

The Visual Impairment and Dementia Summit



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Foreword



Welcome to the report of the Visual Impairment and Dementia (VIDem) Summit, held on 24 February 2015 at the Friends Meeting House, Euston, London.

The VIDem Summit brought together a range of stakeholders to share research into visual impairment and dementia and to discuss priorities for research that would be of most use to people with these conditions. People with dementia and visual impairment, carers, eye health and dementia clinicians, representatives from charities and researchers all learnt from each other and discussed their needs and experiences. I am delighted that we can bring you the summary of all the information and discussion in this report.

As the President of the College of Optometrists, the organisation that took the lead in managing the Summit, I would like to thank the Alzheimer's Society and Thomas Pocklington Trust for helping to make it happen. I would also offer sincere gratitude to Katherine Cowan, our chair on the day, and Rosa Pepe at the College who managed the whole event from inception to the day itself.

The prevalence of both visual impairment and dementia increases with age, and an ageing population coupled with limited research resources means that it is more important than ever to both agree research priorities and to understand how one field impacts on another.

I know from my own experience, as will many of you, that these conditions can make life profoundly difficult for those diagnosed with them, but also that life can be made a lot easier through appropriate treatment and effective management – the right type of care.

This report provides a summary of both the research presented at the VIDem Summit and the process and outcome of the research priority setting exercise undertaken as part of the day. As such, it is both a resource for immediate learning and a set of recommendations for a huge number of stakeholders in this area, including the funders of future research.

Thirty-six delegates were part of the process on the day, but I believe that this report allows anyone who reads it to feel like they were there and to benefit fully from what was achieved. For the full VIDem experience, please read it with your preferred choice of drink and biscuits.

I hope you enjoy the report.

A handwritten signature in black ink, consisting of a stylized 'D' and 'P' followed by a horizontal line.

David Parkins

Immediate Past President, College of Optometrists

Executive summary

The Visual Impairment and Dementia Summit (VIDem Summit) arose from the Prevalence of Visual Impairment in Dementia (PrOVIDe) project, a National Institute for Health Research (NIHR) funded project to investigate the prevalence of visual impairment in the dementia population and identify any barriers to those people receiving the eye care they need, or to eye health professionals delivering the right services.

Some of the organisations involved in that project (The College of Optometrists, The Alzheimer's Society and Thomas Pocklington Trust) decided to use the context of the project to hold an event that would share research in the areas of dementia and visual impairment and suggest priority areas for future clinical research for people with both conditions.

Using an adaptation of a methodology created by the James Lind Alliance (JLA), the VIDem Summit saw 36 patients, carers, researchers and health care professionals come together to create priorities for research into dementia and visual impairment, working with questions previously identified by two JLA Priority Setting Partnerships (one for Dementia and the other for Sight Loss and Vision).

After six presentations about research projects relating to dementia and vision (see Appendix), delegates were divided into four small groups, each with diverse participants, to discuss 13 shortlisted questions for research, drawn from the Partnerships. Each group then agreed three top priorities, describing the reasons for their choices and the difference they felt each one could make to people living with dementia and visual impairment, and those caring for and treating them. Each group's priorities were aggregated to produce five overall priorities.

These five priorities covered:

- appropriate methods of visual assessment
- how to maintain independence
- the timing of cataract intervention
- how to effectively change practice with research
- and routes to early dementia diagnosis.

The discussions also revealed some key underlying themes in the participants' thinking:

- the extent to which these two conditions are uniquely concurrent, or not, compared to other co-morbidities
- the importance of linking communities of research and health care together, both within each community and with each other
- and that listening to patients and carers is crucial to the progression of effective research.

This was the first time that the priorities of two JLA Priority Setting Partnerships had been brought together in this way. The Summit demonstrated the usefulness of such an exercise and its viability for the prioritisation of research into other health co-morbidities.

It is recommended that these priorities are disseminated widely and integrated into the processes used by research funders to evaluate funding applications, and through which research teams identify future projects, to ensure funding is directed to the areas of most use for people living with dementia and visual impairment.

Background

The ProVIDe project

The Visual Impairment and Dementia Summit (VIDem Summit) came about through a shared interest in how dementia and visual impairment, together, impact on people's lives.

In 2011, the College of Optometrists, Alzheimer's Society and Thomas Pocklington Trust began a conversation about eye care for people with dementia. From initial speculation about whether people with dementia were getting the eye care that they needed sprang an application to the National Institute for Health Research (NIHR) Health Services and Delivery Research Programme to undertake (along with some further collaborators) what would become the Prevalence of Visual Impairment in People with Dementia (ProVIDe) project.

ProVIDe was funded to answer the question, "What is the prevalence of a range of vision problems in people with dementia aged 60–89 years and to what extent are these conditions undetected or inappropriately managed?". It used quantitative and qualitative methods to try and answer it, and involved people with dementia, family and professional carers, recruiters, optometrists and a host of expertise and advice from a number of different disciplines in recruiting over 700 participants from six regions of England to undertake an eye examination.

One of the aims, in addition to answering the main research question outlined above, was to share learning between those investigating dementia and those investigating visual impairment. Although there is undoubted crossover between research in these areas already, ensuring that people with both dementia and visual impairment are part of the conversation (and that research that meets their needs is prioritised) was recognised by the organisations involved in the ProVIDe project as being an area for further work.

Priority Setting Partnerships

This work already had a good head start. The James Lind Alliance (JLA) is an initiative that is coordinated by the National Institute for Health Research (NIHR). It has developed a method for involving patients, carers and clinicians in setting priorities for health research, bringing them together in Priority Setting Partnerships. The JLA had facilitated separate partnerships for dementia¹ and sight loss and vision², so 10 priorities for dementia research and 120 priorities covering 12 areas of sight loss and vision research had already been produced. This gave the organisations behind the VIDem Summit the ingredients to bring the two areas together.

The great benefit of the JLA's approach is the involvement of different stakeholders on an equal footing. What might be considered a priority for clinical research can, and should, be informed by patients, researchers, health care professionals and relevant charities, but it can be easy for one group to lead the way to too great an extent.

Historically, the direction for research has been set by the organisations that fund research and by researchers themselves, with patients, carers and clinicians rarely being involved.³ The JLA offers an alternative approach by directly involving the public and clinicians, and by engaging with each group at every stage of the prioritisation, from the first submission of unanswered research questions, through the initial sifting of what is in scope and truly unanswered and what is not, to the final ranking of what will make the biggest difference to them, and is therefore the highest priority.

This means that, in some cases, something like the management of pain relief is agreed to be a greater priority for research than a cure for the condition causing the pain. This sort of shift in focus can sometimes be something that only a patient perspective can guide, and there is evidence to suggest that this perspective continues to be ignored in favour of research into other areas.⁴

Although Priority Setting Partnerships had been undertaken in these two areas, and indeed many others, no two Partnerships had brought their resulting priorities together to create a set of collective priorities before. This, along with the sharing of mutually relevant research into dementia and/or visual impairment, was the aim of the VIDem Summit.

The prioritising process

A VIDem Summit organising team was put together, consisting of representatives from the College of Optometrists, the Alzheimer's Society, Thomas Pocklington Trust and an independent consultant (Katherine Cowan), who had worked with the James Lind Alliance on numerous Priority Setting Partnerships and would be the main facilitator for the VIDem Summit itself.

An attendance list was created, consisting of people with visual impairment and/or dementia, carers, researchers, eye care and neurology professionals and representatives from relevant charities and sector organisations. Invitations were then issued, and alternatives invited where necessary or appropriate, to create a delegate list of 36, which when combined with representatives from the organising bodies and the event team brought the total attendees to the maximum venue capacity and ensured a suitable number for a productive and inclusive discussion.

Some attendees were invited due to having already undertaken interesting and relevant research in the areas of dementia or visual impairment (or both), and agreed to present some of their work as part of the day as well as to take part in the prioritisation process. Abstracts covering each of these projects are included in the Appendix to this report.

Prior to the event, the Dementia and Sight Loss and Vision Partnerships' priorities were first aggregated by the organising team. This involved removing any questions that were clearly specific to either area, the retaining of questions that were specific but relevant to a consideration of the needs of people with both conditions, and the rewriting of questions that could be amalgamated with minimal loss of meaning or intention.

In total, 18 questions about the concurrent issues of dementia and visual impairment were identified. As an initial short-listing exercise, these 18 questions were then sent to all the confirmed attendees, with a request for them to pick their top two questions (not in any order) and to suggest an additional question that they thought should be considered a priority.

Of the 18 questions, 14 had at least one vote. The four which received no votes were removed and two questions were merged, on the suggestion of a number of delegates and with agreement among the organising team. This left a list of 13 questions for the Summit. These were sent to delegates a week in advance of the Summit with instructions to choose and bring their personal top three to the Summit, and to be prepared to discuss their reasons for choosing them on the day.

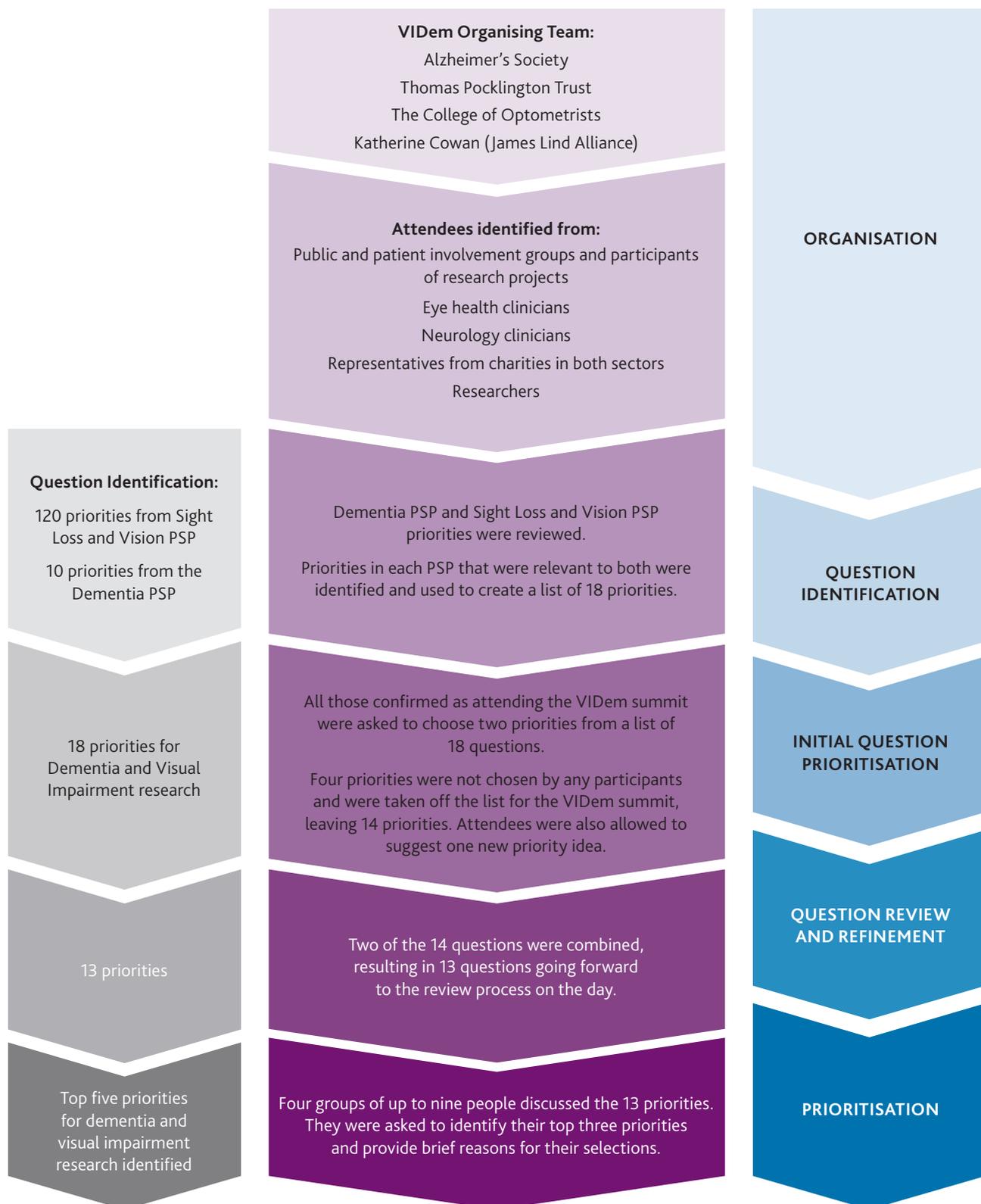
Eleven additional questions were suggested, each by one delegate only. At the event itself, these additional suggestions were laid out in a section of the room called 'Ideas Corner' for delegates to express their interest or approval in any of them (for more on Ideas Corner, see page 8).

During the Summit itself, the 13 questions were each discussed by four different groups. Each group had up to nine individuals, allocated in advance to ensure a mix of people with experience of visual impairment and dementia, clinicians, and researchers with experience or expertise in visual impairment, dementia or both conditions concurrently. Each group was guided by an independent facilitator with experience of James Lind Alliance workshops (Michael Bowen, Katherine Cowan, Sally Crowe and Richard Morley).

Each individual had an opportunity to explain their preferences and to discuss those with each other. They were then tasked with selecting the top three questions for their group and explaining why they were chosen over others, in particular addressing each of the following:

- What difference could this make?
- Why is this important to people affected by dementia and visual impairment concurrently?
- Why is this important to health and social care professionals?

Following the small group discussions, which lasted about 95 minutes, participants reconvened and each group's top three priorities were presented. The choices were amalgamated and five questions emerged as the overarching priorities.



Ideas corner

As well as being invited to choose two of the 18 priorities that they felt were most important for research to answer, delegates were invited to suggest one additional question each. The 11 responses received were laid out in Ideas Corner, for delegates to browse and discuss. They were also invited to suggest any additional questions on the day, and to vote for any question that they thought was important.

Below is a summary of the questions, suggested both before and on the day, how many votes they received on the day (which was zero if no number is given below) and any comments added.



Questions suggested before the day:

- Should an eye test become a compulsory element when diagnosing a possible dementia? (3 votes, 1 comment: "A hearing test would also be good").
- What are the benefits of optimising vision to a person with dementia? (3 votes).
- Does intervention to improve visual impairment for people with dementia improve outcomes for people with dementia, including cognition and quality of life? (1 vote).
- How common is diplopia among people with dementia? (1 vote).
- Are the current treatments (including dosage levels of medication) for people with Posterior Cortical Atrophy (PCA) or other types of dementia and visual impairment effective? What improvements to treatments could be made for those with PCA / dementia and visual impairment? (1 vote).
- How can aids and equipment be designed for people with visual impairment and dementia e.g. provision of safe glasses?
- To what extent does the optic nerve play a part in memory storage? Does the intensity of light entering the eye produce any determination in this?
- What are the main barriers to treatment of visual impairment in people with dementia? How can we best address these barriers to improve uptake of treatment?
- How can ophthalmology clinics and other health care environments be made more dementia friendly, so that they are suitable for people with visual impairment as well as dementia?
- How can quality of life be optimised in people with visual impairment (at all levels of severity) and dementia (at all stages), including both those who live independently in the community and group settings? What are effective interventions?
- How does the implementation of dementia friendly practices enhance or not enhance access to eye examinations?

Questions suggested on the day:

- Should there be a national care pathway for people with dementia looking at their sensory loss and management? (5 votes).
- Help opticians on where to sign post when eyes are healthy – brain blindness (2 votes).
- When making appointments, ask for extra time for patients with dementia (1 vote).
- How do we address cultural (Black and Minority Ethnic) issues?
- Do long duration contact lenses have a role in the management of visual impairment?

Information corner

The VIDem Summit gave those organisations attending the event the opportunity to share useful resources and links related to best practice for people with visual impairment and/or dementia. Below is some more information about each of those resources.

Alzheimer's Society

- Sight, perception and hallucinations factsheet:
www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1408

College of Optometrists

- Guidance on examining patients with dementia or other acquired cognitive impairment: <http://guidance.college-optometrists.org/guidance-contents/knowledge-skills-and-performance-domain/examining-patients-with-dementia>

National Institute for Health Research

- Join dementia research, a service which allows people to register their interest in national dementia research: www.joindementiaresearch.nihr.ac.uk

RNIB

- Information for professionals: www.rnib.org.uk/olderpeople
- Information for people with dementia and carers:
www.rnib.org.uk/eye-health-sight-loss-other-medical-conditions/dementia-and-sight-loss

RNIB Scotland and Alzheimer Scotland

- Dementia and sight loss information leaflet:
www.rnib.org.uk/sites/default/files/Dementia_and_sight_loss_leaflet.pdf

Social Care Institute for Excellence (SCIE)

- Dementia and Sensory Loss (part of the SCIE Dementia Gateway):
www.scie.org.uk/dementia/living-with-dementia/sensory-loss/sight-loss.asp

Thomas Pocklington Trust

- Dementia and sight loss housing design guidelines:
<http://dementia.stir.ac.uk/design/good-practice-guidelines>
- Improving vision and eye health care to people with dementia:
www.pocklington-trust.org.uk/researchandknowledge/publications/rdp8.htm
- Visual hallucinations in sight loss and dementia:
www.pocklington-trust.org.uk/researchandknowledge/publications/rf27op23.htm
- Impact of sight loss in older people in Britain:
www.pocklington-trust.org.uk/researchandknowledge/publications/rf22op19.htm

VISION 2020 UK

- Dementia and Sight Loss Interest Group:
www.vision2020uk.org.uk/interest-groups/dementia-and-sight-loss-interest-group

The priorities

The 13 priorities discussed in the four separate groups were (five priority questions are highlighted):

A	What is the best measure of functional vision loss, due to cataract, for people with dementia? What is the most effective way to monitor development of cataract in people with dementia?
B	What are the outcomes for cataract surgery among people with different levels of cognitive impairment resulting from dementia?
C	What are the most effective design features for producing dementia friendly environments, at both the housing and neighbourhood levels, that are suitable for people with visual impairment as well as dementia?
D	What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people with visual impairment and dementia?
E	What are the best ways to effectively disseminate research findings and to inform care for people with visual impairment and dementia?
F	What are the barriers that prevent people with diabetes and dementia from having regular eye checks?
G	When is the optimal time to move a person with visual impairment and dementia into a care home setting?
H	What are the most effective components of care that keep a person with visual impairment and dementia as independent as they can be at all stages of the disease in all care settings?
I	What is the most effective management for dry eye among people with dementia and can new strategies be developed that are appropriate for people with dementia?
J	What is the most effective way to assess vision in people with neurological visual impairment e.g. stroke, dementia and cerebral/cortical visual impairment? This question includes the following: <ul style="list-style-type: none"> • How can visual impairment, including refractive error, be accurately assessed in people with dementia?
K	What are the most effective ways to encourage people with visual impairment and dementia to eat, drink and maintain nutritional intake?
L	What is the impact of an early diagnosis of dementia for people with visual impairment and how can primary care support a more effective route to diagnosis?
M	What can be done to improve early diagnosis of sight threatening glaucoma among people with dementia? For example: <ul style="list-style-type: none"> • How and at what age should people with dementia be tested if there is glaucoma in the family? • What is the effectiveness of Optical Coherence Tomography (OCT) evaluation of the optic disc in early glaucoma diagnosis among people with dementia?

The results

Each group's discussion led them to an agreed top three priorities for clinical research in this area, but it also led them to consider general themes that were underpinning their thinking and their understanding of life for people with both dementia and visual impairment. In this respect, what was not chosen was sometimes as illuminating as what was chosen, and although there was a fair degree of agreement there were also opposing views that demonstrated alternative approaches to understanding the two conditions.

A summary of the discussion around each of the questions mentioned is presented below, both those prioritised and those felt to be less of a priority but still important, along with the major themes that emerged as part of the process.



The five prioritised questions

J

What is the most effective way to assess vision in people with neurological visual impairment eg stroke, dementia and cerebral/cortical visual impairment? This question includes the following:

- How can visual impairment, including refractive error, be accurately assessed in people with dementia?

The notion of assessment, along with treatment and care, was felt to be a key research priority, and this question was selected by all four groups. It was suggested that evidence from this question could provide much-needed tools and information to practitioners working at the front line of services.

Delegates described the difficulty in ascertaining whether the sight of a person with dementia is deteriorating, or if it is simply a day when the dementia is severe. It was described as an achievable research area, although it would need to be multi-disciplinary and involve optometrists, ophthalmologists, psychologists, orthoptists and others.

It was felt that answering this question could have far-reaching impacts. For example, better assessment could lead to more timely diagnosis and ultimately better care, with better communication with the patient, based on greater understanding between them, their family and their clinician. One group felt that comparisons could helpfully be made between people with dementia and those with learning disabilities, for whom there is an existing pathway for vision assessment. One of the Patient and Public Involvement (PPI) representatives suggested that there would be a benefit to ensuring eye health checks are carried out at the point of a dementia diagnosis.

One group suggested that the second part of the question should explicitly include the interpretation and application of assessment, to make clear the purpose of assessment. Another felt that the terminology of 'vision test' was stressful for people with dementia, and that 'eye health check' may be less intimidating.

The point was made in one of the groups that the patients in this area are not two separate groups with either optical or cortical issues. Yet there are two sets of researchers looking at them separately, rather than in collaboration. This achievable research question would bring them together, and a systematic review of the current evidence base would be a good place to start.

Some groups suggested that due to its broad scope, this question was similar to or could subsume other questions in the list, including A, M and F, although researchers would need to be wary of trying to do too much in any one project.

H

What are the most effective components of care that keep a person with visual impairment and dementia as independent as they can be at all stages of the disease in all care settings?

Chosen by three of the four groups, this question was felt to address the overarching issue of care, interpreting it in the broadest sense and integrating the disciplines of health and social care. Participants said that this question could address a current gap in knowledge about how people with visual impairment and dementia can thrive and enjoy their lives: it is an opportunity to develop evidence which could improve quality of life.

One group emphasised that “all care settings” should include the individual’s own home, particularly given that two in three people with dementia live in the community. It was also suggested that research into this question should include investigations into food and nutrition, behaviour and other conditions such as dry eye. Defining what ‘care’ means to patients and clinicians would be part of the research process, as would another systematic review, this time of the components of care where research has been carried out. It was noted by one group that there is research on this topic, but it is evidently not widely known as there is still a lack of clarity about what works and what does not work.

The importance of individually tailored care was noted, where people’s abilities are maintained and individual abilities are maximised. While the importance of independence was highlighted, one group was concerned that this question made an assumption about the level of independence appropriate or

desirable to an individual, suggesting that the wording could be changed to “as independent as they can be and want to be at all stages...”. Significant impact was felt to be possible here, with one group suggesting that improved care could help improve family relationships.

Arguments against the inclusion of this question as a research priority included that it created an artificial categorisation of populations of people with dementia and people with visual impairment. Grouping people together on the basis of just these two conditions risked missing a bigger picture and an opportunity to consider additional needs. However, some suggested that with earlier diagnosis, evidence for better care could help people develop strategies, preparing their homes and enhancing their ability to cope with the onset of both conditions, while they are still cognitively able, or able to see.

That visual impairment and dementia create unique problems requiring tailored responses was another argument put forward in favour of the question – standard coping and support mechanisms for dementia are often visual. One person described experiencing greater fear of their visual impairment diagnosis than their dementia diagnosis.

Once again, this question was felt to overlap with others, in this case C, K and I.

B

What are the outcomes for cataract surgery among people with different levels of cognitive impairment resulting from dementia?

Two groups voted for this question, noting that cataract is a universal condition that can be effectively treated, albeit not without some risk. It was suggested that there is evidence that people with dementia are less likely to be treated, despite improvements to quality of life among those who have been. For many, the question therefore had immediacy as well as relevance to a large number of people, and it was felt to address a defined, practical assessment that would provide a clear outcome, whether measured in terms of visual acuity or the impact of surgery.

Participants described the ambiguity of the optimal stage of intervention, but noted that intervention is easier during the earlier stages of dementia. Evidence of this could inform guidelines for clinicians and help them when assessing the

suitability and potential benefit of the procedure in this particular population. Indeed, several participants, including PPI representatives, suggested that some professionals are reluctant to perform the operation on people with dementia. Research-generated case studies and the demonstration of impact (not least economic) could help change this. A dementia-friendly cataract pathway could enable earlier surgery, and avoid the necessity of a hospital stay, something the PPI representatives said could be traumatic for people with dementia.

Some people highlighted the issue of informed consent, and the value of discussing preferences early on, before the capacity to consent is lost, an additional reason to consider earlier intervention.

E

What are the best ways to effectively disseminate research findings and to inform care for people with visual impairment and dementia?

This question was prioritised by two of the four groups, and within most groups there was some debate about it. It was agreed that there is a need to raise awareness of the existing evidence among health professionals and commissioners, and that better knowledge among the clinical community would lead to more people accessing care as health professionals would be more able to assist with patient needs that are outside of their core remit.

The importance of implementing the findings or recommendations of research is clear, but it is complicated by the difficulty in ensuring that such recommendations continue to be implemented in care environments that can have high staff turnovers, such as care homes. Research may not result in

change if findings are picked up only by individuals, who then leave, and so the findings are not integrated into the formal systems of care organisations. It was suggested that one route to improvement could be a dementia equivalent of the Eye Clinic Liaison Officer, who liaises with social services.

Some participants believed this not to be a priority, however, as the topic is applicable to all areas of health research, not just visual impairment and dementia. Others believed that dissemination of research into these two concurrent issues did have specific characteristics and barriers to implementation, which would benefit from specific investigation, and that learning in this area could then also inform care commissioning and the delivery of services in other areas of healthcare.

L

What is the impact of an early diagnosis of dementia for people with visual impairment and how can primary care support a more effective route to diagnosis?

One group selected this question as a priority, with broad agreement from the PPI representatives and the clinicians, as well as the researchers. Personal accounts were shared about the potential difference an earlier diagnosis could have made.

The group that selected this question suggested that answering this question could increase the diagnosis of both conditions and allow people to develop adaptive techniques, echoing points made about Question H that, with earlier diagnosis, better, more holistic training could be developed to help people adapt their home environment in advance of a deterioration of their condition, therefore enhancing quality of life. The health

professionals felt that this question could also increase the breadth of tests available, and noted how optometrists sometimes make the first diagnosis of dementia, a possibility that would benefit from practitioners being further informed of the importance of pursuing such a diagnosis if they suspect it.

However, among those for whom this question was not a priority, it was argued once again that the topic is relevant to all older people with dementia, and not unique to these two concurrent conditions. It was also suggested that delayed dementia diagnosis is a universal issue, not just one for those with visual impairment.

Questions which were discussed but not prioritised

Participants were asked to work together to identify three priority questions as a group, but in an unsurprising similarity to more regular Priority Setting Partnerships, the consensus view did not necessarily reflect the many individual views of those taking part. The following questions, while not prioritised by any of the four groups, were highlighted by individuals and discussed to some extent.

A	What is the best measure of functional vision loss, due to cataract, for people with dementia? What is the most effective way to monitor development of cataract in people with dementia?
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For one of the researchers present, a previous cataract project had led to the conclusion that cataracts often go undetected, an issue which may be particularly the case among people with dementia. It was felt that the second part of this question could be helpful in addressing that.

C	What are the most effective design features for producing dementia friendly environments, at both the housing and neighbourhood levels, that are suitable for people with visual impairment as well as dementia?
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A clinician suggested that the importance of good design to change behaviour is well known and has a constant effect, while a professional working with carers noted that this topic is a large training area and takes people beyond the notion of simply seeking to improve vision in order to be more empowered. It was also suggested that work is already happening in this area.

D	What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people with visual impairment and dementia?
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Some concerns were expressed about clinicians prescribing anti-psychotic drugs without looking at alternatives. It was noted that the evidence base to guide care workers and inform their choices about when and how to intervene was minimal.

G	When is the optimal time to move a person with visual impairment and dementia into a care home setting?
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It was noted by a PPI representative in one group that nutrition is a factor here and should be taken into account in any research seeking to address the question, while a PPI representative in another group felt that the question was not useful as people will inevitably move into care homes at crisis point, and that other topics were more pressing.

I

What is the most effective management for dry eye among people with dementia and can new strategies be developed that are appropriate for people with dementia?

A clinician working in visual impairment suggested that this question had been addressed by research and that the issue was more about basic care and nursing practice. It would be preferable to raise awareness of existing research rather than commission new dry eye research purely from a dementia perspective. However, one group noted that people with dementia do not blink as often as they should, resulting in dry eye which can cause behavioural issues. This can be very distressing and can lead to anti-psychotic medication.

K

What are the most effective ways to encourage people with visual impairment and dementia to eat, drink and maintain nutritional intake?

It was felt by some that this question addresses the entirety of the person, treating them as a person rather than a condition in isolation. Nutrition has a huge impact on cognition, energy and independence, but is often forgotten. It was noted that as dementia progresses, swallowing can become difficult, but liquefied food can be unidentifiable to those with memory loss or visual impairment. Evidence to inform practice in this area would be particularly useful, it was suggested, for practitioners working in care homes.

However, it was also highlighted that this is not just about end-stage dementia, and that diet during the earlier stages can also potentially be poor. It was unclear to some whether or not this question was unique enough to be a priority, given its application to dementia more widely. Others suggested that the ability to see food clearly can have a positive impact on people's appetite and diet, making this question an opportunity to address a unique angle to the problem.



Common themes

The importance of concurrency

The VIDem Summit brought together the issue of two conditions – visual impairment and dementia – in concurrence. Many participants felt that there is a unique impact as a result of this dual diagnosis on both patients and families, and on the professionals' options for diagnosis, treatment and care, while others felt that the many possible co-morbidities of dementia (including multiple sensory loss) meant visual impairment was not significantly unique. Whichever view was taken, this theme was regularly returned to.

Connecting communities

A culture of dealing separately with the two conditions is deep rooted. Limited interventions and services for people with visual impairment and dementia, as opposed to the two separate conditions, is a problem. Additionally, within each professional community of interest there are separate areas of expertise which may not link up, such as professionals who treat the back of the eye and those focusing solely on the front. The VIDem Summit as an opportunity to bring these stakeholders together to work as a community with a shared research interest was commented on by many of those present.

Listening to our stakeholders

The importance of listening to people experiencing dementia and visual impairment, as well as their families, clinicians and healthcare workers, was at the heart of the VIDem Summit and informed the discussions throughout the day.

Making a practical difference

There was a strong expression of the need to focus on practical outcomes which will make a difference to people's quality of life, but also to provide professionals with better guidelines, information and tools. Not only is this the right and practical thing to do, it could also have a cost benefit. A common theme was frustration about research dissemination which is focused on journal impact factor rather than practical outcomes that affect patients, carers and clinicians, as well as research which could have an impact on clinical practice and patient experience but which never makes it beyond the journal pages.

To counteract this, it was suggested that findings could be disseminated in tailored ways, including through their justifiable categorisation and promotion as continuing professional development opportunities, in order to make them accessible to all those working with people with dementia and visual impairment, from surgeons in hospitals to care assistants working in the community and in care homes. In addition, providing families and patients with information and resources was felt to be crucial, to help people understand the different stages of the conditions and where to go for support. People with dementia and visual impairment who take part in research should also be provided with feedback.

Conclusions and recommendations

The VIDem Summit demonstrated that there is important and very revealing research going on in the areas of both dementia and visual impairment and that there is an appetite for the two research communities to learn from each other. It also showed the patient and carer needs for such collaboration, as well as the substantial benefits that could be gained from two such communities coming together.

Overall, the event showed that alternative viewpoints, be those of researchers, clinicians or people with certain health conditions, are crucial in ensuring that research progresses in the right directions and for the utmost benefit of patients. In the VIDem Summit's case, it revealed that: appropriate methods of visual assessment, how to maintain independence (however defined), the timing of cataract intervention, how to effectively change practice with research, and routes to (preferably early) dementia diagnosis are the priorities for future research in the area of concurrent dementia and visual impairment.

Although other areas of healthcare will of course have other priorities, we can also conclude that the process used at this event is replicable for other health co-morbidities. Although the process used was not an exact replica of that used by the James Lind Alliance in its Priority Setting Partnerships investigating single conditions, we believe the insights gained can be worth the compromise.

It is recommended that these priorities are disseminated widely and, where possible, integrated into the processes used by research funders to evaluate funding applications. In this way, inevitably limited funding can be focused on the questions that have been demonstrated to be most worth investigating, researchers can ensure that their proposals address the areas of greatest need and unnecessary duplication of research can be discouraged.



References

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- 4 Sally Crowe, Mark Fenton, Matthew Hall, Katherine Cowan, Iain Chalmers, 'Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch'; *Research Involvement and Engagement*, 2015, 1:2 (<http://www.researchinvolvement.com/content/1/1/2>)



Organisations and individuals represented at the VIDem Summit

- Alzheimer's Scotland
- Alzheimer's Society
- British and Irish Orthoptic Society
- BUPA
- City University London
- Clinicians (dementia and vision)
- Family carers
- College of Optometrists
- Fight for Sight
- Local Eye Health Networks
- Local Optical Committee Support Unit
- Optometrists
- Patients
- Practitioner researchers
- RNIB Scotland
- Royal College of Ophthalmologists
- Thomas Pocklington Trust
- University College London
- University of Cambridge
- University of Hertfordshire
- University of Nottingham
- University of Oxford
- University of Stirling
- University of York
- VISION 2020 UK

Appendix

Presentation abstracts

Vision and dementia: a clinician's perspective

Presenter: Dr Sebastian Crutch, Dementia Research Centre, Institute of Neurology, University College London

Description: Visual abilities are critical to living well with dementia, with previous research demonstrating spatial perception to be more strongly associated with activities of daily living than episodic and verbal short-term memory. Visual dysfunction is a core feature of several dementias (e.g. Alzheimer's disease [AD], Dementia with Lewy Bodies), with dementia-related visual dysfunction receiving increased attention recently with the identification of the syndrome Posterior Cortical Atrophy (PCA) which is typically caused by AD but presents with dramatic impairment of vision, not memory.

Individuals with PCA offer a unique perspective on the visual difficulties which may be experienced by many individuals with typical AD at a point when memory, language and insight problems limit their ability to communicate what they are experiencing. The nature of cortical visual problems in PCA may also confound the use of standard optometric assessments. For example, the majority of PCA patients have normal or near-normal visual acuity, yet may struggle with a standard Snellen letter chart because of a reduced effective field of vision (yielding counter-intuitively greater difficulties reading large than small fonts) and/or excessive visual crowding in central vision (yielding difficulty reading letters surrounded by other letters or clutter). Our current ESRC-NIHR *Seeing what they see* project seeks to develop home-based aids and strategies that compensate for the effects of dementia-related vision loss and improve mobility, safety and independence, and patient and carer quality of life.

Acknowledgements: This work was supported by ESRC/NIHR grant ES/K006711/1 and an Alzheimer's Research UK Senior Research Fellowship.

More information: www.ucl.ac.uk/dementia-vision

The Prevalence of Visual Impairment in Dementia – The ProVIDe project

Presenter: Professor David Edgar, Emeritus Professor, Division of Optometry and Visual Sciences, City University London

Description: The ProVIDe study investigated the prevalence and causes of visual impairment in people aged 60–89 years with dementia. It also looked at how often these conditions go undetected and how often vision could be improved with appropriate care such as an up to date spectacle prescription or surgery to remove cataracts. Over 700 participants, living either at home or in a care setting, took part in Stage 1 of the study by having an eye examination. The qualitative research arm of the study, Stage 2, explored the views of participants, family carers, care workers and optometrists on eye care for people with dementia. Over 100 participants took part in Stage 2 through interviews and focus groups. The results of both Stages of the project should lead to recommendations about what could be done to improve eye care for people with dementia and to identify the need for any further research in this area.

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More information: www.college-optometrists.org/research

Social Care & Support Needs of Adults with Dementia and Sight Loss

Presenter: Karen Croucher, Research Fellow, Centre for Housing Policy, University of York

Description: Meeting the social care and support needs of people living with concurrent sight loss and dementia presents complex challenges. This project explored how social care and support for people living with concurrent sight loss and dementia in housing settings could be improved. We adopted a multi-method approach. A literature review was undertaken. 26 people living with sight loss and dementia in a range of housing settings were interviewed, often with their family carers. Almost 50 practitioners, including dementia specialists and sensory impairment specialists, took part in discussion groups or interviews.

The emerging findings were validated at a multi-disciplinary consensus building event. The results highlight the complex needs of people with sight loss and dementia, and the need for timely diagnosis of both conditions, on-going support following diagnosis, assessment that draws on the skills of sight loss specialists and dementia specialists, and care and support that gives familiar staff the time to get to know the person with dementia and sight loss and the person to get to know them. Our work does not suggest there is need for a 'new specialism', however many people with dementia and sight loss would benefit from increased joint working, and sharing of skills by different groups of practitioners. It also highlights the potential role of extra care housing in supporting people living with complex needs.

Acknowledgements:

Project team: Karen Croucher (Principle Investigator) and Mark Bevan, CHP; Julie Barrett, Housing and Dementia Research Consortium; Sarah Buchanan, Thomas Pocklington Trust; Anna Clarke, University of Cambridge; Simon Evans and Jennifer Bray, University of Worcester; Anthea Innes, Samuel Nyman, and Michelle Heward, Bournemouth University.

Supporting Organisations: Alzheimer's Society; Hanover Housing; Housing and Dementia Research Consortium; Macular Society; Thomas Pocklington Trust.

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More information: www.york.ac.uk/chp

Comorbidity and dementia: improving healthcare for people with dementia (CoDem)

Presenter: Dr Frances Bunn, University of Hertfordshire

Description: Many people with dementia also have other medical conditions, such as stroke, diabetes or vision impairment. This study considers how having dementia alongside another long term health problem affects how people access services, have their needs assessed and are supported over time. The project is focusing on people with dementia who have one of three specific medical conditions (stroke, diabetes and visual impairment). The study is based on the principle that people with dementia and other complex health conditions are likely to be seen by a variety of health care providers in different locations and that it is important to consider how we can improve continuity of care for this group.

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Good practice in the design of residential environments for people living with dementia and sight loss

Presenter: Alison Dawson, Research Fellow, University of Stirling

Description: This project aimed to produce evidence-based advice on good practice in the design of homes and living spaces for people with sight loss and dementia and to make that information available and accessible to people with dementia and sight loss, informal carers and supporters, and relevant professional groups. A systematically conducted literature review and evaluation and a series of iterative stakeholder engagement activities informed the development of good practice guidelines, which are available in a variety of formats for different audiences.

Acknowledgements: Research team: Alison Bowes, Alison Dawson, Corinne Greasley-Adams, Louise McCabe, School of Applied Social Science, University of Stirling. This research was funded by, and the project outputs were developed in collaboration with, Thomas Pocklington Trust.

More information: Guidelines available at <http://dementia.stir.ac.uk/design/good-practice-guidelines>

The Dementia Priority Setting Partnership with the James Lind Alliance

Presenter: Dr Sarah Kelly, Research Associate, Department of Public Health and Primary Care, University of Cambridge

Description: The Dementia Priority Setting Partnership aimed to work with people with dementia, their carers/former carers, health and social care practitioners and members of the community from a broad population perspective to identify and prioritise unanswered questions for dementia research relating to the prevention, diagnosis, treatment and care of dementia. Questions relating to visual impairment and dementia, themes of relevance to research in all areas of dementia research and the impact so far of the Dementia Priority Setting Partnership were highlighted.

Acknowledgements: The project was funded by the Alzheimer's Society and NIHR CLAHRC for Cambridgeshire and Peterborough.

More information: List of top 10 priorities available at: www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1804

Downloadable summary of process and the 'long list' of 146 questions available at: http://alzheimers.org.uk/site/scripts/download_info.php?fileID=2226

Sight Loss & Vision Priority Setting Partnership

Presenter: Ade Deane-Pratt, Research Communications Officer, Fight for Sight

Description: The Sight Loss and Vision Priority Setting Partnership in 2012 asked patients, carers and eye health professionals to identify unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions that they wished to see answered. 2,220 people responded to the survey generating 4,461 questions. At workshops held in April and May 2013 the top priorities for each category were agreed. Since then, a significant number of grants aimed at a wide range of priorities have been funded in the UK.

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More information: www.college-optometrists.org/en/research/funded-projects/commissioned-research-2.cfm/SLVPSP

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