

# ANALYSIS

## SPOTLIGHT: PATIENT CENTRED CARE

# Patients and staff as codesigners of healthcare services

**Glenn Robert and colleagues** describe an approach that aims to ensure that healthcare organisations realise the full potential of patients—the biggest resource they have for improving the quality of care

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Over a decade ago Don Berwick suggested that healthcare “workers and leaders can often best find the gaps that matter by listening very carefully to the people they serve: patients and families.”<sup>1</sup> Health professionals are now familiar with a range of approaches—surveys, storytelling, focus groups, online feedback (to name a few)—that can help them listen. A minority use other techniques, such as shadowing patients and observing staff-patient interactions, to find out how and why services work well or not, and how they might be improved. But healthcare staff don't routinely use such data to improve the quality of their services<sup>2-3</sup> unless they have support.<sup>4</sup> Often the patients are only given a passive role with staff making all the decisions about how to respond.

Here we argue that patients can and should take a more direct and ongoing role in identifying, implementing, and evaluating improvements to healthcare services. We discuss examples of projects in which patients and staff have worked together and suggest that codesign methods have the potential to make patient centred services a reality.<sup>5,6</sup>

Growing attention has been paid to the value of applying design thinking to improve public services.<sup>7-10</sup> This is usually based on direct face to face user and provider collaboration to codesign products or services, and includes a focus on the aesthetics of a service—how it looks and feels. Though gaining in popularity, rigorous research into the implementation and impact of design thinking in the public sector remains fragmented and limited in several important respects, not least because of ongoing debates about how it is best interpreted, applied, and evaluated in practice.<sup>11-13</sup>

In healthcare the term codesign refers to patients and carers working in partnership with staff to improve services.<sup>14</sup> Here we focus on one particular approach called experience based codesign (EBCD),<sup>15</sup> a six stage process that usually takes 9 to 12 months to complete:

- Setting up the project
- Gathering staff experiences through observation and in-depth interviews
- Gathering patient and carer experiences through 12-15 filmed narrative based interviews
- Bringing staff, patients, and carers together to share their experiences of a service and identify their shared priorities for improvement, prompted by an edited 30 minute “trigger” film of patient narratives
- Small groups of patients and staff work on the identified priorities (typically 4-6) over three or four months
- Celebration and review event.

Though filming patients is time consuming and resource intensive, our experience shows it is an important catalyst for improvement; seeing and listening to patient experiences helps connect staff and is a persuasive starting point for change. The films also set the process apart from other ways of capturing patient experiences in which anonymity and circumspection can often hinder rather than enable quality improvement. The aim of the patient and staff interviews and observational work is to help patients and staff identify and jointly explore emotional “touchpoints” on the journey of care, with a view to improving these experiences. Touchpoints are interactions between staff

and patients, both positive and negative, that both parties perceive as crucial to the overall experience of receiving or delivering care.<sup>16</sup>

One example is the surgical insertion of a percutaneous endoscopic gastrostomy (PEG) feeding tube to allow liquid feeding of cancer patients. Though staff perceived this as a minor procedure compared with the major surgery and radiotherapy a patient has already had, patients identified it as a major touchpoint because it occurred just when they thought they were “out of the woods.” Patients have described this as “the moment the cancer was made visible” and the “straw that broke the camel’s back.”<sup>15</sup>

Although codesign projects typically bring about a series of incremental quality improvements (in this example, better explanation for patients regarding the nature and timing of the procedure), the partnership between patients and staff in making these small changes often leads to deeper, longer term changes in attitudes and behaviours.

## Using codesign in healthcare quality improvement

EBCD was first piloted in an English head and neck cancer service in 2005.<sup>15</sup> After a subsequent project in an integrated cancer unit an online toolkit was developed as a free guide to implement the approach.<sup>17</sup> The project sought to enhance touchpoint experiences for patients in two breast and two lung cancer services.<sup>18</sup> Fieldwork comprised 36 filmed narrative patient interviews, 219 hours of ethnographic observation, 63 staff interviews, and a series of codesign meetings involving patients and staff that were facilitated by trained quality improvement specialists. In total, 62 improvements were identified and implemented across the four services.<sup>19</sup> Table 1 shows the 19 codesigned improvements implemented and sustained over two years in one of the breast cancer services.

An international survey of EBCD projects in healthcare services identified 59 projects implemented in six countries (Australia, Canada, England, the Netherlands, New Zealand, and Sweden) during 2005-13 and a further 27 projects in the planning stage.<sup>14</sup> Boxes 1 and 2 provide case studies of the outcomes resulting from initiatives to codesign services and products with patients and carers.

As these two case studies show, the original blueprint for EBCD can be adapted and tailored to suit different types of healthcare services as well as local and national contexts. A notable adaptation is an accelerated approach that used existing archive of patient narratives to create the trigger films ([www.healthtalk.org/peoples-experiences/improving-health-care/trigger-films-service-improvement](http://www.healthtalk.org/peoples-experiences/improving-health-care/trigger-films-service-improvement)). The approach was evaluated in two lung cancer services and two intensive care units in England.<sup>23</sup> The use of national trigger films meant that the project took half the time of a standard EBCD project and at only 40% of the cost; the films can be used across NHS settings. Improvements that staff and patients identified and implemented together include redesigned lighting systems, appropriate clocks to aid patient orientation, tablet computer applications to assist ventilated patients communicate, redesign of discharge summaries, v-shaped pillows for postoperative patients, and a new process for effective transfer of patients’ belongings from theatre to recovery ward.

A trial is currently under way in six Australian community mental health teams to evaluate the effect of codesign on psychosocial recovery outcomes (such as willingness to ask for help and personal confidence and hope).<sup>24</sup> Although evaluation is important, reliance on relatively broad and insensitive

outcome measures such as patient satisfaction may overlook the real value placed by patients and staff on changes in the personal behaviour, attitudes, and culture of healthcare teams and organisations (boxes 3 and 4).

Of course, implementing codesign in healthcare settings is not without challenges. Professional service designers can feel frustrated at the pace and scale of change when working within healthcare organisations.<sup>13</sup> And conflict and tension—often relating to issues of power<sup>11 13 14 25</sup>—can emerge between patients and staff. This may be especially true if patients find it difficult to express their views because of a previous experience of very poor care. In such circumstances a highly participative codesign process may not always be the best option for that individual patient.

## Looking forward

Patients provide insight, wisdom, and ideas, and we urgently need to include them more creatively as partners in change. Although there has been substantial investment in refining methods for collecting data about patient experience and satisfaction, we need to better understand how these data can be used locally to improve the quality of care and the culture of health services.<sup>3</sup> Although stronger evidence is needed to justify disinvesting from current practices and shifting some resources to novel ways of using patient experiences to drive up quality, the opportunity costs of current practices are substantial. These costs need to be made clear and the practices formally evaluated against alternative approaches.

We believe that mainstream approaches to improving patient experience place too much emphasis on metrics, lack critical reflection about the insights provided by survey methods (or knowledge of how to enact improvements on the basis of those insights), and are hindered by a deeply engrained perception of patients and families as passive sources of data rather than active partners in implementing change. Rather than marching relentlessly onwards to capture more patient experience data, we should be embedding codesign practices and values in our healthcare organisations. Experience with codesign projects shows that they can enable patients and staff to come together and jointly reflect on their shared experiences of a service in meaningful and sustainable ways. And given the increasing evidence in support of a link between staff wellbeing and patient experience,<sup>26</sup> it is not only patients who may benefit from such a shift.

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Contributors and sources: GR is one of the original developers of EBCD and has been involved in the evolution and adaptation of the approach since the initial pilot project in 2005 which was funded by the NHS Institute for Innovation and Improvement. Of the EBCD projects referred to in the manuscript, he was involved in: the Guys’ and St Thomas’s Charity-funded Integrated Cancer Centre project; the National Institute for Health Research-funded development and testing of accelerated EBCD (NIHR HS&DR 10/1009/14); the international survey of EBCD projects; and the Dimpleby Cancer Care-funded feasibility trial with carers of chemotherapy patients. JC was involved in the Integrated Cancer Centre project and is the chief executive of the Point of Care Foundation which provides training in EBCD. LL is the principal investigator both of the recent study of accelerated EBCD and of an

**Box 1: Improving the experience of carers of patients receiving outpatient chemotherapy**<sup>20</sup>

Supporting someone through chemotherapy can be emotionally and physically demanding. This study tested the feasibility and acceptability of a complex intervention for carers that was codesigned by staff and carers.

The intervention, which became known as Take Care, was developed using EBCD. The design process began with 20 hours of non-participant observation, 20 semi-structured interviews with staff members, and 20 filmed narrative based interviews with carers. Carers and staff reviewed the themes arising from the observational and interview data, discussed these, and then worked together to codesign the intervention.

Take Care eventually comprised:

- A 19 minute supportive and educative DVD
- Accompanying booklet
- 1 hour protocol guided group consultation conducted by one of two chemotherapy nurses trained in group facilitation.

The consultation was provided before patients' first cycle of treatment to groups of no more than five carers. During it, they watched the DVD and were given the opportunity to freely express concerns and ask questions. They were given a copy of the DVD and booklet and were encouraged to consult them when they needed information or support during the patients' treatment.

In a randomised feasibility trial of 47 carers (intervention (n=24) and control (n=23)), those who received the intervention reported significantly better understanding of symptoms and side effects and that their information needs were more often met compared with the control group. Confidence in coping improved between baseline and follow-up for the intervention group and declined for the control (although differences in this measure were insufficient to achieve statistical significance in this small trial).

**Box 2: Improving the experiences of patients with epidermolysis bullosa**<sup>21</sup>

Epidermolysis bullosa (EB) is a rare inherited skin condition causing extensive, painful skin blistering and wounds. Adults have extensive chronic wounds that often cannot be covered by available shapes and sizes of dressing.

During the course of four workshops patients, carers, and specialist nurses gave detailed accounts of their experiences and identified limitations of existing products with regard to fit, stability, comfort, temperature, and exudate. They came up with ideas about how dressings could be improved and used surrogates to test them. This project has led to the development and commercialisation of an innovative range of dressing retention garments, Skinnies, which improve patient experience and significantly reduce costs. The codesigned garments reduced the time taken to apply dressings; they also held the primary dressings in place and reduced the quantity of dressings used because fewer replacements were needed between dressing changes.<sup>22</sup>

**Box 3 An intensive care patient's perspective**

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. Such an environment allowed us as patients to reflect on aspects of our care which we had not been prepared to discuss before and for staff to explore and highlight ways in which their clinical procedures could be improved without fear of criticism.

It was apparent to us as patients during the smaller codesign team meetings that 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; everyone's thoughts and ideas were discussed in full and then developed in a meaningful manner. In my own case rewarding outcomes were the creation of a leaflet to aid the understanding of the cause and effects of hallucinations and the development of new, more effective, and considerate procedures for the transfer of patients from intensive care. These issues can cause considerable stress to both patients and relatives.

**Box 4: A clinical nurse specialist's perspective on facilitating a codesign project**

For me it was about creating an opportunity—a safe social space—for staff to tell their story of what they experience every day; acknowledging the awfulness of what we see was cathartic, empowering, and engaging. Our staff worked alongside the experts in the services we deliver (patients and relatives), who were willing to share such rich and deep reflections on their personal experiences; it was the commitment of our patients and relatives that became the driving force to deliver improvements to our services.

As the facilitator, when asked to provide evidence of outcomes I can demonstrate these through our codesigned information booklets, DVDs on experiences of being voiceless while ventilated, and of hallucinations, the room makeover, etc. However, these do not and cannot convey the changes in personal, professional, and work culture that I witnessed. I saw a paradigm shift in an intensive care consultant who changed from having no insight into the impact of critical illness on patients and relatives to championing the importance of striving to become a patient centred service at every opportunity. I saw a "light bulb" moment in patients when a consultant explained by a simple hand drawn picture why they had become voiceless when intubated. I saw leaders emerge within each codesign team—patients as well as staff. Because of what the staff had heard I saw changes in practice with immediate effect. I saw patients caring for staff in meetings, such was the rediscovered connection and humanity between them. I saw staff reconnect with their fundamental core beliefs and values, which has to impact not only on their wellbeing but on that of the next patient and relative they meet. Sometimes you cannot count what really counts.

**Key messages**

- Codesign represents a radical reconceptualisation of the role of patients and a structured process for involving them throughout all stages of quality improvement
- Our focus needs to shift away from collecting more data on patient experience towards embedding codesign as a way of doing things
- Evidence is growing about the effectiveness of codesign approaches but lack of evaluation of other approaches makes comparison difficult

ESRC-funded project to conduct secondary analyses of an archive of filmed patient narratives in order to produce "trigger" films for future EBCD projects (ES/L01338X/1). AP was the cancer centre director responsible for leading the Integrated Cancer Centre project. GS is a

former ICU patient who participated in an accelerated EBCD project. MG is a clinical nurse specialist who facilitated accelerated EBCD projects in both an ICU and a lung cancer service. GR is the guarantor

of the article and drafted the original manuscript. JC, LL, AP, MG, and GS commented upon early drafts and contributed to the final version.

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## Table

Table 1 | Codedesigned improvements in a breast cancer service<sup>18</sup>

Touchpoint identified for improvement	No of improvements	No sustained at 2 years	Sustained codedesigned improvements
<b>Day surgery</b>			
Lack of information about operating times/having to wait long time	9	6	Dedicated nurse (preoperative) Staff and staff-patient communication
Separated from family and friends too soon			Staff photoboard and call bells Preoperative patients wait in own clothes
Feeling invisible and alone			Improved continuity of nursing care
Being rushed through recovery			Day surgery redesign (including single sex accommodation; dedicated consulting room)
<b>Breast clinic</b>			
More continuity of care	4	4	Clinic procedures reviewed and revised Waiting time notification board
Improved relational care			Reception staff customer care training
Improved care coordination			Staff photoboard
<b>Appointments</b>			
Not receiving letters on time; patients not on lists; lost in system	8	5	Physiotherapy care: routine post-op appointments Post-op appointments arranged before surgery Appointment letters with maps Named clinic clerk contact details on all correspondence Voicemail message returned in stated time
<b>Surgical pathway</b>			
Communication between staff and patients	3	2	Early/less rushed consent process Surgery dates on day of results
Staff spending enough time with patients			
<b>Written patient information</b>			
Importance of written information	3	1	Amount of information discussed with each patient
Information about going through cancer treatment and living with side effects			
<b>Survivorship and support</b>			
Feeling lost at end of treatment; more information about what happens next	1	1	Ongoing development of end of treatment consultation