

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](#).