

PE1446/R

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Mr Andrew Howlett
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The Scottish Parliament
EH99 1SP



LEGACY 2014
XX COMMONWEALTH GAMES
SCOTLAND

e-mail: petitions@scottish.parliament.uk

Your ref: PE1446

21 February 2014

Dear Mr Howlett

Thank you for your letter of 29 January, on behalf of the Public Petitions Committee, in relation to petition PE1446, from Dr Liza Morton on the care of congenital heart disease patients.

The Committee has asked for an update from the Scottish Congenital Cardiac Network (SCCN) on the progress towards the development of national standards of care for people living with adult congenital heart disease (ACHD) in Scotland.

I have been in touch with the SCCN and its commissioners, NHS National Specialist and Screening Services Directorate (NSD), to discuss the Committee's request and we have agreed that I reply jointly, on their and Scottish Government's behalf .

As you are aware, the Committee last considered this petition in September, and I very much welcomed the decision to defer its further consideration until now. This has afforded the SCCN a little time to continue its work with its stakeholders to promote the continued provision of safe and sustainable congenital cardiac services across Scotland.

It is important to remind the Committee about the steps that have been taken to ensure there is active patient involvement in the SCCN. Since October 2012, the network has held meetings involving the Scottish Association for Children with Heart Disorders, Somerville Foundation, the British Heart Foundation, and Chest Heart and Stroke Scotland to ensure that patients and the voluntary sector are fully engaged in its work.

The Scottish Association for Children with Heart Disorders and the Somerville Foundation are members of the network's steering group. The petitioners are also members of these two organisations and have been actively involved from the outset. As members of the network's steering group, these two organisations continue to assist in the development of the

network's strategic direction, including the approaches adopted for patient engagement, and the development of standards of care.

The SCCN has listened to and continues to listen, to its patients. This is evident from its current work plan, which can be accessed at:

http://www.sccn.org.uk/files/SCCN_Workplan_2013-14_for_website.pdf.

The Committee will wish to note that one of the network's objectives (page 9) is to begin work on adult standards of care, to discuss the work under way in England and discuss if and how it might support the delivery of high quality local and national care for people with congenital heart disease in Scotland.

I understand that the first meeting of the Adults Standards Group took place on 24 January. The feedback that I have received is that the meeting went well. There was open dialogue involving consultants, clinical nurse practitioners, referring cardiologists, NSD, representatives from England and Bravehearts and the petitioner.

There was considerable discussion about the process Scotland should agree in developing standards and how closely Scotland should align its standards to England. The Adult Standards Group has agreed to be guided by the principle that Scotland should adopt the English standards unless there is good reason not to, taking into account the need to allow for the specific needs of the service in Scotland and the Scottish ACHD patient population. For example, the service in Scotland will never meet the English standards on staffing numbers, particularly cardiologists and surgeons, because we will not have a volume of patients sufficient to maintain the skills and work plans of a higher number of specialists in line with England. The service in Scotland must be developed to meet the needs of our Scottish population and balance the need to deliver outreach clinics with ensuring that interventional cardiologists and surgeons are able to treat a sufficient number of patients to be able to maintain their skills.

There has been good progress made on agreeing the way forward with the first three adult standards. The group also discussed a request for ACHD specialist cardiologists to be made available on a 24/7 basis in local A&E departments. However the consensus view of the Standards Group is that this request is simply not realistic. It is not available for many other health conditions. NSD has however given a firm commitment to ensuring that access to advice from an ACHD specialist is available by telephone on a 24/7 basis.

The English standards are in the process of being drafted and NSD continues to attend UK meetings to keep up to speed with developments.

The Scottish Standards Group has agreed to meet regularly to support this work and NSD has advised that it expects the work to develop standards suitable for Scottish circumstances to be completed within 12 months.

I hope that this reply, the terms of which have been cleared by the Cabinet Secretary for Health and Wellbeing, is helpful.

Yours sincerely

Craig Bell
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The Quality Unit