

Participant information sheet for young people aged 11 – 13 years

Sudden eye problems seen in healthcare centres and hospitals

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

Before you decide whether you would like to join in, it's important that you understand what the research is, what it is about and what it would mean for you.

Read this information carefully and talk to your family about it. You can ask us if there is anything that doesn't make sense or if you would like to know more.

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?**

- People with sudden eye problems can ask for help from lots of healthcare workers like GPs or pharmacists (the person who gives you medicine if you go to the pharmacy or chemist), or optometrists (someone 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, and how well they are looked after.
- You have been asked if you would like to help us because we want to talk to people who have recently visited healthcare workers for advice because they have had an eye problem that has happened quickly.

➤ **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, they will talk about the information with you and let you ask as many questions as you like. If you want to help with the research, we will ask you and your parent or guardian to fill in a form so we know you're happy to help. Anything you tell us while you're helping with our research will be kept private and anonymous (which means no one will know that any information is about you).

If you or your parent/guardian would like some more time to think about helping us the researcher will give your parent or guardian an envelope with their address on it and the forms you might need. 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. We need to know that both you and your parent or guardian are happy to help with the research. If either if you does not want to help then you won't take part in the research.

If you would rather not take part just let the researcher know.

Later on

If you do decide to help out, the researcher will come back to the place someone looked at your eyes on another day. They will collect some information about your eye problem and how healthy you are.

The researcher will ask for your parent/guardian's telephone number and will arrange a time to call them in a few weeks. The researcher will ask them some questions about your eye problem and how you are doing now. They will also ask why you came to see this type of healthcare worker and how happy your parents or guardians are with your eye care.

➤ **Will anything bad happen if I help?**

Nothing bad can come from helping out. Nothing will change in how you get healthcare. The only downside is that the phone call with your parents may take about an hour.

Wordsearch

Z	K	L	J	Y	S	I	V	P	L	F	Z	R	CARDIFF
V	E	N	H	T	L	U	S	E	R	R	U	V	CARE
E	X	Y	R	Y	C	P	C	Z	G	J	Y	V	DOCTOR
W	E	C	E	C	F	I	N	G	J	H	B	H	EYE
F	H	K	S	A	O	B	D	P	T	J	Q	A	HEALTHY
M	R	R	E	M	D	Z	V	L	X	R	Z	F	OPTICIAN
V	E	Z	A	R	Z	E	A	U	V	P	E	K	PHARMACY
R	R	U	R	A	Z	E	O	V	Y	S	H	H	RESEARCH
O	A	V	C	H	H	P	X	W	A	L	E	S	RESULT
T	C	Z	H	P	V	K	I	C	O	O	S	N	WALES
C	R	J	C	Y	O	P	T	I	C	I	A	N	
O	Q	C	A	R	D	I	F	F	O	L	N	G	
D	T	S	I	Q	W	B	F	C	X	M	M	U	

➤ **Will anything good happen if I help?**

What we find out will hopefully 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. If you say yes and then change your mind and would like to stop later on 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 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 or your GP (Doctor). If you have a problem with the research talk to your parent/guardian and contact the person in charge of the research project together (her contact details are also on this form). If you would like to make an official complaint you and your parent/guardian can contact you 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 say it's okay we will also tell your GP you have helped out with our research. Any information that's collected for the research 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 at Cardiff University for 15 years after the study has finished.



➤ **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?**

The results of this study will show how eye care could be better for patients, for example, whether the eye conditions could be looked after by opticians and pharmacists rather than doctors as doctors are very busy. The results may be shown to the public in the newspapers, on the internet, or on the TV. They will also be talked about with other researchers around the country and around the world and may be published in special magazines called academic journals. No one will be able to tell if you have helped us in any of the reports.

If you would like to find out the results when everything is complete, let us know on the form you send back to us saying you're happy to take part.

➤ **Who will look after my information?**

Cardiff University is the Data Controller for the study. This means that the University is responsible for keeping data which could be used to identify you (like your name and address) safe and secure. The University will not give your name, contact details or information about your eyes or health on to anybody else.



Your information will be managed in particular ways to keep the research trustworthy and truthful. If you decide you don't want to take part anymore, we will keep the information about you that we have already gained. To protect your rights, we will use the smallest amount of 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 reading me!

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