

VISION 2020 UK Prevalence Study Project Board

The United Kingdom Eye Survey

Information for members of the public joining the project board

This information sheet explains:

- What The United Kingdom Eye Survey is
- Why it is taking place
- Who is involved
- What to expect as a lay member of the VISION 2020 UK Prevalence Study Project Board

What is The United Kingdom Eye Survey?

The United Kingdom Eye Survey is a large research project to find out about the eye health of people living in the UK.

Why is the survey happening?

At the moment there is no comprehensive, up-to-date and reliable source of information about eye health in the UK. However, if we had this information, we could use it as evidence to help:

- Adjust NHS and other resources where needed
- Make sure that there is equal access to good eye care
- Raise awareness of how to prevent sight loss
- Raise money for medical research
- Understand the outcomes for people after treatment for sight loss

Who is involved in The United Kingdom Eye Survey?

The United Kingdom Eye Survey is an initiative of VISION 2020 UK, the umbrella organisation for the eye health and sight loss sectors. VISION 2020 UK has brought together a project board to plan the survey and oversee the whole project as it takes place.

The VISION 2020 UK Prevalence Study Project Board members include:

- Ophthalmologists, researchers and statisticians
- Lay people patients, service users, carers, members of the public
- Royal College of Ophthalmologists the professional body for Ophthalmologists in the UK
- Fight for Sight the largest UK charity dedicated to eye research
- Royal National Institute of Blind People(RNIB) UK charity offering practical and emotional support for blind and partially sighted people
- The College of Optometrists the professional body for Optometry in the UK
- Guide Dogs- UK charity providing mobility for blind and partially sighted people
- Thomas Pocklington Trust National charity providing support for people with sight loss.
- The Macular Society the national charity for anyone affected by central vision loss

What type of information will the survey collect?

The project is currently in the development stage so survey questions and methods have yet to be finalised. As an example, information we would like to collate at the end of the project would include:

- How common different eye conditions are for example how many people in the UK have glaucoma or diabetic eye disease
- How common different eye conditions are depending on age, ethnicity, gender, location or financial situation
- The health needs of children born with sight loss
- Who uses eye health services and low vision services
- What types of sight loss affect people in care homes and special schools

When is the survey taking place?

Before the research can take place we need to plan the best methods and process so that:

 We know we are asking questions that it would be useful to have answers to

- We're asking questions that it is possible to answer
- We can gain feedback in the right way. For example a working parent might not have much time for a long interview during the week or a disabled person might find it difficult to get to a clinic
- We know how many people need to take part in the survey
- We know what resources we need, for example how much it will cost and how many people are needed to collect the information

We expect the survey to begin once the development stage is complete, most likely sometime in 2017.

What is expected of lay members of the project board?

Lay members will be expected to:

- Attend project board meetings that take place in London every 3 months
- Share opinions, make suggestions and ask questions about the survey
- Read papers and reports (plain English explanations of any technical documents will be provided)
- Have enough confidence and time to read, question and comment in meetings and by email
- Think about how the project might affect patients and the public overall, not just about issues that affect the lay members themselves

Members do not need to be experts in, or have experience of, research or eye health, although having this experience might be useful.

Meetings are confidential during the planning stages of the project but once the methodology has been agreed the work of the project board will be in the public domain on the VISION 2020 UK website.

How long does this work last?

This is difficult to predict but in the first instance agreeing the methodology might take a number of meetings.

Do lay members of the project board receive expenses?

Travel expenses will be paid by member organisations of the board. A claim form will be provided and receipts are required.

How do I apply?

Please contact <u>info@vision2020uk.org.uk</u> and include 'Lay Member Prevalence Study Board' in the subject box. Please say why you would like to join the board and what skills you can offer. You can also mention any experience you have.

VISION 2020 UK encourages blind and partially sighted people to join the project board as lay members.

Closing date for applications is Friday 13th May 2016.