

## What can real-time continuous glucose monitoring data tell us?

*In this section, a panel of multidisciplinary team members give their opinions on a recently published paper. In this issue, we discuss the results of a recent survey of people and caregivers of children who use continuous glucose monitoring technology.*

### **Real-time continuous glucose monitoring in type 1 diabetes: a qualitative framework analysis of patient narratives.**

Pickup JC, Holloway MF, Samsi K (2015) *Diabetes Care* 38: 544–50

#### **Diabetes Care**

### **Patient and caregivers' responses to CGM technology**

**1** The objective of this UK-based analysis was to analyse the experiences of people with T1D using continuous glucose monitoring (CGM).

**2** People with T1D ( $n=50$ ) and caregivers of people with T1D under 18 years of age ( $n=50$ ) completed an online survey of nine questions. Responders were recruited through online advertising. The last question invited responders to write as much or as little of their personal experiences of CGM as they wished, including benefits, drawbacks, problems or how it affects other parts of their lives.

**3** The anonymous responses of 100 people were included, based on sampling saturation (no new themes emerged from responses 90–100). Framework analysis was used to analyse the

qualitative data.

**4** The duration of use did not differ between adults and children using CGM, and approximately 66% received partial or full NHS funding, while the remainder self-funded.

**5** Four main themes were identified from the responses to question 9: (1) metabolic control; (2) living with CGM (e.g. work, school, sleep exercise); (3) psychological issues and patient/caregiver attitudes; and (4) barriers to CGM use.

**6** Of the responders, 37% noted that CGM helped them achieve better control than self-monitoring of blood glucose and 22% found it useful in predicting or detecting hypoglycaemia.

**7** The trend data from real-time CGM was perceived as more important than complete accuracy of individual readings.

**8** The usefulness of alarms and alerts from CGM was discussed and there were mixed reports from parents. Some thought they may cause a distraction at school, but that CGM could help boost confidence and independence of children at sleepovers and during exercise.

**9** The majority of participants (88%) who mentioned sleep answered that they were able to sleep more easily using CGM.

**10** Patients and responders reported feeling less stressed and anxious than before using CGM.

**11** The most cited barrier to CGM use was that reliability was inconsistent and sensor failure occurred before the expected 6–7 day life span.

**12** Those that were NHS funded worried they would lose their CGM, and those self-funding said it was too expensive.

**13** Some of the limitations reported by the authors were as follows: the responses were based on perception; the participants were selected from a population who engaged with using CGM and maybe hoped that CGM would work; and that the preconceptions of two of the authors might positively impact on the analysis.

**14** All the responses and the framework history are available for audit.

**15** Users of CGM are, on the whole, extremely positive about their experiences using CGM.



#### **Dr Roger Gadsby**

*Principle Teaching Fellow, Warwick Medical School, University of Warwick*

**T**his is an interesting paper describing patient and carer narratives on real-time continuous blood glucose monitoring (CGM) from a UK perspective. Interestingly, the 100

participants (made of CGM users and caregivers of children under the age of 18) report on nine different systems although four systems made by the manufacturer Medtronic are used by 75% of the users. The four themes of issues that were identified by the authors from

the results of the questionnaire – (1) metabolic control; (2) living with CGM; (3) psychological issues; and (4) barriers to CGM use – are well described and illustrated by selective participant quotes.

The limitations of the study are clearly outlined in the discussion. The fact that one of the authors is chief advisor to a charity supporting patient access to diabetes technology and that information about the online survey was advertised through that charity's website and other diabetes charity websites (e.g. Juvenile Diabetes Research Foundation, Insulin Pump Users UK) might imply that people who were recruited were more likely to be pro-CGM in the first place.

It would be interesting to know if there were any differences in answers between the 67% who received at least partial NHS funding and the 33% who self funded. It would also be interesting to know whether there were any differences between responses from carers of children (50% of the sample) and adults using CGM (the other 50%).

The paper reports experiences of improved glycaemic control,

improved diet and exercise management, improved quality of life, improved physical and psychological well being and reduced frequency of self monitoring of blood glucose (SMBG) in regard to CGM use.

The overall conclusion from this study, that the experience of CGM is on the whole extremely positive, is not unexpected given the recruitment strategy. However, to me the more important conclusion is highlighting the much-needed improvements in CGM to improve outcomes. These included inconsistent reliability with inaccuracy at times, incorrect alarms and sensor failure before the expected lifetime of 6–7 days. Issues relating to uncomfortable sensor insertion, sensor adhesion problems and complexity of interpreting CGM data were also mentioned.

I think this paper is important in that it describes the narrative surrounding the use of CGM in a group of people who are generally supportive of the technology. I hope the CGM companies will take this on board and be able to introduce the much needed improvements in technology to make CGM even more beneficial. ■



## Lesley Jordan

*Chief Executive of INPUT and pump user*

**F**irst, I am glad to read a study reporting on the real-life use of continuous glucose monitoring (CGM).

Blood glucose assessment has come on in leaps since I was first diagnosed and it would be interesting to see the findings of this report grouped by respondents' decade of diagnosis. I began by counting five drops of urine into a test tube and then moved on to weeing on a stick. Self-monitoring of blood glucose has since shed more light, but even with today's tiny sample size and quick result, it is still a messy and painful procedure that falls short of what I really want to know: a perfect 5.6 mmol/L is only perfect if it isn't about to plummet.

Trend information is the new gold standard. Many of my friends on social media seem to assume their blood glucose reading is stable at whatever level is displayed, and report true enlightenment from using CGM.

At work or when socialising, CGM allows me to keep an eye on my glucose levels without anyone perceiving any problems (or asking "are you ok?") – very useful when I am trying to be a living example of how diabetes technology can help people achieve good glycaemic control!

In the past, I have dealt with my alarm fatigue by setting the alarms to sound when I am still within my target range. This means they sound even more frequently but the psychological impact of being

in range when I hear a high alarm is great. These limits are my pivot points, and signal the times to take small actions.

I am self-funding my CGM system because I consider it to be worthwhile and I'm not unusual enough to warrant an Individual Funding Request application. My consultant helps me interpret patterns, but I'm very much in charge of making best use of my data.

Regarding accuracy, I have come from urine testing where "blue is probably under 10 mmol/L", to implied accuracy of one tenth of a mmol. Those decimal places are only important at the far ends of my target range. Therefore, CGM accuracy is good enough for me to make small therapeutic adjustments. Half a unit of insulin to bring me down from 6.7 mmol/L (and stable or rising) is fine; to me, it doesn't matter if I'm actually 6 or 7 mmol/L. This is my altimeter. Small adjustments mean a small margin of error, and I can go from day to day only blood testing to calibrate and check suspicious results.

INPUT gets a lot of enquiries about the criteria for funding CGM. I welcome the day when there are criteria. In the meantime, there is a continuous glucose recording product that has made this level of data affordable for many more people. Healthcare professionals: it is time to embrace the technology we have now, with all its imperfections, and keep up with the continuous glucose data users attending your clinic. ■

**Let us know your thoughts by emailing [dd@sbcommunicationsgroup.com](mailto:dd@sbcommunicationsgroup.com)**