Article title: What patients do and their impact on implementation process and outcomes during (and after) participatory quality improvement projects in English acute hospitals: Reflections from an ethnographic study

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What patients do and their impact on implementation processes and outcomes during (and after) participatory quality improvement projects in English acute hospitals: reflections from an ethnographic study

Background

Implementation science is concerned with the use of evidence in health care practice in order to bring about improvements in the quality of healthcare. Growing international interest in implementation science is demonstrated by the establishment of the Global Implementation Initiative (GII) and an international journal 'Implementation Science.' Following a long debate about the role of patient experience in evidence based health care (Partridge and Scadding 2004), patient experience research has slowly gained acceptance as a valuable source of knowledge for policy and practice particularly relating to quality improvement 'work' (Robert and Cornwell 2011; Robert et al 2015). With increased interest in processes of implementation and improvement (Eccles et al 2009), existing frameworks such as the Promoting Action on Research Implementation in Health Services (PARIHS) framework (Rycroft Malone et al 2013) have incorporated evidence from process data - including patient experience research - alongside clinical evidence. Furthermore, the goal of improving patient outcomes drives implementation interventions, with patients sometimes described - narrowly - as the 'target' for implementation science (Nilsen et al 2013).

Although the goals of implementation science align with those of patients, the potential for including patients in implementation processes - and evaluating their impact on quality improvements - has received limited attention. Whilst the importance of staff and patient engagement in improvement processes is acknowledged (Thomson et al 2015), patient engagement typically continues to be dominated by one-off consultation exercises, formal patient complaints procedures and satisfaction surveys (Robert et al 2015). Consequently, participation has been characterised as being limited to the offer of a seat at the table (Coulter et al 2014, Stern and Green 2008). In the UK, impetus to reconsider patient engagement in all aspects of health care research and practice has come from recent high profile scandals in patient care, perhaps most notably the publication of the Francis report (The Mid Staffordshire NHS Foundation Trust Inquiry 2013).

'Trust management had no culture of listening to patients. There were inadequate processes for dealing with complaints and serious untoward incidents (SUIs). Staff and patient surveys

continually gave signs of dissatisfaction with the way the Trust was run, and yet no effective action was taken and the Board lacked an awareness of the reality of the care being provided to patients. The failure to respond to these warning signs indicating poor care could be due to inattention, but is more likely due to the lack of importance accorded to these sources of information' (The Mid Staffordshire NHS Foundation Trust Inquiry 2013: 44)

Given the moral and political pressure to involve patients, this paper examines the impact of actively engaging patients in implementation processes as part of a participatory quality improvement project. A recent overview of the implementation science literature (Ogden and Fixsen 2014) highlighted the importance of stakeholders and suggested that 'bottom up' components to implementation strategies better ensure local needs and concerns are reflected, building ownership and commitment to implementation. However, the 'bottom up' approach to implementation and improvement described in the literature is primarily concerned with the roles and behaviour of front line staff rather than patients and carers (Nilsen et al 2013). Little attention has been paid within existing implementation frameworks to activities and participatory processes involving patients, carers and the public. This study aims to identify the different roles undertaken by patients and carers within a participatory quality improvement project and considers the nature of the impacts arising from such patient and carer involvement.

Methods

<u>The intervention</u>

This paper draws on data from an ethnographic evaluation of a co-design intervention in Intensive Care Units (ICU) and lung cancer (LC) pathways in two English National Health Service hospital trusts (Locock et al 2014a; Locock et al 2014b). The intervention, Experience-based Co-design (EBCD), combines insights from design sciences, organizational learning and patient engagement research and applies these in order to improve the quality of healthcare through a process of participatory action research (Bate and Robert, 2007; Robert et al 2015). EBCD is a six stage process that usually takes 9 to 12 months to complete (Robert et al, 2015) (see figure 1). The six stages are (1) Setting up the project, (2) Gathering staff experiences through observation and in-depth interviews, (3) Gathering patient and carer experiences through 12-15 filmed narrative based interviews, (4) 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, (5) Small co-design groups of patients and staff work on implementing improvements relating to the identified priorities (typically 4-6) over three or four months and (6) Celebration and review event. The wider study from which this paper draws its findings tested an attempt to accelerate the co-design process by replacing a locally produced trigger film of patient narratives with a film produced from a pre-existing national archive of patient experience interviews (Locock et al, 2014a).

The four local quality improvement interventions under study consisted of EBCD as implemented in two clinical pathways (ICU1, ICU2, LC1, LC2) in two NHS Trusts. Local facilitators were mentored throughout the EBCD process and supported by an extensive online toolkit (http://www.kingsfund.org.uk/projects/ebcd). In each ICU and lung cancer pathway, local facilitators conducted staff discovery interviews. Local patients and carers then attended an initial workshop at which they were shown a film created from the national archive to enable them to reflect on their own shared experiences of the pathway and trigger group discussion. The films contained a collection of 'touch points' or crucial moments that shape a patient's overall experience (and have subsequently been made available for online streaming: http://www.healthtalk.org/peoples-experiences/improving-health-care/trigger-films-service-improvement). Patients and carers viewed the film and then took part in a facilitated group discussion, highlighting any different or emerging issues. An emotional mapping exercise was then used to help patients reflect together on the emotional impact of the touch points (Bate and Robert, 2007). Following this group work, patients voted on their shared priorities for improving services. Staff had a separate meeting to discuss the results of their own feedback interviews. Staff and patients then came together in a further workshop to view the film, agree priorities and set up co-design working groups to implement improvements in these priority areas. Ground rules were established from the outset, seeking to ensure that all participants had equal voices.

In order to better enable participation and likely sustainability of any improvements the facilitators were - at this co-design stage - able to refine the implementation process according to the needs of (a) their patient groups and (b) local context. This led to significant variation between the sites (see Table 1). For example, for two interventions (ICU1 and LC1) one person facilitated all the smaller co-design group meetings. For others there were

different facilitators (including co-facilitators) for each group (ICU2 and LC2). There was also variation in terms of the numbers of times these groups met: ranging from 39 (ICU2) to 2 (LC1). Patients were invited to participate as much (or as little) as they felt comfortable with. The facilitator in one site changed the wording in the invitation letter to make this clear and felt that this had boosted recruitment numbers. Scope for engagement was, to some extent, determined by the nature of the patient groups in the two sites. For example, in the lung cancer co-design groups some patients became progressively ill and could no longer attend.

Table 1 Variation in implementing EBCD across the four pathways

Pathway/Trust	Co-design groups	Co-design group facilitator no.	Total number of co-design meetings (average in brackets)	Average number of participants per co-design meeting	Patient and relative participants total
ICU1	4	1	8 (2)	6	16
ICU2	4	5	39 (10)	8	17
LC1	2	1	2 (1)	6	17
LC2	4	6	24 (6)	5	13

At the final stage, these separate co-design working groups reconvened to discuss progress and plan the next stages of the improvement process (see figure 1 for an overview of the stages of EBCD). In total, 96 clinical staff (primarily nursing and medical), and 63 patients and family members across the four pathways took part in the intervention at some stage of the process.

There were 14 co-design groups in total. The co-design groups are characterised by intense involvement in improvement and implementation processes. The online guidance for co-design group facilitators stresses the unique features of this intervention:

'In Experience-based Co-design this role goes beyond usual service improvement facilitation. This is because neither patients nor staff are accustomed to working alongside each other so they may need particular help to overcome barriers, such as brief training in service improvement techniques. This means the facilitator may need to encourage particularly dominant participants to listen and enable others (often patients) to speak up ... To make the most of the unique features of Experience-based Co-design you need to keep involving the

patients throughout the process and asking is this what you had in mind, does this work in the way you envisaged and then fine tuning the solutions accordingly.'
 (Excerpts from the King's Fund on line toolkit used by the project facilitators. http://www.kingsfund.org.uk/projects/ebcd, accessed 12/5/15)

Across the two hospitals, the eight ICU co-design groups focused on the following topics: enhancing basic care, reducing noise and sleep deprivation, communication, patient–doctor communication on ward rounds, transition to the ward: 'lost in translation', hallucinations, ventilation and individualised care. The six lung cancer co-design groups looked at pillows, personal items, information, privacy, diagnosis-giving, support and information. Different quality improvement methods were adopted on the different sites. For example, while one site relied on facilitator-led group working, the other site adopted an explicit quality improvement approach by training all co-facilitators in a technique called 'quality circles' (Hosseinabadi et al 2013; Rohrbasser et al 2013). A quality circle is a participatory management technique that enlists the help of employees in solving problems related to their own jobs; circles are formed of employees working together in an operation who meet at intervals to discuss problems of quality and to devise solutions for improvements.

The evaluation

Our ethnographic process evaluation aimed to observe the implementation process in both pathways in each Trust. The evaluation set out to explore seven research questions (see Box 1) using multiple data sources, including observation, interviews, questionnaires, reflective diaries, service improvement logs, documentary analysis, including previous EBCD evaluation reports and administrative data on costs.

[Insert Box 1 here]

In this paper the focus is on one of these questions: 'What improvement activities does the approach stimulate and how do these activities impact on the quality of health care services?' In particular, we consider the different roles undertaken by patients and carers relating to these activities and impacts. Ethics approval was obtained by proportionate review (Research Ethics Committee reference number: 11/NW/0653). Data collection took place between November 2011 and December 2012. A total of 155 hours of observations took place, including at 2 facilitator training sessions, 12 patient, staff and joint events, 26 co-design

meetings, 3 project advisory group and 3 core group meetings. Thirty interviews with staff, patient and carer participants and with the facilitators and two group interviews with patients and carer participants were conducted. Maximum variation sampling was used to ensure a spread of different types of participants. Interviews, training sessions and events were audio recorded and transcribed. Observations and brief conversations were recorded as field notes. One hundred and sixty-six evaluation forms were completed after co-design meetings.

Analysis

Transcripts, documents, fieldnotes and emails were entered into NVivo. Coding was based on the seven research questions (see box 1), as well as emerging themes. Data were tabulated using Framework Analysis (Ritchie and Lewis 2003) which facilitates a structured thematic approach to data analysis. It is particularly useful for comparing between cases as well as within cases (Gale et al 2013). In this study, Framework Analysis was used to generate comparisons between the intervention sites. For example, as part of the analysis, improvements were categorised based on a previous EBCD study (Adams 2013) in terms of their perceived degree of implementation complexity: small-scale changes; process redesign at the team level; between services; and between organisations. The Framework approach allowed the synthesis of diverse, but heterogeneous sources of data at different levels of processing (interviews, questionnaires, documents and observations)

Data analysis involved the following stages:

(i)   familiarisation with the current and previous EBCD data,

(ii)   thematic analysis of qualitative data and tabulation and graphical representation of quantitative questionnaire data,

(iii)   indexing and developing a comparative framework based on the 7 main questions to compare between current and previous EBCD cases (based on the themes of acceptability of the intervention, impact of film on quality of engagement, representativeness of experiences in national archive, nature and impact of improvement activities, costs of participatory quality improvement, and identification of potential to replicate in other pathways),

(iv)   mapping and interpretation of findings. Members of the project team refined the analysis at a two day workshop. This workshop, along with the project advisory group meetings, core team meetings and reflective diaries completed by team members provided opportunities to reflect and discuss roles, interests and

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preconceptions amongst team members. Further, secondary analysis of the data was conducted to explore the roles undertaken by patients and carers within EBCD and their impacts.

Findings

In the interviews, staff, patients and carers referred to what they perceived as distinct features of EBCD as a quality improvement intervention. In particular, the space (and support) to work together served to dispel preconceptions, improved staff motivation for change, increased the sense of mutual accountability and promoted greater valuing of patient responses. Participants described personal benefits derived from meeting others and taking part in the EBCD process. This intensive approach to engagement felt very different to patients and staff as compared to traditional public and patient involvement and engagement in quality improvement work. Two key themes emerged from our secondary analyses of the data relating to patient engagement: firstly, the different roles adopted by individual patients and carers in relation to implementation and, secondly, the nature and types of quality improvement achieved through close patient and staff engagement.

Roles adopted by patients and carers in relation to implementation

Across the four services and two Trusts a range of different roles were adopted by patients:

- Sharing experiences (acting as a source of expert, experiential knowledge through attendance and contributions at the patient events).
- Identifying priorities for quality improvement in their local services (attending the joint event with staff and first co-design meetings).
- Developing potential solutions through working alongside staff (bringing innovative ideas and solutions as part of the co-design group work).
- Helping to implement and evaluate these solutions (through ongoing engagement with the Trust).

Table 2 illustrates these types of participant role at each stage of the EBCD process which are then subsequently described - in turn - in more detail:

Table 2 Participant roles in EBCD at different stages of the intervention

		Participant roles			
		Sharing experiences	Identifying improvement priorities alongside staff	Developing potential solutions with staff	Helping implement & evaluate solutions
Intervention Stage	Patient event	x			
	Joint event	x	x	x	
	Co-design group	x	x	x	x
	Celebration event	x			x
	Follow-up quality improvement activity beyond the formal stages of EBCD				x

There were different reasons for patients ending their participation including feeling that they did not have anything more to contribute, often because they felt the change process had become too technical and subsequent implementation should be the responsibility of staff. Others (mainly in the lung cancer groups) became too ill to continue.

Below we present two vignettes of how priorities for improvement emerged in conversations after patients viewed the trigger films, subsequently participated in the 'emotional mapping' exercise with other patients, engaged with staff in choosing priorities, and then went on to identify and implement solutions in the smaller co-design groups

[Insert Box 2 and 3 here]

Participation as co-designers (patient event, joint event and co-design groups)

Attending the initial events for patients

The involvement of some patients and carers was limited simply to attending the initial patient event. For example, an expectant mother who nearly died while giving birth agreed to come to the ICU patient event. She attended the meeting with her husband but did not feel able to continue contributing to the project as it was too distressing for her. Others felt that the work of developing solutions was for the health professionals and they had played their part through sharing experiences and participating in the initial event. However, the attendance of patients at the four initial events did provide an opportunity for patients to share their experiences and to inform the priorities taken forward in the subsequent co-design groups. In a group interview, patients and carers also described how they had reacted to this first event, with one participant commenting that he had had a positive experience contrary to his expectation.

> *Interviewer: So what did you think of the first event? The first event was when it was only patients and you were shown the film for the first time.*
>
> *Patient 1: It was thought-provoking.*
>
> *Patient 2: Well, it converted me because I was very sceptical as to whether I could give any contribution to it.*
>
> (Group interview with patients and carers, intensive care)

ICU patient 2 went on to describe how he had been really affected by a patient on the trigger film describing his experiences of hallucinations and the fear that he had lost his sanity. The patient had felt reassured that his was a shared experience: '*I thought, Oh, it's not just me. Thank God. I felt a lot better after seeing that.*'

While patient 2 described an emotional response to the trigger film, participants in the second ICU group responded more directly to the factual information in the film. In a group interview, the participants also mentioned that they had been uncertain that they would have anything to contribute until they saw the film.

> *Interviewer: What were your feelings when you came to the first patient event and you saw the film then as well?*

Patient 1: Well, the film is very interesting, but I didn't... the first reaction is how much use can we be? I didn't know how much... whether we were going to be useful or not.

Patient 2: No.

Patient 1:   Because you don't know, do you?

Patient 2:   I felt the DVD seemed to border on all the negative elements.

Patient 3: Yeah, yeah.

Patient 4: Yeah.

Patient 2: And I don't know that I actually had any negative elements whilst I was in the ICU.

Patient 1: No.

(Group interview with patients and carers, intensive care)

However, in this group participants felt that they had a different experience to that described in the film and this encouraged them to feel that they could bring something to the co-design process.

Patient and staff joint event

Patients and carers spoke positively about their involvement in the joint event with staff. In the individual and group interviews patients and carers spoke positively about coming together with staff at the joint event. Staff were described as '*constructive*' and '*supportive*' and that they '*felt comfortable with them.*' One patient described how the patients had set the tone for the meeting by saying '*'Look, before we start, this is not personal and we thank you very much. You saved our life.' But we felt we had to say that.*' (Patient, group discussion, ICU) A patient in the second group interview commented that staff and patient participants had shared a positive attitude to quality improvement: '*Nobody was apportioning blame. It was, 'What can we do to improve the situation?*''

<u>Co-design groups</u>

As co-design group participants, patient and carers took on a range of roles as illustrated in the following two examples. The information lung cancer co-design group at one site was co-led by a patient and a clinical nurse specialist. The group consisted of 4 patient representatives and 4 staff representatives. They had 6 face-to-face meetings and conducted interim work online. This group sought to address the lack of information available to patients after initial diagnosis from their GP or consultant, diagnosis at the chest clinic and/or following a visit to a tertiary hospital where patients were referred for surgery. The group requested that notes sent to the GP should also be sent to the patient. The patient group leader communicated the need for this information in writing with the consultant. The group then focused on producing a leaflet for a typical patient who would need to undergo surgery. They also worked very closely with the communications team at the tertiary hospital.

Patients' accounts also led to priorities and solutions that would not otherwise have occurred to frontline staff immersed in day-to-day service delivery. For example, delirium in ICUs was identified as an area that would benefit from co-design group working by patients and carers. The co-design group consisted of patients and relatives (with very little staff involvement). Participants in the ICU delirium working group shared their personal experiences of hallucinations, some for the first time, and worked together to produce a leaflet on ICU delirium experiences for the benefit of future patients and relatives. They also reviewed some literature on research into hallucinations and then discussed and proposed what information should be included in the leaflet and worked via email in-between meetings to review contents, wording and provide vignettes.

<u>Celebration event</u>

A small number of patients (1-2 per co-design group) remained involved throughout. They were able to reflect at the final, celebration event on the take up of ideas from the initial meetings:

> *'There was a comment from a patient within the event who said that everything that had been discussed had been taken forward into improvements . . . 'our views were not dismissed, they were looked at and things changed.'*
> (Excerpt from ethnographer's field notes at celebration event)

Ongoing patient engagement as 'experts by experience'

Three patients have remained actively involved with the Trusts after the EBCD process came to an end. For example, one previous ICU patient (a co-author on this paper) has subsequently been involved in promoting EBCD within the local Trust and nationally. He has also delivered sessions to student nurses on his experiences as an ICU patient. He was encouraged to take on these roles by a ward sister who facilitated the links with relevant staff members. He continued to work with the team on the online EBCD tool and in writing up the findings.

During the co-design group on hallucinations another patient participant recounted how after waking up in ICU she hallucinated that she was in a giant feathered nest and that this was a frightening experience because the nest subsumed her. She did not share the experience with the ICU nurses at the time and felt slightly embarrassed at the thought of having experienced something so odd. During the co-design group meeting she felt comfortable to share her experiences for the first time in public as other patients did the same. As part of her healing process she created a feathered nest using materials from an arts and crafts shop and brought the nest to the co-design meeting to share with the group. Patients reported that this experience contributed to their emotional healing from the experience of having had near-death experiences. The facilitator asked her to present the hallucinations group outcomes at the final end-of-project celebration event and to also bring her artefact. Participants reported that the impact of hearing a patient recount this experience was accentuated by the visual impact of seeing the artefact. As a result the patient was invited to give the same presentation and show the artefact at the clinical governance meeting. Due to increasing interest, the patient donated the feathered nest to ICU and it is now being used in medical education in the Trust on delirium.

The nature of impacts: Types of quality improvement achieved through patient and staff engagement
While patient and carers participated in EBCD in a range of different ways, they did so with a shared goal of using their experience to improve the quality of services for future patients. This section focuses on the types of impacts that occurred following patient engagement in EBCD. There are two dominant themes: the tendency towards 'small-scale' quality improvements and the wider changes in staff attitudes and organisational culture.

'Small-scale' changes

Of the total of 48 changes recorded in the quality improvement logs maintained by the facilitators, the majority of the changes were either small-scale changes (21 changes) or involved process redesign within teams (21). Five changes involved process redesign between services and one required process redesign between organisations. Table 3 includes examples of categories one and two (small scale changes and those involving process redesign at the team level).

Table 3: Types of change identified by clinical theme

Examples of changes identified by clinical themes	
Lung cancer	Acquiring more comfortable V-shaped pillows for post-operative patients
Lung cancer	Identified and modified private room for receiving support after the diagnosis
Lung cancer	Patient support group established
Lung cancer	A new process for effective transfer of patients belongings (including dentures and frames) from theatre to the recovery ward
Lung cancer	Patients made aware of support available through clinical nurse specialist
Lung cancer	Consultants agreed to send summary letter to patients after consultation
Intensive Care Unit	Sign created to enhance dignity and privacy
Intensive Care Unit	Promoting the involvement of families in personal care via team news
Intensive Care Unit	Promoting the washing of patients' hair more regularly via team news. New wash basin to be trialled
Intensive Care Unit	Encouraging wards to send patients wash bags to ICU – email to all sisters and managers. Infection control view sourced
Intensive Care Unit	Sourcing appropriate clocks to aid patient orientation
Intensive Care Unit	Encouraging nurses to brush patients' teeth more regularly – via team news and through sourcing new toothbrushes to trial
Intensive Care Unit	Promoting the correct application of CPAP (continuous positive airway pressure) masks. Creation of a guide and teaching on team days
Intensive Care Unit	Informing patients about the potential for hallucinations – via rehab and therapies booklet

The 3 ICU process redesigns between services were:

- Encouraging wards to send patients wash bags to ICU

- changing waste removal to outside of the ICU rest period
- redesigning the ICU discharge summary form.

In lung cancer, the process redesign between services were:

- developing a new process for effective transfer of patients belongings from theatre to the recovery ward
- the establishment of a new multidisciplinary lung cancer service development group.

The one process redesign between organisations was the production of an improved information booklet for lung cancer patients transferring to another hospital for surgery.

The tendency to identify 'small-scale' changes that were felt to be key to improving patient experience was contrary to staff initial expectations that patients would identify large scale, costly changes. However, the interviews with staff and patients challenged the assumption that 'small-scale' should always be equated with trivial change. Participants argued that small scale changes can be of profound value to patients.

For example, one of the ICU co-design groups worked on putting a process in place to ensure that patients' belongings followed them from the ICU to other wards within the hospital. For patients having their false teeth and reading glasses enabled them to eat, talk, read and write – all key to their recovery. However, even seemingly 'simple' small scale changes, such as putting clocks up in intensive care wards, often proved challenging and time consuming due to the procurement protocol that public services need to adhere to. Another small scale change, the sourcing of new electric toothbrushes so that ICU staff could brush patients' teeth more regularly had been put on hold due to health and safety as well as financial constraints.

<u>Changes to staff attitudes and organisational culture</u>

A number of distinct features of EBCD as an improvement intervention were identified by patients, carers and staff in the interviews. In particular, the space (and support) to work together served to dispel preconceptions, improve staff motivation for change, increase the sense of mutual accountability and promote a valuing of the patient responses. Staff found patients and carers were not hostile and demanding (as they feared they might be at the outset):

Well, I think, yes, and I think that's the one big thing I've learned about the healthcare professionals not actually having exposure to patients and relatives, so this whole process has been quite a new experience. And immediately, for whatever reason, be it bad press or... you would just always assume that patients want to engage, have got their own agenda and will criticise, but actually they [staff] were surprisingly not well equipped to deal with patients and relatives, so I think they kind of felt that they had to be quite defensive and couldn't just be themselves with them. (Interview with EBCD Facilitator)

Staff and patients provided examples of positive experiences of working together. One of the facilitators described how a staff member in one of the lung cancer events became upset and was comforted by one of the patient participants.

I think that they [staff] really liked being with patients, and on this equal footing, because often they are with patients, you know, perhaps because there's a complaint being made, and I noticed that there were several things in the meetings. So for instance, one of the patients would say, "Oh come here, we'll look after you," so the relationship between patients and staff became equal, with occasions where patients were taking responsibility for staff. (Interview with lung cancer co-design group lead)

In the interviews, patients and carers were concerned that their involvement would lead to little or no change. This preconception was informed by past experiences of public sector consultation exercises. As a consequence, participants spoke positively about the actions arising from EBCD:

'I wondered what, if anything, will be taken on board. To be honest with you, everything has been taken on board, and that in itself was a complete surprise.' (Patient interview)

In an e-mail to the ethnographer one of the facilitators observed that patients and carers had told them that they were impressed that not only had they been listened to but that change was made possible because of their involvement and the tenacity and passion of staff.

Similarly, staff reflected positively on their engagement in EBCD. A senior manager in one site reported that a member of staff in intensive care had said it was the first time in more than 20 years of practice that he had sat down and talked to patients in this way. A senior lung cancer nurse (unprompted) told a meeting of the project advisory group that it was the most inspiring thing she had done in her professional career. One of the co-design group leads described her experience of attending the events:

> *'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 may me realise what a crazy system we are working at the moment. People are doing their own things; they are assuming lots of things.' (Interview with co-design group lead, intensive care)*

Critical aspects of the process included creating the space to think and to listen to others (both patients and other staff):

> *'I think the most important things were that staff really appreciated the time to think about the experience. It became apparent that they perhaps didn't have or make time to reflect on what they do in their daily workings, so I think they actually found it quite cathartic and therapeutic. It actually raised the thinking of experience, and I think the staff really appreciated that their point of view was being listened to because up until that point the political drive had always been patient experience and now all of a sudden we were interested in staff experience.' (Facilitator, interview)*

The opportunity to hear directly from patients and carers had a transforming effect on some staff participants. One participant described herself on a co-design evaluation form as 'a better nurse because of it.' Significantly, this change was reported prior to the co-design group working, demonstrating an attitudinal shift emerging from the initial encounters with patients and carers. Here a nurse describes her personal experience of EBCD and how their views of patients as people had changed over the course of the project:

> *'I have already changed the way I think and care for patients even though we haven't started implementing changes yet. I have a better understanding now of how things are from the patients' perspective.' (Nurse, intensive care, fieldnote of conversation)*

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Similarly, one of the facilitators reflected on how the active involvement and presence of patients had galvanised staff. She concluded that it now made sense to work with patients on service development and improvement.

> Interviewer*:   Has this project been different to other improvement projects you've been involved in?*
>
> Facilitator*:   Yes, because the absolute core of it is the humanistic connections. Because of hearing patients', relatives' and staff experience it acts as a catalyst and gives you energy to keep going and make the change, and make sure it happens. It's a real driver to keep going and it seems to be the only thing that makes sense.*
>
> Interviewer*:   The only thing that makes sense?*
>
> Facilitator*:   It is. So many people have echoed that without me saying anything. I have not had to convert people into this methodology now. People just get it and wonder why we've never done it before. (Facilitator, interview, ICU)*

Even where groups identified more long term goals for change, such as in the case of the lung cancer co-design group on diagnosis giving, there was a sense that a process of change was underway. For example, the co-design group facilitator commented that, though they still had not solved all the problems the group had set out to address she had observed changes in staff behaviour. She gave the example, of reading in a patient's notes that a member of staff had planned how to give the news of a diagnosis to a patient. She saw this as a shift from previous practice, where staff would go and give news of diagnosis to a patient without planning.

Discussion

Previous studies of implementation and improvement have considered the inclusion of the public and patients through patient experience research (for example in the PARIHS framework (Rycroft Malone et al 2013)). Others have looked at the power of patient insights in setting agendas and priorities (for example, the work of the James Lind Alliance on patient involvement in priority setting), in developing guidelines (see for example, the UK National Institute for Clinical Evidence) and in identifying outcomes (see for example, the development of patient reported outcomes (PROMS)). Here we report on a more intensive

approach to drawing patient experience into local quality improvement 'work'. The EBCD process harnesses patient experience knowledge and then includes patients and carers alongside health care staff in the subsequent quality improvement processes including implementing changes together. Participation in the co-design phase provides opportunities for such local knowledge to drive change that 'fits' the specific context (Bate and Robert 2007).

Our study has identified the different roles undertaken by patients and carers within implementation and service improvement processes. These ranged from sharing experiences, identifying improvement priorities alongside staff, developing potential solutions with the staff to helping with the ongoing implementation of these - and other - solutions. The study also provides further evidence that EBCD often involves seemingly quite 'small-scale' changes. Moore and Buchanan (2013) argue in a study of change processes in acute care, that solving small problems generates important benefits for patients, staff and organisational performance, thereby challenging the current focus on large scale transformational change. They go further to suggest that clusters of small changes - such as those witnessed in our study - support the development of an organisational culture ready to embrace wider organisational change. The findings of our study resonate with Moore and Buchanan. Small scale changes, such as fixing clocks, improving patient information, and ensuring belongings follow patients in moves between wards were considered to be critical to improving patient experiences. At the same time, the process of working together on improvements brought about a shift in both staff attitudes and within the culture of the organisation.

Implementation Science typically focuses on improving the take up of interventions and programmes that have been rigorously tested in research studies. Whereas implementation and improvement tend to favour top-down or evidence-based methods (such as learning from the findings of academic research papers, putting clinical guidelines into practice, monitoring findings from national patient experience surveys), the nature of the evidence used in the four EBCD projects was predominantly more 'bottom up', non-codified sources of knowledge, such as local patient and practitioner experience and local information. This may, in part, have been related to the small scale change activities identified for the groups which did not require the collation of bodies of academic evidence in order to identify design solutions. For example, the decision to wash patient's hair more regularly or to source appropriate clocks to

aid patient orientation did not require evidence derived from effectiveness studies or randomized controlled trials. Furthermore, using knowledge derived from patient experience and local information seemed to make intuitive sense to the co-design groups, successfully enabled clinician buy-in and potentially triggered transformational organizational change. Where there was felt to be a need for additional information - for example in the hallucinations group - the co-design group described how they drew on relevant literature in preparing a patient information leaflet.

EBCD can be seen to be different from other modes of using patients in implementation because it uses local experiences of a small number of patients (and carers) that are not - necessarily - representative of the patient population. Furthermore, the significance of these experiences are not weighted on severity or prevalence. Nevertheless, the results of this small scale bottom-up process echoed those identified in other EBCD studies with similar populations (Locock et al 2014). EBCD was positively received by patients, carers and staff and was contrasted with previous experiences of consultation and complaints procedures (Stern and Green 2008). In adopting and valuing an approach to quality improvement that is concerned with co-production of knowledge and change -rather than a one off consultation exercise - EBCD was considered to offer a distinct, creative and energising approach to improvement.

Implementation Science places considerable emphasis on the role of healthcare practitioners in improvement processes. EBCD acknowledges another important dynamic for change in local service development and delivery; the approach seeks to reset the power balance between stakeholders to enable both patients and staff to work alongside each other as part of the change process (Donetto et al 2015). As a consequence, it also provides a mechanism for improving receptivity for change, influencing professional behaviours and attitudes in the local setting. EBCD offered scope for different levels of involvement depending on the personal circumstances and preferences of individuals. Patients and carers were recast as 'experts by experience' through their direct involvement with the services that formed the focus of the EBCD study (Preston Shoot 2007).

Involvement was also determined by the participants perceptions with regard to how far they could help with co-design; patients and carers often identified a point beyond which they felt it was the job of the professionals to take things forward. As a result, our study identified

different types of involvement ranging from attending a single event, to participating in the co-design work with staff, to on-going partnership working with the organisations beyond the scope of the original EBCD projects. However, consistent with previous studies (for example, Bowen et al 2013) we found lower levels of involvement in the latter co-design process than the patient and joint events, with some patients and carers suggesting that the technical dimensions of implementing quality improvement solutions lay with professional staff. Bowen and colleagues studied an EBCD project focused on improving outpatient services for older people in the UK and recommended that further work (including developing other design-based tools to support ideation and the active and creative engagement of patients and carers in the co-design process) is needed to overcome the tendency towards administrative and bureaucratic processes. Thomson and colleagues (2015) have recently attempted to take this recommendation forward in a study with multiple sclerosis outpatients using future groups, analogies and physical props.

As in previous EBCD studies (Iedema et al 2010) and other studies of quality improvement interventions involving new ways of working (Kitson et al 1998), the role of facilitation is critical and emerged as a consistent theme in our evaluation. In EBCD, facilitation was also critical to bringing patients into the intervention and bringing patients and health care staff together, but was distinct in its location within a process of co-design. Here the supportive and enabling style of facilitation was critical to ensuring engagement and sustained interactions crucial to identifying priorities and developing design solutions. These elements of EBCD reflect the importance of individual agency in improvement processes. Individuals are not viewed as passive recipients but rather key actors in organisational change and improvement processes. Providing dialogic space for patients, carers and staff allows EBCD to harness this agency to bring about change that fits with local needs and context. In their study of EBCD in emergency departments in Australia, Iedema and colleagues (2010) highlight the interpersonal burden for patients, carers and staff in speaking across boundaries, and the sociocultural and organizational boundaries that participants have to overcome to engage in EBCD in particular. This is, as the authors note, emotional work and as such it is likely to require ongoing support and facilitation to ensure that patients can play a meaningful role as partners and co-designers in service improvement and implementation.

EBCD has its roots in a number of traditions: participatory action research, user centred design, learning theory and narrative based approaches to change.   Together these traditions enable a 'resetting' of the power relationship between the key stakeholders, facilitating an approach that makes space for patients and their carers to take an active role in service improvement and implementation. This 'resetting' does not overcome the organisational and wider political constraints in which the service improvement initiatives are taking place (Farr 2013). At the very least, Venoesi and Keasey argue that there needs to be space locally for interpretation and discretion to ensure the 'localized voice' can affect change (Venoesi and Keasey 2015). Nor does it overcome power inequalities between those involved in the quality improvement endeavour and their colleagues (Donetto et al 2015). However, it does begin to unlock the potential of participants to work together in a co-design process that makes both incremental and transformational change possible.

The study was limited to two clinical pathways (lung cancer and ICU) and two UK NHS Trusts. However, it adds to the growing body of knowledge on EBCD through a detailed ethnographic evaluation and an analysis of the different roles of patients, carers and staff within the redesign process of EBCD. The evaluation was not specifically designed to consider the different roles of patients, carers and staff in the EBCD process. Our analysis suggests that the different roles and the impacts they generate are under-evaluated issues in need of further study.

Conclusion

Previous evaluations have suggested that the EBCD intervention leads to both improvements in services and in the inter-personal dynamics of care (Iedema 2010, Piper et al 2012). Implementation studies have addressed the importance of health care staff as both barriers and facilitators of organizational change (Dopson and Fitzgerald 2006). This study focused on the role of patients and carers in EBCD as an intervention designed to facilitate local quality improvement implemented by patients and staff working together. It highlights the range of different roles undertaken by patients and carers: sharing experiences, identifying priorities for quality improvement, developing potential solutions alongside staff, and helping to implement and evaluate these solutions. The space and flexibility within the EBCD approach allowed individuals to become involved in ways that suited their preferences and health status. Furthermore, the early stages (in particular the initial group session) gave

patients and carers an opportunity - prompted by watching the 'trigger' film and the sharing of their reflections - to appreciate the potential role they might play. A small number of patients continued working with the organisations after the end of the formal stages of EBCD.

Others have begun to develop a research agenda for EBCD (Robert et al 2015). Our study suggests that it would be particularly helpful for future research on EBCD to capture more robust data on the relative costs and benefits of implementing the approach compared to traditional patient involvement strategies and to provide greater insights into what happens within the co-design phase of EBCD, particularly in terms of the diverse roles undertaken by patients and carers. In this way our study supports the conclusions of Donetto and colleagues (2015) regarding the importance of more detailed analysis of the co-design work undertaken within EBCD and the extent to which the approach can meet its aspirations in terms of transforming power relations.

Figure 1: Stages of the experience based co-design process

celebration event for all stakeholders

setting up

engaging staff and gathering experiences

engaging patients and sharing experiences

co-design meeting for patients and staff

small co-design teams for patients and staff

Box 1: Research questions
1. Is the accelerated approach acceptable to staff and patients?
2. How does using films of national rather than local narratives affect the level and quality of engagement with service improvement by local NHS staff? Does this have implications for the overall impact of the approach?
3. From local patients' perspective, how well do they feel national narratives capture and represent themes important to their own experience?
4. Does any additional work need to be done to supplement the national narratives at the local level? If so, what form might this take?
5. What improvement activities does the approach stimulate and how do these activities impact on the quality of health care services?
6. What are the costs of this approach compared to traditional EBCD?
7. Can accelerated EBCD be recommended as a rigorous and effective patient-centred service improvement approach which could use common 'trigger' films to be rolled out nationally?

(Locock et al 2014a)

Box 2: Lung Cancer 'Receiving the diagnosis'

During the patient event participants participated in an 'emotional mapping' exercise where they were asked to write their emotions during each part of their 'journey' on a post-it and attach it onto the wall where all the 'touchpoints' were laid out. Participants were asked to place post-its with positive emotions higher up on the wall and post-its with negative emotions lower down the wall. Chosen priorities of improvement were usually selected from post-its that were placed at a very low position. All post-its under 'getting the diagnosis' were placed in medium or low positions and mentioned: *feelings of anger when given a prognosis, fear of seeing Macmillan nurse, stigma, feeling blamed and angry that a relative was told first, feeling too shocked to take things in*. These points were then discussed again in the joint staff-patient event where patients and staff sat in mixed-tables and discussed which issues would be feasible to address within the six-month duration of this project. The following priorities were selected as the most important for patients:

- pain during investigations
- information
- diagnosis given on the ward-rushed and not private
- waiting times for appointments
- uncomfortable chairs in chemotherapy
- support e.g. support group.

The following priorities were suggested by staff:

- ensuring privacy in clinic-quiet room
- time and space to make sense of new news
- staff support-'acknowledge the awfulness of what we see
- provide a truly 24/7 service
- better liaison with doctors-in particular re DNAR(do not attempt resuscitation) orders/advance planning/weekend planning
- staff continuing education-to remain current with best practice
- ability to comfort patients-patients in right environment to meet their needs.

The four priorities that received most votes were: Information, Support, Diagnosis and Privacy and the co-design groups were formed. Staff members with specialist expertise in these fields were chosen to co-facilitate these groups and take a lead in their running. The Diagnosis co-design group lead was the Nurse Consultant for End of Life Care. She had an effective working relationship with all of the consultants and ward staff. The group discussed the process of diagnosis giving and narrowed it down to focus on the 'planning' of giving bad news as the key area on which to focus. Initially there were several patient and relative representatives but only one was able to attend all the meetings. The patient initially felt that 'her experience' should not be the only way to influence the group. However, this theme was highlighted on the DVD used at the patient/carer event and a literature review supported her experiences. This co-design group grew in numbers as it worked to include representation from the acute admitting wards. It was regularly attended by the consultant who was responsible for giving the diagnosis. He was initially slightly defensive and wary of a potential threat of complaints but as the project progressed the fear of scrutiny ceased and participants were able to challenge thinking/processes and culture in a productive way. The consultant was then able to share his experience of what it feels like to 'give bad news' every week. The patient, who had previously explained that she overheard her diagnosis when doctors discussed it at the end of the corridor - and was unhappy with how little planning goes into this process - was then able to sympathize with the consultant and acknowledge the difficulty of his job in front of the group. The consultant agreed to address the patient communication training needs of junior doctors and work proactively with the

Box 3: ICU 'Hallucinations'

During the patient event, patients were given a sheet and asked to note the similarities and differences of their own experiences with those of the film. Four patients commented on the similarities of their own experiences of hallucinations to those described in the film. More specifically they mentioned:

'Not being able to move, not able to communicate, hallucinations- staff killing me, family not understanding, doctors communication, sympathetic, never thought I wouldn't walk out'

'Hallucinations very similar. I wasn't warned about that possibility.'

'Hallucinations, being aware and seeing staff in the unit being part of the hallucination. Staff drinking at the side of the bed. One in particular eating as well. Fear of this particular staff member. My wife being allowed to stay at the hospital. Visiting the unit afterwards and relating the unit to hallucinations. Not being able to communicate to staff, feeling of being stared at.'

'Delirium, hallucinations, medical staff trying to kill me, communication with others, frightened on my own when nurse on break, return to unit, had follow up.'

Later on during the emotional mapping exercise, the patients contributed post-its on experience of hallucinations which described only negative emotions such as *disturbing weird, distressed, scary, angry, frustrated, exhausted, trapped, frightening and stranded*.

The touchpoints were then discussed during the joint patient/staff event, alongside priorities for improvement suggested by staff. Patient priorities included the process of being ventilated, awareness and impact of hallucinations, reducing noise, using photography as part of the therapeutic process, communication with ward staff and improving the relatives' waiting area. Staff priorities included the centralisation of critically ill patients, staff well-being, reducing noise, improving feedback from patients, individualized care and maintaining the humanity of the patients. Then patients and staff were split into four mixed groups to vote on their top improvement priorities. Strong personalities were dispersed across groups and one person was appointed as facilitator. The eleven areas of improvement that emerged from touchpoints and discussion were provided on a piece of paper. Each person ranked them from one to eleven. Each facilitator tried to achieve consensus to select the top four priorities for each table. Hallucinations was one these priorities.

An experienced staff nurse was appointed as the co-design group co-facilitator. The stated aim of each co-design group was to identify the one thing that they could work towards that would make the biggest difference. The group contained 3 medical staff, 7 former patients and 2 relatives and met ten times for an hour. Email communication compensated for any lack of time available in the face-to-face meetings. The co-design group met in a room - local to the hospital - and throughout the process people sat next to different people which helped the group to develop a good working relationship. The meetings were relaxed and everyone had a chance to speak. What most people found important was that everyone in these meetings understood and had shared similar experiences. Some patients were able to talk about their own experiences for the first time and described this as a liberating and therapeutic experience. The group decided to set a goal of producing a leaflet, designed by patients for patients, on the experience of hallucinations. All members of the group knew that they were contributing to a specific output that would make a difference in the care of future ICU patients and relatives. Patients also described their experiences in an intentionally short film that introduced ICU care. This film is now being played in the relatives' waiting area and is also available online:
https://www.youtube.com/watch?v=b9yJrz_7pbM

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