

## **PATIENT EXPERIENCE: A SELECTIVE BIBLIOGRAPHY**

Compiled by the Counties Manukau Health Library, March 2015 [pdf]

(i) Adams, M., Maben, J., & Robert, G. *Improving Patient-Centred Care through Experience-based Co-design (EBCD). An Evaluation of the Sustainability & Spread of EBCD in a Cancer Centre. Final Executive Report.* London; King's College London

Conclusions: Two-thirds of the quality improvements made across the four initial cancer services to implement EBCD were sustained at two-year follow-up. In addition, through pro-active leadership within the Cancer Centre and the support of this leadership within trust-wide leadership networks, EBCD spread from the original four (breast and lung cancer) services to a further three services within the organisation (see Appendix 2 and Appendix 3) and three other services beyond the organisation.

The sustainability of the EBCD approach to service improvement in the longer term will rely on the capacity of trusts and services to support a 'patient-centred approach' to service improvement through 'in-service' and externally positioned quality improvement staff who collaborate to 'drive through' this vision. Without this there is a risk that the spread of the EBCD in the Cancer Centre and beyond will involve slippage from a perspective that values listening to, and working with, patients towards a more organisationally directed view of what constitutes quality improvement.

Such sensitive tailoring of EBCD to accommodate different patient groups and the concerns of frontline staff is, in itself, an important dimension of effective co-design.

Fieldwork observations identified a number of potential priorities for on-going quality improvement work to improve patient experiences.

<http://www.kcl.ac.uk/nursing/research/nnru/publications/Reports/Improving-PCC-through-EBCD-Report.pdf>

(ii) Bate, P. , & Robert, G. "Experience-Based Design: From Redesigning The System Around The Patient To Co-Designing Services With The Patient." *Quality & Safety In Health Care* 15.5 (2006): 307-310. *MEDLINE Complete*. Web. 12 Feb. 2015.

Involving patients in service improvement and listening and responding to what they say has played a key part in the redesign of healthcare processes over the past five years and more. Patients and users have attended stakeholder events, participated in discovery interviews, completed surveys, mapped healthcare processes and even designed new hospitals with healthcare staff. However, to date efforts have not necessarily focused on the patient's experience, beyond asking what was good and what was not. Questions were not asked to find out details of what the experience was or should be like ("experience" being different from "attitudes") and the information then systematically used to co-design services with patients. Knowledge of the experience, held only by the patient, is unique and precious. In this paper, attention is drawn to the burgeoning discipline

of the design sciences and experience-based design, in which the traditional view of the user as a passive recipient of a product or service has begun to give way to the new view of users as integral to the improvement and innovation process.

(iii) Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*. Oxford: Radcliffe Publishing.

(iv) Bate, P., & Robert, G. (2007). Toward more user-centric OD: Lessons from the field of Experience-Based Design and a case study. *The Journal of Applied Behavioral Science*, 43(1), 41-66.

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.

(v) Bessant, John & Mayer, Lynne . Developing radical service innovations in healthcare – the role of design methods

**Abstract:** This paper looks at the management of service innovation. In particular it explores the challenge of public services and argues that there is a need for new approaches to the ways which engage users as more active co-creators within the innovation process. It draws on wider research on radical innovation being carried out as part of a long-term international programme and reports on a series of case studies of experiments in the health sector in the UK using tools like ethnography and prototyping to enable innovation.

The paper argues that a potentially valuable toolkit can be found in the field of design methods. By their nature design tools are used to help articulate needs and give them shape and form; as such they are critical to the 'front end' of any innovation process. Methods like ethnography allow for deep insights into user needs, including those not clearly articulated whilst prototyping provides the possibility of creating a set of 'boundary objects' around which design discussions which include users and their perspectives can be carried out.

<http://www.hqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/Developing-radical-service-innovations-in-healthcare-the-role-of-design-methods-2009-bessant-and-maher-for-IJIM.pdf>

(vi) 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. Paper presented at the 11th Biennial Participatory Design Conference (PDC).

(vii) Bowen, S., McSeveny, K., Lockley, E., Wolstenholme, D., Cobb, M., & Dearden, A. (2013). How was it for you? Experiences of participatory design in

the UK health service. CoDesign: *International Journal of CoCreation and Design and the Arts*. doi: 10.1080/15710882.2013.846384.

Improving co-design methods implies that we need to understand those methods, paying attention to not only the effect of method choices on design outcomes, but also how methods affect the people involved in co-design. In this article, we explore participants' experiences from a year-long participatory health service design project to develop 'Better Outpatient Services for Older People'. The project followed a defined method called experience-based design (EBD), which represented the state of the art in participatory service design within the UK National Health Service. A sample of participants in the project took part in semi-structured interviews reflecting on their involvement in and their feelings about the project. Our findings suggest that the EBD method that we employed was successful in establishing positive working relationships among the different groups of stakeholders (staff, patients, carers, advocates and design researchers), although conflicts remained throughout the project. Participants' experiences highlighted issues of wider relevance in such participatory design: cost versus benefit, sense of project momentum, locus of control, and assumptions about how change takes place in a complex environment. We propose tactics for dealing with these issues that inform the future development of techniques in user-centred healthcare design.

(viii) Boyd, Hilary, et al. "Improving Healthcare Through The Use Of Co-Design." *The New Zealand Medical Journal* 125.1357 (2012): 76-87. *MEDLINE Complete*. Web. 12 Feb. 2015.

**Aim:** This paper describes how co-design methods can be used to improve patient experiences and services within healthcare organisations. Using the Patient Co-design of Breast Service Project as an example, we describe how patient experiences were captured and understood, the improvements made and implications for future work.

**Method:** We used a six-step process: engage, plan, explore, develop, decide and change. Tools and techniques employed were based on service design approaches. These included patient journey mapping, experience-based surveys and co-design workshops.

**Results:** Information, communication, navigation and co-ordination, and environment emerged as key themes for the Breast Service. And as a result, a suite of improvements were made. Key methodological learnings included using co-design alongside traditional quality improvement methodologies, engaging with patients early, the importance of staff buy-in and the necessity of trying things outside one's comfort zone.

**Conclusion:** Use of co-design within the Breast Service has resulted in tangible improvements and has demonstrated the value of engaging patients and focussing on their experiences. It is recommended that: evaluation phases are factored into future co-design work, further research is conducted on sustainability and funding and support is given to allow co-design to become more widespread throughout New Zealand.

(ix) Carroll, K., Iedema, R., Kerridge, R. Reshaping ICU Ward Round Practices Using Video-Reflexive Ethnography. *Qualitative Health Research* 2008 DOI: 10.1177/1049732307313430

In this article, we outline a study method with which structural changes to clinical communication were achieved within a local intensive care unit (ICU). The study method involved in-depth, round-the-clock observation, interviewing, and video filming of how intensivists conducted their practices, as well as showing selected footage to the clinicians for feedback. This feedback component iteratively engaged clinicians in problem-solving their own communication difficulties. The article focuses on one such feedback meeting and describes changes to the morning ward round and planning meeting that this feedback process catalyzed: greater time efficiency, a greater presence of intensivists in the ICU, more satisfied nursing staff, and a handover sheet to improve the structure of clinical information exchanges. We argue that in embodying not a descriptive but an interventionist approach to health service provision, this video-ethnographic method has great significance for enhancing clinicians' and researchers' understanding of the rising complexity of in-hospital practices, and for enabling them to intervene in these practices.

(x) 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*, 15(1), 29-41.

Improving the patient and family experience in hospital and supporting people to deliver compassionate dignified care is a priority on the policy agenda in the UK. The purpose of this paper is to describe our experiences of using the method of emotional touchpoints to learn about compassionate care in hospital settings. This work is part of the Leadership in Compassionate Care Programme which is using an action research approach to embed compassionate care in practice and education. Data were generated using the touchpoint method from 16 patients and 12 relatives from a range of care settings that included medicine for the elderly, older people's mental health and a stroke unit. The benefits of using this approach include its ability to help practitioners to see in a more balanced way both the positive and negative aspects of an experience, and to help service users to take part in a meaningful and realistic way in developing the service. Significant learning arose from these stories that has directly influenced change on the wards. The changes have not only focused on practical solutions but have also provided a platform for discussing some of the more complex cultural aspects that contribute to the delivery of compassionate care.

(xi) Doyle, C., Lennox, L. & Bell, D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. England, 3, 1, Jan. 3, 2013. ISSN: 2044-6055.

**Objective:** To explore evidence on the links between patient experience and clinical safety and effectiveness outcomes.

**Design:** Systematic review.

**Setting:** A wide range of settings within primary and secondary care including hospitals and primary care centres.

**Participants:** A wide range of demographic groups and age groups.

**Primary and Secondary Outcome Measures:** A broad range of patient safety and clinical effectiveness outcomes including mortality, physical symptoms, length of stay and adherence to treatment.

**Results:** This study, summarising evidence from 55 studies, indicates consistent positive associations between patient experience, patient safety and clinical effectiveness for a wide range of disease areas, settings, outcome measures and study designs. It demonstrates positive associations between patient experience and self-rated and objectively measured health outcomes; adherence to recommended clinical practice and medication; preventive care (such as health-promoting behaviour, use of screening services and immunisation); and resource use (such as hospitalisation, length of stay and primary-care visits). There is some evidence of positive associations between patient experience and measures of the technical quality of care and adverse events. Overall, it was more common to find positive associations between patient experience and patient safety and clinical effectiveness than no associations.

**Conclusions:** The data presented display that patient experience is positively associated with clinical effectiveness and patient safety, and support the case for the inclusion of patient experience as one of the central pillars of quality in healthcare. It supports the argument that the three dimensions of quality should be looked at as a group and not in isolation. Clinicians should resist sidelining patient experience as too subjective or mood-oriented, divorced from the 'real' clinical work of measuring safety and effectiveness.

(xii) Entwistle, Vicki et al., Which experiences of health care delivery matter to service users and why? A critical interpretive synthesis and conceptual map [\[4\]](#). *J Health Serv Res Policy* April 2012 vol. 17 no. 2 70-78

**Objective:** Patients' experiences are often treated as health care quality indicators. Our aim was to identify the range of experiences of health care delivery that matter to patients and to produce a conceptual map to facilitate consideration of why they matter.

**Methods:** Broad-based review and critical interpretive synthesis of research literature on patients' perspectives of health care delivery. We recorded experiences reported by a diverse range of patients on 'concept cards', considered why they were important, and explored various ways of organizing them, including internationally recognized health care quality frameworks. We developed a conceptual map that we refined with feedback from stakeholders.

**Results:** Patients identify many health care experiences as important. Existing health care quality frameworks do not cover them all. Our conceptual map presents a rich array of experiences, including health care relationships (beyond communication) and their implications for people's valued capabilities (e.g. to feel respected, contribute to their care, experience reciprocity). It is organized to reflect our synthesis argument, which links health care delivery to what people are enabled (or not) to feel, be and do. The map highlights the broad implications of the social dynamics of health care delivery. Experiences are labelled from a patient's perspective, rendering the importance of responsiveness to individuals axiomatic.

**Conclusions:** Our conceptual map identifies and helps explain the importance of diverse experiences of health care delivery. It challenges and helps policy-makers, service providers and researchers to attend to the range of experiences that matter, and to take seriously the need for responsiveness to individuals.

(xiii) Farr, M. (2011). *Collaboration in public services: Can service users and staff participate together?* In M. Barnes & P. Cotterell (Eds.), *Critical Perspective on User Involvement*. Bristol: Policy Press.

(xiv) Georgina Craig Associates. (2010). Briefing document about DH funded experience led commissioning of end of life care with Pathfinder Healthcare Development Community Interest Company and Health Works GP Commissioning Consortia

([http://www.experienceledcare.co.uk/docs/Briefing\\_document\\_DH\\_experience\\_led\\_commissioning\\_pilot\\_end\\_of\\_life\\_care.pdf](http://www.experienceledcare.co.uk/docs/Briefing_document_DH_experience_led_commissioning_pilot_end_of_life_care.pdf) ).

(xv) Grocott, P., Blackwell, R., Currie, C., Pillay, E., & Robert, G. (2013). Co-producing novel wound care products for Epidermolysis bullosa; an empirical case study of the use of surrogates in the design and prototype development process. *International Wound Journal*, 10(3), 265-273.

The Woundcare for Epidermolysis bullosa (WEB) project aims to enable people with Epidermolysis bullosa (EB), their carers and clinicians to co-produce wound care products to meet their needs. EB is an inherited disorder causing extensive, painful skin blistering and wounds. It is relatively rare, with approximately 300 000 patients worldwide, but it incurs high costs (up to £50 000 per month on products alone). During the course of four workshops, adults with EB, their carers and specialist nurses gave detailed accounts of their experiences with pre-sized, pre-shaped dressings, including the need to patchwork individual dressings over large areas of broken skin. Five themes were identified from the workshop data relating to the limitations of existing products for EB wounds: dressing fit, stability, comfort, temperature and exudate. Novel designs were generated from these themes and although the intention was to develop the designs iteratively with the workshop participants, issues arose necessitating the interim use of surrogates. Our account of the design process is given, presenting the arguments for and against the use of surrogates, with suggestions for incorporating surrogate input into product development in a way that does not undermine the integrity of patient experiences or the co-production process.

(xvi) Gustavsson, Susanne Maria Kristina. "Improvements In Neonatal Care; Using Experience-Based Co-Design." *International Journal Of Health Care Quality Assurance* 27.5 (2014): 427-438. *MEDLINE Complete*. Web. 12 Feb. 2015.

**Purpose:** The purpose of this paper is to identify and improve patient care processes by collaborating patients, relatives and healthcare professionals.

**Design/methodology/approach:** To identify and improve patient care processes by collaborating patients, relatives and healthcare professionals.

**Findings:** Healthcare problems captured from collaboration between patients and healthcare professionals fall into simple, complicated and complex problems. Healthcare staff and patient experiences with patient processes differ, and a collaborative approach is needed to capture all areas needing improvement.

**Research Limitations/implications:** The conclusions are drawn from a project with few participants in a context that probably influenced the results. In contrast, other studies in the same area confirm the results.

**Practical Implications:** The study outcomes have direct implications for healthcare professionals who can learn from patients involved in quality improvements such as this experience-based co-design (EBCD) project.

**Originality/value:** The paper contributes to limited studies on EBCD involving patients in healthcare quality improvements

(xvii) Hodgkiss, F., Barrie, K., & Sinclair, C. (2011). Better together - Experience Based design cancer pilots, interim reflection report. Scotland Patient Experience Programme. <http://www.knowledge.scot.nhs.uk/>

(xviii) 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*, 46(1), 73-91.

This article addresses the issue of how government agencies are increasingly attempting to involve users in the design of public services. The article examines codesign as a method for fostering new and purposeful interaction among service-delivery staff and their customers. Codesign brings together stakeholders who, in the past, have had limited input into the way public services are experienced. By participating in this emerging discourse practice, codesign stakeholders can construct new ways of relating and deliberating. The data presented in this article are drawn from a codesign study initiated by the New South Wales Department of Health in an effort to improve the experience of staff, patients, and caregivers. The article concludes that codesign presents service consumers, professionals, and government officials with new opportunities as well as new challenges. Its opportunities reside in codesign bringing stakeholders together across previously impervious boundaries, producing new understandings, relationships, and engagements. Its challenges reside in these new understandings, relationships, and engagements only becoming possible and only continuing to be relevant if and when stakeholders are prepared to adopt and adapt to the new discourse needed to realize them, implicating them in what has been referred to as the "design competency spiral."

(xix) 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.

(xx) Locock, Louise, 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." (2014): *MEDLINE Complete*. Web. 12 Feb. 2015.

Background: Measuring, understanding and improving patients' experiences is of central importance to health care systems, but there is debate about the best methods for gathering and understanding patient experiences and how to then use them to improve care. Experience-based co-design (EBCD) has been evaluated as a successful approach to quality improvement in health care, drawing on video narrative interviews with local patients and involving them as equal partners in co-designing quality improvements. However, the time and cost involved have been reported as a barrier to adoption. The Health Experiences Research Group at the University of Oxford collects and analyses video and audio-recorded interviews with people about their experiences of illness. It now has a national archive of around 3000 interviews, covering around 75 different conditions or topics. Selected extracts from these interviews are disseminated for a lay audience on [www.healthtalkonline.org](http://www.healthtalkonline.org). In this study, we set out to investigate whether or not this archive of interviews could replace the need for discovery interviews with local patients.

Objectives: To use a national video and audio archive of patient experience

narratives to develop, test and evaluate a rapid patient-centred service improvement approach ('accelerated experience-based co-design' or AEBCD). By using national rather than local patient interviews, we aimed to halve the overall cycle from 12 to 6 months, allowing for EBCD to be conducted in two clinical pathways rather than one. We observed how this affected the process and outcomes of the intervention.

**Design:** The intervention was an adapted form of EBCD, a participatory action research approach in which patients and staff work together to identify and implement quality improvements. The intervention retained all six components of EBCD, but used national trigger films, shortened the time frame and employed local service improvement facilitators. An ethnographic process evaluation was conducted, including observations, interviews, questionnaires, cost and documentary analysis including previous EBCD evaluation reports.

**Setting:** Intensive care and lung cancer services in two English NHS hospital trusts (Royal Berkshire and Royal Brompton and Harefield).

**Participants:** Ninety-six clinical staff (primarily nursing and medical) and 63 patients and family members.

**Intervention:** For this accelerated intervention, the trigger film was derived from pre-existing national patient experience interviews. Local facilitators conducted staff discovery interviews. Thereafter, the process followed the usual EBCD pattern: the film was shown to local patients in a workshop meeting, and staff had a separate meeting to discuss the results of their feedback. Staff and patients then came together in a further workshop to view the film, agree priorities for improvement and set up co-design working groups to take these priorities forward.

**Results:** The accelerated approach proved readily acceptable to staff and patients; using films of national rather than local narratives did not adversely affect local NHS staff engagement, and may in some cases have made the process less threatening or challenging. Local patients felt that the national films generally reflected important themes, although a minority felt that they were more negative than their own personal experience. However, they served their purpose as a 'trigger' to discussion, and the resulting 48 co-design activities across the four pathways were similar in nature to those in EBCD but achieved at reduced cost. AEBCD was nearly half the cost of EBCD. However, where a trigger film already exists, pathways can be implemented for as little as 40% of the cost of traditional EBCD. It was not necessary to do additional work locally to supplement the national interviews. The intervention carried a 'cost' in terms of heavy workload and intensive activity for the local facilitators, but also brought benefits in terms of staff development/capacity-building. Furthermore, as in previous EBCDs, the approach was subsequently adopted in other clinical pathways in the trusts.

**Conclusions:** Accelerated experience-based co-design delivered an accelerated version of EBCD, generating a comparable set of improvement activities. The national film acted as an effective trigger to the co-design process. Based on the results of the evaluation, AEBCD offers a rigorous and effective patient-centred quality improvement approach. We aim to develop further trigger films from the archived material as resources permit, and to investigate different ways of conducting the analysis (e.g. involving patients in doing the analysis).

(xxi) Locock, L., Robert, G., Boaz, A., Vougioukalou, S., Shuldham, C., Fielden J., et al. (forthcoming). 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 ServDeliv Res*

Background: Measuring, understanding and improving patients' experiences is of central importance to health care systems, but there is debate about the best methods for gathering and understanding patient experiences and how to then use them to improve care. Experience-based co-design (EBCD) has been evaluated as a successful approach to quality improvement in health care, drawing on video narrative interviews with local patients and involving them as equal partners in co-designing quality improvements. However, the time and cost involved have been reported as a barrier to adoption. The Health Experiences Research Group at the University of Oxford collects and analyses video and audio-recorded interviews with people about their experiences of illness. It now has a national archive of around 3000 interviews, covering around 75 different conditions or topics. Selected extracts from these interviews are disseminated for a lay audience on [www.healthtalkonline.org](http://www.healthtalkonline.org). In this study, we set out to investigate whether or not this archive of interviews could replace the need for discovery interviews with local patients.

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(xxii) Maben, J et al. [Exploring the relationship between patients' experiences of care and the influence of staff motivation, affect and wellbeing](#). Final report. NIHR Service Delivery and Organisation Programme; 2012

<http://www.hqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/PIC-patient-experience-and-wellbeing-Oct-2013.pdf>

(xxiii) Maben, J., Adams, M., Peccei, R., Murrell, T. & Robert, G. (2012). 'Poppets and parcels': the links between staff experience of work and acutely ill older peoples' experience of hospital care. *International Journal of Older People Nursing* 7, 83–94. doi:10.1111/j.1748-3743.2012.00326.x

Through a mixed methods case study in one MfOP service, we have been able to describe the experiences of care for older people in acute hospital settings as well as to begin to

understand the significance of the work experiences of staff for the quality of patient care. Gordon (2005) argues that care environments that are inadequate for meeting the

emotional needs of patients will inevitably foster nurses who avoid attempting to meet such needs. Being unable to engage with patients in a meaningful way dehumanises nurses themselves (Austin, 2011).

<http://www.hgsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/PIC-poppets-parcels-Oct-2013.pdf>

(xxiv) McHattie, Lynn-Sayers, Grant Cumming, and Tara French. "Transforming Patient Experience: Health Web Science Meets Medicine 2.0." *Medicine 2.0* 3.1 (2014): e2. *MEDLINE Complete*. Web. 12 Feb. 2015.

Until recently, the Western biomedical paradigm has been effective in delivering health care, however this model is not positioned to tackle complex societal challenges or solve the current problems facing health care and delivery. The future of medicine requires a shift to a patient-centric model and in so doing the Internet has a significant role to play. The disciplines of Health Web Science and Medicine 2.0 are pivotal to this approach. This viewpoint paper argues that these disciplines, together with the field of design, can tackle these challenges. Drawing together ideas from design practice and research, complexity theory, and participatory action research we depict design as an approach that is fundamentally social and linked to concepts of person-centered care. We discuss the role of design, specifically co-design, in understanding the social, psychological, and behavioral dimensions of illness and the implications for the design of future care towards transforming the patient experience. This paper builds on the presentations and subsequent interdisciplinary dialogue that developed from the panel session "Transforming Patient Experience: Health Web Science Meets Web 2.0" at the 2013 Medicine 2.0 conference in London.


(xxv) Osborn, R; Squires, D International perspectives on patient engagement: results from the 2011 Commonwealth Fund Survey. *The Journal Of Ambulatory Care Management*. United States, 35, 2, 118-128, Apr. 2012. ISSN: 1550-3267

We analyzed 2011 survey data of patients with complex health care needs in 11 countries (Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States) on their care experiences. Wide country variation was reported in how well patients were engaged by their clinicians; UK and Swiss patients reported the most positive experiences, but gaps were reported in all countries. Disparities by income were found in several countries, with the widest gaps reported in the United States. Across countries, engaged patients reported receiving higher-quality care, fewer errors, and more positive views of the health system.

(xxvi) Main. T. Slywotski, Adrian. [The volume-to-value revolution: Rebuilding the DNA of health from the patient in.](#)

<http://www.hgsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/PIC-volume-to-value-Oct-2013.pdf>

(xxvii) Pearce, V., Baraiter, P., Smith, G., & Greenhalgh, T. (2011). Experience-based co-design. In T. Greenhalgh, C. Humphrey & F. Woodard (Eds.), *User involvement in healthcare* (pp. 28-51). Oxford: Wiley Blackwell.

(xxviii) Perla, Rocco J. Provost, Lloyd P. [Judgment Sampling: A Health Care Improvement Perspective](#) . *Quality Management in Health Care* July/September 2012 - Volume 21 - Issue 3 - p 169-175 doi: 10.1097/QMH.0b013e31825e8806

Sampling plays a major role in quality improvement work. Random sampling (assumed by most traditional statistical methods) is the exception in improvement situations. In most cases, some type of "judgment sample" is used

to collect data from a system. Unfortunately, judgment sampling is not well understood. Judgment sampling relies upon those with process and subject matter knowledge to select useful samples for learning about process performance and the impact of changes over time. In many cases, where the goal is to learn about or improve a specific process or system, judgment samples are not merely the most convenient and economical approach, they are technically and conceptually the most appropriate approach. This is because improvement work is done in the real world in complex situations involving specific areas of concern and focus; in these situations, the assumptions of classical measurement theory neither can be met nor should an attempt be made to meet them. The purpose of this article is to describe judgment sampling and its importance in quality improvement work and studies with a focus on health care settings.

(xxix) Piper, Donella, et al. "Utilizing Experience-Based Co-Design To Improve The Experience Of Patients Accessing Emergency Departments In New South Wales Public Hospitals: An Evaluation Study." *Health Services Management Research: An Official Journal Of The Association Of University Programs In Health Administration / HSMC, AUPHA* 25.4 (2012): 162-172. *MEDLINE Complete*. Web. 12 Feb. 2015.

**Background:** This paper presents the findings of three multisite evaluations of Experience-Based Co-design (EBCD) programmes conducted in Emergency Departments (EDs) and associated departments in seven public hospitals in New South Wales, Australia.

**Method:** Data for the evaluations were derived from: EBCD documentation provided by the participating sites; interviews with 117 key informants; performance data and the policy and academic literature on EBCD.

**Results:** Respondents described EBCD as a successful and sustainable method of improving the individual patient experience and the overall quality of a health service. Demonstrated successes were reported to lead to aspects of the EBCD approach spreading within services. However, like any quality improvement activity, EBCD was not without its challenges. The principal challenge particular to the EBCD projects outlined here was their deployment in ED settings. Because of their ambulant patient populations, these settings made sustaining consumer engagement for the duration of the project problematic and required tailoring EBCD to accommodate consumers' involvement preferences and constraints.

**Conclusion:** The primary strength of EBCD over and above other service development methodologies was reported to be its ability to bring about improvements simultaneously in both the operational efficiency and the interpersonal dynamics of care. However, careful consideration must be given to the constraints inherent in transient patient specialties and what needs to be done to tailor EBCD to suit the particular setting in which it is deployed.

(xxx) Plsek, P. (2014). *Accelerating health care transformation with Lean and Innovation. The Virginia Mason Experience*. Boca Raton, FL: CRC Press

(xxxi) Ream, E., Tsianakas, V., Verrity, R., Oakley, C., Murrells, T., Robert, G., and Richardson, A. (2013). Enhancing the role of carers in the outpatient chemotherapy setting: a participatory action research project. London; King's College London, available at:

<http://www.dimblebycancercare.org/wpcontent/uploads/2013/09/Dimbleby-report-executive-summary-pdf-3rd-Sept.pdf>

(accessed 21<sup>st</sup> November 2013).

(xxxii) Reeves, R. et al., [Facilitated patient experience feedback can improve nursing care: a pilot study for a phase III cluster randomised controlled trial](http://www.biomedcentral.com/1472-6963/13/259). *BMC Health Services Research* 2013, 13:259  
<http://www.biomedcentral.com/1472-6963/13/259>

Background: England's extensive NHS patient survey programme has not fulfilled government promises of widespread improvements in patients' experiences, and media reports of poor nursing care in NHS hospitals are increasingly common. Impediments to the surveys' impact on the quality of nursing care may include: the fact that they are not ward-specific, so nurses claim "that doesn't happen on my ward"; nurses' scepticism about the

relevance of patient feedback to their practice; and lack of prompt communication of results.

The surveys' impact could be increased by: conducting ward-specific surveys; returning results to ward staff more quickly; including patients' written comments in reports; and offering nurses an opportunity to discuss the feedback. Very few randomised trials have been conducted to test the effectiveness of patient feedback on quality improvement and

there have been few, if any, published trials of ward-specific patient surveys.

Methods: Over two years, postal surveys of recent inpatients were conducted at four-monthly intervals in 18 wards in two NHS Trusts in England. Wards were randomly allocated to Basic Feedback (ward-specific printed patient survey results including patients' written comments sent to nurses by letter); Feedback Plus (in addition to printed results, ward meetings to discuss results and plan improvements) or Control (no active feedback of survey results).

Patient survey responses to questions about nursing care were used to compute wards' average Nursing Care Scores at each interval. Nurses' reactions to the patient feedback were recorded.

Results: Conducting ward-level surveys and delivering ward-specific results was feasible. Ward meetings were effective for engaging nurses and challenging scepticism and patients' written comments stimulated interest. 4,236 (47%) patients returned questionnaires. Nursing Care Scores improved more for Feedback Plus than Basic Feedback or

Control (difference between Control and Feedback Plus =  $8.28 \pm 7.2$  ( $p = 0.02$ )).

Conclusions: This study provides preliminary evidence that facilitated patient feedback can improve patients' experiences such that a full trial is justified. These findings suggest that merely informing nurses of patient survey results in writing does not stimulate improvements, even if results are disaggregated by ward, but the addition of ward meetings had an important and significant impact.

<http://www.hqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/PIC-patient-experience-feedback-Oct-2013.pdf>

(xxxiii) Robert, G. (2013). Participatory action research: using experience-based co-design (EBCD) to improve health care services. In S. Ziebland, J. Calabrese, A. Coulter & L. Locock (Eds.), *Understanding and using experiences of health and*

illness. Oxford: Oxford University Press.

(xxxiv)Robert, Glenn , Cornwell, Jocelyn. [Rethinking policy approaches to measuring and improving patient experience.](#) *J Health Serv Res Policy* 2013 18: 67

DOI: 10.1177/1355819612473583

Patients' experiences are increasingly central to assessing the performance of health care worldwide. Alongside measures of clinical effectiveness and patient safety, the patients' views of their experience are now commonly used to judge the quality of care.<sup>1-3</sup>

However, in the context of a range of policy concerns including ensuring value for money, ambitions to make services patient-centred, preventing organizational failures and increasing accountability to local communities, it is timely to take stock of current approaches to measuring patient experience and ask whether they are fit for such a wide variety of purposes.

<http://www.hqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/PIC-rethinking-policy-approaches-Oct-2013.pdf>

(xxxv) Robertson, Sophie, Kate Pryde, and Kath Evans. "Patient Involvement In Quality Improvement: Is It Time We Let Children, Young People And Families Take The Lead?." *Archives Of Disease In Childhood. Education And Practice Edition* 99.1 (2014): 23-27. *MEDLINE Complete*. Web. 12 Feb. 2015.

It is vital to involve children, young people and families in the design, delivery and improvement of their care. Their involvement can range from individuals giving feedback, such as patient stories, to collaborative work including patient groups and communities helping to develop and commission services. The methods for involving individuals and families include questionnaires and innovative ideas such as feedback Apps. Other methods include the 15 Steps Challenge which helps an organisation to view the care it delivers through a patients eyes and includes a 'walk around' involving a patient, carer, staff member and board member. The Experience Based Design approach is another method of reviewing a service and involves assessing how staff and patients feel when delivering and receiving care. Involving patient groups can be facilitated by working with schools and children's centres. The type of involvement will vary, but if carefully designed can allow meaningful participation and improvement of services.

(xxxvi)Scholl, Isabelle, et al. "An Integrative Model of Patient-Centeredness –A Systematic Review and Concept Analysis." *PloS one* 9.9 (2014): e107828

## Background

Existing models of patient-centeredness reveal a lack of conceptual clarity. This results in a heterogeneous use of the term, unclear measurement dimensions, inconsistent results regarding the effectiveness of patient-centered interventions, and finally in difficulties in implementing patient-centered care. The aim of this systematic review was to identify the different dimensions of patient-centeredness described in the literature and to propose an integrative model of patient-centeredness based on these results.

## Methods

Protocol driven search in five databases, combined with a comprehensive secondary search strategy. All articles that include a definition of patient-centeredness were eligible for inclusion in the review and subject to subsequent content analysis. Two researchers independently first screened titles and abstracts, then assessed full texts for eligibility. In each article the given definition of patient-centeredness was coded independently by two researchers. We discussed codes within the research team and condensed them into an integrative model of patient-centeredness.

## Results

4707 records were identified through primary and secondary search, of which 706 were retained after screening of titles and abstracts. 417 articles (59%) contained a definition of patient-centeredness and were coded. 15 dimensions of patient-centeredness were identified: essential characteristics of clinician, clinician-patient relationship, clinician-patient communication, patient as unique person, biopsychosocial perspective, patient information, patient involvement in care, involvement of family and friends, patient empowerment, physical support, emotional support, integration of medical and non-medical care, teamwork and teambuilding, access to care, coordination and continuity of care. In the resulting integrative model the dimensions were mapped onto different levels of care.

## Conclusions

The proposed integrative model of patient-centeredness allows different stakeholders to speak the same language. It provides a foundation for creating better measures and interventions. It can also be used to inform the development of clinical guidance documents and health policy directives, and through this support the shift towards patient-centered health care.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4168256/>

(xxxvii) The King's Fund (2011). The patient-centred care project: Evaluation report. London: The King's Fund. (2012). Experience-based co-design toolkit . Available at

<http://www.kingsfund.org.uk/projects/point-care/ebcd> London: The King's Fund.

(xxxviii) The NHS Institute for Innovation and Improvement. (2011). Method, toolkit and DVD 'how to' use EBCD. Coventry: NHS Institute for Innovation & Improvement, available at

[http://www.institute.nhs.uk/quality\\_and\\_value/introduction/experience\\_based\\_design.html](http://www.institute.nhs.uk/quality_and_value/introduction/experience_based_design.html).

(xxxix) Tollyfield, Ruth. "Facilitating An Accelerated Experience-Based Co-Design Project." *British Journal Of Nursing (Mark Allen Publishing)* 23.3 (2014): 136-141. *MEDLINE Complete*. Web. 12 Feb. 2015.

This article describes an accelerated experience-based co-design (AEBCD) quality improvement project that was undertaken in an adult critical care setting and the facilitation of that process. In doing so the aim is to encourage other clinical settings to engage with their patients, carers and staff alike and undertake their own quality improvement project. Patient, carer and staff experience and its place

in the quality sphere is outlined and the importance of capturing patient, carer and staff feedback established. Experience-based co-design (EBCD) is described along with the recently tested accelerated version of the process. An overview of the project and outline of the organisational tasks and activities undertaken by the facilitator are given. The facilitation of the process and key outcomes are discussed and reflected on. Recommendations for future undertakings of the accelerated process are given and conclusions drawn.

(xl) Tsianakas, Vicki et al. Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Support Care Cancer* (2012) DOI 10.1007/s00520-012-1470-3

**Purpose:** The aim of this paper was to briefly describe how the experience-based co-design (EBCD) approach was used to identify and implement improvements in the experiences of breast and lung cancer patients before (1) comparing the issues identified as shaping patient experiences in the different tumour groups and (2) exploring participants' reflections on the value and key characteristics of this approach to improving patient experiences.

**Methods :** Fieldwork involved 36 filmed narrative patient interviews, 219 h of ethnographic observation, 63 staff interviews and a facilitated co-design change process involving patient and staff interviewees over a 12-month period. Four of the staff and five patients were interviewed about their views on the value of the approach and its key characteristics. The project setting was a large, inner-city cancer centre in England.

**Results:** Patients from both tumour groups generally identified similar issues (or 'touchpoints') that shaped their experience of care, although breast cancer patients identified a need for better information about side effects of treatment and end of treatment whereas lung cancer patients expressed a need for more information post-surgery. Although the issues were broadly similar, the particular improvement priorities patients and staff chose to work on together were tumour specific. Interviewees highlighted four characteristics of the EBCD approach as being key to its successful implementation: patient involvement, patient responsibility and empowerment, a sense of community, and a close connection between their experiences and the subsequent improvement priorities.

**Conclusion:** EBCD positions patients as active partners with staff in quality improvement. Breast and lung cancer patients identified similar touchpoints in their experiences, but these were translated into different improvement priorities for each tumour type. This is an important consideration when developing patient-centred cancer services across different tumour types.

<http://www.hqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/Implementing-patient-centred-cancer-care.pdf>

(xli) Tsianakas, V., Maben, J., Wiseman, T., Robert, G., Richardson, A., Madden, P., Griffin, M., & 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*, 12(1), 271,

**Background:** Patients' experiences have become central to assessing the performance of healthcare systems worldwide and are increasingly being used to inform quality improvement processes. This paper explores the relative value of surveys and detailed patient narratives in identifying priorities for improving breast cancer services as part of a quality improvement process.

Methods: One dataset was collected using a narrative interview approach, (n = 13) and the other using a postal survey (n = 82). Datasets were analyzed separately and then compared to determine whether similar priorities for improving patient experiences were identified.

Results: There were both similarities and differences in the improvement priorities arising from each approach. Day surgery was specifically identified as a priority in the narrative dataset but included in the survey recommendations only as part of a broader priority around improving inpatient experience. Both datasets identified appointment systems, patients spending enough time with staff, information about treatment and side effects and more information at the end of treatment as priorities. The specific priorities identified by the narrative interviews commonly related to 'relational' aspects of patient experience. Those identified by the survey typically related to more 'functional' aspects and were not always sufficiently detailed to identify specific improvement actions.

Conclusions: Our analysis suggests that whilst local survey data may act as a screening tool to identify potential problems within the breast cancer service, they do not always provide sufficient detail of what to do to improve that service. These findings may have wider applicability in other services. We recommend using an initial preliminary survey, with better use of survey open comments, followed by an in-depth qualitative analysis to help deliver improvements to relational and functional aspects of patient experience.

(xlii) 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. *Supportive Care in Cancer*, 20, 2639-2647.

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Conclusion: EBCD positions patients as active partners with staff in quality improvement. Breast and lung cancer patients identified similar touchpoints in their experiences, but these were translated into different improvement priorities for each tumour type. This is an important consideration when developing patient-centred cancer services across different tumour types.

(xliv) Tunney, Anne Marie, and Assumpta Ryan. "Listening To Carers' Views On Stroke Services." *Nursing Older People* 26.1 (2014): 28-31. *MEDLINE Complete*. Web. 12 Feb. 2015.

**Aim:** The aim of this study was to explore how members of a stroke carers' support group perceived that services for stroke patients and their carers could be improved.

**Method:** A qualitative, experience-based design approach was used to explore the views of ten carers of stroke survivors. Experience questionnaires and a listening lab were used for data collection. Data analysis was carried out using thematic content analysis of the questionnaire and audiotaped transcripts.

**Findings:** Common themes identified included carer loneliness, lack of information, effect of stroke on relationships, carer emotions, loss of privacy and need for ongoing support.

**Conclusion:** There are many advantages to be gained for users and organisations from user involvement in service redesign and delivery.

(xlv) Waitemata District Health Board. (2010). Health service co-design toolkit, from <http://www.healthcodesign.org.nz/>

(xlv) Wolstenholme D, Cobb M, Bowen S, Wright P, Dearden, A. Design Led Service Improvement for Older People. *AMJ* 2010, 3, 8, 465-470. Doi 10.4066/AMJ.2010.377

In the UK, outpatient services are a major element of the health service for older people and large numbers are required to attend hospital-based outpatient clinics.

However, it has been reported that outpatient clinics have fallen behind improvements in inpatient and primary care and they are seldom the focus of the patient-centred quality agenda that promotes personalised care. Significant proportions of older people fail to attend their appointments and there are few studies into the experience of older patients using outpatient services.

In this paper we report on a design-led service improvement project that involved older people using a medical outpatient service and its staff. The project was facilitated by an interdisciplinary team of practitioners and researchers from design, software engineering and healthcare. This team is developing new user-centred and participatory design methods that apply design thinking and practices to healthcare settings.

A significant finding of the project is that an outpatient service extends beyond both the clinical encounter and the physical extent of the building, with many touchpoints before and after an appointment, such as confirmation letters, journeys, wayfinding, and staff interactions. These significant interfaces and interactions constitute critical factors in the experience of patients and staff, and impact upon the ability of the service to perform its clinical role.

<http://www.hgsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/PIC-designled-EBD-Oct-2013.pdf>

(xlvi) Ziebland, Sue. Why listening to health care users really matters. *J Health Serv Res Policy* April 2012 vol. 17 no. 2 68-69

The NHS Operating Framework for England (2011) describes each patient's experience as '*the final arbiter in everything the NHS does*':<sup>1</sup> the focus of health care quality improvement appears to have shifted firmly into the territory of patients' experience. Similar developments are occurring in other countries. This has implications for health care delivery, public and patient involvement, and priority setting as well as assessment. If patients' experiences were to improve, how would we know?