

Investigating eye examination-related anxiety in autistic adults**Participant Information Sheet**

You are being invited to take part in a research study to investigate how autistic adults feel when attending an eye examination as part of a PhD research project. 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 carried out by members of the Body, Eye and Movement (BEAM) lab, at The University of Manchester:

Ketan Parmar (PhD student and fully qualified optometrist) under the supervision of:

Dr Emma Gowen (Division of Neuroscience and experimental Psychology),

Prof Christine Dickinson (Division of Pharmacy and Optometry),

Dr Catherine Porter (Division of Pharmacy and Optometry).

What is the purpose of the research?

This study is being conducted as part of a PhD project title “investigating optometric and orthoptic conditions in autistic adults”. The aim of this research project is to describe visual sensory symptoms (e.g. hypersensitivity, sensory overload) and eye conditions (e.g. poor vision, requirement for spectacles, lazy eyes) in autistic adults who do not have learning disabilities. We also want to determine the impact of these on quality of life and gain feedback on any previously attended eye examinations.

We want to understand the experience of autistic adults when visiting an optometrist. It is possible that if an optometrist has limited understanding around autism, an eye test could be a stressful experience for autistic people, leading to incorrect test results and future avoidance of visits. We would like to develop guidelines for optometrists in order to improve the experience and accuracy of eye tests for autistic adults.

We hope to recruit 200 participants in total.

Will the outcomes of the research be published?

The results of this research will be published as part of a PhD thesis. They may also be presented in a peer-reviewed journal article, at talks and through lay summaries on the Autism@Manchester, BEAM lab, and study website.

Disclosure and Barring Service (DBS) Check

Relevant members of the research team have undergone a satisfactory DBS check.

Who has reviewed the research project?

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

What would my involvement be?

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

You will be required to complete an online questionnaire which aims to understand how you feel about different aspects of an eye examination. The questionnaire will firstly confirm your consent to take part in this study, followed by taking some basic background information (further details on what this will ask are given in the “what information will you collect about me?” section). You will need to type a response to some of these questions and select an appropriate option for others.

Thereafter, you will be asked to complete 10 multiple-choice questions about how you feel about the test procedures, communication with the optometrist and your eye-health during an eye examination. You will be required to select one of four given options for each statement.

This questionnaire should take you no longer than 5-10 mins to complete.

Will I be compensated for taking part?

You will be entered into a prize draw with a chance to win £10 worth of Amazon vouchers if you provide your email address at the end of the questionnaire. Your email address will only be used for the purpose of the prize draw and not retained for any other use.

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 do 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 survey to consider taking part, and log back in when you are ready to complete the survey.** 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 you have submitted the questionnaire 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 need to collect the following personal information/data about you when you complete the online questionnaire:

1. Age
2. Gender
3. Autism diagnosis details
4. When you had your last eye examination
5. If you wear glasses or contact lenses, or have had refractive surgery

You can choose whether you want to provide your email address to enter the prize-draw. If you do opt to, we will only use your email address only for the purpose of the prize draw.

Under what legal basis are you collecting this information?

We are collecting and storing this personal identifiable 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”.

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:

Only the study team at The University of Manchester will have access to the questionnaire data which you provide. The questionnaire platform is a University-approved software, and your responses will be stored on a secure University server. When downloaded, this data will be stored on the University's Research Data Storage System for 10 years.

We will not be asking for your personal details in this questionnaire. However, you can provide your email address if you opt to be entered into the prize draw. **We will**

only use your email address for the purpose of the prize draw and not for any other reason, and it will be kept separate from the questionnaire data.

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.

This information will not identify you and will not be combined with other information in a way that could identify you. 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 or to affect your care. It will not be used to make decisions about future services available to you.

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:

Dr Emma Gowen e-mail: emma.gowen@manchester.ac.uk

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

Dr Catherine Porter e-mail: catherine.porter@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: **Ketan Parmar**. Email. ketan.parmar@postgrad.manchester.ac.uk

This project has been reviewed and approved by the University of Manchester's Research Ethics Committee [2020-9668-15811]