Through experience-based co-design, patients’ views about their care and treatment can be explored so that simple but effective changes can be made to improve services.

Designing services in partnership with patients

In this article...

- What experience-based co-design projects involve
- A quicker but equally effective EBCD method
- How the project can benefit patients and staff

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A variety of methods are available to encourage health professionals to listen to patients and relatives, but are not routinely used to improve the quality of services. Experience-based co-design enables staff and patients to design services and/or care pathways in partnership. This article explains how the approach works in practice, outlines its benefits and details the resources available to help health professionals use it to improve patients’ experiences.

Listening to patients is an important activity for health professionals. They can “best find the gaps that matter [in the patient experience] by listening very carefully to the people they serve” (Berwick, 2003).

A range of approaches can help with this, including surveys, storytelling, focus groups and online feedback. Techniques such as shadowing patients and observing staff-patient interactions can also be used to find out how and why services do or do not work well, and how they might be improved. However, staff do not routinely use information to improve the quality of their services (Robert and Cornwell, 2013) unless they have support (Reeves et al, 2013); often patients are only given a passive role in care, with staff making decisions.

The Point of Care Foundation works to improve patients’ experiences of care and increase support for the staff who work with them. It believes patients can, and should, take a more direct and ongoing role in identifying, implementing and evaluating improvements to healthcare services. It also aims to improve services for patients and staff by being patient-focused – starting with the premise of understanding the service through the patient’s eyes.

To achieve this, the foundation teaches and supports experience-based co-design (EBCD), a methodology for groups of patients and staff working together.

The EBCD approach

EBCD enables staff and patients or other service users to co-design the services and/or care pathways relevant to them. This approach differs from other service-improvement techniques, as it involves gathering experiences from patients and staff through in-depth interviews, observations and group discussions, identifying key “touchpoints” – emotionally significant points – and assigning positive or negative feelings. A short, edited film is created from patient interviews, and shown to staff and patients, conveying how patients experience the service. Staff and patients are then brought together to explore the findings and work in small groups over the following few months to identify and implement activities to improve the service or care pathway.

EBCD was designed for, and within, the NHS to develop simple solutions that offer patients a better experience of treatment and care. Piloted in 2005 by Glenn Robert and Paul Bate in Luton and Dunstable University Hospital’s head and neck cancer service (Bate and Robert, 2007), it has since been used in a range of clinical services.
including diabetes, drug and alcohol treatment, emergency, genetics, intensive care, mental health, learning disabilities, orthopaedics, palliative care and surgical units.

**EBCD in practice**

EBCD is a six-stage process and usually takes about a year to complete. It involves:

- Setting up the project;
- Gathering staff experiences through observation and in-depth interviews;
- Gathering patient and carer experiences through 12-15 filmed narrative-based interviews;
- Bringing staff, patients and carers together to share their experiences of a service and identify shared priorities for improvement, prompted by an edited 30-minute film of patient narratives;
- Small groups of patients and staff working on the identified areas for typically 6-12 months;
- A celebration and review event.

**First steps: recruiting staff and patients**

After receiving approval for the project, the project leader sets up a steering group, including key members of staff from the service and their management team. The group recruits a project facilitator to set the timeline and ensure everything runs on track; the facilitator needs protected time to manage the process – typically, they give 40% of their time to a project over a six-month period.

The project leader’s first activity is likely to be observation. This involves spending time in the service watching how the teams and systems operate, trying to imagine they are a patient or seeing the service through fresh eyes as a visitor. The next step is to recruit staff, both clinical and administrative, to take part in the project; some might be suspicious about the agenda, uncomfortable about criticising their workplace or worried about receiving criticism from patients, so it is important to address these fears and build trust.

The project leader also needs to find one or more key staff members, who will work with colleagues to identify around 5-15 patients who have a story to tell and can be filmed. Interviewees should be invited from across the entire patient pathway, giving a diversity of views and roles, and including both sceptics and enthusiasts. The staff identifying them should therefore have an overview of the whole clinical pathway – those well placed to do this may be the clinical nurse specialist, case manager or someone with a pathway-coordination role.

**Box 1: Case study**

Melanie Gager, research facilitator and sister at the intensive care unit, Royal Berkshire Foundation Trust, Reading, talks about her experience of accelerated experience-based co-design:

“In 2011, I was approached to take part in research funded by the National Institute for Health Research. This was looking at using the accelerated EBCD approach for two pathways: an intensive care pathway and a lung cancer pathway. It aimed to evaluate EBCD projects at Royal Berkshire Foundation Trust and Royal Brompton and Harefield Foundation Trust using Healthtalk’s ready-made ‘trigger’ films. Research showed it was just as effective to use a ready-made trigger film – it didn’t matter that the patients and carers on the film were not from our own trust.

“The power of watching a film of patients and relatives is that they are giving their experiences honestly and openly. For example, after having an investigation and getting a diagnosis of lung cancer, rather than talking about the clinical process, patients talked about their emotional experiences.

“These are ‘touchpoints’, when patients, relatives and carers talk about what sticks in their minds – how they feel as human beings about, say, their experience of being in intensive care.

“The trigger films, along with face-to-face interviews with staff, build insight from patients, relatives and health professionals. We invited patients, relatives and staff to a co-design meeting, where we watched the film together. Staff and patients shared their insights about each other’s worlds then, together, both groups agreed their collective list of four priorities aimed at improving the experiences of patients, relatives and staff in future.

“One of the issues that came out of the project was that patients who had been ventilated in intensive care described their experiences of being ‘voiceless’ but said it was important to recognise that they should still have a way of communicating their needs. So we worked with colleagues from the learning disabilities team, who introduced us to an app called Grid Player. We then bought an iPad so patients could tap out their needs.

“Another simple but effective initiative resulting from the EBCD project was to make the room where a lung cancer diagnosis is given more comfortable. This included having a sofa in the room so, for example, a husband and wife can hold each other, cuddle and cry, rather than having to sit separately in hard chairs.

“These sorts of initiatives resulting from the EBCD project have made a tangible difference to the patient experience. One cancer nurse specialist said the project had been the most rewarding thing she had done in her career. Hearing patients’ experiences reconnects you to your beliefs and values as to why you chose nursing as a profession.”

Having identified potential participants, the project facilitator or a staff member will telephone patients, explain the project and compile a list of those interested in taking part before sending follow-up information and consent forms.

**Filming and editing interviews**

The aim of patient and staff interviews and observational work is to help them identify, and jointly explore, the touchpoints – themes that particularly resonate, and that may also come up in other interviews – on the journey of care. Touchpoints can be positive or negative, and are the aspects that both patients and staff perceive as crucial to their overall experience of receiving or delivering care.

Interviews should take place within a couple of weeks of recruitment, in a place where participants feel comfortable. Before filming, participants should be sent notes to help them prepare. Patients should also be asked to consent to the clips that will go into the final version and encouraged to be completely open. Interviews usually take 1-2 hours but are edited down for the final compilation film, which lasts, at most, half an hour.

Although filming patients can be time consuming, it is an opportunity to act as a catalyst for improving services. Seeing and listening to patient experiences, and capturing these, can help to connect staff and prompt changes to health services.

The films also set the process apart from other ways of capturing patient experiences, such as when anonymity and circumspection can often hinder rather than enable improvement.

Editing involves watching all interview footage – either with another person or
alone – to get an overview of what was said and find key touchpoints. Each interview must be edited down to about 10 minutes’ duration. Project leaders will need editing equipment and software, and may require the services of a professional editing team.

The next step is to identify key themes, such as “getting your diagnosis”, and divide clips into those themes, interweaving various patients’ quotations. The final video should show a title screen for each theme, such as “outpatients”, followed by views from a number of patients on that topic.

**Staff and patient feedback**

Once the filming and editing of patients is completed, separate feedback events are organised for patients and staff, at which they see and discuss the film and share their views on it. The feedback from both events is then narrowed down to a shortlist of potential areas for service improvement, which will be raised at a joint patient-staff event.

At the patient-staff event, all who have taken part in the project watch the film and spend 10 minutes discussing the footage. Staff and patient priorities agreed at the separate events are shared, so that all participants are aware of the priorities discussed and can jointly narrow the choice down to three or four key target areas for service improvement.

Finally, participants are invited to join the co-design group that will focus on the area of most interest to them.

**Co-design groups**

These are small working groups of patients and staff set up to design and implement solutions to the priority issues highlighted at the patient-staff event. Project leaders should identify someone to facilitate and organise each group to:

- Encourage discussion;
- Help the group develop ideas into concrete actions;
- Ensure those actions are followed up.

During the course of a project, a common question is: “What has the project achieved so far?” It is important to highlight what has been accomplished to date and achievements can be measured against two sets of goals:

- The delivery of the objectives set by the co-design groups, which will focus on the service changes;
- Project objectives, such as how many people have turned up regularly.

Because EBCD draws on qualitative data, it may not be possible to measure the resulting service improvements through typical approaches, such as audit. However, they can be measured by:

- Listing all the improvements suggested by patients and staff, and detailing which have been achieved to date;
- Using a more formal evaluation approach, such as before-and-after surveys, to test whether patients’ experiences were improved as a result of the intervention.

Evidence suggests EBCD can produce changes that improve patient experience and are acceptable to a range of service users (Ziebland et al, 2013). In an international survey in 2013 (Donetto et al, 2014) 37 of the 41 respondents who had completed an EBCD project said the approach “really engaged patients”; 32 said “it really engaged staff” and 26 said “it allowed discussion of difficult topics in a supportive environment”.

The National Institute for Health Research in England funded an evaluation of the “accelerated” EBCD approach (Locock et al, 2014) – a way of completing a project more quickly by using a ready-made film from the national Healthtalk archive (www.healthtalk.org), which acts as a trigger for patients to talk about their experiences, rather than making your own patient film. Box 1 illustrates one health professional’s experience of using this approach and its benefits.

The Locock et al (2014) evaluation showed its impact on patients and staff. One consultant described it as “phenomenal”, and nurses said “I have already changed the way I care for patients” and “I’m a better nurse because of it”.

EBCD can often reveal hidden factors shaping patient experiences – for example, it might identify that the most frustrating aspect of long waiting times relates to poor communication rather than the wait itself. The approach focuses on solutions that those involved in EBCD projects develop together to produce realistic goals that would benefit staff and patients.

The two-way process develops connections across staff teams and between staff and patients, and can boost confidence and staff motivation.

As patients are involved throughout the process, EBCD offers health professionals the opportunity to check back with them to ensure the changes made succeed in improving their experience of healthcare. Crucially, the approach involves patients and staff working together to design and make improvements to their services. It can also easily be adapted to encompass the views of carers.

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**References**


Donetto et al (2014) Using Experience-based Co-design to improve the quality of healthcare mapping where we are now and establishing future directions. London: King’s College London.


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**For more on this topic go online**

- Patient narratives 1: using patient stories to reflect on care
- Bit.ly/NTPatientNarratives

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**BOX 2. FURTHER RESOURCES**

**Experience-based co-design toolkit**

This toolkit was produced by the King’s Fund in 2013. It incorporates learning and feedback from staff and patients involved in experience-based co-design projects, including the accelerated form of EBCD at www.kingsfund.org.uk/ebcd.

**Masterclasses**

The Point of Care Foundation runs open masterclasses taught by facilitators who have led their own successful co-design projects, which provide a comprehensive step-by-step summary of the process. The foundation can also provide coaching and support to teams throughout their co-design projects.

**Trigger films**

These are free to use: See Bit.ly/HealthtalkFilms

**Further information**

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Bit.ly/PoFCoDesign