

JDRF UK POSITION STATEMENT ON ACCESS TO TYPE 1 DIABETES TECHNOLOGY

2020

Executive summary

- Wearable medical technologies for self-managing type 1 diabetes can improve lives and clinical outcomes
- But for a range of reasons, levels of access to such technologies on the NHS are low
- JDRF believes everybody who wants and needs access to type 1 diabetes technology should receive it
- JDRF is calling for local NHS bodies to follow official guidelines on the provision of such technology; for healthcare professionals to receive mandatory training on it; and for people living with type 1 diabetes to have more time with healthcare professionals to discuss these technologies when appropriate

Introduction

People with type 1 diabetes rely on injected or infused insulin to enable them to use energy from food and keep them alive. Different food, stress levels, activity and other factors have an effect on blood glucose levels. Checking blood glucose levels and responding appropriately to the results – whilst maintaining usual activities including work, school, childcare, exercise, socialising – is a fundamental part of type 1 diabetes management. This management is most commonly done through multiple daily injections¹, using an insulin pen, and a blood glucose meter. But tools that can further support these fundamental needs include:

- Continuous glucose monitors (CGM)
- Flash glucose monitoring
- Insulin pump therapy
- Hybrid closed loop/artificial pancreas systems

These more advanced technologies help with the multiple daily decisions that people with type 1 diabetes need to make to stay within a safe and healthy blood glucose range. They also reduce the frequency of skin punctures. They can help to reduce the impact of the condition.

¹ The Association of British Clinical Diabetologists says multiple daily injections (MDI) is the management regime for the newly diagnosed in 'most circumstances'. Post diagnosis, low access to tech would indicate MDI remains the most common regime among people with type 1 diabetes
http://www.diabetologists-abcd.org.uk/Position_Papers/Type_1_standards_of_care.pdf

Processes around tech access

Access to newer type 1 diabetes technology is most commonly dependent on guidance issued by the National Institute for Health and Care Excellence (NICE), which serves NHS England and Wales. SIGN (Scottish Intercollegiate Guidelines Network) issues guidance for Scotland and Northern Ireland also has its own approval process. In one notable exception, access to a specific technology (flash glucose monitors, see below) has been provided on the NHS in England without NICE guidance.

Current access levels

Levels of access to these type 1 diabetes technologies are currently low. JDRF's 2020 report, Pathway to Choice² found that only a small percentage of those living with the condition in the UK use these more technology-based treatments.

Within the general picture of low levels of access to type 1 diabetes technology, there are particular inequalities faced by certain groups. It has been apparent from the National Diabetes Audit for some years that people from black, Asian and minority ethnic (BAME) groups in England and Wales and lower socio-economic communities are much less likely to use diabetes technologies. The Pathway to Choice research also found that tech access was lowest amongst those from the most deprived UK socioeconomic demographic.

People wishing to access type 1 diabetes technology can often also face 'postcode lottery' variations in access to it depending on where they live in the UK.

Why are access levels so low?

Behind the postcode lottery of access sits variances in clinical knowledge, confidence and funding within the NHS around type 1 diabetes technologies.

JDRF's Pathway to Choice report provides insights into the barriers people with type 1 face in accessing the most appropriate treatment.

Current access levels on specific devices

Continuous glucose monitors

Description: A continuous glucose monitor (CGM) gives information about glucose levels every few minutes, allowing the user to see a current reading and trend of glucose levels rather than just a single measurement at a given point in time. This enables the user to make better-informed treatment decisions. A sensor measures the glucose level in the tissue just below the skin; the sensor connects to a transmitter that transmits the glucose data to a receiver, which can be either a

² Pathway to Choice, JDRF, February 2020 <https://jdrf.org.uk/pathway-to-choice/>

handheld device, a compatible mobile phone or an insulin pump. The sensor is worn for six or more days and then replaced with a new one.

Current situation: Current levels of access to this type of device are very low, and are only due to rise significantly among one group – pregnant women with type 1 diabetes.

NICE has clinical guidance on the provision of CGM to children and young people and to adults. Those who meet the criteria may be able to access funding for CGM but as clinical guidance is not mandatory, there is no obligation on NHS Clinical Commissioning Groups to provide funding. Some Clinical Commissioning Groups will only consider funding CGM through Individual Funding Requests, which will restrict access. NHS England announced in its Long Term Plan (2019) that by 2020/21 all pregnant women living in England with type 1 diabetes will be offered CGM. But we estimate less than 5% of the type 1 population in the UK currently has NHS funding for CGM (there are no UK-wide statistics available).

Flash glucose monitoring

Description: Flash glucose monitoring is similar to CGM in that they both use a glucose sensor and both display glucose trends. Unlike CGM, Flash does not give alerts, so it will not alert the user to low or high glucose levels until they ‘flash’ the sensor with a handset reader.

The only current flash glucose monitoring system on the market is the Freestyle Libre. The Libre system includes a sensor) which is worn on the back of the upper arm for up to 14 days, and a handset which the user flashes or scans over the sensor to obtain a reading. An app can be used in place of the reader in suitable mobile phones. The reading shows: current glucose level, a graph of glucose levels over the last 8 hours, and a trend arrow showing whether the glucose reading is stable, rising or falling.

Current situation: Current levels of access to this device are rising but fall short of reaching all who could benefit.. The use of flash glucose monitoring has increased significantly following the launch of National Criteria and new NHS funding arrangements in April 2019. As of February 2020, uptake in England has reached 27.9%, against a minimum target of 20%.³ All Clinical Commissioning Groups in England provide the device but there is high variation on rates of provision. Some users are still self-funding.

³ Partha Kar, National Specialty Advisor, Diabetes. Twitter
<https://twitter.com/parthaskar/status/1247946677551579140?s=21>

Insulin pump therapy

Description: An insulin pump is a programmable device with a reservoir of insulin which gives tiny doses of insulin every 3 minutes or so, of rapid-acting insulin by a subcutaneous needle or cannula. Insulin pumps do not measure blood glucose levels, but some pumps can receive the signal from a separate glucose sensor.

There are two types of insulin pump:

- A 'tethered' pump uses a fine tube to connect the pump to the cannula; the pump is worn in a pocket or clipped to a belt
- A patch pump or micro pump has no tubing or a very short tube, and the pump is usually stuck on to the skin

Current situation: Levels of access to pumps are low and are not showing indications of climbing. NICE recommends insulin pump therapy for anyone over the age of 12 if multiple daily injections are causing the person disabling hypoglycaemia, or HbA1c levels remain high despite optimised management. For children under the age of 12, NICE recommends insulin pump therapy if multiple daily injections are considered to be impractical or inappropriate.

Uptake of insulin pump therapy has reached a plateau in the last few years as captured by the National Diabetes Audit and remains at around 15% in adults and 32% in children and young people in England and Wales.⁴ In Scotland the most recent Diabetes Survey shows pump usage at 12.8% across the country, with regional variation across different health boards.⁵ There are some problems with access which tend to be related to choice of brand and location of clinic.

Hybrid closed-loop systems

Description: Hybrid closed-loop systems, also known as 'artificial pancreas' systems, connect an insulin pump and a continuous glucose monitor to an algorithm in order to adjust insulin delivery automatically according to the glucose readings and trend. This is intended to improve the amount of time spent in the ideal glucose range by cutting off insulin supply to prevent lows and increasing insulin delivery to minimise highs.

Currently, there are three commercial systems on the market: Medtronic MiniMed 670G and 780G; Tandem Control IQ, which uses a Tandem t:slim pump with

⁴ NHS Digital, National Diabetes Audit - Insulin Pump report 2017-2018, <https://digital.nhs.uk/data-and-information/publications/statistical/national-diabetes-audit/national-diabetes-audit---insulin-pump-report-2017-18>

⁵ Scottish Diabetes Survey, 2018, <https://www.diabetesinscotland.org.uk/wp-content/uploads/2019/12/Scottish-Diabetes-Survey-2018.pdf>

Dexcom G6 CGM sensors; and an algorithm called Cambridge APS FX which uses a Dana insulin pump and a Dexcom G6 CGM sensors. Several other closed-loop systems are currently in development.

Current situation: Levels of access to this type of technology are very low, with only a tiny fraction of people living with type 1 diabetes believed to have been provided with it on the NHS. There is no clear path for these levels to rise.

It is necessary for people to meet both insulin pump and CGM criteria in order to be considered for funding for hybrid closed-loop systems. Some users are required to self-fund the CGM component of the system.

Open source and open protocol approaches in type 1 diabetes

Beyond the above technologies which are regulated for provision via the NHS, there are a number of approaches that have been instigated by parents of children with type 1 and adults with type 1 to be able to better access and share data, particularly the glucose level data that can be obtained from continuous and flash glucose monitors. Some 2,000 people across the world now use 'do it yourself' (DIY) hybrid closed-loop or artificial pancreas systems, combining commercial pumps and CGM systems with an open source algorithm.

Please see JDRF's policy position on DIY tech for more details.⁶

Policy asks

The low levels of access to life-changing type 1 diabetes medical technologies must be addressed.

JDRF believes that everyone with type 1 diabetes who wants and needs it should be able to access type 1 diabetes technology. Therefore, JDRF is calling for the following improvements:

- All NHS Clinical Commissioning Groups to follow national guidelines with regards to type 1 technology provision
- All type 1 diabetes healthcare professionals to receive mandatory training on type 1 diabetes technology to be able to recommend the most suitable device or combination of devices for a person's needs

⁶ Position statement on type 1 diabetes DIY technologies, JDRF, February 2019
<https://jdrf.org.uk/about-us/position-statements-reports/position-statements/jdrfs-uk-position-statement-on-type-1-diabetes-diy-technologies/>

The most recent National Diabetes Insulin Pump Audit 2017/2018 recommends “considering whether there is adequate understanding, capacity and capability to explain and provide pump treatment” to people with type 1 diabetes.

We want the NHS to ensure all type 1 diabetes clinicians are trained and kept up to date on type 1 diabetes technology on a regular basis, to be able to recommend the most suitable device for a person’s needs

The NHS should provide protected time for training of healthcare professionals on type 1 technology and its funding pathways, taking into account shift patterns and agile ways of training.

Details of clinics with trained specialists should be made publicly available, so that people with type 1 diabetes can be confident in approaching their clinician about technology

- More time with specialist healthcare professionals in appointments for people with type 1 diabetes as necessary

People with type 1 diabetes tell us that they don’t get enough time to discuss technology options with their health care professionals.

- Clinical Commissioning Groups to do more to reach people with type 1 diabetes from lower socio-economic groups - and give them the same consideration for technology

Conclusion

Having access to the right technology can be life-changing. It can help people with type 1 diabetes better manage their condition and can save the NHS resources through reduced long term complications and acute events. Current access levels are low. People with type 1 diabetes deserve the best technology currently available to help them self-manage their lifelong condition and keep them out of hospital in the long and short term.