

Experience-based co-design toolkit

For the full toolkit go to www.kingsfund.org.uk/ebcd

Further reading

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. (<http://www.radcliffehealth.com/shop/bringing-user-experience-healthcare-improvement-concepts-methods-and-practices-experience-based>)

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.

Locock L, Robert G, Boaz A, Vougioukalou S, Shuldham C, Fielden J et al. 'Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement', *Health Serv Deliv Res*. In press.

This is the full report on the study which evaluated an 'accelerated' version of EBCD using pre-existing interviews with patients from a national archive. The adapted version was implemented in two Intensive Care Units and two lung cancer services. Information about the study can be found at: <http://www.netscc.ac.uk/hsdr/projdetails.php?ref=10-1009-14>

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.

Greenhalgh T, Humphrey C, Woodard F. (eds) (2010) 'Experience-based co-design' (Vikki Pearce, Paula Baraitser, Gaynor Smith & Trisha Greenhalgh) Chapter 3 in *User Involvement in Health Care* Wiley-Blackwell pp 28-51.

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 experience-based co-design

Bate SP and Robert G. (2007). 'Towards more user-centric organisational development: lessons from a case study of experience-based design'. *The Journal of Applied Behavioural Science*, 43: 1: 41–66.

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.

Bate SP and Robert G. (2006). 'Experience-based design: from redesigning the system around the patient to co-designing services with the patient'. *Quality & Safety in Health Care* 15: 5: 307–10.

An introduction to the original ideas underpinning EBCD.

Bowen S, Dearden A, Wright P, Wolstenholme D, Cobb M. (2010). '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. (<http://research.shu.ac.uk/aces/uchd/external/wp-content/uploads/2010/09/PDCworkshopStoriesUCHD.pdf>)

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 and <http://research.shu.ac.uk/lab4living/user-centred-healthcare-design-uchd>

Boyd H, McKernon S, Mullin B, Old A. (2012). 'Improving healthcare through the use of co-design'. *The New Zealand Medical Journal*, vol 125, no 1357, pp 76–87.

Davies EA, Madden P, Griffin M, Coupland VH, Richardson A. (2011). '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*, vol 1, no 1, pp 177–89.

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

Dewar B, Mackay R, Smith S, Pullin S, Tocher R. (2010). 'Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting'. *Journal of Research in Nursing*, vol 15, no 1, pp 29–41.

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.

Farr M. (2011). 'Collaboration in public services: can service users and staff participate together?', in Barnes M, Cotterell P (eds), *Critical Perspectives on User Involvement*, pp 79–88. Bristol: Policy Press.

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

Hodgkiss F, Barrie K, Sinclair C. (2011). *Better together. Experience based design cancer pilots*. Interim reflection report. Version 1.0. The Knowledge Network website. (<http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/1008115/EBD%20CancerPilots%20InterimReflection%20Report%20Version1.0.pdf>)

An interim stocktake of EBCD work currently under way in cancer services in Scotland.

Iedema R, Merrick E, Piper D, Britton K, Gray J, Verma R, Manning N. (2010). 'Codesigning as a discursive practice in emergency health services: the architecture of deliberation'. *The Journal of Applied Behavioral Science*, vol 46, no 1, pp 73–91.

Iedema R, Merrick E, Piper D, Walsh J. (2008). Emergency Department Co-Design Stage 1 Evaluation - Report to Health Services Performance Improvement Branch, NSW Health'. Sydney: Centre for Health Communication, University of Technology Sydney. Available at: http://www.health.nsw.gov.au/pubs/2008/pdf/edcd_stage1_report.pdf

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 ways in which the approach was successful and less successful, demonstrates the achievements of the work and makes several recommendations for future co-design work.

Piper D, Iedema R (2010). *Emergency Department Co-Design Program 1 Stage 2 Evaluation Report*. Sydney: Centre for Health Communication (UTS) and NSW Health. Available at: http://www.health.nsw.gov.au/pubs/2010/edcd_stage_2_report.html

This is the report of the evaluation of Australia's New South Wales Health (NSW Health) 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.

Robert G. (2013). 'Participatory action research: using experience-based co-design (EBCD) to improve health care services', in Ziebland S, Calabrese J, Coulter A, Locock L (eds), *Understanding and using experiences of health and illness*. Oxford: Oxford University Press.

This chapter explores the origins and development of EBCD before explaining typical implementation and reflecting on the evidence base for such approaches. It then discusses possible future developments in the field of co-design and other 'dialogic' forms of organisational development. It begins by describing efforts to improve patient experiences in the broader context of the quality movement in health care.

The King's Fund. (2011). *The Patient-centred Care Project: Evaluation report* [online]. Available at: 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.

Tsianakas V, Robert G, Maben J, Richardson A, Dale C, Wiseman T. (2012). 'Implementing patient centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services'. *Journal of Supportive Care in Cancer*, vol 20, pp 2639–47.

The aim of this paper was to briefly describe how EBCD was used to identify and implement improvements in the experiences of breast and lung cancer patients. It then compares the issues identified as shaping patient experiences in the different tumour groups and explores participants' reflections on the value and key characteristics of this approach to improving patient experiences.

Tsianakas V, Maben J, Wiseman T, Robert G, Richardson A, Madden P, Davies E. (2012). 'Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both?', *BMC Health Services Research*, vol 12, p271.

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