The PrOVIDe study
Prevalence of Visual Impairment in Dementia

The risks of developing dementia and visual impairment both increase with age. However, prior to the PrOVIDe study, there was limited data about the prevalence of visual impairment in people with dementia in the UK. The research that was available was over 15 years old and had little information about care home residents. It mostly focused on visual impairment in older people, often not examining groups of people with dementia separately to those without.

The PrOVIDe study was designed to better understand how prevalent visual impairment is in people with dementia, and compare this to levels within the wider population of older people. It also aimed to identify the extent to which visual impairment is undetected or inappropriately managed in people with dementia and how eye care can be improved for them. This study included people with dementia who live in their own home as well as those in care homes.

The study had two stages. The first involved more than 700 participants with dementia undergoing an eye examination to determine prevalence of visual impairment in people with dementia. Participants also underwent assessment to determine their level of cognition using the standardised Mini-Mental State Examination (sMMSE).

The second stage was qualitative research investigating any issues around the management of visual impairment in people with dementia. It involved 36 interviews with people with dementia as well as interviews and focus groups with family carers, professional care workers and eye care professionals.

Key features
- Two year study: 2012-2014
- Prevalence study: 708 participants, aged 60-89. 55% lived in their own homes, 45% in care homes
- Qualitative research: 119 participants
- 17 sites across England, supported by NIHR Clinical Research Network
- Funded by NIHR Health Services and Delivery Research programme
- Chief Investigator: Michael Bowen, Director of Research, The College of Optometrists

Led by the College of Optometrists, the study was supported by the National Institute for Health Research (NIHR). It was funded by the NIHR Health Services and Delivery Research programme. The NIHR Clinical Research Network (CRN) provided a package of support throughout the study, from development, through setup and delivery, to study closure. This included helping shape the study design, particularly with the research in non-NHS settings, capitalising on the ENRICH network of research-ready care homes to recruit participants. The CRN also advised on study feasibility and costing to help minimise potential difficulties in these areas during study implementation.

The study was supported by the Alzheimer’s Society; Thomas Pocklington Trust; City, University of London; Newcastle University; Trinity College Dublin; UCL; and the University of Birmingham.
Outcomes and findings
The PrOVIDe study successfully answered the questions about prevalence of visual impairment in people with dementia and gathered valuable insight on how eye examinations, treatment and care can be improved.

- 33.5% of participants in the prevalence study had a form of visual impairment. Visual impairment was 2-2½ times more common in those living in care homes compared to those living at home, and this was often uncorrected or under-corrected.
- Many family and professional carers did not know that it was possible to conduct a full eye examination on people with dementia. However, in the prevalence study, all but 8 participants could undergo at least part of an eye examination, despite varying levels of cognitive impairment.
- 80% of participants could complete key eye tests (including tonometry which tests for glaucoma, and direct ophthalmoscopy which looks at structures within the eye). Those who were unable to complete the test were more likely to live in a care home and have significantly lower sMMSE scores.
- A range of strategies were identified to improve experience of eye examinations for people with dementia. Suggestions included: scheduling longer or multiple appointments, having an informed carer present, providing more information and guidance for optometrists for examining people with dementia.
- People with dementia would want to undergo cataract surgery if needed. However, family carers had concerns around the distress and discomfort it would cause their relative. Many family carers and optometrists would favour earlier than usual (expedited) cataract surgery, when the person with dementia would have greater capacity.
- Multiple problems with spectacles were identified, including reluctance to wear glasses, as well as missing and broken glasses. This was particularly common in care homes.

Additional research needed
The PrOVIDe study generated useful evidence around prevalence and treatment of visual impairment in people with dementia. It also highlighted the following further research that is needed:

- Is a two-stage domiciliary sight test beneficial for people with dementia living in care homes? Pilot research has already been undertaken by The College of Optometrists and the Dementia Research Centre at UCL but funding is needed to take it further.
- Would the benefit of early cataract surgery for people with dementia outweigh the risk? Proposals are in development to explore this further.

Key publications:
- Study site: bit.ly/PrOVIDe
- NIHR Dissemination Centre signal: bit.ly/PrOVIDe-signal

Value to the NHS
Integrating dementia care and eye care
Findings from the PrOVIDe study have led to proposals to ensure eye care is recognised as being as important to those with dementia as the general population. This could be in the form of a Dementia Eye Care Pathway (as proposed by the study authors in a paper in 2015), where a dementia diagnosis would trigger a series of measures to ensure visual ability is reviewed before the dementia progresses, or eye care’s integration into more general dementia health care pathways that provide more specialist care for people with the condition. These proposals are currently being reviewed by the sector.

VIDem (Visual Impairment and Dementia) Summit
The VIDem Summit was initiated as a result of the PrOVIDe study. The College of Optometrists, The Alzheimer’s Society and Thomas Pocklington Trust used the context of the project to prioritise areas for future research for people with both dementia and visual impairment. The event was attended by patients, carers, researchers and healthcare professionals.

“PrOVIDe has given us valuable evidence about visual impairment among people living with dementia in the UK. This has been shared widely with the profession, and will continue to inform the development of resources for clinicians and people living with dementia. This will support more effective access to and benefit from existing eye health services. PrOVIDe has also pointed to further research, which is currently being developed.”

Michael Bowen, Director of Research, The College of Optometrists and PrOVIDe Chief Investigator