

REACH: a mixed-methods study to investigate the measurement, prediction and improvement of retention and engagement in outpatient HIV care

Alison Howarth,¹ Vanessa Apea,² Susan Michie,³
Steve Morris,⁴ Memory Sachikonye,⁵
Catherine Mercer,¹ Amanda Evans,⁶ Valerie Delpech,⁷
Caroline Sabin¹ and Fiona Burns^{1,6*}

¹Research Department of Infection and Population Health, University College London, London, UK

²The Ambrose King Centre, Barts Health NHS Trust, London, UK

³Centre for Behaviour Change, University College London, London, UK

⁴Department of Applied Health Research, University College London, London, UK

⁵UK Community Advisory Board (UK-CAB), London, UK

⁶Royal Free London NHS Foundation Trust, London, UK

⁷Public Health England, London, UK

*Corresponding author

Declared competing interests of authors: Fiona Burns reports personal fees and other from Gilead Sciences Ltd and personal fees from Janssen HIV, outside the submitted work. Caroline Sabin reports personal fees from Gilead Sciences Ltd, ViiV Healthcare, Janssen-Cilag and Bristol-Myers Squibb, outside the submitted work. Steve Morris is a member of the National Institute for Health Research (NIHR) Health Services and Delivery Research Programme Funding Board, which funded this research. He is also a member of the NIHR Public Health Research Funding Board and the NIHR Programme Grants for Applied Research expert subpanel.

Published March 2017

DOI: 10.3310/hsdr05130

Plain English summary

The REACH study

Health Services and Delivery Research 2017; Vol. 5: No. 13

DOI: 10.3310/hsdr05130

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

Plain English summary

Medication for human immunodeficiency virus (HIV) is highly effective but lifelong. People living with HIV need to take their medication regularly and have their health monitored at a specialist HIV clinic. This is vital for their health, and reduces the possible transmission of HIV and cost of missed appointments to the NHS.

We looked at patient data collected over 12 years from HIV clinics across the UK to examine the consequences of not keeping up appointments at the HIV clinic. This showed that people who attend the clinic on a regular basis have a healthier immune system and are likely to live longer.

We conducted a survey among 983 people living with HIV in London, organised interviews and focus groups, and interviewed health-care professionals. Patients were generally satisfied with their HIV care. People who were younger, had been diagnosed for longer, had children or had drug issues tended to have greater difficulties with attendance. We developed a formula that clinics can use to identify people who may find it difficult to keep up their appointments in the future, so that clinic staff can intervene to help them.

The stigma associated with HIV has a strong negative impact on attendance and our study suggests a need to manage the complex psychological, social and economic issues which stop people attending their appointments at the clinic. Our findings support holistic, multidisciplinary approaches to care, including peer support from other people living with HIV. Clinics held in alternative locations may help those who are afraid to be seen at the HIV clinic.

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 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 preceding programmes as project number 11/2004/50. The contractual start date was in March 2013. The final report began editorial review in May 2016 and was accepted for publication in December 2016. 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 2017. This work was produced by Howarth *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 Jo Rycroft-Malone Professor of Health Services and Implementation Research, Bangor University, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the EME 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

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Senior Scientific Advisor, Wessex Institute, UK

Ms Tara Lamont Scientific Advisor, NETSCC, 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 Health Sciences Research, Health and Wellbeing Research Group, University of Winchester, UK

Professor John Norrie Chair in Medical Statistics, 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 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 Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Professor Martin Underwood Director, Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, 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: journals.library@nihr.ac.uk