The Experience-Based Co-Design approach – how the method works

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Experience-Based Co-Design

A change method and process aimed at improving patient and staff experiences of health care by combining:

• a user-centred orientation (EB), and

• a collaborative change process (CD)
“Service design for, with, and by users and staff”
What makes a good service: designing experiences

- **Performance (P)**
  - How well it does the job/is fit for purpose
  - (Functionality & efficiency)
  - Lean, No Delays, Productive Ward/Leader

- **Engineering (E)**
  - How safe, well engineered and reliable it is
  - (Safety)
  - LIPS, SPI

- **The Aesthetics of Experience (A)**
  - How the whole interaction with the product/service feels/is experienced
  - (Experience)
  - EBCD

Physical environment
Human environment
An Experience-Based Co-Design (EBCD) approach to improving healthcare services

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

• putting patient experiences at the heart of the service 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 the care, and the way they feel about those experiences
Different ways of giving patients a voice

Complaints  Information  Surveys  Patient blogs and web-based stories  Consulting & advising  Staff & patients working together to redesign services

Experience-Based Co-Design (EBCD)

Adapted from Bate & Robert, *Quality & Safety in Health Care*, (2006)
Relying on surveys alone is not enough ...

• barriers to using survey results:
  – data not specific enough
  – lack of time and resources
  – not knowing what to do about the survey results
  – lack of statistical expertise

• ‘surveys themselves do not indicate what needs to be done to improve any situation. Further commitment and ingenuity are needed to understand shortcomings in an organisation and develop solutions.’

• ‘well designed questionnaires for patients could contribute usefully to an assessment of both the technical competence and interpersonal skills of doctors. If these surveys are to play a role in quality improvement, they should provide clear factual results that prompt follow-up action.’

Sources: Reeves & Seccombe (2007); Davies & Cleary (2005); Coulter (2006)
Key characteristics of EBCD

- value of patients, carers and staff experiences
- stories not surveys
- ‘deep dives’ and direct observation
- ‘touchpoints’ and emotional mapping
- direct participation in the improvement process through co-design: staff and patients
Welcome to Luton & Dunstable and the ‘Your Experience Matters’ project
How can your experience of head and neck services be improved?

Let a member of the care team know if you would like more information about how you could get involved.

Your Experience Matters
Patients and Staff Designing Services Together.

The aim
We want to work with patients, carers and staff to design the best possible care experience for head and neck cancer patients. The first step is to find out what you like and don’t like about the service.

How will we achieve this?
We would like to learn more about how the service looks through your eyes, by listening to your stories and experiences. What is learnt from your experiences will be used to decide what improvements to make.

Who will decide what improvements if any should be made and how an improved service should look?
A group of patients, carers and staff with a small team of health care design researchers will decide together. The patient and staff get points from the stories to design a service that keeps the patient experience and reduces those that spoil it.

How can I help and what would this involve?
You can help by meeting with one or two of the health care design researchers. You will be asked to tell them about your experience. Later you could also be asked to join a team of carers and staff helping to decide what improvements to make.

You are under no pressure to talk to the team if you do not wish to.

If you want to know more about this ask a member of the Head and Neck team or contact
Elaine Hale: 01582 497417 ext 7417 Elaine.Hale@ldh.nhs.uk
Carole Glover: Specialist Head and Neck Nurse: 0845 1279127 ext 8638 Carole.Glover@ldh.nhs.uk
The Luton and Dunstable Hospital NHS

Making a real difference to patient experiences

**Working together as equal partners**

The power of patients who are involved in service improvement is phenomenal, this guide shows how everyone in healthcare can use patient and staff experience to improve the healthcare services delivered.

Creating a health service, where we no longer do things ‘to and for’ patients, but work with them as equal partners in their own care is right at the centre of health strategy, policy and reform.

It cannot be considered as an optional extra but must be considered as a core component of everything that we do. Creating health services that are designed around customer needs and experiences, where user involvement is integral to everyday practice and where people’s voices lead to action for improvement, must be an ambition for all.
Emotional mapping session

How to run an emotional mapping session.

Understanding the emotional journey of those receiving and giving care can really help improve your service and this is where a technique called emotional mapping comes in. This technique will help you to highlight where your service is working well and where it can be improved from the perspective of your patients, carers and staff.

Emotional mapping is a technique that can be used by patients and staff to describe in detail the emotions (positive and negative) experienced along the patient journey.

It helps to highlight emotional ‘highs and lows’ of the service or pathway.

Different patients may have experienced different emotions at similar points in the service.

This isn’t a problem. It’s actually a great opportunity to get people discussing in detail what it was about their personal experience that led to these different emotions.

You don’t need special equipment for emotional mapping; just a long wall, paper, pens and blu-tack!
And since then ...

**NHS:** major implementation of EBCD in breast and lung cancer services across two major London teaching hospitals, ongoing evaluation by the King’s Fund

**AUSTRALIA:** implementation of EBCD in three emergency departments in hospitals in New South Wales in 2008 (and four further sites in 2009 including base wards), two independent evaluations completed by University Technology Sydney (one exploring sustainability)

**NHS Institute for Innovation and Improvement:** 1 day training courses, 'Facilitator’s Guide’, series of projects

**KCL:** series of funded projects and proposals

- ‘Enhancing the role of carers in the outpatient chemotherapy setting’, funded by Dimbleby Cancer Care
- ‘Using patient, carer and staff experiences to improve palliative care provision for elderly people in A&E departments’, PhD study
- ‘Testing accelerated experience-based co-design: using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement’, proposal to the NIHR Service Delivery & Organisation (shortlisted, outcome expected December 2010)
- ‘Adaptation and feasibility testing of an intervention for managing fear of progression associated with active surveillance for low-risk localised prostate cancer’, proposal to The Prostate Cancer Charity
- ‘Minding the Gap: educating hospice volunteers to enhance person-centred care at the end of life’, proposal to Dimbleby Cancer Care and Marie Curie Cancer Care
Overview of the EBCD process

A 6-stage design process

1. setting up
2. engaging staff & gathering experiences
3. engaging patients and gathering their experiences
4. bringing patients and staff together to share experiences & begin co-design
5. detailed co-design activities
6. coming back together: celebration, review & renewal

Source: Bate & Robert, 2007
Getting at the ‘experience’ part of EB

• not by patient surveys

• ‘deep dives’ and direct observation

• patient and staff stories
What to do with these experiences? Identifying ‘touchpoints’

- critical points
- ‘big’ moments (good and bad)
- moments of truth
- emotional ‘hotspots’
Some typical touch points of head and neck cancer patients

- the breaking of the bad news moment
- the PEG moment
- the ‘waking up moment’ in ICU
- the cancer ward moment
- the mirror moment
- radiotherapy and the radiotherapy planning moment
3 ways to do service improvement:

1. we don’t listen very much to our users and we do the designing
2. we listen to our users then go off and do the designing
3. we listen to our users and then go off with them to do the designing
‘for me this is about ‘Oh God, they’re our patients aren’t they?’ when people watch the film they might think, ‘I remember that lady’, they know they’re our patients - they can’t get away from the fact - but it actually makes it more real for them. Whatever way they’re captured, it’s about capturing it so that people recognise these are patients I have cared for, nursed, met, who are saying this ... and I think that’s what is do different from other improvement work in terms of things like discovery interviews and focus groups: it’s that direct connection between them.’
“And it was quite funny to see them lifting up their chairs ... I think that becomes a symbol of the project ... 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.”
For more information on Experience-Based Co-Design (EBCD)

**Toward More User-Centric OD**

**Lessons From the Field of Experience-Based Design and a Case Study**

Paul Bate
Glenn Robert
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This article argues for a major shift in focus from the strong management orientation of organization development (OD) to a more “user-centric” OD, one that seeks to mobilize and privilege change on behalf of the consumers or users of an organization’s product or service, involving them at every stage of the design process, from problem diagnosis to solution generation and implementation. This reconceptualization of OD draws its inspiration from the rapidly expanding field of experience-based design (EBD), a subfield of the design sciences whose distinctive features are direct user participation in the design process and a focus on designing experiences as opposed to systems or processes. The article reports on an original EBD intervention methodology designed and tested by the authors and colleagues in a cancer clinic within the National Health Service, which following successful “proof of concept” offers OD some promising new directions for the future.

Keywords: change; organization; design; users; experience

REDEFINING THE CLIENT AND THE TASK FOR ORGANIZATION DEVELOPMENT

A frequently asked question in organization development (OD) is, “Who is the client, and whose ‘felt need’ should it be responding to?” Apart from the occasional call for it to become more labor or “worker-centric” (Baba, 1998; Nord, 1974), OD practice for the past half decade has remained stolidly “management- or leader-centric”


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Overview of evaluation findings in NSW

AUSTRALIA:
New South Wales: Emergency departments in Hunter New England, Bankstown Hospital and Manning Hospital in 2008 (and now four further sites in 2009 including base wards)

• led to significant improvements, changes in practice, and learnings for clinical and health departmental staff
• specifically, the approach was successful in the following respects:
  – teaching project staff new skills
  – enabling frontline staff to appreciate better the impact of health care practices and environments on patients and carers
  – engaging consumers in ‘deliberative’ processes that were qualitatively different from conventional consultation and feedback
  – achieving practical solutions that realise the wishes, advice and insights of consumers and frontline staff

And two years on..

• successful in:
  – implementing the majority of solutions proposed in the diagnosis phase of co-design;
  – engaging stakeholders beyond the ED staff and patients including General Practitioners and Ambulance personnel in achieving practical solutions; and
  – laying the foundations for an ongoing and developing relationship between health service providers and consumers

• “On a broader front, Co-design has been shown to strengthen service provider-service user relationships ... co-design harbours a collaborative principle that should be woven into how health services and health departments conceptualise and structure their communication with patients, families and the public.”

Source: Piper, D., Iedema, R. (2010) Emergency Department Co-Design Program 1 Stage 2 Evaluation Report. Sydney: Centre for Health Communication (UTS) and NSW Health (Health Service Performance Improvement Branch)
Methods

• Interviews, stories and observations:
  – 60 interviews with staff working within services provided to breast and lung cancer patients
  – 36 patients telling their story of receiving breast and lung cancer services (filmed)
  – observational data from clinical areas (e.g. outpatient clinic, wards)
Why start with staff?

- establish relationships
- the experience of *giving* the service is as relevant and important as the experience of receiving it
- understanding what EBCD is all about and the role they can play in shaping experience
- important role to play in the early stages of an EBCD project (e.g. identifying informants)
- build trust to initiate and sustain the EBCD process
The role of film

• a tool for reflective learning

• video-reflexive ethnography

“Our main argument is that video-ethnographic research enables researchers and clinicians to work in productive partnerships, providing them with a basis for articulating and thereby rendering negotiable knowledge and practices that clinicians might otherwise take as given.” (Carroll et al, 2008)
Feedback events

- Staff feedback event (pictured)
- Patient feedback event
- Co-design event
Staff priorities for improvement

• less waiting in clinics (particularly ‘one stop’ clinics)
• management of waiting areas, meeting and greeting patients, welcoming environment
• support and morale of staff
• communication - letting patients know what is going on in a timely way, helping patients to know what to expect, ensuring people don’t get lost in the system
• inpatient experience on the wards
• ensure adequate symptom assessment/management for the effects of chemotherapy treatment
• enhance psychological support at all stages but particularly care and support post plastic surgery and at the end of treatment
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The first meeting with your consultant

SPIRITUAL NEEDS
Lost

JULIE ON RECEPTION
Happy

Post-operative ward (ward 21)
Discharge from Luton & Dunstable NHS Trust

WARD ROUNDS
DIGNITY and PRIVACY matter on WARD

NOISE ON WARD
FRIO CONTROL

Visitors - Friends & Family

"The Mirror Moment"
I didn't know how to help or what to say.

Vulnerable
Apprehensive
Numb
Powerless
Patient priorities for improvement

- communicating diagnosis- how diagnosis is conveyed, written information at the time
- information about going through cancer treatment and coping with side effects e.g. hair loss, fatigue
- waiting times in clinics
- inpatient experiences- mixed sex wards, communicating with relatives, nursing care
- enhance support for patients at all stages- support groups and website
- day surgery experience
- appointments system
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Source: Bate & Robert, 2007
Co-design event – patients and staff together

- watched film of patient interviews
- heard what the patients have prioritised
- heard what staff have prioritised
- patients and staff agreed on priorities
- form working ‘co-design’ groups to make these improvements
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Source: Bate & Robert, 2007
Co-design areas for improvement

BREAST:
• **Surgery** (including and beginning with day surgery) ‘I don’t want to feel like I’m on a conveyor belt’

• **Communication** ‘I don’t want to be left in the dark about what is going on’

• **Appointments** ‘I don’t want to have to manage my appointments’

• **End of treatment** ‘I don’t want to feel dropped after my treatment’

LUNG:
• **Communicating diagnosis** ‘It was like falling off a cliff...you should be able to speak to somebody immediately after your diagnosis’

• **Inpatient experience on ward x** ‘The nurse didn’t even look at me when he was talking to me’

• **Information around side effects of treatment** ‘You should have someone sit down with you and explain what’s about to happen to you’
What has happened since? Achievements in day surgery

• patients had felt they were separated from their loved ones very early in day surgery. Once patients were undressed they were moved into gender-specific waiting areas. Staff now ensure that this separation happens as close as possible to the time of surgery.

• the relationship between day surgery nursing staff and the surgeons has been enhanced through meeting and discussing issues with patients. Better communication has contributed to reducing the amount of time patients now wait without their loved ones.

• consultations between patients and surgeons now take place in a dedicated room affording patients privacy and dignity, rather than the changing areas in which this was happening.

• staff worked with patients to review information flows from pre-assessment to operating surgeons and how dates of post-operative appointments are arranged. These are now agreed with patients and documented before they have their surgery.

• breast physiotherapist used the experience to review the best time for patients to receive information about exercises that they are encouraged to do following surgery.
“it’s obviously quite a difficult and isolated thing being a patient, sitting in the clinic, wondering what is going to be said to you, what the future is, and generally being quite apprehensive, and there are a whole lot of other people around you who are probably all feeling the same but nobody knows anybody else and it’s very rare for people to have the courage to actually speak to anybody else. But there’s a completely different atmosphere once there are two or three people who know each other and it is an opportunity to include others so it’s important that it’s not exclusive just to those who know each other because of this project. I think it does hold quite a lot of possibilities just to set people more at ease, and, of course, included in that have been such things as actually improving the seating in the clinic and the environment.”