**PE1446/D**

The Quality Unit
Planning and Quality Division

T: 0131-244 3308
E: elizabeth.porterfield@scotland.gsi.gov.uk

Andrew Howlett
Assitant Clerk to the Public Petitions Committee

e-mail: petitions@scottish.parliament.uk

Your ref: PE1446
Our ref: A4725935
21 December 2012

Dear Mr Howlett

Thank you for your letter of 28 November 2012 about the above Petition, setting out questions for the Scottish Government. I will take each of these in turn in the paragraphs below.

- **What plans are there to develop national standards of service for adults with congenital heart disease in Scotland?**
- **Why has none of the 2006 guidance "A Commissioning Guide for Young People and Grown Ups with Congential Heart Disease" used in England and Wales been adopted in Scotland?**

The Scottish Government is committed to ensuring that people living with congenital cardiac conditions have access to high quality safe, effective and person-centred care.

In 2006 the Department of Health (DH) published their Commissioning Guide for Services for Young People and Grown ups with Congenital Heart Disease (GUCH). This document provided a set of standards for the delivery and commissioning of services in England and Wales.

In 2009 the Scottish Government Better Heart Disease and Stroke Care Action Plan was published. It stated that, *"National Services Division (NSD) and the Golden Jubilee National Hospital (GJNH) should work towards achievement of the DH commissioning standards for adult congenital heart disease and address issues of awareness raising, development of referral pathways and data collection".*

To deliver this action, NSD had hoped it would be possible to address standards as part of the work that was commenced in 2010 via a working group including NSD and national service colleagues, representatives from referring services, NHS regional planning and patient group(s). Although not all of the English standards were applicable to the Scottish service, work was started to audit the national service against these standards. However, this has been delayed because at the same time (2010) DH set up a review of the 2006 commissioning standards. In these circumstances, it was felt sensible to await updated standards against which to begin to look at developing standards appropriate for the SACCS service.

In addition, a new joint paediatric/adult national congenital cardiac managed clinical network will be launched early next year, which will aim to support cardiologists and local services across Scotland to increase their knowledge and awareness of the needs of people living with congenital heart disease. The first task for the adult subgroup of the network will be to look at standards appropriate for the Scottish service.

- **Is there an explanation for the difference between the numbers of patients registered with SACCS and the estimated number of adult congential heart patients in Scotland?**

The 2011-12 SACCS annual report confirmed that –

“The exact prevalence of adult congenital heart disease in Scotland is unknown. However, combining the known birth incidence with expected survival, in excess of 15,000 adults with congenital heart disease are estimated to be living in Scotland. Of this group, over 3000 are estimated to need regular contact with the Service with a further 7000-8000 patients requiring single or intermittent review. Currently SACCS is aware of over 3700 patients with around 1900 falling into the group requiring closer involvement with the Service. The lower than expected number of patients is a common finding in many countries. Although multi-factorial, a significant proportion of the difference will be patients who are known to have congenital heart disease but who have been lost to follow up for one reason or another.”

- **What are your views on what the petition seeks?**

Scottish Government awaits with interest the outcome of the Public Petitions Committee’s consideration of this petition. In the meantime, I hope the foregoing information is helpful.

Yours sincerely

ELIZABETH PORTERFIELD
Head, Planning Team