Lothian NHS Board

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Pubic Petitions Clerks Room T3.40 The Scottish Parliament EDINBURGH EH99 1SP Date 08 February 2013 Your Ref AMcM / AM Our Ref

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Dear Anne,

CONSIDERATION OF PETITION PE1404

Thank you for your letter of 14 January 2013 requesting an assessment of NHS Lothian's position to meet the target for provision of insulin pumps with particular reference to those under the age of 18 years.

I enclose the written response on behalf of NHS Lothian.

Yours sincerely,

Alex McMahon Director of Strategic Planning, Performance Reporting and eHealth



Headquarters Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Dr Charles J Winstanley Chief Executive: Tim Davison Lothian NHS Board is the common name of Lothian Health Board

CONSIDERATION OF PETITION PE1404

Petition PE1404 by Stephen Fyfe, on behalf of Diabetes UK Scotland, calling on the Scottish Parliament to urge the Scottish Government to conduct an immediate review into the provision of insulin pump therapy (CSII) in Scotland in order to address the low and inequitable access across the country.

NHS LOTHIAN RESPONSE

This paper outlines NHS Lothian's response to the request from the Scottish Parliament's Public Petitions Committee on the extent to which NHS Lothian are expecting the ministerial target on insulin pump therapy to be met by the end for March 2013 and outlining the reasons for reaching this assessment.

Adult Insulin Pump Provision (Over 18 Years)

The adult insulin pump provision in Lothian remains on target to ensure that 232 patients are on pump therapy by March 2015, as specified in the CEL 2012 (O4). In December 2013, there were 195 adults on an insulin pump with a further 6 individuals due to commence at the end of January 2013 and a further 7 individuals commencing in March 2013.

NHS Lothian is committed to commencing 70 adults on an insulin pump from April 2013. The service is currently planning for these pump starts throughout 2013/14 which will see the number of adults on a pump exceed the Scottish Government target for NHS Lothian.

Insulin Pump Provision Under 18 Years

NHS Lothian set out in the initial Action Plan submitted to the Scottish Government in March 2012 that achieving the target of 25% was deemed to be very high risk. Whilst NHS Lothian continues to make every effort towards meeting the ministerial commitment, alongside significant financial investment by NHS Lothian, it will not be delivered within the timeframe of March 2013.

There are currently 59 individuals under the age of 18 years with an insulin pump in Lothian, with 2 individuals under the age of 5 years due to commence in February 2013 and a further 6 adolescents, also planned to commence in February 2013. This will result in 67 children on pumps against an initial target of 91 children within NHS Lothian as set out in the CEL 2012 (O4).

Over the previous 10 months, NHS Lothian has put in place a range of actions to support increase delivery of insulin pumps for children. This has included funding to recruit additional Diabetes Nurse Specialists, Psychology and Dietetic staff, the majority of whom are now in post. As expected, there is effective joint working in NHS Lothian across paediatric and adult services to support the commitment for those over the age of 16 years being supported by adult services.

A further development is agreement for diabetes colleagues that a senior, experienced pump trained Diabetes Specialist Nurse and dietetic staff from the adult service will be seconded one day per week to the paediatric service for a 6 month period in the first instance.

There is currently capacity for 2 or 3 pump starts every two months, which will increase to every 6 weeks and then monthly following the completion of recruitment and training of nursing staff. NHS Lothian will continue to prioritise newly diagnosed patients under the age of 3 years for an insulin pump. Within Lothian, children under 7 years of age are commenced on insulin pumps in groups of 2 and children over 7 years of age are commenced in groups of 3. This group method ensures support for patients and parents starting within the same cohort.

However, as noted in the original action plan submitted to the Scottish Government in March 2012 and in the recent update in August 2012, NHS Lothian has consistently highlighted the difficulties in delivering on the 25% commitment by March 2013 with a projected achievement date of December 2013 at the earliest. The main reasons for the delay in achieving the target are set out below.

There are significant challenges associated with starting children on insulin pumps, which are very different to adult services. This requires close liaison with the children, patients, carers and others such as teaching staff. There remains an ongoing need to ensure that only children whom it is deemed clinically appropriate are offered insulin pump therapy and that this is provided within a robust, safe and supportive environment.

A key aspect has been the time taken to recruit specialist staff to support the increase activity for children starting on insulin pump therapy, whilst continuing to deliver a high quality main stream diabetes service. There is also a need to consider what can be done most effectively at a national level. One important issue that should be considered is the development of validated training in insulin pump initiation. As time passes and increasing number of patients of all ages start on pumps the mainstream diabetes service will need to be familiar will pumps as a common treatment. This training is beyond the capacity of local health board in-house training arrangements.

A further aspect that needs to be recognised is that whilst insulin pump therapy will have a positive impact for many children with diabetes, we are also aware that children who are eligible and have been offered insulin pump therapy but have not accepted. Some of the reasons for not accepting insulin pump therapy are set out below :

- Do not wish to wear a device all the time
- Happy with the present insulin regimen
- Do not want to do all the blood glucose testing / carbohydrate counting necessary with an insulin pump
- Wish to wait for more advanced technology

NHS Lothian remains committed to working towards the delivery of the ministerial commitment of 25% of eligible children on insulin pump therapy and will continue to build on the work achieved to date, with the aim of delivering the target by December 2013.

5 February 2013