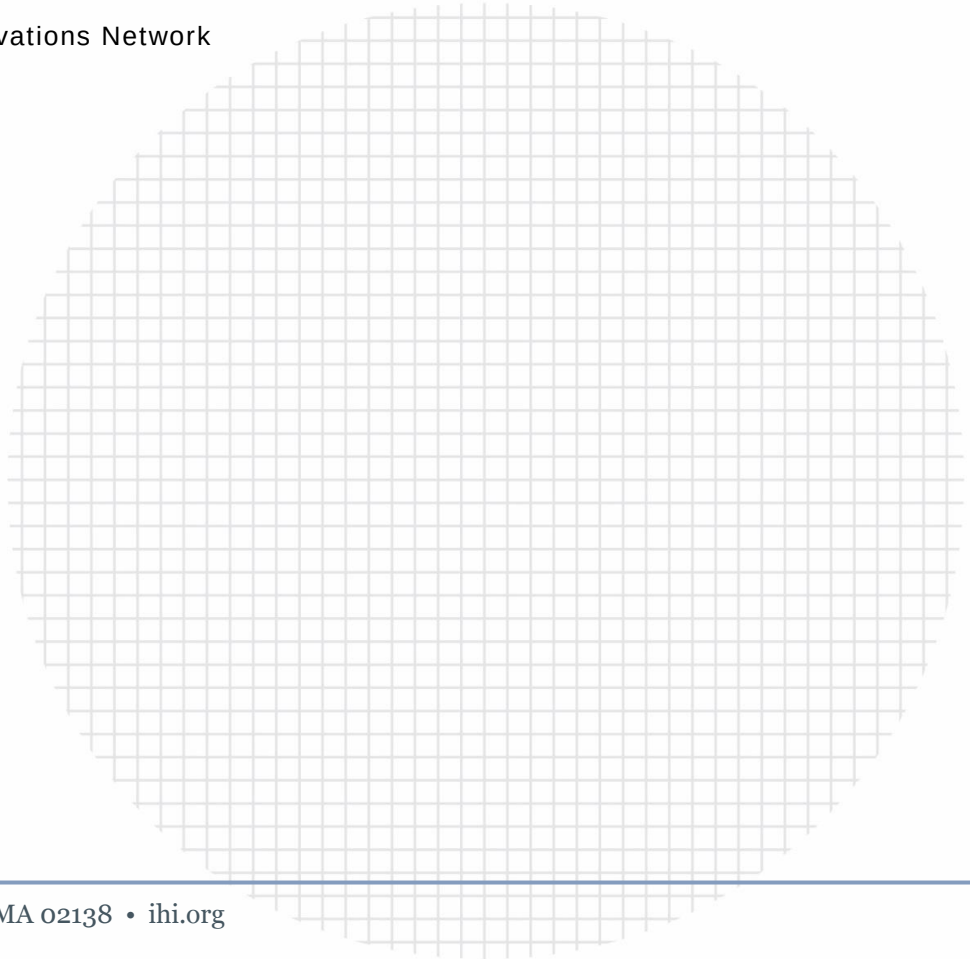
Institute for Healthcare Improvement

# Experience-Based Co-Design of Health Care Services

## A Case Study for US Health Care Delivery System Innovation

IHI/Commonwealth Fund Innovations Network



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# Contents

# Summary

Patients' experiences of care are an important focus for the health systems that serve them, yet few health care organizations deeply involve patients in improving or redesigning services. Experience-based co-design (EBCD), developed in the UK, brings together narrative-based research with service design methods to improve patient and staff experiences of care. Patients and staff are filmed, interviewed, and/or observed to understand positive and negative care experiences. These shared experiences catalyze a change process where patients and staff sit side-by-side to design, implement, and test improvements to health care services. The EBCD method has been used in more than 60 projects in six countries; it has led to improvements in patients' experiences as well as transformations in health care workforce culture, values, and behaviors. EBCD efforts have been associated with reductions in formal complaints in a mental health ward; increases in the percent of patients with cancer who report always being treated with respect and dignity; and greater emergency department staff appreciation for how health care practices and environments affect patients, and how to work with patients to co-design and implement health care services. Successful EBCD requires effective facilitation, an openness to work with uncertainty and creative methods, and six to twelve months to complete a full cycle of improvement. EBCD is adaptable to different health care contexts and is supported by implementation resources.

# Introduction

The problems that plague US health care systems are longstanding and many seem to be intractable. Yet, by studying health care systems in other countries, innovative solutions may be available globally to help solve or improve these problems. To this end, The Commonwealth Fund, in collaboration with the Institute for Healthcare Improvement (IHI), established the International Program for US Health Care System Innovation. This program aims to 1) identify promising frontline delivery system approaches to health care from abroad that might be transferred to the United States to improve quality of care, control costs, and increase value; and 2) test the innovations in the US health care systems to adapt for a US context.

The program established an Innovations Network of 15 leading US-based health care systems to identify and prioritize four intractable problems in the US delivery system. An international panel of experts scanned industrialized countries outside the US for innovative solutions to the intractable problems, evaluated the feasibility and transferability of the innovations, and selected four of the most promising solutions for site visits to gain a firsthand understanding of how the "solution" works in the local context.

This case study presents one of the four selected innovations for which a site visit was conducted, describing the innovation in the local context and discussing considerations for implementing the innovation in the US health care system. A team of three researchers from the Institute for Healthcare Improvement and three health care leaders from the IHI/Commonwealth Fund Innovators Network conducted a three-day site visit in London, UK, in April 2016. The team met with developers, researchers, trainers, and implementers of the EBCD method; documented conversations in detailed notes; and audio-recorded most interviews. After each day, the team discussed findings and unanswered questions and prepared for upcoming discussions. Common themes were identified, and supported by quotes and literature. The case study was written by the primary author, and reviewed by all site visitors and EBCD experts. The research and initial written summary of this innovation were completed in August 2016.

# Overview of the Innovation

Experience-based co-design (EBCD) is a quality improvement approach that combines narrative, participatory-action research with service design methods to improve patient and staff experiences of care (see Table 1).[1,2,3] It focuses on understanding the positive and negative health care experiences of patients and staff, and brings patients and staff together in co-design teams to improve health care services.

Such methods are well established in fields such as software development and architecture, but applying them to improving the performance, engineering, and aesthetics of health care services is in the early stages. EBCD differs from traditional quality improvement methods by focusing on human experiences, rather than workflows; using service design methods to discover and change processes; and establishing a new type of collaborative relationship between patients and staff.[4]

**Table 1. Six Stages of Evidence-Based Co-Design**[5]

| Stage | Key Tasks |
|---|---|
| **Setting Up** | • Establish governance and project management arrangements. |
| **Engaging Staff and Gathering Experiences** | • Observe the clinical service delivery area to understand what happens on a daily basis.<br>• Interview 12 to 15 members of staff (from receptionists to lead clinicians) about their work experiences.<br>• Hold a staff feedback event to review the themes arising from their interviews and identify priorities for improving services that will be shared with patients during the joint patient/staff co-design meeting. |
| **Engaging Patients and Gathering Experiences** | • Video 12 to 15 patients talking about their experience of care, including the positive and negative touch points that shape their overall experience. (Edit videos into a 25- to 30-minute “trigger film” with themed chapters.)<br>• Hold a patient feedback event to watch the trigger film, discuss how the touch points reflect their own priorities and experiences, and identify priorities for improving services. |
| **Co-design Meeting** | • Conduct a joint patient and staff co-design meeting where staff view the trigger film of patient experiences for the first time.<br>• Mixed groups of patients and staff share their experiences of a service and identify shared priorities for improvement.<br>• Patients and staff volunteer to join specific co-design team(s) to design and implement service improvements. |
| **Small Co-design Team(s)** | • Co-design team(s) meet over a three- to four-month period.<br>• Team(s) are facilitated by quality improvement specialists, or other individuals with strong facilitation skills. Guidelines are established to ensure that patient and staff participants have equal voices.<br>• Service design tools are used in the design process. Examples include storyboarding, experience mapping, prioritization of options, prototyping, and testing ideas against the needs of personas.[6] |

| | |
|---|---|
| **Celebration Event** | • Separate co-design team(s) reconvene to discuss their work and celebrate success.<br>• Plan for the next stages of the improvement process or next EBCD cycle. |

# Background

Many policy makers and health care organizations see patient and family engagement as critical to improving quality of services.[7] Health care organizations have attempted to capture the knowledge of patients and families through patient experience surveys, focus groups, and representation on quality committees and other advisory roles. However, patients are rarely engaged as partners in designing services;[8] metrics used are often not seen as timely or clinically relevant;[9] and most survey methods do not enable patients to describe what matters most to them. As a result, services often reflect the perspectives of payers, providers, and the larger health care system.[10] EBCD offers an approach to humanizing health care whereby patients' stories about their care experiences suggest priorities and solutions that may not occur to people immersed in day-to-day service delivery.[11]

Recognizing the limited effectiveness of top-down models for improvement, Helen Bevan of the UK National Health Service challenged Professors Paul Bate and Glenn Robert in 2002 to identify quality improvement approaches grounded in the beliefs and perceptions of patients and staff who experienced services. Bate and Robert sought transformational ways to address the limited involvement of patients in health care service design and delivery. They drew on design sciences to identify techniques that could increase the NHS's ability to improve patients' experiences of care.

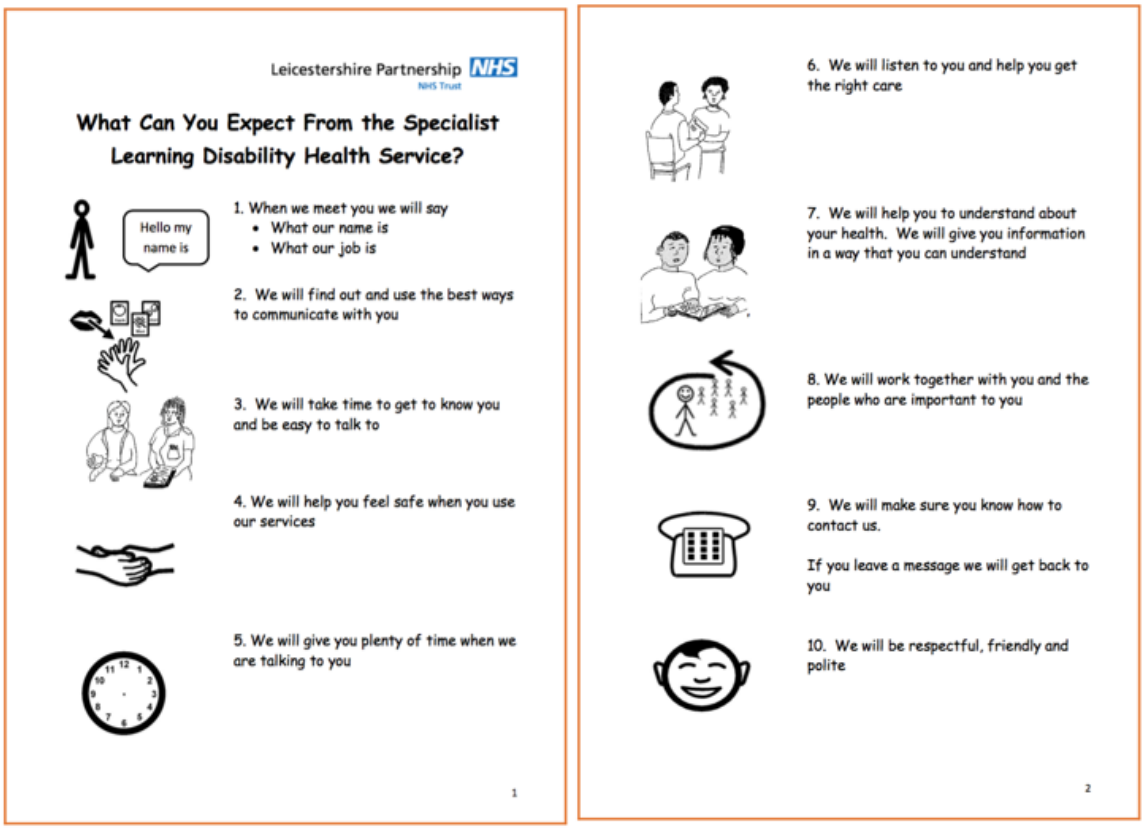
EBCD was pilot tested in 2006 at the Head and Neck Cancer service at the Luton & Dunstable NHS Trust in southern England.[12] Excited by the method's potential to improve patient experiences, independent researchers in New South Wales, Australia, used EBCD to address shortcomings in their emergency department (ED) system.[13] Another early use of EBCD was in the Integrated Cancer Centre at Guy's and St. Thomas' NHS Foundation Trust in central London to address problems identified through patient experience surveys.[14]

These efforts led to the development of a freely accessible, concise, easy to follow online toolkit[15] that describes the principles of EBCD and incorporates case studies and links to implementation resources. By 2013, 59 EBCD projects had been implemented in six countries, and 27 more were in planning stages.[16] Numerous additional projects have since begun. Most projects began with a frontline clinician or manager's desire to improve services or the realization that quality improvement efforts lacked input from patients and caregivers. EBCD sometimes began as a single project and became adopted into the organization's larger quality improvement framework. Use of EBCD in diverse conditions, services, and settings (see Table 2) has resulted in several adaptations. See Figure 1 for an example of EBCD educational materials developed at Leicestershire Partnership NHS Trust.

**Table 2. Spread of the EBCD Method**

| Conditions / Service Areas | Care Settings | Countries |
|---|---|---|
| • Cancer<br>• Rare genetic conditions<br>• Mental health<br>• Diabetes<br>• Orthopedics<br>• Learning disabilities<br>• Hematology<br>• Drug and alcohol services<br>• Emergency services<br>• Intensive care<br>• Palliative care<br>• Neonatal and pediatric care<br>• Surgical units | • Ambulatory<br>• Outpatient<br>• Inpatient | • UK<br>• Australia<br>• Canada<br>• The Netherlands<br>• New Zealand<br>• Sweden |

**Figure 1. Example EBCD Educational Materials Developed at Leicestershire Partnership NHS Trust**



# Key Components of the Innovation

- **Co-design is an essential element of the EBCD method.**

  Originally called experience-based design, it became apparent that co-design was a critical, but sometimes neglected, component of the method. The method was renamed experience-based co-design to emphasize the importance of engaging patients and staff in designing services together.

- **Accelerated Experience-based Co-design (AEBCD) can substantially reduce the timeframe of and staff burden in a project.**

  An EBCD cycle can take 12 months to complete, with several months devoted to creating "trigger films" — short, edited videos of patients sharing their experiences, intended to "trigger" or initiate conversations among staff to inform the co-design process. The accelerated method can reduce that time to six months by using archived trigger films of patients' experiences.[17] The Health Experiences Research Group at the University of Oxford has nearly 20 online trigger films for EBCD projects, with more in development.[18] AEBCD produces service improvements similar to those of EBCD with 40 percent lower costs.[19] Other users have created trigger films with fewer resources, or used different methods to visualize the patient experience.[2021] For example, the Learning Disability Services in the Leicestershire Partnership NHS Trust filmed patients using smartphones and recruited a teenager to edit clips into a trigger film. One trigger film can be used to kick-off multiple cycles of EBCD.

- **Organizations should anticipate that the involvement of patients and staff, as well as their need for support, might change during a project.**

  For instance, EBCD projects in cancer and emergency department settings have found that patients may adopt different roles and engage at different stages of a project.[22,23] Mental health projects have created peer groups to provide emotional support for patients participating in EBCD.[24]

- **Fidelity to the six stages of the EBCD method has been variable.**

  Although EBCD program developers believe that the method is flexible, deviation from the six stages may limit staff engagement with EBCD, limit its impact on staff wellbeing, and increase the risk of EBCD becoming a time-limited project rather than an ongoing cycle of improvement. Stages most often omitted are non-participant observation and the celebration/review event.[25] Opportunities to improve fidelity of the EBCD method have increased as training and consultation resources such as the online toolkit became available.[26]

# Findings

The EBCD method can improve patients' experiences of care and service delivery processes. For example, EBCD-initiated changes at the Oxleas NHS Foundation Trust eliminated formal complaints on a mental health ward for 23 months (compared to 13 formal complaints in the 15 months preceding formation of co-design groups).[27] Likewise, patients in cancer units participating in EBCD reported a 5 percent to 14 percent improvement in "always being treated with respect and dignity."[28]

Individuals who have used the method indicate that EBCD can transform workforce culture, values, and behaviors.[29,30,31] Survey respondents (n=47) from international projects reported that

EBCD had a real effect on engaging patients (90 percent) and staff (78 percent), enabled discussion of difficult topics in a supportive environment (63 percent), led to clear improvement priorities (54 percent), and made a difference to the "way we do things around here" (51 percent).[32] An independent study in emergency departments in New South Wales, Australia, showed that using EBCD enabled staff to learn new skills, better appreciate the impact of health care practices and environments on patients, engage patients in new ways, and implement co-created solutions.[33]

EBCD can have an impact at several levels and surface previously undetected problem areas.[34] Most improvements are small-scale changes or process redesigns within local teams. Projects involving process redesign between service activities or across organizations are less common (see Table 3).

**Table 3. Examples of EBCD-Initiated Changes**[35]

| | |
|---|---|
| **Small-scale changes** | Reviewing and improving patient information |
| **Process redesign within team** | New private room identified for receiving support after diagnosis |
| **Process redesign between service activities** | Redesigned discharge summary with input from all professions |
| **Process redesign across organizations** | Improved cross-site information booklet for patients transferring to another hospital for surgery |

Two-thirds of changes in an integrated cancer delivery center were still in place two years after EBCD project completion. Small-scale changes or quick fixes were most likely to be sustained (24 of 28, or 86 percent), followed by local process redesign and cross-service changes (5 of 9, or 56 percent; and 8 of 14, or 57 percent). Organization-level changes were least likely to be sustained (2 of 5, or 40 percent). Sustained changes were less complex; aligned with other quality improvement work; and were supported by clinical, improvement, and executive leaders.[36]

Estimated costs for a recent EBCD project were £30,870 (US $44,700) for the trigger film, plus £20,276 ($29,300) for design events, for a total of £50,761 (US $73,400) for the EBCD project as a whole. AEBCD reduced expenses by 44 percent, costing £28,565 (US $41,300).[37]

More rigorous evaluations are underway. Researchers are using randomized controlled trial designs to evaluate processes, outcomes, and cultural changes in community mental health centers in Australia[38] and among family caregivers of people receiving outpatient chemotherapy in London.[39] Future research will focus on: 1) establishing the business case for EBCD, 2) exploring the generalizability and scalability of improvements arising from individual projects, and 3) the appropriate roles and added value of including service design experts as core members of EBCD teams.

# Lessons and Implications for US Health Care Organizations Adopting the Innovation

Health care organizations in the US already dedicate resources to improving patients' experiences of care. Patient experience measures are increasingly collected, shared publicly, and linked to financial reimbursement from Medicare and other insurers. However, understanding what drives positive experiences of care remains a challenge. A recent study showed that most US health care senior leaders, clinician leaders, and clinicians report that their organizations use systematic tools

to collect patient engagement data, but most regard their measurement approaches as only somewhat effective.[40] The EBCD method provides a rigorous approach to identifying what lies at the heart of patients' experiences, both positive and negative — and may identify issues that other improvement methods do not.

By starting with the experiences of patients and staff and engaging both parties in co-designing services, EBCD brings industry standards of service design to the health care community.

- **Visualization of patients' experiences is critical.**

  Video is the easiest, quickest, and most valuable approach to visualizing patients' experiences. Trigger films, an integral part of the EBDC approach, are informative, help humanize service delivery, and catalyze patients and staff to collaborate during the co-design process.

  Some US health care systems use video ethnography to support quality improvement[41] and empathy building.[42] However, these efforts do not appear to be used together with co-design methods. The Health Experiences Research Network — a partnership between the University of Wisconsin, Johns Hopkins University, Oregon Health & Science University, and Yale University — is leading efforts to develop a video archive that could be used to create EBCD trigger films for US populations.[43]

- **EBCD requires an effective facilitator.**

  EBCD facilitators engage patients and staff in exploring their positive and negative experiences of receiving or providing services, help navigate interpersonal dynamics, ensure that an effective co-design process is followed, and are responsible for day-to-day operations of a project. Effective facilitators create a safe environment for discussing emotional events and can relieve patient and staff anxieties. Strong facilitators are creative, good at handling uncertainty, able to organize work within an emergent environment, and enjoy working with others. Facilitators can be staff from elsewhere in the organization who are trained in the EBCD method.

- **EBCD must align with organizational priorities and strategies.**

  Health care organization senior leaders play an important role in EBCD, including working alongside co-design teams, engaging key stakeholders, helping teams overcome barriers, providing resources, and encouraging spread of the EBCD method and resulting improvements within the organization. EBCD should be integrated into an organization's quality improvement framework, including support for implementing and tracking changes.[44]

- **Organizations should start first with a team and a care area where success is expected.**

  EBCD is most effective when patients can identify touch points along their care journey and articulate their care experiences, and when solutions for improving patients' experiences are not known at the project's beginning. A physician champion who can influence the culture and care delivery system is essential.

- **Identifying funding sources for using EBCD in the US could be a challenge.**

  EBCD projects around the world have been primarily supported by health care organizations and research grants. Other funding sources include charitable organizations, research and policy foundations, and insurance and pharmaceutical companies. In the US, national and local foundations such as the Beryl Institute,[45] Patient Experience Institute,[46] and Arnold P. Gold Foundation Research Institute[47] provide research grants to improve the patient experience of care.

Given the current focus in the US on patients' experiences of care, adoption and implementation of the EBCD method could have value for patients, providers, and health care delivery systems. Applying the EBCD methodology in the US context should require few, if any, adaptations.

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