



*Users Experiences of Flash Glucose  
Monitoring on Daily Life  
Experiences  
Survey Report*

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## Introduction

Diabetes is a condition that disrupts the body's ability to process blood glucose (sugar). Insulin produced in the pancreatic beta cells normally regulates this process. In diabetes, there is either a complete lack of insulin production (Type 1 diabetes) or relative lack of insulin (Type 2 diabetes). This submission will focus on Type 1 diabetes.

## Type 1 Diabetes

Type 1 diabetes develops over a short timeframe with the person noting distribution in bodily function sufficient to seek medical assistance, diagnosis and treatment by insulin either given continuously (Continuous Subcutaneous Infusion i.e. insulin pump) or by regular injections. The aim of management is the regulation of glucose levels to prevent short term complications – high or low glucose levels, and longer blood vessel and nerve damage due to prolonged exposure to high glucose levels. It is the exposure to high glucose levels that causes, diabetes eye disease, kidney failure, heart and peripheral artery disease and nerve damage sufficient to cause major foot complications of ulceration and amputation. Furthermore, it is both the short and long term complications that result in hospital needed care currently requiring 60-80% of diabetes care spend. The aim of diabetes management is to support people with Type 1 diabetes to live full lives and avoid the acute and long-term complications of both the disease and its treatment. Hence, there is strong focus on the target blood glucose range of 5-7 mmol/l fasting and 4-7 mmol/l during the day so that overall blood glucose control measured by HbA1c is 48mmol/mol. Individual personal characteristics such as daily activity, aspirations, co-morbidities may hinder this achievement and should be accounted for and addressed as appropriate.

## Monitoring Glucose Levels

Monitoring glucose levels on a daily basis is the key to avoiding complications. It is recommended that people test at minimum 4 times per day but up to 10 times daily<sup>1</sup>, if HbA1c not achieved, high or low levels are recorded, during illness, before/during/after intense activity, before/during/after pregnancy etc. This level of frequent testing using traditional finger pricking devices can be painful, inconvenient and difficult to achieve as people go about their daily life.

Traditional finger pricking requires the person to change lancet in their lancing device, open and insert a test strip into a hand held machine, clean hands and prick finger, apply blood to test strip, clean blood of finger and await result while tidying up all equipment. This takes time and makes diabetes very visible when done in public settings. Simple things such as going out or socialising require more planning which can lead to frustration, anger, resentment and more stress about diabetes management.

A major drawback of finger prick blood glucose measurement is it only provides information about the blood glucose at a particular point and therefore significant glycaemic excursions may often go unnoticed<sup>2</sup> but more important to the individual it is unable to detect asymptomatic hypoglycaemia (hypos) or nocturnal hypoglycaemia (night-time), especially in the presence of target HbA1c levels<sup>3</sup> which is a major fear for people living with diabetes.

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<sup>1</sup> Adult Type 1 diabetes mellitus National Clinical Guidelines No 17.

<sup>2</sup> Kesavadev J, Ramachandran L, Krishnan G. Glucose monitoring technologies - complementary or competitive? Role of continuous glucose monitoring versus flash glucose monitoring versus self-monitoring of blood glucose. *J Diabetology* 2017;8:61-7

<sup>3</sup> Weber KK, Lohmann T, Busch K, Donati-Hirsch I, Riel R. High frequency of unrecognized hypoglycaemias in patients with type 2 diabetes is discovered by continuous glucose monitoring. *Exp Clin Endocrinol Diabetes* 2007;115:491-4.

## Hypoglycaemia

One of the most challenging aspects of living with diabetes is the prevention of hypos as they are distressing not only for the person living with the condition but also for parents, spouses and family members. They can be difficult and distressing to manage, the person may become aggressive, irritable, uncooperative, unsteady, confused etc. Parents of young children frequently report interrupted sleeps for protracted periods (years) because they have to check their child's blood glucose levels during the night to avoid life threatening hypos and, where necessary, take remedial actions such as waking the child for blood testing or treatment. This fear of a hypo results in great anxiety about diabetes management, obsessive self-monitoring, deliberate maintenance of high blood glucose levels, co-dependency, feelings of guilt and frustration, a perceived sense of loss of control, embarrassment, relationship stress, and avoidant behavior<sup>4</sup>. Any degree of hypoglycaemia constitutes a unique metabolic brain insult and severe hypoglycaemia may lead to brain damage<sup>5</sup>.

The impact and time required to recover from a severe hypo varies from individual to individual. On average it can take several hours before the person is able to resume normal tasks of daily living. In some instances the person may not be able to attend school, college or university, thus missing vital education; or, if employed, they may be unable to attend work and potentially face disciplinary action. All of which can impact on attainment, future prospects or

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<sup>4</sup> Assessing fear of hypoglycemia in children with Type 1 diabetes and their parents. Gonder-Frederick L, Nyer M, Shepard JA, Vajda K, Clarke W, *Diabetes Manag (Lond)*. 2011; 1(6):627-639.

<sup>5</sup> Hypoglycemic brain damage. Auer R, *Metab Brain Dis*. 2004 Dec;19(3-4):169-75.

life chances, financial security, mental and physical wellbeing and result in premature mortality.

One cannot underestimate the challenges, fear and anxiety faced by people living with diabetes as they constantly seek to monitor glucose levels to facilitate the timely management of glycaemic fluctuations. For many people there is a constant trade off of preventing hypo through more frequent testing and even running glucose levels higher than target balanced against guilt because of the possible consequences such as loss of control, hospital admission, injury through falling while hyperglycaemic, discrimination if seen to use a needle and stigma of being different. The need for constant vigilance can lead to ‘diabetes burnout’, anxiety, obsession, depression and eating disorders.

### **New technology limits diabetes distress**

Flash glucose monitoring (FGM) is carried out via a small sensor that is worn on the upper arm. It measures interstitial fluid glucose levels every minute, with the data stored at intervals of 15 minutes for up to 8 hours. These values can be accessed any time by scanning with a reader or mobile phone. Frequent glucose monitoring is a prerequisite to tight glucose control but it is known that poor engagement with traditional finger pricking glucose monitoring is viewed as a barrier to optimal glucose control<sup>6</sup>. Flash and continuous glucose monitoring are more advantageous than traditional finger pricking because of patient

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<sup>6</sup> Ward JE, Stetson BA, Mokshagundam SP. Patient perspectives on self-monitoring of blood glucose: perceived recommendations, behaviors and barriers in a clinic sample of adults with type 2 diabetes. *J Diabetes Metab Disord.* 2015;14:43.

convenience and the comprehensive data provided<sup>7</sup>. There is also evidence that people scan more frequently when using FGM resulting in improved glycaemic control<sup>8</sup>.

The Health Technology Assessment Group (HTAG) advice note 2017/001 recommended after one year of flash glucose monitoring technology (Libre) usage, data on costs incurred by patients using the device in the PCRS system should be reviewed to ensure that costs are in line with expectations and to help inform the continuation or otherwise of reimbursement. That document predicted that with 5051 people using Libre there would be a minimal cost saving which would escalate as usage developed. Based on the criteria implemented for FGM usage in the 4 to 21 years age group, it is assumed that the uptake would be half that predicted in the Health Technology Assessment Group advice note 2017/001 and it is likely that many of these are not using FGM for the full 12 month period. Hence it is likely that there may be currently no cost savings in monetary terms. Therefore it is vital that other factors be considered i.e. patient or user perspective when this one year review is undertaken.

## **Irish User Perspective of Libre**

During March 2019, Diabetes Ireland invited users of Freestyle Libre to give their views on its usage. 309 people responded i.e. 164 parents of children (132

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<sup>7</sup> Ajjan, R. A., Cummings, M. H., Jennings, P., Leelarathna, L., Rayman, G., & Wilmot, E. G. (2018). Accuracy of flash glucose monitoring and continuous glucose monitoring technologies: Implications for clinical practice. *Diabetes and Vascular Disease Research*, 15(3), 175–184. <https://doi.org/10.1177/1479164118756240>

<sup>8</sup> Al Hayek, A. A., Robert, A. A., & Al Dawish, M. A. (2017). Evaluation of FreeStyle Libre Flash Glucose Monitoring System on Glycemic Control, Health-Related Quality of Life, and Fear of Hypoglycemia in Patients with Type 1 Diabetes. *Clinical medicine insights. Endocrinology and diabetes*, 10, 1179551417746957. doi:10.1177/1179551417746957



women) using LIBRE and 145 (90 women) adult users, thus the responses were predominantly female.

## Usage

Usage varied across all age groups with little usage in the under 5 years (6 children) which is not surprising given that LIBRE is not licenced for under 4 years. The high usage in the 6-13 year old (109) reflects the HSE funded scheme and that younger children do not “mind” the inconvenience and visibility of the sensor on their skin. The older age group (14-21 years) generally have an issue with their diabetes being made visible i.e. pumps/sensors and one would expect as seen a lower uptake (63). The remaining 46% (135) are adults who most likely are all self-funders. It is worth noting that the usage in the over 22 years is almost as high as the under 22 and reflects the desire of people of all ages to use this device.

## Duration of Usage

Over the half the people (56%) are using the device for longer than 12 months which reflects its success in Ireland even prior to the HSE reimbursement. There was equal distribution across all age groups for duration of usage and source of payment for device. In reality, 162 were HSE funded and 142 were self-funded. 21 of the parents declared they were self-funding and 20 of the users declared themselves to be HSE funded. The parents may in fact be carers as it would be unlikely that they are parents self-funding.

## Daily Usage

The majority of people (57%) scanned 9-16 times each day but almost one-third (29%) did more than 17 scans a day. It is proposed that scanning more than 8 times per day would be cost effective when compared to strip costs. In this survey, 86% of users were scanning more than 8 times per day and utilising that information to make informed diabetes self-management decisions. The number of scans for self-funders or HSE funded did not differ significantly but there appears to be an association between funding source and scanning 0-8 times (13% of people) i.e. those that were HSE funded had a higher percentage of people (9%) doing only 0-8 scans daily as opposed to the groups that self-funded (4.5%).

Table 1 – Number of Scans Daily

Respondee	Number of Scans daily			Total
	0-8 scans	9-16 scans	>17 scans	
HSE funded	27 (9%)	90	45	162
Self payer	14 (4.5%)	87	46	147
Total	41 (13%)	177 (57%)	91 (29%)	309

### Strip Usage

People were asked to state how many strips they had collected routinely from their pharmacy per month prior to using LIBRE and in the month previous to the survey. There was a general reduction in the number of strips used. The average reduction was 66 % ( $\pm 17$ ). Almost a half of people (48%) had reduced their usage by greater than or equal to 75% with another third reducing by more than 50%. A fifth of participants (20%) said they reduced by 50%. The self-

funders did not reduce their strip usage as much as the HSE funded i.e. self-funders average reduction was 62 % ( $\pm 19$ ) compared to 69% ( $\pm 16$ ) for those HSE funded ( $p=0.012$ ). This may reflect the need for adults to do a blood glucose meter check prior to driving and every 2 hours while driving.

## **Benefits of Libre Usage**

People were asked if using the FGM had benefited their daily life as an open question. There were 300 replies which were reviewed and a number of recurring themes identified. These were initially 16 themes which were further collated into 4 main topics. Anonymity on the comments has been retained by altering the first name.

### **Makes life easier**

Making life easier was the most commonly recurring theme and reflects the hassle of doing a blood glucose check which requires, washing hands, preparing the equipment, doing the test and clearing up plus dealing with any excess blood from the puncture. When this is compared to opening an app on the phone or using the reader to wave over the Libre sensor regardless of clothes for immediate visualisation of the result plus an arrow to indicate trend, one can understand the massive advantage. Libre also facilitates easier reading of blood glucose levels in public and at busy times or during activities.

*“Wonderful invention. Very convenient especially in public places like restaurant, very subtle.”* Mary from Mayo.

*“It’s made day to day management so much easier. Couldn’t be without it now”* Iris from Donegal.

*“So much easier to monitor it especially when out and about, no stopping to do finger prick just a simple scan and off you go.”*

Female aged 40+

*“Freedom to go out walking and keep walking whilst checking levels without breaking a stride. Confidence to walk further and faster for longer - improving fitness levels. Fingers returning to normal. Don't have to seek out a clean, private, level spot to test. Totally discrete”*

Female aged 40+

The ease of testing without finger pricking also means less sore fingers – something that is not regularly addressed in diabetes management.

*“Life changing as no longer getting sore fingers”*. Rose from Offaly.

*“It has cleared up the soreness of my fingertips plus the sensor tells you if your blood level is steady/rising up/lowering down you have none of this information from a blood finger test”* Sheila from Tipperary.

In addition, finger pricking is an issue for some professions e.g. catering, professions requiring fine motor skills or working with delicate materials.

*“I work in the bridal industry and can't finger prick in work due to the expensive fabrics. It has helped reduce my a1c and has improved my standard deviation considerably”* Michelle from Derry.

Making life easier encourages more frequent testing and also improves glycaemic control which may be partly due to reducing the daily stressors of living with diabetes such as finger pricking.

## **Control**

A lot of participants referred to the extra information provided by the LIBRE as very beneficial.

*“Gave us freedom and more understanding of what is going on.”*

Parent of 6-13 year old.

*“ It gives great information overnight which I would otherwise have missed. It has prevented hypos and hypes on a daily basis.”*

Parent of 6-13 year old.

*“Life changing positive benefits, much better timely control of blood sugars and lower hba1c at reviews, fewer hypos and hypers.”*

Female aged 40<sup>+</sup>

For many it aided improvement in their diabetes management by alerting them to previous unknown highs and lows.

*“My control has greatly improved. I have been able to prevent hypos and my hba1c has reduced. It had also giving me insight into overnight hypos which I did not know I was having.”* Anna from Galway.

*“It highlighted repeated hypos at night that I was unaware of”*

Female aged 40<sup>+</sup>

Part of the reason for improved glycaemic control is the additional information but may also be the increased frequency of available up to date information which facilitates better diabetes management.

*“Better control due to ease of testing resulting in more frequent checks.”*

Patrick from Cork.

*“It definitely improves the control of my type1 because I check my levels more.”* Female aged 40<sup>+</sup>

*“I was waking with very high blood sugar and had a headache both myself and the hosp thought that I needed to increase my long acting insulin when in actual fact because I started using the LIBRE I discovered that I was actually going extremely low during the night and rebounding to a high level. Without the LIBRE I never would of known this and it actually could of lead to a serious situation.”* Female aged 22-39 years.

Overall, glycaemic control has improved through usage of LIBRE but also in many other ways as depicted by

*“It helps countless ways and the information it provides is priceless for my optimum care 1 - it detected lows in my sleep that the body was correcting called dawn phenomenon, 2 - help me catch hypos before needing assistance 3- The arrow system was the best aid, 4- the graphs gave my consultant so much information 5- my hba1c is almost perfect 6- My eyesight has improved as jumps in blood sugar is smaller and less side effects”* Noleen from Kerry.

Other people also mentioned that their eyesight was improved.

*“Eye sight has improved as jumps in blood sugar are smaller”*

Nicola from Kerry.

Transient eye sight difficulties are not an issue that is raised generally in diabetes management but should be an important consideration when control fluctuates.

### **Empowerment**

The additional information gave people confidence in their ability to manage their diabetes and the extra security of knowing if the glucose levels were dropping or rising allowing greater confidence in making adjustments and preventing highs and lows. This results in a more proactive management of diabetes.

*“Reduced hypos and hypens, able to look at trends and use arrows to make decisions regarding insulin and food. Peace of mind. Check basal is correct”* Louise from Galway.

*“the arrows are a big help very helpful to know that a reading of 6 is steady as against dropping fast.”* Parent of 14-21 years old.

*“it's helped me keep a better eye on my levels and shows me what direction they are going”* Female aged 22-39 years.

*“I can keep a better eye on everything as it tells if you are on your way up or down or levelling out”* Parent of 14-21 year old.

This increase in empowerment was very helpful in daily life and permitted people to reduce the intrusion of diabetes in their daily life.

*“The arrow gives me some confidence as well when I'm out and about. Its just everything for me. Total freedom and confidence. LIBRE it's like my angel.”* Female aged 22-39 years.

*“Greatly improved confidence in daily exercise and management of levels.”* Pat from Dublin.

*“I feel safer and healthier and more in control. It is like going from watching the trailer for a film to actually reading the whole book. All the gaps in my knowledge have been addressed. It has completely changed my life!”* Judy from Clare

*“It is much easier to test my blood sugars especially in public & on the go”.* Kieran from Westmeath.

That confidence translates to improved security at night.

*“The arrow is helpful especially when they are going to bed because it gives you an indication on how the night will go and I can treat accordingly and then I can get some sleep. Gives peace of mind.”* Parent of 6-13 year old.

*“Less worry, more sleep, better hBA1c.”* Female aged 22-39 years.

*“Gives much more freedom and had become invaluable for night-time readings”* Margaret from Tipperary.

## **Privacy**

Many people with diabetes do not like testing blood glucose levels in public and also have the issue or visible use of blood stained items. LIBRE aids in maintaining privacy and encourages testing at times it might be omitted due to privacy issues.

*“I used to never do the finger blood test and would go by how I was feeling. Having the LIBRE takes away the annoyance of picking my finger*

*in public or in meetings in work which can be quite lengthy. I can scan myself discretely and because of the LIBRE I scan myself a lot more often than I did.”* Fiona from Dublin.

*“I happy again as its so easy to use and has given me my life back as don't have to finger prick so I don't feel different”* Female aged 40<sup>+</sup>

This is especially relevant to teenagers and young adults with diabetes.

*“Privacy my daughter has more privacy”* Roisin from Tipperary.

*“It is discreet to use for my 13 year old who hates having T1diabetes.”*

Elizabeth from Limerick.

The hatred of having diabetes is not unusual and leads to a very negative attitude to diabetes which can spill over to all parts of life. .

*“Removed my fear of having embarrassing hypos in public Allowed me some quality of life after nearly 30 years with type1 diabetes”*

Female age 22-39 years

## **Conclusion**

People with diabetes were very generous and quick in responding to the invite to give their views on using Libre. Regardless of the funding, Libre is being used across all age groups of the Type 1 diabetes community. The results of this survey reflects an equal number of self-funders and HSE funded users and reflects the views of over 10% of the Libre users in Ireland. There were a few comments on the inaccuracy of the device which most likely reflects that the Libre measures interstitial glucose whereas the finger prick blood glucose measures blood glucose and results should not be compared. There was mention of skin issues with the adhesive used to attach the sensor but there was insufficient information to make any assumptions as to why this was happening.



Without doubt, this survey proved that using the Libre results in increased frequency of checking glucose levels which people report decrease acute highs and lows, improve proactive diabetes management and results in improved glucose control and other side effects of fluctuating glucose levels such as eyesight disturbances. Using Libre also results in less sore fingers, greater security at night resulting in peace of mind and less anxiety.

Participants report Libre as being a major advancement in diabetes self-care and in their own words *“It is invaluable”, “I have dreamed of such a device for years.” “ I would sacrifice the pump before the Libre”, “It is like going from watching the trailer for a film to actually reading the whole book. All the gaps in my knowledge have been addressed. It has completely changed my life!” “Helped more than I could have ever thought. All the information is like turning on the light, you can actually see what's going on.”*

The survey has also shown, although self-reported, that strip usage declined in that cohort of responders by 66%. This highlights potential savings in strip usage for the HSE which in turn should help offset some of the perceived financial costs identified in the HTAG Advice Note 2017/001 report.

Diabetes Ireland would recommend extension of the Freestyle Libre to all people with diabetes based on quality of life improvement for the individual and cost savings resulting from the reduction in strip usage which together will further aid prevention of costly diabetes complications.

In relation to the improved clinical data outcomes, a recent publication by Fraser (2019) on a prospective observational study assessing the impact of introducing flash glucose monitoring in a Type 1 diabetes clinic in Edinburgh confirms significant overall treatment satisfaction with fewer diabetic ketoacidosis admissions but more importantly provides clear evidence of a

significant and clinically important reduction in HbA1c levels <sup>9</sup>. That paper will hopefully enhance these findings and inform the HSE decision to make this treatment available to all people with diabetes based on clinical need and quality of life.

Libre may be the French for free but for people with Type 1 diabetes, Freestyle Libre means freedom from finger pricking, improved glycaemic control and control over their life with diabetes.

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<sup>9</sup> Marked improvement in HbA<sub>1c</sub> following commencement of flash glucose monitoring in people with type 1 diabetes. Tyndall V, Stimson R, Zammitt N, Ritchie S, McKnight J, Dover AR<sup>2</sup>, Gibb FW<sup>4,5</sup>. *Diabetologia*. 2019 Jun 9. doi: 10.1007/s00125-019-4894-1. [Epub ahead of print]