

Participant information sheet for young people aged 14 – 15 years

Sudden eye problems seen in healthcare centres and hospitals

We are researchers from Cardiff University and we are asking if you and your parents would be interested in taking part in a research study.

Please read this information carefully and talk to you parent(s) or carer about the study. Ask us if there is anything that isn't clear to you or if you would like to know more.

Take time to decide if you'd like to take part. It is up to you if you want to do this. If you don't then that's fine, you'll be looked after just the same.

This information sheet explains the aims of this study, what will happen and how the study will be performed.

A large print copy of this information sheet is available from the lead researchers upon request. Their contact details can be found in the table on page three of this document.

➤ **What is research?**

- **Research** is the way we try to find out answers to questions
- A **researcher** is a person whose job it is to find out the answers to these questions

➤ **Why are we doing this research?**

Lots more people need urgent problems with their eyes assessed and this puts a lot of pressure on the people who work in healthcare. People with sudden eye problems can ask for help from lots of different people, GPs (Doctors), or pharmacists (the person who gives you medicine if you go to the pharmacy or chemist), or optometrists (also known as opticians, somebody who is a bit like an eye doctor) or they may go to A&E at the hospital. We want to know what kinds of eye

problems people that come to these places have, how well they were looked after, and how much this costs the NHS.

You have been asked if you would like to help us with this research because we want to speak to about 200 people who have recently had an eye problem that has happened quickly and have visited healthcare staff for help.

➤ **What will happen to me if I take part?**

On the day of you get help for your eye problem

On the day you visit the healthcare worker for advice about your eye problem, a researcher will give you this information sheet to read and another information sheet for your parent or guardian to read. If you want to, they will go over the information with you both and let you ask as many questions as you'd like. If you decide you're still happy to take part, we will ask you and your parent or guardian to sign one form each. This form is called a consent form and it's just our way of confirming that you're happy to be involved. Anything you tell us while you're helping with our research will be kept private and anonymous.

If you or your parent/guardian would like some more time to think about helping us that's fine too. If this happens, the researcher will give your parent or guardian an envelope with their address on it and a copy of the consent forms. If you decide you would like to help us then all you need to do is fill in the forms and send them back to the researcher in the envelope by post.

If you would rather not take part just let the researcher know. We need to know that both you and your parent or guardian are happy to help with the research. If either of you does not want to help then you won't take part in the research.

Later on

If you do decide to take part, the researcher will come back to the place someone examined your eyes on another day. They will look at the notes your healthcare worker made about your eye problem and collect some information about this and how healthy you are overall. Only relevant information will be accessed (i.e. only related to your eye problem).

When you signed the consent forms the researcher will have asked for your parent/guardian's telephone number. The researcher will arrange a good time to call them in a few weeks' time, to find out how you are doing with your eye problem. They will also ask them some questions about what happened with your eye problem and why you came to see this type of healthcare worker for help. Finally there will be some questions about your general well-being and how happy your parent or guardian was with your eye care.

➤ **Will anything bad happen if I take part?**

We do not think that there are any risks related to taking part in this research. Nothing will change in how you receive your health care. The only downside is that the phone call with your parent may take about an hour. If your parent becomes distressed or upset while taking part in the telephone questionnaires the researcher will be able to refer them to a member of the Patient Advice and Liaison Service (PALS)/the university team, or contact the health care worker you visited for help with your eye problem.

➤ **What good things might happen if I part?**

What we find out might not help you specifically but we hope that our results help to improve eye and health care for everyone.

➤ **Do I have to take part?**

No – it is completely up to you and your parent/guardian to decide if you want to take part or not. If you say yes at first and then change your mind and would like to stop taking part that is also fine, you don't need to give us a reason and it will not affect how you are looked after by your healthcare workers. We will not pay you or your parents/guardians for helping us with this research but to say thank you we will give them a gift of a £10 Amazon voucher after the researcher has spoken to them on the phone.

➤ **What if I have any questions?**

You can ask the researcher as many questions as you like while you're at the healthcare centre or on the telephone or by email afterwards (her contact details are on the next page).

➤ **What if there is a problem?**

If you have a problem with your health you should talk to your parents/guardian/GP.

If at any time you feel unhappy with the treatment or care you received you can contact the Concerns Team on 01443 744915 or using the email address CTHB_Concerns@wales.nhs.uk. More information can be found at the following web address; <https://cwmtaf.wales/concerns/>.

If you have a problem with the research talk to your parent and contact the head of the research project together (her contact details are also below). If you would like to make a formal complaint you and your parent/guardian can contact Richard Earlam, School of Optometry and Vision Sciences, Cardiff University on 02920 874852.

Name	Email Address	Telephone Number
Angharad Hobby	HobbyAE2@cardiff.ac.uk	02920 870588
Jennifer Acton	ActonJ@cardiff.ac.uk	02920 870203

➤ **Will anyone else know I'm doing this?**

The people in the research group and the health care centre you visited will know you've taken part. If you agree we will also tell your GP you have helped out with our research, just so that they are aware. Any information that's collected for the study will be kept confidentially. It will also be anonymous so no one can recognise that the information is about you. The study information will be kept for 15 years after it is complete.

➤ **Will any extra tests be done?**

No extra tests will need to be done. We will only need to contact your parent or guardian on the telephone for a chat.

➤ **What will happen to the results of this research?**

The results of this study will show how eye care could be better for patients. For example, we are looking at whether the eye conditions could be managed by optometrists and pharmacists rather than doctors in the GP surgery and A&E at the hospital as doctors are very busy and don't always have the right equipment to test eyes properly.

The results may be shown to the public in the news and published in academic journals. They will also be talked about with other researchers around the country and all over the world. You and your parent/guardian will not be identified in any report or publication. If you would like to find out the results of the study when everything is complete, let us know on the consent form.

➤ **How will my personal data be looked after?**

Cardiff University is the Sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the Data Controller for this study. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 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 and your parent/guardian can find out more about how we use your information at: <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection> or by contacting the University's Data Protection Officer at inforequest@cardiff.ac.uk

The Cardiff University researchers will collect information about you for this research study from Cwm Taf Morgannwg University Health Board. This information will include your name, NHS number, contact details and health information, which is regarded as a special category of information. We will use this information for the purposes of this research study only and to contact your parents/guardian about the study.

➤ **Who is funding and reviewing the research?**

The research is funded by Cardiff University. It was reviewed and approved by North West -Preston Research Ethics Committee.

Thank you for taking time to read this information.