Royal College of Physicians | Future Hospital

Experience-based co-design: designing the future of hospital services

An interview with Catherine Dale, programme manager for patient-centred care at King's Health Partners Comprehensive Cancer Centre.

In conversation with the Royal College of Physicians' Future Hospital Programme, Catherine Dale, programme manager for patient-centred care at King's Health Partners Comprehensive Cancer Centre, talks candidly about the importance of involving patients in designing sustainable and successful hospital services.

What is experience-based co-design and where did it emerge from?

Experience-based co-design (EBCD) was designed for and with the NHS to allow people – both patients and staff – to tell stories about their experiences with the hope of improving services and wellbeing. EBCD involves patients and staff working together to design what the future of that service will look like.

EBCD gives teams a framework within which they can work together to identify how experiences can be improved for patients, their family and staff. Patients and staff are individually interviewed and short videos are prepared of the patients' stories. After watching the video interviews, the same people are asked to work together in small groups of patients and staff to co-design solutions for the future.

It was recognised that, while there were many interventions or quality improvement (QI) methods in health that look at safety and performance, there was nothing for those wanting to look at the aesthetics of experience. EBCD took inspiration and learnings from design industry and its founders collaborated with industry experts to establish how design principles can apply in a healthcare context. Uniting and creating a partnership between service users and service providers allows for a balanced approach to solutions, with both patients and staff grounding these it in the reality of the context.

What is the evidence?

EBCD is a very straightforward and flexible approach that can lead directly to action and genuine improvement. In a recent study (2015), EBCD was used in an acute mental health triage ward at Oxleas NHS Foundation Trust. The trust was attracting high levels of formal service user and family complaints and decided to use EBCD to examine the issues and redesign procedures. This resulted in an immediate eradication of formal complaints over a period of 23 months[1]. Indeed, the results complement the evidence already accumulated for patient and carer involvement in service improvement projects.

Why is it important to involve patients and carers in service improvement?

Simply because we don't know what it's like to be a patient or carer. Additionally, we might misinterpret what they are trying to communicate. You can only really address what people need by asking them directly and then exploring how to address that with them.

When people are creating products they have to sell or services they want to attract people towards, they have to understand how people will experience or use them. We don't have to this in health because people will still need our services no matter how bad those services are. If we want to deliver really great services that don't frustrate the people who use and deliver them, then we have to design the experience. I am extremely passionate about this and sometimes find it surprising that the health service is only just catching up to the concept of understanding services from the point of view of the people experiencing them.

What does EBCD involve in practise?

EBCD is quite qualitative in its methodology. The main stages are:

[1] Springham N and Robert G. Experience based co-design reduces formal complaints on an acute mental health ward. *BMJ Qual Improv Report* 2015: 4

- observation of clinical areas – gain an understanding of what is happening on a daily basis
- conducting open-ended interviews with staff, patients and families – exploring niggles and identifying recurrent themes
- filming and editing interviews of patients into 25–30 minute documents of themes
- facilitating meetings and activities with patients and staff (separately to begin with then together) to help move from individual to collective experience of the service
- in the staff feedback event, agreeing improvement areas staff wish to prioritise and are happy to share with patients
- in the patient feedback event, showing the film to patients and agree improvement areas patients wish to prioritise
- holding a joint patient-staff event to share experiences, agreeing the top priority improvement areas for staff and patients and help move people from feedback to action
- running co-design groups to meet over 4-6 months to work on agreed improvements
- celebrating the achievements of co-design groups and initiating new improvement work.

What kind of resources and budget does EBCD require?

EBCD can be adapted to suit a range of resources and budgets. For example, teams can adopt the accelerated approach which replaces individual patient videos with existing videos (specifically chosen to trigger a similar response in patients but requiring half the resources as the full approach).

You do need people who are involved to have skills and time to conduct the activities. Luckily, in hospitals you tend to have access to people with a wealth of skills and experience. There will usually be those who are experienced at discovery interviews, for example, and those who can be trained-up to do observations. Facilitation skills are really key to many of the activities so ensure that there are people who have experience of facilitating group discussions. I had a lot of experience of working with groups of staff and this was very useful for working with staff and patients together. EBCD would not be a great place to start if you have never conducted any facilitation before.

When we first started, everyone thought suggestions from the patients would be really expensive, but actually it isn't like that. You can assign a budget to your co-design group – including £0! This challenges the teams to be really creative and identify quick fixes which could have great impact on the service.

Can you describe some of the different types of services that have used EBCD?

EBCD can be applied to all sorts of services. It has been used in: mental health; drug addictions; learning disabilities; cancer; children's services; and accident and emergency departments.

When approaching a new service it's important to get the level right. Our evaluation of sustainability showed it had more impact at a local level where people involved can directly make the changes they were talking about introducing. In cases where the improvements identified are more structural, it can be more challenging; for example the way an organisation interfaces with other organisations and its wider governance.

A good rule of thumb is making sure you are able to explain where you're working to ordinary people. My mum was once invited to join a clinical commissioning group (CCG) patient involvement group and she was really surprised by the content of the presentation she was shown. It mainly outlined the new CCG structure which involved lots of acronyms and expert information which was irrelevant to her and her position. That's why we always make sure we return to the key focus of the EBCD in our sessions – think: what is it like to go through this service, have this condition and cope with this place or issue?

What are some of the most challenging aspects of running EBCD? How can people overcome these challenges?

Most service improvement activities start with a problem we want to fix. You have to start EBCD by understanding you don't necessarily know what the problems are until you ask people.. Experiential activities such as EBCD get people to think 'why don't we always do this?' therefore requiring the team to undergo a shift in attitude. Good time management and prioritisation is required to help people take the process seriously.

Sometimes 'patient experience' can be used as a label, but it's not really patient experience that's being discussed – it's a structural or organisational issue. For example, there is a difference between access to GP services across a community compared with an individual's experience of being at the end of a telephone with no one answering their call. EBCD focuses in on the latter.

What are some of the most rewarding aspects of running EBCD?

Enabling staff and patients to talk to each other is fantastic. Spending time with people who are willing to give up their time to participate in exercises which will have lasting impact on their service is a real privilege. We help people get in touch with the 'this is why we are really here' emotions.
That's not to say it's not hard work. It can be difficult sorting out the logistics and a lot of effort is needed by a whole team of people. Ultimately it is very rewarding and it is what we should be doing.

What can people do to get their colleagues to sign up to taking part in EBCD?

All activities through every stage of the EBCD process are engagement activities. We know it's unrealistic to expect sign up for 500 patients and staff on day one; the method is a slow-burner.

You will always be able to find some people who are keen so look out for them initially. Use observation as an engagement tool with staff – people respond positively when you take the time to understand their work and what challenges they face. Also think about people who can help you identify service users who have a story to tell. Work with them on their timescales and with knowledge of their priorities. Make sure it fits in with and complements other activities going on in that service or trust.

Don't necessarily focus all your energy on the negative people, start with the enthusiasts and positives. There will be some people who won't 'get it' but I don't think you should necessarily worry about the entire world getting enthusiastic about this because enough people are and they will lead them along.

How can teams measure the outcome of EBCD?

Don't be afraid of numbers and data – people like them and it's great to collect information about the things people say need changing. Change things and then show people how you have changed them. Sometimes the changes can manifest as a ripple effect and changing culture can be difficult to measure but having concrete examples, even if it is of really small things, can be really helpful.

Why should physicians get involved in EBCD?

All the above! It's been a surprise to me how much doctors have loved the EBCD process. Whereas nurses tend to have more experiential conversations with patients about what it's like to use the service, have a disease or go through the experience of using a service, doctors have less of this and instead focus on the clinical aspects. Therefore, EBCD is a refreshing change for them and patients really appreciate seeing many different members of staff getting involved.

EBCD does not come without its challenges. These are real people with real relationships and it can be the case that a bad experience in the past leads to a clash which might need to be managed carefully in the sessions. However, by shifting the dynamics for people, doctors really find it reminds them of 'this is why we do this'. It can be motivational and help doctors to influence changes so they can make things better.

What resources are available to people interested in using EBCD?

The King's Fund EBCD toolkit

Point of Care Foundation

Experience-based co-design LinkedIn Group

Bate P, Robert G. *Bringing User Experience to Healthcare Improvement: The Concepts, Methods and Practices of Experience-based Design*. Oxford: Radcliffe Publishing, 2007

Catherine Dale is the programme manager for patient-centred care in King's Health Partners Comprehensive Cancer Centre. She has over 15 years' experience of management roles in acute NHS trusts in London, including more than 10 years in service improvement and transformation roles.

Catherine led a programme of work in cancer services using experience-based co-design (EBCD). As a result of this work, Catherine led the original development of the King's Fund's EBCD toolkit. She now supports the Point of Care Foundation to develop and deliver training in EBCD. Catherine has a master's in business psychology.

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