

Participant Questionnaire

Thank you for your interest in taking part in the research study “A qualitative exploration of the psychosocial impact on adults with siblings affected by rare genetic conditions causing developmental disorders”.

If you would like to take part, please complete this short questionnaire about yourself and your brother or sister, and return it to Francesca by email on WicksF1@cardiff.ac.uk along with your signed Consent Form. For gender and ethnicity questions you can choose not to answer or select ‘prefer not to say’.

If you have any questions or concerns, please contact Francesca via email on WicksF1@cardiff.ac.uk. Thank you for your time.

Your Name	
Your Age in Years (Please circle)	18-24 25-30 31-40 41-50 51-60 61-70 71+
What is your Ethnic Group?* (Please circle) <small>*Categories used from UK Census 2021</small>	Asian or Asian British Black, Black British, Caribbean or African Mixed or Multiple Ethnic Groups White Other Ethnic Group (Not listed) Prefer not to say
Which Gender do you most identify with? (Please circle)	Male Female Transgender Male Transgender Female Non-Binary Other (Not listed) Prefer not to say
What is your Brother or Sister’s Genetic Diagnosis? (for example 16p11.2 deletion, Trisomy 8 Mosaic etc.)	
How, if known, was your Brother or Sister’s Genetic Diagnosis Inherited? (Please circle)	Inherited from parent <i>De novo</i> (happened for the first time in your brother or sister) Unknown