



Research Invitation Letter

Dear *Unique* Family Members,

I am writing to invite you to take part in a research study which I am conducting as part of my dissertation project in my MSc degree in Genetic and Genomic Counselling at Cardiff University.

The title of the research is “A qualitative exploration of the psychosocial impact on adults with siblings affected by rare genetic conditions causing developmental disorders”.

This research aims to specifically explore how adults are impacted by having a sibling (brother or sister) affected by a rare genetic condition associated with a developmental disorder. I am looking for participants who are aged 18 or over and who have, or had, a biological sibling (brother or sister) diagnosed with a rare genetic condition which impacted their development, learning and/or behaviour. The inheritance pattern of the rare genetic condition affecting participant’s siblings (if it is inherited from a parent, has happened for the first time (*de novo*) or is not known) does not affect participants’ eligibility to take part in this research.

Taking part in the research involves completing a short questionnaire about you and your sibling’s genetic diagnosis, followed by an audio telephone or online interview with me, Francesca, which can be organised to your convenience, and take approximately one hour. Face-to-face interviews may be possible if you would prefer and best efforts will be made to accommodate this. Participants will be asked about themselves, their views and experiences of growing up with their affected brother or sister, their family life, how this may have impacted their life choices such as education and/or jobs, their identity and what information they received, if any, about the genetic diagnosis that was made. Interviews will be recorded, with your permission, for accurate transcription and analysis. All data will be kept confidential and participants will not be identified in any publication or research output.

In addition to this letter, a participant information pack is enclosed including a Participant Information Sheet, a short Participant Questionnaire and a Consent Form. Please take your time reading the information in this pack before deciding if you want to take part or not. If you have any questions, would like any further information or are interested in taking part, then please get in touch with me, Francesca Wicks, by email on WicksF1@cardiff.ac.uk.

If you would like to take part, please complete, sign and return the Consent Form with your contact details and the short Participant Questionnaire to me, Francesca, on WicksF1@cardiff.ac.uk.

It is up to you to decide whether or not to take part in this research project. Your decision is completely voluntary and will have no impact on your or your family’s membership with *Unique*, and the information and support you or your family receive now or in the future.

With best wishes,

Francesca Wicks, Student, Genetic and Genomic Counselling MSc, Cardiff University

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