University Library



A gateway to Melbourne's research publications

Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:
Dimopoulos-Bick, T;Dawda, P;Maher, L;Palmer, V

Title:
Experience-Based Co-Design: Tackling common challenges

Date:
2018-03-22

Citation:
Dimopoulos-Bick, T., Dawda, P., Maher, L. & Palmer, V. (2018). Experience-Based Co-Design: Tackling common challenges. The Journal of Health Design, 3 (1), pp.86-93. https://doi.org/10.21853/JHD.2018.46.

Persistent Link:
https://hdl.handle.net/11343/208927

License:
Unknown

The Journal of Health Design

CASE STUDY

Experience-Based Co-Design: Tackling common challenges

Tara Dimopoulos-Bick[1], Paresh Dawda[1], Lynne Maher[2], Raj Verma[1], Victoria Palmer[3]

1. NSW Agency for Clinical Innovation, NSW Health, Sydney, NSW, Australia
2. Ko Awatea Counties Manukau Health, Auckland, New Zealand
3. The Department of General Practice, The Melbourne Medical School, The University of Melbourne, Melbourne, VIC, Australia

To Cite: Dimopoulos-Bick T. Dawda P, Maher L, Verma R, Palmer V. Experience-Based Co-Design: Tackling common challenges. JHD. 2018;3(1):86–93. https://doi.org/10.21853/JHD.2018.46

Corresponding Author:
Tara Dimopoulos-Bick
NSW Agency for Clinical Innovation
Sydney, NSW, Australia
tara.dimopoulosbick@health.nsw.gov.au

SUMMARY

There has been a surge in experience-based co-design (EBCD) efforts for quality improvement in health care and systems design globally. Service users together with staff are playing a far greater role than ever before in the redesign of services and systems of care. EBCD offers a systematic, bottom-up approach to improving service user and staff experiences of care. There is growing interest in the application and potential of EBCD; however, studies indicate common shared challenges, which coalesce around power, commitment to the process, methods for gathering experiences, designing improvements, implementation, and subsequent impact.

Key Words

Experience-based design; co-design; quality improvement; patient experience; health care

ABSTRACT

As an improvement method, experience-based co-design (EBCD) is premised on creating better quality experiences and systems of health care. Distinguishing features of EBCD are the way in which experience is central to the identification of and goals for improvements; and combined with participatory action research and design thinking approaches leading to the co-creation of improvements. Commonly shared challenges from completed EBCD studies include: the need to explore power dynamics; commitment to the process; methods to gather experience data; the design of improvements; and variations in implementation and subsequent impact.

We discuss these challenges in the context of five examples from Australia. We offer a contribution to the international discussion on developing the next level of maturity to build on the acknowledged and agreed importance of collaborating with service users and staff to improve health care.

BACKGROUND

From policy formation and systems design to service development and improvement, service users (an umbrella term adopted to refer to patients, consumers, clients, carers, and families), and staff are participating in ways to enhance the quality of services and experiences in health care. One method that has gained popularity is experience-based co-design (EBCD), which can be understood within the broader field of co-production. Co-production has been defined as the "voluntary and involuntary involvement of service users in any of the design, management, delivery and/or evaluation of public services".[1] Co-production is spread across operational, strategic, and service levels, on a continuum encompassing service user co-production, participative co-production, and enhanced co-production.[1]

The EBCD method combines a user-centred orientation ("experience-based") and collaborative change processes ("co-design") to identify and co-design improvements.[2] A relatively young approach originating in 2006 in the United Kingdom's (UK) National Health Service (NHS), the methodologies underpinning the tradition draw on participatory action research, narrative and learning theory, and design thinking, which are steeped in longer traditions.[2,3] The Point of Care Foundation (PoCF) in the UK has produced one of the longest standing and most widely used toolkit and resources to support the implementation of EBCD.[4] EBCD principles include staff and service users actively working together to make decisions and become responsible for decisions throughout the entire improvement process, including the implementation and evaluation.

Interest in EBCD has increased as co-production has become normative within the participation and involvement agendas of policy and practice for health services. This growing focus on co-production is also linked with greater awareness of the importance of patient experience, which is seen to form one of the high-level elements of the "triple aim", together with improving population health and reducing costs. The triple aim was introduced by the US-based Institute for Healthcare Improvement. It is defined as an approach to optimise health system performance; and many organisations are extending it to the "quadruple aim" to include staff and provider experience.[5]

The Beryl Institute's *State of Patient Experience 2017: A Return to Purpose* benchmarking study found 82 per cent of 1,644 respondents identified patient experience as a key priority. The Beryl Institute defined patient experience as the "sum of all interactions shared by an organisation's culture that influence patient perceptions across the continuum of care".[6] Perception of the continuum of care within an organisation is one element of patient experience and evidence is mounting that experience is more than a measure of satisfaction.[6,7] Other dimensions are important beyond perception, which include the quality of interactions, improved treatments, care processes, and increased health outcomes. A small evidence base indicates better patient experience may be associated with improved outcomes in clinical effectiveness and safety.[8] In Australia, the National Safety and Quality Health Service (NSQHS) Partnering with Consumers Standard is a formal structure and accountability mechanism for involving service users in designing quality healthcare improvement. This standard favours health services, experiences, and improving outcomes by drawing on the knowledge, skills, and lived experiences of service users.[9]

In this paper, we explore challenges that have emerged in the past 10 years of EBCD's history and compare them with experiences in Australia, where EBCD adoption is at a much earlier stage.[10,11] In Australia, EBCD is occurring largely without dedicated resourcing and mostly as local service improvement initiatives. The case examples presented draw attention to five commonly shared challenges identified in previously published evaluations of EBCD projects.[10,11] These challenges coalesce around power; commitment to the process; methods for gathering experiences; designing improvements; and implementation and subsequent impact. Future progress to embed service users in re-design efforts depends on the extent to which these critical and common challenges can be addressed, and on EBCD being systematically integrated into quality improvement practices and efforts. This case study examination raises the question of where responsibility lies for addressing these challenges.

METHOD

This paper draws on the expertise of the authors' knowledge of the EBCD method and experience of its application in Australia. Four components have been extensive inputs for this paper:

1. PD completed a rapid search and review of existing publications, including grey literature to identify the use of EBCD in Australia. PubMed and Google Scholar were searched to identify current EBCD projects in Australia and a grey literature search was conducted using Google. Search terms included "co-design", "experience-based co-design", "co-creation", and "co-production". Limits applied to the search criteria included English language and the articles published in the last 15 years. Secondary sources included a scan of hashtag activity on the social media platforms Twitter and LinkedIn. In July 2017, a generalised hashtag search using #EBCD was completed and limited to two years. The focus was to identify case studies for the toolkit. These search terms and limits were a pragmatic agreement with the Australian Healthcare and Hospitals and Consumers Health Forum of Australia (the commissioners). The materials were used to produce the Australian Healthcare & Hospitals Association's "Experience-Based Co-Design – a Toolkit for Australia". LM provided expert review of this toolkit.[4,10,12]

2. TD and RV have been leading the application of EBCD in health provider organisations in New South Wales (NSW) with expert facilitation and feedback from LM and VP. RV led the first pilot of EBCD in emergency departments in NSW Health.

3. VP led the world first cluster randomised controlled trial of an EBCD adapted method called Mental Health Experience Co-Design (MH ECO) using a

stepped wedge design for people living with severe mental illness, carers and staff.[13]

4. LM has led the application of EBCD in 28 initiatives in five different health organisations in Australia.

On the background of the combination of these four components, this paper synthesises five case examples to conduct an exploration of common challenges to applying EBCD.

RESULTS

As identified earlier, existing studies of EBCD[10,11] have identified that power, commitment to the process, methods for gathering experiences, designing improvements, and implementation and impact are critical challenges. Table 1 provides an overview of five case examples, which contextualise the challenges for implementing EBCD in Australia. The table presents the significant differences and similarities between the case examples in terms of involvement of service users, which are reflected upon below.

Power

Each case example raises the repeated theme of power as a challenge for undertaking co-design. The collaborative nature of EBCD seeks to foster an environment where all people have the opportunity for an equal say. Service users are generally taking part in co-design following vulnerable experiences either as patients receiving treatment or living with an illness or disability in their everyday worlds. To suggest that equality exists without acknowledging the contested power relations may generate unintended consequences. The implementation of EBCD creates the opportunity and foundations for disruption of the traditional power arrangements by enabling a voice for people to take part in the conversation.

EBCD ideally challenges core beliefs about decision-making at all stages of the improvement journey, but cases show room for development. Service users and staff can find it difficult to reconfigure relationships and the balance of power. While staff see the benefits of involving service users in improvement efforts as shown in our case examples, the transition to sharing control is difficult. Retaining control of decision-making is often unconscious, ingrained, and reinforced through existing processes and hierarchies.

Commitment to the Processes

EBCD requires psychological and physical commitment to work in a different way. A challenge highlighted across the case examples is building the right mindset for EBCD and keeping service users and staff engaged in and supportive of the design process. A lack of dedicated time and resources makes it difficult for service users and staff to invest in EBCD. Resource-limited settings create the expectation for quality improvement based on speed and cost-effectiveness, which can overlook experience. Staff can also find it challenging to "loosen" the application of strict project management methods that rely on tight scope, deliverables, and timelines. If we do not address these challenges, the natural consequence could impact implementation and sustainability.

Another challenge for service users is the need to balance their intrinsic motivation to improve health care with the demands of their life. This balance can become more difficult when service users' time is often expected to be voluntary rather than a form of recognition or payment. Service users can be less likely to participate in learning activities, which can impact their ability to participate in EBCD with equal voice, decision-making, and responsibility. Recognition of participation has been articulated in the literature as the principle of reciprocity, meaning people get something back for putting something in. Recognition can be through using formal methods and sometimes can also be met by achieving equal relationships between service users and the organisation.[14] Finding ways where service users can play a greater role in driving the implementation effort is also important.

Balancing clinical workload with quality improvement efforts, as demonstrated in the NSW Health Emergency Department case example illustrated in Table 1, is also difficult. There can be limited capacity to support ongoing engagement with service users over a prolonged period of time. An inability to support ongoing engagement can be amplified when staff are unable to invest resources to actively maintain engagement, including regular and personalised communication; equitable access to information and resources; flexibility and choice in engagement activities; and access interactive technologies.

Involving sponsors and decision-makers in EBCD is challenging and essential for the success and ongoing sustainability of the improvement that is undertaken within co-design processes. Often the assumption is that organisations understand the principles and practices of the EBCD method. The philosophical shift that is required can be underestimated as the case examples show. A lack of experience, knowledge, and skills in EBCD (seen in the Northern Health cases) can impact organisational ability to champion, support, and be accountable to the process and outcomes.

Methods for Gathering Experiences

A challenge in EBCD is bringing together experiences and perceptions of health care through narrative and stories. A number of techniques can be used to gather experiences; however, staff can often default to using traditional quantitative methods (such as surveys), which can limit the real depth of understanding in the experience of how it feels to deliver or receive care. The Western Health example in Table 1 illustrates that engagement with the emotional dimension of EBCD is challenging for service users particularly in the use of trigger films.

A strength of EBCD is the flexibility to use a range of tools and techniques to best meet the needs and preferences for different groups. For example, engaging with young people in local community settings; using yarning circles to understand the stories of Aboriginal and Torres Strait Islander people and communities; and choosing methods other than non-participant observation in mental health settings, where observation could be interpreted by some as being under surveillance. However, this flexible and adaptable approach carries with it a risk that key stages are omitted, as illustrated in the case examples. A 2014 review of EBCD studies internationally found that key tools were underutilised and insufficient attention was paid to key components that lead to effective co-design. [10,11]

Another challenge is that often experiences are gathered but not interpreted or contextualised collaboratively. This is a risk in EBCD, which can lead to misinterpretation or misunderstanding of the experiences shared by service users and staff. A general misunderstanding of EBCD can have an impact on feasibility, acceptance, and effectiveness of the method. In the NSW Agency for Clinical Innovation case example described in Table 1, staff were concluding the initiative after gathering experiences with no expectation that improvements would be co-designed or implemented with service users.

Designing Improvements

Despite the increasing use of EBCD, a common challenge is the lack of follow through with an authentic collaborative co-design approach. Staff find it difficult to progress from gathering experiences to designing the why, what, and how of the improvement with service users. Some service users have never been involved in any sort of improvement activity before and do not understand the terminology used or the role they can play. The frequent use of health service terminology, including acronyms, can also be baffling for service users.

Reframing the problem by looking at it from different perspectives can be challenging for staff. Often staff can see opportunities for improvement after gathering experiences. There is a temptation to prematurely jump straight into implementing an improvement, rather than following the process and designing improvements together with service users. While it can take more time to ideate and explore all possibilities for improvement, it is an important step in order to use the expertise from both service users and staff to design and implement meaningful improvements in a collaborative and systematic way.

Implementation and Subsequent Impact

Implementation is hard in any context. Often improvements become stuck between ideation and implementation. Limited resources, including time and money, tight processes, and traditional hierarchical decision-making processes impact or even stall implementation efforts. Three of the five case examples presented in Table 1 describe challenges in accessing resources to support implementation of improvements.

Levels of innovation employed within the co-design of improvements varies. The EBCD process can lead to innovation and opportunities for improvement that sit outside the usual paradigm for health services. The element of unknown can be challenging for sponsors and decision-makers, which can impact decision-making and behaviour. A side effect is an unwillingness to support

and resource the improvements, which ultimately affects implementation and impact. Similarly, organisational challenges such as readiness for change, resources, competing priorities, and economic influences impact decisions to cease, modify, or progress implementation of changes and improvements.

DISCUSSION

At the heart of EBCD is a commitment to co-design improvements that can be implemented without losing touch of the connection with "experience". Current EBCD initiatives show variation in this area and to date there is little evidence about the wider impact of experience-based systems (health outcomes, improved experiences, cost, quality, and safety). The challenges highlighted from the existing literature and within our case examples give cause to ask about who takes responsibility for addressing these concerns. Are organisations taking up the co-production challenge? Is co-production really becoming a normative way of doing healthcare improvement? Have we adequately addressed how the health system environment may shape these challenges differently? Are health systems ready for EBCD?

CONCLUSION

Addressing three of the critical challenges could provide a starting point to ensure that EBCD is implemented effectively and subsequently sustained in organisations:

1. Theoretical analysis of barriers and facilitators to using EBCD (including examination of methods for sharing experience data) and application of change interventions based on the systematic evaluation of evidence and theory.

2. Evaluation of EBCD effectiveness to build an evidence base that demonstrates the method leads to quality improvement outcomes. Evaluating effectiveness requires a greater investment in evaluation and research, and a commitment to sharing outcomes internationally. Robust theoretical models also need to be developed to assist in the interpretation and explanation of EBCD impact and outcomes.
3. Build greater understanding and capability to apply EBCD through a multi-agency coordinated approach in Australia. Understanding and capability includes knowledge and skill development through facilitated learning, mentoring, and collaborating through a community of practice to enhance shared practices.

REFERENCES

1. Osborne S, Radnor Z, Strokosch K. Co-Production and the Co-Creation of Value in Public Services: A suitable case for treatment?. Public Management Review. 2016;18(5):639–53.
2. Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Quality and Safety in Health Care. 2006;15(5):307–10.
3. Robert G, Cornwell J. Rethinking policy approaches to measuring and improving patient experience. Journal of Health Services Research & Policy. 2013;18(2):67–9.
4. EBCD: Experience-based co-design toolkit | Point of Care Foundation [Internet]. Point of Care Foundation. 2018 [cited 2018 January 31]. Available from: https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/
5. Bodenheimer T, Sinsky C. From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider. The Annals of Family Medicine. 2014;12(6):573–6.
6. The Beryl Institute – Improving the Patient Experience [Internet]. Theberylinstitute.org. 2017 [cited 2017 December 13]. Available from: http://www.theberylinstitute.org
7. Coulter A, Locock L, Ziebland S, et al. Collecting data on patient experience is not enough: they must be used to improve care. BMJ. 2014;348(mar26 1):g2225-g2225.
8. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open. 2013;3(1):e001570.
9. Australian Commission on Safety and Quality in Health Care [Internet]. Safetyandquality.gov.au. 2017 [cited 2017 December 13]. Available from: https://www.safetyandquality.gov.au/
10. Donetto S, Pierri P, Tsianakas V, et al. Experience-based Co-design and Healthcare Improvement: Realising Participatory Design in the Public Sector. The Design Journal. 2015;18(2):227–48.
11. Donetto S, Tsianakas V, Robert G. Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions [Internet]. London: King's College London; 2014 p. 1–71. Available from: https://www.kcl.ac.uk/nursing/research/nnru/publ

ications/Reports/EBCD-Where-are-we-now-Report.pdf
12. Dawda P, Knight A. Experience Based Co-Design Toolkit [Internet]. Australian Healthcare & Hospitals Association and Consumer Health Forum of Australia. 2017 [cited 2017 December 13]. Available from: https://ahha.asn.au/experience-based-co-design-toolkit
13. Palmer V, Chondros P, Piper D, et al. The CORE study protocol: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness in the community mental health setting. BMJ Open. 2015;5(3):e006688-e006688.
14. Co-production in social care: what it is and how to do it – At a glance – SCIE [Internet]. Scie.org.uk. 2015 [cited 2017 December 13]. Available from: https://www.scie.org.uk/publications/guides/guide51/at-a-glance/
15. Piper D, Iedema R, Gray J, Verma R, Holmes L, Manning N. Utilising experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: An evaluation study. Health Services Management Research. 2012;25(4):162-172.
16. Cranwell, K., McCann, TV and Polacsek, M. Join the conversation: Evaluating the effectiveness of experience-based co-design in improving the client experience of mental health transition across health sector interfaces. 2015. Canberra: Australian Primary Health Care Research Institute.

ACKNOWLEDGEMENTS

None

PEER REVIEW

Not commissioned. Externally peer reviewed.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

FUNDING

None

ETHICS COMMITTEE APPROVAL

None

ABBREVIATIONS

TDB=Tara Dimopoulos-Bick
PD=Paresh Dawda
LM=Lynne Maher
RV=Raj Verma
VP=Victoria Palmer

Figure 1: Five EBCD case studies from Australia

Overview	Service Users	Challenges	(Potential) Solutions
The NSW Agency for Clinical Innovation supported six initiatives to use EBCD between December 2015 and December 2017. The settings were rehabilitation, young people with urinary incontinence, community mental health, brain injury, blood and marrow transplant, and hospitalisation for people with intellectual disability.	121 service users shared their lived experiences and contributed ideas for prioritisation and co-design of improvements. Seven service users across all six initiatives were involved on a project management and governance level.	• Lack of knowledge and commitment to apply all stages of the EBCD process • Accessing resources to support implementation • Inability to shift power and share decision-making • Staff resistance to uncertainty and new ways to thinking and doing • Moving past gathering experiences to co-designing and implementing improvements	• Prototype a community of practice to promote sustainability • Test relational approaches to creating equal partnerships and working collaboratively with service users and families • Develop and implement evaluation protocols • Engage designers to strengthen the interface with human-centred design methods and tools • Maintain stronger executive sponsorship and governance throughout all stages
The CORE study was a stepped wedge designed, cluster randomised controlled trial of an EBCD method called Mental Health Experience Co-design (MH ECO). There were 287 service users, 61 carers, and 133 staff enrolled. The intervention was delivered in nine community mental health teams in Victoria between 2014 and 2017. Service users completed recovery and experiences questionnaires every nine months and took part in one of three waves of the intervention.[13]	133 people were trained to take part in co-design (59 service users, 13 carers, 61 staff) across all nine teams. Experiences were collected with service users and carers through open-ended telephone interviews; exploration of experiences occurred in focus groups held separately with service users, carers, and staff; and co-design groups were facilitated using a trained peer model to co-develop action plans and implementation plans.	• Enabling active participation of adequate numbers of service users • Balancing creative, big sky thinking with the structured action and implementation plan approach used within the mental health experience co-design model • Continued development and implementation of improvements within a context of changing policy and service landscape • Shared responsibility for implementation and communication	• Use of a peer developed model — Mental Health Experience Co-design — ensured facilitators were trained to lead the process and had lived experience of being service user. This helped to balance the issues of representation of service users to keep power balanced during meetings and discussion • Check in with improvement leads to keep implementation on the radar and to have a reporting mechanism that kept the change process alive for service users and carers who invested their time in the process
The NSW Health Experience-Based Co-design Project used EBCD in seven emergency departments in NSW between 2007 and 2009.[15]	Service users were members of project teams, shared their lived experiences, contributed ideas for improvement, prioritization, and co-designed improvements.	• Service user recruitment and retention was difficult • Sustaining service user engagement • Staff viewing EBCD as a burden • Lack of resources • Lack of reporting opportunities at an executive level • Lack of accountability for implementation	• Embed solutions identified through EBCD into key accountability documentation such as policies and procedures • Deploy specific programs to assist with communication issues • Operate EBCD as a practice improvement and service user engagement tool

Figure 1 (cont'd): Five EBCD case studies from Australia

Overview	Service users	Challenges	(Potential) Solutions
Western Health together with Victoria University and Australian National University used EBCD to improve service users' experiences of mental health services as they transitioned through tertiary services to primary care and self-management support.[16]	16 consumers (12 patients, 4 carers) with mental health and complex healthcare needs, who were frequent presenters to the emergency departments and high users of health care.	• Expectation of staff about composition of focus groups varied • Staff perception that service users may not understand complexities relating to different functions, funding models, or organisational boundaries of different mental health services • Staff reporting feeling confronted by watching the trigger film at joint workshop leading to disengagement • Difficulty engaging champion to drive ideas in the service itself	• Individual consultation with service users and additional meetings with staff (rather than joint working groups) • Reviewing the film, a second time was less confronting • Engagement of staff earlier in the project • An approach that more deliberately combines service design and change management may have produced better results, with commitment (rather than compliance) by all parties supporting the sustainability of improvements
Northern Health Victoria supported five initiatives to use EBCD between October 2016 and May 2017. The settings were maternity, intensive care, rehabilitation, outpatients, community therapy services and day oncology, and emergency departments.	Over 50 service users shared their lived experience, contributed ideas, and co-designed improvements. Three service users were involved at the project management level.	• Ensuring enough time to learn the method and for effective engagement and participation • Identifying the appropriate staff to progress work • Managing scope of project against available staff time and competing priorities • Senior leaders' desire to reduce project time, which led to shortcuts, particularly around service user input • Service managers trying to influence outcome dependent on their own ideas about solutions • Accessing resources to fully implement improvements	• Support in using EBCD method through face-to-face training, monthly web based sessions, and additional coaching as needed • Strong senior leader and sponsor support • Regular reviews to balance scope with time • Provision of additional team members when needed • Monthly updates from teams, which enabled effective tracking • The case for change and improvement opportunities presented to the Board to gain support with resource allocation for implementation