A Qualitative Exploration of the Lived Experiences of Adolescents with Down’s Syndrome

What is the purpose of this study?

We want to understand and improve the care guidelines, developmental outcomes and wellbeing of adolescents with Down’s Syndrome (DS). Oftentimes, the opinions of individuals with DS themselves are not heard within research – we want to change this.

We want to hear directly from adolescents with DS about their lived experiences by conducting focus groups – these are a form of group interview.

How can you and your adolescent help?

Your adolescent will be asked to participate in 2 focus group sessions lasting 60 minutes each with four other adolescents with DS (5 per focus group). These sessions will occur on separate days. We want to ask your adolescent about their experiences with family, education, healthcare, mental health and activities or hobbies. We also want to explore any areas in which they would like to see improvement. These focus groups will help us understand the lived experiences of adolescents with DS from their own perspective and identify areas in which improvement or change is desired, aiding in the development of large-scale PhD projects within Ulster University.

Are there any risks or benefits to taking part in this study?

If you and your adolescent choose to participate, you will be actively helping to develop research that focuses on adolescents with DS and their wellbeing.

Other than the time taken to participate, there are no known risks or disadvantages to taking part!

If you and your adolescent are interested in taking part or would like further information, please follow below or scan the QR code:


This research is being undertaken in collaboration with: