

National Nursing RESEARCH UNIT

Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions

Final report

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PREFACE

It is now almost 10 years since what has become the Experience-based Co-design (EBCD) approach to improving patient experience was first planned and piloted in a head & neck cancer service at Luton & Dunstable NHS hospital in England. A decade on and the roots of over 80 projects in seven different countries can be traced back to the hard work and commitment of the coming together of a small group of staff, patients and carers involved in that original work.

Over time, naturally and quite rightly, the original 'blueprint' for EBCD has been adapted and tailored to better suit different types of healthcare services as well as a wide range of local and national contexts. As part of this evolution, the free-to-access online EBCD toolkit (<http://www.kingsfund.org.uk/projects/ebcd>) has recently been revised and extended. Changes were made based on the feedback of practitioners who have been directly involved in applying the approach in their own services, and further case studies have also been added to highlight the flexibility of the approach. An updated reading list has been included for those interested in digging a little deeper (see Annex 1).

The end of 2013 also sees the convergence of several different strands of work relating to EBCD:

- the launch of the revised toolkit itself and a new LinkedIn group¹ (currently over 100 members) for those interested in learning more and sharing their own reflections with others;
- the successful piloting of a new 'accelerated' version of the approach - using existing nationally collected patient interviews - which was developed in response to practitioners' wishes for a quicker path to identifying co-design improvement priorities and implementation of solutions;
- the inclusion of an introduction to the approach in a new online programme offered by the NHS Leadership Academy which will be delivered to around 4000 health and social care staff in England in the next 3 years;
- the recent decision by NHS England to fund a new 'train the trainers' course in EBCD which will be hosted and facilitated by the Point of Care Foundation in London;²
- the emergence of more rigorous and robust studies of the effectiveness of EBCD, ranging from PhD theses, through feasibility trials of co-designed interventions and onto large-scale cluster randomised controlled trials evaluating impact on patient outcomes.

This report therefore provides something of a stock-take of the 'state of the art' of EBCD, summarising the findings from a recent survey we have undertaken of those leading and involved in projects worldwide.

¹ www.linkedin.com/groups/Experiencebased-codesign-6546554

² <http://www.pointofcarefoundation.org.uk/Home/>

Issues of non-response and ‘response bias’ are inevitable in such an undertaking. The survey will not have captured responses from every EBCD project over the last decade; indeed, we are aware of several significant initiatives that have drawn, to some degree, on the EBCD approach which are not represented here. It is also extremely likely that responses were more likely to be forthcoming from those leading projects that had a positive story to tell. Bearing these limitations in mind, within this report we have highlighted what seem to us as the most significant lessons from the survey results, relating not only to the strengths of the approach but also to the fundamental aspects that need constant attention and nurturing. Foremost amongst these is a renewed focus on co-design.

As some readers will know, the approach was originally called ‘Experience Based Design’ (EBD) but the title was later changed to EBCD. This was in direct response to how those leading early projects - whilst undertaking extensive work to understand patient experience (much of it innovative at the time) - were paying what seemed to be insufficient attention to the co-design phase and relying instead on traditional, narrower approaches to implementing improvements to services. In contrast, and as first conceived, the ‘co’ in co-design refers emphatically to partnership and shared leadership between patients and professionals. And co-design means more than just being responsive to patients and listening to their needs; patients need not just to be active partners ‘having a say’ in their care but directly contributing to the design of that care:

In its complete sense, users may be involved in every step of the design process from diagnosis and need analysis, through envisioning and model building, to prototyping and testing, implementing and evaluating. And in this process they do not just say things, they do things as well; and they do them in person, not through some third party. (Bate & Robert, 2007a, p.30)

Or as the Design Council argued:

The biggest untapped resources in the health system are not doctors but users. [...] We need systems that allow people and patients to be recognised as producers and participants, not just receivers of systems. [...] At the heart of [co-design], users will play a far larger role in helping to identify needs, propose solutions, test them out and implement them, together. (Cottam & Leadbeater, 2004, pp.16-22)

Here’s to that!

We hope that you find those findings of interest and keep in touch. Please do let us have any comments you may have on the report either directly or through the LinkedIn group which anyone can join.

Sara

Vicki

Glenn

It was one of the most meaningful things I've ever done in my entire career I think. That sounds really trite, but I really do mean it, it was wonderful. I am glad I had the opportunity even though I felt like an emotional ragdoll by the end of it. It was a great experience. If we could do more of it I think it would really help. It's the level of engagement that we should do, but we just don't invest the time, and the energy, and the money. We wait for complaints... (Interview#05)

KEY FINDINGS – WHERE WE ARE NOW

- The survey identified at least 59 EBCD projects which had been implemented in 6 countries worldwide during the period 2005-2013 and at least a further 27 projects were in the planning stage at the time of the survey
- EBCD has been implemented in a variety of clinical areas (including emergency medicine, drug & alcohol services, a range of cancer services, paediatrics, diabetes care and mental health services)
- EBCD projects typically take between 6-12 months to complete
- The free-to-access, online EBCD toolkit is a helpful resource for those leading EBCD projects
- Approximately 50% of those who have led EBCD projects did not receive any formal training in the approach
- Non-participant observation has been relatively underused as an approach to understanding patient and staff experiences
- Approximately 50% of respondents reported that their EBCD project(s) included filming patients talking about their experiences
- Approximately 70% of respondents stated their EBCD project(s) included some form of evaluation; evaluations were usually available in the form of an internal report, and less frequently as a peer reviewed journal paper
- 90% of respondents stated that a strength of their project(s) was that it 'really engaged patients'
- Almost 50% of respondents stated that the main weakness of the approach was that 'it took too long'
- Less than half of respondents were aware of the costs of their project(s); no formal cost-benefit or cost-effectiveness studies of EBCD were reported by participants
- Over 60% of respondents reported that their project involved external researchers and/or facilitators
- The majority of respondents facilitating the EBCD approach spent between 1-3 days a week working on the project
- About 50% of respondents reported that they planned to use EBCD again

KEY MESSAGES – FUTURE DIRECTIONS

- **Providing different forms of training and support:** the increasing use of the EBCD approach worldwide is generating a growing demand for training and support in order to transfer knowledge and skills, and thereby build capacity to facilitate projects within healthcare systems. To help address this, a free-to-access and regularly updated online toolkit is available; the toolkit, developed by practitioners for practitioners, includes case studies and illustrative examples of EBCD in practice. For more formal training in EBCD, the Point of Care Foundation with the support of NHS England will be providing a 'train the trainers' course beginning in Summer 2014. For informal sharing of experiences and lessons learned, a LinkedIn peer group was set up in 2013 and can be joined by anyone interested in the approach.
- **The important role of non-participant observation:** although seemingly underused by our study participants, non-participant observation remains in our view a crucial component of the EBCD process. True to the ethnographic roots of EBCD, the use of non-participant observation in several projects has reinforced our belief that devoting even short periods of time to sitting and watching seemingly mundane day-to-day activities can provide rich insights into how and why things work (or not), and how they might be redesigned for the better. Our own experiences (as researchers of the impact of EBCD projects) suggest that the findings from such observations can not only reveal previously unconsidered 'touch points' but also act as an important 'hook' for engaging staff in the EBCD process itself.
- **Retaining the use of film:** the production of the patient film in EBCD is a time-consuming and resource-intensive process. 'Accelerated EBCD' has shown that a trigger film produced by editing existing archived filmed interviews can be as effective. Where possible, we would encourage the adoption of an accelerated route to the creation of the film but would not recommend eliminating the use of film altogether. The film is an important catalyst in the co-design process as the visualisation of patient experiences helps (re)connect people with similar experiences and stories, whether users or providers of a service, and offers an emotionally and cognitively powerful starting point for the co-design process. The visual medium sets the process apart from other consultative formats in which anonymity and circumspection can hinder rather than enable quality improvement.
- **Reinforcing the fundamental importance of co-design:** co-design work is at the very core of EBCD, underpinning service change as well as the broader impacts of EBCD on staff wellbeing and behaviours but it is also, in practice, the most challenging aspect of EBCD. Although examples exist of successful incorporation of co-design into routine organisational practices and a lot can be learned from published evaluations of effective co-design work, we recognise the need expressed by participants in this study for illustrative and accessible resources that would further clarify and bring to life the 'how' and 'why' of co-design in EBCD. Closer collaborations with service designers - with their wide range of proven tools and approaches - must be the way forward, albeit always with an eye to the unique context of healthcare organisations in which this expertise is to be applied.

- **Understanding the nature and scale of changes:** co-design work as envisaged in EBCD and its accelerated version can be transformative in different ways and at different levels of healthcare organisations. Typically EBCD projects are initially more likely to bring about a series of incremental quality improvements rather than radical organisational change. Yet, the individual and collaborative work underpinning these small changes lies at the root of deeper changes in attitudes and behaviours as well as other valuable legacies from EBCD projects. Future projects need to systematically capture this range of impacts and we need to learn more about how well (and why) they are sustained.
- **Strengthening the evidence base:** as our report shows there is a growing evidence base relating to the effectiveness of EBCD and the mechanisms through which it operates in different contexts. However, we remain largely in the dark as to the relative value of this particular approach in comparison to other quality improvement (QI) interventions, as well as broader patient and public involvement (PPI) activities. Research priorities for the future include learning much more about which patient-centred QI interventions are most cost-effective and what proportion of an organisation's limited resources can justifiably be dedicated to such activities.

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INTRODUCTION

This report aims to offer a snapshot of EBCD practices and developments in the period 2005-2013 and an overview of likely future directions of travel. After a very brief overview of the background, methods and aims of our study, we move to presenting the findings from our online survey and follow-up interviews. We then discuss the main themes emerging from our data with a view to critically appraising the strengths and successes as well as the weaknesses and points for reflection that emerge from our study participants' experiences with EBCD. We also include in this report a set of Annexes providing an up-to-date EBCD bibliography, and examples of methods for understanding patients and staff experiences, as well as further details about the questions we asked our participants.

Two brief clarifications are needed. Firstly, as we mentioned in the preface to this report, 'Experience-based Design' (EBD) as developed in the original pilot project later became 'Experience-based Co-design' (EBCD) to emphasise the crucial importance of embedding collaborative design in the approach. Participants in our study referred to EBD or EBCD depending on the literature and training resources they drew on, as well as on the currency of one or other wording in their local context. In this report therefore we refer to EBCD and EBD interchangeably. Secondly, in the pages that follow we talk about 'patients' and 'carers' as users of healthcare services who have been involved in EBCD projects. Preferred terms – 'patient', 'service user', 'service user/survivor', 'client', 'consumer' – vary according to settings and contexts. These terms are all value-laden and politically charged. Bearing this in mind, in this report we only use the terms 'patient' and 'carer' partly because the majority of completed and ongoing EBCD projects have been carried out in the context of hospital care for patients of specific services, and in some instances their carers, and partly with the deliberate aim to preserve participant confidentiality.

BACKGROUND AND STUDY AIMS

Since Experience-based Co-design (EBCD) was first developed and piloted in a Head & Neck Cancer Service in England in 2005-6³, conference papers, reports and published articles have recorded the use of the approach in different healthcare settings and in a number of countries (see bibliography in Annex 1).

EBCD is an approach to improving healthcare services that combines participatory and user experience design tools and processes to bring about quality improvements in healthcare organisations. Through a 'co-design' process the approach entails staff, patients and carers reflecting on their experiences of a service, working together to identify improvement priorities, devising and implementing changes, and then jointly reflecting on their achievements. As explained elsewhere (Robert, 2013) four, overlapping strands of thought have contributed to the development of the EBCD approach, namely:

- participatory action research;
- user-centred design;
- learning theory; and
- narrative-based approaches to change.

In particular, user-centred design offers two particular contributions to quality improvement thinking in the healthcare sector: a new lens, or frame of mind, through which to think about approaches to improving patient experiences of healthcare, and methods, tools and techniques (such as modelling and prototyping) which were little used in healthcare improvement work until recently.

The EBCD cycle is divided into six stages (Figure 1): (1) setting up the project; (2) gathering staff experiences through observational fieldwork and in-depth interviews; (3) gathering patient & carer experiences through observation and 12-15 filmed narrative-based interviews; (4) bringing staff, patients and carers together in a first co-design event to share - prompted by an edited 20-30 minute 'trigger' film of patient narratives - their experiences of a service and identify priorities for change; (5) sustained co-design work in small groups formed around those priorities (typically 4-6); and (6) a celebration and review event (Bate & Robert, 2007a; Robert, 2013).

³ The original pilot work was funded by the NHS Institute for Innovation and Improvement. The NHS Institute closed on 31 March 2013 but its website is being maintained in the short term so that registered users can download documents and view videos. A number of resources have transferred to the NHS Improving Quality's website including the 2009 (hardcopy) 'EBD guide and toolkit', <http://www.nhs.uk/resource-search/publications/nhs-inst-ebd-guide-and-tools.aspx>. A full description of the pilot study is provided in Bate & Robert (2007a).

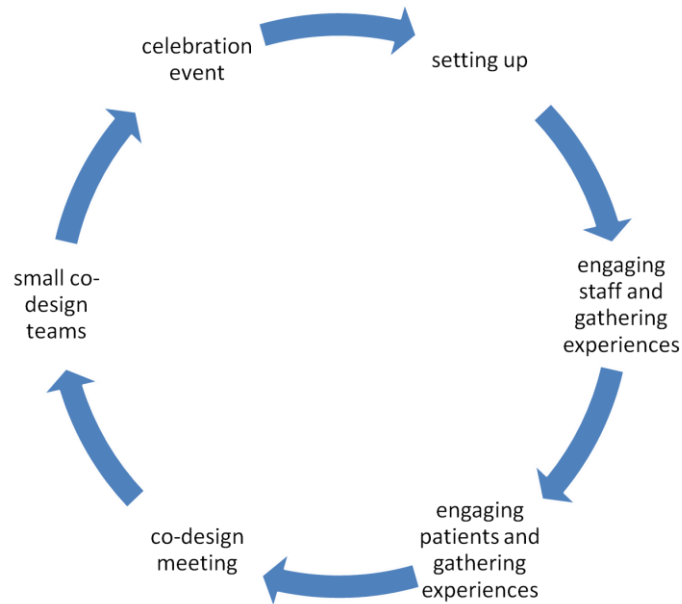


Figure 1 - The Experience-based Co-design cycle

In order to establish how widely the approach had been adopted - and to gather information on practitioners' experiences with EBCD and their plans for future implementation - in the Spring/Summer of 2013 we undertook an international online survey using SurveyMonkey™. We then conducted follow-up telephone interviews with a sample of 18 respondents.⁴ In Annexes 2 and 3 we provide the full sets of questions used in the online survey and interview guide; to summarise, the survey and interviews explored:

- 1) the benefits and challenges that had arisen in relation to the approach in different healthcare services and systems;
- 2) the strengths and weaknesses of the approach itself;
- 3) the adaptations of the approach that had proven useful or necessary in specific settings; and
- 4) the contribution of the online King's Fund EBCD Toolkit to implementation of the approach.

Participants' views and reflections on these themes paint a useful picture of how EBCD has been implemented to date and how it might be tailored and/or strengthened for future use.

⁴ Ethical approval for this research was granted by King's College London Psychiatry Nursing and Midwifery Research Ethics Sub-Committee (Ref PNM/12/13-113). The submission of the completed questionnaire constituted written consent to treatment of personal information and data provided, as specified in the participant information sheet sent to potential participants with the invitation email.

METHODS

In this section we offer a brief summary of our methods. We would be happy to provide further information on request.

Online survey

The survey was sent out to a list of 107 practitioners and researchers who were known to have had experience of implementing - or plans to carry out - an EBCD project. Potential participants were identified either through their professional collaboration/correspondence with Professor Glenn Robert during the last five years and/or through academic publications and publicly available reports from EBCD initiatives worldwide.

Links to the online survey were accompanied by an introductory email and a participant information sheet in which details about the study and the treatment of personal and other information were provided. Participants were reassured that their identity and the healthcare organisation in which they worked would only be known to the research team and that they would not be identifiable from the study report or any other publications from the study.

A first reminder was sent by email two weeks after the introductory email, a second reminder 1 week after the first, and a third and final reminder 1 week after the second reminder. Survey questions (1 to 36 questions, depending on participants' answers, see Annex 2) explored:

- details of the EBCD project participants had been or were planning to be involved in (e.g. duration, cost, team composition, stages of the methodology employed; adaptation of the methodology; training required);
- participants' views on the EBCD approach;
- formal evaluation of the EBCD projects;
- awareness and use of the online King's Fund EBCD Toolkit;
- plans for future implementation of the methodology.

Recruitment took place between April and June 2013. In total, 57 participants took part in the survey.

Follow-up telephone interviews

In the survey, respondents were asked to indicate whether or not they would be willing to be contacted by the research team to discuss their responses. Of those respondents who were, twenty were selected for a follow-up interview. Only completed EBCD projects were included in this sample. The research team purposefully selected a range of completed projects carried out both within the UK and abroad and across a range of services/clinical areas.

Recruitment took place in August-September 2013. An email was sent to respondents inviting them to take part in a 30-40 minute telephone interview to explore some of the central themes emerging from analysis of the survey data and to gather further detail about the EBCD project with which they had been or were involved. Respondents contacted the research team to arrange a telephone interview at a

time that was convenient to them. Verbal consent was obtained before each interview commenced; with participants' permission, telephone interviews were audio-recorded.

The follow-up telephone interviews were semi-structured and explored specific aspects of participants' projects, such as reasons for choosing the EBCD approach, ways of gathering patient and staff experiences, reflections on the co-design process, approaches to securing staff engagement, the costs of the project and adaptations made to the EBCD approach. A topic guide of the interview is attached (see Annex 4). Eighteen interviews were completed.

Data analysis

All interviews were transcribed verbatim. Survey data was analysed descriptively through the SurveyMonkey™ engine and examined closely for content and themes. The interview transcripts were analysed thematically to address questions and points for further exploration that had emerged from the survey responses.

FINDINGS

EBCD past, present and future

Current and completed EBCD projects

Of the 57 respondents who took part in the online survey, 47 (82%) had been involved in one or more EBCD projects and 10 (18%) were planning to become involved in an EBCD project.

At least 59 EBCD projects were either completed or being implemented at the time of the survey in six countries: UK, Australia, New Zealand, Canada, Sweden and the Netherlands. The projects had been undertaken in a range of clinical services including: cancer, mental health, drug and alcohol services, emergency services, diabetes, orthopaedics, intensive care, palliative care, genetics, neonatal and paediatric care, haematology, and surgical units. At least six of these projects involved implementing the approach in more than one clinical department.

Of those 47 respondents who had been involved in an EBCD project, 27 (57%) reported that their project had been completed, 15 (32%) that their projects were 'ongoing - at an advanced stage', and 5 (11%) that they were 'ongoing - at an early stage'. Twenty-seven (57%) respondents reported that they were involved in further EBCD projects and 20 (43%) said they were not. Further projects were being planned in various services including mental health services, diabetes services, acute cardiac care, emergency services, paediatric services, dementia and cancer services.

The earliest project had begun in 2005 but the majority of projects had begun in 2012 (n=19) and 2011 (n=8). The survey identified at least a further 27 projects that respondents were planning or considering implementing in the future (Figure 2).

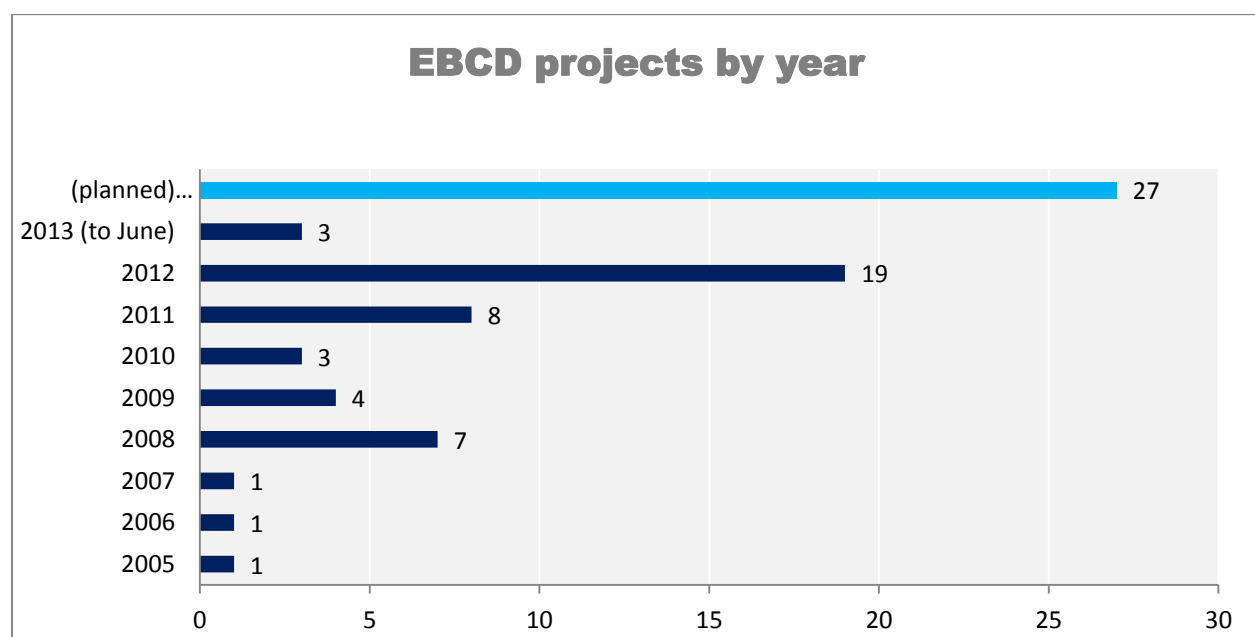


Figure 2 - Completed and planned EBCD projects by year (start date)

In the follow-up interviews we explored in more depth participants' reasons for implementing EBCD in their organisations. Participants reported that the main rationale for choosing the EBCD approach was based on the aspiration of their organisations to provide patient-centred care:

I think the key thing here...was this concept of seeing the person behind the patient. The hospital had a major commitment around a recovery model, patient-centred care... the kind of feedback we were getting is the patients felt that they were not being treated as individuals or as human beings when things went wrong. There were major concerns, really, in some areas around staff attitude and there had been a breakdown in that very personal care. (Interview#02)

I suppose, what was really different to me, I mean we used videos, and I know that's becoming more common now... just really giving them the freedom to tell us everything they wanted to was really quite, well, heart wrenching really. Out of the whole thing what really, really brought home to me is the power of the patient voice. And I know that, like, for years we've captured, we've done surveys, and I very often feel that questionnaires, we sort of ask them the questions that we want the answers to. This was very much tell us about your experience ... (Interview#13)

Time taken to complete EBCD projects

Survey respondents were asked about the length of time it took to complete their project. Of the 42 respondents who answered this question, four (10%) reported that the project had taken less than 6 months to complete, 17 (40%) between 6 months and 1 year, 9 (21%) longer than 1 year, and for 12 (29%) respondents the question was not applicable (Figure 3).

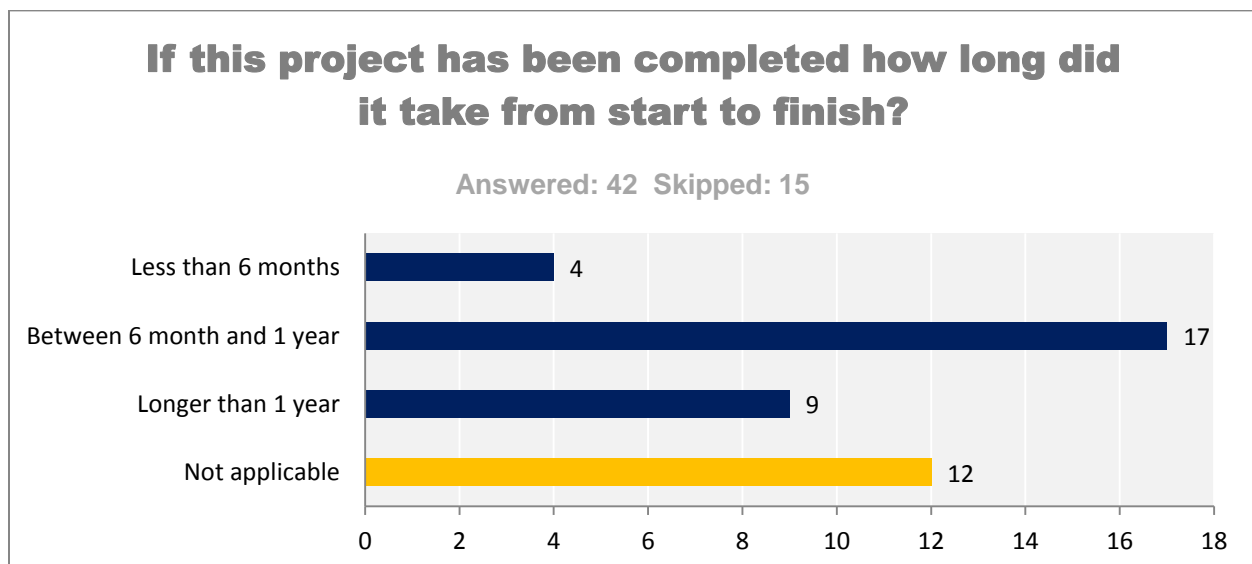


Figure 3 - Length of time to complete EBCD project

EBCD resources

Online EBCD Toolkit

One of the sections in the survey related to the free-to-access King's Fund online EBCD toolkit (<http://www.kingsfund.org.uk/projects/ebcd>). Survey respondents who were or had been involved in EBCD projects were asked whether they had accessed the toolkit for any of their EBCD projects. Nine of the 47 respondents answering this question (19%) reported using the toolkit extensively, 12 (26%) used 'bits' of the toolkit, 10 (21%) were aware of the toolkit but had not used it, 10 (21%) were not aware of it and 6 (13%) were not sure (Figure 4). Eight (17%) respondents reported using other resources such as the NHS Institute for Innovation and Improvement's original Experience-based Design (EBD) manual or Bate and Robert's (2007a) book, as well as other local resources within their own countries.

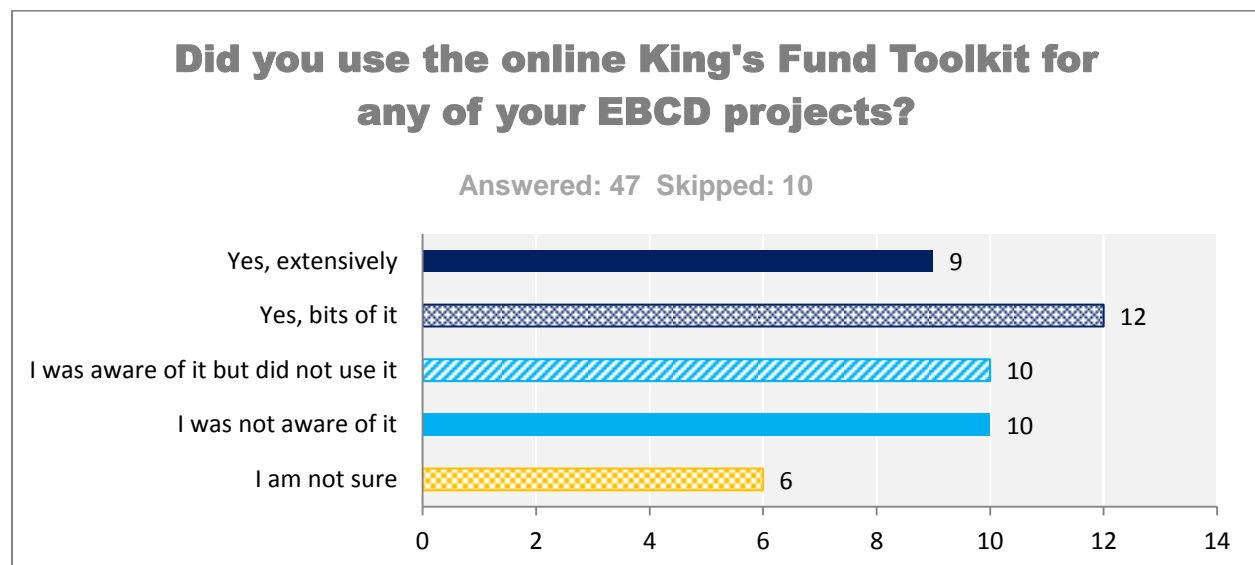


Figure 4 - Use of online EBCD toolkit

Of the 21 respondents who rated the online EBCD toolkit, 11 (52%) indicated it was 'very helpful', 9 (43%) 'somewhat helpful', and 1 (5%) respondent indicated it was 'neither helpful nor unhelpful'.⁵

In their open comments about what they had found most useful about the online toolkit, respondents said it was concise and easy to follow and provided the practical tools for carrying out an EBCD project.

⁵ The EBCD toolkit is divided into 16 sections. We asked survey respondents to tick up to three sections that they had found most helpful. The 21 respondents identified as most helpful (in descending order) the following sections: 'Running the joint patient-staff event' (14/67%); 'Running the patient feedback event' (9/43%); 'Interviewing and filming patients' (8/38%); 'What is experience-based co-design?' (8/38%); 'Running the staff event' (7/33%) and 'Recruiting patients' (7/33%); 'Running the co-design groups' (6/29%); 'Making the case to staff' (5/24%), 'Carrying out observations' (5/24%) and 'Engaging and interviewing staff' (5/24%); 'Developing your project plan' (4/19%); 'Reporting, evaluating and celebrating success' (3/14%); 'What next for your Experience-based Co-design project' (2/10%); and lastly 'Is Experience-based Co-design for you?' (1/5%) and 'Adapting the approach to your budget' (1/5%).

They highlighted the use of video clips in the toolkit as a helpful way of demonstrating the involvement of patients, staff and carers in other EBCD projects:

It came with a track record and this helped to alleviate staff anxiety. The clarity of the films helped us to be decisive in our editing (Respondent#09)

It was an essential tool to guide us through the process. We were very interested in how we could apply this approach to mental health and evaluating what the differences/similarities were to physical health and why. (Respondent#41)

‘Open comment’ suggestions from the survey for improving the toolkit included:

- more detail about the emotional mapping exercise;
- more examples of the events and co-design meetings and the tools used therein;
- more information on how to make co-design events work (e.g. guidance as to fundamental aspects of co-design and where shortcuts can be made; possible alternatives for certain steps; catering for more variability in the approach);
- including films of EBCD meetings;
- more country-specific information;
- access to a hard copy version of the toolkit;
- more advice on running a project (and particularly on getting a service on board) if one is not already working within the organisation; and
- in services such as mental health, advice on building in a way of minimising distress and trauma of recalling lived experience.

EBCD awareness and training

Figure 5 shows how respondents had first become aware of EBCD. Many respondents (18 of 44 respondents/41%) reported first hearing about EBCD through word of mouth or through a colleague, and a significant proportion had either found out about it at a meeting within their organisation or read about it (11/25% and 8/18% of 44 respondents, respectively). Fifteen respondents also mentioned having heard about EBCD through ‘other’ sources; these included country-specific healthcare improvement programmes and/or workshops, education sessions, and EBCD-related reading.

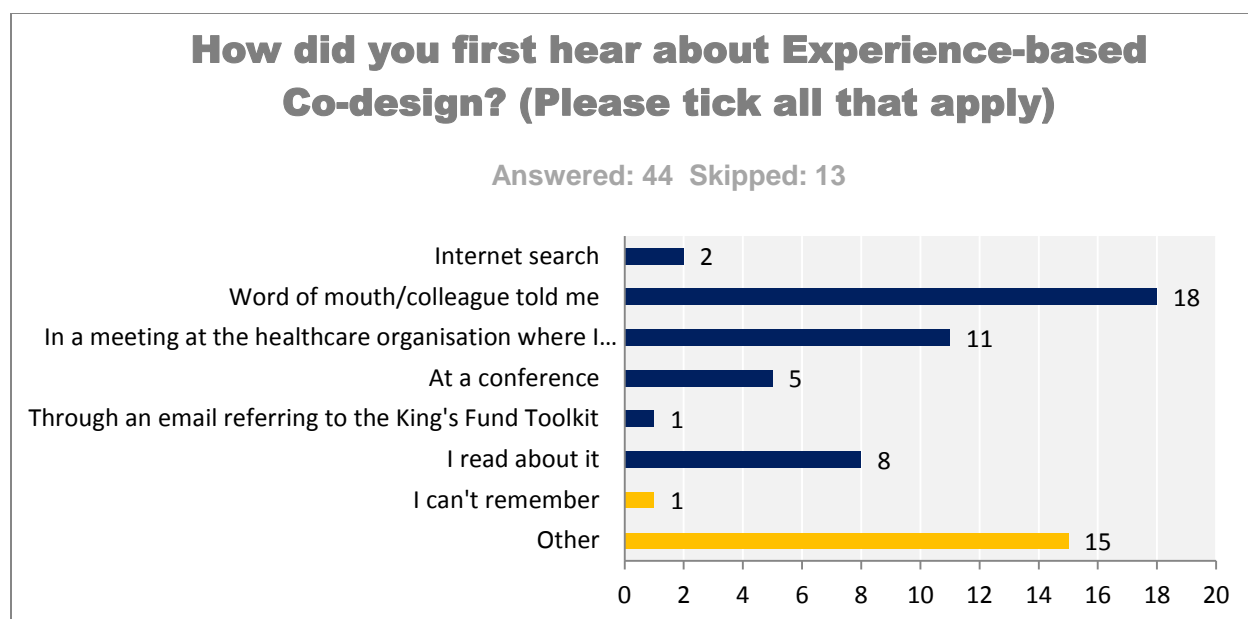


Figure 5 - Hearing about EBCD

For advice on the EBCD approach, 17 of 46 survey respondents (37%) reported contacting the NHS Institute for Innovation and Improvement, 10 (22%) respondents contacted the King's Fund and 19 (41%) contacted people who had direct experience with EBCD in the past. Ten (22%) respondents did not contact any individual or organisation for advice about EBCD.

Nearly half of the 45 survey respondents who provided details about EBCD training did not receive any training before undertaking their project. Seven respondents (16%) received informal training and/or support by those who had undertaken EBCD projects in the past and 15 (33%) attended EBCD training workshops.⁶

EBCD and adaptations of the approach

Elements of EBCD employed and adapted

Survey respondents were asked about which elements of EBCD they had used in their projects (see Figure 6). The elements of EBCD most commonly used were the patient and staff co-design meeting (38 out of 42 respondents/90%), the small co-design groups to work on improvement priorities (37 out of 42 respondents/88%), staff interviews (33 out of 40 respondents/83%), patient interviews (33 out of 40 respondents/83%) and the celebration/review event (19 out of 33 respondents/58%). The least used element of EBCD was the non-participant observation (15 out of 30 respondents/50%).

⁶ In 11 cases these workshops were run by the NHS Institute for Innovation and Improvement or by people with previous experience of EBCD, in three they were country-specific, and in one case the specific training source could not be identified.

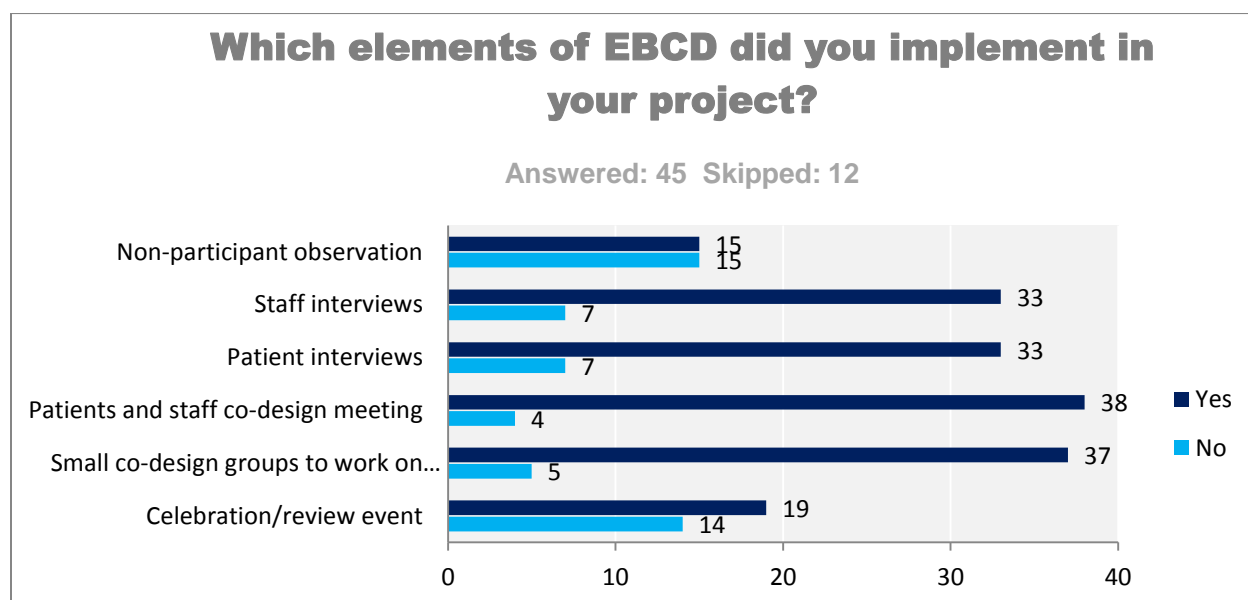


Figure 6 - Elements of EB CD implemented in projects

Ways of capturing and understanding patient and staff experience

Survey respondents reported having used a number of different approaches – alongside or as an alternative to interviews - to capturing and understanding patient experience. More specifically, across survey responses, ten strategies were reported:

1. Interviews/patient stories (face to face and/or telephone interviews), audio recorded and/or filmed
2. Patient diaries
3. Video booth/diary room
4. Disposable camera
5. Archived film
6. Non-participant observation
7. Group dialogue/workshops/ issue-based workshops
8. Emotional mapping exercises
9. Creating personas
10. Survey

Similarly, different approaches had been taken to capturing and exploring staff experiences. In particular, seven strategies were reported in our survey:

1. Interviews/staff stories (face to face and/or telephone interviews), audio recorded and/or filmed
2. Email communication/ informal feedback
3. Video booth
4. Diary room
5. Focus groups/workshops

6. Non-participant observation
7. Survey

In order to explore in greater detail participants' rationale for choosing a particular strategy to capturing experiences we asked interviewees what they perceived to be 'valid' or 'appropriate' ways of understanding patient and staff experience. Interviewees confirmed that a range of methods had been used in practice, with some projects adopting only one approach and others using several approaches in combination. In order to provide more detail about these approaches for current and future users of EBCD, we report some illustrative interview excerpts for each of them in Annexes 4 and 5.

Patient and staff interviews

We asked survey respondents who had conducted patient interviews in their project to provide more detail as to whether they had audio-recorded and/or video-recorded them and whether they had held a feedback event following the interviews. Forty-five respondents provided this information. Twenty-three (53%) video-recorded and 21 (49%) audio-recorded their interviews with patients. In thirty (70%) cases patient interviews were said to have been followed by a feedback event, in 2 (5%) cases to have not and in 7 (16%) cases the question was not applicable (see Figure 7).

As for interviews with staff, 11 (26%) survey respondents said that these were video-recorded and 22 (52%) that they were audio-recorded. Staff interviews were followed by a feedback event in 29 (69%) cases and only 1 (2%) respondent indicated that the staff feedback event did not take place. For seven (17%) respondents the question was not applicable (see Figure 7).

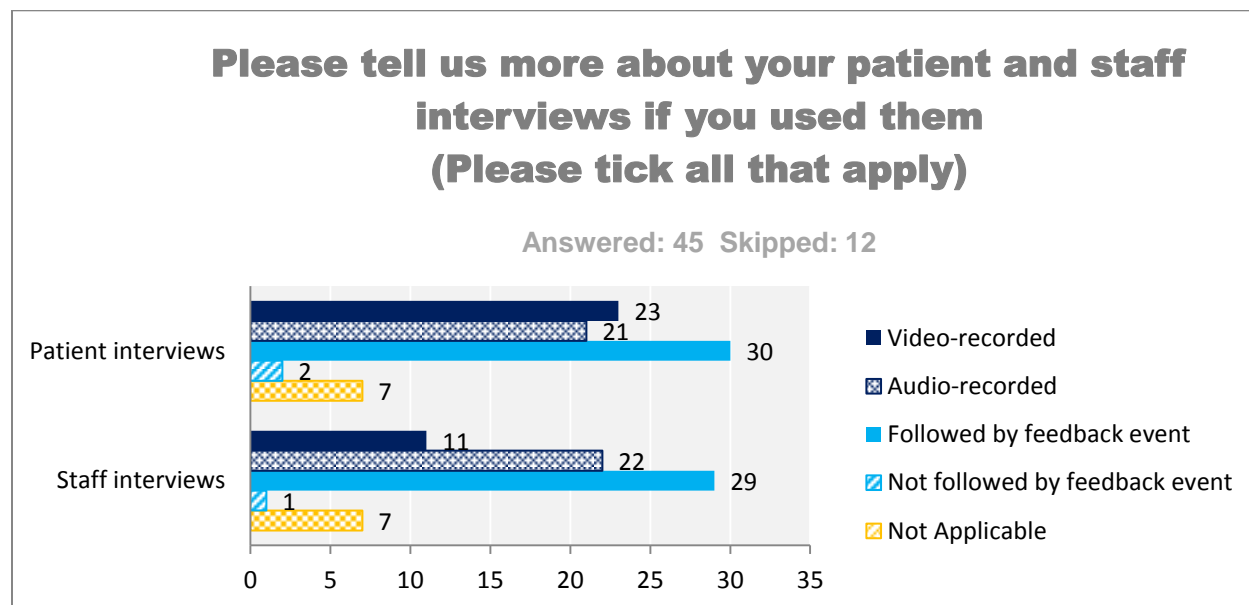


Figure 7 - Patient & staff interviews

We learned from some of the open text survey responses that filmed interviews could prove a powerful tool in the experience of respondents:

The use of the film is powerful, it affects hearts and minds. It reduces strain on service users caused by live feedback at events. The films are highly portable and had a great effect at Board level. (Respondent#09)

In the follow-up interviews we discussed in more detail the advantages and disadvantages of filming interviews with patients and staff. Eight of the participants we interviewed had used film to capture patient experiences. They spoke about the power of hearing the patient voice and the impact of film on staff members. The majority of those who used film in their projects confirmed they would use it again in future projects:

Film was a very important part of helping staff take a step back and have a look at what was really going on, and see people they've been treating as patients as just people, as human beings... it had a dramatic effect for the staff to suddenly see someone who they only perceive, for example, as a problem... seeing somebody's face, hearing their voice, it made a difference. I think if you hadn't seen that, if they had just been written down, it would have just been words. Having that there in front of them made a big difference. You could measure that in the room. (Interview#02)

Now what we found is by showing the staff the films, just showing them, that that had a really big impact. So when we were evaluating why did we show these films to so many people, and why we have subsequently repeated that exercise, it's because the act of watching the films themselves, actually, the feedback was that they reflected quite a lot themselves about how they communicate with patients as well. (Interview#09)

When you see the video and you can see the emotion and you can see what's happened...it's very hard to argue with an experience. You can't argue with that; it's their experience. If it's just written down it's easy to dismiss, it's easy to dismiss opinions. When it's in your face and you see it, it has a much deeper psychological impact. So, I would always, always recommend doing the videos, although I mean it's very time consuming, it's labour intensive and somewhat draining on the interviewer. I would always recommend doing interviews via video. (Interview#03)

The power just blows me away because as soon as the story comes up there's a physical change, they go back in their seats and it's quite confronting even though you prepare them for it and say, 'This is what I'm going to show you.' And these are clinicians that see this stuff every day, but just to be taken out of their clinical environment, to sit and be actually talking about the interaction is so powerful. So yes I would use it more, but I would prepare people more too because sometimes it can be too confronting. (Interview#12)

In our follow-up interviews, we were keen to gather more information on the experience of those respondents who had filmed their interviews with staff, a less common practice in EBCD. Three of the interview participants had done this. They found that staff were less likely to share their experiences on film. As a result, participants questioned the usefulness of filming staff interviews in future projects:

It was quite difficult getting them [staff] to do it, and I did think well, given the usefulness of it in terms of actually the patients were saying the same thing, I'm not sure whether it's worth the stress of trying to get the staff to do it. But that was my experience. (Interview#13)

I suppose we were doing it because we were trying to film all of our interviews. I think that on reflection I would find that less important now to do that. (Interview#10)

Where film had not been used as part of the project, for our interviewees the main reasons for this had been that filmed interviews were time consuming, labour-intensive and not within the scope and time frame of their project:

There is a burden with video editing, and it's a bit like doing transcripts, by analogy, you know, you spend a lot of time on an administrative task. (Interview#17)

For one interview participant who had used videos in various projects these were useful but not the most integral aspect of a project:

Part of my reason for evolving [from interviews] into workshops, and getting people in the room together is that they can talk to each other. And that often works in terms of an overall co-design process that will often work better than sitting staff down in front of a video. (Interview#17)

The use of non-participant observation

Survey responses indicated that non-participant observation was one of the most often eliminated EBCD activities. In our follow-up interviews we explored in more detail any benefits and/or challenges of non-participant observation and participants' reasons for choosing to do without it. Nine interview participants used non-participant observation in their projects, although to different extents. One interviewee reported carrying out some observation work informally prior to starting the project. Eight interview participants said their projects did not include the observation element.

The majority of participants who used observation found that it provided useful insights into patient and staff experience:

To be perfectly honest, I think if you can actually follow someone through a journey I think you pick up so many more things... I think it's a good tool, and I think the other benefit is, actually, showing staff sometimes, so I think it's good for staff to actually see what really happens to their patients because they don't know about the journey. (Interview#04)

I think just to be objective and just to scrutinise things with more clarity. (Interview#08)

From my point of view observation's a much more powerful tool in general, whether it's participant or not, or whatever. And the crucial bit for me is that you get to observe staff and patients interacting, that's the crucial bit because the risk with interviews of any form is you only get one side. And people don't have a self-awareness to actually give an accurate account of what happened or what they did. (Interview#17)

However, for some it did not generate useful data:

I don't feel I came out with very much to be honest... the most powerful stuff for me from EBD was the patient experience rather than staff trying to put themselves in the patient's shoes. (Interview#05)

As mentioned, eight interview participants did not use observation in their projects. They placed more importance on other data collection methods:

I think we just plumped for the things that we chose, and I think we had to limit the amount of data collection, and we felt we already had tons of data because I think we ended up with 22 interviews altogether, which when you've filmed them, is a lot of data, plus any supplementary information that you've got. So I'd always caution people about collecting too much. (Interview#10)

It would depend on the resources for the budget, but honestly, if the budget didn't support it I wouldn't be overly worried. It would be lovely to use as many methods and triangulate and do all that stuff, but to me if the budget only supported interviews and videos that would be fine. (Interview#12)

Co-design

Survey responses clearly indicated that the co-design element of EBCD had been used in a variety of ways and with different aims in different projects. Thirty-eight out of 42 survey respondents (90%) reported using the patient and staff co-design meeting as part of their projects and 37 out of 42 (88%) reported using the small co-design groups to work on improvement priorities (see Figure 6).

Co-design is central to the philosophy and practice of EBCD. In our follow-up interviews, we therefore sought to gather more information as to its use. Seven interviewees said they had used a traditional EBCD approach with separate patient/carer and staff events, followed by a joint event and small co-design groups, although in one case the small co-design groups only included members of staff. Eight interviewees had held only joint meetings followed by a co-design element, which varied across different projects. More precisely, four projects included small co-design group-work with both patients and staff members; in three projects, only staff members worked on improvements after the joint event; and in one project staff worked on improvements alongside patients via email communication rather than through formal meetings. Two further interviewees reported having held patient feedback events only, with staff working on subsequent improvements/developments. And finally, one interviewee explained that their project did not include a co-design element at all.

Below we report some interview extracts to give readers a flavour of the variety of approaches to co-design we came across:

I think that it worked because it was collaborative and there were mixed groups of people doing the work and they held each other to account. And [we] kept people on track where perhaps it might have slid... I think people enjoy the bit of collecting stories, it's like consultation, I think that it's harder to do the co-design or collaboration after that initial

problem solving phase because I think health professionals are used to being in charge of making things happen. And so that's something I talk to people about now, about that you know, keeping that collaboration going. (Interview#10)

Some of our patients come from a three and a half hour drive away, so I mean that's really hard to involve people like that. Once it got to a solution point where people were agreed on the solution, you know, we just needed to work through that then... email was more efficient and more respectful of people's time. (Interview#03)

We got together and we discussed the narratives and we tried to identify, in collective discussion, where or how things could be improved, but when it then came down to what they were actually going to do, those decisions were taken by the frontline managers, the nursing managers, and their line managers. So there was certainly no co-design at that point... I think you can then identify how the hierarchies worked within the organisation, co-designed up to a point, and then it reverted back to a much more hierarchical way of organising things... a workshop with a draft action plan which was then taken away and worked on behind closed doors. (Interview#02)

Adaptations to the EBCD approach

Survey respondents were asked to provide details about any adaptations that had been made to the EBCD approach in their projects. They reported a variety of examples of adaptations, including the use of focus groups, workshops and surveys to capture patient and staff experience - 'experience data' in the words of one interviewee (see page 27, Interview#12).

In our follow-up interviews we aimed to better understand participants' views of and approaches to EBCD as a more or less adaptable methodology. By and large interviewees perceived the EBCD approach to be a flexible framework, which could be tailored to the nature and type of service and the purpose of the project:

I think I saw it more as a very strong approach, I didn't necessarily feel it was THE approach, so I kind of begged, borrowed, and stole from it. (Interview#17)

It sort of evolved. The basic concept of the collaborative model, you know getting everybody together to be involved was the core of it, and then I think it was really just what will we try here, and what have we tried worked, so we stuck with it. (Interview#07)

We have already introduced a range of modifications as opportunity or constraints arise. I think EBCD is first a philosophy and only second a method, and methods need to evolve and grow as organisations grow smarter about working with patients. We use a lot of tools from service design and are evolving ones of our own. (Interview#18)

We learnt a lot from it, and we're still looking at different ways of working now and adapting it. I wouldn't necessarily stick with that approach in other services; I think you just have to

*keep adapting it all the time according to the politics and the budget and the timeframe.
(Interview#01)*

Adaptations to the approach reported in the interviews included:

- using a variety of methods for understanding patient and staff experience (see Annex 4 and 5);
- seeking to understand patient experience only;
- shortening the co-design process - e.g. one joint co-design event only; no follow-up co-design meetings; staff implementing improvements with minimal input from patients;
- varied co-design event formats, e.g. combining sharing of experience and identifying solutions into workshops; no emotional mapping;
- employing a service or industrial designer for the entire project or parts of it;
- using EBCD to develop materials/resources rather than service improvement;
- running EBCD educational sessions for staff and/or patients before participating in co-design.

Impact and dissemination

Evaluations and publications

Thirty (70%) of the 43 survey respondents who provided information on evaluation of their projects indicated that one had been carried out and 13 (30%) that it had not. Some organisations conducted an informal evaluation which was only shared internally to encourage learning. In the open-ended questions on evaluations, survey respondents commented:

Finding ways to evaluate the work is something I am still grappling with. We do evaluate workshops and have training developed through feedback forms, we also use 'before and afters' and have anecdotal feedback. A more robust way is something I would be interested in learning more about. (Respondent#47)

We will be continuously evaluating as we are working with the teams but will also be identifying relevant structure, process, outcome indicators for each of the project elements. We will be utilising hand-held mobile devices to assist with real-time measurement. (Respondent#20)

We raised the issue of EBCD evaluation with our interview participants. Fourteen interviewees had conducted an evaluation of their project. Two projects were to be evaluated upon completion and two completed projects had not been evaluated.

Four of the 14 evaluated projects had been evaluated externally; others internally and sometimes informally:

It was a qualitative approach to interviewing a range of stakeholders who'd been involved, from [patients] to project managers, and hospital managers, and clinical staff on the floor... whether experience-based co-design had assisted staff in gaining skills in collecting patient experience data. And whether the changes brought about by co-design were sustainable and being sustained. And also about spread, whether it was possible to take changes implemented at one site and kind of immediately implement them at another. (Interview#12)

We are evaluating, obviously, all of the initiatives that were put in place... they [the funding body] want to demonstrate the value of experience based co-design so that it can be spread, they have actually hired external evaluators who are evaluating us on all of the processes... So they have hired consultants and they are now based in our committees and are sitting on our project teams and they are evaluating the process from an external perspective, which is good. (Interview#14)

Some re-observations and talking to the patients, not the original patients because they're not going through the system now... New patients that basically say, okay, for example, 'Well did this, meet your needs? How did you find this process? Did it change... were you happy with it? Did it make any difference to you?' (Interview#03)

As the extracts above indicate, our interview data suggested that projects had been evaluated in a variety of ways including:

- Survey evaluations;
- Post implementation surveys;
- Interviews with all stakeholders involved in EBCD project including patients, project managers, hospital managers, clinical staff, designers;
- Interviews with 'new' patients using a service in which EBCD had been implemented;
- Observations of pathway;
- Group meetings where improvements were discussed;
- Informal conversations with staff and patients - 'anecdotal' evidence;
- Measuring quality indicators, before and after project;
- Document analysis of all notes and documents-emails, service improvement logs, recorded interviews, recorded events;
- Real-time measurement using mobile hand-held devices.

With regard to publications, seven out of 41 respondents answering the question (17%) indicated that they had published peer-reviewed papers as a result of their EBCD project, 8 (20%) that they had published a report available online, 17 (41%) that a report had been made available for internal reference, 5 (12%) that their findings were discussed at meetings only and 12 (29%) said that the project was still ongoing and findings were not yet available.

Thirty out of 43 respondents (70%) reported that they had given conference presentations relating to their EBCD project in the UK, New Zealand, Australia, Czech Republic, Scotland, Canada, the Netherlands and Poland. Thirteen (30%) respondents had not presented their work.

Strengths of the EBCD approach

Survey respondents were asked about the strengths of the EBCD process in relation to their project (see Figure 8). Of the 41 respondents who provided this information, 37 (90%) said that 'it really engaged patients', 32 (78%) that 'it really engaged staff', 26 (63%) that 'it allowed discussion of difficult topics in a supportive environment, 22 (54%) that 'it led to clear improvement priorities and 21 (51%) that 'it really made a difference to the way we do things around here'.

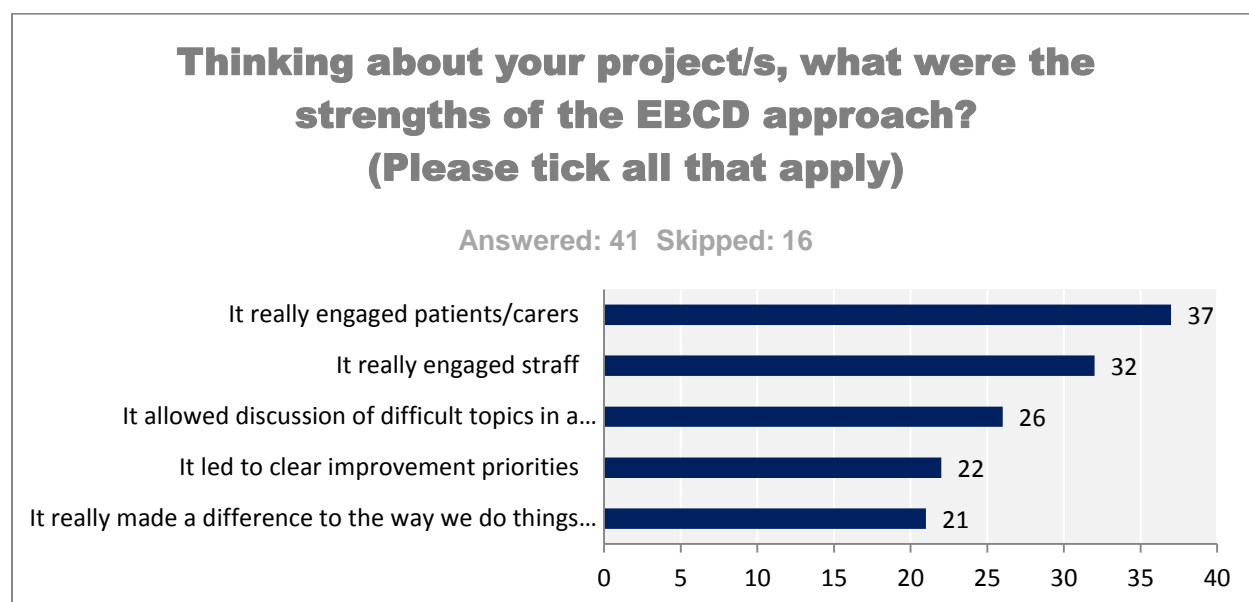


Figure 8 - Strengths of the EBCD approach

Impact on staff

We asked survey respondents to comment further on the strengths of EBCD. The two comments below are examples of the effects on participating staff members reported by survey respondents:

It produced an accountability and responsibility for the staff involved - which has stayed with them beyond the project. (Respondent#18)

The emotional response from staff reminding them why we are here, staff reported just watching the videos had an impact on the way they behave. [The project] led to many other developments to encourage teams to work alongside patient to improve experiences. (Respondent#29).

We investigated the theme of EBCD impact on staff more extensively with our interview participants. Here are some of their comments:

It did help change their [staff] attitude towards really listening... and the value of actually spending some time out of the operational frontline, and that patients had something valuable to say... (Interview#02)

I think the comments that we got back were basically that they really appreciated working with the patients, the staff appreciated being heard, and having the opportunity to tell their experiences, to express whatever it was. And, that being involved in the whole project gave them a different outlook, a different insight into how they're doing their work... And, although we always try to be patient focused or whatever, sometimes we think we are, and we're not. And, I think that by doing the experience based project, people are really beginning to realise that maybe we do need to listen to patients and family more... we don't know everything as healthcare professionals.... It's just been an eye-opener. (Interview#03)

Many of them said, 'Wow, I've never stopped to think of the patient perspective, but hearing it in their voice I can see now...' they just get to see that different viewpoint, and the impact of what they do on patients that they'd sort of stopped, and never had time to consider, it just wasn't in their frame of reference. (Interview#12)

Well, one of them said it had brought back her passion for the work that she does. Another said that it really affected her in a big way, she had never thought about the boxes that we put people in and the impact that has on people. (Interview#14)

The following points summarise the impact of EBCD projects on participating staff members according to our interview participants:

- Emotional impact of hearing the patient voice through films and through co-design events;
- Changing attitudes about ways of working and towards listening to patients;
- Reminding staff why they do what they do, leading to behavioural impacts by changing the way staff do things;
- Staff felt listened to;
- Staff were encouraged and motivated by hearing from patients what they are doing well, (i.e. not just about the negative aspects of the care patients received);
- Gave staff a different outlook/perspective to the way they work;
- A desire among staff to work with patients more often in the future;
- Increased staff knowledge (e.g. greater understanding of how other departments operate/function).

Impact on patients

In their comments on the strengths of EBCD, survey respondents occasionally also mentioned the impact they thought it had had on patients. Some examples are reported below:

The patients and relatives gained a real insight and understanding of the experience for staff working within the NHS which changed their beliefs, values and expectations.
(Respondent#18)

The main difference to the way we do things round here was about encouraging patient participation where EBCD was successful. (Respondent#23)

We asked interview participants to comment specifically on the impact they thought they had seen on participating patients:

I think it was a good opportunity for people to get understanding of each other's perspective. I think they [patients] quite enjoyed it. We always had quite a good time. We used to have really good food and I think they enjoyed sharing their stories. Some of them went on to other things, like one of them wanted to become a patient rep and went through training. So for them, it was an opportunity to kind of grow as well, if they wanted. (Interview#01)

And there was also an effect on the patients and carers who participated, we had post-evaluation quotes that it had been a great experience and they've learnt also what the perspective of staff, where staff are coming from...by the end of the process, the co-design thing they really came to appreciate where staff were coming from in certain areas, it had that sort of effect. (Interview#07)

Summarising the main types of impact on patients identified by our interviewees, our list would include:

- Being given a voice/feeling listened to;
- Improving/developing the way services are delivered to others in the future/ altruistic reasons for being part of project;
- Establishing good relationships with staff members and other patients, sharing stories, social outlet;
- Understanding staff experience of service;
- Story-telling as cathartic/therapeutic experience for patients;
- Feeling empowered by being a part of the co-design process;
- An opportunity to become involved in other projects and training.

Impact on wider organisation

The majority of interview participants reported a wider impact on the healthcare organisation where the project had been carried out. This impact fell into the following main categories:

- A move away from a paternalistic model of care to an 'equal partnership' way of working;
- Incorporating films into staff training sessions;
- Establishing patient advisory groups;
- Improving clinical outcomes for patients;
- Embedding the approach into the organisation so that staff see projects as part of their role.

However, at least three interview participants reported one of the main barriers to the embedding of the approach into the organisation was the organisational restructuring that took place during projects or just shortly after. This restructuring meant that organisational priorities shifted and hindered progress.

Below are some of our interviewees' comments on how the process had had an impact on their organisation:

There was those secondary effects, unexpected effects in some cases where there had been cultural change that they were involving patients and carers more, instead of just consulting, which has been the traditional thing, we'll do something and ask people later what they thought. They actually are involving people in the decision making process, so having patients and carers on staff selection panels and things like that, which hadn't happened before. (Interview#07)

What worked was the formality, we put a discipline in place that was like a forcing function for us not to behave the way we typically behaved because we thought we knew what patients wanted, wow we know actually we don't. And it's just been the most powerful paradigm shifting experience. It's difficult for me to describe just how paradigm shifting it has been. (Interview#11)

And now everything we do it's, 'Oh can we get a patient involved,' you know let's hear it from the patient's point of view. So how do you measure that? And also I think the way they practice now, and the way they teach the new trainees is patient first. So they won't say, 'This is the esophagogastrectomy from yesterday,' they'll say, 'This is Mr Brown, he is a 48-year-old gentleman, he's married with three children, and is an accountant. (Interview#08)

I think it demonstrated to them the power of patient engagement that it could be very positive. It did give staff new tools to interact with patients. And because they prioritised the solutions, obviously, it showed some quick wins, so it got that buy in quite quickly too, in many sites, after initial resistance. (Interview#12)

Thirteen interview participants said that the EBCD approach has or is likely to spread to other services/organisations:

I wouldn't say spreading – seeping...I think there's a very big recognition of co-design as a way to go forward with things, but a lot of the services are steeped in the processes they've already got. And I think they're finding it hard to see where does it fit in with what we currently do. And it's about that medical model I think, where you've got the patient carers who are just the receivers of service, what do they know, you know. So there's just still that wall to be knocked over yet as far as lived experience being something that's a valuable tool in informing services of what they're doing, and how to do it better. (Interview#07)

[As a result of the EBCD projects] we're informing the rest of the hospital on patient involvement and engagement and all of that. So, we've...become the 'go to' people...various departments wanted to learn how to do it. (Interview#03)

I know that if you talk to people now about using the co-design methodology, you don't have to explain it. Previously I had to explain what that actually was. Now, you can just say co-design will know what you're talking about. (Interview#06)

Weaknesses of the EBCD approach

We asked survey respondents about the weaknesses of the EBCD process in relation to their project (see Figure 9). Forty-one respondents addressed this question: 19 (46%) reported that the project 'took too long', 11 (27%) respondents said that 'it was too complicated', 7 (17%) said 'it cost too much', 11 (27%) said 'staff did not engage with the project' and 2 (5%) respondents said 'patients/carers did not engage with the project'.

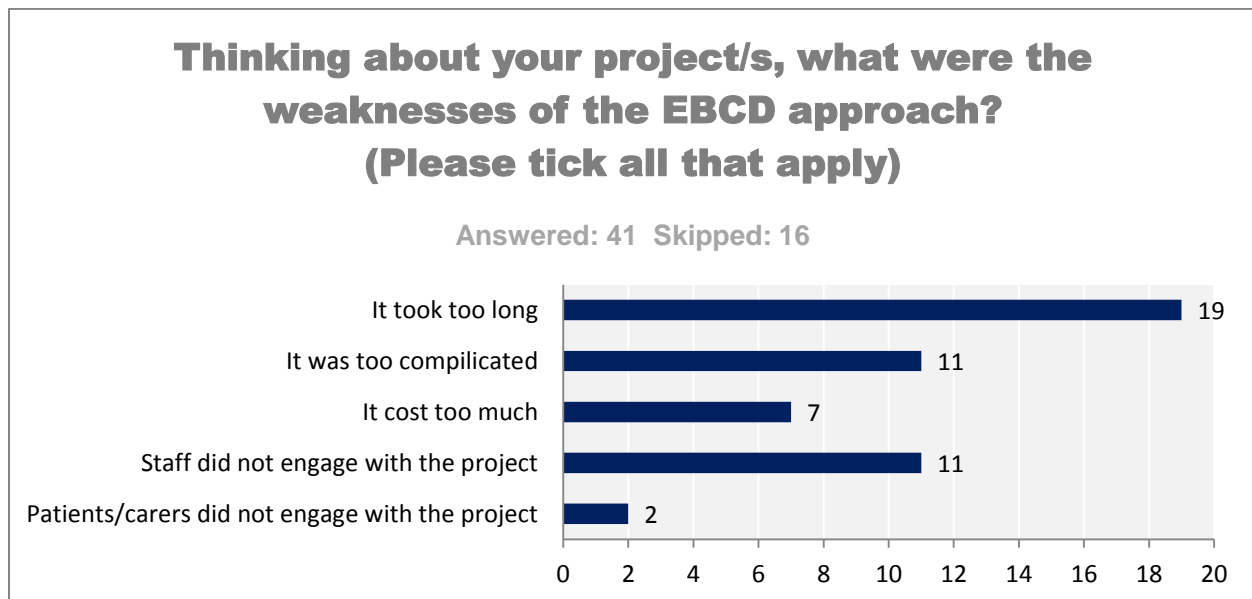


Figure 9 - Weaknesses of the EBCD approach

Time

Some of the open text comments provided a little further insight into the answers to the multiple choice question in Figure 9:

Staff and patient engagement did occur- but was challenging- it had to be tailored to the site and targeted in approach. (Respondent#17)

Translating findings into hard change is extremely difficult. There was probably not enough engagement of middle grade managers. (Respondent#46)

The project takes a lot of time, especially when only one person is actually carrying out most of the project. (Respondent#42)

More detail was provided in interviews, in particular about the issue of the duration of the process:

I think the time it took and the fact there were no results along the way, I think we lost some of the buy-in and the engagement as we went along because we did the big presentation, this is the project we're going to do, this is what we think it can help with, and then they might or might not have been interviewed and then they didn't hear anything for a little while. (Interview#05)

I think part of it was probably looking at time and logistics. We thought, 'Okay, you have a staff one, and then you have a patient one, and then you have a joint one,' and it seemed very complex. It all takes a lot of work, even just to organise one workshop. (Interview#01)

They [staff] are quite used to service improvement falling by the wayside, whether that's unique to this hospital or not I don't really know. So I think sustaining involvement and engagement was a really big challenge. It was almost like the data collection, that just took too long. So whether I could focus that and narrow that down to a smaller timeframe and be much more structured about it was what I'd hoped, and then do the big engagement piece so that they don't feel there's such a huge gap (Interview#05).

Engaging staff

Many interview participants spoke about the challenges of engaging staff members in their EBCD projects. In most cases, engaging staff was challenging in the initial stages of the project. Often, staff became more engaged as they became familiar with the approach and perceived it was making a difference. Interview participants acknowledged that lack of staff engagement could be attributed to a number of factors, among which:

- Lack of time for staff (e.g. staff members attendance at co-design events was difficult due to their already heavy workload);
- Unfamiliarity with the approach; staff were sceptical about the usefulness, purpose and length of the approach;

- Staff discomfort about hearing the patient voice (e.g. staff preference to remain detached from patient for whom they are providing clinical care);
- Culture of organisation (e.g. staff reluctance to change and distrustful of patient engagement projects).

However, in interviews participants also discussed some of the ways in which these challenges were overcome. These included:

- Engaging and involving senior staff members from the beginning and ensuring their presence at co-design events so that other members would feel it would be worthwhile;
- Initial preparatory work, i.e. establishing rapport and trust with staff members at the beginning of the project;
- Identifying staff members in the service who are enthusiastic about change (as they can often help to keep the process moving forward);
- Encouraging staff involvement over time; communicating with staff members at every stage of the process, and increasing their knowledge about the approach;
- Improvement processes implemented quickly so that staff are motivated by seeing changes taking place.

Cost and cost-effectiveness

Funding, associated costs and team composition

We asked survey respondents about how their projects had been funded and asked them to tick all the funding sources that applied to their case. Of the 40 respondents answering this question, ten (25%) indicated that their project had been funded by external funders (e.g. a research council or R&D programme), 20 (50%) that it had been funded by the health service organisation in which it was implemented, 5 (13%) by a charity, 3 (8%) by a different body such as 'think tanks', or insurance and pharmaceutical companies. Four respondents (10%) reported that their projects had been funded jointly by different organisations and 5 (12%) that they had not been funded.

Eighteen of 41 survey respondents (44%) were aware of the costs involved with their project and 23 (56%) were not. In terms of the time they had personally dedicated to the project, the majority of the 38 survey respondents answering this question had spent between one and three days a week on it. More precisely, in increasing order of time spent on the project: ten (26%) respondents reported spending less than half a day per week (less than 10% WTE), 3 (8%) between half a day and a day per week (between 11 and 20% WTE), 12 (32%) between one and two days per week (between 21 and 40% WTE), 10 (26%) between two and three days per week (between 41 and 60% WTE), 1 (3%) between three and four days per week (between 61 and 80%) and 2 (5%) more than 4 days per week (more than 80% WTE).

With regard to team composition, 41 respondents provided further detail about this. Of these, 25 (61%) reported that their project involved external researchers and/or facilitators – this could be experts in the EBCD approach, academic researchers, research companies, design and production experts and quality improvement support - and 16 (39%) that it did not.

Was the cost worth it?

Published economic evaluations of EBCD projects are currently lacking.⁷ We therefore explored the issue of costs and cost-effectiveness in some detail with our interview participants. Six of the 18 interviewees were aware of the amount awarded to undertake the EBCD project. For the internally funded projects, only some participants had captured the cost as they implemented the approach. Also, for these projects costs remained low as most staff members undertook the project as part of their job/role.

When we asked them whether they thought the cost of EBCD was worth the money invested, almost all interview participants agreed that the benefits of the approach far outweigh the costs:

I think this is part of that new way forward. I know that it costs a lot to do it but the returns are great and I think if you refine it, it will become less expensive over time if you get the skills and the workforce (Interview#06)

Sometimes you can't measure what's really important, and you can't measure that humanistic response. So you can measure the times we met, the outcomes, the impact of those outcomes, but you can't measure how people change. It affects the compassion, and it affects their passion for the job they do as well. Some people were looking to leave and this project made them stay... (Interview#08)

I think in the scheme of things it's quite a small sum of money to have such a collaborative process. And it's not just about that project, it's about developing a culture of doing things together, so it's about the future too, and an investment to get people to think that we can do this, we can talk to one another and come up with something that works for everyone. (Interview#10)

⁷ The only rigorous 'bottom up' costing of EBCD projects we are aware of was undertaken as part of the 'Accelerated' EBCD study in two lung cancer services and two Intensive Care Units in England (Locock et al., 2014). A cost spreadsheet was developed by the evaluation team and sent to project facilitators to enable them to log directly incurred costs such as travel and catering expenses as well as indirectly incurred costs such as staff time. The cost spreadsheet explicitly aimed to address the hidden cost of participatory research in terms of staff time released from clinical duties. Comparable EBCD data were extracted from previous project budget files and consisted of cost data on researcher time, film production, facilitation and other costs similar to AEBCD. Overall, the study found that AEBCD cost an average of £28,565 per site, an estimated saving of nearly half over traditional EBCD. Implementing either lung cancer or intensive care AEBCD in the future would cost approximately £20,000 (as the 'trigger' films have already been produced), a saving of almost 60% over traditional EBCD. As more trigger films are produced more hospitals can benefit from this significant cost saving. Given that AEBCD and EBCD produced broadly similar outcomes the evaluation team argued that AEBCD represents good value for money.

Forthcoming EBCD projects

Forty-one survey respondents offered more information about their future plans for EBCD and about other EBCD projects they were aware of. Twenty-one of these respondents (51%) indicated they had definite plans to use EBCD again, 11 (27%) said they would use it again but had no definite plans, 2 (5%) did not plan to use it but knew of colleagues who would, 6 (15%) were not sure whether they would use EBCD again in the future and 1 (2%) said they would not. Twenty-two of the 41 respondents who provided information on colleagues who had used the approach (54%) said they were aware of colleagues who had used EBCD in a different healthcare organisation, 11 (27%) were aware of colleagues who had used this approach in the same organisation where they worked, 3 (7%) knew of colleagues who were planning to use EBCD but did not know where they worked, and 10 (24%) did not know of any colleagues who had used or were planning to use EBCD.

We asked survey respondents to indicate which of the seven elements of EBCD we listed they would use if they were to carry out another EBCD project in the future (see Figure 10). In descending order of inclusion: 35 of 38 respondents addressing this option (92%) indicated that they would use small co-design groups to work on improvement priorities, with only 3 (8%) being unsure. Thirty-three of 38 respondents (87%) said they would use patients and staff events as part of their project, with only 5 (13%) being unsure. Thirty-four of 40 respondents (85%) indicated that they would include patient interviews and feedback in their project with 6 (15%) being unsure. Thirty of 39 respondents (77%) indicated that they would include staff interviews and feedback in their project, 1 (3%) said they would not and 8 (21%) that they were unsure. Twenty-eight of 35 respondents (80%) reported that the celebration and review event would be included in their project, with 7 (20%) being unsure. Twenty-four of 37 respondents (65%) indicated that they would include filming of patient interviews, 2 (5%) that they would not and 11 (30%) that they were unsure. Finally, 19 of 35 respondents (54%) indicated that they would use non-participant observation in the project, 1 (3%) said they would not and 15 (43%) were unsure.

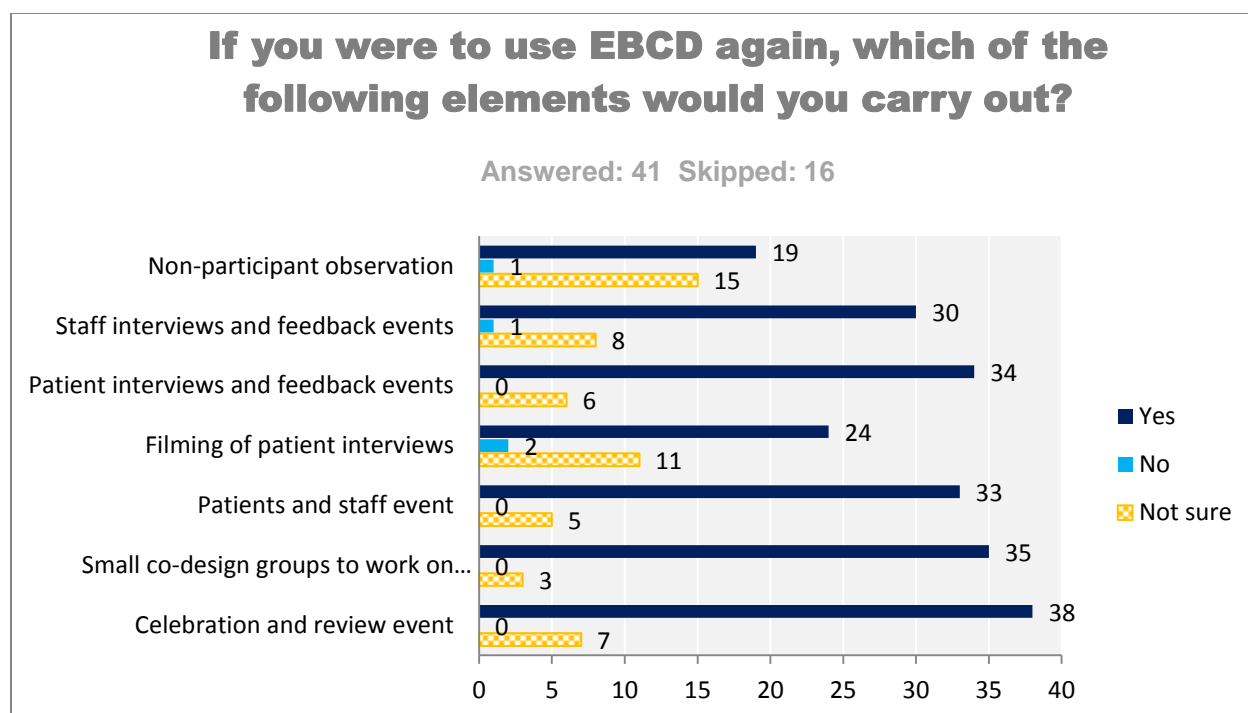


Figure 10 - Elements to be used in next EBCD project

Survey respondents who had already led an EBCD project were asked to provide details about any adaptations or modifications they would introduce in future projects based on what they had learnt from using the approach previously:

We have already introduced a range of modifications as opportunities or constraints arise. I think EBCD is first a philosophy and only second a method, and methods need to evolve and grow as organisations grow smarter about working with patients/clients. We use a lot of tools from service design and are evolving ones of our own. (Respondent#32)

Resource allocation is vital in this approach. Staff are willing to participate as are carers but they are often time poor. I would utilise webinar technology as much as possible to allow people to participate without having to lose as much time. (Respondent#44)

Nineteen of the 41 respondents answering this question (46%) indicated that they would use the online King's Fund toolkit if they were to use EBCD again, 2 (5%) that they would not and 20 (49%) were unsure. For those undertaking projects outside the UK, local resources also appeared to be important.

Of the 10 respondents who had not been involved in an EBCD project yet but were thinking of carrying out one in the future, 9 (90%) indicated that they had concrete plans in progress, and 1 (10%) that they were thinking about it but had no concrete plans. Some areas/services in which EBCD was being considered for application in future projects include: rare genetic diseases, diabetes, emergency care, HIV services for an ageing population, care for patients following discharge from critical care, care during early labour, care for formally incarcerated patients, and in the development of a communication process leading to a mobile phone app. When asked whether they would use the online King's Fund

toolkit for their planned project, 5 of the 10 respondents (50%) said they would use it extensively, 3 (30%) that they would use 'bits' of it, 1 (10%) that they were aware of it but would not use it, and 1 (10%) that they were not sure. We asked these respondents about their plans to contact any organisation/individual for training or advice for their planned EBCD project and offered them a brief menu of options from which to choose. Two of the 9 respondents who answered this question (22%) selected more than one option: they would both contact the King's Fund but one would also contact the NHS Institute for Innovation and Improvement and one would consult with academics involved in the 'accelerated' EBCD study. One respondent (11%) expressed a preference for the NHS Institute for Innovation and Improvement; three respondents (33%) said they would contact another organisation/individual and listed other experts in the open survey comments and 3 (33%) said they would not contact any advisors.

Lessons learned

Interview participants were asked about the lessons they had learned and what they would do the same or differently:

Getting people to design or try things as early as possible. I think people get a bit stuck in research rigour, and we tend to over research things... if I can get people trying new and different things earlier on then we learn a lot quicker, and a lot more practically. (Interview#17)

I think I would give advice that you need to be really clear... not biting off too much...But it's also about understanding continuous quality improvement as well, and it's also about having the right champions in place so that people are truly facilitative because if you aren't valuing the information you are hearing or if you don't truly listen, observe, and understand it will just be an exercise. (Interview#15)

I think more can be done with what is generated, the information generated in a co-design. They [the funding body] should be looking more seriously at sites that are perhaps similar in size, locality, demographics have done in a co-design project to see if it can be implemented elsewhere. (Interview#12)

What worked for us was the frequent short meetings, and keeping in close contact. And I think for the patients and relatives to be there kind of held the staff to account, and to their action points. I mean they did divvy things up... definitely for staff because of that humanistic kind of connection... it really drove them to complete actions. (Interview#08)

A summary of key points from all the suggestions our interview participants offered are outlined below:

Adapting the approach

- Be flexible: look for ways to adapt the approach to fit your service and purpose. A long process can be burdensome particularly if only one person is managing the project.

Staff and patient engagement

- Spend time communicating the approach effectively to staff and patients and so that they do not perceive it to be 'just another project';
- Ensure patients are involved in the project as early as possible;
- Ensure clinical leadership from the beginning;
- Identify 'champions' within services to keep the process moving forward and promote change;
- Keep in close contact with patients and staff and ensure the delegation of actions so that people feel accountable and responsible to follow through;
- Sustaining involvement and engagement can be challenging. Long periods between data collection and implementing changes can sometimes lead to disengagement from patients and staff. Shorter, more frequent meetings are useful;
- Ensure a clear patient engagement strategy is put in place and find different ways of engaging people. Offer alternative ways of becoming involved in project if people cannot attend in person such as Skype call or webinar technology;
- Information about what is required should be given to people at the beginning so that they can choose how they would like to be involved;
- More collaborative work between universities, hospitals and community groups;
- Ensure more time taken to prepare staff and patients in sensitive environments; ensure an understanding of the objectives of the project, e.g. in mental health setting patients may be particularly fearful of speaking about their experiences and concerned that this may affect their care (issues of re-traumatisation and stigma).

Understanding experience

- Recognise that staff experience is as important as patient experience;
- Have a clear plan about how narratives are going to be used to support change and how that process is managed;
- Ensure strategies are put in place to support interviewer as interviewing patients can be emotionally challenging;
- Ensure surveys, if used, are specific enough; they can often be misleading and open to misinterpretation;
- Consider using a pre-existing trigger film;
- Consider using peer mentors to design projects, collect data, contribute to analysis, feedback and development. This may be a better way of establishing trust with participants in sensitive areas such as mental health services.

Co-design

- It may be more beneficial to run workshops at a different site to service/hospital so that participants can be more open and honest without feeling there will be repercussions;
- Ensure the facilitator understands the EBCD approach; the role of the facilitator is key and having the right person to do the job can make all the difference;
- Consider the importance of evaluating your project for helping understand what did and did not work and enable learning for future projects. Documentation related to data collection, co-design events, numbers, changes implemented should be maintained alongside the process;
- Have a clear plan for the co-design process - '*when we get the feedback, what are we actually going to do with it?*' (Interview#09);
- Consider using driver diagrams in the co-design process as these may help to clarify aims, the way of achieving the aims and identifying what the measures will be;
- Ensure co-design groups and follow-up meetings remain collaborative; keep groups mixed, enabling them to hold each other accountable;
- Using external designers can be useful for identifying potential solutions but implementation is the most difficult aspect of project so engagement of managers is key.

Budget

- Ideally, have a dedicated budget rather than trying to do it within '*business as usual*'.

DISCUSSION

This study set out to ascertain the 'state of the art' of EBCD and priorities for future development. In the sections that follow we discuss what we consider the main findings from our analysis of survey responses and follow-up interviews with participants. Before we do so, we wish to alert the reader to two main – and to some extent inevitable – limitations of our study design. Firstly, it is highly likely that our approach to recruiting participants and their willingness to participate in the survey led to a positive 'response bias'; those involved in 'unsuccessful' projects or who had encountered challenges in implementing the approach are less likely to have taken the time to participate. Secondly, we attempted to recruit participants to the survey through several routes but undoubtedly did not contact everyone who has ever sought to implement the approach since 2005. Our mailing list was dependent - to a large degree - on linking into existing networks of which we were a part or on contacting authors of publicly available journal papers or reports of EBCD projects. In addition, relying on publicly available email addresses meant that some of these might not be up to date, leading to some invitations failing to reach their intended recipients. As a consequence, we are aware of at least two projects - both of which

adopted the approach as described in the original NHS Institute EBD guide – for which published material exists but that are not represented in the survey findings. The first is the ‘Better Outpatient Services for Older People (BOSOP)’ project - a 12-month service improvement project carried out in 2009-2010 that focused on the medical outpatient service for older people at the Royal Hallamshire Hospital in Sheffield, UK (Bowen et al., 2013)⁸. The second is a project involving the adoption of the original EBD approach as part of an organisation-wide Lean intervention at Virginia Mason Medical Centre in the United States (Plsek, 2014), where - beginning in 2008 - the hospital has integrated EBD tools into its toolkit for driving innovation.⁹ In our discussion we draw on the emerging findings from these projects and from other projects of which we have become aware after closure of the online survey. Notwithstanding these limitations, our findings and the broader literature suggest four major themes for discussion which we believe will be of most interest to those who either have implemented EBCD in the past or hope to do so in the future.

EBCD training and support

The survey showed how respondents had learnt about EBCD from a wide range of sources over the last ten years. Currently, the most extensive source of information is undoubtedly the free-to-access, online toolkit which - following revisions and updating in autumn 2013 - now incorporates several case studies.¹⁰ The toolkit has been developed through collaboration between quality improvement practitioners and academics, and is disseminated via the King’s Fund charity (<http://www.kingsfund.org.uk/projects/ebcd>). Following the initial launch of the toolkit in August 2011 - when it received almost 11,000 views - views of the toolkit have subsequently averaged 3,500 per month (Adams et al., forthcoming). Our survey results indicated that users of the toolkit found it concise and easy to follow, and that it provided them with the practical tools for carrying out an EBCD project. They also highlighted that the use of videos in the toolkit proved helpful in demonstrating the experience of patients, staff and carers involved in other EBCD projects. Prior to the launch of the online toolkit the only formal source of support for those interested in the approach was via the NHS Institute for Innovation and Improvement which produced a hardcopy toolkit and guide and an introductory DVD, and ran one-day courses. Since the closure of the NHS Institute these resources have been made available on the NHS Improving Quality website but no further opportunities for training have been provided. It was striking from the survey findings that only a few of the respondents who had been or were involved in implementing EBCD had received any training. It is therefore timely that NHS England has agreed to fund a ‘train the trainers’ course via the Point of Care Foundation in London (the first

⁸ The outputs from this project were intended to be generalisable to other outpatient departments in the hospital, and other hospitals.

⁹ As well as providing an overview of the adoption and adaptation of EBD at Virginia Mason from 2008 onwards, Plsek (2014) also provides a case study of how the approach was implemented in the Critical Care Unit at the hospital.

¹⁰ The four current case studies that form part of the online toolkit relate to: implementing the approach in an acute mental health setting; developing a support package for carers of patients undergoing chemotherapy; embedding patient experience in organisational culture; and using archive film to develop an accelerated form of EBCD.

cohort of trainees is expected to undertake the course in the summer of 2014). Informal learning on EBCD is now also supported via the recently established LinkedIn group (currently over 100 members), which is freely accessible to anyone with an interest in the approach or experience of/plans for implementing it.¹¹

Adaptations of the EBCD approach

It is reassuring that over 90% of respondents in the survey reported that EBCD ‘really engaged patients’ and almost 80% said it ‘really engaged staff.’ However, what is evident from the limited published literature as well as from analysis of the survey responses is that the EBCD approach proposed by Bate and Robert (2007a) has undergone a variety of adaptations in response to a variety of local contingencies and organisational circumstances. From the follow-up telephone interviews with respondents to our international online survey, it is clear how those leading the implementation of EBCD perceive the approach as inherently flexible and tailor it to the nature of particular clinical services and their own local contexts.

Role of non-participant observation and the celebratory/review event

Local adaptations have included the elimination of specific phases, and particularly the non-participant observation and the celebratory/review event. We discuss each of these in turn below because in our view these are crucial components of EBCD which contribute significantly to successful and sustainable change.

In its original formulation, EBCD includes a substantive observational phase, through which researchers are able to provide an additional vantage point on how staff and patients ‘go about their business in real time’ (Bate & Robert, 2007a, p.88). Observational data - whether gained through participant, non-participant, ‘user interactive’ or any other specific mode of observation - is an important means to provide context to participants’ narratives and their co-design work. It is particularly illuminating when carried out by members of the project team who are less familiar with the everyday practices of the setting in question and who can therefore contribute fresh vantage points to the identification of significant moments – ‘touch points’ - in the care journey. Observation is also cost-effective, in that it can generate valuable insights with little resources and in a relatively short amount of time. As one of our participants pointed out (see page 24, Interview#10), the data it generates can be copious; however, the analysis of observational data can be guided, where appropriate, by emerging themes from the analysis of interview data and still contribute significant, fresh insights and additional detail to the findings of the ‘discovery phase’.

The celebratory/review event is also integral to the co-design process. It is an opportunity to draw together the ‘facts and figures’ on what a project has achieved and on the practices and processes that

¹¹ www.linkedin.com/groups/Experiencebased-codesign-6546554

need further work or consideration, thus contributing to project evaluation. But it is also an opportunity for participating staff and patients to share and discuss achievements, learning, and ongoing challenges at the end of an often emotionally demanding collaboration. It provides closure but also a platform for future co-design work and continuing involvement in quality improvement. Failure to hold a review event will not directly affect the short-term improvements to the service brought about by the EBCD process; however, it may limit participants' learning and hamper the cyclical, regenerating character of EBCD, preventing the process from directly feeding into ideas and reflections which might engender further collaborative work and behavioural change in the longer term.

Role of film

Although over 80% of projects reported conducting patient interviews many dispensed with the (time- and resource-intensive) filmed component, whilst others dispensed with one-to-one staff and/or patient interviews altogether and resorted to focus groups. Many of the adaptations reported in our data relate to the main criticism moved by study participants to the EBCD approach - it simply takes too long (Figure 3, page 16). Recent research carried out through funding from the National Institute for Health Research in England examined the possibility of reducing the time it takes to carry out EBCD by developing and evaluating an 'accelerated' EBCD (AEBCD) approach in two Intensive Care Units and two lung cancer services (Locock et al., 2014). This 'accelerated' version - which relies on the extensive archives of filmed interviews focusing on people's experiences of their health-related conditions held by Healthtalkonline (<http://www.healthtalkonline.org/>) - proved readily acceptable to staff and patients; using films of national rather than local narratives did not adversely affect local NHS staff engagement, and may in some cases have made the process less threatening or challenging. The resulting 48 co-design activities across the four services were similar in nature to those in EBCD but were achieved more quickly and at lower cost.

The critical function of the patient film in EBCD is to trigger discussion. The recent work carried out by Locock and colleagues on 'accelerating' the EBCD process by producing trigger films from already available interviews with patients shows that the degree of personal identification of participating patients and staff with the content of the film was not crucial to generating fruitful and productive discussions that could lead to the co-design of quality improvements (Locock et al., 2014).

However, whether collected anew or created from existing archives, we maintain that the use of 'mobilising images' (films of patients describing their experiences) remains a key success factor for the approach as a whole. In the original pilot EBD project in 2005/06 the film enabled staff to 'actually sit down and see the [patients'] faces and hear their emotion'; this played an important role in 'keeping the engine of motivation going', as well as offering the ability to 'replay them ... reinforcing the work and pulling people into [the project]' (Bate & Robert, 2007a, p.181). Five years on and patient films were having similar impacts in another EBCD project; discussions soon after screening of the patient films emphasised their potent effect on clinical staff who commented that the films were 'a very powerful reminder of why we are doing what we do', 'very moving, a vivid reminder of patient experiences', and a 'resoundingly powerful look into individuals' lives and experiences with cancer.' In several services

senior clinical staff arranged for the rescreening of the patient films for wider staff training work. One senior nurse in a day surgery unit remarked that the effects of the film screening during an audit day had been remarkable for improving care in the service. She felt that:

...the film was the catalyst to solving the problems... this was the thing that absolutely broke down the wall and made people really see clearly that it had to stop and that people's attitudes had to change... there is something very powerful about film... it engages everybody, it's not just reading things or listening to things... the visual side of it I think is very important.
(as cited in Adams et al., manuscript in preparation¹²)

Overall, the staff involved in these film screenings remarked on the initial value of the patient films as giving them access to a new way of understanding the experiences of patients. Most felt that - at least at the time - the films offered what Chalfen and Rich have described as 'an innocently-derived, transparent 'window on life' view' of patients' experiences of care (2007, p.55). Some clinicians, particularly medical staff, spoke of the privilege of being offered access to this 'world of the patient'.¹³ Other researchers have similarly found the use of video to be an important component of quality improvement interventions; for example, Neuwirth et al. (2012) report that as part of an initiative to improve care transitions for elders with heart failure, video ethnography contributed to greatly reduced thirty-day hospital readmission rates, and that - when embedded within an established quality improvement framework - such an approach can be an effective tool for innovating new solutions, improving existing processes, and spreading knowledge about how best to meet patient needs.

Co-design

Most significant in our view are the adaptations made to the 'small co-design groups' as originally envisaged in the pilot project. It is clear that some of those leading later projects have struggled with the notion of co-design itself, asking in their survey comments for more examples to be provided of co-design meetings and the tools used, more information on how to make co-design events work, and clarity as to the 'fundamental' aspects of co-design and where 'shortcuts' could be made. Although over 85% of survey respondents reported implementing co-design events as part of their project, follow-up telephone interviews revealed a wide range of approaches. Some stark examples included projects which entailed holding just one 'co-design' meeting where experiences were discussed and solutions determined but only with patients present; staff were then charged with developing and testing the 'solution'. Another project leader described how in their project the small co-design groups 'were mainly staff, as most patients felt that they had told us the issues and just wanted to learn what changes we had made' (Respondent#06). In contrast, other respondents to the survey and telephone interviewees reflected on the significance of co-design to which some wished they had paid further attention.

¹² Adams et al. 'Captured Experience: Legacies of Filmed Patient Narratives for NHS Clinicians'. Manuscript in preparation.

¹³ At the same time, we must recognise that patient stories are emotionally demanding; moving into patients' worlds is not without risk, particularly when the possibilities for alleviating distress and suffering may be limited (Donovan & Mercer, 2003).

This accords with Bowen et al.'s (2013) reflections on the application of EBD in their early case study at Royal Hallamshire Hospital in Sheffield, UK, referred to above (see p.41). The authors suggest that 'the modest service improvement that resulted may be due to the specific structuring of participation and the limited ideation tools in EBD', arguing that a reported 'perception of the designing as being something that was done by others' was a key shortcoming in this particular project (Bowen et al., 2013, pp.241-242). Similarly, Plsek in his summation of the experience since 2008 of adapting EBD in Virginia Mason Medical Center in the US, highlights co-design as a persisting challenge:

...the full concept of co-design in EBD provokes a challenge. It involves deliberately empowering multiple patients and family members to be equal partners in decision making and detailed design, training them to be assertive, and engaging them in large numbers so that they feel even more empowered [...] getting to full co-design may still lie further out in Virginia Mason's future but the organization is committed to taking initial steps that seem to lead in that direction. (Plsek, 2014, p.171)

Where successfully implemented in practice, the co-design stages of EBCD have proved powerful (e.g. Iedema et al., 2010; Piper et al., 2012; King's Fund, 2011; Boyd et al., 2012). In the EBCD projects carried out in Emergency Departments in New South Wales, Australia, co-design demonstrated a number of strengths including: allowing project staff to learn new skills; enabling frontline staff to better appreciate the impact of healthcare practices and environments on patients and carers; engaging service users in 'deliberative' processes that were qualitatively different to traditional forms of engagement; and enabling the service to implement solutions that met the wishes, advice and insights of patients and frontline staff (Iedema et al., 2010). However, where preparation, recruitment of patients and engagement of front-line staff were not possible or not consistent, co-design worked less well (Piper et al., 2012). What emerges from all the work to date is that co-design is a complex social intervention whose impact and outcomes are difficult to evaluate and cannot be reduced solely to the design solutions it generates (Bradwell & Marr, 2008; Iedema et al., 2010). Other aspects of the impact of co-design could include, for example: the personal development of those involved in the process; changes in staff motivation, skills and self-confidence; and the development of trust and new relationships between participants in the process.

In an EBCD project carried out in breast and lung cancer services in the UK, the co-design stages also proved challenging: not all the co-design groups that formed were subsequently maintained and there were issues with the composition of some groups, which ended up including mainly or exclusively managers and clinicians (King's Fund, 2011). Looking back, one member of staff considered the emotional demands of working - as clinicians - alongside their own patients in a co-design process:

[The co-design group was] nerve wracking... I was sitting across a [meeting] table from a woman that I knew, I'd looked at her scan and I was going to have to tell her that her cancer had come back in the next clinic ... and she's telling me how brilliant her life is ... (Adams et al, forthcoming)

Another staff perspective on this issue emerging from one of our interviews is that - whilst recognising the potential of co-design - it is very challenging for most healthcare staff to move easily between their

‘expert’ and ‘decision-maker’ role to becoming a partner and colleague. The complexities of ‘co-design’ at the individual staff member and patient level in the healthcare sector become clearer when reflecting upon such points. Implicit in participatory design approaches is the aim to change power relations but the evidence as to whether or not they do so in the healthcare setting is scant; certainly we know little of the circumstances in which they are successful in this regard.

Digging a little deeper into the detailed implementation of participatory design approaches such as EBCD often reveals tensions between co-design’s intended aims and its actual forms in practice. Iedema and colleagues, who were involved in carrying out and evaluating several EBCD projects in Australian emergency care services, make their own recommendations as to how to improve the co-design processes in EBCD - for example, by involving skilled facilitators, using a mix of involvement strategies, performing a ‘co-design readiness’ assessment, and obtaining recognition from management and policy makers (Iedema et al., 2010). Similarly, Plsek highlights several ways of enhancing the implementation of the EBD approach that are being tested in one healthcare organisation in the US including: embedding the approach into work on strategic and operational goals by assigning an EBD adviser to each goal; embedding the concepts and methods into training and certification processes; and more ‘full-scale, active involvement of patients and family members in improvement and innovation work’ (2014, p.171).

Expectations of the scale of change

The question of expectations of the scale of change that may result from co-design approaches is also an interesting one in the healthcare context; witness the contrasting views of two members of staff in the same colorectal cancer service that participated in an EBCD project (Adams et al, forthcoming):

[for] the amount of time it [the EBCD process] takes you need to get some really good stuff out of it ... changing [things] a little bit... that’s good, but is that good enough?

[People talk about minor but] How minor?... if that minor change affects 100 people that year, and it’s a better experience for 100 people, how wonderful is that?

As with the first quotation above, Bowen et al. (2013) were clearly left a little underwhelmed by the changes brought about in the EBD project they led. There are, of course, several potential reasons why only ‘modest’ improvements were observed in this particular case (relative expectations being one) but we would certainly agree with the authors that one key area to focus on is the co-design phase of the approach (see previous section). Interestingly, the authors comment that:

Our own expectations (as participatory designers) about trajectories of change can also be naive when working in unfamiliar and complex organisational contexts. The slow (and uneven) progress from ideas to implementation, and the way that project proposals have been adapted and fused with other inputs to stimulate the actual changes, challenged our own morale and confidence about the impact of the work. (Bowen et al., 2013, p.242)

Although small-scale changes and process redesign within one service area are the most common result of both AEBCD and EBCD (Locock et al., 2014; Adams et al, forthcoming), small-scale change is often remarkably complex to implement in the healthcare context, and what looks like a small change can be immensely valuable to patients (and staff). Moore and Buchanan have recently referred to this as ‘sweating the small stuff’, arguing that the ‘cluster of “soft” benefits emerging from [the small-scale intervention they studied] may thus contribute in significant ways to the support for, and the successful implementation of, the more radical, transformational, disruptive change agenda facing acute healthcare’ (2013, p.16). In a similar vein, Iedema and colleagues, drawing on their findings in relation to the implementation of EBCD in emergency departments in Australia, conclude that:

Design cranks up the functional efficacy of skills, knowledge, and capacities in our effort to accommodate the intensification of feedback from an increasingly complex world. Likewise, codesign answers to this dialogic feedback imperative, enabling not just more public participation in public service decision making leading to more information, but better public participation producing affective and more meaningful (or more feelingful?) relationships. Better participation means more intense and focused communication about issues that really matter to individual people. (Iedema et al., 2010, p.88)

So whilst - on one level - the set of immediate outcomes from approaches like EBCD may appear as small-scale, first order and incremental changes, the implications of participating in the process of co-design itself potentially has much deeper and longer-term implications (provided the practice of co-design becomes embedded in the day-to-day activities of staff and their patients).

Nonetheless, there are also examples of EBCD being used to directly address more complex challenges. For example, in June 2011, The Change Foundation in Ontario, Canada, announced the ‘Partners Advancing Transitions in Healthcare (PATH): A first with Ontario patients’ project. In 2012 the Foundation awarded The Northumberland Community Partnership \$3 million over two years to work closely with the Foundation. The project unites 12 health and social care organisations with patients and caregivers who will identify healthcare transition problems in west Northumberland and across Central East Ontario and work with a full range of service providers to redesign care, improve experiences, and strengthen the system. The Northumberland PATH’s key elements include training and tools for local providers based on the EBD methodology to shift the local healthcare culture to a person-centred model of care.¹⁴

Evaluation

It was clear from the survey results that - with a small number of notable exceptions (Piper, Iedema, & Merrick, 2010; Piper et al., 2012; Ream et al., 2013; Locock et al., 2014) - little formal and systematic evaluation of EBCD projects has taken place to date. Whilst we know of at least two ongoing PhD studies

¹⁴ Source: <http://www.changefoundation.ca/library/backgrounders-partners-advancing-transitions-healthcare-path-northumberland/>, last accessed February 2014.

exploring the implementation and impact of EBCD,¹⁵ we would highlight two examples of more formal approaches to evaluation.

One is a recently completed UK study looking at the experiences of carers of chemotherapy patients and the other is an imminent randomised controlled trial considering the impact of co-design on mental healthcare services in Australia. The former study used EBCD to develop an intervention to enhance carers' experience of supporting someone through chemotherapy, with the aim of also improving patient outcomes as a result of carers being better prepared for, and supported in, their role (Ream et al., 2013). It involved the development of a carer support package - the 'Take Care' intervention - and the assessment of its impact on carers' experiences of supporting chemotherapy patients.¹⁶ Further evaluation of 'Take Care' is currently planned to take place within the context of a randomised controlled trial to determine its effectiveness and cost-effectiveness in practice. Data from the outcome measures pre- and post- intervention revealed the intervention: 1) significantly enhanced carers' knowledge of chemotherapy; 2) significantly reduced unmet needs for information and support; and 3) significantly enhanced experience of, and satisfaction with care. However, this data also indicated that it had limited impact on carers' confidence in caring for patients and that it did not affect their emotional wellbeing. Nevertheless, in post-intervention focus group discussions, carers who received the 'Take Care' intervention reported being informed of symptoms and side effects and feeling empowered, confident and reassured throughout the chemotherapy process as a result of receiving the intervention. These comments matched the views of healthcare professionals participating in focus groups, who perceived the main impact of the package to be about empowering carers and increasing their confidence, knowledge and awareness. Health professionals affirmed that the package was a source of support to carers in that it helped to reduce anxiety about the chemotherapy process; they also highlighted the legitimisation of the carer role the package enabled.

The second study of which we are aware is due to begin in 2014. It is a four year cluster randomised controlled trial which will involve eight community health centres in Australia and aim to evaluate the impact of co-design techniques to optimise psychosocial recovery outcomes for people affected by mental illness.¹⁷ The study also seeks to examine how the MH-ECO (Mental Health-Experience Co-

¹⁵ The first relating to improving the experiences of older palliative care patients, their carers and staff in Accident & Emergency departments, and the second seeking to improve the experience of discharge care for patients who have been admitted to hospital following an acute cardiac episode.

¹⁶ The study employed a 3-phase mixed methods research design. Phases I and II addressed the development of the intervention and used EBCD. These phases resulted in a co-designed 'Take Care' intervention involving an hour-long structured group session for carers (maximum five participants) delivered by a chemotherapy nurse and incorporating: the showing of a Take Care DVD of carers voicing experiences and staff responses; facilitated discussion allowing carers free and uninhibited expression and sharing of emotions and concerns; question and answer session on chemotherapy mechanism, side effects and management; and provision of the Take Care DVD and accompanying Take Care booklet to carers to take home. Phase III of the study then aimed to test and evaluate the impact of the carer support package through a small randomised feasibility trial and sequential focus groups (one for carers and one for staff). Forty-three carers were recruited to the trial, randomised between the intervention (n=21) and control (n=22) groups.

¹⁷ The 'CORE' trial - Getting to the CORE: testing a co-design technique to optimise psychosocial recovery - is being led by Dr Victoria Palmer, University of Melbourne and the A\$1.7 million funding for the trial is from the Mental Illness Research Fund, Victoria. More information available at: http://www.gp.unimelb.edu.au/docs/newsletters/2013_Apr_DeptNewsletter.pdf. Last accessed February 2014.

Design) – as it is called in this particular study - approach¹⁸ can best be used to improve mental health services.

We also wish to mention a recently completed exploratory project which looked at the sustainability of EBCD (Adams et al., forthcoming). This study identified 62 quality improvements ('co-design solutions') as having been implemented across four Cancer Centre case studies as a result of the EBCD approach; 19-22 months after initial implementation, 39 (66%) of the 56 co-design solutions on which the researchers were able to collate data were found to have been sustained (Adams et al, forthcoming). Sustainability was influenced firstly by the type of co-design solution that had been implemented – in the authors' classification: 'quick fix', 'process redesign', 'cross service or interdisciplinary', and 'organisational', in order of being increasingly challenging to implement – and secondly, by the relationship between the co-design solution and (a) the service context (i.e. if the solution was specific to the service or spanned service boundaries) and (b) other on-going quality improvement work. As well as a need for more rigorous research in a range of services and settings into the short-term impact of EBCD on all three components of quality (clinical effectiveness, patient safety and patient experience), there also remains a need to examine the sustainability of the wider impact of the approach, such as attitudinal and behavioural changes amongst staff (and this applies equally to other quality improvement approaches).

Finally, we wish to emphasise that whilst robust evaluations of co-design approaches to healthcare improvement are urgently needed in view of the potential for far-reaching healthcare quality gains, these should be accompanied and complemented by rigorous conceptual analyses of the theoretical and methodological bases of the approach. We agree with design strategist Penny Hagen that much is to be gained from effective integration of evidence-based and user experience-based approaches to design for healthcare services. Although this integration requires "some collaboration and open thinking" to bridge the different philosophical stances of the two approaches, on the basis of her experience in the area of online mental health promotion for young people in New Zealand, Hagen suggests that there is great value in integrating "the human-centred tools and values of user experience design into existing processes and models that already have leverage within organisations" (Hagen, 2014).¹⁹ We believe that for approaches like EBCD the future research and development agenda looks a little like this:

- more rigorous and robust assessments of the costs and benefits of new forms of co-design approaches, such as 'accelerated+' EBCD;²⁰
- mixed methods studies to explore 'best practice' for implementing the approach in different contexts;
- the development and evaluation of broader, community-based interventions that build on lessons from community based participatory research and asset-based community development projects;

¹⁸ http://mhco.org.au/main/page_home.html. Last accessed February 2014.

¹⁹ <http://www.smallfire.co.nz/2014/01/25/integrating-user-experience-and-evidence-based-approaches-to-design/>. Last accessed February 2014.

²⁰ Locock et al. (2014) set out a series of research priorities relating to the further acceleration of the approach.

- a renewed focus on using EBCD to improve staff experiences (alongside patient experiences);
- closer collaboration with designers and service design researchers.

CONCLUSIONS

The last decade has seen EBCD implemented in healthcare organisations around the world. Over this time the approach has evolved and been adapted to take account of local organisational contexts and processes whilst retaining the central tenets of service design practice.

In this report we have illustrated our findings from an international online survey and follow-up interviews exploring researchers' and practitioners' experiences of being, or planning to be, involved in an EBCD project. We have discussed the importance of developing the EBCD approach by: strengthening the provision of training and resources to enable practitioners to implement EBCD; highlighting the advantages and limitations of adaptations of the approach seen to date; encouraging reflection on the likely nature and scale of change that EBCD brings about; and the design of strategies to rigorously evaluate the impact and cost-effectiveness of the approach. To continue the conversations necessary to meet these objectives, we therefore make two invitations. Firstly, to those healthcare staff who have led, are leading, or are interested in leading EBCD projects to: continue to feed back on the strengths and weaknesses of the online toolkit and provide further case studies for others to learn from; share their experiences and reflections via the LinkedIn group; and collaborate on formal evaluations of the approach. And secondly, to design practitioners to share their thoughts on what needs to be borne in mind when using design expertise in the healthcare sector, what their particular form of expertise brings to well-established quality improvement processes in large and complex healthcare organisations, and the nature of the critical thinking needed to increase the impact of co-design approaches in this setting.

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ANNEX 2 SURVEY QUESTIONNAIRE

Path 1 – for respondents who had been involved in one or more EBCD projects

About you

1. Please tell us about you

Your full name	<input type="text"/>
Your role/jobtitle	<input type="text"/>
Organisation	<input type="text"/>
Country	<input type="text"/>

2. Please tick the description that best applies to you

- ☐ I have been involved in one or more Experience-based Co-design project(s)
- ☐ I am planning to become involved in an Experience-based Co-design project for the first time

About your EBCD project

3. When did your first Experience-based Co-design project start? Please specify year.

4. Is this Experience-based Co-design project:

- ☐ Completed ☐ Ongoing, at an advanced stage ☐ Ongoing, at an early stage

5. If this project has been completed, how long did it take from start to finish?

- ☐ Less than 6 months ☐ Between 6 months and 1 year ☐ Longer than 1 year ☐ Not applicable

6. In which clinical service/s was Experience-based Co-design implemented? Please list all, if more than one.

7. Are you involved in any further Experience-based Co-design projects?

- ☐ Yes ☐ No

8. If 'yes', please provide brief details below

The King's Fund EBCD Toolkit

9. Did you use the online King's Fund Toolkit (<http://www.kingsfund.org.uk/projects/point-care/ebcd>) for any of your Experience-based Co-design projects?

- ☐ Yes, extensively
☐ Yes, bits of it
☐ I was aware of it but did not use it
☐ I was not aware of it
☐ I am not sure

10. If you were "aware of it but did not use it", please broadly explain why

The King's Fund EBCD Toolkit - continued

11. How would you rate the King's Fund toolkit?

Not helpful at all

Somewhat unhelpful

Neither helpful nor unhelpful

Somewhat helpful

Very helpful

☐☐☐☐☐

12. The King's Fund Toolkit is divided into 16 sections. Which sections were most helpful to you? Please tick up to three from the following list.

- ☐ Section 1: Is Experience-based Co-design for you?
☐ Section 2: What is Experience-based Co-design?
☐ Section 3: Making the case to staff
☐ Section 4: Developing your project plan
☐ Section 5: Carrying out observations
☐ Section 6: Engaging and interviewing staff
☐ Section 7: Recruiting patients
☐ Section 8: Interviewing and filming patients
☐ Section 9: Editing the film
☐ Section 10: Running the staff feedback event
☐ Section 11: Running the patient feedback event
☐ Section 12: Running the joint patient-staff event
☐ Section 13: Running the co-design groups
☐ Section 14: Reporting, evaluating and celebrating success
☐ Section 15: Adapting the approach to your budget
☐ Section 16: What next for your EBCD project?
☐ None of the above

The King's Fund EBCD Toolkit (continued)

13. What did you find most useful about the King's Fund Toolkit?

14. Do you have any suggestions for improving the King's Fund Toolkit?

Training and advice

15. How did you first hear about Experience-based Co-design? (Please tick all that apply)

- ☐ Internet search
- ☐ Word of mouth/a colleague told me
- ☐ In a meeting at the healthcare organisation where I work
- ☐ At a conference (please specify below)
- ☐ Through an email referring to the King's Fund Toolkit
- ☐ I read about it
- ☐ I can't remember
- ☐ Other

If 'other', please specify

16. Did you contact any organisation/individual for advice on Experience-based Co-design? (Please tick all that apply)

- ☐ Yes, NHS Institute for Innovation and Improvement
- ☐ Yes, King's Fund
- ☐ Yes, other (please specify in comment box below)
- ☐ No

Other (please specify)

Training and advice (continued)

17. Who else worked on the project with you?

18. Did you or other members of your project team have any training in Experience-based Co-design? Please provide details in the box below.

The EBCD project

19. Which elements of Experience-based Co-design did you implement in your project?

	Yes	No
Non-participant observation	<input type="radio"/>	<input type="radio"/>
Staff interviews	<input type="radio"/>	<input type="radio"/>
Patient interviews	<input type="radio"/>	<input type="radio"/>
Patients and staff co-design meeting	<input type="radio"/>	<input type="radio"/>
Small co-design groups to work on improvement priorities	<input type="radio"/>	<input type="radio"/>
Celebration/review event	<input type="radio"/>	<input type="radio"/>

Please provide brief details of any adaptations you made to the approach

20. Please tell us more about your patient and staff interviews, if you used them. (Please tick all that apply)

	Audio-recorded	Video-recorded	Followed by feedback event	Not followed by feedback event	Not applicable
Patient interviews	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff interviews	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Evaluation and dissemination

21. Did you carry out an evaluation of your Experience-based Co-design project?

- ☐ Yes, an evaluation was carried out
- ☐ No, the project was not evaluated

If 'Yes', how was the project evaluated (methods and measures) and by whom?

22. Did you produce any reports from the project? (Please tick all that apply)

- ☐ Yes, a paper has been published (please provide citation/s in box below)
- ☐ Yes, a report is available online (please provide link in box below)
- ☐ Yes, a report was made available for internal reference
- ☐ No, findings were only discussed at meetings
- ☐ No, the project is ongoing and findings are not yet available

Please add any references or links to existing publications/report in the box below

23. Have you given conference presentations relating to your EBCD project?

- ☐ Yes
- ☐ No

If 'Yes', please provide further details

Strengths and weaknesses

24. Thinking about your project/s, what were the strengths of the Experience-based Co-design approach? (Please tick all that apply)

- ☐ It really engaged patients/carers
- ☐ It really engaged staff
- ☐ It allowed discussion of difficult topics in a supportive environment
- ☐ It led to clear improvement priorities
- ☐ It really made a difference to the way we do things around here

Please add any other comments you may have

25. Thinking about your project/s, what were the weaknesses of the Experience-based co-design approach? (Please tick all that apply)

- ☐ It took too long
- ☐ It was too complicated
- ☐ It cost too much
- ☐ Staff did not engage with the project
- ☐ Patients/carers did not engage with the project

Please add any other comments you may have

Funding and resources

26. How was the project funded? (Please tick all that apply)

- ☐ Project was funded by external funder (e.g. research council; R&D programme - please specify in the box below)
- ☐ Project was funded by health service organisation in which it was implemented
- ☐ Project was funded by a charity
- ☐ Project was funded by a different body (please specify in the box below)
- ☐ Project was funded jointly by different organisations (please specify in the box below)
- ☐ Project was not funded

Please provide any further details

27. Do you know how much it cost to carry out the project? If you do, please provide details in the box below.

- ☐ Yes ☐ No

Please provide further details

Funding and resources - continued

28. Did your project involve any external researchers and/or facilitators? If it did, please provide further details in the box below.

- ☐ Yes ☐ No

Please provide further details

29. How much of your time did you dedicate to the project, personally?

- ☐ Less than 10% WTE (less than half a day per week)
- ☐ Between 11 and 20% WTE (half a day to a day per week)
- ☐ Between 21 and 40% WTE (one to two days per week)
- ☐ Between 41 and 60% WTE (two to three days per week)
- ☐ Between 61 and 80% WTE (three to four days per week)
- ☐ More than 80% WTE (more than four days per week)

Other (please specify)

Future EBCD projects

30. Do you personally plan to use Experience-based Co-design again in the future?

- ☐ Yes, I have definite plans to use it again (please provide details in the box below)
☐ Yes, but I have no definite plans
☐ I do not plan to use it myself but I know of colleagues who will (please provide details in the box below)
☐ I am not sure as to whether I would use this approach again in the future
☐ No, I will not use the approach again

Please comment further, if you wish

31. Do you know - directly - of any colleagues who have used Experience-based Co-design? (Please tick all that apply)

- ☐ Yes, I know colleague/s who have used this approach in the healthcare organisation where I work (please provide details in the box below)
☐ Yes, I know of colleague/s who have used this approach in a different healthcare organisation (please provide details in the box below)
☐ Yes, I know of colleague/s who are planning to use this approach but I do not know where they work (please provide details in the box below)
☐ No, I do not know of any colleague/s who have used or plan to use this approach

Please provide further details

Future EBCD projects (continued)

32. If you were to use Experience-based Co-design again, which of the following elements would you carry out?

	Yes	No	Not sure
Non-participant observation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staff interviews and feedback event	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient interviews and feedback event	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Filming of patient interviews	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients and staff event	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Small co-design groups to work on improvement priorities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Celebration and review event	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please provide details of any modifications you would introduce based on what you learnt from using the approach previously

33. If you were to use Experience-based Co-design again, would you use the King's Fund Toolkit?

- ☐ Yes
☐ No
☐ Not sure

Please provide further details, if you wish

Further contact

34. Would you or a member of your team be willing to discuss your use of/plans to use Experience-based Co-design further with us over the telephone/Skype?

☐ Yes

☐ No, I would rather not be contacted

If 'yes', please provide contact details

35. Would you like/be able to be involved in a meeting to share experiences with/plans for EBCD in London in October 2013?

☐ Yes

☐ No

Please provide contact details if not already specified above

36. Would you like to receive an electronic (.pdf) copy of the findings from this study?

☐ Yes, please

☐ No, thanks

Thank you very much for your help!

If you have any questions, or wish to speak to a member of the survey team, please contact:

Glenn Robert: glenn.robert@kcl.ac.uk, Tel. +44(0)7788313167

Sara Donetto: sara.donetto@kcl.ac.uk, Tel. +44(0)2078483791

Thank you again for your help.

Path 2 – for respondents who were planning to become involved in an EBCD project for the first time

About you

1. Please tell us about you

Your full name	<input type="text"/>
Your role/jobtitle	<input type="text"/>
Organisation	<input type="text"/>
Country	<input type="text"/>

2. Please tick the description that best applies to you

- ☐ I have been involved in one or more Experience-based Co-design project(s)
- ☐ I am planning to become involved in an Experience-based Co-design project for the first time

Your plans

3. Please tick the statement that best describes your plans

- ☐ I am currently thinking of carrying out an Experience-based Co-design project in the future and I have concrete plans in progress (please provide details in the box below)
- ☐ I am currently thinking of carrying out an Experience-based Co-design project in the future but I have no concrete plans yet / I am unsure as to how to proceed (please provide details in the box below)
- ☐ I have thought about carrying out an Experience-based Co-design project but I abandoned the idea (please provide details in the box below)

Please provide further details

4. Please provide a brief description of the Experience-based Co-design project/s you are/were planning to carry out

5. How did you first hear about Experience-based Co-design? (Please tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Internet search | <input type="checkbox"/> Through an email referring to the King's Fund Toolkit |
| <input type="checkbox"/> Word of mouth/a colleague told me | <input type="checkbox"/> I read about it |
| <input type="checkbox"/> In a meeting at the healthcare organisation where I work | <input type="checkbox"/> I can't remember |
| <input type="checkbox"/> At a conference (please specify below) | |

Other (please specify)

Your plans - continued

6. Do you plan to use the online King's Fund Toolkit (<http://www.kingsfund.org.uk/projects/point-care/ebcd>) for your Experience-based Co-design project?

- ☐ Yes, extensively
- ☐ Yes, bits of it
- ☐ I am aware of it but do not plan to use it
- ☐ I was not aware of it
- ☐ I am not sure
- ☐ Not applicable

Please provide further details

7. Do you plan to contact any organisation/individual for training or advice on Experience-based Co-design? (Please tick all that apply)

- ☐ Yes, NHS Institute for Innovation and Improvement
- ☐ Yes, King's Fund
- ☐ Yes, other (please specify in comment box below)
- ☐ No
- ☐ Not applicable

Other (please specify)

Further contact

8. Would you or a member of your team be willing to discuss your use of/plans to use Experience-based Co-design further with us over the telephone/Skype?

- ☐ Yes ☐ No, I would rather not be contacted

If 'yes', please provide contact details

9. Would you like/be able to be involved in a meeting to share experiences with/plans for EBCD in London in October 2013?

- ☐ Yes ☐ No

Please provide contact details if not already specified above

10. Would you like to receive an electronic (.pdf) copy of the findings from this study?

- ☐ Yes, please
- ☐ No, thanks

Thank you very much for your help!

If you have any questions, or wish to speak to a member of the survey team, please contact:

Glenn Robert: glenn.robert@kcl.ac.uk, Tel. +44(0)7788313167
Sara Donetto: sara.donetto@kcl.ac.uk, Tel. +44(0)2078483791

Thank you again for your help.

ANNEX 3 TELEPHONE INTERVIEWS: SEMI-STRUCTURED INTERVIEW SCHEDULE

Research study: **“Experience-based Co-design: where are we now?”**

Thank you for taking part in this interview and for completing the online survey earlier in the year. We are now in the process of writing up the survey results. The aim of today’s interview is to explore some of the central themes emerging from our analysis of the survey data and to gather further detail about the EBCD project you were involved in as well as to explore your experience with specific aspects of the project. All participants in the survey and interviews will receive a copy of the full report.

Before we begin,

- Stress confidentiality
- Introduce tape recorder
- Take oral consent

BACKGROUND

Can you tell me a bit about your role and the service/organisation you work at? How long have you been in this post?

EXPERIENCE OF CARE

(Before interview, check aspects of EBCD used in respondents’ projects).

We are interested in finding out a bit more about what you consider ‘valid’ or ‘appropriate’ ways of capturing and understanding patient and staff experience... what strategies were used in your project to capture and understand patient and staff experience?

Did you use films as part of your project? Why/Why not? How was film used? Would you use film if you were doing it again?

Did you use non-participant observation? Why/why not? How was this used? Would you use non-participant observation if you were doing it again?

Any other methods used?

CO-DESIGN

What does co-design mean to you? What types of activities/ processes do you consider to be co-design?

We would like some further detail about the co-design component of your project – how patients & staff worked together to decide upon and implement the changes that were made. Could you tell us a bit more about how you went about this? What worked/ did not work?

How many co-design teams were there working on specific areas of improvement? Were they all mixed patient/staff teams? How were the co-design teams supported?

How did you choose your approach to co-design?

How long (roughly) did the co-design phase last (i.e. from identifying the improvements to actually implementing them)?

ENGAGING STAFF

What were the strengths and challenges of involving service staff in your EBCD project?

Do you think the project had a significant impact on the staff involved? In what way?

EVALUATION

(Check survey responses to check if evaluation was done).

If yes, what was the specific purpose of the evaluation exercise? How was the evaluation conducted?
Can we have a copy?

If no, how do you know what impact the project had?

TAILORING AND ADAPTING

(Before interview, check adaptations made to respondent's EBCD project). Could you please tell me a bit more about the adaptations you made to your project? How did it differ from the way EBCD has previously been done?

What was your rationale for adapting the approach?

How did these adaptations make a difference to the impact of the approach do you think?

COST

(Before interview, check whether respondents were aware of costs of their project). If yes, what were the costs involved with your EBCD project? If not, how much do you think it cost? (approximately)

How were budgets calculated? What funding sources were explored?

In your view was the cost worth it?

ORGANISATIONAL DEVELOPMENT

Why was the service area chosen? How was your project planned? Was there a scoping exercise done within the clinical area?

How did using EBCD impact the organisation as a whole? Did it spread to other services?

Finally, what would you do the same/differently next time?

Many thanks for your time

ANNEX 4 WAYS OF CAPTURING AND UNDERSTANDING PATIENT EXPERIENCES

Interviews/patient stories (face to face and/or telephone interviews), audio recorded and/or filmed	<p><i>We started off with phase one which is a story gathering phase... because we really wanted to be able to understand the stories and... get to what the real issues were. (Interview#14)</i></p> <p><i>I think that what we captured, where we were able to use it [film] to feed back, it was extremely powerful. It told the story so much better than we could have done in text or presentation, it really brought it to life. (Interview#10)</i></p> <p><i>For me it really did bring home to me the power of the patient voice, and how them videos can pull at people's heart strings a bit... to actually get staff on board to help you. (Interview#13)</i></p>
Patient diaries	<p><i>We started off with a number of things; one was a diary... on the first appointment we asked them to start keeping a diary of what their experiences were like. It was looking at the whole system really, what was the GP experience like, what was it like when they first interacted with the Trust, how did they feel when they came in, now they've recovered what do they wish that they'd known, and areas like that...(Interview#09)</i></p>
Video booth/diary room	<p><i>We just set up a diary room and it was a much more relaxed environment for people to go in and share their experiences. (Interview#02)</i></p>
Disposable camera	<p><i>[We] want to look at the admissions procedure as part of the EBD work...and so they asked the people who are going to be admitted to have a disposable camera and to document what they felt about admission. (Interview#10)</i></p>
Archived film	<p><i>Because it was the accelerated experienced based co-design we used the archives from the Health Talk Online. The archives were already there, but for me they really did reflect what I and my colleagues had been hearing in clinic anyway, so I thought they were valid and reliable. (Interview#08)</i></p>
Non-participant observation	<p><i>We had someone sitting in the waiting room and just observing... and that was quite an interesting event, it was just someone that clearly had much more time to sit and look at the things that we would never really see. And I think that's a good thing to sort of pop into projects as well. (Interview#04)</i></p>
Group dialogue/workshops/issue-based workshops	<p><i>One of the problems with cancer, and a lot of those more serious conditions is that people feel very isolated. So we actually tried group research methods, and they worked a lot better because people naturally shared their experiences and we learned a lot more much more quickly. (Interview#17)</i></p> <p><i>Some of our workshops combined the experience and the design into one workshop, because it's an effort to get people together and things like that. We then used those specific workshops to delve more into the experience and then actually come up with either principles or things that we wanted to work on. (Interview#01)</i></p>

Emotional mapping exercises	<i>We started out with interviews and from that data I did emotional maps with the situations that the [participants] had mentioned in the interviews. And under the situation I put the feelings that they had told me about...then we invited them to come and see the maps...together [we] looked at the emotional map, and they could add things or we could take away things that they didn't want to have there. And I think the group dialogue was very good for them to come up with new things. (Interview#16)</i>
Creating personas	<i>We asked them just to create some characters... the personas that were developed, you could recognise people's stories... Some of them made models, some of them did drawings. We actually provided a worksheet which had faces on it for emotions and it had emotional words... people ended up cutting it up. They used the words and placed them around the body and they cut out the faces. (Interview#06)</i>
Survey	<p><i>We actually did some experienced based surveys...That was for patients and family, and we adapted the NHS one...everyone who came through either clinic on clinic days was given a survey which they could either complete at the time or post. (Interview#01)</i></p> <p><i>We've always done questionnaires, but we find that questionnaires are open to interpretation and also open to a broad brushstroke, whereas sometimes it's not until you have that one-to-one focus group that you absolutely get the sense of reality. (Interview#15)</i></p> <p><i>We had some open dialogue boxes on the survey so although they could circle one of the six emotions that we picked, they were adding other emotions in for us, other feelings, and that was good. I definitely would use surveys again. I think it just adds another dimension really. And also, it gives you a much wider capture because you can only interview so many patients, so you get a much wider capture. (Interview#05)</i></p>

ANNEX 5 WAYS OF CAPTURING AND UNDERSTANDING STAFF EXPERIENCES

Interviews/staff stories (face to face and/or telephone interviews)	<i>I interviewed staff... it gave us a real insight into their experiences, but also got them to focus on what they thought it was like for the patients and relatives, which I think was quite interesting because I don't think they had necessarily had the opportunity or the time to think about that before. (Interview#08)</i>
Audio recorded and/or filmed	<i>They [staff] are important too...and I think sometimes they don't realise how important they are. I think if that can be shared with other members of staff... that's a very powerful tool...it's actually got a bit of credibility with the other members of staff. So if you can see them visually I think it's a far more powerful tool... And every one fed back, you know, seeing those images was just so powerful. (Interview#04)</i>
Email communication/informal feedback	<p><i>When I'm going round the wards I'm asking the staff if they feel inclined, to send me an email and tell me about their first experience with this process. Good or bad... With the process that we're introducing, to try and get their feedback on what their thoughts were. And that I think sometimes if they're prompted and there's no prompting and there's no face to face they're clear just to write what they want. And that's actually provided some feedback for me that I wouldn't have got otherwise. (Interview#04)</i></p> <p><i>We did do some meetings with people but I wouldn't say it wasn't sort of formal interviews and transcribing, it was just more to gather some background information and to find out what sort of issues there were from their perspective (Interview#06)</i></p>
Video booth	<i>We gave them the flexibility... the first time we went into some of the units we had what we call a video booth, which really it was like the sort of thing you would have your passport photos taken in, and it was quite a structured environment. (Interview#02)</i>
Diary room	<i>We filmed [staff], we got like a diary room chair, they had to sit in the chair and say what did they feel when they were watching the patients. (Interview#09)</i>
Focus groups/workshops	<p><i>We conducted focus groups... to get the perspective from staff... I think our information was very rich and we were confident in what we learnt from the story... (Interview#14)</i></p> <p><i>A staff workshop day to capture experience. Broke into groups to map the work that they did, and then they talked about the pros and cons, the things that held them back, the things that challenged them, the things that made it work...(Interview#10)</i></p>
Non-participant observation	<i>You're going to the place where the work is actually taking place, and you are understanding not only the staff side of it, but you can talk to the people who are currently in that process at this minute. So they've not had time to reflect or think about it, it's happening real time, so you're getting some immediate feedback. I think that's the invaluable bit. (Interview#09)</i>
Survey	<i>The survey asked staff if they felt they were confident in aspects of care, if they knew enough about this particular, if they had enough knowledge to be able</i>

	<i>to cope with the care, or manage the care of a person in negative care setting. It was a very simplistic thing just to try and gauge where they were at that point in time. I think they had their use, but I think I'm beginning to see that you have to be really structured in the types of questions that you ask because they are so easy to be misinterpreted. (Interview#04)</i>
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