EXPERIENCE-BASED CO-DESIGN

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Overview

① What is Experience Based Co-design (EBCD), and why do it?
② Method
③ Evidence base
④ ... and projects underway in Learning Disability services in England
Closing the ‘relevance’ and ‘utility’ gap: the concept of actionable knowledge

“More practising researchers”

“More researching practitioners”
What is Experience-based Co-design ... and why do it?
Toward More User-Centric OD
Lessons From the Field of Experience-Based Design and a Case Study

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This article argues for a need to shift the role of healthcare organizations from providers of medical care to co-designers of patient experiences. Knowledge of the experience of patients and their families is unique and precious, and an opportunity to be systematically used to co-design healthcare services. This knowledge can lead to a better understanding of what patients and families need and want. The article presents a case study of a project that aimed to improve the experience of patients and staff at a healthcare organization. The project involved working with patients and staff to co-design the experience, resulting in improved outcomes for both patients and staff.

Keywords: change; organization design; service design; patient experience; healthcare services

REDEFINING THE ROLE OF DESIGN FOR HEALTHCARE

A frequently asked question is: "Who is responsible for patient experience?" The answer is not just one person or team, but rather a collective effort involving all stakeholders. Patient experience is not an add-on to the design process; rather, it is an integral part of the design process. When designing healthcare services, it is important to involve patients and staff in the design process to ensure that the final product meets their needs.

In healthcare, the term "redesign" refers to patients and staff working in partnership with staff to improve services. Patients and staff are actively involved in the design process, from identifying problems to implementing solutions. This approach not only improves patient outcomes but also enhances staff satisfaction.

In conclusion, redesigning healthcare services requires a comprehensive approach that involves all stakeholders. By involving patients and staff in the design process, healthcare organizations can create services that meet the needs of both patients and staff, leading to improved outcomes for all.

Paul Bate | Glenn Robert

See and download article for author affiliations

THE JOURNAL OF APPLIED BEHAVIORAL SCIENCE
1. What is experience-based co-design?

Experience-based co-design (EBCD) is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership. The approach is different to other service improvement techniques.
A participatory action research approach that combines: a user-centred orientation (EB) and a collaborative change process (CD)
“Where user and provider can work together to optimise the content, form and delivery of services. At its most highly participative extreme, this process is referred to as codesign and entails service development driven by the equally respected voices of users, providers and professionals.”

DEMOS, 2008
Design theory

• draws its inspiration from a subfield of the design sciences such as architecture and software engineering

• distinctive features are:
  – direct user and provider participation in a face-to-face collaborative venture to co-design services, and
  – a focus on designing experiences as opposed to systems or processes (thereby requiring ethnographic methods such as narrative-based approaches and in-depth observation)
What makes a good service: designing experiences

**Performance**
- Is it functional?
- Lean

**Engineering**
- Is it safe and reliable?
- Safer Patients Initiative

**The Aesthetics of Experience**
- What does it feel like?
  - Physical environment
  - Human environment

EBCD

Berkun, 2004 adapted by Bate
Healthcare quality improvement from a design perspective

- must obviously fulfil the core task and be safe (performance and engineering)
- must ‘appeal’ at the emotional and sensory level (aesthetic)
- patients & carers need to be active rather than passive, using their specialist form of knowledge (experience)
Features of EBCD

- a focus on designing experiences, not just improving performance or increasing safety

- putting patient experiences at the heart of the quality improvement effort – but not forgetting staff

- where staff and patients do the designing together (co-design rather than re-design)

- and, in the process, improving day-to-day experiences of giving and receiving care

The method
Methods

• value of patients, carers and staff experiences

• stories not surveys

• ‘deep dives’ and direct observation

• ‘touchpoints’ and emotional mapping
celebration event

setting up

engaging staff and gathering experiences

goinging patients and gathering experiences

co-design meeting

small co-design teams
Reception – patient experience
Reception – staff experience
Tell your story...

We’re looking for budding Steven Spielbergs to film and make a documentary about their experiences of head and neck services. Why don’t you take the opportunity, you can work with our professional film maker to produce your own documentary.

For more information contact:
8. Interviewing and filming patients

This stage involves creating a comfortable environment for patients to share their stories of services, and capturing those stories effectively, to provide rich information that will guide improvement.

The interviews take place within a couple of weeks of the recruitment process, in a location where the patient feels comfortable. This may be at a hospital, community centre or in their home. Beforehand, send out notes to help them prepare (see example patient interview schedule). When they arrive, welcome them, help them feel comfortable, and take time to develop a rapport. Make sure there are comfy seats, refreshments, tissues, and plenty of privacy. Patients will be asked to consent to the clips that will go into the final version, so encourage them to be completely open at this stage.

The interview itself usually takes between one and two hours. Each individual film is then edited down for the final compilation film, which is half an hour long, divided between 11-12 interviewees. Try to let people tell their story in their own way, but prepare a list of questions for any interviewees who need more structure. While you’re listening, make a note of comments that require clarification or more detail. The interview also forms the start of the editing process, as the interviewer may also be involved in editing the film. So, as the patient is talking, listen out for key points and ‘touch points’ – themes that particularly resonate, and that may have also arisen in interviews with other people.
○ Touchpoints

• critical points

• ‘big’ moments (good and bad)

• moments of truth

• emotional ‘hotspots’
• Watch film of patient stories
• Hear what the patients have prioritised
• Hear what staff have prioritised
• Patients and staff agree on priorities
• Form working co-design groups to make these improvements
Prototyping

Building prototypes helps a group to move beyond talking and thinking about a problem to actually making progress toward action. Perhaps most important, they are real and physical—that is, they assume some material manifestation.

- Building to think
- Learning faster by failing early (and often)
- Giving permission to explore new behaviours

Multiple models of emergency and short-stay services: Luton and Dunstable
Testing solutions – personas

Do the second design solutions work for:

- an old person with dementia
- a car accident victim in/out of consciousness
- a person for whom English is not native tongue
- a young adolescent (or others)
What provision do you have for a person with particular needs e.g. dementia?
It was quite funny to see them lifting up their chairs ... It’s a symbol of the project that those chairs are those patients’ seats, and it’s about the staff and the patients together, just moving everything around, so it becomes the symbol for the whole project.
‘Hands off our stories’

• “... describes a community event organized in response to the appropriation and overreliance on the psychiatric patient ‘personal story.’ The sharing of experiences through stories by individuals who self-identify as having “lived experience” has been central to the history of organizing for change in and outside of the psychiatric system. However, in the last decade, personal stories have increasingly been used by the psychiatric system to bolster research, education, and fundraising interests. We explore how personal stories from consumer/survivors have been harnessed by mental health organizations to further their interests and in so doing have shifted these narrations from ‘agents of change’ towards one of ‘disability tourism’ or ‘patient porn.’”

Stories as commodities

• “We all have stories. Many of our stories are deeply personal. Some of our stories are painful, traumatic, hilarious, heroic, bold, banal. Our stories connect us - they reflect who we are and how we relate to one another. Stories are extremely powerful and have the potential to bring us together, to shed light on the injustice committed against us and they lead us to understand that not one of us is alone in this world.

• “But our stories are also a commodity - they help others sell their products, their programs, their services - and sometimes they mine our stories for the details that serve their interests best - and in doing so present us as less than whole.”

Becky McFarlane, Recovering Our Stories event, June 2011
**Humanising healthcare**

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<thead>
<tr>
<th>Forms of humanization</th>
<th>Forms of dehumanization</th>
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<td>insiderness</td>
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The evidence base
Some examples

• International survey of EBCD projects
• Emergency Departments, Australia
• Integrated Cancer Centre, London
• Carers of chemotherapy patients, London
• ‘Accelerated’ EBCD in lung cancer services & ICUs
• Examples of projects in mental health settings
Survey, 2013

- Online survey to 107 practitioners and researchers
- 18 follow-up telephone interviews
- 59 EBCD projects implemented in 6 countries worldwide (2005–13) and further 27 in planning
- Implemented in a variety of clinical areas (including emergency medicine, drug and alcohol services, cancer services, paediatrics, diabetes care and mental health services)
- Projects typically take 6–12 months to complete
- Free-to-access online toolkit ‘a helpful resource’

Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: an evaluation study

Donella Piper*, Rick Iedema*, Jane Gray*, Raj Verma*, Lee Holmes** and Nicole Manning*

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E-mail: dipiper@une.edu.au
Survey findings

- **Training and support:** 50% of those who have led EBCD projects did not receive any formal training.
- **Role of non-participant observation:** relatively under used as an approach.
- **Role of film:** 50% of projects included filming patients.
- **The scale of change:** ‘sweating the small stuff’.
- **Co-design:** a complex social intervention that is challenging to implement & whose impact and outcomes are difficult to evaluate.
- **Evaluation:** less than half were aware of the costs of their project(s); no formal cost-benefit or cost-effectiveness studies of EBCD have been undertaken.
Common improvement priorities in all seven EDs:
- Patient and carer comfort and privacy
- Physical space for staff and patients
- Communication and information flow

For example:
- Designated nurse to manage waiting room and communicate with patients
- ‘Informed waiting’ training for all staff
- ED redesigned to ensure both triage nurse and clerical staff have clear view of the waiting area

The primary strength of EBCD over and above other service development methodologies was its ability to bring about improvements in both the operational efficiency and the interpersonal dynamics of care at the same time.

EBCD teaches project staff new skills; it enables frontline staff to appreciate better the impact of health care practices and environments on patients and carers; it engages consumers in ‘deliberative’ processes that were qualitatively different from conventional consultation and feedback.

Breast & lung cancer services, London

- **Knowledge & skills transfer:**
  - trained 2 in-house QI specialists
  - mentored through the process

- **Fieldwork involved:**
  - 36 filmed narrative patient interviews
  - 219 h of ethnographic observation
  - 63 staff interviews
  - a facilitated EBCD process over 12-month period

- **Mapped quality improvements and studied sustainability**

- **7 co-design groups**
- **56 quality improvements implemented**
- **19-22 months after initial implementation, 66% of improvements sustained**
  - ‘Quick fix’ solutions: 28 with 24 sustained
  - ‘Process redesign’ solutions: 9 with 5 sustained
  - Cross service or interdisciplinary solutions: 14 with 8 sustained
  - Organisational level solutions: 5 with 2 sustained

- **Crucial role of facilitators in determining staff experiences of the EBCD approach**

The aim

To develop and test a carer support package in the chemotherapy outpatient setting using EBCD

• Understand support provided by healthcare professionals to carers
• Develop a short film depicting carers’ experiences
• Bring healthcare professionals and carers together in co-designing components of an intervention for carers
• Develop and implement a carer intervention.
• Explore feasibility and acceptability, impact on carers’ knowledge of chemotherapy and on their experiences of providing informal care.
Carers of patients receiving outpatient chemotherapy

- Leaflet
- DVD
- Group consultation
<table>
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<tr>
<th>Carer knowledge</th>
<th><strong>All items:</strong> intervention arm sig enhanced knowledge vs control ( (p&lt;0.001-0.012) )</th>
<th>How adequate was info received from Drs &amp; chemo nurses re benefits of chemo?</th>
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<tr>
<td>Information needs</td>
<td><strong>8 of 12 items:</strong> intervention arm sig greater improvement in info needs being met ( (p&lt;0.001-0.03) )</td>
<td>Did you need info on dealing with symptoms &amp; SEs of chemo at home?</td>
</tr>
<tr>
<td>Experience of care</td>
<td><strong>6 of 11 items:</strong> intervention arm sig better experience of care ( (p&lt;0.002 - 0.048) )</td>
<td>How satisfied were you with how friend/rel symptoms managed?</td>
</tr>
<tr>
<td>Coping</td>
<td><strong>1 of 6 items:</strong> intervention arm sig more confident in coping ( (p=0.016) )</td>
<td>How confident do you feel supporting your friend/rel thro chemo if their health declines?</td>
</tr>
<tr>
<td>Emotional wellbeing</td>
<td><strong>No sig differences</strong></td>
<td>Have you recently lost much sleep over worry?</td>
</tr>
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Tsianakas V, Robert G, Richardson A et al. (In press) ‘Enhancing the experience of carers in the chemotherapy outpatient setting: an exploratory randomised controlled trial to test the impact, acceptability and feasibility of a complex intervention co-designed by carers and staff’, *Supportive Care in Cancer*
Evaluations of EBCD

• Suggest it is an effective way to make improvements and leave a legacy of cultural change
• But – costly and time intensive
• Can we make it cheaper and faster? Testing the use of trigger films made from a national archive alongside EBCD techniques
• Re-analysis of lung cancer and intensive care transcripts from HERG/Healthtalkonline collections
Learning disability and health

Gabrielle

Nine people made films about what happened when they were unwell. They talked about doctors, nurses, ambulances and hospitals. Click here to find out how they made the films.

These nine digital stories were made as part of a project called ‘Our Check’ that was funded by the Department of Health. We worked with a group of people from self-advocacy group My Life My Choice, to make these films.
Our research questions

• Is the accelerated approach acceptable to staff and patients?
• How does using films of national rather than local narratives affect the level and quality of engagement with service improvement by local NHS staff?
• How well do national narratives capture and represent themes important to local patients’ own experience?
• What improvement activities does the approach lead to?
• What are the costs compared to EBCD?
‘Accelerated’ EBCD: improvement activities and cost

- similar improvement activities to standard EBCD projects
- 48 improvement activities in total:
  - 21 small scale changes
  - 21 process redesign within teams
  - 5 process redesign between services/activities
  - 1 process redesign between organisations
- costs of AEBCD are around 40% of EBCD (excluding one-off costs of developing a national trigger film)
**Experience based co-design work on Betts Ward**

"Really striking how simple changes can make a big difference."

A Betts Ward staff member

Experience based co-design (EBCD) is a service redevelopment tool devised by the King's Fund that looks at the experiences of service users and staff in terms of both giving and receiving care.

It has been successfully used in acute and cancer care services in other trusts, but Betts Ward at Green Parks House is the first mental health inpatient setting to use it.

A project team from our Adult Acute Mental Health Services directorate has been working with staff and service users over the last few months and a joint EBCC event for staff and service users was recently held at the Ripley Arts Centre in Bromley. The event was a great success with seven service users, one family member and 12 members of staff attending.

Participants watched a video of interviews with service users from ResearchNet (who produced the video) about their experiences with Oxleas services, areas of concern and responses to the following four questions:

1. What would you describe as a well conducted admission?
2. What would you describe as the three most important basic needs of a ward patient?
3. The ward staff have rules they need to apply to all patients regardless of how they have been functioning prior to admission (for example: removing shoe laces; withholding patient’s lights in the office; using plastic cutlery (which sometimes cannot always cut meat)). This is done for safety but can be perceived as demeaning by some patients and can cause conflict. Can you give examples of how such rules can be applied well or badly?
4. Can you give examples, either from your own experience, or your observation of others’ experiences, of conflict between patients and ward staff? Can you give descriptions of how this can be handled well or badly?

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**Toolkit uses patient experiences to improve mental health services**

The toolkit captures the experiences of patients, carers and staff through discussion, observation and filmed interviews.

Neil Springham and Ann Woods
Guardian Professional, Tuesday 7 January 2014 09.00 GMT

Staff at Oxleas NHS foundation trust found that communication had a powerful effect on patient experiences of admissions. Photograph: Alamy

**Mental health** acute wards are frightening for patients and stressful for staff.

Patients feel at their worst and are often terrified about what is happening. Staff must process a high volume of admissions, many of which come with additional complications relating to factors such as housing or benefits.

For these reasons, the patient experience team at Oxleas NHS foundation trust decided to take a new approach to these pressures. The experience-based co-design (EBCD) toolkit is a distinctive approach, which captures the experiences of patients, carers and staff through discussion, observation and filmed interviews; then brings them together...
On the Brink of Genuinely Collaborative Care: Experience-Based Co-Design in Mental Health

Michael Larkin¹, Zoë V. R. Boden¹,², and Elizabeth Newton¹

Abstract
Inpatient mental health services in the United Kingdom are currently dissatisfactory for service-users and staff. For young people with psychosis, being hospitalized is often distressing, and can lead to disengagement with mental health services. This article describes how we took three qualitative research studies about hospitalization in early psychosis (exploring the perspectives of service-users, parents, and staff) and translated them into service improvements developed in collaboration with a range of stakeholders, including service-users, carers, community and inpatient staff, and management. We used an adapted form of experience-based co-design (EBCD), a participatory action-research method for collaboratively improving health care services. The use of EBCD is still relatively novel in mental health settings, and we discuss how we adapted the methodology, and some of the implications of using EBCD with vulnerable populations in complex services. We reflect on both the disappointments and successes and give some recommendations for future research and methodological development.

Keywords
research, action; research, collaborative; mental health nursing; mental health and illness; lived experience; young adults; health care, acute / critical; early psychosis; health care, users’ experiences; health care, work environment
Getting to the CORE: testing a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness

The CORE Study research team would like to thank you all for taking the time to meet with us in 2013. I would like to thank you all for your time, effort and all the information that you have given to the CORE Study so far. Discussions at these initial meetings have been invaluable in informing our research planning. Since commencing the study in June we have been busy piloting aspects of the research, submitting ethics applications and finalising the study protocol among other things.

We are also excited to announce that the CORE Study will officially be launched on Friday 14th March, 2014. An invitation and further details will be coming your way soon. This will be an opportunity for you to meet the study investigators and research team, to hear more about what the CORE Study aims to achieve over the next three years and hopefully how the study can contribute to optimise recovery for people affected by mental illness.

On behalf of the CORE Study team I wish you all a happy and safe break over the festive season and we look forward to seeing you all there.

« CORE will test a co-design method as an approach to optimise recovery for people affected by mental illness in the primary

What is the CORE Research Team currently working on?

- meeting with key staff of the Mental Health Programs at our partner Community Health Centre sites (our “co-design hubs”);
- mapping the policy and service context for trial implementation (see overleaf);
- conducting a systematic review of the evidence relating to co-design methodologies and interventions to improve psychosocial recovery.
EBCD in Learning Disability services in England
Three ongoing projects

• NHS England: testing EBCD with people with learning disabilities who are currently in ‘secure’ accommodation

• Lancaster & Morecambe Learning Disability service: ‘Using stories to improve services; The LD service EBCD project group’

• healthtalk ‘trigger films’
Good reasons

- To have a good look at the LD service
- To hear about what works
- To hear about what needs to improve
- To give the people who use the service a voice
- To give the staff who work in the service a voice
- To find a way to all work together to make things better
HOW?

- Record people talking about their experiences
- Edit into a short film which highlights key points / emotional touchpoints
- Share film at a joint event as the opener for discussions about what works well/what needs to change
- Plan changes and work on them - together
LT group involvement....

- Support with:
  - Materials to promote the EBCD project
  - Developing information and consent forms
  - The launch event
  - Interviewing people who have used the service alongside a service member
  - Input and feedback on the film editing process
  - The joint event
Ideally:
- Launch event March/April 2015
- Collect stories April/May 2015
- Joint event June/July 2015
- Follow up event – 6 months later
New ‘trigger’ films (ESRC)

- BME mental health
- young people and depression
- autism
- asthma
- raising concerns
- communication across organisational boundaries
Autism

Overview

The way in which autism is understood has changed over time and this is reflected in the changing use of language. For some people, autism is a form of difference rather than a disability and they use the term neurodiverse to describe people on the autism spectrum and the neurotypical to describe those who are not.
Trigger films for service improvement

Overview

In this section you will find a range of ‘trigger films’ we have created for use in service improvement projects, including experience-based co-design and experience-led commissioning. Trigger films are designed to be used as part of a facilitated quality improvement process; their purpose is to get local people, patients, families and NHS staff talking together about how they can jointly improve people’s experience.

You can find out more about experience-based co-design here kingstfund.org.uk and experience-led commissioning here experiencedcare.co.uk.

The Point of Care Foundation has developed a training course in experience-based co-design with support from NHS England, pointofcarefoundation.org.uk.

We would welcome feedback from anyone using the films to know how and where they have been used, and what the impact was.
Further information

• EBCD toolkit: www.kingsfund.org.uk/projects/ebcd
• EBCD LinkedIn group: www.linkedin.com/groups/Experiencebased-codesign-6546554
• twitter: @gbrgsy, @PointofCareFdn
• Glenn Robert email: glenn.robert@kcl.ac.uk