

Title of the study: Investigating eye shape and its effect on focusing in Down's syndrome

(Investigating ocular morphological differences as the possible cause of accommodation deficits in Down's syndrome)

Participant information sheet – Down's syndrome group

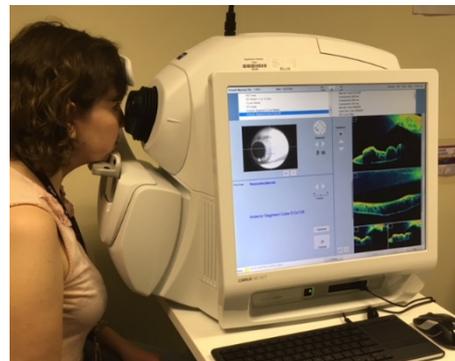
We are doing a study and we would like to ask for your help. This is the way we try to find out the answers to questions!

Why is this study being done?

Many people with Down's syndrome need to wear special glasses to help to see things far away and up close. We would like to know why and we are asking you to help us to find more about this.

What do you have to do to take part?

We would like to take some pictures and some measurements of your eyes with some special cameras. To do so, we will ask you to place your chin and forehead on a rest, very close to the cameras and keep your eyes still.



We will also ask you to have a look at some pictures or letters and to let us shine a light into your eyes for a few seconds.



How many times do I have to do it?

You will only need to visit us once and you will be here for less than 2 hours. You will be able to take breaks whenever you want. If we cannot get the measurements that we need then we may ask you to come back for a second visit.

Do I have to take part?

No, it is up to you. You can say no and no one will be cross or upset. If you say yes, but later change your mind then that's ok as well. Just tell your parents, carer or us.

Does it hurt?

No. The cameras we use to take pictures of your eyes are similar to normal picture cameras. Taking these pictures is not painful or uncomfortable. The cameras will be very close to your face, but will not touch you at all.

Will taking part help me?

We can't promise the study will help you, but what we find might help other people with Down's syndrome who need glasses.

What if something goes wrong?

If you are not happy about the study, you and/or anyone you nominate can talk to any of us and we will try our best to answer all your questions. If we are unable to address your concerns or you wish to make a complaint about the study you and/or anyone you nominate should contact the Aston University Director of Governance, Mr John Walter, j.g.walter@aston.ac.uk or telephone 0121 204 4869.

Will anyone find out if I am on this study?

All the information we obtain from you and the pictures we take from your eyes will be kept secret and will not be given to anybody. These will be stored on a computer and only we will be able to see

this information. If we decide to share the results from the study, no one will know who took part in the study.

What will happen when the study finishes?

When we finish the study, we will write the results and we will talk about them with other people. However, we will never use your name when we write or talk about the results.

Did anyone check that the study is OK to do?

Before any study is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the study is fair. This project has received a Favourable Opinion from the NHS Health Research Authority South Central – Oxford C Research Ethics Committee.

Aston University is organising the study and makes sure we keep your information secret. There is more information about this in Appendix A.

Travel expenses and payment

We will cover your travel expenses up to £50. To say thank you for helping us we will give you a £20 Love2Shop voucher.

What do I do now?

Take time to decide whether or not you want to take part, and please ask us if there is anything you don't understand. If you have any questions you can ask us face to face when you see us or you can email us (Flors and Fiona) at v.vinuela-navarro@aston.ac.uk and/or bakerf7@aston.ac.uk

Aston University takes its obligations under data and privacy law seriously and complies with the General Data Protection Regulation (“GDPR”) and the Data Protection Act 2018 (“DPA”).

Aston University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study. Aston University will process your personal data in order to register you as a participant and to manage your participation in the study. It will process your personal data on the grounds that it is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)(e)). Aston University may process special categories of data about you which includes details about your health. Aston University will process this data on the grounds that it is necessary for statistical or research purposes (GDPR Article 9(2)(j)). Aston University will keep identifiable information about you for 6 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights,

we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at www.aston.ac.uk/dataprotection or by contacting our Data Protection Officer at dp_officer@aston.ac.uk.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).