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Informing the development of NICE Quality Standards through secondary analysis of qualitative narrative interviews on patients’ experiences.

Chief investigator           Sue Ziebland

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Informing the development of NICE Quality Standards through secondary analysis of qualitative narrative interviews on patients’ experiences.

Aims
To identify common, core components of patients’ experiences of the NHS to inform the development, and measurement, of NICE Quality Standards. To examine the reach and limitations of these core components in describing the aspects of care that are important to patients from diverse backgrounds, with experience of different conditions and NHS care pathways.

Objectives
We will
1. conduct qualitative secondary analysis (of collections of narrative interviews) to identify common, core components of patients’ experiences of the NHS
2. test these candidate components with i) further purposive sampling of the interview collections and ii) a series of focus groups with users
3. embed the project alongside the development of NICE Clinical Guidelines and Quality Standards
4. inform the development of measurement tools on patients’ experiences
5. develop and share resources and skills for secondary analysis of qualitative health research

Research Questions
Are there common, core components of patients’ experiences of the NHS? If so, (how) do these vary by type of pathway or conditions? What are the limitations and reach of the core components? How might they best be incorporated into NICE guidelines and Quality Standards and inform measurement?
BACKGROUND

Patients’ experiences are of central importance to the NHS. *Transparency in Outcomes: A Framework for the NHS* makes patient experience one of five ‘outcome domains’ in a new NHS Outcomes Framework. However, the White Paper *Equity and Excellence: Liberating the NHS* notes that ‘healthcare systems are in their infancy in putting the experience of the user first’ and many NHS organisations struggle to identify the best way of involving patients’ experiences in service improvement.

An emphasis on patients’ experiences suggests both a fruitful and equitable way to improve public services. Those with experience of health services often have both the ideas and motivation to contribute to service improvement and people’s accounts of their experiences of care can be inspiring, memorable and encourage staff to improve services. Better experiences of care help people to get better faster, thus is justified both clinically and in terms of value for money. While anxiety and fear delay healing, good communication between staff and patients has been shown to contribute to well-being and hasten recovery (Goodrich and Cornwell 2008).

For patients experiences to be a central plank of service design a robust and evidence-based approach to sampling, collecting and analysis is needed (Dr Foster Intelligence 2010).

The qualitative method of relatively unstructured, in-depth interviewing with purposive (maximum variation), national samples of patients is widely recognised as a key research method for generating understanding of patients’ experiences and perspectives (Pope and Mays 2000, Fulop 2001). But the research is time consuming to conduct, some groups are hard to include and the whole process requires intensive involvement from skilled researchers. Qualitative secondary analysis has the potential to be highly efficient, allowing researchers effective use of time for analysis and rigorous testing of findings (Heaton 1998, 2004).

NICE’s Quality Standards are a central component of the Coalition Government’s vision for the NHS. The White Paper *Equity and Excellence: Liberating the NHS* notes that “to achieve our ambition for world-class...
healthcare outcomes, the service must be focused on outcomes and the quality standards [developed by NICE] that deliver them”, NICE QS provide definitions of what high quality care looks like across a range of clinical care pathways. They will be used by the NHS Commissioning Board to inform the development of the levers, incentives and support that it will provide for GP Commissioning Consortia as they seek to commission for improved outcomes. NICE are tasked to develop a patients’ experience Quality Standard in 2011 and up to 150 further QSs for patient care pathways over the next 5 years, for which there is a remit to include patients’ experiences. NICE regularly, and increasingly, synthesise the results of qualitative studies to generate an evidence base that is used to develop its clinical guideline recommendations. The frequency with which evidence from qualitative studies contributed to NICE guidelines increased from 9 in 2003 to 139 in 2006 (Tan et al 2009). Among the reasons for this increase are the growing number of clinical guidelines on chronic conditions, where patients needs and perspectives are particularly relevant, and NICE’s policy and emphasis on strong patient and carer involvement throughout its guideline development process (Tan et al 2009, NICE Clinical Guidelines Manual 2009). NICE has a dedicated team (the Patient and Public Involvement Programme) which provides advice and support to NICE on patient, carer and public involvement in its work programmes.

The research work of the Health Experiences Research Group in Oxford University has produced an archive of over 2,500 in-depth narrative interviews on over 60 health conditions, all collected since 2000. Despite research council encouragement, there has been some resistance in the qualitative research community to using secondary qualitative analysis including the concern that the loss of context and lack of contact with the original researcher limit the scope of the analysis (Mauthner et al 1998, see also Fielding 2004 for a counter argument). The archive of in-depth qualitative interviews collected by the Oxford group has been an exception to this reluctance in the qualitative research community; widely used by several

Drawing on this unrivalled collection we propose a secondary analysis to identify core components of patients’ experiences to address the needs of the NICE Quality Standards Team and NICE’s Clinical Guideline National Collaborating Centres (co-applicants TS and NO) in a strong and focused collaborative study.

Whilst the NHS pathways that patients follow vary between conditions and health issues, we could anticipate core elements e.g. access and waiting, communication, information, dignity and respect. There may also be discernable patterns in different conditions e.g. regarding the types of information that patients might want, the recent SDO funded study ‘Information for Choice: what people need prefer and use (Wyke et al) ’ found that where there is a strong evidence-based protocol in a life threatening condition (lymphoma) patients preferred information from doctors, while for decisions that were value based (such as residential care for a family member with dementia) information about how other people had made their decisions was more important.

A particular strength of this proposal is that the eventual users of the research output (in this case NICE) are involved from the outset. There is growing evidence in the field of knowledge transfer in health care to support more collaborative models of research production and use, sometimes referred to as co-production. Van de Ven and Johnson (2006) propose a model of ‘engaged scholarship’ in which researchers and research users co-produce knowledge that can advance both theory and practice. It has been argued that involvement of potential research users may be one of the most important
determinants of research impact on policy and elsewhere (Nutley, Walter and Davies, 2007; Armstrong and Alsop 2010). We anticipate that by collaborating in the design, conduct and reporting of research, and by seconding a researcher to spend time with NICE staff, we will ensure the results of the secondary analysis are of maximum use.

**NEED**

Quality Standards consist of a set of descriptive quality statements for high quality care across three agreed dimensions of quality – effectiveness, patient experience and safety – and attendant quality measures. NICE is therefore required to incorporate patients’ experiences into its Quality Standards work. Quality Standards will be developed for up to 150 patient pathway topics over the next 5 years. Quality Standards require an evidence base from which recommendations for care are initially developed, and these recommendations will be distilled into descriptive statements for Quality Standards. The evidence base and recommendations already developed for NICE clinical guidelines will be used where possible. Evidence about patients’ experience is required therefore for:

1. Guidelines currently in development that are also commissioned to become topics for Quality Standards
2. Quality Standards which are being developed where patient experience is not a priority area in the development of a particular NICE guideline
3. Quality Standards for areas where NICE guidelines do not exist and for which patient experience information is also lacking

To conduct original, high quality research on patients’ perspectives of the 150 care pathways is not feasible, nor is it desirable when there is existing qualitative research to inform the process. Where relevant data exist the research and policy leads can concentrate on developing a sensitive and informed analysis and on identifying optimal arrangements for knowledge transfer: these two activities form the backbone of the proposed collaborative project.

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NICE guideline development draws on published evidence, including qualitative data on patients’ experiences. As part of this process guidelines teams have used material published on www.healthtalkonline.org (formerly DIPEX) by the Oxford applicants.

To date this has happened in an ad hoc manner and the NICE teams have only had access to the research published on i) the websites and ii) in peer reviewed articles from the Oxford group. In the proposed project we will use the full interview transcripts (i.e. far more material than is available on the website) to conduct a targeted, secondary analysis of a purposively sampled sub set of the 60 collections currently in the archive, with the specific purpose of informing NICE clinical guidelines and Quality Standards.

The process for NICE Quality Standards (QS) development and measurement in 2011 and beyond is both complex and emerging. Staff central to this important and ambitious work (TS, NO, VT) are keen to incorporate robust qualitative evidence about patients’ experiences of both the generic and topic-specific elements of care pathways to inform clinical guidelines and QS and the identification of appropriate and measurable health outcomes. As an emerging process there is both the opportunity to embed new ways of incorporating patients’ experiences and a need to work together very closely and flexibly using a variety of approaches including secondment arrangements.

METHODS
We propose a qualitative secondary analysis of sets of interviews that have been collected by members of the Health Experiences Research Group in the Department of Primary Care, University of Oxford. As a prelude to the methods we explain how and why the interviews were originally sampled and collected and the implications for the secondary analysis.
THE INTERVIEW COLLECTIONS

The qualitative data that will be analysed for this project were all collected as national, purposively sampled interview collections which aimed for maximum variation. The interviews were all collected by experienced qualitative social scientists working with the Health Experiences Research Group in Oxford. There are currently 60 collections of interviews, each concerning a different health issue (ranging from pregnancy to living with a terminal illness) and each set comprising 40 – 50 interviews. All interviews have been tape recorded, transcribed, checked by the interview participant and copyrighted for a number of non-commercial purposes, including secondary analysis and publication. There is, therefore, no need to seek ethics approval to analyse these data.

The projects share a research question (What are the experiences and information and support needs of people with X? ) and a common interview method that starts with an appropriate variation on an open ended question intended to invite a narrative response (for example ‘Could you tell me all about it from when you first thought there might be a problem?’). When the person has completed their account a semi-structured section of the interview includes questions and prompts about any issues of interest that may not have been fully discussed in the narrative. These typically include questions about treatment decisions, information, support, communication with health professionals. All participants are asked if they have anything they would like to tell other people who are starting out on the same journey and if there is anything they would like to pass on to NHS staff at all levels, who might learn from the participant’s experiences. These questions often add rich, informative data about how services and communication could be improved (Ziebland 2006).

Each of the interview studies starts with a literature and field review and sets up a specialist advisory panel including patients, professionals, researchers, clinicians, and representatives from the voluntary sector and (if appropriate) the funding body. The panel advises on the parameters of the project, including selection and recruitment of participants.
A maximum variation sample (Coyne 1997) of 40-50 people is sought to help generate as diverse a sample as possible, including both people whose experience might be considered ‘typical’ and those with more unusual experiences. For each project recruits are actively sought through: a national network of primary care staff, hospital consultants and specialist nurses, advisory panel members, local and national support groups, advertising online and in local newspapers, snowballing through participants and personal contacts. Analysis and data collection proceed simultaneously and continue until ‘data saturation’ is reached to ensure that the widest practical range of experiences has been included.

Analyses from the interviews are published in the conventional manner in peer reviewed clinical (e.g. Locock et al 2008, 2010a, Chapple et al 2010, Prinjha et al 2009) and social science (e.g. Locock et al 2010b, Ryan 2010, Ridge et al 2007, Cheshire & Ziebland 2005) journals and a series of topics that are important to patients are also published on www.healthtalkonline.org that is run by our colleagues in the DIPEX charity. The website includes analysis and interview extracts on around 25 topics that emerge as important to patients who we interview. These are different for each condition-specific collection but might include early signs and symptoms, treatment choices, work, family life, relationships, side effects, information and support, communication with doctors, access and unmet needs.

The research team in Oxford has spent 10 years working on this series of projects during which time we have raised funding for 68 collections (several more are in progress) as well as establishing international collaborations, written a researchers’ handbook, established training for research staff, secured some core start-up funding (for the cancer collections) from the Department of Health (Section 64) and gained approval for the study methods from an NHS Ethics Committee. The collections have been made available under license from the University of Oxford for several projects incorporating secondary analysis (see below).
Secondary Analysis with the Oxford archive

The relatively unstructured, open-ended nature of the interview method helps to identify the respondent’s own concerns, meanings and priorities (rather than being linked to a highly focussed research interest) and makes the interviews particularly fruitful for secondary data analysis (Sandelowski 1997, Thorne 1994, 1998). Any researcher using secondary analysis is likely to be occasionally frustrated by the lack of follow up questions on their topic (Hinds 1997, Heaton 2004) although the combination of skilled interviewing with open, narrative based methods has helped to reduce these problems in the Oxford data.

Despite Research Council encouragement there has been some resistance in the qualitative health research community to contributing and sharing data for secondary analysis (Fielding 2004, Corti 2004). The Oxford collections are an exception: they have been licensed for use by several well established academic colleagues. Studies using secondary analysis of the Oxford data include an SDO funded Information for Choice project (led by Professor Sally Wyke, Stirling), studies of gender and health MRC Social and Public Health Research Unit in Glasgow (Professor Kate Hunt et al), an ESRC funded project on comparative keyword analysis in health talk (Professor Clive Seale), and an ESRC funded analysis of chronic health issues in young people (Janet Heaton, who is also the author of a widely used text book on secondary analysis), an NIHR programme (Ziebland at al) and a comparison of local and national data on end of life care (Joe Calabrese, 2010). These secondary analyses have already led to peer reviewed publications in leading journals (e.g. see Charteris Black 2009, Emslie 2007, 2009, France 2010, Lowe 2009, Hilton 2008, 2009, Hunt 200)

We are convinced that many of the core components of quality care and patients experience may have a fairly long shelf life, yet others may have emerged more recently (some patient safety concerns, for example). Some of the narrative interviews in the Oxford archive, while all collected within the last 10 years, may include people who were initially treated many years earlier. To reduce the risk of redundancy we will exclude from the secondary analysis
any interviews concerning treatment experiences more than 10 years ago. This will exclude few interviews from the analysis. The healthtalkonline websites are reviewed every 24 months and updated with new interviews if our medical advisers inform us that treatments have changed.

THE PROPOSED PROJECT

We now turn to the methods used to meet each of the proposal objectives.

Objective 1

To conduct qualitative secondary analysis to identify common, core components of patients’ experiences of the NHS. We will conduct an initial secondary analysis of a set of 4 collections on exemplar health conditions, each with approximately 40 in-depth interviews. The analysis will seek candidate core components central to patients’ experiences of the NHS.

Sample: We will select conditions to maximize usefulness to the NICE Quality Standards team. At the time of writing 4 NICE quality standards have been published and a further set of 31 Quality Standards to be developed have been referred from the Department of Health to NICE but when each will be developed has not yet been agreed. Co-applicants TS and NO anticipate that likely topics for Quality Standard development in 2011/12 include epilepsy, asthma, diabetes in children and young adults, schizophrenia and antenatal care. It is possible that agreement on topics for immediate development between January and June 2011 will suggest that analysis of other collections may be more appropriate, in which case the collections involved (but not the methods or ways of working) will change.

Analysis: We will follow a modified framework method (Ritchie and Spencer 1994) which was used successfully by Wyke, Ziebland and colleagues to conduct secondary qualitative analysis for the SDO ‘Information for choice’ project (Wyke et al, Hunt 2009, France 2010). This approach uses charts for a summary description of data from each of the interviews across a set of categories, which are later developed into themes for analysis. The process is
iterative and benefits considerably from the involvement of the full research team during the first analysis while the categories are being developed. We will therefore follow the method used in the Wyke et al project by asking each member of the team to look at an overlapping selection of interview transcripts from the initial two data sets, after which the analysis will be further refined.

Although we will examine themes that would be anticipated from existing literature (e.g. Goodrich and Cornwell 2008) including information, access and waiting, communication, dignity, respect and privacy we will also be particularly alert to emergent themes which we will report and compare across the different data sets. Issues such as safety, access and communication, which have relevance to broader health policy and practice will be explored. Any important new contributions (other than the NICE and PROMS work already identified in the proposal) will be communicated to the appropriate audiences as part of the project dissemination strategy.

**Output:** In a series of iterations during 2011 – 2012 we will develop candidate core components of patients’ experiences of NHS care which will be tested in further analyses and focus groups (see Objective 2, below).

**Objective 2.**
To test these candidate components with i) further purposive sampling of the interview collections and ii) a series of focus groups with users. These focus groups will be needed because some of the interviews for secondary analysis were collected up to 8 years ago and some experiences may seem less relevant today. We are also committed to expanding our findings through involving the experiences of groups whose views are less often heard in research.

We will explore their reach and limitations in two (deliberately challenging) tests:

i) We will perform further comparative analysis with sets of interview from the Oxford groups’ collection, this time the collections will be
sampled purposively with the aim of providing the greatest test of the reach of the candidate core components. The methods used for these further analyses will be based on those described in Objective 1.

ii) We will check our interpretation of the core components of patients’ experiences in up to 6 focus groups with users with experience of the conditions we have covered. We will make particular efforts to include participants who are usually considered hard to involve in research in order to robustly test the findings. Focus groups will be conducted in London, Birmingham, and the north of England; participants will be recruited through our contacts in voluntary organizations and through advertising in free newspapers such as the Metro (which we have used very successfully in other projects to recruit people who are usually considered harder to reach e.g. ethnic minorities, people from lower social class backgrounds). We have included costs for vouchers, room hire, refreshments and travel expenses for the focus group participants, assuming 8-10 participants in each group. Two members of the research team will take part in the groups, which will be audio or video recorded, with the participants permission; and transcribed for analysis.

A comment on the proposed combination of secondary analysis and focus groups

Research findings with different types of respondents using different methods are likely to differ, at least in emphasis. The focus groups are not intended to triangulate our findings from the secondary analysis but to inform and refine our interpretation of the data. In a qualitative investigation data from additional sources is less likely to challenge the initial findings than add levels of explanation, improving our understanding of the reach and limitations of the components of patients experiences that we identify. Informing and refining our findings incrementally through including different health conditions and the
focus groups is expected to enrich our understanding of the circumstances in which the identified core components of patients experience may differ. Any apparently contradictory findings will be examined carefully, explored further in subsequent data collection and theoretically informed explanations will be sought. For example, we know that the provision of health information is important to the vast majority of service users but how, in what format, when and by whom it is provided, supported and responded to are likely to vary in ways that can be described and (hopefully) may either be consistent with, or contribute to, middle range theory.

**Output:** These tests are designed to contribute to our understanding of the reach and limitations of the core components, as well as to suggest modifications to improve their reach and explanations for why the reach might be limited. We will examine how varied are the domains across conditions and explore whether patterns are identifiable so as to offer theoretically informed explanations and illustrations of circumstances in which (otherwise) core components may not apply.

We intend to seek both the generic components of patients experiences and examine how these may vary within different health conditions (condition specific); we will seek theoretically informed explanations for any differences. As well as contributing to a report and a paper for a peer reviewed journal, the results will be presented and illustrated from the interview data (much of which is available in video) in a series of workshops with key staff at the National Collaborating Centres for NICE guidelines (see Objective 3, below) and to contribute to the development of new measurement tools (see Objective 4, below)

**Objective 3**
To embed the project alongside the development of NICE guidelines and Quality Standards.

The project arose from NICE’s need for patient’s experience data and the Oxford team’s desire to make their interviews more widely available within the NHS; as a result activities around knowledge transfer are embedded from
The outset. NICE Clinical Guidelines are built around a series of key clinical questions. The NICE Collaborating Centres use evidence from published qualitative studies when these are relevant. The use of qualitative literature can be challenging since qualitative papers have usually been written to explore an anticipated or emergent issue (which, as is typical in qualitative studies, may not have been predictable at the outset) that may contribute to the social science literature and theory, but probably only indirectly useful in informing NICE recommendations.

The knowledge transfer activities will involve:

i) a part-time secondment to the National Clinical Guidelines Centre for the project’s senior researcher to work (a) with systematic reviewers in use of techniques to analyse qualitative evidence. A need for staff training in the use of qualitative evidence in guidelines development has already been identified (Tan et al 2009) and (b) to work with the NCGC and QS teams in presenting the work of this project to guidance development groups (both clinical guideline and quality standards). A reciprocal arrangement will be offered for a member of the Quality Standards team to be placed within the Health Experiences Research Group in Oxford.

ii) a series of expert facilitated workshops to encourage optimal take up of the findings within NICE. With support from the research team co-applicant Glenn Robert will identify key messages drawn from the secondary analysis of patients’ experiences, which will be illustrated with a series of film montages drawn from the Oxford video and audio collections. The aim of the workshops will be to engage the Collaborating Centres and Quality Standards teams in discussions about how these new syntheses of evidence about patients’ experiences of care can be used most effectively by staff.

Other outputs:
The film montage will be prepared by colleagues in the DIPEX charity and will also appear in the Teaching and Learning section of the website.
www.healthtalkonline.org which is freely available for further use by NICE staff and others who could benefit from guidance about how to use evidence about patients experiences in guideline and QS development.

**Objective 4**

To inform the development of measurement tools on patients experiences (PREMS and PROMS). While the analysis of the interview data are expected to offer rich insights into the contrasting experiences of patients from different backgrounds, with different health conditions and care pathways, the findings will be far more helpful if they also contribute to the development of quantitative measures that can be widely applied in the QS work and the wider NHS.

Measures assessing patient experience require decisions about questionnaire items to reflect aspects of services that are of particular importance to patients and users. Common solutions to these decisions include reference to high level discussions such as the Institute of Medicine’s definition of the dimensions of patient-centred care or statistical analysis of relationships between items in already established questionnaires (Institute of Medicine, Sizmur). Very little research has examined whether domains and then specific items can be identified from qualitative evidence of patients' descriptions of experiences, to make measurement more patient-driven, as, for example, is standard with the development of patient reported outcome measures (PROMs). In addition to identifying domains or components of experience, as described in earlier objectives, analysis will also be carried out to search for specific experiences that could be translated into key questionnaire items. Candidate items will be presented to focus groups to assess alongside broader components.

This will be facilitated by drawing on existing close working relationships between Oxford applicants RF, JC, LL and SZ and the new Green Templeton College Health Experiences Institute (HEXI) focused on integrating qualitative
work on health experiences with the development of quantitative surveys. The work will also draw on a previous SDO project by some of the applicants (RF, SZ) in which analysis of qualitative interviews was used to develop a survey of experiences of services of individuals with long-term conditions.

**Objective 5.**
To develop and share resources and skills for secondary analysis of qualitative health research. Secondary analysis of qualitative data is a highly efficient use of existing data (much of which will have been collected with public money) and allows the research team to concentrate their resources on conducting a rigorous analysis and identifying where they can make a contribution to the literature, clinical practice and service delivery. The Oxford group have shared their data, under licence, with several highly experienced research teams who have found the data a rich source of new insights. The group also run regular and highly regarded courses in Qualitative Research Methods, attended by health researchers from all over the UK (and, increasingly, abroad).

We propose to arrange

i) A workshop with UK researchers who have conducted secondary analyses of qualitative interviews, one of the outputs of which will be recommendations for archiving and preparation of data for sharing.

ii) A one day course in secondary analysis of qualitative data will be prepared for inclusion in our programme of courses in 2011/2012. Feedback will be collected from course participants.

**Outputs:**
Recommendations for archiving and presenting qualitative data for sharing through secondary analysis. These will be informed by our work with NCGC and NICE in-house reviewers and draw on the workshop, course and experience during the project.

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THE TEAM
The team has been assembled to maximise both the research rigour and the impact of the project and benefits from connections through existing working relationships. Victoria Thomas (Associate Director, Patient and Public Involvement Programme, NICE) while not a co-applicant is a key supporter of this work and her involvement further strengthens the relationship between NICE and the Oxford Health Experiences Research Group.

Sue Ziebland (Ci) is a Reader in Qualitative Health Research and Research Director of the Health Experiences Research Group, University of Oxford, which is responsible for the collections of qualitative interviews on experiences of health and illness that will be used for the proposed secondary analysis. Sue has over 20 years experience of research in the academic, health service and voluntary sector, over 100 publications and chapters and has been instrumental in raising over 6.5 million for Health Experience Research Group/ www.healthtalkonline.org projects since 2000. The research group runs highly successful courses in qualitative methods at post graduate and professional level.

Louise Locock (deputy research director) is a member of the NICE Patients’ Experience Quality Standard group and on the Dr Foster Intelligence Board Patient Experience reference group. She has been a key member of the Oxford group since 2004, leading and supervising research on patients’ experiences.

Tim Stokes is Consultant Clinical Adviser, Quality Standards and QOF, NICE, a part-time GP and Honorary Visiting Professor, Department of Health Sciences, University of Leicester. Since 2002 he has led a programme of national clinical guideline development for NICE and since 2009 has provided clinical and methodological leadership for NICE’s work on the Quality Standards and QOF programmes. He has a research track record in both
clinical guideline development and qualitative research and has published over 50 peer reviewed papers.

Norma O’ Flynn is Clinical Director at the National Clinical Guideline Centre and a part-time GP. (The National Clinical Guideline Centre is commissioned and funded to develop guidelines and quality standards for NICE.) She provides clinical and methodological input to guideline development, is a member of the NICE Joint Methodology Review Group and has been involved in supporting the use of qualitative research in NICE guideline development.

Ray Fitzpatrick is Professor of Public Health and Primary Care, University of Oxford. His research is focused on health services research, especially evaluating outcomes of interventions. He directs a programme of research for the Department of Health on patient reported outcome measures (PROMs). RF and SZ are also part of the new (from January 2011) DH Quality and Outcomes Policy Research Unit (also involving Universities of Kent and LSE).

Glenn Roberts is Senior Research Fellow at Kings College, London; an expert in organizational research and service implementation, his work draws on healthcare research policy and practice.

CONTRIBUTION TO COLLECTIVE RESEARCH EFFORT

The project will:

i) identify common, core components of patients’ experiences of the NHS to inform the development and measurement of NICE Quality Standards and clinical guidelines

ii) give examples of patient pathways where these core components may be less applicable and where topic-specific issues arise

iii) engage with user groups to inform further our understanding of the reach and limitations of these core components

iv) offer theoretically informed explanations for these variations
The findings have additional relevance to the NHS and NIHR research community, for example:

INFORMING OUTCOMES MEASURE DEVELOPMENT
The identification of a set of core topics that are central to patients’ experiences in the NHS will be applicable to the development of quality and outcomes measures and PROMS for health care. (RF runs a DH programme on PROMS and SZ & RF are part of the Policy Research Unit on quality and outcomes in health and social care).

INVOLVING USER GROUPS IN IDENTIFYING CORE ISSUES
We will work hard to include people who are usually considered hard to involve in our user groups and whose experiences may therefore be less well reflected in research available for secondary analysis.

KNOWLEDGE TRANSFER TO THE NICE QUALITY STANDARDS AND GUIDELINES TEAM & FOSTERING OF LINKS BETWEEN NICE AND ACADEMIC RESEARCH
Given the emerging and complex process around Quality Standards development it is particularly important that the knowledge transfer activities have been started from the outset: this proposal arises from an identified need within the NICE QS team and the recognition that the Oxford group has data that could address this need. Drawing on evidence about what works in knowledge transfer this collaborative study will include a secondment for the senior researcher to work part time at NICE (with the opportunity for a reciprocal arrangement in 2011/12) and the involvement of an organisational development researcher (GR) who will run workshops with the NICE Guideline Collaborating Centres to communicate the results and establish the optimum methods for incorporating them in NICE processes.

DEVELOP GUIDELINES AND TRAINING FOR QUALITATIVE SECONDARY ANALYSIS IN NHS
This project will help develop methods and training to build capacity for qualitative secondary analysis in health research and data archiving. This will help to maximize the use and value of existing qualitative research for NHS research and policy. The Oxford group will i) run a workshop for researchers using secondary analysis and ii) offer a one day course in qualitative secondary analysis in 2012.

PLAN OF INVESTIGATION AND TIMETABLE
(SEE GANTT CHART, APPENDED)

APPROVAL BY ETHICS COMMITTEE
The Oxford Health Experiences Research Group interview collections which will be used for the qualitative secondary analysis have already been approved for this purpose. Reference: Narrative of health and illness for www.healthtalkonline.org (formerly DIPEX) and www.youthhealthtalk.org Berkshire REC reference 09/H0505/66 22. Interviews are copyrighted to the University of Oxford and can be used for a variety of non-commercial purposes, including research teaching and broadcasting.

Ethics approval has also been obtained for the focus groups (SSD/CUREC1A/11-278).

PROJECT MANAGEMENT and justification of support required
The qualitative researchers appointed to this project will be based in the Department of Primary Health Care in the University of Oxford, where the collections of interviews were originally conducted by members of the team. The Health Experiences Research Group includes clinical, social science, administrative and project management staff who work closely with colleagues in the DIPEX charity (who run the award-winning Healthtalkonline websites). This highly supportive environment includes 15 senior researchers from qualitative social science backgrounds and runs an associated
programme of seminars and research meetings within the department and HEXI (Health Experiences Institute at Green Templeton College).

We recognise that the skills of the qualitative researchers who will undertake the secondary analysis are vital to the success of the project. SZ, research director of the HERG, will take the research lead for the first 12 months of the project, with further input from a senior Grade 9 post for the final 6 months. They will be supported by a Grade 7 research assistant for the full 18 months.

The team will also benefit from proximity and discussion with the researchers who collected the original material, most of whom are still employed in the HERG in Oxford.

RF and SZ will support and guide the identification of items for outcomes measures.

Angela Martin (a research coordinator within the Oxford Research Group) will monitor the progress of the project against milestones and outputs and alert the steering group to any emerging problems.

The main staff costs are for the senior researchers and research assistant – we believe that this combination of skill and seniority level, supported by the rest of the project team, is what is needed for this project. Our experience of secondary analysis of these rich qualitative data suggests that we are not being over generous with the time allocated for this phase.

Costs for the focus groups assume 8 -10 participants in each and are based on the costs associated with other work we have completed. We will offer focus group participants a £30 voucher as well as travel expenses as a token of appreciation for their time.

Overhead costs for NCGC are the costs involved in providing for the employment of members of staff. They cover central service costs for office accommodation, equipment, IT support (hardware provision and maintenance, software licences, technical support etc) and a contribution towards central provision of HR and finance services. The overhead rate charged by Royal College of Physicians to internal departments is calculated at 30% of total staff costs. This is a real cost to the NCGC directly related to the employment of each staff member and the number of hours they work.
Knowledge Transfer

It is important that the project remains closely in touch with the emerging QS landscape at NICE. A senior researcher will have a part time secondment to the National Clinical Guidelines Centre for the lifetime of the project, where s/he will report to Norma O’Flynn. Glenn Robert, an expert in organization development from King’s College London will facilitate implementation meetings with NICE QS and guidelines teams. He is well placed to do this having been closely involved in patients’ experience research for the DH and in collaboration with the King’s Fund and the Oxford Health Experiences Research Group.

Meetings

Co-applicant team meetings will be held every 2 months; phone conferences and individual meetings will be held weekly within the Oxford co-applicants and monthly between sites. A project advisory panel will include service users, quantitative and qualitative researchers in the field, representatives from DH and the voluntary sector, Victoria Thomas (Director of PPI NICE) and the co-applicants.

Value for money

The project is remarkable value for money: the interview collections which will be drawn on for the secondary analysis have cost over £6.5 million to collect and prepare for secondary analysis. No charge will be made for use of the data – thus costs are primarily for the researchers’ time and for project management.

To help ensure effective dissemination of the analysis on experiences of NHS care we include £10,000 for the DIPEx charity to prepare video montages, based on video and audio extracts from the interviews, for the facilitation workshops and also for the teaching and learning section of www.healthtalkonline.org.

These montages (which can be a powerful catalyst for change) will be freely available to NHS staff engaged in service improvement. Costs have also been
included to support meetings, travel and a small contribution to co-applicants’ salaries and expenses.

SERVICE USERS/ PUBLIC INVOLVEMENT
The findings from the secondary analysis will be presented to a series of service user groups in London, Birmingham and the north of England. The aim of the groups will be to check whether our interpretation of the core components of patients’ experiences do cover the topics that are most important to people affected by the selected health conditions (likely to be epilepsy, asthma, diabetes in children and adults, schizophrenia and antenatal care).

We will make particular efforts to recruit people from less advantaged backgrounds for these groups to help balance any possible bias in the interview samples available for secondary analysis (although the original collections do strive for maximum variation sampling that includes people from all backgrounds).

Service users will also be invited to join the project steering group and contribute to disseminating results – e.g. through preparation of video and written clips on a new section on experiences of NHS care on www.healthtalkonline.org

Victoria Thomas (Associate Director, Patient and Public Involvement Programme, NICE) is a key supporter of this work and will be involved on the steering group as well as helping to ensure that the project conforms to high standards of PPI.

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