

PROTOCOL TITLE:

Exploring the Impact of Patient Experience Data in Acute Hospital Trusts in England: using Actor-Network Theory to optimise organisational strategies and practices for improving patients' experiences of care

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## Study Synopsis

Title of study	<u>Exploring the Impact of Patient Experience Data in Acute Hospital Trusts in England: using Actor-Network Theory to optimise organisational strategies and practices for improving patients' experiences of care</u>
Protocol Short Title/Acronym	Impact of patient experience data: an ANT study
Sponsor name	Mr Keith Brennan
Chief Investigator	Dr Sara Donetto
REC number	IRAS ID: 188882
Medical condition or disease under investigation	Health services research (dementia and cancer services)
Purpose of clinical trial	Investigation of how patient experience data is collected, collated and disseminated and the effects it has.
Primary objective	To explore and enhance the organisational strategies and practices through which patient experience data is collected, interpreted and translated into quality improvements in NHS acute hospital trusts
Secondary objective (s)	To understand and optimise the involvement and responsibilities of nurses in senior managerial and frontline roles with respect to such data.
Trial Design	Multi-method design in two related phases: Phase 1 (ethnographic work) and Phase 2 multiple-stakeholder meetings in the format of Joint Interpretive Forums
Endpoints	Exploratory study
Sample Size	80 staff and patient interviewees (dementia and cancer services across 5 NHS acute hospital trusts)
Summary of eligibility criteria	Staff working with patient experience data and staff working in cancer or dementia services in the 5 selected

	NHS acute hospital trusts; patients with capacity who have used cancer or dementia services in the 5 selected NHS acute hospital trusts
Version and date of final protocol	v.4. 06.03.2017
Version and date of protocol amendments	v.1. 06.07.2016 v.2. 20.07.2016 v.3. 09.12.2016 v.4. 06.03.2017

## Full title of project

Exploring the impact of patient experience data in acute NHS hospital trusts in England: using Actor-Network Theory to optimise organisational strategies and practices for improving patients' experiences of care

## Summary of Research

Patients' and carers' experiences of hospital care are an important aspect of healthcare quality. In the NHS, data about patients' experiences are collected through a wide range of research methods that are used in various ways. These include detailed postal questionnaires (such as the national adult inpatient survey), much smaller sets of satisfaction-type questions (including the nationally required 'Friends & Family test), formal and informal complaints and compliments, hand-held devices given to patients on wards to provide 'real-time' data, patient stories recorded through face-to-face interviews, feedback on patient/public websites (such as NHS Choices and Patient Opinion) and as part of internal and external quality inspections and regulatory processes.

Recent research has highlighted that despite the vast quantity of data that is collected about patients' experiences, it is not clear whether and how NHS organisations use these data to identify and implement improvements in healthcare quality. This study will explore the collection, use and impact of patient experience data on the quality of hospital services. As a secondary objective the study will pay particular attention to the role of nurses, given that nurses (whether in managerial or frontline roles) are often responsible for acting on these data. The study is organised in two phases.

Phase 1 – ethnographic work: we will use qualitative research methods in five purposively selected hospitals to explore the objects (or 'artefacts' - see below) and practices used to capture patient experience data (for example, data from patient experience surveys, the real-time devices used to collect patient feedback on the wards, and/or the written reports of complaints filed by patients and carers) and the interactions between these objects and the various individuals and teams who use them. We will study the journeys - and impact on quality - of these objects and patient experience data within two contrasting clinical services in each of the five trusts: dementia and cancer care. There are well-established systems for collating patient experience data in the area of cancer care and, in contrast, considerable challenges in documenting patient experience of dementia services (i.e. dementia care being provided across a range of services within an acute trust; issues of mental capacity; an often prominent role for carers in both decision-making and provision of feedback). Examining two services within each participating trust will enable us to carry out within-case comparisons, shedding light on the mechanisms through which organisation-wide strategies operate at the level of individual services. We will select the objects we will study in these services guided by local practices at the participating sites.

Phase 2 – 'sense-making': we will hold a set of structured feedback meetings with hospital managers, frontline staff, and patients and carers from the five hospitals involved in the study to discuss the findings from our ethnographic work and develop practical recommendations for NHS managers, clinical staff, and policymakers. We will then test the value and appropriateness of these recommendations in a final focus group with invited national policy makers and influential organisations (e.g. The King's Fund; The Health Foundation, The Patients Association, Carers UK, National Voices) as well as representatives from each of the five hospitals; this will explore how to ensure the future alignment of the recommendations with national policies relating to improving patient experiences. A tailored strategy for the dissemination of our research findings will ensure that the study also contributes to empowering patients (and also patients' carers, advocates and patient organisations) by providing accessible information on the ways in which organisations could and should make use of patient experience data to improve quality of care.

The study will generate important new understandings and recommendations at three different levels of healthcare services:

- at the micro-level of everyday practices, by highlighting effective processes for collecting, reporting and making use of patient experience data in NHS clinical services;

- at the meso-level of organisational management, by providing information on the managerial strategies and policies that can help maximise the impact of patient experience data on the quality of care provided by acute NHS hospital trusts;
- at the macro-level of policy, by exploring how strategies and practices at the micro- and meso-level are shaped - and could be better supported - by national healthcare policies.

## **Background and Rationale**

Recent research has examined the types of patient experience data currently in use in the NHS, the systems - or lack thereof - through which these data inform quality improvement, and the initiatives implemented as a result (1,11,16-18). Furthermore, an 'evidence scan' published by The Health Foundation in 2013 reviewed existing approaches to measuring patient experience and their relevance to person-centred care (19), whilst essential aspects of care experiences indicative of good care can be found in national clinical guidelines (20). However, as highlighted in the themed call for this submission, there is little evidence relating to the ways in which patient experience data are and should be used to drive quality improvement in NHS organisations and clinical services. This is particularly problematic in view of the growing policy emphasis on the importance of improving patient experience as a core dimension of overall care quality. This study addresses this identified lack of evidence firstly by examining in detail selected examples of current strategies and practices relating to the collection and use of patient experience data through the lens of Actor-Network Theory (ANT), and by involving multiple stakeholders (NHS policymakers, managers, staff, patients and carers) in discussing the practical implications of the study findings. Through these approaches, the research will generate actionable recommendations on how to optimise organisational strategies and practices for the collection, validation, and use of patient experience data.

Components of the study will build on the 2012 Ipsos Mori's Patient Feedback Survey Patient Feedback Survey (21) which maps the main methods used to collect patient experience data, the frequency with which these data are collected, and the mechanisms through which they are reported and made available to the public. However, this helpful overview of current practices does not address questions around issues of responsibility and accountability for the collection and use of patient experience data. Nor does it examine differences in strategic approaches to the use of patient experience data at the organisational level or shed light on the specific mechanisms through which such data translate into successful quality improvements. By adding such further dimensions to the existing evidence on current strategies, our study will generate a stronger evidence base from which to develop actionable recommendations for both policy and practice.

The proposed study will also contribute to existing scholarship from a methodological perspective. Recent research has highlighted the importance of paying attention to the role of artefacts in supporting the organisation of healthcare work, with particular reference to quality improvement (28,29). Drawing upon ANT (5) and socio-material approaches to healthcare practices (4,22,23), this study will contribute to emerging understandings of the infrastructural context of quality improvement work (3), and complement other HS&DR streams of research focusing on the integration of new technologies in healthcare practice (Project 13/07/68).

## **Evidence explaining why this research is needed now**

This study will contribute to improving patient, carer and staff experience of hospital care by generating theoretically sound and practically relevant recommendations on how to optimise organisational strategies and practices for the collection, validation, and use of patient experience data (with particular reference to the role of nurses and nursing within such strategies). The study addresses a healthcare need, that of improving patient experience of care as a fundamental dimension of overall care quality, which is increasingly emphasised by research evidence as well as the policy agenda (e.g., the NHS Improving Quality 'Experiences of care' programme: <http://www.nhs.uk/improvementprogrammes/experience-of-care.aspx>; or the 'Improving patient experience' programme of NHS England: <http://www.england.nhs.uk/ourwork/pe/>). This research is also important as it contributes to the 6Cs (Care, Compassion, Competence, Communication, Courage, Commitment) strategy for nurses, midwives and care staff (7) and responds to concerns raised by the Francis inquiry (8), Berwick review (9), and Keogh report (10), and also by the Patients

Association, around the need to listen to and act upon patients' concerns and complaints in a timely manner.

As the 2010 'Intelligent Board' report by Dr Foster Intelligence highlights (11), 'the quality of patients' experiences is central to an organisation's reputation and productivity, making it a major risk management issue - and opportunity' - and 'understanding and acting to improve patients' experiences is also core business for the NHS.' (p.5). The report also points to the growing evidence of a positive association between patient experience and clinical outcomes (12-14) and between quality and financial performance (15), thus further emphasising the need - which this study explicitly addresses - to shed light on the processes that enable NHS organisations to act upon their patient experience intelligence.

There is very little good evidence relating to the ways in which patient experience data are translated into quality improvements and only anecdotal evidence as to the allocation of responsibilities for the patient experience strategy at hospital level (1,11). A recently funded HS&DR study to be carried out by Professor Louise Locock and colleagues<sup>1</sup> at the University of Oxford sets out to "explore and analyse how NHS frontline teams use different types of patient experience data for improvement" and "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."<sup>2</sup> Although different in empirical approach our study and the study by Locock and colleagues complement each other. Locock et al.'s formative evaluation of local interventions for better use of patient experience data in six case study organisations is likely to benefit from our Actor-Network Theory study of the journeys of different forms of patient experience data in five case study sites. On the other hand, the 'sense-making' work in Phase 2 of our project is likely to benefit from Locock et al.'s developmental work with the frontline teams in the trusts participating in their study. In addition, the Locock et al.'s study will include a new survey of patient experience leads from all acute NHS hospital trusts in England, the findings of which will become available in Feb-March 2016 and provide timely additional detail to inform our choice of case study sites.

Our findings will provide an in-depth understanding of the relative efficacy of current practices in a selected sample of acute NHS hospital trusts in England. Key lessons will be extracted for the benefit of those who are responsible at various levels of the healthcare system for the collection, interpretation, and practical use of patient experience data for quality improvement purposes, and for those outside the healthcare system who are in a position to influence how these processes take place (patient organisations, regulatory bodies, the press).

## **Aims and objectives**

### *Aims:*

The main aim of the study is to explore and enhance the organisational strategies and practices through which patient experience data are collected, interpreted, and translated into quality improvements in acute NHS hospital trusts. A secondary aim is to understand and optimise the involvement and responsibilities of nurses in senior managerial and frontline roles with respect to such data.

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<sup>1</sup> As advised by the HS&DR Board following review of an earlier version of our application, we have revised our Detailed project description to position our study against the study by Locock and colleagues (HS&DR ref 14/156/06). Professor Locock and her team have kindly shared their study proposal with us. We have discussed possibilities for collaboration and sharing the initial analyses of our respective data (but not any primary data) directly with Professor Locock. We have agreed to compare preliminary analytical findings at relevant stages of the projects to enhance the quality and robustness of both studies. Professor Locock has reviewed and approved the sections of this application referring to our potential collaboration.

<sup>2</sup> The study by Professor Locock and colleagues is entitled 'Understanding how frontline staff use patient experience data for service improvement - an exploratory case study evaluation and national survey.' The study aims to "explore and analyse how NHS frontline teams use different types of patient experience data for improvement" and 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," and to do so it "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." (source: Locock et al.'s Detailed project description, HS&DR ref. 14/156/06, quoted with Professor Locock's permission).

The research aims to answer the overarching question: what are the strategies and practices through which patient experience data are translated into quality improvements in acute NHS hospital trusts? In doing so, it focuses in particular on the role of nurses in these processes in view of their close involvement in improving patients' experiences of everyday hospital care.

*Objectives:*

- 1) To identify, on the basis of a sampling frame which draws upon the Care Quality Commission's reporting of the national adult inpatient survey results and takes into account the findings from the HS&DR study by Locock and colleagues, five suitable case study organisations for our in-depth qualitative fieldwork;
- 2) To carry out an Actor-Network Theory-informed study of the 'journeys' of patient experience data situated within two clinical services (cancer and dementia care) in each of our five case study sites to explore the origins of these data, what these data 'do' and how they 'interact' with human actors to ultimately influence, and/or translate into, quality improvements;
- 3) To distil generalisable principles that may facilitate the journeys of patient experience data to quality improvements in acute NHS hospitals;
- 4) To develop, together with stakeholders from the case study sites (including patients and carers), national policy makers and representatives from patient organisations, practical recommendations and actionable guidance for acute NHS hospital trusts that will optimise their use of patient experience data for quality improvement.

The study will provide a multi-level perspective on the form, function and impact of patient experience data in the hospital setting and on the contribution of nursing to improving patient experience: at the micro-level (clinical service), it will shed light on everyday practices and the socio-material contexts in which they take place; at the meso-level (Board), it will provide insights on the managerial resources and constraints that shape the impact of patient experience data on organisation-wide quality improvement; and at the macro-level (national policy), it will examine the enabling and/or hindering effects of external incentives and policy trajectories on the other two levels.

## **Research Plan / Methods**

*Review strategy and strategy for reviewing literature:*

The academic literature reviewed in the commissioning brief guiding this proposal illustrates the types of patient experience data currently in use in healthcare organisations, the systems - or lack thereof - through which these data inform quality improvement strategies, and the initiatives implemented as a result (1,11,16-18). In addition, the 2012 Ipsos Mori's Patient Feedback Survey provides a sufficiently up-to-date overview of the main strategies for patient experience data collection, the frequency with which these data are collected, and the mechanisms through which they are reported and made available to the public (21). In view of these existing resources, we will not undertake a systematic or scoping review, but will draw upon this evidence and monitor any updates and/or further publications over the duration of our proposed research.

*Design and theoretical/conceptual framework:*

### Study design

The study uses a multi-method design and is organised in two related phases. Phase 1 (ethnographic work) will consist of an Actor-Network Theory (ANT) study of the journey and impact of patient experience data within two services (cancer and dementia care) in each of five case study sites. Phase 2 ('sense-making') will comprise multiple stakeholders meetings (with hospital managers, frontline staff, patients, and carers) in the format of Joint Interpretive Forums (JIFs, a form of group discussion which aims to foster 'perspective taking' and joint decision making) at all participating sites for the collaborative interpretation of research findings and the development of actionable recommendations for policy and practice (6).



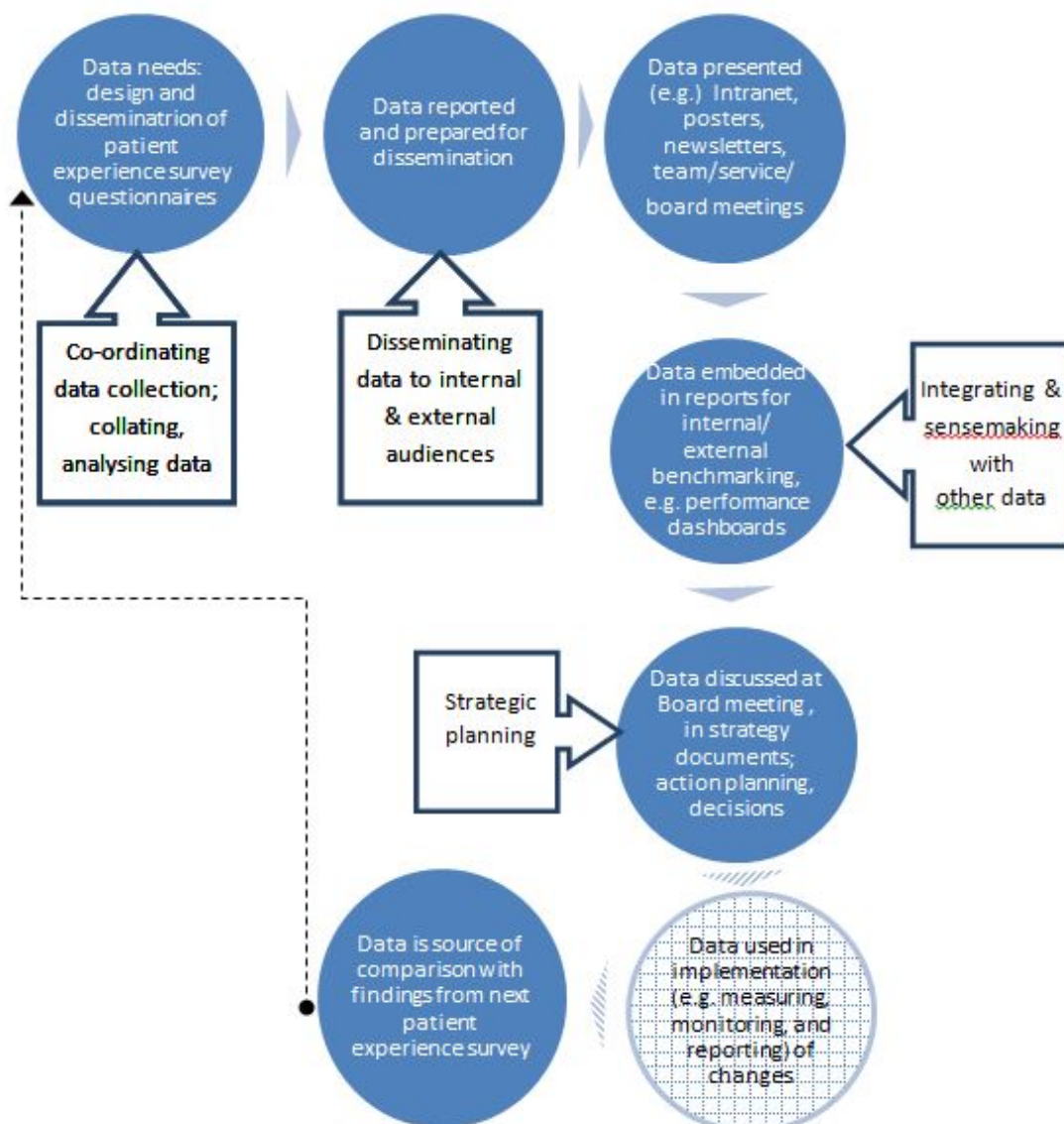
### Theoretical/conceptual framework

In order to be able to illuminate the ultimate impact, in terms of quality improvements, of patient experience data within healthcare organisations, in this study we adopt a methodological approach grounded in Actor-Network Theory (ANT) (5,30,31). In doing so, we will draw upon the broader landscape of socio-material approaches to the study of organisational processes and healthcare practices (3,22-25,32-36). As a family of approaches rather than a unitary theory, ANT provides a framework and tools that allow us to pay attention to the 'materiality' of organisational activity and the inseparability of the technical and the social in organisational practices (37-39). Two key elements of ANT studies that will be central to our research are: (1) they examine human and non-human entities as having no inherent qualities but acquiring their form and characteristics through their relations within networks; and (2) they are concerned with illuminating the processes of 'translation' by which network elements are held together and (temporarily) stabilised, producing a variety of effects (e.g. knowledge, routines, policies, improvements, innovations). In Fenwick, Edwards and Sawchuk's words, ANT analyses share the aim of tracing "how all things [...] become assembled and enacted in networked webs, how they associate and exercise force, and how they persist, decline and mutate;" and crucially for our purposes, they focus "not on what texts and other objects mean but on what they do" (40).

ANT is a useful toolbox for the study of non-linear change in organisations (38,41) and therefore provides an ideal lens for our research focus on the translation of patient experience data into quality improvements. ANT will enable us to look at patient experience as an 'actant' in the context of hospital care quality and to trace the journey and impact of the artefacts through which this is conveyed for quality improvement purposes. In our study, ANT will allow us to examine the actor-networks in which patient experience data are embedded and their characteristics (e.g. how do entities relate to each other, how do the networks hold together) and effects (e.g. knowledge, routines, policies, improvements, innovations). The theoretical/analytical foci and sensitivities afforded by ANT will be key to addressing two of our study's objectives: to distil generalisable principles that may facilitate the journeys of patient experience data to quality improvements in acute NHS hospital trusts (objective 4); and to develop practical recommendations and actionable guidance for acute NHS hospital trusts around enhancing their use of patient experience data for quality improvement (objective 5).

Figure 1, below, provides an illustrative example of a data 'journey' relating to survey data; in reality there will be multiple 'journeys' in any one trust as patient experience data are collected from various sources (e.g. complaints/compliments; patient stories; FFT) in addition to surveys.

**Figure 1 Simplified illustration of patient experience data journey (patient survey as example)**



By allowing us to foreground the journeys and effects of patient experience data - whether they are electronic or hard data, qualitative or quantitative - in NHS organisations, an ANT approach will enable us to study what these data do within such organisations and the relational ties through which they are enabled to act, or not (see pp.10-11 for details of our approach to data collection). In following the journeys of patient experience data, we will also be exploring how, where and when different individuals and/or teams 'come into contact' with the artefacts at each stage of their journey.

We will use a Joint Interpretive Forum (JIF) format to bring together NHS managers, frontline staff, and patients/carers to discuss the findings from Phase 1 data analysis (6). Building on Argyris and Schon's emphasis on reflection as a fundamental dimension for learning (42,43), Joint Interpretive Forums 'bring together members of different communities to *jointly* reflect and interpret information,' and foster 'perspective taking' as the active engagement with different systems of meaning (6). These forums will aim to gather different stakeholders' views on the key findings from the research and to allow for their translation into actionable recommendations for policy and practice.

## Sampling

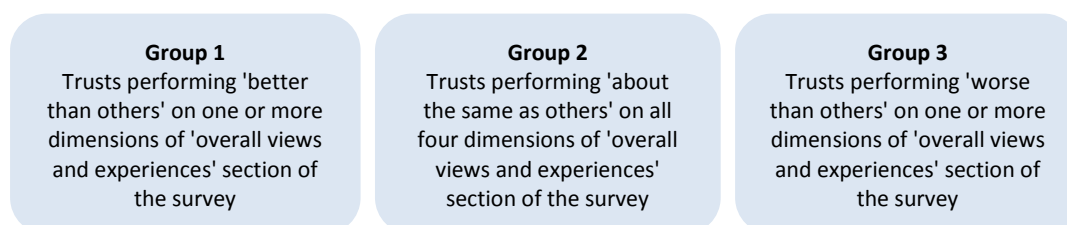
### Ethnographic work

In order to construct a sampling frame for the organisational case studies, for all 160 acute NHS hospital trusts in England we will review the report published by the Care Quality Commission (CQC) which shows how a trust scored for each section in the national adult inpatient survey compared with all other trusts that took part. We will review the four items of the 'overall views and experiences' section (Section 10, see Box 1) of the survey and group trusts according to whether they are performing 'better than others' on one or more dimensions of 'overall views and experiences'; 'about the same as others' on all four dimensions of 'overall views and experiences'; or 'worse than others' on one or more dimensions of 'overall views and experiences' (see Figure 2).

#### **Box 1. 'Overall views and experiences': items from Section 10 of the national adult inpatient survey**

- Q67. Overall, did you feel you were treated with respect and dignity while you were in the hospital?
- Q68. Overall... 'I had a very poor experience' (0) to 'I had a very good experience' (10)
- Q69. During your hospital stay, were you ever asked to give your views on the quality of your care?
- Q70. Did you see, or were you given, any information explaining how to complain to the hospital about the care you received?

**Figure 2. Classification of acute NHS hospital trusts for sampling purposes**



We will select five trusts to be our organisational case studies, ideally two from group 1, two from group 2 and one from group 3. Should this not be possible we will select five trusts that together provide a sufficiently wide range of examples of contemporary use of patient experience data in cancer and dementia services to inform our overall findings and guidance for practitioners. Other criteria informing the selection will be geographical location, trust size, willingness to participate. The exact nature of the (hard or electronic, qualitative or quantitative) artefacts we will 'follow' through the organisation will be established on the basis of our preliminary visits to the study sites. In identifying our five case study sites, we will also take into account the findings from Locock et al.'s survey of patient experience leads from all acute NHS hospital trusts in England. In particular, for our case study sites from Group 1, we will seek to select trusts with consolidated processes for translation of patient experience data into quality improvement projects; for case study sites from Groups 2 and 3, we will prioritise the study of organisations with limited experience of translating patient experience data into quality improvements. To avoid the potential for research burden, we will also exclude the trusts which will have already been recruited to the study by Locock and colleagues.

During Phase 1, we will invite hospital managers, nursing staff, patients and/or patient advocates to take part in individual semi-structured interviews (up to 6-8 interviews in cancer care and dementia care services; total up to 12-16 interviews at each participating trust) which will explore in depth local patient experience data practices. Sampling will be guided by the ethnographic observations carried out in this Phase. We will aim to interview a sample of members of staff at ward, service, directorate

and Board levels and patients (including Non-Executive Directors –NEDs- and Patient/Public Governors of Foundation Trusts) who are involved in ‘interacting’ with patient experience data (that is either involved in generating the data, reporting on it, interpreting it, or translating it into quality improvements).

#### Joint Interpretive Forums (JIFs)

Participants (hospital managers, frontline staff, patients and/or carers) in JIFs at each participating trust and in the final cross-site JIF with policy makers will be purposively identified on the basis of their role in the organisation, participation in earlier phases of the study, willingness and availability to participate.

#### *Setting/context*

#### Ethnographic work

We will carry out our ethnographic work in cancer care and dementia care services at each of five selected case study sites. We are focusing our study on acute NHS hospital trusts in view of the fact that these organisations have more established mechanisms for the measurement and interpretation of patient experience data compared to community trusts and primary care providers. We selected dementia care and cancer care services for our ethnographic work in view of the existence of well-established formats for patient experience data in the area of cancer care, which contrasts with the challenges that documenting patient experience presents in a clinical field of great policy relevance such as dementia care. Since often dementia services do not constitute a discrete environment but a set of care practices distributed across wards and clinics, we will apply for permission to carry out observations in the hospital wards where these practices are most likely to take place more frequently - for example, care of the elderly and respiratory medicine wards (44). For both dementia and cancer services, the main criteria guiding our choice of services at each participating site will be linked to the possibility of observing how patient experience data (for example, the national cancer patient experience survey data) are collected, collated and responded to. Further context to our ethnographic fieldwork with regard to the collection, use, and impact of patient experience data on service provision will be provided by the findings from the HS&DR study by Locock and colleagues.

We will interview members of staff at ward, service, directorate and Board levels and patients (including Non-Executive Directors –NEDs- and Patient/Public Governors of Foundation Trusts) who are involved in ‘interacting’ with patient experience data collected in the same services taking part in the ethnographic work (see above).

#### Joint Interpretive Forums (JIFs)

One JIF will be held at each of the five case study sites selected for the ethnographic work. One final cross-site JIF will be held in London and involve representatives from all case study sites as well as policy makers and representatives from patient organisations.

#### *Data collection*

#### Ethnographic work

At each of the five case study sites we will collect: (a) documentary evidence: current and historical policy documents, Board meetings minutes, strategy documents relating to quality and patient experience specifically, artefacts used for generating, communicating and reporting patient experience data; and (b) ethnographic fieldnotes (eight 4-day visits -total 32 days- at each site during one year) focusing on tracing the journey(s) of the artefacts used locally to record, report, interpret and act upon patient experiences of care and their interactions with social actors (nurses in particular) throughout the organisation. Observations will focus on tracing the journeys of the artefacts under study (see Figure 1 above for a simplified illustration of the journey of patient experience survey data). This means that in each service, we will identify key interactions between human and non-human actors (for example, the procedures for collating patient experience data, or the meetings at which

these data are discussed) and observe the practices in which these interactions are embedded. In the case of Foundation Trusts, we will look at how data are shared and discussed with the Council of Governors and examples of how the Council of Governors uses such data in the fulfilment of its statutory duties. We will also document any evidence of Board actions/recommendations/requests as a result of discussions around the data in question. As part of our ethnographic work, we will record nurse staffing and skillmix details in all the services examined; our observations will pay particular attention to the role different nurse grades play in shaping the journeys of data through the organisation. Observational data will be recorded as low inference fieldnotes in a spiral bound notebook and later word processed. Occasional still photographs will be taken of groups (staff and patients) involved in routine practices of patient experience data collection, processing and use. In the highly unlikely event that no suitable artefacts can be followed in real time during the course of our 12 months of fieldwork, we will examine data journeys retrospectively, tracing the pathways and interactions through the accounts of field informants and documentary evidence (e.g. meeting minutes, action plans, organisation bulletins and news archives). At each of the five case study sites we will also carry out individual semi-structured interviews with hospital managers, board members, nursing staff, patients and/or patient advocates (where possible, we will include patients Non-Executive Directors –NEDs- and Patient/Public Governors of Foundation Trusts) to explore in depth local patient experience data practices. We aim to carry up to 6-8 interviews in each of the participating services (up to 12-16 interviews per trust), for a total of up to 80 interviews. The interviews will be digitally audio-recorded on encrypted devices with participants' permission. Encrypted audio files will be stored on university computers or encrypted portable devices. Transcripts will be anonymised at the point of transcription. Any printed material containing personal information will be stored in a locked cabinet on King's College premises (Dr Donetto's office).

#### JIFs

In Phase 2 of the project, the group discussions in JIFs will be audio-recorded and transcribed verbatim.

#### *Data analysis*

#### Ethnographic work

Data from documents, interviews, observations and still photographs will be analysed in a triangulating fashion to develop concrete descriptions of patient experience data through the organisation and its effects on quality improvement. These data sources will provide both contextual information and specific insights into the patient experience data journeys we will be studying. ANT's approach to analysis can be described as a 'material-semiotic' method. Material semiotics (and actor-network theory) is primarily concerned with understanding the relations between people and objects, that is, the ways in which people and objects shape each other in mutual relations. The methodological commitment of ANT is to describe in detail how these elements may be related and how their associations are enacted in practice. Analysis informed by ANT proceeds through careful reading and re-reading of all data, identification and detailed description of patterns and relations, and examination of the links between data and theoretical framing. In interrogating our ethnographic data we will foreground and prioritise the detailed description of interactions and relations between patient experience data artefacts, human actors, and organisational policies in each service examined.

Within-case and across-case comparisons will seek to draw out any relevant and generalisable facilitating factors in the effective use of patient experience data for quality improvement. Within-case comparisons, in particular, will shed light on the mechanisms through which organisation-wide strategies operate at the level of individual services. Across-case comparisons will enable us to highlight the key dimensions of effective organisational strategies leading to better patient experiences. Coding and data management will be aided by the use of qualitative data analysis software such as Atlas.ti (version 7) and/or Nvivo (version 10).

### Joint Interpretive Forums (JIFs)

JIF transcripts will be analysed thematically with the specific purpose of developing practical and generalisable recommendations for policy and practice as to useful strategies to enhance the use of patient experience data for quality improvement.

### **Dissemination and projected outputs**

#### *Dissemination*

A range of dissemination approaches will be used to target different research audiences. We will produce a final research report for the NIHR journals library detailing all the work undertaken and including an abstract and executive summary focused on results/findings and suitable for use separately from the report as a briefing for NHS managers. We will also prepare a set of 10 PowerPoint slides presenting the main research findings and designed for use by the research team or others in disseminating the findings to the NHS. The slides and the report will be made available on the HS&DR programme website.

We will prepare at least two high impact academic papers (one focusing on implications for quality improvement practitioners and one aimed at academics interested in healthcare quality improvement) and submit abstracts for presentation at national and international conferences related to quality improvement in healthcare (Health Services Research Network – HSRN; Royal College of Nursing – RCN; International Society for Quality in Healthcare – ISQua – conference), as well as prepare short articles for the healthcare professional and NHS management press.

The final JIF meeting with key stakeholders from the five study sites and policy makers will represent an opportunity for cross-site exchanges and dissemination; we will also hold a dissemination event at each of the five sites (these will be open to NHS staff and managers, patients and patient representatives).

We will commission the production of a video animation (4-5 minutes) to convey the main messages from the research to NHS staff and the general public. This will be uploaded onto King's College London website and shown at dissemination events. Links to the study report and the video animation will be circulated to all survey participants and through social media such as LinkedIn, Twitter, and Facebook. We will also give consideration to representing our findings through graphical representations of journeys.

Findings will be shared through NHS Improving Quality, NHS Contact, Help, Advice and Information Networks (CHAINS), NHS networks, and patient organisations (such as Healthwatch, Patients Association, Carers UK, National Voices), and with organisations with a strong interest in this area of research (such as the King's Fund and The Health Foundation). We will engage with Dementia-UK and Cancer Research-UK early in the course of the study and aim to work collaboratively with these organisations to ensure our findings are disseminated to their audiences in the most effective and appropriate way. Press releases will be sent to the Editor of the Health Service Journal and to the health correspondents of the national media.

#### *Outputs*

A key output of this research will be robust evidence about the organisational strategies and practices that can support and enhance good practice in the collation and effective use of patient experience data for the implementation of quality improvements. The study will therefore generate outputs of practical and immediate relevance to all acute NHS hospitals in England. In particular, a set of practical recommendations and actionable guidance will help NHS managers to identify the factors and processes that may be facilitating and/or hampering the journeys of patient experience data in their organisations and enable them to re-examine their quality improvement strategies in the light of these. In line with the current policy emphasis on participatory approaches to healthcare service design and delivery, a tailored strategy for the dissemination of research findings will ensure that the study also contributes to empowering patients (and also patients' carers and advocates) by providing

accessible information on the ways in which organisations, patients and carers could and should make use of patient experience data to improve quality of care.

Overall, the study will contribute to the NHS care quality agenda at three different levels: 1) micro-level of everyday practices and interactions (production of accessible guidance in text and video format for optimising staff's and patients' involvement in monitoring and improving experiences of care); 2) meso-level of service management and organisation (documenting senior management responsibilities as well as the facilitating factors for impact of patient experience data on organisational change); and 3) macro-level of policy and socio-economic drivers (highlighting the ways in which contextual aspects shape and are shaped by the former two levels). A recent review of the existing evidence on the use of patient experience data for guiding quality improvement has called for a 'more coordinated approach' to these data that would help with 'developing and testing more efficient ways to gather the data, and working out how to ensure that the results are used for quality improvement(1).' By generating actionable recommendations for policy and practice, this study will contribute to the development of such an approach, ultimately aiming to improve the healthcare experiences of NHS staff and patients alike.

The study will be overseen and steered by an advisory group which will meet every five months approximately (first and last meeting face-to-face, the others via teleconference). Advisory group members will help to ensure that the study outputs are tailored to and reach the audiences for which they are intended. Details of the Advisory Group membership are provided elsewhere due to confidentiality. Also, AMR is a member of the National Nurse Executive Network and has close links with the Royal College of Nursing Nurse Executive Forum as well as experience of presenting at the Chief Nurses Conference for Directors of Nursing on several occasions. SB has links with patients' and carers' associations nationally and will take responsibility for guaranteeing that research outputs are of relevance to these groups. The main theoretical and methodological contribution of the proposed study will be the exploration of the strengths and challenges of applying an Actor-Network Theory (ANT) approach to the study of organisational practices with a specific focus on nursing and nurses (24-26). Although socio-material approaches such as ANT have a long history in social science and computer-supported cooperative work (CSCW), they have not been used explicitly for quality improvement purposes; this study will therefore be of reference for future research in this field.

### **Plan of investigation and timetable**

Prior to commencement of study: recruit two researchers (one 100%FTE and one 50%FTE).

Months 1-3: classify acute NHS hospital trusts according to sampling strategy; identify and approach suitable case study sites; prepare and submit NRES ethics application through IRAS system; [Milestone 1 (month 3) – application for ethical approval submitted via IRAS system]

Months 4-6: secure access and formal R&D approval from case study sites; carry out preliminary meetings at case study sites; carry out familiarisation visits at case study sites (one 4-day visit at each site); [Milestones 2 and 3 (month 6): NRES ethical approval obtained and successful recruitment of five case study sites]

Months 7-18: data collection visits (eight 4-day visits – total 32 days - at each site during one year) at case study sites to gather documentary evidence, and carry out observations and interviews with hospital managers, nursing staff, patients and/or patient advocates – up to 6-8 per service, 12-16 per site, total up to 80 interviews). Begin data analysis. [Milestone 4 (month 18): fieldwork at five case study sites successfully completed]

Months 19-22: complete analysis of data from the ethnographic work; carry out JIFs; begin analysis of data from JIFs ('sense-making' phase); begin report drafting. [Milestone 5 (month 22): analysis and synthesis of Phase 1 (ethnographic work) findings completed]

Months 23-27: complete analysis of data from JIFs ('sense-making' phase) and integrate with findings; complete report writing; commission video animation; prepare and carry out dissemination

events at study sites; prepare further outputs; wider dissemination.[Milestone 6 (month 27): dissemination events completed and submission of final report to NIHR].

### **Project management**

The study will be led by Professor Glenn Robert (GR) and Dr Sara Donetto (SD), who will coordinate the research team, oversee study progress, carry out fieldwork at one of the sites, and ensure that deadlines for the study outputs are met and project budget is managed effectively. This will be SD's first commitment as PI on a large-scale project; however, she will benefit from support and advice from all three senior academics on the research team: co-applicants Professor Davina Allen (DA), Professor Anne Marie Rafferty (AMR) and Professor Glenn Robert (GR). In addition, to address the reviewing Panel's comment regarding the team's plan for effective mentoring support for the PI, additional arrangements have been made in developing the full study proposal. GR's time on the project has been increased to 12.5%WTE, where 2.5%WTE will be dedicated to regular one-to-one fortnightly mentoring meetings – providing practical advice as well as leadership support - with SD over the course of the study. Since January 2013, GR and SD have successfully collaborated on a number of research projects carried out at the National Nursing Research Unit, King's College London. Professor Alan Cribb, at the Department of Education and Professional Studies, King's College London, who has worked with SD extensively in the past during her doctoral and early post-doctoral research, has also agreed to support SD in a mentor's capacity on an *ad hoc* basis throughout the project. Between 2012 and 2014 SD has undertaken training in "How to become a Principal Investigator" (2012, KCL), "How to manage a research project" (2013, KCL) and "Leadership in action" (2014, inter-university collaboration). In the course of the project, she will attend further relevant professional development training available at King's College London (for example, "Creativity and problem-solving", "Developing your online presence", "The engaging researcher", and "Leadership skills for researchers"). We are confident that these mentoring and professional development arrangements will enable SD to successfully manage the project through to completion within the set time frame.

Three of the co-applicants in the team (SD, GR, and AMR) are based at King's College London, one (DA) at Cardiff University, and one (Sally Brearley) is based in London and will provide input as an independent consultant. To ensure effective communication within the team, regular conference calls and/or video-conferences (via Skype) will be planned and arranged (by booking equipment and conference call facilities) at the beginning of each year of the study. The team will schedule monthly calls/videoconferences and revise the schedule as and when necessary. In order to enable effective team dynamics, we also planned three face-to-face team meetings in the first and second year of the project and an additional one towards the end of the study.

An advisory group will provide input throughout the duration of the study and help to ensure that the study outputs are tailored to and reach the audiences for which they are intended. Details of the Advisory Group membership are provided elsewhere due to confidentiality.

### **Approval by ethics committees:**

The study involves access to NHS premises, observation of working practices in hospital, interviews with members of staff and patients/carers, and group discussion with members of staff as well as patients/carers, and will therefore require full NRES review through the Integrated Research Application System (IRAS). The application process will begin as soon as the project commences. We aim to obtain full NRES ethical approval by the end of month 6. We will also submit applications for R&D approval through the IRAS system in months 4-6 of the study, once we have identified and approach suitable case study sites. Issues of confidentiality and informed consent will be addressed for all participants in the study. Information material including participant information sheet and consent forms will be reviewed by our advisory group. All participants will be required to provide their informed consent to taking part in the study and to the treatment of data. The researcher will obtain written consent for all individual interviews; group photographs and where possible for group discussions. Verbal consent will be obtained for informal conversations and, when written consent is not possible, for group discussions. Signed consent forms will be treated as confidential. We



anticipate the following potential ethical issues: (1) Non-participant observation can be perceived as intrusive by staff and patients/carers. We will make sure that staff and patients/carers on the wards are informed about the ways in which observations will be carried out before giving consent and that they have the option to ask questions and have them addressed. (2) Participating patients who suffer from dementia may lose capacity to consent in the course of the study. We expect to have only one contact with most participating patients and to obtain consent at the time of the observation, interview or group discussion. However, should a participating patient be involved on more than one occasion (for example, for interview and participation in a Joint Interpretive Forum), we will aim to ensure that capacity to consent is ascertained at each encounter (by assessment or communication with carers). Where participants have lost capacity to consent, we will withdraw them from the study and not collect any further data. Existing interview data will be retained and used in its anonymised form. We will include this information in our consent form. (3) Reflecting on issues relating to patients' experiences of care can sometimes prove upsetting for patients, carers and members of staff alike. We will ensure systems are in place to allow participants to receive confidential support (e.g. from local Patient Advice and Liaison Service – PALS), should they find participation in the study challenging in any way. (4) Group discussions in the format of Joint Interpretive Forums (JIFs) are intended to encourage sharing of experiences and 'perspective taking'; nevertheless, these discussions can trigger group dynamics which have the potential to make some participants feel uncomfortable. Although in view of the topics to be discussed at the JIFs in our study, this is unlikely to happen, advice will be sought from the advisory group and its patient/carer members in particular, on how to best prevent and/or handle potential tensions in the groups. All data will be stored securely on university premises or encrypted portable devices.

## **Patient and Public Involvement**

### *Aims of active involvement in this project*

The main purpose of involving patients and/or carers in designing and carrying out this research study is to ensure that their views are duly taken into account throughout the research process and that their perspectives contribute to the generation and dissemination of research findings and recommendations. Ultimately, this involvement aims to ensure that patients and carers have a say in the ways in which attempts are made to optimise and enhance the strategies and systems through which their feedback on their care experiences is elicited and used.

### *Patients, carers or members of the public to be involved*

Co-applicant Sally Brearley is an experienced patient and public representative, former academic and advisor, a patient/public reviewer for several NIHR programmes and a member of a number of professional networks and organisations. We have also invited two PPI advisors, who kindly contributed to the preparation of this application for our January 2015 submission, to become members of our advisory group in view of their experience of using cancer services and of caring for a person with dementia, respectively. They both agreed. At each of our case study sites, two patients and/or carers with experience of using dementia and cancer services will be asked to take part in the JIF we will carry out as part of Phase 2 of the study. Finally, we will engage with Dementia-UK and Cancer Research-UK early in the course of the study and aim to work collaboratively with these organisations to ensure our findings are disseminated to their audiences in the most effective and appropriate way.

### *Methods of involvement*

Sally Brearley will spend 16 days per year as a member of the research team. She will coordinate PPI activities and ensure that they are useful and appropriate at all times. She will be the first point of contact for the two patient/carer advisors on the study advisory group; she will inform them about advisory group meetings, provide details about any further input required outside of these meetings, and offer support and assistance where required. SB will also liaise with patients and/or carers participating in the JIFs in Phase 2 of the study as well as with Dementia-UK, Cancer Research-UK, and patient organisations such as Healthwatch, Patients Association, Carers UK, National Voices to secure their support for the dissemination of the study findings. Patients and carers involved in the advisory group will participate in a total of five 2-hour advisory group meetings (two to be held in

London, the others as teleconferences) and will be asked to review patient information or dissemination material for a total of 4-6 hours each over a 12-month period. At each participating trust 1-2 patients/carers will take part in a JIF. We will invite one or two volunteers from this group to take part in the final JIF to be held in London. PPI advisors will be reimbursed for their participation in meetings and for the time they dedicate to revising material and providing input for the study in line with INVOLVE guidelines.

## Expertise

The study team has relevant expertise in various areas of quality improvement and healthcare research and practice. SD is a social scientist and non-practising physician with expertise in person-centred care, service user involvement, health professional education, and qualitative research methods. She will be PI, coordinating the research team, overseeing study progress, carrying out fieldwork at one of the sites, and ensuring deadlines for study outputs are met and project budget is managed effectively. Senior academics GR, AMR, and DA have vast experience of successfully managing large research projects and grants. GR is acting as CI.

GR has a background in organisational sociology and expertise in the development, study, and evaluation of innovative approaches to healthcare quality improvement. He will help ensure that study outputs are relevant to NHS organisations. AMR's extensive knowledge of nursing policy and practice will help with examining the role of nurses in improving patient experience within the broader policy context. Her access to NHS England and policy networks will help with access to sites, framing actionable recommendations, and supporting dissemination. DA brings expertise in ANT, the 'organising work' of hospital nurses, healthcare organisation and delivery and in particular the role of artefacts; she will contribute to the theoretical framing of the study and data generation strategy. As mentioned earlier, SB an experienced patient and public representative and advisor, a patient/public reviewer for several NIHR programmes, a former Foundation Trust patient governor, and a member of a number of professional networks and organisations. She will coordinate the PPI strategy throughout the study and support patient/carers who are members of the study advisory group where necessary. All team members will contribute to study design, data analysis and study outputs.

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**Glossary**

ANT	Actor-Network Theory
CHAINS	NHS Contact, Help, Advice and Information Networks
CQC	Care Quality Commission
CSCW	Computer-supported Cooperative Work
FFT	Friends&Family Test
FTE	Full Time Equivalent
GSTFT	Guy's and St. Thomas' NHS Foundation Trust
HSRN	Health Services Research Network
IRAS	Integrated Research Application System
ISQua	International Society for Quality in Healthcare
JIF	Joint Interpretive Forum
NED	Non-Executive Director
NRES	National Research Ethics Service
PNM RESC	Psychiatry Nursing and Midwifery Research Ethics Sub-Committee
R&D	Research & Development
RCN	Royal College of Nursing
RDS	Research Design Service