Digital methods to enhance the usefulness of patient experience data in services for long-term conditions: the DEPEND mixed-methods study

Caroline Sanders,^{1*} Papreen Nahar,¹ Nicola Small,¹ Damian Hodgson,² Bie Nio Ong,¹ Azad Dehghan,³ Charlotte A Sharp,¹ William G Dixon,⁴ Shôn Lewis,⁵ Evangelos Kontopantelis,¹ Gavin Daker-White,¹ Peter Bower,¹ Linda Davies,⁶ Humayun Kayesh,³ Rebecca Spencer,⁷ Aneela McAvoy,^{1,7} Ruth Boaden,^{2,7} Karina Lovell,^{1,8} John Ainsworth,⁹ Magdalena Nowakowska,¹ Andrew Shepherd,¹ Patrick Cahoon,¹⁰ Richard Hopkins,¹⁰ Dawn Allen,¹¹ Annmarie Lewis¹¹ and Goran Nenadic³

¹National Institute for Health Research School for Primary Care Research, University of Manchester, Manchester, UK

²Alliance Manchester Business School, University of Manchester, Manchester, UK

³Department of Computer Science, University of Manchester, Manchester, UK

⁴Centre for Epidemiology Versus Arthritis, Manchester Academic Health Science Centre, University of Manchester, Manchester, UK

⁵Division of Psychology and Mental Health, University of Manchester, Manchester, UK

⁶Centre for Health Economics, University of Manchester, Manchester, UK

⁷National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care Greater Manchester, Salford Royal NHS Foundation Trust, Salford, UK

⁸Division of Nursing, Midwifery and Social Work, University of Manchester, Manchester, UK

⁹Centre for Health Informatics, University of Manchester, Manchester, UK

¹⁰Greater Manchester Mental Health NHS Foundation Trust, Manchester, UK

¹¹Patient and public representative

^{*}Corresponding author caroline.sanders@manchester.ac.uk

Declared competing interests of authors: Caroline Sanders was previously a Director (unpaid) for Affigo CIC (Altrincham, UK) (2016–17), a social enterprise providing digital health products for severe mental illness. Peter Bower reports grants from the National Institute for Health Research (NIHR) during the conduct of the study. Richard Hopkins reports that he is a current director of Affigo CIC, which promotes electronic monitoring of patient symptoms through the use of mobile application, outside the submitted work. Ruth Boaden reports that she was the Director of the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester (2013–19), which was hosted by Salford Royal NHS Foundation Trust where she held an honorary (unpaid) as an Associate Director to fulfil her role as Director of the CLAHRC. She was also a member of the NIHR Dissemination Centre Advisory Group (2015-19) and the Health Services and Delivery Research Funding Committee (2015–19). She was a member of the NIHR Knowledge Mobilisation Research Fellowships Panel (2013-15) and chaired the panel (2016-18). She is a member of the NIHR Advanced Fellowships Panel (2019-present). Azad Dehghan is the Managing Director of DeepCognito Ltd (Manchester, UK) and a Data Analytics Advisor for KMS Solutions Ltd (Manchester, UK). William Dixon receives consultancy fees from Bayer AG (Leverkusen, Germany) and Google Inc. (Mountain View, CA, USA). John Ainsworth reports that he is a Director of Affigo CIC. Shôn Lewis reports that he is a Director for Affigo CIC. Humayun Kayesh reports he is a contract engineer for DeepCognito Ltd. Goran Nenadic reports that he was previously a Scientific Advisor (Non-executive) of DeepCognito Ltd.

Published June 2020 DOI: 10.3310/hsdr08280

Plain English summary

The DEPEND mixed-methods study

Health Services and Delivery Research 2020; Vol. 8: No. 28

DOI: 10.3310/hsdr08280

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

Plain English summary

Background

The NHS collects information about the experience of patients using its services (called 'feedback'), usually in written surveys. Staff do not always find this useful, as surveys may be very general. Patients sometimes write detailed comments, but staff find them hard to analyse.

We conducted a study to make feedback easier to collect and more useful to staff for improving services.

What did we do?

We studied patients with severe mental illness (e.g. schizophrenia) or musculoskeletal conditions (e.g. arthritis) in four sites: a large general hospital outpatient department, a mental health trust and two general practices.

We talked to patients and carers about their views and worked with them to design new ways to collect feedback. We talked to staff about how feedback could be most helpful for service improvement.

We used a computer science method called 'text mining' to summarise detailed patient comments more quickly.

We worked with patients, carers and staff to design new resources (a toolkit) to collect and present feedback.

We talked to patients, carers and staff to see if the toolkit made a difference.

What did we find?

We found a lack of understanding and experience of giving feedback. Participants (patients, carers and staff) wanted more meaningful and positive feedback. They also wanted feedback tools to suit the local context and to include informal feedback (e.g. conversations and thank you cards).

We found that text mining could be used to analyse detailed patient comments, although challenges exist.

The toolkit that was designed with participants included iPad (Apple Inc., Cupertino, CA, USA) kiosks to collect data, guides for patients and staff, text-mining programs and new ways of reporting feedback.

Staff were generally positive about the kiosks. Patients gave more mixed responses and the numbers providing feedback were small. Staff were positive about the feedback reports, but observations showed that no changes were implemented to services during our study.

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: journals.library@nihr.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, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The HS&DR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HS&DR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-services-and-delivery-research.htm

This report

The research reported in this issue of the journal was

funded by the HS&DR programme or one of its preceding programmes as project number 14/156/16. The contractual start date was in April 2016. The final report began editorial review in April 2018 and was accepted for publication in June 2019. 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 and Social Care. 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 and Social Care.

© Queen's Printer and Controller of HMSO 2020. This work was produced by Sanders *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. 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).

Editor-in-Chief of **Health Services and Delivery Research** and NIHR Journals Library

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

NIHR Journals Library Editors

Professor John Powell Chair of HTA and EME Editorial Board and Editor-in-Chief of HTA and EME journals. Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Senior Clinical Researcher, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Andrée Le May Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals) and Editor-in-Chief of HS&DR, PGfAR, PHR journals

Professor Matthias Beck Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Senior Scientific Advisor, Wessex Institute, UK

Dr Peter Davidson Consultant Advisor, Wessex Institute, University of Southampton, UK

Ms Tara Lamont Director, NIHR Dissemination Centre, UK

Dr Catriona McDaid Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

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

Professor Geoffrey Meads Professor of Wellbeing Research, University of Winchester, UK

Professor John Norrie Chair in Medical Statistics, University of Edinburgh, 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 Great Ormond Street Institute of Child Health, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

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

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

Professor Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Professor Martin Underwood Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk