Sight Loss and Vision Priority Setting Partnership

Setting Priorities for Eye Research

Final Report

www.sightlosspsp.org.uk

October 2013

Acknowledgements

Partners

The following organisations provided funding and/or in-kind support for this initiative:

College of Optometrists

Fight for Sight

James Lind Alliance

NIHR Moorfields BRC

RNIB

Royal College of Ophthamologists

UK Vision Strategy

Working with:

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Foreword by Earl Howe

Sight is the sense that most people fear losing the most and any loss or impairment can reduce a person's quality of life substantially. Sight loss affects adults and children and as we live longer the number of people affected will increase.

Encouraging people's awareness of eye health and improving the integration and effectiveness of eye health and care services will go some way to reducing the number of people with sight loss. But it is only through research that we will be able to address the questions about the prevention, diagnosis and treatment of sight loss and eye conditions that remain unanswered.

I am delighted that so many individuals and organisations have collaborated to produce this report. I know that the National Institute for Health Research (NIHR) has in place a system for considering topics identified through priority setting partnerships as part of its wider research prioritisation process.

By consulting widely, the Sight Loss and Vision Priority Setting Partnership has enabled patients, carers, relatives and eye health professionals to influence the research agenda. Researchers and research funders now know what is most important to those with experience of eye diseases and eye conditions. This means that they can take these factors into account in considering future research projects to ensure that finite funding can be better targeted.

Earl Howe
Parliamentary Under Secretary of State for Quality at the Department of Health

Foreword by Professor Ruairidh Milne

Earlier this year we were delighted to complete the transfer of the James Lind Alliance (JLA) to the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC). The JLA Priority Setting Partnerships bring together patients, relatives, carers and health professionals to identify priorities for research. These partnerships help ensure that researchers and those who fund health research can focus on what matters to those with experience of the relevant conditions. This is at the heart of the work of the NETSCC and wider NIHR.

The Sight Loss and Vision Priority Setting Partnership has been one of the most ambitious priority setting partnerships undertaken. The partnership has prioritised questions relating not only to treatments but also to prevention and diagnosis. The partnership has encompassed questions relating to over 100 different eye diseases and conditions resulting in priority lists for 12 different categories of eye diseases and conditions. The large number of people involved has clearly demonstrated the enthusiasm for research in this area.

We congratulate the organisations involved in successfully delivering this partnership and we look forward to harnessing the tremendous enthusiasm that has been shown to drive forward research that will make a real difference to patients with sight loss and vision problems.

Professor Ruairidh Milne
Head of NETSCC

Executive summary

> **All funders of research, be they government, charities or private sector companies are faced with competing demands and limited resources. Prioritisation is essential. Fight for Sight is the main charity in the UK dedicated to funding scientific and medical research and we are unable to fund the majority of research proposals that we receive."**
>
> ***Michèle Acton, Chief Executive of Fight for Sight***

Introduction

Despite on-going research 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, relatives, carers and eye health professionals so that future research can be targeted accordingly.

The Sight Loss and Vision Priority Setting Partnership (PSP) has uniquely 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 (NIHR).

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 submitted questions were then **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. 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 the 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 shortlist and identify the top questions for research for each of the 12 eye disease/condition categories. Participants at each workshop comprised a balanced group of patients, relatives, carers and eye health professionals.

Results

The response to the initial survey was significant: 2220 people took part, generating 4461 questions encompassing over 100 different eye diseases and conditions.

The full sets of prioritised lists are found in the results section of this report. 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 treatment 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. Vitroretinal and ocular trauma
How can surgical techniques be improved to save sight for eyes damaged by injury?

> **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***

Next Steps

Funding for eye research 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 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 overlap 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 applications for funding and funding bodies have now begun to include the priorities in their research application process.

Introduction

Why set priorities for eye research?

In the UK it is estimated that almost two million people are affected by sight loss. This number is expected to double by 2050[1]. Despite on-going research 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.

Given that resources for research are limited, it is important that priorities are established. Research funders increasingly want to understand the priorities of patients, relatives, carers and eye health professionals so that future research can be targeted accordingly.

> **I think this was a ground breaking and very valuable piece of work."**
>
> ***Mr Praveen Patel, Consultant Ophthalmic Surgeon***

Background

The UK Vision Strategy is an RNIB led initiative, uniting all those in the UK who want to take action on issues relating to vision. It is a framework which supports the development of excellent services to foster a society in which avoidable sight loss is eliminated and where people with sight loss can fully participate.

The Strategy was launched in 2008 following extensive consultation with over 650 individuals and organisations. It was developed in response to the World Health Assembly's resolution of 2003 to tackle visual impairment. Through VISION 2020 UK, the Strategy is part of the global VISION 2020 initiative, led by the World Health Organisation and the International Association for the Prevention of Blindness. In 2013, following further sector consultation, a refreshed Strategy was launched, for the period 2013–2018. Research is an important part of the Strategy and it sets out how investment in further research to reduce sight loss and improve eye health is vital.

The VISION 2020 UK Eye Research Group (ERG) was formed to bring together people with an interest in eye health and vision research who wanted to ensure that research was well targeted and co-ordinated and funding was maximised.

The ERG decided that a UK research agenda was required. The challenge was to produce a coherently constructed and constituted prioritised research agenda with clear methods and for which there had been inclusive and widespread consultation. It was important also that any methodology adopted was accepted by research funders.

In 2011, Fight for Sight, the College of Optometrists, the UK Vision Strategy and Mr Richard Wormald, on behalf of the Vision 2020 UK Eye Research Group, approached the James Lind Alliance (JLA) to discuss working together. It was clear that the JLA had worked successfully with other health sectors and had developed a tried and tested methodology.

In early 2012, The College of Optometrists and Fight for Sight committed to contributing to the costs of the project. Further commitments were then made by the National Institute for Health Research Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology (the NIHR Moorfields BRC), The Royal College of Ophthalmologists and RNIB. Within a few months, the project had secured the support and financial backing necessary to deliver a priority setting exercise of unprecedented scope and scale in the UK.

> **What a fascinating and worthwhile experience it is to be involved in deciding possible future research projects. As a parent of a child with microphthalmia, I felt that my opinions and concerns were taken into consideration. Listening to the thoughts and ideas of world leaders in the field of ophthalmology was extremely interesting."**
>
> ***Jason Franks, parent of a child with microphthalmia***

James Lind Alliance

The JLA is a non-profit making initiative which was established in 2004. It brings patients, relatives, carers and health professionals together in Priority Setting Partnerships (PSP) to identify and prioritise the unanswered questions about diagnosis, prevention and treatments that they agree are most important for research to address. The JLA was originally funded by the National Institute for Health Research (NIHR) and the Medical Research Council. Since April 2013, the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) has coordinated the work of the JLA, adopting the process as one of its methods for identifying research topics to fund.

Research on the effects of treatments often overlooks the shared priorities of patients, relatives, carers and health professionals. The JLA PSPs involvement of these groups makes them highly distinctive[2]. The pharmaceutical industry and academia play essential roles in developing and testing new treatments, but their priorities are not necessarily the same as those of patients, carers and health professionals[3]. It has been argued that not involving the users of research in setting priorities contributes to waste in research[4]. Most research funders operate in responsive mode, relying on researchers to submit ideas rather than setting priorities themselves and few organisations consider the research priorities of clinicians and patients[5]. Areas of potentially important research are therefore neglected. The JLA exists to address this imbalance.

JLA PSPs focus on a particular condition or healthcare issue. They bring together individuals and organisations representing patients with the condition, their relatives, carers and the health professionals who treat them. Partnerships to date have addressed a diverse range of conditions including schizophrenia, Lyme disease, asthma, incontinence, prostate cancer and tinnitus[5,6]. Participants in the process normally include patient organisations, support groups and charities, professional bodies, colleges and individuals with a patient, carer or clinician perspective. Pharmaceutical companies and researchers with no current clinical practice are excluded from participating in the priority setting exercise.

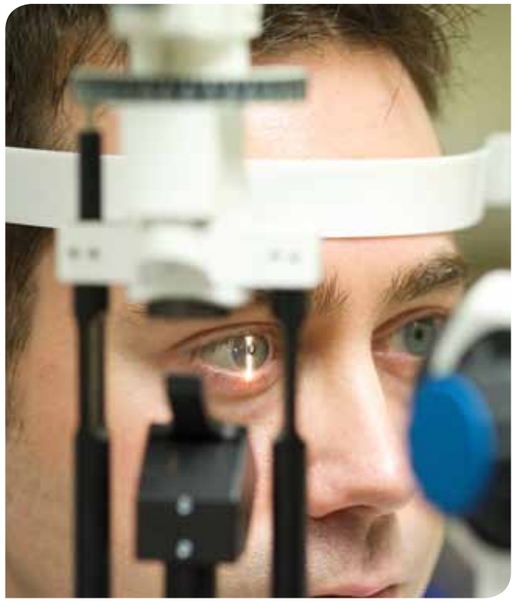
PSPs work to identify and prioritise unanswered questions. The JLA methodology includes a survey, an adapted Delphi exercise and Nominal Group Technique and has been published in detail in the JLA Guidebook (www.JLAguidebook.org) [7]. It typically takes between 12 and 18 months to complete.Questions are defined as being unanswerable by an up-to-date reliable systematic review of existing research evidence. A PSP will go through a process of ranking/voting and discussion to agree a final list of 10 top priorities, which are then promoted to research funders. PSPs aim to publish verified treatment and intervention questions gathered during the exercise on the UK Database of Uncertainties about the Effects of Treatments (UK DUETs – www.library.nhs.uk/duets).

A representative from the JLA chairs each PSP to ensure that the principles of the JLA are upheld. These include: the equal involvement of patients, relatives, carers and health professionals; transparency in declaring interests, decision making and data sharing; and managing and minimising the impact of both personal and professional biases. The JLA does not have a vested interest in any of the conditions which its PSPs address: its aim is to facilitate a fair process in which patients, carers and health professionals participate as collaborative experts.

Limitations

The JLA process aims to be robust and methodologically defensible. Nevertheless, there are limitations to the process. For example, while the survey aims to attract a representative sample of respondents, this is not always achieved. While every effort is made to remove barriers to participation and to engage participants who are under-represented or hard-to-reach, this does not guarantee that everyone who could take part does so. It is hoped that the involvement of healthcare professionals who can represent the interests of a diverse range of patients goes some way to addressing this. Ultimately, however, participants are inevitably self-selecting and may therefore generate a respondent bias.

Similarly, the final workshops can only involve a limited number of individuals. Care is taken to achieve a balance of participants, so that no single perspective, personal or professional, dominates the discussion and the decision-making. The JLA requires participants to declare their interests and compiles and distributes participant biographies before each workshop. Neutral facilitation is intended to help ensure that everyone has their say and that consensus is achieved fairly. Participants are expected to adhere to the principle of partnership working, to respect different opinions and to be pragmatic. By its very nature, consensus decision-making requires compromise.



The Sight Loss & Vision PSP has been one of the JLA's most ambitious partnerships to date, addressing multiple conditions and reaching out to large and diverse communities of patients, carers and clinicians."

Katherine Cowan, James Lind Alliance Consultant

Methodology

The approach taken by the Sight Loss and Vision PSP is illustrated below:

Stage 1
Establishing the Sight Loss and Vision PSP

- Project proposal finalised and funding secured.
- Steering Committee established.
- Protocol agreed.
- Project management and oversight arrangements confirmed.
- Project launched 19 April 2012 at an initial stakeholder meeting.

Stage 2
Survey

- Survey open 1 May 2012 – 31 July 2012.
- Survey disseminated electronically and as hard copy. Available in alternative formats and for completion by telephone.
- Survey circulated by funders and partner organisations, advertised in publications, electronic media (enews, websites etc) and by radio.

Stage 3
Data assessment

- Data Assessment Group established and protocol agreed.
- Out of scope questions removed and collated. Steering Committee consulted as needed.
- Questions grouped by eye disease/condition, rewritten in PICO format.
- Systematic reviews checked.
- Duplicates removed and reviewed by Steering Committee.
- All questions allocated to one of 12 categories.

Stage 4
Interim prioritisation

- Questions in category form sent to survey respondents and other patients, organisations and eye health professionals with expertise in category areas.
- Respondees rank top 10 priorities.
- Combined rankings produced.
- Shortlist of around 30 questions produced.

Stage 5
Final prioritisation

- Papers circulated to participants ahead of each workshop.
- Workshop for each category attended by patients, relatives, carers, members of organisations and eye health professionals.
- Top priorities established for each of the 12 categories.

Stage 1
Establishing the Sight Loss and Vision PSP

Funding was secured from six sources throughout the eye sector not all of which are currently research funders:

- College of Optometrists
- Fight for Sight
- NIHR Moorfields BRC
- RNIB
- Royal College of Ophthalmologists
- UK Vision Strategy

Once funding had been agreed, a Steering Committee was established, chaired by Katherine Cowan, an independent consultant to the JLA. A list of members of the Steering Committee is set out in **Appendix 1**. Members were drawn from a range of backgrounds and primarily included patients, eye health professionals and representatives of organisations in the sight loss sector. Whilst the exercise does not seek the views of researchers, it was felt important to have a representative of the research community on the Steering Committee. A protocol for the Sight Loss and Vision PSP was agreed by the Steering Committee and is set out in **Appendix 2**. It was agreed that Fight for Sight would be responsible for project managing and co-ordinating the exercise, overseen by the Steering Committee.

In April 2012, a stakeholder meeting was held in order to engage the communities and organisations having members and influence in the sector. Their support was secured to ensure that the survey would be completed by as wide a range of patients, relatives, carers and eye health professionals as possible across the UK. Their input informed plans for the scope of the project and its dissemination.

Stage 2
Survey

The Sight Loss and Vision PSP survey was launched on 1 May 2012 and was open for responses until 31 July 2012. Its aim was to identify the unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions that patients, relatives, carers and eye health professionals wished to see answered. The survey asked:

"What question(s) about the prevention, diagnosis and treatment of sight loss and eye conditions would you like to see answered by research?"

Over 40 funders and other partner organisations promoted the survey. A list of these is set out in **Appendix 3**.

The survey was promoted through regional radio and Insight Radio (for blind and partially sighted listeners), websites, at patient days, exhibitions, in newsletters and through the use of social media. Some partner charities also distributed hard copies to their members. In order to make the survey as accessible as possible, it could be completed on-line, by telephone, on paper and in alternative formats including Braille and audio.

Respondents were asked to give certain information relating to their age, location and gender and asked to categorise themselves as a patient, relative or carer, representative of an organisation or an eye health professional. They were also asked whether or not they wished to receive further information about the exercise.

Stage 3
Data Assessment

A Data Assessment Group (DAG) was formed, which reported to the Steering Committee. Members of the DAG are set out in **Appendix 1**. A Protocol for the Analysis of Data was agreed. This is set out in **Appendix 4**.

It was recognised that the open-ended nature of the survey question would result in a wide range of responses. Questions that were deemed to be out of scope were identified and removed from the process. Any social research questions were collated and are being shared with the Social Research Group of VISION 2020 UK and questions that related to a lack of patient information are being shared with relevant patient organisations.

In order to make analysis easier, questions were grouped by type of eye disease/condition. The DAG, overseen by the Steering Committee and the Editor of the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), worked to identify the essence of the uncertainty expressed in each submission[8]. Where possible, questions were formatted to include the patient or problem, the intervention, a comparator and an outcome – Population Intervention Comparison Outcomes (PICO) formatting[9]. This work took place between late 2012 and early 2013.

Placing questions into PICO format, and determining whether questions were in or out of scope, involved some subjectivity. To ensure that different members of the DAG were consistent in their approach, a random sample of 10 per cent of each member's contribution was reviewed by a separate member and any disagreements resolved by discussion amongst the entire team. An example of a PICO formatted question is as follows:

Original submission:
"My son is six weeks old and was diagnosed with retinopathy of prematurity. He was born prematurely at 32 weeks. Whilst he is not blind, what are the chances that he'll develop sight loss as he gets older?"

P – Population/patient (infants)
I – Intervention/indicator (premature)
C – Comparator/control (full-term)
O – Outcome (sight loss)

Question in PICO format:
'In infants diagnosed with retinopathy of prematurity, what is the prevalence of developing sight loss into adulthood compared with those born at full-term?'

Once questions had been re-worded in PICO format, an information specialist from the Cochrane Eyes and Vision Group undertook searches to ascertain if there were relevant systematic reviews published or updated within the last three years, which would answer the questions submitted.

The following resources were searched to identify systematic reviews:

- The Cochrane Database of Systematic Reviews
- Database of Abstracts of Reviews of Effects (DARE)
- NHS evidence
- BMJ clinical evidence
- Scottish Intercollegiate Guidelines Network (SIGN)
- Royal College of Ophthalmologists clinical guidelines
- NIHR Health Technology Assessment Programme

This approach had two purposes: first, questions that could be answered by a systematic review would be deemed as not requiring research and could therefore be removed from the process and secondly, questions which could not be answered by evidence presented in a systematic review would go forward to the prioritisation process. Those relating to treatments and interventions would also be added to the UK Database of Uncertainties about the Effects of Treatments (UK DUETs – www.library.nhs.uk/duets).

Once assessed, questions were assigned to one of the following categories:

- No relevant systematic reviews identified.
- Relevant, reliable up-to-date systematic reviews do not address continuing questions about treatment effects.
- Relevant systematic reviews are not up-to-date.
- Reliable up-to-date systematic reviews have revealed important continuing questions about treatment effects.

When a systematic review that addressed a question was found, the conclusion was checked to ascertain the findings of the review. In many instances, systematic reviews highlighted gaps in the evidence base and further research was recommended. The corresponding question was then coded as a continuing uncertainty and included in the prioritisation process.

While the individual questions were to be coded for inclusion in UK DUETs, the next stage of the project removed all duplicates from the orginal submissions and grouped responses into finalised questions. Areas of duplication were colour-coded to clearly demonstrate questions of a similar nature and common themes were established. The most-asked questions could be subdivided into the following headings:

- Prevention/preventing progression
- Cure
- Efficacy of treatment
- Early diagnosis
- Lifestyle factors
- Dietary interventions
- Genetics/stem cell research
- Risk factors
- Side effects of treatments
- Monitoring rate of decline of disease
- Psychological factors
- Service delivery

After the questions were colour coded and coded for inclusion in UK DUETs they were de-duplicated. All questions were then allocated to one of the following 12 categories in readiness for the interim prioritisation stage:

1. Age-related macular degeneration
2. Cataract
3. Childhood-onset eye disorders
4. Corneal and external diseases
5. Glaucoma
6. Inherited retinal diseases
7. Neuro-ophthalmology
8. Ocular cancer
9. Ocular inflammatory diseases
10. Refractive error and ocular motility
11. Retinal vascular diseases
12. Vitroretinal and ocular trauma

"There has always been consensus across the sector that people with experience of sight loss and eye conditions and eye health professionals should have their say."

Kathy Evans, Chief Executive, Royal College of Ophthalmologists

Stage 4
Interim prioritisation

An interim prioritisation exercise was undertaken for each of the 12 categories for which over 30 questions remained after the data assessment exercise (all categories excluding cataract and ocular cancer). The interim prioritisation exercise took place between March and May 2013. Patients, relatives, carers and eye health professionals were asked to rank their top ten questions from the long list of questions for each disease category in which they had personal or professional experience. People approached at this stage of the exercise included respondents to the original survey and other patients, relatives, carers, patient organisations and eye health professionals.

In each category, responses from patients, relatives, carers and patient organisations were collated and ranked as were the responses from eye health professionals. The rankings were combined to produce a short list of around 30 questions per category.

Stage 5
Final prioritisation

Final prioritisation workshops were held in April and May 2013, in order to reduce the number of questions to around 10 per category. These were attended by a balanced group of patients, relatives, carers, members of organisations, eye health professionals and neutral facilitators. Sessions were chaired by Katherine Cowan, on behalf of the James Lind Alliance.

Participants were asked to complete declaration of interest forms and biographies of each participant were circulated to everyone attending, to encourage transparency and openness. At each workshop, the questions were printed on A4 card and were read out as they were used.

Neutral facilitators encouraged full and fair participation from all those who attended. Some of the workshops were attended by observers who were introduced but did not take part in the discussions.

Each workshop followed the standard JLA approach, using Nominal Group Technique to generate discussion, ranking and consensus agreement. They incorporated the following stages:

- Small group discussions and ranking of all the questions. The groups were mixed in terms of participant background and interest.
- A plenary session which examined the result of combining the separate rankings of the small groups.
- New small groups, which reviewed the combined ranked list of all the questions and made changes where appropriate.
- A final plenary session which brought the rankings of the smaller groups together and reviewed the combined ranking. Changes were then only made through discussion and a vote, if necessary.

This process is described in detail in the JLA Guidebook (www.JLAguidebook.org).

During the discussions, it was not uncommon for participants to suggest combining questions which they felt were sufficiently similar or which they thought would be better addressed together for research. In such cases, agreement was required by the whole group and a 'lead' question was identified. This question was then reworded where necessary, to reflect any other questions merged into it. This has advantages and disadvantages: while it allows a wider range of topics to enter the top 10, it also risks creating very generalised questions. This was highlighted to participants.

JLA priority setting workshops are challenging. They seek consensus among diverse groups and, therefore, require participants to be pragmatic, respectful of different views and accepting of compromise. There was initial concern that eye health professionals attending would have far more of an input and be more outspoken than the patients. However, patients engaged in discussion and debate throughout the process and often eye health professionals aided in explaining current interventions and treatments available to improve understanding and help rank the priorities as a whole group. The facilitators were sensitive to the relative input of different participants and endeavoured to ensure that no one dominated, or was excluded from, the discussion. Many workshop participants had complete or severe sight loss. It was important that the facilitators took steps to explicitly include their input and ensure they could fully contribute at all times.

Results

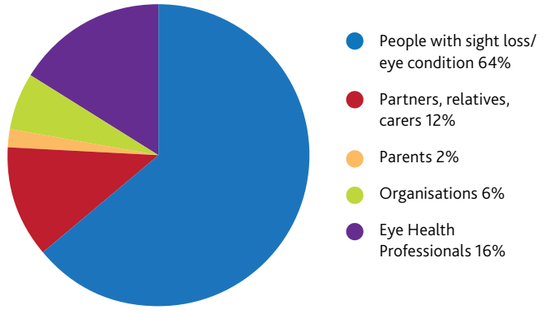
Overview

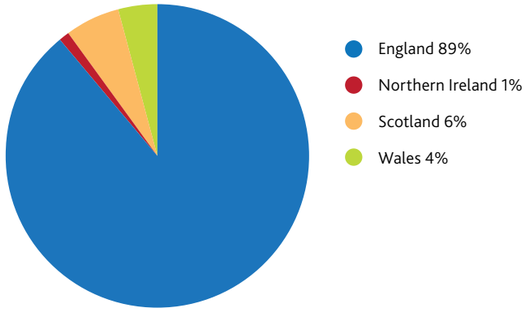
The initial survey was completed and returned by 2220 respondents who asked 4461 questions covering over 100 eye diseases and conditions. Details of the respondents are as follows:

- Oldest person who completed the survey: 105 years old
- Youngest person who completed the survey: adult on behalf of a 16 month old baby
- Average age of survey participants: 65.7 years old
- Gender: men 38%, women 62%
- Geographical split: England 89%; Scotland 6%; Wales 4%; Northern Ireland 1%.
- Percentage eye health professionals: 16%

The number of questions was reduced to 686 after removing those questions deemed out of scope, those for which an up-to-date systematic review provided the answer and duplicate questions.

A large response to the interim exercise was received, with 446 patients, relatives, carers and 218 eye health professionals ranking their priorities for research.





The number of people and organisations (some of which consulted with a wider membership) responding to each category in this interim exercise was as follows:

CATEGORY	NO. PATIENTS, RELATIVES, CARERS, PATIENT GROUPS AND ORGANISATIONS	NO. EYE HEALTH PROFESSIONALS
Age-related macular degeneration	101	25
Childhood-onset eye disorders	12	20
Corneal and external diseases	25	38
Glaucoma	182	25
Inherited retinal diseases	27	25
Neuro-ophthalmology	15	21
Ocular inflammatory diseases	27	21
Refractive error and ocular motility	21	23
Retinal vascular diseases	15	12
Vitreoretinal and ocular trauma	21	8
Total	**446**	**218**

The Priority Setting Partnership has been incredibly important as it has given the public a loud voice. They are telling us that eye and vision research is very important to them and they have also clearly expressed their priorities. Researchers need to know these priorities, embrace and use them to maximise their case for funding."

Professor Sir Peng Khaw, Director of the National Institute for Health Research Biomedical Research Centre in Ophthalmology

Overall, 155 people participated in the final prioritisation workshops. The breakdown is as follows:

CATEGORY	TOTAL NUMBER OF WORKSHOP PARTICIPANTS	NUMBER OF PATIENTS, RELATIVES, CARERS, PATIENT GROUPS AND ORGANISATIONS	NUMBER OF EYE HEALTH PROFESSIONALS
Age-related macular degeneration	17	9	8
Cataract	11	5	6
Childhood-onset eye disorders	16	7	9
Corneal and external diseases	12	5	7
Glaucoma	17	9	8
Inherited retinal diseases	19	11	8
Neuro-ophthalmology	10	6	4
Ocular cancer	10	6	4
Ocular inflammatory diseases	10	5	5
Refractive error and ocular motility	12	5	7
Retinal vascular diseases	11	3	8
Vitreoretinal and ocular trauma	10	7	3
TOTAL	**155**	**78**	**77**

This project is one of the first of its kind to ensure that both the public and clinicians have a say on what they think are the most important areas for research to focus on. We hope that existing research funders from a range of sectors will take note of this and will use these research priorities to support their funding decisions."

Anita Lightstone, Interim Chief Operations Officer for VISION 2020 UK and Programme Director of the UK Vision Strategy

Age-related macular degeneration (AMD)

Conditions included:
- Age-related macular degeneration (wet and dry)
- Charles Bonnet Syndrome

Survey:
763 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 43.

Interim prioritisation:
Participants:
101 patients, relatives, carers, representatives of organisations
25 eye health professionals.

29 shortlisted questions.

Final prioritisation workshop:
Participants:
9 patients, relatives, carers, representatives of organisations
8 eye health professionals.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**Can a treatment to stop dry AMD progressing and/or developing into the wet form be devised?** • Can a treatment to stop progression of dry AMD be developed? • How can dry AMD be prevented from developing into the wet form?
2	**What is the cause of AMD?** • Are the genetic factors responsible for the development/progression of AMD known?
3	**How can AMD be prevented?** • Can AMD be prevented by wearing sunglasses, photochromic glasses or sunglasses/intraocular lenses that filter blue light?
4	**Are there ways of restoring sight loss for people with AMD?** • Can stem cells treat or cure both wet and dry AMD? • How can surgery be improved to repair damage caused by AMD?
5	**Can the development of AMD be predicted?**
6	**What is the most effective way to detect and monitor the progression of early AMD?** • What is the most effective way to monitor AMD? • How can early detection and diagnosis of AMD, both wet and dry, be ensured? • What are the most sensitive biomarkers for AMD and its progression?
7	**What factors influence the progression of AMD?**
8	**Can a non-invasive therapy be developed for wet AMD?** • Is there an alternative to eye injections for the treatment of wet AMD?
9	**Can dietary factors, nutritional supplements, complementary therapies or lifestyle changes prevent or slow the progression of AMD?** • Can dietary measures, nutritional supplements or lifestyle changes prevent AMD? • Can nutritional supplements taken for AMD have an adverse impact on eye health?
10	**What are the best enablement strategies for people with AMD?**

Cataract

Conditions included:
- Cataract

Survey:
191 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 27.

Interim prioritisation:
The number of questions was such that an interim exercise was not required for this category.

Final prioritisation workshop:
Participants:
5 patients, relatives, carers
6 eye health professionals.

Top 11 priorities:
Here are the top 11 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**How can cataracts be prevented from developing?** • What could be done in earlier life to prevent cataract formation? • Are there any lifestyle changes or dietary measures that can be taken to prevent cataract? • What is the effect of sunlight on the development of cataract? • What is the effect of excess alcohol intake on cataract formation?
2	**Can the return of cloudy or blurred vision after cataract surgery known as posterior capsule opacity (PCO) or secondary cataract be prevented?**
3	**How can cataract progression be slowed down?** • Can dietary measures, nutritional supplements or complementary therapies slow down the progression of cataracts?
4	**What alternatives to treat cataracts other than cataract surgery are being developed?**
5	**What is the cause of cataract?**
6	**How can cataract surgery outcomes be improved?**
7	**How safe and effective is laser assisted cataract surgery?**
8	**Should accommodative lenses be developed for cataract surgery?**
9	**What is the best measure of visual disability due to cataract**? • What is the most effective way to monitor development of cataract?
10	**Can retinal detachment be prevented after cataract surgery?**
11	**What are the outcomes for cataract surgery among people with different levels of cognitive impairment (whatever the cause but including dementia, stroke, neurological conditions, head injuries)?**

> **"I thought today's session was a success and have to say my scepticism about the process was unfounded! I hope it stimulates a lot of research and income."**
>
> ***Professor David Spalton, Consultant Ophthalmic Surgeon***

Childhood-onset eye disorders

Conditions included:
- Albinism
- Amblyopia
- Aniridia
- Anophthalmia
- Childhood glaucoma
- Cerebral vision impairment
- Coloboma
- Congenital cataract
- Microphthalmia
- Persistent Hyperplastic Primary Vitreous (PHPV)
- Retinoblastoma

Survey:
125 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 69.

Interim prioritisation:
Participants:
12 patients, relatives, carers, representatives of organisations
20 eye health professionals.

30 shortlisted questions.

Final prioritisation workshop:
Participants:
7 patients, relatives, carers, representatives of organisations
9 eye health professionals.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**How can cerebral visual impairment be identified, prevented and treated in children?**
2	**How can treatment for visual pathway damage associated with pre-term birth be developed?**
3	**How do we improve screening and surveillance from the ante-natal period through to childhood to ensure early diagnosis of impaired vision and eye conditions?** • Can an objective screening method be used nationally in children so that early diagnosis is obtained and treatment can be started? • What is the best way to identify sight loss in babies and young children? • What can be done to identify eye abnormalities before birth? • What is the best way to conduct screening of children to detect amblyopia?
4	**Can the treatment of amblyopia be improved to produce better short and long term outcomes than are possible with current treatments?** • Can the treatment of amblyopia be improved to produce better results than are possible with current treatments? • When patching is stopped in people with amblyopia, what is the likelihood that vision will be maintained? • What are the factors that influence the development of amblyopia? • What is the most effective way to treat amblyopia in children under the age of 7? • Can full binocular vision for children with lazy eye be achieved if the condition is treated or does treatment only ever partially restore vision? • Does the patient's age / developmental stage affect the optimum amount of daily patching for amblyopia? • Is it possible to determine which eyes are likely to benefit from occlusion therapy administered in patients with different types of amblyopia? • Why do some people develop dense amblyopia and others much less severe amblyopia?
5	**How can cataract be prevented in children?**
6	**What are the causes of coloboma and microphthalmia/anophthalmia and how can they be prevented?** • What are the causes of coloboma? • What is the cause of microphthalmia/anophthalmia? • What can be done to prevent coloboma?
7	**Can vision be corrected in later life for people with amblyopia?**
8	**How can retinoblastoma be identified, prevented and treated in children?** • Is there a link between the mutations in the RB1 gene and the way that retinoblastoma presents and develops? • Does proton beam radiotherapy offer a safer and equally effective alternative to conventional radiotherapy in the treatment of retinoblastoma, especially for children under one year of age? • Is it possible to determine genetic markers for retinoblastoma?
9	**Can better treatments for glaucoma in children be developed?**
10	**Can a treatment be developed to improve vision for people with albinism?**

Corneal and external eye diseases

Conditions included:
- Blepharokeratoconjunctivitis
- Chalazion
- Conjunctivitis
- Cornea/Corneal Dystrophy
- Corneal Erosion Syndrome
- Corneal Limbal Stem Cell Deficiency
- Cyst
- Dry Eye
- Fuchs' Corneal Dystrophy
- Herpes
- Keratoconus
- Microbial Keratitis
- Pterygium
- Salzmann's Nodular Degeneration
- Stevens Johnson Syndrome
- Trachoma
- Vernal Keratoconjunctivitis

Survey:
292 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 93.

Interim prioritisation:
Participants:
25 patients, relatives, carers, representatives of organisations
38 eye health professionals.

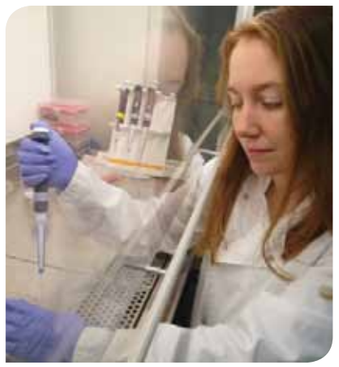
30 shortlisted questions.

Final prioritisation workshop:
Participants:
5 patients, relatives, carers, representatives of organisations
7 eye health professionals.

Although questions were submitted about Trachoma, they were taken out of the process as the condition is not prevalent in the UK.

Top 11 priorities:
Here are the top 11 priorities for this category
(the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**Can new therapies such as gene or stem cell treatments be developed for corneal diseases?** • Can a gene therapy treatment be developed for corneal diseases such as keratoconus and Fuchs' corneal dystrophy? • Can stem cell treatments for corneal diseases including keratoconus and Fuchs' corneal dystrophy be developed? • What is the most effective surgical treatment for corneal limbal stem cell deficiency?
2	**What is the most effective management for dry eye and can new strategies be developed?** • What is the most effective treatment for dry eye? • Can a cure for dry eye be developed?
3	**Can treatments to save eye sight from microbial keratitis be improved?** • Can treatments for acanthamoeba keratitis that are non-toxic to the anterior surface be developed?
4	**How can the rejection of corneal transplants be prevented?** • What is the likelihood of developing topical, as opposed to systemic, immunosuppressants to reduce the risk of corneal transplant rejection?
5	**Can the outcomes of corneal transplantation be improved?**
6	**What causes keratoconus to progress and can progression be prevented?** • What is the effectiveness of collagen cross linking for keratoconus?
7	**Can non-surgical therapy be developed for Fuchs' corneal dystrophy?**
8	**Can corneal infections be prevented in high-risk individuals such as contact lens wearers?** • Can corneal infections for wearers of contact lenses be prevented? • Can microbial keratitis be prevented?
9	**What is the cause of keratoconus and can it be prevented?** • What is the cause of keratoconus? • Can keratoconus be prevented? • What is the genetic component of keratoconus?
10	**What is the most effective management of ocular complications associated with Stevens Johnson Syndrome?**
11	**Can severe ocular surface disease in children, such as blepharokeratoconjunctivitis and vernal keratoconjunctivitis be managed better?**



"Thank you for this and for giving the Keratoconus Group the opportunity to contribute to the priority setting. It was a really interesting day, which we very much enjoyed. It was very worthwhile and we listened to a variety of views from patient groups and health professionals before reaching a consensus."

Anne Klepacz, Keratoconus Group Chair

Glaucoma

Conditions included:
- Glaucoma
- Pigment Disperson Syndrome
- Pseudoexfoliation Syndrome

Survey:
1235 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 78.

Interim prioritisation:
Participants:
182 patients, relatives, carers, representatives of organisations
25 eye health professionals.

30 shortlisted questions.

Final prioritisation workshop:
Participants:
9 patients, relatives, carers, representatives of organisations
8 eye health professionals.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**What are the most effective treatments for glaucoma and how can treatment be improved?** • What is the most effective glaucoma treatment? • What is the effectiveness of surgical treatment compared to treatment with eye drops for glaucoma patients?
2	**How can loss of vision be restored for people with glaucoma?** • Can a stem cell treatment for glaucoma be developed? • Can the optic nerve be repaired or regenerated?
3	**How can glaucoma be stopped from progressing?** • Can a treatment to stop or delay nerve cells dying in the optic nerve be developed?
4	**What can be done to improve early diagnosis of sight-threatening glaucoma?** • What can be done to improve early diagnosis of glaucoma? • How and at what age should people be tested if there is glaucoma in the family? • What is the effectiveness of optical coherence tomography evaluation of the optic disc in early glaucoma diagnosis?
5	**What causes glaucoma?** • Why does vision continue to deteriorate for some people with glaucoma after the pressure levels have been controlled by drops? • What is the relationship between glaucoma and blood pressure?
6	**What is the most effective way of monitoring the progression of glaucoma?** • How can techniques for measuring the progression of glaucoma be improved? • Can better ways of measuring visual fields be developed? • Are there alternative methods for assessing visual fields that are more acceptable to patients? • What is the optimal interval between eye tests for patients with glaucoma?
7	**How can glaucoma patients with a higher risk to progress rapidly be detected?**
8	**Why is glaucoma more aggressive in people of certain ethnic groups, such as those of West African origin?**
9	**How can glaucoma be prevented?**
10	**Is there a link between treatment adherence and glaucoma progression and how can adherence be improved?** • How can patient compliance in glaucoma be improved? • How can eye drops be made easier to administer? • What is the best way of monitoring glaucoma medication compliance?

Inherited retinal diseases

Conditions included:
- Achromatopsia
- Adult Vitelliform Macular Dystrophy
- Alström Syndrome
- Best Disease
- Choroideremia
- Cone Dystrophies
- Juvenile Macular Dystrophy
- Leber's Congenital Amaurosis
- Marfan Syndrome
- Pseudoxanthoma Elasticum
- Retinal Dystrophy
- Retinitis Pigmentosa (RP)
- Sorsby Macular Dystrophy
- Stargardt's Disease
- Stickler Syndrome
- Usher Syndrome

Survey:
280 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 63.

Interim prioritisation:
Participants:
27 patients, relatives, carers, representatives of organisations and 25 eye health professionals.

30 shortlisted questions.

Final prioritisation workshop:
Participants:
11 patients, relatives, carers, representatives of organisations
8 eye health professionals.

Participants at the final workshop agreed that for inclusivity, condition-specific priorities would be reworded to address 'inherited retinal diseases' more generally.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**Can a treatment to slow down progression or reverse sight loss in inherited retinal diseases be developed?** • How can sight loss be treated in people with an inherited retinal disease? • Is it possible to determine which inherited retinal diseases are likely to be treatable with gene therapy? • Can a stem cell therapy stop progression of sight loss and restore sight for inherited retinal diseases and for syndromes associated with RP, such as Usher and Alström? • Will gene therapy stop the progression of sight loss and reverse sight loss in inherited retinal diseases and in syndromes associated with RP, such as Usher and Alström? • What is the likelihood that computerised artificial eyes/retinal implants can restore sight loss due to inherited retinal disease? • Are there any potential long term risks associated with gene therapy for inherited retinal diseases? • Are there any potential long term risks associated with potential stem cell therapies for inherited retinal diseases? • Could a treatment in the form of eye drops be developed for inherited retinal diseases?
2	**How can sight loss be prevented in an individual with inherited retinal disease?**
3	**Is a genetic (molecular) diagnosis possible for all inherited retinal diseases?** • Is access to genetic testing available for all inherited retinal diseases?
4	**What factors affect the progression of sight loss in inherited retinal diseases?** • What are genetic and environmental influences on juvenile macular disease such as Stargardts and Best disease? • Why do some patients with a genetic mutation not develop the disease? • Can the rate of sight loss for people with RP be predicted? • How much is known about the long term prognosis (natural history) for inherited retinal diseases and is it related to the genotype? • Can dietary measures, nutritional supplements, vitamins, complementary therapies or lifestyle changes affect the progression of sight loss in inherited retinal diseases? • Can lifestyle or dietary factors trigger or prevent the onset of sight loss in RP?
5	**What causes sight loss in inherited retinal diseases?**
6	**What is the most effective way to support patients with inherited retinal disease?** • What types of glasses/lenses can be beneficial for people with RP? • What is the likelihood that the use of sunglasses from an early age can prevent sight loss in RP? • Once diagnosed should patients with an inherited retinal disease be regularly seen by an ophthalmologist even when there are no current treatments?
7	**Can the diagnosis of inherited retinal diseases be refined so that individuals can be given a clearer idea about their specific condition and how it is likely to progress?**
8	**What is the relationship between sight loss and mental health for people with inherited retinal diseases?**
9	**Would having a treatment for an inherited retinal disease preclude a patient from having another treatment?**
10	**With regard to inherited retinal diseases what is the role of pre-natal and pre-implantation diagnosis in helping parents make informed choices?**

Neuro-ophthalmology

Conditions included:
- Anterior Ischaemic Optic Neuropathy
- Cerebral Vision Impairment
- Chronic Optic Neuritis (CRION)
- Giant Cell Arteritis
- Hemianopsia
- Leber's Hereditary Optic Neuropathy
- Optic Atrophy
- Optic Neuritis
- Optic Neuropathy
- Pale Optic Nerve
- Pituitary Adenoma
- Posterior Cortical Atrophy

Survey:
125 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 43.

Interim prioritisation:
Participants:
15 patients, relatives, carers, representatives of organisations
21 eye health professionals.

30 shortlisted questions.

Final prioritisation workshop:
Participants:
6 patients, relatives, carers, representatives of organisations
4 eye health professionals.

There was a large representation from patients with Giant Cell Arteritis, and a support group for this condition, at the workshop but this did not appear to prevent other conditions being prioritised in the top 10. This was aided by participants deciding to group conditions together under similar questions.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**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?** • What is the underlying cause of optic nerve damage in optic atrophies such as giant cell arteritis, optic neuritis and other optic neuropathies? • What causes sight loss in giant cell arteritis?
2	**What are the most effective treatments and rehabilitation for optic neuropathies, e.g. Leber's hereditary optic neuropathy and anterior ischaemic optic neuropathy?** • What are the most effective treatments for optic neuropathies? • What are the most effective treatments for Leber's hereditary optic neuropathy? • What is the effectiveness of hyperbaric oxygen therapy compared to Idebenone treatment for Leber's hereditary optic neuropathy?
3	**Can vision loss due to optic nerve diseases such as giant cell arteritis, Leber's hereditary optic neuropathy, optic neuritis and optic atrophy, be restored, for example through gene therapy and stem cell treatment?** • Can vision loss due to optic nerve diseases such as giant cell arteritis, optic neuritis and optic atrophy, be restored? • Can a gene therapy or stem cell treatment be developed for optic nerve diseases e.g. optic neuritis, optic neuropathy and giant cell arteritis? • Can a gene therapy or stem cell treatment for Leber's hereditary optic neuropathy be developed?
4	**What rehabilitation or treatment methods are most effective for vision loss following brain damage due to stroke, brain injury, cerebral vision impairment, tumours and dementias?** • What rehabilitation methods are most effective for vision loss following brain damage due to stroke, brain injury, cerebral vision impairment, tumours and injury? • What visual scanning training is best for treatment of homonymous hemianopia? • What rehabilitation methods are effective for visual field loss for people with homonymous hemianopia?
5	**What is the most effective way to assess vision in patients with neurological visual impairment i.e. stroke, dementia and cerebral/cortical visual impairment?** • How can vision loss be accurately assessed in patients with dementia?
6	**Can the early stages of optic neuropathy be detected?** • How can early stage vision loss be detected in patients with giant cell arteritis? • Why is there so little consensus on remission and relapses and the impact on vision for people with giant cell arteritis? • What is the most effective way to diagnose sight loss in people with giant cell arteritis?
7	**How can optic neuropathies be prevented, for example anterior ischaemic optic neuropathy, Leber's hereditary optic neuropathy, optic neuritis and other optic neuropathies?** • How can optic nerve neuropathies be prevented? • How can sight loss caused by giant cell arteritis be prevented? • How can the onset of Leber's hereditary optic neuropathy be prevented?
8	**Can treatments be developed for visual field and ocular motility manifestations following stroke?** • What are the optimal treatments/interventions to improve visual function for cerebral vision impairment in children and adults?
9	**How can electronic devices improve or restore vision for people with optic neuropathies?**
10	**Can an alternative or new treatment be developed that will treat the sight loss caused by giant cell arteritis?**

Ocular cancer

Conditions included:
- Ocular Melanoma
- Lacrimal Gland Cancer

Survey:
26 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 19.

Interim prioritisation:
The number of questions was such that an interim exercise was not required for this category.

Final prioritisation workshop:
Participants:
6 patients, relatives, carers, representatives of organisations
4 eye health professionals.

It was decided by attendees at the workshop that some of the questions relating to ocular melanoma would be renamed 'ocular cancer' to incorporate all of the different eye cancers.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**What can be done to help ocular cancer sufferers?**
2	**Can gene-based targeted therapies for ocular cancers be developed?** • Can a gene therapy for choroidal melanoma be developed? • Can a treatment strategy be developed to target mutations in GNAQ/GNA11 and BAP1 which are the key gene mutations in ocular melanoma?
3	**How can immunotherapy be used to fight metastatic ocular melanoma?**
4	**What are the most effective detection and screening methods for follow up to detect metastasis of ocular melanoma?**
5	**How can follow-up for ocular complications be managed in patients with ocular melanoma?** • How can an adequate onward screening for ocular melanoma patients be provided? • Why is there no screening program for people with choroidal melanoma who were treated several years ago?
6	**What is the best management of metastatic choroidal melanoma?**
7	**What activates choroidal melanoma metastasis in the liver after the primary melanoma has been treated?**
8	**Can adjuvant therapies be developed to treat ocular melanoma?**
9	**What are the causes of ocular cancer and how can they be prevented?** • What is the cause of ocular melanoma? • How can ocular melanoma be prevented? • What is the genetic component of lacrimal gland tumour?
10	**What is the most effective treatment for primary ocular melanoma?**

> **The programme was very well run and worthwhile and I am sure the final ranking of questions by the James Lind Alliance will assist in the future. From an Ocular Melanoma (OM) perspective I am sure being on the JLA 'list' will help, especially given OM's rarity and unusual split between 'primary' and 'secondary' disease priorities."**
>
> ***Steve Munday, Melanoma Patient***

Ocular inflammatory diseases

Conditions included:
- Behcet's Disease
- Birdshot Retinopathy
- Blepharitis
- Endophthalmitis
- Graves' Eye Disease
- Iritis
- Progressive Outer Retinal Necrosis (PORN)
- Punctate Inner Choroidopathy (PIC)
- Scleritis
- Sjorgen's Syndrome
- Thyroid Eye Disease
- Thyrotoxicosis
- Toxoplasmosis
- Uveitis
- Vogt Kayanagi Harada Syndrome

Survey:
472 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 66.

Interim prioritisation:
Participants:
27 patients, relatives, carers, representatives of organisations
21 eye health professionals.

30 shortlisted questions.

Final prioritisation workshop:
Participants:
5 patients, relatives, carers, representatives of organisations
5 eye health professionals.

It was decided by attendees at the workshop that certain ranked questions that asked the same question but for different conditions would be grouped and replaced with 'ocular and orbital inflammatory disease' to incorporate all of the different conditions.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**What are the most effective treatments for ocular and orbital inflammatory diseases?** • What are the most effective treatments for uveitis? • What is the most effective treatment for thyroid eye disease? • Can a cure for thyroid eye disease be developed? • Can treatments for uveitis be developed that don't involve steroids? • How can uveitis in children be managed, to reduce the long-term risk of blindness? • What is the best treatment for optic neuropathy in thyroid eye disease? • Can new treatments without harmful side effects for thyroid eye disease be developed? Can surgical treatment for thyroid eye disease be improved? • Can improvements in treatments for thyrotoxicosis reduce the risk of thyroid eye disease from developing?
2	**What causes thyroid eye disease?** • What is the link between the antibodies which affect the thyroid in Graves' disease and thyroid eye disease and could this information be used to develop a treatment? • In people with thyroid eye disease, is there some way to remove whatever it is that prompts the immune system to target the eye muscle cells? • Why do some forms of orbital inflammation cause extreme scarring with loss of vision? • Can thyroid eye disease be triggered by environmental factors? • Can a genetic test for Graves' eye disease be developed? • Which patients with Graves' disease are at risk of developing thyroid eye disease?
3	**Can the severity of ocular and orbital inflammatory disease in an individual be predicted?**
4	**Is it possible to prevent further occurrences of retinal damage caused by toxoplasmosis?**
5	**What causes birdshot retinopathy?**
6	**Why does disease burn out in patients with ocular and orbital inflammatory diseases?**
7	**Can early detection methods be developed for ocular and orbital inflammatory diseases?** • Can early detection methods be developed for birdshot retinopathy? • Can methods of early diagnosis, including self diagnosis, of thyroid eye disease/ Graves' eye disease be developed? • What screening techniques could best identify the early symptoms of Behcet's disease?
8	**What medications best prevent the development of eye disease in Behcet's?**
9	**What causes scleritis?**
10	**Can diet or lifestyle changes prevent uveitis from developing?** • What are the risks and benefits of vitamin supplements for autoimmune diseases of the eye?

Refractive error and ocular motility

Conditions included:
- Astigmatism
- Diplopia
- Emmetropia
- Esotropia
- Exotropia
- Hypermetropia/Long-sightedness
- Myopia
- Nystagmus
- Presbyopia
- Refractive Error
- Squint
- Strabismus

Survey:
188 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 70.

Interim prioritisation:
Participants:
21 patients, relatives, carers, representatives of organisations
23 eye health professionals.

31 shortlisted questions.

Final prioritisation workshop:
Participants:
5 patients, relatives, carers, representatives of organisations
7 eye health professionals.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**What factors influence the development of refractive error (myopia, astigmatism, presbyopia and long-sightedness)?** • How can presbyopia be prevented? • How does the wearing of spectacles (of any prescription) affect the progression of refractive error? • What is the cause of myopia? • How do genetic factors cause myopia (short sightedness)? • Is there a relationship between diet and the development of myopia?
2	**What is the cause of both congenital and acquired nystagmus?** • How can both congenital and acquired nystagmus be prevented?
3	**How can the development of binocular vision in young children with squint and amblyopia be promoted, and would the same approach work in older individuals without inducing intractable diplopia?** • Why does the brain suppress vision in squint? • Why do some children with constant esotropia develop amblyopia while others retain equal sight in both eyes?
4	**Would correction of refractive error have a positive impact on early life learning and development?**
5	**Does early diagnosis of refractive error improve long-term prognosis and promote faster, more effective treatment?** • What detection methods can be used for alerting to early stages of long sightedness (hypermetropia) for school entry children? • Is there an effective objective way of screening for vision loss from uncorrected refractive error in children, from an early age?
6	**What is the effect of congenital nystagmus on visual and emotional development?**
7	**What is the most effective treatment for exotropia and when should it be delivered?** • How can the outcome of childhood exotropia surgery be better predicted? • Which children with intermittent exotropia would benefit from surgery?
8	**How can the functional effects of surgical treatment for squint best be assessed?**
9	**Could the accurate testing of refractive error be made less dependent on a subjective response i.e. the person's own response?**
10	**How can myopia be prevented?** • Could gene therapy be used to stop progression of vision loss due to myopia? • How can the progression of myopia be prevented?

Retinal vascular diseases

Conditions included:
- Central Retinal Vein Occlusion
- Central Serous Retinopathy
- Coats' Disease
- Diabetic Retinopathy
- Macular Oedema
- Macular Telangiectasia
- Retinal Vein Occlusion
- Retinopathy of Prematurity

Survey:
205 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 56.

Interim prioritisation:
Participants:
15 patients, relatives, carers, representatives of organisations
12 eye health professionals.

30 shortlisted questions.

Final prioritisation workshop:
Participants:
3 patients, relatives, carers
8 eye health professionals.

The imbalance of patients to eye health professionals was due to a number of patients, relatives and carers having to withdraw from the process at the last moment. Facilitators were conscious of the lack of patient voice in the group and asked the eye health professionals to be mindful of it too.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**What are the best methods to prevent retinopathy of prematurity?**
2	**How can sight loss from diabetic retinal changes be prevented and reduced?** • How can sight loss from diabetic retinopathy be prevented? • How can diabetes lead to sight loss? • How can diabetic retinopathy be prevented? • What are the causes of diabetic retinopathy? • What is the best way to manage and reduce the risk of sight loss for people with diabetic eye disease?
3	**What are the predictive factors for the progression to sight threatening diabetic eye disease?** • Can the likelihood of getting progressive sight threatening diabetic eye disease be predicted? • Why do some people have much worse diabetic retinopathy than others with the same or similar risk factor control?
4	**Is there a way to improve screening of premature babies for retinopathy of prematurity?** • In addition to using gestational age and birth weight as screening criteria for retinopathy of prematurity, could additional factors be used to reduce the number of unnecessary screenings performed?
5	**Can an effective long lasting treatment for diabetic macular oedema, both ischaemic and non-ischaemic, be developed?** • Can a fixed combination slow release monotherapy (preferably topical or intravitrial biodegradable) be developed for diabetic macular oedema treatment?
6	**Can a retinal vein occlusion be predicted and prevented?** • Can a retinal vein occlusion be prevented? • Is there any way to predict if branch retinal vein occlusion will occur? • If central retinal vein occlusion is manifest in one eye, how can it be prevented from affecting the other eye? • What causes retinal vein occlusion?
7	**Can new non-invasive treatments be developed to slow down the progression of diabetic retinopathy?** • Can lifestyle modifications or nutritional supplements slow the progression of diabetic retinopathy?
8	**What are the barriers that prevent diabetic patients having regular eye checks?**
9	**What rehabilitation programmes are best for the management of distorted vision from retinal diseases?**
10	**What is the efficacy and safety of anti-VEGF agents in the treatment of retinopathy of prematurity?**

Vitreoretinal and ocular trauma

Conditions included:
- Degenerative Vitreous Syndrome
- Retinal Detachment
- Epiretinal Fibrosis
- Epiretinal Membrane
- Eye Floaters
- Macular Hole
- Vitreous Detachment
- Vitreous Syneresis

Survey:
265 questions from survey respondents.

Data assessment:
The process of analysis reduced the number of questions to 59.

Interim prioritisation:
Participants:
21 patients, relatives, carers, representatives of organisations
8 eye health professionals.

30 shortlisted questions.

Final prioritisation workshop:
Participants:
7 patients, relatives, carers, representatives of organisations.
3 eye health professionals.

Top 10 priorities:
Here are the top 10 priorities for this category (the final prioritised questions encompass the questions immediately underneath):

RANK	PRIORITIES
1	**How can surgical techniques be improved to save sight for eyes damaged by injury?**
2	**How can the risk of losing sight for people with retinal detachment be reduced?** • How can the success rate of surgery for retinal detachment be improved?
3	**How can better interventions be developed that are effective in treating vitreous opacities/eye floaters?** • What factors are important in deciding whether to surgically treat patients with eye floaters? • Can a cure be developed for vitreous syneresis/degenerative vitreous/eye floaters?
4	**What causes retinal detachment and can it be prevented?** • What causes retinal detachment? • Is there anyway of detecting a retina pre-disposed to detachment? • Can retinal detachment be prevented?
5	**Can more effective diagnostic tools be developed for assessing the vitreous and eye floaters?**
6	**Can a functioning prosthetic eye be developed to replace an eye damaged by injury?**
7	**How can epiretinal membrane/fibrosis be prevented or treated?** • Can epiretinal membrane/fibrosis be prevented from happening? • How can epiretinal membrane/fibrosis be treated? • What is the most effective treatment for epiretinal membrane/fibrosis?
8	**Can stem cells be used to regrow an eye or part of an eye?**
9	**What causes posterior vitreous detachment/vitreous syneresis?** • What causes posterior vitreous detachment? • What causes vitreous syneresis/degenerative vitreous?
10	**Are there methods to prevent and improve the treatment of macular holes?** • What is the most effective and safe treatment for macular holes? • Are there environmental or genetic factors that predispose to macular holes?

Next steps

The Sight Loss and Vision PSP has now produced a list of priorities for research in 12 different categories of eye disease/ condition.

Evidence exists for some of the research priorities identified and a careful review and analysis of this evidence might lead to a relatively fast and cost-effective transition from an unanswered question to an answered one. Other priorities are clearly much more complex and have far less research data available. Many of these will require extensive, complex and time consuming research in order to move us closer to an 'answer'. They may well relate to the fundamental science underpinning our understanding of the disease processes in the eye. Other priorities will sit somewhere between these two points on the research spectrum.

What is clear, however, is that funds for eye research are very limited and no single funder is likely to be able to address all of the agreed priorities. What is required is collaboration by funders that will ensure that research is targeted towards the priorities identified, the case for additional funding is made and the sector can co-ordinate its efforts to be able to recognise the areas that are not receiving funding.

The following are the first steps toward establishing the collaborative ethos that will enable as many of the priorities to be addressed:

1. Existing research funders are encouraged to integrate the priorities into their organisational plans and research strategies. This process has already started with both Fight for Sight and The College of Optometrists embracing the priorities.

2. A resource is developed that demonstrates to the public and research funders the priorities that have attracted funding and the source of funding.

3. Applicants justify the need for research in their grant applications by addressing these priorities in their applications for research funding.

4. Relevant organisations not yet funding eye research are encouraged to do so. It is very clear from this exercise that an enormous demand for research exists amongst patients and eye health professionals. This will require wide dissemination of this report and active dialogue with decision makers.

5. Prioritisation exercises are promoted in other countries in a worldwide effort to focus scarce research resources and to encourage further funding into the sector.

"Supporting and funding the development and delivery for the Sight Loss and Vision Priority Setting Partnership has been one of the most important things that the College of Optometrists has funded within our research strategy. The College has been working hard, on behalf of the public and the profession of optometry, to ensure that patient and clinician views about research are heard."

Doctor Edward Mallen, Chair of the College of Optometrists Research Committee

How to get involved

1. **Contributions and participation in taking the Sight Loss and Vision Priorities forward are actively encouraged:** You can get in touch with the Steering Committee by contacting **sightlossandvisionpsp@fightforsight.org.uk** or **researchteam@college-optometrists.org**

2. **Use the priorities!:** Review the priorities and consider how your organisation can use them to inform the work that you do, or support work to determine what research to fund or which projects to seek funding for. This might range from making the priorities that are most relevant to your organisation's objectives a key explicit part of updated versions of organisational plans, policies or procedures, to ensuring that relevant priorities are referred to in reviewing applications for funding or proposed projects for commissioning. Researchers can make sure that they refer to the priorities when they submit applications for funding.

3. **Tell us how you are using the priorities:** We want to hear about how the priorities are being used – whether this is to revise/update organisational plans or procedures, to inform the commissioning or funding of research or in the process of assessing research applications. The more information you can provide about how you are making use of the priorities and where you have enjoyed success in using them, the greater the opportunity to learn from each other's successes and to demonstrate that the priorities can make an impact on the research processes in the sector.

4. **Tell other people about the priorities:** The more people in the sector talk to each other and people from other sectors about the priorities and how they are being used to improve access to funding and focus research efforts, the more impact they will have. Encourage members of the public that are involved with your organisation to talk about the priorities and their interests in research.

Acknowledgements

The Sight Loss and Vision Priority Setting Partnership would not have existed had it not been for the countless number of patients, relatives, carers, patient groups/organisations and eye health professionals who participated in the survey, the interim exercise and the final prioritisation workshops. Thank you for your time and participation.

"I found it very very interesting and educational! And it has opened my eyes and helped me understand various challenges people have.

It was interesting to hear what the professionals have to say and hearing first hand why things can or can't be done, what is important to the people with eye conditions, and most of all the benefit of a survey of this type."

Tina Roberts, parent of a child with Stargardt's Disease.

Disclosures

The Sight Loss and Vision Priority Setting Partnership was established following work conducted by the Eye Research Group of VISION 2020 UK and then developed as a collaborative project in its own right. All of the funding and project costs were provided by sector organisations that had also contributed to the development of the project and were subsequently involved with the Steering Committee.

Details of funding and the value of in-kind support provided to the study below for transparency. The names and organisational affiliations of all the steering group members are provided on the following pages. There are no conflicts of interest known for either the funding organisations or the individuals or organisations represented on the steering group. All decisions about the project's development, delivery and dissemination were reached by the Steering Committee through democratic means.

Funding / support values by organisation:

ORGANISATION	FUNDING	VALUE OF IN-KIND SUPPORT
College of Optometrists	£50,000	£10,000
Fight for Sight		£60,000
National Institute for Health Research (NIHR) Biomedical Research Centre (BRC) at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology	£30,000	£20,000
Royal College of Ophthalmologists	£5,000	
RNIB	£5,000	
UK Vision Strategy		£5,000

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Appendix 1

The Steering Committee and Data Assessment Group (DAG)

The Steering Committee

The Sight Loss and Vision Priority Setting Partnership was managed by a Steering Committee and led by an independent chair from the James Lind Alliance. The Steering Committee included patient representatives and eye health professionals.

Michèle Acton – Chief Executive, Fight for Sight

Karen Bonstein – Manager of the NIHR Biomedical Research Centre for Ophthalmology

Michael Bowen – Director of Research, College of Optometrists

Carol Bronze – Patient representative

Dr Dolores Conroy – Director of Research, Fight for Sight

Katherine Cowan – James Lind Alliance, Partnership Chair

Kathy Evans – Chief Executive, Royal College of Ophthalmologists

Mark Fenton – Editor, UK Database of Uncertainties about the Effects of Treatments (UK DUETs)

Dr Heather Giles – Patient representative

Dr Robert Harper – Consultant Optometrist, Manchester Royal Eye Hospital

Anita Lightstone – Programme Director, UK Vision Strategy

Dr Fiona Rowe – Senior Lecturer in Orthoptics, University of Liverpool. Research Lead, British and Irish Orthoptic Society

Professor Alan Stitt – Director of the Centre for Vision and Vascular Science, Queen's University Belfast

Professor Heather Waterman – Professor of Nursing and Ophthalmology, University of Manchester

Professor Marcela Votruba – Professor of Ophthalmology & Honorary Consultant Ophthalmologist, Cardiff University

Mr Richard Wormald – Consultant Ophthalmologist, Moorfields Eye Hospital and Co-ordinating Editor, Cochrane Eyes and Vision Group

Sight Loss and Vision PSP Coordinator and Steering Committee Support: **Richard Cable** – Research assistant, Fight for Sight

Data Assessment Group Members

Dr Catey Bunce, Moorfields Eye Hospital

Iris Gordon, London School of Hygiene and Tropical Medicine

Louise Halfhide, Moorfields Eye Hospital

Antra Zekite, Moorfields Eye Hospital

Appendix 2

Sight Loss and Vision Priority Setting Partnership Protocol

Purpose

The purpose of this protocol is to set out the aims, objectives and commitments of the Sight Loss and Vision PSP that were undertaken and the basic roles and responsibilities of the partners therein. The aim of the Sight Loss and Vision PSP was to identify a prioritised list of unanswered questions about sight loss and vision so that research can be targeted accordingly. The Sight Loss and Vision PSP has been led and managed by the following:

- Fight for Sight. Lead: Michèle Acton
- The College of Optometrists. Lead: Michael Bowen
- UK Vision Strategy. Lead: Anita Lightstone
- Mr Richard Wormald, Consultant Ophthamologist, Moorfields Eye Hospital and Co-Ordinating Editor, Cochrane Eyes and Vision Group.

The Partnership and the priority setting process was supported and guided by Katherine Cowan of The James Lind Alliance (JLA).

The Sight Loss and Vision PSP Steering Committee was established to include representatives of patient/service user groups and health care professionals from ophthalmology, optometry, orthoptics, ophthalmic nursing and social care (this group is referred to as eye health professionals). Mr Mark Fenton of UK DUETs agreed to be a member. A researcher was also represented to advise on the shaping of the process, but did not participate in the prioritisation exercise. This ensured that the final prioritised unanswered questions are those agreed by patients/service users and eye health professionals only, in line with the JLA's mission. **Appendix 1** is a list of the members of the Steering Committee and Data Assessment Group (DAG).

The Steering Committee agreed the resources, including time and expertise that they were able to contribute to each stage of the process. The JLA were able to advise on this.

Background to the Sight Loss and Vision PSP

The JLA is a project which is funded by the National Institute of Health Research with support from the Medical Research Council. Its aim is to provide an infrastructure and process to help patients and professionals work together to agree the most important unanswered questions affecting their particular interest, in order to influence the prioritisation of future research in that area. The JLA defines an uncertainty as a known unknown.

The Vision 2020 UK Eye Research Group was formed to bring together people active in eye health and vision research to help find ways to ensure that research is well targeted and co-ordinated, and to maximise the case for enhanced funding. This led to the development of proposals for a UK vision research agenda. In 2011, Fight for Sight, the College of Optometry, the UK Vision Strategy and Mr Richard Wormald, on behalf of the Vision 2020 UK Eye Research Group, asked the JLA to work with them to develop a Sight Loss and Vision PSP consulting with all interested organisations in the sector.

Aims and objectives of the PSP

The aim of the Sight Loss and Vision PSP was to identify the unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions from the perspectives of patients/service users and eye health professionals and then prioritise those which both groups agree are the most important.

The objectives of the Sight Loss and Vision PSP were to:

- work with patients/service users and eye health professionals to identify unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions and to agree by consensus a prioritised list of those unanswered questions for future research
- to publicise the results of the Sight Loss and Vision PSP and process
- to take the results to research commissioning bodies to be considered for funding

Partners

Organisations and individuals were invited to take part in the Sight Loss and Vision PSP, which represent the following groups:

- people who are, have been or may be affected by sight loss
- carers of people affected by sight loss
- eye health professionals with clinical experience of sight loss

It is important that all organisations which can reach and advocate for these groups should be invited to become involved in the Sight Loss and Vision PSP. The JLA took responsibility for advising how the various stakeholder groups are able to participate equally in the process.

Organisations wishing to participate in the Sight Loss and Vision PSP were required to affiliate to the JLA in order to demonstrate their commitment to its aims and values. Details on the affiliation procedure can be found at **www.lindalliance.org**. This process is free.

Exclusion criteria

Some organisations may be judged by the JLA or the Steering Committee to have conflicts of interest. These may have been perceived to adversely affect those organisations' views, causing unacceptable bias. As this was likely to affect the ultimate findings of the Sight Loss and Vision PSP, those organisations were not invited to participate in the prioritising process. It is possible, however, that interested parties may have participated in a purely observational capacity when the Steering Committee considered it to be helpful.

Methods

This section describes the stages completed by the Sight Loss and Vision PSP to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods adopted in any stage were agreed through consultation between the partners, guided by the Sight Loss and Vision PSP's aims and objectives.

1. Identification and invitation of potential partners
Potential partner organisations were identified through a process of peer knowledge and consultation, through the Steering Committee members' networks, including Vision 2020 UK and through the JLA's existing register of affiliates. Potential partners were contacted and informed of the establishment and aims of the Sight Loss and Vision PSP and invited to attend and participate in a stakeholder meeting.

2. Stakeholder meeting
The stakeholder meeting had several key objectives:

- to welcome and introduce potential members of the Sight Loss and Vision PSP
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- to identify those potential partner organisations which could commit to the PSP and identify individuals who would represent these organisations and be the principal contact for the PSP.
- to establish principles upon which an open, inclusive and transparent mechanism can be based Sight Loss and Vision PSP

The meeting was chaired by the JLA.

Following the meeting, organisations which had decided to participate in the Sight Loss and Vision PSP were asked to complete a declaration of interests, including disclosing relationships with the pharmaceutical industry.

3. Identifying unanswered questions
A period of three months was given to complete this exercise. Each partner identified a method for soliciting questions of practical clinical importance relating to the prevention, diagnosis and treatment of sight loss and on or more specific eye conditions from its members.

The methods were designed according to the nature and membership of each organisation, but had to be as transparent, inclusive and representative as practicable. Methods included membership meetings, email consultation, postal or web-based questionnaires, internet message boards and focus group work.

Existing sources of information about unanswered questions for patients/service users and eye health professionals were searched. These included question-answering services for patients/service users and carers and for eye health professionals; research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews being prepared and registers of ongoing research.

The starting point for identifying sources of questions and research recommendations is NHS Evidence: **www.library.nhs.uk/duets.**

4. Refining questions and questions
The JLA observed this process in order to ensure accountability and transparency. The consultation process produced 'raw' unanswered question, which were categorised and refined into 'collated indicative questions' that are clear, addressable by research and understandable to all. Similar or duplicate questions were combined where appropriate. Questions were also categorised by type of eye condition.

The existing literature was surveyed to see to what extent these refined questions have, or have not, been answered by previous research. The Steering Committee agreed exactly who would be responsible for this stage and the JLA advised on the time limit for completing it.

Some of the suggested unanswered questions could be resolved with reference to existing research evidence – i.e. they are "unrecognised knowns" and not questions. Capacity permitting, a record of these questions is being maintained by the Steering Committee and partners can advise their membership as appropriate.

Unanswered questions about treatment that are not adequately addressed by previous research were collated and entered into the Eyes and Vision section within the UK Database of Uncertainties about the Effects of Treatments (UK DUETs). This will ensure that the questions have been actually checked to be questions. This is the responsibility of the Steering Committee, which had agreed personnel and resources to carry this accountability. Unanswered questions about prevention or diagnosis were managed separately. This is a key component of the JLA process, and the next stage of prioritisation could only proceed upon its completion.

5. Prioritisation – interim and final stages
The aim of the final stage of the priority setting process was to prioritise,through consensus, the identified unanswered questions relating to the prevention, diagnosis and treatment of sight loss and eye conditions and in particular in relation to different eye conditions. This was carried out by members of the Steering Committee and the wider partnership that represents patients/service users, carers and eye health professionals.

The interim stage, which reduced a long list of questions for each eye condition to a shorter list (e.g. up to 20), was carried out using email and other means whereby organisations could consult their membership and ask them to consider the long list, then rank their top 10 most important unanswered questions. If the long list was deemed too long, and therefore unmanageable, the Steering Committee agreed a fair and transparent method for reducing it. The JLA also advised on this process.

The final stage, to prioritise the short listed unanswered questions and agree a top 10 for each eye condition, was conducted in a series of face-to-face meetings, group discussions and plenary sessions.

The methods used for this prioritisation process were determined by consultation with the partner organisations and with the advice of the JLA. Methodology included adapted Delphi techniques; expert panels or nominal group techniques; consensus development conference; electronic nominal group and online voting; interactive research agenda setting and focus groups.

The JLA facilitated this process and ensured transparency, accountability and fairness. The Steering Committee agreed available resources and support for convening face to face meetings.

Findings and research

The findings of the Sight Loss and Vision PSP will be communicated to funding and research agenda- setting organisations such as the NIHR HTA Programme and the MRC, as well as the major research funding charities. Steering Committee members and partners are encouraged to develop the prioritised unanswered questions into research questions, and to work to establish the resourcing needs when approaching potential funders, or when allocating funding for research themselves.

Publicity

As well as alerting funders, partners and Steering Committee members are encouraged to publish the findings of the Sight Loss and Vision PSP using both internal and external communication mechanisms, to raising awareness of the results among the public and scientific audiences. The JLA can also capture and publicise the results, through descriptive reports of the process itself. However, production of an academic paper should not take precedence over publication of the final results. The Partnership is asked to keep the JLA informed of activity undertaken to publicise the results of the priority setting exercise.

Appendix 3

Project funders and supporting organisations

The following organisations provided funding and/or in-kind support for this initiative:

- College of Optometrists
- Fight for Sight
- NIHR Biomedical Research Centre for Ophthalmology
- RNIB
- Royal College of Ophthalmologists
- UK Vision Strategy

The following organisations supported 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
- Ocumel
- One Clear Vision
- Organisation of Blind African Caribbeans
- Polymyalgia Rheumatica and Giant Cell Arteritis UK (PMRGCAUKK)
- RP Fighting Blindness
- Royal College of Nursing
- Thomas Pocklington Trust
- Thyroid Eye Disease Charitable Trust
- Uveitis Information Group
- UK & Eire Glaucoma Society
- Visibility
- Vision 2020 UK
- Vision Care for Homeless People
- Visionary
- Wales Vision Strategy Group
- Waltham Forest Low Vision Forum
- West of England School and College

Appendix 4

Sight Loss and Vision Priority Setting Partnership – Protocol for Analysis of Data

1. Remove ineligible submissions (e.g. those with no clearly defined uncertainty around prevention, treatment and diagnosis) and place on a separate list. Circulate list to DAG to confirm ineligibility.

2. Remove submissions that may be questions but fall outside of the scope of the exercise. In particular, create a list of those questions which would not be covered by a social research agenda. Circulate list to DAG to confirm exclusion.

3. Eligible submissions to be categorised into type of eye condition where this has been indicated.

4. Produce list of those submissions that did not state the relevant eye condition. Assign a condition where possible. Circulate list to DAG to confirm.

5. Combine duplicate submissions within each eye condition and record prevalence and incidence. Prevalence is dependent on the number of times one uncertainty is submitted by a particular participant group, and incidence is the uncertainty being submitted by different groups e.g. patients, relatives, carers, eye health professionals or is listed in research recommendations. The frequency of an uncertainty needs to be noted, i.e. the number of times the submission has been made across participant groups, or multiple organisations submitting the same uncertainty, or multiple submissions of the same uncertainty from one organisation.

6. Taking each eye condition at a time, identify true questions after checking submissions against existing systematic reviews knowledge in current systematic reviews. Such reviews should include, but not be limited to, the Cochrane Database of Systematic Reviews, NICE guidelines, SIGN clinical guidelines, the UK Clinical Trials Gateway and the Database of Abstracts of Reviews of Effects etc.

7. Produce two lists for each eye condition: the first of true questions and the second recording submissions received which can be resolved with reference to existing research evidence.

8. Rewrite or rephrase the questions on the first list in order to clarify uncertainty and to ensure consistency in the language used. Use the Intervention, Comparator, Patient/Population and Outcome ICPO format in order to ensure every question is worded, where possible, to include the Intervention, a Comparator, the Patient or Problem and an Outcome. It is important to note that not all the ICPO variables will be available.

9. Enter true questions written in the correct format into UK DUETs.

10. Group eye conditions into categories to be agreed by the Steering Committee. Prioritise each category so that it has its own Top 10 research priority list.

The report was written by members of the Steering Committee and the Data Assessment Group and prepared by Richard Cable, Fight for Sight and Mel Pierce, College of Optometrists. Images provided by the College of Optometrists and Fight for Sight. Images from the workshops reproduced with the kind permission of all participants.

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