



Exploring the experiences and psychosocial aspects of fertility issues for people with Primary Ciliary Dyskinesia (PCD)

I am looking for individuals to take part in my study exploring what are the issues that people with Primary Ciliary Dyskinesia (PCD) face relating to fertility and their experiences. There has been little research in to how fertility issues impact people with PCD and how this may influence family planning or decisions around starting a family.

I am hoping to gain a greater understanding of the psychosocial impacts that people with PCD face when dealing with fertility issues. I am hoping that this may in turn, improve the awareness around fertility issues and increase support to those who are affected by fertility issues in the PCD community from healthcare professionals, support organisations, friends and family members.

Recruitment Criteria:

You can take part in this study if you are over the age of 18 and have a diagnosis of PCD. You must be able to speak and understand English and have capacity to give consent and take part in research.

What do I do if I am interested in taking part

If you have any questions about taking part in this study or would like further information, you can contact me at fitzpatrick2@cardiff.ac.uk. If you are interested in taking part in this study, you will sign a consent form and send this to fitzpatrick2@cardiff.ac.uk. All necessary information regarding the study, participation and consent can be found on the participant information sheet (PIS). This consent form will be stored securely at Cardiff University.

The study involves semi-structured interviews that will last approximately between 45-60 minutes and will take place on Microsoft Teams. The audio from interviews will be recorded and recordings will be stored on the student researcher's password protected Cardiff University OneDrive account. Following your interview, there will be the opportunity to discuss your feelings around the interview and ask any remaining questions that you may have.

This study has been reviewed and cleared by the Cardiff University School of Medicine Research Ethics Committee.

What will my data be used for?

The results from this study will be published as part of the researcher's MSc dissertation project for Cardiff University. Additionally, this research is being carried out as it is a requirement of completing the MSc programme in Genetic and Genomic Counselling. Additionally, the results may be published in peer-reviewed journals and may also be shared on PCD Support UK's website and social media platforms. Please note that none of your personal information will be shared.

If you are interested in taking part in this study, please contact the researcher directly through email at:

Researcher: Sean Fitzpatrick

Email: fitzpatricks2@cardiff.ac.uk