



Ulster Unionist Party Consultation response on Paediatric Congenital Cardiac Services (PCCS) in Northern Ireland

The Ulster Unionist Party welcomes the opportunity to respond to this very important consultation.

At present there is a lack of clarity as to what is driving the present review in Northern Ireland as safety concerns have not been identified. We expect that as with all aspect of health delivery in Northern Ireland, the service must provide safe procedures.

We have concerns that the Safe and Sustainable review has taken place without an adequate time frame for local clinicians and parents to make a fully comprehensive response. The service at the Royal Belfast Hospital for Sick Children (RBHSC) is being judged against the same "Safe and Sustainable" standards as in England when it is not possible for patients in NI to safely drive to other units as in GB. We are unaware of these standards being applied in Scotland.

We note that the recommendations of English review of service are now themselves being independently reviewed.

In England and Wales Clinicians were give one year's notice and three months to complete documentation ahead of the Safe and Sustainable review. However local clinicians were given five working days to complete the documentation. Local parents were given one short meeting with the review team whereas in England and Wales extensive periods of consultation were undertaken with parents.

The HSCT consultation document states:

"We fully acknowledge the public confidence in the Paediatric Congenital Cardiac Service".

However, it highlights that as a result of “new standards” that have been set in England, the NI model of a very small team led by one surgeon is no longer suitable and that:

“Medical and diagnostic cardiology services for children including outpatient follow up and inpatient care at RBHSC (Clark Clinic) will continue to be provided by the skilled and professional cardiac team in the Belfast Trust.”

There is a clear implication that by adopting the standards being adopted in GB, that the Health and Social Care Board seeks to end Paediatric Cardiac surgical intervention at the RBHSC. Yet many parents are concerned that timely intervention in cases of emergency would not be possible should the surgical operations come to an end in Belfast. Whilst operations could have greater resilience, in larger units elsewhere, several patients might not reach the Paediatric Cardiac operating theatre if it was located outside of NI. We would question the weighing being used with 50 points being awarded for resilience but only 20 points for accessibility.

We would also question why there is also a low weighting of 30 for ensuring that “emergency and urgent procedures can be undertaken within clinically indicated timescales”. Surely swift emergency access is critical and this should be reflected in the weighing given to it.

We recognising that at some time in the future that the service could become vulnerable if key personnel could not be attracted to the RBHSC. However we are not aware of any indication of difficulties at present. We recognise that there has been close co-operation between, RBHSC and Our Lady’s Children’s Hospital in Dublin. Indeed this was under Health Minister, Michael McGimpsey MLA that this relationship was developed. We agree that further co-operation should occur to enhance back up arrangements and increase the resilience of the service.

In addition, we would seek closer co-operation with Dublin so that the Clark Clinic could provide a base to support patients from border counties and so further increase the resilience of the RBHSC service.

There is likely to be a greater need for surgical intervention in the future. We now have children who underwent Paediatric Congenital Cardiac Services and have grown into adulthood and may have further need for intervention in the future. So the numbers of patients indicated in the consultation document may have been under estimated.

At present, a small number of children must transfer to GB centres of excellence for particularly complex paediatric cardiac procedures such as hypoplastic left heart or transplant operations. We recognise that there will be an ongoing need to utilise world recognised expertise and services from other Hospitals in such cases.

We also note had such lifesaving intervention elsewhere comes at great cost to families. If a child is flown in an emergency to other GB centres, the mother endures separation from her child and the limited support that is available at a distance from her family and friends. Careful assessment should be made of such situations and procedures developed to improve support and minimise the stress involved.

We recognise that should Paediatric Cardiac surgical intervention end in Belfast, as in other GB centres, there could be difficulties in attracting and sustaining key medical specialists such as paediatric cardiologists and paediatric anaesthetists. We also note the need to collocate Critical Independence services and pose the question as to what effect will be of the suggested removal of paediatric cardiac surgery to other critical services at RBHSC.

We believe that Paediatric Cardiac Surgery should be commissioned from Belfast in close co-operation with centres in Dublin and elsewhere in GB. If such services were commissioned from elsewhere, we would be concerned that this could increase the risk of surgical procedures ending at RBHSC. This would risk the full service at RBHSC unravelling.