Further reading

Resources about how to do experience-based co-design


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.


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.nets.nihr.ac.uk/projects/hsdr/10100914

New Zealand Health Service Co-design toolkit
http://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 experience-based co-design


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.


An introduction to the original ideas underpinning EBCD.


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


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


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.


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

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


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.


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.


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.

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.


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.


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