

BMJ Open Evidence-informed, experience-based co-design: a novel framework integrating research evidence and lived experience in priority-setting and co-design of health services

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ABSTRACT

Objective To describe a new co-design framework termed Evidence-informed, Experience-based Co-design (E2CD).

Background Involving consumers and clinicians in planning, designing and implementing services results in the end-product being more likely to meet the needs of end-users and increases the likelihood of their uptake and sustainability. Different forms and definitions of co-design have been described in the literature and have had varying levels of success in health service redesign. However, many fall short of including people with lived experience in all aspects of the process, particularly in setting priorities for service (re)design. In addition, health services need to deliver evidence-based care as well as care that meets the needs of users, yet few ways of integrating research evidence into co-design processes are described. This paper describes a new framework to approach co-design which addresses these issues. We believe that it offers a roadmap to address some of healthcare's most wicked problems and potentially improve outcomes for some of the most vulnerable people in our society. We use improving services for people with high healthcare service utilisation as a working example of the Framework's application.

Conclusion Evidence-informed experience-based co-design has the potential to be used as a framework for co-design that integrates research evidence with lived experience and provides people with lived experience a central role in decision-making about prioritising and designing services to meet their needs.

BACKGROUND

Involving consumers and clinicians in the planning, design and implementation of services results in the end-product being more likely to meet the needs of end-users,^{1,2} thereby increasing the livelihood of uptake and sustainability of new services.³ Co-production is an umbrella term covering an array of evolving methods of including consumers in the design of health and social care services.⁴

While definitions and uses of different 'co' methods have caused some confusion and much discussion in the academic literature, a recent review has called for a shift in focus away from different definitions and towards advocating for the often similar principles of these methods to be operationalised and translated in practice.⁴

Experience-based co-design (EBCD) is one approach to health system (re)design that is founded on the principles of action research and design thinking.⁵ The co-design principles of equal partnership, openness, respect, empathy and design together have been suggested by one Australian group as critical to ensure that consumers are considered as equals at all stages of the design process.⁶ EBCD has been defined as *an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership*.⁷ Developed in the UK, EBCD is described as being about more than simply promoting greater patient participation, but about placing the patients' experiences at the centre of the design process.⁸ The Point of Care Foundation (UK) proposes eight stages in EBCD, namely, observation, interviews of service users, development of a trigger film, service provider feedback, service user feedback, joint service user and provider feedback, co-design groups and celebration event.⁷ Bate and Robert state that the storytelling, or identification of 'touch points' from the trigger film, is the very basis of experience-based design.⁸ However, EBCD in practice has undergone many adaptations, often due to costs and time constraints.^{9,10} In many instances, this has resulted in a process commonly called accelerated EBCD, where adaptations include using stock 'trigger films',

or absence of a celebration event.¹¹ A recent systematic review of EBCD use highlighted its frequent adaptation due to costs and time constraints.¹⁰ Two phases, each with consumer involvement, were considered crucial, namely, experience gathering and co-design.¹⁰ Additionally, Green *et al* recommend supplementing the process with service provider experiences, due to the potential differences in priorities and beliefs of users and providers.¹⁰ This review noted that EBCD's predominant use has been for *service improvement in local settings* but notes that its use could be extended beyond this, for example, for developing new services or redesign of health policy.¹⁰ However, it is less clear how EBCD can be integrated earlier into setting priorities for health service and policy design.

While health services need to meet the needs of its users, it is imperative that they also deliver evidence-based care. However, researchers commonly drive design processes in healthcare research, for example, undertaking literature reviews prior to engaging with stakeholders.¹² This may

narrow the range of potential solutions from the outset or leave teams conflicted as to whether published literature or stakeholder views should be given priority.¹² Indeed, one qualitative evaluation of participants' experiences of co-design identified the need to *limit researcher domination* of the co-design process to enable the establishment and maintenance of genuine partnerships.¹³ Approaches to using research evidence to supplement user experience in co-design are also infrequently described. One proposed approach to improving commissioning of health services integrates research evidence into a co-creation process in a limited way but does not emphasise the role of people with lived experience in decision-making or the importance of incorporating knowledge from lived experience in co-design.¹⁴ This is a critical gap that needs to be addressed.

People with high healthcare service use (HSU) are the small proportion of people who use a disproportionately high amount of healthcare services, determined by



Figure 1 Graphic depiction of the Evidence-informed, Experience-based Co-design (E2CD) Framework. The process moves iteratively through 5 phases, with a focus on people with lived experience at all times as shown by their central placement in the Figure. Participants at any time can call on rapid responsive focused evidence synthesis to support the process as shown by this surrounding the process (outer circle of figure). In the **understanding and refining** phases, holistic understanding of the issue being examined from consumer, clinician, and policy-maker perspectives is sought. A formal process is then undertaken to develop a person-centred, stakeholder-informed, and evidence-based list of priority areas for new and/or improved models of care and service (**Prioritising phase**). The highest priority area is then addressed using an EBCD-based approach to co-design a new, or re-design an existing model of service delivery and its evaluation (**Service and evaluation co-design phase**). The improvements are implemented and evaluated with results from the Implementation and Evaluation phase informing service development for the next priority area.

frequency of healthcare use such as hospital admissions, emergency department (ED) presentations, primary care visits or by incurring high healthcare costs.¹⁵ Indeed, there are calls for HSU to be considered a *red flag of patients' physical, mental, spiritual and social deprivation*.¹⁶ Healthcare service redesign is a recognised priority for improving services for people with HSU,¹⁷ though not a panacea given how factors outside the health system, such as unemployment and homelessness, contribute to their issues.¹⁸ Interventions to reduce health service use by people with HSU have often been ineffective. Failure to recognise patient needs in intervention design may contribute to this. Reviews highlight the importance of considering patients' unique needs¹⁹ and contexts.²⁰ Despite this, the diverse needs of people with HSU are poorly understood. Systematic reviews of interventions are silent on whether and how lived experience has been incorporated into the design of interventions.^{20–22} Failing to do this may lead to services being designed that do not address patient needs or barriers to access.²³

This paper aims to describe a new framework building on EBCD to address the limitations of co-design approaches identified above, using the complex problem of HSU as an example to its potential application.

The framework: evidence-informed, experience-based co-design

We have developed a new framework called Evidence-informed, Experience-based Co-design (E2CD) that applies mixed methods research methodologies to integrate research evidence with lived experience in a co-design process in which people with lived experience have a central, decision-making role. Components of the framework are shown in figure 1, which also shows that it builds on EBCD,⁷ retaining its strong emphasis on the primacy of views of people with lived experience and of their involvement in co-design. The process is cyclic and iterative and can begin at any phase depending on the context in which (re)design is needed. Key features that together distinguish it from other approaches are that:

- ▶ people with lived experience are kept central to the process by their lived experience informing each step and by them being involved in all phases including explicit decision-making roles for priority setting and co-design.
- ▶ data analysis, lived experience and evidence synthesis are integrated and incorporated throughout the process, without *a priori* decisions made by the researchers.
- ▶ researchers are responsive to participants' needs and generate evidence as requested, thereby acting as equal partners in rather than drivers of the process. Throughout, participants are encouraged to voice questions that can be addressed by rapid, focused syntheses of existing evidence.
- ▶ it has a priority-setting phase that gives people with lived experience a role in deciding co-design priorities.

- ▶ services and their evaluations are co-designed in one contiguous process.
- ▶ it is applicable to both the design of new services and redesign of existing services.
- ▶ it is iterative. Phases can be revisited when more information emerges.

Evidence-informed, experience-based co-design in action

We are piloting the application of the E2CD framework to the issue of HSU in our local context in Tasmania. Tasmania is Australia's only island state and has a population that is older, more geographically dispersed and more socioeconomically disadvantaged than the rest of Australia,^{24 25} which magnifies the effects of HSU on access and availability of healthcare services. We use the issue of HSU as an example to illustrate how the E2CD framework could be applied (illustrated in figure 2).

Understanding

The understanding phase has three components: understanding lived experience, using available data to understand HSU and including lessons from evaluations of initiatives already in place. To do this, we are:

1. evaluating a new, co-designed, nurse-led service that offers wrap-around care for people who have experienced ≥ 4 hospital admissions in a 12-month period²⁶;
2. undertaking a data linkage study that links Tasmanian public hospital admission, ED presentation and cause of death data to enable a comprehensive understanding of the characteristics and patterns of different manifestations of HSU locally, and;
3. conducting a qualitative study interviewing Tasmanians with lived experience with different types of HSU to gain an in-depth understanding of the causes, consequences and needs of people with HSU in Tasmania ($n=60$ approx.). We will use purposive sampling to ensure a diverse range of people are included (eg, by age, sex, rurality and region).

Refining

In the refining phase, approximately 20 policymakers, clinicians (acute and primary/community care), commissioners of services, funders and other stakeholders will be interviewed to gain their perspectives on aspects of HSU such as its causes, consequences, priority areas and potential solutions. This will augment information from the understanding phase. Although using focus groups to gather participant experience is recommended in EBCD,⁷ we have chosen to undertake interviews as EBCD facilitators have reported that individually interviewing service providers has the added benefit of engaging and enhancing their commitment to the process.²⁷ Service mapping will also be undertaken to identify services already available to people with HSU.

Prioritising

In the prioritising phase, a facilitated workshop with membership from all stakeholder groups previously involved including people with lived experience will be



Figure 2 Application of Evidence-informed, experience-based co-design (E2CD) to high healthcare service utilisation (HSU).

held to determine local priorities. This may be a service use pattern in one area (eg, ED presentations in a particular region) or a particular condition (eg, diabetes). We plan to use Nominal Group Technique²⁸ as this is a consensus method used to avoid domination of decision-making by individuals who have a vested interest in the outcome²⁹ and so aligns with the goals of E2CD.

Service evaluation and co-design

During this phase, a group, including members from all stakeholder groups involved thus far, will be convened to co-design/redesign a service to address the agreed highest priority. If needed, interviews with people who are potential end-users of that specific service will be undertaken, ensuring that potential end-users are central to the process. Evidence from all preceding phases will be communicated to the design group. EBCD principles will be used⁷ to ensure that the voice of people with lived experience is central to all decisions (figure 2). The evaluation framework for the new service will be co-designed simultaneously.

Implementation and evaluation

Involving all key stakeholders from the outset, including funders and commissioners of services, is intended to facilitate early implementation of the co-designed service.⁹ The evaluation of the new service will run concurrently with its implementation, with lessons learnt informing ongoing improvements within the service. This evaluation is important, as there is a reported lack of robust evaluation of interventions that are co-produced, leading

to a paucity of evidence that co-designed services lead to improved health outcomes.³⁰ Once this is implemented, the co-design group can revisit the priority setting phase and select the next priority for another co-design phase.

Rapid, responsive, focused evidence synthesis

To reduce the risk that researchers drive co-design outcomes rather than evidence synthesis being a tool used by people participating in co-design, at any phase of E2CD, stakeholders, including people with lived experience, can identify questions they would like the research team to address. The research team is equipped to rapidly respond to these requests, ensuring that the relevant information is summarised and provided to the stakeholders in a timely manner to support decision-making. Methods such as rapid reviews will be used for this.

DISCUSSION

With current expenditure on health growing faster than GDP in most countries,³¹ it is critical to ensure that expenditure on new initiatives and services is channelled to those that are both evidence-based and acceptable to end-users. Many governments, including Australia, are moving towards ensuring that healthcare is value-based and that the voice of consumers is included at all stages of healthcare planning.³² Involving all potential end-users in prioritising and co-designing services may provide some assurance of acceptability and thereby sustainability of new initiatives. The E2CD approach we propose

provides a framework that systematically involves all stakeholders in service (re)design from priority setting right through to implementation and evaluation, integrates research evidence with lived experience and gives people with lived experience a central, decision-making role. It offers a roadmap to address some of healthcare's most wicked problems and potentially improve outcomes for some of the most vulnerable people in our society, such as people with HSU. In doing so, it has the potential to be a guide for researchers seeking to improve integration of lived experience into designing and testing complex interventions, and it has potential application in the commissioning of health services. In addition, it has the potential to address the researcher/consumer power imbalance often identified as an issue in health service redesign.

The potential for power imbalances between co-design participants is widely acknowledged.^{2 4 5 11 33 34} This is not always considered a negative, with one study finding that co-design can challenge traditional relationships between patients and clinicians and may blur the boundaries between practice and academia.² Nonetheless, co-design leaders need to be aware that real and perceived power imbalances can derail the process and ensure no one group dominates. This can be achieved by setting up power-sharing structures and promoting collective ownership.^{2 13 33 34} The E2CD framework, in which researchers are equal partners rather than drivers of co-design, aims to avoid 'researcher dominance'.¹³ Having a research team work in partnership to provide evidence synthesis as requested by the co-design participants could help prevent researchers' *a priori* judgements of evidence from outweighing the evidence of lived experience and unduly influencing co-design outcomes. It may also lessen the power disparity that is so often an impediment to true partnerships in co-design.¹³

The E2CD framework can be applied to healthcare research and could be particularly useful when undertaking research aiming to improve health services or implement complex interventions. Many research funding bodies now strongly encourage or even mandate that researchers engage with consumers when designing research studies.^{35 36} They believe that the inclusion of consumer priorities, values and experiences is a means of ensuring research delivers fit-for-purpose outcomes that will be adopted by end-users.³⁶ The Framework provides a way for researchers to work with people with lived experience and integrate evidence into choosing research topics to address (prioritisation) and the co-design of any interventions/models of care they choose to study. This is likely to result in a greater alignment of research with stakeholder needs and improve the impact of research performed. It is important, however, to ensure that all stakeholders are cognisant of the time, costs and risks associated with using co-design in research.³⁷ These need to be acknowledged by funding bodies in terms of available funding and timelines and researchers in terms of deciding when to best use this approach.

The commissioning of health services is another area in which the E2CD framework could be useful. Commissioning is defined as *a continual and iterative cycle involving the development and implementation of services based on needs assessment, planning, co-design, procurement, monitoring and evaluation*³⁸ and occurs in countries including the UK, New Zealand and Australia.³⁹ Undertaking a needs analysis with end-user involvement is the basis for sound commissioning decisions.⁴⁰ However, consumer involvement in the commissioning process to date has been mainly limited to making changes to minor aspects of service provision rather than any engagement in strategic planning or priority setting.⁴¹ The lack of flexibility in how funds can be expended has been identified as another constraint, as it limits the ability to be innovative with services at a local level.^{39 41 42} We believe that the E2CD framework could help address these limitations. First, if adhered to, it provides a blueprint for the incorporation of lived experience and the involvement of end-users, including consumers, at every stage of the commissioning process, ensuring that the expressed needs of local communities are understood by providers and incorporated into service (re)design. Second, it provides a structure for Primary Health Networks to engage proactively within their communities to identify local needs and generate evidence to lobby for funds to address local priorities.

This article has some limitations. First, E2CD describes an overarching approach rather than a detailed methodology, so when applying it, users will need to choose methods appropriate for each phase. These choices will depend on factors including the context in which E2CD occurs, the health issue it aims to address and any specific barriers to engagement for people with lived experience. Choosing sensitive engagement processes and tailoring methods for priority-setting and co-design to meet the needs of specific groups of people with lived experience will be critical to its successful application. Second, we use HSU as an example to illustrate the potential utility of the E2CD framework. Therefore, a detailed explanation of the specific methods to be used in its application is beyond this article's scope. Finally, as consumers were not involved in developing the framework, evaluating its use in practice with people with lived experience is essential.

CONCLUSION

As the cost of healthcare continues to rise, it is crucial that services deliver evidence-based care that meets the needs of its users. Involving all stakeholders in decisions regarding prioritising areas for service provision as well as designing services increases the likelihood that they will be embraced by end-users and outcomes will be sustained. While not a panacea, evidence-informed, experience-based co-design provides a framework to potentially address some of healthcare's most wicked problems.

Contributors CM and TW conceptualised the framework. CM, KJ, SEH, KS, DM, MW and TW provided input into the framework design. CM and TW drafted the paper with input from KJ, SEH, KS, DM and MW. CM, KJ, SEH, KS, DM, MW and TW approved the final version of the paper. TW is the guarantor.

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