



Briefing for the Public Petitions Committee

Petition Number: [PE1446](#)

Main Petitioner: Dr Liza Morton

Subject: Scottish Standards for the Care of Adult Congenital Heart Patients

Calls on the Parliament to urge the Scottish Government to mandate National Standards for the care of Adult Congenital Heart Patients and to adequately resource the Scottish Adult Congenital Cardiac Service (SACCs).

BACKGROUND

The Petitioner is calling for the introduction of national standards for care of adults with congenital heart conditions in Scotland, similar to the national standards for care for England that are under review by the Department of Health. The Petitioner is also calling for “adequate” resources to be provided to the Scottish Adult Congenital Cardiac Service (SACCs).

What is Congenital Heart Disease?

[NHS Inform](#) states that Congenital Heart Disease (CHD) is a general term used to refer to a series of birth defects affecting the heart. It is the most common type of birth congenital condition found.¹ Half of all babies born with CHD will require immediate surgery after birth, while the other 50 per cent may require future surgery or medication at some point during childhood. In some cases CHD is diagnosed during an ultrasound scan prior to birth. More commonly, it is a condition that is identified once a baby is born.²

NHS Inform state that the outlook for children with congenital heart disease varies depending on the type and severity of the heart defect. However, in most cases, the outlook is reasonably good. Due to advances in heart surgery, NHS Inform notes that 85 per cent of children with CHD will survive into adulthood. As more people with CHD are now living into adulthood, new challenges are posed for the healthcare system as some adults with CHD have complex health needs and require lifelong specialist care.

¹ Healthcare Improvement Scotland and National Services Division (2012) “Scottish Perinatal and Infant Mortality and Morbidity Report” Edinburgh: Healthcare Improvement Scotland. Available [here](#)

² British Heart Foundation [website](#) - Information on Congenital Heart Disease (Accessed 1 November 2012)

National Standards for Services to Adults with CHD (England)

Given that there are greater number of children with CHD living well into adulthood³ - partly as a result of improvements in paediatric care and treatment - there is now greater demand for adult cardiac services among this group. In response, the Department of Health produced a [guide](#) for service commissioners working with young people and adults with congenital heart disease.⁴ This set out expected service levels to be provided by the NHS in England for the care of adults with CHD, both during the important transition from children's services and throughout adult life.

In May 2012, NHS Specialised Services (England) published a [review report](#) inviting views on NHS services for adults with CHD. The report notes the growing number of adults living with congenital heart disease in England, with CHD affecting a number of areas of people's lives. In this context, there is concern to ensure that high quality specialist advice, services and care are available to meet this group's needs. The report recognises that specialist care has not always been developed in a planned and systematic way, and that high quality service provision is not always available across the whole of England. While there are examples of good practice, the review aimed to ensure that this high quality was available to everyone regardless of what part of the country they live in.⁵

This document sets out areas for improvement and a model of how adult CHD services could be organised within the NHS in England. It also sets out draft minimum standards (draft national designation standards) believed to help the NHS deliver excellent care in the future. Accompanying the above report is a further [document](#) from NHS Specialised Services⁶ focusing specifically on the proposed model of care and draft designation standards. It is recommended that this document is read in conjunction with the review report.

As the Petitioner notes, as yet there has not been any public consultation or publicly held discussion on the development of national standards of service for adults with congenital heart disease in Scotland.

Provision for adults with CHD in Scotland

The main provision for adults with congenital heart disease in Scotland comes through the Scottish Adult Congenital Cardiac Service (SACCS) – formerly known as Grown Up Congenital Heart Disease Services. Designated in 2007,

³ The term 'grown-up congenital heart disease' (GUCH) is sometimes used to refer to adults with congenital heart disease.

⁴ Department of Health (2006) "A Commissioning Guide for Services for Young People and Grown Ups with Congenital Heart Disease (GUCH)". Available [here](#)

⁵ NHS Specialised Services (2012) "Improving Everyday Life for Adults with Congenital Heart Disease" Available [here](#)

⁶ NHS Specialised Services (2012) "Draft National Designation Standards and Proposed Model of Care". Available [here](#)

the SACCS provides a range of services for adults with CHD, including surgical procedures and interventional cardiology services⁷.

The [SACCS](#) operates from a base at the Golden Jubilee National Hospital in Clydebank, providing specialist advice and care for people aged 16 and over throughout Scotland who have congenital heart defects. In the first full year of operation (2009/10) the service was able to offer a one-stop outpatient clinic where patients received checks to allow timely decisions about the use of potentially invasive forms of clinical care (e.g. surgery or interventional cardiology). Almost 2,000 patients were seen in the 179 clinics held during 2010/11. The service also works closely with the teenage clinic at the Royal Hospital for Sick Children in Glasgow to provide continuity of care from paediatric to adult services. SACCS clinicians also provide support for pregnant women with congenital heart conditions.⁸

A recent article in [The Herald](#) (17 September 2012) highlights that for adults with CHD, the Golden Jubilee Hospital offers a valuable service. However, the absence of 24 hour access to this facility leads to patients who need treatment outside hours using general hospitals that are not equipped or informed about how to deal with adult patients with CHD. In response to experiences of poor service elsewhere, the article suggests that patients are waiting for the Golden Jubilee Hospital to open before going for treatment, which is said to be both “risky and frightening”. The article also reports that the specialist service in Clydebank is now stretched, having only three consultants and one nurse in post. The concern is that demand may be beginning to exceed resource availability.

Audit Scotland: Cardiology Services

Audit Scotland’s report on [Cardiology Services](#)⁹ noted that a range of national activity had been pursued since the mid-1990s to improve services for people with heart disease. The Scottish Office, the Scottish Executive and now the Scottish Government have all identified heart disease and stroke in Scotland as national priorities¹⁰, with a number of national strategies and targets produced with the aim of preventing heart disease, improving treatment and reducing waiting times.

⁷ Adult Congenital Cardiac Service [website](#) (National Services Division, NHS) Accessed 1 November 2012

⁸ The most up to date publicly accessible annual report for the SACCS is for 2009/10 (available [here](#)). Based on personal communication with the Scottish Government we are informed that more up to date annual reports are available on request from National Services Division, NHS.

⁹ Audit Scotland (2012) Cardiovascular Services. Available [here](#)

¹⁰ Audit Scotland highlight the following publications: The Acute Services Review, Scottish Office Department of Health, June 1998; Coronary Heart Disease/Stroke Taskforce Report, Scottish Executive Health Department, 1999; Coronary Heart Disease and Stroke Strategy for Scotland, Scottish Executive Health Department, October 2002; Coronary Heart Disease and Stroke in Scotland Strategy Update, Scottish Executive Health Department, December 2004; Better Health, Better Care: Action Plan for NHSScotland, Scottish Government, December 2007; Better Coronary Heart Disease and Stroke Care: A consultation document, Scottish Government, July 2008 (Audit Scotland, 2012).

The Scottish Government's strategy¹¹ on heart disease and stroke focuses on improving services for people with heart disease or who have had a stroke, as well as preventing cardiovascular disease and tackling health inequalities. The action plan set out 32 actions to be delivered by the end of 2011, including one focused on improving adult congenital cardiac services. Audit Scotland note that, while the Scottish Government had set up a National Advisory Committee on Heart Disease to monitor NHS board's performance against the action plan, progress to address the targets was initially slow. However, since 2010, the Scottish Government has been involved in strategic leadership to ensure implementation of the action plan.

To help measure progress against the actions and targets set, Healthcare Improvement Scotland developed indicators to support the Scottish Government and NHS boards to measure and monitor their performance against clinical standards.¹² To date, there is no publicly available information on progress toward the target of improving adult congenital cardiac services in Scotland.

SCOTTISH GOVERNMENT ACTION

The Scottish Government report [Better Heart Disease and Stroke Care Action Plan](#) stated that NHS National Services Division and the Golden Jubilee Hospital should work towards achievement of the Department of Health commissioning guidelines for adult congenital heart disease, including awareness raising, development of referral pathways and data collection.

Following publication of this action plan, NHS National Services Division and the SACCS¹³ were required to:

- Develop outreach clinics to facilitate the provision of local care with continuing support from the specialist centre.
- Develop proposed referral pathways.
- Develop proposals for a shared care model.
- Implement the Department of Health's Commissioning Guide "Adult Congenital Heart Disease: A Commissioning Guide for Services for Young People and Grown Ups with Congenital Heart Disease".
- Develop and maintain a database of people in Scotland living with a congenital cardiac condition to inform service improvements.

The Scottish Government has stated that representatives from Braveheart (the Scottish ACHD patients association) have been involved in work to design patient pathways and will be involved in work to adapt the English adult congenital heart disease standards for Scotland. The Scottish Government has also stated that "Scottish standards will be consulted on when the time is appropriate". Finally, it is noted that SACCS is working to

¹¹ Scottish Government (2009) Better Heart Disease and Stroke Care Action Plan. Available [here](#)

¹² Links to these reports can be accessed [here](#)

¹³ NHS Scotland (2012) "The Scottish Adult Congenital Cardiac Service North of Scotland Update" Available [here](#)

develop outreach clinics and a joint clinic is now up and running in Inverness¹⁴ and a second clinical nurse has been appointed to the SACCS service and will soon take up post¹⁵.

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7 November 2012

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¹⁴ The Scottish Government has highlighted that SACCS are commissioned only to provide the national specialist element of the service, not the regional and local components, which is the responsibility of the NHS boards.

¹⁵ Information from personal communication with the Scottish Government.