

The AIVI Study

AIVI – A virtual rehabilitation assistant to offer timely and relevant information and advice to individuals with visual impairment.

Participant Information Sheet

If you have any difficulty with reading this information, please contact us to let us know how you would prefer to receive this information. Please e-mail: chris.dickinson@manchester.ac.uk or leave a message at Tel. 0161 306 3874.

You are being invited to take part in a research study to find out about the experiences of individuals with visual impairment and those involved in supporting individuals with visual impairment. We would like to find out in particular what information those with visual impairment find most useful to help support their rehabilitation and adaptation to sight loss, and how they prefer to access this information. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

Who will conduct the research?

The research will be conducted by a research team consisting of Professor Christine Dickinson and Dr Jacob Taylor (Division of Pharmacy and Optometry, University of Manchester), Dr Andre Freitas and Deborah Mendes Ferreira (Department of Computer Science, University of Manchester) and Dr Ahalya Subramanian (Division of Optometry and Vision Sciences, City University of London). The research is conducted in collaboration with Mark Belcher (Henshaws Society for the Blind).

What is the purpose of the research?

The aim of the research is to carry out a questionnaire to find out about the information that those with visual impairment (VI) find most useful to help support their rehabilitation and adaptation to sight loss, and how they prefer to access that information. The results will be used to design a prototype digital computer-based device that can offer relevant information to those with VI.

You have been chosen because you are either an individual with visual impairment, or a family member/carer of an individual with visual impairment, or a rehabilitation professional providing support for those with visual impairment.

Will the outcomes of the research be published?

The results of this research will be published in a peer-reviewed journal article, and presented at conferences. Summaries of the research will be published by the Macular Society in their newsletter/website.

Who has reviewed the research project?

This project has been reviewed by The University of Manchester Proportionate Research Ethics Committee.

Who is funding the research project?

This project is funded by a Research Grant from the Macular Society.

What would I be asked to do if I took part?

You will be asked to complete an online questionnaire which aims to understand the information that those with visual impairment (VI) have found most useful in helping support their rehabilitation and adaptation to sight loss, and how they prefer to access that information. The questionnaire will firstly confirm your consent to take part in the study, and then take some basic background information (multiple choice) followed by a series of short answer questions and should take about 15 minutes to complete (further details on what the questionnaire will ask is provided in the section below “what information will you collect about me?”).

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you decide to take part, you can proceed to the questionnaire after confirming your consent. You are also able to read this participant information, exit the questionnaire to consider taking part, and log back in when you are ready to complete the questionnaire. If you decide to take part you are still free to exit the questionnaire at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the study once it has been submitted as we will not be able to identify your specific data. This does not affect your data protection rights.

Data Protection and Confidentiality

What information will you collect about me?

We will ask some general questions about you: such as your age group, registration status (if applicable) and any devices you use to help you access information, and then some questions about your experiences of what information someone with visual impairment finds most useful in helping support rehabilitation and adaptation to sight loss. The questionnaire does not ask you to disclose any personally identifiable information.

Under what legal basis are you collecting this information?

We are collecting and storing this information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”. The information will only be used for the purpose of health and care research, and cannot be used to contact you regarding any other matter. Please note that **we cannot respond to any of the questionnaires** as the responses are anonymous.

What are my rights in relation to the information you will collect about me?

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you.

If you would like to know more about your different rights, please consult our [privacy notice for research](#)

(<http://documents.manchester.ac.uk/display.aspx?DocID=37095>).

Will my participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

Your questionnaire responses will be safely stored on the University of Manchester Research Data Storage system for 10 years. This data may also be used in later stages of the research project.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

Contact details for complaints

If you have a complaint that you wish to direct to members of the research team, please contact:

Prof Christine Dickinson e-mail: chris.dickinson@manchester.ac.uk

Dr Ahalya Subramanian e-mail: ahalya.subramanian.1@city.ac.uk

Dr Jacob Taylor email: j.j.taylor@manchester.ac.uk

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Governance and Integrity Officer, Research Office,
Christie Building, The University of Manchester, Oxford Road,
Manchester, M13 9PL, by emailing:
research.complaints@manchester.ac.uk or by telephoning 0161
275 2674.

If you wish to contact us about your data protection rights, please email
dataprotection@manchester.ac.uk or write to The Information
Governance Office, Christie Building, The University of Manchester,
Oxford Road, M13 9PL at the University and we will guide you through
the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's
Office about complaints relating to your personal identifiable information](#)
Tel 0303 123 1113

Contact details

If you have any queries about the study then please contact the
researcher: Chris Dickinson e-mail: chris.dickinson@manchester.ac.uk
or leave a message at Tel. 0161 306 3874 and we will call you back

**This project has been reviewed and approved by the University of
Manchester's Proportionate Research Ethics Committee**