Experience-Based Co-Design of Health Care Services

Implementation Guide

IHI/Commonwealth Fund Innovations Network

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How to Use This Implementation Guide

This guide provides details on implementing the experience-based co-design (EBCD) innovation based on the experience of US health care systems participating in the International Innovations Network Learning and Action Community, led by The Commonwealth Fund and the Institute for Healthcare Improvement (IHI).

The implementation guide outlines the sequence of activities vetted by three health system teams that strove to test, adapt, and adopt EBCD in their systems. The EBCD innovation developed in the UK is described in more detail in the original case study published on this work.¹

The intended audience for this guide is health system leaders and point-of-care staff, providers, and teams who seek to engage with patients and other community members in the co-design of care delivery.

Background

US health care systems participating in the International Innovations Network Learning and Action Community learned about the experience-based co-design (EBCD) innovation from King’s College London and The King’s Fund in the UK. The EBCD innovation in its original form brings together narrative-based research with service design methods. Patients and staff are filmed, interviewed, and/or observed to understand positive and negative care experiences, and these experiences catalyze a change process whereby patients and staff co-design and test improvements to health care services.

During the 18-month Learning and Action Community, three US health care systems resourced teams to adapt and adopt the EBCD innovation in their settings. The teams applied the IHI Idealized Design Process² and the Model for Improvement³ to develop a prototype and test the EBCD innovation in one setting. This implementation guide shares their learning, which may be applied in other US health care systems.

For the teams working to adopt EBCD in their settings, their goals involved local improvement and adoption rather than system-wide scale-up. Because of the nature of the innovation and what teams were able to achieve during the Learning and Action Community, further testing is needed to understand what scale-up of EBCD entails.

Adapting and Adopting Experience-Based Co-Design in Your Health Care System

Getting Started

Health system teams in the Learning and Action Community that tested the EBCD innovation identified two important “getting started” steps to consider before embarking on testing this approach.
1. Recognize the Important, Distinct Features of EBCD

EBCD is a methodology in which patients and clinical staff work together, side by side, to co-design improvements and innovations to health care services. The EBCD approach to co-design has two distinguishing characteristics:

- Patients are engaged as full partners in improvement throughout the entire improvement project or initiative. This is a different level of engagement from the typical approach many health systems employ to solicit input from patients using surveys or focus groups.

- Videos of patients and staff describing their experiences with the health system are a central component of the EBCD methodology. The three health system teams that tested EBCD found low-cost, low-technology approaches for making videos. For instance, one team used an iPad to record patient interviews, testing the best placement of the iPad for sound and image quality and who should conduct the interviews, and then used a video editing app to create video clips to share with staff.

2. Determine the Applicability of EBCD in Your Health System

Teams interested in testing the EBCD innovation should first review and familiarize themselves with the step-by-step EBCD Toolkit. Identify the ways in which the EBCD co-design methodology is similar to or different from how your health system currently engages patients in improving care delivery.

Consider the following questions:

- Where is your health system on the continuum of patient engagement in improvement?
  - No/low engagement
  - Moderate engagement (e.g., asking for patient input using surveys and focus groups)
  - High engagement (e.g., patients are full partners in improvement such as EBCD, a high-functioning Patient and Family Advisory Council [PFAC] that participates in improvement efforts, or a similar approach)

- If your system has no experience with soliciting patient input, is it ready to test EBCD on a small scale? Are staff prepared to listen to patient input without judgment and partner with patients in a meaningful way? Or is patient input not welcomed by all staff?

- If your system has prior positive experience with soliciting patient input, is it ready to test EBCD as an alternate, perhaps more robust, method for patient engagement? If your system already has a high-functioning PFAC or partners with patients on improvement work in another way, EBCD may provide a structured approach for unit-level feedback and engagement with patients, rather than at a system or organizational level.

Establish a Meaningful Aim

It takes will, ideas, and hard work to improve health care services by implementing experience-based co-design. Qualitative and quantitative data inform where there are opportunities to co-design and where there is the will among patients and staff to undertake this work. Relevant data may include:
• Patient satisfaction survey data stratified by unit to identify potential areas for co-designing improvements with patients;

• Interviews and surveys with staff, pharmacists, physicians, and nurses to identify areas where patient input and engagement are needed; and

• Patient-centered care efforts and other improvement initiatives already underway that might be accelerated by integrating co-design into the process.

Use the data to establish an aim for experience-based co-design that is meaningful to your health system. The aim articulates what you will achieve (i.e., specific improvements), by when, and with what population (i.e., with whom you will partner to co-design improvements). For example, one health system team established the following aim statement: By January 2018, develop a successful pilot in which patients (users) and professionals co-design and improve health care services for the inpatient experience, so that our HCAHPS patient satisfaction scores in selected domains increase by more than 2 percentage points “top-box” [i.e., response is “Always”]; and staff satisfaction improves, as measured by qualitative feedback.

Identify a Leadership Sponsor and Local “Champion”

If you decide to test the EBCD methodology, identify a sponsor and champion who is passionate about EBCD and its distinct characteristics. Perhaps they have had an experience engaging one or two patients in co-design and have recognized how impactful it can be. Your sponsor may be a physician or administrative leader.

Support from the performance improvement area is useful to shepherd the design work. The quality improvement function in two of the health systems that tested EBCD either initiated or advised the testing. Engagement of the quality improvement function may be useful to move the work forward, but likely does not replace the need for a sponsor.

Begin Testing on a Small Scale

The health system teams that tested implementing EBCD did so on a small scale initially so that the teams could learn what works and does not work before committing more resources to implementing the change. The teams used Plan-Do-Study-Act (PDSA) cycles to conduct multiple, iterative small-scale tests of the stages outlined in the EBCD Toolkit:

• Observe clinical areas — gain an understanding of what is happening on a daily basis

• Interview staff, patients, and families — exploring niggles

• Edit interviews into a 25- to 30-minute film of themed chapters

• Hold staff feedback event — agree on areas staff are happy to share with patients

• Hold patient feedback event — show the film to patients, agree on areas for improvement

• Hold joint patient/staff event to share experiences — agree on areas for improvement

• Run co-design groups to meet over a 4- to 6-month period to work on improvements

• Hold a celebration event
The EBCD Toolkit also advises that the team leading the project to test and implement experience-based co-design meet at key steps: before the project starts, before feedback events, after the first co-design group, and after the celebration event.

### Lessons Learned and Implementation Tips

Health system teams in the Learning and Action Community that tested EBCD adapted the original guidelines to a minimal degree; they largely retained key elements of the original methodology, making some minor modifications for their local contexts. Employing this methodology as a means to achieve health system strategic goals for enhancing patient-centered care, these teams learned how to integrate the EBCD approach into high-priority work, make improvements, and plan to spread its use more broadly throughout the system.

Their lessons learned and tips for implementing experience-based co-design are described below.

- **A strong interest in both patient-centered care and innovation, from frontline teams to leadership, is a must.** The EBCD methodology is a rigorous and intensive approach that likely has the positive impact of designing improvements that meet the needs of both patients and staff. But the rigor and intensity of EBCD require a commitment of resources over a duration of time that necessitates fully aligned leadership across the organization to support this work over the long term.

- **The EBCD Toolkit is a tremendously rich resource — use it.** While the teams were tempted to modify the EBDC method or design their own approach, they often returned to the EBCD Toolkit to find templates and suggestions that accelerated their work. In hindsight, they wished they had started their work with a stronger adherence to the toolkit.

- **Make the videos.** The videos ground the work in the voice of the patients and staff and are thus essential. Teams identified low-cost, low-technology approaches to making the videos with off-the-shelf, personal electronic devices and freely available video editing software.

- **Commit to a fair process and be transparent about deviations from the co-design principles.** As a health system, it is acceptable to decide that you are going to pause or stop application of the EBCD approach and its distinct characteristic of co-design. However, it’s important to be honest and transparent about this with patients and staff engaged in the work. Patients, in particular, need to know if and when this transition occurs so they can decide how they want to commit themselves to the process and manage their expectations.

- **Consider sustainability planning for re-educating and engaging staff in EBCD.** Given that EBCD is a methodology that is learned rather than a standard protocol in health systems, staff turnover (e.g., medical residents who transition in and out of the system) impacts the work and makes it necessary to create a process for EBCD education for new staff.

- **Publicize and celebrate the work.** Share the method and results with internal staff and external stakeholders, including those engaged in the co-design process. Celebrate progress and successes, and learn from failures.
References

1. Van Citters A. *Experience-Based Co-Design of Health Care Services*. Cambridge, MA: Institute for Healthcare Improvement; 2017. [www.ihi.org/resources/Pages/Publications/Experience-Based-Co-Design-Health-Care-Services-Innovation-Case-Study.aspx](www.ihi.org/resources/Pages/Publications/Experience-Based-Co-Design-Health-Care-Services-Innovation-Case-Study.aspx)


5. “Science of Improvement: Setting Aims.” Institute for Healthcare Improvement. [www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementSettingAims.aspx](www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementSettingAims.aspx)

6. “Science of Improvement: Forming the Team.” Institute for Healthcare Improvement. [www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementFormingtheTeam.aspx](www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementFormingtheTeam.aspx)

7. “Science of Improvement on a Whiteboard Video: PDSA Cycles (Part 1).” Institute for Healthcare Improvement. [www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/Whiteboard5.aspx](www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/Whiteboard5.aspx)