Further reading resources on experience-based co-design

Resources about how to do experience-based co-design

Bate SP and Robert G (2007)
Bringing user experience to health care improvement: the concepts, methods and practices of experience-based design. Oxford; Radcliffe Publishing

This is the comprehensive textbook about experience-based co-design (EBCD). It explores the underlying concepts of EBCD and provides a thorough guide to the methods and practices of EBCD illustrated by a detailed case study of an EBCD project with head and neck cancer patients, carers and staff in an acute hospital in the south of England. It includes a chapter on evaluating patient experience and experience-based design.

The Experience Based Design Approach
www.institute.nhs.uk/quality_and_value/introduction/experience_based_design.html

The NHS Institute for Innovation and Improvement supported the initial pilot of EBCD in Luton and Dunstable Hospital NHS Foundation Trust. They have developed a number of tools to assist with EBCD, including a concepts and case studies book, and a facilitator’s pack. Most tools are free to NHS employees.

New Zealand Health Service Co-design toolkit
www.healthcodesign.org.nz

This site has lots of useful tips and a number of different tools and techniques that can be used for co-designing health services with patients or users.


This chapter describes a number of different ways in which staff worked with service users to learn from users’ experiences and co-design improvements. They identify a number of challenges and suggest tips for successful co-design.

Evaluations, reports and journal articles about EBCD

Iedema, R, Merrick, E, Piper, D and Walsh, J (2008)

This is a report of the evaluation of the experience-based co-design work carried out in several emergency departments in New South Wales, Australia. The evaluation looks at how the approach was successful and less successful, demonstrates the achievements of the work and makes several recommendations for future co-design work.

Piper D and Iedema R (2010)
‘Emergency Department Co-Design Program 1 Stage 2 Evaluation Report’. Sydney: Centre for Health Communication (UTS) and NSW Health
This is the report of the evaluation of the New South Wales Health (NSW Health) (Australia) Emergency Department Co-Design Project. It includes a description of the specific achievements at the three emergency department sites. The evaluation looks at how the sites sustained and extended the improvements, changes in practice and learning for clinical and other staff achieved during the first stage of the project. The report includes a chapter describing other EBCD projects internationally including several in England.

**The King’s Fund (2011)** ‘The Patient-centred Care Project: Evaluation report.’ Available at: [www.kingsfund.org.uk/ebcdreport](http://www.kingsfund.org.uk/ebcdreport)

This independent evaluation report, commissioned by The King’s Fund, describes the process and impact of an evidence-based co-design project within breast cancer services at Guy’s and St Thomas’ NHS Foundation Trusts and King’s College London.

**Hodgkiss F, Barrie K, Sinclair C (2011)**


An interim stock-take of EBCD work currently underway in cancer services in Scotland.

**Mackay R, Dewar B 2009**

*Using Emotional Touchpoints to learn about the experience of receiving care*

Edinburgh: University of Napier

[www.napier.ac.uk/fhls/NMSC/compassionatecare/practicemethods/Pages/EmotionalTouchpoints.aspx](http://www.napier.ac.uk/fhls/NMSC/compassionatecare/practicemethods/Pages/EmotionalTouchpoints.aspx)

As part of the Leadership in Compassionate Care project in Edinburgh (NHS Lothian and Napier University), nurses adapted from EBCD the idea of selecting emotional touchpoints as part of informal interviews with patients and staff on their ward. The interviews were typed up and staff discussed the content to find ways of improving practice. Staff reported finding it ‘helpful and positive’ to hear what they were doing well, as well as finding it easier to address negative comments through this approach.


‘Co-designing Better Outpatient Services for Older People: Inspiration stories for Participatory Design with Health and Social Care Institutions Workshop’. 11th Biennial Participatory Design Conference


A report on the successes and challenges of using EBCD to improve outpatient services in Sheffield. Further information on this project can be found at [www.uchd.org.uk](http://www.uchd.org.uk) and [http://research.shu.ac.uk/lab4living/user-centred-healthcare-design-uchd](http://research.shu.ac.uk/lab4living/user-centred-healthcare-design-uchd)

**Farr, M (forthcoming)**

‘Collaboration in public services: Can service users and staff participate together?’, in Critical Perspective on User Involvement, M Barnes and P Cotterell (Eds.), Bristol: Policy Press.

This chapter describes different EBCD, co-design and co-production projects.


This paper describes the EBCD intervention designed and tested by the authors and colleagues in a cancer clinic in an NHS hospital in England. The authors discuss how EBCD could enable organisational development to have a more user-centric approach, so that service users can be involved in change at every stage of the design process, from diagnosing problems to generating solutions and implementing them.

**Evaluations of EBCD currently in progress**

Accelerated Experience Based Co Design
www.tvhiec.org.uk/programmes/care-closer-to-home/accelerated-experience-based-co-design

This is a current project and is testing a shortened version of EBCD.

Testing accelerated experience-based co-design
www.sdo.nihr.ac.uk/projdetails.php?ref=10-1009-14

This is a current study evaluating a shortened version of EBCD using pre-existing interviews with patients from a national archive.

**Journal papers associated with the project at King's Health Partners Integrated Cancer Centre from which this toolkit has been developed**

Elizabeth A Davies, Peter Madden, Mairead Griffin, Victoria H Coupland, Alison Richardson. Comparing breast and lung cancer patients’ experiences at a UK Cancer Centre: implications for improving care and moves towards a person-centred model of clinical practice. *International Journal of Person-Centred Medicine* 1 (1) 177-189

This paper compares the findings of a survey of lung cancer patients with those of breast cancer patients.


This forthcoming paper compares the findings of the patient survey (above) and the patient interviews undertaken as part of the EBCD work.