



Lord Ribeiro  
Chairman  
Independent Reconfiguration Panel  
6<sup>th</sup> Floor  
157-197 Buckingham Palace Road  
London  
SW1W 9SP

29 December 2012

Dear Lord Ribeiro

**Referral to Secretary of State for Health**  
**The Safe and Sustainable review of children's congenital heart services**

I am writing on behalf of the Ben Williams Trust, a charity that supports the development of excellent paediatric cardiac electrophysiology services. It is our opinion that the decision to close Paediatric Cardiac Surgery at the Royal Brompton following the Safe and Sustainable review of children's congenital heart services is fundamentally flawed. Our comments in this submission are necessarily restricted to paediatric cardiac electrophysiology services, although the impact of closure will be equally severe in other areas where the Royal Brompton provides services of world-class quality.

Paediatric Cardiac Electrophysiology is a specialist discipline within the already specialist field of Paediatric Cardiology and we believe that the treatment of children and adults with arrhythmias (abnormal heart rates) requires proper consideration, particularly given the risk of sudden death associated with these types of condition.

There are factors fundamental to the continued provision and development of Paediatric Cardiac Electrophysiology services in London that in our opinion were not addressed by the original Consultation Document, and therefore not taken into consideration by the JCPCT during the decision making process. Indeed, surprisingly, there was no reference to arrhythmia related services at all.

1. Paediatric Electrophysiology Services Currently Provided by the Royal Brompton

The Royal Brompton currently provides paediatric electrophysiology services that are highly rated and appear to meet all the Safe and Sustainable criteria. These services include:

- Two full time, dedicated Paediatric Cardiac Electrophysiology Consultants operating in a unit that is a national referral centre for children and adults with heart rhythm problems. The consultants see over 1,000 children a year and undertake the full range of transcatheter and pacing interventions;
- An inherited cardiac disease clinic, in which over 500 children and adults have been seen in the last year, and which most importantly allows families to be treated together rather than as unconnected individuals;
- A full time, dedicated Paediatric Cardiac Electrophysiology Nurse Specialist. The nurse provides support to families across the wide geographic area covered by the hospital, visiting homes and liaising with schools, GPs, and other care workers and interested parties. She is also available to provide physical and emotional support to children who may be at risk of sudden death and to their parents and families;

- Full links with the adult electrophysiology services at the Royal Brompton, providing the benefits set out in (2) below.

We see no evidence that these services and their rapid development been recognised and considered in the Consultation Document as part of the overall framework of paediatric cardiac care and children's congenital heart services.

## 2. Linkage between Paediatric and Adult Services

The Consultation Document was based on the premise that the future model for the delivery of paediatric services can be determined in isolation to the future model for delivery of adult services. Many cardiac electrophysiological conditions are inherited, and parents and other family members of such children may have the same condition. Such conditions may be life threatening and put the child and other family members at risk of sudden death. Our experience as a charity shows that in cardiac electrophysiology there are considerable benefits to patients and families from the joint provision of adult and children's services.

These benefits include:

- In a dedicated family multidisciplinary clinic, all members can be seen during the same visit, under the same roof and the complex physical and psychological issues and family dynamics can be addressed. The family needs to be confident that at a very stressful and traumatic time, there will be *seamless care across age groups* to all those affected, as Professor Qureshi is quoted as saying in the Consultation Document. They will not want to keep going over the same complex and potentially painful case history with a succession of new and different medical advisors. All members of the family will want to know that the team dealing with them is fully conversant with both the individual case history and the picture of the family as a whole;
- Many affected children are in the adolescent age group and need care from their teenage years to young adult life. A joint service facilitates a seamless transition from paediatric to young adult and then full adult services;
- Children with rhythm abnormalities may require an implanted device such as a pacemaker or an implantable cardioverter defibrillator, as part of their management. Worldwide, such devices are much more commonly used in adult patients. A joint adult and paediatric service is better placed to provide optimum management for children needing devices as they can use the extensive experience gained from the adult patients to best serve these children and provide ground breaking treatment;
- In a joint paediatric-adult environment, those caring for children will have access to the most recent technology and expertise on site. This is unlikely to be the case in a dedicated children's hospital as such expensive technology and staff are not justifiable for a limited number of patients.

We see no evidence that the JCPCT either considered or was able to satisfy itself that the benefits of joint paediatric and adult cardiac electrophysiology services will continue to accrue in a model that is based upon the provision of paediatric care in isolation.

## 3. Impact of Closure of Paediatric Cardiac Surgery at the Royal Brompton

Should the decision be made to close paediatric cardiac surgery at the Royal Brompton, the impact on the paediatric cardiac electrophysiology service will be severe:

- The Paediatric Intensive Care Unit (PICU) will no longer be viable;
- Without a PICU and surgeons on site, the complex treatments for children with rhythm disturbances such as ablation and implanting pacemakers and defibrillators would have to stop;
- The benefits of joint paediatric adult service linkage would be lost;

- The foetal cardiology service and associated research would no longer be sustainable, with subsequent knock-on impact on paediatric and adult electrophysiology and congenital heart services.

The Consultation Document is silent about whether the remaining paediatric electrophysiology service at the Royal Brompton would be viable in the absence of the ability to undertake more complex interventions. The overall impact would appear to be a “down-skilling” move in conflict with the core principles of Safe and Sustainable.

4. Provision of equivalent levels of paediatric electrophysiology services following closure of paediatric cardiac surgery at the Royal Brompton.

It is unclear as to how the current level of paediatric cardiac electrophysiology service provided by the Royal Brompton will be maintained in the event of the closure of paediatric cardiac surgery at the hospital. What we do know is that the specialist expertise, capacity, physical equipment, links to adult services and dedicated resources required to provide, maintain and improve these services does not currently exist in London outside the Royal Brompton.

It has been of great concern to us during this process that paediatric cardiac electrophysiology services have been either ignored or misunderstood. It is not clear why the world class and expanding service provided by the Royal Brompton would be dismantled, particularly when there is no cogent plan or guarantee that it could be recreated elsewhere.

We respectfully ask that during the forthcoming visit to the Royal Brompton, the IRP members familiarise themselves with the role and context of the paediatric cardiac electrophysiology service, and ensure that proper consideration is given to safeguard the future provision and development of this world class service.

Yours faithfully

Philip Williams

Chair of the Trustees