

PE1446/M

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Mr Andrew Howlett
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The Scottish Parliament
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Your ref: PE1446

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Dear Mr Howlett

Thank you for your letter of 8 February, on behalf of the Public Petitions Committee, in relation to PE1446, from Dr Liza Morton, on the care of congenital heart disease patients. Please accept my apologies for the delay in replying to you. The Committee has asked three further questions in relation to congenital heart disease care. The Scottish Government's response follows:

When does the Scottish Government expect to progress the development of national standards for the care of adult congenital heart patients in Scotland, and what action can be taken in this regard whilst it awaits the updated standards from the Department for Health?

The Scottish Government is keen to ensure that children and adults living with congenital heart disease in Scotland can access high quality care, wherever they happen to live. The Cabinet Secretary for Health and Wellbeing approved a new Scottish Congenital Cardiac Network (SCCN), on 22 January.

The SCCN will be formally established on 1 April this year and will seek to ensure that an improved network of congenital cardiac care exists at local, regional and national level for people living with congenital heart disease. As part of the new network's remit, the SCCN will be asked to look at appropriate standards of care for congenital heart disease, to help ensure that services are safe, effective and person centred.

What funding has been made available to SACCS to ensure it is able to meet the increased demand for its services from the growing population of ACHD patients, as well as undertaking to locate and treat the large numbers of missing patients that there are estimated to be in Scotland?

NHS Boards are expected to plan, fund and deliver healthcare services to meet the needs of their local resident populations. NHS Boards are expected to meet the totality of a person's

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healthcare needs. The cost of caring for an individual may be met from several internal NHS Board budgets. The Scottish Government does not therefore, have centrally-held information on the total amount of funding that NHS Boards spend on caring for people living with congenital heart disease at a local level.

The Scottish Adult Congenital Cardiac Service (SACCS) however, is a national service which provides a highly specialist service for people who requiring dedicated advice, investigation, intervention or surgery for a congenital heart condition. The Committee might be interested to learn that National Services Division (NSD) has increased its funding for SACCS by 60% in recent years to help meet demand: A note of SACCS funding for the last three years follows:

2010/11:	£1,396,183
2011/12:	£1,772,367
2012/13:	£2,232,611 (forecast)

Local cardiac services have an important role in managing more routine episodes of care for people living with a congenital heart condition. The new SCCN will therefore support local cardiologists and local cardiac services across Scotland to increase their knowledge and awareness of the needs of people living with congenital heart disease and help ensure that SACCS continues to support people who require continued specialist care.

SACCS has also made significant efforts to ensure that people living with the condition that require continued specialist care are followed up. The Scottish Congenital Cardiac Network will work to promote the services available throughout Scotland and help ensure that in future, any person with congenital heart disease can receive high quality, person centred care.

When will the joint paediatric/adult national congenital cardiac managed clinical network referred to in your previous letter be launched, and what plans are there to utilise this to ensure that medical records of people living with congenital heart disease are accessible wherever a patient seeks or receives treatment?

The Scottish Congenital Cardiac Network will be launched on 1 April 2013. The new network presents the ideal opportunity for NHS Boards, regional planning groups, clinicians and people living with the condition to work together to plan and deliver improved services.

The network will work with local services across Scotland on the development of education and training, patient pathways, and access to specialist advice. It is expected that all of this work will ultimately improve the quality of services for people living with congenital heart disease in Scotland.

Work is on-going across NHS Scotland on a number of electronic solutions to ensure that electronic medical records are integrated and available regardless of where people present. The Scottish Congenital Cardiac Network will explore options to ensure that the relevant medical information is available when and where it is needed.

I hope this information is helpful.

Yours sincerely

Craig Bell
The Quality Unit