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

Professor Sue Ziebland Nuffield Department of Primary Care Health Sciences University of Oxford, UK[1]

Dr Louise Locock Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Ray Fitzpatrick Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Tim Stokes NICE, Manchester and University of Leicester, UK[2]

Professor Glenn Robert Kings College London, UK

Dr Norma O' Flynn Clinical Director of National Clinical Guideline Centre, London, UK

Dr Kristina Bennert Nuffield Department of Primary Care Health Sciences, University of Oxford, UK[3]

Dr Sara Ryan Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Victoria Thomas Associate Director of the Patient and Public Involvement Programme at NICE

Dr Angela Martin Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

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[1] Corresponding author, Department of Primary Care Health Sciences, University of Oxford, 23-38 Hythe Bridge Street, Oxford, OX1 2ET. sue.ziebland@phc.ox.ac.uk

[2] Affiliation since changed to University of Birmingham

[3] Affiliation since changed to University of Bristol

This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

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Scientific Summary

Background

This proposal was submitted to the NIHR Service Delivery and Organisation call for proposals for secondary research studies. We wanted to explore whether an archive of qualitative, narrative interviews covering over 60 health issues could be used to inform the development of National Institute of Health and Care Excellence (NICE) Clinical Guidelines (CG) and Quality Standards (QS). At the time of the application the NICE process for QS was still emerging and it was not clear which topics would be selected for QS during the 2011/12 timetable. We felt reasonably confident that we would have data to contribute to at least four of the QS that would be developed during the 18 months of the project.

The team of applicants was composed to include members of the Health Experiences Research Group (HERG) in Oxford, a Clinical Director at the National Clinical Guideline Centre (NCGC) and a Consultant Clinical Adviser for Quality Standards at NICE, an expert in organisational research and service implementation and a leading researcher on patient reported outcome measures (PROMS) and patient reported experience measures (PREMS).

Objectives

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

Methods

We used qualitative, thematic methods to analyse collections of interviews from the HERG archive; reports were written on four of these to feed into NICE product development (Objective 1). At the time the study began the HERG archive contained over 60 collections of interviews on a wide variety of topics. Interviews had been collected by experienced, social scientist researchers using a combination of open narrative and semi structured interview techniques. Interviews had all been copyrighted to the University of Oxford for use in research, teaching, broadcasting and publications.

One member of the team interviewed HERG and NICE/NCGC colleagues about their views of the process of reporting the secondary analyses to the NICE teams, including ideas about the barriers to including these secondary analyses in NICE product development (Objective 3).

The qualitative secondary analyses were also use to compare which aspects of patients' experiences were important to people facing different health issues and to test these findings in another two health conditions and in a series of focus groups, chosen to include participants who we believed to be under-represented in the HERG collections (Objective 2).

Dissemination of the findings included publishing a selection of interview extracts on a website, discussing the findings (in particular the focus groups examining the reach of the core components) with PROMS and PREMS researchers and holding a workshop on qualitative secondary analysis to share skills and inform future training courses (Objectives 4 and 5).

Results (research findings)

We analysed interview collections on experiences of mycocardial infarction (MI), rheumatoid arthritis, asthma and diabetes in young people. We prepared reports on each of these four health issues, covering the aspects of care that were described as important to the people we had interviewed. Some aspects of care (for example being taken seriously when presenting with health concerns, taking time to answer questions, involvement in decisions), were described as important in all of the collections while other aspects of care (for example, building confidence, providing rapid access to specialist services, demonstrating how to use treatment devices, acknowledging uncertainties about treatment outcomes) were only raised as important in one or more of the collections. Two further collections, on experiences of autism and experiences of fertility problems, were included in the next stage of the analysis. This analysis drew attention to the particular importance of good communication for people with autism and of empathy from staff for people dealing with fertility problems.

The results from the six secondary analyses were then examined in a modified framework analysis to identify a set of eight common core components of good healthcare. These were

- Having a friendly and caring attitude
- Having some understanding of how my life is affected
- Letting me see the same health professional
- Guiding me through difficult conversations
- Taking time to answer my questions and explain things well
- Pointing me towards further support
- Efficient sharing of my health information across services
- Involving me in decisions about my care

The next stage of the project involved testing these components in a series of focus groups with participants who we knew to be under-represented in the HERG interview collections. We conducted groups with people with learning disabilities, Irish travellers, illegal drug users (some of whom were also homeless), young men, recent immigrants in manual occupations and a group of older people. We also ran an on-line discussion group so that people with limiting chronic conditions could take part without the need to leave home. The groups were all run during the early part of 2013 and used a similar format, although it was necessary to adapt the groups to allow for group characteristics such as attention span and literacy. Each group started with a discussion of what was important when dealing with health care and a sorting task involving discussion of the core components and any other aspects of care that the people in the group thought were important. This raised a few issues that were not easily subsumed under other categories.

The focus groups confirmed that the original set of core components were also important aspects of health care to members of these groups. In interpreting differences in priorities between individuals it was very evident that the participants drew on their own experiences of (ill) health, caring and interactions with health services, and that these experiences clearly affected what they regarded as most important and also what they thought was ‘basic’, ‘good’ and ‘aspirational’ aspects of care. Seen in this light it is understandable that the young men we talked to (a generally healthy group) were not at all concerned about seeing the same doctor while this was quite important to the people with long term conditions (LTCs). Experiences of care also affected how confident people were that certain aspects of care were indeed ‘fundamental’ and could be taken for granted. This applied both to the trust that people put in their doctors’ specialist training (and consequent inter-changeability) and their confidence that the health system would share information appropriately across services. Older adults and those with LTCs were more aware, for example, that health professionals might sometimes be uncertain about what was the best treatment and that there would sometimes be a lack of good evidence about what treatments were effective.

For objective 3 we considered how the reports on the first four secondary analyses were received by the NICE teams. Intended to contribute to NICE clinical guidelines and quality standards development; the asthma report highlighted several issues but only the importance of proper inhaler training contributed to a quality statement. Three of the CG/QS teams (STEMI, diabetes type 1 and rheumatoid arthritis); felt that there was unlikely to be any value in considering their respective reports one of the others found that it did not add anything to the (reasonably extensive) review of the qualitative literature that they had conducted (secondary prevention of MI).

There was a lack of fit between the focus of the topics under review and the data available in the HERG archive – sometimes the material concerned experiences that were too long ago, or too tangential to the quite focussed clinical topics. A co-investigator in knowledge transfer interviewed the HERG researchers and the members of the NICE/National Collaborating Centres (NCC) teams to help us identify reasons why the reports seemed to have little impact on the NICE products. Reasons included uncertainty about the status of the material, further exacerbated by some confusion about the various HERG products (which include peer reviewed papers, a website including peer reviewed summaries of approximately 25 topics per condition and the targeted secondary analysis reports which were not publicly available).

Objective 4 was to inform the development of measurement tools: we presented findings to a group of researchers (experts in PROMs and PREMS) who helped us to think about the implications of our work both for developing questionnaires and for interpreting responses and explaining differences between populations.

We organised a workshop for objective 5 which helped us to clarify gaps in the methods literature and training provision for secondary analysis of qualitative data. We have developed a course to help fill this gap, the first of which will be run as part of the HERG qualitative research training programme in 2014.

Conclusions

We compared the perspectives of people with different health conditions about what is most valued in health care. There was considerable agreement about which aspects were important, even among groups whose views are rarely included in health research who we interviewed in focus groups in an attempt to challenge the reach of our eight core components. By including people from ‘seldom heard’ groups we found that the different experiences of healthcare relationships varied enormously and affected their views about what aspects of care might be considered ‘fundamental’.

With regard to NICE clinical guideline and quality standard development process, the usual source of evidence is published qualitative or quantitative research.. Unpublished secondary analysis of qualitative data did not fit the usual criteria for evidence. The asthma report was the only report that can be seen as having directly contributed to a quality statement and was written by the primary researcher at a point when the data were still very familiar .Writing one extra report at this stage is a relatively efficient use of a primary researcher's time and suggests to us that when the HERG researcher is preparing or updating the topic summaries they might, as part of their analysis, write a brief report on the aspects of care that are particular and important to patients with this condition. In collaboration with NICE, the interview collections could be mapped to the guidelines and QS programme. A targeted analysis on the precise topic of a guideline might seem efficient in theory but there may not be a good match of data available – the strengths and limitations of any specific data set need to be decided on a case by case basis. We suggest that targeted secondary analysis has more potential when the qualitative literature is sparse, unclear or contradictory.

1765 words

Plain English Summary

What do people with health problems value about their healthcare and do different groups with different experiences have different priorities? We studied a modern archive of interviews with people who had a heart attack, rheumatoid arthritis, diabetes and asthma. We identified eight consistently important aspects of care: a friendly and caring attitude; understanding how life is affected; seeing the same health professional; guidance through difficult conversations; taking time to explain; identifying further support; efficiently sharing health information across services and involving the patient in decisions. We tested these in focus groups with people with learning disabilities, migrant workers, homeless people, illegal drug users, Irish travellers, young men and older people. We found that they valued the same things but that their expectations about their health care varied considerably, in line with their experiences and health care relationships.

We worked with the National Institute of Health and Care Excellence (NICE) to see if our findings (presented as a series of tailored reports) might inform their guidelines (which set out clear recommendations for treatment and care) and 'quality standards' (which identify priority areas for quality improvement). We observed their meetings and interviewed staff. One report contributed to a 'quality statement' but not all teams valued the reports. Reports based on interviews from a modern archive may be more likely to contribute to NICE products, when there is little published evidence. Uncertainty remains about the status of (unpublished) analysis. The potential contribution of qualitative research needs to be better understood and recognised.

274 words