

Institution: King's College London		
Unit of Assessment: 3		
Title of case study: Using Experience-based Co-design to improve patient and staff experiences of healthcare services around the world		
Period when the underpinning research was undertaken: 2005 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Glenn Robert	Professor of Healthcare Quality & Innovation	2008 – present
Dr Sara Donetto	Lecturer	2011 – present
Dr Vicki Tsianakas	Lecturer	2011 – present
Professor Ruth Harris	Professor of Health Care for Older Adults	2015 – present
Period when the claimed impact occurred: August 2013 - December 2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

Healthcare policy frameworks in many countries describe 'patient experience' as a core component of health care quality. Scandals of poor care remain chastening examples of what happens when a focus on financial and other performance targets displaces listening to and learning from the views and experiences of patients (and staff). Over the last 12 years King's research has advanced, implemented and disseminated Experience-based Co-design (EBCD) as an innovative approach to engaging patients and staff to work together to improve services. Use of EBCD around the world has led to: practical, tangible quality improvements that have been felt by patients and staff; legacies in terms of patient-centred working, support groups, and information for patients; cultural change (for example, greater and more open team working between departments, clinicians and other staff); and a recognition by staff and patients that EBCD's collaborative approach is very different to other change initiatives.

2. Underpinning research

Experience-based Co-design (EBCD) is a radical way of enabling patients and carers to directly partner staff in improving their experiences of health care services. Developed by Professor Glenn Robert and colleagues, it uses filmed patient narratives alongside design methods and tools as part of a structured change process to enable patients and staff to work collaboratively to improve local healthcare services. The approach was piloted in 2005 in the head & neck cancer service at Luton & Dunstable NHS Trust in England.

Significant advancements took place following Professor Robert's move to King's in 2008. This work has explored and tested how the method can be adapted to different services and settings, how to successfully engage staff and service users throughout the process, how the approach can be streamlined for faster implementation, and how it can be scaled up to bring about improvements faster in more services, as well as the delivery of evidence of its effectiveness in improving patient and staff experiences.

King's helped to create an accelerated method of EB CD developed to save time and money. Feedback from users of the approach was that - whilst effective - EB CD was time-consuming. They wanted to be able to realise the benefits sooner. In response we helped develop a new 'accelerated' form of EB CD and conducted an ethnographic process evaluation of this in two Intensive Care Units and lung cancer pathways within NHS acute trusts [1]. The main adaptation made was to use an existing library of filmed patient narratives (healthtalk). We found that the

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accelerated approach halved the project time (from 12 to 6 months) and proved readily acceptable to staff and patients; the resulting 41 quality improvements across the four pathways were similar in nature to those in EBCD and the 'accelerated' approach could be implemented for as little as 40% of the cost [1]. A subsequent prospective, mixed methods comparative study found that this 'accelerated' EBCD approach was also as effective as EBCD on acute stroke wards in English NHS acute Trusts in improving the quality and amount of cognitive, physical and social activity for patients [2,3].

King's research incorporated EBCD and other co-design approaches in the development and evaluation of complex interventions. For example, EBCD was used in the co-design of a complex intervention to support carers of family members having outpatient chemotherapy in a hospital in London. A feasibility randomised controlled trial showed that (a) recruitment to the study was unproblematic and attrition was low thereby suggesting a full randomised controlled trial was feasible, and (b) carers in receipt of the 'Take Care' intervention reported better understanding of symptoms and side-effects and their information needs being more frequently met than carers in the control group [4].

EBCD was implemented successfully nationally and internationally from 2008 onwards. In 2015, Professor Robert and Dr Donetto conducted an international survey of EBCD projects and found that between 2005-13 over 58 EBCD projects had been implemented - with a further 27 projects in the planning stage - in the UK, Canada, the Netherlands, Sweden, Australia and New Zealand [5]. An overview article published in the *British Medical Journal* in 2015 summarised the approach and included examples of projects to that date [6].

3. References to the research

1. Locock L, **Robert G**, Boaz A, Vougioukalou S, Shuldhham C, Fielden J, et al. (2014) 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*, 2(4)
2. Jones, F, Gombert-Waldron, K, Honey, S, Cloud, GC, **Harris, R**, Macdonald, A, McKevitt, C, **Robert, G** & Clarke, D. (2020) Addressing inactivity after stroke: The Collaborative Rehabilitation in Acute Stroke (CREATE) study. *International Journal of Stroke*, <https://doi.org/10.1177/1747493020969367>
3. Jones F, Gombert-Waldron K, Honey S, Cloud G, **Harris R**, Macdonald A, McKevitt, C, **Robert, G** & Clarke, D. (2020) Using co-production to increase activity in acute stroke units: the CREATE mixed-methods study. *Health Serv Deliv Res*, 8(35)
4. **Tsianakas V**, **Robert G**, **Maben J**, Richardson A, Dale C and 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(11): 2639-2647
5. **Donetto S**, Pierri P, **Tsianakas V** and **Robert G**. (2015) Experience-based Co-design and healthcare improvement: realising participatory design in the public sector. *The Design Journal*, 18(2): 227-248
6. **Robert G**, Cornwell J, Locock L, Purushotham A, Sturmey G and Gager M. (2015) Patients and staff as co-designers of health care services. *British Medical Journal*, 350:g7714

4. Details of the impact

King's research helped to improve healthcare services nationally and in high, middle and low-income countries. The EBCD approach - in collaboration with patients, families, staff and policy makers - has directly led to better patient experiences of health care services in various settings, care pathways and countries. Between 2013 and 2020 the number of EBCD projects in clinical services worldwide increased from 59 (6 countries) [5] to approximately 100 (in 8 countries

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including the UK, United States, Australia, New Zealand, South Africa, Canada, Czech Republic and Sweden). Some examples of recent projects include:

- In a **South African township** focusing on the nutrition and wellness of malnourished or HIV positive children, they found that the integration of mothers/caregivers and staff into co-design teams led to the identification of 38 concrete practical improvements both within a paediatric service and spanning the boundaries of hospital and primary health clinic care [A]. These included, for example: a point of care blood machine being bought to shorten the time in the emergency department whilst waiting for laboratory results; a play area being organised for children attending the HIV clinic; the development of three standard operating procedures to improve clinical handover and waiting times; and privacy screens installed to improve privacy in reception.
- In **Los Angeles**, to improve access to health and social care services for formerly incarcerated prisoners, it was found that EBCD was effective at identifying 4 high priority topics for improvement, comprehensive perspectives on service needs and gaps in these areas, and key design principles for each [B]. The priority topics were: setting up key re-entry needs before release from jail (including housing, health and mental health providers, IDs and documentation); one-stop service hubs (key services located in same location or nearby, structured comprehensive re-entry plan, getting up-to-date, useful info on available services to returning citizens and on client background and needs to providers); housing (affordable, safe, long-term, located near work and family); and long-term support (mentoring and peer support, housing, financial stability, family reunification, drug treatment and wrap-around services).

One specific example of how the approach has had international impact is through the work of the Vermont Oxford Network (VON), an international network of 1,300 neonatal units, based in the USA. During 2019 EBCD webinars were delivered to VON members – the first time EBCD has been applied in a large-scale programme [C]. A blog post from one participating staff member in Oregon in the US states: *“Caregivers are engaged, empowered and have been inspired by hearing from the families we serve. They sincerely desire to understand what is uniquely important to all of their patients and are thrilled to deliver when possible. And parents have expressed their gratitude for the ability to give back and to thank those caregivers and providers who cared so compassionately for their newborns.”* [D]

In relation to the EBCD accelerated method [1] with the further support of an Economic & Social Research Council grant we helped develop a library of ‘trigger’ films that are freely available online for anyone interested in implementing the accelerated EBCD approach. As of August 2020, 26 such films have been compiled, including on topics such as autism, ethnic minority mental health and Parkinson’s disease [E].

EBCD projects have led to specific improvements in the delivery of local healthcare services. For example, use of the accelerated EBCD approach in two Intensive Care Units and two lung cancer services was found to have resulted in 48 improvements [1]. The improvements included:

- Small-scale changes; for example, sourcing clocks to aid patient orientation in ICU; more comfortable V-shaped pillows for postoperative patients.
- Process redesign with healthcare teams; new private room identified for receiving support after cancer diagnosis; introducing compassionate care rounds on ICU.
- Process redesign between service activities; changed process for porters to remove waste avoiding ICU rest times; redesigned discharge summary with input from all professions.
- Process redesign between organizations; improved cross-site information booklet for patients transferring to another hospital for surgery.

In a more recently completed project more than 40 improvements were co-designed and implemented across 4 participating acute stroke units [2,3]. The improvements related to three priority areas identified by patients and staff. Examples, with testimonies, included:

Space previously used to store wheelchairs was transformed into a new social space, for shared meals, groups activities and meeting with visitors: *"We had a gentleman who wouldn't really engage in therapy, but I gave him the job of watering the plants [in the new social area] every day and he started doing that and apparently he did better in therapy after the engagement sessions"* (Staff member).

Activity boxes were provided for every four-bedded bay; items were chosen and boxes put together by groups of patients and staff: *"We have huge gaps in the day where your patient's doing nothing, they're bored, they become institutionalised, so with these extras, like your volunteers coming in, you've got various groups, you've got your cooking group, your breakfast club, your lunch club, it just makes for a, well it's a more positive experience"* (Staff member).

Communication; a new webpage, information leaflet and posters were co-designed to emphasize activity and the importance of bringing in familiar and stimulating items from home, e.g. photos, games, electronic devices; *"I think the information leaflet's quite good because it says, it tells you things like where the day room is and that you can go into the garden and things like that..."* (Family carer).

As just one further example at the local organisational level, in a mental health trust in London, the use of EBCD on an acute mental health ward in 2013-14 led to a reduction in complaints [F] through patients, carers and staff working together to improve the patient experience. One member of staff said it was *"really striking how simple changes can make a big difference"* and the EBCD approach has subsequently been adopted by other wards and units in the trust [G].

Participating in EBCD projects has had profound impacts on individual patients. An Intensive Care Unit patient in an English hospital reflected on his experience of taking part in an EBCD project: *"For patients like myself and our relatives, being involved in such a codesign project is one of the most constructive ways of giving something back for the care shown to us during a very difficult period in our lives. The developing of interpersonal relationships between patients, their relatives, and healthcare professionals was rewarding in itself and enabled the creation of a safe social environment in which to work ... staff were inspired by what we had to say and it felt as if they were reconnecting to the beliefs and values they had when they first chose healthcare as a profession. As the project moved forward my initial expectations of what to expect were far exceeded."* [H]

King's research and training increased knowledge, skills and commitment of staff. Since September 2014, in collaboration with a third sector organisation based in London - the Point of Care Foundation - we have run a day-long EBCD 'Open Course' on 11 occasions and over 30 bespoke courses commissioned by healthcare organisations [I, p.1-3]. In total over 1,600 individuals from over 470 organisations around the world have been trained in the EBCD method [J, p.4]. The online EBCD toolkit has been visited by 34,382 users from 159 countries since July 2017 (50% from UK, 15% from US, 8.5% from Canada and 8% Australia). The monthly average of users is approximately 1,000 (range 700 – 1,350) [I].

In reviewing studies of EBCD projects one recurring theme from observing and interviewing staff participants is that of 'connection'. Or rather - as it was often framed by interviewees themselves - the re-connection of staff to the reasons they became healthcare practitioners in the first place. Staff participants have reflected on the 'different insights ... outlooks' the process provided, as well as it 'being the most meaningful thing I've done in my career'. And so it is that nurses in a cancer centre talk of being 'stirred enough' to want to change something, or speak of 'light bulb moments' and the importance of having opportunities to reflect and think, of how 'moving' and 'powerful' it was to hear the carer's voice, and describe the impact of the process in terms of 'opening our eyes'. The following sentiment from an Intensive Care Nurse is commonly expressed after staff have participated in an EBCD project: *"It was very interesting. It was a light bulb moment, because you had four different groups, nurses, doctors, patients, and relatives. It was one of the first times I've sat down and talked about the same problem and how we all view it, and some of the things other people were concerned about I didn't think anything of that, and then at the same time some of the things I thought were important, other people didn't think they were important. It was very, very interesting. It made me realise what a crazy system we are working in at the moment."* [J]

King's approach has helped healthcare systems and organisations to increase their focus on patient experience. Four cancer pathways in an Integrated Cancer Centre in Central London implemented EBCD and this led to the development of an online, free to use EBCD toolkit (<https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>). Professor Robert and Dr Tsianakas were closely involved in the development of this toolkit. Subsequently updated with further case studies and resources, the toolkit continues to be used by healthcare practitioners interested in applying it to their local services, as well as supporting ongoing training courses in the approach for both service users and healthcare staff. The toolkit has also been adapted and continues to be disseminated as a recommended approach for improving services by state-level organisations in **Australia** (New South Wales – Agency for Clinical Innovation [K]) and **Canada** (Ontario – the Change Foundation [L]).

5. Sources to corroborate the impact

- A. Van Deventer C, **Robert G** and Wright A. (2016) Improving childhood nutrition and wellness in South Africa: involving mothers/caregivers of malnourished or HIV positive children and health care workers as co-designers to enhance a local quality improvement intervention. *BMC Health Services Research*, 16: 358 DOI 10.1186/s12913-016-1574-4 (page 11, table 3)
- B. RAND Review. (2019) [A Novel Approach to Helping People Returning from Prison](#)
- C. Vermont Oxford Network. [iNICQ: Internet-Based Newborn Improvement Collaborative for Quality](#) [see iNICQ for Critical Transitions Features sub-heading and bullet 4)
- D. Susan Giboney. [“If only we had known”: learning what really matters to parents of premature babies” Blog 16/11/19](#)
- E. [Catalyst films for service improvement](#)
- F. Springham N and **Robert G**. (2015) Experience based co-design reduces formal complaints on an acute mental health ward. *BMJ Open Quality*, 4:u209153.w3970 doi: 10.1136/bmjquality.u209153.w3970
- G. Oxleas NHS Foundation Trust. [Experience based co-design work on Betts Ward](#)
- H. Patient testimony as included in reference 6, doi: 10.1136/bmj.g7714 (page 3, box 3)
- I. Experience-based Co-design. July 2020. A report detailing the training in EBCD until July 2020 collated by the Point of Care Foundation Pages 4-5
- J. Staff testimonies as included in **Robert G**. (2016). Developing person-centred services: the contribution of Experience-based Co-design to high quality nursing care. in S Tee (ed.), *Person-centred approaches in healthcare: a handbook for nurses and midwives*. Open University Press, Buckingham (page 26)
- K. New South Wales, Agency for Clinical Innovation. [Patient Experience and Consumer Engagement](#).
- L. The Change Foundation. (2017) [Creating new linkages between the caregiver, the community and health care is essential](#)