

An exploration of the implementation of open disclosure of adverse events in the UK: a scoping review and qualitative exploration

Yvonne Birks,^{1*} Reema Harrison,² Kate Bosanquet,² Jill Hall,² Melissa Harden,³ Vikki Entwistle,⁴ Ian Watt,² Peter Walsh,⁵ Sarah Ronaldson,² David Roberts,⁶ Joy Adamson,² John Wright⁷ and Rick Iedema⁸

¹Social Policy Research Unit, University of York, York, UK

²Department of Health Sciences, University of York, York, UK

³Centre for Reviews and Dissemination, University of York, York, UK

⁴Health Services Research Unit, University of Aberdeen, Aberdeen, UK

⁵Action against Medical Accidents, Croydon, UK

⁶Capsticks LLP, Leeds, UK

⁷Bradford Institute for Health Research, Bradford Royal Infirmary, Bradford, UK

⁸Centre for Health Communication, Faculty of Arts and Social Sciences, University of Technology, Sydney, Australia

*Corresponding author

Declared competing interests of authors: David Roberts has declared a competing interest. Capsticks LLP acts on behalf of, and so has a financial relationship with, a number of organisations who participated in this research.

Published July 2014

DOI: 10.3310/hsdr02200

Plain English summary

Exploration of open disclosure of adverse events in the UK

Health Services and Delivery Research 2014; Vol. 2: No. 20

DOI: 10.3310/hsdr02200

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Plain English summary

Open disclosure of adverse events, in terms of health care, refers to the practice of telling people if they have been harmed by a mistake when receiving care. In 2009, the National Patient Safety Agency relaunched its Being Open framework to support open disclosure in the UK. We explored how this guidance has been received, combining the literature on open disclosure with findings from interviews. We reviewed the international literature on open disclosure since 1980, identifying over 600 papers, predominantly from the last 12 years. Simultaneously, we conducted 86 interviews with respondents from a range of stakeholder groups, including policy-makers, health professionals, NHS managers, representatives from professional bodies and patients. Evidence from both the literature and the interviews showed that the principle of truthfulness was widely supported but not always upheld. Many factors seem to create uncertainties over what should be disclosed, by whom, when and how. Being honest and open about mistakes is theoretically supported but seems considerably more difficult in practice. In conclusion, the evidence suggests that open disclosure should be a process and not a one-off event as it is often described. Open disclosure should be a conversation whereby information is shared and the patient is both listened to and responded to. The key message from this report seems to be that while open disclosure is widely regarded as the right thing to do, creating a culture of openness remains challenging, yet necessary, if patients are to be involved effectively in all aspects of their care.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

The full HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

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: www.netscc.ac.uk/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 10/1007/47. The contractual start date was in September 2011. The final report began editorial review in March 2013 and was accepted for publication in October 2013. 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 Birks *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, University College London, 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