



THE COLLEGE
OF OPTOMETRISTS



Sight Loss and Vision Priority Setting Partnership

Survey

Setting the Priorities for Research

Despite ongoing research activity in the UK and other countries, 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 for research funders to understand how patients, carers and eye health professionals prioritise these unanswered questions so that future research can be targeted accordingly.

Through survey methodology this initiative aims to produce lists of priorities for a wide range of eye diseases and conditions. Please note that the results of this survey will not prioritise unanswered questions relating to one particular eye disease or condition over another.

HOW CAN YOU GET INVOLVED?

We are inviting you to take part in this survey by contributing what you think are the unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions.

BACKGROUND INFORMATION

The aim of the Sight Loss and Vision Priority Setting Partnership (PSP) is to identify the unanswered questions about prevention, diagnosis and treatment of sight loss and eye conditions from the perspective of patients, carers and eye health professionals. Once identified, these unanswered questions will then be prioritised. The results of this project will then help shape the future of eye research in the UK.

The project will be independently overseen by The James Lind Alliance, a non-profit making initiative. They specialise in bringing patients, carers and health professionals together to identify and prioritise uncertainties, or 'unanswered questions' that they agree are most important. The James Lind Alliance is internationally recognised as an authoritative and independent organisation to guide this work and produce an unbiased result, which gives equal weighting to the views of the different groups.

The James Lind Alliance is funded by the National Institute for Health Research (NIHR). For further information see www.lindalliance.org

Why are we doing this?

In the UK it is estimated that almost 2 million people are affected by sight loss and this number is expected to double by 2050. Currently the sight loss affecting half of people in the UK is avoidable and half is not. Whether it is to address childhood conditions or those affecting adults, research is needed to inform us about prevention, to develop new techniques for early diagnosis and to develop new and more effective treatments.

The outcome of the PSP will be sets of unanswered questions prioritised by patients, carers and eye health professionals. These can then be used to encourage researchers to investigate what is most important to these groups. Research funders can then use the lists to identify research applications which will answer questions that these groups have agreed are a priority.

The PSP will also help to increase awareness of why research into sight loss and vision is necessary and important. It will be used to campaign for major funders to invest in sight loss and eye conditions, as there will have been an independent process to identify what research is necessary and relevant.

What are 'unanswered' questions about prevention, diagnosis and treatment of sight loss and eye conditions?

These are questions that cannot be answered at the moment by existing research.

To help you understand what is an 'unanswered question', here are some examples of unanswered questions that were submitted for other diseases:

- Is it possible to constantly and accurately monitor blood sugar levels in people with type 1 diabetes?
- What is the role of complementary therapies in asthma management?
- Is there a vaccine that can prevent prostate cancer?
- Are there any dietary measures that can prevent prostate cancer or slow its progression?
- What is the most effective treatment for vestibular migraine?
- What is the best way to treat people with schizophrenia that is unresponsive to treatment?

YOUR UNANSWERED QUESTION/S

What question(s) about the prevention, diagnosis and treatment of sight loss and eye conditions would you like to see answered by research? (You can submit as many or as few as you like, on one or more eye conditions).

Question 1

Please insert the name of the eye disease or condition (if known) to which your question relates:

.....

Question 1:

Question 2

Please insert the name of the eye disease or condition (if known) to which your question relates:

.....

Question 2:

Question 3

Please insert the name of the eye disease or condition (if known) to which your question relates:

.....

Question 3:

Question 4

Please insert the name of the eye disease or condition (if known) to which your question relates:

.....

Question 4:

Consent:

As part of the process, your questions may be published in the UK Database of Uncertainties about the Effects of Treatments (DUETs), and by participating in the survey you are agreeing to allow us to publish your question(s). Your name/organisation will NOT be published in association with the question. For further information, or to see an example of what this will look like, please go to www.library.nhs.uk/duets.

SOME QUESTIONS ABOUT YOURSELF

These questions will help us to understand the range of people who have responded to our survey. However, if you prefer not to answer then please leave them blank. These details will NOT be published in association with your response or linked in any way to the UK DUETs database.

5. Which of these categories best describes you? (Please tick all that apply)

- I am a person with sight loss/eye condition
- I am a partner or relative or carer of someone with sight loss/eye condition
- I am the parent of a child aged under 16 who has sight loss/eye condition
- I am part of an organisation representing people with sight loss/eye condition
- I am a healthcare professional
- Other: please describe.....

If you are a healthcare professional please go straight to question 10. If you are a carer please answer questions on behalf of the person you care for.

6. Gender: Are you (or the person with the eye condition)?

- Male Female

7. Age: What is your (or the person with the eye condition) age?

years

8. In which part of the UK do you (or the person with the eye condition) live?

- England Scotland
 Wales Northern Ireland

9. Ethnic group: Are you (or the person with the eye condition)?

- White Black
 Asian Mixed race
 Chinese Other ethnic group

10. You only need to answer this question if you are answering as an eye health professional (Please tick ONE box). Which is your primary profession?

- Ophthalmic Nurse Ophthalmologist
 Optician Optometrist
 Orthoptist Social Care
 Other (please specify) _____

11. Would you like more information about the next stage of the project, where the research questions will be prioritised?

- Yes No

If 'yes', please supply your contact details. Your contact details will be treated with complete confidentiality, in accordance with the Data Protection Act.

Name _____

Organisation _____

Address _____

Address _____

City/Town _____

Postal Code _____

Country _____

E mail address _____

Phone number _____

What is your preferred method of contact?

Email Post Telephone

Thank you for your invaluable time in completing this survey.

Please return your completed survey by **31 July 2012** by email to sightlossandvisionpsp@fightforsight.org.uk, by Fax to 020 7488 3041 or by post to:

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