



Participant Information Sheet

Study: A Qualitative Exploration of the Experiences of People Living with Cluster Headache.

You are invited to take part in a qualitative research study being conducted by a researcher at the University of Edinburgh to explore your experiences of living with cluster headache. To help you decide whether to take part, it's important for you to understand why the research is being done and what it will involve. Please take the time to read the following information. If you wish, you may find it helpful to talk to others about the study. If anything is not clear, please contact the researcher who can provide you with more information.

What is the research project about?

This research project is looking at the first-hand experiences and views of people living with either chronic or episodic cluster headache in the UK. It aims to get a better understanding of the experiences of those with the condition to find out how care and support could best be improved.

Why is recruitment taking place via OUCH UK?

OUCH UK, as the cluster headache charity in the UK, has agreed to work with the researcher at the University of Edinburgh to help send information about the research study she is conducting out to its members. OUCH UK members are likely to be suitable participants for this research project, so it is a great help to have information about this research opportunity shared by OUCH.

Do I have to take part?

It is entirely your decision whether or not you wish to participate. If you have any questions about participating, the researcher would be very happy to speak to you.

If you decide that you do wish to take part in the research, you will be free to leave the study at any time, without needing to give a reason. Please let the researcher know that you no longer wish to take part in the study, or that you would like to finish the interview. Withdrawing from the study or deciding not to take part will not affect the healthcare that you receive, the support received from OUCH UK, or your legal rights.

What will I have to do if I take part?

If you wish to participate in the research, please contact the researcher using the details at the bottom of this document and a telephone interview will be arranged at a time that is suitable for you. It will be relatively informal and will encourage you to talk about your personal views and experiences of cluster headache. We are keen to hear your views in your own words, and there is no obligation to answer any questions that you don't want to. The interview will likely last around one hour, depending on how much there is to discuss.

You will need to sign a consent form before the interview confirming you are happy to take part. This consent to participate includes agreement to audio-recording of the interview, so that the researcher can go through the interview afterwards and think about what was said.

Will I get paid for taking part?

You will not receive any money or other payment as a result of your taking part in this study.

Are there any benefits to taking part?

While the study may not have any direct or immediate benefits to you personally, the information may be used to improve the experiences and care provided for people living with cluster headache in the future.

Are there any disadvantages of taking part?

During interviews, people sometimes can become upset if they are discussing personal thoughts or feelings that are important to them. The research project will work to ensure that your feelings about issues or personal matters are respected at all times.

If you would like to stop or take a break during the interview, then just let the researcher know and they will stop the recorder for as long as you need or end the interview there. If you would like, the researcher can also provide you with information regarding whom to contact for advice based on what you talk about during the interview.

What happens if I don't want to continue the study?

If you don't want to continue with the study then you can withdraw from it at any time, without having to give a reason. To do this, please let the researcher know that you no longer wish to take part by contacting her via email, or her supervisor via phone, using the details listed at the end of this document.

Should you decide that you wish to withdraw mid-interview, please let the researcher know that you no longer wish to take part and the interview will end there. If you have had an interview but withdraw during it or anytime up to 2 weeks after the interview date, then your interview data will be entirely deleted and not used in the final report. Should you withdraw later than that, your interview transcript and contact details can be deleted, but it would not be possible to remove your anonymised data from the final report.

What happens after the interview?

After the telephone interview, the researcher will listen to the audio-recordings of the interviews, and will type up what has been said. This is so that the written versions of all of the interviews can be analysed to compare different people's experiences of cluster headache, which will be included in the final report. The researcher will also write up a short summary of the findings from all of the interviews which will likely be developed around September 2019, and can send you a copy of this if you wish.

Should you wish to receive a copy, please let the researcher know using the contact details that are listed at the end of this document. If you would like a copy, the researcher will need to keep your email or postal address until late September/early October 2019. After it has been sent to you, all of your contact details and previous correspondence will completely be deleted.

You will not be identifiable from any published results. The fact of your participation, and your data, will be kept confidential throughout.

How will my information be stored?

Your interview will be recorded, with your permission, and this audio-recording and written transcript will be stored on a password-protected computer. Recordings will be deleted after the study is completed in August 2019. The transcripts will be stored without your name and any other information that you provide which might be used to identify so that you cannot be recognised.

These anonymised transcripts will be kept for potential use in future research until September 2020, at which point they will be deleted.

Any information that you provide and anything that you say in the interview will be kept confidential and there are strict laws which safeguard your privacy at every stage. Your name will be kept separately from your interview transcript and only the researcher will see this information. Your name and contact information will also be deleted after the study ends. This will be after a copy of the results has been sent to you, should you have requested this.

Who is organising and funding the research?

This study is organised by Laura Andre, the researcher, as part of a Master of Public Health dissertation. She is overseen by Dr Debbie Cavers, Research Fellow at the University of Edinburgh. This study has received no funding to be conducted.

Who has reviewed the study?

The study has been reviewed and approved by the Postgraduate Office and the Ethics Committee at the Usher Institute of Population Health Sciences and Informatics at the University of Edinburgh.

Researcher contact details

If you have any questions about the study, please contact Laura Andre or her supervisor, Dr Debbie Cavers, using the following details:

Laura Andre (Researcher)



Master of Public Health Candidate
University of Edinburgh
Email: ClusterHeadacheStudy@outlook.com

Dr Debbie Cavers (Supervisor)

Research Fellow
Usher Institute of Population Sciences and Informatics
University of Edinburgh
Email: Debbie.Cavers@ed.ac.uk
Tel: 0131 650 6990

What if there is a problem?

If you have any concerns or complaints about any aspect of this study, you should speak to the researcher or her supervisor in the first instance, who will do their best to answer your questions. If you remain unhappy and wish to make a complaint, you can do this by contacting:

Professor Harry Campbell

Professor of Genetic Epidemiology and Public Health / Acting Dean of Molecular, Genetic and Population Health Sciences
Email: harry.campbell@ed.ac.uk

Tel: +44 (0)131 650 3218

For queries regarding data protection issues and the General Data Protection Regulation (GDPR) please contact the University's Data Protection Officer.

Email: dpo@ed.ac.uk

We would like to thank you for reading this Patient Information Sheet and for considering taking part in this study.