

PE1446/Q

The Quality Unit

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**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
Our ref: A6806155

25 September 2013

Dear Mr Howlett

Thank you for your letter of 1 August 2013, on behalf of the Public Petitions Committee, in relation to PE1446 from Dr Liza Morton on the care of congenital heart disease patients.

I note that it is the Committee's intention to defer consideration of this petition until the new year. The Scottish Government welcomes this decision as it will give the Scottish Congenital Cardiac Network (SCCN) some time to work with local healthcare services to promote the continued provision of safe and sustainable congenital cardiac services across Scotland.

In the interim, I note that the Committee has asked two further questions in relation to congenital heart disease care. The Scottish Government's replies follow:

Is the statement in your letter of 21 May that there is "a large cohort of patients with minor lesions, who do not need to be urgently followed up", consistent with the recommendation, highlighted by the petitioner in her submission, that "all adults with congenital heart disease whatever the level of complexity are seen by an 'expert' from a specialist centre at least once and receive a written care plan"?

The developing clinical network for Adult Congenital Heart Disease (ACHD) will greatly improve the access to specialist review irrespective of the complexity of the cardiac lesion.

Specialists from the National Scottish Adult Congenital Cardiac Service (SACCS) will visit local ACHD clinics to augment local expertise, and help ensure that patients receive expert advice as close to home as possible. Including patients in correspondence about their care will also be encouraged to ensure that people living with the condition are fully up to speed and involved in decisions about their care.

All patients seen by SACCS already have a management plan in place. However the specialist support provided by SACCS will help ensure that local cardiologists and cardiac services across Scotland increase their knowledge and awareness of the needs of people living with congenital heart disease and deliver better outcomes.

What steps have been taken to ensure that there is patient involvement in the Scottish Congenital Cardiac Network and the development of national standards for the care of adult congenital heart patients, and is there scope for the petitioner to be invited to join the SCCN and contribute to this process?

The Scottish Congenital Cardiac Network has held meetings with 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 have been invited to join the network's steering group and the petitioners are members of these two organisations and have been involved in this process from the outset.

As members of the network's steering group, these two organisations will be able 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. It is envisaged that other relevant voluntary sector organisations and patients will also be involved in the network should they wish. It is expected that by involving patients and their representatives in the work of the network that the resulting improvements in local services will be truly person centred.

National Services Division (NSD) of NHS National Services Scotland have an agreed timetable to review the SCCN's progress. The Committee might wish to note the proposed timetable for this work:

- Initial progress review – 23rd September 2013
- Interim progress review – March/ April 2014
- Annual performance review – October 2014

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