

Exploring whether the UK Genetic Services meet the support needs of families affected by developmental disorders

You are being invited to take part in a research project conducted by a Genetic Counselling student, as part of their dissertation 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. Contact information can be found at the end.

Thank you for reading this.

1. What is the purpose of this research project?

Little research has been conducted to understand whether parents/ guardians of children with developmental disorders feel in need of further support from the Clinical Genetic service and what characteristics indicate those most in need. Your feedback might help to alter the services provided for families of children with a developmental disorder, and guide Clinical Genetics service planning.

2. Why have I been invited to take part?

You have been invited because you are fluent in written English, are older than 18 years, are the parent/ guardian of a child with a developmental disorder, have attended an appointment in a UK Regional Genetics Service for your child within the last 10 years and are a member of either SWAN UK or UNIQUE.

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, we will discuss the research project with you and ask you to sign a consent form. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights or your child's healthcare.

You are free to withdraw your consent to participate in this research project at any time, without giving a reason, even after signing the consent form.

4. What will taking part involve?

Participation consists of a telephone interview which will need to be audio-recorded and will last approximately 30-60 minutes depending on the level of detail you go in to. You will be read the role of the Clinical Genetics service at the start of the interview. The interview itself will include several demographic questions, followed by several open-ended questions regarding your experience with the Clinical Genetics service. The demographic questions are asked to help with the identification of characteristics that indicate people most in need of additional support.

5. Will I be paid for taking part?

No, there will be no compensation for participation in this study.

6. What are the possible benefits of taking part?

There will be no direct advantages or benefit to you from taking part in this study, but your contribution will help us understand whether the needs of parents/ guardians of children with developmental disabilities are being met by clinical genetics or whether there is a gap that clinical genetics could fill. This in turn may help Clinical Genetics Services to tailor service delivery and to direct the limited resources more appropriately.

7. What are the possible risks of taking part?

There is a risk that the interview may bring up memories of a difficult or challenging time, therefore it may trigger distress and affect your emotional and psychological wellbeing. If this occurs, you can stop the interview at any time. You are welcome to contact us using the details

below should you wish to discuss this with us at a later time. Please note we are not able to give you genetic counselling support. If you feel you have unresolved support needs, you may find it helpful to discuss this further with your GP or the support group you heard about this study through.

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

All information collected from you in this study will be kept confidential and any personal information will be managed in accordance with data protection legislation. Consent forms will be sent to the Academic Supervisor for secure storage on the Cardiff University shared drive. Interviews and transcripts will be anonymized and pseudonyms will be used. Recordings of the interview will be uploaded on to the Cardiff University LearnPlus storage system and deleted off the recording device. The consent forms and the interview recordings will be stored in accordance with Cardiff University's Records Management Policy and Records Retention Schedules. Interview transcripts will be kept on a password protected laptop which will then be deleted once data analysis is complete.

9. What will happen to my Personal Data?

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>

If you are unable to view the information using the link above, printed copies of the above-mentioned documentation and privacy notices are available upon you request.

Participant recruitment will be done through SWAN and UNIQUE support groups, Cardiff University will not need to share personal data (consent forms) with these groups for the purposes of this research.

After the consent forms are received, your consent form will be emailed to the Academic Supervisor immediately and stored within the secure Cardiff University shared drive. These will be retained for a minimum of 5 years or at least 2 years post-publication in accordance with the Cardiff Record Retention Schedule 2.8-2.11. The interview recordings and transcripts will be kept on a password protected laptop during data analysis. Once data analysis is complete, the recordings and transcripts will be sent to the Academic Supervisor immediately and stored within the secure Cardiff University shared drive for a minimum of 5 years or at least 2 years post-publication. The consent forms, recordings and transcripts 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.

If you choose to withdraw from the research project, all your personal data collected will be destroyed. However, it will not be possible to withdraw any anonymised data that has already been published or irreversibly anonymised.

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

At the end of the project, any data shall be stored for a minimum of 5 years or at least 2 years post-publication within the secure Cardiff University shared drive in accordance with the University guidelines and relevant GDPR legislation

What will happen to the results of the research project?

Results of the research project will be included in a Cardiff University MSc Dissertation. This is expected to be finalised June 2023. A copy may be obtained either through the Cardiff University Library or by contacting a member of the research team. The findings may also be published in an academic journal or presented at any relevant conferences. No identifiable information will be reported in any publication or presentation but anonymized verbatim quotations may be used as appropriate.

11. What if there is a problem?

Participants should contact lead researcher Emma Carter on e.cartere9@cardiff.ac.uk should they wish to raise a complaint. If your complaint is not managed to your satisfaction, you may wish to contact someone independent from the research team. Dr Marion Mc.Allister is the Programme Director for the MSc in Genetic and Genomic Counselling at Cardiff University and can be contacted on mcallistermf@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.

12. Who is organising and funding this research project?

The research is organised by Emma Carter, MSc Student in genetic and genomic counselling at Cardiff University, under the supervision of Flora Joseph, Registered Genetic Counsellor. This research project has not received funding.

Who has reviewed this research project?

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

13. Further information and contact details

Should you have any questions relating to this research project, you may contact us during normal working hours:

Emma Carter (lead researcher)

e.cartere9@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.