Informing the development of NICE (National Institute for Health and Care Excellence) quality standards through secondary analysis of qualitative narrative interviews on patients’ experiences

Sue Ziebland,¹* Louise Locock,¹ Ray Fitzpatrick,² Tim Stokes,³,⁴,⁵ Glenn Robert,⁶ Norma O’Flynn,⁷ Kristina Bennert,¹,⁸ Sara Ryan,¹ Victoria Thomas⁹ and Angela Martin¹

¹Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK
²Nuffield Department of Population Health, University of Oxford, Oxford, UK
³National Institute for Health and Care Excellence, Manchester, UK
⁴Department of Health Sciences, University of Leicester, Leicester, UK
⁵Primary Care Clinical Sciences, University of Birmingham, Birmingham, UK
⁶National Nursing Research Unit, Florence Nightingale School of Nursing and Midwifery, King’s College London, London, UK
⁷National Clinical Guideline Centre, London, UK
⁸School of Social and Community Medicine, University of Bristol, Bristol, UK
⁹Patient and Public Involvement Programme, National Institute for Health and Care Excellence, London, UK

*Corresponding author

Declared competing interests of authors: Norma O’Flynn is seconded to the National Clinical Guideline Centre which is funded by NICE to develop clinical guidelines. Tim Stokes does occasional work for pharmaceutical companies on the work of NICE and primary care; any honoraria received are paid directly to the University of Birmingham. Ray Fitzpatrick is a member of the NIHR Journals Board.

Disclaimer: this report contains transcripts of interviews conducted in the course of the research, or similar, and contains language that may offend some readers.

Published November 2014
DOI: 10.3310/hsdr02450
Plain English summary

Informing development of NICE quality standards
Health Services and Delivery Research 2014; Vol. 2: No. 45
DOI: 10.3310/hsdr02450

NIHR Journals Library www.journalslibrary.nihr.ac.uk
Plain English summary

What do people with health problems value about their health care, and do different groups with different experiences have different priorities? We studied a modern archive of interviews with people who had experienced a heart attack, or had rheumatoid arthritis, diabetes or asthma. We identified eight consistently important aspects of care: involving the patient in decisions; 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; and efficiently sharing health information across services. We tested these in focus groups with people with learning disabilities, migrant workers, illegal-drug users (some of whom were also homeless), 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 for 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.
Criteria for inclusion in the Health Services and Delivery Research journal

Reports are published in Health Services and Delivery Research (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: http://www.nets.nihr.ac.uk/programmes/hsdr/

This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its proceeding programmes as project number 10/1011/19. The contractual start date was in November 2011. The final report began editorial review in October 2013 and was accepted for publication in March 2014. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors’ report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

© Queen’s Printer and Controller of HMSO 2014. This work was produced by Ziebland et al. under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).
Health Services and Delivery Research Editor-in-Chief

Professor Ray Fitzpatrick  Professor of Public Health and Primary Care, University of Oxford, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley  Director, NIHR Evaluation, Trials and Studies and Director of the HTA Programme, UK

NIHR Journals Library Editors

Professor Ken Stein  Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May  Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key  Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck  Chair in Public Sector Management and Subject Leader (Management Group), Queen’s University Management School, Queen’s University Belfast, UK

Professor Aileen Clarke  Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly  Director, Crystal Blue Consulting Ltd, UK

Dr Peter Davidson  Director of NETSCC, HTA, UK

Ms Tara Lamont  Scientific Advisor, NETSCC, UK

Professor Elaine McColl  Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

Professor William McGuire  Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads  Professor of Health Sciences Research, Faculty of Education, University of Winchester, UK

Professor Jane Norman  Professor of Maternal and Fetal Health, University of Edinburgh, UK

Professor John Powell  Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

Professor James Raftery  Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma  Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts  Professor of Child Health Research, UCL Institute of Child Health, UK

Professor Helen Snooks  Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Please visit the website for a list of members of the NIHR Journals Library Board:
www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: nihredit@southampton.ac.uk