Participant information sheet for adult participants

Acute eye conditions in primary and secondary care

Dear Sir/Madam,

Cardiff University invites you to participate in a study evaluating the outcomes of patients with eye problems who present to A&E, GPs, optometrists and pharmacists.

Before you decide whether or not you take part, it is important that you to understand why the study is being done and what it involves for you. Please take time to read this information sheet carefully and talk to others about the study if you wish. Before the study takes place, we will go through this information sheet with you and answer any questions you may have. Please ask us if there is anything that is not clear. We are happy to provide you with more information.

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 this study about?**

The high demand for urgent eye care in the UK means that sometimes eye care services can be over-burdened. People with acute eye problems may seek help from optometrists, pharmacists or GPs, or they may go to A&E. For each of these services, we want to know more about the different types of presenting eye problems, about the patient journey, and about the related costs.

You have been asked to participate in this research study because you have had a recent urgent eye problem and have attended one of the locations mentioned above for help and/or advice.

On the day of your visit to the A&E department/GP/optometrist/pharmacist

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

If you decide to take part in this study, on the day you visit the health care provider about your eye problem, a researcher will give you this information sheet to read. If you want to, they will go over the information with you and give you an opportunity to ask questions. If you are happy to continue, we will ask you to sign a consent form. All information given during the process will be kept confidential.

We will give you some information about the study. If you choose to take part, on a later date, we will collect some information about your medical and eye history and about the eye problem that was assessed. This information will be collected from your medical records and only relevant information will be accessed (i.e. data related to acute eye care only).

If and when you choose to participate in the study, we will ask for your telephone number and arrange a good time to call you in a few weeks' time, to find out if and how your eye problem was resolved. With your permission, we will also notify your GP of your participation in the study.

On the Telephone

The telephone call could take up to an hour. We will ask you some questions about the course of your eye problem, whether it got better or worse, and whether you saw another health care professional. We will also ask about your decision to choose a particular health care provider. We will then go through some questionnaires with you about your satisfaction with your eye care and about your quality of life related to your health and related to your vision.

Responses to the questions will be documented in field notes and also digitally audio recorded. You can request this audio recording be stopped, rewound, edited and/or deleted if needed.

Further Interviews

A few participants will be selected at random to be invited to a further extended interview either face to face at a mutually suitable location or via telephone. This interview will involve more in-depth questions about your eye problem, in which you will be asked to expand on some of the themes from the first interview.

Again, responses to the questions will be documented in field notes and also digitally audio recorded. You can request this audio recording be stopped, rewound, edited and/or deleted if needed.

- **What are the possible risks or disadvantages from taking part?**

We do not think that there are any risks related to taking part in this study. Taking part will not affect the way you receive your health care. The only disadvantage is the time it takes to complete the telephone call.

Please let the researcher know if you become distressed or upset while taking part in the telephone questionnaires or interviews. They will be able to refer you to a member of the Health Board's Patient Advice and Liaison Service (PALS)/the university team, or contact the health care worker you visited for help with your eye problem if you require further assistance.

- **What are the possible benefits of taking part?**

The results of this study may not benefit you directly. However, we hope that the information we get from this study will help us to better understand the patient journey related to urgent eye problems. This will help different health care providers improve their services available for urgent eye care.

- **Do I have to take part?**

No – it is up to you to decide if you want to take part or not. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form on the day of your visit for your eye problem. You may withdraw from the study at any point without giving us a reason, but we may need to keep any information you provided up until the point you withdrew for inclusion in the final study results. This will not affect you or your health care in any way.

- **What if I have any questions?**

Please ask a member of the research team if you have any questions (contact details below). We are very happy to discuss any aspect of the study. Please do not send personal information regarding your medical status by e-mail, as this may not be a secure means of communication. Further information can be found at the following web address:

https://www.cardiff.ac.uk/optometry-vision-sciences/research/acute-eye-care-study

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

- **What if there is a problem?**

For medical advice or questions about your health your GP is your first point of contact. For aspects of the study, you should speak to the study lead who will do their best to answer your questions. If you wish to complain formally, you can contact you can contact Richard Earlam, School of Optometry and Vision Sciences, Cardiff University on 02920 874852.

If at any time you feel dissatisfied with the treatment or care you have received you have a right to raise a concern. If you wish to make a complaint 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/.

- **Will my taking part in this study remain confidential?**

All information that is collected about you will be kept strictly confidential in accordance with the General Data Protection Regulation (GDPR) EU/2016/679 and the Data Protection Act 2018. All information collected during the study will be processed and stored securely by Cardiff University researchers using password-protected computer files and lockable filing cabinets. We may share the data we collect with other researchers but the data will be anonymous meaning your identity will not be known.

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 can find out more about how we use your information here: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection. The University's Data Protection Officer may be contacted at: inforequest@cardiff.ac.uk

Cwm Taf Morgannwg University Health Board (UHB) will collect information from you and your medical records for this research study in accordance with our instructions. The data collected by Cwm Taf Morgannwg UHB will include your name and contact details and a copy of your consent form. This would be done after you give your consent to take part in the study at the clinic where attended for your urgent eye condition problem.

After 1 year your personal data will be anonymised, meaning we will remove any identifiers that can identify you from the data you have provided. This anonymous information may be kept

indefinitely and/or published in support of the research. Other personal data we may have collected, such as your consent to participate in the study will be kept for 15 years following the end of the project.

Cardiff University will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Cardiff University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Staff on the clinical team in A&E, or at the GP practice, optometrists or pharmacists in Cwm Taf Morgannwg UHB will pass these details to Cardiff University along with the information collected from your medical records. The only people in Cardiff University who will have access to information that identifies you will be people who need to contact you about the study or to audit the data collection process. The research assistant will analyse the information collected.

Cwm Taf Morgannwg UHB will keep identifiable information about you from this study for 15 years after the study has finished.

- **Expenses and payments**

There are no expenses for taking part in this research. As a thank you for taking the time to participate we will issue you a £10 Amazon voucher by post upon completion of the telephone interviews with the researcher.

- **What will happen to the results of this study?**

The results of this study will inform us about how urgent eye care services could be delivered better, for example, whether the services delivered by optometrists and pharmacists could reduce A&E and GP visits. The results may be made available to the public by a press release following publication in the academic literature. The findings will also be presented at national and international scientific conferences. You will not be identified in any report or publication. If you wish to be provided with a summary of the results at the end of the study, please confirm this on the consent form. The researchers will need to keep your contact details for 2 years in order to do this.

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

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

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Thank you for taking time to read this information. Further copies can be found at the following web address;

https://www.cardiff.ac.uk/optometry-vision-sciences/research/acute-eye-care-study