

New Study Highlights the Impact of Diabetes Technology in Wolfram Syndrome

People living with Wolfram syndrome face unique challenges when managing their insulin-dependent diabetes due to progressive sight and often hearing loss, making everyday diabetes care much more difficult than it is for most people with type 1 diabetes. Despite this, very little research has explored how diabetes technologies such as continuous glucose monitors (CGM) and insulin pumps work for people with Wolfram syndrome.

This study, carried out by Dr Josie Elliott with colleagues at the University of Birmingham, Washington University, and Wolfram Syndrome UK, aimed to better understand these experiences and identify ways that diabetes care and technology could be improved.

The research took place in two stages. First, members of the Wolfram Syndrome UK community completed an online survey about their experiences of diabetes management. Ten people took part, seven adults with Wolfram syndrome and three parents of people with Wolfram syndrome. Overall, survey respondents reported that diabetes technology had a positive impact on both glucose control and quality of life by reducing the number of finger pricks required, increasing independence, and improving control of sugars, but they also highlighted challenges relating to accessibility for people with visual impairment. The survey findings helped shape the interview questions used in the second stage of the study.

Eight interviews were then carried out with five people living with Wolfram syndrome and three parents of children or adults with the condition. These conversations provided a much deeper understanding of people's day-to-day experiences.

One of the strongest messages from the interviews was that Wolfram syndrome diabetes is not the same as type 1 diabetes. Participants described unpredictable insulin needs and explained that healthcare professionals sometimes don't recognise these differences.

Participants also described the significant impact that progressive sight loss has on diabetes management. Tasks such as checking blood glucose, giving insulin injections, and reading food labels can become increasingly difficult over time. Many explained that without diabetes technology, they would need much greater support from family members or carers.

For almost everyone interviewed, continuous glucose monitors and insulin pumps were described as life changing. Participants said these technologies reduced the stress of constantly thinking about diabetes, improved blood glucose control, reduced injections and finger-prick testing, and made them feel safer. Parents particularly valued being able to monitor their child's glucose levels remotely, while adults described feeling more confident at work, exercising, travelling, and living independently.

However, the interviews also highlighted that many diabetes devices are not designed with visual impairment in mind. Small text, poor colour contrast, inaccessible packaging, and screens that cannot be enlarged or read aloud all made devices harder to use. Many suggested improvements such as adjustable text size, voice guidance, better colour

contrast, and more accessible packaging so that people with severe sight loss can use the technology independently.

Access to diabetes technology was another important issue. Some participants described delays in receiving devices through the NHS, while others had paid for equipment themselves before it became available on prescription. Experiences often depended on where people lived and whether they had healthcare professionals who understood Wolfram syndrome and could advocate on their behalf.

Overall, this study shows that diabetes technology offers much more than improved glucose control for people living with Wolfram syndrome. It helps people maintain independence, reduces worry, and supports everyday life despite progressive sight loss. The findings also highlight the need for better awareness of Wolfram syndrome among healthcare professionals, more accessible diabetes technology, and fair access to these life-changing devices for everyone living with the condition.

A huge thank you to everyone who completed the survey or took part in an interview. By sharing your experiences, you have helped generate the first UK study exploring diabetes technology from the perspectives of people living with Wolfram syndrome. The next steps of this work are designing a patient information leaflet on diabetes technologies for people with Wolfram syndrome and publishing the findings of this study in a scientific journal with the hope that it will lead to can more inclusive and accessible designs of diabetes technologies.