

PE1446/O

The Quality Unit

Planning and Quality Division

T: 0131-244 2763

E: craig.bell@scotland.gsi.gov.uk



**The Scottish
Government**
Riaghaltas na h-Alba

Mr Andrew Howlett
Assistant Clerk
Public Petitions Committee
The Scottish Parliament
EH99 1SP



LEGACY 2014
XX COMMONWEALTH GAMES
SCOTLAND

e-mail: petitions@scottish.parliament.uk

Your ref: PE1446

21 May 2013

Dear Mr Howlett

Thank you for your letter of 19 April, 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 slight delay in replying to you. The Committee has asked four further questions in relation to congenital heart disease care. The Scottish Government's response follows:

What will happen to patients while the Scottish Congenital Cardiac Network is being developed, particularly regarding emergency care?

It is understood that many people living with congenital heart disease value greatly the care and support they receive from NHS Scotland, particularly the national specialist service – the Scottish Adult Congenital Cardiac Service (SACCS) based at the Golden Jubilee National Hospital. However we acknowledge the petitioner's concerns about the standards of care received by some people at some local A&E departments. This issue cannot be resolved overnight.

This issue is however, a priority for the new Scottish Congenital Cardiac Network (SCCN), launched on 1 April 2013, which will promote the improvement of high quality, safe and person centred services for children and adults living with congenital heart disease in Scotland.

The network will start work this summer to explore the underlying issues that some people with congenital heart disease have experienced with A&E and other emergency services and identify solutions to address them. Representatives from NHS 24, emergency care, primary care, and obstetrics will all be involved in this work.

The network will also 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.

What is the timescale for the development of standards of care and their implementation?

As part of the network's remit, the SCCN will look at appropriate standards of care for congenital heart disease to help ensure that services are safe, effective and person centred. I understand the petitioners are aware that the network will promptly begin work on standards of care when its standards working group first meets in the summer.

How will the issues of out-of-hours care, non-specialist and local care, with GPs and obstetric care, be addressed?

As with local emergency (A&E) care, the network will explore the underlying issues and generate and implement appropriate solutions. The SCCN expects people living with congenital heart disease to have an active role in this process.

How exactly will the missing patients be located?

The adult congenital population includes a large cohort of patients with minor lesions, who do not need to be urgently followed up. The SCCN will examine data on the congenital cardiac population and will work to identify patients according to their need. The SCCN will aggregate data from local NHS systems and as a result, the population being followed up in various services will become clearer. The network will then be able to estimate the number of patients who require follow-up and this will inform the level of services required for people living with congenital heart disease.

Local cardiac services also have an important role in managing more routine episodes of care for people living with congenital heart disease. 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 the national Scottish Adult Congenital Cardiac Service (SACCS) continues to support people who require continued specialist care.

The network will promote of congenital cardiac care including appropriate pathways and protocols and it is envisaged this will raise awareness of congenital heart disease among local NHS providers and people living with the condition.

This awareness raising and use of available data will ultimately improve the existing rate of referrals and self-referrals to the national specialist service at the Golden Jubilee National Hospital.

People living with congenital heart disease including campaigners, have been actively participating and engaging with the new network. In order to help ensure that future service improvements are person centred, the Scottish Government very much hopes that this will continue.

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
The Quality Unit