



## **Public Petitions Committee Consideration of PE1446 Questions Arising from Committee Meetings Response from the Children's Heart Federation**

### **About us**

The Children's Heart Federation is the UK's largest children's heart charity and an umbrella organisation representing 22 heart charities and support groups. CHF provides a voice to children and young people who are born with heart conditions, as well as providing support, advice and grants.

### **Petition 1446**

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).

### **What are the Children's Heart Federation's views about what the petition seeks?**

The Children's Heart Federation (CHF) has supported the development of national standards for care of congenital patients in England through the Safe and Sustainable Review for children and now the ACHD review currently taking place in England directed towards care for adults with CHD.

We have supported these reviews, and throughout stressed a number of key principles which should underpin changes. These were the need for high quality treatment throughout the patient care pathways; equal access to quality services; the recognition that the needs of acquired heart disease patients can vary from congenital heart patients; the need to develop effective heart networks that provide care as close to the home as possible and the need to make data accessible that allows patients to understand the quality of service throughout the system.

**We believe these principles enshrined in new standards of care will deliver better care, outcomes and improved patient experience. This is why we would support the development of standards of care for adults with congenital heart disease in Scotland.**

### **Driving forward towards the highest quality services:**

There have been great advancements in medical treatment for those with congenital heart conditions, with new treatments available and examples of

top quality treatment leading to increased life expectancy for many. This means that today there are for the first time, more adults living with congenital heart disease than children. This is certainly something to celebrate, however it presents a whole new set of challenges, and advancements must be encouraged further along with improvements to care and how it is planned. It is vital that CHD is treated as a long-term condition and patients receive the best quality care along their life-course.

Whilst the quality of treatment is largely good, it is sometimes patchy and quality in some instances variable. This is why CHF support the development of new standards of care which aim to ensure that all patients have access to the highest quality specialist surgical units. It is important units offer round the clock care and can reduce the levels of cancellations due to emergencies. We feel that new standards must be led by independent expert clinicians with input from patients and their representatives.

There must be a strong culture of learning and ongoing professional development, for all forms of medical professionals. Mentorship and appraisal should be a common feature of life for medical professionals ensuring that their skills continue to be refreshed and they are continually advancing. There should be the sharing of expertise and clinical support as well as leadership across cohesive care networks, ensuring that at the specialist surgical units, cardiology centres or more local and community level care, there is improved care and patient experience.

### **Ensuring that the pathways of care are clearly defined:**

Across all ages of treatment it is important to have clear care pathways; for antenatal care and scans, for children or for adults with CoHD. Clear, well drawn, easy to understand pathways, will ensure consistent care across the country as well as enabling patients to best understand their treatment, what to expect and how to hold to account their healthcare providers. Far too often the routes patients must follow are a complex mystery and access to certain services and timescales seem arbitrary. Patients and young people want to have clear indications of what length of time they can and should be able to expect before treatment with clear routes to access services.

### **A better managed transition between child and adult services:**

The transition between childhood and adulthood is a difficult time for any young person, let alone those with an ongoing medical condition. These difficulties are often compounded further by the movement between child and adult services in the health system. The problems with transition are well documented and discussed.

A successfully managed transition process clearly needs to look at the whole family. **Young people's** needs and wishes will often vary, as will the level of involvement of their parents in their care. This needs to be taken into

account and a one-size fits all approach to transition will not be suitable for young people with long-term and complex conditions. It is vital that during this crucial phase, young people do not fall out of the system.

### **A stronger role for the voices patients, young people and their families:**

Patients, young people and their families must be at the centre of their care and at a suitable age be involved in decisions about services. They should be involved in planning services. Patients tell us often that they are not given or told of their right to second opinions. It is essential that patients and young people are given information about external bodies of support and information who can offer independence advice and guidance. Patients and young people should be made aware and given a real choice about what hospital, what treatment and what clinician is involved in their care.

### **The promotion of self-management for young people and patients:**

The growing focus in healthcare on the importance of patient self-management is very welcome. This implementation of these advances in practice however is patchy. Patients must be involved in their care. **Self-management of individuals' conditions must be a priority, allowing maximum independence.** Currently the NHS does not do all it can to ensure that patients are supported to live independent lives. Focus on care close to home where possible and self-management of their condition must be a priority for all patients including those with CoHD.

### **Improved data collection and clearer measures of service quality:**

Data about the quality of services and outcomes is lacking. It is clear that if improvements are to be made, meaningful choice an option for patients and young people, then good quality data is needed on which services can be judged. There should be greater measurement of patient satisfaction with the services they use and it should be ensured that questionnaires are available for patients and young people to give views about the quality of the service they received to feed into Patient Reported Outcome Measures (PROMS).

The Central Cardiac Audit Database (CCAD) which is an information resource for patients to look at surgical outcomes is not easy to navigate or to understand for many. Patients also want more rounded and adequate analysis of care quality on which to base their decision about treatment options. They particularly want to see measures of quality based on morbidity. In determining the quality of care, patients with CoHD also value indicators such as the rate of cancellations of surgical procedures and the facilities on offer at units.