

# The Prevalence of Visual Impairment in People with Dementia (the PrOVIDe study): a cross-sectional study of people aged 60–89 years with dementia and qualitative exploration of individual, carer and professional perspectives

Michael Bowen,<sup>1\*</sup> David F Edgar,<sup>2</sup> Beverley Hancock,<sup>1</sup> Sayeed Haque,<sup>3</sup> Rakhee Shah,<sup>1,4</sup> Sarah Buchanan,<sup>5</sup> Steve Iliffe,<sup>6</sup> Susan Maskell,<sup>7</sup> James Pickett,<sup>8</sup> John-Paul Taylor<sup>9,10</sup> and Neil O’Leary<sup>11</sup>

<sup>1</sup>Research Department, College of Optometrists, London, UK

<sup>2</sup>Division of Optometry and Visual Science, City University London, London, UK

<sup>3</sup>Primary Care Clinical Sciences, University of Birmingham, Birmingham, UK

<sup>4</sup>The Outside Clinic, Swindon, UK

<sup>5</sup>Research Department, Thomas Pocklington Trust, London, UK

<sup>6</sup>Department of Primary Care and Population Health, University College London, London, UK

<sup>7</sup>Public and participant involvement representative, Alzheimer’s Society Research Network, London, UK

<sup>8</sup>Research Department, Alzheimer’s Society, London, UK

<sup>9</sup>Institute for Neuroscience, Newcastle University, Newcastle upon Tyne, UK

<sup>10</sup>Northumberland, Tyne and Wear NHS Foundation Trust, Newcastle upon Tyne, UK

<sup>11</sup>The Irish Longitudinal Study on Ageing (TILDA), Trinity College Dublin, Dublin, Republic of Ireland

\*Corresponding author

**Declared competing interests of authors:** Michael Bowen reports financial support from the College of Optometrists, London, during the conduct of the study and outside the submitted work as full-time employee of the College of Optometrists. Dave Edgar reports financial support from City University London during the conduct of the study and outside the submitted work and other support from the College of Optometrists during the conduct of the study and outside the submitted work. Beverley Hancock reports financial support from the College of Optometrists outside the submitted work. Sayeed Haque reports support from the College of Optometrists during the conduct of the study and outside the submitted work, and support from the University of Birmingham during the conduct of the study and outside the submitted work. Sayeed Haque provides statistical advice to the College of Optometrists Small Grants holders under a paid consultancy agreement. Rakhee Shah reports support from The Outside Clinic during the conduct of the study and outside the submitted work. Sarah Buchanan reports support from the Thomas Pocklington Trust during the conduct of the study and outside the submitted work. Steve Iliffe reports grants from the European Commission during the conduct of the study and grants from the

Thomas Pocklington Trust outside the submitted work, and other support from University College London, during the conduct of the study and outside the submitted work. James Pickett reports other support from the Alzheimer's Society outside the submitted work and during the conduct of the study. John-Paul Taylor reports support from the Institute for Neuroscience, Newcastle University, outside the submitted work and during the conduct of the study; and support from the Northumberland, Tyne and Wear NHS Trust, Newcastle upon Tyne, outside the submitted work and during the conduct of the study. Neil O'Leary reports support from Trinity College Dublin outside the submitted work and during the conduct of the study and grant funding from The Irish Longitudinal Study on Ageing (TILDA) during the conduct of the study.

**Published July 2016**

DOI: 10.3310/hsdr04210

## **Plain English summary**

### **Visual impairment and dementia**

Health Services and Delivery Research 2016; Vol. 4: No. 21

DOI: 10.3310/hsdr04210

NIHR Journals Library [www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)

## Plain English summary

The key research questions of this study were (1) what is the prevalence of (how common are) vision problems in people with dementia aged 60–89 years?; and (2) how often are these problems undetected or inappropriately managed?

In stage 1, 708 people with dementia had an eye examination. Nearly one-third of participants in whom vision could be measured were visually impaired (had significant sight loss) according to an established definition. Almost half of the visually impaired were no longer visually impaired with up-to-date spectacle prescriptions. Among the remainder, nearly half were visually impaired as a result of cataracts, which could be removed. Important parts of the eye examination were possible in > 80% of participants.

In stage 2, interviews were conducted with people with dementia and care workers. Focus groups (small groups of people brought together to give their opinions) were held with family carers, care workers and optometrists.

The focus groups with family and professional carers revealed that:

- eye examinations were considered important
- there was uncertainty regarding whether or not eye examinations for people with dementia were possible
- there was insufficient information about the availability of domiciliary (provided to people in their own homes) eye-care services
- there was room for possible improvements to eye care for people with dementia.

The focus groups with optometrists revealed:

- the desire to gain knowledge about, and skills needed to provide better services to, people with dementia
- advance information, given when making the appointment, that a patient had dementia would help the optometrist to accommodate individual needs.

Research is needed to see if early cataract removal, by improving vision, slows the progression of cognitive impairment.



# 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/](http://www.publicationethics.org/)).

Editorial contact: [nihredit@southampton.ac.uk](mailto:nihredit@southampton.ac.uk)

The full HS&DR archive is freely available to view online at [www.journalslibrary.nihr.ac.uk/hsdr](http://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](http://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 11/2000/13. The contractual start date was in October 2012. The final report began editorial review in October 2014 and was accepted for publication in December 2015. 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 2016. This work was produced by Bowen *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](http://www.journalslibrary.nihr.ac.uk)), produced by Prepress Projects Ltd, Perth, Scotland ([www.prepress-projects.co.uk](http://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

**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 Eugenia Cronin** Senior Scientific Advisor, Wessex Institute, 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, Health and Wellbeing Research and Development Group, University of Winchester, UK

**Professor John Norrie** Health Services Research Unit, University of Aberdeen, 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](http://www.journalslibrary.nihr.ac.uk/about/editors)

**Editorial contact:** [nihredit@southampton.ac.uk](mailto:nihredit@southampton.ac.uk)