

PE1446/I

PETITION [PE1446](#)

Calling on the Scottish 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).

British Heart Foundation Scotland

What are your views on what the petition seeks?

As the nation's heart charity British Heart Foundation (BHF) Scotland wishes to see continued improvements in the quality and safety of NHS services, which will benefit people living with heart disease in terms of better clinical outcomes, improved quality of life and better experiences of NHS care.

Continuing improvements in diagnostics and treatment have led to steady increases in the numbers of children growing up with congenital heart disease and surviving to reach adulthood. The Scottish Government ([Better Heart Disease and Stroke Care 2009](#)) estimated that by 2010 there would be 15,600 patients in Scotland living with adult congenital cardiac disease. The Scottish Adult Congenital Cardiac Service has been established at the Golden Jubilee National Hospital, Clydebank as a designated National Service covering all of Scotland.

BHF Scotland played a very active part in the process of developing Heart Disease Clinical Standards for Scotland published by NHS Quality Improvement Scotland (now Healthcare Improvement Scotland) in 2010. Congenital heart disease is not covered by the Heart Disease Clinical Standards, these being focused on services for coronary heart disease, arrhythmias, and heart failure. Such standards give NHS boards objective criteria against which to compare services and identify where there is need for improvements.

The development of these clinical standards took approximately 2 years and was quite labour intensive, with input from a broad range of clinicians, NHS managers, academics, voluntary sector representatives and patient/carers. It would, in our view, be inappropriate to go through the same process to develop standards for congenital heart disease when these are currently in development as part of the [NHS Specialist Commissioning review of ACHD](#) services. The review has consulted on and agreed a model for provision of services for ACHD patients in 2012 and is now defining the standards against which service provision can be assessed. The development of these standards has been robustly clinically led, involved representatives of broad range of relevant patient organisations, and has had representation from NHS Scotland colleague. There will need to be a process of ratification by Healthcare Improvement Scotland before these are used by the National Adult Congenital heart disease service and local partners, to benchmark themselves and identify areas for improvement, but this should be a far less labour-intensive process than that required for the Healthcare Improvement Scotland standards.

In its [2009/10 annual report](#) the service itself acknowledges areas for service improvement,

'Whilst the Service does provide care across Scotland, a degree of inequality of access to specialist care between the regions undoubtedly exists. A review of the referral pathways and use between the of the Service in conjunction with local cardiologists underway will help to improve access to the Service whilst clarifying the regional components of care allowing appropriate resource allocation...(including a stated desire to meet National (UK) standards)

Despite the marked development of the SACCS service in Glasgow over recent years, we do not yet meet all of the National Standards. Whilst aspects of these standards will have to be modified to overcome the geographical distances in Scotland, further development of the Service will be required to bring the service into line with other units in the United Kingdom. A gap analysis will shortly be undertaken to clarify the areas in which further investment will need to be considered.'

Better Heart Disease and Stroke Care describes it as essential that the service should reflect the indicators of high-quality care included in the commissioning guide published by the Department of Health in 2006 and requires the service to work towards achieving these along with addressing other issues of awareness raising, development of referral pathways, and data collection. This commissioning guide has been followed by the development of standards in England and there are plans to audit services in England against these criteria later this year.

So while it has been national policy for a number of years that the Scottish service should align itself with indicated high-quality care south of the border, and the service itself seeks to bring the service into line with other units in the United Kingdom, the petitioners present evidence that progress has been slow. We would agree with this criticism, however, would also hope that the development of the clinical consensus as part of the process will lead to timely implementation once agreement on these standards has been reached.

In summary, we support the petitioners' aims of introducing national standards for the care of Adult Congenital heart patients and we believe that these should have the same status as the current Heart Disease Clinical Standards for Scotland published by NHS Quality Improvement Scotland, which cover a range of other heart conditions. It is essential that following the introduction of such standards there should be funds available to support areas identified for service improvement.

BHF Scotland
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