

Citizen Participation and Public Petitions Committee
Wednesday 29 May 2024
10th Meeting, 2024 (Session 6)

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

Introduction

Petitioner Maria Aitken on behalf of Caithness Health Action Team

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to ensure that children and young people in Scotland who have type 1 diabetes, and would benefit from a lifesaving insulin pump, are provided with one, no matter where they live.

Webpage <https://petitions.parliament.scot/petitions/PE2031>

1. [The Committee last considered this petition at its meeting on 20 September 2023.](#) At that meeting, the Committee agreed to write to Diabetes Scotland, the Insulin Pump Awareness Group and NHS regional health boards.
2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
3. The Committee has received new written submissions from 8 of the 14 NHS regional boards, and Diabetes Scotland which are set out in **Annexe C**.
4. [The Committee has received one written submission prior to its last consideration of the petition.](#)
5. [Further background information about this petition can be found in the SPICe briefing](#) for this petition.
6. [The Scottish Government gave its initial position on this petition on 6 July 2023.](#)
7. Every petition collects signatures while it remains under consideration. At the time of writing, 428 signatures have been received on this petition.

Action

8. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee
May 2024

Annexe A: Summary of petition

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

Petitioner

Maria Aitken on behalf of Caithness Health Action Team

Date Lodged

8 June 2023

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to ensure that children and young people in Scotland who have type 1 diabetes, and would benefit from a lifesaving insulin pump, are provided with one, no matter where they live.

Previous action

We have raised this issue with our MSP, Edward Mountain, and also met with him personally to discuss this issue of inequality for access to the monitoring devices for diabetic children in Highland areas.

Background information

Scotland has more than 327,000 people with diabetes, of whom 10% have type 1 diabetes. Almost 13,500 people died from diabetes in 2020; this is a major concern. People need assurances that they will have equitable access to monitoring devices to help manage their diabetes and prevent injury or death.

There is currently a postcode lottery with the provision of vital continuous monitoring pumps for children with diabetes. Some Scottish NHS Boards provide the pumps and have no waiting lists for children with type 1 diabetes, while others have only a 2 or 3 month wait.

NHS Highland has waiting lists for children up to 3 years. NHS Highland currently has 25 children waiting for a diabetic insulin pump and only provide funding for 8 pumps a year.

There are currently 167 children diagnosed with type 1 diabetes in NHS Highland areas; Caithness itself has an average of 20 children a year diagnosed with type 1 diabetes.

This indicates an equity issue for children receiving lifesaving diabetic insulin pumps in the NHS Highland area.

Annexe B: Extract from Official Report of last consideration of PE2031 on 20 September 2023

The Convener: Our final petition this morning is PE2031. I have a feeling of déjà vu. When I first joined the Public Petitions Committee, some 12 years ago, one of the first petitions that we considered was on the availability at all of insulin pumps at that time. Here we are again, with a petition, lodged by Maria Aitken on behalf of the Caithness Health Action Team, which calls on the Scottish Parliament to urge the Scottish Government to ensure that children and young people in Scotland who have type 1 diabetes, and would benefit from a lifesaving insulin pump, are provided with one, no matter where they live.

The petitioner highlights what she views as a postcode lottery relating to the provision of continuous glucose monitoring and insulin pumps for children with diabetes, with a particular concern about the waiting lists for those devices across NHS Highland.

Responding to the petition, the Scottish Government refers to the diabetes improvement plan, which aims to increase access to existing and emerging diabetes technologies that can significantly benefit people with type 1 diabetes. The Scottish Government response highlights that, between 2016 and 2021, it invested an additional £15 million to support the increased provision of insulin pumps and continuous glucose monitoring. The Government also points to current work to roll out diabetes technology with a particular focus on reducing regional variation.

Do members have any comments or suggestions?

Foyso Choudhury: We should write to Diabetes Scotland to get its view. Did you write to Jenny Minto, the responsible minister, for an update? I see that there is a suggestion that we do that.

The Convener: I think that we might get to that. I might quite like to write to the different health boards to ask what the current status within each health board is. The assertion is that provision is a postcode lottery. I have a recollection that, right back at the start when the issue was whether insulin pumps would be provided at all, it was a health board lottery. I think that, all that time ago, NHS Greater Glasgow and Clyde embraced their provision and other health boards did not.

It would be interesting to know what the provision is within each health board and what policies they have surrounding the award of insulin pumps to children. This sits within a framework in which—I think—it is the case that children are meant to get them if they need them, so we need to find out where we are at with all that.

Diabetes Scotland and the Insulin Pump Awareness Group might be able to help us in that work as well. That would be helpful in the first instance. These are very important matters to those people who in life depend on them.

Do we agree to take that action?

Members *indicated agreement.*

CPPP/S6/24/10/9

The Convener: We will keep the petition open, and we will make those inquiries and consider it afresh when we get responses.

Annexe C: Written submissions

NHS Tayside submission of 2 October 2023

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

Thank you very much for your letter of 21 September 2023 highlighting the above petition, and for the opportunity to contribute to the Committee's discussion on behalf of NHS Tayside.

NHS Tayside is a member of the Accelerated National Innovation Adoption Pathway, which is a national initiative focused on harnessing technological innovation to effectively address some of the most complex health challenges in Scotland. The Pathway actively seeks out complex health problems to develop innovative solutions with the objective of ensuring a direct and enduring positive impact on patient outcomes.

You may be aware that the Pathway's approach to innovation is focused on deriving value across services to promote specific improvement objectives in relation to the following:

1. Patient outcomes
2. Patient experience
3. Staff experience
4. Productivity
5. Environmental sustainability

The Committee will wish to know that the Accelerated National Innovation Adoption Pathway is founded on the principle of collaboration among key organisations across Scotland, and is led by the Centre for Sustainable Delivery to rapidly bring proven innovations into service.

In regard to Diabetes Closed Loop Systems, the Scottish Health Technologies Group has undertaken a detailed Health Technology Assessment of Closed Loop System technology that led to a formal recommendation for the deployment of the technology to people living with Type 1 Diabetes in Scotland. This recommendation contributed to the Scottish Government's decision to invest £14.6 million in 2021/2022 to improve patient access to a range of diabetes technologies, monies that were subsequently allocated to Boards to support rapid deployment.

To take forward the recommendation established by the Scottish Health Technologies Group, NHS Tayside currently follows NICE Guidance in managing Type 1 Diabetes and considers any person, adult or child, with Type 1 Diabetes to be eligible for insulin pump therapy. Indeed, the following patient groups are prioritised by NHS Tayside for insulin pump therapy:

- Those under 5yrs
- Those with high glucose levels on average, i.e. HbA1c >75mmols/mol
- Those waiting more than 1 year
- Those with severe hypoglycaemia and/or recurrent diabetic ketoacidosis.

NHS Tayside therefore offers Closed Loop Systems to all children and young people that meet the appropriate clinical criteria and engages with neighbouring boards i.e. NHS Fife, NHS Grampian and NHS Highland, to support the care of their patients in certain cases where there is a need to work collaboratively to mitigate health inequalities and digital exclusion. Indeed, it is NHS Tayside's policy to positively discriminate individuals with poor glucose health, pre-school children and those who have been waiting for more than one year, as outlined above, regardless of where they live.

The Committee should know that NHS Tayside does not maintain a quota of funded Closed Loop Systems or Continual Glucose Monitoring systems and is committed to continuing the prioritised development and implementation of technology in line with guidance, recommendations and emerging evidence base in a controlled and sustainable manner. More specifically, NHS Tayside is committed to the provision of Closed Loop Systems to all children and young people to align with NICE guideline 18, section 1.2.63 - 1.2.65, Guidance 116 published by the Scottish Intercollegiate Guidelines Network that relates to the Management of Diabetes, and Commitments 2.2 and 8.1 noted in the Scottish Government's (2021) Diabetes Improvement Plan.

Currently 95 children and young people with Type 1 Diabetes in Tayside, i.e. 44.6% of current caseload, are provided with Closed Loop Systems and we project approximately 30 new diagnoses in the next year, with a similar number of existing patients transitioning to adult services in the next year also. NHS Tayside's aspiration is, of course, to deliver enhanced outcomes and improved wellbeing to all children and young people receiving care, support and treatment for Type 1 Diabetes through person-centered care planning. NHS Tayside looks forward to completion of the ongoing national tendering exercise in regard to the procurement of Continuous Glucose Monitoring technology and publication of enhanced guidance in respect of interoperability of devices available in what is a rapidly developing technological environment.

I hope very much that this response is considered helpful to the Committee and informs the development of the petition and policy in regard to the provision of insulin pumps across Scotland.

NHS Grampian submission of 17 October 2023

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

Thank you for your email, received on 21st September 2023, in relation to PE2031: Provide insulin pumps to all children with type 1 diabetes in Scotland.

I can confirm that within Grampian any child who would like to manage their diabetes with a pump has access to one, unless deemed by the team to be unsafe.

Currently 60% of our diabetes patient population are pump users and the number continues to go up.

Hope this information answers your question.

NHS Ayrshire and Arran submission of 18 October 2023

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

NHS Ayrshire & Arran have utilised Scottish Government funding over the last few years to substantially increase the number of children accessing insulin pump therapy. The current insulin pump provision is 47% from a type 1 population of 264 patients less than 18 years old.

The number of children on the waiting list for pump therapy is 11, with an average length of time to issue of insulin pump around 6 months, and for urgent cases around 1 month.

NHS Ayrshire and Arran are following the Scottish Health Technology Group (SHTG) 2022 recommendation for providing insulin pump for children.

SHTG recommendation - Single hormone closed loop systems should be available to people with type 1 diabetes (paediatric and adult) who:

- under their current diabetes care plan, continue to have suboptimal glycaemic control, a high risk of severe hypoglycaemia, or impaired awareness of hypoglycaemia, or
- experience diabetes-related distress, measured using a validated tool, that adversely affects quality of life or their ability to manage diabetes, and which is likely to be improved by moving to a closed loop system.

NHS Fife submission of 18 October 2023

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

In NHS Fife we currently have 251 patients with type 1 diabetes under the age of 18. We agree that all paediatric patients with type 1 diabetes should have access to insulin pump therapy. We also support the new NICE guidance that will be published later this year that paediatric patients have access to continuous glucose monitoring (CGM) and hybrid pump technology.

In NHS Fife we have worked hard at providing these technologies to our families and currently 70% of our patients are on insulin pump therapy & 71% of our patients using CGM. This is compared to the Scottish average for under 18's of 50.1% pump use and 44.2 % using CGM.

Our criteria for insulin pump therapy is that the young person is on insulin therapy. Within our current population those that are not on pump therapy are because either they do not want pump therapy or are early in their diagnosis and still learning about diabetes management, such as carbohydrate counting. We currently do not have a waiting list for paediatrics pump therapy. Once a family choose to move onto pump therapy the pump is ordered and training dates and on-boarding arranged with the specialist nurses.

We believe it important to be able to offer a choice with regard to pump therapy as the different systems all have their individual benefits and what is right for one person may not work for another. We currently provide Medtronic Pumps (680g & 780g), Tandem T-slim, Omnipod (Dash & 5), Ypsomed and Dana RS.

In order to get the maximum benefits from these technologies it is imperative that there are enough staff to support and educate patients and families in their use otherwise the full benefit of these systems will not be realised. We would ask that Scottish Government ensure that there is funding to meet the minimum staffing requirements as per the ISPAD guidance (International society for paediatric and adolescent diabetes).

The combination of insulin pump therapy with CGM in the form of a hybrid closed loop pump is quickly becoming the main therapy in type 1 diabetes with its benefits in improved control and quality of life. National guidance is moving towards this being the mainstay of treatment for type 1 diabetes in the paediatric population.

NHS Highland submission of 19 October 2023

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

The Paediatric Diabetes Team and responsible managers in NHS Highland have received and read the request for information regarding insulin pump provision which came from the Scottish Government Citizen Participation and Public Petitions Committee following receipt of a petition on behalf of Caithness Health Action Team. We've studied the original petition and minutes of the discussion at the CPPP Committee.

Provision of Hybrid Closed Loop Systems, (termed "continuous monitoring pumps" in the petition) for children with diabetes is widely regarded as gold standard care, due to improved blood glucose control, reduced risk of complications and quality of life benefits.

The Scottish Health Technology Group recommends that Hybrid Closed Loop Systems should be offered to all patients with type 1 diabetes who:

- under their current diabetes care plan, continue to have suboptimal glycaemic control,
- have a high risk of severe hypoglycaemia/impaired awareness of hypoglycaemia

- experience diabetes-related distress, measured using a validated tool, that adversely affects quality of life or their ability to manage diabetes, and is likely to be improved by this system.

Hence Diabetes UK set up the campaign 'Diabetes Tech Can't Wait' showing the variations between percentage of patients on pumps across Scottish Health boards.

We accept the significant disparities in the provision of diabetes technology, currently NHS Highland provision (on most recent comparative statistics) is jointly lowest in Scotland and the lowest of any mainland board. We're addressing this situation as a priority. We commenced implementation of a detailed plan prior to the petition.

In terms of overall diabetes control (HbA1c), which is the main risk indicator of long-term complications, national comparative statistics show Highland Paediatrics as consistently better than the Scottish average. The teenage 12-17year old group, who often struggle with their diabetes management, Highland's HbA1c figures are the lowest of any mainland board.

Petition information:

Petition figures:

This statistic appears incorrect "Caithness has an average of 20 children per year diagnosed with Type 1 diabetes". This is the prevalence rather than the incidence; the Caithness Clinic population is approximately 20.

NHS Highland paediatric clinic population: 120 (0-16 year olds with Type 1 diabetes)

Current pump users: 50

Current hybrid closed loop pump system users: 46

Percentage of caseload on any pump: 42%

Percentage of Highland pump users on hybrid closed loop systems: 92%

Scottish average for any pump: 51%

Challenges and Solutions:

Diabetes teams rely on separate funding for Technology (as opposed to drugs/other interventions), therefore each Health-board allocates an annual budget independent of patient need. This may be the root cause of the current inequalities clearly demonstrated across Health-boards. With the aim of care being to offer 100% of eligible patients pumps as early as possible, this funding disparity should disappear, presuming Diabetes Technology provision is appropriately supported by the Scottish Government.

In addressing the current disparity, NHS Highland have identified additional funding from within current resource to support the Paediatric Diabetes team to initiate significantly increased pump starts in the current financial year with a plan to also support additional pump starts in the next financial year (2024- 2025).

Our aim is for 70% of our present Paediatric caseload to be on hybrid closed loop insulin pump therapy within 18 months. It's unclear where Highland may be ranked against other Health Boards as we're aware every Board is aiming to increase pump provision. We aim to ensure that pump provision in Highland is delivered safely, effectively and equitably to our patients. Providing the technology on its own may not improve diabetes control and quality of life, support for families which is critical to optimising success.

We're significantly increasing nursing resource by approximately 7.5 hours per week (from current staffing) between November-March this financial year which will allow additional children to be started on hybrid closed loop who otherwise wouldn't. The nursing team who prepare and deliver the bulk of the training for patients on insulin pump therapy in conjunction with company representatives continue to work hard at streamlining the pump start process whilst ensuring quality and patient safety is maintained. We continuously work on the criteria for prioritisation and selection of patients and aim to further increase the number of patients being commenced on pumps. Please note that one of our two Diabetes Consultants is currently on Maternity Leave, adding additional strain to the single-handed consultant leading the service.

We face additional geographical challenges in rapidly initiating pump therapy. Nurses provide training to nursery/school staff via face to face/virtual sessions to ensure both the families and education/learning staff are informed and adequately supported.

We have very frank discussions about what's achievable within current nursing, medical and dietetic resources, we all recognise the major challenges faced in improving the care provided. We're all committed to providing the best possible care to all patients and will continue to look at further improvements to optimise safe delivery of pump services to our population.

Whether the Petition is Realistic:

We feel that Caithness Health Action Team have appropriately petitioned on behalf of children with Diabetes across Scotland. We accept the current statistical shortfall of NHS Highland but provide evidence we're working hard to address this quickly.

Other work ongoing to address the petition:

Internationally, diabetes care is shifting increasingly towards higher tech solutions, with more sophisticated sensors and pumps being developed which should make it easier to safely commence greater numbers of children on optimal therapy. This is a rapidly developing field and all Diabetes teams have the challenge of keeping abreast of technological advances that benefit patients. In addressing the concerns raised in this petition, we will continually strive to provide safe, timely, appropriate access to pump therapy.

The NHS Highland Paediatric Diabetes Team and Women and Children's Directorate Senior Management Team would welcome the opportunity to discuss the concerns raised in the petition with the petitioners, to directly share with them what

we're doing and our timescales for improvement. Likewise, we would welcome discussion with Edward Mountain, and other MSPs regarding the concerns.

NHS Lothian submission of 19 October 2023

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

Thank you for your letter of 21 September 2023 highlighting the above petition, and for the opportunity to contribute information on behalf of NHS Lothian to the Committee's discussion. NHS Lothian has had a long commitment to maximising the use of this technology, which can be transformative for users.

Current provision of insulin pumps in NHS Lothian to children 0-17

Approximately 343 children and young people are currently supported by pump therapy, equating to 65% of patients. 51% of children and young people are supported by Continuous Glucose Monitoring (CGM) and 28% are supported by Flash Glucose Monitoring.

The number of children we support and the proportion with insulin pumps, or waiting for one, changes frequently as new children are diagnosed each year, and others transition to the adult service. Approximately 50 children are newly diagnosed each year. However, significantly more children were newly diagnosed in Lothian in 2022 – a total of 83. Approximately 53 young people transition into the adult service annually.

Current NHS Lothian policy for providing pumps to children

All children are offered pumps [if they fulfil the criteria outlined in SIGN guidelines](#). Children under 5 years old at diagnosis are prioritised. Children are offered the choice on whether they wish to use a pump and discuss this with their diabetes team and family. If they wish to use a pump, they are placed on a waiting list. Not all children and young people wish to use one.

In line with [the new SHTG Recommendation](#), government funding, and [the work of the ANIA collaborative](#) from [CFSD](#), a key focus of NHS Lothian over the last few years has been to increase the number of children and young people supported by Closed Loop Systems. Therefore, some of the funding and staff capacity from the service has been used for CGM. The 2021/2022 Scottish Government funding was used to start an additional 218 patients who had a compatible pump on CGM technology - significantly increasing the number of children with a closed loop system.

Challenges - Budget and Capacity

Last year (22/23) we provided 64 new pumps.

Approximately 50 new referrals are added to the pump waiting list each year. The current recurring annual children's technology budget funds 44 new pump

purchases, as well as replacement pumps. This funding does not meet the current demand.

The average wait is currently approximately 22 months and will increase in the future due to the gap between the demand and number of new funded pumps. 89 children and young people are currently on a waiting list for pump therapy.

The current service budget also funds 12 new CGM a year. Children under 5 years old at diagnosis are prioritised for CGM.

To meet the demand and provide all young people with a pump - with no wait - would require; significant additional funding in both children's services, and in adult services; additional capacity in terms of staffing, space and time to deliver training; administrative support; and support from pump companies.

Challenges - Replacements and Ongoing Costs

All pumps need to be replaced and upgraded every 4 years. At present the paediatric service delivers approximately 62 replacements per year. This has both a financial and workforce impact, as staff must deliver training on these replacements alongside any new pumps. As the number of children and young people on pumps increases, the resource needed for replacements each year will increase.

Each pump distributed also incurs regular consumables costs, including the cost of infusion sets, which are replaced every 2 to 3 days. Supporting pumps introduced in paediatric services requires significant ongoing investment within adult diabetes services for the lifetime of each person. As more young people are supported to get pumps in paediatric services, this has a bigger impact on adult services.

There are several developments in technology which may reduce both purchasing and the ongoing costs of pumps and closed loop systems. However, it is not yet clear what will happen, when, and the impacts of this.

Other work and considerations

The aim of providing pumps is to support young people to manage their diabetes effectively, including helping them to reduce their HbA1c levels. Average glucose control over a period of a few months can be measured in the blood via HbA1c values. Better HbA1c values over longer periods of time indicate better diabetes management and reduces the likelihood of developing complications from diabetes later in life. Clearly the impact is amplified when management is effective for children and changes the course of their life.

Although it is important to consider the number of children and young people receiving pumps in each health board. The committee may want to consider:

- An equalities perspective. Are pumps going to the young people most in need across Scotland? Are they being distributed equally to girls and boys, to young people from different areas of deprivation, and to young people from ethnic minority communities? Do care experienced children and young people have equal access to pumps?

- The impact pumps have had in supporting young people to manage and reduce their HbA1c levels. Are all young people across Scotland seeing a positive impact? How big an impact does the technology have? And if technology is not creating the impact we would expect then what else do we need to consider?
- The [work of the world-leading Diabeter Clinic in Holland](#), who have won awards for their holistic approach to the management of Type 1 Diabetes in Children and Young people and are also able to demonstrate excellent HbA1c results. This includes mental health support, support with self-management and peer support.

As a long-term condition, which requires ongoing management, a holistic approach is required to best support children and young people to live well with diabetes. This includes supporting them with the physical and mental challenges of the condition, stigma they may face and self-management skills. Technology, including pumps, is only one aspect that can help to support them to live well with their diabetes. NHS trusts in England have successfully used youth workers to better support young people with diabetes in a holistic way. [The RCPCH has an example of this work and the impacts here.](#)

NHS Forth Valley submission of 19 October 2023

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

Thank you for your letter of 21 September 2023, seeking information on the provision of insulin pumps to children with type 1 diabetes in NHS Forth Valley.

In Forth Valley, access to insulin pump therapy is provided in line with the criteria provided in NICE guideline [NG18] Diabetes (type 1 and type 2) in children and young people: diagnosis and management. All children with type 1 diabetes are eligible to use an insulin pump if the family wishes this and they are able to use it consistently and safely (after training).

The Forth Valley specialist diabetes team has reviewed our local information. As of 28 September 2023, Forth Valley had a total of 186 children under the age of 16 years with type 1 diabetes. 155 of these children are currently using insulin pump therapy, which is approximately 83%. Please note that these numbers can vary slightly on a month-to-month basis.

The use of insulin pumps in the Forth Valley paediatric population is increasing year on year, and Forth Valley currently sits above the Scottish average.

It is recognised that starting and looking after children on insulin pumps requires intensive support, which can be a challenge to services across Scotland. The waiting time in Forth Valley for a child wishing to commence insulin pump therapy is currently well below 6 months.

I hope that this provides the information requested. However, if you have any further questions then please let me know.

NHS Shetland submission of 5 February 2024

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

In Shetland, paediatric diabetes care is separate from the adult service and is provided by NHS Grampian. NHS Shetland is on track with insulin pump therapy for children and young people. Everyone who wants to use a pump and is suitable for pump therapy in this group has access to an insulin pump.

NHS Orkney submission of 19 February 2024

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

NHS Orkney works closely with NHS Grampian, as this is where our paediatric consultants are based, and where emergency provision of paediatric support for those with Type 1 diabetes is provided.

All children are considered for insulin pumps and are usually offered one in the first year post diagnosis.

There are clinical reasons why an insulin pump could not be suitable and all decisions for insulin pumps are made by the Diabetes specialist team, comprising of Consultant - NHS Grampian and Diabetes specialist nurse in conjunction with the family and young person affected.

Current figures are provided in the table below, of the 2 paediatric patients without an insulin pump; 1 is due to clinical reasons which are being addressed, and 1 due to length of diagnosis at less than 3 months.

		Orkney Paediatric Specialist Service as at 14-Feb-2024 16:14:47			Orkney Q4/23 as at 1-Jan-2024		
		Total	Met Criteria		Total	Met Criteria	
Categories for this measure							
	Type 1 Age 0-17 Using CSII	7	71.4%	5	8	62.5%	5
	Type 1 Age 18+ Using CSII	0	0%	0	145	16.6%	24
Additional categories							
Type 1 patients who have no record of any pump usage							

	Type 1 Age 0-17 no pump record	1			
	Type 1 Age 18+ no pump record	0			

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 range¹. 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 year².

“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

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>

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

“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 DKA³. 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 2004⁴. 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 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

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>

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.