



Health and Social
Care Board

**Consultation on the future commissioning of Paediatric
Cardiac Surgery and Interventional Cardiology for the
population of Northern Ireland.**

September 2012

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FOREWORD

Congenital Cardiac Disease is the term used to describe heart conditions which are present from birth. Heart defects occur in just less than 1 in 100 live births. Some are minor requiring no treatment but more major defects require surgical treatment or an interventional catheter procedure.

The services for children with congenital cardiac disease are becoming increasingly complex with surgery and interventions demanding great technical skill and expertise from all professionals in the cardiac teams.

This consultation document sets out the need for change in regard to current Paediatric Congenital Cardiac Services and in particular the Paediatric Cardiac Surgery and Interventional elements of these services and seeks views on the standards and criteria against which future models of care will be considered.

We recognise that the need for change to existing services is often difficult to understand and accept. We fully acknowledge the public confidence in the Paediatric Congenital Cardiac Service and recognise a desire among members of the public to continue services as they have been provided for many years.

The climate and context has however changed dramatically. New standards have been introduced in recent years: while previously it may have been acceptable in units across the UK for such specialised services to be provided by a very small team led by one surgeon, this model of care is no longer able to ensure the sustainable provision of appropriate emergency, urgent and planned care for children.

Any development in Paediatric Cardiac Services locally must build on the strengths of Northern Ireland's long tradition of providing high quality care to many generations of children and their families. It must also ensure that children are able to access the very best care that can be offered.

Our challenge in commissioning is to ensure that the number, experience and skills of staff are appropriate, that facilities are suitable to meet

needs and, most importantly, that services are of high quality and are safe, sustainable, timely and accessible into the future.

Before any decision is taken by the Minister on the future provision of Paediatric Cardiac Surgery and Interventional Cardiology, the Board wants to ensure that everyone has the opportunity to carefully consider the options and their likely impact and to respond with their views. Over the next 12 weeks we welcome comments on the document and its proposals and will take full account of all responses when reaching a decision on the definitive way forward by early 2013.

I would like to extend my thanks to all those on the Working Group who have committed considerable time and energy to this work.

John Compton
Chief Executive
HSC Board

1.0 INTRODUCTION

The purpose of this document is to consider the future service model for the provision of Paediatric Cardiac Surgery and Interventional Cardiology services for the population of Northern Ireland with the aim of reaching a view on the definitive way forward by early 2013.

The DHSSPS has asked that the HSC Board working with the Public Health Agency and in collaboration with parents, patient group representatives and clinicians to:

- develop a detailed service specification for commissioning Paediatric Cardiac Surgery and Interventional Cardiology;
- establish clear criteria (with agreed rationale for inclusion and weighting and scoring) against which the service for children from Northern Ireland should be assessed;
- set out the implications of the criteria on potential service model options including an all-Ireland model; and
- develop a document for consultation setting out each of the strands above.

The shared objective of all parties is to secure a service model which will provide a high quality, safe, sustainable, accessible and timely service. The work above will be subject to HSC Board and DHSSPS/Ministerial approval.

This document sets out the draft service specification, the proposed evaluation criteria and the potential generic options. The document also sets out the implications of the proposed criteria on each of the potential generic options.

It should be emphasised that all the material in the consultation document refers to Paediatric Cardiac Surgery and Interventional Cardiology. 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.

This consultation process offers an opportunity for all stakeholders to consider and comment on the draft service specification and proposed criteria for assessment/scoring of potential generic options, taking account of the potential implications of each of the options.

In parallel, as a separate process, the Board is undertaking a robust analysis of the current transport arrangements for children including those with congenital cardiac disease to determine the best way to deliver these services.

What happens after the Consultation?

Following the end of the consultation period, the Working Group will develop a post-consultation document, incorporating an analysis of responses and recommendations on the future delivery of services for the population of Northern Ireland. The Minister will consider this document before making a decision on the future model for provision of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland in early 2013. Equality screening and, as appropriate, an equality impact assessment will be undertaken as part of this phase of the process.

2.0 BACKGROUND

2.1 Overview

Children in Northern Ireland with heart disease have, for many years, received high quality care provided by a team of highly skilled and experienced doctors, nurses and support staff.

The Paediatric Cardiac Surgical and Interventional Cardiology elements of the services provided in Belfast have been recognised for over a decade to be inherently vulnerable, given the small number of patients being treated each year. This has given rise to concerns regarding the long term sustainability of the Paediatric Cardiac Service. In this context the Minister for Health, Social service and Public Safety, Mr Edwin Poots, announced, on 29 March 2012, the Board's intention to undertake an external review. Now, on completion of that review, this document sets out the considered views of a Working Group with representation from parents, patient group representatives and clinicians on how future services for children with heart disease could be delivered to provide excellent care and excellent outcomes.

2.2 Current Services

There are a number of different aspects to the care of children with heart disease. The particular management of any individual child will depend on their condition, its severity and other relevant health problems. While each year some 250 babies in Northern Ireland are born with congenital heart disease, other children may be referred to paediatric cardiology services for clinical consideration of, for example, heart murmurs or cardiac symptoms that have developed during their childhood.

For the majority of children who attend a paediatric cardiologist because of concerns about heart disease or heart abnormalities, surgery will not be required but follow up by the paediatric cardiology team may be necessary. This ongoing care which includes investigation, diagnosis and ongoing review is a central component of care for children with heart disease and this service will not only remain in Northern Ireland but steps will be taken to explore its development to ensure that service excellence can be achieved and maintained. The paediatric cardiology team includes doctors, nurses, allied health professionals, technical and

support staff. The expertise and commitment of this team is recognised and, regardless of any reconfiguration that may be needed for the provision of children's cardiac surgery, the medical care provided by the paediatric cardiology team will be provided locally for children in Northern Ireland, ensuring continuity of care close to home.

As it is fully anticipated that paediatric cardiology services will continue to be provided by Belfast Trust for the population of Northern Ireland, this document focuses only on the care that children may require in regard to surgery or interventional cardiology. Surgical services include all heart operations including major open heart procedures. Interventional cardiology procedures are those undertaken when a child's heart abnormality can be treated by a procedure that involves a catheter being introduced into the heart through one of the child's major veins or arteries. In the event of complications, such procedures may require the child to progress immediately to surgery and therefore they can only be undertaken when access to heart surgery can be guaranteed. Therefore, any change to Paediatric Cardiac Surgery will, by extension, apply to interventional cardiology because it cannot be undertaken in the absence of surgical cover.

During 2011/12, there were around 3,800 paediatric cardiology outpatient attendances, of which about 1,200 were new referrals. From this number there were some 140 operations on children and around 50 interventional cardiology procedures.

For some of these children the complexity of their condition requires access to specialist care beyond Northern Ireland. It should also be emphasised that for children who do require an operation almost 9 out of 10 will only need one surgical procedure.

It is recognised that for each family, surgery is likely to be a significant and stressful event. However, it is crucially important that all children can access, in a safe and timely manner, the very highest quality of care from skilled and experienced professional teams, which at times necessitates travel to a centre beyond Northern Ireland.

Locally, Paediatric Cardiac Surgery is undertaken at the Belfast Trust by two surgeons. Through a partnership arrangement with Dublin (Our

Lady's Children's Hospital Crumlin) they have support from two Dublin-based cardiac surgeons who visit the Belfast Trust where they too perform operations. Work has been ongoing for a number of years between the two jurisdictions to explore and develop working arrangements between the two centres. As the consultation process is taken forward, opportunities to further explore and develop these arrangements will be pursued.

The Working Group examined the paediatric cardiac surgical and cardiology interventional activity for the year 2011/12. This analysis showed that surgical procedures undertaken in Belfast in the last year were predominantly planned elective procedures, performed during the planned surgical lists which are scheduled on Mondays. A small number were considered urgent or emergencies and had procedures at times other than the scheduled surgical lists. In total, of the 91 procedures undertaken in Belfast in 2011/12, some 70-75 could be considered planned and in the region of five cases were dealt with as emergencies requiring surgery within 24 hours. The balance of around 15-20 cases were considered urgent and surgery was undertaken within a matter of days or weeks. This group included some children who had surgery in their first weeks of life and others who had lengthy inpatient hospital stays prior to surgery.

Arrangements are in place for children who require certain complex procedures to be referred to a specialist centre. Of the children referred to other centres during 2011/12, around half had their surgery as a planned procedure and their journey to the centre (primarily Birmingham Children's Hospital) was by commercial transport. For the other half, procedures were considered urgent or emergency and transport arrangements were typically made by the Belfast Trust and involved air or road ambulance.

During 2011/12, seven older children, aged 16-18, required surgery and all procedures were as planned elective operations undertaken in Belfast Trust.

For interventional cardiology procedures during 2011/12, there were a total of 36 involving children under the age of 16 years undertaken in Belfast, with a further 13 procedures being undertaken at other centres.

Each year in Northern Ireland approximately five babies require interventional cardiology within hours of birth to stabilise the baby in advance of surgery. It is essential for arrangements to be in place to ensure that this group of children have early access to the emergency treatment that they need.

Understandably, parents will worry about a child needing emergency transport and whether it is safe to transfer them. It should be emphasised that of those children who required to be transported by air/road ambulance no adverse incidents have been reported.

Nonetheless, work being taken forward by the HSC Board is fully exploring the detail of current transport arrangements to determine the best way to deliver these services for the population of Northern Ireland, both for children with congenital cardiac disease and for children with other conditions.

2.3 Review of Paediatric Congenital Cardiac Services

A review of Paediatric Congenital Cardiac Services currently provided by Belfast Trust was commissioned earlier in 2012 by the Health and Social Care Board, in conjunction with the Public Health Agency, and was undertaken by a Review Panel which was led by Professor Sir Ian Kennedy and included a number of clinical specialists and a parent group representative.

Services were assessed against the *Safe and Sustainable* standards which have been used to assess children's cardiac surgical units in England. These standards have been endorsed by the relevant professional associations in the UK. The review provides advice and direction on the best way to secure high quality care for all children needing specialist cardiac care in the future.

The Review Panel concluded that children in Northern Ireland with congenital heart disease are well served by a dedicated and experienced team of consultant paediatric cardiologists and nurses. The review highlighted that there are many excellent features in the current service that present opportunities for the development in the future of a model children's cardiology centre.

The Review Panel did not identify any immediate safety concerns with the current arrangements for the provision of Paediatric Cardiac Surgery in Belfast but did conclude that the surgical element of the service in Belfast was not sustainable. The review recommended that the potential safety risks identified be addressed within a period of six months. Any change to Paediatric Cardiac Surgery will, by extension, apply to interventional cardiology because it cannot be undertaken in the absence of surgical cover.

The report of the Review Panel was published on 1 August 2012.

2.4 Developments elsewhere in the UK

Changes in the provision of Paediatric Cardiac Services are anticipated in other parts of the UK. On 4 July 2012 it was announced that across England the number of paediatric cardiac surgical units would be reduced from 10 to seven units over the next two years. In Wales, children who require surgery access such care in England. These changes reflect the action agreed by the NHS in England and Wales to improve the quality of care by ensuring that all centres comply with *Safe and Sustainable* standards.

2.5 Establishment of Paediatric Congenital Cardiac Services Working Group

Following publication of the review on 1 August 2012, the Minister made a statement to the Assembly outlining his expectation that the Board consider the safety and sustainability of the service in Belfast and the findings of the report. In addition the Board was asked to ensure all options available including the potential for an all-island service and/or networking arrangements with other centres in the UK are robustly considered.

The Minister indicated the need to consider the impact of any proposed service change on patients and their family including accessibility of the service and the impact any proposed service change would have on other paediatric and cardiac services.

In light of the Minister's statement, the Board and PHA have established a Working Group (membership attached as Appendix 1). The remit of the

Working Group includes the development of a detailed service specification for the commissioning of Paediatric Cardiac Surgery and Interventional Cardiology and development of clear criteria against which generic service options will be considered.

In Northern Ireland it is important to ensure that health services provided for the population are consistent with evidence-based best practice. Specifically it is important that every child with heart disease in Northern Ireland receives the high quality care they require to effectively manage their condition and provide the very best outcome.

3.0 DRAFT SPECIFICATION FOR PAEDIATRIC CARDIAC SURGERY AND INTERVENTIONAL CARDIOLOGY

This section sets out the proposed standards against which the HSC Board would plan to commission services from early 2013, for the population of Northern Ireland. These standards are detailed in a draft service specification.

Services for children with particular complex needs such as hypoplastic left heart or transplantation will continue to be commissioned through existing arrangements with providers in England. The continued appropriateness of these arrangements will be reviewed in the context of the Minister's decision in early 2013. All children receiving ongoing care who have an established relationship with a particular unit will continue to be seen at that unit in line with clinical need and patient/parent choice.

The Board would welcome your comments on whether these proposed standards are appropriate and if there are other areas which should be considered.

DRAFT SERVICE SPECIFICATION FOR PAEDIATRIC CARDIAC SURGERY AND INTERVENTIONAL CARDIOLOGY

1. Safety and Quality

To ensure the delivery of a high quality service for the population of Northern Ireland, the HSC Board will commission services consistent with agreed standards. The specific standards proposed by the Board in this regard are those developed by the Safe and Sustainable process. These standards are endorsed by relevant professional organisations in the UK. The standards and their underpinning rationale can be accessed at www.specialisedservices.nhs.uk/safeandsustainable.

Staffing and Activity

- The service must be staffed by a minimum of 4 full-time consultant congenital cardiac surgeons
- The service must perform a minimum of 400 paediatric surgical procedures a year, sensibly distributed between the 4 surgeons

- The service should perform a minimum of 500 paediatric surgical procedures a year
- The services must provide enough staff to provide a full 24-hour emergency service within legally compliant rotas, including cover by consultant paediatric cardiologists
- Paediatric Intensive Care consultants should be available to the paediatric intensive care unit on a 24/7 basis
- Each child should have a named Children's Cardiac Specialist Nurse, working within a Cardiac Liaison team

Interdependent Services

Critical interdependent services must be co-located as defined by the Department of Health document 2008 - *Framework of Critical Interdependencies*:

- Paediatric cardiology
- Paediatric intensive care
- Paediatric Ear Nose Throat (Airways)
- Specialised paediatric surgery
- Specialised paediatric anaesthesia
- Paediatric neurology
- Paediatric respiratory medicine
- Neonatology
- Paediatric nephrology
- Clinical haematology

Facilities and Capacity

The service must demonstrate that it has sufficient staff to meet the demand for inpatient beds, critical care beds and theatre capacity; sufficient capacity to ensure that the demands of emergency and elective surgery can be flexibly managed; there must be facilities in place to ensure easy and convenient access for parents and carers.

Age Appropriate Care

All care will be individually tailored to reflect the child's developmental age, and appropriate transitional arrangements will be in place.

Strength of Network

The service (in partnership with commissioners) will provide active leadership in its clinical network. This will include managing and developing referral, care, treatment and transfer pathways, policies, protocols and procedures. The service should demonstrate how it will manage the performance of the network and ensure as much care close to home as possible. The network should have good transition arrangements in place and be able to demonstrate effective multi-disciplinary team working.

Information and Choices

The service must demonstrate that arrangements are in place that allow parents, carers, children and young people to actively participate in decision making at every stage in their child's care.

Ensuring Excellent Care

- The service must have a dedicated management group for the internal management and coordination of service delivery
- Clinical teams will operate within a robust and documented clinical governance framework

- The service must have, and regularly update, a research strategy and research programme that documents current and planned research activity
- The service must demonstrate how it develops innovative working practice

2. Monitoring of Outcomes

The Board's expectation is that commissioned provider(s) submit data to the Congenital Cardiac Audit Database (CCAD) and can demonstrate patient outcomes are within acceptable control limits as set by CCAD.

3. Access to Services

Belfast Trust will routinely be responsible for ongoing medical management of children with paediatric congenital cardiac conditions. Arrangements should be in place to ensure the effective handover of children travelling elsewhere or returning to Northern Ireland. This should be delivered by dedicated cardiac liaison staff.

For children requiring cardiac surgery or interventional investigation / procedures access requirements are:

- Emergency and urgent procedures should be available within clinically indicated timescales. For emergency cases, this should be consistent with the standards set out by the Paediatric Intensive Care Society that a retrieval team should be available at the referring centre within three hours.
- Elective or planned activity should be provided within extant NI waiting time standards.

Appropriate arrangements should be in place to ensure a seamless care pathway for children and parents.

4. Clinical Engagement

Appropriate links should be developed between the Belfast Trust and other service providers. As a minimum, there should be a MDT

discussion for every child requiring surgery irrespective of the provider. For any child that needs to travel outside Northern Ireland the service provider should be in a position to provide both the interventional cardiology and Paediatric Cardiac Surgery care.

The service provider would be expected to support paediatric cardiologist(s) from Belfast Trust in undertaking interventional procedures at the providing centre.

For children travelling outside Northern Ireland, there should be an agreed care pathway between Belfast Trust and the providing site.

5. Arrangements for Parents

Appropriate, tailored information for parents of children requiring surgery should be available. Support should also be available from trained cardiac liaison staff before, during and after treatment.

Where parents seek to visit the unit treating their child in advance of their child's treatment, this should be facilitated as far as possible.

Appropriate accommodation and other facilities should be available for parents who travel with their child.

4.0 GENERIC OPTIONS AND CRITERIA FOR ASSESSMENT

Section 3 of the consultation document sets out the proposed standards against which the HSC Board would plan to commission services for the population of Northern Ireland. This section details the broad generic options for the future provision of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland and the proposed criteria against which these options will be assessed and scored.

Belfast Trust currently undertakes around 90 procedures per year. A further 20 are provided at other centres on a case by case basis. In addition, services for children with particular complex needs such as hypoplastic left heart or transplantation will continue to be commissioned through existing arrangements with providers in England (around 30 of the 140 procedures undertaken in 2011/12). The continued appropriateness of these arrangements will be reviewed in the context of the Minister's decision in early 2013. All children receiving ongoing care who have an established relationship with a particular unit will continue to be seen at that unit in line with clinical need and patient/parent choice.

In any future service model there will be, as there is currently, the ability to meet the clinical needs of individual children. This will be supported through the normal process for referral outside Northern Ireland.

The Board would welcome your comments on the generic options identified and whether the proposed assessment criteria are relevant for considering the most appropriate option for future service provision.

4.1 Generic options considered

The following generic options for the future provision of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland have been identified.

1. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast.

2. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Dublin. With this option there would be no surgery or interventional cardiology in Belfast.
3. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from a provider(s) in GB. With this option there would be no surgery or interventional cardiology in Belfast.
4. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from providers in Belfast and Dublin on an all island basis.
5. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from providers in Dublin and GB. With this option there would be no surgery or interventional cardiology in Belfast.
6. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from providers in Belfast, Dublin and GB.

4.2 Criteria for assessment/scoring of generic options

The following criteria and weightings, linked to the standards contained in the service specification, are proposed for assessing/scoring the options for the future provision of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland:

	Criteria	Weighting
1.	<p>The option ensures that the services commissioned are:</p> <ul style="list-style-type: none"> • safe, sustainable and of high quality, consistent with prevailing professional standards; • compliant with CCAD control limits. <p><i>(Rationale: The overriding priority for the HSC Board as commissioner is to ensure that services are safe, sustainable and of high quality. This priority is reflected in the relative weighting of this criteria.)</i></p>	50

2.	<p>The option ensures emergency and urgent procedures can be undertaken within clinically indicated timescales.</p> <p><i>(Rationale: Each year about 20 emergency and urgent procedures are required for Northern Ireland children and it is important that the future model of service is able to respond within a timeframe to optimise outcomes for each child.)</i></p>	30
3.	<p>The option ensures the required volume of activity can be delivered reliably and consistently, in accordance with extant NI waiting time standards, from early 2013.</p> <p><i>(Rationale: Each year a total of some 110⁽¹⁾ surgical and up to 50 interventional cardiology procedures are required. It is important that the future model of service is in place in appropriate provider(s) to deliver this volume of activity.)</i></p>	30
4.	<p>The option ensures that services are accessible, in a safe and timely manner, taking account of and being responsive to the practical and emotional needs of patients and families.</p> <p><i>(Rationale: The issue of accessibility is important for parents and families taking account of the practical difficulties of travelling with ill children, particularly where this requires an air journey.)</i></p>	20
5.	<p>The option ensures, through partnership working, the continued provision of medical and diagnostic paediatric cardiology services and other paediatric and cardiac services in</p>	20

	<p>Belfast and takes account of the need for multi-disciplinary training.</p> <p><i>(Rationale: Medical and diagnostic services for children with heart disease will continue to be provided in Northern Ireland. It is important that any future provider of surgical and interventional procedures is in a position to provide appropriate support and collaboration with the local service.)</i></p>	
6.	<p>The option ensures the effective use of resources.</p> <p><i>(Rationale: A key role for the HSC Board as a commissioner is to ensure the effective use of resources and that value for money in services is provided.)</i></p>	10

(1) This figure excludes services for children with particular complex needs such as hypoplastic left heart or transplantation which will continue to be commissioned through existing arrangements with providers in England.

5.0 IMPLICATIONS OF THE PROPOSED CRITERIA ON POTENTIAL SERVICE MODELS.

This section sets out the implications of the proposed criteria on the generic options identified in section 4 of this document. The section goes on to outline the potential implications on other services particularly congenital cardiac services for older children and adults but also other paediatric and cardiac services.

5.1 Option 1 – Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast.

Safety/Sustainability – While there are no immediate safety concerns with the current arrangements for the provision of Paediatric Cardiac Surgery in Belfast, the service is not sustainable and there is no realistic prospect of this option meeting the safety and quality standards set out in the draft service specification.

Timely Emergency/Urgent response – This option should be able to respond to the majority of emergency and urgent cases, but would not ensure the provision of these services within clinically indicated timescales on a reliable, consistent basis because robust 24/7 arrangements are not possible. This option would minimise the risks and difficulties associated with air travel.

Available Capacity – While this option would be expected to provide most of the planned activity required by children in Northern Ireland, it would be inherently vulnerable because of the low levels of activity.

Accessibility – This option would offer the benefit to patients and families of local accessibility.

Clinical Linkages – This option should ensure continued strong linkages into related services within Belfast for children with heart disease. The option should have either no impact or only minimal impact on other specialised paediatric services. It would also not be anticipated that the service model for adolescents and adults with congenital heart disease would change materially with this option although it would remain inherently vulnerable. (The issue of clinical linkages is considered further in section 5.7 below.)

This option would not facilitate the local training of the paediatric cardiology or cardiac surgery clinical team.

5.2 Option 2 – Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Dublin.

Safety/Sustainability – While units in GB have been subject to formal assessment against the safety and quality standards set out in the draft service specification, a comparable assessment has not been required or undertaken for the unit in Dublin. The unit in Dublin has recently started submitting data to the Congenital Cardiac Audit Database (CCAD).

With this option there would be no surgery or interventional cardiology in Belfast.

Timely Emergency/Urgent response – The option should be able to ensure emergency and urgent procedures are undertaken within clinically appropriate timescales. This option would minimise the risks and difficulties associated with air travel.

Available Capacity – This option will be able to deliver a proportion of the volume of activity required for Northern Ireland patients by 2013, but it is not clear at this time how much capacity can be made available within the required timeframe. The availability of capacity will be clarified in parallel with the consultation process.

Accessibility – This option should offer reasonable access to patients and their families, avoiding the need for air travel.

Clinical Linkages – Linkages to services in Belfast for children with heart disease should be possible but would be more challenging than with Option 1. With this option there may be a potential impact on other services, particularly specialised paediatric services and services for adolescents and adults with congenital heart disease. (The issue of clinical linkages is considered further in section 5.7 below.)

This option may facilitate the training of the Belfast based paediatric cardiology clinical team.

5.3 Option 3 – Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from a provider(s) in GB.

Safety/Sustainability – This option would improve the quality and safety of care by ensuring that services would adhere to the standards set out in the draft service specification.

With this option there would be no surgery or interventional cardiology in Belfast.

Timely Emergency/Urgent response – It is not clear that this option would ensure the provision of all emergency and urgent procedures within clinically indicated timescales and consistent with advice from the *Safe and Sustainable* team. Under this option, there will be the requirement for emergency cases to travel by air ambulance. There are a small number of children for which air transport may present particular risk. The evidence for air transport is that it is normally safe and effective but it is recognised that if there is a clinical emergency during the flight e.g. if resuscitation is required, this can be exceptionally challenging. The consistent availability of air transport may be impacted by severe weather and other factors.

Available Capacity – The option should be able to ensure the required volume of activity by early 2013 but may require a number of providers to do so. The availability of capacity will be clarified in parallel with the consultation process.

Accessibility – Under this option all children would be required to travel to a provider(s) in GB for both planned and unplanned procedures and would require air travel which will make the service considerably less accessible and may contribute to a more stressful experience for patients and families.

Clinical Linkages – Linkages to services in Belfast for children with heart disease should be possible but would be more challenging than with Option 1. With this option there may be a potential impact on other services, particularly specialised paediatric services and services for adolescents and adults with congenital heart disease. If it is necessary to commission services from more than one provider in GB this would make the development of clinical linkages more challenging than with a single

provider. (The issue of clinical linkages is considered further in section 5.7 below.)

This option would not facilitate the local training of the paediatric cardiology or cardiac surgery clinical team.

5.4 Option 4 – Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from providers in Belfast and Dublin on an all island basis.

Safety/Sustainability – While there are no immediate safety concerns with the current arrangements for the provision of Paediatric Cardiac Surgery in Belfast, the service is not sustainable as currently provided.

While units in GB have been subject to formal assessment against the safety and quality standards set out in the draft service specification, a comparable assessment has not been required or undertaken for the unit in Dublin. The unit in Dublin has recently started submitting data to the Congenital Cardiac Audit Database (CCAD).

Even in the context of a fully collaborative working arrangement between Belfast and Dublin, it is not clear that an integrated all island service that retains surgical and interventional services in Belfast would meet safety and quality standards set out in the draft service specification.

Timely Emergency/Urgent response – This option should be able to ensure emergency and urgent procedures are undertaken within clinically appropriate timescales. This option would minimise the risks and difficulties associated with air travel.

Available Capacity – This option should allow the majority of the required volume of activity to be delivered by early 2013.

Accessibility – This option would offer reasonable access to patients and their families for both planned and unplanned procedures (including emergencies), avoiding the need for air travel.

Clinical Linkages – This option should ensure strong linkages into related services within Belfast for children with heart disease. The option should have either no impact or only minimal impact on other specialised paediatric services. It would also not be anticipated that the service

model for adolescents and adults with congenital heart disease would change materially with this option although it would remain inherently vulnerable. (The issue of clinical linkages is considered further in section 5.7 below.)

This option may facilitate the local training of the paediatric cardiology and cardiac surgery clinical team.

5.5 Option 5 – Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from providers in Dublin and GB.

Safety/Sustainability – While units in GB have been subject to formal assessment against the safety and quality standards set out in the draft service specification, a comparable assessment has not been required or undertaken for the unit in Dublin. The unit in Dublin has recently started submitting data to the Congenital Cardiac Audit Database (CCAD).

With this option there would be no surgery or interventional cardiology in Belfast.

Timely Emergency/Urgent response – This option should ensure emergency and urgent procedures are undertaken within clinically appropriate timescales. This option would minimise the risks and difficulties associated with air travel.

Available Capacity – This option should be able to ensure the required volume of activity by early 2013. The availability of capacity will be clarified in parallel with the consultation process.

Accessibility – This option should offer reasonable access to patients and their families for both planned and unplanned procedures (including emergencies), although under this option a proportion of children would be required to travel to a provider(s) in GB and would require air travel which may contribute to a more stressful experience for patients and families.

Clinical Linkages – Linkages to services in Belfast should be possible but would be more challenging given the need for linkages with multiple providers. With this option there may be a potential impact on other services, particularly specialised paediatric services and services for

adolescents and adults with congenital heart disease. (The issue of clinical linkages is considered further in section 5.7 below)

This option may facilitate the training of the Belfast based paediatric cardiology clinical team.

5.6 Option 6 – Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from providers in Belfast, Dublin and GB.

Safety/Sustainability – While there are no immediate safety concerns with the current arrangements for the provision of Paediatric Cardiac Surgery in Belfast, the service is not sustainable and there is no realistic prospect of this option meeting the safety and quality standards set out in the draft service specification.

While units in GB have been subject to formal assessment against the safety and quality standards set out in the draft service specification, a comparable assessment has not been required or undertaken for the unit in Dublin. The unit in Dublin has recently started submitting data to the Congenital Cardiac Audit Database (CCAD).

However, assurance on safety and sustainability of services would be available for the GB provider(s).

Timely Emergency/Urgent response – This option should offer reasonable access to patients and their families for both planned and unplanned procedures (including emergencies). This option would minimise the risks and difficulties associated with air travel.

Available Capacity – This option should be able to ensure the required volume of activity by early 2013.

Accessibility – Under this option a proportion of children would be required to travel to a provider(s) in GB and would require air travel which may contribute to a more stressful experience for patients and families.

Clinical Linkages – Linkages to services in Belfast should be possible but would be more challenging given the need for linkages with multiple providers. The option should have either no impact or only minimal

impact on other specialised paediatric services. It would also not be anticipated that the service model for adolescents and adults with congenital heart disease would change materially with this option although it would remain inherently vulnerable. (The issue of clinical linkages is considered further in section 5.7 below)

This option may facilitate the local training of the paediatric cardiology or cardiac surgery clinical team.

5.7 Implications of options on other services particularly congenital cardiac services for older children and adults but also other paediatric and cardiac services.

In addition to the service implications set out above, there are also potential implications of the proposed criteria on other service areas in Belfast, particularly other specialised paediatric services and other cardiac services.

The options that retain some Paediatric Cardiac Surgery and Interventional Cardiology in Belfast (i.e. option 1, 4 and 6) are likely to have either no impact or only minimal impact on other specialised paediatric services. Belfast Trust paediatric cardiology services would be expected to continue to provide care for children across Northern Ireland.

In regard to other cardiac services, particularly cardiac surgery for adults with congenital heart disease, it is anticipated that under options 1,4 and 6 the service model would not change significantly from that currently in place. Options that retain Paediatric Cardiac Surgery services in Belfast may however have an impact on the ability to sustain services for young people and adults with congenital heart disease who require surgery or interventional cardiology.

A NHS document *Adult Congenital Heart Disease Review* was issued recently for consultation. This document sets out a proposed model for the future delivery of services for adults with congenital heart disease. Consistent with the strategic direction for paediatric cardiac services, the suggested approach to adult congenital heart disease (ACHD) services is for surgery and interventional catheterisation to be undertaken in a specialist centre. A specialist centre is one which would be expected to have four full time surgeons operating on children and adults with

congenital heart disease. It is expected that a specialist centre would provide a sustainable service 24 hours a day, 365 days a year.

If the standards set out in the recent consultation document were to be endorsed and considered in the context of Northern Ireland it is not clear that it would be possible to meet such standards for adults with congenital heart disease in Belfast. This is because the volume of activity would not support the recommended staffing levels and sustaining safe 24/7 surgical cover would be exceptionally challenging.

Therefore if Paediatric Cardiac Surgery and Interventional Cardiology were to be maintained in Belfast, adult services would have difficulty meeting the proposed standards of care.

For those options where services would be primarily provided in Great Britain or Dublin (options 2, 3 or 5) there may be a potential impact on other services, particularly specialised paediatric services and other cardiac services.

If Paediatric Cardiac Surgery and Interventional Cardiology were no longer to be provided in Belfast, paediatric cardiology services may need to be developed, with enhancement to current staffing levels to ensure that skilled and experienced staff are available to support children and families who need to travel to access surgery in other centres. Also, appropriate service development would be necessary to help build multidisciplinary team working with other providers, fully explore the appropriate training opportunities for all staff and to ensure that the continuity of care for patients was assured, wherever their surgery was undertaken.

In regard to other specialised paediatric services, the Review Team, led by Sir Ian Kennedy, considered that the cessation of Paediatric Cardiac Surgery would not have detrimental impact on other paediatric services at the Royal Belfast Hospital for Sick Children.

There may however be an impact on maternity or neonatal care. There are rare instances when a newborn may require an urgent interventional procedure prior to surgery. If it were not possible to undertake this in Belfast, a very small number of women may need to have arrangements

made for their baby's delivery to take place in a hospital that can provide access to emergency surgical care if needed.

There may also be a very small number of infants who require referral or transfer to another centre within hours of birth and facilitating a parent to travel with the child may be challenging. As noted earlier, where such transfers necessitate air transfers, this is normally safe and effective, but it is recognised that if there is a clinical emergency in-flight, this can be exceptionally challenging. The consistent availability of air transport may be impacted by severe weather and other factors. There may also be practical difficulties with transferring mothers in the period immediately following delivery.

If Paediatric Cardiac Surgery was not undertaken in Belfast there is likely to be an impact on services for the small number of adults with congenital heart disease who require surgery or interventional procedures. The number of adults undergoing surgery is relatively small, currently amounting to some 30 cases each year but expected to increase over time; nonetheless this service would be exceptionally vulnerable. It is normal practice that paediatric congenital cardiac surgeons also undertake surgery in adults with congenital disease. Therefore if Paediatric Cardiac Surgery were no longer performed in Belfast it would be extremely challenging to provide the skilled and experienced surgical input to effectively meet the needs of all adults with congenital heart disease.

6.0 Your Opportunity to Have Your Say – Consultation Questions

This document represents a formal consultation on the draft service specification, proposed assessment criteria and potential service model options for the future commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland. The consultation period will run **from Wednesday, 26 September 2012 to Friday, 21 December 2012.**

Comments are invited from all interested parties on the Consultation Questions listed below.

You can respond to the consultation document online, by e-mail or in writing. Responses must be received no later than **5pm on 21 December 2012.**

Before you submit your response, please read Annex A regarding the confidentiality of responses to public consultation exercises in the context of the Freedom of Information Act 2000.

The electronic web-form is available on the HSC Board website at www.hscboard.hscni.net/consult/PCCS_Consultation

Responses should be sent to:

E-mail: PCCSConsultation@hscni.net

Written: Paediatric Congenital Cardiac Services Consultation
Health and Social Care Board
12-22 Linenhall St
Belfast, BT2 8BS

**Consultation on the Service Specification, Options and Assessment
Criteria for the future delivery of Paediatric Cardiac Surgery and
Interventional Cardiology for the population of Northern Ireland**

QUESTIONNAIRE

1. I am responding:

- As an individual _____
- As a health and social
care professional _____
- On behalf of an
organisation _____

(please tick one option)

2. About you or your organisation:

Name:	
Job Title:	
Organisation:	
Address:	
Tel:	
Fax:	
E-mail:	

Service Specification

3. Are the proposed standards set out in the draft service specification appropriate?

Yes _____

No _____

If 'no' please comment

4. Are there other areas which should be considered?

Comment

Options

5. Are the options for future service provision appropriate?

Yes _____

No _____

If 'no' please comment

6. Are there other options which should be considered?

Comment

Assessment Criteria/Weightings

7. Are the assessment criteria relevant for considering the most appropriate option for future service provision?

Yes _____

No _____

If 'no' please comment

8. Are the associated weightings appropriate?

Yes _____

No _____

If 'no' please comment

9. Are there other criteria which should be considered?

Comment

Other Comments

10. Please provide any other comments, evidence or information that you wish to share.

Thank you for completing this response

Annex A to consultation response

Freedom of Information Act (2000) – Confidentiality of Consultations

The Board will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Board can only refuse to disclose information in exceptional circumstances. **Before** you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Board in this case.

This right of access to information includes information provided in response to a consultation. The Board cannot automatically consider as confidential information supplied to it in response to a consultation.

However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Lord Chancellor's Code of Practice on the Freedom of Information Act provides that:

- the Board should only accept information from third parties in confidence if it is necessary to obtain that information in connection with the exercise of any of the Board's functions and it would not otherwise be provided

- the Board should not agree to hold information received from third parties “in confidence” which is not confidential in nature
- acceptance by the Board of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner

For further information about confidentiality of responses please contact the Information Commissioner's Office (or see web site at: **<http://www.informationcommissioner.gov.uk/>**).

Paediatric Congenital Cardiac Services Working Group

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