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

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Co-investigators	Listed in appendix 1
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Testing accelerated experience-based co-design: using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement

1. Aims/Objectives:

Aim:

To use a national video and audio archive of over 2,000 recently collected patient experience narratives to help develop, test and evaluate a rapid patient-centred service improvement approach ('Accelerated experience-based co-design').

Our objectives are to:

- Identify common themes arising from the University of Oxford's national patient narrative archive in each of two exemplar care pathways
- Use these analyses to create 'trigger films' illustrating these themes which can be accessed and used by all NHS acute trusts
- Test these films alongside techniques that are part of the existing experience-based co-design (EBCD) approach to stimulate service improvement work led by staff, patients and carers in two provider organisations (Royal Brompton and Harefield NHS Foundation Trust and Royal Berkshire NHS Foundation Trust) in each of the two pathways
- Observe what happens in both pathways in each trust and evaluate the acceptability to patients and staff – and the impact - of this adapted approach to patient-centred service improvement
- Measure the costs of this accelerated approach compared with traditional EBCD
- Make recommendations for quality improvement practice in the NHS.

A traditional EBCD cycle typically takes around 12 months' work in each trust to complete one pathway. In the accelerated version, we propose to halve the cycle to 6 months per pathway.

2. Background:

Improving patient experience is a key aim for the NHS. The new White Paper, 'Equity and Excellence: Liberating the NHS', emphasises 'putting patients and the public first', and ensuring that the way care and information are provided reflect what patients themselves think is important (Secretary of State for Health, 2010). To do this the NHS needs to draw on the narratives and experiences of those who have used and observed healthcare services at first hand, but there is considerable debate about the best methods for gathering and understanding patient experience information and then using it to improving the experience. Narratives are a powerful way to engage care

providers at a deep emotional level in thinking how services could be improved (Greenhalgh et al 2005). Patient experiences can suggest priorities and solutions that may not occur to people who are immersed in service delivery (Locock 2001; Iles & Sutherland 2001). Many NHS organisations are now successfully experimenting with ways of gathering user views and using them to improve services. However, it is important that such work is based on rigorous research with a broad sample of users and a full range of different perspectives, rather than relying on a single representative on a committee or the collection of a few anecdotes (Daly et al. 2007).

This project draws on and seeks to combine two existing initiatives that recognise the value of narratives: a national collection of 2,000 video and audio recorded narrative interviews with UK service users and a participatory action research approach to service improvement using patient experiences, Experience-Based Co-Design (EBCD).

The Health Experiences Research Group at the University of Oxford collects and analyses video and audio-recorded interviews with people about their experiences of illness. It now has an innovative national archive of over 2,000 interviews, all collected between 2000 and 2010, and covering 55 different conditions, which provides a unique source of evidence on patient experiences and priorities. The interviews are approved for use in research, teaching, publication, broadcasting and dissemination on the award-winning Healthtalkonline website, one of the first health information sources to meet the Department of Health's new Information Standard. The interviews are increasingly used in teaching health professionals, and to inform health policy – for example, NICE guideline development now frequently incorporates evidence from Healthtalkonline, and the recent GMC guidance on end of life care drew on a specially comissioned analysis of interviews from the University of Oxford archive. The Oxford end of life care analysis has recently been compared with local interviews conducted by one PCT on end of life care. This showed that very few themes were identified locally that could not have been anticipated from the national dataset (Calabrese, 2010). The University of Oxford archive thus has enormous potential as an evidence base of patients' experiences to support service change.

EBCD (Bate & Robert 2007a) has been implemented in collaboration with patients, families and staff in service improvement efforts in various settings, care pathways and countries. Integral to the approach is that patient, carer and staff experiences are used systematically to co-design and improve services. To date, this has involved an intensive local diagnostic phase, using rigorous qualitative research, including video or audio-recorded narrative interviews in which participants are invited to recount their experiences using a story-telling approach, highlighting concerns and priorities and identifying 'touchpoints' (key interaction points) along their journey. Trigger films based on these experiences are then used, firstly to enable patients and carers to share and discuss their experiences with each other, and then to stimulate discussion between local staff and patients, who can then jointly identify actions to bring about systematic, sustainable improvements. Building a coalition for change between staff and patients is central. The approach is

being widely used in the UK, Australia and the Netherlands; the King's Fund is currently evaluating it as one of two improvement approaches in the Point of Care programme. There is evidence from independent evaluations that EBCD can bring about changes which significantly impact on patient experience, and are acceptable to a range of service users (Piper & Iedema, 2010).

Whilst EBCD may be effective, the diagnostic phase is undoubtedly lengthy and costly. Replicating 5 months of qualitative interviewing on each pathway in each trust is impractical at a time of recession. EBCD and the Oxford group use very similar narrative interview techniques. We will therefore develop and test a new accelerated form of EBCD by using the University of Oxford archive to provide the majority of the evidence on patients' experiences and thereby scale up EBCD more efficiently across different settings. What we do not know is how far using national rather than local narratives will affect local credibility and buy-in, and whether anything else may need to be done locally to supplement national data. This project seeks to investigate the question of whether Accelerated EBCD can provide a rigorous and less costly alternative to conventional EBCD.

3. Need:

There is a clear and consistent high-level policy imperative to improve patient experience. But understanding what really matters to patients and how best to translate the policy rhetoric into real practical change remains a challenge. This project is supported by the newly formed Thames Valley Health Innovation and Education Cluster (TVHIEC) in South Central SHA. TVHIEC was funded to deliver an innovative skills development programme driven by a strong patient and client focus. The lead applicant (Louise Locock) is a member of the TVHIEC Partnership Board and its patient and public involvement sub-group, and will be the main link between the project and the HIEC.

Care which is redesigned around patient needs and preferences can improve:

- acceptability (e.g switching care to a more convenient location)
- effectiveness (e.g. increased adherence to treatment regimes)
- cost-effectiveness (e.g. combining previously separate activities or appointments)
- targeting and equity (e.g. by challenging perceptions of particular patient groups, or by by understanding and tackling what motivates some groups to resist or decline care)
- quality of life (by developing care that responds to issues patients think are important).

Two provider organisations have already signed up as partners in the project. The Director of Nursing at the Royal Brompton & Harefield NHS Foundation Trust (Caroline Shuldham) had already approached the Health Experiences Research Group to enquire about possible ways of using the interview archive to support service change. The trust was enthusiastic to discover the application was planned and that they could become a partner. Since this,

another trust within South Central, the Royal Berkshire NHS Foundation Trust, has committed to become a partner. This project comes at a time when trusts are facing severe financial difficulties, and offers a valuable way to keep the quality of patient experience at the heart of trust priorities despite cuts in staffing and other resources. An advisory group of patients will be established in each local site for each pathway.

4. Methods:

a. Setting

The two partner provider sites have been selected partly on the basis of senior clinical managerial commitment to the project, which has been shown to be an important enabling factor for change (Dopson et al, 2001). Royal Brompton and Harefield's early enthusiasm determined the selection of pathways relevant to their specialist services, and in discussion with Royal Berkshire we have settled on two exemplars: intensive care and lung cancer. Our co-applicants Caroline Shuldham and Jonathan Fielden bring invaluable expertise in cardiac and intensive care nursing, and intensive care medicine respectively.

These two pathways offer interesting potential contrasts. In intensive care, patients themselves are often unable to take part in decision making at certain stages and may have difficulties communicating, yet their utter dependence on staff is a key feature of their experience. Family carers have a different perspective, having to take responsibility for many decisions and interactions with staff, but often feeling helpless and potentially excluded from a specialised, high tech, automated world. The Health Experiences Research Group archive includes interviews with patients themselves (40 interviews) and with family carers and close friends (38 interviews), so we can identify touchpoints from both groups. By contrast lung cancer (45 interviews) offers a more traditional pathway through symptom recognition (and delays in consultation), investigations, diagnosis, treatment choices, recovery, short and long term management and medication. Given the often poor prognosis for lung cancer, it may also involve coping with progression and potentially end of life care. The Research Group also has an interview collection on end of life care which can shed additional light on this aspect of the pathway.

In recruiting a second provider site, we sought a trust with a more general hospital profile, within the catchment area of the Thames Valley Health Innovation and Education Cluster, again with senior clinical managerial commitment to the project (Royal Berkshire). The contrast between a tertiary specialist provider and a general hospital will help demonstrate whether the approach is equally acceptable and practicable in both types of setting.

b. Design

The evaluation will be a process evaluation and cost analysis, building on existing evidence already available about the effectiveness of patient-led service improvement approaches. Whilst we will document improvement

activities that take place as a result of the intervention in each trust, our aim is not to evaluate EBCD in itself. Our starting-point is that it has already been shown to be an effective approach, and our aim with the evaluation is rather to demonstrate whether an accelerated version of it is a workable, cost-effective and acceptable alternative.

The evaluation will be led by an organisational ethnographer, supervised by Annette Boaz, using a longitudinal comparative case study design and observational methods which are well suited to the study of complex change. (Pettigrew, Ferlie, Mckee 1997; Fitzgerald and Dopson 2010). In effect we will have four 'cases': two different pathways in each of two trusts. The ethnographer will be in post throughout the project and will thus be able to observe the set-up period during which the Oxford research group will be creating the trigger films, as well as the implementation phase. The evaluation will use multiple data sources, including observation, interviews, documentary analysis and administrative data on costs. Members of the project team will also be encouraged to keep reflective diaries of their experiences.

c. Study participants and recruitment

All staff who work in the four participating services will be invited to participate in the project and a sample of these staff will be invited to participate in the staff evaluation interviews. All patients over the age of 18 and under the age of 65 who receive care in the four participating services during the 6 months period of fieldwork and who can give informed consent will be invited to participate in the project. A sample of these patients and/or the carers will be invited to participate in the patient/carer evaluation interviews. The role of carers in this action research project will be solely determined by the individual patients; we are unable to specify at this stage how many carers may or may not be involved as it is for the patients to decide whether they wish to invite carers to become involved by accompanying them to the workshop.

There are no exclusion criteria with regards to staff working in the four participating services. All patients who are unwilling or unable to give informed consent (as identified by staff) will be excluded (including for example patients with dementia or learning disabilities); any patients under the age of 18 or over the age of 65 will be excluded.

In each of the two participating NHS organisations a 'site captain' has been identified and will be asked to assist the research team in arranging staff interviews and other meetings (as necessary). The site captain is the senior individual in each organisation who has discussed the research in detail with the research team and agreed to participate as a coinvestigator (see appendix 1). In each service the site captain has helped identify a local service improvement facilitator who will take day-to-day responsibility for the project locally including the identification and recruitment of participants.

Potential staff interviewees will be identified through discussions between the local site captain, facilitator and other relevant managers of the selected services. A sample of patients who are cared for in each of the services will be

identified through a combination of (a) discussions between the local facilitator and staff in each of the services, and (b) as a result of the nonparticipant ethnographic observation of routine care undertaken by the local facilitator. Ethnographic observation (a) of routine care will take place in appropriate settings depending on the specific service (for example, on wards or in outpatient clinics) and (b) at the AEBCD meetings; the presence of the observer will be renegotiated with both staff and patients as required.

Staff will be sent a covering letter in the internal post from the research team, together with the staff information sheet, and an outline of the appropriate semi−structured interview schedule will be sent (or delivered by hand) to each potential interviewee at least 24 hours prior to the time of the proposed interview. The staff information sheet and covering letter both make clear that participation is entirely voluntary and that staff can withdraw at any time without giving a reason.

Patients will be invited to participate either through (a) a letter from the research team sent to patient's home address by the NHS organisation or by hand together with a patient information sheet, and outline of the semi−structured interview schedule to be used at least seven days prior to proposed interview taking place. The participant information sheet and covering letter both make clear that participation is entirely voluntary and that patients can withdraw at any time without giving a reason; or (b) informal approach during observation of AEBCD meeting and leaving the patient with a patient information sheet and asking whether they agree to being telephoned by research team to arrange interview at a later date.

Relevant member(s) of staff will be informed by researcher of his/her wish to observe routine daytoday activities. Patients who may be directly observed will be verbally informed of presence of observer and the purpose of the research.

Informed consent will be obtained by the local service improvement facilitator in each of the two NHS Trusts prior to any individual participating in the project. Staff and patients will be given an information sheet describing the study and asked to complete the attached consent form.

The number of staff and patients from each pathway are intended to be sufficient to give a broad range of views as to issues influencing staff wellbeing and patient experiences, and to allow the research team to be able to qualitatively assess the impact of the Accelerated Experience-Based Co-Design approach. Typically this will mean 12-15 patients/carers and 12-15 staff members from each of the four services participating.

Patients & carers will be offered to have their travel expenses to meetings and/or an evaluation interview reimbursed. Lunch and refreshments will be provided at meetings.

d. Data collection

The intervention will not require substantial new data collection in the first

instance, as we will be using secondary analysis of our existing interview archive to elicit the important themes for people experiencing lung cancer and intensive care. We will use a thematic analysis approach; the data will be coded using techniques of constant comparison and deviant case analysis, and looking specifically for 'touchpoints' in the care pathway. Trigger films will be created on the basis of this analysis.

In each trust, the local facilitators will use a combination of observation and one-to-one interviews with staff to learn about their own experiences of the 2 care pathways and their views and expectations about local patients' experiences. Findings will be presented and discussed at a staff feedback meeting.

One of our key research questions is how well local users feel national narratives capture themes important to their experience, and whether anything else needs to be done to supplement them at local level. At this point, therefore, the trigger films will be shown to two specially convened focus group workshops of local patients and carers with experience of intensive care and lung cancer. Participants will discuss how far the analysis of the national archive has captured their own priorities and experiences, and whether there are specific additional issues they would like to raise about local services. Depending on the outcome of these discussions, some further local data collection may be undertaken by the service improvement team in each partner provider site to supplement the national dataset, with support and advice from Glenn Robert. This could include new interviews or further focus groups. Patients in intensive care are often given diaries recording details of their stay, and these could also contribute to local analysis, for example.

As the intervention progresses, local staff and patients/carers will be working together to map existing care pathways, and make changes agreed as part of the co-design process. Their records of their activities will be used both for their own service improvement processes and to feed into the evaluation (see below). All workshops of staff and patients will be filmed (with consent) to help document the process of the intervention and to help answer our evaluation questions about the acceptability and credibility of using nationally collected patient experience data. We will also use a brief post-event survey to gauge participant reactions to the style and content of the workshops. This informs the unfolding intervention but can also feed into the evaluation.

e. Data analysis

Observations and brief conversations will be recorded as field notes; interviews will be transcribed for framework analysis (Ritchie and Spencer, 2004). Framework analysis is a widely used matrix based approach to organising and analysing qualitative data. It can be used to generate descriptive accounts, identify themes and develop explanatory theories.

The cost analysis will draw on administrative records from previous EBCD projects to develop a list of cost items associated with EBCD. Detailed records will be completed throughout the study period of costs associated with

AEBCD. In particular, any costs associated with additional activities conducted at the local level to supplement the national narratives will be recorded. Data on staff and non-staff costs and time input will be systematically collected through micro-costing procedures and compared to data collected in existing EBCD evaluations (including Jocelyn Cornwell's work on the Point of Care Programme, a soon to be completed evaluation of a large-scale EBCD project in two London teaching hospitals), with the support of a health economist and local trust staff. We will keep a careful record of how much time is committed to the intervention by staff at different levels in each trust as part of this comparison. Those involved in the co-design process will also contribute to the evaluation their record of service improvement activities undertaken and changes made.

At all stages of the evaluation, the ethnographer will be collecting data to address our research questions:

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

5. Contribution of existing research:

EBCD and other patient-centred improvement techniques have already been widely adopted in practice settings. This research will add to our collective knowledge about how best to ensure patient perspectives are at the heart of service change, and to ensure this is done as quickly and cost-effectively as possible.

The archive of patient interviews collected by the Health Experiences Research Group has added significantly to our understanding of patient experiences across a range of conditions; their dissemination through the Healthtalkonline website already provides a resource for patients themselves, and around 80 peer review publications in social science and clinical journals have reached an academic and clinical audience. The interviews are also used in clinical education in a number of universities, and professional training packages have been produced in partnership with NHS Education South Central. Recently, a secondary analysis on end of life care has contributed to the new GMC guidance on end of life care. But there is considerable untapped potential to use this archive more effectively to support service change and to

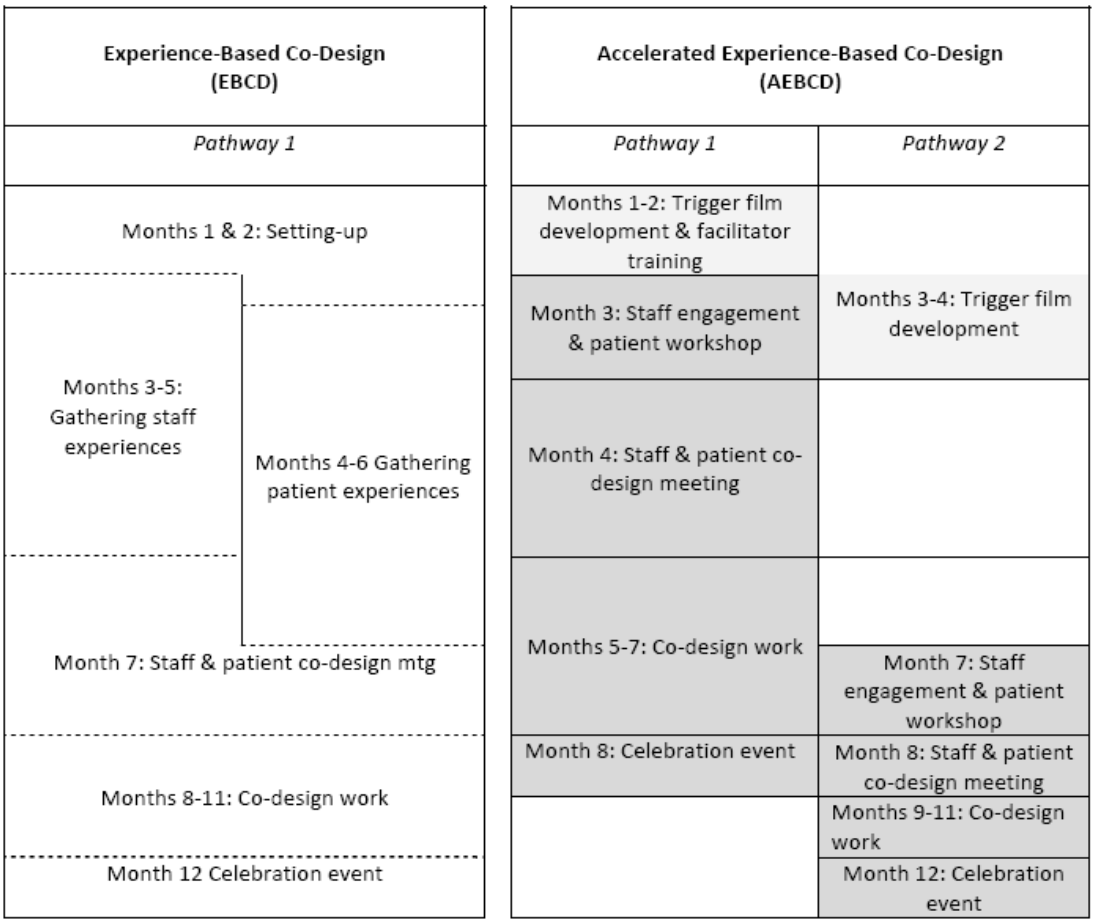
inform policy-makers, managers and practising clinicians, providing a high standard of qualitative research evidence and reducing the need to replicate local research into patient experience. Both EBCD and the work of the Health Experiences Research Group are fundamentally concerned with drawing on people's accounts of their experiences to identify commonalities and potential improvements, as well as providing a channel for patients' voices in what it is like to have their condition. All the health experiences interviews are copyrighted for use in teaching and learning, as well as research, publication and the website.

For many participants, knowing that their experience may be used to help improve things for other people is an important motivator. Each local provider site will have patients directly involved in helping us explore the important research question of how far nationally derived trigger films resonate with local patient concerns and what additional work needs to be done locally to identify additional issues. They will then be engaged in co-designing services with staff, and monitoring the results. The researchers involved in the bid all have a track-record of working at the interface between research and practice, and take seriously the need for knowledge transfer.

Within TVHIEC, the results of the project will feed directly into future plans for innovative staff development, and will be extended to other conditions and sites. The TVHIEC user panel will be closely involved throughout the project. Nationally, the HIECs are working together to share learning and new approaches. We anticipate that the project would result in the production of a wide range of trigger films and a supporting service redesign methodology which would be available to other provider organisations through a subscriber website, in partnership with TVHIEC and the DIPEx Charity, which runs the Healthtalkonline website. We propose to hold two major dissemination events, one led by TVHIEC and one led by the King's Fund, to ensure findings and recommendations are widely shared. We will of course also publish in peer review journals and present at national conferences, especially the SDO joint annual conference with the Health Services Research Network and the Organisational Behaviour in Health Care Symposium.

6. Plan of Investigation:

As noted above, our accelerated EBCD model is expected to halve the amount of time spent per care pathway in each trust. The figure below provides an overview of how our proposed timetable compares to a traditional EBCD cycle.



MONTHS 1-2

A core group (chaired by the Chief Investigator, Dr Louise Locock) and advisory group (chaired by Catherine O'Sullivan, Thames Valley HIEC Chair) will be established. In each site, a local service improvement facilitator will be identified and trained (by Glenn Robert) to lead the intervention. The ethnographer will begin observations, collate costing data from previous EBCD studies and put in place systems for recording economic data for AEBCD. The Oxford-based researcher will conduct secondary analysis of relevant interviews from the Health Experiences Research Group's archive and develop a 'trigger film' around the first pathway.

MONTHS 3-4

The first trigger film will be shown at a workshop with a local patient and carer advisory group in each site, to test for resonance with their concerns and identify specific local service issues not adequately captured in the about their own experiences of the first care pathway and their views and expectations about local patients' experiences. Findings will be presented and discussed at a staff feedback meeting in each site. In month 4, the local facilitators (supported by Glenn Robert) will lead a workshop on the first pathway, including the trigger film, with patients, carers and staff to begin the process of co-design. Participants will share their experiences of giving and receiving care and identify priorities for improvement. The ethnographer will conduct

interviews and observations during this period. Meanwhile, the Oxford-based researcher will continue secondary analysis of relevant interviews from the archive to develop a ‘trigger film’ around the second pathway.

MONTHS 5-7

Co-design subgroups for pathway one will be established to respond to the agreed priorities for improvement; these may occur anywhere along the patient pathway. The ethnographer will continue observations and interviews, and monitor co-design activities and impact. Staff and non-staff cost data will be collected. Once the co-design groups for pathway one are established, the local facilitators will start work in month 7 on the second pathway, conducting staff observation and engagement, and showing the trigger film to a workshop of local patients. In month 4, the local facilitators (supported by Glenn Robert) will lead a workshop on the first pathway, including the trigger film, with patients, carers and staff to begin the process of co-design. Staff and patients will share their experiences of giving and receiving care and identify priorities for improvement. Evaluation fieldwork will continue throughout.

MONTH 8

Patients, carers and staff involved in co-design in each trust around the first pathway will conclude their activities and come together as a group to celebrate and share achievements and lessons from the collaboration. The local facilitators (supported by Glenn Robert) will lead a workshop in each site on the second pathway, including the trigger film, with patients, carers and staff to begin the process of co-design.

MONTHS 9-11

Co-design subgroups for pathway two will be established in each site to take forward their own work programme, supported by their local facilitator. Evaluation fieldwork continues.

MONTH 12

Those involved in co-design around the second pathway will conclude their activities and come together for a celebration event in each trust.

MONTHS 13-15

Complete evaluation fieldwork and analysis (ethnographer and Annette Boaz), collect any further health economics data on costs, compare with existing cost data on EBCD. Make recommendations to TVHIEC.

MONTHS16-18

Dissemination workshops with the King's Fund and TVHIEC. Preparation of final report and peer review articles. Trigger films and supporting service

redesign methodology will be made available through a subscriber website.

7. Ethics

Assurances will be given to participants that all discussions and interviews are entirely confidential. All interviews and field notes will be coded for anonymity and stored in a locked filing cabinet. Participants identities will be protected through anonymisation or pseudonymisation of data as required. It is intended that anonymous abstracts from the interviews may be used in publications arising from this research but any materials will not be used without the full permission of participants.

The study team will ensure that it adheres to the Research Governance Framework with respect to confidentiality. Any communication by email will not identify participants and their identities will be protected by identity codes. Publication of direct quotations from research participants may be included in project outputs, such as the final report, conference presentations and articles submitted to peer reviewed journals. However, all identifying information about participants will be removed to ensure their anonymity and to protect their identity.

8. Insurance

The University of Oxford maintains Public Liability and Professional Liability insurance which will operate in this respect

9. Project Management:

Funding has been included to enable the Thames Valley HIEC to provide project management support throughout the project. The new HIEC Programme Manager, Richard Freeman, will take on this role and will liaise with team members in different institutions to ensure each stage of the project is completed on time. We will establish a core group and a project advisory group at the outset of the project.

The project manager will convene regular meetings of both groups. The core group will comprise the coapplicants and project manager, and will be chaired by Louise Locock as Principal Investigator. The project advisory group will comprise staff, patient and carer representatives from both our partner provider sites, representatives from the Department of Health Public Engagement and Patient Experience directorate, and core group members. It will be chaired by Cathy O'Sullivan, Interim Director of the HIEC.

The individual components of the project will be managed on a day-to-day basis by Louise Locock (analysis of interview archive and production of trigger films), Glenn Robert (development and implementation of accelerated EBCD intervention), and Annette Boaz (evaluation). Glenn Robert will work closely with service improvement facilitators at Royal Brompton and Harefield and Royal Berkshire Hospitals, who will also have day-to-day managerial support within their trusts from Caroline Shuldham and Jonathan Fielden.

The investigators will be involved in reviewing drafts of the manuscripts, abstracts, press releases and any other publications arising from the study. authors will acknowledge that the study was funded by the NIHR SDO programme. Authorship will be determined in accordance with the ICMJE guidelines and other contributors will be acknowledged.

10. Service users/public involvement:

Both EBCD and the work of the University of Oxford Health Experiences Research Group are fundamentally concerned with giving patients (and family carers) a voice as the experts in what it is like to have their condition or face a particular health situation. The project team do not believe that including patients as participants in research is sufficient in terms of PPI and we have used many other ways of involving patients and public, for example in guiding our research strategy, as members of steering groups, in helping to appoint new researchers, disseminating results, co-authoring articles and commenting on conceptual frameworks.
The Health Experiences Research Group has been primarily focused on using in-depth patient narratives to support other people going through a similar condition or facing similar health choices, through www.healthtalkonline.org, as well as providing insights for personal professional practice. EBCD has used similar narratives to stimulate service improvement. Both use in-depth interviewing, with an initial unstructured invitation to 'tell me your story', to give people space to elaborate on what matters to them, not driven by a professional or organisational agenda. Both use video recording to enable patients to give vivid and direct testimony. A key principle at the heart of both these existing workstreams is that we should base our understanding of what matters to patients and carers on rigorously conducted and analysed research with a broad range of people, rather than relying on a few anecdotes or the involvement of one or two representatives on daunting NHS committees. At the same time, this project seeks to address the problem that trying to replicate such research in each locality for each pathway is not only expensive but very demanding of patients and carers who may be facing an extremely difficult and emotional time in their lives. We have recently compared themes emerging from the University of Oxford archive on what matters to patients in end of life care with interviews on the same topic done locally by one PCT. This demonstrated that very few themes were identified locally that could not have been identified from the national dataset (Calabrese, 2010). We therefore feel confident that the archive has great potential to be used as an evidence base of patient experiences to support service change.

Once the trigger films have been developed, Glenn Robert will work with our two provider partner organisations and their service improvement teams to identify a group of local patients and carers with an interest in intensive care and lung cancer. Stage one of their involvement will be a focus group workshop at which they will view the trigger films and then discuss whether the films adequately capture the things that matter to them, and whether there are specific additional issues they would like to raise about local services. Depending on the outcome of these discussions, some further local data

collection may be undertaken by the service improvement team to supplement the national dataset. Stage two will be to convene co-design working groups of both staff and patients/carers, to agree and implement specific service redesign projects. Building a coalition between staff and service users is central to this process. The project advisory group will include patient and carer representatives from both our partner provider sites.

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This protocol refers to independent research commissioned by the National Institute for Health Research (NIHR). Any views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health.

APPENDIX 1 CO-INVESTIGATORS

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