

## Exploring family planning decisions by people with a visible difference which can be inherited

### Research Advisor/ User representative information sheet

#### What is a Research Advisor/ User Representative?

A user representative group is an individual who has lived experience related to the research. The individuals in this group work collaboratively with the researcher, providing advice and guidance on the development, and design of research. User representatives also work with researchers to develop outputs of research (e.g., support materials).

#### Why do we include people with lived experience in research?

People with lived experience or “experts by experience” bring perspectives and insights that researchers often don’t have. Their contributions are therefore very valuable in research. Involving Research Advisors/User Representatives is essential in conducting sensitive, meaningful, and relevant research. User representatives can advise whether a topic is important or appropriate, whether the language used in research projects are accessible, and how research should be shared with the wider community.

#### Who can be a user representative?

We are inviting people who have an inheritable visible difference who have considered having a family.

#### Do I have to take part?

No, taking part is entirely voluntary. If you decide to take part and then change your mind you can leave the user representative group at any time without giving a reason.

If you change your mind and you decide you no longer wish to be involved, please contact me at [Kerry.montgomery@uwe.ac.uk](mailto:Kerry.montgomery@uwe.ac.uk)

#### Will I be identifiable, will my contributions be shown to anyone and who will see them?

Your contributions as a Research Advisor/ User Representative will be anonymous. Any personal or identifying information that is shared during these discussions will be anonymised and you will not be personally identifiable.

Only my supervisor – Professor Diana Harcourt and I will have access to information from the User Representative Groups. Others will only see the anonymised outcomes of the group discussions. We will present demographic data from everyone who takes part in the user representative group (e.g., sex, age, relationship status) but you will not be individually identifiable.

#### What are the benefits of taking part?

By participating, you will be helping to shape the research study and ensure we gather important and meaningful information in order to help shape support resources. You will also receive compensation for your time as a thank you for your involvement in the project.

### **Are there any risks of being involved?**

There are no major risk associated with being involved in this project.

If you decide you no longer wish to be involved in the user representative group, your contributions up until that point will also be withdrawn. If you decide you wish to withdraw your contributions after your involvement, you can do so by contacting [Kerry.montgomery@uwe.ac.uk](mailto:Kerry.montgomery@uwe.ac.uk) for up to 2 weeks after any user involvement has taken place.

### **How will my contributions be used in research?**

As a Research Advisor/User Representative you will help shape the questions we ask participants in the research study and help us ensure that any participant information is understandable and suitable. After the research study has been conducted we invite you to help us decide the best ways of disseminating the findings and making sure we reach as many people as possible.

### **What if I have questions?**

If you have any questions about the research, please contact me at:

Email: [Kerry.montgomery@uwe.ac.uk](mailto:Kerry.montgomery@uwe.ac.uk)

### **Sources of support**

If you feel that you need support with any of the topics mentioned, the following websites list some helpful resources:

Mind Mental Health charity: <https://www.mind.org.uk/>

Samaritans charity <https://www.samaritans.org/>

[Changing Faces charity: supports individuals and families affected by appearance altering conditions and injuries:](#)

[Website: https://www.changingfaces.org.uk/](https://www.changingfaces.org.uk/)

[Advice and support information line: 0300 012 0275 \(open Mon-Fri 10am-4pm\)](#)

### **Privacy notice**

The personal information collected for the Study will be processed by the University of the West of England in accordance with the General Data Protection Regulation as applied, enacted and amended in UK law. The data controller is the University of the West of England. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. Your personal information will be used and processed as follows:

a) The data you provide will be collected by the University of the West of England for the purposes of academic research and shall be stored, used, analysed, disseminated and published for these purposes. Only members of the research team (being employees of the University of the West of England who are members of or affiliated to the Centre for Appearance Research and are involved in the performance and/or interpretation and analysis of the Study and its results) will have access to the raw data you provide.

b) No dissemination or publication of the data you provide shall identify you individually. Your data and the results of the Study will be disseminated and published (presented at talks and conferences, published including in publicly available places such as on websites, and also in reports, books, academic and specialist journals, and conference proceedings) in aggregate form, combined with other study participants.

c) The data you provide will be stored securely by the University of the West of England on its secure servers and/or in a locked cabinet and shall be kept for a maximum period of 3 years from the completion of data collection of the study (which may be several weeks or months after you provide your data). It will be destroyed or deleted at the earlier of:

- i. the expiration of this 3 year period; and
- ii. the date at which all planned use of the data in the process of intervention development and all planned publications and presentations of the results of the research have (respectively) been accepted for publication or delivered.

To find out more or to exercise any of these rights please contact the University of the West of England's Data Protection Officer

All personal data is processed in accordance with the applicable UK data protection legislation. The Data Controller is the University of the West of England. For data protection queries, please write to the Data Protection Officer, UWE Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY, or [dataprotection@uwe.ac.uk](mailto:dataprotection@uwe.ac.uk)