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.