

DIABETES TECH CAN'T WAIT!



**DIABETES
SCOTLAND**

KNOW DIABETES. FIGHT DIABETES.

Acknowledgements

Thank you to everyone who has helped bring this campaign to life, particularly:

- people who joined the campaign, took action, and shared their stories with us
- members of the Tech Collective, who have campaigned tirelessly for the cause
- healthcare professionals who spoke to us about their experiences
- MSPs who supported the Parliamentary Motion on diabetes tech.

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FOREWORD

Innovation in diabetes tech is undoubtedly one of the biggest health success stories in recent years. Glucose monitoring and insulin pumps have paved the way for hybrid closed loop systems, transforming what it means to live with diabetes.

We launched the Diabetes Tech Can't Wait campaign because people living with diabetes and their families told us they were having to fight to get access to this life-changing tech – if they were able to get it at all.

The campaign has brought together people from across Scotland and in this report, you'll hear the joy and relief of those using diabetes tech and the frustration, worry and anger of the thousands desperate to have access to it.

I joined Diabetes Scotland during the campaign and was blown away by the passion and commitment of our campaigners, and the Tech Collective in particular, who have led the way in calling for proper funding for diabetes tech and an end to the fight for access. They are passionate because they live with diabetes day in, day out, and know the difference that tech can make to the relentless physical and mental toll of this condition.

We've listened to these voices and worked with colleagues across the health system to develop a set of recommendations that we think will transform what it means to live with diabetes.

People in Scotland are waiting too long for diabetes tech, they must not wait any longer.



John Kinnear,
National Director





THE TECH COLLECTIVE



are a group of activists determined to see fair and equal access to diabetes tech across Scotland. They've driven the Diabetes Tech Can't Wait campaign, providing Diabetes Scotland with valuable insight and ensuring lived experience is at the heart of the campaign.

Being part of the Tech Collective ensures that our voices are amplified – our voice is stronger as a collective, than as an individual. Hopefully, we will bring about change for the benefit of us all.

We deal with diabetes 24 hours a day, 365 days a year – there is no respite. Diabetes is complicated enough without having to fight for tech. Tech will ultimately benefit everyone – not just those living with diabetes, but the health system too. It shouldn't be this much of a battle. Access should be equal for all of us throughout Scotland – it shouldn't depend upon a postcode lottery, your socio-economic background, your ethnicity, or how hard you battle to get it. It should be a human right.

We're already battling around 180 extra decisions a day. We're already having to fight to maintain our health, do a full-time job, be full-time parents, be full-time human beings, and yet we have to fight for something that improves our quality of life and makes sure that our pancreas does what most people's will do automatically. It is utterly crazy to be expected to mimic a highly complex major organ 24/7 without access to the best tools available, as well as no general access to any mental health counselling at regular diabetes clinics either.

At long last there is revolutionary, life-changing tech, proven to help relieve our lifelong burden. You're introducing, for the first time ever, a system where you're automating insulin delivery. The problem is that despite the fact that some money is put in, the message is coming back that there isn't enough funding to do it.

Quite often we're made to feel guilty for asking for this. Health Boards can make us feel very guilty, make us feel insignificant. Diabetes tech is not a luxury. We're not queuing for the latest smartphone. It's our life-saving equipment, it improves our quality of life, it prevents complications because you spend more time in range. No other health condition requires someone to take a diagnostic reading and calculate a dose of life-saving medication based on so many variables, including nutrition, health, exercise, impact of other hormones, and so much more. The mental burden we carry is immense. Diabetes is hard! So please give us a break.

We're hoping to make this the gold standard of diabetes care. It's evolved over the years from when we had to test our urine and do two injections a day, then we went onto blood meters and the basal-bolus routines, this is the next evolutionary step.

If we don't invest in diabetes tech now, when will we? We have to provide this tech, we have to expedite it, and in the end, it's going to be both money saving and revolutionary to people who use it. We need to future-proof our healthcare system.

We, the Tech Collective, are a reminder to decision makers that diabetes won't go away. No one knows what it's like to live with this relentless, chronic condition better than we do. Nothing about us, without us.

The Tech Collective



EXECUTIVE SUMMARY

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.

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.



We're calling for diabetes tech for everyone who could benefit, without having to fight for it. To achieve this, we need:



new national targets, aiming for 100% of children and 70% of adults living with type 1 diabetes to be using hybrid closed loop tech by 2030



access to tech for everyone who uses insulin and could benefit from tech, including those with type 2 diabetes



sustained, ringfenced funding to meet the demand for diabetes tech



proactive approach to offering tech so no one has to fight for it



collaboration on national tech training for diabetes clinicians



better use of data to tackle ethnic and socioeconomic inequalities



adequate staff in diabetes teams to support people to use tech



a permanent national tech onboarding pathway, if the temporary pathway is successful



fewer barriers to accessing tech, like mandatory structured education



procurement of tech determined by what people with diabetes want.



fair and inclusive prescribing of diabetes tech based on need



INTRODUCTION

Diabetes tech can be life-changing. But far too many people are missing out – unable to access the tech they need to help them live well with diabetes.

At the beginning of 2022, following new guidance from the Scottish Health Technologies Group,¹ the Scottish Government allocated £14.6 million for Health Boards to increase access to hybrid closed loop (HCL) tech across Scotland.² HCL tech is one of the most exciting developments in type 1 diabetes care in recent years, offering huge benefits to both health and quality of life. But too many people are still struggling to access this vital medical equipment.

We launched our **Diabetes Tech Can't Wait** campaign to call on the Scottish Government and Health Boards to go further and faster in the rollout of diabetes tech to make

sure everyone who wants and is eligible for tech has access to it. Driven by the **Tech Collective** – a movement of people passionate about improving access to diabetes tech in Scotland – we've raised vital awareness and challenged decision-makers to support our cause, but we're not stopping there.

This report shares our learning from the campaign, bringing together insights from people who have accessed or tried to access diabetes tech. It reflects on areas of good practice in the NHS and considers innovative approaches to prescribing tech. And it sets out clear recommendations for the Scottish Government and NHS Scotland to continue their crucial work towards delivering fair and equal access to diabetes tech.

What do we mean by diabetes tech?

Diabetes tech includes any tech that helps people with diabetes to take insulin or monitor their blood sugar levels. The main types of wearable tech are:

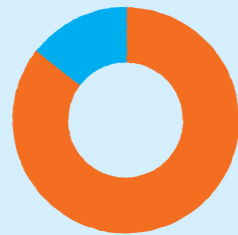
- **insulin pumps**, which release insulin into the body through a tube, avoiding the need for multiple daily injections
- **continuous glucose monitors (CGMs) and flash glucose monitors**, which measure your blood sugar levels through a sensor so you don't have to do painful finger prick tests
- **hybrid closed loop (HCL) systems**, which connect an insulin pump with a CGM, enabling the pump to adjust your insulin dose automatically in many cases.



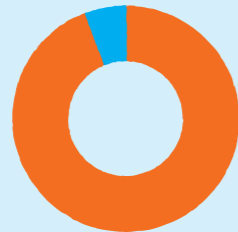
DIABETES TECH USE IN SCOTLAND: AT A GLANCE

Among adults aged 18+ with type 1 diabetes in Scotland:

14.5% are using an insulin pump



5.9% are using CGM



Among children and young people aged 0 to 17 with type 1 diabetes in Scotland:

48.2% are using an insulin pump

31.1% are using CGM

These numbers are too low. Health Boards are seeing huge increases in demand for tech. NHS Lothian, for example, are reporting that two thirds of their patients with type 1 diabetes are interested in using HCL tech. But for too many across Scotland, it simply isn't available.

We don't have data on how many people with type 2, gestational, or other types of diabetes are using diabetes tech in Scotland. Not everyone with these types of diabetes takes insulin or monitors their blood sugar levels intensively, but for those who do, tech can be hugely beneficial.

If this is you, we'd love to hear from you to help us understand your experiences of accessing or trying to access tech.

Scan the QR code or visit www.diabetes.org.uk/forms/diabetes-tech to share your story.



Note: this data was correct as of 7 March 2023. Throughout July and August 2023, the Freestyle Libre 2 sensor was upgraded from a flash glucose monitor to a continuous glucose monitor for people using a compatible smartphone. This means CGM use is likely to be significantly higher now than it was in March. However, the Libre 2 is not yet 'loopable' with any insulin pumps, so the data shown here is more reflective of how many people are using CGMs that could be, or may already be, integrated into a hybrid closed loop system.

WHY DOES DIABETES TECH MATTER?

Improving diabetes management

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.⁴ 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 use wearable diabetes tech agreed or strongly agreed that their tech helped them to manage their diabetes in the past year.⁵

Researchers have also found an association between the use of diabetes tech and reductions in the frequency of **diabetic ketoacidosis** or DKA.⁴ 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 2004.⁶ This is yet another reason we need to accelerate work to roll out diabetes tech.


"Since being put on a pump, I have had a reduction in my HbA1c level from 7.5% down to 6%, which is an amazing result in such a short time."

Gary, living with type 1 diabetes

"My diabetes tech has greatly reduced the amount of hypos I have, as it can predict them and suspend insulin."

Rubyann, living with type 1 diabetes





“Both the CGM and the pump greatly improve my ability to control my blood sugars. I like to be in control and these amazing pieces of tech enable this to a high degree.”

Jo, living with type 1 diabetes

Improving mental wellbeing

The impact of diabetes tech on mental wellbeing can't be overstated. Diabetes is relentless and managing it can feel like a huge burden. People with type 1 diabetes are estimated to make an additional 180 decisions per day compared to people without diabetes.⁷ It's a full-time job, 24/7, 365 days a year – there are no days off.

“My son is 16 and seriously struggles with diabetes, his already fragile mental health has plummeted as well as having ADHD. He hates injecting, it's sore, he has lumpy injection sites all over and forgets to take his insulin a lot resulting in high blood sugar levels. He's rarely in range and I think having access to a pump and closed loop would benefit him massively.”

Zoe, parent of a child with type 1 diabetes

“My nephew has gone from being the happiest and funniest boy I knew, to a child who is scared and wondering why it is happening to him. Anything to make his life easier would be a godsend and less worrying for all involved.”

Vicky, family member of a child with type 1 diabetes

By reducing the difficulty, complexity and physical pain involved in managing diabetes, wearable tech can significantly lessen the burden of the condition.⁸ It won't take away your diabetes, but it has the potential to relieve some of the worry and distress associated with diabetes – from hypo anxiety and phobia of needles to exhaustion and even burnout from having to make so many extra decisions per day.

“The mental load that has been taken off me since closed looping is amazing.”

Tracy, living with type 1 diabetes



Supporting 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.^{9, 10}

“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

“CGM allows me to monitor her without having to constantly be reminding her to do checks.”

Karen, parent of a child with type 1 diabetes



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.^{11, 12}

“As my son is only three, he relies heavily on people around him directing his care. Due to his childminder being anxious about calculating the dose of insulin based on carb counting, I have to be free every day at work at 11.45 to administer his insulin. At nursery in the afternoons, staff call me every day to ask questions about his care. Due to not having an insulin pump this is having a massive strain on me as a parent.”

Carly, parent of a child with type 1 diabetes



“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 night trying to control her blood glucose levels to keep her safe and healthy, but this is impacting on my own health now. We are hoping to get moved onto a closed loop pump in the near future and this would make my daughter's life so much easier and safer. It would also make such a difference to me as her carer.”

Pasha, parent of a child with type 1 diabetes





Farhana's story

"My mother has been living with type 2 diabetes for 35 years. Her fingers were sensitive from all the daily finger prick tests to check her blood sugar. This was made worse because she had fluctuating blood sugar levels, so frequent blood sugar checks were needed.

I was made aware of the Libre sensor tech through word of mouth. It was the answer we were looking for. Getting sugar readings from scanning the sensor would mean she wouldn't have to use the finger prick blood glucose meter so often which would offer her some relief.

I asked for the system at her next diabetes review appointment. We were not given a prescription for the system because at the time they were only being issued to people living with type 1 diabetes, this is what was in the guidelines.

For a year and a half, we funded the sensors ourselves, which cost £90 per week. However, the impact it had on our quality of life was tremendous. I realise not everyone is fortunate enough to be able to self-fund, especially now due to the cost of living.

After persistently requesting the Libre sensors during my mother's diabetes reviews, the consultant finally agreed. Perhaps seeing the evidence of how it improved our lives and the cost we had been bearing played a role in their decision. As a family, we were relieved that it was now covered by the NHS.

My mother is now 79 – we now have a diagnosis of dementia in the mix as of the last three years. This has brought a whole different scenario – where my mother is finding it difficult to manage her diabetes as she can forget she has eaten – this has made the tech even more vital.

Thanks to the Libre sensor tech, we can monitor her readings more frequently as per the doctor's advice. It has markedly improved the quality of life for my mother and all of those that care for her. Be it the grandkids who use the mobile app or my brother who prefers to use the reader – and we are all linked, so we get the information as and when it's needed."

Providing equal opportunities for children with diabetes

Teachers and other adults who work with children and young people don't always feel confident being responsible for a child with diabetes, and parents and carers often worry more about their child's safety. This can mean children with diabetes sometimes get excluded from everyday activities like sports, playing with friends and attending after school activities. This is clearly unfair – and thanks to tech, it's also unnecessary.

Diabetes tech can allow children the freedom and independence to do the things that other children their age are able to do. Less testing and injecting means more time to play and learn, and with continuous glucose monitoring, parents can keep an eye on their child's blood sugar levels remotely during sleepovers and school trips. Given how isolating diabetes can be, it's hugely important that children are supported to live as normal a life as possible with the condition.

"My daughter has no quality of life as Guides and after school clubs won't carry out finger prick testing, and I can't follow and advise without CGM."

Jill, parent of a child with type 1 diabetes

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

Linda, parent of a child with type 1 diabetes





Sandra and Aiden's story

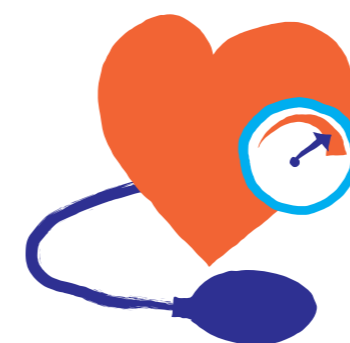
“Aiden was diagnosed at six. He’s now 16 and he’s still on the insulin pump but he’s also got the Guardian 4 sensors for the hybrid closed loop. Before the technology you’re testing multiple times a day with finger pricks and making the decisions of how you’re going to work things out, how you’re going to balance things. The carb counting, ‘Is it going to be right, is it a slow acting food?’ So now with the technology if you did carb count and maybe you’re a wee bit off or something like that then the sensors and the pump will work together and sort that out for you.

It was a bit daunting for a start, it was a completely different way of treating hypos. I must admit we weren’t keen on it for the first few weeks, we were like this is just not working. But we battled away, we persevered with it, and now I don’t think we could do without it. Even with sport, it balances out because you can put it on a sport mode and then it knows he’s doing exercise. Before hybrid closed loop, it was a constant thing, ‘How are you going to work this out? Check at half time. How’s

he feeling himself, is he feeling low or is he feeling high?’ Checking ketones, all that. So it goes a long way. It’s better for quality of life because I’m not on his back 24/7 all the time.

It is vital, it is 100% vital because of the stress that it takes off of families alone without the long-term health conditions and things like that. Everybody should be entitled to it.” – Sandra

“I play football close to every day and I’ve just recently started going to the gym every day after school, so I’m really enjoying that as well. I think it’s really easier having a closed loop when I’m playing football because before going on the pitch, I don’t need to do a finger prick, it’s on my pump. Having a closed loop stops it from going low so I don’t need to take a biscuit, and then when I’m going high it auto-corrects so I don’t need to take a pen injection or do my finger prick again because it does it all for me. It makes me feel a lot more relaxed knowing that it doesn’t rely on me, that I can rely on it telling me.” – Aiden



Reducing the risk of long-term complications

Prolonged high blood sugar levels can lead to long-term health complications including **nerve damage, sight loss, kidney problems, heart attacks, and strokes**. Effective management of diabetes is crucial to preventing or delaying these complications.¹³

We know that the use of diabetes tech can improve diabetes management and reduce the risk of diabetic ketoacidosis, so it’s no surprise that tech use is also associated with fewer long-term complications. There is evidence that this is the case for various types of diabetes tech¹⁴⁻¹⁷ but the benefits are greatest with HCL systems,¹⁸ which come the closest to mimicking the behaviour of a healthy human pancreas.

Preventing complications helps people with diabetes to live better for longer. It’s crucial both to physical health, avoiding the pain and difficulty that comes with treatments like amputation, and to mental wellbeing, reducing the fear that people experience in the face of potential future complications. Diabetes tech isn’t right for everyone, but for many, it’s a key tool in the challenge to prevent or delay complications.



Cost-effectiveness

The Scottish Health Technologies Group’s 2022 recommendations about hybrid closed loop tech are informed by evidence that HCL is clinically cost-effective. This means that its cost is justified by the clinical benefits it brings to people who use it – from improved diabetes management and mental wellbeing to reduced risk of short and long-term complications. Research from around the world has found similar results, concluding that hybrid closed loop systems are likely to be cost-effective, and numerous studies have found the same for insulin pumps and CGMs.^{14, 19-24}

Diabetes tech also has the potential to save the NHS money in the longer term by reducing the costs associated with diabetes complications.²⁵ An estimated 10% of the NHS budget is spent on diabetes, and of this, over 75% is spent on complications.²⁵ By reducing the risk of complications, diabetes tech represents an investment in both the long-term health of people living with diabetes, and in the future of the NHS.

FAIR AND EQUAL ACCESS TO DIABETES TECH

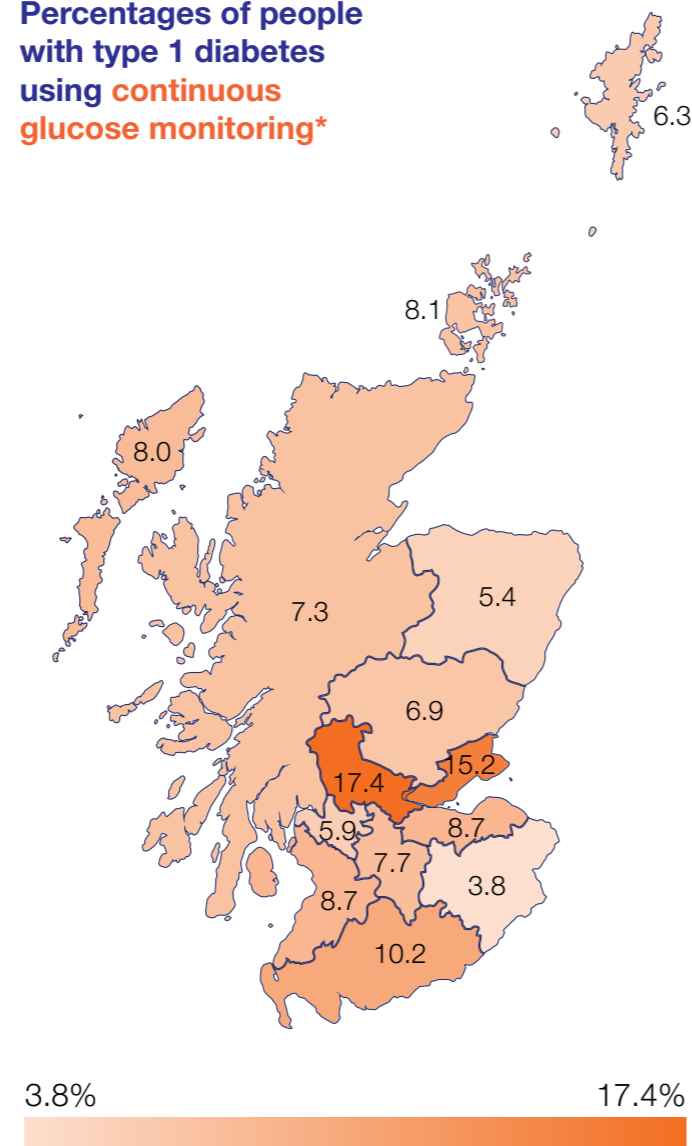
Access to diabetes tech should be based on your need, not where you live or how much you earn. But right now, there are significant regional and socioeconomic disparities in access to diabetes tech in Scotland. We don't believe this is fair.

The following maps show the percentages of people with type 1 diabetes who are using continuous glucose monitors and insulin pumps in Scotland's 14 regional Health Boards, as of March 2023. They reveal large variations between Health Boards.

"We know people who can access CGM in other areas and England, but unfortunately because of a 'postcode lottery', much needed tech is not available to us and we are not treated equally."

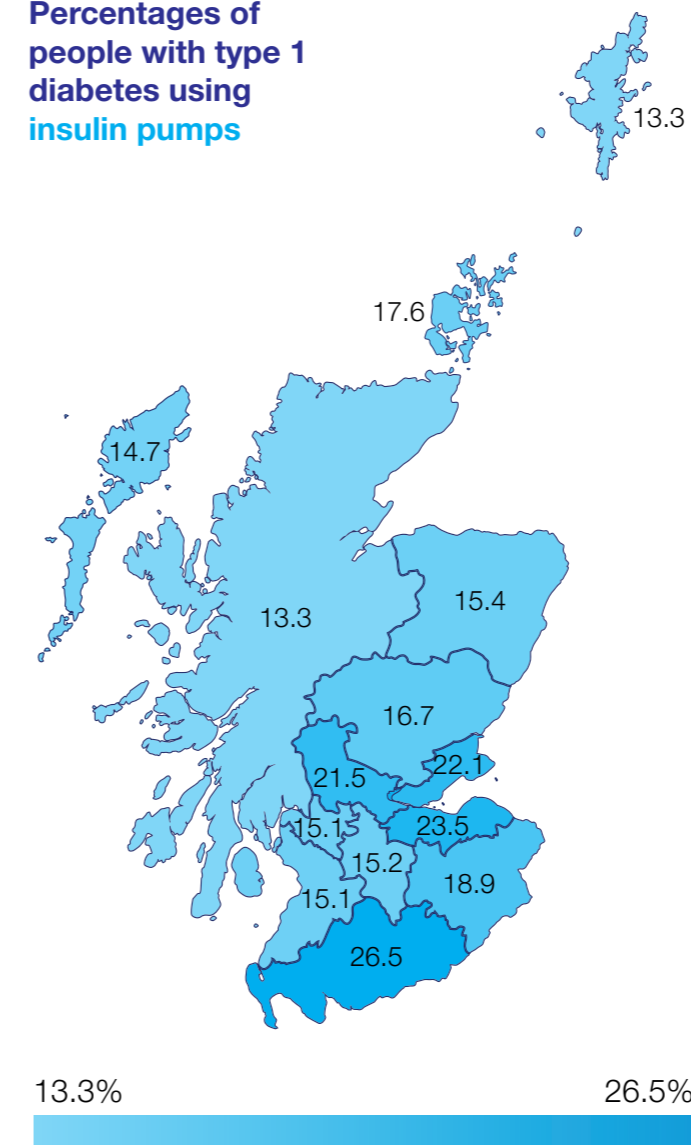
Lisa, parent of a child with type 1 diabetes

Percentages of people with type 1 diabetes using **continuous glucose monitoring***



*excluding the recently upgraded Freestyle Libre 2 sensors – see page 12.

Percentages of people with type 1 diabetes using **insulin pumps**



"My son's heart broke when I had to tell him that due to us moving house, we would no longer get the tech or opportunities we had been offered."

Victoria, parent of a child with type 1 diabetes

Socioeconomic inequalities

Levels of tech use aren't just unequal across Scotland. There is also major inequality in access between people from the richest and poorest backgrounds.

Research suggests that health professionals in the NHS prescribe diabetes tech less frequently to people living in more deprived or worse-off areas of Scotland.^{27,3} And for people living in poverty, the demands that come with surviving on a low income while managing their diabetes mean they're less likely to have the time or energy to fight for the tech they need.

Results of our 2023 Diabetes is Serious survey show the extent of these inequalities. We found that people living in better-off areas of Scotland were **14.5% more likely to use wearable diabetes tech** and **18.1% more likely to have been offered diabetes education**, which is often required before you can start using tech.⁵

Low levels of access to tech on the NHS also mean that some people end up self-funding while others miss out. This sustains a two-tier system of private and public healthcare which is bad news both for inequalities and for the future of the NHS.

Outcomes for people living with diabetes are already worse in the most deprived areas of Scotland.²⁸⁻³¹ As more advanced technologies are developed, offering even more transformative benefits to those who can access them, it's vital that these benefits are shared by everyone. Otherwise, inequalities in diabetes outcomes will only grow.

Ethnic inequalities

The NHS lacks ethnicity data for around one in five people with a diagnosis of diabetes in Scotland,²¹ making it difficult to compare levels of access to tech by ethnicity. But we know there are significant ethnic inequalities in other areas of healthcare in Scotland.^{33,34} So it's likely these are similar for diabetes tech.

Better data will be crucial to understanding the situation for people of different ethnicities and ensuring that all ethnic groups have fair and equal access to diabetes tech.

"If we want our NHS to be free at the point of use for every single citizen, we've got to remove the barriers that mean that you have to pay, out of your pocket, for a piece of equipment that absolutely is essential for your quality of life."

Humza Yousaf, First Minister of Scotland, March 2023



Best practice

Tackling inequalities in access

NHS Fife recognises the significant barriers that people can face to attending structured diabetes education, from taking time off work to the costs of transport and childcare. Existing structured education courses seek to teach people all the basics of diabetes self-management, requiring up to a full week's commitment. But skills like carb counting and insulin dose adjustment are now built into the process of diagnosis in Scotland, so people don't need to undergo such intensive education to become confident with them.

Considering this, NHS Fife has developed an innovative group programme to

help new pump users learn to use their tech. This involves four or five weekly appointments which are offered online or in person to increase accessibility.

NHS Fife's paediatric diabetes team has also shown real determination to make sure people can access tech regardless of their circumstances. For children in foster care who want to use CGM but don't have a smartphone, clinicians have either prescribed them a reader or pushed for the social work department to buy them a compatible smartphone. This commitment means more people can benefit from diabetes tech in Fife, reducing inequalities.

BARRIERS TO ACCESSING DIABETES TECH

Accessing the healthcare you need shouldn't be a struggle, yet we've heard from countless people who are having to fight to access diabetes tech. We know many clinicians want to support people to access the tech they are eligible for. But right now, Health Boards simply don't have the capacity to make this a reality for everyone who needs it.

People have also told us that they aren't always made aware of the tech they're eligible for. Instead, they have to find out about their options on their own and advocate strongly for themselves to be considered for tech. This means people who don't have the resources to research and make a case for themselves end up being left behind, which only makes inequalities worse.

"Nobody tells you about technology at your appointments unless you look into something yourself. It's like you have to beg to get the technology that could make such a difference to your life."

Avril, living with type 1 diabetes

We've heard from people with type 2 diabetes who are on multiple daily injections but have been refused tech because it's only prescribed to people with type 1 or gestational diabetes in their Health Board. And we've seen major inconsistencies in the way the eligibility criterion of "multiple" daily injections is defined – with some Health Boards interpreting it as two or more and others as four or more.

Some people told us they've been denied diabetes tech because their blood sugar levels are "too good" for them to be eligible – even though they're experiencing significant distress managing their diabetes. Others have been refused tech because their blood sugar levels are "not good enough" or their needs are "too complex".

"As he has high blood sugar levels, the team are very reluctant, so it's a vicious cycle of not being able to access the pump while his health continues to become a worry."

Zoe, parent of a child with type 1 diabetes

It's true that for some people there can be added risks associated with starting diabetes tech. But having more complex needs or difficulties with diabetes management shouldn't automatically disqualify someone from accessing tech³ – it may mean they need it even more.

"We got knocked back for a pump in 2018 as we were told my daughter with additional needs wouldn't be able to use it."

Jill, parent of a child with type 1 diabetes





Mel and Gregor's story

“Initially, after my son Gregor’s diagnosis, we had to navigate the complexities of the diabetes management regime. Learning about counting carbs, calculating insulin doses, and adjusting fast-acting and long-lasting insulin to keep Gregor’s blood sugar within target range. It was a steep learning curve, and Gregor would probably say I’m bit of a nag, constantly reminding him about checking his bloods and managing his diabetes.

Gregor is an active young boy, plays football and basketball, which sometimes poses challenges in managing his diabetes. He often experiences hypos before school due to his active morning routine. He is also involved in the Scouts and has to manage his diabetes during outdoor expeditions, estimating his carb intake, taking insulin, and dealing with fluctuating blood sugar levels in unpredictable environments.

The Libre 2 sensor has been a game-changer for us. It has eliminated the need for constant finger pricking to check Gregor’s blood sugar levels. Instead, alarms on our phones can alert us to any fluctuations.

Accessing diabetes technology beyond the Libre sensor has become another significant challenge for us. We considered switching to an insulin pump, which would reduce the number of daily injections Gregor needs to take. The clinic put Gregor on the waiting list for a closed loop system, specifically the T-Slim pump with Dexcom, in January 2022. However, despite being on the waiting list for 18 months, we were repeatedly told that due to backlogs and Covid-related delays, it was unlikely that Gregor would receive the pump.

We feel frustrated by the lack of progress in obtaining the insulin pump. During clinic visits, the consultant informed us that the waitlist was not moving forward and that we might not receive the pump at all. This news was disheartening for us, we had hoped the pump would offer better diabetes management and alleviate some of the burdens of daily injections.”

Best practice

Prescribing tech safely and inclusively

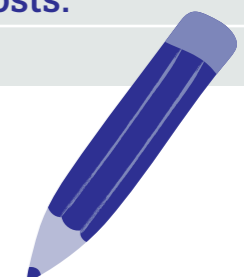
In NHS Fife, the paediatric diabetes clinic has supported several young people who were struggling to manage their diabetes, and largely disengaged from care, to start using insulin pumps. This included visiting their homes if they were not attending the clinic. They have since seen massive improvements in these patients’ HbA1c levels, with no hospital admissions for DKA, showing the benefits of their efforts.


Clinicians in NHS Dumfries and Galloway, too, understand the importance of getting people who are struggling with their diabetes management onto tech where it could benefit them. Instead of assuming people experiencing frequent DKA are “too high risk” to cope with tech, they acknowledge that this can happen for numerous different reasons, including diabetes distress, and doesn’t necessarily make someone unsuitable for tech. Clinicians also understand that while there are many factors affecting someone’s suitability for tech, these must be weighed against the risk of leaving someone without tech and with a high HbA1c for years.

People living with diabetes have also told us of broader issues within their Health Boards involving funding and staffing issues. From our conversations with NHS diabetes teams, and insights we’ve received from letters between MSPs and Health Boards – quoted anonymously below – we know that these are key concerns for the health system, too.


Health Board representatives have emphasised that while the Scottish Government funding in 2022 was key to getting more supplies of diabetes tech out to Health Boards, it doesn’t cover the ongoing costs of tech.

“Recent government funding was welcome, however, we must recognise the full cost of this technology includes recurring four-year warranty renewal costs of the pumps, renewals of CGM transmitters, three-monthly or 12-monthly depending on brand, and associated ongoing revenue costs such as staffing for education and training and consumable costs.”






“The insulin pump service is already over-budget with significant projected increases if the service is to meet the increasing demand.”



“Being able to offer continuous glucose monitoring systems to all groups who meet the criteria will come at a significant financial cost.”

Diabetes leads have also pointed out the need for specialist healthcare professionals who can train people to use diabetes tech. This requires adequate numbers of staff with enough time to undertake training and then deliver it to patients.

“Maximising the benefits of the technology requires considerable time educating patients in how to use it safely and effectively.”




Best practice

Increasing staff capacity

In preparation to scale up the rollout of diabetes tech, NHS Lothian have changed the way they deliver pump starts. Previously they required three healthcare professionals to get a group of six people started on insulin pumps, but they have reduced this to two with the support of an enhanced staff training offer. And in October, they moved away from a pan-Lothian approach, where staff and patients often had to travel to different areas for pump starts, to a more localised system where sessions are delivered at staff and patients' usual clinics. This means that once sufficient funding is allocated to purchase more insulin pumps, staff will have double their previous capacity to support people to start using them.

“Ongoing challenges faced in supporting insulin pump therapy include recruitment and retention of specialist diabetes dieticians, who are a core component to help people with diabetes to use insulin pumps to the best of their ability.”



Best practice

Learning from industry partners

As the experts in their products, diabetes tech companies have an important part to play in supporting the rollout of tech to people living with diabetes. Several Health Boards have taken advantage of training provided by industry partners to upskill both patients and staff in the use of diabetes tech.

In NHS Dumfries and Galloway during the Covid-19 pandemic, groups of patients attended virtual insulin pump training along with a member of the NHS diabetes team. This meant patients and staff were learning together, and when face-to-face pump starts became possible again, clinicians had experience and weren't starting from square one with new pump users.

NHS Lothian have also been upskilling staff with rolling training sessions delivered by insulin pump companies. And with demand for continuous glucose monitoring growing exponentially in the Health Board, patient education sessions on CGM have predominantly been delivered by industry partners, with follow-up taken on by NHS diabetes staff, allowing as many people as possible to start using these technologies with the available funding.

Similarly, in NHS Forth Valley, industry partners provide significant support to train patients on how to use diabetes tech. Regular training from tech companies also supports clinicians' confidence with diabetes tech and means they only need a short update session whenever a new device is released.

Best practice

Accelerating tech rollout through a national onboarding pathway

In June 2023, the Centre for Sustainable Delivery approved a proposal through the Accelerated National Innovation Adoption (ANIA) pathway, awarding £350,000 to create a national diabetes tech onboarding team. This team's focus is on delivering virtual training to equip people with diabetes to start using the hybrid closed loop (HCL) systems that were purchased using the Scottish Government's investment of £14.6 million in 2022, or using the Health Board's own funds where they have already rolled out the Scottish Government funded tech. The aim is to accelerate tech rollout in areas where progress has been limited by a lack of staff capacity, as well as supporting continued rollout in areas that have been delivering well.

The training has been designed based on engagement with people living with type 1 diabetes in Scotland, including people using hybrid closed loop systems. The staff team also includes peer educators

who are using HCL systems or are the parents or carers of children who are using them. This ensures the experiences of people living with and affected by diabetes are centred in the development and delivery of the pathway.

If the evaluation of the programme shows positive results, it's hoped that the programme will be maintained as a long-term model of delivery to complement existing local pathways. This would allow healthcare professionals to direct people who are happy to be onboarded virtually onto the pathway, freeing up capacity to focus on providing more intensive in-person support to people who need it locally. It could also provide an opportunity for people to be onboarded onto their chosen brand and model of tech if clinicians in their Health Board aren't trained and don't have the capacity to undertake training to support them with this.

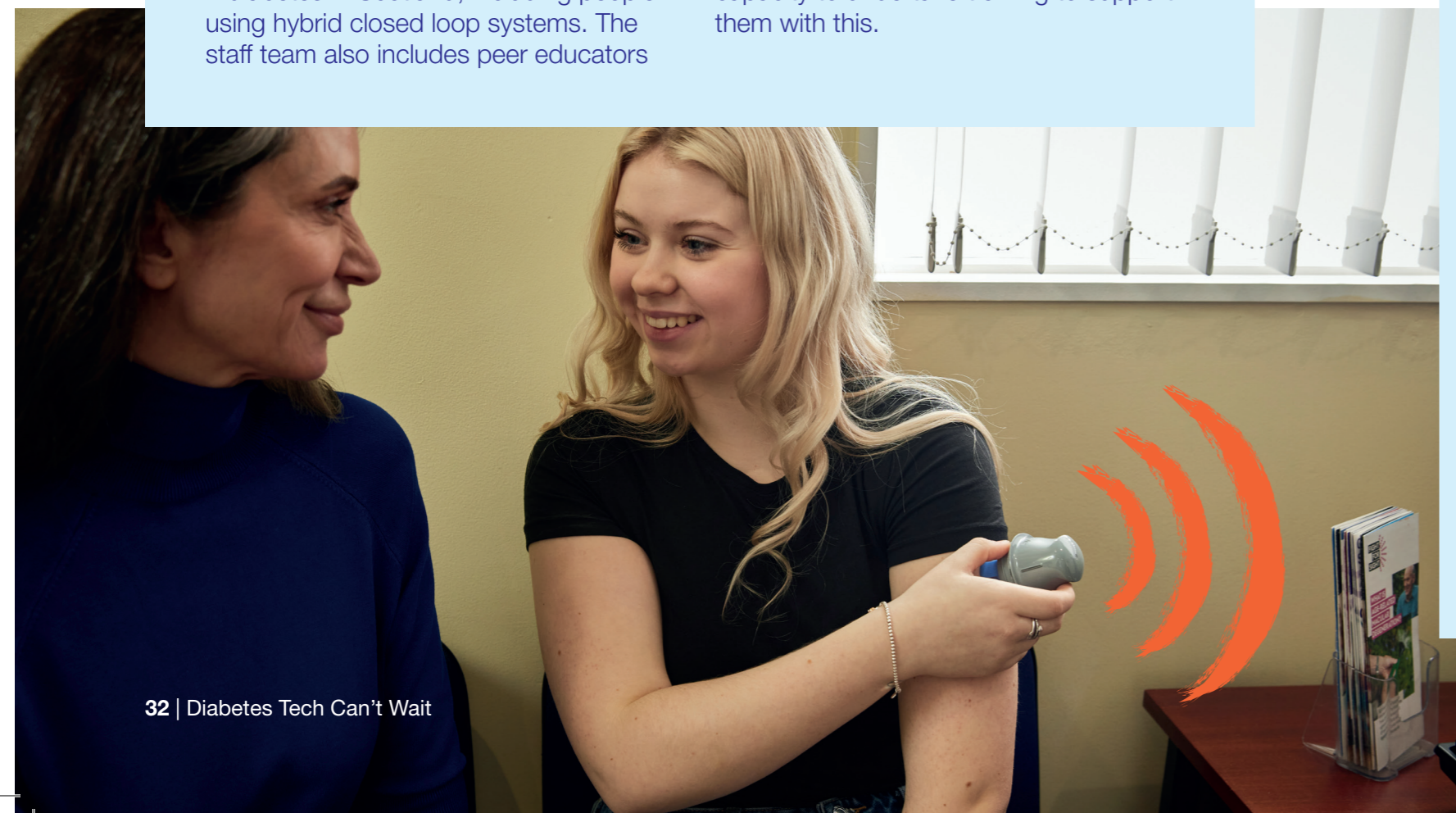


Best practice

Championing the benefits of tech

For the diabetes team in NHS Dumfries and Galloway, the benefits they saw from hybrid closed loop systems were "unbelievable". Tech became a priority for them, and they began sharing their findings with senior colleagues and taking opportunities to spread the word locally. The team submitted a poster to a local quality improvement competition showing the significant improvements in blood sugar levels, time in range, and quality of life that they had seen in people using HCL tech. This gave them the opportunity to deliver a presentation which was attended by chief executives and managers in the health system, raising the profile of diabetes tech and showcasing the transformative change that NHS Dumfries and Galloway has achieved through their commitment to rolling out tech.

Clinicians in NHS Forth Valley have also been working hard to make sure diabetes tech is a priority for their local health system decision-makers. They are finalising a business case for submission to the Health Board for funding to support their goal to get 50% of people, both adults and children, using hybrid closed loop tech in five years. This includes a request for two more dietitians, two more diabetes specialist nurses, and an admin support role. While a decision at Health Board level is awaited, this represents a welcome shift towards longer-term strategic planning for the rollout of diabetes tech. If approved, it will help ensure the capacity and resources required are built into the health system so improvements in access to tech are sustainable.



DIABETES SCOTLAND CALLS FOR


diabetes tech for everyone who could benefit, without having to fight for it.

To achieve this, decision-makers need to:


1. 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.

2. 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 people 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.

3. 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.



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- Quotations from people living with diabetes and their parents or carers were taken from stories submitted through the **Diabetes Tech Can't Wait** 'share your story' form. We collected these stories primarily for use in our online campaign materials and this report, but if you didn't get the chance to share your story, we'd still love to hear from you to help us better understand the range of experiences of accessing or trying to access diabetes tech across Scotland. See page 12 for more information.

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