Diabetes Scotland submission of 14 March 2024

PE2031/K: Provide insulin pumps to all children with type 1 diabetes in Scotland

Thank you for the Committee's letter of 21st September 2023 seeking our views and evidence on PE2031: Provide insulin pumps to all children with type 1 diabetes in Scotland.

Why does diabetes tech matter?

Diabetes is a serious and complex condition where the pancreas is unable to produce insulin or use it properly. Everyone with type 1 diabetes, and some people with type 2 and other types of diabetes, have to take insulin to live – traditionally requiring a regimen of multiple daily injections, finger prick testing, and carb counting. It's relentless. But diabetes tech is changing this.

From insulin pumps and continuous glucose monitors (CGM) to hybrid closed loop systems, tech is catalysing a revolution in diabetes care. It's been shown to improve blood sugar management and reduce the risk of complications like stroke, eye damage and kidney disease. It can improve mental wellbeing and quality of life, both for people living with diabetes and their families. And it's cost-effective, meaning the cost is justified by the clinical benefits it provides.

Evidence shows that diabetes tech can improve people's management of their diabetes. It leads to improvements in HbA1c, a measure of blood glucose levels over two to three months. It reduces the frequency and severity of hypo- and hyperglycaemia, low and high blood sugar. And it increases time in range[1]. This is exactly what people living with diabetes tell us, too.

In our 2023 survey of over 1,500 people living with and affected by diabetes in Scotland, we found that over four in five respondents who

[1] Dovc, K., & Battelino, T. (2020) Evolution of Diabetes Tech. Endocrinology and Metabolism Clinics of North America. 49(1), 1-18. https://doi.org/10.1016/j.ecl.2019.10.009

use wearable diabetes tech agreed or strongly agreed that their tech helped them to manage their diabetes in the past year[2].

> "*I cannot put into words the difference it has made. The closed loop system has dramatically improved the quality of life for my son and reduced the burden on us all*." – Suzanne

> "*It's been totally life-changing for him, at 10 years old he can have some independence now and play with his friends*." - Linda

Researchers have also found an association between the use of diabetes tech and reductions in the frequency of diabetic ketoacidosis or DKA[3]. DKA is an acute and life-threatening complication of diabetes. Concerningly, rates of DKA have been increasing among all age groups except ages 10 to 19 – one of the groups with the highest levels of tech use – in Scotland since 2004[4]. This is yet another reason we need to accelerate work to roll out diabetes tech.

Parents and Carers

For parents and carers of people with diabetes, tech can enable them to provide better support, reducing the strain on their own wellbeing and their relationship with the person they care for[5] [6].

Caring for a child with diabetes can affect all areas of a parent or carer's life, from their work and social life to their own health. Diabetes tech offers parents and carers some relief from this constant responsibility[7] [8].

> "*I have not had a full night's sleep since my daughter was diagnosed two and a half years ago. I am up numerous times a*

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[2] Diabetes Scotland (2023) Diabetes is Serious briefing. https://www.diabetes.org.uk/get_involved/campaigning/diabetes-is-serious/ accross-the-UK/scotland

[3] Dovc, K., & Battelino, T. (2020) Evolution of Diabetes Tech. Endocrinology and Metabolism Clinics of North America. 49(1), 1-18. https://doi.org/10.1016/j.ecl.2019.10.009

[4] O'Reilly, J. E., et al. (2021) Rising Rates and Widening Socioeconomic Disparities in Diabetic Ketoacidosis in Type 1 Diabetes in Scotland: A Nationwide Retrospective Cohort Observational Study. Diabetes care, 44(9), 2010–2017. https://doi.org/10.2337/dc21-0689

[5] Kimbell, B., et al. (2022) Parents' experiences of using a hybrid closed-loop system (CamAPS FX) to care for a very young child with type 1 diabetes: Qualitative study. Diabetes Research and Clinical Practice, 187, 109877. https://doi.org/10.1016/j.diabres.2022.109877

[6] Cobry, E. C., et al. (2022) Improvements in Parental Sleep, Fear of Hypoglycemia, and Diabetes Distress With Use of an Advanced Hybrid Closed-Loop System. Diabetes Care, 45 (5), 1292–1295.

[7] Mueller-Godeffroy, E., et al. (2018) Psychosocial benefits of insulin pump therapy in children with diabetes type 1 and their families: The pumpkin multicenter randomized controlled trial. Pediatric Diabetes, 19(8), 1471-1480. https://doi.org/10.1111/pedi.12777

[8] Ng, S.M., et al. (2023) Real world use of hybrid-closed loop in children and young people with type 1 diabetes mellitus—a National Health Service pilot initiative in England. Diabetes Medicine, 40, e15015. https://doi.org/10.1111/dme.15015

night trying to control her blood glucose levels to keep her safe and healthy but this is impacting on my own health now. A closed loop pump would make my daughter's life so much easier and safer. It would also make such a difference to me as her carer." - Pasha

"*I cannot put into words the difference it has made. The closed loop system has dramatically improved the quality of life for my son and reduced the burden on us all. The mental health impact of not having to remember so much and have real time readings and alarms is priceless. Everyone should have access to this – it can only benefit patients and caregivers. My son now sleeps better, relaxes better and his general moods have improved dramatically since having the closed loop system*." - Suzanne, parent of a child with type 1 diabetes

Barriers to access diabetes technology across Scotland

Access to diabetes tech should be based on your needs, not where you live or how much you earn. But right now, there are significant regional and socioeconomic disparities in access to diabetes tech in Scotland. We don't believe this is fair.

The Scottish Government has taken some important steps to support the rollout of diabetes tech. But access to this vital medical equipment is still too low. In March 2023, only 14.5% of people living with type 1 diabetes in Scotland were using an insulin pump and 5.9% were using CGM. There were large disparities between levels of access in different Health Boards and people from worse-off areas were less likely to be using tech.

Through our Diabetes Tech Can't Wait campaign, we've heard from people across Scotland about their experiences of accessing or trying to access diabetes tech on the NHS. We've found that funding and staff shortages are key obstacles, and some people are being unfairly excluded from accessing tech. And we've learned that many people feel they have to fight for the tech they need to live well with diabetes, meaning those without the time or energy to do so are missing out.

Providing insulin pumps and diabetes tech for all children

On the 14th of November 2023, we launched our Diabetes Tech Can't Wait report which included recommendations for the Scottish Government and Health System to help go further and faster in the

rollout of diabetes tech. The report and the recommendations were endorsed by the three opposition parties in the linked letter. The key recommendation is for Scottish Government to set targets to drive forward progress, aiming for 100% of children and 70% of adults living with type 1 diabetes to be using hybrid closed loop tech by 2030.

Go further and faster in the rollout of diabetes tech:

- Scottish Government: set targets to drive forward progress, aiming for 100% of children and 70% of adults living with type 1 diabetes to be using hybrid closed loop tech by 2030.
- Scottish Government and Health Boards: guarantee sustained, ringfenced funding to meet the demand for diabetes tech and cover ongoing costs.
- NHS Scotland: collaborate with diabetes tech companies to upskill diabetes clinicians through national training.
- Scottish Government and Health Boards: ensure adequate staff in diabetes teams to support people to use tech.
- Health Boards and healthcare professionals: remove unnecessary barriers to accessing tech, like structured education for people who are experienced in managing their diabetes.

Tackle inequalities in access to diabetes tech:

- Healthcare professionals: ensure that prescribing guidelines are applied consistently, and that people aren't denied tech because they are managing their diabetes "too well" or "not well enough".
- Health Boards and healthcare professionals: ensure that everyone who uses insulin who could benefit from tech has access to it, including people living with type 2 diabetes.
- Healthcare professionals: proactively offer diabetes tech so no one has to fight for it.
- Healthcare professionals: improve recording of ethnicity data, report on access to tech by socioeconomic background, and act on these findings to tackle inequality.

Increase the choice of diabetes tech available:

- Scottish Government: develop the National Diabetes Tech Onboarding Pathway into a long-term programme if successful.

- Scottish Government and Health Boards: procure diabetes tech based on consultation with people living with diabetes about what tech they want.

We appreciate the Citizen Participation and Public Petitions Committee seeking our advice and evidence on this important issue. We support the petition to provide insulin pumps to all children with type 1 diabetes in Scotland.