

Citizen Participation and Public Petitions Committee

13th Meeting, 2023 (Session 6), Wednesday
20 September 2023

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

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

Introduction

1. This is a new petition that was lodged on 8 June 2023.
2. A full summary of this petition and its aims can be found at **Annexe A**.
3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B**.
4. Every petition can collect signatures while it remains under consideration. At the time of writing, 414 signatures have been received on this petition.
5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered. A response has been received from the Scottish Government and is included at **Annexe C** of this paper.

Action

The Committee is invited to consider what action it wishes to take on this petition.

Clerk to the Committee

Annexe A

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



Briefing for the Citizen Participation and Public Petitions Committee on petition PE2031: Provide insulin pumps to all children with type 1 diabetes in Scotland, lodged by Maria Aitken on behalf of the Caithness Health Action Team

Brief overview of issues raised by the petition

The petitioner is 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 an insulin pump, are provided with one, no matter where they live.

One particular concern is the inequality of access to such pumps, depending on where a child lives. The petitioner states that in some health boards there is no wait, and in others it can be up to 3 years. They say this is the case in NHS Highland, and that 25 children are currently waiting for a pump.

Insulin monitoring devices and insulin pumps

There are devices that simply monitor insulin levels so that people with type 1 diabetes can manage their blood sugar levels, but there are also devices which both constantly monitor and deliver insulin via a pump as required. The background information to the petition is not wholly clear about whether they are asking solely about insulin pumps or also continuous glucose monitoring devices. This briefing is based on the assumption that the petitioners are concerned about the availability of insulin pump devices, rather than the ones that simply monitor insulin levels. The use of these pumps is also known as Continuous subcutaneous insulin infusion (CSII) therapy.

NHS Scotland has a website dedicated to diabetes information: [Diabetes My Way](#). In the section on insulin pumps it states the following:

“Insulin pumps are usually only recommended for type 1 diabetes. They are small electronic devices that deliver insulin continuously day and night through a small tube called a cannula that sits just under your skin (replaced every few days).

The small pump (containing a reservoir of insulin) is usually worn on a belt or in a pocket. It delivers a constant background insulin rate, which is known as basal insulin throughout the day. It can also be instructed to deliver rapid or quick-acting insulin, called bolus insulin when you eat.”

The [NHS website also provides links to local services, organised by health board](#). Information on the NHS Highland link includes the names of the diabetes consultants, specialist nurse teams, dietitians, education teams and area-specific links. Under the ‘Caithness and Sutherland’ area link, there are the contact details for the three specialist diabetes nurses.

Scottish Government commitment regarding insulin pump therapy

[A Chief Executive Letter \(CEL\) was issued to all health boards in February 2012](#). This stated that:

“On 21 October 2011, the Cabinet Secretary for Health, Wellbeing & Cities Strategy announced the decision to commit NHS Scotland to substantially increasing the availability of insulin pump therapy across Scotland to ensure equity of access.

Consequently, a quarter of young Scots with type 1 diabetes must have access to insulin pumps by March 2013, and by March 2015, the number of insulin pumps available to people of all ages with type 1 diabetes in Scotland will almost triple to more than 2,000.”

Table 2 in the annex to the CEL provides information on provision across all health boards in 2009-2010. This shows that the average in Scotland was 3.1% of people with type 1 diabetes used an insulin pump. The highest use was in NHS Borders, with 8.2% and lowest in the Western Isles with 0.6%. NHS Highland had 1.6% of people with diabetes using a pump.

The Scottish Government said it would set up monitoring processes to assess the progress of all health boards, with data published via the [Scottish Diabetes Survey](#) against the targets set (25% of people under age 18 to be using a pump by March 2013). Table 3 shows that in 2012, 51 more pumps were needed by NHS Highland to meet the target for under 18s, taking the number from 0 young people to 51. Table 4 shows the costs for the pumps and consumables to be £245,667 for the health board for the first year, and a total of £609,855 over 3 years, to 2014/15.

Scottish Diabetes Survey

This is an annual survey, but the [most recent publication covers the year 2021](#). This provides a wide range of data, on the epidemiology of diabetes (both types), characteristics, morbidity, numbers of children with diabetes in each health board area, and data on the use of insulin pumps (as well as the use of continuous glucose monitoring technology).

Section 3 is on national and regional aspects of paediatric diabetes. NHS Highland has a total of 156 children under the age of 16 with diabetes, out of a total of 2,587 in Scotland (Table 26). NHS Highland has the second highest incidence rate per 100,000 population in 10-15 year olds (Figure 5). Note that the data doesn't separate type 1 and type 2 diabetes, although Table 6 shows that very few children have type 2 diabetes.

In terms of receiving applicable processes of care, NHS Highland is performing above the national average of 90% for children 0-11 with type 1 diabetes. (Figure 6 and Table 29). It is also the highest performing board for 12-17 year olds, although the levels receiving all process of care across the boards is under 30% (figure 7 and Table 30).

On the use of insulin pumps and other technology, NHS Highland is below the national average, but is not the lowest, with 35.9% of children under age 16 using a pump (national average 41.2%). The board with the highest use is NHS Fife, with 65.6% using a pump.

National guidelines for management of type 1 diabetes

There are [Scottish Intercollegiate Guidelines Network \(SIGN\) guidelines for the management of type 1 diabetes](#), It discusses the evidence for insulin pumps (CSII) and research carried out. In national guidelines both the evidence and the recommendations are graded according to how sound they are believed to be (1++ being the highest rated evidence, and A being the highest grade of recommendation):

“Intensive insulin therapy (four injections or more per day or pump insulin) significantly improves glycaemic control over a sustained period compared with conventional insulin therapy (two injections per day). The Diabetes Control and Complication Trial (DCCT) did not include children aged less than 13 years and, due to the study design, it is impossible to separate the benefits of intensive insulin therapy from intensive support.” (Para. 5.3.2 ‘Insulin Regimen’)

The section goes on to describe the evidence considered from the various clinical trials and studies carried out, in arriving at the recommendations made. There is some concern over the independence of some of these trials, and an observation that more larger scale trials were required.

The recommendations for CSII (insulin pump therapy) are:

A - CSII therapy is associated with modest improvements in glycaemic control and should be considered for patients unable to achieve their glycaemic targets.

B - CSII therapy should be considered in patients who experience recurring episodes of severe hypoglycaemia.

- An insulin pump is recommended for those with very low basal insulin requirements (such as infants and very young children), for whom even small doses of basal insulin analogue may result in hypoglycaemia.
- Pump therapy should be available from a local multidisciplinary pump clinic for patients who have undertaken structured education.
- Targets for improvement in HbA1c and/or reduction in hypoglycaemia should be agreed

by patients using CSII therapy and their multidisciplinary diabetes care team. Progress against targets should be monitored and, if appropriate, alternative treatment strategies should be offered”

The other main source of national guidelines on disease management is the National Institute for Health and Care Excellence, NICE. There have been a number of iterations of guidance on the management of diabetes in children, but the most recent was published in 2015 and update in May 2023 [‘Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management.](#)

The recommendations state that different insulin delivery mechanisms should be considered and shared decision making used in agreeing the most appropriate for the child or young person. (See 'Insulin Therapy' recommendations 1.2.17 – 1.2.31, most of which were agreed in 2015.

Newer recommendations relate to continuous glucose monitoring devices (ie **not** devices that also deliver insulin). These do recommend the use of real time monitoring devices for children and young people. See Continuous Glucose Monitoring 1.2.60 – 1.2.70. The guideline also highlights links to the [rationale and impact section on CGM](#) as well as to the [evidence review of CGM in children and young people](#).

Position in NHS Highland

[NHS Highland has an Insulin pump pathway and criteria for adults](#), but this is 256 days past its review date.

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July 2023

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at spice@parliament.scot

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

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Annexe C

Scottish Government submission of 6 July 2023

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

Policy context

Diabetes is a clinical priority for the Scottish Government and we are committed to improving the care and outcomes for everyone living with diabetes.

In February 2021, we published a refresh of the [Diabetes Improvement Plan](#). The Plan outlines our commitments for diabetes care in Scotland and sets out an ambitious programme of work to deliver the aims and priorities of providing safe, effective and person-centred care, treatment and support to everyone living with diabetes in Scotland.

The Plan outlines eight priority areas and a focused set of actions overseen by the Scottish Diabetes Group. The priority areas are:

- Prevention and Early Detection of Diabetes and its Complications
- Type 1 Diabetes
- Person-Centred Care
- Equity of Access
- Supporting and Developing Staff
- Inpatient Diabetes
- Improving Information
- Innovation

Through the delivery of our Plan, we are committed to designing and developing services that meet the needs of everyone living with diabetes, with a focus on those that are experiencing health inequalities.

Diabetes Technologies

The Scottish Government is aware that the management of diabetes can be challenging, especially for children and younger people. We are committed to ensuring that people in Scotland living with diabetes can access clinically appropriate, safe, effective, and person-centred healthcare, treatment and support.

Diabetes technologies are a rapidly evolving area and we aim to ensure that everyone who would benefit from them have access at the earliest opportunity.

Our Diabetes Improvement Plan contains a key commitment to further increase access to existing and emerging diabetes technologies that can significantly benefit people with Type 1 diabetes and improve their quality of life.

Our national approach is to support the increase in provision of insulin pumps and Continuous Glucose Monitors (CGM) for people of all ages who would benefit. We have provided additional funding to Boards to ensure timely and affordable access to such technologies.

National Clinical Guidelines

It is a key recommendation in National Institute for Health and Care Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) that patients with frequent and or severe hypoglycaemia should be considered for insulin pump therapy as part of their treatment for diabetes. A link to the appropriate guidelines can be found at:

- NICE insulin pump guidelines: [insulin-pump-therapy-for-diabetes-pdf-374892589 \(nice.org.uk\)](https://www.nice.org.uk/guidance/374892589);
- SIGN insulin pump guidelines: (page 34, 5.3.2): <https://www.sign.ac.uk/assets/sign116.pdf>

In June 2022, NICE updated their guidance for the management of diabetes in children and young people. They recommend that all children and young people with type 1 diabetes should have access to CGM. A link to their updated recommendation can be found at: [Overview | Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management | Guidance | NICE](#).

Additional funding provided to NHS Boards to increase access to diabetes technologies

Between 2016 and 2021, the Scottish Government invested £15 million of additional funding to specifically support the increased provision of insulin pumps and CGM. A further £14.6 million was allocated in January 2022 to support increased access to diabetes technologies including closed loop systems.

It is important to note that this funding was in addition to, and not a replacement for, local budgets, and NHS Boards are expected to continue to fund provision locally to meet the needs of their local populations.

We also work closely the Diabetes Managed Clinical Networks (MCNs) within each board, including NHS Highland, to identify and resolve any issues raised by NHS Boards regarding accessing diabetes technologies to ensure that all resource is targeted to support the needs of local populations.

Accelerated National Adoption Pathway

We do recognise that there are still significant challenges for NHS Boards to provide technology to everyone who would benefit from it. We know that workforce capacity remains an issue across several boards and so have initiated the partnership with the Centre for Sustainable Delivery to tackle this directly.

The Accelerated National Innovation Adoption (ANIA) pathway team will support the roll out of diabetes technology, and in particular closed loop systems, as an innovation challenge. There has been significant engagement with the diabetes community and stakeholders have shared their views on the benefits of closed loop systems. A key focus of this project is reducing regional variation and making access to technology more equitable across Scotland.

Through the ANIA pathway workstream, the Scottish Government has invested a further £350,000 to accelerate the distribution of Closed Loop Systems. Closed Loop Systems are considered the most significant development in diabetes treatment in recent years and can transform lives, particularly for children and young people.

This investment will see a dedicated team created to support NHS health boards to rollout the technology faster and more efficiently across Scotland.

Conclusion

I hope this information provides the committee with assurances that the Scottish Government is committed to increasing access to diabetes technologies to all who would benefit. We will continue to work with key partners and stakeholders including third sector to ensure that everyone

living with diabetes in Scotland is able to access these important technologies.

Clinical Priorities Unit
Healthcare Quality and Improvement Directorate