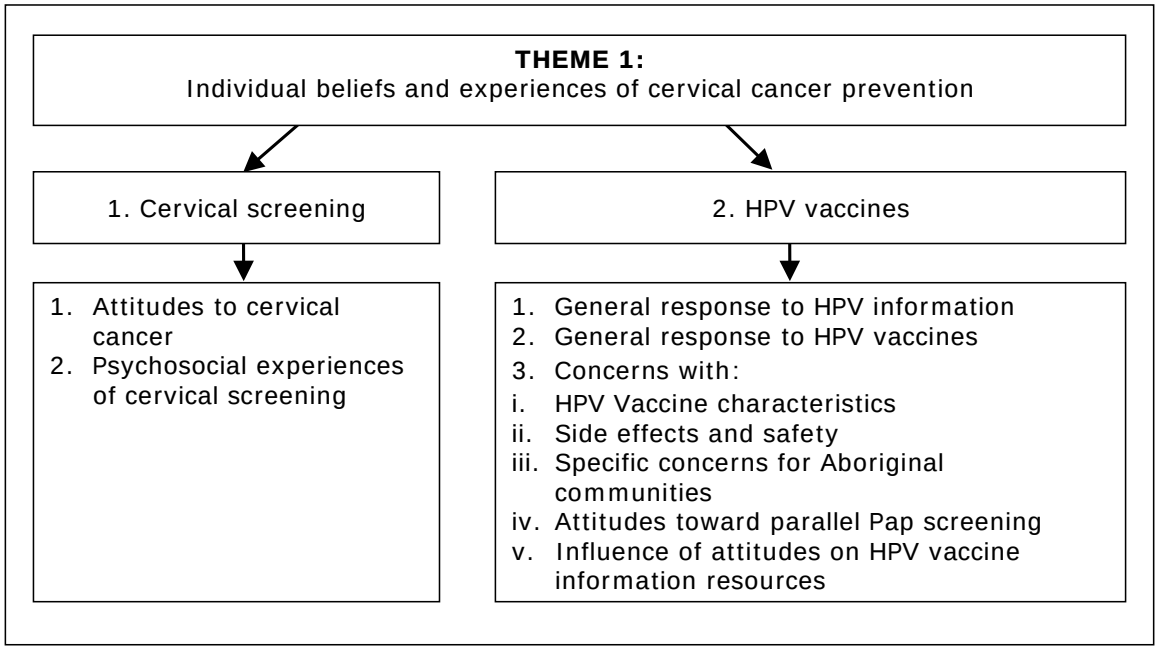
Parents saw high benefit for their daughters (as ICC prevention) and moderate benefit for their son's health. Acceptance for young adolescent vaccination was bounded by immunity factors rather than sexuality factors, and the ideal age for vaccination of girls varied between ages 16 to 18 plus. These opinions corresponded to individual expectations of late onset of sexual debut, and the potential for promiscuity after adolescent vaccination was a broadly held concern.

Chapter 11: Results from Aboriginal parents

11 Introduction to results: Theme 1- Individual beliefs and experiences of ICC prevention

Theme 1 (Figure 14) describes participants' own beliefs of cervical cancer (ICC) prevention through their experiences and attitudes toward ICC screening and HPV vaccines.

Figure 14: Theme: Individual beliefs and experiences of cervical cancer prevention among Aboriginal women



11.1 Cervical screening: Attitudes toward ICC

The burden of ICC was understood as present and significant within both Aboriginal communities. Furthermore, participants appreciated that whilst deaths from ICC within a community created awareness within the general community, most women remained unaware that the death could have been prevented through regular cervical screening. In Central Australia there was an acceptance that cancer in general did not discriminate between populations and age groups; that everyone was potentially at risk; *"Cancer is real*" (1CA[3]). However the high incidence rate of ICC in the

[3] The Aboriginal parent results will be cited by specific identifiers.
(e.g. 1CA) Community group number + Central Australia location
(e.g. 2V) Community group number + Victoria location
(e.g. 4VP2) Community group number + Victoria location + parent number

region was not well understood by the general community and the arrival of the vaccine was seen as an opportunity to educate the community.

> "[We] *need to promote the fact* [to the communities] *that Aboriginal women have higher rates of cervical cancer"* (1CA).

In the same community another participant was concerned for those with a prior diagnosis, and who might be offended by public discussions about ICC.

11.1.1 Women's psychosocial experiences of cervical screening

Most participants reacted in a positive manner toward the need for cervical screening, but deterrents to engage in Pap screening were expressed. Whilst women knew about the Pap test, one Victorian community felt that there was not sufficient formal information for women explaining why Pap tests were necessary. Women intimated they had a generally ambivalent attitude toward attending for Pap screening, and that attitude, combined with their feelings during Pap screening, influenced their health behaviour.

> *"Embarrassing as Pap tests are, we don't have them as we know we should. It is a necessary part of a female's routine care"* (4VP3).

For some women in Victoria, who understood the importance of cervical screening, they indicated it required psychological discipline to undergo Pap screening procedures. Both regions perceived that women's sense of vulnerability and their relationship with the health provider influenced rates of Pap screening uptake.

There were particular concerns with the Pap test's association with sexual factors which in some women lead to feelings of stigma and shame.

> *"Some women feel 'shame' at 'women's business'* [and] *sex"* (1CA).
>
> *"Sense that if* [you are] *having a Pap smear it means you have a sexually transmitted infection"* (1V).

Furthermore the presence of a male health provider also provoked feelings of '*shame*' and '*embarrassment*' because a male is participating in '*women's business'*.

> *"We feel shame when we go for Pap screens – like we have done something wrong. We need a female doctor to do it"* (2V).

Women who did engage in cervical screening spoke of several factors that acted as a deterrent to recommending Pap screening to others. The term '*frightened*' was expressed within several communities due to the invasive nature of the test and fear-induced tension during the procedure. Whilst the elder women and AHWs in Central Australia had a good understanding of the need for Pap tests, they also understood that the education about Pap smears requires sensitivity, largely in part because of the private nature of the reproductive system. The participants explained that they educated adolescent girls about Pap smears in a sensitive manner, to ensure their ongoing screening behaviour.

> *"We tell story* [sic] *about women's health and Pap smears. But we don't want to frightened (sic) them about Pap smear test talking put in speculum inside the vaginal (sic) to the young girl at (age) 9 to 12"* (4CA).

Moreover there was concern that the impact of a negative Pap screening experience in older women or mothers, or women who did not undertake screening, might act as a deterrent for ongoing Pap screening and education in the next generation of vaccinated women.

11.2 HPV vaccines: General responses toward HPV information

Responses to HPV information varied. Victorian women who were not trained health workers generated most discussion about the HPV information, because they knew less than the participants who were AHWs with some knowledge. In general, the women initially had little knowledge or awareness of HPV factors before the group discussions, although after the HPV education intervention, most felt that they had a better understanding of ICC factors. Some participants in Central Australia

and Victoria queried the risk of HPV infection to the newborn during labour.

> "*If you have HPV – when the baby comes out, will the baby get HPV"* (4VP1)?

Several Victorian communities displayed frustration and anger, targeted primarily at GPs, for not disseminating information about HPV during clinical consultations. Some were also angry at their partners for potentially infecting them with HPV.

> *"All information was new to the women. Others who have abnormal cells and treatment had no idea what HPV was, that it is transmitted by sexual activity… Total shock – why hasn't this information been available?* [Some women were] *angry at previous partners* [and] *medicos: Partners for passing HPV on – medicos for not informing us about HPV"* (6V).

The distinction between HPV and HIV was specifically mentioned among Central Australia participants who were also AHWs involved in STI screening programs.

> *"HPV is not HIV"* (3CA).

Although they felt that HIV was mostly well understood through STI screening in the community, not all people sufficiently understood the difference between HPV and HIV, and this now presented the potential for confusion as to what the HPV vaccine actually prevents.

11.2.1 General responses to the HPV vaccines

Discussions focused mainly on the 4vHPV vaccine as it was the only vaccine licensed at the time, and to be used in the Government immunisation program. Initially participants expressed astonishment at the development of a vaccine that could prevent cancer.

> *"Mind boggling" that an immunisation could prevent cervical cancer. …… they were excited there was a vaccine to prevent cervical cancer"* (1V).

Whilst participants in Central Australia and Victoria were pleased for better health outcomes for the next generation, knowledge about HPV and the vaccine provoked some contrasting attitudes toward HPV vaccination. All communities were pleased in principle that there was a vaccine for ICC prevention. Moreover, despite the fact that these communities had received very little information about the HPV vaccine, they accepted that once the Government immunisation program began, it was an opportunity to protect females. Paradoxically, some women who were ambivalent toward cervical screening agreed that vaccination for ICC prevention would be better for their daughters and they fully supported HPV immunisation.

> *"It's great and if it's gunna* [sic] *stop young girls from getting cancer of the cervix, why not?"* (4VP5)

11.2.2 Concerns with HPV vaccine characteristics

Parents who were also AHWs indicated that their communities wanted explicit details about the HPV vaccines to allay their concerns about the vaccine, given its unique features. Concerns emerged about the lack of information about efficacy, long term safety and side effects, and the target age group. Their lack of trust in safety of the manufacturing processes of vaccines, especially the vaccine technology and its components, as well as potential allergic reactions to it for Aboriginal people, vaccine trials and efficacy, and the impact of the vaccine on pregnancy were other factors that were raised, particularly in one Victorian community.

The vaccine being 'new' and that Australia was the pioneer of a national HPV immunisation program was also significant for Victorian women who also raised concerns about being 'guinea pigs' for the vaccine as so many factors of the vaccine were unknown.

> *"We're guinea pigs! The vaccine has not been around long enough because the "experts" do not know the long term effects. …it hasn't yet proven to be effective"* (2V).

These concerns were not expressed by participants in Central Australia.

11.2.3 Attitudes toward side effects and safety of HPV vaccines

Because of the yet unknown risk of both short and long term side effects for newly introduced vaccines, participants expressed fear and needed reassurance, especially on fertility.

> *"Sterile – what would happen in the long time effect* [sic]*"* (4VP3)?

In one northern-Victorian community, that had experienced presumed adverse events after TB vaccination, their fear about long term side-effects far exceeded the concerns of other communities.

> *"We're worried about the long term side effects – they don't know at this stage –early days –something could happen – what will happen in the future? It could make us die or shorten life?"(*Stated by two "Aunties" who have a large influence in the community*)* (1V).

In contrast among other Victorian communities, participants accepted that the chance of experiencing a vaccine-induced adverse event was lower than the chance of getting ICC. Furthermore, despite adverse media coverage at the time of data collection, many Victorian participants were pragmatic about short term side effects such as fainting, short term redness and muscle soreness; and the need for three doses

> *"Parents had heard the media reports about girls fainting from the vaccine but* [the women] *accepted that some people react like that to vaccines (AHW facilitator)* (3V).

11.2.4 Specific concerns for Aboriginal communities

The specific impact of HPV vaccination on Aboriginal women was important for two communities in Victoria.

> *"What (drugs) is actually in the vaccine that might trigger a reaction…? Some people will lose their hair. We want information on the side effects; if Indigenous women got reactions to it"* (2V).

Participants were keen to be informed of the technical detail of the HPV vaccines. Much opinion was based on prior vaccine experiences of more than thirty years when 'live' viruses were a component of the vaccine, and some women queried the risk of vaccinating children with a 'live' virus. Additionally in Victoria there was a perception of difference in the immune systems of Aboriginal people.

> *"Has the* [vaccine trial] *tests been done with Indigenous women? Our immune systems are set for things in the land…if this has not been tested on us, and the vaccine has things that are not from the land, it could make us very sick. Our immune systems are different because Aboriginals are under a lot of stress"* (2V).

11.2.5 Attitudes toward parallel Pap screening with HPV vaccination

Initially participants thought the HPV vaccines due to the authorised information emphasising them as 'cervical cancer prevention' vaccines. When they learnt that the vaccine prevented HPV types which account for 70% of ICC ("*Different to other vaccines"* (3CA) participants were annoyed that Pap screening was still required and some questions arose.

> *"If the coverage helps 70% unless you are given a guarantee how would you know if you were the unlucky one"* (6V)?

Some women questioned the relevance of the vaccine when ongoing Pap smears are required, and parents who were also AHWs raised this as an issue for health providers to consider in patient management.

> *"Why have the vaccination* [sic] *if you need to still have Pap smears"* (6V)?

Participants in both regions established that because the vaccine was newly introduced and they considered it "*not proven"* (2V) globally, the Pap screen message was important for all age groups, not just the vaccinated group for ongoing protection against ICC. There was also unanimous support for this message to be given at the time of vaccination.

11.2.6 Influence of attitudes on HPV vaccine information resources

All communities universally agreed that vaccine promotion to parents was needed to reassure them that the HPV vaccines are safe. Furthermore the need for ongoing communication of important vaccine messages continuing "*between needles*"; especially that it is not just a single-dose vaccine, and the importance of completing three doses. Getting women to understand the need for regular Pap screening was seen as important as getting young girls vaccinated and an important message in all HPV vaccine literature.

Ways of effectively educating remote communities in Central Australia drew on women's experiences with other health interventions, and suggestions included HPV education in a group setting at the time of vaccination with culturally appropriate visual based resources, such as diagrams and flipcharts as was commonly used for other women's health education.

> *"One page of the flipchart with pictures of cells* [would be] *useful; not too much text, keep it simple...Pap smear message needs to be always there"* (1CA).

In Victoria ongoing peer messaging and support was also considered an effective education strategy with the potential to discourage complacent attitudes toward Pap screening among the vaccinated group. One Victorian community questioned the current role of preventative Pap screening in detecting cancer.

> *"What if we have no needle, and still have Pap smear…that will show the cancer up"* (2V).

However, this was not a major concern for other Victorian groups.

Because of the sensitive issues situated within HPV information, participants indicated that there was a need for public media to act responsibly in their reporting of the vaccine. The local radio and television stations in one region had broadcast that the HPV vaccine was

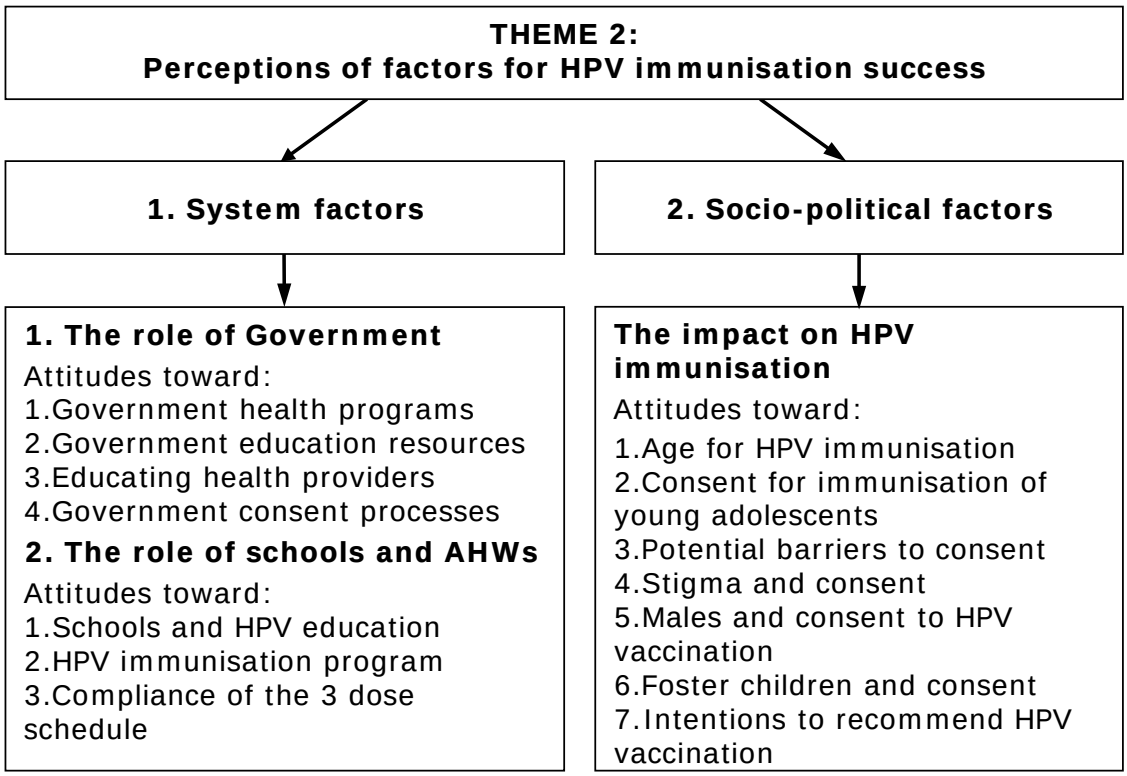
'compulsory' for school age girls and one parent signed a consent form on this basis.

> *"The vaccine is compulsory. I saw the vaccine on TV and thought it was compulsory. Didn't know I had a choice. My daughter had it but the vaccine was not explained. I am pleased* [that] *it* [the vaccine] *helps with stopping cancer" (*2V).

11.3 Theme 2: Aboriginal parent perceptions of factors for HPV immunisation success

This theme (Figure 15) captures participants' own beliefs of the role and expectations of both system and socio-political factors for a HPV immunisation program. Key stakeholder groups such as Government, schools, public health providers and media that are involved in immunisation programs were considered, and in particular how they will contribute to parent and guardian consent for HPV immunisation.

Figure 15: Theme 2: Perceptions of factors for HPV immunisation success



11.3.1 System factors: the role of Government: Attitudes toward Government health programs

During the discussions in both regions, negative views toward Government and management of Aboriginal health overall were expressed. Despite support for previous Australian Government immunisation programs, one Victorian community believed that the Government had a poor understanding of the needs of Aboriginal people, especially in the provision of culturally relevant health services.

> "[The Government] *need*[s] *to have an understanding of Aboriginal people.* [They] *need to have good partnerships between people to stop women falling through the cracks because many Indigenous women move about from* [sic] *and between communities"* (1V).

This view was supported by another Victorian community who considered that the Government was under-prepared when starting its national program, and queried the haste in which decisions were made about its introduction and the determination of the target group for vaccination.

> *"The Government went in too quick to give it to the girls. Very surprised that it will be provided for girls and women up to 26…It all came very fast. What was the rush"* (2V)?

There was an unequivocal view that without the Government subsidy of HPV immunisation, the HPV vaccine would not be affordable. Participants were supportive of the subsidised cost for the 4vHPV vaccine *"fantastic, removes a barrier to receiving the vaccine"* (1V). It was important that parents knew of the real cost of vaccination ($450 per course) and that the Government was fully subsidising the vaccine. Furthermore, the fact it was a 'free' vaccine would be an inducement for HPV vaccine uptake.

> *"It would be more encouraging, and I think more girls will get vaccinated*" (4VP4).

11.3.2 Attitude toward Government HPV education resources

Contrasting views emerged on the role that the Government-mandated HPV information resources (Appendix 17) would have in the education of

the general community about HPV immunisation. In Central Australia, one community where some women were also AHWs felt that there had been insufficient HPV vaccine information through mainstream media prior to the vaccine's introduction, and the difficulties this would place on the AHW's ability to adequately educate communities prior to the HPV immunisation program.

> *"We have not seen any of above"* [referring to the Government information brochures]. *Not enough information about HPV virus has been done on newspaper, radio and leaflet. …no information of this has been sent to remote communities. We are not informed as Aboriginal Health Workers about the new vaccine and screening"* (4CA).

There was no universal endorsement of the HPV resources produced by the Australian Government agencies (Appendix 17). There were mixed views toward the images of Aboriginal women on the Government advertisement (Appendix 22) that were generally seen as not being relevant to their communities. Attitudes surfaced about the importance for them that this was a universal health issue, and Aboriginal people were not perceived to be the only group being offered the vaccine, that it was for all young women in Australia within the licensed age-range.

> *"Let them know its for all young women, Aboriginal and non-Aboriginal…let younger kids know they will get it later on"* (3CA).

The importance of applying culturally relevant images to demonstrate HPV and ICC prevention for Aboriginal women was discussed. The women suggested that a better way of informing their communities about HPV issues would have been with a combination of Aboriginal and non-Aboriginal women in the visual images on the advertisements.

> *"*[An] *advertisement with a young Aboriginal girl and non-Aboriginal girl walking to school and talking about it* [sic]*"* (1CA).

Parental ability to understand the content in the HPV information resources varied across individuals and communities. In Victoria, where

English language is commonly spoken, participants in one community found the information straight forward. However there were diverse views within that community about the level of detail in Government produced HPV vaccine resources. One participant indicated her need for very detailed information about all aspects of the vaccine.

Concern about the viability for text based resources for those with low English literacy were expressed by Central Australian participants. Furthermore, the women felt that detailed and scientific HPV information was not needed within the public resources, and that alternative resources could be developed for those that required this level of detail.

> *"*[It] *needs to be in* [an Aboriginal] *language. Keep information simple,* [and] *be aware of sensitive information…just basics such as age groups. Posters with* [a] *free call number, and* [the] *name of contact people in* [the] *community* – [a] *choice of people to speak to"* (3CA).

Another group suggested multi-media resources in language to support young women's understanding.

> "*We need Aboriginal language groups to talk on video, because some of our young Aboriginal girls still don't understand English*" (4CA).

Parents who were also AHWs felt it was important for optimal vaccine uptake that HPV vaccine messages need to be specific about what the vaccine protects against, and what it does not. Pervading nearly all opinion was support for messages that promoted the vaccine as a 'cancer' preventative regardless of the age group. Nevertheless, and similar to the discussions on the preferred age for vaccination, there were variations in the recommended vaccine messages.

Contrary to some opinions, that considered young children were not ready for complex health information about cancer and STIs, some participants supported the need for resources targeted to young people, age 9 years, and offered through a supported education program at school, and in remote communities. Pamphlets, posters and videos were offered as appropriate resources. Early education of young girls about reproductive

health was suggested with very specific education about all aspects of cervical disease and the HPV vaccine, especially in remote communities, to encourage acceptance of the vaccine.

11.3.3 Educating health providers

Parents in both regions who were AHWs said their role is perceived as an underutilized, but useful resource in the delivery of HPV immunisation, especially in remote regions. With HPV immunisation, they viewed their roles as being a support to the nurse immuniser during the HPV vaccination program; to deliver HPV education to communities; and to encourage eligible females to be vaccinated.

Participants in both regions expressed the importance of firstly educating AHWs about the HPV vaccine, Pap smears and STIs prior to the introduction of HPV mass immunisation into community. This would enable the subsequent education of all adult women in the community (*"mothers, aunties, daughters"*) who would then later adopt an ongoing role as community educators of younger women. One Victorian community suggested that to enable optimum uptake of the HPV vaccine and to increase Pap screen rates, then Government funding would be needed beyond the provision of generic HPV information resources and a school based immunisation program.

> *"*[We need] *funding for workshops for mothers, aunties, and daughters* [for them] *to assist with community education about Pap smears, HPV, STIs etc"* (1V)*.*

The preferred mode of delivery of HPV education was raised. In Central Australia a range of sites were suggested for community education, , including local amenities where there was 'through traffic, especially those that were the domain of women only, such as schools, clinics, women's centre, posters on the back of female toilet doors', and to support the needs of those females who do not attend health clinics regularly. Concerns were raised about maintaining community education in remote areas due to the transient movements of AHWs. It was considered

essential that AHWs recorded the ways they educated the general community.

> *"*[It is] *important to use it* [ways of disseminating HPV information] *as a resource – share that information with other AHWs as a teaching tool. i.e. "we did this program in our community – you might get ideas from them"* (3CA).

11.3.4 Government consent processes

The Government consent processes created concerns among some Victorian communities, and their dissatisfaction with the complexity of the consent form was aired. They found previous consent forms from prior school-based immunisation confusing and challenging to complete. Furthermore, some parents in one Victorian community who had recently completed HPV consent forms for their daughter felt the information was incomplete, because of the lack of detail on the form about the 4vHPV vaccine's long term safety.

> *"Information about HPV* [is] *hard to understand on the forms.* [We] *should have had the information twelve months ago. about the long term side effects"* (2V).

Parents felt the lack of knowledge would not assist them to give informed consent. Furthermore because it was being made available through a school program at a specific time, parents felt they were not given the option for their daughters to be vaccinated at the local Aboriginal Medical Service with Aboriginal nurse immunisers. In contrast, and despite their difficulties in understanding the technical information, other Victorian participants in the same community found the consent form had sufficient information.

11.4 System factors: The role of schools: Attitudes toward schools and HPV education

Schools were perceived as having a dual role as health educators and as a convenient location for HPV immunisation. Some parents indicated their reliance on the school to introduce sexual health-related information to their children, therefore making it easier for them to have subsequent STI

discussions. It was felt that because schools would have more comprehensive resources about HPV issues that young adolescents would receive more inclusive information than through family education. However, it was important for them as Aboriginal parents that school resources included not only culturally relevant materials but teachers who were qualified to teach HPV information.

11.4.1 Attitudes towards school for a HPV immunisation program

The implementation of HPV immunisation through schools generated different opinions. Not all participants in Victoria were accepting of school as the best locale for HPV immunisation and some parents expressed their preference to accompany their children to immunisations to provide support and comfort.

Dissatisfaction with mainstream clinics was expressed. One Victorian community expressed their fears with the waiting room environment in the clinic where vaccines were administered.

> "[It is] *scary sitting in the surgery waiting for an injection…quicker* [they give it] *the better"* (1V).

The major concern of another Victorian community with mainstream medical clinics was their perceived loss of privacy with their personal medical records, and loss of confidentiality.

There was a consistent view in both regions, based on previous experiences, that the age group to receive the vaccine through a school based program was primarily going to be determined by the availability of the cohort, and especially in remote Australia where there are few secondary schools. Concerns were expressed for the young people who have irregular school attendance beyond their primary school years, and unanticipated school absences, such as illness at the time of vaccination. Therefore, because more children reside within their community during primary school years, it was agreed that a younger age for vaccination would capture the target population for three vaccine doses.

"*Easier if* [the girls were] *younger e.g. 10 years in some communities – won't be at school after that (very few secondary schools out bush). In primary schools when* [they are] *still in the communities and before* [they become] *sexually active*" (1CA).

11.4.2 Attitudes towards compliance of the 3 dose schedule through schools

Parents in both regions were generally pragmatic about adolescent's dislike of needles but they did not see this as a reason for incomplete vaccination. They conceded that compliance with HPV vaccination would be dependent on a range of approaches, and problems were identified for adolescents in both regions in the delivery of a school-based HPV immunisation program., The complexities of dosage compliance, the need for information about emerging adverse events, and the need for booster shots were raised as key factors. Additionally it was not known if participants understood that school age vaccination at clinics was as part of the time-limited catch-up program.

In Central Australia, the geographical and education dislocation of the remote environment was reinforced as a key factor that impacted on the vaccinated target group's compliance, despite the best intentions of the community. Participants who were involved with remote communities in Central Australia recalled their challenging experiences with adolescent compliance with HBV immunisation programs. For example, in order to get young women to complete the three dose schedule, a 'whole of community' support was required, utilising the community 'grapevine', and influence of elders to make sure the girl stayed within the community and did not move to another region during the immunisation schedule period.

In Victoria, partnerships between health services such as *"Aboriginal Health Worker, School Medical clinic, Aboriginal Medical Service, and Doctors or nurses"* (4VP1; 4VP2) were also considered essential for optimum HPV vaccine delivery especially for those who are mobile and able to travel to these services. Concerns about *"crowd hysteria"* (6V) at the short term effects, such as pain, experienced immediately after

vaccination were raised as another factor that may inhibit adolescents compliance with the dosage schedule. It was agreed this factor may potentially present a challenge in convincing young women about the benefit of the vaccine, and therefore it would be necessary to alert them to the possibility of short term side effects.

> "*Let them know it will hurt but it's really important to have all 3 needles to protect against cancer* – [that its] *really important women's business"* (3CA).

An incentive for dosage completion that was of value to the girls, such as a music CD voucher, was suggested. One participant maintained there should be no choice in having the vaccination, and that it should be compulsory.

11.5 Socio-political factors: Attitudes toward age for HPV immunisation

The attitudes toward age of immunisation were bounded by Government recommendations for school-age immunisation. There were variations in opinions for the preferred age for 4vHPV immunisation, largely determined by the physical and emotional phase of the child. Some participants stated they would explain the vaccine's importance when their daughter was older. Age 9 (youngest of the HPV licensed group and primary school students) was recommended as the optimum age for HPV vaccination in Central Australia and for some Victorian communities.

Not all agreed on a young age for vaccination and many women proposed early adolescence at age 12 to 13 as a better time to support adolescent understanding of why they had been vaccinated and its importance, whilst some parents suggested age 11 to 12 years when puberty commenced.

> *"The girls are getting their periods…and Mothers have the 'birds and bees' talk then" (2V).*

There were concerns about the licensing restrictions on the eligibility of older women for vaccination. In Victoria, where the 4vHPV had become publicly available at full price, one participant shared an anecdote about

one woman's insistence for the vaccine, and when advised against it by a GP, sought vaccination from another who was compliant.

11.5.1 Attitudes toward consent for HPV immunisation of young adolescents

Overall, most participants indicated their strong willingness to consent to their children being vaccinated after understanding the cancer prevention benefits of the vaccine.

> *"It's coming.* [We] *would want them to be immunized against* [ICC]. *It's good – I would encourage it with the young ones"* (1V).

Others intentions were based on prevailing awareness of the emotional burden and mortality from ICC. Two Victorian communities indicated that as it was a new vaccine, their consent would be influenced by their levels of knowledge and understanding about the vaccine.

> "[Because of] *the importance of the vaccination [there] has to be more information … As this is all totally new information to us we want all possible information at our level of understanding– if we don't have the information– we can't make a decision" (6V).*

Notwithstanding these concerns, once participants had been given factual information and knowledge their attitude toward the HPV vaccine often changed. Moreover, most stated that now they had HPV knowledge they would be able to discuss the HPV vaccine with their child and as parents, give informed consent.

> *"The women are more aware*. [They are now] *more able to talk with their daughters and other family members" (1V).*

11.5.2 Attitudes toward potential barriers to consent

Government policy on the ascribed age for vaccination through a school-based program was considered to be an influential factor for giving consent to vaccinate adolescents. However, not all participants were willing to consent, and their fears surfaced, particularly among Victorian participants.

"There's a lot of negative information out there about the vaccine. [We need to be] *getting the information out there to break down fears. What can it do to us down the track" (5V)?*

In Victoria, one participant had an anti-vaccine stance and considered vaccination and the process of immunisation '*dirty*'.

"I still wouldn't get it…sticking something in yourself is dirty. I'm anti-vaccine" (2V).

In particular, the unknown risks and fear was a strong deterrent for consent with another Victorian despite the health benefits of HPV vaccine being understood.

"Not until we get more information about the long term side effects. Why would I put that in my [9 year old] child" (4VP5)?

One community had heard negative HPV vaccination messages arising from reports through the media of school girls fainting, *("Bad media regarding the side effects"* (5V); another Victorian community had heard through the television news that the vaccine was compulsory, and these factors had created fear.

"I saw the vaccine on TV and thought it was compulsory. Didn't know I had a choice. A lot think it is compulsory, [that we] have to get it done and if we don't [we] won't get our [welfare] payments" (2V).

11.5.3 Influence of stigma of HPV on consent

In Victoria, most groups considered community education vital to not only facilitating consent, but to diffuse the stigma associated with the sexual connotations of the vaccine.

"The info [information] *makes me terrified, considering the dramatic things it* [sexual activity] *can have on a woman" (6V)*

In contrast, for one Victorian community and the Central Australian communities, the sexual association with the vaccine was not a significant factor in the attitudes of participants, and participants were pleased to be

able to consent to vaccination as a protection against HPV infection. Conversely, one participant in a Central Australian community believed it would be confronting for some parents of young sexually naïve girls in having to make a vaccine decision.

11.5.4 Males and consent to HPV vaccination

Specific barriers to consent for men emerged. The need to sufficiently inform men (including male '*Grandparents*' (1V) factors, and especially those who were sole parents and carers and required to give consent) about HPV was raised in both regions. Two Victorian participants highlighted their difficulties in giving consent if they discussed sensitive sexual information about the 4vHPV vaccine with their husband.

> *"Both* [of our husbands] *would go 'berserk'" (4VP).*

Women raised the possibility of men not consenting due to men's lack of information and overriding concerns about the HPV vaccine's long term side effects, even if the mothers endorsed it as *'women's business'.* There was also resistance by some women to consenting to immunising boys because of the lack of information about side effects in males.

11.5.5 Foster children and consent

The issue of consenting to vaccinate children in foster care was raised. One Victorian parent raised concerns about whose responsibility it was for signing the consent form if they were an unofficial 'guardian', and if the child was not registered as a "*ward of the state*" (1V).

11.5.6 Intentions to recommend HPV immunisation

Some participants in Victoria, who held a high opinion of the benefit of HPV immunisation for ICC prevention and who wanted to promote health and well being for their children, indicated they were going to recommend the HPV vaccine to others .

Participants in Central Australia indicated that all women in the communities would encourage young women to be immunised.

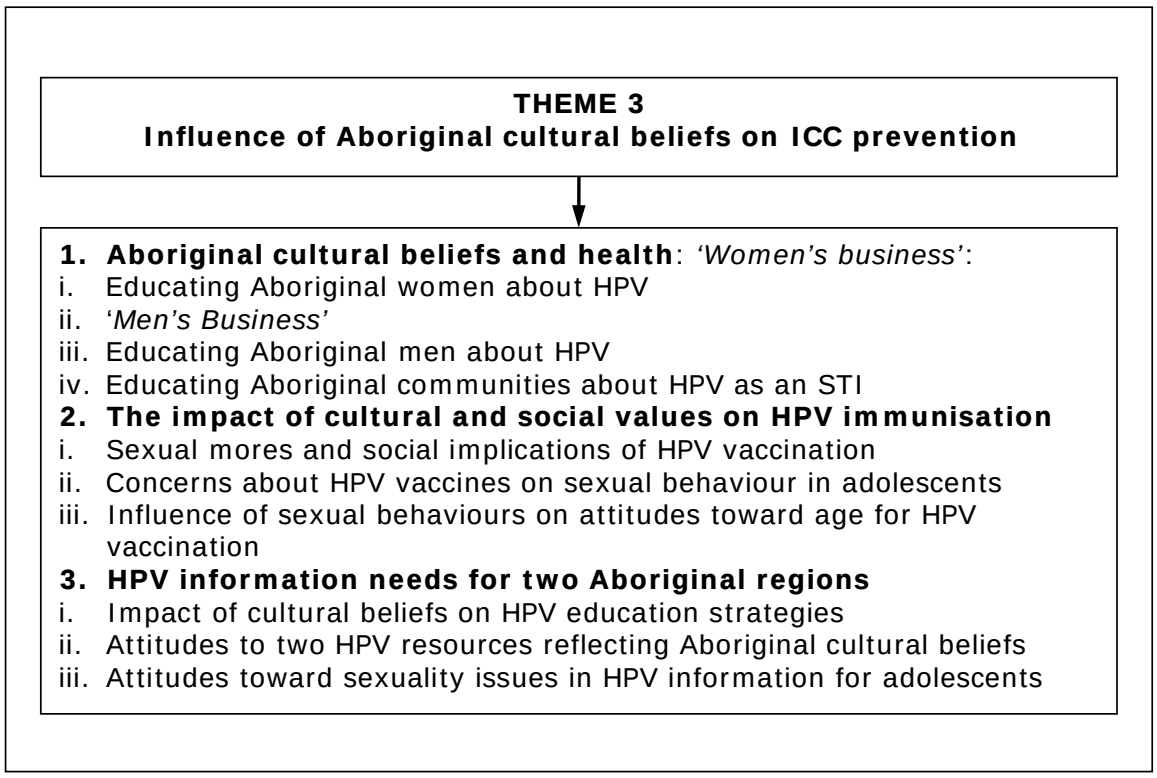
11.6 Theme 3: The influence of Aboriginal cultural beliefs on ICC prevention

This theme (Figure 16) captures the cultural beliefs of Aboriginal parents that influence their attitudes toward ICC prevention. In particular, issues around gender and generational roles in the management of community health (*women's and men's business*); sexual mores and social implications of HPV vaccination; and the influence of cultural beliefs on HPV education strategies.

11.6.1 Aboriginal cultural beliefs and health: 'Women's business'

The reference by the Central Australia Advisory Group (CAAAG) to HPV vaccine and related issues as "*really important women's business"* (1CA) highlighted the gender distinctions that the community imposes on health matters, and that it was inappropriate to discuss detailed female health issues in the presence of men.

Figure 16: Theme 3: Influence of Aboriginal cultural beliefs and practices on ICC prevention



11.6.1.1 Educating Aboriginal women about HPV vaccines

As well as educating girls, participants from both regions indicated the need for the whole community to receive full information on all aspects of the HPV vaccine. There was some frustration that older women did not know about HPV, when they have a primary role in community of shared responsibility in educating young girls.

> *"Didn't even know about it and now young girls need to know more about it, and maybe put it on TV ads and pamphlets for the younger generation"* (4VP2).

There was persistent comment about the involvement of the female wise elders in community HPV education.

> *"Educate senior women as well …to involve* [them] *in educating our young girls in our communities…It could be good to invite older women from remote communities to get together to have big meetings with 9 year old girls to 26 year old girls, and staff from the health centre and school teachers"* (4CA).

Importantly, the women advised that where health information deals with '*important women's business*' and in particular that which relates to reproductive and sexual issues, there is a preference for materials that are contained within women-only environments such as the women's centre, and which are discreet. Participants who were also AHWs in Central Australia felt that utilising all female resources through a networking approach were effective ways to educate communities with key information.

> *"Have a women's health day /week and information day – put on BBQ. Take young girls out bush and talk to them while hunting. Use all female resources in community to help. Work within family groups – need key people in each group. Most people will find out from other people / friends"* (3CA).

11.6.2 *'Men's Business'* and educating males about HPV

Participants noted that the current Government-produced resources are biased toward female vaccination with female-centric messages, and these do not sufficiently consider the sensitivities of educating Aboriginal males about HPV.

> *"Is there a man version of you that could come and speak with the men about this? How they [men] get it... Men need to have different brochures explaining HPV"* (2V).

There was also a very strong view that HPV promotion needs to be more gender balanced. It was important to these women that HPV was not just seen as a '*women's disease*', and that men needed to know it was a shared infection.

> *"The way they are doing the advertisements – put out there as a women's issue/ women's' disease"* (2V).

In addition to their lack of HPV awareness the women had little understanding that genital warts can result from sexual activity and were common to men and women.

> *"Stunned …Surprised and interested to know it can also prevent genital warts. (The women went real quiet on that part of the discussion when they realized what they can catch from sex)"* (1V).

It was felt that understanding HPV was necessary and that men should not be discriminated against. Whilst the issue of vaccinating males was not a key point for discussion in Central Australia, some Victorian participants were unhappy that males were not being vaccinated. One Victoria participant displayed incomplete understanding about the HPV vaccine's efficacy when she raised the issue of ongoing HPV immunisation for older females.

Whilst many participants considered that it was important that all members of the community had access to the full facts, the level of detail within the information could not be generalised as needed by all people; that

individuals determine the level of detail they want. However, this need for education was not shared across both regions. The importance of educating men about HPV as a STI was central to discussions. Participants in Central Australia reinforced that any education message about HPV should also discuss how men acquire HPV in addition to women. In Central Australia the women noted that men with traditional Aboriginal cultural values would not want to be educated, combined with the maintenance of respect those men are afforded.

> *"Traditional men would not entertain the idea of talking about it* [HPV]*"* (1CA).

Out of respect for Aboriginal cultural norms, Central Australian participants advised that because the women culturally were unable to speak on behalf of men, certain protocols needed to be respected. For example, before any male education strategy could be undertaken, female AHWs would first need to confer with health professionals who are central to, and advise on, the best ways to educate men, particularly single fathers. Furthermore, the level of education had to be on a construct of 'self-determination'. The information could not be generalised across the entire Australian Aboriginal male community, and it was important that individual males determine the level of detail they require.

> *"Some men might want more information – depends on the individual"* (1CA).

11.6.3 Educating Aboriginal communities about HPV and as an STI

The range of attitudes toward informing communities that the HPV vaccine prevented a sexually transmitted infection was determined by the context of whether HPV vaccines were targeted toward parents or girls.

> *"It's* [all] *about getting the right message out"* (5V).

Whilst women's wellbeing is seen as a '*whole of community*' responsibility, not just within the female cohort, in communities in both regions there were concerns about men's ignorance of female health prevention.

"Men need to know about this HPV virus, Aboriginal men and boys don't know what HPV virus is, they need education because the women have Pap smear and the men /boys don't know what's going on" (4CA).

"*Men need to be also educated so they can encourage their wives and daughters to have the immunisation and Pap test"* (1V).

After comprehending that HPV is sexually transmitted, the majority of women in Central Australia felt that because discussion of sexual issues generated negative perceptions among people, care had to be taken with open discussion of HPV and sexuality in the community.

11.7 The impact of cultural and social values on HPV immunisation: Sexual mores and social implications

Despite sexual issues being covert topics among Aboriginal people several themes emerged around the impact within communities once the knowledge of HPV as a STI was realised. In particular its consequence on women and potential marginalisation of relationships, impact on incidence of STIs, and adolescent sexual relationships were raised. Victorian communities conceded that HPV information had the potential for both positive and negative social implications when men realized that HPV is not only relevant for both males and females, but significantly that it is a sexually transmitted infection.

"Men should be aware of it – might make them think of it when sleeping around" (2V).

Some participants spoke of the potential negative effect that educating men could have on personal relationships: in particular, a disruption to domestic harmony. In both regions it was considered that if their partners had access to detailed information, this could have a negative impact on their sexual relationships i.e. once the impact of HPV being sexually transmitted was understood.

"*Might be off-putting… relating it to sex*" (1CA).

There was a tacit recognition that sexual abuse occurred in both regions and some Victorian women felt that if the whole community understood HPV and its sexual association with ICC, the knowledge could act as a deterrent to sexual abuse.

> *"It* [HPV information] *will have an impact on men who are perpetrators, On what interfering with young girls might lead to"* (2V).

11.7.1 Concerns about HPV immunisation and adolescent sexual behaviour

Concerns with promiscuity among adolescents after HPV immunisation were expressed. There was a belief in several communities that any sexual association with the vaccine would encourage sexual activity in young girls after vaccination.

> *"One parent said that it will make her daughter promiscuous. This will be a big* [and] *common female concern"* (5V).

Conversely other participants expressed that parents might think vaccination was only for sexually active young women.

> *"Some people might think 'my child's not having sex' therefore they don't need the immunisation"* (1V).

In contrast, some communities, whilst protective of their children, were pragmatic about the sexual activities in adolescents, and believed that HPV vaccination would not increase current levels of promiscuity, and ongoing safe sex education was needed.

11.7.2 Influence of sexual behaviours on attitude toward age for HPV vaccination

In determining the age for HPV vaccination participants considered adolescent behaviour and sexual practices in each community to be important factors. AHWs in both regions viewed the current generation of adolescents as being more liberal in their sexual behaviours than their elders were at that age.

> "*Need to target more younger* [sic] *girls before they get sexual active* [sic]. *A lot of peer pressure these days on the sex subject.* [The vaccine] *should be recommended at the age of 12, target 'em* [sic] *young"* (4VP).

Participants accepted that adolescent sexual behaviours were beyond their control and this would impact on vaccine efficacy if HPV infection had occurred.

The issue of sexual naivety and vaccine efficacy raised mixed views between the regions. In Victoria, the need for vaccination of young sexually naïve girls was queried and the impact that may have on consent to vaccination. The information about the need for vaccination in young girls because of their stronger immune responses was considered more important, than informing parents of the need for the vaccine to be given before sexual debut. In contrast, the importance of vaccination before sexual debut was considered the most critical element.

In Central Australia the views around vaccine efficacy and sexual naivety were mixed. Although the benefits of vaccination prior to sexual transmission were understood, there were notions of parental denial about the age of voluntary sexual debut in one community in Central Australia. Some participants were concerned about the risk of vaccinating girls at age 12 or beyond and proposed vaccination at earliest age possible because of the age of sexual debut. Another Central Australian community suggested that in time infant girls could be vaccinated because of the concern that the vaccine efficacy would be greatly reduced for 9 year old girls who had already been exposed to genital HPV infection.

The CAAAG had divulged that sexual debut does occur in early adolescence, or even younger, so parents who were AHWs accepted that the HPV vaccine needed to be given before the commencement of secondary school. This was important for participants who noted that older adolescents had proven to be resistant to being immunised, and their

lifestyle factors, especially the early onset of pregnancy, would limit the vaccine's benefits for some of them.

> *"At year 10 at school, about age 15, they are a bit more resistant – primary school easier before they get pregnant and more independent. 3 shots will be really hard to give. Some will get pregnant before finished"* (1CA).

The implication of vaccination with pregnancy was understood by the parent AHWs, but there was confusion about whether to delay the vaccination schedule during or after pregnancy. However, *"peer group pressure"* (6V) on young girls to engage in sexual activity was also claimed as important in determining the age for HPV vaccination.

11.8 HPV Information needs for two Aboriginal regions: Impact of cultural beliefs on HPV education strategies

Attitudes toward the public messaging of HPV vaccination were varied, and not only based on the sensitive and controversial characteristics of the HPV vaccines, but embedded within their Aboriginal cultural beliefs of communication and health practices. Discussion on the potential information needs of differing adolescent age groups and of their parents indicated the diverse range of information that would need to be shared. These included HPV, risk factors and ICC facts, and features of the HPV vaccine. Several issues were raised, including their need for information that reassured them and encourages vaccination; to appropriately inform the diverse needs of multiple age groups; and to be responsible in its content.

The overriding response to HPV education needs focused on information resources that reflected the specific cultural characteristics of the region. Participants advised that Aboriginal communities across Australia depict information symbolically, often in different styles, through visual media, and it was suggested that a symbol could be developed for HPV information and HPV education resources that Aboriginal people could easily relate to.

Victorian participants offered specific ideas for how the information should be presented, such as verbally and print-based materials in simple language. They also reinforced that whilst types of education resources cannot be generalised for specific cultural groups they must be culturally sensitive and community approved by being, for example, "*Koori specific*" (5V).

> *"Koori friendly fact sheet, but of Aboriginal art work info made simpler for Koori community's"* (4VP2).

Suggestions for culturally relevant and visual resources that align with their social activities of Victorian Aboriginal people were mentioned, such as decks of playing cards with HPV messages, similar to those developed for an STI education intervention. Electronic and print materials were also proposed.

> *"Our mob* [sic] *are 'oral' people. Indigenous people like face to face sessions and resources to take home. Need to have a DVD about it so we can sit down with the kids and talk about it.* [The] *brochures* [will] *need to have a lot of drawings* [sic]" *(*2V*).*

In Central Australia, where there are variations in English language capability and the majority of the population speak one of five main Aboriginal languages, there were diverse views. Women advised that information resources need to be both customised to community needs and presented in languages that are distinctive for each community. For example, one community indicated they have different descriptors of anatomy to mainstream terms. For instance, '*cervix*' is described differently: *"Explain the cervix as 'the baby bag'. Not everyone knows what a cervix is"* (1CA); and vaccines are described as *'the needle'.*

They also suggested that communities could be sensitively educated about the HPV vaccine through several mediums, including dedicated Aboriginal radio programs. This would be providing the education messages were couched in general terms, and no visual images or specific details, especially of intimate female matters.

"Let community as a whole know that it's a new vaccine that protects women against cancer but no pictures or further explanation" (3CA).

This suggestion was refuted by another community.

"Media such as brochures and flipcharts [are] more useful than radio or TV" (1CA).

However in the same community a contrasting opinion was offered that brochures are not universally read, and are often only sought at times of risk or disease.

"How many people read pamphlets? "I only look at them if I have the problem …. Not useful for young people. Media will be more useful especially radio [because of its geographic reach and high listener ratio]*" (1CA).*

One community suggested the Internet and access to a free telephone number as a useful source for information.

11.8.1 Attitudes toward two HPV resources reflecting Aboriginal cultural beliefs

Participants in Central Australia discussed two locally produced HPV vaccine brochures that reflected Aboriginal cultural beliefs. One brochure (Appendix 25) developed by the Northern Territory Government ('Top End') generated diverse views. It was mostly deemed culturally and linguistically inappropriate for their communities because there was "*too much information* [and the] *'Wandjana figures' are scary*" (1CA) (a contrasting style to the images used to depict people in Central Australia). One community considered the amount of text in the brochure as too lengthy and difficult to comprehend, especially information about female anatomy and the cervix, and the way the vaccine dosage schedule was described. However, not all participants shared this view, and some thought the brochure was *"very good"* (2CA) because it had a lot of information. However the need for a brochure that incorporated simplified information written in local Central Australian languages, with local artwork

was reinforced and women proposed the development of a ‘flipchart’ or small booklet as alternatives.

The second brochure (Appendix 26) was created by a Central Australian AHW, and despite a mixed response to it across communities, participants in one community preferred this brochure to the ‘Top End’ brochure. Visually, the graphics depicted Aboriginal people in healthy lifestyle activities rather than reproductive or traditional cultural images. One section that made an analogous reference to HPV as being as common as ‘*the common cold’* and that ‘*HPV is not HIV’* confused people. However, other women thought this was an important distinction to help people understand the HPV vaccine.

11.8.2 Attitudes toward sexuality issues in HPV information for adolescents

In discussions about the preferred HPV and sexuality messages for girls between ages 9 and 15 years, Victorian participants mainly showed a preference for an incremental progression from information about the vaccine’s health benefit at younger ages, to more detailed sexuality discussions as the child matured. However, information for the younger age group presented parents with dilemmas in the level of explicit content to discuss. Importantly, and despite what information was included, content had to be to “*true and accurate”* (1CA) and in a language level compatible with the adolescent’s age.

Parents were concerned about how to discuss HPV vaccine as both a cancer and STI preventative with 9 year old children, who are mostly at the pre-pubertal stage, and despite them not being considered for a school-based HPV immunisation program. In Victoria this was a predominant attitude for two communities who were outspoken on early sexual debut. Some Victorian women indicated that 9 year old children were ignorant about sexual issues and contrasting opinions about the age to begin discussion on sexuality issues with their children emerged.

Other Victorian communities considered that at this young age children are aware of sexual behaviours between males and females, and that some parents had initiated discussions with their 10 year old children. Whilst the difficulties of generalising the needs of specific age groups needs was acknowledged, it was agreed they, as parents, would mostly discuss the vaccine as a cancer preventative, despite most 9 year old children being ignorant about cancer. Furthermore the need for official resources to support these discussions was stated.

The onset of a daughter's puberty at age 11 to 12 years was considered an important milestone for parents to commence discussion of sensitive and intimate issues. Participants in two Victorian communities maintained that broaching HPV information at puberty would support girls understanding of the vaccine and facilitate parental ease in explicit sexual discussions, although girls of age 11 would not be included in the school-based program. However a participant in the same community thought age 12 to14 years was more appropriate to impart sexual information with females because of their physical development and awareness wrought by pubertal changes. Girls aged 13 to 15 years age [first years of Australian secondary schooling] were considered by two Victorian communities to be the preferred age to have a complete discussion on all aspects of the HPV transmission and HPV vaccination because of the girls' maturity.

There were differing attitudes in Central Australia, where in one community a broader message of ICC prevention was proposed with the importance of inclusion of HPV as a sexually transmitted infection. In contrast, others in Central Australia differed and participants were adamant the vaccine should not be promoted as an STI protective to young people. There were sentiments that the sexual messages associated with the vaccine should be minimised because it might "*put up barriers"* (1CA) to the vaccine. As an alternative, it was suggested that the focus in information to parents and girls should be reasons why vaccination needs to occur at a young age and for cancer prevention. To

avoid misunderstanding, participants considered it essential to convey the message that the HPV vaccine does not protect against all STIs and is not to be confused as a form of contraception like Depo-Provera ^{TM}. This was considered especially important given the extensive education that is regularly offered on these two themes. Further issues relating to the potential confusion between Depo-Provera ^{TM} and HPV vaccines were not discussed.

11.9 Summary of Aboriginal parent results

Participants across both regions had a high acceptance toward a vaccine for their daughters to prevent ICC, although there were variations in the strength of their acceptance due to biomedical factors (Table 21). Participation in Pap screening as a primary means of ICC prevention was *ad hoc* and not undertaken by all women, despite many understanding its importance, and their attitudes were bounded by perceptions of shame and stigma. Participants had low levels of knowledge regarding the Pap test and HPV and after receiving HPV information, the women expressed their commitment to reinforcing the message of ongoing Pap smears after HPV vaccination, especially to young women.

Table 21: Summary of key biomedical factors on attitudes toward adolescent HPV vaccination: Aboriginal parents

BIOMEDICAL FACTORS	Aboriginal: CA	Aboriginal: Vic
Pap screen participation	L – M	L - M
Vaccine safety	L	L
Vaccine efficacy	L	L
Medical contraindications	M	H
HPV type specificity -bivalent	H	H
HPV type specificity -quadrivalent	M	H
Natural immunity	M	L

Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable

Victorian women showed high acceptance for both HPV vaccines and Central Australian women's preference was for the 2vHPV if it was shown to have stronger ICC protection, and moderate acceptance overall for the 4vHPV vaccine due to the low prevalence of GW among them. Concerns were widely held toward the lack of safety and efficacy information for the

4vHPV vaccine, and Australia being the first nation to offer it through a public program. Misinformation about the vaccine's efficacy prevailed, especially among Victorian participants, with one community expressing their fears about the impact of the vaccine on Aboriginal people's genetic makeup.

System factors influenced parental attitudes (Table 22). Even though there was low acceptance toward mainstream Australian Government medical services, there was high trust in the Government immunisation programs.

Table 22: Summary of key system factors on attitudes toward adolescent HPV vaccination: Aboriginal parents

SYSTEM FACTORS	Aboriginal: CA	Aboriginal: Vic
Trust of Government and health agencies	L	L
Trust in Govt. immunisation programs	H	H
Access to HPV vaccines: schools	L – M	L – M
Access to HPV vaccines: AMS clinics	H	M - H
Cost (if not subsidised)	L	L
Cues to action	H	L -M
Dosage schedule compliance	L	L -M
Perceived pain of vaccines: adolescents	H	H

Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable

Low to moderate acceptance for HPV vaccination through schools was shown in both regions, with a higher preference through their local AMS by Central Australian parents, and moderate to high preference by Victorian parents. Compliance with the three-dose schedule through secondary school and the cost was deemed a significant challenge, especially for remote communities.

Cultural and normative factors influenced parental acceptance for the vaccines (Table 23). Knowledge levels of HPV vaccines was low or non-existent in both regions, therefore community education about HPV was vital to help parents, including fathers, make informed consent. The high benefits of HPV vaccination to redress ICC risk and STI acquisition, ICC morbidity and to protect their children's health shaped parental attitudes, but variations emerged, particularly among Victorian parents. Participants

were pragmatic about adolescent sexual behaviour in their communities, and HPV as an STI was not a significant factor in parental attitudes toward the vaccine, especially among Central Australian parents, although some individuals in Victoria expressed concerns about the potential for promiscuity after HPV vaccination.

Table 23: Summary of key cultural and normative factors on attitudes toward adolescent HPV vaccination: Aboriginal parents

CULTURAL & NORMATIVE FACTORS	Aboriginal: CA	Aboriginal: Vic
Knowledge levels of HPV vaccines	L	L
Normative values: HPV vaccination	H	M - H
Perceived benefits from HPV vaccination	H	M-H
Perceived susceptibility and risk	H	H
Perceived severity (cancer)	M	M-H
Perceived severity (STI risk)	H	H
HPV vaccines & promiscuity	L	L - M
Protect daughter's health	H	H
Protect son's health	L - M	M
Parental responsibility and level of control	H	H
Parent's personal experience of STIs	U	U
Cultural influences "Women's business"	H	H
Cultural influences "Men's business"	H	H
Religious beliefs	U	U
Age for vaccination*	9	12
Need for culturally differentiated resources	H	H

Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable
*Age for vaccination varied. These are the general majority views.

AHWs suggested that the key message should emphasise ICC prevention as it may be difficult to explain to some parents why sexually naïve children will benefit from a vaccine that is for a sexually transmitted virus.

There were differing opinions as to the ideal age for vaccination of girls, varying between age 9 (at primary school stage) in Central Australia to age 12 to 13 (at secondary school stage) in Victorian communities. The issue of boys being vaccinated with HPV vaccine was not a key consideration, but there was strong agreement that males needed to be educated about all aspects of HPV and HPV vaccines, despite this being '*men's business*' and outside their domain. All participants across both regions wanted more detailed HPV information that was differentiated culturally.

Chapter 12: Results from General Practitioners (GPs)

12 Introduction to results: GPs: personal characteristics

GPs varied by gender, cultural background with the majority being of Anglo descendency; and years in general practice with the majority with more than ten years experience (see Table 24). With respect to GPs professional qualifications, the majority had additional qualifications to their initial medical degree of MBBS.

Table 24: Personal characteristics: GPs, Victoria

GPs	n = 15
Gender	
Male	8
Female	7
Cultural background of doctor	
Anglo	11
Chinese	1
Vietnamese	1
Indian	1
Yugoslavian	1
Educational qualifications	
Basic medicine	3
Basic medicine + other	12
Professional associations	
Yes	12
No	3
Year in General Practice	
0 - 5	1
6 - 10	2
11 - 20	5
21 - 30	4
31+	3
Work hours in General Practice	
Full time	13
Part time	2
Number of GPs at the clinic	
1	3
>3	0
4 - 6	4
7+	8
Fee structure	
Bulk billing	4
‘Pay as you visit’	3
Mix	8

The two most experienced male GPs (31 and 46 years clinical experience respectively) had basic medical qualifications only, were not members of professional medical associations, and practiced in the traditional mode of 'family' practitioner. Two of the female GPs with less than 10 years experience (4 years and 7 years) had a specialist interest in women's and sexual health respectively.

12.1 GPs: characteristics of clinical practice

GPs clinical practices varied and were influenced by socio- geographic characteristics (Table 25). Their practice reflected mainly full-time work status, with a range in the number of other GPs working in their practice. Three GPs worked in a single GP practice, four GPs had between 4 to 6 other GPs in their practice, and the remaining eight GPs had 7 or more GPs working in the practice.

Nine of the clinics offer allied health services in addition to general practice, and one clinic of a male GP was not computerised. Six clinics that are located in inner-city Melbourne have either a high concentration of patients that are university students, recently settled immigrants; or employees in corporate professional roles, and who are primarily highly educated, and of moderate to high socio-economic status. Three clinics that are situated in the Western and Northern region of Melbourne have a high concentration of patients who are from lower socio-economic backgrounds; and with many patients either recently settled immigrants; and with some patients who are from recent 'refugee' status. Six clinics that were situated across the Eastern and Southern regions have patients who are predominantly of Anglo descendency and of middle to upper-middle class socio-economic status.

There was a mixture of remuneration for services, with a mixture of 'bulk-billing' (a payment option under the Medicare system of universal health insurance in Australia, where there is an economic constraint on the doctor's fee (Medicare Australia 2010)) and fee paying practice (where the fee for service is determined by the doctor).

Table 25: Profiles of GPs clinical practice

Geographic region (Metropolitan Melbourne, Australia)	
Inner city	6
Western /Northern region	3
Eastern region	3
Southern region	3
Other health services	
Yes	9
No	6
Patients profile	
Low socio-economic	0
Medium socio-economic	7
High socio-economic	3
Economic mix	5
Patient consultations per week	
Children < 10yrs	0 - 60 per week
Children 10 -15	0 - 20 per week
15 -18	<2 - 30 per week
18 -25	4 -31 per week
Parents / Adults 26+	5 – 80 per week
Patients: dominant cultural profile	
Aboriginal	0
Anglo / USA / Canadian	17
Chinese / Other Asian	6
Middle Eastern	2
African	4
Patients: dominant status	
Refugees	3
University students	4
Professionals	5
Childhood immunisations	
Yes	12
No	2
Very few	1
Giver of informed consent	
Mother	14
Father	0
Both	1
Other	0
Pap smears	
Recall	15
Infrequently	0
Never	0
Patient education: Pap smears	
Routine: at Pap test	4
Specific: at abnormal result	8
On request	3
Never	0

Twelve clinics administer child and adolescent immunisation and generally the mother or female guardian is the main giver of informed consent. Two clinics did not immunise young people (one clinic that specialises in women's and sexual health, and one clinic located in the corporate professional precinct of inner-city Melbourne); and one clinic that specialises in women's health immunises 'very few' children and adolescents. The experiences of GPs with cervical cytology screening and education of patients about cervical and HPV issues varied, and will be described in the next section.

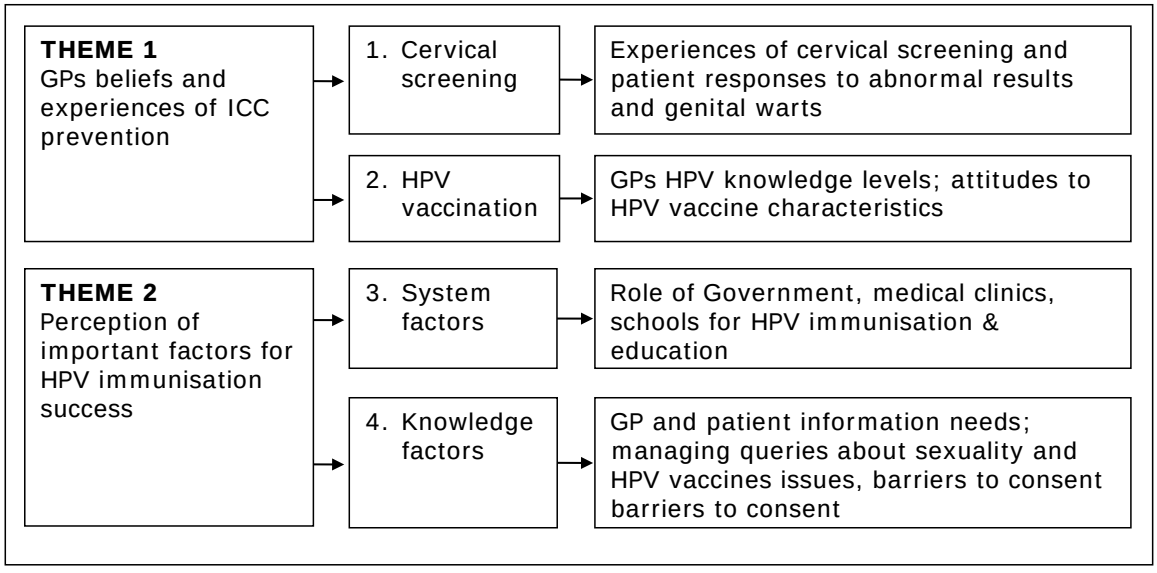
12.1.1 Presentation of results: Thematic categories

Two recurrent themes emerged from the GP data (Figure 17) and relate to

(i) GPs individual beliefs and experiences of ICC prevention;

(ii) GPs perception of factors for immunisation success.

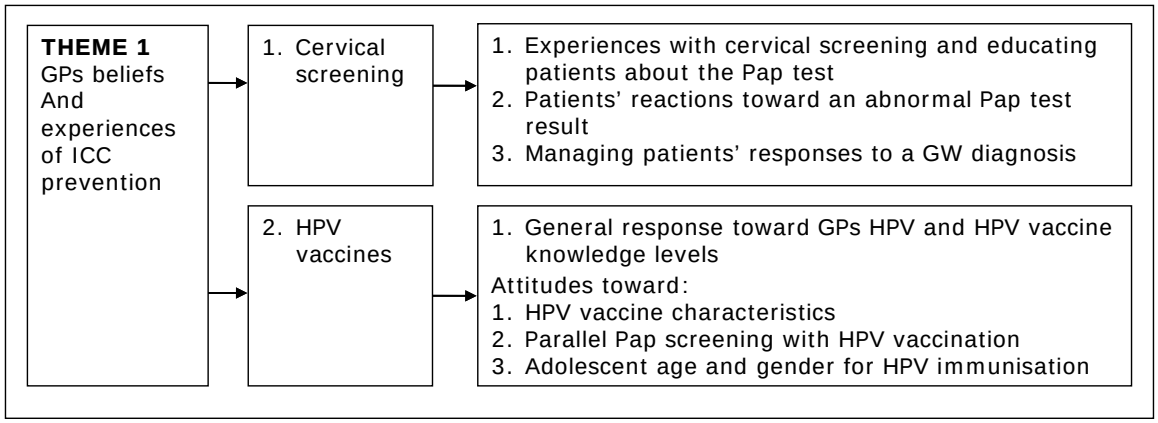
Figure 17: Thematic categories: GPs



12.2 Theme 1: GPs beliefs and experiences of ICC prevention

This thematic category (Figure 18) captures GP participants' own beliefs of ICC prevention through their attitudes and experiences of Pap screening; and their attitudes toward HPV vaccination with patients, and especially adolescents.

Figure 18: Theme1: Individual beliefs and experiences of cervical cancer prevention among GPs



12.2.1 Cervical screening: GPs experiences of cervical screening and educating patients about the Pap test

All GPs administer Pap tests (Table 25) regularly and in response to the Australian Government's organised cervical screening recall service. One female GP of Yugoslavian background commented on the adjustments she had to make as a GP when she migrated to Australia and experienced the reluctance of Australian women to undergo Pap screening compared to Yugoslavian women who accepted it as '*totally normal'* (1GP; F, 13 years GP[4]), and not deterred by it. The gender of the doctor when examining women was raised as a staffing issue, particularly for clinics in the inner-city, Western and Northern regions. In particular GPs were aware of the preference for female doctors by many older immigrant women, especially of Middle Eastern backgrounds, and the impact of the shortage of female GPs in the delivery of health services to these women in some clinics was discussed.

> "*The African Muslim ladies don't want male doctors looking at that part of their anatomy* [genitalia]" (9GP: M, 29 years GP).

Differences were noted with the level of GPs education of patients about Pap screening and HPV factors. Most GPs revealed that they do not

[4] The GP verbatim quotations are cited in parenthesis: participant number + gender + years in profession. For example (4GP: M, 30 years GP)

provide explicit explanation of Pap screening factors until there was an abnormal test result, or unless the patient requested it. Four GPs educated patients on Pap test issues at the time of screening , eight GPs educated patients only at the time of an abnormal test result, and three GPs gave information 'on request'. Among the GPs who gave information on request, two were Anglo male GPs.

> *"Sometimes you do an internal check …and you don't exactly explain what a Pap smear is for. I haven't really been totally explicit about it. Some people are more inquisitive than others… I haven't really particularly asked about sexual partners that much"* (3GP: M, 46 years GP).

The Chinese-Singaporean GP who only explained explicit details to patients "*if asked"* (2GP: M, 31 years GP) explained that the level of detail he gave was also determined by the patient's personality. In contrast, the GP of Yugoslavian descendency 'explained everything" and routinely referred patients with an abnormal Pap test result to a gynaecological specialist. Several GPs routinely referred patients with low-grade (LSIL) and high-grade (HSIL) results to a gynaecologist, whilst others made referrals only with HSIL abnormalities.

Factors that contributed to GPs approaches to patient education reflected the GPs relationship with, and understanding of, the patient and included time management; patient's relationship status, especially if the patient was monogamous or from a patriarchical culture (patients who were from a 'Middle Eastern' were cited by several GPs); religious background (patients who practised the Muslim faith were cited by several GPs); English language capabilities; or their lack of perceived need for knowledge in the patient.

Time constraints within a standard consultation time were cited as a common constraint with patient education. Explaining the complex characteristics of HPV was seen to require '*up to half an hour*' (5GP: F, 28 years GP) of clinical time, and this limitation was expressed as a key factor in GPs decisions to '*not raise it that often*' (4GP: M, 30 years GP).

Variations were noted with one GP who had a special interest in women's health and routinely delivering explicit details on Pap smear issues at the patient's first test, to both inform her patients and minimise their future concerns. Another GP raising the issue of educating women about the risk of ICC risk for lesbians and women who had had a partial hysterectomy.

The challenge of open discussions with some females who had a male escort present at examination was raised.

> *"It's difficult, because so many of them* [female patients] *are still brought in* [to the clinic] *by the husband or the father. The male …does the talking. A lot of them* [the female] *are unable to ask for that* [a gynaecological examination] *to be taken care of"* (6GP: F, 13 years GP).

However, GPs noted that once trust was established the women eventually attended the clinic alone.

12.2.2 GPs management of patients' reactions to an abnormal Pap test result

There was general consensus among GPs that many women found Pap screening to be a 'distressing' experience. Most GPs revealed that they tended to not discuss explicit details of Pap tests in advance of an abnormal Pap test result with their patients because of the emotional responses it raised in some patients.

> *"People freak out. Especially young women, they totally dramatise it, it's kind of like the worst thing to happen, they're dying of cancer and they don't understand that…it's real to them*" (5GP: F, 28 years GP).

However, other patients in the same clinic "*just take it on the chin*" (5GP: F, 28 years GP). One GP who practiced in a clinic with a high number of international university students as patients discussed the stigma that they attached to an abnormal result.

> *"I think people are quite shocked with the diagnosis; they're quite unaware of it being such an asymptomatic condition that can be*

spread. There's not a lot of knowledge about it" (8GP: F, 19 years GP).

With patient communication of abnormal Pap results, different approaches were undertaken to reduce patient concerns and anxiety. Some GPs who gave patients limited information about the abnormal result at the consultation provided an information brochure, and an offer to explain the condition further at the next consultation if the patient had queries.

GPs explained that longer consultations with patients about abnormal Pap test results were uniformly required to allay women's fears and anxieties. Whilst most GPs reassured the patient that a LSIL result was not ICC, two GPs considered that a LSIL condition did not merit detailed explanation because of its potentially transient nature. Several GPs noted that for some patients, once the patient had accepted that imminent death from cancer was not an outcome of the result, they stopped listening to further detail; for another GP the level of detail given was dependent on the patient's personality.

"Sometimes they [the patients] *panic. I think it's their personality. The sensible ones don't panic so much…each one is different, and some of them have chronic anxieties"* (2GP: M, 31 years GP).

For some, the depth of discussion was influenced by the GPs relationship with the patient.

"With people I know, even just asking about … risk factors of their sexual behaviour, it's hard to get that intimacy to be able to ask about those things…I think people don't like the idea that they've got a STI…they get very concerned they might pass it onto someone else" (5GP: F, 28 years GP).

The patient's relationship status with their partner influenced other GPs.

"I think in terms of patient reaction…and the guilt…a whole range of emotional issues. I must confess I don't raise it that often…I might

raise the issue of safe sex but I certainly wouldn't highlight the issues around the transmission" (4GP: M, 30 years GP).

GPs reported that women's responses to an HPV-related diagnosis varied according to their age and background, and older females were more accepting of the diagnosis. Furthermore some GPs advised that sexuality issues were not discussed among some groups of women, and one GP held a perception that these women were unlikely to be sexually active before marriage.

"If they're born and grew up here it's not a problem…some of the Muslims [women] *would have a problem with it. If they're newly arrived immigrants, refugees, Islamic women from Pakistan, Afghanistan, its* [sexual issues] *just something they never talk about…The women always come with their husbands. The very traditional women are unlikely to be sexually active before marriage, but that's not to say their husband isn't"* (9GP: M, 29 years GP).

Some GPs who discussed HPV as an STI claimed that the information reduced patient anxiety, and that patients generally accepted an HPV-related diagnosis as a result of their sexual history. Furthermore, the information assisted women to understand the association of HPV with their cervical health. For others, their patient's confusion between HPV and HSV was expressed.

"Some people get it confused with HSV…so I have to tell them they don't have HSV they have the 'wart virus' in their system" (15GP: F, 48 years GP).

It was generally agreed by GPs that if patients were formally educated about HPV factors by external entities it would increase women's knowledge of Pap screen and other STI issues, and consequently reduce the consultation time.

12.2.3 Managing patients' responses to a genital wart diagnosis

There were mixed opinions about the impact of a genital wart diagnosis and subsequent realisation of its sexual association on patients. There was agreement that female and male patients are concerned, and some patients show distress, other patients display guilt, and others have concerns about the impact on their current relationships.

> *"It varies obviously. Some of them take it* [information about genital warts being a sexually transmitted virus] *very readily and easily, some do get quite disturbed, distressed …Some of the younger girls get worried …* [about] *the impact on* [their] *sexual relationships"* (10GP: F, 18 years GP).

Whilst most GPs mentioned that an herpes or gonorrhoea diagnosis are "*diseases well known to the public*" (9GP: M, 29 years GP), a genital warts diagnosis was considered to carry the most stigma, but GPs experiences showed that patients' reactions were diffused once the population prevalence of genital warts and HPV infection was explained.

> "*Like anything to do with people's sexual emotional level or what sex means to them, some people feel that it's a 'dirty thing' because they get confused. And the horror that … they just pass it onto somebody*" (15GP: F, 48 years GP).

One GP discussed the need to adopt a sensitive approach when discussing a STI diagnosis with Chinese university students who attached stigma to their condition.

> "*They glaze over when you talk about herpes, they don't want to know, it's not going to happen to me, can't think about it, how disgusting, eeew*" (6GP: F,13 years GP).

12.3 HPV vaccines: General response toward GPs knowledge levels of HPV and HPV vaccine

GPs were asked to self-assess their HPV knowledge levels on a scale of 1 to 10, and indicate where they obtained their information. HPV

knowledge levels varied, with female GPs rating their knowledge higher than their male peers (Table 26).

Table 26: GPs: Self-assessed levels of knowledge: HPV and HPV vaccines

Rate	Male (n = 6)	Female (n = 9)
HPV knowledge		
1 - 4	1	1
5 - 6	4	4
7 - 8	1	2
9 - 10	0	2
Quadrivalent HPV vaccine (Gardasil)		
1 - 4	4	2
5 - 6	1	5
7 - 8	1	1
9 - 10	0	1
Bivalent HPV vaccine (Cervarix)		
1 - 4	5	7
5 - 6	0	1
7 - 8	1	1
9 - 10	0	0

Ten GPs initially described their knowledge to be ‘poor’ or ‘moderate’ , and then after being asked to rate it numerically, rated themselves as less than 6 (points out of 10). In contrast two female GPs with a special interest in women’s health initially described their knowledge as ‘excellent’, and rated it as ‘9 or 10’. Three GPs initially described their knowledge as ‘good’, and then rated themselves between 7 and 8 points. Most GPs regularly referred to HPV as the ‘*wart virus*’ with their patients, and they generally believed that prior to the introduction of HPV vaccines not a lot of HPV knowledge was needed to manage their routine clinical work with taking Pap smears and managing the test results, but that they would now need further education to respond to patient queries.

GPs generally reported they had lower levels of knowledge of the HPV vaccines. All GPs were aware of the 4vHPV vaccine, with twelve GPs reporting their knowledge was lower than 6 (out of 10) points. One female and one male GP rated their knowledge as ‘*good*’ (7 to 8) and one female rated herself as having ‘*excellent*’ (9 to 10) knowledge. Several GPs were not aware that boys were eligible for vaccination and most GPs could not

identify the HPV types covered in the vaccines. One GP (who rated her knowledge as between 9 to 10) confused the HPV types in the vaccine.

> *"I believe its 6,11,15,18 and 15 and 18 are the ones that are more for cervical cancer"* (8GP: F, 19 years GP).

Most GPs knew little about the 2vHPV vaccine, which could be attributed to it still being in Phase lll clinical trials at the time of interviews. Thirteen GPs reported low or no knowledge, and six GPs were not aware of its existence. Two GPs rated their knowledge levels as 'moderate'. There was very little understanding or recall of a '*second*' or '*other*' vaccine Cervarix ^{TM}, other than it also prevented ICC, and GPs confused with its characteristics. One GP thought the 2vHPV vaccine protected against seven HPV types.

GPs who rated their knowledge higher than '6 out of 10' gained information from a range of sources including specific female health and Pap screening workshops, and Division education forums. Other GPs had seen recent preliminary information about the 4vHPV vaccine through brochures, or a visit from the pharmaceutical company, but they indicated this information lacked clinical case details for sexually active women. Sources of information for GPs with low knowledge levels included their original medical school training, pharmaceutical representatives, or health journals. They conceded that HPV knowledge was an evolving field and some had received no information about either HPV vaccines and were not aware of information sessions through their Division. One GP had not attended an HPV information session for three years.

Accountability issues were raised. Concerns were raised that GPs had not been appropriately educated about HPV vaccination protocols, before they became publicly available. Moreover, that the success of HPV education strategies was dependent on the GPs specific interests, patient demographic, status of accreditation 'points' and time, and therefore not of interest to the entire profession.

> *"The ones who don't come (to the information meetings) are the ones who aren't interested anyway, so you can beat them around the head with a stick but they're not going to be interested"* (7GP:F, 14 years GP).

The consequences of their lack of knowledge about the 'new' vaccines among GPs emerged. As an example, one long-term GP recalled administering the Thalidomide drug in good faith to pregnant women on the recommendation of experts and the subsequent profound severe adverse events. Furthermore GPs felt they were bound by political and medico-legal guidelines for recommendations with public immunisation programs.

> *"I suppose we're the 'foot soldiers' at the end of line and you do what you're told. It's like the meningococcal C vaccine, that only with passage of time you'll know whether it's effective or not, it's going to be the same with this"* (9GP: M, 29 years GP).

Their lack of HPV vaccine knowledge prior to its introduction did not overly concern most GPs, who were confident that appropriate education would be undertaken closer to public availability. Many GPs indicated that they often referred to the official vaccine guidelines or a specialist if they were unsure, and because of these resources, they would still commence HPV immunisation despite their incomplete knowledge. There was a general assumption among the GPs that education sessions would be offered in the near future, and prior to implementation of the broad-based immunisation program.

Several GPs commented that because HPV vaccination was considered to have complex implications for different age groups, education for medical professionals was considered to require more involvement than required for the introduction of previous 'new' vaccines. Two GPs expressed dissatisfaction that they first heard about HPV vaccination through a television report or their patients, and a similar experience with another vaccine was described.

> "*Before we get* [information] *from Government or the Division we hear it on the TV, which is terrible. I was so angry when they changed the schedule for one of the vaccines* [meningococcal] *and they didn't inform us, they informed the parents* [first] *…I think it's very poor*" (1GP: F, 13 years GP).

Whilst some GPs expressed a desire to attend vaccine information sessions, frustration was expressed that repeat sessions were not offered by the Division to those who were unable to attend the first offer. All GPs expressed the need for increased GP education, and especially their need for more information through case studies on ways of dealing with HPV issues particular to certain sub groups of the population, especially sexually active and older women.

Clinical meetings with gynaecological specialists who gave impartial information were the preferred source of information for many GPs. Other GPs with time constraints preferred the internet or pharmaceutical representative as the primary source, but the inadequacies of summary information from these sources was noted. One GP was sceptical about information from commercial enterprises, and commented on the lack of detail in some printed resources, especially patient brochures.

12.3.1 Attitudes toward HPV vaccine characteristics

The HPV vaccines were considered an important health initiative by almost all GPs, and they anticipated that ICC morbidity would be eventually reduced as a result of it being factored into immunisation programs. GPs were pragmatic about the vaccines offering only partial protection against ICC; this did not impact on their decisions to recommend HPV vaccination because of their desire to reduce colposcopy treatments and ICC in their patients.

> "*If we can prevent it we are doing a very great job*" (1GP: F, 13 years GP).

12.3.2 Attitudes toward parallel Pap screening with HPV vaccination

GPs intimated that the need to continue Pap screen practices after vaccination would not negatively impact on their endorsement of the vaccine to women. GPs anticipated that if the vaccinated cohort were complacent toward Pap screening, there may be an unintended increase in cervical disease due to people thinking they were fully protected. GPs agreed on the need for consistent and ongoing education about the need for Pap screening

> *"I think there is a perception in the community that if you have this vaccine you're never going to get cervical cancer... I think it's really important to reinforce that they must still continue to do their regular smears and reinforcing* [this need] *to parents as well"* (13GP; F, 7 years GP).

Queries arose from several GPs about their need to now HPV type women at the time of Pap screening to determine the patient's eligibility for HPV vaccination.

12.3.3 Attitudes toward adolescents' gender and age for HPV immunisation

There were differing opinions toward the gender of the adolescent to be vaccinated, and the age at which HPV vaccination should commence (Table 27).

Table 27: HPV vaccination – GPs preferences for age for adolescent HPV vaccination

Gender	Male (n = 6)	Female (n = 9)
Boys only	0	0
Girls only	5	6
Both	1	3
Age	**Male**	**Female**
9 -11	1	3
12 -13	2	4
14 -15	1	1
16+	2	1

Most GPs considered females to be the primary target group for vaccination (as a prevention for ICC), and some GPs were waiting for the recommendation of health specialists before they considered male vaccination. At the time of the interviews, the scientific data on male HPV infection and association with male genital cancers was emerging. Although GPs understood the advantage of herd immunity, many of them did not see a justification for male HPV vaccination due to the insufficient data on the vaccine's efficacy for boys. In contrast some GPs thought there was benefit in vaccinating both girls and boys. Their experiences with males and rubella immunisation were raised, but their responses showed their ignorance about male HPV-related cancers.

> *"I would have thought girls is a natural answer, because if we cover all the girls, I don't see the need for the boys to be given it really. It's a bit like Rubella, you don't give that to boys initially* [sic]*… And it is cancer of the cervix that we're really trying to prevent, and boys can't get it*" (10GP: F, 18 years GP).

Preferences for age of vaccination varied with several GPs (including the GPs of Singaporean-Chinese, and Yugoslavian, background) recommending pre-adolescents (age between 9 and 11 years) due to the early age of sexual debut among the adolescent cohort, and to give them time to develop immunity against HPV infection.

> *"There are a lot of 14 year olds who might be* [sexually active]. *Some communities you might have to give it at 10* [years] *and others* [communities] *12 or 13* [years] [with] *some communities where there's a lot of under-age sex you'd have to think of even 9* [years] *would* [be] *the time to give it* (5GP: F, 30 years GP).

Many GPs considered age 9 to 12 years too young for vaccination due to several factors: the unknown need for a booster; and a potential barrier to parent consent because of the sexual naivety of the child; and the child's lack of understanding about cancer. Because of these factors, some GPs, especially those from non-Anglo backgrounds, suggested that the less information parents had, the better, and they would advise parents the

vaccines were to "*prevent infection*" (2GP: M, 31 years GP; 1GP: F, 13 years GP) and emphasise the protection against cancer, rather than sexually transmitted HPV information. Therefore they would not give parents complete information about the vaccines,

> *"They* [children 9 to 12 years] *don't know what cancer means. It's in the future. It's going to waste a lot of time talking about cancer. I think if we don't make too much fuss about it, it's going to be easy* [to get parents to consent]*. Sometimes the less information you give* [the parents] *the better it is…as long as you don't emphasise too much on the sexual things and just say it's a vaccine against cancer"* (2GP:M ; 31 years GP).

Among other GPs there was a higher preference for vaccination for adolescents aged 12 to 13 years because of puberty and immunity factors; two GPs recommended mid adolescent (age 14 to 15 years) and three GPs preferred adolescents to be older than 16 years. One GP queried which professional entity had determined the recommendations for age of vaccination.

> *I want to know if the scientists recommended it from age 9 to 29* [years]*, or if the company that made the drug* [recommended that age range]" (15GP: F 48 years GP).

Concerns were raised about the potential marginalisation of women in some cultures if females only were vaccinated, and the need for balanced education of HPV to eliminate bias was foreshadowed.

> *"I think that in some cultures this could isolate females, but…if we explain it properly it will not be seen as a female disease"* (1GP: F, 13 years GP).

The negative impact of targeting females for vaccination was refuted by another.

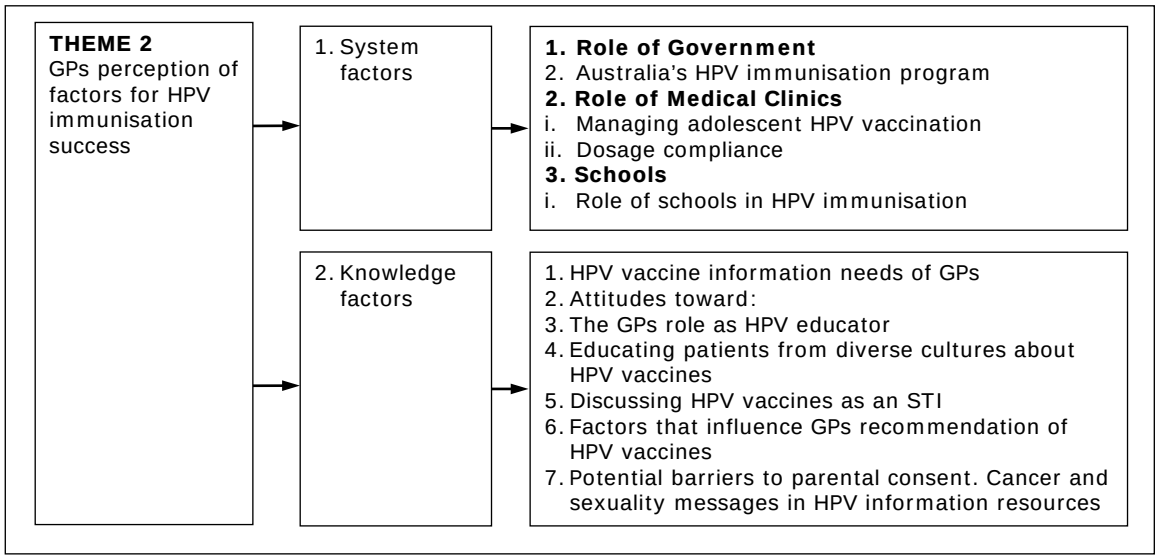
> *"If there was a program that targeted boys because there was an illness that protected boys predominantly, would that marginalise boys necessarily? That's a reflection of the cultural practice…I don't*

know…it depends on the message you give them [the general community]*"* (4GP: M, 30 years GP).

12.4 Theme 2: GP perceptions of factors for HPV immunisation success

The sub-categories in this theme (Figure 19) capture GPs perceptions of system factors and beliefs about what is needed for HPV immunisation to be successful.

Figure 19: Theme 2: Perceptions of factors for HPV immunisation success



12.4.1 System factors: the role of Government

High trust and integrity in Australian immunisation programs was held by all GPs, and several GPs expressed 'pride' that the HPV vaccines had been developed in Australia, and this factor influenced acceptance of the vaccine for some. Several GPs, who were first advised during the interview of the implementation of a school-based HPV program in April 2007, commented on the speed at which the Government's implementation decision had been made, and their imminent need to increase their knowledge to manage patient queries.

12.4.1.1 Attitudes toward an Australian HPV immunisation program

Whilst there was universal support for a national subsidised school-based immunisation program, opinions about the subsidised 'catch-up' program

varied. One GP considered that women aged over eighteen years had a public responsibility for self-care and self-funding of HPV vaccination, and that a subsidy should only be given for school-age recipients.

> *"I think it's good what they're doing in terms of offering to vaccinate free for high school students, that's fantastic. They're still minors and they're not earning their own money. But I think once they're over 18* [years of age] *it's …not the responsibility of Government…I would like to see people showing responsibility for their own health"* (14GP: F, 4 years GP).

GPs had high awareness of their role in the professional endorsement of HPV vaccines to patients, and the trust that was placed in them. Several GPs advised they had started opportunistically promoting the 4vHPV vaccine with various categories of patients, despite their incomplete information about the vaccines. In contrast, other GPs stated that opportunistic immunisation was often dependent on the prior relationship that GPs had with their patients. One GP whose clinic was in an affluent area, and who had a key interest in women's health, said that she expected that her patients would pay the cost of the vaccines due to its ICC prevention factors, and her clinic had generated information on the HPV vaccines and started informing patients of its availability through a mail out. Another GP, whose clinic was not computerised, intended to manually check his clinical files for relevant patients to advise them by telephone of the 4vHPV vaccine's availability.

12.4.2 The role of medical clinics: attitudes toward managing adolescent HPV immunisation

The issue of adolescent HPV immunisation surfaced different clinical experiences. Clinically, adolescents and older patients presented for specific purpose vaccination such as overseas travel and occupational requirements. Although adolescents did not generally form a large part of their clinical practices, parents presented their school-age children for immunisation for a variety of reasons including the child's fear of vaccines,

the parent's concern about side effects, or a perception that immunisation through school was more painful.

> *"It takes a long time to do vaccinations. At least 15 to 20* [minutes]*… …It's a waste of time and you don't achieve anything. Schools should give more vaccinations. Of course they* [school children] *come to us because … the nurses* [immunisers in schools] *are quite abrupt with their technique"* (2GP: M, 31 years GP).

The issue of 'informed consent' with adolescents was raised. One GP was hesitant to recommend HPV vaccination for adolescents without parental consent, because of its newness, and lack of data for some age groups. Some GPs considered parental consent unnecessary to administer HPV vaccines to 'mature' adolescents, age 15 or 16 years.

> *"I'd certainly be happy giving it to a mature 15, 16 year old without parental consent. If they came and asked, perhaps even a 14 year old."* (10GP: F, 18 years GP).

12.4.2.1 The role of medical clinics and dosage compliance

At the time of the interviews the national HPV vaccine register had not been announced. Concern with dosage compliance through clinics was raised, in particular with adolescents who lacked family support, or because of mobility and forgetfulness.

> *"If you're trying to do it* [vaccinate adolescents] *out of school, it's a problem because they don't come back. So if you're trying to deal with adolescents on their own without their family support, it's not going to work"* (7GP: F, 14 years GP).

Experiences with the significantly lower uptake (20 to 30%) of the third HBV dose were recalled by some GPs who were considering a range of electronic recall strategies, such as text messaging, to ensure compliance. Privacy issues with recall through email in particular were raised as a key factor.

The challenge of recall for dosage completion with patients who "*doctor shopped*' (11GP: M, 30 years GP) was raised, in particular, patients who were not on their data base and had minimal, or no recall, of their vaccination history. 'Catch-up' queries with this cohort arose, with one GP querying how he would identify what adolescents had been vaccinated.

> *"Patients can't remember what vaccine's they've had. We get it all the time with kids that are independent: There should be a national register or 'smart card' so there's someway we know. It's a problem"* (4GP: M, 30years GP).

Because of these factors, there was general support for an extended national vaccine data base and a school-based HPV immunisation program to ensure compliance.

12.4.3 Schools: Attitudes toward the role of schools in HPV immunisation programs

Parallels were drawn with GPs experiences with HBV and rubella virus school-based immunisation, and similar expectations were held for adolescent HPV vaccination. There was unanimous endorsement of the benefits of school-based immunisation programs due to the influence of peer acceptance among adolescents that resulted in higher vaccine uptake rates and dosage compliance; and clinical cost savings for the consultation time taken for vaccination, as previously mentioned.

GPs anticipated that a school-based program would reduce some of the sensitivity toward the vaccines because national immunisation programs usually require a broad-based community education approach at implementation. Issues about age - appropriate messages for children were raised. Caution was advised with the way HPV vaccine information was presented to school children, with a suggestion from one GP "*the less information you give, the better it is*" (2GP:M, 31 years GP). Other GPs recommended a more sensitive approach, and to describe it as a vaccine against 'cancer' for children in lower secondary school. GPs generally considered discussing cancer issues with children aged 9 to 11 years as a waste of time because of their ignorance about cancer and general health

matters. In contrast some GPs thought that this age group had heightened awareness of cancer because of their exposure to mass media.

Information that emphasised the sexual transmission of HPV infection for middle to later school students was deemed acceptable by most GPs, but concerns arose that if STI prevention was a key message, some parents may interpret it as a license for sexual activity.

> *"I think that they* [parents] *realise that children have sex quite early now. I think I'd stress its* [HPV vaccine] *another vaccine against another virus"* (2GP: M, 31 years GP).

12.5 Knowledge Factors: Role of GPs as HPV vaccine educators

Several GPs considered it was the Government's responsibility to fully educate the public on the new HPV vaccines through public health systems, and to parents and adolescents through schools, and due to the limited resources in medical clinics. One GP maintained that if the vaccines were not available through a school-based immunisation program there would be a dependency on the doctor to explain the vaccine to each patient, and the potential for the vaccine be seen as disreputable.

> *"People are actually very non-resistant* [to new vaccines]*. If it's on that national program they're quite happy to go along with it, it gives it some kind of kudos I think, it's like it must have been tested, it must be safe, it must be alright, it must be important" (*6GP:F, 13 years GP).

Patient understanding of HPV was rated by GPs as '*generally poor*' (6GP: F, 13 years GP) with '*a lot of misunderstanding, lack of basic knowledge.*' (12GP: M, 4 years GP), and because of this GPs were aware that many parents will rely on them for detailed information about the HPV vaccines because the limited detail in public HPV resources.

> "*I believe that GP's provide a cornerstone in preventative health. I think that (as) this is a preventative kind of thing, it is part of our duty*

of care to give people all the options so that they can make their decision" (14GP: F, 4 years GP).

The media reports of the HPV vaccines that generated patient interest was considered useful in encouraging vaccine discussions and uptake. GPs had noted an increase in queries about both the vaccine and ICC factors, mainly from patients who presented for gynaecological checks, but less so in other groups of individuals. One GP thought HPV vaccine education for patients was "*a bit of nonsense*" (4GP: M, 30 years GP) because patients generally showed no interest in specific details of vaccines. Furthermore, that the general population did not query if HBV was an STI at the time of HBV immunisation.

Another GP noted that many '*mothers*' do not seek information about the vaccines at time of immunisation for their child. Mothers simply complied believing that vaccines were compulsory, and that the financial incentives given by the Australian Government on completion of immunisation in children would be withheld if they did not comply.

"*Even mothers don't ask too many questions about the vaccine, it's all out there, you don't get your money if you don't have your vaccine, so let's have it*" (11GP:M, 30 years GP).

12.5.1 GPs attitudes toward their role of educating patients from diverse cultures about HPV vaccines

English language difficulties, rather than cultural issues, in patients were seen as a challenge to discussing HPV vaccination with them and especially with those patients who were irregular patients to their clinics.

"*Unless you've got a long standing relationship… you see quite a few patients episodically…it's easier to broach that* [HPV] *topic than if you're just raising it out of the blue. There are language barriers; some of them don't speak English that well, so that's going to be hard*" (4GP: M, 30 years GP).

Two GPs (of Anglo and Chinese-Singaporean background respectively) felt that some cultural communities in particular, would have high acceptance of the vaccine because of its ICC protective properties.

> "*It's a really nasty way to die* [and] *this will help prevent it*" (9GP: M, 29 years GP)

Another GP recognised some groups would 'struggle' with its STI association.

> *"It would be hard to get approval from an 'Arab' mother or an 'Asian' parent" (5GP: F, 30 years GP).*

Therefore they considered that an effective way for HPV education would be through cultural community centres with female-only participants.

12.5.1.1 Attitudes toward discussing HPV vaccines as a STI preventive with patients

Differences in GPs approach to discussing HPV vaccines and sexuality factors emerged. GPs were aware of the lower age of sexual debut among some adolescents (at age 12 to 14 years, with a median age in Australia of 16), and they appreciated the importance and challenges of privately informing mid-age adolescents about the sexuality factors associated with the HPV vaccines. Most GPs generally broached safe sex discussions and immunisation with sexually active adolescents when prescribing contraception, or at Pap screening appointments. Several GPs approached HPV education like other STI advice and incorporated safe sex messages, and the need for regular gynaecological checks, into their discussions. However, this approach was not universal as some GPs indicted they would wait for their patients to raise the issue.

> *"I think we'll wait for patients to raise it* [HPV as a STI]. *Maybe we should be more proactive in talking about the sexual nature of it but…it's really reliant on the individual and the individual practitioner*" (4GP: M, 30 years GP).

In contrast one GP considered that most parents were pragmatic about the emerging sexuality of their adolescent children and therefore factual and general 'low-key' information about basic sexuality could be given routinely. Furthermore that if an adolescent was presenting with a parent it was assumed that sexual discussions had already been initiated.

> *"And I tend to say this is the information, this is not recommendations in terms of having pre-marital sex or not having pre-marital sex, this is information for you to consider*" (7GP: F 14 years GP).

This view was shared by another GP who considered that parents were open-minded, and she actively encouraged her patients to be proactive with their adolescent's sexual health prevention.

> *"We're not in the 5th century, it's the 21st century. Everyone knows that people get to be sexually active. It's all about prevention in my clinic, it's the same with the* [HPV] *vaccine"* (1GP: F, 13 years GP).

Another GP discussed safe sex practices, but not HPV as a STI because of the anxiety it created. Another GP advised her patients "*If they don't ever have HPV they're probably not having enough sex*" (7GP: F, 14 years GP).

Several GPs admitted they found sexuality issues '*hard to broach'* (5GP: F, 28 years GP) with older patients, because of the *'emotional issues*' (4GP: M, 30 years GP) it surfaced.

> *"It raises questions about fidelity within relationships…especially what they think is a monogamous, ongoing relationship. It's really difficult for people*" (7GP: F 14 years GP).

Correlations with shyness and menarche, and vulnerability in adolescent females, were provided as other explanations.

> *"They're* [12 to 14 year old] *a difficult age to discuss anything to do with sexuality. Sometimes they go a little bit shy as puberty comes and they're more vulnerable that way. So I find them sometimes a little bit harder"* (3GP: M, 46 years GP).

Culturally, the GP of Singaporean-Chinese background admitted he only discussed sexual health issues if the patient broached it, whilst the GPs of Indian, Yugoslavian, and Vietnamese descendency, were not perturbed by sexuality discussions. Discussing sexuality aspects of HPV immunisation with patients who display specific cultural norms presented challenges for some GPs.

One GP anticipated there would be a demand for the HPV vaccines by Chinese international university students in early sexual activity ("*their big fear is they'll go home with an STI*" (6GP: F 13 years GP). However, this also showed the confusion that prevailed among GPs and students about the efficacy of the HPV vaccines.

> "*Even though culturally they might not be supposed to be having sex, they would still take on board what you were saying* [about HPV vaccination]*… they still know that they have to do that* [continue with Pap smears]. *So you* [the GP] *could say* '*you* [the patient] *could prevent the changes in a Pap smear' and leave it at that, rather than talking about STIs"* (5GP: F, 28 years GP).

Because of their differing sensitivities toward sexual health discussions, GPs considered that any HPV immunisation campaign needed to be sensitive to the differing perspectives toward sexuality among the population, and some were unsure about promoting such factors.

> *"I'm not sure if sex should be brought into to it to be honest, I don't know. Sex is such an individual thing. If it's a mass campaign, and if you're trying to involve everyone, maybe leaving the sexuality side of it out and concentrating on preventing cancer is the way to go."* (3GP: M, 46 years GP).

12.5.2 Factors that influence GPs recommending HPV vaccines

GPs anticipated potential barriers for them recommending the vaccines (Table 28) and differences in opinion between male and female GPs arose with some factors. The lack of information was a key barrier for most male GPs, and almost half of the female GPs.

Table 28: Barriers to GP's recommendations for HPV vaccines

Factor	Male (n = 6)	Female (n = 9)
Barriers		
Efficacy	3	4
Long term safety	2	2
Unknown side effects	1	5
Need for booster	1	1
3 dose schedule	1	0
Cost	3	6
Lack of information	4	4
Ethics - wrongly presented as ICC preventive	0	1
Legal liability	0	1
STI inhibition and culture	0	1
Sexual history of patient	1	1

Whilst some concerns were raised about some implementation factors, GPs concerns were driven by the newness of the vaccines; unknown long-term side effects, especially the absence of a 20 year safety net, as with other 'new' vaccines; and that the vaccines had not being implemented on a large-scale elsewhere globally. The unknown side effects were a key barrier to recommendation for half of the female GPs while only one male GP held this concern.

The lack of efficacy data, which GPs said impacted confidence in recommending the vaccines, was raised as a barrier by half of the male GPs and two thirds of the female GPs. This presented concerns to them on how they would manage patients who were insistent they have the HPV vaccine despite them not being within the age specifications for vaccination, and who were considered by the GP to gain little benefit because of their sexual history.

The high cost of the vaccines was raised as a potential barrier to recommendation by two thirds of the female GPs and half of the male GPs, and particularly by those practicing in less affluent regions, or whose patients were university students. Most GPs indicated they would inform patients about both HPV vaccines, but that the final choice rested with the patient, with several GPs bothered that the choice of two HPV vaccines had the potential to confuse the patient. Key factors contributing to GPs

final recommendations (Table 29) would be the endorsements made by specialist gynaecologists, and their patients' specific needs.

Table 29: Factors contributing to GPs recommendation of HPV vaccination

Contributors Male (n=6) Female (n=9)		
Specialist recommendation	2	2
Trust in Government	2	2
Trust in scientific research	1	2
Reduction in clinical costs for genital warts and dysplasia	1	2
Cancer prevention	3	8
HPV infection (STI) prevention	1	8
Sexual history of patient	0	1

Half of the male GPs specifically mentioned that their recommendations were based on the vaccines as an ICC preventive, and genital warts factors were important for only one male GP. In contrast there was almost total support by the female GPs for the 4vHPV vaccine as preventing ICC and genital warts (Table 30).

Table 30: HPV vaccine recommendation

Type	**Male (n = 6)**	**Female (n = 9)**
Bivalent	2	0
Quadrivalent	2	7
Undecided	2	2

Many GPs endorsed the 4vHPV vaccine based on the clinical cost of genital warts treatment that requires multiple visits, and that the management of genital warts is perceived as a burden on the health budget. The additional prevention was important for some GPs who dealt with the psycho-social responses of their patients to a GW diagnosis.

> *"I'll probably have to relook at the data, but the fact that genital warts is covered by Gardasil, …although its not dangerous but has a lot of stigma associated with it, it brings a lot of concerns for individuals"* (13GP; F, 7 years GP).

In contrast, other GPs who had a preference for the 2vHPV vaccine perceived genital warts as a '*cosmetic*' or '*social*' problem, and some GPs who saw very few clinical presentations of genital warts did not consider this to be as important as the reduction of ICC. Four GPs were undecided because of their incomplete knowledge about both vaccines.

There was one exception, and this GP held ethical concerns toward the 4vHPV vaccine being promoted as an 'ICC preventative', and she maintained that it was specifically a vaccine against four types of HPV, and therefore the public was being misled, and because of this they could misperceive the level of protection they had against cancers and STIs.

> "*I'm appalled that it's* [public advertising of the 4vHPV vaccine] *…a misrepresentation. But the patients seem now to think that it protects them against cervical cancer... and everything* [STIs], *and its not … it's a vaccine against four types of 'wart virus' … and they* [Government health agencies] *know the correct thing to say to the community is 'infection with these wart viruses may lead to cervical cell dysplasia'* (15GP: F 48 years GP).

During the interview GPs were asked their recommendation if the 2vHPV vaccine was shown to have stronger efficacy against ICC than the 4vHPV vaccine. One male GP who preferred the 4vHPV vaccine indicated his preference would not change toward the 2vHPV vaccine *"because I will have got used to it, and if my patients have a good response to it, I see no likelihood to change"* (11GP; M, 22 years GP). Two male GPs changed their preference for the 2vHPV vaccine after considering that stronger protection against ICC was the most important factor, and because that is how the vaccine was being marketed to the public.

There was mixed awareness that the 4vHPV vaccine was also to be made available for boys. Whilst several GPs stated they would offer HPV vaccines to males, they would prioritise females' aged between 17 and 25 years. One GP was going to recommend it to boys as '*a form of insurance'* (15GP: F, 48 years GP). Several GPs indicated that because of the emerging distinctions between the two vaccines their

recommendations would be based more on a patient's medical and sexual history rather than entirely on a patient's demands.

> *"I think you've got to know about a women's sexual history, their cultural history. If they* [the patients] *come in and demand something, unless I feel it's going to do them irreparable damage and I believe it* [the HPV vaccine] *has some efficacy, and then I would agree they can have it"* (15GP; F, 48 years GP).

Many GPs revealed they were confused about the clinical management with HPV vaccination of older sexually active women changing from a monogamous to more sexually active lifestyle. Several GPs indicated that the greatest challenge would not be so much with their recommendation, but with the patient having enough time for the GP to explain the benefits of vaccination and the patient actually acting on the recommendation.

> *"They* [the patients] *often say 'I haven't got time today'; you've really got to spend time on the benefits of it…Sometime if you go too deeply into the side effects they'll usually run away"* (5GP: F, 28 years GP).

One GP stated that his recommendations for HPV vaccination were going to be made on a case-by-case basis, and the patient's sexual profile was a key factor. In particular, his urgency to recommend the 4vHPV vaccine to his '*more promiscuous patients*' versus delaying a recommendation for '*normal people*' who were monogamous, indicated his lack of understanding of the vaccine's characteristics as a prophylactic vaccine.

> *"I suppose I'm going to target the more promiscuous patients. So the normal people who have just got one steady partner, I mightn't worry about until later on. At the moment case by case. I will blitz everyone between age 18 and 25* [years]*, and ask them all to get the vaccine"* (3GP: M, 46 years GP).

Not all clinics were providing a choice of HPV vaccines because of the unknown licensure details and lack of subsidy for the 2vHPV vaccine. One GP with a financial interest in one of the pharmaceutical companies raised ethical concerns about the need for disclosure to her patients.

12.5.2.1 Beliefs about potential barriers to parental consent to adolescent HPV immunisation

Promiscuity, sexuality norms, and cost were seen as potential barriers to parental consent. Most GPs believed parental concerns about promiscuity was not a potential barrier because parents do not consider their adolescent children as being sexually active, although most parents would accept this as a future occurrence; and promiscuity increases were not reflected in outcomes with HBV vaccination. However the GP of Singaporean-Chinese background held a strong view that the "*churches"* would raise promiscuity as a key issue to parents against consent for the vaccine and therefore the information on HPV and sexual transmission should not be "*emphasised".*

> *"Promiscuity and the sexual transmission aspect of it [sic]… encouraging pre-sex active children to become sex-active There are people with extreme views around* [sic] *so they might not like the idea of having a vaccine that protects…giving the wrong message to young girls"* (2GP: M, 31 years GP).

In contrast GPs considered parents' normative values toward pre-marital sexual activity, unisexual partnerships, and vaccine relevance for sexually naïve daughters to be more significant barriers than promiscuity, especially for parents from some cultural populations.

> "*Oh, Lord yes! I've had a patient come in and put a thumb at my chest and say 'tell me my daughter is a virgin'. That's right, the virginity aspect*" (15GP: F, 48 years GP).

The high cost of the full course of immunisation was also considered a barrier for parents, resulting in high agreement among GPs that the Government should subsidise HPV immunisation for females. Some GPs practicing in affluent areas conceded that there would still be patient demand for it because similar costs were involved with other vaccines.

12.6 Summary of GP results

GPs had high compliance with conducting regular Pap screening as ICC prevention but differences emerged in GPs approaches to patient education about the sexual transmission of HPV infection and cervical morbidity. Factors that influenced these approaches were clinical time constraints, the GP-patient relationship, and the patient's interpersonal and cultural characteristics. GPs generally held a positive attitude toward a vaccine for ICC prevention (Table 31) but concerns arose with the biomedical factors.

Table 31: Summary of key biomedical factors on attitudes toward adolescent HPV vaccination: GPs

BIOMEDICAL FACTORS	GPs
Vaccine safety	L
Vaccine efficacy	L
Medical contraindications	M
HPV type specificity -bivalent	M
HPV type specificity -quadrivalent	H
Natural immunity	H

Key: H: High acceptance M: Moderate acceptance
L: Low acceptance U: Unknown NA: Not applicable
*Age for vaccination varied. These data are the majority views

GPs had a higher preference for the 4vHPV vaccine because of its broader protective factors, although some GPs preferred the 2vHPV vaccine if it was shown to have higher protection against ICC. Concerns were raised about the public introduction of the 4vHPV vaccine when there was overall lack of education and lack of data on safety and efficacy, guidance on managing sexually active women, and GPs information needs to meet patient expectations. Most GPs intended to administer the vaccine to their patients within the licensed age range, including mature adolescents under age 16 without parental consent, due to their trust in Government and gynaecological specialist recommendations. Several older GPs were not overly concerned about the lack of information due to their past experiences with new vaccines.

With system factors (Table 32), GPs showed high support for a Government subsidised adolescent school-based HPV immunisation

program due to more efficient access, delivery, and dosage compliance. A national HPV immunisation register was seen as essential to track dosage completion.

Table 32: Summary of key system factors on attitudes toward adolescent HPV vaccination: GPs

SYSTEM FACTORS	
Access and delivery of the vaccines: Clinics	M -H
Cost (if not subsidised)	L - M
Cues to action (GP education)	M-H
Dosage schedule compliance	M-H
Trust of Government agencies	M -H
Endorsement by health professionals	H
Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable *Age for vaccination varied. These data are the majority views	

GPs considered it to be the Government's role to educate the public about the HPV vaccines, and to subsidise adolescent HPV vaccination, but some had begun promotion of the 4vHPV vaccine to their patients. Whilst the high cost of the vaccines was seen as a barrier to uptake, several GPs anticipated demand among adult women due to the precedent set with other vaccines.

With knowledge factors and the HPV vaccines (Table 33), GPs self-rating of their HPV and HPV vaccine knowledge varied with higher knowledge among GPs who had a specific interest in women's and sexual health. Some male GPs had not updated their knowledge about HPV factors since their initial medical training. Many GPs had no knowledge of the 2vHPV vaccine and impact of HPV infection on males.

Sexual activities of adolescents and HPV and ICC risk were key factors for GPs support for female adolescent HPV vaccination, and males because of their risk of genital warts. Opinions as to the ideal age for vaccinating girls varied, and although there was general agreement for age 12 to 13 at the onset of puberty, the majority view was for females age 14 to 16 years due to their extra maturity, and unknown vaccine efficacy data. Some GPs held concerns that a female-only vaccination may marginalise females in some cultural groups.

Table 33: Summary of key knowledge factors on attitudes toward adolescent HPV vaccination: GPs

KNOWLEDGE FACTORS	
Knowledge levels of HPV vaccines	L-M-H
Perceived susceptibility & risk: adolescents	M-H
Perceived severity (cancer)	M-H
Perceived severity (STI risk)	M-H
Perceived benefits for adolescents	M-H
Normative values: STIs	H
Normative values: promiscuity	L
Normative values: vaccination	H
Protect patients' health -female	H
Protect patients' health -male	L
Religious beliefs	U
Age for vaccination*	14 -16
Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable *Age for vaccination varied. These data are the majority views	

GPs had different attitudes toward the level of HPV vaccine information that parents required. Many GPs found sexual health discussions sensitive and challenging, especially with older women and patients with low English literacy levels. GPs recalled their regular experiences of psychosocial responses, especially in young women, once the sexual association was discussed. The GPs cultural background was not a significant factor in their approaches to sexuality discussions, but culture was a constraint for some patients with gynaecological examinations. GPs had more frequent sexual health conversations with sexually active adolescents.

Many GPs anticipated it may be difficult for parents to accept the sexuality association with the vaccines, resulting in their high support for vaccine promotion as an 'ICC' preventive rather than a 'STI' preventive. One GP held concerns about parental religious and culturally derived fears of promiscuity. Another GP had ethical concerns about the public representation of the HPV vaccines as a 'cancer preventive' and that this message was misleading the public.

PART 4: OUTCOMES OF THE RESEARCH

Chapter 13: Discussions, Conclusions and Implications

13 SECTION A: DISCUSSION

13.1 Overview of the thesis

Prior to the introduction of HPV vaccines into vaccination programs there was no published literature on Australian parental and GP attitudes toward adolescent HPV immunisation with an emphasis on cross-cultural factors. This is the first Australian study that I am aware of that identifies the attitudes of Australian GPs (Melbourne, Victoria), and Australian parents from three distinct cultural groups (Aboriginal parents from Victoria and Central Australia; Anglo and Chinese-Australian [Chinese] parents from Melbourne, Victoria) towards their acceptance of HPV vaccines for adolescent children, and the influence of cultural factors on parental attitudes, the unique element of this study.

13.2 Summary of key findings

The results of this qualitative study indicate that there are both shared norms and important socio-cultural and environmental differences in the attitudes of the participant groups (Appendix 27) toward adolescent HPV vaccination. Two themes emerged from the results that are discussed in the next section:

(i) individual beliefs and experiences of cervical cancer prevention and the influence of biomedical, system and environmental factors on attitudes;
(ii) the influence of culturally derived normative values on attitudes.

13.2.1 The influence of biomedical factors on parental and GP attitudes

The HPV vaccines were developed within the context of a Western biomedical paradigm and in this study the results show that parents and GPs attitudes toward the HPV vaccines are influenced by several biomedical factors. Vaccine safety, particularly the unknown long-term

side effects, is a major barrier to acceptance among all parent groups in this study, and this finding builds on international studies of parental attitudes and safety (Hilton et al. 2006; Brewer and Fazekas 2007; Marlow et al. 2009; Reiter et al. 2009; Ogilvie et al. 2010). Some safety concerns were moderated by the concept of a 'vaccine-risk threshold' (Raithatha in Serpell and Green 2006) particularly in both parent and GP opinions on adolescent risk susceptibility to HPV infection versus cervical cancer (ICC), and safety concerns of a new vaccine (Hilton et al. 2006). At the time of the data collection later findings of anaphylactoid reactions (Brotherton et al. 2008b; Halsey 2008) had not been reported, therefore data could not be captured on this rare adverse event for HPV vaccines.

Some Chinese participants who had initial concerns about the safety of new vaccines held more confidence in the HPV vaccines because they are an Australian discovery. My findings about the safety concerns within the Aboriginal population, being equivalent to the concerns held by the Anglo and Chinese parents, challenges the findings in studies of African-American mothers who found that 'black' mothers were more concerned than 'white' mothers about vaccine safety (Serpell and Green 2006; Shui et al. 2006). Moreover, the questioning of the HPV vaccine's manufacturing components and trial population characteristics by some parents in the Anglo and Aboriginal (Victoria) groups indicates that parents do draw on their previous vaccine experiences in framing their attitudes about new vaccines that are untried in other populations.

Factors influencing the positive attitudes towards the HPV vaccines by the Anglo and Chinese parents in this study were also shown in a UK study (Marlow et al. 2009) (n = 950 of which 200 women were 'white British' [Anglo] and 73 women of Chinese origin). This study found almost identical attitudes toward HPV vaccines as a protection against ICC between the Anglo parents, and Chinese parents who were first generation immigrants (29% and 30% respectively); and similarly with the vaccines as important for daughter's health (9% and 7% respectively) in the UK.

Parents and GPs initially preferred the 4vHPV vaccine on the perception of broader coverage of HPV types. There was stronger preference for the 4vHPV vaccine particularly among the GPs, Chinese and Aboriginal (Victoria) participants, and moderate to high preferences among the Anglo participants, and moderate for Aboriginal (Central Australia) participants. A similar preference for the 4vHPV vaccine was also shown by young Australian females in two hypothetical Australian studies (McClelland and Liamputtong 2006; Skinner et al. 2007). Attitudes toward HPV vaccines protecting against an STI had lower acceptance among GPs than its function as an ICC preventive. This attitude was also shown by other physicians internationally (Mays et al. 2004; Zimet 2005), and although vaccine efficacy was a factor influencing their attitudes (Raley et al. 2004) there was greater acceptance for recommending the 4vHPV vaccine (Kahn et al. 2005; Riedesel et al. 2005).

In this study, although the 2vHPV vaccine had not been licensed at the time of interviews and its efficacy was speculative, there was high acceptance by the Aboriginal (Central Australia) participants, and some Anglo, Aboriginal (Victoria), and Chinese parents changed their preference to 2vHPV, if its protection were shown to be stronger against ICC. Among the Chinese participants, genital warts were up to that point an unknown medical condition to them, which links with their low understanding of HPV infection overall.

13.3 The influence of system and environmental factors on acceptance

Australian parents have demonstrated they are generally pro-vaccination (ACIR 2010) with high uptake in general for infant immunisation, but system factors in the economic and regulatory environment are shown to influence parent and GP attitudes toward the HPV vaccines. There is universal agreement that the Government subsidy of the vaccines is essential for adolescent vaccination. Cost and dosage compliance are prohibitive factors for the Aboriginal population, partially for the Anglo

population based on the socio-economic profile of individuals, and less so for the Chinese participants.

Trust in Australian vaccine research processes varied, with the Chinese parents and GPs overall displaying high trust in Government vaccine policies, moderate to high trust among Anglo parents, and very low trust among Aboriginal participants. A small number of Aboriginal (Victoria) and Anglo parents in this study expressed low trust in Government immunisation programs, or anti-vaccine sentiments, and this suggests that attention needs to be given to what will encourage Australian parents to give informed consent, and / or to ensure women and their daughters participate in regular cervical screening.

The results of this study confirm the lack of consistency among urban Victorian GPs in their levels of biomedical knowledge of HPV and the HPV vaccines, and their disparate approaches in the management of cervical screening practice and education in women. The results report the contrasting expectations between participants and health providers HPV knowledge levels and their role in the dissemination of that information.

High knowledge of key HPV issues is only found among those GPs, mainly female, who have a specialist interest in women's health. The remaining GPs rate their knowledge levels as poor to moderate, and this is true especially for males. This finding is not unique to GPs in this study, as an early study by Kahn and colleagues (2005) identified that a cohort of USA pediatricians had poor knowledge. Most GPs in this study state they are under-prepared for the anticipatory concerns, especially among their sexually active patients about HPV vaccination, and these implementation factors are noted by GPs in other Australian studies ((Stanton 2004; McCaffery and Irwig 2005; Smith et al. 2008; Leask et al. 2009; Ogilvie et al. 2010).

Attitudes to patient HPV education through a clinical environment vary among GPs. Those GPs who have a specialist women's health interest routinely give detailed explanations. However when psychosocial

responses emerge in women with an abnormal cervical diagnosis, most of the male GPs consistently adopt a 'protectionist discourse' (Braun and Gavey 1999a, 1999b) through their simplified responses that it is not 'cancer'. Their attitudes are that this basic information is sufficient to allay women's fears, and they do not provide detailed explanation of HPV issues as they perceive the information may create anxiety in women (Giles and Garland 2006; Gonik 2006; McCaffery et al. 2006; McCave 2009). Their responses signify the tension between 'protectionists' and 'right to know' discourses among health professionals, a phenomenon common to other GPs in other Australian and USA studies (Zimet 2005; Skinner et al. 2007). Some GPs in this study withhold detailed information due to time constraints, cultural and religious factors, and some consider it the role of Government agencies to educate the public.

Female Anglo participants (who were all 40 years plus) were consistent in their frustration that critical information about HPV and Pap screen factors had been withheld from them during medical consultations, or until an abnormal Pap test result occurs. Some Anglo participants found secondary information resources, such as brochures, that GPs rely on to educate them are inadequate, and similar outcomes were found among a diverse sample of parents (n=30) in the USA (Downs et al. 2008). This detrimental impact on women's knowledge signals that GPs may need to change their approach to meet patient information needs. Importantly, their need is substantiated by the participants who commented on their increased awareness of ICC factors after the education intervention in the interview, and their intentions to now regularly participate in cervical screening. The issue of doctor-patient relationships was not broached with the Aboriginal participants because of the focus in their topic guide (Appendix 15) on getting information about the HPV vaccines.

The need for GPs to adopt an educative role about HPV factors with their patients has been raised in several studies (Zimet 2005; Kane 2006; Pitts et al. 2007,2009 a b; Downs et al. 2008; Rosenthal et al. 2008; Garland and Smith 2010), and this onus may enforce a paradigm shift for them.

Whilst this new role will be in addition to cervical screening there are views that this may 'underscore' their primary role of management of illness (May 2007; Jenson 2009).

Paradoxically, in this study parents are shown to place high value on the credibility of doctor's information and recommendations for new vaccines. It is important for GPs in this study that the HPV vaccines are endorsed by gynaecological specialists and professional associations before recommending it to their patients (Mays et al. 2004; Raley et al. 2004; Zimet 2005; Zimet et al. 2006). Trust in doctors' [or AHWs] recommendations (Prislin et al. 1998; Giles and Garland 2006; Lenselink et al. 2007) is also a key factor for the majority of Chinese and Aboriginal and most Anglo participants in this study to consent to adolescent HPV vaccination (a 'cue for action' (Reiter et al. 2009). However, for the very small number of Anglo and Aboriginal (Victoria) parents who experienced adverse vaccine- related events their trust was not 'absolute' (Streefland et al. 1999), and their scepticism reinforces their doubts about giving a new vaccine to their children.

GP's preferences for their role in HPV vaccine delivery and education are shown in other Australian studies (Bailey et al. 1999; Garland and Quinn 2006; Giles and Garland 2006; Pitts et al. 2007; Rosenthal et al. 2007; Skinner et al. 2007). This indicates that the success of the introduction of HPV vaccines into the adolescent immunisation schedule will be enhanced by GPs recommendation of the vaccine, despite them indicating in this study that time factors are a barrier in them administering vaccines.

All parents agree that knowledge and assurances about the HPV vaccine characteristics need to be more widely disseminated in the public domain (McCaffery and Irwig 2005; Leask 2009), and they identify appropriate avenues for knowledge dissemination for themselves or their communities. Different views toward the 'promotive strategies' emerged among the Aboriginal and Anglo participants, and are based on their social and normative experiences and different perceptions of credibility of the medical profession.

13.3.1 Attitudes toward school-based HPV vaccination programs

GPs in this study are not supportive of the public's reliance on them as primary HPV information providers, due to clinical constraints and the complexity of the information, and they hold universal support for a school-based HPV immunisation program for convenience and economic factors (Leask et al. 2009), and where HPV education will be abrogated to teachers. The involvement of schools in HPV education and immunisation is also supported by most Victorian-based parents. Although some Chinese and Aboriginal parents have mixed preferences for vaccinating through schools and health clinics, for Anglo parents it is for convenience rather than trust factors (Downs et al. 2008:1602).

Aboriginal parents in both regions expressed concerns that targeting HPV immunisation through a school-based program disadvantages Aboriginal adolescents who do not regularly attend school, especially in remote areas, and school-absenteeism was raised in international studies (Cheng 2006; Rosenthal et al. 2007). The standard consent procedures, which are seen as complex and a barrier, are another disadvantage for parents who are not English literate, especially for Aboriginal (Central Australia) and Chinese parents.

Anglo and Chinese participants acknowledge that schools play a pivotal role in public health education (Raffaelli et al. 1998), but some Anglo parents see this as a source of disinformation (Downs et al. 2008) through schoolyard 'gossip'. Aboriginal parents consider AHWs to be a credible source of information or information shared by community women elders. In this study most parent participants and GPs are in agreement that sexual (and HPV) education should be conducted through schools. Several Anglo and Chinese participants display a philosophical opposition to this on the grounds that children mature at different rates, and their perceptions about the lack of control over their child's sexual knowledge, and this role is also held by several Aboriginal participants.

Most Anglo and Aboriginal participants are willing to have these conversations with young adolescents, which is consistent with South

Australian findings (Marshall et al. 2007). Parents agreement in this study that sexuality discussions should be first broached by the school, were mostly supported by parents in Slomovitz and colleagues' bi-cultural study (2006) (n = 200: English and Spanish). However in that study some parents (14.3%) were also against this approach because of the loss of control over their child's knowledge.

13.4 The influence of psychosocial factors on parental acceptance

13.4.1 Knowledge factors and parental attitudes

Awareness and knowledge about HPV and HPV vaccines is new knowledge to all but one parent participant across all sample groups. Once key facts about sexually acquired HPV types and ICC were known the information became a significant factor for giving consent, especially for adolescent females, and among parents who have initial doubts about adolescent HPV vaccination.

Parental uncertainty about the vaccines (Stoto 1998) is apparent through displays of 'naïve' (superficial) and 'focused' (more detailed) understanding (Downs et al. 2008: 1596, 1602) coupled with 'risk' and 'health' oriented concerns in their discussions. This uncertainty increases the potential for misinformation and disinformation (Downs et al. 2008) when either sharing HPV vaccine information through social networks, or consenting to adolescent vaccination. Once participants understood the 'incompleteness' in their knowledge they indicated their intentions to seek further information from a variety of sources.

Currently in Australia, HPV vaccine information is mainly available through the Australian Government website, supported with print-based summary information through schools and health clinics, and through consultations with doctors, but this approach disadvantages Aboriginal parents and some Chinese parents based on cultural and literacy factors. This need to fill the knowledge gap was also a key factor for USA parents (Downs et al. 2008:1604), but a key difference with them was their preference to first search the Internet as a primary information source rather than ask their

doctor, and the USA preferences could be bound by the medical costs incurred.

Variables such as gender and age do not significantly impact on parental attitudes (Slomovitz et al, 2006). However, within the 'non-acceptor' profiles differences are evident between this study and a recent UK study (Marlow et al. 2009). In my study the need for more information is consistently strong across all parent groups, whereas in the UK study (Marlow et al. 2009) the knowledge factors ('need for more information') were slightly higher among Chinese participants than Anglo participants (20% Chinese and 16% Anglo). This could be attributed to differing public education approaches in each country, although another explanation is the timing of the data collection.

My interviews were conducted with the Aboriginal, Anglo and half the Chinese participants before the implementation of the Australian HPV immunisation program and when little public education had been undertaken, and the UK study (Marlow et al. 2009) was conducted after the corresponding process had commenced. The knowledge needs of parents with the HPV vaccines in my study clearly relate to the six dimensions that were identified by Marlow and colleagues (2009:29) that were referred to in the literature review: identity; cause; timeline, consequences; cure-control; and procedural aspects of vaccination and testing.

'Anticipated regret' (or 'omission bias' (Downs et al. 2008) was a factor noted in Reiter and colleague's USA study (2009), but this concept only emerged in two Anglo and one Chinese participants in this study. Mitigating factors such as vaccine safety and incomplete knowledge about efficacy were factors that impacted on parental consent to vaccinate both daughters and sons in this study, and my findings reinforce parental roles found in Marlow and colleagues' UK study (2009).

In my study all parents displayed a strong desire to protect their children from cancer, and the gender of the consenter is not a contributing factor

among the Anglo population, where vaccine decisions are made by either the ‘mother’ or shared with the male partner. Due to cultural factors such as ‘women’s business’, gender is a strong factor for the Aboriginal participants where female vaccine decisions are made by mothers or ‘aunties’ in the community, unless there is a male sole parent; and among the Chinese parents who are the primary decision maker after discussion with their male partner.

Vaccine decision making by adolescents from age 16 was supported by Anglo, some Chinese, and GP participants, and this abrogation of decision making to children was discussed by Mays and colleagues (2004). This study did not explore whether the parents would adopt an ‘apprenticeship model’ (Mays et al. 2004) to support their children in making informed decisions as young adults.

13.4.2 Normative values and attitudes toward age for adolescent HPV vaccination

The normative values in participant responses are framed within cultural, social and religious contexts. Parents in this study as ‘acceptors’ for vaccinating daughters over males is largely because of the message framing as ‘cervical cancer’ vaccines and their risk perception for HPV infection (Stanton 2004). These preferences were held by parents in international studies (Rosenthal et al. 2008; Donders et al. 2009; Liddon et al. 2010; Ogilvie et al. 2010) and overrode their values toward adolescent sexuality (Rosenthal et al. 2008).

The attitudes of the Aboriginal and Chinese participants toward HPV vaccination influenced by the importance they place on ‘community as relationships’ demonstrates heterogeneous normative values within the sub-cultures (Rozin 2003). Therefore the success of the HPV vaccination program through schools may be determined by whether it is in conflict with or supportive of the sub-cultural norms and values, particularly when other research shows the importance of social networks on vaccine decision making (Leask et al. 2006).

The interdependencies that occur through social endorsement within a HPV 'vaccine culture' as a 'specific benefit' (Streefland et al. 1999) emerged as a key factor for parents consenting to HPV vaccines. The preference to vaccinate older female adolescents, (Mays et al. 2004; Raley et al. 2004; Reidesel et al. 2005; Kahn et al. 2005; Zimet et al. 2006) held by GPs, Chinese, and some Anglo parents appears to be an influence of their subjective norms (Askelson et al. 2010). With GPs, some findings in this study are in direct contrast with other studies. For example, Riedesel and colleagues (2005) found that there was higher acceptability for adolescent HPV vaccination among female physicians, whereas there was equal acceptability among both genders in my study. Key barriers that are common to both studies were GPs' acquiescence to strong parental objection, and a reluctance to vaccinate younger adolescents because of their sexual naivety.

13.4.3 Sexuality norms and attitudes toward HPV vaccination

A society's attitudes towards sexuality have been reported as generally formed by historical and religious factors, but knowledge of these factors is not a predictor of sexual attitudes and behaviours (Rissel et al. 2003; Sinha et al. 2005). Attitudes toward sexual behaviour are shown to be a key predictor of the intentions of GPs and parents to vaccinate adolescents, particularly among the Chinese participants including Chinese GPs, and as a secondary factor for Anglo and Aboriginal participants.

The parents in this study are bounded by factors found in other studies. The unpredictability of adolescent sexual activity and behaviour control (Constantine and Jerman 2007); the sexual association with HPV vaccines (May et al. 2004; Dempsey et al. 2006; Marshall et al. 2007; Kwan et al. 2009); delaying HPV vaccination until their child is sexually experienced (Zimet et al. 2000, 2006; Marlow et al. 2007; Kwan et al. 2009). This concept of maternal [parental] judgment of sexual activity in children (Mays et al. 2004; Kwan et al. 2009; Marlow et al. 2009) was a

strong view of Chinese participants and for some Anglo participants who hold conservative sexual and religious norms.

Positive attitudes by parents towards vaccines that impact on STIs is shown in the literature review, but sexuality factors and perceptions of the age of sexual debut in this study influences both GP and parental attitudes toward the acceptable age for vaccination, and this was also found in early studies of parental attitudes (Lazcano-Ponce et al. 2001; Davis et al. 2004; Mays et al. 2004). The questioning of the relevance of the vaccines for their sexually naïve daughters by all parent participants demonstrates that normative values are potent factors (Slomovitz et al. 2006).

Anglo and Aboriginal (Victoria) parents in this study generally preferred vaccination between age 12 to 14 at the onset of puberty and this was less accepted by Chinese parents (similarly for 'South Asian' parents: 10% Chinese versus 2% Anglo, in Marlow et al. 2009) where early sexual debut was found to be the antithesis of their familial and normative values. Their preference for late adolescent (age 16 to 18 with the majority being age 18) is based on the assumption that by that age adolescents can make their own decisions about the HPV vaccines. In contrast Aboriginal parents in Central Australia had a more pragmatic acceptance of sexual activity within their populations and preferred pre-adolescence (age 9) for HPV vaccination.

The acceptance of adolescent sexuality among GPs, and Anglo and Aboriginal parents is also shown in the ASHR study (DHA 2002; Smith et al. 2007) and surveys in other English-speaking western countries (Sprecher and Hatfield 1996; Weinberg et al. 1998; Monk and Wiley 2006). Additionally, the attitudes of the Chinese parents toward sexuality issues was similar to findings in the ASHR study where cross-cultural variation in attitudes towards sex were identified, with findings of a lower attitude toward permissiveness by participants who spoke a language other than English. Furthermore higher levels of liberalism and decreasing age of first intercourse in Australia were associated with greater sexual

adventurism and health risk taking (Rissel et al. 2003; Smith et al. 2003, 2007).

Chinese parents' fears about promiscuity mirror changes in social trends evident in China where recent data from a multi-centre study (n = 11,852 women) across 7 geographic regions in China (Zhao et al. 2010) on age of sexual debut in Chinese women concluded that the median age of sexual debut varied between age 18 to 22 years, but trends to a younger age (15 years) in a small minority were noted (Chan et al. 2007; Zhao et al. 2010). This denotes how important it is for all parents and policy makers to understand that knowledge of sexuality in adolescents will not necessarily promote promiscuity (Gull and Tepper 1997; Meheus 2000; Smith et al. 2003; Sinha et al. 2005; Dempsey et al. 2006; Zimet 2006; Pitts et al. 2007), as was recognised by the majority of Anglo parents.

These parental fears also indicate the ongoing absence in Australia of a coordinated and comprehensive adolescent sexual health education, despite recommendations for this. For example, Skinner and Hickey (2003) found that in Australia, sexual health and contraceptive education is given in varying degrees, and as a consequence Australia has very high teenage STI and pregnancy rates. These findings are an important factor for countries adopting the HPV vaccine, especially those with mixed-culture populations, and where broad-based community education that is gender neutral and prior to immunisation programs will be critical to allay these fears. However, precedents set with the HBV immunisation program show that promiscuity as a result of HPV vaccination is also unlikely (Lawrence and Goldstein 1995; Gull and Tepper 1997; Meheus 2000; Smith et al. 2003; Mays et al. 2004; Sinha et al. 2005; Cameron et al. 2007).

The reticence displayed by some GPs (particularly male and/or non-Anglo background) toward sexuality discussions with patients in this study seems to be a common factor, with a similar reluctance shown in the BEACH study (Freedman et al. 2006), and USA health care professionals (Zimet 2005). This highlights the gaps in health service delivery; similarly

among physicians internationally (Verhoeven et al. 2003; Kahn et al. 2007; McCave 2010). This is a concern as the BEACH data showed that among young people aged 12 to 24 years, 12% of their encounters with GPs were related to family planning which assumes the requirement of cervical screening in this sexually active cohort, and the opportunity for sexuality discussions. The subjective assessments of the cultural and religious traits of the patient by GPs in this study mirrors Belgium physicians' reluctance to discuss STIs which was based on embarrassment and fear of being obtrusive, and influenced by subjective values (Verhoeven et al. 2003).

13.4.3.1 Sexual message framing

Aboriginal, Anglo parents and GPs criticism of the HPV vaccines being targeted at females as the sole focus of HPV infection (under the umbrella of 'women's business' in the Aboriginal populations) is derived from fears that this approach potentially marginalises vulnerable women. Their support for HPV promotion being gender neutral, targeting boys as well as girls indicates wide-spread dissatisfaction with the current message framing of HPV vaccines. Participants' concerns that the ignorance among men regarding cervical screening will also result in their widespread ignorance about HPV vaccination was found in other studies (Aggarwal et al.1993; Baer et al. 2000; McPartland et al. 2005; Giuliani 2007; Pitts et al. 2007, 2009), as well as concern for their role in HPV infection in relationships (Crosbie and Brabin 2009:139), which is raised by some Aboriginal women in Victoria.

Little support is shown among parents and GPs for framing adolescent HPV vaccines as STI prevention, suggesting an underlying sexual conservatism. Parents indicate they will potentially resist HPV vaccination for their young adolescent children under age 13, if this is the vaccine's primary purpose. This filters through to the language applied around HPV vaccines and the normalising of HPV infection through semantics (Pallecaros and Vonau 2007). In this study, several male Anglo and female Aboriginal (Victoria) participants' reclassified HPV from a STI to a

common ‘virus’ to remove it from a stigmatised cluster. However this raises concerns about unintended consequences of complacency in the vaccinated cohort toward STI acquisition (Constantine and Jerman 2007). On that premise, and with the age of sexual debut varying within cultural groups with a younger trend (Zimet 2005; Pitts et al. 2007; Smith et al. 2008; Zhao et al. 2010) an unmitigated approach to message framing may be required to aid understanding of risk factors.

Parental responses to information exposing HPV as an STI shows that sensitivity is integral to the way people respond to HPV messaging. The awareness of HPV infection as an STI generated negative psychosocial responses, particularly among the Chinese participants (Kwan et al. 2009). In interpreting the strong negative views of Chinese participants against STI messaging, we need to be mindful they may have underestimated their child’s risk of HPV infection which was also shown in ‘Asian’ studies (Chan et al.2007). However, this is contrary to the findings from other studies (Zimet et al. 2000b; Gonik 2006; McClelland and Liamputtong 2006) that suggest that the message framing of HPV vaccines with an STI was not a barrier to parental acceptance in other population groups.

13.4.4 Religious factors

Whilst religion is not a key phenomenon under investigation in this study, several individuals among Chinese and Anglo participants strongly expressed that their religious and ‘conservative’ values are an important factor on their attitudes toward age for vaccination. The strong Christian religious beliefs held by these parents do not condone premarital sexual activity, and Chinese parents who have resided in Australia more than seven years hold concerns about the influence of Western values on their child’s behaviour and the subsequent potential early onset of sexual debut. Religion was not raised by the Aboriginal participants.

The influence of religion on parental attitudes differed across studies, and my finding has been supported (Marlow et al. 2007; Rhodes and Yee 2007; Donders et al. 2009) and negated (Sam et al. 2009) in international

studies. Religion was not a key attitudinal factor in British Columbia, which had similar access to HPV vaccines as Australia (Ogilvie et al. 2010), but religion did have some impact in UK studies (Brabin et al. 2006; Marlow et al. 2009).

13.5 Unique factors relating to the attitudes of two specific participant groups

The strength of 'cultural rationality' (which appeals to cultural traditions and trust in the political culture) (Plough and Krimsky in Leask et al. 2006:7243) is a persistent theme among the responses of Aboriginal and Chinese participants.

13.5.1 Aboriginal participants

The concept of 'shame' was found to be integral to Aboriginal people's responses to engagement with a medical model (as opposed to cultural model) of health services, and 'black' women in Serpell and Green's study (2006) displayed similar responses to their utilisation of preventive services. The variability shown in women's experiences with cervical screening shows that normative values and connections toward 'stigma' and 'shame' are found to affect screening behaviour among the Aboriginal (and Chinese) participants, and the notion of STIs as a taboo topic underpin their attitudes.

However, in accepting this lack of congruence within medical models, one must be cautious about generalising to all communities as a variety of beliefs and participation in screening services is shown among Aboriginal women in Central Australia and Victoria. One could argue that it has been these set of assumptions, based on a deficit or risk model that is the underlying basis of health disparities among the Aboriginal population.

Aboriginal people's perception of marginalisation with public health vaccine programs, (Menzies et al. 2004; Cunningham et al. 2008) is raised in this study by Aboriginal parents in both regions who questioned if the HPV vaccines were for all Australians, or just them. Serpell and Green (2006), who explored parental decision making in child vaccination

suggests this attitude is due to perceptions of racism and abuse of trust among the 'black' mothers, but this notion was not explored in this study.

Despite their concerns about the HPV vaccines, some Victorian Aboriginal parents perceive they are under pressure to integrate into a national HPV 'vaccine culture' (Streefland et al. 1999) because of their fear of ineligibility for a Government child-welfare allowance. Furthermore the misinformation about the vaccine being compulsory relayed through local media contributes to their 'passive acceptance', and these factors relate to the experiences of other parents with the introduction of new vaccines (Streefland et al.1999; Serpell and Green 2006).

The high level of support for the HPV vaccines in adolescents under age 13 among Aboriginal participants in Central Australia, where a high incidence of ICC is recorded, is in direct contrast to the attitudes of Californian African-American women in Constantine and Jerman's (2007) study. Some Victorian Aboriginal participants expressed doubts about the vaccines' relevance for them although the precise prevalence of HPV types for this particular population group is unknown. Their general perception of Aboriginal people's genetic incompatibility with Western vaccines was also found to be a barrier to vaccine acceptance among other Aboriginal Australians (Menzies et al. 2004).

These attitudes are not unique to Australian Aboriginal women, as similar concerns have also been found in African-American mothers (Shui et al. 2006; Serpell and Green 2006). There could be some basis for the women's concerns if we consider the findings of the global HPV prevalence studies that revealed variations between geographical locations. This raises questions about the potential efficacy of these vaccines for some adolescents, and lends further weight to conclusions that in Australia 'HPV genotypes varies between geographical regions' (Brestovac in Brotherton and McIntyre (2004:251). For example, HPV-52 infection was only found in the Kimberley region (in remote Australia with a predominantly Aboriginal population).

This study shows that not all parents in Australia embrace western biomedical approaches to preventative health strategies and adolescent sexual norms. Participants within one Victorian Aboriginal community show their adversarial attitudes towards Western medical interventions, and these normative values were found to be a key facilitator of public acceptance (Marlow et al. 2007). However their prior negative experiences with vaccination had a significant impact on their perceptions of the benefits of vaccination in general, and this reinforced their doubt about these new HPV vaccines (Mills et al. 2005).

Aboriginal parents reinforce the value of culture in shaping attitudes toward health interventions, demonstrating the benefit of cultural integration being expressed in a socio-ecological context. Bingham and colleagues (2009) presented research outcomes that substantiates the belief that the integration of socio-cultural and psycho-social approaches in HPV immunisation programs will not only influence positive community attitudes within diverse cultures toward the HPV vaccines, but will also attract critical stakeholders as advocates.

13.5.1.1 Communicating HPV vaccines to Aboriginal parents

With the implementation of the HPV immunisation program, Aboriginal participants' criticisms of the concurrent introduction of the HPV immunisation program without prior adequate community HPV education, and the lack of regard that was being shown in introducing new sensitive information to communities vulnerable to STI issues. Their concerns reinforces Bowden and Fethers (2008) findings that criticise the current 'individual' versus 'community' approaches to STI management in Australia's remote communities.

The Aboriginal literature continually refers to a 'whole of community' approach to health prevention, which implies their need for a socio-ecological approach to resource development incorporating 'psychological', 'structural' and geographical' interactions (McLeroy et al. 1988) rather than being considered in isolation. Jureidini and Poole (2003:210) assert that Aboriginal people occupy a 'unique but ambivalent

position' in Australian contemporary social life, especially in terms of equitable access to health services; and that promotion of these services has an *inclusionary* intention. However the *exclusionary* sentiments expressed in this study about the Government's advertisement for the Aboriginal population demonstrates persistent structural inequalities in the manner and style of health media.

Australia's cultural and social complexity has been earlier described but the statement *"One mob cannot speak for another"* by an Aboriginal participant in Central Australia demonstrates the heterogeneity between each Aboriginal clan across Australia, just within one 'cultural group'. The socially constructed interpretations of realities about themselves and others result from the manner in which Aborigines, with their various historical and cultural backgrounds, and other Australians of different ethnic origins are derived. Oral-based cultures are seen as being derived from historical experiences of social exclusion and imported westernised cultural concepts (Denzin and Lincoln 1998), and this has important implications for the development of HPV education resources. Furthermore "*We are oral people*" is not a statement of inferiority by one Victorian Aboriginal participant, but her disclaimer to an ethnocentric perspective, indicating that oral communication-based cultures are *different from* rather than *inferior* to written word-based cultures.

Parents who are AHWs in both Central Australia and Victoria recommend a story-telling approach to community education as being critical for women's understanding of the need for cervical screening and the importance of HPV vaccination for young women. An earlier urban Sydney study (Koori Elders et al. 1999) demonstrated that story-telling, as an oral tradition of the Aboriginal peoples of Australia, can be used effectively as a vehicle for disseminating health promotion messages in urban Aboriginal communities.

In Central Australia, sexual issues are not a key barrier to HPV vaccine acceptance, and parental attitudes are more framed by geographical, environmental and social factors. Their preference for age 9 years due to

early sexual debut (also the preference of South African parents for the same reason (Harries et al. 2009) and more regular school attendance necessitates the need for a differentiated HPV education program, and will allay parents concerns about dosage compliance. Victorian Aboriginal parents prefer age 12 to 13 years for vaccination, and through their local culturally aligned Aboriginal Medical Service. Optimal uptake requires co-ordination and coalition building to influence community attitudes toward HPV vaccine uptake.

13.5.2 Chinese participants

In Australia, the 'Chinese' diaspora are often referred to as a homogenous group, but their attitudes in this study clearly show that the Chinese population are heterogeneous and should not be stereotyped. This builds on the findings of other studies in China (Zhang and Beck 1999; Yeo et al. 2005) that found heterogeneity by diverse geographic regions, economic zones and intercultural differences.

The strength of social interdependencies in health decision making (Ho et al. 2003; Yeo et al. 2005; Lee-Lin et al. 2007) is a persistent theme in Chinese participant responses, especially those who have resided in Australia more than seven years. This is particularly significant for the acceptance of HPV vaccination for Chinese adolescents where privacy and sensitive issues is relational, and usually confined within the family. This notion of 'immunisation as a social practice' was found in the findings of Leask and colleagues (2006:7242) small Australian cross-cultural study (n=37) which showed that vaccine decision making among parents was 'socially reinforced' (Leask 2006:7243), and 'a vehicle for expressing their wider social norms and values'. However Constantine and Jerman (2007) found that Asian-American women were 'less likely' to agree to vaccination of adolescent children, and this attitude is only apparent in this study among the Chinese-participants with strong religious convictions.

The low level of HPV knowledge and Pap screen adherence among the Chinese participants is explained by their culturally-reinforced perceptions, with the term 'cancer' not having a shared meaning among the Chinese

participants (Bair 2003; Wray 2004; Kwong 2006; Kwan et al. 2009). These characteristics are not unique to Chinese-Australian women. Chinese-American women had the lowest rates of participation in culturally diverse USA studies (Constantine and Jerman 2007; Lee-Lin et al. 2007), and low levels of awareness are widespread across the SE Asian region (Hoover et al. 2008; Kwan et al. 2009). The non-existent or low levels of awareness of cervical screening and a low understanding of the role that HPV plays is also shown for other Australians at the time of pre-licensure of the HPV vaccines (Hausdorf et al. 2007; Marshall et al. 2007).

The shame associated with external discussions of family matters among Chinese people may explain why the participants are reluctant to talk openly about their cervical screening behaviours (Kwan et al. 2009) or sexual issues with their children. These perceptions may contribute to complacency in the vaccinated cohort in undertaking cervical screening because of their misconceptions about Pap screening (Zimet 2006), and if their mothers do not encourage them. Other Australian studies (Skinner et al. 2008; Smith et al. 2008b) also suggest that HPV vaccination could influence women's perceived risk of ICC and impact on screening compliance.

Stanton (2004) raises the issue of different perceptions of vulnerability between the scientific and local populations and this is evident across my three cultural samples. These differences, if not well understood could impact negatively on the success of new vaccine programs. As example, Stanton (2004) reported that in China there is a 'collectivism' approach to health decision-making (where decision making occurs at the local or communal level) as opposed to that which occurs in Anglo populations where an 'individualism' (decision making that impacts on the self) approach is dominant. Building on the 'collectivist' notion, the Chinese parents also indicate their confidence in vaccines that are part of a Government 'promotive strategy' (Stanton 2004: 288), and in this study

this is especially evident among those participants who have resided in Australia less than seven years.

My study also found that acculturation in the Chinese diaspora modified this belief and emerges as a contributory factor of their attitudes toward adolescent sexual behaviour. Chinese parents who have resided in Australia beyond seven years indicated they will validate new vaccines with their health professional or social networks before automatically agreeing to consent. Whilst these parents see the most benefit for HPV vaccination being in older adolescents (16 -18 years) or young adults (19+ years), their hesitant agreement for young adolescent vaccination (12 to 13 years) is based on the information about the vaccine's benefit and immune factors, and social acceptability factors if the vaccine is given through a school-based program. Californian Chinese-American women (Constantine and Jerman 2007) also held concerns about HPV vaccination for pre-adolescents under age 13.

The Chinese participants in this study were perplexed as to how they will discuss sexuality issues with their young daughters (Kwan et al. 2009), but this concern is not unique to them as a cultural group (Askelson et al. 2010), and did not overly impact on their overall acceptance of the HPV vaccines. The Chinese participants' agreement for sexuality education through schools to facilitate parent discussions could be perceived as an 'avoidance' strategy given their self-reported lack of sexual education. A study of 'Asian women (Brotto et al. 2005: 622) on acculturation and sexual liberalism shows that culture plays a 'meagre role' in sexual attitudes when cultural traditions are maintained, suggesting that conservative views also prevail among other Chinese-Australians.

The diverse opinions among Chinese parents about sexuality issues and adolescent HPV vaccination demonstrate that 'cultural rationality' (Leask et al. 2006:7243) is not necessarily shared by all people in a population group. The outliers (Ezzy 2001) in this study describe their difficulties in condoning the broader Australian acceptance of pre-marital sex and the need to protect the sexually naïve with HPV vaccination, thereby resisting

the boundaries imposed by others and generalising the intentions of their social networks to themselves (Leask et al. 2006), despite their disease-related concerns for their children. These attitudes may be in response to the stigmatisation of STI issues as shown in Kwan and colleagues Hong Kong study (2009), and the potential detriment to family relationships or reputation. This demonstration of rational logic among parents is the opposite of the 'technical rationality' as 'characterised by explicit scientific norms' (Leask et al. 2006:7423) in the key HPV vaccine message of 'cancer prevention'.

13.6 Strengths and limitations of the research

The implications of this study need to be considered within its methodological strength and limitations, and factors that may influence the design of similar studies in the future.

13.6.1 Methodological considerations of the qualitative approach

One of the primary aims of this study was to explore the extent to which culture as a social phenomenon influences the attitudes of parents toward adolescent HPV vaccination. Multiple methodological approaches are employed as an attempt for validation, but not in the pure sense of 'triangulation', as discussed in Chapter 6, which can be an alternative to validation (Denzin and Lincoln 2003: 8). Whilst qualitative research in the context of 'bricoleur' and the complexity principle is considered to widely apply to triangulation, this study shows that it can undermine its traditional notions (Kincheloe 2005: 333).

The approaches applied in this study affirms Morgan and Smircich's (1980) position that the researcher must not be preoccupied with the notion that it is the methods themselves rather than the human researcher that generates knowledge, rigor and richness to any inquiry. This is particularly evident through the subjective and contextual contributions of the Aboriginal advisors and facilitators and Chinese 'gatekeepers' that I then applied to the research process. What is important is that throughout this research the social structures of participants' lived experience

(cultural ‘relativism’, where the differences in cultures as a social phenomena impacts on health outcomes) (Thakker and Ward 1998)) in a public health paradigm are identified and considered in terms of their contextual contingency (Kincheloe 2005: 330). This is evident in the cultural traditions that underpin women’s attitudes toward ICC prevention, and these factors are important in the final conclusions.

13.6.2 Ontological position

In view of the methodological complexity, one could argue that the ontological position of this research is only partially constructed. It is difficult for me as a researcher of Anglo cultural background to fully attempt to understand the social world of parents from Aboriginal and Chinese cultural backgrounds, albeit accepting Thakker and Ward’s proposition (1998) that we as ‘culture’ researchers unintentionally make comparisons with our own socio-cultural environment. If access had been made available for me to engage with all Aboriginal participants, it may have enabled me to undertake deeper interpretations of the ‘social reality’ of the Aboriginal cultures than that which occurred. The results could have then been reinterpreted in the context of my new social reality to that point, resulting in more ‘fluid meanings’ of the data (Finlay and Ballinger 2006: 7, 20). Therefore the limitation of coming to an acceptance of ‘reality’ is acknowledged, knowing that it is difficult for ‘the truth’ to be attained in such circumstances (Pope and Mays 2006), and this acceptance is also a strength of the research.

13.6.3 Epistemological position

It was important for me as the researcher to embrace the philosophy of multidisciplinarity (Kincheloe 2005: 324,325). If Kincheloe’s (2005) position of contextual contingency is accepted, one can therefore legitimately question whether the interpretive bricolage is grounded on an epistemology of complexity as claimed. The research undertaken within the Aboriginal and Chinese communities (described in Chapter 8) reflects an epistemology of complexity, and cultural ‘relativism’ that pushes the methodological approach in this study into new conceptual terrain.

Kincheloe (2005: 324) viewed this approach to managing multiple factors as ‘an eclectic process which maintains theoretical coherence and epistemological innovation’, and it requires me the researcher, as a bricoleur, to have a heightened research self-consciousness and awareness of the numerous contexts in which the research operates.

The application of Ritchie and Lewis’s Framework approach (2003) to qualitative analysis has enabled me to draw on a range of social research traditions, and to provide rigour to fulfil the research aims in heterogeneous population groups. Epistemological factors within the Framework approach (Ritchie and Lewis 2003), with its philosophy of eclecticism, further support the challenges that were experienced in attaining the ‘truth’. For example*, interpretivism*, which takes a stance that objective understanding is impossible, is partially borne out because I, the researcher, was able to recognise part of the world I was studying (Finlay and Ballinger 2006) through my prior experiences in women’s health; and the second factor, *pragmatism,* endorses the value for me in choosing the most appropriate research methods to address the research questions within each participant group rather than a philosophical consistency across all groups, particularly the parent participants.

13.6.4 Generalisability

Another limitation of this study is its generalisability, more traditionally associated with a population. This study adopts Yin’s (1989 in Stenbacka 2001:552) concept of ‘analytical generalisability’, where understanding parental and GP attitudes toward adolescent HPV immunisation through purposively (or ‘strategic choice’ (Stenbacka 2001)) selected participants ‘lifts the empirical material to a general level’ (Stenbacka 2001:552). This stance allows me to understand the motivations for participant attitudes and the attainment of ‘situational representativeness’ (Horsburgh 2003), whilst acknowledging that because of the variations in their adaptation to the Australian environment, ‘cultural generalisations’ (Halcomb et al. 2007) can not be made.

The purposive samples are confined to participants who reside in specific geographic locations as earlier described. Although there are compelling reasons for recruiting Anglo and Chinese parents through hospital waiting rooms, or doctor referrals (as with the Chinese snowball sample), using this discrete population may have biased the sample towards those parents who naturally undertake health preventive measures, and excluded parents who do not. Furthermore, this sampling strategy did not yield the spread of Chinese male parent respondents required to give a balanced sample, and thus a 'constant comparative method' (Barbour 2001) in the parent results and analysis does not significantly address gender issues.

The sampling profile (Table 13) reveals the minimal diversity in the education profile of the Anglo and Chinese participants, and thus the attitudes of parents with low education (those who did not attain the last year of secondary school in Australia) have not been captured. Although sub-groups of parents and GPs are shown to share common beliefs which are consistent with other vaccine studies (Sturm et al. 2008), the results from this study are not generalisable to the broader Australian population, or to fathers and male guardians within these cultural groups.

As the majority of the participants are female mothers or guardians (and 100% of females in the Chinese and Aboriginal population samples), the views of males in the Chinese and Aboriginal populations, and other heterogeneous factors within the broader cultural groups was not accounted for. As HPV vaccines are considered 'women's business' in Aboriginal communities it was not culturally appropriate to include males in the same forum. Although there is sufficient data to enable me to identify trends and draw conclusions about the women's attitudes, the putative second-degree constructs (Calder 1977:356) developed from the Aboriginal data reflects the paucity of detail in the transcription of the group discussions. Moreover, the small sample size of each population group (Anglo, Chinese, and GP; n=15) does not enable sample

generalisability, although the data indicates that saturation point has been reached.

The purposive sampling approach to recruitment of the Chinese-Australian participants limits the variability in their demographic traits that may offer richer insights and broader relevance to the conceptualisation of key factors (Mays and Pope 2000), especially sexuality. Therefore the conclusions drawn in this study are limited to the discrete participant population groups, and this outcome reinforces the challenges that Zimet (2006) had previously identified where there is a lack of methodological congruence. Additionally, in the absence of similar cross-cultural Australian studies, the degree of transferability of the findings of this study to other Anglo or Chinese-Australians may be limited to others with similar parent profiles.

Whilst two studies were published in Australia during the data collection phase of this study, neither of those studies had direct comparability with my population sample. With McClelland and Liamputtong's (2006) small qualitative study (n = 14) the sample population was sexually active young adults aged 18 to 23 years from Melbourne, and the unique element was gender difference in attitudes. Marshall and colleagues' quantitative study (2007) (n = 2,000) assessed community attitudes toward the introduction of HPV vaccines; their method was confined to South Australia, was largely Anglo-centric with low cross cultural participation (201 out of 2000: 10%) and had minimal Aboriginal participant representation (13 out of 2,000, less than 1% of the sample population with telephone access). Its unique element was gender, age, and geographical location (rural versus urban) differences.

Recruiting GPs through a letter of invitation from a gynaecological oncologist may have biased the sample toward those who naturally engage in research surveys or women's health, or were attracted by more relational factors. However, the final sample had a balance of gender, age and clinical experiences. Other limitations with the GP study were the restrictions on the time available for interviewing (30 minutes within their

standard work day), and therefore some psychosocial and cultural issues are not as deeply explored as they could have been; and GPs self-assessing their levels of HPV knowledge which may not be an accurate reflection if a formal scale had been applied.

13.6.5 Role of the Aboriginal and Chinese advisory groups

Prior to this study I was not fully aware of the extent of the impact of perceived power and privilege on relationships between non-Aboriginal and Aboriginal communities, and research participants. Aboriginal populations experienced health inequalities and sociological vulnerabilities until the 1970s, (Boulton 2004), and if we consider Foucault's exploration of 'governmentality' (Finlay and Ballinger 2002:202), where populations are increasingly regulated and controlled through health systems as an outcome of research, it was important that the sample populations (and in particular the Aboriginal communities) had a sense of 'possession' rather than 'dispossession' over the implementation of HPV immunisation to the adolescents in their communities.

With the Aboriginal participants, their historical experiences of research and my non-existent relationship within the Aboriginal communities at the outset influenced the types of engagement I could have with their communities. This required me to develop my understanding of their culturally related protocols to enable me to engage with particular communities, and in the pre-recruitment phase I initially underestimated the time required for this. This constraint was also found to be a challenge for other cross-cultural researchers (Knobf et al. 2007), but due to my openness to new knowledge and willingness to embrace appropriate cultural processes, meaningful partnerships were successfully formed with both regions.

My effective engagement with the Aboriginal and Chinese participants is attributed to the 'unique insights' (Knobf et al. 2007:1190) that the study advisers gave to ensure culturally respectful research protocols. Their guidance facilitated participant recruitment strategies, the modified interview topic guides (Appendix 15.1), and allowed for trust and

collaboration (Halcomb et al. 2007: 1002) toward the study to develop among the parents that resulted in sampling adequacy and sufficient data to be obtained for comparisons. Specific protocols for research in Aboriginal populations that are described in Part 2 are inconsistent with some elements of Western cultural research practices. Aboriginal women generally do not publicly discuss intimate or sexuality issues therefore their engagement with the research process validates the appropriateness of the research methods.

In Central Australia, the recruitment of a high proportion of parents who are also Aboriginal Health Workers may have engendered bias in participant responses, due to their base knowledge of HPV infection, and their affinity with immunisation as disease prevention. However, an unanticipated benefit of empowerment (Halcomb et al. 2007) emerged through the focus group approach where participants state that their involvement in the HPV study has empowered them to better educate their communities.

Reciprocal relationships are important in Aboriginal research relationships (Donovan and Spark 1997) and it was important to me that any outcome from this study would have a tangible benefit for these populations. The collaborations arising from this research has also led to reciprocal outcomes listed in the preliminary section of this thesis, including the development and funding of HPV radio advertisements in five customised languages for the Central Australia region (Appendix 28).

13.6.6 Timing of the study

This study was originally timed to pre-empt the introduction of HPV vaccines into the Australian HPV immunisation program. However, the unanticipated haste in which the 4vHPV vaccine was introduced into a school-based program (April 2007) meant that some data from three of the Chinese parents was collected just before its implementation, and they may have had a higher level of knowledge of HPV vaccines due to increased community advertising. Parent and GP attitudes were also captured in advance of the availability of specific data for the 2vHPV

vaccine, and therefore suppositions based on Phase 3 trial data were made about its efficacy for ICC.

13.6.7 Data management

Applying a ‘Framework’ approach to this study has enabled our knowledge to be advanced, although some limitations emerged. Because the ‘Framework’ utilises an ‘a priori’ approach that requires a highly structured and deductive approach (Pope et al. 2000; Barnett-Page and Thomas 2009) the iterative approach to coding may not adequately reflect the original accounts of the Aboriginal population in particular. The third-party approach to capture important data in the interview process with Aboriginal participants was necessary, but their need to transcribe the participants’ responses during the focus groups was a limitation.

My reliance on multiple investigators in Victoria and Central Australia to simultaneously conduct the discussion and transcribe impacted on their potential to capture in-depth description (Herriott and Firestone 1983), due to the pace of discussion. Although all AHWs were trained in the interview schedule and HPV information prior to data collection, the loss of meaningful detail (Halcomb et al. 2007) was evident in some of the transcriptions. Only the key issues raised within the discussion are provided and further insights and rich data are not recorded. Furthermore, more attention could have been given to disconfirming and negative cases (Mays and Pope 2000), particularly in Victoria where the phenomenon of compatibility with women’s attitudes toward Western medical models of female health prevention were not sufficiently explored and reported.

This lack of detailed reporting by AHWs may be due to several factors. The women’s levels of interviewing skills were not ascertained and assumptions were made about their capabilities, based on the advisory group’s recommendations. Additionally during the training session in Victoria, my expectations about capturing rich data may not have been well enough articulated; and therefore it appears that the requirements were not well enough understood by the AHWs undertaking the interviewer role. Additionally, AHWs being part of the community they

were collecting data from may have instinctively understood the context in which the responses were made, and therefore they may have underestimated their need to draw further information from the women, or transfer information about the contextual framework sufficiently to me. Whilst I attempted to clarify elements of the data through post-interview telephone conversations, because limitations with recall were evident, their responses did not always engender the amount of detail I was seeking about particular points.

An alternative approach for future research would be to provide greater training in interview techniques and data transcription in focus group discussions, requiring longer lead times in the research relationship between the principal investigator and communities. The approach developed for this research typifies the difficulties of acquiring detailed information about the attitudes of participants where English is not often the first language, as in communities in Central Australia (ABS 2006 census; Dunbar et al. 2007).

With the Chinese participants, the absence of a Chinese bi-lingual interviewer to carry out the Chinese may have impacted on the quality of the data collected, especially with those participants who were resident in Australia less than seven years and had some difficulties with English articulation. However, my undertaking of the interviews has several benefits. It eliminates the ‘cultural bias’ and ‘cultural responsiveness’ variables (Okazaki and Sue 1995:371; Knobf et al. 2007) that can influence research participation, especially with sensitive issues where interpreters may distort the responses to ‘normalise discussions’ and ‘avoid stigma or embarrassment to their group’. However, other investigators have noted that ethnic and gender-matching in research influences health research (Flaskerud and Nyamathi 2000:3, 8, 9; Knobf et al. 2007) and this may be an important consideration for future research.

13.6.8 Issues encountered with researching 'culture'

This thesis did not attempt to undertake a comprehensive discussion on Aboriginal or Chinese 'culture' per se, due to each having nebulous and intricate characteristics. The scope of 'culture' as a vaccine research focus has been limited by the paucity of systematic and theoretical literature in other vaccine-related studies, and especially on Aboriginal culture (Morrissey et al, 2004), Chinese culture, and their vaccination practices. Moreover, the influence of 'culture' on attitudes toward adolescent HPV vaccination had not been a particular focus in the HPV-related literature but was embedded in a limited number of studies that I reviewed up to 2006, mainly from the UK (Waller et al. 2004), the USA (Zimet 2006), and Mexico (Lazcano-Ponce et al. 2001).

Recently, literature on normative values and HPV vaccines within specific cultures emerged from the South East Asia region (Pitts et al. 2009; Wong et al. 2009), but 'culture' is inferred from comparisons made through geography (i.e. place of birth) or skin colour. Whilst acculturation was found to be a key factor in a study with New York Chinese immigrants and their experiences of cancer education and screening (Kwong 2006), this phenomenon is not included in this study's design due to its extensive theoretical underpinnings which may limit the analysis on cultural influences on attitudes.

The comparison of findings from this study with previous studies is challenged by the lack of comparative data and methodological consistency about cross cultural attitudes toward HPV vaccination. Although several studies examined racially diverse samples (McClelland and Liamputtong 2006; Slomovitz et al. 2006; Marlow et al. 2009; Reiter et al. 2009) the low numbers of Chinese and / or Indigenous or 'non-Hispanic African-American' participants in those studies make cultural comparisons difficult. A possible explanation for this is the lack of conceptual consistency in defining 'cross-cultural' populations.

The absence of a standardised classification of population groups for cross cultural health research (Okazaki and Sue 1995; Bradby 2003) limits

the ability to compare the results of this study with other cross cultural populations. For example, in the health literature, a range of inconsistent classifications and static categories (Chiu 2004; Pfeffer 2004; Elkans et al. 2006) have been applied when referring to people of different cultural ancestries. The terms ‘culture’, ‘race’ ‘ethnicity’, ‘ethnic minorities’, ‘black’ or ‘white’ have been applied interchangeably despite these classifications being neither homogenous nor immutable (Modood 1998; Ashcraft and Allen 2003; Bradby 2003; Pfeffer 2004; Elkans et al. 2006; Ogilvie et al. 2007; Tissot et al. 2007; Bhatla et al. 2008; Shin 2008; Marlow et al. 2009; Hughes et al. 2009; Reiter et al. 2009). The classification by colour such as ‘black’ and ‘white’ in international studies implies that there is homogeneity across skin colour, and does not appropriately distinguish between intracultural differences within similar population groupings.

Inherent in the proposition of a generic classification is the risk of inaccurate generalisations such as ‘the ‘black’ perspective’, or ‘the Aboriginal perspective’ (Morgan et al. 1997), [or ‘the Chinese perspective’], across and within the heterogeneity of these cultural groups (Peberdy 1997; Bond and Brough 2004; McMurray and Param 2008). In this study, racial differences in levels of HPV knowledge (Cates et al. 2009) were found to account for some disparities within knowledge levels especially among the Aboriginal and Chinese participants. However the validity, or the implication that ‘colour’ or ‘geographical region’ as the defining trait, can be questioned as my data indicates it was due to system and educational factors, influenced by cultural norms.

The application of ‘geographical’ classifications to define cultural groups also has limitations (Elkans et al. 2006). For example, in Australia the term ‘Asian’ is used to constitute a ‘racial category’, and infers a homogenous group, although there is, for example, diversity and complexity between people of, for example, Chinese, Malaysian, Singaporean and Korean descent, and this inaccuracy is borne out in comments made by the Chinese participants about the image on the Pap smear brochure.

I found that the methodological approach by 'ethnic' cultural grouping allowed the phenomena to be explored in distinct population groups. As a result, insights have emerged across cultural groups that might not be obtained from a general population sample, especially with the Aboriginal parents. With the GPs, there is not sufficient ethnic cultural diversity among the sample to make meaningful cultural comparisons.

13.7 SECTION B: CONCLUSION

13.7.1 Overall conclusions

Participant attitudes toward adolescent HPV vaccination reflect the fundamental complexity in gaining acceptance for new public health initiatives in nations with diverse populations. The novel findings in this study demonstrate why there is still a disparity in cervical screening practices among some groups of Australian women, and their cultural needs with the implementation of the HPV vaccines. This has implications for the current and future vaccinated cohorts in being sufficiently protected against ICC. Whilst some parental attitudes towards HPV vaccines are found to be culturally bound, there are common normative factors across all three parent population groups toward sexually related adolescent vaccines. This reflects attitudes also found in other international studies that suggest that moral imperatives are paramount in parental attitudes, regardless of ethnicity. In this study, geographical, social and environmental contexts that shape cultural norms are shown to influence parental attitudes.

The disparity evident in knowledge levels among Australian people, including GPs, indicates that the current bio-medical approach to a broad-based HPV immunisation program in Australia may have limitations in empowering decision making (Haas et al. 2009), especially as it is a mixed culture nation. However some studies (Dempsey et al. 2006; Lenselink et al. 2007) posit that knowledge is not a significant predictor of acceptance. The assumption that greater awareness of HPV implies correct knowledge (Abramoff 2007; Gerend and Magliore 2008) or that providing factual information to parents enables 'focused' (more detailed)

(Downs et al. 2008:1596, 1602) understanding and support is not borne out in the literature (Dempsey et al. 2006; Leask et al. 2006; Downs et al. 2008), and may in fact polarise people against consent.

This study clearly demonstrates that within seemingly homogeneous cultural groups heterogeneity exists, and that cultural groups within the Australian population have specific needs in relation to education approaches to adolescent HPV vaccination. As our participants noted, the media efforts of the Australian Government by providing generic HPV vaccine information translated into different languages did not sufficiently meet their diverse cultural and information needs. Understanding these differences presents challenges in the development of targeted educational strategies for cross-cultural populations that remain at risk of transubstantive error (Wells 1985; Robinson 1997) when key factors are ignored.

In Australia, the very short lead times between licensure and the 4vHPV immunisation program did not allow for adequate culturally appropriate communication to key stakeholders, as shown by the low knowledge levels in parents and GPs. This is despite recommendations from an Australian study (Rosenthal et al. 2007) and WHO (WER 2005:301) that knowledge gaps and attitudes toward ‘cervical cancer, genital warts, HPV and HPV vaccine’ of health providers and the general population should be identified before HPV vaccines are introduced.

Furthermore a resource-development strategy that involves the dominant cultural groups or its underscreened or non-vaccinated members is essential. Understanding the diverse characteristics of a population can engender parental support and empower groups to develop dedicated HPV education strategies and messages, as was successfully undertaken with a Vietnamese-American community with HBV vaccines (McPhee et al. 2003), albeit recognising the resource implications in achieving this in Australia.

The HPV vaccine is being publicly promoted as a ‘specific benefit’ (‘cervical cancer’ vaccine) and this may pose challenges for some cultural groups in Australia whose paradigms of disease and health are culturally bounded and diverse (Dein 2004). Moreover, that one’s cultural background explains a person’s perspective of the rubric ‘cancer’, and in particular the emotional response that ultimately frames attitudes to health and illness.

As Kwong (2006) noted, recommended medical regimens will only be adopted in cross-cultural populations if they fit their belief systems. This study found that there were a range of mental models among participants determined by the participant’s personal experience and cultural values. Participants’ attitudes toward the HPV vaccines provides insights to the influences of subjective norms (McClelland and Liamputtong 2006) and conceptual limitations within their existing mental models (Downs et al. 2008), and reinforces the notion of cultural rationality (Leask et al. 2006) where multiple factors interplay in parent decision making toward vaccination.

Aboriginal and Chinese parents are particularly challenged by the relational consequences of the HPV information. Therefore the consent processes toward acceptance of HPV vaccine may be impacted upon negatively if there is perceived social stigma and tensions of differing degrees of acceptance across communities, especially for those with strong religious principles (Gonik 2006). Waller and colleagues’ UK study (2005) demonstrates the impact that education levels and causal associations of HPV and ICC can have on paradigms of ICC prevention and shame and anxiety, especially among women from ‘non-white’ ethnic groups, who have irregular screening practices and of low education. This reinforces that HPV educational materials need to meet the information needs of women from diverse socio-demographic groups to reduce anxiety and encourage ICC preventive measures.

Congruence between the parent and their health provider is a crucial element that influenced the acceptance of new vaccines (Gonik 2006;

Tissot et al. 2007) of all three cultural groups and GPs. Whilst the data demonstrates the inconsistent quality of communication among GPs, this seems to be the symptom of a more fundamental system and socio-political problem where the cultural features that a patient brings to a consultation are not always well understood within the paradigm of disease and illness (Kwong 2006).

My findings show that Australian Aboriginal and Chinese women have important gynaecological health concerns that are not being sufficiently met through current system, information or education strategies. We now know that communities have specific needs, and that involving the targeted community in the development and framing of adolescent vaccine approaches has the potential to significantly empower and enhance vaccine uptake. Regardless of what paradigm of care is determined for future ICC prevention, it is clear from participant responses that Australian women want to be empowered to make informed health decisions. As Armstrong and Murphy (2008) suggest, withholding HPV information has negative consequences when women lack the causal mechanisms.

The implementation of the HPV vaccines in Australia shows an absence of respect for applying the findings from previous vaccine studies undertaken in diverse populations, and the recommendations of peak bodies. The findings in this study reinforce the emergence of greater parental control over adolescent vaccination when it is not deemed compulsory, and when the vaccine's benefits are not perceived (Downs et al. 2008). However, of concern is that parents who adopt this attitude to HPV vaccination may be operating from a construct of 'naïve understanding', where the link between vaccination and disease prevention may be sufficient, but leaves parental consent vulnerable to negative reporting of the HPV vaccines.

Consideration of social and environmental factors is clearly low in the Australian development of the HPV immunisation program, especially for how people will make sense of information about HPV and its link to ICC

and its sexual transmission. HPV as an STI is not well understood and has connotations of stigma among the participants which is shown in previous empirical research. Parental responses to information exposing HPV as an STI may influence both the uptake of HPV vaccination and dosage completion, and an opposite and unintended outcome may occur as feared by some AHWs in Central Australia and Victoria because of psychosocial factors.

A system-change approach to ICC prevention must deal with the conflicting values in democratic and pluralistic societies (McLeroy et al. 1988; Stanton. 2004); and hence there is potential to change the social environment and paradigms toward stigma and taboo in relation to HPV and other STIs that is evident in the three cultural groups. An Australian study (Boyle et al. 2008) on optimal health provision for Aboriginal women's health found that 'culturally safe' care is the key factor in health-care provision. This requires actions on the part of the non-Aboriginal health provider, such as training in cultural competence, to overcome language and cultural barriers, and alienation from mainstream health services that Aboriginal women consistently face. Moreover the bicultural schemas of the Aboriginal and Chinese participants guided their attitudes, and exposed the heterogeneous socio-cultural characteristics among groups that are often perceived as monocultural. This notion of the influence of cultural relativism on HPV vaccination was also found in the implementation of HPV vaccines in resource-poor countries (Bingham et al. 2009).

This study shows that parents and health professionals are critical 'gatekeepers' of adolescent vaccination (Stanton, 2004) and the responses of the Aboriginal and Chinese participants indicate the influences of professional and societal norms and values as a mediating structure on individual attitudes. The research findings of this study present a number of challenges for GPs with the implementation of HPV vaccines, including public expectation as a key educator on critical health

matters (Gust et al. 2005), although Australian GPs are found to adopt the role of ‘persuader’ rather than ‘informer (Leask 2009:121).

13.8 SECTION C: PRACTICAL IMPLICATIONS

13.8.1 Assisting diverse cultural groups to make an informed choice about adolescent vaccination

With HPV vaccination the new paradigm of ICC prevention for young Australian women encompasses a three-fold approach through combined cervical screening, immunisation and education. There are a range of factors that arise from this study in supporting parents or guardians in making informed choices about adolescent HPV vaccination. Fundamental to these factors is that generalisations about appropriate national HPV education strategies to cannot be made for a socio-culturally diverse Australian population.

13.8.2 Planning HPV vaccine programs that engender parental acceptance

Embracing a homogenous perspective of ‘communities’ as sharing common characteristics overlooks the relationship of subgroups and their inherent diversity of values, norms, attitudes and behaviors within the broader group that was identified by the Anglo and Chinese parents, and impacts on parental attitudes. McLeroy and colleagues (1988) suggest that it is the convergence or divergence within networks and subcultures that will define whether health initiatives will be resisted or supported. Therefore it is important for policy makers to understand the relational features of cultural groups to encourage support for adolescent HPV vaccinations. However, in fairness in a culturally diverse nation such as Australia, it is a complex undertaking to adequately identify the homogeneous or heterogeneous characteristics of network groups with their designated levels of multiplexity, and the economic viability of catering to this level of need.

Parent attitudes toward HPV vaccines were shown to be framed by multiple principles and are dependent on their ‘fit’ within individual, relational and contextual variables. Pasick and colleagues (in Kwong

2006) also recommend that when designing health promotion activities for cross-cultural populations specific approaches need to be undertaken.

Strategies for successful implementation of new vaccines have been raised in earlier studies (Stanton 2004; Di Clemente et al. 2005), and in this study the following features for successful HPV mass immunisation programs emerged:

i. The need to understand the socio-cultural norms of the local population and their health practices
ii. linking HPV education to intensified cultural paradigms
iii. targeting cultural structures that foster a positive environment for parents and guardians to consent to young adolescents being vaccinated

The conclusions of this study highlights the benefit of taking a socio-ecological approach (McLeroy et al. 2008; Stokols 1996; Bingham et al. 2009) when planning the implementation of controversial vaccines targeted at minors, in this case the HPV vaccines. A socio-ecological approach as a demonstration project that was successfully applied in 'Least Developed Country' environments (which reflect conditions in remote Australia) concluded that 'individual health behaviours are influenced at different levels within a complex environment' (McPhee et al. 2003; Herdman and Demspey 2005; Bingham et al. 2009:3, 2009a; Garland 2009; PATH 2010). In Australia, this approach has the potential to overturn the fear- reward based behavioural hypothesis (you can prevent ICC in your daughter by consenting to the HPV vaccine), evident particularly in the responses of Aboriginal and Chinese parents. The current concentration on a paradigm that supports the individual at the expense of socio-cultural and environmental determinants 'ignores the crucial connection between individual behaviour and social norms' (Tesh in McLeroy et al. 1988:351).

Australia is now embarking on the next wave of its HPV immunisation program for the foreseeable future through new policy recommendations of a national implementation strategy. With the changing paradigms of

screening approaches and intervals, now is the ideal time for health educators to also revise the cervical screening messages, and integrate them in more culturally effective ways into a broader community education program on HPV vaccination to satisfy parental factors for acceptance.

A ‘preventive synergy’ approach is the integration of biomedical with socio-ecological principles, and the cumulative reinforcement of messages and ability to influence policies (Di Clemente et al. 2005). If we apply this notion within the cultural context of those being targeted for the implementation of HPV vaccines, a co-ordinated network approach may enhance preventive services and fulfil parental and GP needs. This view is consistent with Stanton (2004) who noted the importance of cultural consideration for the successful introduction of vaccines. We can therefore surmise that the prevailing attitudes among the participants in this study toward HPV vaccines are a reflection of aspects of their integrated environment (relational, familial, community and societal) (Di Clemente et al. 2005) and in which socially-derived cultural norms are an integral component. Importantly this approach reduces the individual lifestyle hypothesis and a ‘victim blaming ideology’ (McLeroy et al. 1988:351) that was inherent in many of the participant approaches to a STI diagnosis, and thereby influencing their attitudes toward HPV vaccination.

Among all participant groups in this study ‘community as a power structure’ (McLeroy et al. 1988) was evident through the placement of female-centric ideology and the public agenda, and especially with the attitudes of several female Anglo parents. McLeroy and colleagues (1988) emphasised the political and economic factors of health promotives within this ideology. This study takes this proposition further by suggesting that the implementation of HPV immunisation globally has overlooked the social and system ramifications of the current agenda that positions females as the cause and victim of HPV infection. McLeroy and colleagues (1988:364) maintain that such oversights ‘can lead to programmatic failure because important community power structures

actively or passively block effective program implementation'. With the potency of the interpersonal processes at force within the Australian Aboriginal and Chinese-Australian communities in particular, this outcome could be of concern.

The solution to enhancing outcomes of HPV vaccination through 'linking agents' such as health clinics and schools requires program initiation and continuation by health professionals and educators (McLeroy et al. 1988:367). However from the findings in this study there is evidently a [mis-]perception of Australia Government coercion with child and adolescent immunisation (such as withholding the family financial allowance) and such a paternalistic approach needs to be addressed.

If critical lessons from population-based HBV immunisation strategies are heeded (Heffernan et al. 2010) we may well see an earlier reduction of HPV related disease globally. Importantly the engagement of key community stakeholders in all aspects of HPV vaccine implementation strategies to better understand the specific needs of diverse population groups will minimise the difficulties experienced with HBV immunisation and contribute to optimum uptake and sufficient coverage.

13.8.3 A socio-ecological framework for HPV immunisation in cross-cultural populations

Emerging data (Garland 2010) indicates the HPV vaccines now offer considerable protection against other HPV related diseases for both men and women, and this may influence future HPV vaccine implementation strategies. However, findings from my study suggest that the public benefit may be enhanced through a strategy that requires an understanding of intra and inter-cultural differences within the Australian population before males are included in a broad-based HPV vaccine program. Furthermore, the notion of 'informed consent' (seen as a 'western concept' (Stanton 2004) is not possible if all aspects of the biomedical and social consequences of HPV vaccination are not well understood by community members. This then poses a risk of 'therapeutic

misconception' (Stanton 2004:290) especially among those with limited education about ICC, who may benefit most from HPV vaccination.

The effectiveness of a socio-ecological intervention in changing sexual health paradigms was demonstrated in a study (Di Clemente et al. 2005) on adolescent STI control showed that a partnership approach with males toward knowledge and shared information about sexuality issues influenced sexual cognition (O'Sullivan and Brooks-Gunn 2005 in Ferris et al. 2006). Social capital (trust, reciprocity, and co-operation) was also found to influence attitudes toward STI issues, and this is an important factor for participants in this study. In order to satisfy the concerns raised by GPs and parents in this study, this alternative approach to new health initiatives has the potential to achieve a sustainable uptake of the HPV vaccines, and empower the population in decision making through an ecological lens.

Applying a socio-ecological framework into controversial vaccine implementation strategies will require involvement of critical cultural and religious stakeholders over a longer planning period than that afforded the Australian population in its initial implementation of HPV vaccines. The model shown in Figure 20 incorporates novel findings from this study into earlier concepts that enables an examination of the influences on behaviour from *micro-, meso-, exo-, and macrosystem* levels. This conceptual framework illustrates the multiple levels of influence on parents and HPV vaccination of pre-adolescents.

If the parent responses in this study are considered through a socio-ecological framework it is evident, with hindsight, that the implementation of HPV vaccines in Australia ignored the multiplicity of influences that shape attitudes and behaviour (Di Clemente et al. 2005). In particular, the cultural paradigms and environmental determinants as influences on parent consent are critical. For example, among the Aboriginal and Chinese participants the *microsystem* (intrapersonal factors such as interactions within one's family or informal social networks) is cited as a key source of information for consenting to vaccination for their children.

Figure 20: A socio-ecological model for HPV vaccine acceptance in cross-cultural populations

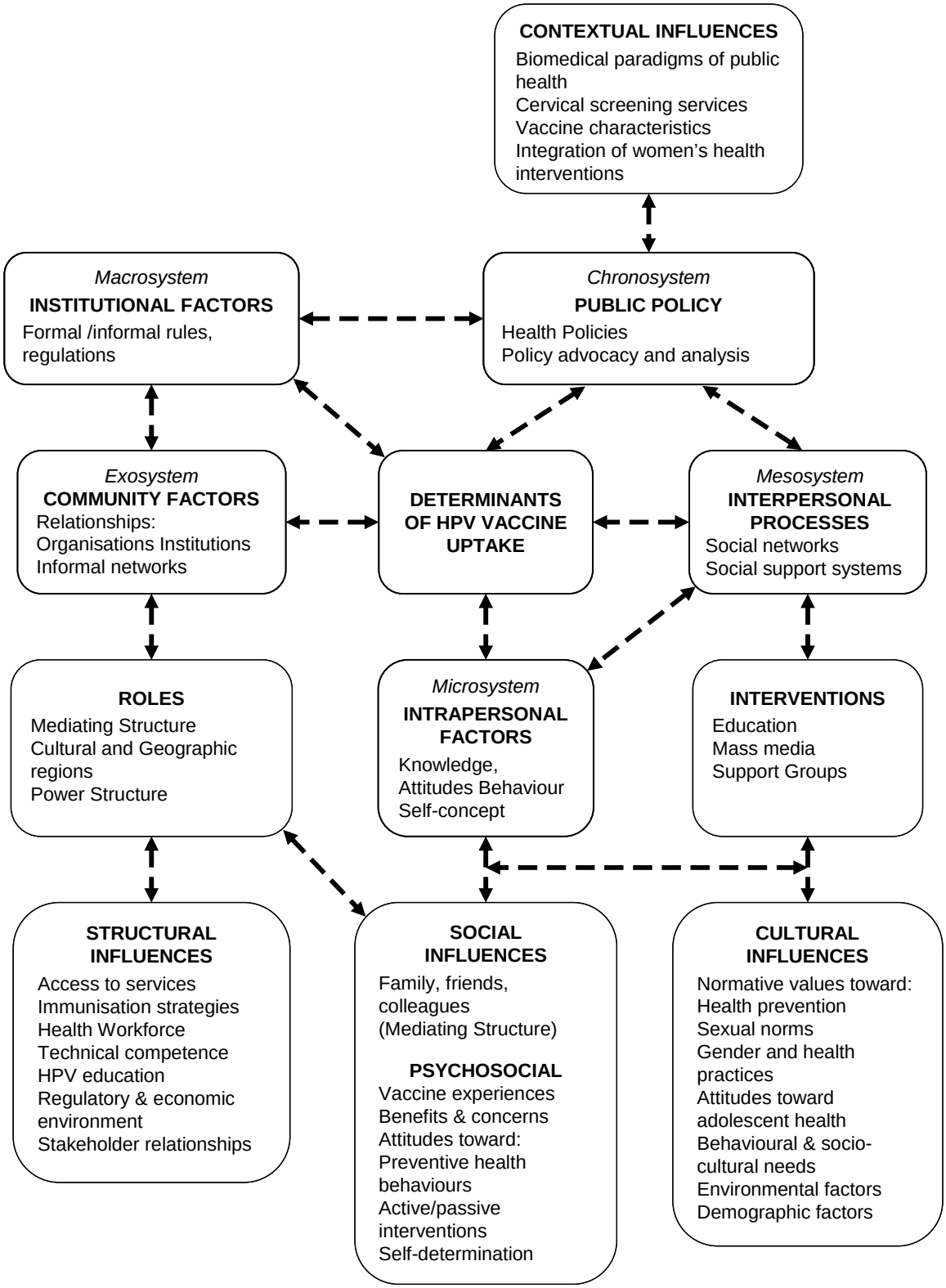


Figure developed by Margaret E Heffernan, 2010 © Adapted from (i) Brofenbrenner et al. in McLeroy et al 1988; (ii) Stokols 1996; (iii) Bingham et al 2009.

At the individual level, intrapersonal and interpersonal factors are shown to be important influences on attitudes toward HPV vaccination. The strength of interpersonal processes was evident among the Chinese-Australian participants in this study, and their relationship with significant others (family members and friends) especially for vaccine information was considered to be an important mediator of women's attitudes.

This study has shown that generalisations cannot be made for Aboriginal, Chinese or Anglo parents as interculturally they present heterogeneous characteristics. For example, among the Chinese participants some indicated strong religious affiliations, therefore the *mesosystem* (the interrelations among settings in which the individual is involved such as school, peer groups, and church) was a stronger influence on child health decisions than the *microsystem*, which was the norm for other Chinese parents.

Adding to the complexity for health policy planning, the *exosystem* (forces within the larger social system in which the individual is embedded) was an influence in which the unknown vaccine efficacy and safety data and high cost of the vaccine were perceived as deterrents to vaccine acceptance. The *macrosystem* (cultural beliefs and values that influence both the *microsystem* and the *macrosystem*) was an additional subsystem influencing attitudes and decision making especially among the Aboriginal and Chinese participant groups.

At the *microsystem* level Anglo and Chinese parents considered the media to be a potent factor in shaping societal norms, and thereby influencing behaviour and socialisation of adolescents and parents (Di Clemente et al. 2005). Furthermore, that mass media campaigns will promote acceptability of HPV vaccines as an ICC preventive, supporting McLeroy and colleagues (1988) assertion that such interventions at the intrapersonal level need to consider the needs of the targeted cohort.

A dyadic and culturally congruent service has been shown to be necessary for an effective partnership between health providers and the

individual. The family is also a key social influence where increased communication between the parent and adolescent will be instrumental in engendering support for HPV vaccination. At the community or *exo-system* level, broad-based education programs that create acceptable social norms around HPV prevention will help reduce stigma and normalise HPV infection but this is reliant on the stakeholders promoting and enhancing the social capital within the community (Di Clemente et al. 2005).

Because these subsystems are not static there is the potential for ongoing change or transactions that further influences behaviours, such as advances in our knowledge about the HPV vaccines, or unanticipated adverse events, or other as yet unknown factors. This study strongly recommends that health policy makers more fully understand the complexity of influences inherent in diverse groups, and incorporate these into future HPV and STI vaccine implementation strategies (Wong 2009).

13.8.4 Contributions of this study to knowledge of ICC prevention in Australia

The summary of key findings from this research (Table 34) highlights the critical implementation factors that still need to be considered if the adolescent Australian population is to benefit from HPV vaccination. Cultural 'ethnicity' influenced by 'social' and 'environmental' determinants *is* shown to influence parent attitudes toward HPV vaccination in Australia. This finding offers a different insight to the findings of two international studies (Davis et al. 2004; Korfage et al. 2008) where 'ethnicity' as a determinant of vaccine acceptance was dismissed.

Table 34: Key findings from the research about attitudes toward adolescent HPV vaccination

Key findings from the research about attitudes toward adolescent HPV vaccination
► Cultural ‘ethnicity’ influenced by social norms and environmental factors does influence attitudes toward adolescent HPV vaccination among three groups of Australian parents. ► Sexually related normative values are common among parents toward adolescent HPV vaccines. ► Inter- and intraculturally diversity among Australia’s population influences parental decision making about adolescent HPV vaccination. ► The preferred age for adolescent HPV vaccination varies among parents and is socially and culturally determined. ► The ‘female-centric’ approach to HPV vaccination limits public awareness about HPV infection and acceptance for adolescents. ► A holistic and socio-ecological approach to Australian adolescent HPV vaccination will empower and engender support for HPV vaccination among diverse population groups. ► A universal HPV vaccine education strategy does not satisfy the specific needs of diverse cultures, and the transubstantive error in current Australian HPV education resources limits cultural understanding. ► Cultural concordance between doctors and patients influences parental attitudes. ► Australian GPs and patients have ambiguous expectations toward the GPs educative role in ICC prevention. ► Aboriginal and Chinese women have important cervical health issues that are not being met through mainstream services.

The results in this study show that parents across ethnic cultures share normative values toward their children's care and protection, but differences occur around attitudes toward adolescent sexuality issues and information sharing as a result of socially and environmentally derived cultural norms. This in turn influences their perceived need for HPV vaccination in young children and attitudes toward age for vaccination. We now know that cultural concordance will enable a better understanding of contrasting norms toward Western medical models of health prevention which is based on 'individualism, competitiveness and materialism' (Flaskerud and Nyamathi 2000:5).

The study also reveals that the current female-centric and biased biomedical approach (as a 'cervical cancer' preventive) in HPV vaccine implementation strategies has limitations in terms of overall public awareness about HPV infection, and especially for males. This approach is further compounded by two key factors:

(i) the 'protectionist discourse' approach adopted by many GPs in patient sexuality and HPV education;
(ii) transubstantive error in current HPV public education resources.

Furthermore, Australian GPs and patients have ambiguous expectations on the role of GPs in educating patients about ICC prevention issues. A holistic approach to adolescent HPV vaccination that incorporates socio-ecological and multiple perspectives has the potential to be more effective in empowering parental acceptance of vaccines in Australia, a culturally and geographically diverse nation.

This study makes a distinctive contribution to the literature on Australian cross-cultural implications through the rich information gained from the Anglo, Aboriginal and Chinese populations, and subsequent understanding of how the initial immunisation strategy did not adequately meet their specific needs. The current landscape of HPV vaccination globally now lends further opportunities to build on our knowledge to enhance the implementation for the next generation of HPV vaccines.

13.9 Future research on HPV vaccines

1. Although the uptake results for Australia's first HPV immunisation program are encouraging, there are some states in Australia where these rates need to improve if the objective to reduce the Australian incidence of ICC through HPV immunisation is to be met. (Table 6 shows dosage completion for year 10 to 12 students in Northern Territory 80-64%; Victoria 82-69%; and lower uptake for South Australia, 70-64%; and Tasmania 73-57%).

Further research is needed to determine the barriers to parental consent and completion of the HPV vaccine schedule through school-based programs in diverse Australian populations, and the factors underpinning the attitudes of the 'vaccine rejectors' (Slomovitz et al. 2006) [those who did not consent through a school-based program];

2. With emerging data on males (Garland 2010) it will be important to capture quantitative data from a large-scale representative cross-cultural sample of Australians to determine the extent of influences especially cultural norms and religious beliefs on future male/female HPV vaccination programs.

3. Further investigation on the attitudes of a larger sample of the Aboriginal and Australian-Chinese population toward HPV vaccination, and the piloting of a socio-ecological approach to HPV immunisation in these population groups to determine if this approach increases acceptance of HPV adolescent vaccination.

4. The attitudes and clinical approaches of a representative sample of Australian GPs toward cervical screening, HPV vaccines, and education of HPV issues with patients particularly from cultural groups where these and sexuality issues are taboo.

References

AACR: Australian Association of Cancer Registries (AACR). 1999

AAP: Australia: Teens having sex earlier but first-time mums older: Report. *Australian Associated Press* (11.08.05) - Thursday, November 10, 2005

Abramoff B. Communication issues associated with the likelihood of HPV vaccine acceptance among college students. Honors Thesis, Cornell University May 2007

ABS 2002: Australian Bureau of Statistics: National Aboriginal and Torres Strait Islander Social Survey (NATSISS) 2002 .*Aus Bureau Statistics*, Cat. No. 4714.080

ABS 2005 Australian Bureau of Statistics and Australian Institute of Health and Welfare 2005

ABS 2006: Australian Bureau of Statistics .Causes of death, Australia*,* 2006. *Australian Bureau of Statistics* Cat. No. 3303.0

ABS 2006a. Australian Bureau of Statistics. Health literacy, Australia. *Australian Bureau of Statistics* 2006a Cat. No. 4233.0

ABS 2008: Australian Bureau of Statistics. Census 2006. Australian distribution of the population across Remoteness Areas. Australian Social Trends 2008. *Australian Bureau of Statistics* Cat. No. 4102.0

ABS 2008a: Year Book Australia. Cultural diversity in Australia 2008. *Australian Bureau of Statistics* Cat. No. 1301.0

ABS 2008b: Australian Bureau of Statistics. Population characteristics: Aboriginal and Torres Strait Islander Australians. Canberra: *Australian Bureau of Statistics* 2008; Cat No. 4705.0, 4713.0

ABS 2010: Australian Bureau of Statistics: Education attainment - Year Book Australia, 2009 -2010. Cat. No.1301.0

ABS 2010a: Australian Bureau of Statistics. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples, *Australian Bureau of Statistics* 2010.Cat 4704.0

ABS2010b: Australian Demographic Statistics. December Quarter 2009.Cat No.3101.0

ACC: Australia Cancer Council: Best practice in cervical cancer immunisation .Report of a roundtable discussion about the impact of the human papillomavirus vaccine in Australia. March 2008

ACIR: Australian Childhood Immunisation Register (ACIR) statistics. http://www.medicareaustralia.gov.au/provider/patients/acir/statistics.jsp. (Accessed: 22 January, 2010)

Adams M, Jasani B, Fiander A. Human papillomavirus (HPV) prophylactic vaccination: challenges for public health and implications for screening. *Vaccine* 2007; **25** (16): 3007 – 3013. Epub 2007 Jan 18

Agarwal SS, Sehgal A, Sardana S, et al. Role of male behaviour in cervical carcinogenesis among women with one lifetime sexual partner . *Cancer* 1993*;* **72** (5):1666-1669

Agius PA, Dyson S, Pitts MK, et al. Two steps forward and one step back? Australian secondary students' sexual health knowledge and behaviors, 1992–2002. *J Adol Health* 2006; **38** (3): 247-252

Agius PA, Pitts MK, Smith AMA, et al. Human papillomavirus and cervical cancer: Gardasil ® vaccination status and knowledge among a nationally representative sample of Australian secondary school students. *Vaccine* 2010; **28**: 4416-4422

Agorastos T, Chatzigeorgiou K, Brotherton JML, et al. Safety of human papillomavirus (HPV) vaccines: A review of the international experience so far*. Vaccine* 2009; **27** (52): 7270-7281

Agosti JM, Goldie SJ. Introducing HPV vaccine in developing countries. Key challenges and issues. *N Engl J Med* 2007; **356** (19):1908-1910

AGPN: Australian General Practice Network http://www.agpn.com.au/programs/immunisation (accessed 18 3 2010)

Aguilar LV, Lazcano-Ponce E, Vaccarella S, et al. Human papillomavirus in men: comparison of different genital sites. *Sex Transm Infect* 2006; **82**(1): 31–33

Agurto I, Arrossi S, White S, et al. Involving the community in cervical cancer prevention programs. *Int J Gyn & Obstetrics* 2005; **89** (Suppl 2): S38-S45

AHMRC: Aboriginal Health and Medical Research Council of New South Wales. http://www.ahmrc.org.au/AboriginalHealthInformation.htm (Accessed 19 Sept 2009)

AIHW: Australian Institute of Health and Welfare. Australasian Association of Cancer Registries. Cancer in Australia 2001. *AIHW cancer series* No. **28**. Canberra: AIHW, 2004

AIHW: 2009a Australian Institute of Health and Welfare. Cervical screening in Australia 2005-2006. Cancer series no **41** cat no CAN 36 AIHW. Canberra: AIHW, 2008 in **'**Abnormal Pap tests after the HP V vaccine'. Heley S, Brotherton JML. *Aust Fam Physician* 2009; **38** (12): 977-979

AIHW: 2009b Australian Institute of Health and Welfare. Cervical screening in Australia 2006-2007. *AIHW* cat. no. **CAN 43**; Published 2 April 2009; ISSN 1039-3307; ISBN-13 978 1 74024 912 6; http://www.aihw.gov.au/publications/index.cfm/title/10676; http://www.aihw.gov.au/publications/can/can-43-10676/can-43-10676-c01.pdf (Accessed 28 July 2010)

AIHW: 2009c Australian Institute of Health and Welfare. Australia's Welfare 2009. Australia's welfare series no. 9. Cat. No. AUS117. Canberra AIHW

Aldrich T, Becker D, García SG ,et al. Mexican physicians' knowledge and attitudes about the human papillomavirus and cervical cancer: a national survey. *Sex Trans Infec* 2005; **81**: 135 -141

Allen JD, Coronado GD, Williams RS et al. A systematic review of measures used in studies of human papillomavirus (HPV) vaccine acceptability. *Vaccine* 2010; **28**: 4027-4037

Andersen P. Cues of culture: The basis of intercultural differences in non-verbal communication. In: Samovar LA, Richard EP (Editors). *Intercultural Communication: A Reader* 2000: 258 - 269

Anderson I. Grass roots' input key to effective policy for Indigenous health. *The University of Melb Voice* 2007; **1**(10)

Anderson I, Baum F, Bentley M. Beyond Bandaids: Conclusion: Pg 281 – 289. Papers from the *Social Determinants of Aboriginal Health Workshop*, Adelaide, July 2004 Edited by Anderson I, Baum F and Bentley M

Anderson I, Crengle S, Kamaka ML, et al. Indigenous health 1: Indigenous health in Australia, New Zealand and the Pacific. *The Lancet* 2006; **367** (9524):1775 -1786

Anderson J. Literature review of women's understanding of HPV: Australian research and current gaps. *Papscreen Victoria* April 2006a

Andreasyan K, Hoy WE, Kondalsamy-Chennakesavan S, et al. Indigenous mortality in remote Queensland, Australia. *ANZ J of Public Health* 2007; **31** (5): 422 - 427

Aresu A. Sex education in modern and contemporary China: Interrupted debates across the last century. *Int J Educational Development* 2009; **29** (5):532 - 541

Armstrong N, Murphy E. Weaving meaning? An exploration of the interplay between lay and professional understandings of cervical cancer risk. *Soc Sci Med* 2008; **67**:1074 - 1082

Arredondo EM, Pollak KI, Costanzo P, McNeilly M, Myers E. Primary care residents' characteristics and motives for providing differential medical treatment for cervical screening. *J Nat Med Assoc* 2003; **95** (7): 576 - 584

ASCCP: American Society of Colposcopy & Cervical Pathology. Clinical use of HPV DNA testing. 2007

Ashcraft KL, Allen BJ. The racial foundation of organizational communication. *Communication Theory* 2003; **13** (1):5 - 38

Askell-Williams H, Coughlan M, Lawson M, et al. Beyond Bandaids. Chapter 4: You can't have one without the other: transactions between education and wellbeing for Indigenous peoples. Paper from the *Social Determinants of Aboriginal Health Workshop* Adelaide, July 2004: 56 -76. Edited by Anderson I, Baum F and Bentley M

Askelson NM, Campo S, Lowe JB, et al. Using the Theory of Planned Behavior to Predict Mothers' Intentions to Vaccinate Their Daughters Against HPV. *J Adol Health* 2010; **17**:248–254

Atkinson K. Schattner P, Margolis S. Rural secondary school students living in a small community: their attitudes, beliefs and perceptions of general practice. *Aust J Rural Health* 2003; **11**:73 - 80

Ault KA. Effect of prophylactic human papillomavirus L1 virus-like-particle vaccine on risk of cervical intraepithelial neoplasia grade 2, grade 3, and adenocarcinoma in situ: a combined analysis of four randomised clinical trials. *Lancet* 2007; **369:**1861 -1868

Ault KA, Giuliano AR, Edwards RP, et al. A phase I study to evaluate a human papillomavirus (HPV) type 18 L1 VLP vaccine. *Vaccine* 2004; **22** (23-24): 3004-3007

Baay MF, Verhoeven V, Peremans L, et al. General practitioners' perception of risk factors for cervical cancer development: consequences for patient education. *Patient Educ Couns* 2006; **62** (2):277 - 281

Baer H, Allen S, Braun L. Knowledge of human papillomavirus infection among young adult men and women: implications for health education and research. *J Commun Health* 2000*;* **25**: 67-78

Bailey EJ, Erwin DO, Belin P. Using cultural beliefs and patterns to improve mammography utilization among African-American women. The witness project. *J Nat Med Assoc* 2000; **92**:136-142

Bailey HD, Kurinczuk JJ, Kusel MM, et al. Barriers to immunisation in general practice. *ANZ J Pub Health* 1999; **23** (1): 6-11

Baillie R, Sibthorpe B, Anderson I, et al. Data for diagnosis, monitoring and treatment in Indigenous health: the case of cervical cancer. *Aust N Z J Pub Health* 1998; **22** (3 Suppl) 303-306

Bair RM, Mays RM, Sturm LA, et al. The acceptability of STD vaccination to Latino parents. *J Adol Health* 2005; **36** (2): 123-124

Bair RM, Mays RM, Sturm LA, et al. Acceptability of the human papillomavirus vaccine among Latina mothers. *J Pediatr Adolesc Gynecol* 2008; **21**(6):329-334

Bao YP, Smith JS, Qiao YL, et al. Human papillomavirus type distribution in women from Asia: a meta-analysis. *Int J Gynecol Cancer* 2008; **18**(1): 71-79

Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001; **322**: 1115-1117

Bardenheier B, Yusuf H, Schwartz B, et al. Are parental vaccine safety concerns associated with receipt of measles-mumps-rubella, diptheria and tetanus toxoids with acellular pertussis, or hepatitis B vaccines by children? *Arch Pediatr Adolesc Med* 2004; **158**: 569-575

Barnett-Page E, Thomas J. Methods for the synthesis of qualitative research: a critical review. ESRC National Centre for Research Methods. *NCRM Working Paper Series*. **01**/09

Barriball KL, While A. Collecting data using a semi-structured interview: A discussion paper. *J Adv Nursing* 1994; **19**: 328 -335

Baseman JG, Koutsky LA. The epidemiology of human papillomavirus infections. *J Clin Virol* 2005; **32** (Suppl 1): S16-24

Bastien JW. Cross cultural communication of tetanus vaccinations in Bolivia. *Soc Sci Med* 1995; **41** (1): 77-86

Bates Averill J. Matrix analysis as a complementary analytic strategy in qualitative inquiry. *Qualitative Health Research* 2002; **12**: 855-866

Baum F. Researching public health: Behind the qualitative-quantitative methodological debate. *Social Science and Medicine* 1995; **40** (4): 459-468

Baum F. The new public health: An Australian perspective. 2002. Oxford University Press, Melbourne

Bearinger LH, Sieving RE, Ferguson J, et al. Adolescent Health 2. Global perspectives on the sexual and reproductive health of adolescents: patterns, prevention and potential. *The Lancet* 2007; **369**: 1220-1231

Benet-Martinez V, Leu J, Lee F. Negotiating bi-culturalism: cultural frame switching in biculturals with oppositional versus compatible cultural identities. *J Cross-Cultural Psychology* 2002; **33**: 492-516

Benin AL, Wu AC, Holmboe ES, et al. How can we communicate about vaccines with adolescents and their parents? *Clin Pediatr* 2010; **49** (4): 373-380

Benítez-Bribiesca L. Ethical dilemmas and great expectations for human papillomavirus vaccination. *Archives of Med Res* 2009; **40** (6): 499-502

Beral V. Cancer of the cervix: a sexually transmitted infection? *Lancet* 1974; 1037-1040

Berlioz-Arthaud A, Perolat P, Buisson Y. 10 year assessment of infant hepatitis B vaccination program, in the Loyalty Islands (New Caledonia). *Vaccine* 2003; **21**: 2737 - 2742

Bernat DH, Harpin SB, Eisenberg ME, et al. Parental support for the human papillomavirus vaccine. *J Adol Health* 2009; **45** (5):525 - 527.Epub 2009 Jun 12

Berumen J, Ordoñez RM, Lazcano E, et al. Asian-American variants of human papillomavirus 16 and risk for cervical cancer: a case-control study. *J Natl Cancer Inst* 2001; **93** (17):1325 - 1330

Bhatla N, Lal N, Bao YP, et al. A meta-analysis of human papillomavirus type-distribution in women from South Asia: Implications for vaccination. *Vaccine* 2008; **26** (23): 2811 - 2817

Bhopal, R. Is research into ethnicity and health racist, unsound, or unimportant science? *BMJ* 1997; **314** (7096):1751 - 1757

Biellik R, Levin C, Mugisha E, et al. Health systems and immunization financing for human papillomavirus vaccine introduction in low-resource settings. *Vaccine* 2009; **27** (44):6203 - 6209

Bingham A, Drake JK, LaMontagne DS. Sociocultural issues in the introduction of human papillomavirus vaccine in low-resource settings. *Arch Pediatr Adolesc Med* 2009a; **163** (5):455-461

Bingham A, Janmohamed A, Bartolini R, et al. An approach to formative research in HPV vaccine introduction planning in low-resource settings. *The Open Vaccine J* 2009b; **2**:1-16

Binns PL and Condon JR. Participation in cervical screening by Indigenous women in the Northern Territory: a longitudinal study. *MJA* 2006; **185**: 490–494

Birley HDL. Continuing medical ignorance: modern myths in the management of genital warts. *STD & AIDS* 2001; **12** (2): 71-74

Black LL, Zimet GD Short MB, et al. Literature review of human papillomavirus vaccine acceptability among women over 26 years. *Vaccine* 2009; **27**: 1668-1673

Blake DR, Weber BM, Fletcher KE. Adolescent and young women's misunderstanding of the term 'Pap smear'. *Arch Ped & Adol Med* 2004; **158** (10): 966-970

Blaikie N. Designing social research. *Polity* 2000. Cambridge

Blair EM, Zubrick SR, Cox AH. The Western Australian Aboriginal Child Health Survey: findings to date on adolescents. *MJA* 2005; **183** (8):433-435

Block SL, Nolan T, Sattler C, et al. Comparison of the immunogenicity and reactogenicity of a prophylactic quadrivalent human papillomavirus (types 6, 11, 16, and 18) L1 virus-like particle vaccine in male and female adolescents, and young women. *Pediatrics* 2006; **118** (5):2135-2145

Blount A. Integrated primary care: organizing the evidence. *Family Systems & Health* 2003; **21**:121 -133

Bond C. A culture of ill health: public health or Aboriginality. *MJA* 2005; **183** (1):39 - 41

Bond C, Brough M. Beyond Bandaids: Chapter 14: The meaning of culture within public health practice – implications for the Study of Aboriginal and Torres Strait Islander Health. 2004:229 -236 Papers from the *Social Determinants of Aboriginal Health Workshop*, Adelaide, July 2004.Edited by Ian Anderson, Fran Baum and Michael Bentley

Bond L, Nolan T, Pattison P, et al. Vaccine preventable diseases and immunisations: A qualitative study of mothers' perceptions of severity, susceptibility, benefits and barriers. *ANZ J of Public Health* 1998; **22** (4): 441- 447

Bonhoeffer J, Heininger U. Adverse events following immunization: perception and evidence. *Curr Opin Infect Dis* 2007; **20**: 237 - 246

Borg AJ, Medley G, Garland SM. Polymerase chain reaction. A sensitive indicator of the prevalence of human papillomavirus DNA in a population with sexually transmitted disease. *Acta Cytol* 1995; **39**: 654-658

Borreani C, Miccinesi G, Brunelli C, et al. An increasing number of qualitative research papers in oncology and palliative care: does it mean a thorough development of the methodology of research? Health and Quality of Life Outcomes 2004; **2**: 7 - 15

Bosch FX, de Sanjosé S. Human papillomavirus in cervical cancer. *Curr Oncol Rep* 2002; 4:175 - 183

Bosch X, Harper D. Prevention strategies of cervical cancer in the HPV vaccine era. *Gynecol Oncol* 2006; 103:21-24

Bosch FX, Lorincz A, Munoz N, et al. The causal relation between human papillomavirus and cervical cancer. *J Clin Pathol* 2002; 55:244 - 265

Bosch FX, Manos MM, Munoz N, et al. Prevalence of human papillomavirus in cervical cancer: A worldwide perspective. International biological study on cervical cancer (IBSCC) Study Group. *J Natl Cancer Inst* 1995; **87**:796 - 802

Bosch FX, Munoz N. The viral etiology of cervical cancer. *Virus Res* 2002; **89:**183 - 190

Boudville IC, Wong SY. Health care systems in transition II: Singapore Part II--The current status of HIV-AIDS. *J Public Health Medicine*, 1998; **20**: 23-28; in Zhang K, Beck EJ. Changing sexual attitudes and behaviour in China: implications for the spread of HIV and other sexually transmitted diseases. *AIDS Care* 1999; **11**(5): 581 - 589

Boulton M. Challenge and Innovation: Methodological advances in social research on HIV /AIDS. Taylor and Francis, London, 1994

Bowden FJ. Controlling HIV in Indigenous Australians. *MJA* 2005; **183** (3):116-117

Bowden FJ, Fethers K. Let's not talk about sex: reconsidering the public health approach to sexually transmissible infections in remote Indigenous populations in Australia. *MJA* 2008; **188** (3): 182-184

Bowden F J, Paterson BA, Mein J et al. Estimating the prevalence of Trichomonas vaginalis, Chlamydia trachomatis, neisseria gonorrhoeae, and human papillomavirus infection in Indigenous women in northern Australia. *Sex Trans Infec* 1999; **75** (6): 431 - 434

Bowden F, Tabrizi S, Paterson BA, et al. Determination of genital human papillomavirus genotypes in Northern Australia using a novel, self-administered tampon technique. *Int J Gynecol Cancer* 1998; **8**: 471–475. doi: 10.1046/j.1525-1438.1998.09847.x

Boyce T, Peckham S, Hann A, et al. A pro-active approach. Health promotion and ill-health prevention. An inquiry into the quality of general practice in England. The Kings Fund 2010

Boyle FM, Dunne MP, Purdie DM, et al. Early patterns of sexual activity: Age cohort differences in Australia. *Int J STD & AIDS* 2003; **14**(11): 745-752

Boyle J, Rumbold AR, Clarke M, et al. Aboriginal and Torres Strait Islander women's health: Acting now for a healthy future. Editorial . *ANZ J Obs & Gyn* 2008; **48** (6): 526 - 528

Brabin L, Roberts SA, Farzaneh F, et al. Future acceptance of adolescent human papillomavirus vaccination: A survey of parental attitudes. *Vaccine* 2006; **24** (16): 3087-3094

Brabin L, Roberts SA, Kitchener HC. A semi-qualitative study of attitudes to vaccinating adolescents against human papillomavirus without parental consent. *BMC Public Health* 2007; **7**: 20-26

Brabin L, Roberts R, Stretch D, et al. Uptake of first two doses of human papillomavirus vaccine by adolescent schoolgirls in Manchester: prospective cohort study. *BMJ* 2008; **336**: 1056-1058

Bradby H. Describing ethnicity in health research. *Ethnicity and Health* 2003; **8**(1): 5-13

Brady M. Culture in treatment, culture as treatment. A critical appraisal of developments in addiction programs for Indigenous North Americans and Australians. *Soc Sci Med* 1995; **41** (11):1487 -1498

Braun V, Gavey N. “Bad girls” and “Good girls”? Sexuality and cervical cancer. *Women’s Studies International Forum* 1999a; **22** (2): 203 - 213

Braun V, Gavey N. With the best of reasons: cervical cancer prevention policy and the suppression of sexual risk factor information. *Soc Science & Med* 1999b; 48 (10):1463 - 1474

Braun-Courville DK, Rojas M. Exposure to sexually explicit web sites and adolescent sexual attitudes and behaviors. *J Adol Health* 2009; 45 (2): 156 -162

Breitkopf CR, Pearson HC, Breitkopf DM. Poor knowledge regarding the Pap test among low-income women undergoing routine screening. *Persp Sex Repro Health* 2005; **37** (2):78 - 84

Breitkopf CR, Pearson HC, Dinh TA, et al. Human papillomavirus vaccine decision-making in Da Nang, Vietnam: Perceived spousal and adolescent-parent concordance. *Vaccine* 2009; **27**(17): 2367 -2371

Brestovac B, Harnett GB, Smith DW, et al. Human papillomavirus genotypes and their association with cervical neoplasia in a cohort of Western Australian women. *Med Virol* 2005; **76:**106 - 110

Brewer NT, Fazekas KI. Predictors of HPV vaccine acceptability: A theory-informed systematic review. *Prev Med.* 2007; **45:**107 -114

Britt H, Miller GC, Charles J, et al. General practice activity in Australia 2008–2009. *General Practice Series* No. 25. 2009 Cat. No. **GEP 25**.Canberra: *Australian Institute of Health and Welfare*

Bronfenbrenner U. The ecology of human development: experiments by nature and design. Cambridge, MA: 1979.Harvard University Press

Brookman RR, (ed.) Koff RS, Schnaffer W, et al. Critical issues surrounding Hepatitis B: vaccination for adolescents: a roundtable. *J Adol Health* 1995; **17**:208 - 233

Brotherton JML. How much cervical cancer in Australia is vaccine preventable? A meta-analysis. *Vaccine* 2008*;* **26**:250 - 256

Brotherton JML, Deeks SL, Campbell-Lloyd S, et al. Interim estimates of human papillomavirus vaccination coverage in the school-based program in Australia. *Communicable Diseases Intelligence* 2008a; **32** (4):457- 461

Brotherton JML, Gold MS. Monitoring vaccine safety: a critical component of every immunisation program. *MJA* 2008c; **189** (5): 243 - 244

Brotherton JML, Gold MS Kemp AS, et al. Anaphylaxis following quadrivalent human papillomavirus vaccination. *CMJ* 2008b; **179:**525-533

Brotherton JML, Heywood A, Heley S. The incidence of genital warts in Australian women prior to the national vaccination program. *Sexual Health* 2009; **6** (3): 178 -184

Brotherton JML, Leask J, Jackson C, et al. National survey of general practitioners' experience of delivering the National Human Papillomavirus Vaccination Program. *Sexual Health* 2010; **7** (3): 291-298

Brotherton JML, McIntyre PB. Planning for human papillomavirus vaccines in Australia: Report of a research group meeting. *Communicable Diseases Intelligence*, *Communicable Diseases Australia* 2004; **28**: (2):129 -134

Brotto LA, Chik HM, Ryder AG, et al. Acculturation and sexual function in Asian women. *Arch Sex Beh* 2005; **34**(6):613-626

Brough M. Healthy imaginations: A social history of the epidemiology of Aboriginal and Torres Strait Islander health'. *Medical Anthropology* 2000; **20**:89 - 98

Brough M, Bond C, Hunt J. Strong in the city: Towards a strength-based approach in Indigenous health promotion. *Health Promotion J Aust* 2004*;* **15**: 215

Brown DR, Fife KH, Wheeler CM, et al. Early assessment of the efficacy of a human papillomavirus type 16 L1 virus-like particle vaccine. *Vaccine* 2004; **22** (21-22):2936-2942

Brown ECF. Some issues around consent remain unresolved. Letters. *BMJ* 2008; **336**: 1146

Brown ECF, Little P, Leydon G. Communication challenges of HPV vaccination. *Fam Pract* 2009; **0**: cmp087v1-cmp087:1-6

Brumder TP. Integrating mental health services with primary care assessing the psychological and social components of HPV provider education. Alliant International University; Clinical Dissertation April 2009

Budd A. AIHW's Health Registers and Cancer Monitoring Unit in cervical screening in Australia 2006-2007.*Health Insit*

http://www.healthinsite.com.au/news/Cervical_Screening_in_Australia_2006_2007 (accessed 8 3 2010)

Bulmer M. Race and ethnicity (Chapter 4); in Burgess RG. Key variables in social investigation. Routledge and Keegan Paul, London.1986

Burchell AN, Winer RL, de Sanjosé S, et al. Chapter 6: Epidemiology and transmission dynamics of genital HPV infection. *Vaccine* 2006; **24** (Suppl 3): S52-S61

Burk RD, Ho GY, Beardsley L, et al. Sexual behavior and partner characteristics are the predominant risk factors for genital human papillomavirus infection in young women. *J Infect Dis* 1996; **174** (4):679-689

Burke NJ, Jackson CJ, Thai HC, et al. Honouring tradition – accepting new ways: development of a hepatitis B control intervention for Vietnamese immigrants. *Ethnicity and Health* 2003; **9**:153- 169

Bush J. It's just part of being a woman: cervical screening, the body and femininity. *Social Science & Medicine* 2000; **50** (3):429-444

Buttery JP, Madin S, Crawford NW, et al. Mass psychogenic response to human papillomavirus vaccination. *Med J Aust* 2008; **189**: 261-262

Cain JM, Ngan H, Garland S, et al. Control of cervical cancer: Women's options and rights. *Int J of Gynecology & Obstetrics* 2009; **106** (2):141-143

Calder BJ, Focus groups and the nature of qualitative marketing research. *J Marketing Research* 1977; **14**(3):353-364

Calloway C, Jorgensen CM, Saraiya M, et al. A content analysis of news coverage of the HPV vaccine by US newspapers, January 2002 June 2005. *J Women's Health* 2006:**15** (7): 803 - 809

Callréus T. Perceptions of vaccine safety in a global context. *Acta Pædiatrica* 2010 ; **99**(2):166-71. Epub 2009 Nov 4.

Cameron C, Wallace LA, Ahmed S, et al. HPV vaccine: positive insights from universal adolescent HepB vaccination. *J Epidemiol Community Health* 2007; **61**: 1018 -1019

Campbell D, Pyett P, McCarthy L, et al. Beyond Bandaids: Chapter 9: Community Development and Empowerment. A review of interventions to improve Aboriginal health. Pg 165-172 Papers from the *Social Determinants of Aboriginal Health Workshop*, Adelaide, July 2004 Edited by Anderson I, Baum F and Bentley M

Campion MJ, Brown JR, McDance DJ, et al. Psychosexual trauma of an abnormal smear. *Br J Obstet Gynaecol* 1988; **95:**175 - 181

Canfell K, Sitas F, Beral V. Cervical cancer in Australia and the United Kingdom: comparison of screening policy and uptake, and cancer incidence and mortality. *MJA* 2006; **185:**482 - 486

Carinci IC, Garces-Palacia IC, Partridge EE. An examination of acceptability of HPV vaccination among African American Women and Latina immigrants. *J Women's Health* 2007; **16** (8):1224 - 1233

Carlos RC, Resnicow K, Dempsey AF. Maternal cultural barriers correlate with adolescent HPV vaccine use. *Cancer Epidem Biomarkers & Prev* 2010; **19:** 895

Carter JJ, Madeleine MM, Shera k, et al. Human papillomavirus 16 and 18 L1 serology compared across anogenital cancer sites. *Cancer Res* 2001; **61***:* 1934-1940

Casiday R, Creswell T, Wilson D, et al. A survey of UK parental attitudes to the MMR vaccine and trust in medical authority. *Vaccine* 2006; **24**:177 - 184

Cassell JA. Estimating STI morbidity in primary care. Editorial. *Sex Transm Infect* 2006; **82**:67

Cassidy WM, Mahoney FJ. A Hepatitis B vaccination program targeting adolescents. *J Adol Health* 1995; **17**: 244 - 247

Cassidy B and Schlenk EA. Uptake of the human papillomavirus vaccine: a review of the literature and report of a quality assurance project. *J Ped Health Care* 2010; Article in Press, Corrected Proof. doi:10.1016/j.pedhc.2010.06.015

Castellsague X. Natural history and epidemiology of HPV infection and cervical cancer. *Gynecologic Oncology* 2008; **110:** S4 - S7

Castle PE, Fetterman B, Akhtar I, et al. Age-appropriate use of human papillomavirus vaccines in the US.*Gynecol Oncol.* 2009; **114** (2):365 - 369

Castle PE, Scarinci I. Should HPV vaccine be given to men? Editorial. *BMJ* 2009; **339**:b4127

Cates JR, Brewer NT, Fazekas KI, et al. Racial differences in HPV knowledge, HPV vaccine acceptability, and related beliefs among rural, southern women. *The J Rural Health* 2009; **25** (1): 93 - 97

CCDP: Surveillance and Risk Assessment Division, CCDP *Health Canada* 2004 [Accessed 20.12.2004 on http:www.who.int/]

CDC from the Centres for Disease Control and Prevention. Hepatitis B vaccination coverage among adults – United States 2004. *JAMA* 2006; **296**: 33 - 34

Cervical Cancer Statistics: National Cervical Cancer Coalition (NCCC). (Reproduced from the *Reproductive Health Outlook* (RHO) Website (http://www.rho.org), 2000)

Chan SS, Cheung TH, Lo WK, et al. Women's attitudes on human papillomavirus vaccination to their daughters. *J Adolesc Health* 2007; **41**: 204 - 207

Chao C, Slezak JM, Coleman KJ, et al. Papanicolaou screening behavior in others and human papillomavirus vaccine uptake in adolescent girls. *Am J Pub Health* 2009; **99** (6):1137- 42

Cheek J, Fuller J, Gilchrist S, et al. Vietnamese women and Pap smears: issues in promotion. *ANZ J Public Health* 2008; **23** (1): 72 - 76

Chen CJ, Wang LY, Yu MW. Epidemiology of hepatitis B virus infection in the Asia Pacific region. *J Gastro & Hepatol* 2000; **15**: Supp E3-E6

Chen DS. Public health measures to control hepatitis B virus infection in the developing countries of the Asia - Pacific region. *J Gastro & Hepatol* 2000; **15**: Supp E7- E10

Chen DS (ed.).Long term protection of hepatitis B vaccine: lessons from Alaskan experience after 15 years. Editorial. *Ann Internal Med* 2005; **142**: 384 - 385

Chen QS Jr, Ngo-Metzger Q, Tran LQ, et al. Hepatitis B vaccination among Vietnamese-American children in a Boston community clinic. *Asian Am and Pacific Islander J Health* 2001; **9**:179 - 187

Cheng MH. Hepatitis B vaccination in China. *Lancet Infec Dis* 2006; **6** (9): 548

Chew-Graham C, Mole E, Evans LJ, et al. Informed consent? How do primary care professionals prepare women for cervical smears: a qualitative study**.** *Patient Educ Couns* 2006; **61**(3):381 - 388

Chilton JA, Gor BJ, Hajek RA, et al. Cervical cancer among Vietnamese women: Efforts to define the problem among Houston's population. *Gynecologic Oncology* 2005; **99**(3) Suppl 1:S203 - S206

Chingang LC, Bischof U, Andall-Brereton G, et al. Have a Pap smear! – Doctors, their clients, and opportunistic cervical cancer screening. *Int J STD AIDS* 2005; **16**: 233-236

Chiu L. Minority ethnic women and cervical screening: a matter of action or research? *Primary Health Care Research and Development* 2004; **5**: 104-116

Cho, LJ, Yada M. Tradition and change in the Asian family. *East-West Center*, Honolulu, 1994

Chow SN, Soon R, Park JS, et al. Knowledge, attitudes, and communication around human papillomavirus (HPV) vaccination amongst urban Asian mothers and physicians. *Vaccine* 2010; **28**(22):3809-3817

Chu C. Cross-cultural issues in contemporary Australia. *Ethnicity and Health* 1998; **3** (1 / 2): 125- 134

Chung PJ, Travis R, Kilpatrick SD, et al. Acculturation and parent-adolescent communication about sex in Filipino-American families: A community-based participatory research study. *J Adol Health* 2007; **40** (6): 543- 550

Clark LR, Jackson M, Allen-Taylor L. Adolescent knowledge about sexually transmitted diseases. *Sex Transm Dis* 2002; **29**:436- 443

Clarke O, Ebel C, Catotti D, et al. The psychosocial impact of human papillomavirus infection: implications for health care providers. *Int J STD AIDS* 1996; **7** (3):197-200

Clement R, Noels KA. Towards a situated approach to ethnolinguistic identity: the effects of status on individuals and groups. *J Language & Social Psychology* 1992; **11**:203- 232

Clifford GM, Franceschi S, Diaz M et al. Chapter 3: HPV type-distribution in women with and without cervical neoplastic diseases. *Vaccine* 2006; **24** (Suppl 3):S26- 34

Clifford GM, Gallus S, Herrero R, et al. IARC HPV Prevalence Surveys Study Group. Worldwide distribution of human papillomavirus types in cytologically normal women in the International Agency for Research on Cancer HPV prevalence surveys: a pooled analysis. *Lancet* 2005a; **366** (9490): 991-998

Clifford GM, Rana R, Franceschi S, et al. Human papillomavirus genotype distribution in low-grade cervical lesions: comparison by geographic region and with cervical cancer. *Cancer Epidemiol Biomarkers Prev* 2005b; **14** (5):1157-1164

Clifford GM, Smith JS, Aguado T, et al. Comparison of HPV type distribution in high-grade cervical lesions and cervical cancer: a meta-analysis. *Br J Cancer* 2003; **89**:101 - 105

Colucci R, Hryniuk W, Savage C. HPV vaccination programs in Canada. Are we hitting the mark? *Report Card on Cancer in Canada* 2008; 7-10

Condon JR , Barnes T , Cunningham J, et al. Long term trends in cancer mortality for Indigenous Australians in the NT. *Med J Aust* 2004; **180** (10): 504-507

Condon JR, Cunningham J, Barnes T, et al. Cancer diagnosis and treatment in the Northern Territory: assessing health service performance for Indigenous Australians. *Internal Med J* 2006; **36** (8): 498-505

Condon JR, Rumbold AR, Thorn JC, et al. A cluster of vulvar cancer and vulvar intraepithelial neoplasia in young Australian Indigenous women. *Cancer Causes and Control* 2009; **20** (1): 67-74

Conner M, Norman P. Predicting Health Behaviour. McGraw Hill, Berkshire; 2005

Conroy K, Rosenthal SL, Zimet GD, et al. Human papillomavirus vaccine uptake, barriers to vaccination, and predictors of vaccination in young women . *J Adol Health* 2009; **44** (2): Suppl 1: S13

Constantine NA, Jerman P. Acceptance of human papillomavirus vaccination among Californian parents of daughters: A representative statewide analysis. *J Adol Health* 2007; **40** (2):108-115

Coory MD, Fagan PS, Muller JM, et al. Participation rates in cervical cancer screening by women in rural and remote Aboriginal and Torres Strait Islander communities in Queensland. *Med J Aust* 2002; **177**:544-547

Correll P, Hayen A, Eyeson-Anan M. Hepatitis B immunisation in children aged 10 - 13 years in New South Wales. *NSW Health Bulletin* 2003; **14** (1-2):17-21

Cotton SC, Sharp L, Seth R, et al. Lifestyle and socio-demographic factors associated with high-risk HPV infection in UK women**.** *Br J Cancer* 2007; **97**(1): 133-139

Couzos S. A focus on Aboriginal women for cervical cancer prevention. (In 'Best practice in cervical cancer immunisation).Report of a roundtable discussion about the impact of the human papillomavirus vaccine in Australia. *Australia Cancer Council* March 2008

Creswell JW. Research Design: Qualitative, quantitative and mixed methods approaches *Sage*, Thousand Oaks 1995; 2003: 59

Creswell JW. Qualitative inquiry and research design: choosing among five traditions. *Sage*, Thousand Oaks, 1998, 2007(Prev. ed.1995)

Croft CA, Asmussen L. A developmental approach to sexuality education: Implications for medical practice. *J Adol Health* 1993; **14** (2): 109-114

Cui N, Li M, Gao E. Views of Chinese parents on the provision of contraception to unmarried youth. *Reproductive Health Matters* 2001; **9** (17):137-145

Cullen J, Schwartz M, Lawrence W, et al. Short-term impact of cancer prevention and screening activities on quality of life . *J Clin Oncol* 2004; **22** (5): 943-952

Cunningham J, Rumbold AR, Zhang X, et al. Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia. *The Lancet* 2008; **9**: 585-595

Cuschieri K. Should boys receive the human papillomavirus vaccine? No. *BMJ* 2009; **339**:b4921

Cutts FT, Franceschi S, Goldie S, et al. Human papillomavirus and HPV vaccines: a review. *Bulletin of WHO* 2007; **85** (9): 719-726

Cuzick J. Role of HPV testing in clinical practice. *Virus Res* 2002**; 89**: 263-269

Cuzick J, Mayrand MH, Ronco G, et al. Chapter 10: New dimensions in cervical cancer screening. *Vaccine* 2006; **24**: S90-S97

Dahlström LA, Tran TN, Lundholm C, et al. Attitudes to HPV vaccination among parents of children aged 12-15 years-A population-based survey in Sweden. *Int J Cancer* 2009; **000**: 000-000 UICC

Dai M, Bao YP, Li N, et al. Human papillomavirus in Shanxi Province, People's Republic of China: a population-based study.*Br J Cancer* 2006; **95**:96-101

Dai M, Zhang W, Clifford GM, et al. Human papillomavirus infection among 100 oesophageal cancer cases in the People's Republic of China. *Int J Cancer* 2007; **121**(6): 1396-1398

Dai Y, Huang YS, Tang M, et al. Distribution and clinical significance of human papillomavirus subtypes in Shenzhen city, People's Republic of China. *Int J Gynecol* 2008; **18**: 295 - 299

Daley EM,Perrin KM, Vamos C, et al. HPV knowledge among HPV positive women. *Am J Health Beh* 2008; **32**(5); 477-487

Daley MF, Liddon N, Crane LA et al. A national survey of pediatrician knowledge and attitudes regarding human papillomavirus vaccination, *Pediatrics2006;* **118**: 2280 - 2289

D'Andrade R. The development of cognitive anthropology. *Cambridge University Press* 1995

Da Ros, CT, da Silva Schmitt C. Global epidemiology of sexually transmitted diseases. *Asian J Androl* 2008; **10** (1):110 - 114

Das A, Madhwapathi V, Davies P, et al. Knowledge and acceptability of HPV vaccine by school children and their parents in Birmingham. *Vaccine* 2010; **28** (6):1440 -1446

Davis K, Dickman E, Ferris D, et al. HPV acceptability among parents of 10 -15 yr old adolescents. *Obs and Gyn Survey* 2004; **59** (12):820 - 822

Dawar M, Dobson S, Deeks S. Literature review on HPV 6, 11, 16 and 18: Disease and vaccine characteristics. *Public Health Agency of Canada* June 2007:1 - 33

Dearnley E, Spencer A, Williams H. Knowledge and acceptability of the HPV vaccine by schoolchildren and their parents in Birmingham. *Vaccine* 2010; **28:**1440 - 1446

de Carvalho NS, Teixeira LM, Pradel EM, et al. Vaccinating against HPV: physicians' and medical students' point of view. *Vaccine* 2009; **27**(20): 2637 - 2640

Dein S. Explanatory models of, and attitudes towards, cancer in different cultures. *The Lancet Oncology* 2004; **5**: 119 -124

De Ishtar Z. Living on the ground: The 'culture woman' and the 'missus'. *Women's Studies International Forum* 2005; **28** (5): 369 - 380

Dempsey AF. Vaccination against human papillomavirus. *Am J Manag Care* 2006; **12** (17 Suppl):S460 - 461

Dempsey AF, Abraham LM, Dalton V, et al. Understanding the reasons why mothers do or do not have their adolescent daughters vaccinated against human papillomavirus. *AEP* 2009; **19**(8): 531 - 538

Dempsey AF, Zimet GD, Davis RL, et al. Factors that are associated with parental acceptance of human papillomavirus vaccines: a randomized intervention study of written information about HPV. *Pediatrics* 2006*;* **117**: 1486 - 1493

Denny-Smith T, Bairan A, Page MC. A survey of female nursing students' knowledge, health beliefs, perceptions of risk, and risk behaviours, regarding human papillomavirus and cervical cancer. *J Am Academy Nurse Pract* 2006; **18**: 62 - 69

Denzin NK, Lincoln YS. The Landscape of qualitative research: Theories and issues. *Sage*, Thousand Oaks; 2003

de Sanjosé S, Bosch FX, Muñoz N, et al. Social differences in sexual behaviour and cervical cancer. *IARC Sci Publ* 1997; **138**: 309-317

de Sanjosé S, Diaz M, Castellsague X, et al. Worldwide prevalence and genotype distribution of cervical human papillomavirus DNA in women with normal cytology: a meta-analysis. *Lancet Infec Dis* 2007; **7**: 453-459

de Sanjosé S, Quint WGV, Alemany L, et al. Human papillomavirus genotype attribution in 10,575 cases of invasive cervical cancer worldwide. *Lancet Oncology* September 2010; (Accepted Draft version)

Descamps D, Hardt K, Spiessens B, et al. Safety of human papillomavirus (HPV)-16/18 AS04-adjuvanted vaccine for cervical cancer prevention: a pooled analysis of 11 clinical trials. *Hum Vaccin* 2009; 5 (5): 332-340

de Villiers EM. Human pathogenic papillomavirus types: An update. *Curr Top Microbiol Immunol* 1994; **186**:1-12

de Villiers EM, Fauquet C, Broker TR, et al. Classifications of papillomaviruses. *Virology* 2004; **324** (1): 17-27

de Visser RO, McDonnell E. Correlates of parents' reports of acceptability of human papillomavirus vaccination for their school-aged children. *Sex Health* 2008; **5**: 331-338

de Visser RO, Smith AMA, Richters J, et al. Associations between religiosity and sexuality in a representative sample of Australian adults. *Arch Sex Behav* 2007; **36:33**–46

Dew K. A health researcher's guide to qualitative methodologies. *ANZ J Public Health* 2007; **31**(5): 433-437

DHA: 2005 National Sexually Transmissible Infections Strategy 2005 - 2008, Department of Health and Ageing, Commonwealth of Australia, Canberra, June 2005

DHA 2005a. Department of Health and Ageing Australia. Aboriginal and Torres Strait Islander sexual health and blood borne virus strategy: 2005 – 2008. *OATSIH Publications* 2005. http://www.health.gov.au/internet/main/publishing.nsf/content/health-oatsih-pubs-sexhealth.htm (Accessed 23 8 2009)

DHA: 2007a Department of Health and Ageing. Vaccine Preventable Diseases and Vaccination Coverage in Australia, 2003 to 2005. *Communicable Diseases Intelligence* June 2007; **31**: Suppl

DHA: 2007b: Australian Government: Health, 2007 http://www.health.gov.au/internet/standby/publishing.nsf/Content/schools (Accessed 23 8 2009)

DHA: 2008 Overview of the Divisions of General Practice Program. Department of Health and Ageing: Government of Australia. 2008 http://www.health.gov.au/internet/main/publishing.nsf/Content/health-pcd-programs-divisions-index.htm

DHA: 2010a. National Cervical Screening Program. Australian Government, Department of Health and Ageing. http://cancerscreening.gov.au /internet/screening/publishing. nsf/Contents/facts (accessed 8/3/2010)

DHA: 2010b Immunise Australia Program: Immunisation Program (NIP) Schedule. Australian Government, Department of Health and Ageing: http://immunise.health.gov.au/internet/publishing.nsf/Contents/nips2 (accessed 8/3/2010)

DHANHVP: Australian Government, Department of Health and Ageing. Immunisation Provider Guidelines: Cervical Cancer Vaccination, National Human Papillomavirus (HPV) Vaccination Program, 2007

DHS. Immunisation News. Department of Human Services, Victorian Government: 2008 http://www.dhs.vic.gov.au/humanservicesnews/nov08/immun.htm (Accessed 2 Dec 2008)

DHS. Victorian immunisation strategy 2009-2012. Department of Human Services, Victorian Government: September 2008a

DIC: The People of Australia: Statistics from the 2006 Census. Department of Immigration and Citizenship. *Commonwealth of Australia,* 2008

Dickinson JA. Cervical screening: lessons from the Australian experience. *HKMJ* 1999; **5** (3): 226-228

Dickinson JA. Cervical screening: Time to change the policy. *MJA* 2002; **176** (3):547-550

Dickinson JA, Chan CSY. Opinion survey of Hong Kong primary care doctors about cervical screening. *HKMJ* 2001; **7**:284-290

DiClemente RJ, Salazar LF, Crosby RA, et al. Prevention and control of sexually transmitted infections among adolescents: the importance of a socio-ecological perspective – a commentary. *Pub Health* 2005; **119** (9): 825-836

Di Giuseppe G, Abbate R, Liguori G, et al. Human papillomavirus and vaccination: knowledge, attitudes, and behavioural intention in adolescents and young women in Italy. *Br J Cancer* 2008; **99** (2): 225-229

Dilraj A, Strait-Jones J, Nagao M, et al. A statewide hepatitis B vaccination program for school children in Hawaii; vaccination series completion and participation rates over consecutive school years. *Public Health Rep* 2003; **118**:127-133

DIMA 2001.Immigration: Federation to century's end.1901 - 2001.Canberra.ACT: *DIMA* Retrieved from www.immi.gov.au/amep/reports/reports/age_table.pdf

Dinh TA, Rosenthal SL, Doan ED, et al. Attitudes of mothers in Da Nang, Vietnam toward a human papillomavirus vaccine. *J Adolesc Health* 2007; **40** (6): 559-563

Doescher MP, Saver BG, Franks P, et al. Racial and ethnic disparities in perceptions of physician style and trust. *Arch Fam Med.* 2000; **9**:1156-1163

Domingo EJ, Novani R, Noor MR, et al. Epidemiology and prevention of cervical cancer in Indonesia, Malaysia, Philippines, Thailand, and Vietnam. *Vaccine* 2008; **26**(Suppl 12):M71-79

Domino G, Hannah MT. A comparative analysis of social values of American and Chinese children. *J Gross-Cultural Psychology* 1987; **18**: 58-77

Donders GG, Gabrovska M, Bellen G, et al. Knowledge of cervix cancer, human papillomavirus (HPV), and HPV vaccination at the moment of introduction of the vaccine in women in Belgium. *Arch Gynecol Obstet* 2008; **277**(4):291-298

Donovan B, Franklin N, Guy R, et al. Quadrivalent human papillomavirus vaccination and trends in genital warts in Australia: analysis of national sentinel surveillance data. *The Lancet Infectious Diseases*, Published online November 9, 2010 DOI: 10.1016***/S1473-3099***(10)70225-5

Donovan RJ, Spark R. Towards guidelines for survey research in remote Aboriginal communities. *ANZJ Public Health* 1997; **21**(1): 96-97

Dow S. AIDS fight aims at gay men, Aborigines. *The Age* 19 December 1996: **4**

Downs JS, de Bruin WB, Fischoff B. Parents' vaccination comprehension decisions. *Vaccine* 2008; **26** (12):1595-1607

Downs LS, Smith JS, Scarinci I, et al. The disparity of cervical cancer in diverse populations. *Gynecologic Oncology* 2008; **109** (2) Suppl 1: S22-S30

D'Souza G, Kremier AR, Viscidi R et al. Case-control study of human papillomavirus and oropharyngeal cancer. *N Engl J Med* 2007; **356**(19):1944-1956

Dudgeon MR, Inhorn MC. Men's influences on women's reproductive health: medical anthropological perspectives. *Soc Sci Med* 2004; **59**:1379-1395

Dunbar M, Moberley S, Nelson S, et al. Clear, not simple: An approach to community consultation for a maternal pneumococcal vaccine trial among Indigenous women in the Northern Territory of Australia. *Vaccine* 2007; **25** (13):2385-2388

Dunne EF, Unger ER, Sternberg McQuillan G, et al. Prevalence of HPV infection among females in the United States. *JAMA* 2007; **297**: 813-819

Durie M. The health of Indigenous peoples: Depends on genetics, politics, and socioeconomic factors. *BMJ* 2003; **326** (7388): 510-512

Dursun P, Altuntas B, Kuscu E, et al. Women's knowledge about human papillomavirus and their acceptance of HPV vaccine. *Aust N Z J Obstet Gynaecol* 2009; **49**: 202-206

Duval B, Gilca V, McNeil S, et al. Vaccination against human papillomavirus: A baseline survey of Canadian clinician's knowledge, attitudes and beliefs. *Vaccine* 2007; **25**: 7841-7847

Edstam JS, Dulmaa N, Nymadawa P, et al. Comparison of hepatitis B vaccine coverage and effectiveness among urban and rural Mongolian 2-year-olds. *Prev Med* 2002; **34**:207 -214

Einstein MH, Baron M , Levin MJ, et al. Comparison of the immunogenicity and safety of *Cervarix*™ and *Gardasil*® human papillomavirus (HPV) cervical cancer vaccines in healthy women aged 18–45 years. *Human Vaccine* 2009; **5** (10): 705 - 719

Eisenberg DJ. Information amount and patient empowerment: Participation in the HPV vaccination decision-making process. Thesis: Master of Arts, the Ohio State University, 2009

Eisenberg ME, Bernat DH, Bearinger LH, et al. Support for comprehensive sexuality education: Perspectives from parents of school-age youth. *J Adol Health* 2008; **42** (4): 352-359

Elfregen K, Kalantari M, Moberger B, et al. A population-based five-year follow-up study of cervical human papillomavirus infection. *Am J Obstet Gynecol* 2000; **183**: 561-567

Elkan R., Avis M., Cox K, et al. The reported views and experiences of cancer service users from minority ethnic groups: A critical review of the literature. *European J Cancer Care* 2007; **16** (2):109-121

Esposito S, Bosis S, Pelucchi C, et al. Pediatrician knowledge and attitudes regarding human papillomavirus disease and its prevention. *Vaccine 2007;* **25**: 6437-6446

Etzioni A. The active society. New York: Free Press, 1968

Ezzy D. Are qualitative methods misunderstood? *Aust NZ J Public Health* 2001; **25**:294-297

Fairley CK, Bowden FJ, Gay NJ, et al. Sexually transmitted diseases in disadvantaged Australian communities. Letter. *JAMA* 1997; **278** (2)**:** 117-118

Fairley CK, Chen S, Tabrizi SN, et al. The absence of genital human papillomavirus DNA in virginal women. *Int J STD AIDS* 1992; **3**(6):414-417

Fairley CK, Chen S, Ugoni A, et al. Human papillomavirus infection and its relationship to recent and distant sexual partners. *Obstet Gynecol* 1994a; **84**(5):755-759

Fairley CK, Hocking J, Gurrin LC, et al. Rapid decline in warts after national quadrivalent HPV vaccine programme for young women. *Sex Transm Infec* 2009; 85:499-502

Fairley CK, Robinson PM, Chen S, et al. The detection of HPV DNA, the size of tampon specimens and the menstrual cycle. *Genitourin Med* 1994b; **70**(3):171-174

Fairley CK, Tabrizi S, Garland SM, et al. Canadian and Australian Aborigines: Similar epidemiology and needs? Letter to the Editor. *STDs* 1998; **25** (1):55-56

Fairley CK, Tabrizi S, Gourlay SG, et al. A cohort study comparing the detection of HPV DNA from women who stop and continue to smoke. *ANZ J Obstet Gynaecol* 1995; **35**(2):181-185

Farnsworth A, Mitchell HS. Prevention of cervical cancer. *MJA* 2003; **178** (16): 653-654

Farrer J. Opening Up: Youth sex culture and market reform in Shanghai. University of Chicago Press, 2002.Chicago; in Parish WL, Laumann EO, Mojola SA. Sexual behavior in China: trends and comparisons. (Survey) Publication. *Population and Development Review* 2007; **33** (4):729-756

Fazekas KI, Brewer NT, Smith JS. HPV vaccine acceptability in a rural southern area. *J Women's Health* (15409996) 2008; **17** (4): 539-548

Feather NT .Cross-cultural studies with the Rokeach Values Survey: The Flinders program of research on values. *Aust J Psych* 1986; **38**: 269-283

Feemster K, Winters S, Fiks A, et al. Pediatricians' intention to recommend HPV vaccines to 11 -12 year old girls post-licensing. *J Adol Health* 2008; **43**(4): 408-411

Fenton KA, Mercer CH, McManus CH, et al. Ethnic variations in sexual behaviour in Great Britain and risk of sexually transmitted infections: a probability survey. *Lancet* 2005; **365**:1246-1255

Ferris DG, Cromwell LBS, Waller JL, et al. Most parents do not think receiving human papillomavirus vaccine would encourage sexual activity in their children. *J Lower Genital Tract Disease* 2010; **14** (3):179-184

Ferris D, Horn L, Waller JL. Parental acceptance of a mandatory human papillomavirus (HPV) vaccination program. *The J Am Board Fam Med* 2010; **23** (2): 220-229

Ferris DG, Middleman AB, Rosenthal SR. Facing the future: The impact of HPV vaccination on adolescent health Symposium (Slide presentation) .*SciMed CME Activity* March 24, 2006

Fiebig DG, Haas M, Hossain I, et al. Decisions about Pap tests: What influences women and providers? *Soc Sc Med* 2009; **68**:1766-1774

Finlay L. Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qual Rsch.* 2002; **2**: 209-230

Finlay L, Ballinger C. Qualitative research for allied health professionals: Challenging choices. *Wiley*, Chichester, 2006

Finn LD, Pepper A, Gregory P, et al. Improving Indigenous access to cancer screening and treatment services: descriptive findings and a preliminary report on the Midwest Indigenous Women's Cancer Support Group. *Aus Med J* 2008; **1** (2): 1-22

Fisher DA, Huffman SE. Management of chronic hepatitis B virus infection in remote-dwelling Aboriginals and Torres Strait islanders: an update for primary health care providers*. MJA* 2003; **178** (2): 82-85

Flaskerud J, Nyamathi A. Attaining gender and ethnic diversity in health intervention research: cultural responsiveness versus resource provision. *Advances in Nursing Science* 2000; **22**(4): 1-15

Forster AS, Marlow LAV, Wardle J, et al. Understanding adolescents' intentions to have the HPV vaccine. *Vaccine* 2010; **28** (7):1673-1676

Forster A, Wardle J, Stephenson J et al. Passport to promiscuity or lifesaver: press coverage of HPV vaccination and risky sexual behavior. *J Health Communication* 2010; **15** (2):205 - 217

Franceschi S, R Herrero R, GM Clifford GM, et al. Variations in the age-specific curves of human papillomavirus prevalence in women worldwide. *Int J Cancer* 2006; **119**: 2677-2684

Franceschi S, Munoz N, Bosch XF, et al. Human papillomavirus and cancers of the upper aerodigestive tract: A review of epidemiological and experimental evidence. *Cancer Epidem Bio & Prev* 1996; **5**: 567-575

Franceschi S, Plummer M, Clifford G, et al. Differences in the risk of cervical cancer and human papillomavirus infection by education level. *Br J Cancer* 2009; **101** (5):865-870. Epub 2009 Aug 4

Franco EL, Cuzick J, Hildesheim A. et al. Chapter 20: Issues in planning cervical cancer screening in the era of HPV vaccination. *Vaccine* 2006; **24**(3): S171-S177

Frazer I. Vaccines for papillomavirus infection. *Virus Res* 2002; **89**: 271-274

Frazer IH, Cox JT, Mayeaux EJ, et al. Advances in prevention of cervical cancer and other human papillomavirus-related diseases. *The Pediatric Infectious Disease Journal* 2006; **25**:2:S65-81

Fredrickson DD, Davis TC, Arnould CL, et al. Childhood immunization refusal: provider and parent perceptions. *Fam Med* 2004; **36**: 431-439

Freed G, Bordley W C, Clark SJ, et al. Universal Hepatitis B immunization of infants: reactions of paediatricians and family physicians over time. *Ped* 1994; **93**: 747-751

Freed GL, Clark SJ, Hibbs BF, et al. Parental vaccine safety concerns: the experiences of pediatricians and family physicians. *Am J Prev Med 2004*; **26**:11-14

Freedman E, Britt H, Harrison CM, et al. Sexual health problems managed in Australian general practice: a national, cross sectional survey. *Sex Transm Infect* 2006; **82**: 61-66

Friedman AL, Shepeard H. Exploring the knowledge, attitudes, beliefs, and communication preferences of the general public regarding HPV: findings from CDC focus group research and implications for practice. *Health Educ Behav* 2007; Jan 3 epub

Gao W, DeSouza R, Paterson J, et al. Factors affecting uptake of cervical cancer screening among Chinese women in New Zealand. *Int J Gynecol & Obst* 2008; **103** (1):76-82

Garcia SG, Becker D, Tatum C, et al. Linking cervical cancer to the Human papillomavirus: findings from a qualitative study with Mexican women. *Health Care Women Int* 2007; **28** (2):192 - 205

Garland SM. Can we really beat cervical cancer? *Med J Aust* 2003; **178**: 647-649

Garland SM. Can cervical cancer be eradicated by prophylactic HPV vaccination? Challenges to vaccine implementation. *Indian J Med Res* September 2009; **130**: 311-321

Garland SM. Prevention strategies against human papillomavirus in males. *Gynecol Oncol* 2010; **117**(2): Suppl 1:S20-S25

Garland SM, Brotherton JML, Skinner SR, et al. Human papillomavirus and cervical cancer in Australasia and Oceania: Risk-factors, epidemiology and prevention. *Vaccine* 2008b; **26**: Suppl 12:M80-M88

Garland SM, Cuzick J, Domingo EJ, et al . Recommendations for cervical cancer prevention in the Asia Pacific. *Vaccine* 2008a; **26** Suppl 12:M89-98

Garland SM, Hernandez-Avila M, Wheeler CM, et al. Quadrivalent vaccine against human papillomavirus to prevent anogenital diseases. *N Engl J Med* 2007; **356**; 19:1928 -1942

Garland SM, Park SN, Ngan HYS, et al . The need for public education on HPV and cervical cancer prevention in Asia. Opinions of experts at the AOGIN Conference. *Vaccine* 2008; **26**(43):5435-5440

Garland SM, Quinn MA. How to manage and communicate with patients about HPV? *Int J Gynecol Obstet* 2006; **90**:S104-110

Garland SM, Smith JS. Human papillomavirus vaccines. Current status and future prospects. *Drugs* 2010; **70** (9): 1079-1098

Garland SM, Steben M, Sings H, et al. Natural history of genital warts: Analysis of the placebo arm of 2 randomized phase III trials of quadrivalent HPV (types 6, 11, 16, 18) vaccine. *J Infec Dis* 2009; **119**:1-10

Gath DH, Hallam N, Mynors-Wallis L, et al. Emotional reactions in women attending a UK colposcopy clinic. *J Epidemiol Community Health* 1995; **49**:79-83

Gerend MA, Magloire ZF. Awareness, knowledge and beliefs of human papillomavirus in a racially diverse sample of young adults. *J Adol Health* 2008; **42**:237-242

Gerhardus A and Razum O. A long story made too short: surrogate variables and the communication of HPV vaccine trial results. Editorial. *J Epidemiol Community Health* 2010; **64**(5): 377-378

Giles M, Garland SM. A study of women's knowledge regarding Human papillomavirus infection, cervical cancer and human papillomavirus vaccines. *Aust NZ J Obstet Gynaecol* 2006; **46**:311-315

Gillison ML, Shah KV. Role of mucosal human papillomavirus in nongenital cancers. *J Natl Cancer Inst Monograph* 2003; **9**:57-65

Giordano L, Webster P, Anthony C, et al. Improving the quality of communication in organised cervical cancer screening programmes. *Patient Education and Counselling* 2008; **72**:130-136

Giuliano AR. Human papillomavirus vaccination in males. *Gynecol Oncology* 2007; **107**: S24-S26

Giuliano AR and Palefsky J. Quadrivalent HPV vaccine efficacy against male genital disease and infection. Presented at the 25th International Papillomavirus Conference. 2009 May 8 -14; Malmo, Sweden. Abstract 001-07

GLOBOCAN. Cervical cancer incidence and mortality worldwide in 2008. Cancer fact sheet. *GLOBOCAN* 2008 (IARC)
http://globocan.iarc.fr/factsheets/cancers/cervix.asp (1 of 5). Accessed 26/06/10

Goldie SJ. Health economics and cervical cancer prevention: A global perspective. *Virus Res* 2002; **89**: 301-309

Goldie SJ, Kohli M, Grima D, et al. Projected clinical benefits and cost-effectiveness of a human papillomavirus 16/18 vaccine. *J Natl Cancer Inst* 2004; **96**: 604 - 615

Goldstein ST, Cassidy WM, Hodgson W, et al. Factors associated with student participation in a school-based hepatitis B immunization program. *J School Health* 2001; **71**:184 -187

Goodman MT, Shvetsov YB, McDuffie K, et al. Prevalence, acquisition, and clearance of cervical human papillomavirus infection among women with normal cytology: Hawaii Human Papillomavirus Cohort Study. *Cancer Res* 2008; **68** (21): 8813-8824

Gong XD, Wang QP, Jiang WH. Epidemiologic status and analysis of STDs epidemic in China. *Chinese J Prev Control STD / AIDS* 1998; **4**:186-189

Gonik B. Strategies for fostering HPV vaccine acceptance. *Infect Dis Obstet Gynecol* 2006; Article ID 36797: 1-4

Gordon RG Jr. (ed.), 2005. Ethnologue: Languages of the World, Fifteenth edition. Dallas, Tex.: SIL International. http://www.ethnologue.com/show_country.asp?name=Australia

Gracey MS, Spargo RM. Let's not talk about sex: reconsidering the public health approach to sexually transmissible infections in remote indigenous populations in Australia: Matters Arising. *MJA* 2008; **188** (3):182-184

Greer CE, Wheeler CM, Ladber MB, et al. Human papillomavirus (HPV) type distribution and serological response to HPV type 6 virus-like particles in patients with genital warts. *J Clin Microbiol* 1995; **33** (8): 2058-2063

GSK: GlaxoSmithKline. Another Australia first in the fight against cervical cancer: new vaccine for women 27-45 years. *GSK Press Release*, 14 August 2007. Available from: http://www.gsk.com.au/media-centre_detail.aspx?view=220

Guilamo-Ramos V, Jaccard J, Dittus P et al. Parent - adolescent communication about sexual intercourse: an analysis of maternal reluctance to communicate. *Health Psych* 2008; **27** (6):760-769

Gulati A, Lazebnik R, O'Riordan MA. HPV vaccination: Assessment of parental knowledge and reasons for acceptance or denial. *J Adol Health* 2009; **44** (2) Suppl 1:S3

Gust DA, Kennedy A, Shui Smith PJ, et al. Parent attitudes toward immunizations and healthcare providers: The role of information. *Am J Prev Med* 2005; **29** (2):105-112

Haas M, Ashton T, Blum K, et al. Drugs, sex, money and power: An HPV vaccine case study. *Health Policy* 2009; **92** (2-3):288-295

Hak E, Schonbeck Y, De Melker H , et al. Negative attitude of highly educated parents and health workers towards future vaccination in the Dutch childhood vaccination program . *Vaccine* 2005*;* **23**:3103-3107

Halcomb EJ, Gholizadehl L, DiGiacomo M, et al. Literature review: considerations in undertaking focus group research with culturally linguistically diverse groups. *J Clin Nursing* 2007; **16**(6): 1000-1011

Hall B, Howard K, McCaffery K. Do cervical cancer screening patient information leaflets meet the HPV information needs of women? *Patient Education and Counselling* 2008; **72** (1):78-87

Halsey NA. The human papillomavirus vaccine and risk of anaphylaxis. *CMAJ* 2008; **179**: 509-510

Hamilton M, Corwin P, Gower S, et al. Why do parents choose not to immunise their children? *N Z Med Assoc* 2004; **117** (1189)

Hammersley M. The dilemma of qualitative method: Herbert Blumer and The Chicago Tradition. Routledge, London, 1989

Hancock L, Sanson-Fisher R, Perkins J, et al. Effect of a community action intervention on cervical cancer screening rates in rural Australian Towns: the CART project. *Preventative Med* 2001; **32** (2):109-117

Hardon A. Immunisation for all? A critical look at the first GAVI partners meeting. *HAI Europe,* March 2001; **6** (1):2-9

Harmsen JAM, Bernsen RMD, Bruijnzeels MA, et al. Patients' evaluation of quality of care in general practice: What are the cultural and linguistic barriers? *Patient Education and Counselling* 2008; **72**:155-162

Harper DM. Impact of vaccination with Cervarix ^{TM} on subsequent HPV-16 / 18 infection and cervical disease in women 15 - 25 years of age. *Gynecol Oncology* 2008; **110**: S11-S17

Harper DM, Franco EL, Wheeler C et al. Efficacy of a bivalent L1 virus-like particle vaccine in prevention of infection with human papillomavirus types 16 and 18 in young women: a randomised controlled trial. *The Lancet* 2004; **364**:1757-1765

Harper DM, Franco EL, Wheeler CM, et al. Sustained efficacy up to 4.5 years of a bivalent L1 virus-like particle vaccine against human papillomavirus types 16 and 18: follow-up from a randomised control trial. *Lancet* 2006; **367**:1247-1255

Harris Cheng M. Aboriginal workers key to Indigenous health in Australia. *The Lancet* 2007; **370** (9598):1533-1536

Harris MF, Mercer PJT. Reactive or preventive: the role of general practice in achieving a healthier Australia. *MJA* 2001; **175**:92-93

Haug CJ. Human papillomavirus vaccination - reasons for caution. *New Eng J Med* 2008; **8** (359):861-862

Haug C. The risks and benefits of HPV vaccination. *JAMA* 2009; **302** (7):795-796 (doi:10.1001/jama.2009.1215)

Hausdorf K, Newman B, Whiteman et al. HPV vaccination: what do Queensland parents think? *Aust N Z J Public Health* 2007; **31** (3):288-289

Health InfoNet (a) .Frequently Asked Questions: What do we know about sexually transmitted infections (STIs) among indigenous people? http://www.healthinfonet.ecu.edu.au/html/html_keyfacts/faq/faq_specific_health/stis Accessed 06/12/2005

HealthInfoNet (b): What is known about the Indigenous population?

http://www.healthinfonet.ecu.edu.au/html/html_keyfacts/keyfacts_plain_lang_summary.htm#introduction (Accessed 06/12/2005)

Heffernan ME, Garland SM, Kane MA. Global reduction of cervical cancer with human papillomavirus vaccines: insights from the hepatitis B virus vaccine experience. *Sexual Health* 2010; **7**:383-390

Heininger U. An internet - based survey on parental attitudes towards immunization. *Vaccine* 2006; **24**: 6351 – 6355

Henninger J. Knowledge, attitudes, and intentions of general practitioners and practice nurses in Christchurch about human papillomavirus. *J Primary Health Care* 2009; **1**(4):278–285

Herdman C; Demspey M. Introducing HPV vaccines in developing countries: Overcoming the challenges. *PATH Publications:* Fact Sheet .Sept 2005; 206.285.3500 | 206.285.6619 http://www.path.org/publications/details.php?i=1121 (accessed 4 March 2010)

Hernandez BY, McDuffie K, Goodman MT, et al. Comparison of physician and self-collected genital specimens for detection of Human papillomavirus in men. *J Clin Microbiology* 2006; **44** (2): 513-517

Herriott RE, Firestone WA. Multisite qualitative policy research: Optimizing description and generalisability. *Educational Researcher* 1983; **12**(2): 14-19

Herzog TJ, Huh WK, Downs LS, et al. Initial lessons learned in HPV vaccination. *Gynecol Oncology* 2008; **109**:S4-S11

Higgins LT, Zheng M, Liu Y, et al. Attitudes to marriage and sexual behaviors: A survey of gender and culture differences in China and United Kingdom. *Sex Roles* 2002; **46** (3 / 4): 75-89

Hillard PJ, Kahn JA. Understanding and preventing human papillomavirus infection during adolescence and young adulthood. *J Adol Health* 2005; **37**(6): S1

Hilton S, Hunt K, Langan M, et al. Newsprint media representations of the introduction of the HPV vaccination programme for cervical cancer prevention in the UK (2005 - 2008). *Soc Sci Med* 2010; **70**: 942-950

Hilton S, Petticrew M, Hunt K. 'Combined vaccines are like a sudden onslaught to the body's immune system': Parental concerns about vaccine 'overload' and 'immune vulnerability'. *Vaccine* 2006; **24**: 4321-4327

Hinds A, Cameron JC. Acceptability of universal Hep B vaccination among school pupils and parents. *Com Disease and Pub Health* 2004; **7**(4): 278-282

Hipgrave DB, Nguyen TV, Vu MH, et al. Hepatitis B infection in rural Vietnam and the implications for a national program of infant immunization. *Am. J of Tropical Medicine and Hygiene* 2003; **69** (3): 288-294

Hippelainen M, Syrjanen S, Hippelainen ML, et al. Prevalence and risk factors of genital human papillomavirus (HPV) infections in healthy males: a study of Finnish conscripts. *Sex Trans Dis* 1991; **18** (2): 321-328

Hoffner B. Vaccination against the human papillomavirus: The lessons we have not learned. *Vaccine* 2009; **27** (16): 2195-2198

Hofstede, G. (1983) Dimensions of national cultures in fifty countries and three regions, in: J. Deregowsk (Ed.) Expiscations in cross-cultural psychology (Lisse, International Organization for Cross-Cultural Psychology, Swets & Zeitlinger) in Yuan, BJ, Shen J. Moral values held by early adolescents in Taiwan and Mainland China. *J Moral Education* 1998; **27** (2):191-207

Holling CS. Understanding the complexity of economic, ecological and social systems. *Ecosystems* 2001; **4**: 390-405

Horsburgh D. Evaluation of qualitative research. *J Clin Nursing* 2003; **12**:307-312

Holzner BM, Oetomo D. Youth, sexuality and sex education messages in Indonesia: Issues of desire and control. *Reproductive Health Matters* 2004; **12** (23): 40-49

Hong D, Ye F, Chen H, et al. Distribution of human papillomavirus genotypes in the patients with cervical carcinoma and its precursors in Zhejiang Province, China. *Int J Gynecol Cancer* 2008; **18**:104-109

Hooper K, Thomas Y, Clarke M. Health professional partnerships and their impact on Aboriginal health: An occupational therapist's and Aboriginal health worker's perspective. Aust *J Rural Health* 2007; **15** (1): 46-51

Hoover DR, Carfioli B, Moench EA, et al. Epidemiology of human papillomavirus infection and cervical cancer and future perspectives in Hong Kong, Singapore and Taiwan. *Vaccine* 2008; **26** (Suppl 12): M60-70

Hopenhayn C, Christian A, Christian WJ, et al. Human papillomavirus vaccine: knowledge and attitudes in two Appalachian Kentucky counties. *Cancer Causes Control* 2007; **18**: 627-634

Horenczyk G. Immigrants' perceptions of host attitudes and their reconstruction of cultural groups. *Applied Psychology-an International Review* 1997; **46** (1): 34-38

Hoskins CN, Mariano C. Research in nursing and health: Understanding and using quantitative and qualitative methods. Springer, New York, 2004

Howlett RI, Larsh S, Dobi L, et al. Promoting cancer screening among Ontario Chinese women. *Can J Pub Health* 2009; **100** (4):315-320

Hoy WE, Norman RJ, Hayhurst BG, et al. A health profile of adults in a Northern Territory Aboriginal community, with an emphasis on preventable morbidities [online]. *ANZ J Public Health* 1997; **21** (2): 121-126

Hoyle RH, Harris MJ, Judd CM. Research methods in social relations. Thomson, South Melbourne, 2002

HPV PREV: HPV prevalence of related cancers: Annual cases worldwide. 2010. http://anacondapharma.com/index.php?page=markets-for-hpv-treatments. (Downloaded 26 3 2010)

HRDOP: Cervical cancer: promising approaches. *Human Resources Development and Operation Policy*; Number 46, March 27 1995

Huberman AM, Miles MB. The qualitative researcher's companion. Sage, London, 2002

Hughes J, Cates JR, Liddon N, et al. Disparities in how parents are learning about the human papillomavirus vaccine. *Cancer Epidemiology, Biomarkers & Prevention* 2009; **18** (2): 363-372

Huh WK, Roden RBS. The future of vaccines for cervical cancer. *Gynecologic Oncology* 2008; **109**: S48-S56

Hull BP, McIntyre PB, Couzos S. Evaluation of immunisation coverage for Aboriginal and Torres Strait Islander children using the Australian Childhood Immunisation Register. *Aust NZ J Pub Health* 2004; **28** (1):47-52

Humiston SG, Rosenthal SL. Challenges to vaccinating adolescents. Vaccine implementation issues. *Ped Infec Dis J* 2005; **24** (6):S134-S140

Hunt JM, Gless GL. Straton J. Pap smear at an urban Aboriginal health service: report of a practice audit and an evaluation of recruitment strategies. *Aust NZJ Public Health* 1998; **22:**7(6): 720-725

IARC: International Agency for Research on Cancer. *Cervix Cancer Screening: IARC Handbooks of Cancer Prevention.* Lyon: IARC Press; 2005

Ishibashi KL, Koopmans J, Curlin FA, et al. Pediatricians are more supportive of the human papillomavirus vaccine than the general public. *South Med J*. 2008; **101**(12):1216 -1221

Ishibashi KL, Koopmans J, Curlin FA, et al. Paediatricians' attitudes and practices towards HPV vaccination. *Acta Paediatr* 2008; **97** (11):1550-1556

Jackson LR, Ward JE. An analysis of resources for Indigenous women in NSW about cervical screening. *ANZ J Pub Health* 2000; **24** (3):327 - 331

Jacobs EA, Rolle I, Ferrans CE, et al. Understanding African Americans' views of the trustworthiness of physicians . *J Gen Intern Med* 2006; **21** (6): 642-647

Jain N, Euler GL, Shefer A, et al. Human papillomavirus (HPV) awareness and vaccination initiation among women in the United States, National Immunization Survey - Adult 2007. *Prev Med* 2009; **48**: 426-431

Jaspan DM, Dunton CJ, Cook TL. Acceptance of human papillomavirus vaccine by gynecologists in an urban setting. *J Low Genit Tract Dis* 2008; **12**(2):118-121

Jeffreys E (editor). Sex and sexuality in China. Routledge, London and New York, 2006

Jelfs P. Cervical cancer in Australia. *Aust Inst Health and Welfare: Cancer Series* 1995; **3**

Jennings-Dozier K. Perceptual determinants of Pap test up-to-date status among minority women. (published erratum appears in Oncol Nurs Forum1999; 26 (1): 1587]. *Oncol Nurs Forum* 1999; **26** (8):132 7-1333

Jenson HB. Human papillomavirus vaccine: a paradigm shift for pediatricians. *Curr Opin Pediatr* 2009; **21** (1):112-121

Jirojwong S, Manderson L. Beliefs and behaviors about Pap and breast self-examination among Thai immigrant women in Brisbane, Australia. *Women's Health.* 2001; **33**(3 -4): 47-66

Johnson AM, Mercer CH, Erens B, et al. Sexual behaviour in Britain: partnerships, practices, and HIV risk behaviours. *Lancet* 2001; **358**:1835-1842

Johnson CE, Mues KE, Mayne SL, et al. Cervical cancer screening among immigrants and ethnic minorities: A systematic review using the Health Belief Model. *J Lower Genital Tract Disease:* 2008; **12** (3): 232-241

Johnston VJ, Britt H, Pan Y, et al. The management of sexually transmitted infections by Australian general practitioners. *Sex Transm Infect* 2004; **80**: 212-215

Jordon L, Bayly C, Sawyer SM. The sexual and reproductive health of young Victorians: A collaboration between Family Planning Victoria, Royal Women's Hospital, and Centre for Adolescent Health, 2004, Melbourne

Joura EA, Kjaer SK, Wheeler CM, et al. HPV antibody levels and clinical efficacy following administration of a prophylactic quadrivalent vaccine. *Vaccine* 2008; **26** (52): 6844-6851

Julian, R. Ethnicity, Health and Multiculturalism, in J. Germov, *Second Opinion: An Introduction to Health Sociology*, Oxford University Press, Oxford, UK 2003

Jureidini R, Poole M (Ed.). Sociology: Australian Connections, *Allen and Unwin*, Crows Nest, 2003:**210**

Kagitcibasi C. Family and human development across cultures: a view from the other side*. Mahwah* 1996; NJ: Lawrence Erlbaum Associates

Kahn JA. Vaccination as a prevention strategy for human papillomavirus - related diseases. *J Adol Health* 2005; **37**: S10-S16

Kahn JA. Maximizing the potential public health impact of HPV vaccines: A focus on parents. *J Adol Health* 2007; **40** (2):101-103

Kahn JA. HPV vaccination for the prevention of cervical intraepithelial neoplasia. *N Engl J Med* 2009; **361**:271-278

Kahn JA, Chiou V, Allen JD, et al. Beliefs about Papanicolaou smears and compliance with Papanicolaou smear follow-up in adolescents. *Arch Pediatr Adolesc Med* 1999; **153**:1046-1054

Kahn JA, Cooper HP, Vadaparampil ST, et al. Human papillomavirus vaccine recommendations and agreement with mandated human papillomavirus vaccination for 11-to-12-year-old girls: a statewide survey of Texas physicians. *Cancer Epidemiol Biomarkers Prev* 2009; **18**: 2325-2332

Kahn JA, Emans SJ, Goodman E. Measurement of young women's attitudes about communication with providers regarding Papanicolaou smears. *J Adol Health* 2001; **5**: 344 - 351

Kahn JA, Huang B, Rosenthal SL, et al. Coercive sexual experiences and subsequent human papillomavirus infection and squamous intraepithelial lesions in adolescent and young adult women. *J Adol Health* 2005; **36** (5): 363-371

Kahn JA, Rosenthal SL, Hamann T, et al. Attitudes about HPV vaccine in young women. *Int J STD and Aids* 2003 **14** (5): 300-306

Kahn JA, Rosenthal SL, Jin Y, et al. Rates of human papillomavirus vaccination, attitudes about vaccination, and human papillomavirus prevalence in young women. *Obstet Gynecol* 2008; **111**:1103-1110

Kahn JA, Rosenthal SL, Tissot AM, et al. Factors influencing Pediatricians' intention to recommend human papillomavirus vaccines. *Ambulatory Pediatrics* 2007; **7** (5): 367-373

Kahn JA, Slap GB, Bernstein DI, et al. Psychological, behavioral, and interpersonal impact of human papillomavirus and Pap test results. *J Women's Health* 2005; **14** (7): 650-659

Kahn JA, Slap GB, Bernstein DI, et al. Personal meaning of Human papillomavirus and Pap test results in adolescent and young adult women. *Health Psychology* 2007; **26** (2):192-200

Kahn JA, Zimet GD, Bernstein DI, et al. Pediatricians' intention to administer human papillomavirus vaccine: the role of practice characteristics, knowledge and attitudes: *J Adol Health* 2005; **37**: 502-510

Kaiser 2010: CDC says teen vaccination rates up but should go higher (Daily Report: Hobson, 8/19).http://www.kaiserhealthnews.org/Daily-Report.aspx? (Reportdate=8-23-2010)

Kaljee LM, Pack R, Pach A, et al. Sociobehavioural research methods for the introduction of vaccines in the Diseases of the Most Impoverished programme. *J Health Popul Nutr* 2004; **22** (3):293-303

Kane MA. Delivering HPV vaccine in the industrial and developing world: the role of the ob-gyn community. *Int J Gynecol Obs* 2006; **94** (Suppl 1):S89-S94

Kane MA. Global implementation of Human papillomavirus (HPV) vaccine: Lessons from hepatitis B vaccine. *Gynecol Oncol* 2010; 117 (2): Suppl 1:S32-S35

Kang LW, Crawford N, Tang MLK, et al. Hypersensitivity reactions to human papillomavirus vaccine in Australian schoolgirls: retrospective cohort study. *BMJ* 2008; **337**: a2642

Karasz A, McKee M, Roybal K. Women's experiences of abnormal cervical cytology: illness representations, care processes, and outcomes. *Ann Fam Med* 2003; **1**(4):196-202

Kattampallil J, Mathew R, Zardawi I, et al. Mucocutaneous cancer and human papillomavirus In the Top End of Australia**.** *Pathology International* 2002; **51**(12): A7-A7

Katz ML, Reiter PL, Heaner S, et al. Acceptance of the HPV vaccine among women, parents, community leaders, and healthcare providers in Ohio Appalachia. *Vaccine* 2009; **27**(30): 3945-3952

Kavanagh AM, Broom DH. Women's understanding of abnormal cervical smear test results: a qualitative interview study. *BMJ* 1997; **314**:1388

Keane MT, Walter MV, Patel BI. Confidence in vaccination: a parent model. *Vaccine* 2005; **23**: 2486-2493

Keating KM, Brewer NT, Gottlieb SL, et al. Potential barriers to HPV vaccine provision among medical practices in an area with high rates of cervical cancer. *J Adol Health* 2008; **43**:S61-S67

Kelaher M, Gillespie A G Allotey P, et al. The Transtheoretical Model and cervical screening: its application among culturally diverse communities in Queensland, Australia. *Ethnicity and Health* 1999; **4** (4) 259-276

Kelly J. Yaitya tirka madlanna warratinna: culture nothing without language: a research project exploring what sexual health nurses need to know and do in order to meet the sexual health needs of young Aboriginal women in Adelaide, 2003-2005. Unpublished Master of Nursing thesis, Flinders University, Adelaide, South Australia

Khan A, Plummer D, Hussain R, et al. Preventing sexually transmissible infections in Australian general practice. *Int J STD AIDS* 2008; **19**: 459-463

Kharbanda EO, Stockwell M, Fox H, et al. The role of human papillomavirus vaccination in promoting delivery of other health services. *J Adol Health* 2010; **46** (2): S1- S68 Society for Adolescent Medicine Annual Meeting Program Issue - Adolescent Clinical Care: Integrating Art & Science

Kim JJ. Human papillomavirus vaccination in the UK is projected to be beneficial and cost effective. Editorial. *BMJ* 2008; **337**: 303-304

Kim JJ, Andres-Beck B, Goldie SJ. The value of including boys in an HPV vaccination programme: a cost-effectiveness analysis in a low-resource setting. *British J Cancer* 2007; **97**:1322-1328

Kim JJ, Goldie SJ. Cost-effectiveness analysis of including boys in a human papillomavirus (HPV) vaccination programme in the United States. *BMJ* 2009; **339**:b3884 (10 pages)

Kim K, Zang R, Choi SC, et al. Current status of gynecological cancer in China. *J Gynecol Oncol* 2009; **20** (2): 72-76

Kimmel SR. Practical implementation of HPV vaccines in clinical practice. *J Fam Prac* 2006; Suppl: 18-22

Kincheloe JL. On to the next level: continuing the conceptualization of the Bricolage. *Qualitative Inquiry* 2005; **11**: 323-350

Kincheloe JL. Bricolage and the quest for multiple perspectives: new approaches to research in ethnic studies. http://freire.mcgill.ca/articles/node%2065/Research/Bricolage.doc) Accessed 31 7 2008

Kirby D. The impact of schools and school programs upon adolescent sexual behavior. *J Sex Res.* 2002; **39**: 27-33

Kirk M, Hoban E, Dunne A, et al. Barriers to and appropriate delivery systems for cervical cancer screening in Indigenous communities in Queensland. Herston: *Australian Centre for International & Tropical Health & Nutrition* 1999

Kirkman M, Rosenthal D, Feldman SS. Being open with your mouth shut: the meaning of 'openness' in family communication about sexuality. *Sex Education* 2005; **5**(1): 49-66

Kjaer S, Tran T, Sparen P, et al. The burden of genital warts: a study of nearly 70,000 women from the general female population in the 4 Nordic countries. *J Infect Dis* 2007; **196**:1447–54

Klein JD, Sabaratnam P, Pazos B, et al. Evaluation of the 'Parents as Primary Sexuality Educators' program. *J Adol Health* 2005; **37** (3) Suppl 1: S94-S99

Klein JD, Wilson KM. Delivering quality care: Adolescents' discussion of health risks with their providers. *J Adol Health* 2002; **30**: 190-195

Klessig J. Cross-cultural medicine a decade later the effect of values and culture on life-support decisions. *Western J Med* 1992: **157**: 316-322

Klug SJ, Hukelmann M, Blettner M. Knowledge about infection with human papillomavirus: a systematic review. *Prev Med* 2008; **46**: 87-98

Kmietowicz Z. Australian cervical cancer vaccination leads to rapid decline in genital warts. *BMJ* 2009; **339**: b4241

Knobf MT, Juarez G, Lee SYK, et al. Challenges and strategies in recruitment of ethnically diverse populations for cancer nursing research. *Oncology Nursing Forum* 2007; **34**(6):1187-1194

Kollar LM, Kahn JA. Education about human papillomavirus and human papillomavirus vaccines in adolescents. *Curr Opin Obstset Gynecol* 2008; **20** (5): 479-483

Konno R, Shin H-R, Kim Y-T, et al. Human papillomavirus infection and cervical cancer prevention in Japan and Korea. *Vaccine* 2008; **26(**Suppl 12): M30-42

Konya J, Veress G, Juhasz A, et al. Additional Human papillomavirus types detected by the hybrid capture tube test among samples from women with cytological and colposcopical atypia. *J Clin Microbiol* 2000 **38**: 408-411

Koori Elders, Newman J, Acklin F, et al. Story-telling: Australian Indigenous women's means of health promotion. *Aboriginal and Islander Health Worker J* 1999; **23** (4):18-22

Korfage I, Essink-Bot M, Daamen R, et al.Women show mixed intentions regarding the uptake of the HPV vaccinations in pre-adolescents: A questionnaire study. *Eur J Cancer* 2008; **44** (9):1186-1192

Koukari A. National HPV Vaccination Program: Rolling out the vaccine program – impact on the National Cervical Screening Program *in* Best practice in cervical cancer immunisation. Report of a roundtable discussion about the impact of the human papillomavirus vaccine in Australia. *Australia Cancer Council* March 2008

Koulova A, Tsui J, Irwin K, et al. Country recommendations on the inclusion of HPV vaccines in national immunization programmes among high-income countries, June 2006 - January 2008 *Vaccine* 2008; **26** (51): 6529-6541

Koutsky LA, Ault KA, Wheeler CM, et al. A controlled trial of a human papillomavirus type 16 vaccine. *N Engl J Med* 2002, **347**:1645-1651

Kreimer AR, Clifford GM, Boyle P, et al. Human papillomavirus types in head and neck squamous cell carcinomas worldwide: a systematic review. *Cancer Epidemiol Biomarkers Prev* 2005; **14** (2):467-475

Kuitto K, Pickel S, Neumann H, et al. Attitudinal and socio-structural determinants of cervical cancer screening and HPV vaccination uptake: a quantitative multivariate analysis. *J Public Health* 2010; **18** (2): 179-188, DOI: 10.1007/s10389-009-0308-z

Kwan TT, Chan KK, Yip AM, et al. Barriers and facilitators to human papillomavirus vaccination among Chinese adolescent girls in Hong Kong: a qualitative-quantitative study. *Sex Transm Infect* 2008; **84** (3):227-232

Kwan TT, Chan KK, Yip AM, et al. Acceptability of human papillomavirus vaccination among Chinese women: concerns and implications. *BJOG* 2009; **116** (4):501- 510

Kwan TTC, Tam K, Lee PWH, et al. The effect of school-based cervical cancer education on perceptions towards human papillomavirus vaccination among Hong Kong Chinese adolescent girls. *Patient Education and Counseling* July 21 2010; doi:10.1016/j.pec.2010.06.018. Article in Press, Corrected Proof

Kwong KK. Access to cancer education and screening: A long and difficult journey for Chinese immigrants in New York City. A PhD dissertation, 2006 The City University of New York. *UMI Microform* **3213249**, Proquest Information and Learning Company, MI, USA

Lacey CJ, Lowndes CM, Shah KV, et al. Chapter 4: burden and management of non-cancerous HPV-related conditions: HPV-6/11 disease. *Vaccine* 2006; **24**(Suppl 3):S3/35-S41

LaFromboise T, Coleman HLK, Gerton J. Psychological impact of biculturalism: evidence and theory. *Psychological Bulletin* 1993; **114**: 395-412

Lai JY, Tinker AV, Cheung WY. Factors influencing the uptake of the human papillomavirus (HPV) vaccine to prevent cervical cancer (CC).*J Clinical Oncology*, 2010 ASCO Annual Meeting Proceedings (Post-Meeting Edition) 2010; **28** (15): 6008 suppl (May 20 Supplement)

Lam LP, McLaws ML. Hepatitis B vaccination coverage of Vietnamese children in south-west Sydney. *ANZ J Pub Health* 1998; **22**: 502-504

LAN: Editorial: Women's Health in Rural China. *The Lancet* 2009; **374** (9687): 358

Lannin DR, Matthews HF, Mitchell J, et al. Impacting cultural attitudes in African - American women to decrease breast cancer mortality. *Am J Surg* 2002; **184**: 418-423

Larson HJ, Brocard P, Garnett G. The India HPV-vaccine suspension. *The Lancet* 2010; **376**(9741): 572-573

Latimer J. (ed.) Advanced qualitative research for nursing.2003; Blackwell, Oxford

Lau MC, Markham C, Chacko M. Dating and sexual attitudes in Asian adolescents: an exploratory study. *J Adol Health* 2005; **36** (2):111

Lau M, Markham C Lin H, et al. Dating and sexual attitudes in Asian-American adolescents. *J Adol Research* 2009; **24** (1):91-113

Laumann EO, Youm Y. Racial / ethnic group differences in the prevalence of sexually transmitted diseases in the United States: a network explanation. *Sex Transm Dis* 1999; **26**: 250-261

Laumann EO, Mojola SA. Sexual behavior in China: trends and comparisons. (Survey) *Population and Development Review* 01Dec 07

Lawrence MH, Goldstein MA. Hepatitis B immunization in adolescents. *J Adol Health* 1995; **17**: 234-243

Lazcano-Ponce E, Rivera L, Arillo-Santillán E, et al. Acceptability of a human papillomavirus (HPV) trial vaccine among mothers of adolescents in Cuernavaca, Mexico. *Arch Med Res* 2001; **32** (3):243-247

Leader AE, Weiner JL, Kelly BJ, Hornik RC, Cappella JN. Effects of information framing on human papillomavirus vaccination. *J Women's Health* 2009; **18**:225 - 233

Leask J. How do general practitioners persuade parents to vaccinate their children? A study using standardised scenarios. *NSW Public Health Bulletin* 2009; **29**(7-8): 119-124

Leask J, Chapman S. The cold hard facts' immunisation and vaccine preventable diseases in Australia's newsprint media 1993–1998. *Soc Science and Medicine* 2002; **54** (3): 445-457

Leask J, Chapman S, Hawe P, et al. What maintains parental support for a vaccination when challenged by anti-vaccination messages? A qualitative study. *Vaccine* 2006; **24**: 7238-7245

Leask J, Jackson C, Trevena L, et al. Implementation of the Australian HPV vaccination program for adult women: qualitative key informant interviews. *Vaccine* 2009; **27**(40): 5505-5512

Lee-Lin F, Pett M, Menon U, et al. Cervical cancer beliefs and Pap test screening practices among Chinese American immigrants. *Oncology Nursing Forum* 2007; **34**(6): 1203-1209

Lee PW, Kwan TT, Tam KF, et al. Beliefs about cervical cancer and human papillomavirus (HPV) and acceptability of HPV vaccination among Chinese women in Hong Kong. *Prev Med* 2007**; 45**:130–134

Lehtinen M, Idanpaan-Heikkila I, Lunnas T, et al. Population based enrolment of adolescents in a long-term follow –up trial of human papillomavirus efficacy. *Int J STD and AIDS* 2006; **17**: 237 - 246

Lenehan JG, Leonard KC, Nandra S, et al. Women's knowledge, attitudes, and intentions concerning human papillomavirus vaccination: Findings of a waiting room survey of obstetrics-gynaecology outpatients, *J Obstet Gynaecol Can* 2008; **30**: 489-499

Lenselink CH, Gerrits MM, Melchers WJ, et al. Parental acceptance of human papillomavirus vaccines. *Eur J Obstet Gynecol Reprod Biol* 2008; **137**:103 - 107

Lenselink CH, Schmeink CE , Melchers WJ, et al. Young adults and acceptance of the human papillomavirus vaccine, *Public Health* 2008; **122**: 1295-1301

Lerman C, Miller SM, Scarborough R, et al. Adverse psychologic consequences of positive cytologic cervical screening. *Am J Obstet Gynecol* 1991; **165**: 658-662

Lerner R, Brennan AL, Noh ER, et al. The parenting of adolescents and adolescents as parents: A developmental contextual perspective. *Parenthood in America* http://parenthood.library.wisc.edu/Lerner/Lerner.html) (Accessed 5/07/2007

Lesjak M, Hua M, Ward J. Cervical screening among immigrant Vietnamese women seen in general practice: current rates, predictors and potential recruitment strategies. *ANZ J Public Health* 2008; **23** (2): 168-173

Lewis LK, Hamel SA, Richardson BK. Communicating change to non-profit stakeholders: Models and predictors of implementers' approaches. *Management Communication Quarterly* 2001:**15** (5): 5-41

Lewis L, Stanberry L, Rosenthal S, et al. Attitudes regarding vaccinations of STDs and other diseases. *Int J STD and Aids* 2000; **11**:170-172

Li J, Li LK, Ma JF, et al. Knowledge and attitudes about human papillomavirus (HPV) and HPV vaccines among women living in metropolitan and rural regions of China. *Vaccine* 2009; **27**(8):1210-1215

Li N, Franceschi S, Howell-Jones R, et al. Human papillomavirus type distribution in 30,848 invasive cervical cancers worldwide: Variation by geographical region, histological type and year of publication. *Int J Cancer* 2010; **000**: 000-000 Apr 19. [Epub ahead of print] http://www.ncbi.nlm.nih.gov/pubmed/20473886 Accessed 2 August 2010

Liamputtong P. Researching the vulnerable. Sage London, 2007

Lichtenstein B. Stigma as a barrier to treatment of sexually transmitted infection in the American Deep South: issues of race, gender and poverty. *Soc Sci & Med* 2003; **57**(12): 2435 - 2445

Liddon N, Hood J, Wynn BA, et al. Acceptability of human papillomavirus vaccine for males: a review of the literature. *J Adol Health* 2010; **46** (2): 113-123

Liddon, N Pulley, LV Cockerham, et al. Herpes. *J Adol Health* Sept 2005; **37**(3): 187-193

Lin M, Yang LY, Li LJ, et al. Genital human papillomavirus screening by gene chip in Chinese women of Guangdong province. *ANZ J Obst and Gynecol* 2008; **48**: 189-194

Link BG and Phelan JC. Conceptualizing stigma. *Ann Rev Soc* 2001; **27**: 363-385

Lippman A. Human papillomavirus HPV vaccination and the development of public policies. *J Epidemiol Community Health* 2008; **62**: 570-571

Lister S, McIntyre PB, Burgess MA et al. Immunisation coverage in Australian children: a systematic review 1990-1998. *CDI* 1999; **23**(6): 145-170

Liu DL. Sexual behaviour in modern China: a report of the nation-wide 'sex civilization' survey on 20,000 subjects in China. Shanghai: 1992. Shanghai Sanlian Publishing House; in Zhang K, Beck EJ. Changing sexual attitudes and behaviour in China: implications for the spread of HIV and other sexually transmitted diseases. *AIDS Care* 1999; **11** (5): 581-589

Lloyd GP, Marlow LA, Waller J, et al. An experimental investigation of the emotional and motivational impact of HPV information in adolescents. *J Adolesc Health* 2009; **45**(5): 532-534.Epub 2009 Jul 30

Lo B. HPV vaccine and adolescents' sexual activity. Editorial. *BMJ* 2006; **332**:1106-1107

London L. Ethical oversight of public health research: Can rules and IRBs make a difference in developing countries? *Am J Pub Health* 2002; **92** (7):1079 -1084

Lovell S, Kearns RA, Friesen W. Sociocultural barriers to cervical screening in South Auckland, New Zealand. *Soc Science & Medicine* 2007; **65** (1):138-150

Lowndes CM, Gill ON. Cervical cancer, human papillomavirus, and vaccination. Editorial. *BMJ* 2005; **331**: 915-916

Lowenthal RM, Grogan PB, Kerrins ET. Reducing the impact of cancer in Indigenous communities: ways forward. *MJA* 2005; **182**(3): 105-106

Lui CW, Ip D, Chui WH. Ethnic experience of cancer: A qualitative study of Chinese-Australians in Brisbane, Queensland. *Social Work in Health Care* 2009; **48** (1):14-37

Lush L, Walt G, Ogden J. Transferring policies for sexually transmitted infections: What's wrong with global guidelines? *J Health Policy and Planning* 2003; **18**: 18-30

Madhivanan P, Krupp K, Yashodha MN, et al. Attitudes toward HPV vaccination among parents of adolescent girls in Mysore, India. *Vaccine* 2009; **27** (38): 5203-5208

Maher P. A review of traditional Aboriginal health beliefs. *Aust J Rural Health* 1999; **7**: 229-236

Maissi E, Marteau TM, Hankins M, et al. Psychological impact of human papillomavirus testing in women with borderline or mildly dyskaryotic cervical smear test results: cross sectional questionnaire study. *BMJ* 2004, **328** (7451): 1293

Major B and O'Brien LT. The social psychology of stigma. *Annu Rev Psychol* 2005; **56**:393-421

Mak DB, Straton JAY. The Fitzroy Valley Pap smear Register: cervical screening in a population of Australian Aboriginal women. *Med J Aust* 1993**; 158**: 163-166

Mak DB, Straton JAY. Effects and sustainability of a cervical screening program in remote Aboriginal Australia. *ANZ J Public Health* 2008; **21** (1):67-70

Mandelblatt JS, Gold K, O'Malley AS, et al. Breast and cervix cancer screening among multiethnic women: role of age, health, and source of care. *Prev Med* 1999; **28** (4):418-425

Manhart LE, Holmes KK, Koutsky LA, et al. Human papillomavirus infection among sexually active young women in the United States: implications for developing a vaccination strategy. Sex *Transm Dis* 2006; **33**: 502-508

Manos MM, Kinney WK, Hurley LB, et al. Identifying women with cervical neoplasia: Using human papillomavirus DNA testing for equivocal Papanicolaou results. *JAMA* 1999; **281**:1605-1610

Mao C, Koutsky LA, Ault KA, et al. Efficacy of human papillomavirus-16 vaccine to prevent cervical intraepithelial neoplasia: a randomized controlled trial. *Obstet Gynecol* 2006; **107**:18-27

Markowitz LE, Dunne EF, Saraiya M, et al. Quadrivalent Human Papillomavirus Vaccine: Recommendations of the Advisory Committee on Immunization Practices (ACIP). *MMWR Recomm Rep* 2007; **56**: 1-24

Marlow LAV, Forster AS, Wardle J, et al. Mothers' and adolescents' beliefs about risk compensation following HPV vaccination. *J Adol Health 2009*; **44** (5): 446-451

Marlow LAV, Waller J, Evans REC, et al. Predictors of interest in HPV vaccination: A study of British adolescents. *Vaccine* 2009; **27**: 2483-2488

Marlow LAV, Waller J, Wardle J. Parental attitudes to pre-pubertal HPV vaccination. *Vaccine* 2007a; **25**: 1945-1951

Marlow LAV, Waller J, Wardle J. Trust and experience as predictors of HPV vaccine acceptance. *Human Vaccines* 2007b; **3:**171-175

Marlow LAV, Waller J, Wardle J. Sociodemographic predictors of HPV testing and vaccination acceptability: results from a population-representative sample of British women. *J Med Screen* 2008; **15** (2): 91-96

Marlow LA, Waller J, Wardle J. The impact of human papillomavirus information on perceived risk of cervical cancer. *Cancer Epidemiol Biomarkers Prev* 2009; **18** (2):373-376

Marlow LAV, Wardle J, Forster AS et al. Ethnic differences in HPV awareness and vaccine acceptability. *J Epidemiol Community Health* 2009; **63**: 1010-1015

Marlow LAV, Wardle J, Grant N, et al. Human papillomavirus (HPV) needs: a theoretical framework. *J Fam Plann Reprod Health Care* 2009; **35**(1): 29-33

Marlow LAV, Wardle J, Waller J. Attitudes to HPV vaccination among ethnic minority mothers in the UK: an exploratory qualitative study. *Human Vaccines* 2009; **5**: 105 - 110

Marmot M. Social determinants of health: From observation to policy. *Med J Aust* 2000; **172**:379-382

Marshall H, Ryan P, Roberton D, et al. A cross-sectional survey to assess community attitudes to introduction of human papillomavirus vaccine. *ANZ J Public Health* 2007; **31**: 235-242

Marshall S, Swerissen H. A qualitative analysis of parental decision making for childhood immunisation. *ANZ J Public Health* 1999; **23** (5): 543-545

Mason J. Qualitative Researching. *Sage*, London.2002

Mast TC, Zhu X, Demuro-mercon, et al. Development and psychometric properties of the HPV Impact Profile (HIP) to assess the psychosocial burden of HPV. *Current Medical Research & Opinion* 2009; **25** (11):2609-2619

Maw R, Reitano M, Roy M. An international study of patients with genital warts: perceptions regarding treatment and impact on lifestyle. *Int J STD & AIDS* 1998; **9**: 571-578

May J. HPV vaccination – a paradigm shift in public health. *Aust Fam Physician* 2007; **36**:10-12

May T. Qualitative Research in Action. *Sage*, London, 2002

Mays N, Pope C. Assessing quality in qualitative research. *BMJ* 2000; **320**:50-52

Mays RM, Sturm LA, Zimet GD. Parental perspectives on vaccinating children against sexually transmitted infections. *Soc Sc Med* 2004; **58**: 1405-1413

Mays RM, Zimet GD. Recommending STI vaccination to parents of adolescents: the attitudes of nurse practitioners. *Sex Transm Dis.* 2004; **31**:428-432

Mays, RM Zimet, GD Winston, Y, et al. Human Papillomavirus, genital warts, pap smears and cervical cancer: Knowledge and beliefs of adolescent and adult women. *Health Care for Women Int* 2000; **21**:361-374

McCaffery K, Forrest S, Waller J, et al. Attitudes towards HPV testing: a qualitative study of beliefs among Indian, Pakistani, African-Caribbean and white British women in the UK. *British J Cancer* 2003; **88** (1): 42-46

McCaffery K, Waller J, Forrest S, et al. Testing positive for human papillomavirus in routine cervical screening: examination of psychosocial impact. *BJOG* 2004; **111**(12):1437-1443. Erratum in: *BJOG*. 2004; **111**(12):1489

McCaffery K, Irwig L. Australian women's needs and preferences for information about human papillomavirus in cervical screening. *J Med Screen* 2005; **12**:134-141

McCaffery K, Waller J, Nazroo J, et al. Social and psychological impact of HPV testing in cervical screening: a qualitative study. *Sex Transm Infect* 2006; **82** (2):169-74

McCave EL. An examination of health providers' HPV vaccination behaviours, perceived barriers and supports. A four state analysis. PhD thesis, University of Kansas (2009)

McClelland A, Liamputtong P. Knowledge and acceptance of human papillomavirus vaccination: perspectives of young Australians living in Melbourne, Australia. *Sexual Health* 2006; **3**: 95-101

McDonald H. Beyond Bandaids: Chapter 16: Culture in health research and practice: 255 -280: Papers from the *Social Determinants of Aboriginal Health Workshop*, Adelaide, July 2004. Edited by Ian Anderson, Fran Baum and Michael Bentley

McDonald TW, Neuten JJ, Fischer LM, et al. Impact of cervical intraepithelial neoplasia diagnosis and treatment on self-esteem and body image. *Gynaecol Oncol* 1989; **34**: 345 -349

McDonnell A, Lloyd Jones M, Read S. Practical considerations in case study research: the relationship between methodology and process. *J Advanced Nursing* 2001; **32** (2): 383-390

McGrath P, Holewa H, Ogilvie K, et al. Insights on Aboriginal peoples' views of cancer in Australia. *Contemporary Nurse* 2006; **22** (2): 240-254

McIntyre PB, Menzies RI. Immunisation: reducing health inequality for Indigenous Australians. *MJA* 2005; **182** (5): 207-208

McIntyre PB, Williams A, Leask J. Refusal of parents to vaccinate: dereliction of duty or legitimate personal choice? *MJA* 2003; **178**:150-151

McKee M, Coker R. Trust, terrorism and public health. *J Pub Health* 2009; **31** (4):462 - 465

McLeroy KR, Bibeau D, Steckler A, et al. An ecological perspective on health promotion programs. *Health Education Quarterly* 1988; **15**: 351-377

McMichael C, Kirk M, Manderson L, et al. Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland. *ANZ J Public Health* 2000; 24: 515-519

McMurray A, Param R. Culture-specific care for Indigenous people: A primary health-care perspective. *Contemp Nurse: A Journal for the Australian Nursing Profession* 2008; **28** (1 / 2):165-173

McNaughton R, Shucksmith J, Spratt J, et al. Parents' and children's negotiations around health: the case of the HPV vaccine. *Centre for Research on Families and Relationships* 2010; Briefing 48

McPartland TS, Weaver BA, Lee SK, et al. Men's perceptions and knowledge of human papillomavirus (HPV) infection and cervical cancer. *J Am Coll Health* 2005; **53** (5): 225-230

McPhee SJ, Nguyen T, Euler GL, et al. Successful promotion of hepatitis B vaccinations among Vietnamese-American children ages 3 to 18: results of a controlled trial. *Pediatrics* 2003; **111**:1278-1288

Mechanic D, Meyer S. Concepts of trust among patients with serious illness. *Soc Sci Med.* 2000; **51**:657- 668

Medeiros LR, Rosa DD, da Rosa MI, et al. Efficacy of human papillomavirus vaccines: a systematic quantitative review. *Int J Gynecol Cancer* 2009; **19** (7):1166-1176

Meheus A. Teenagers' lifestyle and the risk of exposure to hepatitis B virus. *Vaccine* 2000; **18** (S1); S26-S29

Menzies RI, McIntyre PB, Beard F. Vaccine preventable diseases and vaccination coverage in Aboriginal and Torres Strait Islander people, Australia, 1999 to 2002. *Commun Dis Intell* 2004; **28** (2); 127-159

Menzies R, McIntyre P, Reid R, et al. Vaccine preventable diseases in indigenous populations—International perspectives Satellite Symposium of the 5th International Symposium on Pneumococci and Pneumococcal Diseases, April 2006, Alice Springs, Australia. *Vaccine* Oct 2007; 25(42): 7281-7284

Menzies R, Turnour C, Chiu C, et al. Vaccine preventable diseases and vaccination coverage in Aboriginal and Torres Strait Islander people, Australia 2003 to 2006. *Commun Dis Intell* 2008; **32**: Suppl: S2-67

Meneses LM, Orrell-Valente JK, Guendelman SR, et al. Racial / ethnic Differences in Mother-daughter Communication about Sex. *J Adol Health* 2006; **39** (1) 128-131

Merle P, Trepo C. Hepatitis B immunization in children. *Arch de Pédiatrie* 1998; **5**: 326 - 332

Meschke LL, Bartholomae S, Zentall SR. Adolescent sexuality and parent-adolescent processes: promoting healthy teen choices. *J Adol Health* 2002; **31** (6) Suppl 1: 264 – 279

Meyer JF. Moral education in the People's Republic of China. *Moral Education Forum* 1990; **15**: 2-26

Meyer T, Arndt R, Beckmann ER, et al. Distribution of HPV 53, HPV 73 and CP8304 in genital epithelial lesions with different grades of dysplasia. *Int J Gynecol Cancer* 2001; **11**:198-204

Michaud PA, Blum RW, Slap GB. Cross-cultural surveys of adolescent health and behavior: progress and problems. *Social Science & Medicine* 2001; **53** (9):1237-1246

Middleman AB. Race/ethnicity and gender disparities in the utilization of a school-based hepatitis B immunization initiative. *J Adol Health* 2004; **34**: 414-419

Middleman AB, Guajardo AD, Sunwoo E, et al. Parent knowledge and attitudes about school-based Hepatitis B immunization programmes. (Health Service Applications) *J School Health* 2002; **72**: (8): 348-350

Middleman A, Tung J. Parent's willingness to get vaccines in schools. *J Adol Health* 2010; **46** (2):S1:S69-70.Society for Adolescent medicine Annual Meeting Program issue –Adolescent Clinical Care: Integrating Art and Science

Miles J, Gilbert P. A Handbook of Research Methods for Clinical and Health Psychology. *Oxford*, New York, 2005

Miles MB, Huberman AM. Qualitative Data Analysis: An Expanded Sourcebook*. Sage*, Thousand Oaks, 1994

Miller GC, McDermott R, McCulloch B, et al. Predictors of the prevalence of bacterial STI among young disadvantaged Indigenous people in north Queensland, Australia. *Sex Transm Infect* 2003; **79**: 332-335

Mills E, Jadad AR, Ross C, et al. Systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccination identifies common barriers to vaccination. *J Clin Epidemiol* 2005 Nov; **58**(11):1081-1088

Mitchell M, Hussey LM. The Aboriginal health worker. *MJA* 2006; **184** (10):529-530

Mobbs R. In sickness and health: The sociocultural context of Aboriginal well-being, illness and healing. In: Reid J, Trompf P. *The Health of Aboriginal Australia*. Sydney: Harcourt Brace and Company, 1991; 292-325

Modood T. Anti-essentialism, multiculturalism and the 'recognition' of religious groups. *J Political Philosophy* 1998; **6**: 378-399

Monk BJ, Wiley DJ. Will widespread human papillomavirus prophylactic vaccination change sexual practices of adolescent and young adult women in America? *Obstet Gynecol* 2006; **108**:420

Mooney-Somers J, Erick W, Scott R, et al. Enhancing Aboriginal and Torres Strait islander young people's resilience to blood-borne and sexually transmitted infections: findings from a community-based participatory research project. *Health Prom J Aus* 2009; **20** (3):195-202

Moore-Caldwell SY, Werner MJ, Powell L, et al. Hepatitis B vaccination in adolescents: knowledge, perceived risk, and compliance. *J Adol Health* 1997; **20**: 294 -299

Moorthy S. Global physician and consumer perception of human papillomavirus (HPV) disease and attitudes toward HPV vaccination: results of multinational surveys. Poster presentation IPV conference, Prague 2006. Merck and Co. Inc. New Jersey

Moos RH. Social-ecological perspectives on health: in Stone GC, Cohen F, Adler NE (Eds) *Health Psychology: A Handbook* 1979: 523- 548, San Francisco, Jossey Bass

Moreira ED Jr, Oliveira BG, Ferraz FM, et al. Knowledge and attitudes about human papillomavirus, Pap smears, and cervical cancer among young women in Brazil:

implications for health education and prevention. *Int J Gynecol Cancer* 2006; **16** (2): 599 - 603

Morgan D, Slade M, Morgan CM. Aboriginal philosophy and its impact on health care outcomes. *ANZ J of Public Health* 1997; **21** (6): 597-601

Morgan G, Smircich L. The case for qualitative research. *The Academy of Management Review* 1980; **5** (4):491-500

Morison LA, Cozzolino PJ, Orbell S. Temporal perspective and parental intention to accept the human papillomavirus vaccination for their daughter. *Br J Health Psychol* 2010; **15**(Pt 1):151-65. Epub 2009 Apr 28

Morrissey M, Pe-Pua R, Brown A et al. Beyond Bandaids: Chapter 15: Culture as a Determinant of Aboriginal Health. pg 239 Papers from the *Social Determinants of Aboriginal Health Workshop*, Adelaide, July 2004; edited by Ian Anderson, Fran Baum and Michael Bentley

Morse JM, Field PA. Qualitative research methods for health professionals. *Sage*, Thousand Oaks, 1995

Mortensen GL. Drivers and barriers to acceptance of human-papillomavirus vaccination among young women: a qualitative and quantitative study. *BMC Public Health* 2010; **10**: 68 (ISSN: 1471-2458)

Mortensen GL, Larsen HK. The quality of life of patients with genital warts: a qualitative study. *BMC Public Health* 2010, **10**:113

Mosavel M and El-Shaarawi N. "I have never heard that one": Young girls' knowledge and perception of cervical cancer. *J Health Communication* 2007; **12**:707-719

Moscicki AB. Impact of HPV infection in adolescent populations. *J Adol Health* 2005; **37**: S3-S9

Moscicki AB. HPV vaccines: Today and in the future. *J Adol Health* 2008; **43**: S26 -S40

Moscicki AB, Schiffman M, Kjaer S, et al. Chapter 5: Updating the natural history of HPV and anogenital cancer. *Vaccine* 2006; **24**: S42-51

Moscicki AB, Smith JS. Issues in human papillomavirus vaccination in adolescents. *J Adol Health* 2008; **43**:S1-S4

Mosavel M, El-Shaarawi N. "I have never heard that one. "Young girls' knowledge and perception of cervical cancer. *J Health Comm* 2007; **12**:707-719

Mulhall BP Hart G, Harcourt C. STDs in Australia: A decade of change - epidemiology and surveillance. *Ann Acad Med Singapore* 1995; **24** (4):569-578

Mullins T, Zimet G, Rosenthal S, et al. Perceptions of STI Risk and Need for Safer Sexual Behaviors Following First HPV Vaccination. *J Adol Health*, February 2010; **46** (2): S1:S67 .Society for Adolescent Medicine Annual Meeting Program Issue - Adolescent Clinical Care: Integrating Art & Science

Mulvey G, Temple-Smith MJ, Keogh LA. Sexually transmissible diseases – knowledge and practices of general practitioners in Victoria, Australia. *Genitourin Med* 1997; **73**: 533-537

Munger K. The role of human papillomaviruses in human cancer. *Front Biosci* 2002; **7**: 641-649

Munoz N, Bosch FX, de Sanjose S, et al. Epidemiologic classification of human papillomavirus types associated with cervical cancer *N Engl J Med* 2003; **348**:518-527

Muñoz N, Manalastas J R, Pitisuttithum P, et al. Safety, immunogenicity, and efficacy of quadrivalent human papillomavirus (types 6, 11, 16, 18) recombinant vaccine in women aged 24-45 years: a randomised, double-blind trial. *Lancet* 2009; **373**:1949–57

Myers ER. HPV vaccines: Now that they're here, how do we maximize their benefit? *Vaccine* 2006; **24**:5571-5583

Naki MM, Çelik H, Api O, et al. Awareness, knowledge and attitudes related to HPV infection and vaccine among non-obstetrician-gynecologist healthcare providers. *J Turkish-German Gynecol Assoc* 2010; **11**: 16-21

Naish J. Brown J, Denton B. Intercultural consultations: Investigation of factors that deter non-English speaking women from attending their general practitioners for cervical screening. *BMJ* 1994; **309**:1126-1128

NCHIVECR National Centre in HIV Epidemiology and Clinical Research .HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia annual surveillance report 2002. Sydney 2002

NCIRSa: Significant events in Hepatitis b immunisation practice in Australia. http://www.ncirs.usyd.edu.au/publ/publ-79-histtab5.html (Accessed 28 11 2005)

NCIRSb: *Vaccine Preventable Diseases and Vaccination Coverage in Australia 2001-2002*, National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases. (Accessed 28 11 2005)

NCSR: National Centre for Social Research: http://www.natcen.ac.uk/index.html 2010

Neuhauser L, Kreps GL. Online cancer communication: Meeting the literacy, cultural and linguistic needs of diverse audiences. *Patient Education and Counselling* 2008; **71**:365 - 377

Newall AT, Brotherton JML, Quinn HE, et al. Population seroprevalence of human papillomavirus types 6,11,16,18 in men, women and children in Australia. *Clin Infec Dis* 2008; **46**:1647-1655

Newton D, McCabe M. Sexually transmitted infections: Impact on individuals and their relationships. *J Health Psychology* 2008; **7** (7):864-869

Nguyen HN, Liamputtong P, Murphy G. Knowledge of contraceptives and sexually transmitted diseases and contraceptive practices among young people in Ho Chi Minh City, Vietnam. *Health Care for Women International* 2006; **27**: 399-417

NHMRC: National Health and Medical Research Council. Values and ethics. Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research. Canberra, Commonwealth of Australia, 2003

NHMRC: National Health and Medical Research Council. Screening to prevent cervical cancer: guidelines for the management of asymptomatic women with screen detected abnormalities. Canberra. *NHMRC* 2005:**5**

NHPVVPR: The National HPV Vaccination Program Register: www.hpvregister.org.au/ 2009

NIASHS The National Indigenous Australians' Sexual Health Strategy 1996-97 to 1998-99 (NIASHS) *Department of Health and Ageing*, Government of Australia 2000

Nindl I, Lotz B, Kuhne-Heid R, et al. Distribution of 14 high risk HPV types in cervical intraepithelial neoplasia detected by a non-radioactive general primer PCR mediated enzyme immunoassay. *J Clin Pathol* 1999; **52**:17-22

NIS: National Immunisation Strategy 1993. *National Health and Medical Research Council*, Commonwealth of Australia 1993

Noakes K, Yarwood J, Salisbury D. Parental response to the introduction of a vaccine against human papillomavirus, *Human Vaccines* 2006; **2**:243-248

NPHP 2001. National Public Health Partnership Group. News. Joint meeting of the National Public Health Partnership Group and National Health Priority Action Council. Hobart February 2001. Issue **15** March-April 2001

NSW Department of Health. Communicating positively: A guide to appropriate Aboriginal terminology. 2004: 9

O'Brien ED, Baillie RS, Jelfs PL. Cervical cancer mortality in Australia: contrasting risk by Aboriginality, age and Rurality. *Int J Epidemiol* 2000; **29** (5):813-816

O'Donoghue L. Towards a culture of improving Indigenous health in Australia. *Aust J Rural Health* 1999; **7**(1): 64-69

Ogilvie G, Anderson M, Marra F, et al. A population-based evaluation of a publicly funded school-based HPV vaccine program in British Columbia, Canada: Parental factors associated with HPV vaccine receipt. *PLoS Med* 2010; **7**(5): 1 -11 e1000270

Ogilvie GS, Remple VP, Marra F, et al. Parental intentions to have daughters receive the human papillomavirus vaccine. *Canadian Med Assoc J* 2007; **177**:1506-1512

Ogilvie GS, Remple VP, Marra F, et al. Intention of parents to have male children vaccinated with the human papillomavirus vaccine. *Sex Transm Infect* 2008; **000**:1-7

Okazaki S, Stanley S. methodological issues in assessment research with ethnic minorities. *Psych Assessment* 1995; **7**(3): 367-375

O'Keefe EJ, Gardner A, Currie MJ, et al. Prevalence of genital human papillomavirus DNA in a sample of senior school-aged women in the Australian Capital Territory. *Sex Health* 2006; **3** (2): 91-94

Olshen E, Woods ER, Austin SB, et al. Parental acceptance of the HPV vaccine. *J Adol Health* 2005; **37** (3): 248-251

Olsson SE, Villa LL, Costa RL, et al. Induction of immune memory following administration of a prophylactic quadrivalent human papillomavirus (HPV) types 6/11/16/18 L1 virus-like particle (VLP) vaccine. *Vaccine.* 2007; **25**:4931–4939

Paavonen J, Jenkins D, Bosch FX, et al. Efficacy of a prophylactic adjuvanted bivalent L1 virus-like-particle vaccine against infection with human papillomavirus types 16 and 18 in young women: an interim analysis of a phase III double-blind randomised controlled trial. *Lancet* 2007; **369**:2161-2170

Paavonen J, Naud P, Salmeron J, et al. Efficacy of human papillomavirus (HPV)-16/18 AS04-adjuvanted vaccine against cervical infection and precancer caused by oncogenic HPV types (PATRICIA): final analysis of a double-blind, randomised study in young women. *The Lancet* 2009; Published online July 2, 2009 DOI: 10.1016/SO140-6736(09)61248-4

Pagliusi S. Human papillomavirus infection and cervical cancer. *World Health Organisation* 2001

Pagliusi SR, Aguado MT. Efficacy and other milestones for human papillomavirus introduction. *Vaccine* 2004; **23** (5):569-578

Paul-Ebhohimhen V, Huc S, Tissington H, et al HPV vaccination: vaccine acceptance, side effects and screening intentions .*Community Practitioner* 2010; **83**(6):30-33(4)

Palefsky JM. HPV infection in men. *Disease Markers* 2007; **23**: 261-272

Palmer B, Macfarlane G, Afzal C, et al. Acculturation and the prevalence of pain amongst South Asian minority ethnic groups in the UK. *Rheumatology* (Oxford) 2007; **46** (6):1009-1014

Palmer LE. HPV vaccination for men. *TuftScope* 2009; **9**(1): 6-7

Pan SM. The contemporary situation of sexuality in China. 1995 Beijing: Guangming Daily Publishing House; in Zhang K, Beck EJ. Changing sexual attitudes and behaviour in China: implications for the spread of HIV and other sexually transmitted diseases. *AIDS Care* 1999; **11** (5):581-589

Panaretto KS, Dallachy D, Manessis V, et al. Cervical smear participation and prevalence of sexually transmitted infections in women attending a community-controlled Indigenous health service in North Queensland. *ANZ J Public Health* 2006; **30** (2):171-176

Papaevangelou G. Hepatitis B immunization: lessons learnt in Greece. *Vaccine* 1998; **16** (S45-S47)

Parish WL, Laumann EO, Mojola SA. Sexual behavior in China: trends and comparisons (Survey publication). *Population and Development Review* 2007; **33** (4):729-756

Parkin DM, Whelan SL, Ferlay J, et al. Cancer incidence in five continents. *IARC Scientific Publications* 2002; **8** No. 155 Lyon: IARC Press

Parkin DM. The global health burden of infection-associated cancers in the year 2002.*Int J Cancer* 2006; **118**(12):3030-3044

PATH: A vaccine for women's health; Preparing the way for a new tool in the fight against cervical cancer.http://path.org/ (accessed 4 March 2010)

PATHa: Progress in preventing cervical cancer: Updated evidence on vaccination and screening. *Outlook* May 2010; **27**(2)

Paulussen TGW, Hoekstra F, Lanting CI, et al. Determinants of Dutch parents' decisions to vaccinate their child. *Vaccine* 2006; **24**:644-651

Peachey, LG. McBain, KE, Armstrong, RM. Indigenous health: burden or opportunity? *MJA* 2006; **184** (10):483-484

Pearson N. Our Right to Take Responsibility: Discussion Paper, Cape York Land Council, Cape York, Qld) in Campbell D, Pyett P, McCarthy L, Whiteside M and Tsey K. Beyond Bandaids: Chapter 9: Community development and empowerment. A review of interventions to improve Aboriginal Health. Pg 165-172 Papers from the *Social Determinants of Aboriginal Health Workshop*, Adelaide, July 2004 Edited by Anderson I, Baum F and Bentley M. 2000

Pederby A. Communicating across cultural boundaries in: Siddle M, Jones L, Katz J, Pederby A. Editors, *Debates and Dilemmas in Promoting Health: A Reader*, Open University, Buckinghamshire;1997:99-107

Pedersen C, Petaja T, Strauss G, et al. Immunization of early adolescent females with human papillomavirus type 18 and 18 L1 virus-like particle vaccine containing AS04 adjuvant. *J Adol Health* 2007; **40**: 564-571

Persson G, Dahlof LG, Krantz I. Physical and psychological effects of anogenital warts on female patients. *Sex Transm Dis* 1993; **20**:10-13

Petousis-Harris H, Goodyear –Smith F, Turner N, et al. Family physician perspectives on barriers to childhood immunisation. *Vaccine* 2004; **22** (17-18):2340-2344

Pfeffer N. Screening for breast cancer: candidacy and compliance. *Soc Sci Med* 2004; **58**:151-160

Phelan P, Davison AL, Cao HT. Students' multiple worlds: negotiating the boundaries of family, peer and school cultures. *Anthropology and Education Quarterly* 1991; **22**:224-250

Phinney JS, Horenczyk G, Liebkind K, et al. Ethnic identity, immigration and well being: an interactional perspective. *Social Issues* 2001; **57***:*493-510

Ping K. Cultural presuppositions and misreadings. *Meta* 1999; **44** (1):133-143

Pirotta MV, Stein AN, Conway EL, et al. Genital warts incidence and healthcare resource utilisation in Australia. *Sex Transm Infec* 2010; **86**:181-186

Pirotta MV, Stein AN, Fairley CK, et al. Patterns of treatment of external genital warts in Australian sexual health clinics. *Sex Transm Dis* 2009a; **36** (6):375-379

Pirotta M, Ung L, Stein A, et al. The psychosocial burden of HPV-related disease and screening interventions. *Sex Transm Infec* 2009b; **85** (7): 508-513

Pitts MK, Dyson SJ, Rosenthal DA, et al. Knowledge and awareness of human papillomavirus (HPV): attitudes towards HPV vaccination among a representative sample of women in Victoria. *Aust Sex Health* 2007; **4**: 177-180

Pitts MK, Fox C, Willis J, et al. What do gay men know about human papillomavirus? Australian gay men's knowledge and experience of anal cancer screening and human papillomavirus. *Sex Transm Dis* 2007; **34** (3):170-173

Pitts MK, Heywood W, Ryall R, et al. Knowledge of human papillomavirus (HPV) and the HPV vaccine in a national sample of Australian men and women. *Sexual Health* 2010; 7 (3): 299-303

Pitts MK, Smith A, Croy S, et al. Singaporean men's knowledge of cervical cancer and human papillomavirus (HPV) and their attitudes towards HPV vaccination. *Vaccine* 2009a; **27**(22): 2989-2993

Pitts M, Smith A, Croy S, et al. Singaporean women's knowledge of human papillomavirus (HPV) and attitudes toward HPV vaccination. *Vaccine* 2009b; **49**(4): 334-351

Plaitano S, Sagliocca L, Mele A, et al. Hepatitis B mass immunisation of adolescents: a pilot study in a community. *Eur J Epidemiol* 1993; **9** (3): 307-310

Plummer D, Forrest B. Factors affecting Indigenous Australians' access to sexual health clinical services. *Venereology* 1999; **12** (2): 47-52

Plummer M, Franceschi S. Strategies for HPV prevention. *Virus Res* 2002; **89**: 285-293

Poland GA, Jacobson RM, Koutsky LA, et al. Immunogenicity and reactogenicity of a novel vaccine for human papillomavirus 16: a 2-year randomized controlled clinical trial. *Mayo Clinic Proceedings* 2005; **80** (5): 601-610

Polzer J, Knabe S. Good girls do…get vaccinated: HPV, mass marketing and moral dilemmas for sexually active young women. *J Epidemiol Comm Health* 2009; **63** (11): 869-870

Ponce NA, Chawla N, Babey SH, et al. In there a language divide in Pap test use? *Medical Care* 2006; **44** (11):998-1004

Pope C, Mays N. Qualitative Research: reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995; **311**:42-45

Pope C, Mays N. Qualitative research in health care. Blackwell, Oxford, 2006

Pope C**,** Ziebland S, Mays N. Qualitative research in health care: Analysing qualitative data. *BMJ* 2000; **320**:114-116

Porta M. The improbable plunge.What facts refute reasons to expect that the effectiveness of HPV vaccination programs to prevent cervical cancer could be low? *Prev Med* 2009; **48**: 407- 410

Posner T, Vessey M. Prevention of cervical cancer: the patient's view. London: King's Fund, 1988

Prior D. Don't mention the 'C' word: Aboriginal women's view of cancer. *Aborigin Isl Health Worker J* 2005; 29: 7-10

Prislin R, Dyer JA, Blakely CH, et al. Immunization status and sociodemographic characteristics: The mediating role of beliefs, attitudes, and perceived control. *Am Pub Health Assoc* 1998; **88** (12):1821-1826

Prislin R, Nader PR, De Guire M, et al. Physicians' immunization knowledge, attitudes and practices. A valid and internally consistent measurement tool. *Am J Prev Med* 1999; **17** (2): 151-152

Pritchard C. Aussies tout hepatitis B vaccine for all kids. *Medical Post* 1997; **33**: 54

Pyett P. Working together to reduce health inequalities: reflections on a collaborative participatory approach to health research. *ANZ J Pub Health* 2002; **26** (4): 332-336

Quillam S. Positive smear. London: Penguin Books, 1989

Raffaelli M, Bogenschneider K, Flood MF. Parent-teen communication about sexual topics. *J Fam Issues* 1998; **19** (3):315-333

Raley JC, Followwill KA, Zimet GD, et al. Gynecologists' attitudes regarding human papilloma virus vaccination: a survey of Fellows of the American College of Obstetricians and Gynecologists. *Infec Dis in Obst and Gyn* 2004; **12** (3-4): 127-133

Rand CM, Szilagyi PG, Albertin C, et al. Additional health care visits needed among adolescents for human papillomavirus vaccine delivery within medical homes: A national study. *Pediatrics* 2007; **120**:461-466

Raupach J, Rogers W, Magarey A, et al. Advancing health promotion in Australian general practice. *Health Education & Behavior* 2001; **28** (3): 352-367

Rawson HA and Liamputtong P. Culture and sex education: the acquisition of sexual knowledge for a group of Vietnamese Australian young women. *Ethnicity and Health* 2010; 1-22. First published on 20 May 2010; *iFirst article* [Downloaded 16 July 2010]

Read DS, Joseph MA, Polishchuk V, et al. Attitudes and perceptions of the HPV vaccine in Caribbean and African-American adolescent girls and their parents. *J Ped Adol Gynecol* 2010; **23** (4): 242-245

Reason P, Bradbury H. Handbook of action research: participative inquiry and practice. London: Sage, 2001

Reath JS. Preventing cervical cancer: strategies for a remote Aboriginal community. *Aboriginal and Islander Health Worker Journa*l 1999; **23** (3): 7-10

Reath JS, Patel M, Moodie R. Cervical cytology in Central Australian Aboriginal women. *Aust Fam Physician* 1991; **20**: 600-606

Reed D. Employing normative stakeholder theory in developing countries: A critical theory perspective. *Business Society* 2002:**41** (2):166-207

Reeve C, De La Rue S, Pashen D, et al. School-based vaccinations delivered by general practice in rural north Queensland: an evaluation of a new human papillomavirus vaccination program. *Communicable Diseases Intelligence* 2008; **32**(1):94-98

Reidesel JM, Rosenthal SL, Zimet GD, et al. Family physician's attitudes about HPV Vaccines. *J Adol Health* 2005; **36** (2):124-125

Riedesel JM, Rosenthal SL, Zimet GD, et al. Attitudes about human papillomavirus vaccine among family physicians. *J Pediatr Adolesc Gynecol* 2005; **18**: 391-398

Reisinger KS, Block SL, Lazcano-Ponce E et al . Safety and persistent immunogenicity of quadrivalent human papillomavirus types 6, 11, 16, 18 L1 virus-like particle vaccine in preadolescents and adolescents: a randomized controlled trial. *The Ped Infec Dis J* 2007; **26** (3): 201-209

Reiter PL, Brewer NT, Gottlieb SL, et al. Parents' health beliefs and HPV vaccination of their adolescent daughters. *Social Science & Medicine* 2009; **69** (3): 475-480

Rhodes SD, Yee LJ. Using hepatitis A and B vaccination as a paradigm for effective HIV delivery. *Sexual Health* 2007; **4**: 121-127

Richards HM, Schwartz LJ. Ethics of qualitative research: are there special issues for health services research. *Fam Prac* 2002; **19** (2):135-139

Ring IT, Brown N. Indigenous health: chronically inadequate responses to damning statistics. *MJA* 2002; **177** (11): 629-631

Rissel CE, Richters J, Grulich AE, et al. Sex in Australia: First experiences of vaginal intercourse and oral sex among a representative sample of adults. *Aust NZ J Public Health* 2003; **27**(2):131-137

Ritchie J, Lewis J. Qualitative Research Practice. *Sage,* London, 2003

Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, eds. *Analysing Qualitative Data.* London: Routledge, 1993: 173-194.

Robbins SCC, Bernard D, McCaffery K, et al. 'Is cancer contagious?' Australian adolescent girls and their parents: Making the most of limited information about HPV and HPV vaccination. *Vaccine* 2010; **28** (19): 3398-3408

Robinson, JD. Correlations and Implications of Enthusiasm for Learning and Academic Performance in Urban Youth: An Evaluation of the Children's Defense Funds. *Black Community Crusade for Children* 1997

Robinson N. The use of focus group methodology – with selected examples from sexual health research. *J Advanced Nursing* 1999; **29**: 905-913

Rogstad KE. The psychological impact of abnormal cytology and colposcopy. *BJOG 2002;* **10**: 364-368

Romo LF, Nadeem E, Au TK, et al. Mexican-American adolescents' responsiveness to their mothers' questions about dating and sexuality. *J Applied Developmental Psych* 2004; **25** (5): 501-522

Rondy M, Van Lier A, van de Kassteele J, et al. Determinants for HPV uptake in the Netherlands: a multilevel study. *Vaccine* 2010; **28**: 2070-2075

Rosenthal DA, Dyson S, Pitts M, et al. Challenges to accepting a Human Papillomavirus (HPV) vaccine: A qualitative study of Australian women. *Women Health* 2007; **45** (2): 59-73

Rosenthal D, Feldman SS. The nature and stability of ethnic identity in Chinese youth. *J Cross-Cultural Psychology* 1992; **23**: 214-227

Rosenthal SL. Protecting their adolescents from harm: parental views on STI vaccination. *J Adol Health* 2005; **37** (3):177-178

Rosenthal SL, Kottenham RK, Biro FM, et al. Hepatitis B vaccine acceptance among adolescents and their parents. *J Adol Health* 1995; **17**:248-254

Rosenthal SL, Rupp R, Zimet GD, et al. Uptake of HPV vaccine: Demographics, sexual history and values, parenting style, and vaccine attitudes. *Adol Health* 2008; **43** (3): 239-245

Rosenthal SL, Stanberry LR. Parental acceptability of vaccines for sexually transmitted infections. *Arch Pediatr Adolesc Med* 2005; **159**:190-192

Rosenthal SL, Weiss TW, Zimet GD, et al. Predictors of HPV vaccine uptake among women aged 19-26: Importance of a physician's recommendation. *Vaccine* 2010

Ross, MW, Fernández-Esquer ME. Ethnicity in sexually transmitted infections and sexual behaviour research. *The Lancet* 2005; **365** (9466): 1209-1210

Rothman SM, Rothman DJ. Marketing HPV vaccine. Implications for adolescent health and medical professionalism. *JAMA* 2009; **302**(7):781-786

Roughead E, Gilbert A, Vitry A. The Australian funding debate on quadrivalent HPV vaccine: A case study for the national pharmaceutical policy. *Health Policy* 2008; **88** (2): 250-257

Rozin P. Five potential principles for understanding cultural differences in relation to individual differences. *J Research Personality* 2003; **37**:273-283

Rumbold A, Nickels M. Vulva cancer, HPV and results from the SISTER study Research. Oral paper, RANZCOG 2008 Indigenous Women's Health Meeting, 14-16 August 2008,Darwin Convention Centre, Darwin, Australia (http://www.ranzcog.edu.au/meetingsconferences/pdfs/IWH-darwin2008-program.pdf)

Rupp R, Rosenthal SL,Stanberry LR. Pediatrics and herpes simplex virus vaccines. *Seminars in Pediatric Infec Dis* 2005; **16**(1): 31-37

Ryan H, Pasternak RH, Cheng TL, et al. Parent and adolescent views of risk behavior research and consent. *J Adol Health* 2005; **36** (2): 104-105

Sam IC, Wong LP, Rampal S, et al. Maternal acceptance of human papillomavirus vaccine in Malaysia. *J Adol Health* 2009; **44** (6): 610-612

Sanci LA, Sawyer SM, Kang MSL, et al. Confidential health care for adolescents: reconciling clinical evidence with family values. *MJA* 2005; **183** (8): 410-414

Sankaranarayanan R, Bhatla N, Gravitt P, et al. Human papillomavirus infection and cervical cancer prevention in India, Bangladesh, Sri Lanka and Nepal. *Vaccine* 2008; **26**(Suppl 12): M43-52

Santistebatan DA, Mitrani VB. Influence of the acculturation processes on the family in Chun K, Balls-Organista P, Marin G (eds.) *Acculturation: Advances in theory, measurement and applied research* 2002; 121-136.Washington: APA press

Saslow D, Castle PE, Cox JT, et al. American Cancer Society Guideline for human papillomavirus (HPV) vaccine use to prevent cervical cancer and its precursors. *CA Cancer J Clin* 2007;**57**: 7-28

Sauvageau C, Duval B, Gilca V, et al. Human papillomavirus vaccine and cervical cancer screening acceptability among adults in Quebec, Canada. *BMC Public Health* 2007*;* **7**: 304-309

Saxena S, Copas AJ, Mercer C, et al. Ethnic variations in sexual activity and contraceptive use: national cross-sectional survey. *Contraception* 2006; **74**(3): 224-233

Scarinci IC, Garcés-Palacio IC, Partridge EE. An examination of the acceptability of HPV vaccination among African-American women and Latina immigrants. *J Women's Health* 2007; **16** (8): 1224-1233

Schiffman M, Castle PE. Human papillomavirus. Epidemiology and public health. *Arch Pathol Lab Med* 2003; **127**: 930-934

Schiffman M, Castle PE, Jeronimo J, et al. Human papillomavirus and cervical cancer. *Lancet* 2007; **370**: 890-907

Schiffman M, Clifford G, Buonaguro FM. Classification of weakly carcinogenic human papillomavirus types: addressing the limits of epidemiology at the borderline. *Infec Agents and Cancer* 2009; **4**: 8

Schiffman M, Kjaer SK. Chapter 2: Natural history of anogenital human papillomavirus infection and neoplasia. *J Natl Cancer Inst Monogr* 2003; **31**:14-19

Schlecht NF, Kulaga S, Robitaille J et al. Persistent human papillomavirus infection as a predictor of cervical intraepithelial neoplasia. *JAMA* 2000; **268** (24): 3106-3114

Schmiedeskamp MR, Kockler DR. Human papillomavirus vaccines. *Ann Pharmacother* 2006; **40**:1344-1352

Schnatz PF, Humphrey K, O'Sullivan DM. Assessment of the perceptions and administration of the human papillomavirus vaccine. *J Lower Genital Tract Dis* 2010;14 (2):103-107

Schouten BC, van den Putte B, Pasmans M, et al. Parent–adolescent communication about sexuality: The role of adolescents' beliefs, subjective norm and perceived behavioral control. *Patient Education and Counseling* 2007; **66** (1): 75-83

Schwarz TF, Dubin G, HPV Vaccine Study Investigators for Adult Women. AS04-adjuvantedHPV16/18 L1 Vaccine for preventing cervical cancer is highly immunogenic and well tolerated in women over 25 years of age. American Society of Clinical Oncology 2006 May. *ASCO Annual Meeting 2007 Proceeding* 2007; Part I; **25**: (18) S58

Schwarz TF, Spaczynski M, Schneider A, et al. Immunogenicity and tolerability of an HPV-16/18 AS04-adjuvanted prophylactic cervical cancer vaccine in women aged 15-55 years. *Vaccine* 2009; **27** (4): 581-587

Scrimgeour DJ. Let's not talk about sex: reconsidering the public health approach to sexually transmissible infections in remote indigenous populations in Australia: Matters Arising. *MJA* 2008; **188** (3):182-184

Seale C, Gobo G, Gubrium JF, Silverman D. Qualitative research Practice. *Sage,* London 2004

Senghaas D. The Clash within Civilizations: Coming to terms with cultural conflicts. Routledge, 1998 London

Senior K. Global aspirations for HPV vaccination. Newsdesk. *The Lancet Infec Dis* 2008; **8** (3): 150

Serpell L, Green J. Parental decision-making in childhood vaccination. *Vaccine* 2006; **24** (19): 4041-4046

Shah KV. Asia Pacific: Cervical cancer screening and human papillomavirus vaccination policy and delivery. Foreword. *Vaccine* 2008; **26S**: iii-iv

Shahid S, Bessarab D, Howat P, et al. Exploration of the beliefs and experiences of Aboriginal people with cancer in Western Australia: a methodology to acknowledge cultural difference and build understanding. *BMC Medical Research Methodology* 2009; **9**: 60-67

Shank G. Semiotics and Qualitative Research in Education: The Third Crossroad. *The Qualitative Report* Dec 1995; **2** (3)

Sharma S. Vaccines against human papillomavirus and cervical cancer: An overview. *Indian J Community Medicine* 2008; **33** (3):143-145

Shaw AR. HPV vaccines in development: If they're successful in clinical trials, how will they be implemented? *Gyn Onc* 2005; **99** (3): Suppl 1:S246-248

Shefer A, Markowitz, Deeks S, et al. Early experience with human papillomavirus vaccine introduction in the United States, Canada and Australia. *Vaccine* 2008; **26S**: K68-K75

Shelley JM, Irwig LM, Simpson JM, et al. Who has Pap smears in New South Wales? Patterns of screening across socio-demographic groups. *Aust J Public Health* 1994; **18**: 406-411

Sherris J, Friedman A, Wittet S, et al. Chapter 25: Education, training and communication for HPV vaccines. *Vaccine* 2006; **24S3**: S3 / 210-S3 / 218

Shew, M Fortenberry JD, Tu W, et al. Association of condom use, sexual behaviours and sexually transmitted infections with the duration of genital HPV infection. *J Adol Health* 2005; **36** (2):102-103

SHFPA: Sexual Health and Family Planning Australia, 2005 http://www.shfpa.org.au/images/stories/publications/srh_call_to_action.pdf

SHHIV: Sexual health and HIV: Measures for success in England. Sept. 2007, (http://www.fpa.org.uk/attachments/published/822/Sexual health and HIV measures for success in England. pdf)

Shi JF, Qiao YL, Smith JS, et al. Epidemiology and prevention of Human Papillomavirus and cervical cancer in China and Mongolia. *Vaccine* 2008; **26S**: M53-M59

Shin GY. Effect of ethnic group should be clarified. *BMJ* 2008; **336**:1146 doi:10.1136/bmj.39583.71699.3A

Short MB, Rupp R, Stanberry LR, et al. Parental acceptance of adolescent vaccines within school-based health centres. *Herpes* 2005; **12**: (1):23-27

Shui IM, Weintraub ES, Gust DA. Parents concerned about vaccine safety. Differences in race/ethnicity and attitudes. *Am J Prev Med* 2006; **31** (3):244-251

Siahpush M, Singh GK. Sociodemographic predictors of Pap test receipt, currency and knowledge among Australian women. *Prev Med* 2002; **35** (4): 362-368

Siddiqui M, Asif A, Perry CM. Human papillomavirus quadrivalent (types 6, 11, 16, 18) recombinant vaccine Gardasil ^{R}. *Drugs* 2006; **66** (9):1263-1271

Siegrist CA, Lewis EM, Eskola J, et al. Human papilloma virus immunization in adolescent and young adults: a cohort study to illustrate what events might be mistaken for adverse reactions. *Pediatr Infect Dis J* 2007; **26**: 979-984

Silverman D. Doing qualitative research. *Sage*, London, 2005

Silverman D. Interpreting Qualitative data: Methods for analysing talk, text, and interaction. *Sage*, London, 1993

Simatherai D, Bradshaw CS, Fairley CK, et al. What men who have sex with men think about the human papillomavirus vaccine. *Sex Transm Infect* 2009; **85**: 148-149

Singh S, Madge S ,Ford C. National Sexual Health & HIV Strategy – RCGP Response, 2002. (http://www.rcgp.org.uk/news__events/college_viewpoint/college_responses/national_sexual_health_and_hiv.aspx)

Sinha S, Jayakody A, Curtis K, et al. How much does ethnicity influence adolescent sexual behavior? *J Adol Health* 2005; **36** (2):140-141

Skinner SR and Cooper Robbins SC. Voluntary school-based human papillomavirus vaccination: an efficient and acceptable model for achieving high vaccine coverage in adolescents. Editorial. *J Adol Health* 2010; **47**: 215-218

Skinner SR, Garland SM, Stanley MA, et al. HPV vaccination for the prevention of cervical neoplasia: is it appropriate to vaccinate women over 26? *Med J Aust* 2008; **188** (4): 238-242

Skinner SR, Hickey M. Current priorities for adolescent sexual and reproductive health in Australia. *MJA* 2003; **179**:158-161

Skinner SR, Imberger A, Nolan T, et al. Randomised controlled trial of an educational strategy to increase school-based adolescent hepatitis B vaccination. *ANZ J Pub Health* 2000; **24** (3): 298-304

Skinner SR, Kang M, Rosenthal SM. Vaccinating young adults against human papillomavirus: the importance of understanding health decision-making and behaviour. *Sex Health* 2007; **4** (2):129-132

Skinner SR, Nolan T. Adolescent hepatitis B immunisation- should it be the law? *Aust N Z J Public Health* 2001*;* **25** (3): 230-233

Skinner SR, Nolan T, Bowes G. Measles-mumps- rubella and hepatitis B vaccination uptake in adolescents: a survey in metropolitan Melbourne. *Med J Aust* 1998; **168** (11): 546-549

Skinner SR, Smith J, Fenwick J, et al. Perceptions and experiences of first sexual intercourse in Australian adolescent females. *J Adol Health* 2008; **43**: 593-599

Slade BA, Leide Ll, Vellozzi C, et al. Postlicensure safety surveillance for quadrivalent human papillomavirus recombinant vaccine. *JAMA* 2009; **32**(7): 750-757

Slomovitz BM, Sun CC, Frumovitz M et al. Are women ready for the HPV vaccine? *Gynecol Oncol* 2006; **103**: 151-154

Slonim AB, Roberto AI, Downing CR, et al. Adolescents' knowledge, beliefs, and behaviours regarding hepatitis B: insights and implications for programs targeting vaccine-preventable diseases. *J Adol Health* 2005; **36**: 178-186

Smith A, Agius P, Dyson S, et al. Secondary students and sexual health 2002: Results of the 3rd National Survey of Australian Secondary Students, HIV/AIDS and Sexual Health 2003. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne

Smith AMA, Pitts MK, Shelley JM, et al. The Australian longitudinal study of health and relationships. *BMC Public Health* 2007; **7**:1-4

Smith AMA, Rissel CE, Richters J, et al. Sex in Australia: reflections and recommendations for future research. *ANZ J of Pub Health* 2003; **27** (2): 251-256

Smith AMA, Rissel CE, Richters J, et al. Sex in Australia: The rationale and methods of the Australian Study of Health and Relationships. *ANZ of Public Health* 2003; **27** (2):106 - 117

Smith JS, Lindsay L, Hoots B, et al. Human papillomavirus type distribution in invasive cervical cancer and high-grade cervical lesions: A meta-analysis update. *Int J Cancer* 2007; **121**(3): 621-632

Smith JS, Melendy A, Rana RK, et al. Age-specific prevalence of infection with Human Papillomavirus in females: A Global Review. *J Adol Health* 2008a; **43**: S5-S25

Smith K, Watson C, Senior K, et al. Central Australian STI risk factor study. Oral abstracts from the 2009 Australasian Sexual Health Conference, Gold Coast, Queensland Australia. Abstract 79 *Sexual Health* 2009; **6**: 350-386

Smith KB, Humphreys JS, Wilson MGA. Addressing the health disadvantage of rural populations: How does epidemiological evidence inform rural health policies and research? *Aus J Rural Health* 2008; **16** (2): 56-66

Smith LT. Decolonizing methodologies: research and Indigenous peoples. University of Otago Press, Dunedin NZ, 1999

Smith MA, Canfell K, Brotherton JML, et al. The predicted impact of vaccination on human papillomavirus infections in Australia. *Int J Cancer* 2008b; **123** (8):1854-1863

Smith PJ, Kennedy AM, Wooten K, et al. Association between health care providers' influence on parents who have concerns about vaccine safety and vaccine coverage. *Pediatrics* 2006; **118** (5):e1287-e1292

Smith-McCune KK. Human papillomavirus vaccine efficacy: Aligning expectations with reality. *Gynecologic Oncology* 2008; **111**(1): 1-2

Song A, Richters T, Crawford J, Kippax, S. HIV and sexual health knowledge and sexual experience among Australian born and overseas born students in Sydney. *J Adol Health* 2005; **37** (3): 243.e9-243.e14

Songthap A, Pitisuttithum P, Kaewkungwal J, et al. Knowledge, attitudes and acceptability of a human papillomavirus vaccine among healthcare providers. *SouthEast Asian J Trop Med Public Health* 2009; **40** (5):1048-1056

Spencer L, Ritchie J, Lewis J, Dillon L. Quality in Quality Evaluation: A framework for assessing research evidence. Government Chief Social Researcher's Office, United Kingdom, 2003

Sperber NR, Brewer NT, Smith JS. Influence of parent characteristics and disease outcome framing on HPV acceptability among rural, Southern women. *Cancer Causes Control* 2008; **19**: 115-118

Sprecher S, Hatfield E. Premarital sexual standards among U.S. college students: comparison with Russian and Japanese students. *Arch Sex Behav* 1996; **25**: 261-288

Stanley M. Immunobiology of HPV and HPV vaccines. *Gynecologic Oncology* 2008; **109**: S15-S21

Stanley M, Lowy DR, Frazer I. Chapter 12: prophylactic HPV vaccines: underlying mechanisms. *Vaccine* 2006; **24**: Suppl 3:S106-S113

Stanton BF. Assessment of relevant cultural considerations is essential for the success of a vaccine. *J Health Popul Nutr* 2004; **22** (3): 286-292

Stark A, Gregoire I, Pilarski R, et al. Human papillomavirus, cervical cancer, and women's knowledge. *Cancer Detection & Prev* 2008; **32**: 15-22

Stenbacka C. Qualitative research requires quality concepts of its own. *Management Decision* 2001; **39**(7): 551-555

Stephens C, Nettleton C, Porter J, et al. Indigenous people's health – why are they behind everyone, everywhere? *The Lancet* 2005; **366** (9479):10-13

Stevens MP, Tabrizi SN, Quinn MA, et al. Human papillomavirus genotype prevalence in cervical biopsies from women diagnosed with cervical intraepithelial neoplasia or cervical cancer in Melbourne, Australia. *Int J Gynecol Cancer* 2006; **16**: 1017-1024

Stevens W, Walker D. Adolescent vaccination in the developing world: time for serious consideration? *Vaccine* 2004; **22** (5-6): 782-786

Stewart P, Shibasaki S, Anderson I, et al. Aboriginal and Torres Strait Islander participation in ethical review of health research. *ANZ J Pub Health* Jun 2006; **30** (3): 291 -292

STI: Editorial comment: *Sexually Transmitted Infections* 2001; **77**: 229-303

Stockwell F, Youyi L (Eds.). Modernization in China: The effects on its people and economic development. *Foreign Language Press* 2004

Stokols D. Translating social ecology theory into guidelines for community health promotion. *Am J Health Promotion* 1996; **10** (4): 282-298

Stoto, MA, Evans G, Bostrom A. Vaccine Risk Communication. *Am J Prev Med* 1998; **14** (3): 237-239

Strasburger VC. Adolescents and the media: Medical and psychological impact. Sage,1995.Thousand Oaks, CA, in DiClemente RJ, Salazar LF, Crosby RA, Rosenthal SR. Prevention and control of sexually transmitted infections among adolescents: the importance of a socio-ecological perspective – a commentary. *Pub Health* 2005; **119** (9): 825-836

Strauss A, Corbin J. Basics of qualitative research: Techniques and procedures for developing Grounded Theory. *Sage,* London, 1998

Streefland PH. Public doubts about vaccination safety and resistance against vaccination. *Health Policy* 2001; **55** (3): 159-172

Streefland PH. Introduction of HIV vaccine in developing countries: social and cultural dimensions. *Vaccine* 2003; **21** (13-14): 1303-1309

Streefland PH, Chowdhury AMR, Ramos -Jimenez P. Patterns of vaccination acceptance. *Soc Sc Med* 1999; **49**: 1705-1716

Stretch R, Roberts SA, McCann R, et al. Parental attitudes and information needs in an adolescent HPV vaccination programme. *Br J Cancer* 2008; **99**:1908-1911

Sturm LA, Mays RM, Juliar B, et al. 'What, me worry?' Parents' reasons for worry and non-worry about adolescent risk for sexually transmitted infections (STIs). *J Health Psych* 2008; **13**:1060-1071

Sullivan P, Oliver K. Beyond Bandaids: Chapter 10: Governance, Indigenous and Non-Indigenous as a Social Determinant of Aboriginal Health. *Papers from the Social Determinants of Aboriginal Health Workshop* Adelaide, July 2004: 181 -190 Edited by Anderson I, Baum F and Bentley M

Summers A. Mental health consequences of cervical screening. *Psychol Health Med* 1998; **3**: 113 - 126

Sundaram SS, Roberts C, Rowen D, et al. Parental attitudes towards the human papillomavirus vaccine in ethnic minorities: a community survey. *Int J STD AIDS* 2010; **21**:449

Syme S. Social and Economic disparities in health: thoughts about intervention. *The Milbank Quarterly* 1998; **76** (3) 493 - 502

Szarewski A. HPV vaccine: Cervarix. *Expert Opinion on Biological Therapy* 2010; 10 (3): 477-487

Taira AI, Neukermans CP, Sanders GD. Evaluating the human papillomavirus vaccination program. *Emerging Infectious Diseases* 2004; **10** (11):1915 - 1923

Tay EH, Garland S, Tang G, et al. Clinical trial experience with prophylactic HPV 6/11/16/18 VLP vaccine in young women from the Asia-Pacific region. *Int J Gynecology & Obstetrics* 2008; **102** (3):275 - 283

Tay SK, Ngan HY, Chu TY, et al. Epidemiology of human papillomavirus infection and cervical cancer and future perspectives in Hong Kong, Singapore and Taiwan. *Vaccine* 2008; **26** (Suppl 12): M60-70

Taylor RJ, Mamoon HA, Morrell SL, et al. Cervical screening in migrants to Australia. *ANZ J Public Health* 2001; **25** (1):55-161

Temple-Smith MJ, Mulvey G, Keogh L. Attitudes to taking a sexual history in general practice in Victoria, Australia. *Sex Transm Infect* 1999; **75**: 41-44

Tepper ML, Gully PR. Lovers and livers: hepatitis B as an STD. *Can J of Human Sexuality* 1997; **6** (2):135-142

TGA: Human papillomavirus vaccine (Gardasil). Advice from the Therapeutic Goods Administration. (http://www.tga.gov.au/alerts/medicines/gardasil.htm) (Accessed Jul 2008)

Thakker J and Ward T. Culture and classification: the cross-cultural application of the DSM-IV. *Clin Psych Rev* 1998; **18**(5):501-529

The FUTURE II Study Group. Quadrivalent vaccine against human papillomavirus to prevent high-grade cervical lesions. *N Engl J Med* 2007; **356**:1915-1927

Thom DH, Campbell B. Patient-physician trust: an exploratory study. *J Fam Pract* 1997; **44**:169-176

Thomas D, Flaherty E, Binns H, et al. Parent expectations and comfort with discussion of normal childhood sexuality and sexual abuse prevention during office visits*. Ambulatory Pediatrics* 2004; **4** (3): 232-236

Thomson N, Burns J, Hardy A, et al. Overview of Australian Indigenous Health Status. May 2008*.* (http://www.healthinfonet.ecu.edu.au/ouroverview)

Thompson SC, Green SK, Stirling EJ, et al. An analysis of reporting sexually transmissible infections in Indigenous Australians in mainstream Australian newspapers. *Sexual Health* 2007; **4** (1):9 - 16

Thompson SC, Kickett DM, Leahy TG. 'Let's not talk about sex': reconsidering the public health approach to sexually transmissible infections in remote indigenous populations in Australia: Matters Arising. *MJA* 2008; **188** (3):182-184

Thurecht K. Aboriginal women talk about Pap smear screening for cervical cancer in southeast Queensland. *Aborig Isl Health Work J* 2000; **24**: 21-23

Timmermans DRM, Henneman L, Hirasing RA, et al. Attitudes and risk perceptions of parents from different ethnic backgrounds regarding meningococcal C vaccination. *Vaccine* 2005; **23**: 3329 - 3335

Tissot AM, Zimet GD, Rosenthal SL, et al. Effective strategies for HPV vaccine delivery: The views of paediatricians. *J Adol Health* 2007; **41**:119 - 125

Tjalma WAA, Van Damme P. Is the public enough aware to accept a vaccination program against human papillomavirus? Letter to the Editor. *Vaccine* 2005; **25**: 3231

Torné A, Alonso I, Puig-Tintoré LM, et al. Clinical role of cervical cancer vaccination: when and whom to vaccinate? *Gynecol Oncol* 2008; **110** (Suppl 2):S15 - 16

Toussaint S, Mak D, Straton J. Marnin business: anthropological interpretations of cervical screening among Australian Aboriginal women. *Aust J Primary Health – Interchange* 1998*;* **4**(2): 43 - 52

Tozzi AE, Ravà L, Stat D, et al. Attitudes towards HPV immunization of Italian mothers of adolescent girls and potential role of health professionals in the immunization program . *Vaccine* 2009; **27** (19): 2625-2629

Trees J. Cultural and historical factors in Aboriginal women's sexual health. *Issues* 2008; **83**: 17-21

Trottier H, Mahmud S, Costa MC, et al. Human papillomavirus infections with multiple types and risk of cervical neoplasia. *Cancer Epidemiol Biomarkers Prev* 2006; **15**: 1274-1280

Tsai-Chae AH, Nagata DK. Asian values and perceptions of intergenerational family conflict among Asian American students. *Cultural Diversity and Ethnic Minority Psychology* 2008; **14** (3):205-214

Tsey K. Aboriginal self determination, education and health: towards a radical change in attitudes to education *ANZ J Public Health* 1997; **21** (1): 77-83

Tsey K, Whiteside M, Deemal A, et al. Social determinants of health, the 'control factor' and the Family Wellbeing Empowerment Program. *Australasian Psychiatry* 2003; **11** (Suppl: S34-39)

Tuckerman J, Rajesh S, Oeppen C, et al. Review of the evidence of the effectiveness and cost effectiveness of interventions to address differences in the uptake of immunisation (including targeted vaccines) in people younger than 19 years. Draft for consultation: 24 September - 22 October 2008. *National Collaborating Centre for Women's and Children's Health*, London, 2008

Tung CS, Middleman AB. An evaluation of school-level factors used in a successful school-based hepatitis B immunization initiative. *J Adol Health* 2005; **37**: 61-68

Twinn S. An analysis of the effectiveness of focus groups as a method of qualitative data collection with Chinese populations in nursing research. *J Advanced Nursing* 1998*;* **28:** 654-661

Twinn S. Social aspects of women's health. *HKMJ* 2000; **6** (4):412-414

Twombley R. U.S. Girls to receive HPV vaccine but picture unclear on potential worldwide use, acceptance. *JNCI* 2006; **98** (15):1030-1032; doi:10.1093/jnci/djj341

UKDH: The national strategy for sexual health and HIV, UK Department of Health http://www.medfash.org.uk/publications/documents/nat_shs-2001.pdf

UNESCO. Universal Declaration on Cultural Diversity.2002 (http://unesdoc.unesco.org/images/0012/001271/127160m.pdf)

United Nations, 2002 - 2005. OHRLLS, Room UH-900, New York, NY 10017, USA. The Criteria for the identification of the LDCs: (E/2004/33)

Upchurch DM, Levy-Storms L, Sucoff CA, et al. Gender and ethnic differences in the timing of first sexual intercourse. *Fam Plann Perspect* 1998; **30** (3):121-127

Vaccarella S, Franceschi S, Herrero R, et al. Sexual behavior, condom use, and human papillomavirus: pooled analysis of the IARC human papillomavirus prevalence surveys. *Cancer Epidem Biomarkers Prev* 2006; **15**(2): 326-333

Valery PC, Coory M, Stirling J, et al. Cancer diagnosis, treatment, and survival in indigenous and non-Indigenous Australians: a matched cohort study. *Lancet* 2006; **367**: 1842-1848

Vallely LA, Roberts A, Kitchener HC, et al. Informing adolescents about human papillomavirus vaccination: What will parents allow? *Vaccine* 2008; **26** (18): 2203-2210

Van Damme P, Kane M, Meheus A. Integration of hepatitis B vaccination into national immunization programmes. *BMJ* 1997; **314**:1033-1037

Vanslyke JG, Baum J, Plaza V, et al. HPV and cervical cancer testing and prevention: knowledge, beliefs, and attitudes among Hispanic women. *Qual Health Res* 2008; **18** (5): 584 - 596

Vavrus M. Sexuality, schooling, and teacher identity formation: A critical pedagogy for teacher education. *Teaching and Teacher Education* 2009; **25** (3): 383-390

Verhoeven V, Baay M, Baay P.People seeking health information about human papillomavirus via the internet have a very high level of anxiety. *Sex Health* 2009; **6** (3): 258-259

Verhoeven V, Baay M, Colliers A, et al. The male factor in cervical carcinogenesis: a questionnaire study of men's awareness in primary care. *Prev Med.* 2006; **43** (5): 389 - 393. Epub 2006 Jul 26

Verhoeven V, Bovijn K, Helder A, et al. Discussing STIs: doctors are from Mars, patients from Venus. *Fam Pract* 2003; **20**: 11-15

Vetter KM, Geller SE. Moving forward: Human papillomavirus vaccination and the prevention of cervical cancer. *J Women's Health* 2007; **16** (9):1258-1268

Villa LL, Ault KA, Giuliano AR, et al. Immunologic responses following administration of a vaccine targeting human papillomavirus Types 6, 11, 16, and 18. *Vaccine* 2006; **24** (27-28): 5571-5583

Villa LL, Bernard H, Kast M, et al. Past, present, and future of HPV research: Highlights from the 19th International Papillomavirus Conference–HPV2001.*Virus Res* 2002; **89**: 163-173

Villa LL, Costa RL, Petta CA, et al. Prophylactic quadrivalent human papillomavirus (types 6, 11, 16, and 18) L1 virus-like particle vaccine in young women: a randomised double-blind placebo-controlled multicentre phase II efficacy trial. *Lancet Oncology* 2005; **6**: 271-278

Wain, GV. Cervical cancer prevention: the saga goes on, but so much has changed! *Med J Aust* 2006; **185**: 476-477

Walboomers JMM, Jacobs MV, Manos MM, et al. Human papillomavirus is a necessary cause of invasive cervical cancer worldwide. *J Pathol* 1999; **189**:12-19

Wallace LA, Bramley JC, Ahmed S, et al. Determinants of universal adolescent hepatitis B vaccine uptake. *Arch Dis in Childhood* 2004; **89**:1041-1042

Waller J, Marlow LAV, Wardle J. Mothers' attitudes towards preventing cervical cancer through human papillomavirus vaccination: a qualitative study. *Cancer Epidemiol Biomarkers Prev* 2006; **15**: 1257-1261

Waller J, Marlow LAV, Wardle J. Anticipated shame and worry following an abnormal Pap test result: The impact of information about HPV. *Preventive Medicine* 2009; **48** (5):415-419

Waller J, McCaffery K, Forrest S, et al. Awareness of human papillomavirus among women attending a well woman clinic. *Sex Transm Infect* 2003; **79**:1-3

Waller J, McCaffery K, Forrest S, et al. Human papillomavirus and cervical cancer: Issues for biobehavioral and psychosocial research. *Ann Behav Med.* 2004; **27**:68-79

Waller J, McCaffery K, Kitchener H, et al. Women's experiences of repeated HPV testing in the context of cervical cancer screening: a qualitative study. *Psychooncology* 2007; **16** (3):196-204

Waller J, McCaffery K, Nazroo J, et al. Making sense of information about HPV in cervical screening: a qualitative study. *British J Cancer* 2005; **92**:265-270

Waller J, McCaffery K, Wardle J. Beliefs about the risk factors for cervical cancer in a British population sample. *Prev Med* 2004; **38**(6):745-753

Walpole BG. Let's not talk about sex: reconsidering the public health approach to sexually transmissible infections in remote Indigenous populations in Australia: Matters Arising *MJA* 2008; **188** (3): 182-184

Wang H, Ren SD, Wei LH, et al. Knowledge concerning HPV vaccine in Chinese women from rural and metropolitan areas. 24th International Papillomavirus Conference and Workshop, Beijing, China. November 3-9 2007: 253

Wang KL, Jeng CJ, Yang YC, et al. The psychological impact of illness among women experiencing human papillomavirus-related illness or screening interventions. *J Psychosomatic Obs & Gyn* 2010; **31**(1): 16-23

Wang YF, Zhang KL. A KABP investigation on overseas labourers about STDs/AIDS. 1995 Beijing: Master of Science Thesis, Peking Union Medical College; in Zhang K, Beck EJ. Changing sexual attitudes and behaviour in China: implications for the spread of HIV and other sexually transmitted diseases. *AIDS Care* 1999; **11** (5): 581-589

Warburton J, Chambers B. Older Indigenous Australians: their integral role in culture and community. *Australasian J Ageing* 2007; **26** (1):3-7

Ward J. Indigenous men's sexual health in Central Australia. *Second National Men's Health Conference 1997;* Fremantle, Curtin University of Technology

Ward J, Donnelly N, Holt P. Impact in general practice of the policies of the organised approach to preventing cancer of the cervix. *ANZ J Pub Health* 1998; **22**:336-341

Ward J, Sanson-Fisher R. Accuracy of women's recall of opportunistic recruitment for cervical screening in general practice. *ANZ J Pub Health* 1997; **21** (3): 335-336

Wardle J, Waller J, Brunswick N, et al. Awareness of risk factors for cancer among British adults. *Public Health* 2001; **115:173**-174

Washam C. Targeting teens and adolescents for HPV vaccine could draw fire. *J Natl Cancer Inst* 2005; **97**(14): 1030-1031

Wass A. Promoting Health: The primary health care approach. 2000. *Harcourt Brace Javanovich* Marrickville, NSW

Waters JL. Transnational family strategies and education in the contemporary Chinese diaspora. *Global Networks* 2005; **5** (4): 359-377

Watson J, Hodson K, Johnson R. Developing strategies to gather information about the maternity experiences of indigenous women in an acute care setting. *Aust. J Rural Health* 2002; **10**:147-153

Watson M, Shaw D, Molchanoff L, et al. Challenges, lessons learned and results following the implementation of human papillomavirus school vaccination program in South Australia. *Aust NZ J Public Health* 2009; **33** (4):365-370

Watts LA, Joseph N, Wallace M, et al. HPV vaccine: A comparison of attitudes and behavioral perspectives between Latino and non-Latino women. *Gynecol Oncol* 2009; **112**: 577-582

Webb C, Kevern J. Focus groups as a research method: a critique of some aspects of their use in nursing research. *J Adv Nurs* 2001; **33** (6):798 -805

Weinberg M, LottesFerrand A, Marquet J, et al. Social networks and normative context. In: Hubert M, Bajos N, Sandfort T, editors. Sexual Behaviour and HIV / AIDS in Europe. London: *UCL Press* 1998; 303-327

Weisberg E, Bateson D, McCaffery K, et al. HPV vaccination 'catch up' program – utilisation by young Australian women. *Aust Fam Physician* 2009; **38**: 72-76

Weiss MG and Ramakrishna J. Health-related stigma: Rethinking concepts and interventions. Background paper. Research Workshop on Health-related Stigma and Discrimination. Royal Tropical Institute (KIT) Amsterdam. 29 November – 2 December 2004

Wells L. Misunderstandings of and among cultures: The effects of transubstantive error. *Sunrise Seminars* 1985; **2** ed. Vails-Weber D, Potts J

WER: Weekly Epidemiological Record *(WER*).118: Human papillomavirus vaccines WHO position paper. *WHO* 2007; **28 / 29** (82): 245-260

WER: Weekly Epidemiological Record. Human papillomavirus vaccines WHO position paper. *WHO* 2009; **15** (84):117-132

WER: WHO consultation on human papillomavirus vaccines. *Releve Epidemiologique Hebdomadaire* 2005; **35**: 299-302

Wetzel C, Tissot A, Kollar LM, et al. Development of an HPV educational protocol for adolescents. *J Pediatr Adol Gynecol* 2007; **20**:281-287

WHO Report of the meeting on HPV vaccine coverage and impact monitoring 16-17 November 2009, Geneva, Switzerland. *Immunization, Vaccines and Biologicals* 2010

WHO/IVB/10.05

Wilkinson C, Jones JM, McBride J. Anxiety caused by abnormal result of cervical smear test: a controlled trial. *BMJ* 1990; **300**: 440

Williams L, Labonte R, O'Brien M. Empowering Social Action through Narratives of Identity and Culture. *Health Promotion International* 2003; **18** (1): 33-40

Willis J, Anderson I, Morris K. Sexual Health Promotion for Aboriginal and Torres Strait Islander People. A community guide to evidence-based best practice in social and behavioural interventions. February 2005

Wilson T, Condon JR, Barnes T. Northern Territory Indigenous life expectancy improvements: 1967-2004. *ANZ J Public Health* 2007; **31** (2): 184-188

Women's Cancer Team. HPV and Cervical cancer: A summary of information and Implications with the likely introduction of a HPV Vaccination program. *The Cancer Council WA* March 2006

Wong LP. Young multiethnic women's attitudes toward the HPV vaccine and HPV vaccination. *Int J Gynecol Obstet* 2008; **103** (2): 131-135

Wong LP. HPV information needs, educational messages and channel of delivery preferences: views from developing country with multiethnic populations. *Vaccine* 2009; **27**:1410-1415

Wong LP. Physicians' experiences with HPV vaccine delivery: Evidence from developing country with multiethnic populations. *Vaccine* 2009; **27**(10) 1622-1627

Wong LP, Sam IC. Current issues facing the introduction of human papillomavirus vaccines in Malaysia. *Malaysian Fam Physician* 2007; **2**: 47-53

Wong LP, Sam IC. Ethnically diverse female university students' knowledge and attitudes toward human papillomavirus (HPV), HPV vaccination and cervical cancer. *Eur J Obstet Gynecol Reprod Biol* 2010; **148**(1): 90-5

Wong LP, Wong YL, Low WY, et al. Knowledge and awareness of cervical cancer and screening among Malaysian women who have never had a Pap smear: a qualitative study. *Singapore Med J* 2009; **50** (1):49-53

Wood K and Aggleton P. promoting young people's sexual and reproductive health. Stigma, discrimination and human rights. Thomas Coram Research Unit, Institute of Education, University of London. 1999. ISBN 0 85432 806 8

Woodhall SC, Lehtinen M, Verho T, et al. Anticipated acceptance of HPV vaccination at the baseline of implementation: a survey of parental and adolescent knowledge and attitudes in Finland. *J Adolesc Health* 2007; **40**: 466-469

Woodruff B A, Unti L, Coyle K, et al. Parents' attitudes toward school-based Hepatitis B vaccination of their children. *Pediatrics* 1996; **98**: 410-413

Wray N. Culture and perception of gynaecological cancer. (Unpublished PhD thesis, University of Melbourne) 2004

Wright MR, Giele CM, Dance PR, et al. Fulfilling prophecy? Sexually transmitted infections and HIV in Indigenous people in Western Australia. *MJA* 2005; **183**(3): 124-128

Wright TC, Huh WK, Monk BJ, et al. Age considerations when vaccinating against HPV. *Gynecol Oncol* 2008; **109** (2): Suppl 1; S40-S47

Wu R, Dai M, Qiao Y, et al. Human papillomavirus infection in women in Shenzhen City, People's Republic of China, a population typical of recent Chinese urbanisation *. Int J Cancer* 2007; **121**(6): 1306-1311

Yang LH. Application of mental illness stigma theory to Chinese societies: synthesis and new directions. *Singapore Med J* 2007; **48**(11): 977

Yang L, Huangpu XM, Zhang SW, et al. Changes or mortality rate for cervical cancer during 1970s and 1990s periods in China. *Acta Acad Med Sin* 2003; **25**: 386-390

Yang L, Parkin DM ,Li L, et al. Time trends in cancer mortality in China: 1987-1999. *Int J Cancer* 2003; **106**: 771-783

Yao EL. Working effectively with Asian immigrant parents. *The Phi Delta Kappan* 1988 **70** (3): 223-225

Yao EL. Families and schools in a pluralistic society. Chavkin, NF (Ed.) Albany, NY: State University of New York Press. 1993

Yeo SS, Meiser B, Barlow-Stewart K, et al. Understanding community beliefs of Chinese-Australians about cancer: initial insights using an ethnographic approach. *Psycho-Oncology* 2005; **14**: 174-186

Yu CK, Rymer J. Women's attitudes to and awareness of smear testing and cervical cancer. *Br J Fam Plann* 1998; **23** (4): 127-133

Yuan, BJ, Shen J. Moral values held by early adolescents in Taiwan and Mainland China. *J Moral Education* 1998; **27** (21): 191-208

Zardawi I, Kattampallil J, Rode J. Vulvar precancers and cancers in the Northern Territory of Australia. *Pathology* 2004; **36** (1): 87-89

Zhang K, Beck EJ. Changing sexual attitudes and behaviour in China: implications for the spread of HIV and other sexually transmitted diseases. *AIDS Care* 1999; **11**(5): 581-589

Zhang L, Gao X, Dong Z, et al. Premarital sexual activities among students in a university in Beijing, China. *Sex Trans Dis* 2002; **29** (4): 212-215

Zhao FH, Xu LN, Niyazi M, et al. A multi-center survey on age of sexual debut in Chinese women: suggestions for optimal age of HPV vaccination in China. Abstract: Poster presentation, *HPV 2010* conference July 3 -8 2010, Montreal, Canada

Zhao Y, Dempsey K. Causes of inequality in life expectancy between Indigenous and non –Indigenous people in the Northern territory, 1981 - 2000: a decomposition analysis. *MJA* 2006; **184** (10): 485-486

Zhao Y, Guthridge S, Magnus A , et al. Burden of disease and injury in Aboriginal and non-Aboriginal populations in the Northern Territory. *MJA* 2004; **180**: 498-502

Zhou J, Sun XY, Stenzel DJ et al. Expression of vaccinia recombitant HPV 16 L1 and L2 ORF proteins in epithelial cells is sufficient for assembly of HPV virion-like particles. *Virology* 1991; **185**: 251-257

Ziarnowski KL, Brewer NT, Weber B. Present choices, future outcomes: anticipated regret and HPV vaccination. *Prev Med* 2009; **48**: 411-414

Zimet GD. Improving adolescent health: focus on HPV acceptance. *J Adol Health* 2005; **37**: S17-S23

Zimet GD. Understanding and overcoming barriers to human papillomavirus vaccine acceptance. *Curr Opin Obstet Gynecol* 2006; **18** (Suppl 1): S23-28

Zimet GD, Blythe MJ, Fortenberry JD. Vaccine characteristics and acceptability of HIV immunization among adolescents. *Int J STD & AIDS* 2000; **11**: 143-149

Zimet GD, Fortenberry JD, Blythe MJ. Adolescents' attitudes about HIV immunization. *J Pediatric Psych* 1999; **24**: 6-75

Zimet GD, Fortenberry JD, Fife KH, et al. Acceptability of genital herpes immunization: the role of health beliefs and health behaviours. *Sex Trans Dis* 1997; **24**: 555-560

Zimet GD, Liddon N, Rosenthal SL, et al. Chapter 24: Psychosocial aspects of vaccine acceptability. *Vaccine* 2006; **24**(Suppl 3): S201-S209

Zimet GD, Mays RM, Fortenberry JD. Vaccines against sexually transmitted infections: promise and problems of the magic bullets for prevention and control. *Sex Transm Dis* 2000; **27**: 49-52

Zimet GD, Mays RM, Sturm LA, et al. Parental attitudes about sexually transmitted infection vaccination for their adolescent children. *Arch. Pediatr. Adolesc Med.* 2005a; **159**: 132-137

Zimet GD, Mays RM, Winston Y, et al. Acceptability of HPV Immunization. *J Women's Health & Gender Based Med* 2000b; **90** (1): 47-50

Zimet GD, Perkins SM, Sturm LA, et al. Predictors of STI vaccine acceptability among parents and their adolescent children. *J Adol Health* 2005; **37**: 179-186

Zimet GD, Rosenthal SL. HPV vaccine and males: Issues and challenges. *Gynecol Onc* 2010; **117** (2) Suppl 1:S26-S31

zur Hausen H. Condylomata acuminata and human genital cancer. *Cancer Res* 1976; **36**: 12pt21 794

zur Hausen H. Papillomavirus infections: a major cause of human cancers. *Biochem Biophys Acta* 1996; **1288**: F55-F78

Zwi KJ, Henry RL. Children in Australian society. *MJA* 2005; **183**(3): 154-160

Appendices

Appendix 1: Regional distribution of Aboriginal, Anglo and Chinese-Australian people within Australia at 30 June 2006 (ABS, 2008, 2010a)

REGION %	DC Major Cities	DC Inner Regional	DC Outer Regional	LDC Remote	LDC Very Remote
Australia	68.4	19.7	9.5	1.5	0.8
Aboriginal	31.8	20.9	21.9	9.6	15.8
VIC	74.8	20.2	4.9	0.1	0
Chinese VIC	94	6	0	0	0
Aboriginal VIC	49.6	34.8	15.4	0.1	0
NT	0	0	54.8	21.7	23.5
Aboriginal NT	0	0	20.7	23.3	56

KEY:

AUS	Australia
NT	Northern Territory
VIC	Victoria
DC	Developed Country
LDC	Least Developed Country

In the NT, **Aboriginal people** are the second largest population group (27.8%) of the NT population (Fisher and Huffman 2003; Zhao et al. 2004; Valery et al. 2006; Thompson et al. 2008), and 79% of the NT Aboriginal population reside in the VR region of Apatula surrounding Alice Springs. In contrast, 0.6% of Aboriginal people reside in Victoria.

A significant proportion of the **Chinese** diaspora (Chinese nationals who have immigrated to Australia) arrived in Australia when the Government immigration policy changed in 1992 (Waters 2005; Lui et al. 2009), and since 2001 the Chinese-Australian population has doubled in number.

Appendix 2: Australian population Profiles of Aboriginal, Anglo and Chinese-Australian People (ABS 2010b)

AUSTRALIAN POPULATION: ~21.5 million (20 December 2009)

	CATEGORY Based on 2006 ABS Census Data	2006 (n x people)	%
	POPULATION		
1	Australia	19,855,287	100
	ANCESTRY		
1	Australian born	14,072,949	70.9
	: Victoria	3,434,458	69.6 of Vic pop
	: Northern Territory	148,180	76.8 of NT pop
2	Aboriginal / Torres Strait Islander (ATSI)	455,026	2.3
	ATSI: Victoria	30,152	0.6 of Vic pop
	ATSI: Northern Territory	53,675	27.8 of NT pop
3	Resident population born outside Australia	4,416,029	22.2
	: Victoria	1,173,224	23.8 of Vic pop
	: Northern Territory	26,526	13.8 of NT pop
4	China born	669,900	3.4
	Most arrived 1981 - 2005		3.5
	China 3rd highest birthplace group in Australia		22.9
	Age 0 -14		37.2
	Age 15 - 24		24.1
	Age 25 - 65		12.3
5	United Kingdom (English speaking)		
	England	6,283,600	31.6
	Ireland	1,803,700	9.1
	Scotland	1,501,200	7.6

Key: **Vic**: Victoria **NT**: Northern Territory

In the NT, 20.7% of Aboriginal people live in OR region, 23.3% live in the R regions; The opposite profile is found in Victoria where the majority of Aboriginal people live in MC regions (49.6%), and IR regions (34.8%); and a small proportion (15.4%) live in OR regions, and very few (0.1%) in R regions and none in VR regions (ABS 2009, 2010a).

Remote areas in the NT are only accessible by aircraft, especially in the wet season (Fisher and Huffman, 2003) which creates co-dependency on transport to travel to health services.

With Chinese-Australian residents in Victoria, Chinese-Australian people reside predominantly (94%) in the MC region; a very small proportion (6%) live in the IR region, and none reside in OR, R, or VR regions (ABS 2009, 2010a).

Appendix 3: Age profile of three Australian population groups (ABS 2010b)

AGE RANGE			
Median age: Australia 36.9 years: Females:37.7 years Males:36 years			
	ABORIGINAL	**ANGLO:**	**CHINESE**
Median age	36.9 years Female: 37.7 years Male: 36 years	32 years *	39 years *
Age 0 -14 TOTAL FEMALE MALE	19.6% 1,936,802 2,031, 313	*Females*: 50.7% of population *Males:*	*Females*: 54.8% of population *Males*:
Age 15 – 64 TOTAL FEMALE MALE	67.3% 6,764,709 6,881,863	49.3% of population	45.2% of population
Age 65+ TOTAL FEMALE MALE	13.1% 1,478,806 1,170,589		

Key:
***** No specific data on gender available.

37% of Aboriginal people were aged less than 15 years, compared with 19% of non- Aboriginal people. Only 3 % of the Aboriginal population was aged 65 years or over, compared with 13% of the non-Aboriginal population (ABS 2010a).

Appendix 4: Language profile of Australia for Aboriginal (Indigenous) languages, English language, and Chinese languages (ABS 2008a)

	LANGUAGES		
	Language	Population	% of population
1	**Australian Indigenous languages: Central Australia**	55,698 Male n=27,107 Female n=28,591	0.3
	Alyawarr	1,664	3.0
	Anmatyerr	1,008	1.8
	Arrernte	2,834	5.1
	Gurindji	593	1.1
	Jaru	358	0.6
	Walmajarri	514	0.9
	Warlpiri	2,507	4.5
2	**LANGUAGES OTHER THAN ENGLISH**		
	Speak a language other than English at home	3,146,183	15.8
	Speak English not well or not at all.	561,414	2.8
	Cantonese	244,558 Male:115,711 Female: 128,847	1.2
	Mandarin	220,603 Male: 103,317 Female:117,286	1.2
	Speak Cantonese at home + speak English not well or not at all.	62,360	26.0
	Age 0 -14	6,653	18.0
	Age 15 - 24	3,034	7.0
	Age 25 - 44	12,982	18.0
	Age 45 - 64	23,704	35.0
	Age 65+	15,982	69.0
	Speak Mandarin at home + speak English not well or not at all.	50,699	23.0
	Age 0 -14	6,615	21.0
	Age 15 - 24	5,068	9.0
	Age 25 - 44	13,268	17.0
	Age 45 - 64	17,205	40.0
	Age 65+	8,543	77.0

The Adult Literacy and Life Skills (ALLS) survey found that ‘around 25% of Australian immigrants had adequate or better health literacy compared with 44% of people whose first spoken language was English’. (ABS 2006a, 2008a)
A NT study (Condon et al. 2004) found a much higher risk of cancer death among those speaking an Aboriginal first language than English language speakers, as well as poorer treatment and outcomes.
43% of people living in R and VR regions do not have access to a working telephone (O’Brien et al. 2000).
Communication difficulties between Aboriginal and non-Aboriginal peoples are perceived as a result of social, cultural, political, and geographic factors (Panaretto et al. 2006), and stereotyping (de Ishtar 2005).

Appendix 5: Australia's sexual health

The Government expenditure on Selected Health Promotion in 2007-2008 was $366.6 million and represents 17.0% of all public health expenditure, and average (~) of $17.26 per person for that period. However, differences in expenditure occurred across Australian states.

The secondary analysis by Freedman and colleagues (2006) (of sexual health data from the BEACH program (April 2000 to March 2003: a cross sectional national survey of GP activity with patients aged 12 to 49 years; 299 000 encounters with 2990 GPs, 3499 (1.17 per 100 encounters) reported that the majority of STIs diagnosed (81.1%) was in female patients. GPs addressed symptomatic clinical presentations with specific tests for diagnostic STIs being rare. The study finding of inadequate counselling of an STI diagnosis to an 'at-risk' asymptomatic patient or when asking for contraception was consistent with other studies (Temple et al. 1999; Verhoeven et al. 2003).

The two most common viral STIs in Australia are HPV and genital herpes simplex virus (HSV), but because they are not notifiable diseases their occurrence has been difficult to monitor (AIHW 2002; Thomson and Burns 2005). The first strategy to be developed, ((i) the *National Indigenous Australians' Sexual Health Strategy (NIASHS) 1996-97 to 2003-04* and (ii) the *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2005-2008* (DHA 2005a)). It provided Australia's first comprehensive approach to preventing the spread of STIs (*C trachomatis,* syphilis, gonorrhoea, and hepatitis B), and blood borne viruses (HIV and hepatitis B [classified in both categories]) in Aboriginal and Torres Strait Islander communities (DHA 2005a). In 2005, the *National Sexually Transmissible Infections Strategy 2005-2008* (DHA 2005) was launched, but as its priority areas were limited to *C trachomatis* control and prevention, and specific population groups, including Aboriginal people.

In response to the strategic gap in Australian sexual health policies, several public health associations formally reiterated the need for a national sexual and reproductive health strategy for Australia, despite the

outcomes of the previously enacted Aboriginal sexual health strategy (SHFPA 2005). *The National HIV/AIDS Strategy 2005-2008*; the *National Hepatitis C Strategy 2005-2008* ; and the *National Sexually Transmissible Infections Strategy 2005-2008*, were subsequently developed to control STIs in response to this need.

The *Australian Longitudinal Study of Health and Relationships* (ASHR) (Smith et al. 2007) [a cross sectional representative study] documented the natural history of the sexual and reproductive health of the Australian adolescent and adult population, but did not sufficiently delineate between cultural groupings, including the Aboriginal population, in its reporting. The study has under-representation of Aboriginal Australians in remote communities therefore the findings can not be generalised for specific Aboriginal population groups in Australia. An adequate knowledge of HIV / AIDS and hepatitis C (from a well organised social marketing campaign) was found in one cohort (Smith et al. 2007), but they had poor knowledge of the most common STIs, genital warts, and other blood-borne viruses (Smith et al. 2007).

A state-wide Aboriginal community child health survey (Blair et al. 2005) (n=1480 aged 12-17 years) on the sexual knowledge and experiences of Western Australian Aboriginal adolescents reported sexual health education, mainly through school, had been delivered to adolescents aged between 12 and 17 years. Despite this education, 74.5% of the study's cohort were reported as sexually experienced at 17 years of age; with 33.4% of 15 year olds being sexually active; and 21.9% of girls aged 16 had been pregnant at least once, and 33.7% of 17 year old females. This data mirrors sexual behaviour in other Australian population groups (Smith et al. 2007), but some Aboriginal females in other Australian regions are younger overall for age of sexual activity (Women's Cancer Team 2006).

Appendix 6: Timeline of the development and implementation of the first generation HPV Vaccines. Focus: Australia

YEAR	ACTIVITY
1980s	The development of the VLP/L1 vaccine - an incremental process with multiple contributors. The research that led to the development of the vaccine was by groups at the University of Rochester, Georgetown University, the University of Queensland, and the US National Cancer Institute
1982	HPV16,HPV 18 discovered
1982-1992	Activities of the HPV Oncogenes determined
1990 - 1998	Case control /cervical cancer studies
1991	First VLPs discovered: Ian Fraser and Jian Zhou of the University of Queensland found a way to form non-infectious virus-like particles VLPs, which could also strongly activate the immune system Expression of the human papillomavirus L1 and L2 proteins together, but not L1 alone, resulted in the formation of small VLPs described as "incorrectly assembled arrays" of subunits (reported by Jian Zhou, Ian Frazer, and colleagues at Queensland; *Virology*).
1992	HPV L1 expression in mammalian cells led to an L1 in cells that was recognized by monoclonal antibodies that bind conformational epitopes. No VLPs were produced in this study but it was considered important because the ability of L1 to self-assemble into VLPs and produce neutralizing antibodies depends on the native conformation of L1, which involves conformational epitopes (reported by Shin-Je Ghim, A. Bennet Jenson, and Richard Schlegel of Georgetown; *Virology)* L1 from bovine papillomavirus type 1 self-assembled into morphologically correct VLPs that induced high levels of neutralizing antibodies in immunized animals (reported by Reinhard Kirnbauer, Doug Lowy, and John Schiller at NCI and colleagues; *Proceedings of the National Academy of Sciences*
1993	L1 from HPV 11 self-assembled into VLPs, later shown to induce neutralizing antibodies (reported by Robert Rose at Rochester and colleagues; *Journal of Virology* L1 from HPV 16, taken from lesions that had not progressed to cancer, self-assembled more efficiently than the HPV 16 L1 that researchers everywhere had been using; the old strain was shown to be a mutant, possibly because it had been isolated from a cancer (reported by Kirnbaueer, Lowy, and Schiller at NCI and colleagues; *Journal of Virology*
1994	UniQuest, (University of Queensland) licensed the HPV technology to Australia's largest biotechnology firm, CSL (who then licensed to Merck & Co. Controversy involving intellectual property initiated by GSK arose between the inventors 'Gardasil' was attributed to the Australian researchers and 'Cervarix' to the US researchers
1995 -2001	Prospective HPV neoplasia studies
1997	AUSTRALIA: Federal Government established: *Immunise Australia: the Seven Point Plan* The GPII scheme was one of a wide range of initiatives introduced under the Plan
1998	General Practice Immunisation Incentives (GPII scheme) implemented Aim: to encourage > 90 % of practices to achieve 90 % proportions of full immunisation. This milestone was accomplished in the May 2003 quarter
1999	HPV proposed as a necessary cause of cervical cancer VLP clinical trials begin
2001	Initial report of efficacy
Dec 2004	First reports of the quadrivalent HPV vaccine in the Australian media (Roughead et al.2008)
April 2005	Australian media reports on the HPV vaccine's 'blockbuster' potential against cervical cancer (Roughead et al.2008)
May 2005	Results of Phase II trials reported in the Australian media as 'Vaccine will save women." (Roughead et al.2008)
31 October 2005	Australia: Media reports on Phase III clinical trials "medical miracle…cervical cancer lifesaver." (Roughead et al.2008) USA: Concern that the HPV vaccine will encourage teenage sexual activity – clash between health advocates and social conservatives Although the vaccine will not become available until next year at the earliest,

	activists on both sides had begun manoeuvring to influence how widely the immunisations will be employed In the hopes of heading off a confrontation, officials from the companies developing the shots -- Merck & Co. and GlaxoSmithKline -- have been meeting with advocacy groups to try to assuage their concerns
Dec 2005	Australian media announced application for approval of HPV vaccines to USA FDA and Australian TGA (Roughead et al.2008)
Jan 26,2006	Ian Frazer announced as Australian of the Year for his role in developing the HPV vaccines (Roughead et al.2008)
27 February 2006	The independent Data and Safety Monitoring Board recommended the Phase III study (named FUTURE II) clinical trials be terminated on ethical grounds, so that young women on placebo could receive 'Gardasil'
March 2006	Quadrivalent vaccine ,Gardasil® first licensed, in Gabon
8 June 2006	'Gardasil' approved by the US Food and Drug Administration (FDA) US Food and Drug Administration (FDA) approved 'Gardasil' for mass-prescription
June 2006	Australia – Gardasil registered by the Therapeutic Goods Association (TGA) for use in females age 9 – 26 and males aged 10 -15 years based on Phase 111 clinical trials and immuno-bridging data (Shefer A, Markowitz ,Deeks S, Tam T, Irwin K, Garland SM, Schuchat A. early experience with Human papillomavirus Vaccine Introduction in the United States, Canada and Australia. *Vaccine* 2008;**26S**:K68-K75)
29 June 2006	Advisory Committee on Immunisation Practices (ACIP) recommended 'Gardasil' be placed on the childhood immunisation schedule at the 11 to 12 year old visit The vaccine is included in the federal Vaccines for Children Program, which would provide the vaccines free of charge to children under the age of 18 who are uninsured Groups for Which Vaccine is Not Licensed Vaccination of Females Aged <9 Years and >26 Years Vaccination of Males Special Situations Among Females Aged 9--26 Years Equivocal or Abnormal Pap test or Known HPV Infection. Although data on immunogenicity and safety are available for males aged 9--15 years, no data exist on efficacy in males at any age. Efficacy studies in males under way
28 Aug 2006	Quadrivalent HPV vaccine launched in Australia with first female adolescent vaccinated (Roughead et al.2008)
8 Nov 2006	AUSTRALIA: The Pharmaceutical Benefits Advisory Committee (PBAC) [the government's pharmaceutical advisory body] rejected an application from Australian manufacturer CSL to have the vaccine 'Gardasil' available free to all females aged 12 to 26 due to its high price
9 Nov 2006	AUSTRALIA: The Prime Minister John Howard declared that the HPV vaccine ''Gardasil'' would be subsidised, despite the PBAC recommending against it. The mass campaign was anticipated to start on the first of January 2008 subject to agreement between parties
29 Nov 2006	AUSTRALIA: Australian Government announced funding for the HPV vaccination program to commence in 2007, for Australian for females aged 12 with a catch-up to age 26 years The Australian Prime Minister announced that the government will provide about $342 million for a program that will offer Merck's HPV vaccine 'Gardasil' at no cost to girls and women ages 12 to 26 living in the country
27 Feb 2007	'Gardasil' clinical trials have been halted due to of the success of the product. The independent Data and Safety Monitoring Board for two trials had recommended they be terminated on ethical grounds, so that young women on placebo could receive 'Gardasil'
11 Mar 2007	AUSTRALIA: Advertisements for the program targeting parents and the general public begin to appear in the media. Information resources include A dedicated page for general practitioners on the National HPV Vaccination Program Website at www.australia.gov.au/cervicalcancer A 'cheat sheet' summarising patient eligibility, vaccine dosage and contraindications, distributed via the Divisions of General Practice and available online A direct mail-out to general practitioners across Australia in mid-March Advertising in medical journals in mid-April

20 Apr 2007	GlaxoSmithKline (GSK) developed ‘‘Cervarix’’ (females from 10 to 45 years of age) as an alternative to CSL's ‘Gardasil’, (females aged between nine and 26.) The Australian Drug Evaluation Committee (ADEC) said it would not oppose registration of 'Cervarix' which was submitted to it in 2006 ‘Cervarix’ will be registered when it is listed on the Australian Register of Therapeutic Goods (ARTG) when the product information (PI) has been finalised. GSK in discussion with the TGA regarding the PI GSK awaiting the outcome of a submission to the Pharmaceutical Benefits Advisory Committee for ‘Cervarix’ to be included in the National Immunisation Program. ‘Cervarix’ submitted to regulators in the US and Europe but is yet to be approved for marketing in either jurisdiction
April 2007	AUSTRALIA: The HPV vaccine (‘Gardasil’) funded on an ongoing basis under the National Immunisation Program. Vaccination is *not* compulsory in Australia and is not required for school entry. There is no financial penalty for not vaccinating with HPV vaccines. 2007: Girls Years 7 10 11 12~Ages 13,15,16,17 School 2008: Girls Years 7 9 10 ~Age 13,14,16 School July 2007 – June 2009:Girls Age 13 – 26: GP or Local Health Service 2009(ongoing)Girls: Year 7: ~Age 13:School
21 May 2007	AUSTRALIA: the first major country to approve ‘Cervarix’. Therapeutic Goods Administration (TGA) has licensed ‘Cervarix’ and approved for use in women aged 10 to 45 years old. Concerns that it may not get to market in the United States before 2008
22 May 2007	AUSTRALIA: 7 Victorian schoolgirls from Sacred Heart Girls' College, Melbourne were briefly hospitalized after receiving an injection of the ‘Gardasil’ vaccine One was temporarily paralysed Health authorities do not believe that these are directly related to the vaccine Sixteen other girls were reported sick
June 2007	WHO Global Advisory Committee on Vaccine Safety (GAVCS) concluded that both HPV vaccines had good safety profiles (Weekly Epidemiological Record. *WER* 2007;**82**:245-260)
24 June 2007	Merck & Co., Inc. announced that the Food and Drug Administration (FDA) has accepted for standard review a supplemental Biologics License Application (sBLA) for GARDASIL The sBLA includes data on protection against vaginal and vulvar cancer caused by HPV types 16 and 18 and data on immune memory. Under the Prescription Drug User Fee Act (PDUFA), for standard sBLAs filed in 2007, the FDA's goal is to review and act on 90 percent of sBLAs within 10 months of receipt. Merck anticipates action by the FDA in the first quarter of 2008 GARDASIL® (sold in some countries as SILGARD®) is approved for use in 80 countries, many under fast-track or expedited review including Australia, Brazil, Canada New Zealand, Canada, Mexico, Croatia, Malaysia, Brazil, Serbia, Taiwan Israel 27 countries of the European Union, United States of America Additional applications for ‘GARDASIL’ under review with regulatory agencies in many more countries around the world
17 Oct 2007	Merck to donate three million doses of ‘Gardasil’® to 2012, to support vaccination programmes in lowest income nations To implement this program, Merck will establish a partnership with a non-governmental organisation to establish formal criteria for the program and to review proposals from developing world nations working independently and/or with non-governmental organisations, governments, or international organisations
Jan 2008	A total of 15 countries: 2 in North America, 12 in Western Europe, and Australia, had issued formal recommendations or delivery and finance plans about HPV vaccines (Koulova A, Tsui J, Irwin K, Van Damme P, Biellik R, Aguado MT. Country recommendations on the inclusion of HPV vaccines in national immunisation programs among high-income countries, June 2006–January 2008 *Vaccine* 2008;26 (51):6529-6541)
March 2008	The quadrivalent vaccine ,Gardasil®-was licensed in 98 countries The bivalent vaccine Cervarix licensed in 44 countries (Koulova A, Tsui J, Irwin K, Van Damme P, Biellik R, Aguado MT. Country recommendations on the inclusion of HPV vaccines in national immunisation programs among high-income countries, June 2006–January 2008 *Vaccine* 2008;26 (51):6529-6541)

2008	Australian national HPV Vaccination program register commences Monitors vaccination coverage, and population based studies of vaccine effectiveness (Shefer A, Markowitz, Deeks S, Tam T, Irwin K, Garland SM, Schuchat A. early experience with Human papillomavirus Vaccine Introduction in the United States, Canada and Australia. *Vaccine* 2008;**26S**:K68-K75)
March 2009	>60 million HPV vaccine doses administered in 21 countries (WHO 2010:12) Thus far WHO has examined safety issues on 3 separate occasions. Assessments on the vaccines' safety profiles were reassuring
April 2009	WHO position on HPV vaccination released in the Weekly Epidemiological Record. (*WER* 2009;**15 (84)**:117-132) WHO recommends that HPV vaccines should be introduced as part of a coordinated strategy to prevent cervical cancer and other HPV-related diseases records of coverage should be kept and safety monitored Community education programs about cervical cancer and HPV be applied as a strategy for increasing vaccine acceptance
May 2009	A considerable reduction in the clinical presentation of genital warts in men who have been vaccinated with the quadrivalent HPV vaccine is reported (Fairley, C, Hocking J, Chen M, Donovan B, Bradshaw C. Rapid decline in warts after national quadrivalent HPV vaccine program. *25th International Papillomavirus Conference* Malmo, Sweden, 8-14 May 2009)
19 Oct 2009	PATH report on formative research related to HPV vaccine introduction in India, Peru, Uganda and Vietnam as part of the 5 year *HPV Vaccine: Evidence for Impact Project.* They conclude that 'low-resource settings may be able to successfully adopt the HPV vaccines, provided the health system structures and immunisation financing options were well understood the delivery strategy built off the existing strengths of national EPI programs. Schools could be effectively used as a venue for mass immunisation in all four countries overcoming institutional and implementation barriers will be key to success.' (Biellik R, Levin C, Mugisha E, LaMontagne DS, Bingham A, Kaipilyawar S Gandhi S. Health systems and immunisation financing for human papillomavirus vaccine introduction in low-resource settings. *Vaccine* 2009;**27** (44):6203-6209)
31 Dec 2009	HPV 'catch-up' program in Australia ceases. The ongoing target group is girls in first year of Australian secondary school (aged 11 – 12 years)
21 April 2010	The bivalent vaccine is now licensed in 120 countries worldwide (Garland and Smith 2010:1089).
14 May 2010	The quadrivalent vaccine is now licensed in 120 countries worldwide (Garland and Smith 2010:1089).

BIBLIOGRAPHY: TIMELINE

The timeline was compiled from data in the following sites.

Garland SM, Smith JS. Human papillomavirus vaccines. Current status and future prospects . *Drugs* 2010; **70** (9): 1079-1098

http://www.adgp.com.au/site/index.cfm?display=1813#;

http://www.fda.gov/bbs/topics/NEWS/2006/NEW01385.html

http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/hpv-vac-prog

http://www.iranian.ws/iran_news/publish/article_21479.shtml

http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=45058

http://www.medicalnewstoday.com/articles/75085.php

http://www.nature.com/nrmicro/journal/v2/n4/fig_tab/nrmicro867_I1.html

http://www.news-medical.net/?id=21166

http://www.onlineopinion.com.au/view.asp?article=5917

http://www.racgp.org.au/guidelines/immunisation/hpv

http://www.redorbit.com/news/science/555590/vaccine_advised_for_girls_age_11_12_'Gardasil'_immunization_prevents/index.html?source=r_science

http://www.scoop.co.nz/stories/GE0710/S00085.htm

http://vaccine.immunodefence.com/cancer_vaccine_news/

http://www.vaccinerx.com/news/cervical-cancer/'Gardasil'-trials-end-on-tuesday-due-to-success-20070227-9_3-26.html;

http://www.visainfo.org.au/pages/01_Home/SpecialPages/Cervical_cancervaccine_deception.pdf; http://en.wikipedia.org/wiki/'Gardasil'; JNCI Journal of the National Cancer Institute 2006 98(7):433; doi:10.1093/jnci/djj144;

http://www-dep.iarc.fr/WHO 2010)

Appendix 7: Related HPV studies 1995 - 2005

PUBLICATION , METHOD, SAMPLE	ISSUES	OUTCOMES
2005 USA: Herpes Liddon N, Pulley LV, Cockerham WC, et al. Parents /guardians willingness to vaccinate their children against genital Herpes. *J Adol Health* 2005; **37**(3): 187-193 Quantitative: RDD Telephone interview x 40 minutes Random selection Parents / Guardians 1 child <18 years n = 315 / 870 Response rate 53%	Attitude to genital herpes vaccine STD vaccines Age of vaccination Child vaccination status Perceived consequences of STD vaccination	Genital herpes vaccine at 11-13 years age Need for interventions that differentially target those who would not support child vaccination Vaccination after sexual debut Interventions should focus on encouraging vaccination + attitudes for optimal timing of vaccination
2005 USA: STIs Zimet GD, Perkins SM, Sturm LA, et al. Predictors of STI vaccine acceptability among parents and their adolescent children. *J Adol Health* 2005; **37** (3):179 -186 Quantitative: cross sectional study Non-random A-CASI interviews Payment: $15 –parents, $5 adolescent Adolescent health clinics Ped offices – private practice Age 12 -17, English literate Parents who accompanied children to medical clinics n = 320 adolescents	Acceptability of 3 STI vaccines [HPV not inc.] Intent to vaccinate Parent health beliefs as a predictor of intent	Parents rated vaccines very acceptable Health Beliefs and history predictors of intent to vaccinate Parents accept providers recommendations Results similar to Davis Dickman (2004) FUTURE RESEARCH: Issues that influence STI vaccine acceptance Religious beliefs Acceptability for younger children
2005 USA: STIs Zimet GD, Mays RM, Sturm LA, et al. Parental attitudes about sexually transmitted infection vaccination for their adolescent children. *Arch Ped Adol Med* 2005; **159** (2):132-137 Quantitative: AudioCA, Questionnaire 9 hypothetical vaccine scenarios Conjoint analysis, Clinic waiting room Preliminary semi-structured interviews 278 parents who accompanied children to medical clinics Chn 12 -17 Limited ethnic diversity	Evaluate parent attitudes about adolescent vaccination Explore sociodemographic predictors of acceptability of STI vaccines.	Parents accepting of STI vaccination Infection Severity /Vaccine efficacy salient issues, NOT sexual transmissibility (concern 5.8%) Favoured vaccines that had no method of behavioural prevention
2005 USA Olshen E, Woods ER, Austin SB, et al. Parental acceptance of the HPV vaccine. *J Adol Health* 2005; Vol **36** (2): 124 **Qualitative:** Convenience samples 6 x Focus groups,3 x Individual interviews Sessions preceded by HPV education Open ended questions Urban academic adolescent clinic Suburban private Paed clinic Recruited until thematic saturation reached Audio taped, Professionally transcribed Parents n = 25 At least one child 10 -15 yrs.	Explored parental views on HPV vaccine Child vaccine experiences Likes and concerns of tetanus vaccine Thoughts on HPV vaccine Information needs Concerns about child infected with HPV Consent issues – daughter /son Issues against consent HPV as an STI	Low HPV knowledge levels Confused HPV and HIV Generally positive –weigh risks and benefits Seek doctor recommendation Queried why vaccinate if child not at risk of HPV Education target parental beliefs& optimal age for HPV vaccine Concerns re promiscuity Vaccine dosage & efficacy FUTURE RESEARCH Parent and provider HPV education Risk beliefs of HPV Age at vaccination
2005 USA Sturm LA, Mays RM, Zimet GD. Parental Beliefs and Decision Making About Child and	Conceptual model to frame a review of research on the role of	FUTURE RESEARCH: Parent attitudes toward sexual activity

Adolescent Immunization: From Polio to Sexually Transmitted Infections. *J Dev & Beh Pediatrics* 2005; **26**(6): 441- 452 Focuses on theory-based Social-environmental and parent-specific personal factors as potential influences on vaccine decision making. Social-environmental issues: media coverage of vaccines, perceived social norms; persuasive influence of peer groups. Health care provider recommendations an exemplar of factors related to the family's interface with the health care system. Personal factors: parental health beliefs, attitudes; knowledge related to vaccine preventable diseases and immunization; cognitive heuristics employed in the decision-making process (e.g., omission bias, protected values, framing of information)	parental attitudes and beliefs in decision making about child and adolescent immunization Describe the historical context of vaccine-related decision-making research.	STI and stigma STI vaccination promote promiscuity
2005 USA Zimet GD. Improving adolescent health: Focus on HPV acceptance. *J Adol Health* 2005;**37**: S17-S23 **Qualitative** Review of relevant literature Review article	Research on knowledge and attitudes about HPV infection Acceptability of HPV vaccine to individuals, parents health care providers attitude to recommendation	Research to date misunderstanding about HPV and issues Providers less comfortable about vaccinating younger adolescents Endorsement by a professional association important Most parents interested in child having HPV vaccine Parents value health care provider recommendation
2005 USA Rosenthal SL, Stanberry LR. Parental acceptability of vaccines for sexually transmitted infections. *Arch Ped & Adol Med* 2005; **159**(2): 190 -193 Review of prior research Editorial	Parents(urban clinics) more pro-child with STI vaccinate Delay vaccination until child sexually experienced Influences: vaccine efficacy & disease severity	Parents more supportive of vaccines where a behavioural strategy for prevention available. FUTURE RESEARCH Understanding how parents evaluate behavioural options in terms of efficacy and acceptability for vaccine decisions
2005 USA Short MB, Rupp R, Stanberry LR, et al. Parental acceptance of adolescent vaccines within school-based health Centres. *Herpes* 2005;**12**:1 Quantitative Snowball: Convenience sampling strategy Telephone survey. Questionnaire Parents n = 85 Adolescent 14-18 years	Attitude to vaccine Location of site for vaccine STIs and stigma Vaccine uptake	Parents supported offering HSV via SBHCs Consent to adolescent receiving it. Predictors: SBHC perceptions; a belief that all adolescents should be vaccinated for genital herpes. Perceptions of stigma/shame associated with STIs not related to herpes vaccine acceptability. Efforts to enhance vaccine uptake focus on promoting positive perceptions of the location of vaccination and universal recommendations
2005 USA Rosenthal SL. Protecting their adolescents from	IMPORTANT SUMMARY OF RESEARCH Research by Olshen et al (2005);Liddon et al (2005);Zimet, Perkins et al (2005) found parental support for STI vaccines	STI vaccine likely recommendation 11-12 years Parent consent necessary

harm: parental views on STI vaccination. *J Adol Health* 2005; **37**:177-8 Editorial Review of research	Davis et al (2004) found brief intervention change acceptance attitude Zimet, Perkins et al (2005) found parents had similar attitudes	Parents target for intervention efforts
2005 USA Allred NJ, Shaw KM, Santibanez TA, et al. Parental vaccine safety concerns results from the National Immunisation Survey, 2001-2002. *Am J Prev Med* 2005; **28** (2) Quantitative; NIS survey; Random digit-dialling Mail survey Homes Chn 19 -35 months Parental knowledge and experiences Model	Vaccine safety Side effects Simultaneous vaccine administration Acceptance of new vaccines Derived from lit review	Low vaccine safety concerns Misperceptions about side effects and contraindications common Heightened concern associated with lower coverage Whites believed vaccines unsafe Provider attitudes and beliefs important to consent Further studies on racial and ethnic differences regarding vaccine safety
2005 USA Gust DA, Kennedy A, Shui, et al. Parent attitudes toward immunizations and healthcare providers: the role of information. *Am J Prev Med* 2005; **29** (2): 105 -112 Quantitative; Healthstyles mail survey 4 pages Small gift Parents child >6 n = 4035 / 5845 (63%)	67% had good information to make vaccine decision	Perceived lack of information associated with negative attitudes about immunisation and health care providers. Providers important in giving information Basic information about benefits and risks of vaccine improve trust and confidence in immunisation process.
2005 USA Keane MT, Walter MV, Patel BI, Moorthy S, Stevens RB, Bradley KM ,Buford J, Anderson EL, Anderson LP, Tibbals K, Vernon TM . Confidence in vaccination: A parent model. *Vaccine* 2005;**23**(19): 2486 -2493 Quantitative; Mail surveys stratified by child age group 56 attitude and belief HBM statements Multivariate analysis Parents of children < 16 N = 2018 / 4115 (49%)	Vaccine importance and safety Disease experience Sources / credibility of vaccine information Vaccination status of child	Parents rely on healthcare providers as primary, credible source & carry substantial influence 4 parent groups: 1. Vaccine believer – convinced of vaccine benefits 2.Cautious –high emotional investment in child 3.Relaxed – less involved parenting style; sceptic about vaccines 4.Unconvinced –distrust of vaccines and vaccine policy Customise vaccine messages to parent attitudes and beliefs to foster acceptance
2005 UK Yarwood J, Noakes K, Kennedy D, et al. Tracking mothers attitudes to childhood immunisation 1991-2001. *Vaccine* 2005; **23** (48-49): 5670 -5687 Review of 20 surveys 1991 - 2001 15,000 interviews Mothers	Knowledge of immunisation attitudes towards immunisation Experience of immunisation Recall of vaccine information	Immunisation programs complex & require long-term planning Parents and providers specific information needs to be accessible, transparent, understandable Greater concern for vaccine safety rather than disease prevention and

		influences parental consent Perceived risk of vaccine Information sources: health professionals; social networks; leaflets; advertising(TV)
2005 USA: STIs Bair RM, Mays RM, Sturm LA, et al. The acceptability of STD vaccination to Latino parents. *J Adol Health* 2005; **36** (2):123 -124 Quantitative: Convenience sample A-CASI interviews Latino parents /guardians n = 101 24 -60 years,90% female who accompanied adolescents to health clinic	*part of larger study [see Mays, Sturm and Zimet (2005)	STI vaccines acceptable Latino parents favoured high efficacy vaccines
2005 Netherlands Timmermans DRM, Henneman L, Hirasing RA, et al. Attitudes and risk perceptions of parents' different ethnic backgrounds regarding meningococcal C vaccination. *Vaccine* 2005 ; **23**: 3329 - 3335 **Qualitative** Structured interview x 30 interviewers Dutch language ; Purposive sampling Female for interview if accompanied child Parents of children presenting for MC vaccine n = 1763 / 2910	MC vaccine information awareness Vaccine awareness Perceived risk Side effects Disease risk	Risk perception and attitude in mass vaccination campaign showed differences among parents with different ethnic backgrounds. Moroccan and Antilles parents less likely to read information leaflet Streefland et al (1999) note that immigrants often perceive immunisation as self evident. OUTCOME; Different information needs for different ethnic groups
2004 USA Freed GL, Clark SJ, Hibbs BF, et al. Parental vaccine safety concerns: The experiences of pediatricians and family physicians. *Am J Prev Med* 2004; **26** (1): 11-14 Quantitative: Mail survey National random sample n= 750 pediatricians n=750 family physicians	Experience with parent vaccine safety concerns	The most common concerns of parents were related to short-term reactions and pain from multiple injections.
2004 USA Kahn JA, Rosenthal SL, Hamann T, et al. Attitudes about HPV vaccine in young women. *Int J STD and Aids* 2004; **14**:303 -306 Quantitative: Survey Females n = 52 18 -35 years Mean age 25	Knowledge, attitudes HPV vaccination Risk behaviours Intention to HPV vaccinate	Positive attitude toward HPV vaccine Intention to vaccinate high for self and daughter
2004: Unknown HPV Medical & community sites Davis K, Dickman E, Ferris D, et al. HPV Vaccine Acceptability among Parents of 10 -15 yr old adolescents. *Obs and Gyn Survey* 2004; **59** (12) Quantitative: Anon self-administered 30 item questionnaire (ii) HPV fact sheet intervention English literate Parents: mothers fathers/ guardians other relatives 10-15 yr old boys, girls n = 575	Vaccination status Vaccine acceptability Health beliefs Knowledge of HPV Acceptance HPV vaccine	HPV fact sheet significantly improved parent acceptance of HPV vaccine Fears HPV vaccine condone early sexual debut minimal
2004 USA: STIs Midwest urban Mays RM, Sturm LA, Zimet GD. Parental perspectives on vaccinating children against sexually transmitted infections. *Soc Sc Med*	STI knowledge Intention to vaccinate Vaccine decision	24/34 intend to vaccinate with all 4 25/34(73%0 HPV vaccine 1 /34 objected on moral

2004; **58**: 1405 -1413 **Qualitative:** Conjoint analysis Phase 1 ongoing study Individual semi-structured interviews Paed primary care – private practice /urban hospital clinic Parents age 26 - 55 Mother /female guardian n =29 Fathers /male guardians n = 5 Chn age 8 -17 n = 34 /38 [89%] Education intervention	maker	grounds STI stigma diminished Chn 18+ make own vaccine decisions Parent delay vaccination until child's sexual debut FUTURE RESEARCH: (i)Understand how age of child/adolescent will influence parent consent /Health providers attitudes inc. vaccinating 9-11 year olds (ii)Extent to which consent influenced by vaccine immunity
2004 UK Waller, J McCaffery K, Wardle J. Beliefs about the risk factors for cervical cancer in a British population sample. *Prev Med* 2004;**38**: 745 - 753 Quantitative Survey Representative sample Women n = 1940		14% aware of link between HPV and STI <1% named HPV FUTURE RESEARCH Public awareness re HPV and ICC needs to be improved Urgent need for sexual health programs to reduce taboo
2004 UK Waller J, McCaffery K, Forrest S, et al. Human Papillomavirus and cervical cancer: Issues for bio behavioural and psychosocial research. *Ann Behav Med* 2004; **27**(1):68 - 79 Review of current findings of HPV bio-behavioural and psychosocial research. KEY THEMES: Issues with HPV testing Public awareness of STI nature of ICC Psychosocial issues Management of HPV infection Primary prevention		FUTURE RESEARCH Public understating of link between HPV and ICC Patient centred information Psychosocial consequences Promotion of preventative behaviours
2003 UK Waller J , McCaffery K Forrest S, et al. Awareness of human papillomavirus among women attending a well woman clinic. *Sex Transm Infect* 2003; **79**:1-3 Quantitative Self administered survey English literate White Females attending a well woman clinic. Mean age: 30.2 n = 1032 / 1045: not representative	Cervical screening HPV self sampling	First UK study to evaluate HPV knowledge Poor HPV knowledge (70% higher educated never heard of HPV) Awareness associated with STI experience 30% heard of HPV Public HPV education essential Clear messages
2003 UK Urban McCaffery K, Forrest S, Waller J, et al. Attitudes towards HPV testing: A qualitative study of beliefs among Indian, Pakistani, African-Caribbean and white British women in the UK. *Brit J of Ca* 2003; **88** (1):42 - 46 **Qualitative** Purposively selected; 8 x Focus group Ethnically matched community researchers Audio taped, transcribed (1994) Ritchie & Spencer Framework Females n =71; Aged 20 -59 years 4 ethnic groups; Indian, Pakistani, African-Caribbean and white British women in the UK	HPV education intervention at beginning of focus group Attitudes toward HPV testing Reactions to HPV as STI linked to ICC Testing + for HPV Family attitudes to HPV testing Religious and cultural influences	HPV testing may be negative for some [psychosocial] HPV education needed Accurate information accessible to all ethnic groups Informed choice at screening
2003 USA Gust DA, Woodruff R, Kennedy A, et al. Parental perceptions surrounding risks and benefits of	Risk – benefit perception of vaccination	Vaccines benefit children Reliance on doctor's advice and knowledge

immunization. *Seminars in Ped Infec Dis* 2003; **14**(3):207 - 212 Quantitative Healthstyles survey Parents of child 0- 6 years	Preferred information to understand risk Safety confidence Reliance on child's physician	Healthcare providers constrained by time Provide parents with information sheet while waiting for appointment Vaccine safety influence beliefs and decisions
2003 USA Kahn JA, Rosenthal SL, Hamann T, et al. Attitudes about HPV vaccine in young women. *Int J STD and Aids* 2004; **14**:303 -306 Quantitative: pilot study self-administered survey 76-items Community and clinical sites for two separate studies of HPV 16/18 vaccine. Women 18 - 30 years n= 53 eligible for the survey study. n=52 (98%) enrolled in the HPV vaccine acceptability study. Attitudes about HPV vaccine personal beliefs (global and specific), normative beliefs perceived risk perceptions of whom should receive the vaccine, intention to receive the vaccine	Positive global and specific beliefs about the outcomes of targeted HPV vaccination strategies v. universal High intention to receive HPV vaccine & consent to teenage daughter receive the vaccine.	FUTURE RESEARCH Attitudes and intentions regarding HPV vaccination Larger study samples - variety of racial and sociodemographic groups Provider & Parental attitudes Association between (i) intention and actual vaccine-related behaviour (ii) attitudes and actual behaviour
2002 UK Pitts M, Clarke T. Human papillomavirus infections and risks of cervical cancer: what do women know? *Health Ed Res* 2002; **17**(6): 706 Quantitative: 3 page self- administered questionnaire; 27 items Female work force n = 400 / 985	Knowledge of cervical screening, treatment for abnormalities and HPV.	Major gaps in knowledge of role in HPV in cervical abnormalities Knowledge of early ICC Detection and screening methods good. Risk factors for ICC not well known. Need to convey accurate HPV information publicly
2001 USA Urban schools Middleman AB, Guajardo AD, Sunwoo E, et al. Parental knowledge and attitudes regarding hepatitis b immunization. *J Ped and Adol Gyn 2001*;**14**(3):150 Quantitative: Survey Mixed race; Black 62%; White 27%; Asian 1%; Other 10%Parents ;4th grade students	Child vaccine history Knowledge re HBV transmission, perception of risk Immunisation provider Consent	Low knowledge of HBV risk factors Income ethnicity, primary language, race not associated with preferences. Preferred school for immunisation parents want involvement in consent
2001 Mexico: HPV Lazcano-Ponce E, Rivera L, Arillo –Santillan E, et al. Acceptability of a HPV trial among mothers of adolescents in Cuernavaca, Mexico. *Arch Med Rsch* 2001; **32**: 243 -247 Quantitative: Probabilistic Random sample Standardised questionnaire ICC & HPV fact sheet intervention Females: n =880; Age 15 - 49 Mothers, Adolescents	ICC risk factors Knowledge of vaccine benefit Acceptability / usefulness of HPV vaccine	Low HPV knowledge Public education toward mothers and teenage daughters need Agree to vaccinate teenage daughter
2000 USA Urban Lewis L, Stanberry L, Rosenthal S, et al. Attitudes regarding vaccinations of STDs and other diseases. *Int J STD and Aids* 2000;**11** (3):170 -172 Quantitative: Questionnaire 2 groups different risk profiles Undergrad urban university (psych) n = 518 / 87	Attitude toward STI vaccination	STI list did not include HPV disease Vaccine compliance influenced by pragmatic reasons: cost, transportation attitudinal: side effects Importance of public health messages that support vaccination

2000 USA Zimet GD, Mays RM, Winston Y, Kee R, Dickes J, Su L. Acceptability of HPV immunization. *J Women's Health & Gender Based Med* 2000; **90** (1) 47 - 50 **Qualitative** Convenience sample (40): Health clinic waiting rooms: Adolescent health clinic: urban STI clinic Interviews, semi-structured (20 -30 minutes) 2 groups females Adolesc 14 -18 yrs n =20 Women n = 20 (STD clinic)	Knowledge of HPV, genital warts, CC Pap smears Ranked 9 hypothetical HPV vaccines	Efficacy, physician's recommendation and cost influenced rankings Certain features of HPV vaccine might influence vaccine acceptability Given HPV information pamphlet at end of interview HPV poorly understood infection
2000 Canada City Dell DL, Chen H, Ahmad F, Stewart DE. Knowledge about human papillomavirus among adolescents. *Obs and Gynec* 2000; **96**(5:1): 653 - 656 Quantitative: written surveys High school students n = 523	HPV Other STIs Pap testing	Low HPV knowledge: 87% not heard of HPV Pap testing knowledge Failure to identify STI risk Programs modelled on HIV education might be effective Physicians need to take greater responsibility for sexual health education
2000 USA Chicago Indianapolis Health clinics Mays RM, Zimet GD, Winston Y, et al. Human Papillomavirus, genital warts, Pap smears and cervical cancer: Knowledge and beliefs of adolescent and adult women. *Health Care for Women Int* 2000; **21**:361 -374 Quantitative: Convenience sample Individual semi-structured Interview 20 -30 minutes HPV information leaflet post interview Audio taped, Transcribed Female adults n =20 95% African American Adolescents 75% Hispanic White Age 15 -18 n =20	STI knowledge HPV knowledge and beliefs	Low HPV knowledge [see other research: pg 371] Vague understanding re Pap smears Need for open discussion on sexuality and associated HPV issues
1999 USA Freeman VA, Freed GL. Parental knowledge, attitudes and demand regarding a vaccine to prevent varicella. *Am J Prev Med* 1999; **17**(2): 153 -155 Quantitative: Cross sectional study Random selection from birth cert. 4 page postal survey Mothers of 500 children born 1993 (23 -35 months) n = 247 / 500 (65%)	Had heard of new vaccine from media v physician Disease experience and physician recommendation important determinants	Using the media to publicise a new vaccine effective than relying on health care providers for information Provider recommendation important factor in vaccine consent
1999 Aus Marshall S, Swerissen H. A qualitative analysis of parental decision making for childhood immunisation. *ANZ J Public Health* 1999;**23**(5): 543 - 546 **Qualitative** Snowball sample, Informal network Semi-structured in-depth interviews 1 hour audio taped, Thematic analysis Mothers, middle-class > 1 preschool child Age 24 - 41 n = 20	Child vaccine history Decision making perceptions and reactions	HBM model explains partial immunisation behaviour
1998, Aus Vic Melb Bond L, Nolan T, Pattison P, et al. Vaccine preventable diseases and immunisations: A qualitative study of mothers' perceptions of severity, susceptibility, benefits and barriers.	Child's health Experience Experience, familiarity and concerns /	Preventing disease important for good health HBM explains some behaviour

ANZ J Pub Health 1998 ; **22** (4): 441 **Qualitative:** Stratified Purposive sampling strategy**,** Maternal health nurses gatekeeper**;** 5 Melb councils Semi-structured interviews: 45 -90 minutes Saturation not reached for partial immunisers First time mothers / experienced 14-30 mths n= 45 / 95	Perceptions of vaccine preventable diseases	Perceptions of safety and susceptibility dynamic Vaccine side effects and susceptibility to disease separate issues
1997 USA: Urban university Zimet GD, Liau A, Fortenberry JD. Health beliefs and intention to get immunized for HIV. *J Adol Health* 1997;**20**:354 -359 Quantitative: Self-administered questionnaire (20 minutes) Undergrad. Students n=125 / 127 (98%) Age 18 -29 Female 65% Mixed race: 75% non-Hispanic white; 7% African American; 18% other	Susceptibility Severity Benefits Pragmatic obstacles Fear of vaccine	Intention for HIV vaccine not universal Health beliefs influence acceptance Low susceptibility Doubts re vaccine benefits Vaccine safety Educate behaviour leads to HIV infection, not membership of a identified risk group
1995 USA Hospital based adolescent clinic Rosenthal SL, Kottenham RK, Biro FM, et al. Hepatitis B vaccine acceptance among adolescents and their parents. *J Adol Health* 1995;**17**:248 - 254 Quantitative Questionnaire Urban hospital based clinic Face to face/ telephone recruitment Parents; n =65 Adolescents: n =80 New patients	Cost Potential pain & side effects Dosage schedule Perception of disease severity; Susceptibility; vaccine efficacy	Parent values and opinion important for adolescent consent Parents agreed to consent Disease risk prevention important factor
2005 USA Riedesel JM, Rosenthal SL, Zimet GD, et al. Attitudes about HPV vaccine among family physicians. *J Pediatr Adolesc Gynecol* 2005; **18**:391 - 398 Cross-sectional survey instrument national random sample n =145 / 1,000 American Academy of Family Physicians (AAFP) members.	Provider & practice characteristics, knowledge about HPV, attitudes about HPV vaccination Intention to administer two hypothetical HPV vaccines (an ICC/GW vaccine and an ICC vaccine) to boys and girls of different ages.	Female gender, HPV knowledge; attitudes about vaccination independently associated with family physicians' intention to recommend HPV vaccines. Vaccination initiatives for family physicians focus on HPV knowledge and vaccine attitudes
2004 USA Freed GL, Clark SJ, Hibbs BF, et al. Parental vaccine safety concerns: The experiences of pediatricians and family physicians. *Am J Prev Med* 2004; **26**(1): 11-14 Quantitative: National random sample survey postal; AMA master file, 29 close ended questions 1054 /1500 Paediatricians; n =430 / 750 Family physicians; n =313 / 750	Parental vaccine refusals in 1 year Parent vaccine safety concerns Physician action on refusal	Low level of parental refusal Frequent Parental concerns re vaccine safety and increasing – need for community safety education Physicians frequent source of contact with healthcare system for majority of parents – in frontline to manage safety concerns PDs and FPs must be well prepared to respond to safety concerns.
2004 USA Columbia +28 states *2nd survey on this theme Oster NV, McPhillips –Tangum CA, Averhoff F, et al. Barriers to adolescent immunization: A	Source of vaccine recommendation Adolescent	Barriers to immunising adolescents esp. as adolescent aged

survey of family physicians and paediatricians. *JABFP* 2005;**18**(1)13 - 19 Quantitative: Random sample questionnaire: 94 item fixed response + several open ended Self –administered; Piloted; Postal Physicians: n =210 / 358 (400) paediatricians.	immunisation Barriers to immunising adolescents UTD importance Recall systems	Need more knowledge on overcoming barriers, use of recall systems, and practical ways to enhance adolescent immunisation.
2004 NZ Petousis-Harris H, Goodyear-Smith F, Turner N, et al. Family physician perspectives on barriers to childhood immunisation. *Vaccine* 2004; **22**:2340 -2344 Converging quantitative and qualitative text data; Triangulation multi-method investigation CATI ~ 20 mins. GPs n =150	Educational needs preferred sources for immunisation information immunisation—knowledge, attitudes, needs and practices Patient barriers to immunisation.	Parental barriers: vaccine safety; fear (53%); information(misinformation / lack of information); difficulties in accessing services as an unlikely barrier to improving immunisation (13% totally agreeing with the statement.) 44%: lack of funding to health providers
2004 USA Mays RM, Zimet, GD. Recommending STI vaccination to parents of adolescents: the attitudes of nurse practitioners. *Sex Trans Dis* 2004; **31** (7): 428 – 433 Quantitative: Conjoint analysis 13 hypothetical vaccine scenarios Nurse practitioners	Examine willingness to recommend STI vaccines to parents of adolescents Infection, Patient age, Gender, Paeds endorsement	Agree recommending STI vaccines Paeds endorsement(AAP) important, infection and patient age influenced willingness Older age adolescents preferred candidates
2003 Aus (NSW) Milledge JT, Cooper CD, Woolfenden SR. Barriers to immunization: Attitudes of GPs to varicella, the disease and its vaccine. *J Paed Child Health* 2003; **39**:368 – 371 Quantitative: Cross sectional 8 –item questionnaire (5 minutes completion) (67% response) Pilot 4 GP trainees GPs; Small area of SW Sydney: n = 160 (67%)	Demographic issues Experience of disease Complications of varicella Patient admissions Varicella and vaccination knowledge	GP concern about unknown side effects (36%) Long term vaccine efficacy (44%) 'Cost to parents' a factor
1999 Aus (Perth) Bailey HD, Kurinczuk JJ, Kusel MM, et al. Barriers to immunisation in general practice. *ANZ J Public Health* 1999; **23** (1): 6 -11 Quant: Cross sectional postal survey Metro Perth (3 / 7 Div. GPs) Open/closed ques. Pilot: random sample 35 GPs from Perth metro [4th Div GP] GPs n = 301 (72%)	Need for education program aimed at health professionals	Attitude to HBV vaccine given with other vaccines Follow NHMRC guidelines Opportunistic immunisation Contra-indications Storage / transport of vaccines Cost to patients Recall systems
1999 USA Prislin R, Nader PR, De Guire M, Hoy PL, Pung MA, Ross S, Goerlitz MJ, Sawyer M. Physicians' immunization knowledge, attitudes and practices. A valid and internally consistent measurement tool. *Am J Prev Med* 1999 (17) **2**: 151-152 Quantitative:14-item, multiple-choice scale Convenience sample / entire population 4 groups: 34 Ped residents; 11 graduating Ped residents 53 generalists 111 subspecialists	Immunization schedule, efficacy and adverse events, contraindications, and prevalence rates of vaccine-preventable diseases. Perceived barriers	Additional immunization education on influencing office and clinic practices to immunize every child Attitudes may serve as motivational basis, and ensure physicians responsive to educational interventions.

Appendix 8: Thematic Chart Summary: (Parents and GPs)

	THEME	SUBTHEME
1	**Vaccine experience**	1.1 Attitudes to vaccines 1.2 Vaccine information 1.3 Adverse events 1.4 Influence of others 1.5 Other / miscellaneous
2	**HPV knowledge**	2.1 Level of knowledge / attitude to Cerv ca 2.2 Level of knowledge / attitude to Pap screen 2.3 Feelings about knowledge level 2.4 HPV and stigma 2.5 Feelings about HPV information 2.6 Other issues
3	**HPV vaccine knowledge**	3.1 Level of knowledge 3.2 Feelings about HPV vaccine 3.3 Target population 3.4 Vaccine information 3.5 Ease of understanding 3.6 Vaccine concerns 3.7 Other issues
4	**HPV vaccine message attitudes**	4.1 [1.1][3.2] Response to vaccine data / Important messages 4.2 [1.2][3.3.1] Response to HPV as STI 4.3 [1.3[3.3.2] Response to HPV as ca prevention 4.4 [1.4][3.3.3] Response to HPV as combined message 4.5 [1.5][3.4] Target groups [age / gender] 4.6 [1.6] Barriers to recommendation (Cost post April 2007) 4.7 [1.7] [3.6] Vaccine concerns (Safety ,efficacy, dosage schedule other) 4.8 [1.8] Role of AHW /AMS /health professional 4.9 [1.9] Adolescents and giving vaccines 4.10 [1.10] Message by age group 9- 15+ 4.11[1.11][3.9] Other issues

5	**STI & Influence of culture on beliefs**	5.1 Attitudes to STIs 5.2 Influence of culture 5.3 Attitude to adolescent sex Issues 5.4 Other issues
6	**Impact of HPV information**	6.1 [3.1] Appropriateness 6.2 level of detail 6.3 Range of information 6.4 [3.5] Information provider 6.5 Ability to understand 6.6 Access to information 6.7 Concerns /response to information 6.8 Additional information needs
7	**HPV vaccine delivery**	7.1 [6.1] Attitudes to National HPV program 7.2 [6.2] Role of Government 7.3 [6.3] Role of school 7.4 [4.8] [6.4][10.8] Giver of vaccine 7.5 [3.7] Girls and Pap smears
10.	**HPV Vaccine Information Development**	10.1 [3.2] Important HPV / vaccine messages 10.2[4.1] Information provider 10.3[4.2] Information resource requirements 10.4[4.3] Gender / Multi languages 10.5[3.8] [4.4[10.1] Males and information 10.6[4.5] Access to information 10.7[4.6] Attitudes to information resources 10.8[4.7] Additional information needs 10.9 [10.9][4.9] Other issues
8	**Intention to consent**	8.1[7.1] Willingness to consent 8.2 [7.2] Resistance to consent 8.3 [7.3] Consent issues 8.4 Intention to recommend the vaccine

11.	**HPV vaccine and males**	11.1 [2.1] Educating males / Important messages 11.2 [2.2] Barriers to informing males 11.3 [2.3] Role of health professional 11.4 Benefits of educating males 11.5 [2.5] Other issues
9	**Other issues**	9.1 [8.1] Personal 9.2 [8.2] Vaccine related 9.3 [8.3] Pharmaceutical Industry

Appendix 9: HREC Application, University of Melbourne (Victoria)

3 May 2006

THE UNIVERSITY OF MELBOURNE

Professor S Garland
Faculty of Medicine, Dentistry & Health Sciences

Dear Professor S Garland

Thank you for providing the additional information about the project.

I am pleased to advise that the Health Sciences Human Ethics Subcommittee approved the following project:

Humanpapillomavirus vaccine and community intent
Professor S Garland, Dr K McCaffery, Professor S Sawyer & Ms M Heffernan
Associate Professor M Quinn
HREC No. 050264

The Project has been approved for the period **3/5/06** to **31/12/06** subject to the provision, when available, of the necessary approvals associated with the indigenous sample.

It is your responsibility to ensure that all people associated with this particular project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

(a) **Limit of Approval:** Approval is limited strictly to the research proposal as submitted in your application.

(b) **Variation to Project:** Any subsequent variations or modifications you might wish to make to your project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised project.

(c) **Incidents or adverse affects:** Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on subjects or unforeseen events that might affect continued ethical acceptability of the project. Failure to do so may result in suspension or cancellation of approval.

(d) **Monitoring**: Projects are subject to monitoring at any time by the ethics committee.

(e) **Annual Report:** You must submit an annual report on this project at the end of the year, or, at the conclusion of the project if it continues for less than a year. Requests for annual reports are sent out by the Human Research Ethics Office in November/December of each year. Failure to submit a progress report at the end of the year will mean approval for your project will lapse.

(f) **Auditing:** All projects may be subject to audit by members of the Sub-Committee.

If you have any further queries on these matters, or require additional information, please do not hesitate to contact me on telephone no. 8344 2073 or e-mail: k.murphy@unimelb.edu.au.

Please quote the HREC registration number and the name of the project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Yours sincerely

Ms Kate Murphy
Executive Officer, Human Research Ethics

Melbourne Research and Innovation Office
The University of Melbourne Victoria 3010 Australia
T: +61 3 8344 2000 F: +61 3 9347 6739
W: http://www.research.unimelb.edu.au/

c.c. Head, Faculty of Medicine, Dentistry & Health Sciences
Ms M Heffernan

Appendix 10: The Royal Children's Hospital Melbourne HREC (Victoria)

Royal Children's Hospital, Melbourne

Flemington Road, Parkville
Victoria, Australia, 3052

Telephone (03) 9345 5522
ISD (+613) 9345 5522
Facsimile (03) 9345 5789

ETHICS IN HUMAN RESEARCH COMMITTEE APPROVAL

EHRC REF. No:	**25103 A**
PROJECT TITLE:	Humanpapilomavirus vaccine and community intent to vaccinate their pre-adolescent children.
Documents approved:	Phase I Qualitative Interview guide (within mod 1) dated 6 March 2006, PIS&Consent dated 8 Mar 2006, Flyer (with phone numbers) dated 8 Mar 2006, Contact details dated 8 Mar 2006, Project Information Statement dated 8 Mar 2006, Interview contact agreement dated 8 Mar 2006.
Approved Protocol:	Protocol v3 dated 8 Mar 2006,
INVESTIGATOR(S):	S Garland, K McCaffery, S Sawyer, M Quinn, M Heffernan

DATE OF ORIGINAL APPROVAL:	**5th April 2006**
DURATION:	36 months
DATE OF APPROVAL EXPIRY:	**5th April 2009**
SIGNED: ..... COMMITTEE REPRESENTATIVE	9.4.06

APPROVED SUBJECT TO THE FOLLOWING CONDITIONS:

ALL PROJECTS

1. Any proposed change in protocol, or any approved documents, or the addition of any documents (including flyers, brochures, advertising material etc) and the reasons for that change or addition, together with an indication of ethical implications (if any), must be submitted to the Ethics in Human Research Committee for Approval prior to implementation.
2. The Principal Investigator must notify the Secretary of the Ethics in Human Research Committee of:
   - Any adverse effects of the study on participants and steps taken to deal with them.
   - Any unforeseen events.
   - Investigators withdrawing from or joining the project.
3. A progress report must be submitted annually and at the conclusion of the project, with special emphasis on ethical matters.
   Please note: It is the responsibility of the investigator(s) to ensure that the RCH EHRC approval remains current for the entire duration of the project. Investigator's undertaking projects without current EHRC approval put at risk their indemnity, grant and publication rights.
4. All research information collected whilst individual participants are children, must be kept until the individual turns 25 (i.e 7 years after their 18th birthday).

DRUG TRIALS

5. The investigator(s) must report to the Sponsor and the Ethics in Human Research Committee within 24 hours of becoming aware of any serious adverse event experienced by any subject during the trial.
6. The investigator(s) must ensure that all externally sponsored Clinical Drug Studies have insurance coverage that is current for the entirety of the study.

002378

Appendix 11: The Royal Women's Hospital Melbourne HREC (Victoria)

The Royal Women's Hospital
132 Grattan Street, Carlton 3053
Australia

Mr. Arthur C. B. Hui
Administrative Officer
Research and Ethics Secretariat
Tel: (03) 9344 2759
Fax: (03) 9344 2377
E-mail: arthur.hui@rwh.org.au

10.1.06

Ms M Heffernan
Department of Paediatrics
The University of Melbourne
PO Box 262
Albert Park VIC 3206

Dear Ms Heffernan,

Re: Project 05/32 - Human papillomavirus vaccine and community intent to vaccinate their pre-adolescent children

Thank you for submitting the clarification and amendments on 22.12.05 as requested by the RWH Human Research Ethics Committee.

I confirm the project is now approved.

Enclosed please find Project Approval and Notification of Project Commencement Forms for your record.

Please return the completed Notification of Project Commencement Form to me when the project begins.

Yours sincerely,

A. C. B. Hui
Administrative Officer
Research and Ethics Secretariat

Encl:

THE ROYAL WOMEN'S HOSPITAL

RESEARCH AND HUMAN RESEARCH ETHICS COMMITTEES

PROJECT APPROVAL

PROJECT NO:	**05/32**
PROJECT TITLE:	Human papillomavirus vaccine and community intent to vaccinate their pre-adolescent children
INVESTIGATOR (S):	S Garland, K McCaffery, S Sawyer, M Quinn, M Heffernan
DATE OF APPROVAL:	10 January 2006
DURATION:	Thirty (30) months

SIGNED .....
Secretary, Research & Human Research Ethics Committees **DATE**

CONDITIONS OF APPROVAL

The Principal Investigator is reminded of the following:-

1. ***A Project may commence once the Principal Investigator has received written confirmation that the Human Research Ethics Committee has approved the Project.***
2. ***Substantial changes in protocols must be submitted to the Research/Human Research Ethics Committees for approval.***
3. ***Progress reports must be submitted annually. A request will be forwarded to the Principal Investigator. If no report is supplied, permission to continue the project may lapse.***
4. ***The Research/Human Research Ethics Committees must be notified IMMEDIATELY of any untoward or unexpected complications or side affects arising during the project or of any ethical or medico-legal problems that may arise.***
5. ***Consent forms must be available for audit and retained on file for five (5) years.***
6. ***Raw data and details of analysis must be retained by the Principal Investigator for five (5) years.***
7. ***Principal Investigator MUST upon leaving the Institution, inform the Human Research Ethics Committee as to the nominated person to replace him/her.***

PLEASE QUOTE PROJECT NO. AND TITLE FOR ALL CORRESPONDENCE

RWH PROJECT NUMBER **05/32**

THE ROYAL WOMEN'S HOSPITAL

RESEARCH AND HUMAN RESEARCH ETHICS COMMITTEES

NOTIFICATION OF PROJECT COMMENCEMENT

PROJECT TITLE: Human papillomavirus vaccine and community intent to vaccinate their pre-adolescent children

INVESTIGATOR (S): S Garland, K McCaffery, S Sawyer, M Quinn, M Heffernan

DATE OF APPROVAL: 10 January 2006

DURATION: Thirty (30) months

DATE OF COMMENCEMENT ……/……/……

PRINCIPAL INVESTIGATOR:

NAME……
(PLEASE PRINT)

SIGNATURE…… **DATE**……/……/……

Appendix 12: Central Australian HREC for Indigenous Research in Northern Territory

CENTRAL AUSTRALIAN
HUMAN RESEARCH ETHICS COMMITTEE
PO BOX 721
ALICE SPRINGS NT 0871

Margaret Heffernan
Principal Researcher
PO Box 262
ALBERT PARK VIC 3206

Dear Ms Heffernan

The CAHREC has considered the re-submission of your application for approval for the research project entitled **'HPV vaccine and the Aboriginal Community intentions to vaccinate their pre-adolescent children.'**

The committee notes the revision and changes incorporated in response to our previous comments, including the reference committee finalisation and the role of Aboriginal health Workers.

The Committee decided to grant approval for your project to proceed.

The Committee requires that you submit a progress report every six months, and a final report on completion of the project.

Good luck with your project.

Yours sincerely

for **Metta Young**
A/Chair
Central Australian Human Research Ethics Committee

February 2007

Appendix 13: Memorandum of Understanding, Aboriginal Communities

ABORIGINAL REFERENCE GROUP – VICTORIA

'Project Agreement' between the HPV Vaccine PhD research team and the Aboriginal Reference Group (Victoria) November 2006

1. Background - what the project is about

It is the right of all Aboriginal communities in Victoria to have access to proper information, health care, preventative measures, education and resourcing in regard to human papillomavirus (HPV) and its association with cervical cancer and the HPV vaccine, and issues to do with abnormal Pap smears and cervical cancer.

Cervical cancer, which can be caused by the human papillomavirus (HPV), is a big health problem for women worldwide. A new HPV vaccine (Gardasil) has been developed that will help reduce cervical cancer and is now available in Australia by prescription from a doctor. HPV vaccine will be the second vaccine against a major human cancer (the other being HepatitisB Virus vaccine which prevents primary liver cancer).

HPV is a very normal condition and is spread through genital skin contact. Nearly 50% of women who have sexual intercourse will get HPV but in most cases it clears up naturally. Some women, with HPV that does not clear up on its own, may have an increased risk of developing cervical cancer. Because of this risk, the medical point of view is that it is very important for Aboriginal children to be vaccinated with the HPV vaccine. Because Aboriginal Health Workers [AHWs] and parents might have some concerns about the vaccine, we want to find out find out what they think about giving the HPV vaccine to their children.

In Australia, invasive cervical cancer (ICC) is the eleventh most common cancer in women, (262 deaths in 2001). Since 1983 17,708 cases of cervical cancer have been diagnosed in Australia with an annual diagnosis average of 800 cases per year. In 1998-2000 life expectancy for Australian Aboriginal females was 63 years which is 20 years less than for the total female population and Aboriginal women are reported to have high mortality rates for cervical cancer. The mortality rate is in part due to the low level of Pap smear uptake. The immunisation status of Aboriginal children is half that of the overall Australian population. However, remote Aboriginal communities have higher coverage than urban & less remote Aboriginal communities due to targeted vaccination programs.

2. The Partners

The *HPV Vaccine PhD research team* is a group comprising a University of Melbourne (Department of Paediatrics) PhD student [Margaret Heffernan], four Academic supervisors [Prof. Suzanne Garland; Dr. Kirsten McCaffery; Prof. Susan Sawyer; Prof.Michael Quinn] ; Victorian Aboriginal Project Supervisors: Marika Kalargyros (Senior Aboriginal Women's Support and Education Worker, Aboriginal Women's Health Business Unit, Royal Women's Hospital); Peta Reynolds [Aboriginal Community Project Officer Papscreen Victoria]); and a Central Australian Field Supervisor, Kirsty Smith.

The project is examining the attitudes of some Australians toward the HPV vaccine and if they will recommend children and adolescents to be vaccinated with it. The Australian groups selected are (i) parents from three cultural groups in Australia (Aboriginal [Victoria and Central Australia] Anglo, and Chinese) and (ii) health providers (Victorian Aboriginal Health Workers [AHWs] and Victorian General Practitioners [GPs]).

The Aboriginal Reference Group (Victoria) [ARG] is a group advising the research team and comprises professional and community representatives of the Aboriginal community in Victoria [Aboriginal Project Supervisors: Marika Kalargyros and Peta Reynolds ; Kate Broun, Manager Papscreen Victoria; and Kellie Loughron, Koori Maternity Services]. All members have extensive and direct experience in understanding the needs of, and working with, the Aboriginal community. The principal function of the ARG is to provide to the research team non-discriminatory, expert mentoring and advice in regard to non–Aboriginal researchers undertaking research within the Aboriginal community.

Research aim: The aim of the project is to understand the perspectives of parents from different cultures within Australia to enable every parent to have access to appropriate information and education about the HPV vaccine in a manner that is sensitive to the specific cultural needs of the community. Therefore the research team is committed to obtaining data from each community sector in a manner that is respectful to their cultural expectations.

This Project Agreement has been developed by the partners to provide a framework for support in working effectively with Aboriginal communities in regard to HPV vaccine to reduce the incidence of cervical cancer in Aboriginal women.

3. Partnership

The research team recognises that given the need for a collaborative effort to effectively create awareness and education about HPV and the HPV vaccine within the Victorian Aboriginal community, the ARG is a representative group experienced in working with the Victorian Aboriginal community to facilitate the development and provision of appropriate information and education in regard to HPV as a necessary cause of cervical cancer, and HPV vaccine.

We recognise VACCHO as the peak representative organisation that, through its members, coordinates statewide opinion and direction on Aboriginal health issues in Victoria. We recognise PapScreen Victoria as the peak representative organisation that coordinates statewide cervical screening communication and recruitment initiatives in Victoria.

4. Principles

This agreement is based on recognition of the following principles:

1. The research team recognises the guiding spirit of VACCHO and the ARG and will work within the framework of Aboriginal self-determination and community control.
2. Aboriginal peoples have a fundamental right of ownership over their own knowledge and information.
3. Effective improvements in health outcomes will only be achieved when Aboriginal peoples and their community controlled health services are empowered to act on their own behalf.
4. Improved awareness and education about HPV, and HPV vaccine as a preventative measure for cervical cancer, will primarily result from education strategies developed and implemented at the local level via PapScreen Victoria and with the expertise and experience of the ARG.
5. Programs concerned with Aboriginal health issues in regard to HPV, and HPV vaccine in Victoria will be developed in partnerships with local ACCHOs.
6. Adequate information, resources and support need to be shared between all participating groups to ensure the development of effective partnerships.

7. Such a relationship is dependent on the commitment of all participants to be honest, open and frank in their communication with each other, at all levels of their interaction.

5. The Agreement

This agreement commits the research team and the ARG to cooperatively act together on an ongoing basis with a common purpose:

1. To support the provision of information, education and resources in regards to HPV and HPV vaccine within the Victorian Aboriginal community.
2. To enhance each other's awareness about Aboriginal health and social health needs and education in regard to HPV and HPV vaccine
3. To make a difference in regard to education and information about HPV and HPV vaccine in Aboriginal communities through:
    a. Providing accessible and culturally sensitive education in regard to HPV and HPV vaccine to AHWs and others associated with women's health issues.
    b. Building capacities within Aboriginal communities in Victoria to have a sustainable and practical approach in regard to both the management of HPV, and harm reduction in regard to HPV vaccine.
    c. Providing an ongoing state network and resource base for Aboriginal workers in relation to HPV and HPV vaccine with both Aboriginal and non-Aboriginal organisations.
    d. Develop a sound body of knowledge on HPV and HPV vaccine with Aboriginal communities throughout the state of Victoria.
4. To develop joint planned strategies that will add value and enrich all partners by:
    a. Broadening our visions and work practice
    b. Developing a shared knowledge around HPV and HPV vaccine in regard to Aboriginal communities in order to strengthen the voice for improved health and social health in Aboriginal communities.
    c. Developing, building and sustaining quality relationships between Aboriginal and mainstream services and government in the area of HPV and HPV vaccine.

6. Implementation

The research team and the ARG will meet as required to determine priorities, timelines, development of education sessions and to discuss and evaluate progress. Other organisations or workers who may be involved in the development and/or training may be invited to attend specific meetings as required. Progress of the partnership will be reviewed at each meeting and adjusted upon mutual agreement if required.

Protocols for Consultation and Collaboration with Victorian Aboriginal Community Controlled Health Organisations

These protocols provide guidance to the research team and the ARG about ways of working with ACCHOs based on respect for Aboriginal community processes and cultural expertise. Each local ACCHO will have its own ways of doing things, which will be respected. The research team and the ARG understand that these protocols provide working guidelines only. Building partnerships will be based on the development of trust and mutual respect over time.

Accepting the need for ACCHO ownership of consultative and collaborative processes

- Aboriginal peoples assert a fundamental right of ownership over local programs and their own knowledge and information about health issues. This will be recognised and respected by the research team and the ARG.
- The research team and the ARG will seek to form true partnerships with ACCHOs both as a matter of respect and best practice.
- No consultation with Aboriginal community members for research needs assessment or other program related activities would take place without the prior consent of the ACCHO concerned.
- Any information the research team and the ARG collect from ACCHOs about community issues and needs will be kept entirely confidential between the research team and the ARG representative present and the community members present in a particular assembly.
- The research team and the ARG representative will not discuss such issues with any person outside of the assembly, including other members of the research team or ARG members, unless written consent has been approved by the ACCHO concerned.

- In addition, information collected for publication purposes will be agreed and cleared in writing by the ACCHO in accordance with informed consent protocols.
- The ARG recognises that the student is working to set deadlines to meet the reporting requirements of the University, the scholarship funding bodies and submission of a thesis for examination and, with good faith, the ARG will enable these deadlines to be met.

Effective communication between ACCHOs, the research team and the ARG

The following protocols will be followed in communication:

- Each ACCHO's ways for organising discussions and formal meetings will be respected.
- The research team and the ARG will respect the local ACCHO's judgments about what initiatives and programs are appropriate for them.
- The research team and the ARG will plan ahead for people to properly consider the issues involved and a program's relevance to the community. The research team and the ARG will listen and incorporate people's comments.
- The research team and the ARG recognise local community resources are there for the local community's use and that many ACCHOs are under-resourced. Any programs being discussed in partnership with the research team and the ARG will be budgeted for to include associated costs. The research team and the ARG will identify costs at the planning stage and present them to the local ACCHO before processing.
- The research team and the ARG will not get involved in the organisation's business that is not related to their program partnership.
- The research team and the ARG will not promise programs or services they cannot deliver.
- The research team and the ARG will seek the advice of the local ACCHO on social and gender issues and respect the rules and processes they establish.
- To avoid misunderstandings, ACCHOs and the research team and ARG representatives should check back at each meeting to ensure that both parties agree about information and/or the meeting's outcomes before it is over.
- The research team and the ARG recognise both the ACCHO's and individual Aboriginal people's ownership rights over their information.

- Permission will be sought from relevant ACCHOs for the use or publication of information upon the advice of the ARG and in accordance with informed consent protocols.
- All research tools will be thoroughly checked over and test run with the ARG.

Effective Partnerships

Effective partnerships for improving information and education outcomes in regard to HPV vaccine as a preventative measure against cancer of the cervix and genital warts for Aboriginal communities will involve a sharing of power between all participants and the identification of mutual benefits. HPV vaccine education programs with Aboriginal communities that result from effective partnerships will provide opportunities to improve the health and quality of life of Aboriginal women and men and their families in local communities.

PhD Research Team

Principal researcher:	Margaret Heffernan
Academic Supervisors:	Professor Suzanne Garland
	Dr. Kirsten McCaffery
	Professor Susan Sawyer
	Professor Michael Quinn
Aboriginal Field Supervisors:	Marika Kalargyros (Victoria)
	Peta Reynolds (Victoria)
Project Field Supervisor	Kirsty Smith (Central Australia)

Aboriginal Reference Group (Victoria)

Field Supervisor: Marika Kalargyros (Senior Aboriginal Women's Support and Education Worker, Aboriginal Women's Health Business Unit, Royal Women's Hospital) .....

Field Supervisor: Peta Reynolds (Aboriginal Community Project Officer PapScreen Victoria) .....

Koori Maternity Services: Kellie Loughron Coordinator .....

PapScreen Victoria: Kate Broun, Manager .....

For the PhD Research Team

Principal researcher: Margaret Heffernan .....

Principal Academic Supervisor: Professor Suzanne Garland .....

November 22, 2006

Appendix 14: Recruitment posters: Anglo and Chinese Parents



Appendix 15: Anglo and Chinese Parent Topic Interview Guide

"HUMAN PAPILLOMAVIRUS VACCINE AND COMMUNITY INTENT TO VACCINATE THEIR PRE-ADOLESCENT CHILDREN"
QUALITATIVE INTERVIEW TOPIC GUIDE: ANGLO & CHINESE COMMUNITY **M.HEFFERNAN ID: 1983 29555**

CULTURE ANGLO / CHINESE **GENDER** M F **INTERVIEWER** MH ID NO:

INTERVIEW SCHEDULE FOR GENERAL COMMUNITY [ANGLO and CHINESE]

☐ This interview schedule is adapted from a Topic Guide developed for a HPV psychosocial study by Dr. Kirsten McCaffery, 2005.

KEY RESEARCH QUESTION: The extent to which attitudes and perspectives of adults from diverse cultures [Anglo, Indigenous and Chinese Australian] differ towards intentions to participate in an immunisation program of the human papillomavirus [HPV] vaccine?

THEME	RESEARCH QUESTION ADDRESSED	ISSUES EXPLORED	COMMENT
1. Introduction [Pre record] ☐ Consent form ☐ Confidentiality ☐ Tape recording ☐ How this will help HPV vaccine research		☐ **Introduce self** (mention not from medical background) and that will give **background** about the study first… This research is funded by the Murdoch Research Children's Institute. ☐ Scientific studies show that the HPV vaccine can reduce cervical cancer by up to 70%; would like to hear what you think about the vaccine, and vaccines in general ☐ Talking to parents and GPs in Australia about the new Human Papillomavirus (HPV) vaccine as part of preventing cervical cancer. ☐ We also need to know how parents feel about giving consent to vaccinate their adolescent child/guardian with HPV vaccine ☐ The results will help decide what the key messages are and information that the community needs to help parents make an informed decision about their intention to agree that their child receive the HPV vaccine ☐ Brief **outline** of the interview: background about you; child vaccines; your information needs about HPV and cervical cancer and the HPV vaccine; **about an hour.**	

2. General background ☐ Ethnic and class identity is important so probe for these.	**PRE RECORD** **DATA ENTERED ON INFORMATION SHEET PRIOR TO DISCUSSION STARTING**	Can you tell me a bit about yourself: ☐ Who lives with you (partner, children)? ☐ Age of children ☐ Employment (current job; usual job if not working) ☐ Partner's occupation (or parents' occupation if live with them) ☐ Ethnic background (birthplace; parents birthplace; where educated). *Suggested*: We're interviewing men and women from a range of ethnic backgrounds; Can you describe yours?	
3. Vaccine history	What is the attitude toward child vaccination and the usefulness of preventative vaccines? Is the information giver [e.g. GP /school] important?	**VACCINE HISTORY:** ☐ Can you tell me about **the last time** you had your **child vaccinated?** ☐ What was the vaccine for? ☐ What helped you make the decision to vaccinate? ☐ What **information** did you receive about the vaccine either before or after the vaccine? ☐ Who gave you the information? ☐ If doctor – why is it important for your doctor to give you information? ☐ Why? ☐ If before, how did it help make the decision to be vaccinate your child? ☐ Who gave the vaccine? ☐ If doctor, was it linked with another **medical visit?** ☐ Past experience of **adverse reactions to vaccine** (management and impact of result; how did the respondent feel out about it) how does this influence your decision to vaccinate with a new vaccine? ☐ Do **friends/ family** have vaccinations; how does this influence your decision to vaccinate?	

4. HPV VACCINE – Information and knowledge HPV and HPV VACCINE – Information and knowledge Note: Build on prior discussion about HPV and knowledge/ beliefs about HPV and cervical cancer.	What is the level of awareness about the aetiology of HPV, and its association with cervical cancer? What is the level of awareness about the HPV vaccine, and its association with cervical cancer reduction?	**HPV BACKGROUND KNOWLEDGE** ☐ Do you know what factors cause cancer of the cervix? ☐ Have you heard of, or are you aware of HPV? If yes what have you heard about HPV **HPV VACCINE KNOWLEDGE** ☐ What do you know about the HPV vaccine? ☐ What is the vaccine trying to do? ☐ What information have you received about HPV vaccine? ☐ Where did you receive your information? ☐ If YES, was the information detailed enough? ☐ What did it tell about the HPV vaccine? ☐ How easy was the information to understand? ☐ Where there any parts that was confusing? ☐ Worrying or of concern to you? ☐ If NO, what info would you like to have? ☐ In what form – print, media, magazines? **HAND INTERVIEWEE (PINK) INFORMATION CARD ABOUT HPV** ☐ What information on the cards is *new* information? ☐ What are your feelings about this (new) information? ☐ Is this (new) information surprising to you? ☐ What do you think about it? ☐ What do you feel about it? **HAND INTERVIEWEE INFORMATION CARD ABOUT HPV VACCINES [Bivalent ; Quadrivalent]** ☐ What information on the cards is *new* information? ☐ Is this (new) information surprising to you? ☐ What do you think about it? ☐ What do you feel about it? ☐ Would you be willing to vaccinate your child? ☐ Why?	

5. **HPV VACCINE Intention to vaccinate**	What type of information would inform a positive or negative choice toward age, gender of recipient and vaccine option? (Bi /quad valent) Is there a gender related attitude toward the gender of recipient? Who receives it? Will the order of receipt impact on the guardian adult attitude? Is there an attitude difference in each age sector [older / younger adolescent or guardian?]	☐ Who should the vaccine be given to? Girls, Boys or both? ☐ What age would you prefer a child/ adolescent to be vaccinated at between 9 -16? ☐ Is the age of the child important when making a decision whether to vaccinate or not? – ☐ Which of the vaccine types would you prefer you child to be vaccinated with, the quadrivalent (CA + genital warts type) or the bi valent (CA only type)? ☐ Why? (explore possible partner involvement; will it be discussed with friends/family /doctor /other) ☐ What factors might stop you from giving consent for the vaccine to be given to your child?	
6. Ethnic background and beliefs regarding HPV vaccine education messages "I'd like to ask about some of your cultural beliefs – do not have to discuss any of the questions"	What type of information would inform a positive or negative choice toward immunisation? Medical (anti-cancer) versus sexual model? Whether cultural attitudes and values toward premarital sexual behaviour influence HPV education messages and intentions to consent to vaccinate pre- adolescent children with HPV vaccine.	**HAND INTERVIEWEE MESSAGE CARDS ABOUT HPV VACCINES** ☐ What do you think when you hear that the HPV vaccine is to give 70% prevention against cervical cancer? ☐ To prevent sexually transmitted infection? ☐ Still requiring a Pap smear? ☐ How do these messages differ? ☐ What message would assist your decision to consent to vaccinate your child? ☐ Deter you from giving consent? ☐ Where do you get your information about health matters? ☐ What media sources? ☐ Some of the beliefs about health and relationships that stem from your upbringing (cultural background) ☐ View about adolescent relationships ;premarital sex; sexually transmitted infections	

7. HPV and STI – impact	Whether the vaccine might be perceived by parents to endorse early sexual behaviour.	I would now like to explore in more detail the way we get a genital HPV infection and its association with cancer of the cervix ... ☐ In general, how does the knowledge that HPV is an infection got through sexual activity make you feel in relation to vaccinating your child for HPV? ☐ Emotional reactions (explore reasons for feelings) ☐ How might this impact on your decision to consent to vaccinate your child? ☐ Has having more knowledge about the HPV vaccine changed the way you think about vaccinating children to prevent cervical cancer?	
8. Vaccine implementation, scheduling dosage	Parent views on vaccine scheduling and implementation. Whether cost and age are deterrents to consent.	☐ What are your views on a national immunisation program for children between 9 -12 with catch up vaccines to 16 years of age? ☐ Who will give your child the vaccine, and what location? ☐ How do you feel about HPV vaccine being delivered by injection into the muscle in three doses over a 6 month period? ☐ What challenges will this present to your child receiving it? ☐ Is the cost of the HPV vaccine important when making a decision whether to vaccinate or not? Can you explain why?	

9. Improvements in community HPV awareness screening in the future.	Whether age of child is a significant determinant in level of detail in information that parents are willing to give their child about HPV vaccine. What detail and source of information [govt v public service v community] would assist their choice?	☐ How easy will it be to explain to your child what the HPV vaccine is for and why they are receiving it? ☐ If the vaccine program was given at certain ages, what detail of information would you be willing to give your child: ☐ 9 -10 ☐ 11-12 ☐ 12 -14 ☐ 15+ ☐ If it was a school based information should the school be involved in giving information? ☐ Sort of ways the HPV information process could be improved (and features of HPV /HPV vaccine that would be helpful) ☐ What additional information would be useful for *you* to have before the vaccine is given (enough info before decision to participate?)? ☐ What information would you want *your child* who was going to have the vaccine to be given? ☐ Would you recommend the HPV vaccine to friends/family?	
10. Closing the interview	☐ How have you found the interview? ☐ Any important issues that haven't been raised, extra comments about HPV, HPV vaccine, cervical cancer or STIs in general? ☐ Give help-line number (as some people still have questions) ☐ Have time to chat about other things after the interview Reassure about confidentiality and repeat info provided at the beginning		
OTHER ISSUES:			

KEY RESEARCH QUESTION:

The extent to which the attitudes and perspectives of adults from diverse cultures, [Anglo, Indigenous and Chinese Australian] differ in their intentions to participate in an immunisation program of the human papillomavirus [HPV] vaccine?

- Whether 'national culture' is a significant determinant of difference [if differences are seen to exist] in intention to vaccinate pre-adolescent children with HPV vaccine
- Whether gender of guardian and child is a significant determinant in intention of parents to consent to vaccinate pre-adolescent children with HPV vaccine
- Whether awareness of HPV and its origins and impact is a significant determinant in intention to give consent to vaccinate pre- adolescent children with HPV vaccine
- Whether cultural attitudes and values toward premarital sexual behaviour predict intentions to vaccinate pre- adolescent children with HPV vaccine

SUB QUESTIONS

- Is the information giver [e.g. GP /school] important?
- What is the level of awareness about the aetiology of HPV, and its association with abnormal pap smears and cervical cancer?
- What is the level of knowledge toward the risk factors of cervical cancer?
- What is the attitude toward the usefulness of preventative vaccines?
- Is there a culturally related difference toward the acceptability of the HPV vaccine for pre-sexually active /sexually active adolescents?
- Is there a gender related attitude toward the gender of recipient? Who receives it? Will the order of receipt impact on the guardian adult attitude?
- Is there an attitude difference in each age sector [older / younger adolescent or guardian?]
- What type of information would inform a positive or negative choice toward immunisation? Medical (anti-cancer) versus sexual model?
- What detail and source of information [govt v public service v community] would assist their choice?
- What is their primary information source: radio, TV + cable TV, internet, newsprint -daily paper, magazine, school newsletter, word of mouth, other
- Whether the vaccine might be perceived by parents to endorse early sexual behaviour.

Appendix 15.1: Topic Interview Guide: Aboriginal communities in Central Australia and Victoria

<table>
<tr><th colspan="2">TOPIC GUIDE: ABORIGINAL COMMUNITIES</th></tr>
<tr><td colspan="2">PART 2: HPV and CERVICAL CANCER VACCINE EDUCATION
(a) HPV background knowledge
(b) Cervical cancer vaccine knowledge
Instructions to interviewer: Please refer to “A Vaccine to Prevent Cervical Cancer”: a Papscreen Victoria Fact Sheet (February 2007) that is in your Information Pack.
Please read out all the information on the sheet to the group before you start the group discussion.</td></tr>
<tr><th>CENTRAL AUSTRALIA</th><th>VICTORIA</th></tr>
<tr><td># Not directly questioned. Emerged from the discussion.</td><td>1. Parent reactions to the HPV information
(i)Let’s talk about what we have just learnt about HPV and how it causes cancer of the cervix?
(ii)What do you think about this?
(iii)What do you think about Pap tests now?
(iv)Why?
2. Parent reactions to the cervical cancer vaccine information
(i)Let’s talk about what we have just learnt about the cervical cancer vaccine and how it can help prevent cancer of the cervix?
(ii)What do you feel about the cervical cancer vaccine information we have just told you about?
(iii)What do you think about it being given to your girls?
(iv)Will you be willing to agree to vaccinate your child with the cervical cancer vaccine?
(v)What things might stop you from agreeing to let your child get the cervical cancer vaccine?</td></tr>
<tr><td>What are the important messages about HPV and the cervix cancer vaccine for Aboriginal parents and girls?</td><td>Giving specific information about the cervical cancer vaccine
(i)Should the school be involved in giving information about HPV and the cervical cancer vaccine?
(ii)What information about HPV and the cervical cancer vaccine would you like to have that will help you make a decision</td></tr>
</table>

	about whether to give the cervical cancer vaccine to your child? (iii)What information about HPV and the cervical cancer vaccine **would stop you from agreeing** to have your child given the cervical cancer vaccine? (iv)Has having more knowledge about the cervical cancer vaccine changed your opinion about giving children a vaccine to prevent cancer of the cervix? (v) Would you recommend the cervical cancer vaccine to friends / family?
Who should provide the information to the girls about this vaccine?	**Giving parents and children information about the vaccine** (i)How easy will it be to explain to your child what the cervical cancer vaccine is for and why they are getting it? (ii)What information would you want *your child* who was going to have the vaccine to be given? (iii)If the vaccine program was given at certain ages, what information about the vaccine would you be willing to give your child , if the child was: 9 -10 years of age; 11 -12;13 -14;15+
In what setting should the information be given e.g. school, clinic, women's centre, somewhere else?	**Government funding of the cervical cancer vaccine** (i)What do you think about the Government providing the cervical cancer vaccine free for girls aged between 12 and13 with 'catch-up' vaccines to 26 years of age? (ii)Who would you like to give your child the vaccine? (Aboriginal Health Worker, nurse, GP, other person…) (iii)What location would you like it given at? (e.g. School, Medical clinic, Aboriginal Medical Service, Town Hall, other place?) (iv)What will be some of the problems in giving children of our community this vaccine?
Should Aboriginal men / boys be informed about HPV and the vaccine?	# Not directly questioned. Emerged from the discussion.
If so-what are the key messages for Aboriginal men/ boys?	
What do AHWs think about the <HPV>'ads' <advertisements> (radio and leaflet)?	

Do AHWs think the vaccine should be promoted as a vaccine for cervical cancer……. or should we talk about HPV as an STI?	**HPV as a sexually transmitted infection…….** (i) What did you think when you heard that the HPV is a sexually transmitted infection? (ii)In general, how does the knowledge that HPV is an infection got through sex make you feel in agreeing to give your child the cervical cancer vaccine? (iii) How might this affect your decision to agree to vaccinate your child?
What resources are needed to help inform Aboriginal people about the vaccine (TV, posters, video, brochure)?	# Not directly questioned. Emerged from the discussion.
Does information need to be provided in different languages?	
At what age do AHWs think the vaccine should be given to girls?	**Age of the child that the cervical cancer vaccine should be given to...** (i)What is the best age between 9 -16 for a child or teenager to be given the cervical cancer vaccine? (ii)Why is the age of the child important when you are making a decision whether to agree to give permission for the cervical cancer vaccine?
(i)Do AHWs think there will be problems in giving the girls 3 needles over 6 months? (ii) If so what might be some of the problems?	**Giving children the vaccine** (i) How do you feel about cervical cancer vaccine being given by injection into the arm in 3 doses over 6 months? (ii) What will your child think about having to have 3 shots? (i) What will be some of the things that will stop your child from getting 3 shots over 6 months? (ii)
Do AHWs think it will be necessary for the girls who are vaccinated to continue having 'Paps'? Why?	**Cervical cancer vaccine and the need for ongoing Pap tests** What do you think when you hear that females will still need to have a Pap test because the cervical cancer vaccine only protects against 2 types of HPV that cause up to 70% of cervical cancers, and doesn't provide protection against all cancer-causing HPV types?
How can we make sure the girls get this message?	Not directly discussed with Victorian participants

Any other comments about HPV or the HPV vaccine you would like to make?	Are there any important issues that haven't been raised, extra comments about HPV, cervical cancer vaccine, cancer of the cervix cancer or sexually transmitted infections in general?

Appendix 16: HPV Education Intervention

HPV VACCINES

There are two HPV vaccines that will be available

- The HPV vaccine will prevent 70% of cervical cancers, but about 30% of cervical cancers and 10 % of genital warts will *not* be prevented by these vaccines
- Neither of the HPV vaccines will provide complete protection against infection with other HPV types that are not covered by the vaccine, some of which cause cervical cancer
- The HPV vaccines do not prevent other sexually transmitted diseases, nor do they treat HPV infection which is already in the body, or cervical cancer
- Because the vaccines will not protect against all infections that cause cervical cancer, it is important for vaccinated women to continue to have a Pap smear

VACCINE 1: Gardasil™ is called a *quadrivalent* vaccine because it protects against four HPV types: 6, 11, 16 and 18.

- HPV Types 6 and 11 protect against genital warts
- HPV Types 16 and 18 protect against cancer of the cervix

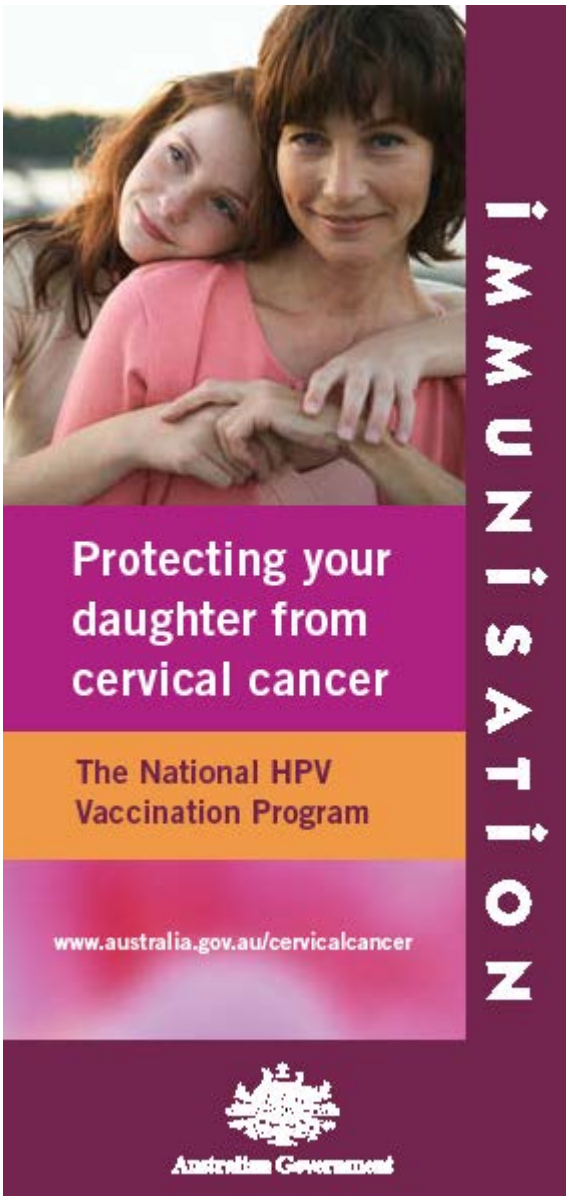
Gardasil is given through a series of 3 injections into muscle tissue (arm) over a 6-month period.

VACCINE 2: Cervarix™ is called a *bivalent* vaccine because it protects against two HPV types: 16 and 18 which protects against cancer of the cervix

Cervarix is given through a series of 3 injections into muscle tissue (arm) over a 6-month period.

HPV MESSAGE 1
To be most effective in preventing cancer of the cervix the HPV vaccine needs be given to young adolescents before they become sexually active.
HPV MESSAGE 2
One HPV vaccine will be given to young adolescents to prevent cancer of the cervix and genital warts. The other HPV vaccine will only prevent cancer of the cervix.
HPV MESSAGE 3
Although the HPV vaccine will help prevent 70% of cases of cancer of the cervix, women will still need to have a regular Pap smear.
HPV MESSAGE 4
The HPV vaccine will be given to young adolescents to prevent some types of HPV. HPV is a sexually transmitted infection.

Appendix 17: Australian Government HPV Information (English)





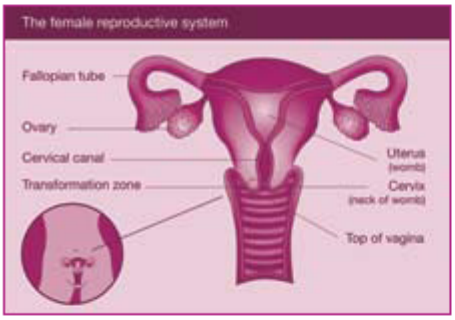
What is cervical cancer?

Cervical cancer (cancer of the cervix*) is a disease where abnormal cells grow uncontrollably and spread throughout the body from the cervix*.

Cervical cancer is not common in Australia, because of the success of Pap smears (National Cervical Screening Program). However, over two hundred women die each year in Australia from cervical cancer.

A vaccine, which has recently been developed, can also prevent cervical cancer.

*The cervix is a part of the female reproductive system between the vagina and the uterus (womb).



What causes cervical cancer?

Genital infection with particular types of human papillomavirus (HPV) can cause cervical cell changes that may lead to cervical cancer. This usually takes more than 10 years to develop.

Most women who have HPV, slowly clear the virus naturally and do NOT develop cervical cancer.

What is HPV (human papillomavirus)?

Human papillomavirus (HPV) is the name for a group of viruses that cause skin warts, genital warts and some cancers.

Many different types of HPV can affect different parts of the body. Some of these types can infect the genital area. Warts on other parts of the body, such as the hands, are caused by different HPV types.

HPV types that can cause genital warts or cervical cancer can be spread by direct, skin-to-skin contact during all types of sexual activity with a person who has the virus.

Anyone who has ever had sexual contact could have HPV – it is so common that four in five people will have had genital HPV infection at some time in their lives. Most genital infections with HPV do not cause any symptoms and people do not know they have the infection.

Can HPV infection be treated?

No. Treatments are only available for the effects of the virus, such as genital warts and abnormal changes to cells in the cervix.

Don't confuse human papillomavirus (HPV) with human immunodeficiency virus (HIV) or herpes virus, as they are different infections.

Can HPV infection be prevented?

Yes. A HPV vaccine called GARDASIL®, which is available in Australia, can prevent infection with four HPV types. Two types cause 7 out of 10 cervical cancers. The other two types cause 9 out of 10 cases of genital warts.

If your daughter has had sexual contact then she may have been infected with some of these HPV types. If she has already been infected with any of these four HPV types, her protection against cervical cancer and/or genital warts after vaccination may be reduced.

The HPV vaccine cannot protect females against cervical cancer and genital warts caused by other HPV types that are not in the vaccine.

Regular Pap smears are still essential because the HPV vaccine does not prevent all cervical cancers.

Why should my daughter be vaccinated at this age?

Vaccination with HPV vaccine is most effective when it is given to females before they are likely to be exposed to HPV. That is, before they start having sexual contact.

Should my daughter be vaccinated if she has had sexual contact?

Yes. You should still consider her having the vaccination if she has had sexual contact with someone.

There are benefits in vaccinating young women who are sexually active, as they are likely to have had fewer sexual partners and a lower risk of exposure to HPV.

If she has had sexual contact, she may still benefit from the vaccine because it is unlikely she will have been infected with the two HPV types that can cause cervical cancer and the two HPV types that can cause genital warts, which are covered by the vaccine.

What if my daughter is exposed to HPV between doses?

Exposure to any of the four HPV types covered by the vaccine before the three doses are completed may slightly lessen the effect of the vaccine. She should still have the full course of the vaccine.

How can my daughter be vaccinated against HPV?

From April 2007, free HPV vaccine will be provided through school-based programs for:

- females aged between 12 and 13 years (ongoing program); and
- females aged between 13 to 18 years - until the end of the school year in 2008 (catch-up program).

The timing of when HPV vaccine doses will be given in schools is different for each state and territory.

Females aged 18-26 years, and girls aged 12-18 years who are not attending school, can get free HPV vaccine from their general practitioner or community immunisation provider between July 2007 and June 2009.

Is vaccination compulsory?

No. However, your daughter cannot be vaccinated until a signed consent form has been returned to her school.

What should I do if my daughter misses any doses during the school program?

Free HPV vaccine for missed doses will be provided by local council and public health unit immunisation providers, schools and general practitioners, depending on which state or territory you live.

The vaccine is free, but it is important to note a consultation fee may be payable to general practitioners.

Is free HPV vaccine available for boys?

No. HPV vaccine for boys is available from general practitioners, but it will not be provided free and a consultation fee may also need to be paid to the general practitioner.

GARDASIL® has been approved by the Therapeutic Goods Administration (TGA) for males aged 9 to 15 years, which means it has been tested for safety. However, research into the effectiveness of the vaccine in preventing HPV infection and related diseases in men has not been completed.

Is HPV vaccine available for women older than 26 years?

No. Older females are likely to have had more exposure to HPV, so the benefits of HPV vaccine may be reduced. Clinical trials into the benefits of the HPV vaccine for women older than 26 years has not been completed.

How is the vaccine given?

GARDASIL® is given as a series of three injections into upper arm muscle. It is usually given within a six month period:

- dose one: at a chosen date;
- dose two: 1-2 months after the first dose;
- dose three: 4-6 months after the first dose.

The vaccine is most effective when all three doses have been given, that is, the full course is complete. Missed doses should be given as soon as possible.

How safe is GARDASIL®?

The vaccine was shown to be safe during large clinical trials.

Your daughter may experience minor side effects such as redness, pain, mild fever and swelling at the injection site. For arm soreness and swelling or fever she can take paracetamol as directed on the package and place a cool, moist cloth over the injection site. If the pain and swelling continue for more than two days she should see a general practitioner.

She should not have the HPV vaccine if she is pregnant or if she has had a serious allergic reaction to yeast or any other vaccine components (aluminium phosphate, sodium chloride, L-histidine, polysorbate and sodium borate).

Will my daughter need to have booster doses of HPV vaccine?

Current research shows it is unlikely booster doses will be needed, but the need for booster doses will continue to be reviewed.

Should my daughter have Pap smears after vaccination against HPV?

Yes. The HPV vaccine does not protect against all HPV types that can cause cervical cancer. All females, whether vaccinated against HPV or not, should have regular Pap smears as recommended.

The current recommendations are that women should have a Pap smear every two years from the age of 18 or two years after having sex, whichever is later.

Regular Pap smears are still essential because the HPV vaccine does not prevent all cervical cancers. Pap smears detect abnormal changes to cells in the cervix so treatment can start before cancer develops.

For more information about Pap smears and cervical screening see the National Cervical Screening Program website at http://www.cancerscreening.gov.au

What is a Pap smear?

A Pap smear is a quick and simple test in which a number of cells are collected from the cervix and sent to a laboratory where they are tested for changes. No medications or anaesthetics are required and a doctor or women's health nurse can easily do it.

Will information about my daughter be collected if she is vaccinated with the HPV vaccine?

A National HPV Vaccination Program Register (HPV Register) is being developed by the Australian Government to collect data about the Program. Personal details identifying your daughter will be kept confidential.

Personal information collected will be used to evaluate the impact of the HPV Vaccination Program on cervical cancer rates, to issue reminders if the course is incomplete, to issue confirmation the course is complete, and to contact vaccine recipients if booster doses are required. If your daughter's details are not included in the Register it will not be possible to contact her about missed or booster doses.

Information will not be sought or collected about your daughter's sexual history.

You can decline having your daughter's details included in the HPV Register.

Where can my daughter and I get more information?

Information on HPV infection and HPV vaccine is available on the Immunise Australia Program website at www.immunise.health.gov.au

You can also phone the National Immunisation Infoline on 1800 671 811 or contact your general practitioner, school or women's health nurse and state or territory health department for more information.

Information about Pap smears and the National Cervical Screening Program is available on the Cancer Screening website at www.cancerscreening.gov.au

Note: This information is correct as at March 2007.

Appendix 18: GP topic guide

THE UNIVERSITY OF MELBOURNE

Margaret HEFFERNAN OAM
Department of Microbiology and Infectious Diseases
Unit 1, 234 Cardigan Street, CARLTON 3053
Victoria, Australia
Tel: +61 3 9344 3686 / +61 (0)419 339 724
Fax: +61 3 9344 3685
Email: m.heffernan2@pgrad.unimelb.edu.au

25 10 2006

We are seeking your support for a study being conducted about the new human papillomavirus vaccine that will be available in Australia September 2006.
General Practitioners and other health providers across Australia are going to have an important role in advising patients, especially parents and young people about this vaccine that will reduce the risk of cervical cancer by up to 70%.
I am a PhD student undertaking this research, and seeking 10 -15 General Practitioners from Victoria to interview face –to – face for half an hour to gain opinions about the vaccine and what your information requirements are to meet patient queries.
Your clinic has been identified as one that meets our sample requirements.

During and after the interview you will be given the most recent information about the HPV vaccine which may assist you with patient queries. You will be moderately compensated for participation ($100 Myer voucher).

We would be pleased if you could you assist us by displaying the enclosed poster in your staff area, and encouraging staff to participate.
We have also included a Fax return form for doctors who would like to assist with this study.

Yours sincerely,

.....

Margaret Heffernan OAM

Prof. Suzanne Garland, Director: Microbiology and Infectious Disease, RWH, Melbourne
Dr Kirsten McCaffery, School of Public Health, University of Sydney
Prof. Susan Sawyer, Director: Centre for Adolescent Health, RCH, Melbourne
Prof.Michael Quinn, Director: Gynaecology Oncology RWH, Melbourne

8 12 2006

Appendix 18.1: GP Information Statement and Consent Form

GP INFORMATION STATEMENT 2

MELBOURNE UNIVERSITY LETTERHEAD

STANDARD PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Project Title: "Human papillomavirus vaccine and Australian community intentions to vaccinate Pre-adolescent children"

Investigators: Margaret Heffernan, Professor Suzanne Garland, Dr Kirsten McCaffery, Professor Susan Sawyer, Professor Michael Quinn

Thank you for taking the time to read this Information Statement.
This information statement and consent is **6** pages long. Please make sure you have all the pages.

For people who speak languages other than English:
If you would also like information about the research and the Consent Form in your language, please ask the person explaining this project to you.

You are invited to participate in a Research Project that is explained below.

What is an Information Statement?

These pages contain information about a research project we are inviting you to take part in. The purpose of this information is to explain to you clearly and openly all the steps and procedures of this project. The information is to help you to decide whether or not you would like to take part in the research.

Please read this information carefully. You can ask us questions about anything in it. You may also wish to talk about the project with your parents or guardians, friends or health care worker. Once you have understood what the project is about, if you wish to take part please sign the consent form at the end of this information statement. You will be given a copy of this information and consent form to keep

What is the Research Project about?
This project is to find out what parents think about giving a new vaccine to children, to prevent cancer of the cervix.

The vaccination will be available in 2007 -2008 and it is important that doctors and other health providers understand how the community will respond to it. The research project will also help plan the educational messages so the community is aware of the benefits of the vaccination and help make their decision in giving consent to have their child vaccinated.

This part of the research project is Stage 1 of a larger study. In Stage 1, we will interview forty [40] parents from Anglo, Indigenous and Chinese culture backgrounds in Victoria and Central Australia; and 10 General Practitioners from Victoria to find out their views about the HPV vaccine. The information from these interviews will be analysed, compiled in a report, and used to help develop Stage 2 of the project - a quantitative questionnaire survey which will be distributed to 900 -1,000 people across Australia.

We are asking you to participate in Stage 1.

Who are the Researchers?
Margaret Heffernan is a PhD student at the Department of Paediatrics at RCH. This project is part of Margaret's doctorate at the University of Melbourne. Margaret is supervised by:

(1) Professor Suzanne Garland of the University of Melbourne who is a specialist doctor in microbiology and has been researching the Human papillomavirus for over twenty years
(2) Dr. Kirsten McCaffery from the University of Sydney is a researcher who studies the community's feelings and attitudes toward Human papillomavirus
(3) Professor Susan Sawyer is a Paediatrician and Head of Adolescent Health at the Royal Children's Hospital in Melbourne
4) Professor Michael Quinn from the Royal Women's Hospital in Melbourne is a gynaecological cancer specialist and researches the association between Human papillomavirus and cancer.

Why am I being asked to be in this research project?

We are asking 10 General Practitioners who are prepared to be interviewed about their understanding of what causes cancer of the cervix and about a vaccine that might prevent cervical cancer. You were selected when you responded to an invitation to participate that was sent to your clinic. By contacting Margaret Heffernan you have indicated you might be interested in giving your opinion in an interview.

What are the alternatives to participating in this project?

You do not have to be in this research project if you don't want to. It is of a volunteer nature. If you agree to participate, you may withdraw your consent at any time without giving a reason. You can also ask to withdraw any interview information before it is analysed.

What do I need to do to be in this research project?

Please think about the study and fill in the contact details in the attached slip. If you agree to be contacted, Margaret will contact you to give you more information about the interview. She will be able to answer any questions that you have and you can tell her whether or not you wish to take part.

Margaret will send you details about the interview. You will be interviewed by yourself – there will be no one else other than Margaret Heffernan at the interview. You can choose the place and time where you would like the interview to take place. The interview will ask about your opinion on health matters and giving children vaccinations as well as specific questions on the HPV vaccine that will prevent cancer of the cervix. It will take about half an hour (30 minutes) of your time and will be audio recorded (voice recorded) if you agree.

A copy of the final report will be available at the end of the study.

Is there likely to be a benefit to me?

There is no direct benefit to you but you may feel good about giving your opinion that will help research that might help other medical practitioners, especially General Practitioners, in advising patients about the HPV vaccine.

Is there likely to be a benefit to other people in the future?

The new vaccine will help prevent cancer of the cervix. This research project will help us understand the best way to inform and educate the community about the HPV vaccine and its benefits. It will help us provide important information to general Practitioners, parent, guardians, and adolescents to help them decide about their child getting the new vaccine.

What are the possible risks and/or side-effects?

There are no risks or side effects from participating in this project.

What are the possible discomforts and/or inconveniences?

The interview will take half an hour of your time. Margaret will make it at a time that suits you and can interview you in a place of your choice if that is more convenient for you.

The interview will ask your views about health matters including vaccinations. Some questions will focus on how some infections are caused by sexual intercourse. You may find some questions sensitive. You will not have to answer any questions you feel uncomfortable with. If you agree, the

interview will be audio [voice] recorded. You can ask the recorder to be stopped at any time and may change or withdraw information if you are not happy with it. You will be able to ask as many questions as you like.

Margaret Heffernan, who will be interviewing you, will provide a telephone contact number at the end of the interview should you wish to discuss any issues later.

What will be done to make sure the information is confidential?

The transcript of the interview and audiotape will be identified by a study number and not by your name.

Access to the data is restricted to researcher and supervisors. The audiotapes and the transcripts and will be kept in a locked filing cabinet, unless subjected to legal requirements, for seven years from the date of publication, as prescribed by University of Melbourne and NHMRC regulations, and then destroyed. Results may be discussed or published at conferences, in professional journals but participants will not be identified

Will I be informed of the results when the research project is finished?

In general, a meaningful summary will be made available to participants at the end of the study, if you want to receive it.

The summary will give results for the whole group of 50 people and not give individual information. If you wish to receive the summary of the interview you need to contact Margaret Heffernan .It will take at least four months to analyse all the interview results.

You can decide whether or not to take part in this research project. You can decide whether or not you would like to withdraw at any time without explanation.

You may like to discuss participation in this research project with your colleagues. You can ask for further information before deciding to take part.

If you would like more information about the study or if you need to contact a study representative in an emergency, the person to contact is:

Name: Margaret Heffernan, PHD student
PO Box 262, Albert Park 3206

Contact telephone: Tel: 03 9344 3686 / 0419 339 724

What are my rights as a participant?

1. I am informed that except where stated above, no information regarding my medical history will be released. This is subject to legal requirements.

2. I am informed that the results of any tests involving me will not be published so as to reveal my identity. This is subject to legal requirements.

3. The detail of the procedure proposed has also been explained to me. This includes how long it will take, how often the procedure will be performed and whether any discomfort will result.

4. It has also been explained that my involvement in the research may not be of any benefit to me personally. I understand that the purpose of this research project is to improve the quality of medical care in the future.

5. I have been asked if I would like to have a family member or a friend with me while the project is explained to me.

6. I understand that this project follows the guidelines of the National Statement on Ethical Conduct in Research Involving Humans (1999).

7. I understand that this research project has been approved by the Royal Children's Hospital Ethics in Human Research Committee on behalf of the Royal Children's Hospital Board.

8. I have received a copy of this document.

If you have any concerns about the study, and would like to speak to someone independent of the study, please contact the Executive Officer of the Human Research Ethics Committee of the University of Melbourne on (phone) 03 8344 7507 (Monday to Friday 9am-5pm).

STANDARD INFORMED CONSENT
FOR PARTICIPANT TO PARTICIPATE IN A RESEARCH PROJECT

Title of Project

Project Title:	"Human papillomavirus vaccine and Australian community intentions to vaccinate Pre-adolescent children"

Principal Investigator(s)

MARGARET HEFFERNAN [PhD student]
SUPERVISORS (1) PROF SUZANNE GARLAND (2) DR. KIRSTEN McCAFFERY
(3) PROF SUSAN SAWYER (4) PROF MICHAEL QUINN

I (Participant name) _____

voluntarily consent to take part in the above titled Research Project, explained to me by

Margaret Heffernan

- I have received a Participant Information Statement to keep and I believe I understand the purpose, extent and possible effects of my involvement
- I have been asked if I would like to have a colleague with me while the project was explained
- I have had an opportunity to ask questions and I am satisfied with the answers I have received
- I understand that the researcher has agreed not to reveal results of any information involving me, subject to legal requirements
- If information about this project is published or presented in any public form, I understand that the researcher will not reveal my identity
- I understand that if I refuse to consent, or if I withdraw from the study at any time without explanation, this will not affect me.
- I understand I will receive a copy of this consent form

SIGNATURE _____ Date _____

I have explained the study to the participant who has signed above, and believe that they understand the purpose, extent and possible effects of their involvement in this study.

RESEARCHER'S SIGNATURE _____ Date _____

Note: All parties signing the Consent Form must date their own signature.

This page has some important general information about taking part in research studies approved by the University of Melbourne. Details about this study are on the Information Sheet/Letter.

Your rights as a Participant are:

1. To choose to take part or not to take part
2. To withdraw from the study at any time
3. To have the study fully explained to you

You should feel free to ask the researchers any questions about the study.

Other information you should know about being part of this study

1. Your answers to the questions on this study will be kept private. This is subject to legal requirements.
2. No information from this study will reveal your identity
3. You should have been told what you need to do for this study, and how long it will take.
4. If you do not wish to take part in this study, this will not affect your relationship with the University of Melbourne
5. This research project has been approved by the University of Melbourne Human Research Ethics Committee.

If you have any concerns about the study, and would like to speak to someone independent of the study, please contact the Executive Officer of the Human Research Ethics Committee of the University of Melbourne on (phone) 03 8344 7507 (Monday to Friday 9am-5pm).

If you would like more information about the study or if you have any questions about the study, the person to contact is:

Name: **MARGARET HEFFERNAN**

Contact telephone: 03 9344 3686 / Mobile: 0419 339 724

STATUS GP **GENDER** M F **INTERVIEWER** MH ID NO:

INTERVIEW SCHEDULE FOR GENERAL PRACTITIONERS

This interview schedule is adapted from (1) a Topic Guide developed for a HPV psychosocial study by Dr. Kirsten McCaffery, 2005
(2)"Attitudes about HPV Vaccine Among Family Physicians" J Pediatr Adolesc Gynecol (2005) 18:391 -398 [USA study]
(3) "Family Physician Perspectives on Barriers to Childhood Immunisation" J.Vaccine 22 (2004) 2340 -2344' [A New Zealand study]
(4) Prislin, R. Nader PR De Guire, M Hoy, PL Pung, MA Ross, S Goerlitz, MJ and Sawyer, M "Physicians' immunization knowledge, attitudes and practices. A valid and internally consistent measurement tool" Am J Prev. Med (17) 2: 1999 pages 151-152

KEY RESEARCH QUESTION: The extent to which attitudes and perspectives of adults from diverse cultures [Anglo, Indigenous and Chinese Australian] differ towards intentions to participate in an immunisation program of the human papillomavirus [HPV] vaccine?

THEME	RESEARCH QUESTION ADDRESSED	ISSUES EXPLORED	COMMENT
1. Introduction ☐ Consent form ☐ Confidentiality ☐ Tape recording		☐ **Introduce self** (mention not from medical background) and that will give **background** about the study first... ☐ Talking to GPs and AHWs in Victoria and Central Australia about the new HPV vaccine as part of preventing cervical cancer. ☐ Scientific studies show that the HPV vaccine can minimise cervical cancer; would like to hear what you think about the vaccine, and vaccines in general ☐ We also need to know how doctors feel about recommending the HPV vaccine to their patients ☐ This research is funded by the Murdoch Research Children's Institute. The results will help decide what the key messages are and information need that the community needs to help them make an informed decision about their intention to recommend the HPV vaccine to patients ☐ Brief **outline** of the interview: background about you; past experiences of vaccine history; attitude toward child vaccines; your information needs about HPV and cervical cancer and the HPV vaccine; **about ½ an hour.**	**1. Introduction** ☐ Consent form ☐ Confidentiality ☐ Tape recording

2. General background ☐ Ethnic and class identity is important so probe for these. ☐	How ethnicity might influence intent to recommend HPV vaccine	**DETAILS ENTERED ON SEPARATE DOC PRE-RECORD** Can you tell me a bit about yourself: ☐ Year born ☐ Who lives with you (partner, children)? Do you have children /grandchildren /intend to have children? ☐ Educational background (i.e. qualifications) ☐ Ethnic background (birthplace; parents birthplace; where educated). ☐ Years of practice as a GP /Paed (current job; always done same job? Part time/Full time) ☐ Professional associations or involvements ☐ Post code of practice ☐ Type of patients at practice – socio-demographic ☐ Vaccine policy at the clinic? Or self managed? ☐ *Probe*: why?	SEE SEPARATE SHEET
3. HPV and HPV VACCINE – Information and knowledge Vaccination dosage	Is the information giver [e.g. GP /school] important? What is the level of awareness about the aetiology of HPV, and its association with abnormal pap smears and cervical cancer? What is the level of knowledge toward the risk factors of cervical cancer? What type of information would inform a positive or negative choice toward immunisation? Medical (anti-cancer) versus sexual model?	**HPV KNOWLEDGE** ☐ How would you rate the HPV knowledge of your patients? Scale 1 – 10 (10: Excellent) – (1 : poor) ☐ What impact does this level of knowledge have on you clinically? ☐ How would you rate your HPV knowledge? Scale 1 – 10 (10: Excellent) – (1 : poor) ☐ Compare, some people mention taboo associated with STIs, do abnormal cells / HPV attract the same **taboo** or not? ☐ Feelings about the **uncertainty** of information about HPV ☐ What level of detail do you give patients when time for Pap screen? Abnormal pap result? **HPV VACCINE KNOWLEDGE** ☐ How **aware** are you of HPV vaccines? Gardasil? Cervarix? ☐ What do you know about them? ☐ Who they are recommending it for? ☐ HPV types covered? ☐ What is the vaccine trying to do?	

	What detail and source of information [govt v public service v community] would assist their choice?	☐ Do you have any concerns about what you feel least prepared to deal with, with HPV vaccine patient queries ☐ Is there anything you feel uncomfortable about with this vaccine compared to other vaccines? **INTENTION TO RECOMMEND** ☐ Will you recommend the HPV vaccine to all patients, or specific groups of patients? ☐ Which of the 2 vaccines will you recommend [once Cervarix is licensed] ☐ How will you make your decision on which one to recommend? ☐ Are there any cultural groups that it may be difficult to recommend it to? ☐ Chinese ☐ Indigenous ☐ What will be the key challenges in recommending it to patients? ☐ Can you anticipate what the most likely asked questions will be from patients? ☐ Will you approach your recommendation for this vaccine differently to other vaccines e.g. HBV? ☐ What factors might stop you from recommending the HPV vaccine? ☐ Is the cost of the HPV vaccine important when making a decision whether to recommend vaccinating or not? ☐ Is it the role of the GP to 'talk up' or recommend the vaccine? ☐ Who will give the patient the vaccine, and what location? ☐ How do you feel about HPV vaccine being delivered in three doses? ☐ Your thoughts on having to give adolescents 3 doses? **INFORMATION SOURCES** ☐ What **info** have you received about the HPV vaccines? ☐ What did it tell about the vaccine? ☐ What type of information is available from professional	

		sources about the vaccines? ☐ What will be the key information you give to patients about the vaccine? ☐ How easy is it for the patients to understand HPV information? ☐ How do you access the information? Internet /conference/newsletters/other ☐ What other HPV information would you like access to? ☐ Where did you receive your information? ☐ Who provides the information? ☐ Is the information detailed enough to assist you in your clinical practice? ☐ Any aspects confusing or worrisome?	
4. Ethnic background and beliefs regarding vaccinations	**Whether** cultural attitudes and values toward premarital sexual behaviour predict intentions to recommend patients vaccinate pre-adolescent children with HPV vaccine.	**HPV MESSAGES** ☐ Does the HPV vaccine demand different things of you as a GP v demands with younger children? ☐ What does respondent think patients will react when hear that the HPV vaccine is to prevent cervical cancer? ☐ To prevent sexually transmitted infection? ☐ Association of HPV with pap screens? ☐ How do these messages differ? ☐ What message would assist your decision to recommend patients vaccinate pre- adolescent children with HPV vaccine?	
5. HPV and STI – impact	Whether the vaccine might be perceived by parents to endorse early sexual behaviour.	**HPV and STI** ☐ What is your view on the fact that patients lack HPV knowledge v fact HPV is an STI? ☐ In general, how does the knowledge that HPV is an STI make your patients feel? ☐ What might go through their head when they understood this? Impact of diagnosis of an **STI** on patients(if this is understood) ☐ Perceptions of cancer risk ☐ Impact on decision to consent to recommend vaccinating child patient /pre-sexually active child?	

		☐ How does the GP feel about HPV vaccination now (any anxieties, questions or concerns?)	
6. Changes in self-identity, vaccination attitudes and intended behaviour	Whether awareness of HPV and its origins and impact is a significant determinant in intention to recommend to vaccinate pre- adolescent children with HPV vaccine	☐ Has having more knowledge about the HPV vaccination changed the way you think about vaccination to prevent cervical cancer? ☐ Role of Pap screen?	
7. Improvements in community HPV awareness screening in the future.	Whether gender of guardian and child is a significant determinant in intention of doctors to recommend vaccinating pre-adolescent children with HPV vaccine. Is there a gender related attitude toward the gender of recipient? Who receives it? Will the order of receipt impact on the guardian adult attitude? Is there an attitude difference in each age sector [older / younger adolescent or guardian?]	☐ Sort of ways the HPV information process could be improved (and features of HPV /HPV vaccination that would be helpful) ☐ Additional information that would be useful before the vaccine (enough info before decision to participate?). ☐ What info would you want a patient who was going to have the vaccine to be given? ☐ What strategies should be applied to inform GPs of the vaccine? ☐ Inform patients of the vaccine? ☐ Thoughts on the possibility of a national vaccination programme –who? ☐ Where? ☐ What age? ☐ Gender…? ☐ Cost? ☐ If the vaccine program was given at certain ages, what detail of information could be given to each age group: ☐ 9 -10 ☐ 11-12 ☐ 12 -14 ☐ 15+ ☐ If it was a school based information, should the school be involved in giving information?	

8. Closing the interview	☐ Any important issues that haven't been raised, extra comments about HPV, or the HPV vaccines? ☐ How have you found the interview? ☐ **While tape still running**, explain about possible **follow-up questionnaire** ☐ Give help-line number (as some people still have questions) ☐ Have time to chat about other things after the interview Reassure about confidentiality and repeat info provided at the beginning
OTHER ISSUES:	

KEY RESEARCH QUESTION:

The extent to which attitudes and perspectives of adults from diverse cultures [Anglo, Indigenous and Chinese Australian] differ towards intentions to participate in an immunisation program of the human papillomavirus [HPV] vaccine?

- Whether 'national culture' is a significant determinant of difference [if differences are seen to exist] in intention to vaccinate pre-adolescent children with HPV vaccine
- Whether gender of guardian and child is a significant determinant in intention of parents to consent to vaccinate pre-adolescent children with HPV vaccine

- Whether awareness of HPV and its origins and impact is a significant determinant in intention to give consent to vaccinate pre- adolescent children with HPV vaccine
- Whether cultural attitudes and values toward premarital sexual behaviour predict intentions to vaccinate pre- adolescent children with HPV vaccine

SUB QUESTIONS

- Is the information giver [e.g. GP /school] important?
- What is the level of awareness about the aetiology of HPV, and its association with abnormal pap smears and cervical cancer?
- What is the level of knowledge toward the risk factors of cervical cancer?
- What is the attitude toward the usefulness of preventative vaccines?
- Is there a culturally related difference toward the acceptability of the HPV vaccine for pre-sexually active /sexually active adolescents?
- Is there a gender related attitude toward the gender of recipient? Who receives it? Will the order of receipt impact on the guardian adult attitude?
- Is there an attitude difference in each age sector [older / younger adolescent or guardian?]
- What type of information would inform a positive or negative choice toward immunisation? Medical (anti-cancer) versus sexual model?
- What detail and source of information [govt v public service v community] would assist their choice?
- What is their primary information source: radio, TV + cable TV, internet, newsprint -daily paper, magazine, school newsletter, word of mouth,
- Whether the vaccine might be perceived by parents to endorse early sexual behaviour.

Appendix 19: Consent Form – Central Australian Aboriginal Participants

THE UNIVERSITY OF MELBOURNE

The Cervical Cancer (HPV) vaccine project 2007

Central Australian Aboriginal community group discussion

Guidelines for Aboriginal Health Workers and Discussion Group leaders

ABORIGINAL HEALTH WORKER PARTICIPATION CONSENT FORM

Please read, sign and date this form. You will be given a copy of the form to keep for your records. You will be asked to give the form to the project researcher when you meet to discuss the opinions from your group discussion.

I / We (AHW name/s) (1).....(2).....have explained the cervical cancer vaccine project with parents and carers from ..... (Region).

The parents and carers have verbally given their consent to take part in the research project.

I / We have explained the study to the parents and carers in my group, and I / we believe:

- The parents and carers understand their involvement in the project and group discussion and that they will have an opportunity to ask questions during the group discussion
- They understand that the AHW has agreed not to reveal the identity of parents participating in the group discussion
- They understand that the AHW will be discussing the general opinions from the group discussion with the University of Melbourne researcher but no names will be given as to who said what.
- They understand a copy of the report from the Aboriginal community discussion will be given to the AHW and made available to the community after the opinions have been analysed and written in the report

AHW SIGNATURE / S: **1**..... **Date**

2.....

Note: The date must be written when you have signed your signature.

Appendix 19.1: Consent Form - Victorian Aboriginal Participants

Victorian Aboriginal Community
Research participant statement: AHWs

THE UNIVERSITY OF MELBOURNE

Project: "What do people in the Victorian Aboriginal community think about the vaccine that is going to be given to children to prevent cancer of the cervix?"

I (name).....

voluntarily consent to take part in the above titled research project, explained to me by the researcher Margaret Heffernan.

- I understand my involvement in the project and group discussion
- I have had an opportunity to ask questions and I am satisfied with the answers I have received
- I understand that the researcher has agreed not to reveal results of any information involving me
- I understand that the researcher will not reveal my identity
- I understand I will receive a copy of this consent form

SIGNATURE _____ Date _____

I have explained the study to the participant who has signed above, and believe that they understand the purpose, extent and possible effects of their involvement in this study.

RESEARCHER SIGNATURE _____ Date _____

AHW Info Consent 18 7 2006

Appendix 19.2: Consent Form – Release of Data (Aboriginal Participants)

THE UNIVERSITY OF MELBOURNE

The Cervical Cancer (HPV) vaccine project 2007

Central Australia Aboriginal community group discussion

CONSENT FORM TO RELEASE OPINIONS FOR PUBLICATION

(APP 20)

This form is your agreement to give Margaret Heffernan (HPV vaccine researcher with the University of Melbourne) permission to use the report from the discussion held in your community with Aboriginal parents about the HPV vaccine.
By signing this form you have agreed that the report is an accurate representation of the opinions that were given.
The details of your community will be kept strictly confidential. You will be given a copy of the form to keep for your records. Please read, sign and date this form.
Return the form to: Margaret Heffernan, PO Box 262, Albert Park 3206, Victoria.

I / We (AHW name/s) (1)..... (2).....

(3.....) have read the report from the community discussion for the HPV vaccine project with Aboriginal Health Workers, parents and carers from ..... (Region).

- I / We agree that the report is an accurate reflection of the general opinions given during the group discussion about the HPV vaccine.
- I / We have been given a copy of the report from the Aboriginal community discussion and will make it available to the community.
- I /We understand these opinions will be analysed and written in the final report which will include the opinions from all Aboriginal communities.

AHW SIGNATURE / S: 1..... Date .....

2..... Date .....

3..... Date .....

(Note: The date must be written on the day you signed your signature)

CA REPORT CONSENT FORM 1 of 1 16 5 2007

Appendix 20: Anglo and Chinese Parent Consent Form

THE UNIVERSITY OF MELBOURNE

STANDARD PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Project Title: "Human papillomavirus vaccine and Australian community intentions to vaccinate pre-adolescent children"

Investigators: Margaret Heffernan, Professor Suzanne Garland, Dr Kirsten McCaffery, Professor Susan Sawyer, Professor Michael Quinn

Thank you for taking the time to read this Information Statement.
This information statement and consent is **6** pages long. Please make sure you have all the pages.

For people who speak languages other than English:
If you would also like information about the research and the Consent Form in your language, please ask the person explaining this project to you.

You are invited to participate in a Research Project that is explained below.

What is an Information Statement?

These pages contain information about a research project we are inviting you to take part in. The purpose of this information is to explain to you clearly and openly all the steps and procedures of this project. The information is to help you to decide whether or not you would like to take part in the research.

Please read this information carefully. You can ask us questions about anything in it. You may also wish to talk about the project with your parents or guardians, friends or health care worker. Once you have understood what the project is about, if you wish to take part please sign the consent form at the end of this information statement. You will be given a copy of this information and consent form to keep

What is the Research Project about?
This project is to find out what parents think about giving the new HPV vaccine to children, to prevent cancer of the cervix.

The HPV vaccine is now available and it is important that doctors and other health providers understand how the community will respond to it. The research project will also help plan the educational messages so the community is aware of the benefits of the vaccination and help make their decision in giving consent to have their child vaccinated.

This part of the research project is Stage 1 of a larger study. In Stage 1, we will interview forty [40] parents from Anglo, Indigenous and Chinese culture backgrounds in Victoria and Central Australia; and 10 General Practitioners and Aboriginal Health Workers from Victoria to find out their views about the HPV vaccine. The information from these interviews will be analysed, compiled in a report, and used to help develop Stage 2 of the project - a quantitative questionnaire survey which will be developed and piloted in Victoria.

We are asking you to participate in Stage 1.

Who are the Researchers?
Margaret Heffernan is a PhD student at the Department of Paediatrics at RCH. This project is part of Margaret's doctorate at the University of Melbourne. Margaret is supervised by:
(1) Professor Suzanne Garland of the University of Melbourne who is a specialist doctor in microbiology and has been researching the Human papillomavirus for over twenty years
(2) Dr. Kirsten McCaffery from the University of Sydney is a researcher who studies the community's feelings and attitudes toward Human papillomavirus
(3) Professor Susan Sawyer is a Paediatrician and Head of Adolescent Health at the Royal Children's Hospital in Melbourne
4) Professor Michael Quinn from the Royal Women's Hospital in Melbourne is a gynaecological cancer specialist and researches the association between human papillomavirus and cancer.

Why am I being asked to be in this research project?
We are asking parents of Anglo background who are prepared to be interviewed about their understanding of what causes cancer of the cervix and about a vaccine that might prevent cervical cancer. You were selected when you responded to an invitation to participate. By confirming your participation with Margaret Heffernan you have indicated you might be interested in giving your opinion in an interview.

What are the alternatives to participating in this project?
You do not have to be in this research project if you don't want to. It is of a volunteer nature. If you agree to participate, you may withdraw your consent at any time without giving a reason. You can also ask to withdraw any interview information before it is analysed.

What do I need to do to be in this research project?

Please think about the study and fill in the contact details in the attached slip. If you agree to be contacted, Margaret will contact you to give you more information about the interview. She will be able to answer any questions that you have and you can tell her whether or not you wish to take part.

Margaret will send you details about the interview. You will be interviewed by yourself – there will be no one else other than Margaret Heffernan at the interview. You can choose the place and time where you would like the interview to take place. The interview will ask about your opinion on health matters and giving children vaccinations as well as specific questions on the HPV vaccine that will prevent cancer of the cervix. It will take about an hour (60 minutes) of your time and will be audio recorded (voice recorded) if you agree.

A copy of the final report will be available at the end of the study.

Is there likely to be a benefit to me?

There is no direct benefit to you but you may feel good about giving your opinion that will help research that might help other medical practitioners in advising patients about the HPV vaccine.

Is there likely to be a benefit to other people in the future?
The new vaccine will help prevent cancer of the cervix. This research project will help us understand the best way to inform and educate the community about the HPV vaccine and its benefits. It will help us provide important information to General Practitioners, parent, guardians, and adolescents to help them decide about their child getting the new vaccine.

What are the possible risks and/or side-effects?
There are no risks or side effects from participating in this project.

What are the possible discomforts and/or inconveniences?
The interview will take an hour of your time. Margaret will make it at a time that suits you and can interview you in a place of your choice if that is more convenient for you.

The interview will ask your views about health matters including vaccinations. Some questions will focus on how some infections are caused by sexual intercourse. You may find some questions sensitive. You will not have to answer any questions you feel uncomfortable with. If you agree, the interview will be audio [voice] recorded. You can ask the recorder to be stopped at any time and may change or withdraw information if you are not happy with it. You will be able to ask as many questions as you like.

Margaret Heffernan, who will be interviewing you, will provide a telephone contact number at the end of the interview should you wish to discuss any issues later.

What will be done to make sure the information is confidential?

The transcript of the interview and audiotape will be identified by a study number and not by your name.

Access to the data is restricted to researcher and supervisors. The audiotapes and the transcripts and will be kept in a locked filing cabinet, unless subjected to legal requirements, for seven years from the date of publication, as prescribed by University of Melbourne and NHMRC regulations, and then destroyed. Results may be discussed or published at conferences, in professional journals but participants will not be identified

Will I be informed of the results when the research project is finished?

In general, a meaningful summary will be made available to participants at the end of the study, if you want to receive it.

The summary will give results for the whole group of people who were interviewed and not give individual information.

If you wish to receive the summary of the interview you need to contact Margaret Heffernan .It will take at least four months to analyse all the interview results.

You can decide whether or not to take part in this research project. You can decide whether or not you would like to withdraw at any time without explanation.

You may like to discuss participation in this research project with family and friends. You can ask for further information before deciding to take part.

If you would like more information about the study or if you need to contact a study representative in an emergency, the person to contact is:

Name: Margaret Heffernan, PHD student
PO Box 262, Albert Park 3206

Contact telephone: Tel: 03 9344 3686 [w] 0419 339 724 [mobile]

What are my rights as a participant?

1. I am informed that except where stated above, no information regarding my medical history will be released. This is subject to legal requirements.

2. I am informed that the results of any tests involving me will not be published so as to reveal my identity. This is subject to legal requirements.

3. The detail of the procedure proposed has also been explained to me. This includes how long it will take, how often the procedure will be performed and whether any discomfort will result.

4. It has also been explained that my involvement in the research may not be of any benefit to me personally. I understand that the purpose of this research project is to improve the quality of medical care in the future.

5. I have been asked if I would like to have a family member or a friend with me while the project is explained to me.

6. I understand that this project follows the guidelines of the National Statement on Ethical Conduct in Research Involving Humans (1999).

7. I understand that this research project has been approved by the University of Melbourne and the Royal Women's Hospital Ethics in Human Research Committee on behalf of the Royal Women's Hospital Board.

8. I have received a copy of this document.

If you have any concerns about the study, and would like to speak to someone independent of the study, please contact the Executive Officer of the Human Research Ethics Committee of the University of Melbourne on (phone) 03 8344 7507 (Monday to Friday 9am-5pm).

STANDARD INFORMED CONSENT
FOR PARTICIPANT TO PARTICIPATE IN A RESEARCH PROJECT

Title of Project

Project Title:	"Human papillomavirus vaccine and Australian community intentions to vaccinate Pre-adolescent children"

Principal Investigator(s)

MARGARET HEFFERNAN [PhD student]
SUPERVISORS (1) PROF SUZANNE GARLAND (2) DR. KIRSTEN McCAFFERY
(3) PROF SUSAN SAWYER (4) PROF MICHAEL QUINN

I (Participant name) _____

voluntarily consent to take part in the above titled Research Project, explained to me by

Margaret Heffernan

- I have received a Participant Information Statement to keep and I believe I understand the purpose, extent and possible effects of my involvement
- I have been asked if I would like to have a colleague with me while the project was explained
- I have had an opportunity to ask questions and I am satisfied with the answers I have received
- I understand that the researcher has agreed not to reveal results of any information involving me, subject to legal requirements
- If information about this project is published or presented in any public form, I understand that the researcher will not reveal my identity
- I understand that if I refuse to consent, or if I withdraw from the study at any time without explanation, this will not affect me.
- I understand I will receive a copy of this consent form

SIGNATURE _____ Date _____

I have explained the study to the participant who has signed above, and believe that they understand the purpose, extent and possible effects of their involvement in this study.

RESEARCHER'S SIGNATURE _____ Date _____

Note: All parties signing the Consent Form must date their own signature.

This page has some important general information about taking part in research studies approved by the University of Melbourne. Details about this study are on the Information Sheet/Letter.

Your rights as a Participant are:

1. To choose to take part or not to take part
2. To withdraw from the study at any time
3. To have the study fully explained to you

You should feel free to ask the researchers any questions about the study.

Other information you should know about being part of this study

1. Your answers to the questions on this study will be kept private. This is subject to legal requirements.
2. No information from this study will reveal your identity
3. You should have been told what you need to do for this study, and how long it will take.
4. If you do not wish to take part in this study, this will not affect your relationship with the University of Melbourne
5. This research project has been approved by the University of Melbourne Human Research Ethics Committee.

If you have any concerns about the study, and would like to speak to someone independent of the study, please contact the Executive Officer of the Human Research Ethics Committee of the University of Melbourne on (phone) 03 8344 7507 (Monday to Friday 9am-5pm).

If you would like more information about the study or if you have any questions about the study, the person to contact is:

Name: **MARGARET HEFFERNAN**

Contact telephone: **03 9344 3686 [w] , 0419 339 724 [mob]**

Appendix 21: Personal Details Anglo and Chinese Participants

Project: **What do people think about giving a vaccine to children, to help prevent cancer of the cervix?**

AGREEMENT TO BE CONTACTED

Thank you for indicating you are willing to be interviewed about the HPV vaccine project. Please complete this form and post to the researcher, Margaret Heffernan in the attached stamped envelope (PO Box 262, Albert Park, Victoria 3206)

PLEASE NOTE: Giving your details at this stage will not put you under any obligation to participate in the research. ALL DETAILS WILL BE KEPT STRICTLY CONFIDENTIAL.

I agree to be interviewed about the cancer of the cervix vaccine research project YES / NO

MY NAME IS: (please print) Mrs. Mr. Ms. Miss

.....

My telephone number is: Day.....Evening.....

My post address is .....

I prefer to be contacted by (please circle) TELEPHONE / POST

If telephone: What time of day is most suitable to call?

.....

I prefer to be interviewed on (date)..... (time)..... at

(location – if you do not wish to be interviewed at a place of your choice, paid travel will be provided for interviewing at the Centre for Adolescent Health Parkville.)

.....

Finally, a few questions about you to help us with our study: Your details will be kept strictly confidential and not used in the report or disclosed to anyone else.

What is your year of birth? 19.....

What is your marital status? (Please circle)

Married /living with partner single divorced separated widowed

Do you have children? YES / NO

If Yes: How many? ..... Gender: MALE / FEMALE

Age/s.....

Have your children been vaccinated? YES / NO

Who makes the decision regarding child vaccination? Mother Father Both parents Other.....

Highest level of education completed..... ...

What is your cultural background? ....

INTERVIEW CONTACT AGREEMENT 13 12 06

Appendix 22: Victorian Aboriginal Health Worker Recruitment Poster



PapScreen Victoria

Well Women's

Health Training Day

An information day for Aboriginal health workers to learn more about Pap tests, the Human Papilloma Virus (HPV) and the cervical cancer vaccine

This is your chance to sit in a relaxed atmosphere and listen to the facts about women's health issues and a chance to ask questions that women are often too embarrassed to ask.

The session covers:

- Why it is important to have regular Pap tests
- What is HPV and how is it involved in cervical cancer?
- What is the cervical cancer vaccine?

Guest speaker:

Dr Stella Heley, Liaison Physician, Victorian Cytology Service

Date:

Thursday 8 March 2007

Time:

9.30am – 3.00pm

Place:

Victorian Aboriginal Community Controlled Health Organisation (VACCHO), 5–7 Smith Street, Fitzroy
Lunch will be provided

How can we help you to attend?

If your workplace is located outside Melbourne, we are able to reimburse your travel expenses at a rate of:
$100 for travelling between 80 and 249kms to Melbourne
$120 for travelling more than 250kms to Melbourne
$120 for travelling more than 300kms to Melbourne plus one night accommodation

Enquiries:

Peta Reynolds, PapScreen Victoria
Phone: 9635 5316
Email: Peta.Reynolds@cancervic.org.au

RSVP:

By Friday 1 March 2007 to Kaye Cromie
Phone: 9635 5148
Email: Kaye.Cromie@cancervic.org.au
Fax: 9635 5360

Name: Organisation:

Address:

Suburb/Town/City: Postcode:

Phone: Mobile: Fax:

I will be claiming for travel reimbursement: Yes / No *(if yes, please tick one of the boxes)*

- ☐ $100 for travelling between 80 and 249kms to Melbourne
- ☐ $120 for travelling more than 250kms to Melbourne
- ☐ $120 for travelling more than 300kms to Melbourne plus one night accommodation *(we will contact you to arrange the accommodation)*



Appendix 23: Chinese Fact Sheet

預防您的女兒罹患子宮頸癌

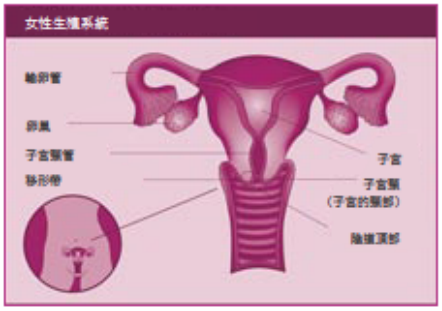
國家HPV疫苗接種計劃

何謂子宮頸癌？

子宮頸癌（子宮頸的癌症*）是子宮頸*內長出異常細胞的一種疾病。這種癌症可能會蔓延到全身。

由於巴氏子宮頸癌篩檢法（Pap smears）（國家子宮頸篩檢計劃）（National Cervical Screening Program）實施成功的緣故，子宮頸癌在澳洲並不常見。然而，澳洲每年有兩百多名婦女死於子宮頸癌。

最近開發出來的一種疫苗亦可預防子宮頸癌。



*子宮頸是女性生殖系統的一部份，位於陰道和子宮之間。

子宮頸癌的成因為何？

帶有特定類型人類乳頭瘤病毒（HPV）的生殖器感染會引起子宮頸細胞變化，這些子宮頸細胞變化則可能導致子宮頸癌。這通常需10年以上的時間才會形成。

大部份患有HPV的婦女，病毒會慢慢自然清除，而不會形成子宮頸癌。

何謂 HPV（人類乳頭瘤病毒）？

人類乳頭瘤病毒（HPV）是一群造成皮膚疣、生殖器疣和某些癌症的病毒名稱。

許多不同類型的HPV可能會影響身體的不同部位。其中有些類型可能會感染生殖器部位。身體其他部位的疣，像是手部的疣，便是由不同的HPV類型所造成。

可能造成生殖器疣或子宮頸癌的HPV類型，可能會在與帶有病毒的人從事各種類型的性活動期間，經由直接的皮膚對皮膚接觸而傳播。

任何不曾有過性接觸的人也可能會感染HPV－每五個人中有四個人曾在他們一生中的某個時候感染生殖器HPV，這是常見的事。 大部份生殖器HPV感染並不會引起任何症狀，而且人們並不知道他們已經感染。

HPV感染能夠治療嗎？

不能。只有病毒感染，像是子宮頸和生殖器疣內細胞的異常變化才能治療。

切勿將人類乳頭瘤病毒（HPV）和人類免疫不全病毒（HIV）或肝炎病毒搞混，因為它們是不同的感染。

HPV感染能夠預防嗎？

是的。澳洲有一種稱為GARDASIL®的HPV 疫苗可預防四種HPV類型的感染。其中兩種類型會使10個人中的7個人產生子宮頸癌。其他兩種類型則會使10個人中的9個人產生生殖器疣。

若您的女兒已經有過性接觸，那麼她可能已經感染某些HPV類型。若她已經感染這四種HPV類型中的任何一種，她在接種疫苗後，對子宮頸癌及/或生殖器疣的預防效果可能會降低。

對於不在HPV疫苗預防之列的其他HPV類型，HPV疫苗恐無法預防女性罹患這些類型所引起的子宮頸癌和生殖器疣。

定期巴氏子宮頸癌篩檢依然很重要，因為HPV疫苗並不能預防所有子宮頸癌。

為何我的女兒應該在這個年紀接種疫苗？

女性在可能暴露於HPV的危險之前，也就是說，在她們開始性接觸之前接種HPV疫苗，效果最好。

若我的女兒已有過性接觸，她應該接種疫苗嗎？

是的。若她已經和某人有過性接觸，您應該還是要考慮讓她接種疫苗。您女兒的性史將不會被詢及。

接種疫苗對性活躍的年輕婦女有益，因為她們的性伴侶可能較少，而且暴露於HPV的風險較低。

如果她已經有過性接觸， 還是可以從疫苗獲得好處，因為她不可能曾經感染過造成子宮頸癌的兩種HPV類型，以及可能造成生殖器疣的兩種HPV類型，而這些病毒都在疫苗預防的範圍中。

免疫

Traditional Chinese / 繁體中文

www.australia.gov.au/cervicalcancer

Australian Government

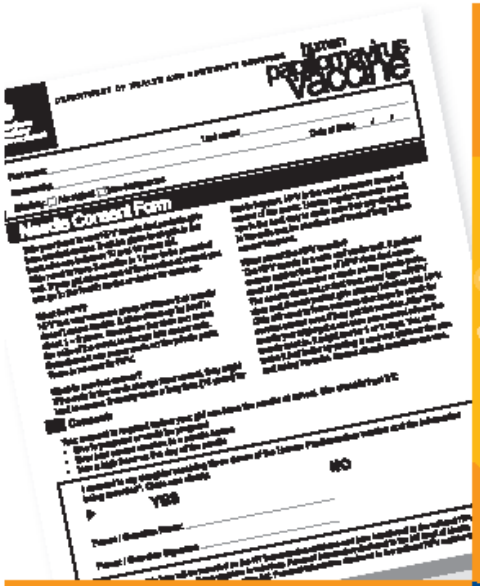
Appendix 24: Government HPV advertisement – Aboriginal people

Advertisement



Authorised by the Australian Government, Capital Hill, Canberra

Appendix 25: Northern Territory Government 'Top End' Brochure



You may need to sign a consent form for your child to have the HPV needle at school. But in most communities visit the clinic for the HPV needle.

Your name will be kept on a list so that the health mob knows you have had the needle and to remind you when you need the next one. This information will also be sent to the Commonwealth Government. Your name will be kept private.

To find out more talk to the health mob at your clinic.

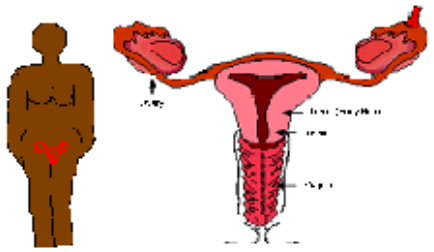


Appendix 26: Central Australian HPV vaccine brochure

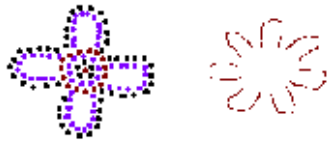
WHAT IS HUMAN PAPILLOMAVIRUS (HPV)?

HPV is a group of viruses. Some of these can affect women's parts, causing genital warts and changes in the **cervix**. This is why we have Pap Smears (women's checks). You can get HPV by skin contact of the private parts during sexual activity. HPV is so common that 4 in 5 people will have it at some stage.

HPV usually goes away by itself, but sometimes it can grow into cancer. If the cancer is not found and treated women will get sick and might die from it.



After years of study and meetings they have made a vaccine (needle) to protect girls from the types of HPV (virus) that cause most cervical cancer. This will be given to girls aged 10-26.



GETTING THE VACCINE (NEEDLE)



For your girls to be safe/protected they need 3 needles at different times in the year



Afterwards they may have a sore arm, but this should go away in 1-2 days.
Girls should not get this vaccine if they are pregnant or have had a bad reaction to another needle.

Studies have shown it is 9 times more likely for indigenous women to have cervical cancer than other women in Australia.

The HPV needle protects against most **but not all HPV viruses** that can cause Cervical Cancer.



PREVENTING CERVICAL CANCER

All women aged 18 to 69 who have ever had sex, should have regular Pap smears (women's check), whether they have had the needle or not. The needle and Pap smears are both needed for stopping cervical cancer.
So the girls will still need to keep having regular Pap smears when they are older just like their mothers and grandmothers.

As more girls have the HPV vaccine (needle), less women will have to have treatment such as operations and less women will die from Cervical Cancer.

You may need to sign a form to give your permission for your child to have the needle, if they are having it at school. Depending on individual communities. Otherwise visit your local health centre for the needle.



Your name will be kept on a list so that the health centre nurse/health worker knows you have had the needle and to remind you when you need the next one. This information will also be sent to the Commonwealth Government. Your name will be kept private.

To find out more you can talk to the nurse/ health worker at your local health centre.

Northern Territory Government

Department of Health and Community Services

Centre for Disease Control

Darwin	**8922 8044**
Katherine	**8973 9049**
Barkly	**8962 4259**
Alice Springs	**8951 6907**
East Arnhem	**8987 0357**

CERVICAL CANCER VACCINE

Human Papillomavirus (HPV)

This pamphlet includes information and pictures about *Women's business*.



Appendix 27: Summary of key factors for parental acceptance of HPV vaccines

FACTOR: BIOMEDICAL	Aboriginal: CA	Aboriginal: Vic	Anglo	Chinese
Vaccine safety	L	L	L	L
Vaccine efficacy	L	L	L	L
Medical contraindications	M	H	L	M
HPV type specificity -bivalent	H	H	M	M -H
HPV type specificity -quadrivalent	M	H	M -H	H
Natural immunity	M	L	H	H
FACTOR: STRUCTURAL & ENVIRONMENTAL				
Access and availability of the vaccines: schools	L – M	L – M	H	M -H
Cost (if not subsidised)	L	L	M-H	M-H
Cues to action	H	L -M	M -H	H
Dosage schedule compliance	L	L -M	M-L	H
Trust of Government and health agencies	L	L	M -H	H
FACTORS: PSYCHOSOCIAL factors				
Knowledge levels of HPV	L	L	L	L
Perceived susceptibility and risk	H	H	M-H	L -M
Perceived severity (cancer)	M	M-H	H	L
Perceived severity (STI risk)	H	H	M-H	L
Perceived benefits	H	M-H	M-H	H
Perceived pain of vaccines by adolescents	H	H	H	H
Normative values: STI vaccines & promiscuity	L	L - M	L -M	L
Normative values: vaccination	H	M- H	M-H	H
Protect daughter's health	H	H	H	H
Protect son's health	L - M	M	L - M	L -M
Parental responsibility and level of control	H	H	H	H
Parent's personal experience of STIs	U	U	M	L
Religious beliefs	U	U	M	H
Acculturation	NA	NA	NA	H
Age for vaccination*	9	12	12 -14	16 -18

Key: H: High acceptance M: Moderate acceptance L: Low acceptance U: Unknown NA: Not applicable

*Age for vaccination varied in the Anglo and Chinese samples. These are the general majority views.

Appendix 28: Central Australian HPV Vaccine Radio Advertisements

SCRIPT: HPV Vaccine Radio Advertisements

Translate into 5 local Indigenous languages
Broadcast on CAAMA radio, Alice Springs Central Australia
Commencing 2007 at the implementation of the National HPV Vaccine program

Script

Did you know there's a vaccine that helps prevent cervical cancer. And the great thing is it's free for girls and women aged 12 to 26.

The vaccine involves three injections over six months and must be completed by June 2009. So you need to start soon.

If you have missed a dose or want to start visit your local health centre or clinic. For further information contact the Centre for Disease Control on 89517549. Authorized by the Northern Territory Government Darwin,

Spoken by: