

Dear Wolfram syndrome community,

Birmingham Children's Hospital Endocrine team are conducting a research study to find out more about how we can best support our patients with Wolfram syndrome to manage their insulin-dependent diabetes. We would like to hear from patients with Wolfram syndrome and their families.

This research will contribute to an understanding of the experiences of people living with Wolfram syndrome and how they feel about managing their insulin-dependent diabetes. Understanding what helps people with Wolfram syndrome to manage their diabetes will help us to better support our patients, including advocating for glucose sensors and/or insulin pumps, if these are felt to be useful to patients.

The study will take part in two steps – you can choose to do both steps, just the first step, or none at all.

Data will be gathered via an online survey and interviews with patients over 18 years old, or with their parents if patients are under 18 years old.

Stage 1: Online survey asking questions about how you or your child finds managing your/their insulin-dependent diabetes, what challenges you/they face, what makes it easier, and how it impacts on quality of life. This survey has been designed with Wolfram Syndrome UK charity and should take less than 15 minutes to complete.

This survey will be anonymous unless you give your name and number at the end of the survey to indicate that you are happy to be contacted for stage 2.

Stage 2: Interviews with patients or parents/carers via video-call to further explore your (or your child's) experience of managing insulin-dependent diabetes in Wolfram syndrome and a chance to elaborate on some of your answers from the online survey. This stage will require signed consent prior to taking part. Interviews will take part over a video call and are designed to take 30-60 minutes.

Please see attached the patient information sheet for further information on the study and how to get involved.

If you have any questions about the study or need any adjustments made in order to take part in the study (e.g. interview by phone rather than video), please send an email to the study email address: wolfram.diabetes.research@gmail.com.

Thank you so much for taking the time to read,

Dr Renuka Dias and Professor Tim Barrett