

Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement

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Declared competing interests of authors: none

Published February 2014

DOI: 10.3310/hsdr02040

Scientific summary

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Health Services and Delivery Research 2014; Vol. 2: No. 4

DOI: 10.3310/hsdr02040

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Background

Measuring, understanding and improving patients' experiences is important to health care systems worldwide. To provide high quality care, health care organisations need – among other things – to draw on the experiences of those who have used services at first hand but there is debate about the best methods for gathering and understanding patient experiences and how to then use them to improve care.

Experience-based co-design (EBCD), a narrative-based, participatory action research approach, marks a significant contribution to involving patients in quality improvement in health care. There is evidence that narratives can engage care providers in reflecting upon how services could be improved. Patients' accounts can suggest priorities and solutions that may not occur to people immersed in day-to-day service delivery. EBCD projects typically last 12 months, beginning with a 6-month 'discovery' phase, in which local patients and staff are interviewed about their experiences of a service. The patient narratives are video-recorded, and from these a 'trigger film' is developed to stimulate discussion between staff and patients about potential quality improvements. An important characteristic of the EBCD discovery phase is that it draws on rigorous, narrative-based research with a broad sample of users, rather than relying on a single representative on a committee or a few anecdotes. Equally important is the subsequent co-design phase, in which patients, families and staff come together as equal partners in small working groups to set priorities for quality improvement, and to design and implement change.

Independent evaluations of recent EBCD projects in both the UK and Australia have shown EBCD to be effective in making specific quality improvements to particular services as well as wider improvements within – and sometimes between – health care organisations. However, the discovery phase before quality improvement can begin is felt by staff to be lengthy and costly, and has been reported as a barrier to adoption of the approach. Undertaking 5–6 months of qualitative interviewing on each pathway in each hospital is seen as impractical.

The Health Experiences Research Group (HERG) at the University of Oxford collects and analyses video- and audio-recorded interviews with people about their experiences of illness. It now has a national archive of around 3000 interviews, covering over 80 different conditions or topics. Selected extracts from these interviews are disseminated for a lay audience on www.healthtalkonline.org. In this study we set out to investigate whether or not this archive of interviews could replace the need for discovery interviews with local patients.

Objectives

Our objective was to use a national video and audio archive of patient experience narratives to develop, test and evaluate a rapid, patient-centred service improvement approach ('accelerated experience-based co-design' or AEBCD). To achieve this we:

- identified common themes arising from the University of Oxford's national patient narrative archive in two exemplar care pathways (lung cancer and intensive care)
- used these analyses to create 'trigger films' illustrating these themes (which will be made publicly available via The King's Fund's EBCD toolkit website)
- tested these films alongside existing EBCD techniques in two hospital organisations in the two pathways

- observed what happened in both pathways in each hospital
- collected data on the costs of this accelerated approach compared with traditional EBCD.

By using national rather than local patient interviews, we aimed to halve the overall cycle from 12 to 6 months. Our evaluation focused on the following research questions:

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

Methods

Design

The intervention was an adapted form of EBCD, using national trigger films, a shorter time frame and local service improvement facilitators. An ethnographic process evaluation was conducted, including observations, interviews, questionnaires, reflective diaries, and service improvement logs. We also analysed cost data and documents, including previous EBCD evaluation reports.

Setting

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

Participants

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

Intervention

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

Evaluation

The ethnographic evaluation aimed to observe the implementation process in both pathways in each trust. The evaluation used multiple data sources, including observation, interviews, questionnaires, reflective diaries, service improvement logs, documentary analysis and administrative data on costs. Ethics approval was obtained by proportionate review from National Research Ethics Service Committee North West – Greater Manchester West, REC reference number: 11/NW/0653.

Data collection took place between November 2011 and December 2012. A total of 155 hours of observations took place, including facilitator training sessions, patient/staff events, co-design meetings, and

project advisory group and core group meetings. Thirty interviews and two group interviews were conducted. Maximum variation sampling was used to ensure a spread of different types of participants. Interviews, training sessions and events were audio-recorded and transcribed. Observations and brief conversations were recorded as field notes. Twenty-two reflective diaries were completed. One hundred and sixty-six evaluation forms were completed after co-design meetings. Twelve previous EBCD evaluation reports, books and papers were analysed to inform comparison with EBCD practice.

Transcripts, documents, field notes and e-mails were entered into NVivo (QSR International, Warrington, UK). Coding was based on the seven research questions, as well as emerging themes. Data were tabulated using framework analysis. Data analysis involved the following stages: familiarisation with AEBCD and EBCD data; thematic analysis of qualitative data; tabulation and graphical representation of quantitative questionnaire and quality improvement data; and indexing and developing a comparative framework based on key themes. Members of the project team refined the analysis at a 2-day workshop.

Results

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

Conclusions

Accelerated experience-based co-design delivered an accelerated version of EBCD, generating a comparable set of quality improvement activities. The national film acted as an effective trigger to the co-design process. Based on the results of the evaluation, AEBCD offers a rigorous and effective patient-centred quality improvement approach.

Implications for health care

Identifying local facilitators

As in any quality improvement initiative, we observed the central importance of the facilitator role. The two hospitals chose their own approaches to local facilitation. One appointed a single person – with a clinical background in one pathway but not the other – to facilitate both pathways. The other appointed a different person from within each pathway: one from a clinical background and one from a service management role. Other hospitals might choose to use a central quality improvement team. There are advantages to both approaches; each hospital will need to assess its own resources and preferred approach, and this may differ from one pathway or service area to the next.

Training and support for facilitators

The facilitators in our study were given training and encouraged to use The King's Fund's online EBCD toolkit. However, they reported that when they began work on the first pathway (intensive care), they

would have liked more opportunities to learn directly from the experience of other facilitators who had already used the approach, particularly around practical methods of supporting the co-design groups.

Three practice implications arise from this. First, we have expanded The King's Fund's toolkit to include reflections from the facilitators in this study and other participants, so that future facilitators can benefit from their learning. Second, we suggest there would be benefits in providing more opportunities for EBCD and AEBCD facilitators to network, to cascade learning and provide a continuing source of information and support. Third, we identify a need for more regularly available face-to-face training alongside the EBCD toolkit. This could be self-financing.

Generating new trigger films

For this study, we conducted secondary analysis and produced two trigger films from interview collections in the HERG archive on lung cancer and intensive care. At the time of writing, the archive contains collections on over 80 different conditions and topics, and 8–10 collections are added per year.

There are several options for how we might create further trigger films from this archive. In addition to costing this work into future HERG grant proposals, there is potential to:

- use a forthcoming 'scrapbook' feature on the Healthtalkonline website, enabling site users to create collections of clips for specific purposes such as EBCD and share these with others
- encourage local patients and carers in future EBCD projects to search the website for clips they feel capture issues important to them and which they would like to show to local staff – extending co-design principles into a 'co-discovery' approach, empowering patients to create their own trigger films
- work with future EBCD projects collecting new local patient discovery interviews to share these online (through Healthtalkonline or The King's Fund's EBCD toolkit).

These various potential solutions may require further research (see *Implications for research*, below).

The fundamental importance of co-design

As the intervention progressed, it became apparent to the research team that the extent of agreement or identification with the content of the films was not the central issue. It is important to remember that the purpose of the films is to 'trigger' discussion. In traditional EBCD, too, they are only the start of a process of sharing ideas and concerns, and then working together to redesign care. If the national trigger films are sufficient to initiate such conversations, then local specifics can be brought into discussion along the way, and even disagreement with the content can generate fruitful discussion. But the element of the intervention that has left both staff and patients feeling energised and empowered is the direct encounter with each other, the active partnership in co-design groups to achieve change, and the sense of tangible results.

When staff – as they did in this study – volunteer the information that this is the first time in 20 years that they have really talked to patients in this way or that it is the most rewarding thing they have ever done in their careers, the full potential of EBCD to reconnect staff with their fundamental values of care and compassion is striking. Patients, too, report a different level of appreciation for staff, a belief that they will be listened to and that change is possible, and a renewed sense of trust in local NHS services.

The fact that both hospitals have decided to invest staff time and funding to adopt co-design more widely in their organisations demonstrates their view of its value as a quality improvement intervention benefiting the whole organisation.

Implications for research

Accelerated experience-based co-design as designed for this study has reduced the cost of using co-design. Nevertheless, there may be scope for further economies in developing trigger films.

In particular, we have identified the following research questions:

- Would it be equally effective to develop trigger films from clips already published on Healthtalkonline, rather than a new secondary analysis of full interview transcripts from the Oxford archive?
- What would the advantages and disadvantages be of involving patients in 'co-discovery' as well as 'co-design' – selecting and presenting material for their own trigger films?
- Would films developed from patient discovery interviews for one local EBCD project work in another local setting?

Additionally, HERG is experimenting with secondary analysis of the archive for other audiences and purposes, such as commissioning and National Institute for Health and Care Excellence quality standards. An as yet unexplored question is:

- To what extent can different policy and practice audiences make use of common secondary analyses and trigger films, or do they require separate tailored resources?

One question that has emerged from our study but which our study design was not intended to address is:

- Does AEBCD bring less personal therapeutic benefit to individual patients involved than EBCD?

There is limited evidence on the costs and cost-effectiveness of patient-centred quality improvement. This study has for the first time provided detailed analysis of EBCD costs. The next stage is to understand more about cost-effectiveness, prompting the following research questions:

- How should we measure the relative cost-effectiveness of different patient-centred quality improvement initiatives?
- Does patient-centred quality improvement translate into measurable longer-term changes in patient satisfaction rates and the quantity and content of patient ratings on sites such as NHS Choices and Patient Opinion?
- Does patient-centred quality improvement impact on clinical and organisational outcomes such as length of stay, infection rates and medication errors?
- Does patient-centred quality improvement lead to improved staff well-being?

Funding

The National Institute for Health Research Health Services and Delivery Research programme.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

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The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 10/1009/14. The contractual start date was in September 2011. The final report began editorial review in March 2013 and was accepted for publication in July 2013. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

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