

Participant Information Sheet

Exploring family planning and decision making for people with a visible difference which can be inherited.

You are invited to take part in research taking place at the Centre of Appearance Research at the University of the West of England, Bristol. It is funded by the VTCT Foundation. Before you decide whether to take part, it is important for you to understand why the research study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact Kerry Montgomery, Centre of Appearance Research, College of Health, Science, and Society, University of the West of England, Bristol kerry.montgomery@uwe.ac.uk.

Who is organising and funding the research?

The project lead is Kerry Montgomery and the co-investigator is Diana Harcourt. The research is funded by the VTCT Foundation.

What is the aim of the research?

To date, very little research has been done to understand how people make decisions about having a family where one parent (or both) parents has/have a visible difference which could be inherited by their child. By exploring what factors influence people's decision making it will help us to understand what support and resources might be useful to people when they come to think about potentially growing their family.

Who can take part?

We are inviting people who are:

- Aged 18 years old+ who have a visible difference which can be inherited and identified by a genetic test AND;
- considering starting a family OR have started a family in the last five years (e.g., a biological child, adoption) OR have decided not to start a family.

Additionally, you will need to be able to

- read and speak fluent English so they can understand all the materials and participate in an interview conducted in English.

You must be currently living in the UK

Finally, you should be comfortable talking about having children and options they have considered. We understand this is an emotive topic so if this is likely to trigger difficult feelings, please consider if taking part is right for you.

This is exploratory research so at this stage we are not including individuals who have conditions for which there is not a genetic test, for example some conditions are considered to run in families (e.g., eczema), but there is not a test to understand the likelihood of inheritance. At the moment we are looking for individuals who have started a family in the last 5 years due to advances in science and practice which may mean options are available now that were not available years ago.

What will this research involve?

If you agree to take part, you will be asked to provide your email address so Kerry can contact you to arrange a suitable date and time for the interview. If you work during the day and would prefer to do the interview in an evening or at a weekend, we can accommodate this. The interview will take place online via Microsoft Teams and will last approximately 60 minutes so please allow for this time when you are arranging an interview. Before the interview Kerry will send some information which will include how the interview will be audio recorded, and ensuring that you are in a quiet and confidential place when we are speaking.

Do I have to take part?

Not at all, it is up to you if you would like to be involved. If you decide to take part and change your mind that's fine too. You can withdraw without giving a reason. You can also withdraw your data for up to two weeks after participating in the interview at which point your data is anonymised and can therefore no longer be traced back to you. If you want to withdraw from the study within this period or at any point during the study, please write to Kerry Montgomery – Kerry.montgomery@uwe.ac.uk
Any data or any information regarding your participation will not be shared with others including health professionals or charitable organisations.

What are the benefits of taking part?

Taking part will help us understand the experiences of people with a visible difference who are thinking about having children or who have children. Your experiences can help shape resources to help others.

What are the possible risks of taking part?

We do not foresee or anticipate any significant risk to you in taking part in this study. However, as family planning and decision making about having children can be an emotive subject, topics that you find sensitive may be covered. You can disclose as much or as little as you want, and can stop the study, or have a break, at any time. The research team are experienced and are sensitive to the subject area. We have provided information on where you can access further support if the interview does raise difficult subjects that you want to discuss further. You are encouraged to contact Kerry.Montgomery@uwe.ac.uk if you have any questions or concerns.

What will happen to your information?

All the information we receive from you will be treated in the strictest confidence and will be kept confidential and anonymised. The only circumstance where we may not be able to keep your information confidential is if we believe you or someone else is at risk of harm. In that instance, we would have to follow UWE Bristol Safeguarding policy and share our concerns with a member of the Safeguarding team at the university.

Digital copies of data collected within the research will be stored in secure password protected UWE OneDrive for Business folders. Audio recordings of interviews will be deleted securely immediately after transcription. Your anonymised data will be analysed together with other data, and we will ensure that there is no possibility of identification or re-identification from this point. Data will be stored securely for 5 years following the completion of the study after which point it will be deleted from all secure files.

Where will the results of the research study be published?

The results of the study will be published in a peer reviewed journal, an internal report, conference presentations and digital media. The project is funded by the VTCT Foundation, and they will also receive a report of the study. Anonymous and non-identifying direct quotes may be used for all publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by the University of the West of England University Research Ethics Committee. Any comments, questions, or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at: Researchethics@uwe.ac.uk

What if something goes wrong?

In the unlikely event that something goes wrong, the researcher will contact their supervisor or the research ethics committee to report the issues and act accordingly on their advice.

Sources of support

If you feel that you would benefit from speaking to someone about how you feel there are lots of organisations and services available to support you. Some of these organisations are specifically designed to support people with a visible difference (for a full list of charities please see [Condition Specific Information | Disfigurements | Changing Faces](#)).

Below are charities offering support resources to people with a condition which affects appearance.

Changing faces

- Provides information and support to individuals and families affected by appearance altering conditions and injuries.
- Website (includes information and free downloadable resources): <https://www.changingfaces.org.uk/>

- Advice and support information phone line: 0300 012 0275 (open Mon-Fri 10am-4pm)

Face Equality International

- A group of international NGOs focussed on advocating and campaigning for an equitable society for individuals with facial differences.
- Website (includes information and free downloadable resources):

<https://faceequalityinternational.org>

Unique

- Provide information and support for understanding rare chromosome and gene disorders. You can find information leaflets including what is genetic testing?
- [Unique | Understanding Rare Chromosome and Gene Disorders](#)

There are also support options available via the NHS and charity sector.

Mental health resources:

NHS Talking Therapies Services:

- If you find it helpful to speak to someone about how you are feeling and look at ways of managing your mood, you can contact your local talking therapies service.
- You can self-refer or ask your GP to make a referral
- Services offer options such as online cognitive behavioural therapy, group-based support, 1:1 talking therapies
- Find an NHS talking therapies services - NHS (www.nhs.uk)

Mind charity:

- A charitable organisation that provides information and support to individuals experiencing challenges related to their mental health.
- Website (Information about mental health conditions, types of support, tips for everyday living etc.) <https://www.mind.org.uk>
- Infoline – confidential helpline for the price of a local call – 0300 123 3393
- Legal line – information on mental health related to law – 0300 466 6463

Samaritans:

- A charitable organisation aimed at providing emotional support anyone in emotional distress.
- Website (information on available services) <https://www.samaritans.org>
- Helpline – 116 123 (Free to call and open 24 hours a day, 7 days a week)

If you would like to speak to someone regarding family planning, pregnancy or options available we would encourage you to speak to your GP. You might also find advice and support from the following organisations,

The NCT is the UK's leading charity for parents, supporting them through pregnancy and the early days of having a baby. You can find lots of information on their website, including practical and emotional support, as well as being able to link with local groups. [The UK's leading charity for parents | NCT](#)

If you've been affected by miscarriage, molar pregnancy or ectopic pregnancy, we hope this website will provide the information and support that you're looking for. [The Miscarriage Association: Pregnancy Loss Information & Support](#)

What if I have more questions or do not understand something?

If you would like any further information about the research please contact in the first instance:

Dr Kerry Montgomery
Research Fellow
Centre for Appearance Research
University of the West of England
Bristol, BS16 1QY.

kerry.montgomery@uwe.ac.uk

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