Introduction

Despite on-going research activity in the UK and worldwide, there are still many questions about the prevention, diagnosis and treatment of sight loss and eye conditions that remain unanswered. Funding for research is limited, so it is important for research funders to understand the unanswered questions of greatest importance to patients, carers and eye health professionals so that future research can be consolidated and targeted accordingly.

The Sight Loss and Vision Priority Setting Partnership (PSP) has captured these vital views to identify what research into sight loss and eye conditions should be addressing. It is rare that those with direct experience of conditions are able to influence the research agenda.

The Sight Loss and Vision PSP was overseen by the James Lind Alliance, a non-profit making initiative which brings patients, carers and health care professionals together to identify and prioritise unanswered questions for health research. The James Lind Alliance is internationally recognised as being both authoritative and independent, and is managed by the UK’s National Institute for Health Research.

Methodology

A survey collected unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions from patients, relatives, carers and eye health professionals.

The questions were analysed, formatted and categorised into disease specific groups. Searches were then undertaken to ascertain whether or not each question could be answered by an up-to-date systematic review, those which could were then removed. All unanswered questions were allocated to 12 different eye disease/condition categories and similar or duplicate submissions were combined.

A series of interim prioritisation exercises was conducted to reduce the number of questions for categories which had a large number of submissions. This resulted in a shortlist of questions for each category.

Final prioritisation workshops were held to rank each list and identify the top questions for research for each of the 12 eye disease/condition categories. Participants at each workshop were a balanced group of patients, their family members, carers and eye health professionals.

“I am delighted that the College has been able to support the development of this important project. For research to have the right impact, the views of those that it affects must be heard and it is refreshing that we have consulted with patients, carers and clinicians alike to help focus our efforts in the right direction.”

Dr Kamlesh Chauhan, President of the College of Optometrists
Results
The response to the initial survey was significant: 2200 people took part, generating 4461 questions encompassing over 100 different eye diseases and conditions.

The full sets of prioritised lists can be found in the results section of the main report at www.sightlosspsp.org.uk.

The top priority for each category is as follows:

1. **Age-related macular degeneration (AMD)**
   Can a treatment to stop dry AMD progressing and/or developing into the wet form be devised?

2. **Cataract**
   How can cataracts be prevented from developing?

3. **Childhood-onset eye disorders**
   How can cerebral visual impairment be identified, prevented and treated in children?

4. **Corneal and external eye diseases**
   Can new therapies such as gene or stem cell treatments be developed for corneal diseases?

5. **Glaucoma**
   What are the most effective treatments for glaucoma and how can treatments be improved?

6. **Inherited retinal diseases**
   Can a treatment to slow down progression or reverse sight loss in inherited retinal diseases be developed?

7. **Neuro-ophthalmology**
   What is the underlying cause of optic nerve damage in optic neuropathies, such as anterior ischaemic optic neuropathy, Leber’s hereditary optic neuropathy, optic neuritis and other optic neuropathies?

8. **Ocular cancer**
   What can be done to help ocular cancer sufferers?

9. **Ocular inflammatory diseases**
   What are the most effective treatments for ocular and orbital inflammatory diseases?

10. **Refractive error and ocular motility**
    What factors influence the development of refractive error (myopia, astigmatism, presbyopia, and long-sightedness)?

11. **Retinal vascular diseases**
    What are the best methods to prevent retinopathy of prematurity?

12. **Vitreoretinal and ocular trauma**
    How can surgical techniques be improved to save sight for eyes damaged by injury?

Next Steps
Eye research funding is limited. The findings of the Sight Loss and Vision PSP will enable existing funders of eye research to target the priorities that matter most to those affected by sight loss and eye conditions. The results will enable researchers applying for funding to demonstrate that their research targets important priorities. Charitable funders and researchers will also be able to use the results to campaign for greater research funding, and for the first time, the exercise will enable research funders to begin to co-ordinate their funding to avoid overlaps and maximise opportunities to address as many priorities as possible.

Encouragingly, the Steering Committee is now aware of researchers starting to use the priorities in their research application process.
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Supporters
The following organisations are supporting the initiative:

Action for Blind People
Age UK
Association of British Dispensing Opticians
Behcet’s Syndrome Society
Birdshot Uveitis Society
Blind Veterans UK
British and Irish Orthoptic Society
British Thyroid Foundation
Contact a Family
Eyecare Trust
Guide Dogs
International Glaucoma Association
Juvenile Diabetes Research Foundation
Keratoconus Group
Kingston Association for the Blind
Macular Society
Micro and Anophthalmic Children’s Society
Moorfields Eye Hospital NHS Foundation Trust
National Blind Children’s Society
National Federation of the Blind of the UK
Nystagmus Network
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One Clear Vision
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The full report is available at www.sightlosspsp.org.uk