

How aware are autistic people of the Easy Eyecare Pathway?

Participant Information Sheet (PIS)

You are being invited to take part in an online survey to understand how aware autistic adults of the Easy Eyecare Pathway. 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?**

Dr Ketan Parmar (Primary Investigator), School of Health Sciences, Division of Pharmacy and Optometry, The University of Manchester

Dr Emma Gowen, School of Health Sciences, Division of Psychology Communication and Human Neuroscience, The University of Manchester

Dr Sarah Rhodes, School of Health Sciences, Division of Population Health, Health Services Research & Primary Care, The University of Manchester

Dr Kathy Leadbitter, School of Health Sciences, Division of Psychology & Mental Health, The University of Manchester

Lisa Donaldson, Head of Eyecare and Vision, SeeAbility

Dr Ciara Kelly (Research Associate), School of Health Sciences, The University of Manchester

⇒ **What is the purpose of the research?**

Autistic people can be more likely to need spectacles and develop eye coordination problems (e.g., a squint or lazy eye). Therefore, autistic people should be having regular eye examinations. However, our previous research has found that autistic people can experience multiple challenges when going for eye examinations, and some may avoid eyecare as a result.

With supporting research evidence, an eyecare pathway for people with learning disabilities was introduced in 2012. In 2020, the pathway was refreshed and new training requirements were developed. The pathway is now known as the Easy Eye Care Pathway for people with learning disabilities and autism. Further information about the pathway can be found here: <https://www.seeability.org/eye-care/locsu-pathway>. The pathway can be accessed in community practices in Southeast London, Northwest England and Durham.

The purpose of this research is to investigate how aware autistic adults are of the Easy Eyecare Pathway. We want ~100 autistic adults to complete an online survey.

⇒ **Am I suitable to take part?**

To take part in this study, you must:

- Be diagnosed **OR** self-identified as autistic, without a learning disability.*
- Be aged 18 years or over.
- Live in England

**a learning disability is not the same as a learning difficulty. You can take part in this study if you have a learning difficulty such as dyslexia, dyspraxia or ADHD. Please contact the research team (details at the end of this sheet) if you are unsure if you can take part.*

⇒ **Will the outcomes of the research be published?**

We aim for the outcomes of this study to be published in a scientific journal, and presented at conferences.

⇒ **Disclosure and Barring Service (DBS) Check**

Dr Ketan Parmar has an enhanced DBS check as required for all qualified optometrists.

⇒ **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 study is being funded by Translation Manchester.

What would my involvement be?

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

Please note, you do not need to know about the Easy Eyecare Pathway to part in this study. You will be required to complete an online survey hosted on Qualtrics. The survey will first confirm your consent to take part.

The survey will require approximately 5 minutes to complete. You will firstly be asked some basic background information (your age, your gender, and about your autism). Thereafter, you will answer up to 7 questions, most of which are multiple choice, about the Easy Eyecare Pathway. This is to understand how aware you are of the existence of the Easy Eyecare Pathway.

At the end of the survey, you can provide your email address to enter a random prize draw for a £25 Love2Shop UK voucher-this is optional.

During the survey, if you indicate that you have had an Easy Eyecare Pathway eye test, you will have the option to provide your email address so that the research team can ask you more details about your experience. This is optional. If you do provide your email address, the research team will send you details about another study, linked to this project, where you will be asked more details about your Easy Eyecare Pathway experience. You will have the choice to take part or not.

Please note, we will not be collecting information about your location or IP address.

⇒ **Will I be compensated for taking part?**

If you provide your email address when prompted, you will be entered into a random prize draw for a £25 Love2Shop UK voucher. 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 survey 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 survey 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 survey 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?**

In order to participate in this research project we will need to collect information that could identify you, called “personal identifiable information”. Specifically, we will need to collect your age, gender, and whether you are diagnosed or self-identified as autistic.

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 for the purpose of the prize draw.

If you indicate you have had an Easy Eyecare Pathway eye test, you can choose whether you want to provide your email address to be contacted about our other study. If you do opt to, we will use your email address only for this purpose.

⇒ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK 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, including audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research \(https://documents.manchester.ac.uk/display.aspx?DocID=37095\)](https://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:

For your security, we recommend using a trusted internet connection when completing this survey.

Only the study team at The University of Manchester will have access to the survey data which you provide. The survey platform (Qualtrics) is University approved. When downloaded, this data will be stored on the University's Research Data Storage System for 5 years.

We will not be asking for your personal details in this survey. However, you can provide your email address if you opt to be entered into the prize draw, or to be contacted regarding our other study. We will only use your email address for these purposes and not for any other reason. If you provide your email address for either of the above, your survey responses will not be anonymous in the first instance. However, to ensure your anonymity as soon as possible, when the survey is closed and data downloaded at the end of the study, email addresses will be immediately separated and removed so we won't be able to tell which responses belonged to you. We aim to close the survey and download the data by the end of September 2025.

If you win the prize draw, your email address will be shared with our Finance department who will send the voucher to you. Your email address will be securely retained by Finance for a period of up to 7 years for audit purposes only and then destroyed. It will not be used for them for any other purpose.

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:
Dr Ketan Parmar (ketan.parmar@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 Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

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](https://ico.org.uk/make-a-complaint/) (<https://ico.org.uk/make-a-complaint/>) about complaints relating to your personal identifiable information Tel 0303 123 1113.

Contact Details

If you have any queries about the study or if you are interested in taking part, or feel distressed after taking part then please contact **Dr Ketan Parmar** (ketan.parmar@manchester.ac.uk)

