Detailed project description – Locock 14/156/04

Full title of project

Understanding how frontline staff use patient experience data for service improvement - an exploratory case study evaluation and national survey

Summary of Research

Aims:
To explore and analyse how NHS frontline teams use different types of patient experience data for improvement.
To develop a practical toolkit for the NHS on strategies for making patient experience data more convincing, credible and useful for frontline teams and Trusts.

Background:
Patient experience - alongside patient safety and clinical effectiveness - is a key component of quality of care. It is important both as an end in itself, and because positive patient experience has been shown to be correlated with other clinical and organisational outcomes. Improving patient experience is thus a priority for the NHS, which has led the way in developing measures of patient experience such as the NHS Inpatient Survey. There is a considerable body of quantitative and qualitative evidence on what matters to patients and how they experience care. However, whilst the Inpatient Survey shows small incremental improvements in some aspects of experience, the pace of change remains slow on some of the most important questions for person-centred care. There is a need to move beyond collecting patient experience data to using it to improve care, but the evidence for the most effective ways to do this remains weak. We know little about how frontline staff make sense of or contest the data, what supports or hinders them in making person-centred improvements and what motivates staff - and patients and families - to get involved in improvement work.

Methods:
This proposal combines quantitative and qualitative components, involving analysis of existing national survey data, a new survey of NHS Trust patient experience leads, followed by a formative and exploratory case study evaluation of how frontline staff in 6 sites use patient experience data for improvement, with baseline and follow-up surveys of the experience of medical patients in each site.

We will analyse existing data from the NHS Adult Inpatient Survey, NHS Staff Survey questions on patient experience, Friends and Family Test (FFT) response rates, and Patient Opinion usage data. The FFT analysis is limited to response rates because variability in collection methods has been shown to skew the response data to the actual question - making meaningful comparisons between organisations impossible. The chief nurse or other designated patient experience lead in all NHS acute Trusts will be surveyed about what data they currently collect, how often, and whether and how the data are used for improvement.

Results will be used to put together an assessment of trusts' current performance on and operational practice around patient experience. Data from the NHS inpatient survey and NHS staff survey will provide key evidence on existing levels of performance; meanwhile our survey of designated patient experience leads and analysis of engagement with Patient Opinion will provide evidence about how trusts approach and respond to issues relating to patient experience and person-centred care. Taken together, these will inform selection of 6 case study sites (3 high performing and 3 with more mixed performance). From each site a frontline general medical ward team will be invited to work with us. We already have expressions of interest from a number of trusts (further detail available on request); feedback so far suggests participation would be regarded not only as feasible but also attractive (see also Research Plan section 2.2. below).

We will conduct a baseline patient experience survey in the 6 wards, plus in-depth interviews. The 6 frontline teams, including patients, will join a face-to-face learning community hosted by the Oxford Health Experiences Institute. Different approaches to learning from and improving patient experience

will be presented with facilitated discussion of the issues involved. Teams will be supported to develop and implement their own interventions and measures. We will observe what happens in each site using focused ethnographic case study data collection and analysis. Emerging findings from the case studies will be shared formatively with frontline teams to help them identify problems and maximise their chances of effective person-centred service improvement. A follow-up repeat survey of medical ward patients' experiences will be conducted.

Outputs:
Practical toolkit for the NHS on using patient experience data (disseminated online and through NHS England).

Background and Rationale

Patient experience - alongside patient safety and clinical effectiveness - is a key component of quality of care. Improving patient experience is thus a priority for the NHS, which has led the way in developing measures of patient experience such as the NHS Inpatient Survey. Patients have a right to expect care that is compassionate, respectful and convenient, as well as safe and effective. As co-applicants on this proposal have argued, collecting data about patient experience, while important, is not enough: the data need to be used for improvement, and it is arguably unethical to ask patients to comment on their experience if these comments are going to be ignored. We need to act on the evidence we already have (14).

Recent evidence suggests positive associations between patient experience, patient safety and clinical effectiveness for a wide range of disease areas, and between patient experience and self-rated and objectively measured health outcomes (15, 16). At a time of global recession, there is a risk that better quality patient experience may be seen as a luxury rather than a top priority. But the apparent conflict between maintaining tight financial control and providing good patient experience may not be as stark as is sometimes supposed.

Firstly, we know that many of the things which matter most to patients are relational, for example paying attention to dignity, courtesy and kindness. These are rarely resource-intensive. Secondly, there is growing evidence linking person-centred care with decreased mortality and lower hospital-acquired infection rates, as well as a range of other organizational goals such as reduced malpractice claims, lower operating costs, increased market share and better staff retention and morale. Hospital organisations where care is person-centred are reported to have shorter lengths of stay and fewer medication errors and adverse events (17-22, 30-31).

Yet despite these good reasons for paying close attention to experience data, the quality of patient experience remains a concern, and recent problems (for example at Mid Staffordshire NHS Trust and Winterbourne View) have suggested there is a long way to go in developing care which is genuinely and consistently person-centred at all levels of the organisation.

Whilst the NHS Inpatient Survey shows small incremental improvements in some aspects of experience, including information provision, communication with staff, hospital cleanliness, and privacy (9), the pace of change remains slow on some of the most important questions for person-centred care (9-10). Only 54% of patients feel 'definitely' as involved as they want to be in decisions about their care, and only 50% feel doctors and nurses 'definitely' gave their families all the information they needed (9). Furthermore, 79% of patients said they had not been asked during their stay in hospital to comment on the quality of their care. Although this was an improvement on the 86% saying they had not been asked in 2012, it nonetheless indicates a substantial missed opportunity to learn from patients.

Dr Foster Intelligent Board research into how Trust boards use patient experience data found substantial variation in what data were collected but more importantly in the degree to which they were effectively analysed and used to improve services (11). Strikingly, the research found that over 95% of the time, hospital boards' minuted response to patient experience reports was to note the report but take no further action. Examples where patient experience data was used to spark debate and action were rare, as were examples of non-executive directors challenging performance on patient experience measures. Understanding how to use qualitative evidence, including narrative and

observational data, as well as numerical evidence can be challenging (11-13), and this is undoubtedly one of the key areas where Trusts need support and training. Meanwhile, they also face an explosion of online sources of patient experience data (e.g. NHS Choices, Care Connect, Patient Opinion and Twitter) with little guidance on how to use them.

There is already good evidence of what matters most to many patients and how they experience services (23); the gap is how Trusts can respond to available local and national data and use them to improve care (10-11; 14; 23-25). As the original call for proposals 14/156 points out, there is a lack of evidence about how organisations can move beyond collecting patient experience data to using it for improvement, and how best to use different types of quantitative and qualitative data. We know remarkably little about how frontline staff make sense of or contest patient experience data, what supports or hinders them in making person-centred improvements and what motivates staff - and patients and families - to get involved in improvement work.

While quality improvement programmes and techniques abound, few are strongly evidence-based and few take seriously the need to involve patients and families throughout the process. A few studies have provided some evidence of promising approaches. For example, Reeves, West and Barron (26) showed that facilitated feedback of survey findings at ward team level has potential to improve patient experience scores. PI Locock recently reported positive findings to HS&DR on the use of nationally collected narrative data alongside local observational data in experience-based co-design to generate improvements (27), However, there remains insufficient evidence to say which types of data or quality improvement approaches are more or less likely to be useful with frontline teams in making care more person-centred in different contexts and settings, and how well these are received.

Some studies have identified a mismatch between managerial expectations and how engaged and supported clinicians and other frontline team members feel to make improvements. For example in a survey of hospital clinicians Rozenblum et al (28) found that 90.4% of clinicians believed improving patient satisfaction with their experience of hospitalisation was achievable, but only 9.2% thought their department had a structured plan to do so. Friedberg at al (29) found physicians' use of patient experience reports was variable, and importantly that little training in communication skills was provided, even though improving communication with patients was thought to be fundamental to the provision of person-centred care. These findings suggest that not enough is being done to make patient experience data available in a useful and credible way to clinical staff, and empower them – with positive organisational support – to see improving patient experience as a priority that they can lead on.

Our 'theory of change' is that high level organisational support is necessary but not sufficient for person-centred service improvement; that many experiences which matter most to patients happen in frontline encounters; and that bottom-up engagement in person-centred improvement (as opposed to top-down managerially driven initiatives) can be motivating for frontline staff (27), consistent with evidence that patient experience seems to be better in wards with motivated staff (30).

This proposal will use a formative and exploratory case study approach to understand how frontline staff can be supported and encouraged to work with patient experience evidence, and subsequently to develop a practical toolkit for the NHS. It builds on a body of internationally recognised patient experience work to which members of this research team have made a major contribution, as highlighted in the commissioning brief.

It should of course be noted that the *process* of gathering and analysing data on patient experiences at local level can itself be part of building momentum for their use in improvement; in reality collecting narratives and using them for improvement are closely linked as part of the same process of cultural change in approaches such as experience-based co-design (35). Frontline teams involved in this study will be invited to engage in local data collection, and comparisons between cases looking at how this is approached and what influence it has will form part of our ethnographic observations. However, given the nature of the research call, our focus is primarily on using rather than collecting experience evidence.

Why this research is needed now

As noted above, improving patient experience is currently a high priority for the NHS but change has been slow and examples of failure to listen to patients remain all too common. In order to give patient experience greater prominence and policy drive, 'Patient Experience' is now a separate 'domain' in the NHS Outcomes Framework, and has a dedicated NHS England team. NHS England has expressly supported the need to move beyond data collection to action, but needs the support of the research community to generate evidence on how best to achieve this.

This current high policy profile has stimulated many actions and initiatives at local level, and there is thus a context of awareness of the importance of patient experience and willingness to engage, which should facilitate recruitment of case study sites. We need to capitalise on this enthusiasm and this burst of (sometimes poorly directed and un-evidence-based) activity to learn lessons about what works in which contexts and share learning across the NHS. Given the unstable and evolving nature of many of the interventions being tried out within trusts at the moment, trial methods are unlikely to be feasible; flexible case study methods with realist evaluation are more likely to be informative and workable.

The interdisciplinary Oxford Health Experiences Institute (HEXI) and individual research team members already work with NHS England on understanding and using patient experience. HEXI currently holds a small ESRC grant to run a workshop series on patient experience data for NHS England, the Care Quality Commission (CQC), Monitor and other national policy bodies. The workshop content is being designed currently and will feed into the design of the learning community sessions. This application builds on a strong expressed policy and management need for the work proposed, and we are confident we have the relationships to recruit study sites and disseminate findings effectively for maximum impact across the NHS.

In sum, there is substantial evidence from policy and practice that supporting frontline teams to a) appreciate the range of data available and how they might use them, b) design and implement their own plans for person-centred service improvement and c) share ideas with colleagues from other trusts within a dedicated learning space is likely to maximise the chances of successful implementation, and enable us to generate useful and timely guidance for the NHS.

Aims and objectives

Aims:

To explore and analyse how NHS frontline teams use different types of patient experience data for improvement.

To develop a practical toolkit for the NHS on strategies for making patient experience data more convincing, credible and useful for frontline teams and Trusts.

To achieve these aims, we will

- analyse existing data related to patients' experiences of care and conduct a new national survey of NHS Trust patient experience leads
- work with 6 frontline general medical ward teams, using a formative and exploratory case study approach

Objectives:

Phase 1: To analyse the national picture and select case studies

1.1 Analyse existing data from the NHS Adult Inpatient Survey; NHS Staff Survey questions on patient experience; Friends and Family Test; Patient Opinion

1.2 Conduct new national online survey of patient experience leads in all acute Trusts covering types of data collected; level and frequency of collection; use of results for quality improvement, including barriers and facilitators

1.3 Combine evidence from these different sources to investigate how trusts a) perform on these measures and b) organise themselves to work on patient experience and respond to patient experience data. The aim is to gather summary-level data from these sources into a matrix to identify high, average and poor performing trusts – in other words to see which trusts consistently demonstrate high performance and strong engagement with patient experience, those which do not, and those where no clear pattern emerges. This stage will inform selection of 6 case study sites (3 high performing and 3 with more mixed performance). Each site will identify a frontline general medical ward team to work with us.

Phase 2: To observe organisational responses to using patient experience data for service improvement in the 6 medical wards case studies

2.1 Conduct a baseline survey of patients from the 6 wards, using questions drawn from existing surveys, followed by 8 in-depth interviews per ward.

2.2 Create a learning community for the 6 ward teams, including patients and family members. Approaches to learning from and improving patient experience will be presented with facilitated discussion of issues involved. Teams will develop and implement their own interventions and measures

2.3 Observe what happens in each site using focused ethnographic methods; how staff make sense of (or contest) different types of data; what supports/hinders them in making person-centred improvements. Ongoing support will be provided to teams through a 'virtual campus' led by the research team with further feedback and discussion; two further face-to-face meetings; support from an improvement scientist; and improvement support from NHS England, building on previous experience and learning from the Cancer Patient Experience programme. Emerging findings will be shared formatively with teams to help them identify problems and maximise their chances of effective person-centred service improvement.

2.4 Repeat local survey of medical ward patients' experiences, and compare with baseline and with national Trust-level survey findings.

Phase 3. To disseminate findings to support NHS Trusts

3.1 Produce toolkit for NHS with a range of strategies for using patient experience data, summarising best evidence, likely organisational and cultural conditions for successful implementation, and how to involve patients and families in the process.

3.2 Disseminate both online and through national seminars co-organised with NHS England; social media; conference presentations; academic publications

Research Plan/methods

The study design combines quantitative and qualitative components, involving analysis of existing national survey data, a new survey of NHS Trust patient experience leads, followed by a formative and exploratory case study evaluation of how frontline staff in 6 medical wards use patient experience data for improvement, with baseline and follow-up surveys of the experience of medical patients in each site.

We will adopt a realist evaluation perspective in conducting the case study data collection and analysis. Our 'theory of change' is that high level organisational support is necessary but not sufficient for person-centred service improvement, and that many experiences which matter most to patients are relational and attitudinal, and happen in frontline encounters. We hypothesise that real

engagement in understanding experiences and working towards person-centred improvement can be motivating and rewarding for frontline staff, reconnecting them with the values of patient care and compassion which initially inspired them to work in healthcare (27). This is consistent with evidence that patient experience seems to be better in wards with motivated staff (30).

Phase 1. Analysing national patient experience data collection and use and case study selection

Analysis of existing data and a survey of patient experience leads will be carried out with the aim of a) setting the national scene around the collection and use of patient experience data and b) selecting the six case study sites (acute trusts) to take part in this research.

1.1 Secondary analysis of existing national patient data (months 1-4)

Secondary analysis of existing patient and staff experience data collections will be carried out. The datasets to be used, the specific variables targeted within these, and how we will analyse the data are detailed below:

- The NHS Adult Inpatient Survey 2014. The survey contains 70 questions plus demographics. Items will be selected using the following approach, which emphasises data availability and utility:
    - First the research team will disqualify questions based on low variation in scores between trusts. The focus will be on questions where there is the largest variance against the mean – ie those that most efficiently discriminate between trusts.
    - Next the research team will disqualify questions that have high levels of missing data, including those relevant only to a subset of respondents.
    - Following this, items from the remaining question set will be selected to correspond to the four areas of care covered in the survey of medical patients (see section 2.1 of the Detailed Project Description). Four 'domain' composites will be created with constituent items identified on face value to correspond to the four areas of care.
    - Finally, we will test the internal consistency of each of the four domains using Cronbach's alpha; where composites fail to reach a threshold level of alpha = 0.6, we will review the performance of the composite with individual items removed. If the removal of a single item cannot raise the internal consistency of each domain to an acceptable level, we will discard the use of composites and instead review results for each selected question individually.
- NHS Staff Survey 2014. Three domain composites will be calculated from questions related to training and development, standards of care and patient/service user feedback. As with the inpatient survey data, we will test each domain for internal consistency using Cronbach's alpha. Should groups fail to meet a threshold level of alpha = 0.6, we will discard the use of composites and instead review results for each selected question individually. The questions within each domain are:
    1. Training and development
        - Q1f 'Have you had any training, learning or development in how to deliver a good patient / service user experience?'
        - Q2c 'My training, learning and development has helped me to deliver a better patient / service user experience.'
    2. Standards of care
        - Q9a 'I am satisfied with the quality of care I give to patients / service users.'
        - Q9b 'I feel that my role makes a difference to patients / service users.'
        - Q9c 'I am able to deliver the patient care I aspire to.'
        - Q12d 'If a friend or relative needed treatment I would be happy with the standard of care provided by this organisation.'
    3. Patient/service user feedback
        - Q13a 'Is patient / service user experience feedback collected within your directorate/ department? (e.g. Friends and Family Test, patient surveys etc.)'

    - Q13b 'I receive regular updates on patient / service user experience feedback in my directorate / department (e.g. via line managers or communications teams).'
    - Q13c 'Feedback from patients / service users is used to make informed decisions within my directorate / department.'
- NHS Friends and Family Test (FFT). Trust level response rates to the NHS Friends and Family Test carried out on inpatient wards will be reviewed. The data from the three most recently available months will be used and given the earliest start date of September 2015 for this research it is likely that the data will cover three months in late Summer/Autumn 2015. Three months will provide a good level of data whilst also providing a balance in case of any abnormalities in data. The data will be downloaded from the NHS Friends and Family Test website hosted by NHS England. The FFT response rates will provide useful contextual data, helping to give a sense of the importance organisations place on collecting feedback via the FFT, when viewed alongside other measures.
- Patient Opinion; measures will include the number of staff registered, proportion of stories read, proportion of stories responded to and/or actioned. As with the FFT data, these are intended to be contextual rather than evaluative measures.

1.2 New survey of trust patient experience leads (months 1-4)

Concurrently, an online survey of patient experience leads in all acute trusts will be carried out to get an understanding of the national picture regarding the collection and use of patient experience data. The survey will cover topics such as:

- Types of data collected and from what patient groups
- Who leads the process
- Level and frequency of data collections
- How data is reported and who the different audiences are
- How data are used for service improvement projects
- Any facilitators and barriers or challenges they identify to using the data to improve services

This survey will provide important national contextual information on the collection, use, and impact of patient experience data on service provision. It will also provide additional information useful for selecting our case study sites. For example, we will use the data to see how potential case study sites compare to other organisations in terms of collections and improvement practices.

1.3 Overarching analysis and case study selection (months 4-5)

Results from both the existing national data and the new survey of patient experience leads will be used to construct a matrix allowing us to select the 6 case study sites; general medical wards in 6 trusts. General wards have been selected on the basis that they will offer a more generalisable context than specialist wards.

An average score for the two national survey collections (the NHS Staff Survey 2014 and the NHS Adult Inpatient Survey 2014) will be computed and calculated for each trust. This will allow for comparisons across trusts. Trusts will then be sorted by the average score to identify the top and bottom thirds of the distribution. By looking at the contextual information within each of the distribution bands we will be able to explore trusts' use and engagement with patient experience further. This contextual data comes from the NHS Friends and Family Test response rate information, web metrics from Patient Opinion, and responses from the survey of patient experience leads. This information taken together will be reviewed by the project team to determine those trusts to target for participation. We will seek to include as case studies two trusts each in the top, middle, and bottom thirds of the distribution based on survey results. Moreover, we will seek to ensure that the case study sites include a mix of those that appear, based on the contextual variables, to be focusing relatively more or less than others on patient experience information.

The work in Phase 1 will be led by co-applicants from the Picker Institute, with support from the Nuffield Department of Population Health. We already know of two trusts keen to collaborate, one high and one lower performing, and their positive views about the feasibility of the study helped shape our initial outline. The Picker Institute has now identified several trusts with wards that would in principle be keen to take part (further details on request), subject to meeting criteria for selection in phase 1. The degree of support and expertise offered by the research team is seen as an attractive opportunity, including by trusts who are struggling to address patient experience and would value help, as those who already performing at a high level and are keen to develop. The Picker Institute has extensive links with trusts and experience of recruiting sites for research, and PI Locock has recent experience of successfully recruiting sites for an intensive period of quality improvement work in her HS&DR study on accelerated experience-based co-design (27). We are confident that recruitment will not be an issue, particularly given the strong policy imperative for trusts to take action on improving experience. (See also 2.2 'establishing and supporting a learning community' below).

Phase 2. Local case studies

2.1 Baseline survey of medical patients' experiences (months 6-8)

Case studies will begin with a baseline postal experience survey of medical patients over 3 months. The questionnaire will focus on experience of four areas of care:

- Referral to service and accessing care, such as route of admission to the hospital and information received on or prior to admission
- Inpatient care, particularly focusing on relational aspects of care, including involvement in decisions and interactions with ward staff
- Discharge, such as information provision, discharge planning and danger signals to watch out for at home
- Support for self-management, such as support and information received for managing health day-to-day

A database of questions will be compiled and will be mapped against the four areas of care. The questions will come from extensively tested, reputable sources such as the NHS Adult Inpatient Survey, Oxford Patient Involvement and Experience scale (OxPIE) (1), previously developed questions about self-management and demographic indicators.

A shortlist of questions will be selected from this database. The questionnaire will be created through selection of the most relevant items from this database and face validity of the instrument will be assessed by the research team.

The survey will be administered using a postal methodology. Fieldwork will lasting for 12 weeks with 2 reminder mailings being sent to non-responders during this period. Before each mailing sites will be asked to carry out a DBS check to check for any deaths. An opt-out approach will be used with all survey materials stating that participation in the survey is completely voluntary. Materials will provide clear instructions on how people can opt-out if they wish. The methodology (such as the use of reminders and the length of fieldwork) are based on best practice in social research (37). A sufficiently long fieldwork period and the use of reminders is particularly important for patient experience surveys covering acute care settings as this has been shown to improve the representativeness of results and obtain more feedback from people with poorer experiences (38).

We propose to survey a census of all discharged patients from each of the six medical wards in a given three month period. According to response rate data from the NHS Friends and Family Test, on average in acute trusts approximately 80 people are discharged per ward every month[1]. Using this as a guide, we expect to achieve an estimated sample size of 240 patients per ward. This approach will help maximize the volume of responses.

[1] FFT data shows that on average each ward in acute hospitals discharge 80 per month. This data does not identify which of these are medical wards.

The average sample of 240 patients per ward should provide 120 responses, assuming a 50% response rate (the response rate for the NHS Inpatient Survey 2013 which uses a similar methodology was 49%). This will allow for a minimum detectable difference of 11 percentage points for wards in the pre and post surveys; a good compromise between sample power and avoiding an excessively long sampling period. This minimum detectable difference of 11 percentage points is calculated based on the number of responses we believe to be achievable from the survey based on typical ward-level activity. Achieving a larger sample and a greater sample power would involve increasing the numbers of patients going through the medical wards in the three month sampling period, and this is out of the research team's control. As such, we will not have access to the kinds of sample sizes required for high precision estimates and detection of small changes. Due to this, the pre-and post-intervention surveys should be viewed as part of the overall package of information collected rather than the only source of evidence. The survey will be used alongside the in-depth interviews (noted below) and the ethnographic work (see section 2.3) to provide an understanding of the changes that have been made within different sites and to gauge the impact of these.

The survey will be accompanied by in-depth interviews with patients and family or carers to gather more detailed information on their experiences. Up to forty-eight interviews will be conducted, with the aim being to carry out eight interviews per ward. Each interview will be face-to-face and will last for approximately an hour. Interview participants will be recruited via the patient experience survey. A question will be included in the survey allowing participants to indicate if they would be happy to be contacted to take part in a follow up interview. This method of recruitment is associated with a degree of bias, as survey non-respondents will be excluded from the subsequent face-to-face interviews. However, this is acceptable because the findings from these interviews are not intended to be representative of the overall patient population; they are to provide further descriptive information helping form a rich overall quantitative and qualitative dataset.

The interviews will be recorded, transcribed, and analysed using NVivo coding software. Thematic analysis will be used to identify, analyse and report themes and patterns within the responses from each ward.

Reports showing survey and interview data for each case study site, will be generated. They will detail:

- Response rate information
- The demographic profile of respondents
- Results for each question in the survey. Caveats about interpretation of the data and the limits of significance testing will also be noted.
- Results from the in-depth interviews

The Picker Institute will lead on this aspect of the research with input from the Nuffield Department of Public Health, and will ensure the survey captures key domains of patient experience and adheres to best practice in survey research.

2.2. Establishing and supporting a learning community and developing frontline interventions (month 9 and onwards)

The 6 frontline teams will join a facilitated learning community to share and discuss findings from the baseline data. The initial meeting will be a 2-day event in Oxford (with travel and accommodation covered for all team members and patient advisers). Learning sessions will include presentations on different approaches to learning from and improving patients' experience; different features, uses strengths and limitations of both quantitative and qualitative data; how to include experiences of 'seldom heard' groups; the evidence base for various quality improvement approaches. In designing these sessions we will be drawing on experience from our current ESRC grant to develop a workshop series for national policy organisations (including NHS England) on using patient experience data for improvement (see 'why this research is needed now' above), and adapting the content for frontline teams. We will also draw on the expertise of the improvement scientist to be appointed as part of the study.

Teams will then develop and implement their own interventions and measures and select priorities for improvement. Although we will not want to constrain ward teams' choice of focus, we will encourage them to consider, for example, the experience of frail elderly people and/or people with dementia. Given the topical importance of this we anticipate it might well be an attractive choice for one or more wards. This would allow for interesting experimentation with collecting and using carer/visitor experience data, and using techniques such as staff- or user-led observation, shadowing and 'in your shoes' exercises. Regardless of whether any of the sites choose to focus specifically on the experiences of a particular 'seldom-heard group', we see this as an important issue for all of the participating wards. If services are to provide a good experience to all of their users, they must be mindful of issues of diversity and ensure that care and information are tailored, where possible, to meet the needs of different patients and groups. To that end, we envisage encouraging staff at pilot sites to give consideration to issues related to diversity when planning interventions, and to identify areas where these may need adaptation or tailoring to be of greatest benefit to different groups.

Senior trust managers will be expected to sign up to ensuring internally that frontline staff are given time and support for taking part in the project, as part of the trusts' general commitment to improving patient experience. It is important not to set a precedent that successful person-centred improvement can only be undertaken with external research funding. All trusts should be working on this topic and devoting staff resources and expertise to improving quality. However, we will include funding in our research costs for the additional time required for the frontline teams to be involved in the learning community meetings and other additional tasks specifically related to the research, such as being interviewed by the ethnographers.

The exact size and composition of teams will be determined by each site, but we anticipate up to 5 people from both clinical and non-clinical backgrounds, including, for example, ward administration and support staff, and a patient or family member We will encourage ward teams to think creatively about whom they might involve, whilst recognising that attendance at the learning community events will necessarily be limited to a sub-set of the wider group of people who will get involved in the project at local level, for example ward clerks, healthcare assistants and cleaning staff.

One advantage of whole team attendance is that it fosters continuity and capacity-building regardless of staff turnover (compared to a model where a single facilitator is trained). Teams will be strongly encouraged to include patient and family members in the group attending the learning community meetings. There will also be independent patient advisers present with the research team led by our PPI co-applicant (see also Patient and Public Involvement below). Their role will be to help teams think through what kind of improvements matter to patients and to develop realistic and acceptable improvement plans. If teams plan to collect any new local data as part of their plans, our PPI lead will also be able to advise them on involving patients in data collection, for example interviewing and observational work. At subsequent learning community meetings, they will be involved in reflecting on interim findings with the research team and the frontline ward teams, and discussing how to adapt their quality improvement work to overcome any difficulties encountered.

During the fieldwork phase (see below) the teams will have access to a 'virtual campus' facilitated by the improvement scientist where they can exchange ideas and experiences, a monthly webinar with the research team and ongoing informal support from the improvement scientist. In addition, NHS England has developed an improvement support package for Trusts working to improve care as part of the Cancer Patient Experience programme. NHS England has agreed to extend this package to wards participating in this study.

Two further face-to-face learning community meetings will be organised in months 14 and 21. The first of these will provide an opportunity for formative feedback of interim findings from the case study ethnographic work, and for reflection on successes and problems so far. Each team will plan its next steps with support from the research team and the improvement scientist, and with input and shared learning from the other teams. The third and final meeting in month 21 will be a time to report on final outcomes, reflect on learning and help the research team shape the form and content of the guidance to be disseminated across the NHS.

The prioritisation panel and subsequent reviewers have noted that burden on participating wards may be a factor affecting the success of the project. We acknowledge this possibility, but the PI's experience in her previous HS&DR study (10/009/14) on accelerated experience-based co-design (27) found staff embraced the opportunity to take part in genuinely person-centred improvement led from the frontline (as opposed to feeling subject to yet another burdensome top-down initiative). They reported that they found it motivating, liberating & rewarding, and that they felt reconnected to the values of care and compassion which originally inspired them to join the NHS. This prompted a comment from one of the reviewers which we included in the final draft:

> We are grateful to one of our anonymous reviewers for the comment that 'far from being a burden, involvement in this work helped to lighten (in many ways) the emotional and other forms of labour in which people are engaged'. (27, p.58)

Patients, too, reported a different level of appreciation for staff, a belief that they would be listened to and that change was possible, and a renewed sense of trust in local NHS services. We also found in study that the involvement of local patients in quality improvement was a powerful motivator for staff to keep going and make sure improvements were implemented. Good patient experience & high staff motivation are closely linked (30). In the learning community meetings we will stress the importance of paying attention to staff experience and morale as well as patient experience. We do not believe staff come to work to deliver poor care, but system and cultural pressures sometimes prevent them from living up to their own ideals. Getting involved in person-centred improvement efforts can break this cycle of disaffection and sub-optimal care, becoming a reciprocal benefit for all parties involved. The learning community & improvement scientist will provide ongoing practical & emotional support to ward teams, monitor potential burden & make adjustments as needed.

Senior management commitment is of course also essential to ensure staff are supported to take part. We will suggest to trusts that local participation in quality improvement can be counted as formally allocated staff development or education time, which was the approach chosen by one trust in HS&DR study 10/1009/14. We have also included costs for staff time to attend the learning community events and take part in other specific research-related activities.

2.3 Ethnographic case study fieldwork and analysis incorporating realist evaluation (months 10-17)

Organisational ethnographers will use longitudinal observations, interviews and documentary analysis to assess what happens in each site and record service changes made, with input from the frontline teams.

The case studies will be formative and exploratory; this means that findings will be fed back to the teams on an ongoing basis to help them develop and adapt their approach, and reflect on what has worked well or less well and why. A 'focused ethnography' approach (2) will underpin the case studies. Focused ethnographies share many characteristics with classic ethnographies (3) i.e. they are exploratory rather than hypothesis-testing; elicit unstructured data in the form of field notes and transcripts; involve a small sample, collect rich data and result in narrative description (4). Unlike classic ethnography, rather than embedding a sole researcher in a setting for a lengthy continuous period, more targeted observation periods are used.

There will be two main formal interviewing periods at the start and end of the quality improvement work, with a smaller number of interviews with key team leads at the midway point. The exact number of interviews to be conducted will depend to some extent on the composition of the frontline teams (including patients and family members) from each site, but we estimate a maximum of 10 at the beginning and end of the intervention, with 2-3 with key improvement leaders on each ward at the mid-point, and 2-3 senior managers at the end of the fieldwork period, totalling approximately 25 in each site. The two ethnographers will thus conduct around 75 local interviews each in total (each ethnographer taking responsibility for 3 sites). They will also share the conduct of interviews with the 12 members of the research team, the improvement scientist and independent patient advisers at the two main time points. In addition they will observe all the learning community meetings and webinars, and conduct observations for approximately 10 days in each site. The observation periods will include opportunities to record further informal conversations with members of the teams, as well as

observing quality improvement meetings and workshops, general staff meetings, and reviewing meeting notes and improvement plans. Formal interviews will be recorded and transcribed verbatim; detailed observational fieldwork notes will be written by the ethnographers.

With the help of the frontline teams, the ethnographers will complete a 'service improvement log', recording planned and implemented changes as a result of the project, and categorising them as small-scale change; process redesign within team; process redesign between services; and process redesign between organisations (the categorisation used previously in HS&DR study 10/1009/14 on accelerated experience-based co-design).

As noted under 'Background and rationale' above, the separation of patient experience evidence from the process of collecting and analysing it at local level is somewhat artificial, as collecting such data can itself be part of building momentum for their use in improvement and generating momentum for cultural change (35). Frontline teams involved in this study will be invited to engage in local data collection as well as using existing sources such as survey data or patient comments; comparisons between cases looking at how this is approached and what influence it has will form part of our ethnographic observations. However, given the nature of the research call, our focus is primarily on the stage of using rather than collecting experience evidence.

Our analysis of the case studies will draw on realist evaluation methods (33). The aim is to 'make sense' of different patterns of actions and outcomes, understanding why, for whom and in what circumstances particular approaches work or not, rather than developing a predictive model. Realist evaluation produces generalisable findings, but does so by disaggregating interventions into component middle-range theories which we can then reasonably apply in other settings. In practice trusts are likely to use a mix of complementary data sources and approaches; the toolkit will therefore include advice on how these may be used effectively in different circumstances and for different audiences.

When introducing change in complex systems, there are ideally two 'evaluations'. One is an internally-facing evaluation, usually done by the staff in the organisation that asks 'how is this project going here?' This typically uses techniques like plan-do-study-act, and the data sources are chosen accordingly. Another kind of evaluation, which may draw on some of the same data, analysed differently and supplemented by other data, asks 'what general conclusions can we draw about the interaction between context, mechanism and outcome?' We will encourage and support staff in the first task and draw on realist methods to achieve the second, using both the results of the teams' own evaluation and the service improvement logs, and the ethnographic material collected. The analytic process will be supported by NVIVO coding software. Coding will be both deductive and inductive, with codes derived both from organisational change theory and existing empirical literature, and from emergent themes in the data collected, focusing on the context-mechanism-outcome formula.

This study will run in parallel with the RAMESES II study to develop methodological standards for realist evaluation (HS&DR 14/19/19). The principal investigator and lead researcher on RAMESES II have recently transferred to the University of Oxford. This study could form one of the 'cases' in RAMESES II. The lead researcher can provide methodological and analytic support to this work as part of his (already funded) RAMESES II study.

Whilst realist evaluation will inform and guide elements of the analysis, we recognise that clearly articulating mechanisms of change and distinguishing these from aspects of context can be challenging (36). We will also adopt a wider comparative case study analytic approach as outlined by Fitzgerald and Dopson, taking an interpretive and holistic approach to understanding each case and how it compares with others (5-8). Comparative case study analysis lends itself to 'the exploration of complex "how" and "why" questions' (7:481) and will provide a rich source of information, understanding and pattern detection to inform a toolkit for the NHS. As in any case study design, gathering contextual information about concurrent events such as CQC inspections and changes of leadership will be an important component of data collection. Participants will be invited by the ethnographers to reflect on the significance of such contextual factors.

The face-to-face learning community meetings with frontline teams are very much intended to be two-way discussions rather than simply passive dissemination of research findings. The frontline teams

and the patient advisers will contribute formatively to the analysis as well as using it to help them plan their next steps. Their feedback on the issues identified by the ethnographers and their response to the interpretations of the research team will be an important contribution to our understanding of the context and mechanisms at play in each site.

Given the fluid and evolving nature of the interventions we anticipate, we do not propose to conduct a formal cost analysis in each site for this study, though we will ask teams to work with the ethnographers to keep a record of numbers of meetings held and numbers of staff and patients/family members attending, to compare the level of effort and intensity involved with the number and type of changes made in each case. Our priority will be to focus on the process of using experience data of different types and the impact in terms of service improvements and changes in measured patient experience (see section 2.4 below).

2.4 Post-intervention survey (months 18-20)

The local baseline patient survey will be repeated a year on with a new set of patients to measure what, if any, change has occurred in measured patient experience following local quality improvement work. This will again be a postal survey with the same anticipated sample size of 240 per ward and will be sent to a census of all discharged patients from the 6 participating wards.

Results will be compared to data from the pre-intervention survey to see if there are any detectable ward-level changes to question scores. To explore whether ward level changes are observable at a trust level, results (for those questions that map) will also be compared to trust level data from the most recent NHS Adult Inpatient Survey.

The main outcome measure (or measures if all wards cannot be evaluated on the same measure) used for evaluating change will be determined through discussions amongst the research team, the project steering group, and with input from each ward team. This approach has the added benefit of allowing participating trusts to be involved in the selection of measures, increasing their sense of ownership and 'buy-in' to the study.

Forty-eight in-depth interviews with patients and family or carers will also be carried out to gather more detailed information on the quality of the experience of recently discharged patients.

As for stage 2.1 reports showing survey and interview data for each case study site will be generated. They will detail:

- Response rate information
- The demographic profile of respondents
- Results for each question in the survey (with historical and trust-level comparisons where appropriate). Caveats about interpretation of the data and the limits of significance testing will also be noted.
- Free text comments included as part of the survey
- Results from the in-depth interviews

3. Synthesising analysis, writing up and preparation of toolkit (months 21-27)

Following the completion of the fieldwork, the qualitative and quantitative data from Phase 2 will be brought together by the whole research team to create an overarching understanding of what changes were made and how in each site; what facilitated or hindered the process; how different types of data were received and acted on; what impact (if any) the process had on measured patient experiences; and what we can learn about successful strategies and pitfalls to include in guidance for the NHS. Early explanations will be tested and refined at the final learning community meeting with staff and patient and family advisers. We have scheduled a writing workshop for the research team in month 22 and again in month 25; this is an approach we have used successfully in the past to share out writing tasks and produce and share initial drafts, which will then be refined further in between workshops. From these workshops we will produce both the final NIHR report and the NHS toolkit (see dissemination). We have allowed 6 months for this process; although analysis will have

been ongoing since the start of fieldwork, it is our experience that successful analysis requires repeated revisiting and reflection on the data to develop a nuanced account.

Dissemination and projected outputs

Findings from Phase 2 will inform the development of a toolkit for the NHS on using patient experience data for service improvement (see below). This will be disseminated online and promoted through a series of national dissemination workshops in partnership with our co-applicant from NHS England.

Project management

A Study Steering Committee (SSC) will be appointed with external chair to be appointed by HS&DR, meeting approximately 6 monthly during the fieldwork and analysis phase. In addition to the chair, the SSC membership will include members covering the following areas of expertise:

Two or three patient/carer advisers
Two senior NHS clinicians (one nursing, one medical)
A senior NHS manager
An improvement science/organisational change specialist

The SSC will meet six-monthly. The full co-applicant team will also meet 6-monthly with our collaborating patient advisers.

The core research team will also have at least a two-monthly meeting either face-to-face in Oxford or by telephone. In the set-up phase and in the run-up to the first learning community event, these meetings may be scheduled more frequently and include other co-applicants for specific agenda items. The PI will coordinate the meetings with the support of the part-time project manager (who is already in post and an established member of the health experiences research group in Oxford). Nearly all the co-applicants are based in Oxford, which will facilitate more frequent informal contact.

We will also arrange separate briefing and training meetings for our patient advisers, led by our PPI co-applicant, to ensure they can participate fully in meetings and in the learning community meetings.

To support the assessment of risks and barriers associated with this research project a risk assessment table will be created. The table will list identified risks, potential impacts to the project, what will be done to mitigate risks, and the current status of all items (using red/amber/green flagging).

Approval by ethics committees

Ethics approval will be initiated (via the Integrated Research Approval System) between final approval of the grant and the planned start date of November 2015. Although full ethics approval will not be in place before the start of the grant, Phase 1 (which is secondary analysis of existing data and a senior manager survey) already has CUREC ethics approval with HRA approval pending, and we can therefore start work while we wait for Phase 2 approval to be confirmed. This research includes minimal risk to participants; all potential risks and burdens have been identified and accounted for in our methodology. The project has already been registered and given the IRAS identifier 180418.

Ethnographic observation in NHS settings raises some potential ethical challenges. However, we have successfully obtained ethical approval for similar studies in the past and foresee no major difficulties. We will make clear to all involved that the focus of the observation is on the quality improvement process and interactions, and will not include direct observation of ward care or patients who are currently being cared for. The observations will thus be mainly of meetings and workshops, supplemented by interviews with participants in the frontline teams (including patient and carer team members) and documentary analysis, We will draw on advice from our PPI co-applicant who is a lead reviewer for an NHS ethics committee, an ethics consultant to the RDS and research ethics trainer.

Staff involved in improvement interventions may conduct their own patient interviews or observations, but these will not form part of the research and will be treated as service improvement work.

Interviews with medical ward patients conducted as part of the baseline and post-intervention analysis of changes in experience will take place after discharge, and will be included in the ethics application, along with the patient experience surveys. Documents such as the interview topic guide, questionnaire and associated covering letters will be submitted to the ethics committee.

There are two potential risks with regards the local baseline and follow up survey and associated patient experience interviews; the transfer of patient identifiable data outside of the NHS and the confidentiality of participants who participate. A suitable model will need to be implemented to ensure the safe and proper handling of patient identifiable data needed for the patient experience survey. We will explore a number of specific options for handling this. Firstly, we will consider seeking support under section 251 of the Health and Social Care Act or seeking Caldicott Guardian approval at each of the sites allowing the sharing of patient name and address details with the Picker Institute for the purpose of participating in the survey. These are the preferred options as they minimise risk and burden, and we have experience of using both of these approaches successfully and without complaints. Should these options be impractical for any reason, an alternative is for participating trusts to conduct the mailings for the survey themselves. This means that no patient identifiable information required to conduct the survey will be transferred outside of the NHS – but at the cost of increasing the workload for trusts.

Recruitment for participation in the in-depth interviews will be carried out using an opt-in process. A question will be included in the survey asking participants if they would like to take part in a follow-up interview. Patients will be selected at random from those who consent to take part and will be re-contacted to seek their further involvement. Patient information leaflets will stress that further participation in the interviews is voluntary and that consent may be withdrawn at any time without adverse consequences.

The confidentiality of patients is a potential risk. Picker Institute Europe operate under strict information security and data protection guidelines. Survey and interview responses will remain confidential and data will be held securely. As the survey will collect respondents' basic demographic information, in order to protect their confidentiality, results from the survey will only be fed back to staff when there are at least 20 respondents. Any patients' comments, from the survey or interviews, which could lead to the identification of any individual patient/staff member will be redacted before being circulated.

As we have noted under 'dissemination', for the toolkit to be credible it is important that difficulties and barriers are aired as well as examples of success, and that Trusts which are struggling with patient experience can see examples that resonate with them. The toolkit will therefore take an honest view of things which worked less well and explore why this may have been. The use of formative feedback during the process will offer teams an opportunity to address problems during the study, and to explain in the toolkit what they did and how this helped. However, examples may be anonymised in the toolkit where appropriate to ensure participating teams can share their learning without feeling judged. This will all be explained in the ethics application.

Patient and Public Involvement

Members of the research team have a long track record in patient experience research with strong patient and public involvement. Both in our research findings (see for example www.healthtalk.org) and in our discussions with patient and public advisers the need to do something useful with our findings (and not stop at data collection and academic publication) has been a recurring theme. The topic and direction of our proposal has thus been shaped by years of activity in this field and many repeated contacts with patients who tell us time and again that the NHS is often not listening to them, as well as more specific input on the details of the proposal itself, led by our PPI co-applicant. Our PPI lead is an existing collaborator on an Oxford-based Department of Health study on 'Measuring Patient Experience' from which she brings insight into patient perspectives and key ethical concerns about the importance of improving as well as measuring experience. She is also a core representative on

the QORU public involvement implementation group – QORU is the Quality and Outcomes of Person-centred Care Policy Research Unit in which University of Oxford is a partner.

At outline stage she reviewed the application, edited the lay summary, and made changes including introducing patients into the learning community events and patient advisors co-presenting findings at dissemination events. She has played an equal role in preparing the full proposal. Given the nature of this study we see PPI as crucial to its success. A strong patient focus will not only aid the research but also encourage frontline NHS teams to involve local patients actively in improvement work now and in future.

We will advertise for patient, carer and public advisers through QORU, www.patientsactiveinresearch.org.uk (a new Thames Valley initiative to put patients and researchers in contact with each other), and local GP practices. We will recruit several advisers (minimum of 8) to join our research team and be part of the team advising the learning community. Individuals may get involved in both or just one of these activities, depending on their interests and availability. Having a group of people is important both to ensure they feel that they have a strong and equal presence, but also so that people feel they can take time out if need to, for example if they have periods of illness. We will seek a mix of people to be involved, paying attention to demographic diversity as well as people who have different types of experience of healthcare. We will particularly encourage people who have been involved in previous service improvement work to apply as well as people with no improvement experience. The group of advisers will join the six-monthly meetings of the whole research team. Honoraria, travel and other costs have been included in the budget. Our PPI advisers will review study documents and consent procedures and advise on case study data collection methods to ensure the study is ethical and acceptable.

Our PPI lead will oversee the involvement plan and ensure it continues to meet the needs of the study. As an experienced trainer, she will deliver any training needed, with the support of the research team, and provide ongoing support to less experienced or less confident advisers to ensure they can all contribute effectively. Training will include a 'mini learning set' day for those who would like to advise the learning community. This will take place with members of the research team, before the frontline ward teams are brought in, to familiarise our patient advisers with the kinds of patient experience data available and how these data can be used, and what is known about successful organisational change and service improvement. At the first learning community meeting, the patient advisers will help teams think through what kind of improvements matter to patients and to develop realistic and acceptable improvement plans, and advise on involving patients in the local improvement interventions. At subsequent learning community meetings, they will be involved in reflecting on interim findings with the research team and the frontline ward teams, and discussing how to adapt their quality improvement work to overcome any difficulties encountered, thus participating in our formative analysis stages. At dissemination stage our PPI lead and other patient advisers will co-author articles and the final report, and present findings to relevant lay and academic audiences to ensure the patient voice is heard.

As noted in the research plan, ward teams will be positively encouraged to bring patients or family members along as part of their team. We appreciate that some teams may involve people better than others in their improvement work, but the ethnographers will be looking out for the nature and extent of patient involvement as one of the factors which may affect outcomes and reporting on this in their analysis.

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N.B. numbering applies to both the application form and the detailed project description

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