

**PUBLIC PETITIONS COMMITTEE CONSIDERATION OF PE1446
QUESTIONS / ISSUES ARISING FROM COMMITTEE MEETINGS**

TUESDAY 8 DECEMBER 2015

Scottish Government –

- Please provide a written update on the work currently being undertaken on the petition since the Committee’s last update was received.

TUESDAY 13 JANUARY 2015

Scottish Government–

- The Committee brings to the Scottish Government’s attention the petitioner’s most recent submission of 8 January 2015.

TUESDAY 28 OCTOBER 2014

Scottish Government—

- Can you provide an update on the progress towards the development of national standards of care for people with adult congenital heart disease in Scotland?

TUESDAY 25 JUNE 2013

Scottish Government—

- Is the statement 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”?
- 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?
- Can the Scottish Congenital Cardiac Network provide an update on the progress towards the development of national standards for the care of adult congenital heart patients in Scotland? (Requested by the Committee on 29 January 2014)

TUESDAY 16 APRIL 2013

Scottish Government—

- What will happen to patients while the Scottish Congenital Cardiac Network is being developed, particularly regarding emergency care?
- What is the timescale for the development of standards of care and their implementation?
- How will the issues of out-of-hours care, non-specialist and local care, with GPs and obstetric care, be addressed?
- How exactly will the missing patients be located?

TUESDAY 5 FEBRUARY 2013

Scottish Government—

- When it expects 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?
- 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?
- 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?

TUESDAY 27 NOVEMBER 2012

Scottish Government—

- 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 Congenital Heart Disease” used in England and Wales been adopted in Scotland?
- Is there an explanation for the difference between the numbers of patients registered with SACCs and the estimated number of adult congenital heart patients in Scotland?
- What are your views on what the petition seeks?

NHS England—

- What is the status of guidance relating to adult congenital heart patients, and is it subject to further review and/or implementation?
- What are your views on what the petition seeks?

Scottish Adult Congenital Cardiac Service—

Scottish Association for Children with Heart Disorders—

**Children’s Heart Federation—
British Heart Foundation—**

- What are your views on what the petition seeks?

**Bravehearts—
Health and Social Care Alliance Scotland—
Somerville Foundation—**

- Following the oral evidence session on 27 November, where the Committee heard evidence from the petitioner, do you wish to submit a revised written response to the petition or do you wish your original letter to be used?