

Congenital Cardiac Service Consultation
Department of Health, Social Services and Public Safety
Room1, Annex 1
Stormont Estate
Belfast
BT4 3SQ

22 January 2015

Dear Colleague

The Office of the Northern Ireland Commissioner for Children and Young People is pleased to provide advice to the consultation on the future delivery of Paediatric Congenital Cardiac Surgery and Intervention Cardiology for the population of Northern Ireland. This submission is not intended to be comprehensive but instead highlight key reflections and concerns. Paediatric cardiac surgery and cardiology is a very specialist and complex area of medicine, and so consultation on the future of such services for children and young people from Northern Ireland must reflect on the informed opinion of medical and professional staff who are experts in delivering care and treatment for Northern Ireland children, including NGO support groups. The consultation process should also take steps to hear the views of children, young people and families directly affected by these changes. For children and young people, this should always be done in a proactive, age appropriate way.

The future delivery of Paediatric Congenital Cardiac Services has been unclear for some time and many families in Northern Ireland will be anxious about the implications of their child having to travel to Dublin for heart surgery. However, we are pleased that proposals as to how a cross border model could work in practice have now been more fully considered by an independent panel of experts.

Addressing the clinical needs of these extremely vulnerable children by ensuring they receive safe, high quality and accessible care is the paramount concern. As duty bearers for the United Nations Convention on the Rights of the Child, the NI government and statutory agencies are obliged to ensure that children and young people have access to care and treatment which will enable them to fully enjoy their rights. This includes the article 6 right to life, survival and development to the maximum extent possible and the article 24 right to enjoy the highest attainable standard of health as outlined in the Convention.

It is also imperative that families / carers / guardians of sick children are given the emotional, practical and financial support. According to the response to a recent assembly question the average length of stay for families travelling outside Northern Ireland for their child's heart surgery or treatment is 16 days (17 days if travel time is included) but this can vary between 1 and 116 days (AQW 40196/11-15). This can lead to considerable financial pressure on families at what is an already stressful time. We also understand that the HSCB are currently developing one regional policy on the subsistence and travel needs for families travelling outside Northern Ireland for their child's medical treatment and that there will be a formal engagement exercise with relevant stakeholder groups and with a representative sample of patients who have previously sought reimbursement in respect of such costs (AQW 40197/11-15). NICCY welcomes this review and would call for a particular focus being placed on support for those families likely to be most disadvantaged by the costs attached to travelling and temporarily living away from home because of their child's condition.

We understand that even with the new all island model of service, there will be circumstances where children with particular types of congenital heart conditions will have to go to England for treatment. In the unhappy circumstances where a child dies whilst undergoing treatment in England it is imperative that their remains are treated with dignity and respect and that the family is supported in transporting their child's remains back to Northern Ireland. We understand that at the moment the HSCB policy is that deceased children are returned in the hold of a commercial plane as it does deemed the 'exceptional circumstance' threshold which would allow them to be returned in an air ambulance. If this is indeed the case, we would ask that this policy is reviewed as a matter of urgency.

We are pleased to see a number of proposals such as the development of the family advisory group and family liaison co-ordinators which seek to ensure that the voice of patients and their families are sought in a proactive and structured way. It is important that this process is meaningful for families and that their views are considered and actioned. Although it is not always possible to gather the views directly from children themselves because of their age or frailty, it is important that efforts are made to speak to them directly- as outlined in Article 12 of the UNCRC, it is a fundamental right for a child to have a say in decisions affecting them and to have their views taken into account. Furthermore, we are pleased that DHSSPS representatives have provided reassurances to the Health Committee that the active involvement of families will be sought when developing plans over the next number of months (22 October 2014).

We reinforce the important point made by the IWG that the establishment of one all island

paediatric cardiac surgery and interventional cardiology centre in Dublin is just one of 14 recommendations, and that each recommendation is equally important and inter-dependent and therefore should be addressed as a 'collective package' i.e. given equal due weight. We understand that the implementation will require a phased approach, however each recommendation should be taken forward to develop specialist capabilities in Belfast and Dublin.

We agree that an all island governance committee with appropriate representation from both jurisdictions including clinical and family representation is crucial for overseeing the delivery of this partnership service. This will be a key way of ensuring transparency and confidence in the process. A review process whereby the quality and safety of care will be assessed and monitored is critical.

While accepting that children will have to travel outside Northern Ireland for surgery, NICCY supports the maintenance of other paediatric cardiology services in Northern Ireland, we believe that where possible and clinically appropriate, patients should be treated and cared for as close to their home as possible – causing less disruption and stress during difficult periods. For most children, the surgical element of their care will be a 'single episode', the ongoing treatment and care, such as cardiology and nursing care will continue for the rest of that person's life from child to adulthood. We are pleased that the DHSSPS has acknowledged within the consultation document that the development of a paediatric cardiology centre of excellence at the Belfast Trust is a key part of the IWG's proposed model of an all island congenital cardiac service (pg 11). We look forward to seeing the proposals on this, including the purpose / function of the Belfast centre and investment plans attached to it. We trust that it will be in line with the views of the IWG but also the strategic vision set out for the wider review of paediatric care which includes promoting new ways of working, an appropriate skills mix to complement current and future population needs, recognising the importance of access to services, workforce training and development, and new technologies in the assessment, diagnosis, treatment and support of children and young people¹. It is important that the partnership approach is followed through in the re-configuration of paediatric cardiac surgery and cardiology services and that no undue pressure is placed on one side of the partnership which would affect waiting lists for non surgical care or treatment.

NICCY seeks assurances from the DHSSPS that the impact of changes to the delivery of paediatric cardiac surgery are minimised for other 'low volume' paediatric surgical

¹ <http://www.dhsspsni.gov.uk/p-consultation-document.pdf>

specialities currently being provided in Northern Ireland, such as renal transplant, spinal surgery and neurological surgery. Maintaining specialist services in Northern Ireland will minimise that risk, especially if specialist clinical skill sets for treating and caring for children and young people such as paediatric cardiology, physiologists and anaesthetists remain in Northern Ireland.

Furthermore, although Minister Wells has stated in an answer to a recent written assembly question that the revised service model is proceeding on the basis of the existing facilities in both Belfast and Dublin, and not dependent upon the proposed new hospitals at either location (AQW 38844/11-15), it would be important for the plans for the new paediatric cardiology centre to consider the most practical location with respect to the children's hospital site. It is also recommended that this centre is developed as a multi-functional base which includes all elements attached to a cardiology service e.g. out-patient, clinics, day cases, adolescent provision, diagnosis and treatment.

It is important that provisions meet the specific needs of particular groups of patients – it is understood that teenagers with congenital cardiac heart problems were consulted as part of this review where they raised concerns about where they would be treated and what the wards on which they would be placed would look like. Recognition of the developmental, emotional and psychosocial needs of adolescents in the planning and design of services and facilities, and smooth transition to adult services is important and in line with the wider strategic direction of the Paediatric Review². NICCY has identified gaps or weaknesses in transitional planning between children and adult care provision across a range of services, and therefore emphasise the importance of seamless pathways planning between paediatric and adult cardiac / cardiology services. We also note that it is proposed within the Paediatric Review of Care on Hospital and Community Care that Children (from birth up to 16th birthday) should usually be cared for by the paediatric team in paediatric settings, and those aged 16-17 years should be managed in age appropriate settings within either paediatric or adult settings. This is a progressive step and one which reflects the recommendation set out in the 2012 RQIA 'Baseline Assessment of the Care of Children Under 18 Admitted to Adult Wards in Northern Ireland'. We seek reassurance that this is a policy which will apply to children and young people from Northern Ireland who are accessing cardiac services in either the North or South of Ireland.

² <http://www.dhsspsni.gov.uk/p-consultation-document.pdf>

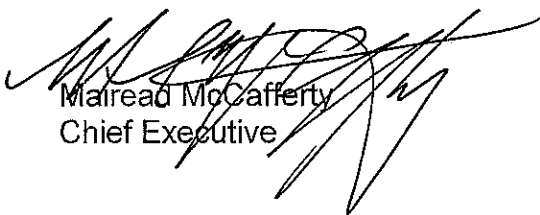
Ensuring that appropriate regulation and inspection arrangements are in place on both sides of the Border which meets high standards of safety is very important. This includes timely arrangements for the dual registration of clinicians practising in the North and South of Ireland and agreements on cross border clinical practice standards so that nursing arrangements on a day to day basis can continue unhindered and to a high standard.

The provision of central databases for both jurisdictions to collate and analyse information on outcomes, resource utilisation and other areas is important, as this is required for the proper oversight and governance of this service. This is particularly important as the service is bedding down and where data collation and analysis will be used to review developments.

In conclusion, the 14 recommendations set out by the IWG require significant investment and resourcing to implement. Steps need to be taken quickly to progress this, including a detailed update from the Health Minister on the budget, time frame and schedule for implementation of these recommendations. We understand that the Northern Ireland Assembly is living through very tight financial pressures and will continue to do so for a number of years however, where possible, monies for this programme of work should be ring fenced and we seek reassurances that investment in this area will not negatively affect funding for other front line children's services.

Please do not hesitate to get in contact with my office if you require any further information on this response.

Yours Sincerely



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