

The survey highlights

The context for the survey: This report is a summary of evidence gathered on the request of the HSE National Centre of Pharmacoeconomics as part of the Health Technology Assessment of Freestyle Libre Flash Glucose Monitoring (FGM) device. Diabetes Ireland conducted an online survey in November 2021 gathering responses from 754 participants: people living with type 1 and type 2 diabetes, parents of children with diabetes and healthcare professionals living and working in Ireland.

Reimbursement:

Freestyle Libre is currently reimbursed only for people with Type 1 diabetes under 21 years of age, following a decision taken by the HSE in 2018. Since then, despite petitions, reports, letters, and plenty of scientific evidence on the huge clinical benefits and improved quality of life, adults with diabetes still have to pay out-of-pocket to manage their diabetes with FGM. The Diabetes Ireland survey reveals the disappointment and frustration of the Irish diabetes community.

Technology improves lives

The outstanding response of the diabetes community with 754 survey completions in three weeks of data collection, reflects how important the topic of access to technology that improves diabetes management, and the quality of life is for those living with this burdensome condition. Libre users (397 participants) assessed on a scale from 0 to 10 that Libre is, when compared to finger-pricking, very useful in:

- ✓ adjusting insulin doses (10 out of 10);
- ✓ preventing daytime and night-time hypoglycaemia (9 out of 10);
- ✓ helping to treat low glucose levels and during exercise (9 out of 10);
- ✓ more frequent glucose monitoring (9 out of 10).

Participants also assessed their diabetes management as much better and that they test much more frequently than they did with standard finger-pricking.

The majority of respondents positively assessed the impact of Freestyle Libre use on the aspects related to the quality of life and care. Participants assessed that since using Libre their motivation to keep up their diabetes management improved (89%), and that they test their blood glucose levels more frequently (87%); they also feel less overwhelmed by the demands of living with diabetes (88%), that it takes much less mental and physical energy each day (87%), and that diabetes does not control their life as much as before (75%).

Without a doubt, this survey proved that using the FGM:

- Give people with diabetes, their carers and healthcare professionals the information, tools, and support to live safe and well with diabetes, and to understand how the condition is affected by everyday tasks that those without diabetes take for granted. People with diabetes and their carers need to know the actions to take to stay healthy and to avoid excessive high and low blood glucose levels.
- Reduce the burden of diabetes self-management and the need for painful and inconvenient finger prick glucose monitoring.
- Reduce the daily and long-term physical and mental burden of diabetes management that is usually associated with stress and anxiety in people with diabetes and their families, minimize the risk of diabetes distress, burnout, depression and eating disorders.
- Reduce the risk of short-term and severe complications, such as hypo- and hyperglycaemia, severe hypoglycaemia, diabetes ketoacidosis (DKA).
- Reduce the risk of developing devastating complications such as sight loss, amputation, renal failure, stroke, acute and chronic depression.
- Allow people with diabetes the opportunity to live as normal as possible lives, despite diabetes and empower patients in self-managing diabetes.

Using FGM also results in less sore fingers, greater security at night-time resulting in peace of mind and less anxiety, reducing the burden of living with diabetes, providing more safety and minimizing the risk of diabetes-related complications.

Self-funding, unaffordability, inequality

Regardless of the funding, Libre is being used across all age groups of the Type 1 diabetes community, and by some with Type 2 diabetes. Unfortunately, for many people with diabetes in Ireland it means that they have to choose whether they will pay bills such as TV broadband, or invest in their own health, as the majority of Libre users had to pay for it privately.

Of 292 of the Libre adult users who responded to the survey, 76% have or had to pay for Libre privately at an approximate, minimum monthly cost of €120. 131 people declared that they are not using Libre anymore, mainly due to its cost. Of 152 of those who have never tried Libre (152), the main reason why was that they could not afford it. The cost and the lack of reimbursement seem to be the greatest barrier to flash glucose monitoring use. This report aims to acknowledge that many people living with diabetes feel discriminated against and 'let down' by the Irish health service because of their age or type of diabetes, although they have hugely similar clinical needs as children and adolescents using insulin under 21. Some people are lucky enough to have the means to be able to self-fund Libre, but this means that those on lower wages are discriminated against due to their socio-economic status. For many, self-funding Libre is not affordable, and for some, it means that in some months they have to *'choose between better diabetes management or paying bills'*.

Acknowledgement of HCP expertise

Healthcare professionals who responded to our survey felt that their clinical expertise, knowledge of the patients' needs, and recent scientific knowledge is not acknowledged by the HSE, as their requests for access to life-changing technologies are often rejected. 73% of HCP respondents (almost all in adult diabetes services or general practices) declared that applications they have made for individual adult patients have been rejected by the HSE, often with no reason provided. This is discouraging for both, healthcare providers and their patients, it limits the trust in the Irish health service and does not empower healthcare professionals to work in line with their expertise.

Ensuring access to technology

On behalf of the Diabetes Community in Ireland, through this report, we would like to highlight and address the gap of not providing diabetes technology to people living with diabetes in Ireland, and that this gap is addressed urgently by making Freestyle Libre available to all people with diabetes **based on clinical need**.

Participants report FGM as being a major advancement in diabetes self-care and in their own words *'it is a gamechanger'*. It also improves the quality of care for healthcare professionals. In light of having other, more expensive CGM approved on the LTI scheme, and also newer models of Freestyle Libre that provides the same information as expensive CGMs (alerts on highs and lows), making FGM available to all people with diabetes based on their clinical need, surely improve diabetes management practices in the cohort of people living with diabetes in Ireland, and as a consequence, will save money for the Irish health service by reducing the risk of severe and long-term complications. It is proven that in the other countries which implemented the wider use and access to FGM/CGM, the last few years show significant improvement in diabetes management outcomes in whole societies (England, UK, Germany, Sweden etc.).

We in Diabetes Ireland agree with the 92% of HCPs and 98% of people with diabetes who believe that FGM should be reimbursed for all people with diabetes based on clinical need. After 40 years of finger-pricking, it is the high time to provide equal access to better devices to self-manage diabetes daily for those with clinical need and improve the quality of diabetes care and its outcomes in Ireland.

'The Freestyle Libre has changed my life, my HbA1c is the lowest it has been in 18 years because I can closely monitor changes in my sugars and identify patterns which allows me to adjust insulin dosage. Sadly, it comes with a huge cost burden, and I have to sacrifice many things in order to keep my health intact. It should be available to everyone there should not be a price tag on people's health'

(Adult, type 1 diabetes)