

PE1446/H



Response from the Golden Jubilee National Hospital (NHS National Waiting Times Centre Board), to Petition PE1446

Introduction

We welcome this opportunity to feedback on the SACCS petition.

The Golden Jubilee National Hospital is one of the UKs largest heart and lung centres. It provides all adult heart and lung surgery for the West of Scotland – including all bypasses, heart valve surgery and other complex procedures.

In addition, Interventional Cardiology services, as well as three of the country's national services – the Scottish Advanced Heart Failure Service (including the heart transplant unit), the Scottish Pulmonary Vascular Unit and the Scottish Adult Congenital Cardiac Service are provided at the hospital.

Due to the nature of our organisation, we are perhaps able to offer a unique perspective on the petition. Therefore, we have responded on the areas where we have gained direct or indirect experience as providers of the Scottish Adult Congenital Cardiac Service (SACCS).

Background

The Scottish Adult Congenital Cardiac Service (SACCS) is committed to providing high quality care to adults living with adult congenital heart disease (ACHD) throughout Scotland.

There are estimated to be more than 15,000 adults living with ACHD in Scotland. As a result of the success of paediatric cardiology cardiac care, this number will continue to grow with already far more adults living with congenital heart disease than children.

A large proportion of adults with ACHD will require ongoing cardiology follow-up throughout their lives. Care of the adult with congenital heart disease is highly specialised and increased demand for expert care is inevitable as the numbers increase. Added to this, the need to provide good care close to the patient's home with access to experts when required has provided a major stimulus for the redesign of services throughout the UK.

SACCS was commissioned in 2007 to provide specialist surgical and catheter interventional care for adults living in Scotland with ACHD. The service is based within the Golden Jubilee National Hospital in Clydebank providing the National Centre for ACHD care in Scotland.

The rapid growth in demand of the service combined with a desire to ensure equity of access and good local care delivery led to a major review of ACHD care in Scotland in 2010.

A wide range of stakeholders met to review the structure of ACHD care in Scotland and to consider the way forward for the future. The conclusions from this process led on to assist in the design of the proposed strategy for delivery of ACHD care (The Scottish Adult Congenital Cardiac Service. The future delivery of the service – a strategy document, June 2012).

The current strategy

SACCS has always recognised the National Standards in England and Wales as the foundation for achieving best current practice and measured the National Service against the 2006 standards as part of the review process in 2010 (see also Annual Report 2010-2011). The need to meet these Standards has defined the strategy for future ACHD care in Scotland.

SACCS and NSD have been observers in the ongoing revision of the National Standards in England and Wales. A similar model of care to that proposed for the rest of the UK is detailed in the Scottish Strategy. A network of local care providers throughout Scotland will work with SACCS to deliver a shared care model that ensures patients receive care as close to their homes as possible but can access an expert level of care when required.

Central to this model will be the support of local services including ACHD clinics by SACCS, whilst maintaining the highest quality expert care with the National Centre itself. The network will additionally be supported by a structured education programme for current and future cardiologists and a focus on optimal communication and IT solutions.

Links with the paediatric cardiac network through the overarching Scottish Congenital Cardiac Network encompassing both paediatric and adult networks will assist in improving transition and help co-ordination of care between the services.

Person centred

Patient, relative and carer involvement in the service is of paramount importance to SACCS. Feedback through our Board's existing communications channels allows the service to improve the quality of care provided and ensure a person centred approach that listens to, validates and respects the patient's experience of their condition and knowledge about their symptoms.

Patient involvement has shaped our strategy and will continue to be the cornerstone of our service going forward. Over and above the strategy engagement programme across Scotland, we have established a small working group of service users who are developing a terms of reference and operating structure which we anticipate will lead to a full operational patient panel in the spring. This advisory panel will provide feedback on the care provided within the National Centre whilst maintaining a patient focus on the development of the service.

A patient forum held in September 2012 provided wider feedback on the care pathway and will be repeated at regular intervals to help guide the development of the network. Links with the rest of the UK will be maintained through the Somerville Foundation.

Challenges

Implementation of the strategy and helping to ensure success of the network are immediate challenges for the Service. Further challenges that lie ahead include the need to offer patients who have been lost to follow-up appropriate access to specialist healthcare. There are many reasons for the disruption to ongoing follow-up including equity of access to services, failure of referral when patients move location, lack of transition or even historical discharge practices within paediatric services.

The number of people with ACHD known to SACCS in Scotland reflects those patients attending recognised ACHD clinics in Scotland. In keeping with other countries, the number of patients known to specialist services is less than that estimated from birth incidence and observed survival statistics. A major explanation for this is the high loss to follow-up rates in all countries. Part of the development of ACHD care in Scotland will inevitably involve strategies to offer access to specialist healthcare for all patients with ACHD.

Going forward

The vast majority of the existing Standards in England and Wales will need to be met within Scotland to ensure the same high quality of care. It is anticipated that this requirement will remain following the revision of the Standards. Nevertheless, there will be variance with what is felt to be optimal care in Scotland. The development of Scottish Standards will be one of the first tasks of the Scottish Congenital Cardiac Network.

Conclusion

We welcome the opportunity this petition has provided us to highlight the current service and future strategy for SACCS patients.

The Golden Jubilee National Hospital is home to one of the largest heart and lung centres in the UK, and as such, we strive to be a centre of excellence.

Once fully implemented, we believe that the current strategy will deliver a consistent, equitable, Scotland wide referral pathway for Scottish Congenital Cardiac patients through:

- a shared care model that ensures patients are supported by local provision but can access expert level of care when required;
- specialist clinical input at local ACHD clinics from the National Service;

- a clinical Adult Congenital Heart Disease network supported by the National Service managed through a governance framework;
- a structured education and training programme for current and future cardiologists to secure the sustainability of ACHD care; and
- an improved model of effective communication and clinical support to ensure the highest quality of clinical care is provided.

We therefore completely support the drafting of Scottish Standards for ACHD care, provided:

- the same high level of care embedded within the National Standards from England and Wales remains the major aim; and
- there is an undertaking to provide the necessary resources to meet these Standards once agreed.