

PE1404/Y

Petitioner Letter of 7 March 2013

Petition PE1404: Access to insulin pumps

Thank you for this further opportunity to respond to the recent set of submissions from Health Boards and the Scottish Government in response to our petition PE1404: “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.”

As the Scottish Government identify in PE1404/W, there has been welcome progress during 2012 and we wish to record our thanks to the clinical teams who have worked very hard over the last year to not only make progress against the target but who have delivered insulin pump therapy to 146 children and young people.

Meeting the target set in CEL04(2012)

The committee will recall the Scottish Government’s clear target set in March 2012 set out in CEL04(2012):

“On 21 October 2011, the Cabinet Secretary for Health, Wellbeing & Cities Strategy announced the decision to commit NHSScotland 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.”

CEL04(2012) our emphasis

The CEL also sets out the numbers required by each health board and across Scotland 487 under 18s were expected to start insulin pumps by March 2103.

However, as table 1 demonstrates, using responses to the Public Petitions committee from Health Boards and from data provided through written questions, it is clear that, except in a minority of Health Boards, the first target of 25% of under 18s having access to insulin pumps will not be met by 31 March 2013. In some areas it will not be met until 2015, well beyond the original target date by the Scottish Government. It is our understanding that the targets set in CEL04(2012) were drawn up in consultation with Health Board leads, so it is particularly disappointing that this target will be missed in so many Health Board areas.

Table 1

Health Board	Anticipated progress against 25% target for under 18s by March 2013	Anticipated date to meet 25% target for under 18s
Ayrshire and Arran*	11.3%	n/a
Borders	25%	Target met
Dumfries and Galloway*	6.3%	n/a
Forth Valley	18.1%	August 2013
Fife	17.5%	n/a
Grampian*	9.9%	March 2014
Greater Glasgow and Clyde**	17%	Summer 2013
Highland***	0%	December 2015
Lanarkshire	9.1%	March 2015
Lothian	18%	December 2013
Orkney*	20%	n/a
Shetland*	11.8%	n/a
Tayside	33%	Target met and exceeded
Western Isles	0%	April 29 2013

* Data from S4W-11803

** estimated data from PE1404/O

*** Service for under 18s starts April 2013

The most extensive delays are evident from those Health Board areas where no provision for children or young people existed and services were required to be developed from scratch with no existing staff, knowledge, or direction from Health Boards or budget in place.

Governance issues

Two Health Boards (Lanarkshire, Highland) have indicated that their own local Action Plans set out a planned delay towards full implementation of the 25% target. Lothian Health Board also state that reaching the target within the set timescale would be a **very high risk** activity. Health Board plans were submitted to the Scottish Government in 2012 and were offered for comment by the Scottish Diabetes Group. However we are unclear how these were agreed and what support has been offered by the Scottish Government to help reduce any expected delay. We are also unclear as to the sign off and governance processes surrounding the plans. Have the plans published by Health Boards been formally agreed on beyond Health Boards themselves, for example by the Cabinet Secretary, or do they stand as stated intent - in which case, what is the mechanism to address plans that state an intent to not reach the target?

With at a minimum three Health Boards needing at least a further year to implement their insulin pump service for children and young people we would now ask how the process will be managed for under 18s after 31, March 2013.

Implementing insulin pumps safely

Several Health Boards have quite rightly stressed the need to initiate an insulin pump service safely and in a manner that respects the varying life stages and choice of children and their families.

However, there are some points made by health boards that we would challenge and unless resolved will further delay full implementation of the 25% target.

Identifying and selecting suitable patients has been raised as an issue by NHS Fife and Grampian. NHS Grampian state that “demand is lower than expected and reject rates are higher than expected”, NHS Forth Valley also indicate that an initial lack of understanding of insulin pumps is also an issue. The lack of support and enthusiasm expressed by patients does seem to be peculiar to these few Health Board areas and without other evidence we can only assume that local clinical resistance still exists and consequently children and families in these areas are still requiring to inject insulin as much as six times a day. It is a concern to Diabetes UK Scotland that if these families lived in another area that was enthusiastic about insulin pumps and who accepted the clinical evidence as set out in SIGN 116 they would already have been accepted onto a pump programme.

NHS Lothian state that local health board in-house training is unable to deliver wider knowledge of insulin pumps to mainstream diabetes staff. We would ask NHS Lothian and other Health Boards who perceive this to be a problem to contact NHS Education for Scotland for advice on how this can be delivered and confirm what steps they are taking to address this.

NHS Lanarkshire also suggests that there are problems with local schools not being insured to be involved in the care of pupils on insulin pumps. We are pleased to see NHS Lanarkshire working with their local authority colleagues on this issue, but this should never have been as problem as **The Standards in Scotland's Schools etc Act 2000** places a duty on education authorities to educate children to their fullest potential. A failure of a school to deliver medication would also be a contravention of the **Equality Act 2010**. NHS Boards are statutorily responsible for the medical treatment of pupils in schools and there should be a joint agreement between NHS Boards and Education Authorities covering a range of issues including the administration of medicines in schools. Children should not be excluded from their education and/or appropriate health care measures on the basis set out by Lanarkshire Health Board.

Scottish Government

As we acknowledge the publication of CEL04(2012) has seen some progress and we look forward to seeing more children and young people being freed from multiple daily injections of insulin. As NHS Lanarkshire say: “The ministerial target was very helpful in focussing minds and funding for pumps has been a good catalyst for progress”. The Scottish Government have also allocated £2.5m to NHS procurement to purchase 558 insulin pumps and associated equipment to meet the expected demand arising from the CEL. However, with 202 adults and children starting on insulin pumps in 2012, we estimate that there are over 356 pumps awaiting distribution to Health Boards.

The Scottish Government have previously indicated that there will be a review of progress published soon after 31 March. We would, with this update, like to see a breakdown of how the £2.5m has been invested.

Conclusion

It is now almost one year on from the Scottish Government announcement, while there has been substantial and welcome progress that fact remains that CEL04(2012) has delivered insulin pumps to 146 children, there is still some progress to be met before the other 341 families receive confirmation that they will have the benefit of this technology.

The targets set were not 'stretch' targets. They were designed to correct Scotland's position at the bottom of the league table on pump usage in Europe, reduce inequity and, more importantly ensure children could access the best treatment for their diabetes care. The progress is welcome, but it does not fully address these points.

It is clear that one year on, there is some progress in delivering pumps but that there are substantial local variations in delivery. We ask the committee to examine the issues presented with the witnesses from NHS Western Isles and Greater Glasgow and Clyde, keep the petition open, and suggest that the Cabinet Secretary for Health and Wellbeing be invited to a future meeting of the committee in response to the issues raised and to report on the review of progress of insulin pumps being conducted by the Scottish Government soon after March 2013.

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Diabetes UK Scotland

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