

PARTICIPANT INFORMATION SHEET

Research Project: A qualitative exploration of the psychosocial impact on adults with siblings (a brother or sister) affected by rare genetic conditions causing developmental disorders

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

Thank you for reading this.

1. What is the purpose of this research project?

This research project has been designed by MSc student, Francesca Wicks as part of her dissertation in the Genetic and Genomic Counselling MSc at Cardiff University. The aim of the project is to explore the experiences of adults with a brother or sister affected by a rare genetic condition which impacts their development, learning and behaviour, sometimes collectively called a developmental disorder. Currently, little is known about how unaffected brothers and sisters are impacted, especially when the genetic condition is rare.

This project will ask adults from different families about their family life. Topics will include what it was like to grow up with their affected brother or sister and how their experiences may have shaped their identity and life choices. Participants will be asked about information they received about the inheritance pattern of their brother or sister's genetic condition and what they think healthcare professionals could do better to support brothers and sisters. It is important more information is gathered so healthcare professionals and genetic counsellors can provide support to all family members when a rare genetic condition is diagnosed.

2. Why have I been invited to take part?

You have been invited because you are aged 18 or over, had or have a biological brother or sister diagnosed with a rare genetic condition causing a developmental disorder and your family is registered with the charity, *Unique* and/or someone you know has given you this information because they thought you may be interested.

3. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part after reading through this information, you need to sign and complete the Consent Form with your contact details, complete the short questionnaire, and return these both by email to Francesca (WicksF1@cardiff.ac.uk). Francesca will also check with you at the start of the interview if you are still happy to take part in the research. If you decide to not take part, you do not have to explain your reasons and it will not affect your legal rights.

If you or your family are registered with the charity, *Unique*, membership, information or support you receive from them will not be affected in any way by your decision to take part in this research. If you received this information from someone you know, your decision to take part or any

information you provide will not be shared with them. You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing and returning the Consent Form and short questionnaire.

4. What will taking part involve?

After returning your signed Consent Form and completed short questionnaire by email, you will be invited to take part in an interview with the researcher, Francesca. You will be asked to discuss your experiences of being a brother or sister of someone affected by a rare genetic condition. Topics will include your experiences of growing up in your family, your relationship with your brother or sister, your wellbeing, how you cope and any information you received about the genetic condition. This interview can be online (through a secure platform), by telephone or where possible, face-to-face. The interview will be scheduled at a time convenient to you and will take approximately one hour. With your permission, the interview will be audio recorded so that the interview can be accurately transcribed for analysis. After all interviews have been completed with approximately 10-15 participants, all results will be combined and analysed. Only combined data will be used in any reports or publications and you will never be identified.

5. Will I be paid for taking part?

No, there is no financial benefit from taking part in this research.

6. What are the possible benefits of taking part?

There are no direct benefits to you from taking part in this research project. However, your contribution is important in helping learn more about the experiences of brothers and sisters of people affected by rare genetic conditions. The project's results will be shared with genetic counsellors with the aim of enhancing practice, family support and knowledge. This may provide indirect benefits including improved support for brothers and sisters in the future, through genetic counselling and patient organisations including *Unique*.

7. What are the possible risks of taking part?

Some people may find it difficult or distressing to talk about their experiences of a rare genetic condition in their family and their affected brother or sister. It may be that talking about these topics, including your wellbeing and relationships, is upsetting to you. If you become upset, the researcher, Francesca, will assist you to decide if you wish to continue. You may take as many breaks as you want, or you can stop the interview completely at any time. You do not have to answer any questions you find upsetting and you may withdraw from the study, at any point, without having to explain your decision. If you find you need further help and support, then the charity, *Unique* will assist you in providing this and/or signpost you to other relevant organisations.

8. Will my taking part in this research project be kept confidential?

All information collected from you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information. As we will be discussing your brother or sister who may still be a child or is a vulnerable adult, it is possible something may be discussed that raises the possibility of a safeguarding concern. In this situation, the research team may need to over-ride confidentiality and disclose information obtained from you to statutory bodies or relevant agencies including, if appropriate, the charity, *Unique* who can

instigate their relevant safeguarding procedures. Where appropriate, this will be done with your permission.

9. What will happen to my Personal Data?

All personal data and information collected about you, what you choose to tell the research team about you and your family will be kept confidential. Some personal data will be collected from you on the Consent Form and the short questionnaire. When you have completed and returned both of these forms, they will be scanned and stored on the Cardiff University Secure Drive. Any paper copies will be shredded.

All material the research team collects, including the recorded interview, will be stored securely on a password protected computer and stored in the Cardiff University Secure Drive. Each participant will be allocated a unique identification number and all data will be anonymised, that is, all names and addresses will be removed. Only the research team will be able to link this identification number back to you. We will never share personal information about you (e.g., name, contact details) with anyone outside the research team. Your data may appear in journals, publications and/or reports but you will never be identified because the information will be anonymous. Direct quotes will be taken from transcripts for inclusion within report and journal articles, but these quotes will not contain any information linking the quotes to you.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection> Paper copies of these documents and notices are available upon request from the research team.

The research team will anonymise all the personal data it has collected from, or about, you in connection with this research project, with the exception of your Consent Form. Your Consent Form will be retained for five years in accordance with the University Records Retention Schedules and may be accessed by members of the research team and, where necessary, by members of the University's governance and audit teams or by regulatory authorities. Anonymised interview information will be kept for a minimum of five years following the end of the project and may be published in support of the research project, however no details that could identify you will be used in publications. However, anonymised interview quotes from you may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

If you choose to withdraw from the research project, any personal data collected up until the point of your withdrawal will be deleted. However, it will not be possible to withdraw any anonymised data that has already been published.

10. What happens to the data at the end of the research project?

At the end of the research project, the data will be disposed of in accordance with Cardiff University processes and GDPR legislation.

11. What will happen to the results of the research project?

The results of this research project will be written up as a dissertation for Francesca's MSc in Genetic and Genomic Counselling and may be reported in academic journal articles and/or presented at academic conferences. The results will be summarised in an information sheet, which will be sent to everyone who participated in the research and wants to receive this. Results will also be used to update an information leaflet "Supporting Siblings of Children with a Rare Genetic Condition" published on the *Unique* charity website, where it will be freely available. Quotes from anonymised participants may be used in papers or presentations, but participants will never be identified in this guide or any report or publication.

12. What if there is a problem?

If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Francesca Wicks at WicksF1@cardiff.ac.uk (Research Student) or Professor Marion McAllister at mcallistermf@cardiff.ac.uk (Research Supervisor and Programme Director of the MSc in Genetic and Genomic Counselling). If your complaint is not managed to your satisfaction, please contact the Chair of the School Research Ethics Committee, Dr Ned Powell at PowellNG@cardiff.ac.uk. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

13. Who is organising and funding this research project?

The research, part of a dissertation project, is organised by Francesca Wicks, a student on the Genetic and Genomic Counselling MSc at Cardiff University. The research is supervised by Professor Marion McAllister, Programme Director of the MSc in Genetic and Genomic Counselling. This research is not funded.

14. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the Cardiff University School of Medicine Research Ethics Committee.

15. Further information and contact details

Should you have any questions relating to this research project, you may contact Francesca on the following email address:

Francesca Wicks: WicksF1@cardiff.ac.uk

Thank you for considering to take part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed Consent Form to keep for your records.