Exploring the psychosocial impact of living with facial palsy and experiences of accessing and receiving treatment in the United Kingdom.

Who is carrying out the research?

Researchers at the Centre for Appearance Research at the University of the West of England in Bristol, are conducting this study in collaboration with the charity, Facial Palsy UK.

What is the purpose of the study?

To explore the experiences of adults whose lives are (or have been) affected by Facial Palsy in the United Kingdom It is hoped this will contribute to a greater understanding of the psychosocial impact of the facial palsy and peoples experiences of accessing and receiving treatment. This initial study might also highlight areas for further research.

Who can take part?

Anyone over the age of 18, living in the UK, who has experienced facial palsy (of any type) and is willing to share their experiences. We are hoping to interview around 10-15 people.

What will participation involve?

Participation in the study is entirely voluntary. Participation will involve a telephone interview, if for any reason this is not a suitable option for you, depending on your location, the researcher could travel to your home. Interviews can also be conducted by Skype or email. Interviews should take around one hour, but if you would like to continue the interview beyond this point you can. The interview will cover details such as your experiences of living with Facial Palsy, your experiences of accessing and receiving treatment and how you were supported. We will take consent before we proceed with an interview. If you complete your interview over the phone or by Skype, consent will be taken verbally by asking you to confirm a series of statements. If your interview is face-to-face or by email we will ask you to complete and sign a written consent form

Will the information I provide remain anonymous

Recorded answers from the interview will be transferred to a university computer and deleted from the recorder. Interviews will then be typed into a document and any identifying information removed so that you cannot be identified Recording will be stored in a password protected file on a secured university drive that is only accessible to the researcher. Any information that identifies you, will be separated from your interview document. At all times the information you provide will be treated in accordance with the Data Protection Act.

The data from this study might be published in an academic journal (or elsewhere) and presented at conferences. Although direct quotes may be used in a paper or report, you will remain entirely anonymous and a pseudonym (a fictitious name) will be used. The data collected will only be accessible to those working on the study.

Can I withdraw?

If you decide to take part, you can ask to withdraw your data up until 2 weeks after being interviewed, by contacting the researcher using the contact details below. After this time, your answers will have been analysed and it will not be possible to remove them from the study. You do not have to give a reason why you wish to withdraw and your data will be deleted.

What are the potential advantages or disadvantages of taking part?

Currently there is a lack of research into adults' experiences of living with Facial Palsy, so you will be contributing to a better understanding of what it is like to live with the condition. We hope this research will inform the future care and provision of support for those affected by Facial Palsy in the UK.

You will also receive a summary of the findings, which you might find interesting. You will need to give up around an hour of your time to complete the interview. You may not benefit from taking part in the study and might find some of the topics difficult to talk about. However you may also find sharing your experiences beneficial. You will see the types of questions we plan to ask you before taking part, so you can let us know if there are any you are uncomfortable answering. You can also decline to answer any particular questions during the interview or stop at any point. If, when answering the questions you feel you need extra support, please let the researcher know, speak to your GP and/or contact Facial Palsy UK.

Who has reviewed the study?

This study has been reviewed and approved by the University of the West of England Research Ethics Committee.

Contacts for further information

If you need further information, please contact Claire Hamlet (claire.hamlet@uwe.ac.uk) or Heidi Williamson (Heidi3.williamson@uwe.ac.uk) who are leading this research.

Thank you for taking the time to read this information sheet