



CONSENT FORM

Research project: A qualitative exploration of the psychosocial impact on adults with siblings affected by rare genetic conditions causing developmental disorders

SREC reference and committee: Cardiff University School of Medicine Research Ethics Committee

Name of Chief/Principal Investigator: Francesca Wicks

**Please
initial box**

I confirm that I have read the Participant Information Sheet dated 7 th September 2022 Version 2.0 for the above research project.	
I confirm that I have understood the Participant Information Sheet dated 7 th September 2022 Version 2.0 for the above research project and that I have had the opportunity to ask questions and that these have been answered satisfactorily.	
I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason and without any adverse consequences.	
I understand that data collected during the research project may be looked at by individuals from Cardiff University or from regulatory authorities, where it is relevant to my taking part in the research project. I give permission for these individuals to have access to my data.	
I consent to the processing of my personal information from interviews, the Consent Form and the short Participant Questionnaire for the purposes explained to me. I understand that such information will be held in accordance with all applicable data protection legislation and in strict confidence, unless disclosure is required by law or professional obligation.	
I understand who will have access to personal information provided, how the data will be stored and what will happen to the data at the end of the research project.	

I consent to being audio recorded taken for the purposes of the research project and I understand how it will be used in the research.	
I understand that anonymised excerpts and/or verbatim quotes from my interview may be used as part of the research publication.	
I understand how the findings and results of the research project will be written up and published.	
I agree to take part in this research project.	

Name of participant (print) **Date** **Signature**

Contact details of participant (to arrange interview):

Email Address: _____

Telephone number: _____

Name of person taking consent (print) **Date** **Signature**

Role of person taking consent (print)

THANK YOU FOR PARTICIPATING IN OUR RESEARCH

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP