Essay

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Experience-Based Co-Design in Health Services Research: A Participatory Model for Knowledge Generation, Translation, & Implementation in Health Systems

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Abstract

Participatory engagement is a well-documented and commonly pursued goal in healthcare. Yet, models to involve patients, staff, and other stakeholders in research are few, with many uncertainties about how their expertise should be framed, captured, measured, and applied towards change. In this paper, we reflect on the utility of Experience-Based Co-Design (EBCD) in activating—and acting upon—diverse experiential knowledges and serving as a model for involvement in health systems and services research. Derived from design studies and used predominantly in the improvement sciences, EBCD draws upon people's experiences for simultaneous knowledge production and utilisation to trigger and sustain changes in small, localised settings or across large, complex systems. Like other participatory models, it establishes research partnerships between stakeholders, but also leverages those partnerships to collectively develop, implement, and evaluate interventions. Essentially, EBCD enables stakeholders to exchange mutual experiences of providing, receiving, and organising care, resulting in the shared identification of problems, decisions about preferred solutions, and collective ownership of research end-outputs. As a promising and successful—if underemployed—model for research engagement, EBCD has applications in many forms of health systems and services research.

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1. An Experience-Driven Model for Collaborative Knowledge Production and Utilisation

With the growing emphasis on democratically engaged healthcare provision [1–3], there is a corresponding need to foster cultures of collaborative knowledge generation and use in health research, education, and practice. Increasingly, health system goals are formulated as shared endeavours, uniting discrete social resources and integrated with dialogic exchange among healthcare providers, educators, users, and decision-makers. Thus framing health provision as a collective goal, health services can be regarded as social innovations that produce relational goods—trust, attention, and care—while contributing to social cohesion, sustainability, and resilience, with an overall positive impact on people's lives [4,5]. In this view, the health system may be regarded as a collaborative ecosystem of interdependent stakeholders, aiming to deliver care in accord with the desires and expectations of the communities it serves.

Collaborative communities are said to generate two crucial outcomes that support iterative knowledge exchange and implementation cycles: services to meet community needs and networks of engaged actors [6]. Yet, effective collaboration between diverse actors—patients, caregivers, researchers, staff, clinicians, managers, and policymakers—is an ambitious task fraught with many logistical and epistemological challenges. In this context, improving patient experience and patient engagement emerge as key transdisciplinary objectives, combining widely varying skillsets, aims, and interests in the shared quest for equitable, integrated, and patient-centred care [7]. Despite its promise, the co-creation and incorporation of experiential knowledge remains infrequent within mainstream medicine.

This paper considers the role and value of Experience-Based Co-Design (EBCD)—past quality improvement projects (where it is primarily employed)—in and for patient, staff, and stakeholder involvement in scientific inquiry. EBCD extends beyond a singular research objective or procedure, offering a contextually adaptable, multi-method, multi-step model and process. Still a relatively novel—or at least less common—approach from the design sciences, with early applications in cancer care nearly 20 years ago [8], EBCD has since been found useful for integrating patient participation in health intervention development [9], and more broadly, in improving healthcare quality [10]. We do not seek to provide an exhaustive description of all its applications, nor do we offer an in-depth field guide for conducting EBCD projects. Instead, our objective is to contribute a critical synopsis of the scope and fit of EBCD in participatory research, education, and collaborative exchange in healthcare. The forthcoming discussion begins with a brief overview of the traditions inspiring EBCD and the mechanisms it involves, followed by an examination of how EBCD may promote research engagement and knowledge translation, as well as its potential applications in healthcare investigations. Finally, we reflect on some common scientific and ethical concerns about EBCD, and end by summarising its value for patient-centred and patient-engaged health futures.

2. What is EBCD?—Origins, Values, and Mechanisms

At its core, EBCD is a framework for utilising people's experiences to guide the development, generation, and implementation of health system evidence and change. Usually employed in quality improvement projects at or for a single organisation or health service segment, it has also been used, although less frequently, in large-scale, multi-centred studies [11,12]. EBCD originated from a broader set of participatory design and education practices that aimed to transcend positivistic traditions, while collaboratively addressing intricate human and societal dilemmas [13]. Influenced by participatory action research [14,15], participatory design practices date at least as far back as the 1970s, in the collaborative work undertaken by trade unions and employer federations as part of the workplace democracy movement in Russia and Scandinavia [16]. In the 1980s, the UTOPIA and Florence projects became one of the earliest and most significant examples of stakeholder involvement in the design of organisational and technological practices [17]. EBCD has also been linked to influences from learning theory [18] and organisational development and workplace psychology [19]. These early principles, methods, and lenses were applied to and advanced further in the field of Human Computer Interaction (HCI). Here, terms like *human-centred*, *user-centred*, and *person-centred design* were engendered, with these being most frequently associated with user experiences of technology.

Subsequently, various participatory practices emerged from the design fields/professions to improve a range of products and services in a shift that is often known today as *collaborative* or *co-design*. In more recent years, these participatory and user-oriented values and methodologies transcended the design sciences, permeating other realms such as business, management, education, public policy—and notably—health and medicine [20]. Within the latter, participatory design models (like EBCD) find synergy with the allied notion of patient-centred care—a critical pursuit across healthcare organisations today. Patient-centred care objectives are commonly advanced by partnering with users in quality improvement projects, although many have characterised quality improvement as needing to be distinguished from scientific investigation [21–23]. We argue that achieving and operationalising patient-centred care goals requires the robust engagement of multiple stakeholders (including patients and staff) in various forms of and at different points along the

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research spectrum, rather than being limited to quality improvement endeavours alone. Here, participatory design extends a concrete, sequenced, and outcomes-focused structure for embedding patient involvement in scientific research.

A growing body of evidence has demonstrated the efficacy of several participatory design methods and models, including their many variations, globally across the public sector [24–26]. Of these, EBCD is distinguished from other strands by its emphasis on designing not only *services*, but also designing *experiences*. In healthcare, this might involve treating people's experiences as the source of their expertise—about their health conditions, on navigating the health system, with receiving/delivering medical services, and on community attitudes, supports, barriers, etc. More generally, participatory design fosters a “culture of argument [that] frames doubt and doubts, openness, incompleteness and lack of closure, iterative processes, critique of both the product and processes of design, and argumentation, as important resources to be valued in the design process" [27], promoting the idea that "power and dominance are [...] meant to be visualised, not neutralised” [27].

There are many adaptations of the EBCD approach, but a widely accepted outline is provided by the Point of Care Foundation in the United Kingdom, with steps including contextual observation, filmed interviews, feedback events, and co-design workshops [28]. In a similar model, Donetto and colleagues have described the six stages of EBCD, involving setting up the project, engaging staff, engaging patients, holding co-design meetings, creating small co-design teams, and organising celebration events [29]. Toolkits have also been produced in other countries to aid researchers and healthcare managers in EBCD-driven quality improvement projects with step-by-step guidelines and resources for effective engagement and implementation [30,31].

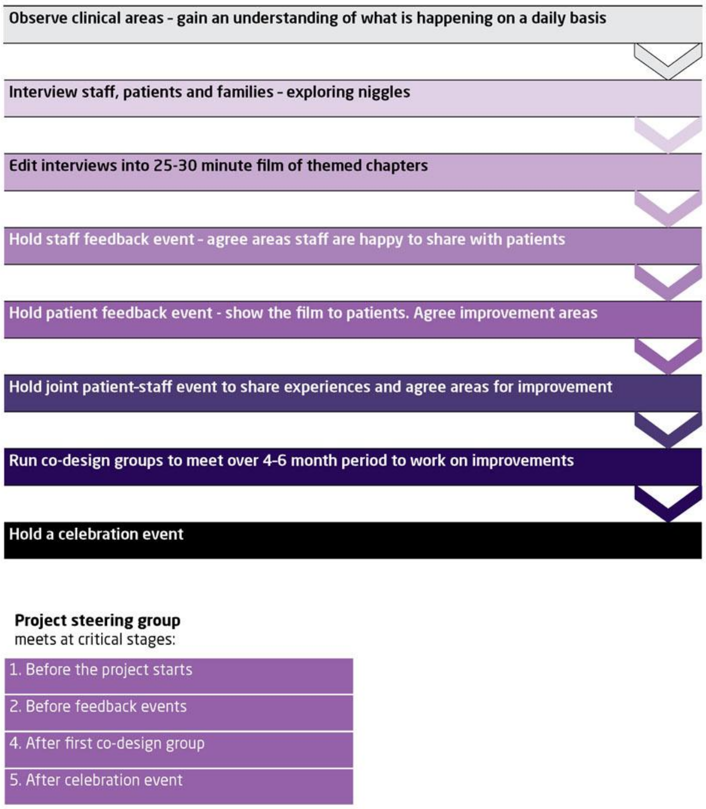

Figure 1. Stages in Experience-Based Co-Design, Point of Care Foundation [28]

Despite the availability of these guidelines, there remain many differences in how EBCD is understood and undertaken. Depending on the setting, budget, and purpose, EBCD may be modified to varying degrees to broadly involve these stages, which we summarise as follows:

i) Contextual Inquiry: The initial phase of EBCD includes the examination of the context in which the users experience a particular problem or need. This phase is characterised by the collection of data through observation, interviews, and other methods—both qualitative and quantitative, although narrative data is typically a key component.

ii) Co-creation Workshops: Designers, users, and other stakeholders come together to generate potential solutions to the problem at hand. This stage involves collaborative brainstorming, low-fidelity prototyping, and iteration.

iii) Prototyping: Based on the insights gathered from the co-creation workshops, designers create or refine prototypes of potential solutions. These prototypes can be physical or digital, serving as a means for testing the final solutions with users.

iv) Testing and Refinement: The prototypes are tested with users to gather feedback and make improvements. The feedback obtained in this phase is used to refine the prototypes and make them more user-centred in their final application.

v) Implementation: Once the prototypes have been refined, final designs can be developed and integrated into the real-world setting. At this stage, designers may work with stakeholders to ensure that the solutions are implemented effectively.

vi) Evaluation: EBCD can also be used to assess the impact of the implemented solutions on users and the wider system. This may include qualitative, quantitative, or mixed approaches, such as, the collection of post-intervention interview data, the administration of surveys, and the contextual observation of the solutions in use, often returning to an earlier stage, resulting in a cyclical process of refinement and sustenance.

In conclusion, EBCD offers a complex and iterative—but flexible and contextual—research process informed by the principles of collaboration, empathy, and user-centredness. It is adaptable for different objectives and scales, and can incorporate several methods to obtain and interpret data. Overall, EBCD seeks outcomes built upon the needs, perspectives, and experiences of those involved in the reception and delivery of a particular service, or the operation and organisation of a broader system of services.

3. Does EBCD Align with Patient Engagement, Knowledge Transfer, and Evidence Implementation Goals?

A discussion on EBCD (or any other participatory approach in health) is not possible without a brief comment on patient engagement, its meaning, and scope. While there are many definitions of patient engagement [32–35], as Nass and colleagues have explained, “Engaging patients in health care research makes (investments in) research more accountable and transparent, provides new insights that could lead to innovative discoveries, and ensures that research is relevant to patient concerns. The international experience with engaging citizens and patients in research has shown that involving them early in the design of studies, ideally as early as at the planning stage, leads to better results” [36].

Patient engagement has been identified as an essential tenet of modern health research, with many countries institutionalising this goal in health policy frameworks, funding program criteria, and organisational mandates [37,38]. In Canada, this objective has been formalised through a national Strategy for Patient-Oriented Research (SPOR), which describes patient engagement as being fundamental for "patients, researchers, health care providers and decision-makers to actively collaborate to build a sustainable, accessible and equitable health care system and bring about positive changes in the health of people living in Canada" [38]. Similarly, in the USA, the Patient-Centered Outcomes Research Institute (PCORI), and in the UK, the NIHR Centre for Engagement and Dissemination (and prior to 2020, INVOLVE) are other organisations that have supported the engagement of patients, families, staff, and other stakeholders in health research and service improvement.

Despite the consensus on its value, there remains a scarcity of trusted tools, methods, and approaches within the clinical research tradition that lend themselves well to patient engagement in scientific studies, and indeed, to critiquing the mechanisms being used to achieve engagement, knowledge translation, and system uptake [39]. Some healthcare professionals may believe that patient perspectives could nullify or contest evidence from conventionally 'unbiased' sources [40,41]. In yet another view, patient engagement ideally requires that patients help determine—from the outset—the research question and data collection methods, conduct the study, co-author the interpretations, and own the outcomes of the research. Moreover, despite the widespread interest in embedding patient engagement within traditional investigator-led research, concerns have also been raised about what patient engagement really entails, how researchers might avoid tokenism, and whether specific models, methods, and prescribed curricula may, in fact, fail to adequately or meaningfully capture patient perspectives and priorities that do not fit well within these agendas [42].

EBCD is not entirely free of these residual issues, some of which are discussed subsequently in this paper (see *section Scientific Rigour and Ethics in EBCD*). Nevertheless, EBCD supplies a compelling alternative to end-of-project knowledge outreach and change implementation (usually occurring after the evidence has been collected and analyzed), where the scientist shares the outcomes of research with those who may then act upon it. In contrast, EBCD is able to involve stakeholders and end-users in—and across—the life cycle of a project, treating their knowledge as a channel for concurrent evidence generation and action. Importantly, it enables the gathering of evidence deemed most useful to those whom it directly affects [43]. Finally, EBCD can combine and contextualise traditional forms of scientific evidence with the experiential knowledges of various groups (staff, patients, and other actors). Due to its reflexive and iterative components, EBCD may also contribute a measure of the quality of engagement, helping evaluate change implementation, monitoring, and optimisation processes [9].

The average time taken for evidence from typical scientific venues, i.e., scholarly publications, to be implemented in practice is approximately 17 years [44,45]. As such, there is reasonable incentive for exploring other means of knowledge transfer and implementation that have been used successfully for collaborative exchange and changemaking outside clinical research contexts. Like participatory methods from sociology and education, the EBCD model, derived from design studies and applied commonly within improvement science, motivates stakeholders to act upon the evidence they have helped produce—and for such evidence to cater to local settings or specific target groups implicated in the problem of interest. Therefore, the outcomes generated through an EBCD framework are more likely to produce immediate and stakeholder-prioritised changes, be locally applicable at specific healthcare sites, offer value to the staff/patient groups they affect, and ultimately, be actionable by relevant decision-makers positioned at key experiential touchpoints within the health system [13].

In summary, its innate alignment with research engagement and knowledge translation goals situates EBCD as a transformative agent, where patients and stakeholders are active co-creators of evidence and action. Driven by an ethos of equity and empowerment, EBCD emerges as a versatile and iterative methodology, not only for quality improvement but also for other types of health services research.

4. Applications of EBCD in Health Services Research

EBCD is a participatory model for the co-creation of change. Informed by diverse traditions and spanning a wide field of practice, EBCD can be limited in scale to a single healthcare organisation or service; it can also be expanded to multiple sites—locally, nationally, or internationally [11,12,46–48]. It can incorporate qualitative, quantitative, or mixed methods as and when needed—although narrative interviews, visual artifacts (e.g., trigger films), and qualitative focus groups (often called co-design workshops/meetings) are a hallmark feature of the model. It may address immediate and pragmatic concerns affecting a narrow user segment. It may also trigger long-term cultural shifts by democratising, decentralising, and decolonising health system structures [49–53]. EBCD accommodates these varied aims and outcomes through several points of application.

The first application of EBCD in health services research is at the stage of protocol development, where it can be useful for setting appropriate research questions [54,55]. There is a long history of

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discussions around wicked problems within participatory design [13,56]. Much design-led research—particularly in the areas of services, systems, and policy design—is concerned with interventions that address complex issues. By focusing on experiential knowledge, EBCD can be used to determine stakeholder priorities in complex research areas, favouring the discovery and mobilisation of local needs and local evidence for locally preferred changes—thus enabling tailored community solutions with greater chances of systemic uptake.

Second, EBCD holds great potential for integrated service organisation and delivery, including in the management of care continuity. While there have been fewer instances of such applications, the relevance of EBCD in large-scale or multi-site health programs is becoming increasingly evident [11,12,46–48]. By bringing together stakeholders from different sites, types, and levels of care, EBCD views the health system as a collaborative ecosystem and the care pathway as a set of many moving parts. It can be used to identify and bridge crucial gaps in care transitions; for example, by optimising how patients plan for and experience the move from hospital to home (or between healthcare sites), communicate with various health professionals, and manage care routines through the course of treatment or at different points of transition. Additionally, EBCD can be useful for health program administration, management, and appraisal. National and provincial health programs are typically designed to work in the average context and local adaptation becomes necessary when dealing with situations that deviate from this average [57]. Here, EBCD provides mechanisms for programs to maintain ongoing effectiveness through periodic revisions and refinements in response to changed conditions, new stakeholder needs, emerging outliers, and vulnerable groups.

Third, EBCD offers a robust framework to account for and resist tokenism in patient/public engagement—a common but important critique of participatory health research strategies [11,58]. With increasing funding-related and organisational directives for integrating patient engagement objectives within scientific protocols, there is a risk of incorporating patient voices as checkboxes to authenticate research objectives and findings. In contrast, EBCD relies upon stakeholders to determine the nature, form, and content of the desired changes, creating genuine opportunities for shared authorship and ownership of the research design, processes, and outcomes.

A fourth application of EBCD is in health intervention development, where it can be employed from the priority-setting stage through to output generation. EBCD can facilitate stakeholder and end-user involvement in the development of patient- and caregiver-oriented products, tools, settings, and services in several ways. For example, it can guide research involving the design of patient decision aids [59], patient education materials [60,61], self-management tools for those with chronic illnesses [62], complex healthcare facilities like emergency departments [63], interventions and applications for healthcare team coordination or patient-provider communication [64–66], mobile or web-based patient portals [67,68], and electronic medical record systems [69,70]. Using EBCD to guide the design of these and other interventions may help enhance their patient-centredness, assess change impact, and optimise similar interventions in the future, and reflexively, produce measures to evaluate engagement [71–73]. On the whole, EBCD can help improve the relevance, usability, and uptake of a broad range of structural interventions and service processes in the health system.

5. Scientific Rigour and Ethics in EBCD

As stakeholders are opted into the EBCD process earlier than in conventional investigator-led inquiry, research decisions and implementation strategies can be checked or negotiated from multiple standpoints, generating a wider spectrum of insights and better management of power imbalances. From a scientific perspective, this indicates an opportunity to increase the soundness of data-gathering techniques, the reliability of research findings, and the richness of analytic insights. Ethically, the inclusion of stakeholders in the project steering group can enhance the transparency of consent procedures, recruitment criteria, and informed participation mechanisms, while improving the overall study design, the likelihood of community acceptance, and the impacts of organisational or system-wide change.

Despite clear benefits, certain methodological challenges and ethical issues persist. Often, these are not restricted to EBCD; rather, they indicate broader apprehensions about the interpretation, legitimacy, and rigour of approaches that seek patient involvement in the conduct of scientific studies [74,75]. For example, the use of EBCD in highly sensitive areas (such as, mental health; reproductive services; care for marginalised groups; etc) may involve greater concerns with confidentiality and decision-making autonomy, given that EBCD participants will typically be aware of each other's identity. Here, recent literature has highlighted the need for assessing how best to adapt EBCD for vulnerable populations, especially where previous experiences of care may have been disempowering [76,77]. Further, shared decisions may trigger feelings of resentment—or even imposition—among individuals who disagree with the collectively chosen course of action, potentially affecting group dynamics. Differences may also emerge from diverse interpretations of design thinking and co-design processes [11]. While the EBCD model is structured to avoid unidimensional thinking, research involvement is uncertain and messy by nature, with the inherent risk of becoming reductionist and discounting nuanced power differentials [78]. Many of these issues can be ameliorated through competency training—for both researchers and stakeholders—in cultural safety, bias management, data stewardship, respectful communication, and consensus-building.

Finally, EBCD can be perceived as being limited in scale for reasons of feasibility; for example, useful in incremental quality improvement projects at the local level, but lacking generalisability of emerging evidence [58]. While EBCD has demonstrated improvements in health service quality, the time and expense associated with its standard procedures may not be pragmatic or efficient for some healthcare settings or stakeholder groups, thereby posing barriers to widespread adoption and implementation [7]. Consequently, many modified versions—namely, accelerated EBCD or AEBCD—have been developed and tested over the years with encouraging results [79]. As Robert [7] notes, even when "accelerated forms of EBCD do not work as well as the traditional approach, they may work 'well enough' to be worth pursuing" [9]. Future research in EBCD should evaluate the usefulness and impact of diverse co-design processes, how implemented changes can be sustained, and whether there are direct links to improvements in health outcomes [76,80–82].

6. Conclusions

In response to the rising importance of patient-centred care within health systems and organisations, there is a parallel imperative for advancing patient-engaged research. Accordingly, it is necessary to reassess the nature, scope, and modes of engagement being sought, and look towards disciplines outside the clinical and biomedical sciences, where open-ended and exploratory approaches have been used previously for successful change generation at both macro and micro levels. Stemming from broader movements around co-production in public services, organisational research, and the user-centred development of products, services, and systems, participatory design presents a promising alternative for collaborative evidence generation and use. In this paper, we have focused on EBCD, a strand of participatory design, which has remained largely confined to quality improvement, receiving less attention in other forms of health services research.

Overlaps across disciplines, mutations in terminology, and modifications for diverse scales and purposes may obscure what EBCD entails and what benefits it holds for health systems. Additionally, some of the scientific and ethical concerns surrounding participatory research in general—but more specifically, concerns with the meaning and scope of engagement—overlap with dilemmas in the appropriate and ethical use of EBCD. Hence, several preoccupations—about the legitimacy and effectiveness of participatory health research models (like EBCD)—must be probed further to better understand contemporary challenges and limitations. Despite these caveats, by treating patients, staff, and other stakeholders as partners in care, EBCD can be adapted for health services research across many domains and levels. Its key strength lies in the intent for research outcomes to align with the priorities of those who will benefit from or utilise them, making the best possible use of participants' time, experience, and expertise, as well as limited health system resources. EBCD offers a rich, diverse, and yet, underutilised framework and process for participatory engagement in health research, and ultimately, for conceiving equitable, democratic, and collaboratively designed health futures.

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