Health and Social Care Board

Future commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland.

Post Consultation Document

February 2013

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FOREWORD

Consideration of the future arrangements for the commissioning of paediatric cardiac surgery and interventional cardiology is an issue of the very highest priority for the HSC Board. To support us with this work we have established a Working Group involving service providers, clinicians, parents and parent group representatives. The input provided by Working Group members has been hugely beneficial in ensuring a robust, transparent process.

In September 2012, the HSC Board issued for consultation the commissioning framework developed by the Working Group. During the consultation process, five public meetings and four focus groups were held to facilitate input from interested parties, and nearly 650 written responses were received.

Informed by the responses received during the consultation, this post-consultation document now provides a revised commissioning framework for paediatric cardiac surgery and interventional cardiology. The framework includes a revised service specification, revised generic options and revised criteria and weightings against which the options can be assessed.

Subject to the Minister's approval, the revised framework will be used to determine a preferred model for the commissioning of paediatric cardiac surgery for children in Northern Ireland.

I would like to extend my sincere thanks to all those who contributed during the consultation process, particularly parents and families who have shared their personal experiences. I am also hugely grateful to the members of the Working Group for their continued input and support.

JOHN COMPTON
CHIEF EXECUTIVE
HSC BOARD

EXECUTIVE SUMMARY

This document sets out a framework for the commissioning of paediatric cardiac surgery and interventional cardiology for children in Northern Ireland and takes forward the work requested by the Minister for Health, Social Services and Public Safety, in August 2012.

For many years, paediatric cardiac surgical services in Northern Ireland have been recognised as vulnerable. This is primarily because of the small population served, and consequently a lower activity level than recommended by professional organisations. However, following an external review of the service in April 2012, specific and significant concerns were articulated about the sustainability of paediatric cardiac surgery and interventional cardiology services in Belfast, and the potential safety risks that may ensue from continuing to provide services under current arrangements.

It was in this context that the Department of Health Social Services and Public Safety (DHSSPS) asked the HSC Board to draft a consultation document setting out a proposed service specification, options for the delivery of services and criteria against which services could be assessed. Furthermore the Department asked that the HSC Board conduct a consultation process and produce a post consultation document that reflects appropriately the consideration of input received from those individuals and organisations who responded to the consultation document.

A Paediatric Congenital Cardiac Services (PCCS) Working Group was established to take forward this work and throughout its deliberations ensured a robust approach. The Working Group included commissioning service providers, clinicians, parents and parent group representatives.

This post consultation document reflects the commissioning framework agreed by the Working Group. The framework is considered to provide a structure by which services for children can be commissioned to ensure that every child in Northern Ireland who may require specialised cardiac care is able to have such care provided in a manner that meets the very highest standards.

The public consultation period commenced on 25 September 2012 and closed on 21 December 2012. The consultation was specifically in respect of the following three key areas:

1. A detailed service specification for commissioning Paediatric Cardiac Surgery and Interventional Cardiology
2. The range of potential service model options including an all-Ireland model
3. Criteria (with agreed rationale for inclusion and weightings and scoring) against which the options for children from Northern Ireland should be assessed.

Unlike the majority of other consultation processes, the HSC Board was not consulting on a preferred option, rather the focus was on the development of an appropriate framework which could be used to determine a preferred option.

During the consultation process, the Working Group held five public meetings and four focus groups to facilitate input from stakeholders. In addition there were 647 written responses to the consultation, the majority of which were received from individuals who had friends or family who had received treatment for congenital heart disease.

Many of those who responded expressed concern that the Safe and Sustainable standards were not necessarily applicable to Northern Ireland, primarily because of the local geography and demography.

A small number of individuals who expressed such concerns suggested specific changes which the Working Group considered in detail.

Furthermore, a significant proportion of those who responded indicated a preferred model of service provision, namely one which retained surgical services in Belfast. A number of clinicians in responding to the consultation expressed concerns about the potential impact on patient care if surgical services were removed from Belfast. This was noted and acknowledged by the Working Group but could not be taken further at this stage which is focussed on developing a framework for the commissioning of paediatric cardiac surgery and interventional cardiology.

Following the extensive analysis of responses, the Working Group carefully considered the major themes arising from respondents and also any key clinical issues that were raised by clinicians.

Subsequently a number of changes were made to the service specification, primarily in response to issues the Working Group considered to be priorities. Some of the areas in which the service specification was amended included:

- Inclusion of a more rigorous standard on emergency access
- Inclusion of a specific standard to ensure babies in neonatal intensive care who were unfit to travel for surgery have timely and appropriate access to surgery
- Inclusion of a more robust standard on clinical engagement to help ensure that the clinical team in Belfast remain central to all decision making and are full and active participants in the care of children, wherever they receive that care
- Inclusion of a more robust standard in regard to arrangements for families to help ensure that those who need to travel have access to liaison staff to provide advice and support.

Similarly, amendments were made to the options in light of respondents' suggestions and specifically two additional service options have been included in the final framework.

On the criteria, changes were made to both the criteria and weightings. One additional criterion was added and changes were also made to the weighting of criteria, with the criterion on emergency access being given a greater weighting and priority, reflecting respondents' concerns that emergency access is a priority matter.

In determining the amendments required, the Working Group took due account of the number and nature of responses from the public. The Working Group also took full account of the specific clinical issues raised, particularly those regarding the safety and timeliness of care for infants and children at higher risk because of their cardiac condition.

The Working Group has agreed the following commissioning framework, which includes a revised service specification, revised generic options and revised criteria and weightings by which options can be assessed. This final framework provides robust, specific and evidence based standards against which the HSC Board/PHA can commission high quality care for children. Application of the framework will also ensure the Belfast team remain central to the provision of care for children with heart disease.

Service specification for paediatric cardiac surgery and interventional cardiology services for the population of Northern Ireland

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 HSC Board draw on those developed by the Safe and Sustainable process but have been amended to reflect the specific needs of the Northern Ireland population.

Staffing and Activity

- The service must provide enough staff to provide a consistent and robust 24-hour emergency service within legally compliant rotas, including cover by consultant paediatric cardiologists
- Each surgeon in the team must perform a minimum of 100 and ideally 125 paediatric cardiac surgical procedures a year
- The service should be working towards performing a minimum of 400 and ideally 500 paediatric cardiac surgical procedures a year, consistent with Safe and Sustainable standards
- 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. The providing centre should be in a position to accommodate all children and young people who require to be cared for in a paediatric environment.

Also appropriate transitional arrangements should be in place for patients who require surgery as adults. Ideally the providing centre

should have links or arrangements for ensuring the provision of services for adults with congenital heart disease.

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 HSC 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 paediatric cardiac surgery or interventional / diagnostic investigations or procedures access requirements are:

- Emergency cases i.e. those requiring immediate treatment, the totality for time for the patient journey from the clinical decision being made that a child requires emergency intervention to the time that the child is in the centre where surgery takes place should be consistent with clinically indicated timescales to meet the needs of the child and achievable ideally within three hours and not taking longer than four hours.
- Urgent procedures should be available within clinically indicated timescales - 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
- For those neonates in the regional neonatal intensive care unit who require patent ductus ligation, arrangements must be in place for this group of patients to undergo surgery in Belfast. This must be provided by a specialist surgical team dispatched from the centre providing the paediatric cardiac surgical service for Northern Ireland. The team should be suitably equipped in terms of staff and equipment

- 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 multi-disciplinary team discussion for every child requiring surgery irrespective of the provider. There should also be 24/7 access for the Belfast team to consultant surgical advice and support.

The service provider would be expected to support paediatric cardiologist(s) from Belfast Trust in undertaking interventional or diagnostic investigations / 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.

For those children and families that are required to travel for treatment, there should be a seamless pathway that ensures continuity of care and ongoing advice and support as required. Specifically, support should also be available from trained cardiac liaison staff before, during and after treatment.

Where parents seek to visit the centre 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. Where possible accommodation should also be available for siblings in the eventuality of a child having a lengthy stay in a centre outside Northern Ireland.

Options for the future provision of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland

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.

7. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery.

8. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with an increase in the number of procedures in Belfast by bringing children from elsewhere to make the local service sustainable / a Centre of Excellence.

Criteria and associated weightings for the assessment and scoring of options for the future provision of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland

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.	**The option ensures that the services commissioned are:** • **safe and of high quality, consistent with prevailing professional standards** • **compliant with CCAD control limits.** *(Rationale: The overriding priority for the HSC Board as commissioner is to ensure that services are safe and of high quality. This priority is reflected in the relative weighting of this criterion.)*	**50**
2.	**The option ensures emergency and urgent procedures can be undertaken within clinically indicated timescales.** *(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.)*	**50**
3.	**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.**	**35**

	(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.)	
4.	**The option ensures that services are sustainable / deliverable with:** • **The service is deliverable and able to be sustained 365 days a year** • **The service sufficiently resilient to respond to expected and unexpected absences among key clinical staff** • **The service able to recruit and retain key clinical personnel** • **The service able to train/mentor staff, particularly doctors in training.** (Rationale: A priority for the HSC Board as commissioner is to ensure that the service is available at all times.)	**35**
5.	**The option ensures the required volume of activity can be delivered reliably and consistently, in accordance with extant NI waiting time standards (currently 9 weeks for diagnostics, 9 weeks for outpatients and 13 weeks for inpatients/daycases), from early 2013.** *(Rationale: Each year a total of some 110[(1)] surgical, up to 50 interventional cardiology and up to 60 appropriate diagnostic 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.)*	**25**

6.	**The option ensures, through partnership working, the continued provision of medical and diagnostic paediatric cardiology services and other paediatric and cardiac services in Belfast and takes account of the need for multi-disciplinary training.** *(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.)*	**25**
7.	**The option ensures the effective use of resources.** *(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.)*	**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.

1. BACKGROUND

Overview – In this section of the report the Working Group sets out the current service provision, background to the independent review, establishment of the Working Group and consultation timeline.

Current Services

1.1 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.

1.2 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. 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.

1.3 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.

1.4 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. For children who require surgery approximately 9 out of 10 undergo a single surgical procedure. These children may, however, subsequently need longer term follow up for their medical condition.

1.5 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.

1.6 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) there has been over recent years support from two Dublin-based cardiac surgeons who visit the Belfast Trust where they too perform operations.

1.7 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.

1.8 In summary, around 90 procedures were provided in Belfast Trust in 2011/12 of which approximately 70 were planned cases and approximately 20 were urgent or emergency cases.

1.9 Pending a decision on the future arrangements for commissioning paediatric cardiac surgery and interventional cardiology for children in Northern Ireland, and in response to inherent vulnerabilities in current services, precautionary measures have been put in place. Specifically, the volume and type of surgery undertaken in Belfast Trust has been adjusted in the context of the need to minimise risk. As a consequence of these precautionary measures, the projected number of procedures expected to be delivered in Belfast will be fewer than in previous years.

1.10 Arrangements have been in place for a number of years for babies and children from Northern Ireland who require certain complex procedures to be referred to a specialist centre elsewhere. Of the babies and 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.

1.11 These arrangements, involving babies and children being referred to other specialist centres, have been expanded to take account of the change in the profile of services provided in Belfast in recent months.

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

1.13 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.

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

1.15 Work is being taken forward by the HSC Board to fully explore 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. The output of the work will be forwarded separately to the HSCB Board and DHSSPS in February 2013.

Independent Review of Paediatric Congenital Cardiac Services

1.16 A review of paediatric congenital cardiac services currently provided by Belfast Trust was commissioned in summer 2012 by the HSC Board, in conjunction with the PHA, 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.

1.17 Services were assessed against the *Safe and Sustainable* standards which have been used to assess children's cardiac surgical centres in England. These standards have been endorsed by the relevant professional associations in the UK. The review

provided advice and direction on the best way to secure high quality care for all children needing specialist cardiac care in the future.

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

1.19 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.

1.20 Following publication of the report of the Review Panel on 1 August 2012, the Minister made a statement to the Assembly outlining his expectation that the HSC Board consider the safety and sustainability of the service in Belfast and the findings of the report. In addition the HSC 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, were robustly considered.

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

Establishment of the Paediatric Congenital Cardiac Services Working Group

1.22 Subsequent to the Minister's statement on 1 August 2012, the DHSSPS asked the HSC Board working with the PHA to establish a Paediatric Congenital Cardiac Services (PCCS) Working Group

with representation from 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 weightings 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.

1.23 A copy of the correspondence from the DHSSPS to the HSC Board of 6 August 2012 is attached as annex 1. Full details of the membership of the PCCS Working Group are attached as annex 2.

Consultation Timeline

1.24 A consultation document was prepared by the Working Group during August and early September 2012. Following approval of the document by the HSCB Board at its meeting in September 2012, the consultation document was forwarded to the Minister.

1.25 The consultation document was approved by the Minister on 25 September 2012, and a 12-week period of consultation then took place ending on 21 December 2012.

1.26 This post consultation document incorporates an analysis of written responses received during the consultation and feedback from a series of public meetings and focus group events, both specifically in relation to the service specification, options and assessment criteria, and more generally.

1.27 Taking account of these responses the document makes recommendations in relation to a final service specification, together with options for service delivery and criteria / associated weightings to assess the options.

2. CONSULTATION PROCESS

Overview – In this section of the report the Working Group sets out the overview of the consultation, the key stakeholders, the process adopted and a summary of the inputs received.

Background

2.1 The public consultation period commenced on 25 September 2012 and closed on 21 December 2012. The consultation was specifically in respect of the following three key areas:

- A detailed service specification for commissioning paediatric cardiac surgery and interventional cardiology
- The range of potential service model options including an all-Ireland model
- Criteria (with agreed rationale for inclusion and weightings and scoring) against which the options for children from Northern Ireland should be assessed.

2.2 Unlike the majority of other consultation processes, the HSC Board was not consulting on a preferred option; rather the focus was on the development of an appropriate framework which could be used to determine a preferred option.

2.3 From the outset, the Working Group agreed that the consultation process be open and transparent. This was essential for:

- Ensuring meaningful engagement and two-way communication with all key parties, including parents, parent groups and clinicians
- Ensuring a wide range of stakeholders were consulted with, using a variety of communication channels
- Ensuring effective communication of the outcome of the consultation process to key stakeholders and the wider public.

2.4 A communication plan for securing this approach was developed. This plan took account of the HSC Board guidelines on consultation

arrangements, and all relevant legislative and statutory requirements, including equality considerations.

2.5 Comments received on the areas above have informed changes which are proposed to the service specification, options and criteria/weightings. A number of more general comments have also been received and are incorporated within this document.

Key Stakeholders

2.6 The consultation process included a significant focus on engagement; ensuring that all key stakeholders were aware of the consultation and how to get involved.

2.7 The key stakeholders identified included:

- Parents and families
- Patient Groups
- Children
- Belfast Health and Social Care Trust staff
- The general public
- Section 75 groups
- DHSSPS/Minister
- NI Assembly Health Committee
- MLAs
- HSC Board including LCGs
- Public Health Agency
- HSC Trusts
- Patient and Client Council
- NIAS
- Children's Commissioner

- Staff side organisations
- Primary Care
- NIMDTA
- Media.

Process

2.8 Correspondence was sent to stakeholders from the key interest groups outlined above informing them of the consultation process, asking that they use available networks of communication to ensure that as many stakeholders as possible were informed of the consultation. The correspondence was issued to around 600 stakeholders.

2.9 The letter outlined how stakeholders could respond to the consultation. Copies of the consultation document and response template were available:

- From www.hscboard.hscni.net/consult/PCCS_Consultation
- By e-mailing pccsconsultation@hscni.net;
- By phoning 02890 553904 – *for text relay prefix with 18001*

2.10 Responses could be sent by e-mail, in writing or by completing an online response form via the HSC Board website. A copy of the response template is attached as annex 3.

2.11 A series of public meetings and focus group events were held across Northern Ireland to enhance awareness and understanding of the consultation process, encourage people to formally respond and to capture views from key stakeholders.

2.12 The dates and locations of the five public meetings are set out in table 1 below. The meetings were advertised in advance in the local media and notifications were also issued to each of the stakeholder groups that were initially advised about the consultation.

Table 1 - PCCS Consultation – Public Meetings

Date	Location	Number who attended
19 November 2012	Enniskillen	30
21 November 2012	Ballymena	24
26 November 2012	L'Derry	22
5 December 2012	Belfast	70
10 December 2012	Craigavon	30

2.13 Four focus group events were also held (see table 2). Three of the focus groups were arranged for parents and family members of children who have had or are awaiting surgery or interventional cardiology for congenital heart disease. A fourth event took place with a group of teenagers and young adults who had undergone surgery/ interventional cardiology or may do so in the future.

Table 2 - PCCS Consultation – Focus Group Events

Date	Location	Number who attended
22 November 2012	Portadown	11
27 November 2012	Belfast	11
12 December 2012	Omagh	3
3 January 2013	Belfast	3

2.14 The focus groups for parents and families were facilitated by Parenting NI, an independent voluntary organisation. Participation Network, a voluntary organisation, funded by OFMDFM, who support the public sector to engage children and young people, facilitated the focus group for teenagers and young adults.

Summary of consultation input

2.15 A total of 176 people attended the five public meetings and 28 stakeholders attended the focus group events.

2.16 A total of 647 written responses were received to the consultation.

2.17 Table 3 and chart 1 below summarise the number of written responses that were received. Table 4 and chart 2 provide a breakdown of the method of responding.

Table 3 – Summary of Consultation responses

Responses	**Number received**
Total consultation responses	647
Responses from individuals	594
Responses from HSC professionals	16
Responses on behalf of organisations	37

Chart 1 – Summary of Consultation responses

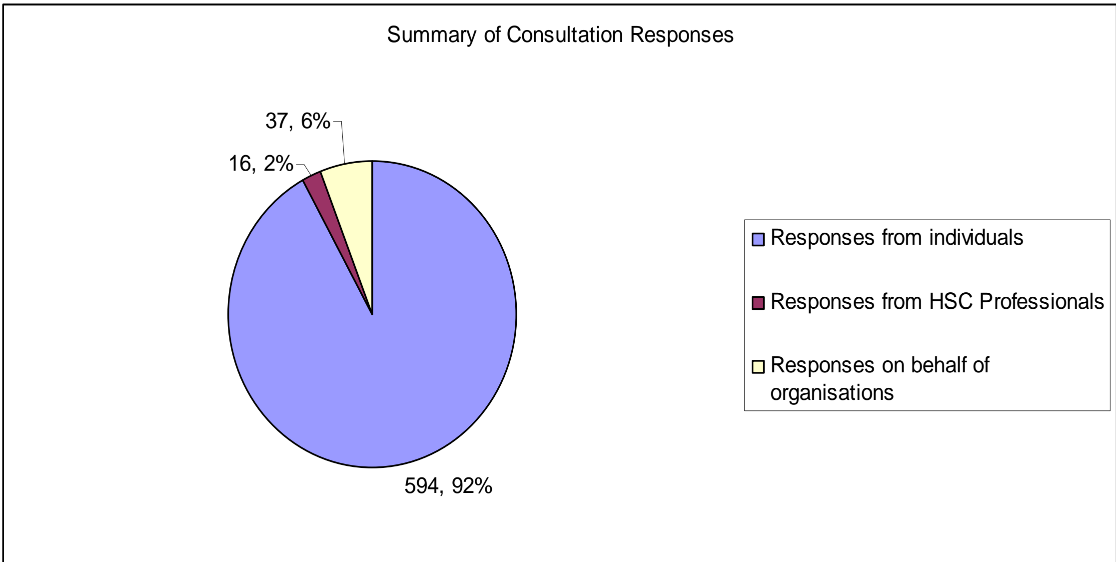
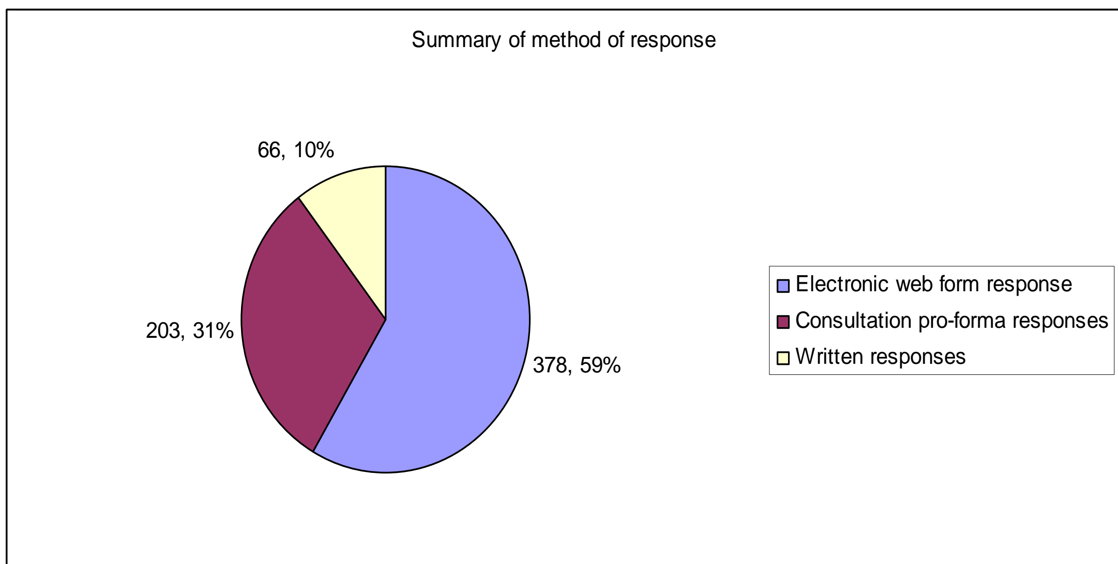


Table 4 – Summary of method of response

Method	Number received
Electronic web form response	378
Consultation pro-forma responses (Via e-mail) (Via post)	203 (44) (159)
Written responses (Via post) (Via e-mail)	66 (10) (56)
Total Consultation Responses	647

Chart 2 – Summary of method of response



3. PROCESS FOR ANALYSING INPUT TO THE CONSULTATION PROCESS

Overview – In this section of the report the Working Group sets out the process that was used to review and analyse the input received to the consultation; including the written responses, input from the public meetings and input from the focus groups.

3.1 A preliminary review of all the written consultation responses was undertaken by senior HSC Board / PHA staff in the days immediately following the consultation period in late December and early January. This was followed up with a detailed analysis and documentation of each of the 647 written responses. The analysis was carried out by a small team of HSC Board and PHA staff in a dedicated office.

3.2 The responses were collated for each specific consultation question and more general comments for each of the areas (service specification, options and criteria / weightings) were also recorded.

3.3 A similar approach was followed in analysing the discussions at the five public meetings and four focus groups.

3.4 To ensure that the process for analysing the input from the written responses, public meetings and focus groups was transparent, an independent assessment of the process to confirm robustness and objectivity was undertaken by a representative from Parenting NI.

3.5 The Parenting NI representative attended a series of Working Group meetings in January to advise members on her observations in relation to the process for reviewing responses to the consultation and to provide assurance as to the robustness and objectivity of the process.

4. SUMMARY OF WRITTEN RESPONSES

Overview – In this section of the report the Working Group summarises the 647 written consultation responses received and outlines the proposed changes, additional areas identified or other comments received. The analysis is presented by service specification, options, criteria / weightings and other comments.

4.1 A total of 647 written responses to the consultation were received. Table 5 below summarises the questions from the response template and also includes information on the answers to those questions where respondents were asked for a view on the appropriateness of each of the areas i.e. service specification, options, criteria and weightings.

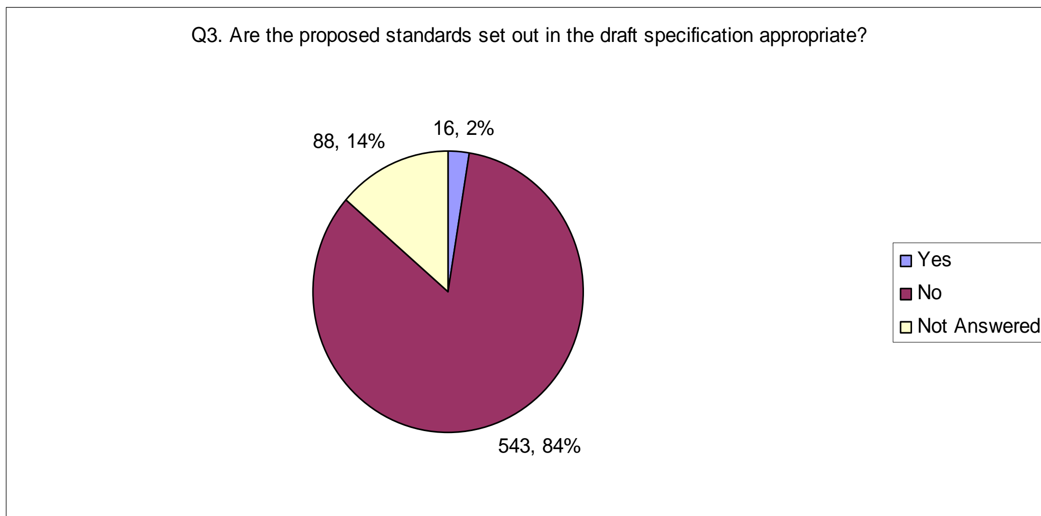
Table 5 – Summary of response template consultation questions

No.	Question	Yes	No	Not Answered
1.	Are you responding as an individual, HSC professional or on behalf of an organisation?	Responses to this question are summarised in table 3 on page 26		
2.	Please provide information about you or your organisation.	This information is not included in the document.		
3.	Are the proposed standards set out in the draft specification appropriate?	16	543	88
4.	Are there other areas which should be considered?	Not applicable		
5.	Are the options for future service provision appropriate?	40	520	87
6.	Are there other options which should be considered?	Not applicable		
7.	Are the assessment criteria relevant for considering the appropriate option for future service provision?	51	491	105

8.	Are the associated weightings appropriate?	33	511	103
9.	Are there other criteria which should be considered?	Not applicable		
10.	Please provide any other comments, evidence or information that you wish to share.	Not applicable		

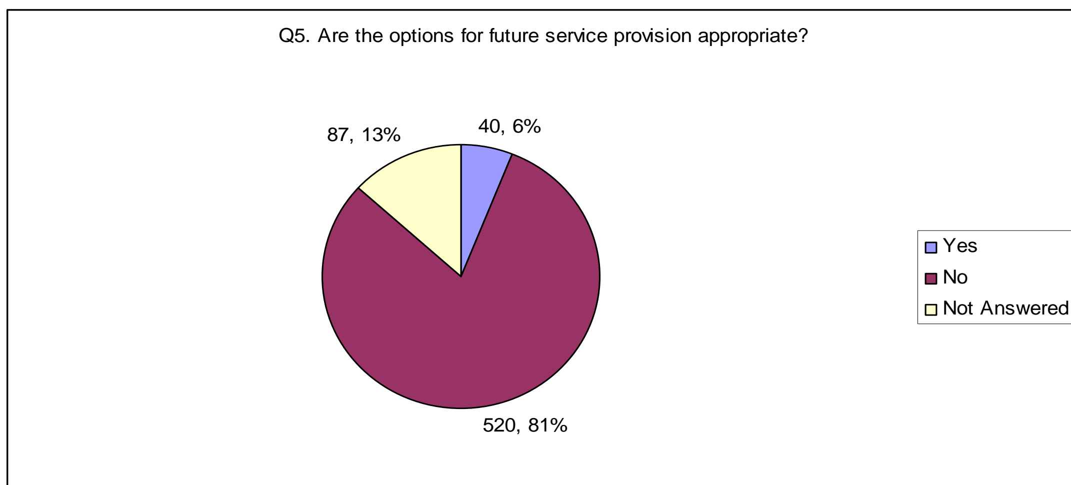
4.2 The table above shows that of the 559 responses to question 3 on the appropriateness of the standards set out in the draft service specification included in the consultation document, 16 responses indicated that the standards were appropriate and 543 indicated that the standards were not appropriate. This information is summarised in chart 3 below.

Chart 3 – Summary of responses to question 3



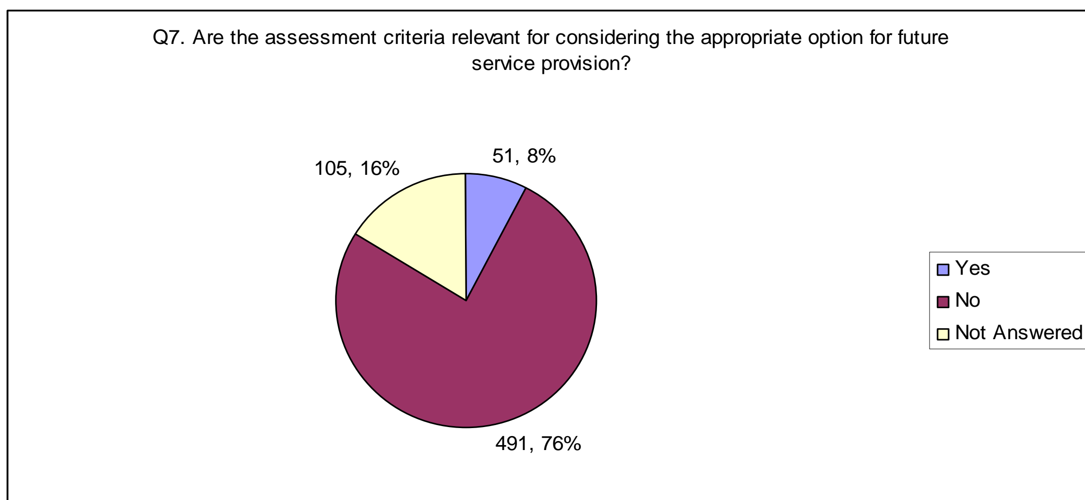
4.3 There were a total of 560 responses to question 5 on the appropriateness of the draft options listed in the consultation document. Of this number 40, indicated that the draft options were appropriate and 520 indicated that the draft options were not appropriate. This information is summarised in chart 4 below.

Chart 4 – Summary of responses to question 4



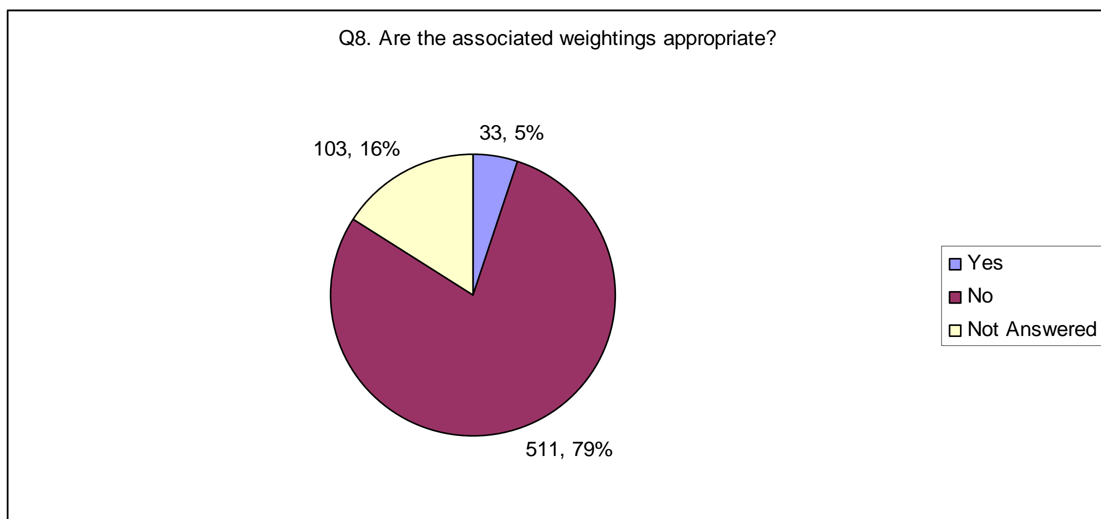
4.4 There were a total of 542 responses to question 7 on the appropriateness of the draft criteria included in the consultation document. Of this number 51, responses indicated that the draft criteria were appropriate and 491 responses indicated that the draft criteria were not appropriate. This information is summarised in chart 5 below.

Chart 5 – Summary of responses to question 7



4.5 There were a total of 544 responses to question 8 on the appropriateness of the draft weightings included in the consultation document. Of this number 33, responses indicated that the draft weightings were appropriate and 511 responses indicated that the draft weightings were not appropriate. This information is summarised in chart 6 below.

Chart 6 – Summary of responses to question 8



4.6 All proposed changes and additions that have been suggested by respondents, to specific questions, are included under the response information below.

4.7 With regard to other supporting comments provided in respect of each of the questions, these are included below where 10 or more respondents made the same comment. A full list of all comments received to each question is included as annex 4.

4.8 In addition to the comments on the areas being consulted on, and to the more general comments that were received, a significant number of parents and family members reflected their personal experiences. The Working Group recognised that the experience for each individual patient and their family is personal and unique and will be influenced by a range of issues including the clinical condition and particular family circumstances. Nonetheless, at the end of this section of the report the Working Group has sought to capture the essence of those experiences without including any potentially identifiable information.

Comments on the service specification

4.9 In relation to the draft service specification, the response template included two specific questions:

- Question 3 - Are the proposed standards set out in the draft specification appropriate?; and
- Question 4 - Are there other areas which should be considered?

4.10 Of the 559 responses received to question 3, 16 indicated that the proposed standards set out the draft service specification were appropriate, and 543 responses indicated that the proposed standards were not appropriate. The information below sets out proposed changes to the draft service specification in response to question 3, additional areas for inclusion in the service specification in response to question 4 and other comments recorded in response to these two questions.

4.11 The information in table 6 below provides a summary of the proposed changes to the service specification as suggested in the written responses to the consultation.

Table 6 – Proposed changes to the service specification

***Q3. Are the proposed standards set out in the draft specification appropriate?* (Yes – 16, No – 543)**	
Proposed changes:	No. of responses
A tailored set of standards should be developed for the population of Northern Ireland	17
Revise the number of procedures to be delivered by a service in Northern Ireland	3
Include more detail in the section on clinical linkages	2
Recommendations about number of surgeons should be same for anaesthetics	1

4.12 The information in table 7 below outlines the additional area suggested for inclusion in the service specification in the written responses to the consultation.

Table 7 – Suggested addition to the service specification

Q4. Are there other areas which should be considered?	
Additional area:	No. of responses
There should be more emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres	59

4.13 The information in table 8 below summarises the other comments that were received in the written responses to questions 3 (Are the proposed standards set out in the draft specification appropriate?) and question 4 (Are there other areas which should be considered?).

Table 8 – Other comments received in response to service specification questions

Comments received in response to the service specification questions	
Comment	No. of responses
Review in England was not meant for NI / no NI rep on review panel	241
Unique geography / population size of NI	186
Retrieval team to be available within 3 hours / 3 hours by road	174
Timescales for review in NI rushed / not consistent with England / Process and timescales flawed	146
Reliability and/or timeliness of access to air travel	131
Need to consider teenagers/young people and adults	127

Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)	90
Emergency Cases - concerns about the transfer of newborns and their fitness to travel	69
Standards in England have not been uniformly applied / centres do not meet all standards	59
Support provided by family is important but not available if surgery outside Belfast / impact on siblings	32
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed	27
Belfast should have a centre/service enhanced	24
NI can not meet all standards but a service is still needed	17
Stress of Travelling/suitability of accommodation in GB	17
Potential to lose experienced staff (cardiology) if no surgery in Belfast	16
Dublin can not cope with demand from ROI and couldn't deal with activity from NI	12
Standards not accepted in Scotland	10

Comments on the options

4.14 In relation to the draft list of six options, the response template included two specific questions:

- Question 5 - Are the options for future service provision appropriate?
- Question 6 - Are there other options which should be considered?

4.15 Of the 560 responses received to the question 5 above, 40 indicated that the draft six options were appropriate, and 520 responses indicated that the draft six options were not appropriate.

The information below sets out proposed changes to the draft options in response to question 5, additional options proposed in response to question 6 and other comments recorded in response to these two questions.

4.16 The information in table 9 below outlines that there were no changes suggested to the proposed six options.

Table 9 – Proposed changes to options

Q5. Are the options for future service provision appropriate? **(Yes – 40, No – 520)**
There were no changes suggested to the proposed six options.

4.17 The information in table 10 below provides a summary of the additional options as suggested in the written responses to the consultation.

Table 10 – Suggested additional options

Q6. Are there other options which should be considered?	
Proposed options	No. of responses
Bring consultants from other Centres to Belfast to undertake surgery	99
Increase capacity in Belfast to make sustainable/Centre of Excellence/bring children to Belfast from elsewhere	60

4.18 The information in table 11 below summarises the other comments that were received in the written responses to question 5 (Are the options for future service provision appropriate?) and question 6 (Are there other options which should be considered?).

Table 11 – Other comments received in response to options questions

Comments received in response to the generic options questions	
Comment	No. of responses
Prefer option 4 (Surgery in Belfast and Dublin)	255
Options with no surgery in Belfast not appropriate	142
For all reasons discussed at meetings	52
Enhance and retain service in Belfast	48
More emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres	39
Prefer option 1	37
Reliability and/or timeliness of access to Air Travel	33
Options about location rather than service/children focused	30
Emergency Cases - concerns about the transfer of newborns and their fitness to travel	27
Should fully explore all island solution	21
Does Dublin/other Centres have the capacity to take on additional cases	20
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)	19
Surgical Services outside NI will mean some mothers are unable to transfer with their child immediately after giving birth	17
Retrieval team to be available within 3 hours / 3 hours by road	13

Comments on the criteria and weightings

4.19 In relation to the draft criteria / weightings, the response template included three specific questions:

- Question 7 - Are the assessment criteria relevant for considering the most appropriate option for future service provision?
- Question 8 - Are the associated weightings appropriate?
- Question 9 - Are there other criteria which should be considered?

4.20 Of the 542 responses received to question 7 above, 51 indicated that the draft criteria were appropriate, and 491 responses indicated that the draft criteria were not appropriate.

4.21 Of the 544 responses received to question 8 above, 33 indicated that the draft weightings were appropriate and 511 indicated that the draft weightings were not appropriate.

4.22 The information below sets out proposed changes to the draft criteria in response to question 7 (Are the assessment criteria relevant for considering the most appropriate option for future service provision?), the proposed changes to the draft weightings in response to question 8 (Are the associated weightings appropriate?), and the additional criteria proposed in response to question 9 (Are there other criteria which should be considered?). The information below also includes other comments recorded in response to the three questions included in this section of the response template.

4.23 The information in table 12 below provides a summary of the proposed changes to the criteria as suggested in the written responses to the consultation.

Table 12 – Proposed changes to criteria

Q7. ***Are the assessment criteria relevant for considering the most appropriate option for future service provision? (Yes – 51, No – 491)***	
Proposed change	No. of responses
Safety and sustainability should appear as separate criteria, and/or sustainability should be lower	213
Safety and access should be considered together	18

4.24 The information in table 13 below provides a summary of the proposed changes to the weightings as suggested in the written responses to the consultation.

Table 13 – Proposed changes to weightings

Q8. Are the associated weightings appropriate? (Yes - 33 No - 511)	
Proposed change	No. of responses
Criterion 2 (Emergencies and Urgent Cases) should be increased and/or the same as safety	192
Criterion 4 (Accessibility) should be increased and/or the same as safety	166
Criterion 5 (Clinical Linkages) should be increased	10

4.25 The information in table 14 below provides a summary of the proposed additional criteria as suggested in the written responses to the consultation.

Table 14 – Suggested additional criteria

Q9. Are there other criteria which should be considered?	
Other area	No. of responses
Financial effect on family	4
If other services must be co located then this should be a criterion	2

4.26 The information in table 15 below summarises the other comments that were received in the written responses to question 7 (Are the assessment criteria relevant for considering the most appropriate option for future service provision?), question 8 (Are the associated

weightings appropriate?) and question 9 (Are there other criteria which should be considered?).

Table 15 – Other comments received in response to criteria / weightings questions

Comments received in response to the questions on criteria / weightings	
Comment	No. of responses
Timescales for review in NI rushed / not consistent with England / Process and timescales flawed	67
Safety paramount	61
Unique geography / population size of NI	59
S&S review in NI was not undertaken fairly/flawed process	33
Why has Dublin not previously submitted to CCAD	29
Reduced access for emergency and urgent cases compromises right to life	21
Families should be given higher weighting	18
Review in England was not meant for NI / no NI rep	14
Transport should be included	13
Process to develop criteria flawed	11
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed	11
Need to consider teenagers/young people and adults	10

Other Comments

4.27 The response template included a final question which asked respondents to record any other comments, evidence or information

that they wished to provide. The information in table 16 below outlines the comments received in the written responses under question 10.

Table 16 – Other general comments received in response to question 10

Comments received in response to question 10, other comments, evidence or information	
Comment	No. of responses
Quote re family/friend experience	195
More emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres	123
Support provided by family is important but not available if surgery outside Belfast / impact on siblings	113
Children are used to Clarke clinic/continuity of care within range of specialities in Belfast Trust	111
Quote re personal experience	103
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)	95
Reliability and/or timeliness of access to Air Travel	76
Concern regarding arrangements for timely intervention for urgent / emergency cases	43
Timescales for review in NI rushed / not consistent with England / Process and timescales flawed	38
Concern over expecting sick children to have to travel outside NI	27
Retrieval team to be available within 3 hours / 3 hours by road	25
Transport is an issue	23
Unique geography / population size of NI	18

Document hard to understand / template difficult to complete	16
Finance/budget issue	15
Ideal solution would be Belfast/Dublin	13
NI can not meet all standards a service is still needed	12
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed	12

Summary of personal experience comments

4.28 The responses to question 10 above highlighted that a significant number of respondents had referred to their personal experience of the service. A number of these responses indicated that a family member had used the paediatric cardiology, paediatric cardiac surgery or interventional cardiology services in Belfast or in another centre. A proportion of the responses included more detailed comments on their experience. A sample of these comments is captured in table 17 below.

Table 17 – Sample of personal experience comments

Comments received on personal experience in response to question 10, other comments, evidence or information
Comment
Respondents commented that in their opinion, if services are no longer provided in Belfast, it would have a negative effect on not only the patient but the whole family in regards to mental and emotional well being.
Respondents referred to the financial and emotional burden on families whose child has surgery outside Belfast. This includes the difficulties with care arrangements for other family members (older relatives, disabled family members, other children) during long periods away from home.
Respondents referred to the lack of family support available when surgery is provided outside NI

Respondents indicated that the service should provide 'cradle to grave' joined up care.
Respondents referred to the positive experience of care provided in RBHSC i.e. standard of care, being able to stay with their child, staff being very accommodating.
Respondents made a number of comments in respect of Clark Clinic. These included • Clark Clinic has provided excellent care and support right through to adulthood, why remove it? • Clark Clinic very busy during time there • World class treatment at Clark Clinic • Other centres lack the expertise of Clark Clinic • Issues around continuity of care if no service in Clark Clinic.
Respondents referred to practical arrangements associated with travelling for surgery and the arrangements post surgery for getting back home.
Respondents made reference to issues related to separating mother and baby including fears of not seeing the child again if anything were to happen when travelling, issues around mother and baby bonding, mother not being able to travel following childbirth.
Respondents indicated that travel adds to stress of an already difficult situation.
Respondents referred to timescales for emergency cases as some children are too ill to travel.
Respondents made reference to the need to consider improving arrangements for early diagnosis of congenital heart conditions and the need to consider the pathway for those expectant mothers diagnosed ante-natally if there is no surgical provision in Belfast.
Respondents expressed concerns about access to other centres and the conditions in other centres that were already busy.
Respondents referred to the negative impact that the consultation has had on patients and families and some indicated a view that input from patients and families was not being taken into account.
Respondents stated that the cardiac liaison nurse services provide reassurance for patients and families.
Respondents indicated that there are issues for those that are self employed and loss of earnings while away from home. If a parent has to return home

there is no support for the other parent.
Respondents referred to current access issues from rural areas in Northern Ireland and the fact that a 3 hour travel time is not feasible for many patients.
Respondents stated that the consultation document does not consider patients as humans
Respondents indicated a feeling of being treated as second class when compared to children in GB.

5. SUMMARY OF RESPONSES FROM HSC ORGANISATIONS AND INDIVIDUAL PROFESSIONALS

Overview – In this section of the report the Working Group summarises the subset of the written consultation responses that were received from HSC organisations or HSC professionals. The analysis is presented by Service Specification, Options and Criteria / Weightings.

5.1 In addition to the analysis of the 647 written responses outlined in the previous section, the Working Group undertook an analysis of a subset of the written responses received from HSC organisations and individual HSC professionals.

5.2 In total there were 25 responses from individuals or organisations directly or indirectly involved in the commissioning or provision of paediatric cardiac services. Of the 25 responses, the majority were received from individuals, with 9 from groups of clinicians. Two responses were received from Trusts. One response was received from an LCG. One of the responses was from an individual who was also a member of the Working Group, although this was written on behalf of a hospital paediatric department.

5.3 Table 18 summarises the responses to those questions where respondents were asked for a view on the appropriateness of each of the sections.

Table 18 – Summary of responses (HSC organisations and professionals)

No.	Question	Yes	No	Not Answered
3.	Are the proposed standards set out in the draft specification appropriate?	4	10	11
5.	Are the options for future service provision appropriate?	8	6	11
7.	Are the assessment criteria relevant for considering the appropriate option for future service provision?	8	6	11
8.	Are the associated weightings appropriate?	6	9	10

5.4 It should be noted that, for those who responded to the consultation but did not answer specific questions, this was primarily because the response was by letter rather than on the response template.

5.5 The table above shows that of the responses received to question 3 on the appropriateness of the standards set out in the draft service specification included in the consultation document, 4 responses indicated that the standards were appropriate and 10 indicated that the standards were not appropriate.

5.6 In response to question 5 on the appropriateness of the draft options listed in the consultation document, 8 indicated that the draft options were appropriate and 6 indicated that the draft options were not appropriate.

5.7 In response to question 7 on the appropriateness of the draft criteria included in the consultation document, 8 responses indicated that the draft criteria were appropriate and 6 responses indicated that the draft criteria were not appropriate.

5.8 In response to question 8 on the appropriateness of the draft weightings included in the consultation document, 6 responses indicated that the draft weightings were appropriate and 9 responses indicated that the draft weightings were not appropriate.

5.9 A significant proportion of responses were received in letter format and the key issues were not necessarily included under distinct headings. It is not considered appropriate to attempt to quantify specific points. The issues raised are documented and quantified within section 4 which analyses all 647 written responses.

5.10 This section aims to provide particular reference to the key issues articulated by HSC organisations and professionals that may not have been reflected in other responses. In that regard, much of what HSC organisations and professionals have emphasised correlates well with other responses. However, the major themes which are particularly prevalent in this subset of responses are:

- Concerns about the safety of transferring children in emergency situations, particularly the safety of patients who may need emergency surgery or balloon atrial septostomy
- Concerns about the safety of transferring babies who are inpatients in neonatal intensive care units and who require access to surgery because of a patent ductus arteriosus (PDA)
- Concerns about transport / travel arrangements that may be needed if patients had to access services from a centre outside Northern Ireland, particularly concerns regarding air travel
- Concerns regarding the implications for groups of patients other than children with cardiac disease e.g. pregnant women whose infant may have heart disease, adults with congenital heart disease, children with co-morbidities in addition to heart disease
- Concerns regarding the impact on staff, particularly the potential impact on recruitment and retention of cardiology consultant staff
- An expressed wish among the majority of responses from HSC organisations and professionals to retain paediatric cardiac surgery in Belfast

5.11 The Belfast Trust submitted a response to the consultation. In addition, individual clinicians and groups of clinicians within the Trust (Neonatologists, Fetal Medicine clinicians, Paediatric Intensive Care clinicians, Paediatric Neurologists, Paediatric Cardiologists, RBHSC Medical Staff Committee, Adult Congenital Service) also submitted responses. Some clinicians were party to more than one response. Also, groups of clinicians in other Trusts submitted responses (Paediatricians from Altnagelvin Hospital, Paediatricians/Neonatologists from Northern Trust and the Northern Ireland Neonatal Network).

5.12 The responses from clinicians within the Belfast Trust included the following additional comments:

- Clinicians from the Belfast Trust, responding either as individuals or clinical groups, indicated they were broadly in favour for

retaining some form of cardiac surgical service with linkages to another unit - a number suggested this would enable local paediatric cardiologists to continue to perform interventional cardiological procedures within Belfast.

- A number of clinicians highlighted the potential implications for the adult congenital service if paediatric cardiac surgery was no longer undertaken in Belfast
- Clinicians also highlighted the possibility of a purpose built solution for Northern Ireland
- There was a suggestion that paediatric cardiac surgery should be provided within the RBHSC
- There was a suggestion of building a hospital for the children of Ireland.

5.13 The response from Belfast Trust included the following additional comments:

- The Trust acknowledged that Belfast does not have the service capacity to continue to function as a standalone centre
- The Trust accepts that the paediatric cardiac surgical service cannot be sustained in Belfast in the long term and indicated a preference for a Dublin solution with services being delivered by both Belfast and Dublin staff
- During a transition (up to 1 year) the Trust recognises the need to continue an arrangement with a UK specialist centre.

5.14 A summary of the comments/issues raised in the responses from HSC organisations and individual professionals is set out below.

Comments on the service specification

5.15 In relation to the draft service specification, the response template included two specific questions:

- Question 3 - Are the proposed standards set out in the draft specification appropriate?, and

- Question 4 - Are there other areas which should be considered?

5.16 The information in table 19 below provides a summary of the comments made by HSC organisations and individual professionals in the written responses to the consultation in respect of question 3:

Table 19 – Summary of comments received to question 3

Q3. Are the proposed standards as set out in the draft specification appropriate? (Yes – 4, No – 10)
Comment
Standards were nationally recognised but not necessarily applicable to Northern Ireland
Clarification sought over whether the minimum of 400 procedures is by site or by region?
An assertion was made that the activity in a centre (400) is not scientific
There was a suggestion that the lack of outcome data on the Dublin service should not preclude Dublin from consideration
Particular concerns were expressed regarding emergency and urgent cases with specific reference to the need for patent ductus ligation in neonates who are considered unfit to travel
Concerns were raised regarding infants who may require a balloon septostomy in an emergency situation
Risks associated with the timeliness and/or reliability of air travel were raised
Impact on the skills of staff and the potential consequence that staff may become deskilled was raised as an issue
Respondent indicated that there may be potential implications for training of medical staff
There may be implications for mothers whose infant may have Congential Heart Disease and who may need to be transferred prior to delivery if there is no surgery in Belfast

5.17 The information in table 20 below provides a summary of the comments made by HSC organisations and individual professionals in the written responses to the consultation in respect of question 4:

Table 20 – Summary of comments received to question 4

Q4. Are there other areas which should be considered?
Comment
There should be access to neonatal transport on a 24/7 basis
There should be access to a 24/7 retrieval / transfer service
There should be access to a separate cardiac transport service
The recommended number of anaesthetists should be the same as the number of surgeons
There is a need to consider the potential impact on young people and adults who require congenital cardiac surgery
There is a need to consider the potential impact on elective patients
There is a need to consider the potential impact on pregnant women whose baby has complex heart disease
There is a need to consider the potential impact on the cardiology team
There will be a potential impact on diagnostic catheterisation— one respondent indicated that this will cease
There is a potential impact on babies with patent ductus arteriosus in neonatal ICUs
There is a need to consider the quality of the entire patient journey
Consider implications on other specialty areas
Consider the implications for children with heart disease who require other services

Comments on options

5.18 In relation to the draft list of six options, the response template included two specific questions:

- Question 5 - Are the options for future service provision appropriate?
- Question 6 - Are there other options which should be considered?

5.19 The information in table 21 below provides a summary of the comments made by HSC organisations and individual professionals in the written responses to the consultation in respect of question 5:

Table 21 - Summary of comments received to question 5

Q5. Are the options for future service provision appropriate? (Yes – 8, No – 6)
Comment
The Belfast service cannot remain as a standalone centre
Options don't take account of the financial implications
A surgical service linked to Dublin would enable paediatric cardiologists to undertake interventional cardiology in Belfast
A Dublin solution/option 4 was a stated preference among some

5.20 The information in table 22 below provides a summary of the comments made by HSC organisations and individual professionals in the written responses to the consultation in respect of question 6:

Table 22 - Summary of comments received to question 6

Q6. Are there any other options which should be considered?
Proposed options
One suggestion to develop a Service Level Agreement with a larger centre to include in reach/outreach

One suggestion for 2 full time surgeons in Belfast working between Belfast and Dublin

Comments on the criteria / weightings

5.21 In relation to the draft criteria / weightings, the response template included three specific questions:

- Question 7 - Are the assessment criteria relevant for considering the most appropriate option for future service provision?
- Question 8 - Are the associated weightings appropriate?
- Question 9 - Are there other criteria which should be considered?

5.22 The information in table 23 below provides a summary of the comments made by HSC organisations and individual professionals in the written responses to the consultation in respect of question 7:

Table 23 - Summary of comments received to question 7

Q7. Are the assessment criteria relevant for considering the most appropriate option for future service provision? (Yes – 8, No – 6)
Comment
Assessment criteria do not make provision for young people or adults
Criterion 3 (Volume / Waiting Times) does not take account of Northern Ireland population
Criterion 4 (Accessibility)
Concern that there was a potential that the Belfast service could be deskilled

5.23 The information in table 24 below provides a summary of the comments made by HSC organisations and individual professionals in the written responses to the consultation in respect of question 8:

Table 24 - Summary of comments received to question 8

Q8. Are the associated weightings appropriate? (Yes – 6, No – 9)
Comment
Reluctant to liaise with RoI because of absence of benchmarking data
Criterion 4 (Accessibility) should have higher weighting
Criterion 1 (Safe, Sustainable, High Quality) should have lower weighting
Criterion 5 (Clinical Linkages) should have higher weighting
Criterion 2 (Emergency/Urgent) and 3 cannot be weighted equally
Criterion 5 (Clinical Linkages) should have a weighting of 30

5.24 The information in table 25 below outlines that no additional criteria were suggested by HSC organisations and individual professionals in the written responses.

Table 25 - Summary of comments received to question 9

Q9. Are there other criteria which should be considered?
There were no additional criteria identified by the HSC organisations and individual professionals who responded.

5.25 The response template included a final question which asked respondents to record any other comments, evidence or information that they wished to provide. The information in table 26 below outlines the comments received in the written responses under question 10.

Table 26 - Summary of comments received to question 10

Comments received in response to question 10, other comments, evidence or information
Comment
Reluctant to liaise with RoI because of absence of benchmarking data

6. SUMMARY OF ADDITIONAL ISSUES RAISED AT PUBLIC MEETINGS / FOCUS GROUPS

Overview – In this section of the report the Working Group summarises the additional comments from the five public meetings and four focus groups over and above those identified from the written consultation responses.

6.1 As outlined earlier in the document five public meetings and four focus group events were held to enhance awareness and understanding of the consultation process, encourage people to formally respond, and to capture views from key stakeholders.

6.2 The transcripts from the public meetings and reports of the focus group events were analysed in the same way as the written responses. This analysis showed that the issues discussed at these events were mainly consistent with those included in the written responses.

6.3 A full list of all the issues raised at the public meetings and focus group events is attached at annex 5. Table 27 below outlines the additional comments raised at these events over and above those received in the written consultation responses.

Table 27 – Additional comments raised at public meetings and focus groups

Additional issues raised at the public meetings and focus groups
Comment
What are the arrangements if there is an emergency coming back from a centre outside NI?
Patients/parents should have a choice where surgery is carried out
Medical notes should travel with the patient to the centre undertaking the surgery
Medical care and the support care provided by the local centre is crucial in terms of preparing children and families for the surgical procedure
More expensive to provide a service outside NI

Access to information / package of support particularly for those having to travel
What professional bodies endorsed the standards for NI
Congenital Heart Disease is most common birth defect
Figures include interventional cardiology
Not consulting on diagnostic catheterisation
Report not about safety
Are NI children less important?
Feeling of isolation in other centres
Surgeons from Belfast could operate elsewhere to maintain skills
Surgical team required to provide a service not just the surgeon
Review team didn't support all island model
Visits to England premature / waste of resources
Perception that decision already made
Minister's decision should be on basis of evidence presented
Consistency of panel membership at public meetings/impartiality
Process biased against Belfast
Process not consistent with Transforming Your Care
Need to listen to views of parents
Document very clear and easy to understand / sound framework for assessing future service model
Need to consider future needs/new procedures and technologies
Need to have clear communication with parents in the short term whilst decisions are made
Clinical and family views are crucial
Panel's job is to reflect parents' views

7. KEY ISSUES ARISING FROM CONSULTATION PROCESS

Overview – In this section on the basis of the analysis of the data from the previous three sections, the Working Group outlines the most significant issues for consideration in finalising the service specification, options and criteria / weightings.

7.1 On the basis of the analysis of all of the input provided to the consultation process including the written responses, public meetings, and focus group events, a range of issues were identified for consideration by the Working Group in finalising the service specification, options and criteria / weightings for submission to the Minister.

7.2 The following paragraphs set out the specific areas for consideration under each heading.

Key issues for consideration in respect of the service specification

7.3 On the basis of the analysis of the input to the consultation as set out in sections 4 to 6, the most significant issues raised in relation to the service specification were as follows:

- Should the standards in the service specification be tailored to take account of Northern Ireland population/geography?
- Should section 3 of the service specification (Access to Services) be amended to reflect total transfer time for emergency transfers / retrievals?
- Should the service specification be amended to include a specific standard that the providing centre will provide a service for infants who require patent ductus ligation?
- Should the service specification be amended to include reference to capacity being required for paediatric cardiac surgery, interventional and diagnostic catheterisation?
- Should section 4 of the service specification (Clinical Engagement) be amended to include reference to support/advice

being available 24/7 (to address the issue of decision making required re: septostomy etc)?

- Should section 5 of the service specification (Arrangements for Parents) be amended to include more focus on improving arrangements for parents/families?
- Should the service specification be amended in relation to age group of patients?

7.4 The Working Group's consideration of each of these issues and the changes proposed is provided in section 8.

Key issues for consideration in respect of the options

7.5 The consultation document included the following six options:

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.

7.6 On the basis of the analysis of the input to the consultation as set out in sections 4 to 6, the most significant issues raised in relation

to the options was the suggestion that the following potential options be included:

- Paediatric cardiac surgery and interventional cardiology commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery.
- Paediatric cardiac surgery and interventional cardiology commissioned primarily from Belfast with an increase in the number of procedures in Belfast by bringing children from elsewhere to make the local service sustainable / a Centre of Excellence.

7.7 The Working Group's consideration on whether these options should be included is provided in section 8.

Key issues for consideration in respect of the criteria

7.8 The consultation document included the following six criteria:

1. The option ensures that the services commissioned are:
   - safe, sustainable and of high quality, consistent with prevailing professional standards
   - compliant with CCAD control limits.
2. The option ensures emergency and urgent procedures can be undertaken within clinically indicated timescales.
3. 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.
4. 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.
5. The option ensures, through partnership working, the continued provision of medical and diagnostic paediatric cardiology services and other paediatric and cardiac services in Belfast and takes account of the need for multi-disciplinary training.

6. The option ensures the effective use of resources.

7.9 On the basis of the analysis of the input to the consultation as set out in sections 4 to 6, the most significant issues raised in relation to the criteria were as follows:

- Should criterion 1 be split into two parts to separate safety and sustainability?
- Should criterion 3 be amended to include reference to diagnostic catheterisation capacity?

7.10 The Working Group's consideration of each of these issues and the changes proposed is provided in section 8.

Key issues for consideration in respect of the weightings

7.11 The consultation document included the following weightings associated with the original six criteria:

1. Safety, sustainability and quality (Weighting 50)
2. Emergency / urgent cases (30)
3. Volume / Waiting Time (30)
4. Accessibility (20)
5. Partnership Working / Clinical Linkages (20)
6. Use of Resources (10)

7.12 On the basis of the analysis of the input to the consultation as set out in sections 4 to 6, the most significant issues raised in relation to the weightings of the original criteria were as follows:

- Criterion 2 (Emergencies and Urgent Cases) weighting should be increased and/or the same as safety
- Criterion 4 (Accessibility) weighting should be increased and/or the same as safety
- Criterion 5 (Clinical Linkages) weighting should be increased

7.13 The Working Group’s consideration of each of these issues and the changes proposed is provided in section 8.

8. PROPOSED CHANGES TO THE SERVICE SPECIFICATION, OPTIONS AND CRITERIA / WEIGHTINGS

Overview – In this section the Working Group considers the proposed revisions to the service specification, options and criteria / weightings informed by the inputs provided to the consultation through the written responses, public meetings and focus groups.

8.1 On the basis of the analysis of all of the input provided to the consultation process including the written responses, public meetings, and focus group events, a range of key issues were identified for consideration by the Working Group in finalising the service specification, options and criteria / weightings for submission to the Minister. These key issues were set out in section 7 of the post consultation document.

8.2 The following paragraphs set out the specific areas considered under each heading and the proposed changes discussed and agreed by the Working Group. The revised service specification, options and criteria / weightings are included in section 9. For ease of reference the service specification, options and criteria / weightings with tracked changes are included at annex 6.

Proposed changes to service specification

8.3 On the basis of the analysis of the input to the consultation as set out in sections 4 to 6, the most significant issues raised in relation to the service specification were as follows:

- Should the standards in the service specification be tailored to take account of Northern Ireland population/geography?
- Should section 3 of the service specification (Access to Services) be amended to reflect total transfer time for emergency transfers / retrievals?
- Should the service specification be amended to include a specific standard that the providing centre will provide a service for infants who require patent ductus ligation?

- Should the service specification be amended to include reference to capacity being required for paediatric cardiac surgery, interventional and diagnostic catheterisation?

- Should section 4 of the service specification (Clinical Engagement) be amended to include reference to support/advice being available 24/7 (to address the issue of decision making required re: septostomy etc)?

- Should section 5 of the service specification (Arrangements for Parents) be amended to include more focus on improving arrangements for parents/families?

- Should the service specification be amended in relation to age group of patients?

8.4 The Working Group's consideration of each of these issues is provided in the paragraphs below.

Issue 1: Should the standards in the service specification be tailored to take account of Northern Ireland population/geography?

8.5 The staffing and activity section of the draft service specification refers to the need for a service to be staffed by four full time consultant congenital cardiac surgeons and that the service must perform a minimum of 400 procedures and ideally 500 procedures per annum. The number of procedures undertaken in a surgical centre is linked to the quality of patient outcomes.

8.6 To deliver a service consistently on a 24/7 basis across the year, it is recommended that a minimum of four surgeons comprise the surgical team. The figure of 400 procedures is then linked to each individual surgeon delivering an agreed volume to maintain skills. The current recommendation is that each surgeon should undertake a minimum of 100 procedures annually and ideally 125 procedures.

8.7 A significant number of responses referred to the need for a tailored set of standards specific to the geography and population of Northern Ireland. Respondents indicated that this needed to be

taken into account when planning the number of procedures required as part of the service model that is developed for the population of Northern Ireland.

8.8 The position in terms of centres in GB providing a paediatric cardiac surgical service is that only a small number would currently meet the requirement in terms of both procedure levels and consultant staffing set out in the draft service specification.

8.9 Taking account of all the issues above and following detailed consideration and discussion, the Working Group agreed that the wording included in the specification is amended to include more focus on the delivery of a consistent and robust 24/7 service in which each surgeon undertakes at least 100 procedures, and that the centre should be working towards the delivery of 400 procedures annually.

Issue 2: Should section 3 of the service specification (Access to Services) be amended to reflect total transfer time for emergency transfers / retrievals?

8.10 Section 3 of the draft service specification refers to emergency and urgent procedures being available within clinically indicated timescales consistent with the standards set out by the Paediatric Intensive Care Society i.e. that a retrieval team should be available at the referring centre within three hours.

8.11 A significant number of respondents raised concerns in respect of the timescales associated with the retrieval / transport of children in emergency situations. A number of respondents were of the view that the specification should indicate the time for the totality of journey.

8.12 In relation to *urgent* cases, Working Group members were content with the current wording regarding the retrieval team being at the referring centre within three hours.

8.13 However, for the very small number of *emergency* cases i.e. those requiring immediate treatment, Working Group members agreed that it would be appropriate to amend the specification to include a

proposed time for the totality of time for patient journey from the clinical decision being made to a child being in the centre where the surgery takes place.

Issue 3: Should the service specification be amended to include a specific standard that the providing centre will provide a service for infants who require patent ductus ligation?

8.14 Infants in neonatal care units may have a cardiac condition known as a 'patent ductus' that requires correction (ligation) but for which the infant, because of their prematurity or other health problems, is not stable enough to travel. Such procedures are not as complex as many other cardiac surgical procedures and can, when necessary, be undertaken in a neonatal intensive care unit avoiding the need to transfer the infant.

8.15 The issue of patent ductus ligation was not specifically included in the draft specification. However, this matter was highlighted in a number of the responses from clinicians and was highlighted during exploratory visits to centres in GB.

8.16 The Working Group considered the position and agreed that a reference would be included in the service specification that the providing centre would need to be in a position to provide this service on an outreach basis, consistent with the arrangements being considered in other parts of GB.

Issue 4: Should the service specification be amended to include reference to capacity being required for paediatric cardiac surgery, interventional and diagnostic catheterisation?

8.17 The clinical engagement section of the draft service specification states that the providing centre should be in a position to provide both paediatric cardiac surgery and interventional cardiology care. This was consistent with the remit of the Working Group.

8.18 A number of responses to the consultation document highlighted that if interventional cardiology was to stop in Belfast it would be reasonable to assume that diagnostic catheterisation may also

cease and arrangements would need to be in place to have this provided by an appropriate centre.

8.19 The Working Group considered this position and agreed that reference to the potential need for a providing centre to provide for diagnostic catheterisation capacity would be included in the service specification.

Issue 5: Should section 4 of the service specification (Clinical Engagement) be amended to include reference to support/advice being available 24/7 (to address the issue of decision making required re: septostomy etc)?

8.20 The clinical engagement section of the draft service specification makes reference to the need for multi-disciplinary team discussion for every child requiring surgery.

8.21 The Working Group agreed that the current section on clinical engagement should be strengthened and made more explicit in terms of the requirements for Northern Ireland. It was agreed that this section should include a statement that 24/7 access for the Belfast team to consultant surgical advice and support.

Issue 6: Should section 5 of the service specification (Arrangements for parents) be amended to include more focus on improving arrangements for parents/families?

8.22 Section 5 of the draft service specification relates to the arrangements that should be in place for parents as part of the service being provided including dedicated liaison support, the facility for parents to visit the providing centre in advance of their child's treatment and appropriate accommodation and other facilities.

8.23 A number of responses to the consultation flagged up issues in respect of the practical, emotional and financial issues for those families accessing services outside Northern Ireland.

8.24 The Working Group agreed that the section on arrangements for parents should be strengthened to highlight that a seamless pathway is required to address the issues raised. This should

include more robust liaison arrangements between the cardiology service in RBHSC and the centre providing the surgical service.

Issue 7: Should the service specification be amended in relation to the age group of patients?

8.25 The draft service specification includes a section on age appropriate care under the safety and quality heading and is presented to reflect that the review was specific to paediatric care.

8.26 A significant number of respondents referred to the need to consider the ongoing needs for teenagers / young adults and adults. This group of patients were not included within the remit of the Working Group; UK wide standards are currently being developed for this group of patients. However, Working Group members were of the view that in light of responses the specification be amended.

8.27 Reference has been made to the need for the providing centre to accommodate all children and young people who require to be cared for in a paediatric environment. The statement around transitional arrangements will be expanded to indicate that ideally the provider should have links or arrangements for ensuring the provision of services for adults with congenital heart disease.

<u>Service specification - summary</u>

8.28 Reflecting all of the above issues raised and the amendments agreed by the Working Group, a revised service specification is provided in section 9. For ease of reference the service specification with tracked changes is included at annex 6.

Proposed changes to options

8.29 The consultation document included the following six options:

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.

8.30 On the basis of the analysis of the input to the consultation as set out in sections 4 to 6, the most significant issues raised in relation to the options was the need to add two further potential options (to increase the total number of options to eight).

8.31 The Working Group agreed that the following two additional options would be included in a revised list of options:

- Paediatric cardiac surgery and interventional cardiology commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery.
- Paediatric cardiac surgery and interventional cardiology commissioned primarily from Belfast with an increase in the number of procedures in Belfast by bringing children from elsewhere to make the local service sustainable / a Centre of Excellence.

<u>Options - summary</u>

8.32 Reflecting on the above issues and the amendments agreed by the Working Group, a revised list of eight options is provided in section 9. For ease of reference the options with tracked changes are included at annex 6.

Proposed changes to criteria

8.33 The consultation document included the following six criteria:

1. The option ensures that the services commissioned are:
    - safe, sustainable and of high quality, consistent with prevailing professional standards
    - compliant with CCAD control limits.
2. The option ensures emergency and urgent procedures can be undertaken within clinically indicated timescales.
3. 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.
4. 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.
5. The option ensures, through partnership working, the continued provision of medical and diagnostic paediatric cardiology services and other paediatric and cardiac services in Belfast and takes account of the need for multi-disciplinary training.
6. The option ensures the effective use of resources.

8.34 On the basis of the analysis of the input to the consultation as set out in sections 4 to 6, the most significant issues raised in relation to the criteria were as follows:

- Should criterion 1 be split into two parts to separate safety and sustainability?
- Should criterion 3 be amended to include reference to diagnostic catheterisation capacity?

8.35 The Working Group's consideration of each of these issues is provided in the paragraphs below.

Issue 1: Should criterion 1 be split into two parts to separate safety and sustainability?

8.36 Criterion 1 from the draft list of criteria links safety and sustainability under one heading. A significant number of consultation responses indicated that these two issues need to be considered separately.

8.37 The Working Group considered the comments made and agreed that criterion 1 should be split into two separate areas and that there would be seven criteria in total. Furthermore, it would be appropriate for the new standalone sustainability criterion to also include the issue of deliverability of each of the proposed options.

8.38 The additional criterion of sustainability/deliverability is defined as:

- The service is deliverable and can be sustained 365 days a year;
- The service is sufficiently resilient to respond to expected and unexpected absences among key clinical staff;
- The service can recruit and retain key clinical personnel;
- The service can train/mentor staff, particularly doctors in training.

Issue 2: Should criterion 3 be amended to include reference to diagnostic catheterisation capacity?

8.39 Criterion 3 from the draft list of criteria included in the consultation document relates to the providing centre being in a position to deliver the required level of activity reliably and consistently in line with Northern Ireland waiting time standards. The rationale for this criterion outlines the level of paediatric cardiac surgery and interventional cardiology required to be delivered.

8.40 In paragraphs 8.17 to 8.19 above the Working Group agreed that reference to the potential need for a providing centre to deliver paediatric cardiac surgery and interventional/diagnostic catheterisation would be included in the service specification. As a result the Working Group also agreed that the potential level of diagnostic catheterisation activity required should be included as part of this criterion.

Criteria - summary

8.41 Reflecting on the above issues and the amendments agreed by the Working Group, a revised set of criteria is provided in section 9. For ease of reference the criteria with tracked changes are included at annex 6.

Proposed changes to weightings

8.42 The consultation document included the following weightings associated with the original six criteria:

1. Safety, sustainability and quality (Weighting 50)
2. Emergency / Urgent cases (30)
3. Volume / Waiting Times (30)
4. Accessibility (20)
5. Partnership Working / Clinical Linkages (20)
6. Use of Resources (10)

8.43 On the basis of the analysis of the input to the consultation as set out in sections 4 - 6, the most significant issues raised in relation to the weightings of the original criteria were as follows:

- Criterion 2 (Emergencies and Urgent Cases) weighting should be increased and/or the same as safety
- Criterion 4 (Accessibility) weighting should be increased and/or the same as safety
- Criterion 5 (Clinical Linkages) weighting should be increased.

8.44 The Working Group considered carefully the rationale for the original weightings as reflected in the consultation document, the comments received in relation to the weightings and the addition of a seventh criterion. Following detailed consideration, the Working Group agreed the proposed ranking of the seven criteria and then following further discussion agreed the proposed weighting of each of the criteria.

8.45 On the basis of the discussions above, the Working Group agreed the following ranking and weighting associated with the seven criteria:

- Safety and quality (50);
- Emergency / Urgent cases (50);
- Accessibility (35);
- Sustainability / deliverability (35);
- Volume / Waiting Times (25);
- Partnership Working / Clinical Linkages (25);
- Use of Resources (10).

8.46 There was detailed discussion regarding the relative weighting of accessibility and sustainability / deliverability. A number of members of the Working Group considered sustainability should have a higher weighting than accessibility. The Working Group however agreed to take account of the significant number of people who responded to the consultation suggesting an increased weighting for accessibility (166 responses). Therefore, the Working Group agreed that accessibility and sustainability / deliverability should be equally weighted.

Weightings - summary

8.47 Reflecting on the above issues and the amendments agreed by the Working Group, the revised weightings associated with each of the criteria are provided in section 9. For ease of reference the weightings with tracked changes are included at annex 6.

9. REVISED SERVICE SPECIFICATION, OPTIONS AND CRITERIA/ WEIGHTINGS

Overview – In this section the Working Group sets out the revised service specification, options and criteria / weightings taking account of the key issues identified through the written responses, public meetings and focus groups and consideration of these issues by the Group.

9.1 The Working Group has agreed the following commissioning framework, which includes a revised service specification, revised generic options and revised criteria and weightings by which options can be assessed.

9.2 This final framework provides robust, specific and evidence based standards against which the HSC Board/PHA proposes to commission high quality care for children.

Service specification for paediatric cardiac surgery and interventional cardiology services for the population of Northern Ireland

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 HSC Board draw on those developed by the Safe and Sustainable process but have been amended to reflect the specific needs of the Northern Ireland population.

Staffing and Activity

- The service must provide enough staff to provide a consistent and robust 24-hour emergency service within legally compliant rotas, including cover by consultant paediatric cardiologists
- Each surgeon in the team must perform a minimum of 100 and ideally 125 paediatric cardiac surgical procedures a year

- The service should be working towards performing a minimum of 400 and ideally 500 paediatric cardiac surgical procedures a year, consistent with Safe and Sustainable standards
- 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. The providing centre should be in a position to accommodate all children and young people who require to be cared for in a paediatric environment.

Also appropriate transitional arrangements should be in place for patients who require surgery as adults. Ideally the providing centre should have links or arrangements for ensuring the provision of services for adults with congenital heart disease.

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 HSC 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 paediatric cardiac surgery or interventional / diagnostic investigations or procedures access requirements are:

- Emergency cases i.e. those requiring immediate treatment, the totality for time for the patient journey from the clinical decision being made that a child requires emergency intervention to the time that the child is in the centre where surgery takes place should be consistent with clinically indicated timescales to meet the needs of the child and achievable ideally within three hours and not taking longer than four hours.
- Urgent procedures should be available within clinically indicated timescales - 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
- For those neonates in the regional neonatal intensive care unit who require patent ductus ligation, arrangements must be in place for

this group of patients to undergo surgery in Belfast. This must be provided by a specialist surgical team dispatched from the centre providing the paediatric cardiac surgical service for Northern Ireland. The team should be suitably equipped in terms of staff and equipment

- 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 multi-disciplinary team discussion for every child requiring surgery irrespective of the provider. There should also be 24/7 access for the Belfast team to consultant surgical advice and support.

The service provider would be expected to support paediatric cardiologist(s) from Belfast Trust in undertaking interventional or diagnostic investigations / 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.

For those children and families that are required to travel for treatment, there should be a seamless pathway that ensures continuity of care and ongoing advice and support as required. Specifically, support should also be available from trained cardiac liaison staff before, during and after treatment.

Where parents seek to visit the centre 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. Where possible accommodation should also be available for siblings in the eventuality of a child having a lengthy stay in a centre outside Northern Ireland.

Options for the future provision of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland

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.
7. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery.

8. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with an increase in the number of procedures in Belfast by bringing children from elsewhere to make the local service sustainable / a Centre of Excellence.

Criteria and associated weightings for the assessment and scoring of options for the future provision of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland

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.	**The option ensures that the services commissioned are:** • **safe and of high quality, consistent with prevailing professional standards** • **compliant with CCAD control limits.** *(Rationale: The overriding priority for the HSC Board as commissioner is to ensure that services are safe and of high quality. This priority is reflected in the relative weighting of this criterion.)*	**50**
2.	**The option ensures emergency and urgent procedures can be undertaken within clinically indicated timescales.** *(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.)*	**50**

3.	**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.** *(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.)*	**35**
4.	**The option ensures that services are sustainable / deliverable with:** • **The service is deliverable and able to be sustained 365 days a year** • **The service sufficiently resilient to respond to expected and unexpected absences among key clinical staff** • **The service able to recruit and retain key clinical personnel** • **The service able to train/mentor staff, particularly doctors in training.** (Rationale: A priority for the HSC Board as commissioner is to ensure that the service is available at all times.)	**35**
5.	**The option ensures the required volume of activity can be delivered reliably and consistently, in accordance with extant NI waiting time standards (currently 9 weeks for diagnostics, 9 weeks for outpatients and 13 weeks for inpatients/daycases), from early 2013.**	**25**

	(Rationale: Each year a total of some 110[1] surgical, up to 50 interventional cardiology and up to 60 appropriate diagnostic 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.)	
6.	**The option ensures, through partnership working, the continued provision of medical and diagnostic paediatric cardiology services and other paediatric and cardiac services in Belfast and takes account of the need for multi-disciplinary training.** *(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.)*	**25**
7.	**The option ensures the effective use of resources.** *(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.)*	**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.

10. EQUALITY CONSIDERATIONS

Overview – In this section of the report the Working Group sets out the current baseline profile of services for paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland. The Working Group then goes on to consider the Section 75 groups that might be potentially impacted by any change to the existing profile of services, the likely impacts on these groups under each option, and any potential issues in respect of Human Rights. Finally the Working Group considers potential mitigating arrangements to address the issues identified.

Introduction

10.1 As part of the consultation process on the future commissioning of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland, the Working Group sought to ensure that organisations representing the Section 75 groups were identified and that the consultation document was made widely available.

10.2 Unlike the majority of other consultation processes, at this stage, the HSC Board is not consulting on a preferred option; rather the focus is on the development of an appropriate framework which will be used to determine a preferred option. At the point when the Working Group is recommending a preferred option, it is acknowledged that formal equality screening and, as appropriate, an equality impact assessment in relation to the proposed future service model for the provision of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland will be required.

10.3 At this stage of the process, the Working Group has sought to identify the potential implications that each of the proposed options might have on relevant Section 75 groups, together with any potential impacts on the Human Rights of children, and mitigating arrangements that are or could be put in place.

Current baseline profile of services

10.4 The Working Group included in the consultation document detail of the paediatric cardiac surgical and interventional cardiology activity for the year 2011/12. In summary, around 90 procedures were provided in Belfast Trust in 2011/12 of which around 70 were planned cases and around 20 were urgent and emergency cases.

10.5 In addition to the paediatric cardiac surgery activity referred to above, during 2011/12, there were a total of 36 interventional and around 60 diagnostic catheterisation procedures undertaken in Belfast, with a further 13 interventional procedures undertaken at other centres. These interventional procedures were undertaken on patients who had previously had complex surgery at those centres. Each year in Northern Ireland approximately five babies require interventional cardiology within hours of birth to stabilise the baby in advance of surgery.

10.6 Pending a decision on the future arrangements for commissioning paediatric cardiac surgery and interventional cardiology for children in Northern Ireland and in response to inherent vulnerabilities in current services, precautionary measures have been put in place. Specifically, the volume and type of surgery undertaken in Belfast Trust has been adjusted in the context of the need to minimise risk. As a consequence of these precautionary measures, the projected number of procedures expected to be delivered in Belfast will be fewer than in previous years.

10.7 As the arrangements described above in 10.6 have only been introduced recently, for the purposes of considering equality and Human Rights implications it is more appropriate to consider the implications for the 110 children referred to in the original consultation document. Therefore the following sections reflect the potential implications for 110 children who may require paediatric cardiac surgery and those children who may require diagnostic or interventional cardiology.

Options to be considered

10.8 In considering equality and Human Rights implications the Working Group considered the following eight options:

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.
7. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery.
8. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with an increase in the number of procedures in Belfast by bringing children from elsewhere to make the local service sustainable / a Centre of Excellence.

Overview of potential impact on Section 75 groups

10.9 The Working Group considered the potential impact of any change to the existing profile of services for each of the Section 75 groups. These potential impacts, if any, are summarised below.

- Age – There is a potential impact on children under the age of 18 who may need to travel outside of Northern Ireland for their treatment
- Ethnicity – It is not anticipated that there will be any impact for this group
- Gender – There is a potential impact on gender, specifically the impact on mothers with infants who may need to travel outside of Northern Ireland prior to or shortly after the birth of their child
- Marital Status – There may be a potential impact on those couples given that they may be more likely that single people to have a child.
- People with dependants – There is a potential impact on those with dependants, i.e. parents and/or guardians of children under the age of 18 who may need to travel outside of Northern Ireland for their treatment.
- People with a disability – There is a potential impact on those with disability who may need to travel outside of Northern Ireland for their treatment. Specifically this impact is likely to be evident on those children with heart disease who also have co-morbidities e.g. Down's syndrome.
- Political Opinion – It is not anticipated that there will be any impact for this group.
- Religion – It is not anticipated that there will be any impact for this group.
- Sexual Orientation – It is not anticipated that there will be any impact for this group.

10.10 In summary, following consideration by the Working Group, of the nine Section 75 groups, there may be an impact on up to five groups;

- Age - children under the age of 18
- Gender - mothers with infants who may need to travel outside of Northern Ireland prior to or shortly after the birth of their child
- Marital Status – couples with children may need to travel outside of Northern Ireland if their child requires treatment.
- People with dependants - parents and/or guardians of children under the age of 18 who may need to travel outside of Northern Ireland for their treatment
- People with a disability - those with disability who may need to travel outside of Northern Ireland for their treatment.

Consideration of potential impacts on proposed options

10.11 The following paragraphs set out the Working Group assessment of the potential impact on the relevant Section 75 groups of each of the eight options identified.

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

10.12 With this option paediatric cardiac surgery and interventional cardiology would be provided primarily in Belfast and would have the potential of increasing the volume of surgery and interventional cardiology. The potential impacts on the relevant Section 75 groups as identified by the Working Group are as follows:

- Age – With this option there may be a potential impact on travel time for this Section 75 group, with a small proportion of children who currently travel to Dublin or GB having treatment in Belfast. Under this option it is likely that travel time will be reduced for this Section 75 group.
- Gender **–** With this option there may be a potential impact on a small number of women who may currently need to travel

antenatally to Dublin or GB to give birth or who are transferred immediately after giving birth. Under this option it is likely that the travel time will be reduced for this Section 75 group.

- Marital Status - With this option there may be a potential impact on couples whose child may currently be transferred to Dublin or GB. Under this option it is likely that the travel time will be reduced for this Section 75 group. Also, personal inconvenience and issues around employment, specifically if self-employed may be reduced.
- People with dependants **–** With this option there may be a potential impact on people with dependants whose child may currently be transferred to Dublin or GB. Under this option it is likely that the travel time will be reduced for this Section 75 group. Also, personal inconvenience and issues around employment, specifically if self-employed may be reduced. Parents/guardians who may also have caring responsibilities for other individuals may find it more manageable to provide the same level of support for those individuals.
- People with a disability – With this option there may be a potential impact on children with some disabilities (e.g. Down's syndrome) who may be more likely to have congenital heart disease and who currently travel to Dublin or GB for treatment. Under this option it is likely that the travel time will be reduced for this Section 75 group.

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

10.13 With this option paediatric cardiac surgery and interventional cardiology would be provided primarily in Dublin. The potential impacts on the relevant Section 75 groups as identified by the Working Group are as follows:

- Age – With this option there may be a potential impact on travel time for this Section 75 group, with up to 110 additional children being required to travel to Dublin for surgery and up to 40

additional children being required to travel to Dublin for interventional cardiology, where previously they would have received care in Belfast. In addition, a number of children may have to travel to Dublin for diagnostic catheterisation.

- Gender – With this option there may be a potential impact on a small number of women (less than 10 per annum) who need to be transferred to Dublin antenatally to give birth or on women who are transferred in the early post natal period where previously these women would have given birth in Belfast. There may also be a potential impact on women who are unable to travel immediately after giving birth and may be separated from their child for a short period of time.

- Marital Status - With this option there may be a potential impact on couples particularly where their child requires care in Dublin. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted.

- People with dependants – With this option there may be a potential impact on people with dependants particularly where the dependant child requires care in Dublin. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted. Parents/guardians who may also have caring responsibilities for other individuals may find it more difficult to provide the same level of support for those individuals.

- People with a disability – With this option there may be a potential impact on children with some disabilities (e.g. Down's syndrome) who may be more likely to have congenital heart disease, if these children were required to travel to Dublin for treatment where previously they would have received care in Belfast.

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

10.14 With this option paediatric cardiac surgery and interventional cardiology would be provided primarily in GB. The potential impacts on the relevant Section 75 groups as identified by the Working Group are as follows:

- Age – With this option there may be a potential impact on travel time for this Section 75 group, with up to 110 additional children being required to travel to GB for surgery and up to 40 additional children being required to travel to GB for interventional cardiology, where previously they would have received care in Belfast. In addition, a number of children may have to travel to GB for diagnostic catheterisation.

- Gender **–** With this option there may be a potential impact on a small number of women (less than 10 per annum) who need to be transferred to GB antenatally to give birth or on women who are transferred in the early post natal period where previously these women would have given birth in Belfast. There may also be a potential impact on women who are unable to travel immediately after giving birth and may be separated from their child for a short period of time.

- Marital Status - With this option there may be a potential impact on couples particularly where their child requires care in GB. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted.

- People with dependants **–** With this option there may be a potential impact on people with dependants particularly where the dependant child requires care in GB. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted. Parents/guardians who may also have caring responsibilities for other individuals may find it more difficult to provide the same level of support for those individuals.

- <u>People with a disability</u> – With this option there may be a potential impact on children with some disabilities (e.g. Down's syndrome) who may be more likely to have congenital heart disease, if these children were required to travel to GB for treatment where previously they would have received care in Belfast.

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

10.15 With this option paediatric cardiac surgery and interventional cardiology would be provided primarily in Belfast and Dublin. The potential impacts on the relevant Section 75 groups as identified by the Working Group are as follows:

- <u>Age</u> – With this option there may be a potential impact on travel time for this Section 75 group, with a proportion of children being required to travel to Dublin for surgery and a proportion of children being required to travel to Dublin for interventional cardiology, where previously they would have received care in Belfast. In addition, a number of children may have to travel to Dublin for diagnostic catheterisation.

- <u>Gender</u> **–** With this option there may be a potential impact on a small number of women who need to be transferred to Dublin antenatally to give birth or on women who are transferred in the early post natal period where previously these women would have given birth in Belfast. There may also be a potential impact on a small number of women who are unable to travel immediately after giving birth and may be separated from their child for a short period of time.

- <u>Marital Status</u> - With this option there may be a potential impact on couples particularly where their child requires care in Dublin. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted.

- <u>People with dependants</u> **–** With this option there may be a potential impact on people with dependants particularly where the dependant child requires care in Dublin. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted. Parents/guardians who may also have caring responsibilities for other individuals may find it more difficult to provide the same level of support for those individuals.

- <u>People with a disability</u> – With this option there may be a potential impact on children with some disabilities (e.g. Down's syndrome) who may be more likely to have congenital heart disease, if these children were required to travel to Dublin for treatment where previously they would have received care in Belfast.

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

10.16 With this option paediatric cardiac surgery and interventional cardiology would be provided primarily in Dublin and GB. The impacts on the relevant Section 75 groups are as follows:

- <u>Age</u> – With this option there may be a potential impact on travel time for this Section 75 group, with up to 110 additional children being required to travel to Dublin or GB for surgery and up to 40 additional children being required to travel to Dublin or GB for interventional cardiology, where previously they would have received care in Belfast. In addition, a number of children may have to travel to Dublin or GB for diagnostic catheterisation.

- <u>Gender</u> **–** With this option there may be a potential impact on a small number of women (less than 10 per annum) who need to be transferred to Dublin or GB antenatally to give birth or on women who are transferred in the early post natal period where previously these women would have given birth in Belfast. There may also be a potential impact on women who are unable to travel immediately after giving birth and may be separated from their child for a short period of time.

- <u>Marital Status</u> - With this option there may be a potential impact on couples particularly where their child requires care in Dublin or GB. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted.

- <u>People with dependants</u> **–** With this option there may be a potential impact on people with dependants particularly where the dependant child requires care in Dublin or GB. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted. Parents/guardians who may also have caring responsibilities for other individuals may find it more difficult to provide the same level of support for those individuals.

- <u>People with a disability</u> – With this option there may be a potential impact on children with some disabilities (e.g. Down's syndrome) who may be more likely to have congenital heart disease, if these children were required to travel to Dublin or GB for treatment where previously they would have received care in Belfast.

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

10.17 With this option paediatric cardiac surgery and interventional cardiology would be provided primarily in Belfast, Dublin and GB. The potential impacts on the relevant Section 75 groups as identified by the Working Group are as follows:

- <u>Age</u> – With this option there may be a potential impact on travel time for this Section 75 group, with a proportion of children being required to travel to Dublin or GB for surgery and a proportion of children being required to travel to Dublin or GB for interventional cardiology, where previously they would have received care in Belfast. In addition, a number of children may have to travel to Dublin or GB for diagnostic catheterisation.

- Gender – With this option there may be a potential impact on a small number of women who need to be transferred to Dublin or GB antenatally to give birth or on women who are transferred in the early post natal period where previously these women would have given birth in Belfast. There may also be a potential impact on a small number of women who are unable to travel immediately after giving birth and may be separated from their child for a short period of time.
- Marital Status - With this option there may be a potential impact on couples particularly where their child requires care in Dublin or GB. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted.
- People with dependants – With this option there may be a potential impact on people with dependants particularly where the dependant child requires care in Dublin or GB. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted. Parents/guardians who may also have caring responsibilities for other individuals may find it more difficult to provide the same level of support for those individuals.
- People with a disability – With this option there may be a potential impact on children with some disabilities (e.g. Down's syndrome) who may be more likely to have congenital heart disease, if these children were required to travel to Dublin or GB for treatment where previously they would have received care in Belfast.

Option 7 - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery.

10.18 With this option paediatric cardiac surgery and interventional cardiology would be provided primarily in Belfast. The potential impacts on the relevant Section 75 groups as identified by the Working Group are as follows:

- Age – With this option there may be a potential impact on travel time for this Section 75 group, with a small proportion of children who currently travel to Dublin or GB having treatment in Belfast. Under this option it is likely that travel time will be reduced for this Section 75 group.
- Gender **–** With this option there may be a potential impact on a small number of women who may currently need to travel antenatally to Dublin or GB to give birth or who are transferred immediately giving birth. Under this option it is likely that the travel time will be reduced for this Section 75 group.
- Marital Status - With this option there may be a potential impact on couples whose child may currently be transferred to Dublin or GB. Under this option it is likely that the travel time will be reduced for this Section 75 group. Also, personal inconvenience and issues around employment, specifically if self-employed may be reduced.
- People with dependants **–** With this option there may be a potential impact on people with dependants whose child may currently be transferred to Dublin or GB. Under this option it is likely that the travel time will be reduced for this Section 75 group. Also, personal inconvenience and issues around employment, specifically if self-employed may be reduced. Parents/guardians who may also have caring responsibilities for other individuals may find it more manageable to provide the same level of support for those individuals.
- People with a disability – With this option there may be a potential impact on children with some disabilities (e.g. Down's syndrome) who may be more likely to have congenital heart disease and who currently travel to Dublin or GB for treatment. Under this option it is likely that the travel time will be reduced for this Section 75 group.

Option 8 - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with an increase in the number of procedures in Belfast by bringing children from elsewhere to make the local service sustainable / a Centre of Excellence

10.19 With this option paediatric cardiac surgery and interventional cardiology would be provided primarily in Belfast. The potential impacts on the relevant Section 75 groups as identified by the Working Group are as follows:

- Age – With this option there may be a potential impact on travel time for this Section 75 group, with a proportion of children who currently travel to Dublin or GB having treatment in Belfast. Under this option it is likely that travel time will be reduced for this Section 75 group.

- Gender **–** With this option there may be a potential impact on a small number of women who may need to travel antenatally to Dublin or GB to give birth or who are transferred immediately giving birth. Under this option it is likely that the travel time will be reduced for this Section 75 group.

- Marital Status - With this option there may be a potential impact on couples whose child may currently be transferred to Dublin or GB. Under this option it is likely that the travel time will be reduced for this Section 75 group. Also, personal inconvenience and issues around employment, specifically if self-employed may be reduced.

- People with dependants **–** With this option there may be a potential impact on people with dependants whose child may currently be transferred to Dublin or GB. Under this option it is likely that the travel time will be reduced for this Section 75 group. Also, personal inconvenience and issues around employment, specifically if self-employed may be reduced. Parents/guardians who may also have caring responsibilities for other individuals may find it more manageable to provide the same level of support for those individuals.

- People with a disability – With this option there may be a potential impact on children with some disabilities (e.g. Down's syndrome) who may be more likely to have congenital heart disease and who currently travel to Dublin or GB for treatment. Under this option it is likely that the travel time will be reduced for this Section 75 group.

Human Rights Considerations

10.20 The Working Group undertook an assessment of the potential impact of the proposed eight options for the future provision of paediatric cardiac surgery and interventional cardiology on individual's Human Rights. Table 28 below sets out the initial assessment of the Working Group on which particular Human Rights Articles might be affected.

Table 28 - Summary Human Rights Assessment

Article	Potential Effect
Article 2 – Right to life	Yes
Article 3 – Right to freedom from torture, inhuman or degrading treatment or punishment	Yes
Article 4 – Right to freedom from slavery, servitude and forced or compulsory labour	There is no evidence to indicate there is any effect
Article 5 – Right to liberty & security of person	There is no evidence to indicate there is any effect
Article 6 – Right to a fair & public trial within a reasonable time	There is no evidence to indicate there is any effect
Article 7 – Right to freedom from retrospective criminal law & no punishment without law	There is no evidence to indicate there is any effect

Article 8 – Right to respect for private & family life, home and correspondence	Yes
Article 9 – Right to freedom of thought, conscience & religion	There is no evidence to indicate there is any effect
Article 10 – Right to freedom of expression	There is no evidence to indicate there is any effect
Article 11 – Right to freedom of assembly & association	There is no evidence to indicate there is any effect
Article 12 – Right to marry & found a family	There is no evidence to indicate there is any effect
Article 14 – Prohibition of discrimination in the enjoyment of the convention rights	Yes
1st protocol Article 1 – Right to a peaceful enjoyment of possessions & protection of property	There is no evidence to indicate there is any effect
1st protocol Article 2 – Right of access to education	Yes

10.21 For each of the Articles where there is a potential effect, the Working Group's consideration is provided in the paragraphs below:

- Article 2 – Right to life - all patients have the right to life and the preferred way forward must ensure that a safe and sustainable service is provided in accordance with individual patient needs. As a public body, there is an obligation on the HSC Board to positively promote a safe and sustainable service. It is clear that there are sustainability issues with the current service in Belfast which must be addressed. The preferred way forward must also

ensure that patients have timely access to urgent and emergency care when required.

- Article 3 – Right to freedom from torture, inhuman or degrading treatment or punishment - the preferred way forward must ensure that all patients/parents/carers are treated with dignity and respect and are not subject to any degrading treatment during treatment and/or attendance for treatment.
- Article 8 – Right to respect for private & family life, home and correspondence - the need to address the sustainability issues with the current services is in pursuit of a legitimate aim, most notably for the protection of health and the rights of the patients and is considered both necessary and proportionate in a democratic society. The preferred way forward must ensure that all patients/parents/carers are treated with dignity and respect and are not subject to any degrading treatment during treatment and/or attendance for treatment. It is acknowledged that parents/carers/patients may be apprehensive and/or inconvenienced as a result of the requirement to travel for treatment, with surgery being a significant and stressful event. However, the overriding priority is that patients receive a high quality of care provided by skilled and professional teams. The preferred way forward must ensure that appropriate support is provided to family members/carers who attend with patients including those in same-sex relationships as well as patients and to ensure that appropriate arrangements are in place for patients to travel for treatment with their parents/carers. The dignity of patients and their privacy and family arrangements must be respected throughout.
- Article 14 – Prohibition of discrimination in the enjoyment of the convention rights - the preferred way forward must ensure that services are delivered without discrimination on any ground.
- 1st protocol Article 2 - Right of access to education: the preferred way forward must ensure that children's education is not unduly impacted where their treatment requires them to travel and remain in hospital outside NI for a prolonged period. It is acknowledged that patients may have the continuity of their education affected and/or inconvenienced as a result of a

prolonged hospital stay outside Northern Ireland. In circumstances where pre-school / school age children are required to travel outside Northern Ireland, arrangements are currently in place for the respective hospital to provide appropriate educational support and such arrangements should continue.

UN Convention on the Rights of the Child

10.22 As part of its consideration of Human Rights, the Working Group considered the UN Convention of the Rights of the Child (UNCRC). The Working Group was advised (through HSC Board members) that the UNCRC has not been incorporated into UK domestic law at this time and therefore there is no requirement to take it into account in decision making. Nonetheless, the Working Group was of the view that due regard should be given to the UNCRC when formally considering equality implications and Human Rights issues in determining a preferred way forward.

Summary of key impacts

10.23 In the paragraphs above the Working Group has identified a range of potential equality and Human Rights impacts that a change to the current service profile may have. In summary the key potential impacts are as follows:

- The potential impact on children under the age of 18 who may need to travel outside of Northern Ireland for their treatment
- The potential impact on gender, specifically the impact on mothers with infants who may need to travel outside of Northern Ireland prior to or shortly after the birth of their child
- The potential impact on marital status, specifically the impact on those couples who may have a child who requires to travel outside Northern Ireland for treatment
- The potential impact on those with dependants, i.e. parents and/or guardians of children under the age of 18 who may need to travel outside of Northern Ireland for their treatment

- The potential impact on those with disability who may need to travel outside of Northern Ireland for their treatment. Specifically this impact is likely to be evident on those children with heart disease who also have co-morbidities e.g. Down's syndrome
- The potential impact on the right to life where children do not have access to the highest quality of care (Article 2 of the Human Rights Act)
- The potential impact on right to freedom from torture, inhuman or degrading treatment or punishment to ensure that patients/parents/carers are treated with dignity and respect and are not subject to any degrading treatment during treatment and/or attendance for treatment (Article 3 of the Human Rights Act)
- The potential impact on right to respect for private and family life home and correspondence where children are required to travel outside of Northern Ireland for treatment (Article 8 of the Human Rights Act)
- The potential impact on prohibition of discrimination in the enjoyment of the convention rights where all services are delivered without discrimination (Article 14 of the Human Rights Act)
- The potential impact on right of access to education where children are required to travel outside Northern Ireland for treatment (1st protocol Article 2 of the Human Rights Act).

Mitigating Arrangements

10.24 A number of children requiring cardiac surgery and interventional cardiology travel outside Northern Ireland for their treatment. Of these, a proportion have protracted stays in hospital, often for several weeks or even months. For these patients and their families, arrangements are in place – involving the HSC Board, Belfast Trust and receiving organisations – to ensure that all reasonable needs of children and their families are met. This includes meeting the full cost of travel, accommodation and all reasonable incidental costs.

10.25 In the event that the preferred way forward requires a number of the children who currently receive paediatric cardiac surgery or interventional cardiology in Belfast to receive treatment outside Northern Ireland, the HSC Board would ensure that similar support arrangements (in terms of travel, accommodation etc) are in place. Indeed it is the HSC Board's intention to look at opportunities to strengthen the existing arrangements, and in doing so the HSC Board has drawn on the issues highlighted during the consultation and also raised at a patient experience workshop held on 5 February 2013.

10.26 It is also the HSC Board's intention, regardless of the preferred way forward for the future provision of paediatric cardiac surgery and interventional cardiology, to enhance emotional support for parents by ensuring that robust communication and liaison arrangements are in place between parents, the Belfast Trust nurse liaison staff and the providing centres.

10.27 There is also the potential for the two local charities to play a greater role in this regard. It is the view of the Working Group that the above steps will help to mitigate any potential impact in relation to Article 2, Article 8 and 1st protocol Article 2.

10.28 In relation to a child's human right to life (Article 2), the independent review commissioned by the HSC Board undertaken in 2012 advised that the current arrangements for providing paediatric cardiac surgery and interventional cardiology in Belfast are not safe and sustainable in the longer term. Particular issues are the ability of the service in Belfast to provide 24/7 cover, including timely access to emergency treatment, and the ability of the service in Belfast to meet other current quality standards.

10.29 In the context of a child's human right to life, it will be crucial that any change to the existing arrangements ensures appropriate and timely access to emergency life-saving treatment.

11. NEXT STEPS

Overview – In this section of the report the Working Group sets out the next steps proposed in identifying a preferred way forward for the provision of paediatric cardiac surgery and interventional cardiology.

11.1 The consultation process has provided an opportunity for a range of key stakeholders to provide their views on the future commissioning of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland. The Working Group undertook a significant body of work to give due consideration to all responses to the consultation, including written responses, proceedings from the five public meetings and discussions at the four focus groups.

11.2 Following the extensive analysis of responses, the Working Group carefully considered the major themes arising from respondents and also any key clinical issues that were raised by clinicians.

11.3 Subsequently a number of changes were made to the service specification, options and criteria / weightings primarily in response to issues the Working Group considered to be priorities.

11.4 Drawing on the input from those who have responded to the consultation the Working Group now proposes a revised service specification, options and assessment criteria and associated weightings for the Minister's consideration (at annexes 6 to 8 respectively).

11.5 Subject to the Minister's approval the Working Group will proceed to assess each of the identified options using the proposed assessment criteria and associated weightings, with a view to identifying a preferred way forward for the commissioning of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland.

11.6 This work is expected to be completed in the coming weeks, with a further paper being produced for Ministerial consideration.

Annex 1

From the Permanent Secretary
and HSC Chief Executive

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Our Ref: AMCC 3952
SECCOR/233/2012
DH1/12/198759

Date: 6 August 2012

Dear John

Review of Paediatric Congenital Cardiac Services

Thank you for your letter of 9th July and for the copy of the revised final report of the Expert Panel's review of the paediatric congenital cardiac services in the Belfast Trust. As you point out the Expert Panel's report contains some positive comments about the services for children with congenital cardiac disease which are being provided by the Belfast Trust, and it is reassuring that the Panel did not identify any immediate safety concerns. Nevertheless the conclusion arrived at by the Panel is that the surgical element of the service in Belfast is not sustainable and that the potential safety risks should be addressed within six months.

You will have seen the Minister's statement of 1st August, announcing the publication of the Expert Panel's Report, in which he expects the HSCB to develop criteria and a service specification for the future commissioning of this service in Northern Ireland. On foot of that, I am now writing to you formally to ask the HSCB, working with the PHA, to establish a Working Group to:

(i) develop a detailed service specification for commissioning paediatric cardiac surgery and interventional cardiology;
(ii) establish clear criteria (with agreed rationale for inclusion and weighting and scoring) against which the service for children from Northern Ireland should be assessed – this will provide a firm basis for decision making;
(iii) set out the implications of the criteria on potential service models including an All-Ireland model; and
(iv) develop a document for consultation setting out each of the strands above.

The Minister has asked that the Working Group includes parents, patient group representatives and clinicians.

Working for a Healthier People

The impact of any service changes on patients and families will need to be clearly set out in the document and I note The Expert Panel's report stated that it was for the Board to assess the relative importance of accessibility of services for patients. This is an issue I expect to see clearly addressed in the consultation document. In addition it will also be important to see in the draft consultation document, an analysis of the impact any proposed changes to paediatric cardiac surgery and interventional cardiology services might have on other paediatric and cardiac services.

As ever, in all this it goes without saying that it is important for the Board to demonstrate transparency, fairness and an absence of predetermination or bias in discharging its responsibilities.

The Minister has asked for a draft consultation document by September 2012, which he will wish to approve prior to public consultation. A 12 week public consultation will then be required, following which an analysis of the consultation responses and a preferred way forward should be submitted by the HSCB to the Department. The final decision on the model for paediatric congenital cardiac services for children in Northern Ireland will be taken by the Minister in early 2013. As a separate exercise (but in parallel with this work) I wish to see a robust analysis of the current paediatric retrieval and transfer system in Northern Ireland. The results of which will need to be available before final decisions are taken on the future model.

As a first step in taking forward this work, I would be grateful if you would submit a draft Terms of Reference by 9th August for consideration by the Department.

I appreciate the time constraints within which this piece of work will need to be completed and I am grateful for your support in taking forward this work.

ANDREW McCORMICK

Working for a Healthier People

Annex 2

Paediatric Congenital Cardiac Services Working Group

Membership

Dean Sullivan (Chair), Director of Commissioning

Dr Damien Armstrong, Consultant Paediatrician, Western Trust

Rosie Byrne, Lead Nurse, Belfast Trust

Dr Nigel Campbell, Chair of South Eastern LCG

Dr Frank Casey, Consultant Cardiologist, Belfast Trust

Clare Caulfield, Heartbeat NI

Pat Cullen, Assistant Director of Nursing, Public Health Agency

Dr Patricia Donnelly, Director of Acute Services, Belfast Trust

Mr Alastair Graham, Clinical Director, Belfast Trust

Julie Greenaway, Children's Heartbeat Trust

Maeve Hully, Chief Executive, Patient and Client Council

Teresa Magirr, Assistant Director of Commissioning, Specialist Services

Dr Miriam McCarthy, Consultant in Public Health Medicine

Irwyn McKibbin, Heartbeat NI

Dr David McManus, Medical Director

Philip Moore, Head of Communications

Sarah Quinlan, Children's Heartbeat Trust

Dr Steve Robinson, Consultant Anaesthetist

Observers

Margaret Rose McNaughton, Director of Secondary Care, DHSSPS

Dr Paddy Woods, Deputy CMO, DHSSPS

Project Support

Paul Cunningham, Commissioning Lead, HSC Board

Annex 3

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 4

Summary of Comments Received in Written Consultation Responses

SERVICE SPECIFICATION

Q3. Are the proposed standards set out in the draft specification appropriate?

Change Proposed	Number of Responses
Develop a tailored set of standards for the population of Northern Ireland	17
Revise the number of procedures to be delivered by a service in Northern Ireland	3
Include more detail on the section on clinical linkages	2
Recommendations about number of surgeons should be same for anaesthetics	1

Q4. Are there other areas which should be considered?

Additional areas	Number of Responses
More emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres	59

Comments received in respect of the service specification questions

Comment	Number of Responses
Review in England was not meant for NI / no NI rep	241
Unique geography / population size of NI	186
Retrieval team to be available within 3 hours / 3 hours by road	174
Timescales for review in NI rushed / not consistent	146

with England / Process and timescales flawed	
Reliability and/or timeliness of access to air travel	131
Need to consider teenagers/young people and adults	127
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)	90
Emergency Cases - concerns about the transfer of newborns and their fitness to travel	69
Standards in England have not been uniformly applied / centres do not meet all standards	59
For all reasons discussed at meetings	52
Support provided by family is important but not available if surgery outside Belfast / impact on siblings	32
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed	27
Belfast should have a centre/service enhanced	24
NI can not meet all standards a service is still needed	17
Stress of Travelling/suitability of accommodation in GB	17
Potential to lose experienced staff (cardiology) if no surgery in Belfast	16
Dublin can not cope with demand from ROI and couldn't deal with activity from NI	12
Standards not accepted in Scotland	10
Funding issues	9
Make Belfast service sustainable/training of local staff	7
Not all cases diagnosed antenatally - robust plans needed for these cases	7
Issue of travel for mother immediately post natal	6
Staff and activity should not be compared to England	6
Reduced access for emergency and urgent cases compromises right to life	6
Statistics are inaccurate / Tetrology of fallot cases are not included	6
Number of babies not considered - ligation of patent ductus	5
All island service would allow some service in Belfast making it sustainable as well as safe	5
Should seek to enhance services in Clark Clinic	5
Criteria altered negatively for NI	5
Role of liaison nurses needs to be developed for	5

transfer of patients	
Service safe in NI	4
Transport issues need to be considered	4
Waiting for emergency procedure there can be delays and extra waits	3
All Ireland option difficult to implement but only robust option	3
Clarke Clinic closing	3
The rights of NI Children should be the same as GB	3
Concern over sustainability of GB Centres	2
Interventional Cardiology - small number of emergency cases each year	2
More money should be invested	2
Children with cardiac and other complex conditions (e.g. haemophiliac) will require specialist input for other conditions be available elsewhere	2
All areas considered	2
Minimising risks by transferring all babies, exposes small group to additional risks if there is no interventional cardiology	2
Didn't explore detail of network arrangement with Dublin	2
Concern about standard of care for children if service removed from NI	2
Don't agree with moving service to England	1
Fix surgical cover in Belfast and don't close	1
Don't agree with moving service to England	1
Cath Procedures require surgeon on-call	1
If Working Group don't agree on a recommendation for the Health Minister, who makes the decision	1
Should be an MRI in RBHSC	1
Retain one surgeon in Belfast	1
Commissioners/managers only concerned with own issues and budgets	1
Is the Air ambulance fit for purpose?	1
Panel should be able to provide better options	1
Will routine operations be carried out overseas?	1
Service should meet its requirements rather than minimum number	1
NI does not have a population based congenital anomaly registry like GB / funding requirement	1

Split the 400 procedures over 2 sites e.g. Dublin/Belfast	1
NI neonate transport team is not a 24/7 service	1
Added strain of receiving more cases	1
Commission services consistent with agreed S&S standards	1
Document doesn't meet the needs of Children	1
Sustainability is not relevant	1
Best Outcomes from Centres of Excellence	1
Standards not endorsed by Professional bodies for application in NI	1
Develop care pathways for seamless cardiac surgical care	1
Fully support the concentration of expertise	1
To ensure best outcomes children must be operated on by best surgeons	1
Teams must be large enough to meet day to day demands on services	1
Service must be able to respond to emergencies at any time	1
Centres which regularly perform range of complex heart operations tend to have best results	1

OPTIONS

Q5. Are the options for future service provision appropriate?

There were no changes suggested to the options proposed.

Q6. Are there other options which should be considered?

Additional options proposed	Number of Responses
Bring consultants from other centres to Belfast to undertake surgery	99
Increase capacity in Belfast to make sustainable/Centre of Excellence/bring children to Belfast from elsewhere	60

Comments received in respect of the options questions

Comment	Number of Responses
Prefer Option 4 (Surgery in Belfast and Dublin)	255
Options with no surgery in Belfast not appropriate	142
For all reasons discussed at meetings	52
Enhance and retain service in Belfast	48
More emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres	39
Prefer Option 1	37
Reliability and/or timeliness of access to air travel	33
Options about location rather than service/children focused	30
Emergency Cases - concerns about the transfer of newborns and their fitness to travel	27
Should fully explore all island solution	21
Does Dublin/other centres have the capacity to take on additional cases	20
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)	19
Surgical Services outside NI will mean some mothers are unable to transfer with their child immediately after giving birth	17
Retrieval team to be available within 3 hours / 3 hours by road	13
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed	7
Support the local campaign for the full range of PCC Services in the region	5
Standards in England have not been uniformly applied / centres do not meet all standards	5
Not providing service for vulnerable babies if they have to travel on a commercial airline	5
Current service safe without being available 24/7	5
Preference for surgical service linked to Dublin which would enable Paediatric Cardiologists to undertake	4

interventional cardiology in Belfast when required	
Service provision for NI should not be compared with standards for England and Wales	4
Only highly complex cases should be sent to England	4
Preference for options 1 or 2 (Belfast or Dublin)	3
Draw up refined NI standards	3
Sustainability not more important than safety	3
Issues about travelling home with a sick child following surgery on a commercial flight.	3
Funding should not be an issue	3
Option 4 would allow NI to maintain medical expertise	2
Prefer Option 5 (Surgery in Dublin and GB)	2
Travel delays due to having to travel	2
Unique geography / population size of NI	2
Reduced access for emergency and urgent cases compromises right to life	2
All island model would reduce dependence on air travel	1
RBHSC could not perform all procedures	1
Would an all island model work	1
Current retrieval service not fit for purpose	1
Clarification sought on who pays for travel	1
The process is biased against children of NI through use of word sustainable	1
Retain surgery in Belfast linked with another larger centre on an agreed interdependent network	1
Options do not reflect cost implications	1
Highly specialised services will require commissioning from GB	1
No child should have to travel	1
Number of surgeons is the issue not number of children needing surgery	1
Options should not discriminate against NI children	1
Prefer Option 6	1
All six options safe?	1
No preferred option	1

CRITERIA / WEIGHTINGS

Q7. Are the assessment criteria relevant for considering the most appropriate option for future service provision?

Change proposed	Number of Responses
Safe and Sustainable should be separate / sustainability should be lower	213
Safety and access should be considered together	18

Q8. Are the associated weightings appropriate?

Change proposed	Number of Responses
Criteria 2 (Emergencies and Urgent Cases) should be increased and/or same as safety	192
Criteria 4 (Accessibility) should be increased and/or same as safety	166
Criteria 5 (Clinical Linkages) should be increased	10

Q9. Are there other criteria which should be considered?

Other criteria proposed	Number of Responses
Financial effect on family	4
If other services must be co located then this should be a criteria	2

Comments received in response to the questions on criteria / weightings

Comment	Number of Responses
Timescales for review in NI rushed / not consistent with England / Process and timescales flawed	67
Safety paramount	61

Unique geography / population size of NI	59
For all reasons discussed at meetings	52
S&S review in NI was not undertaken fairly/flawed process	33
Why has Dublin not previously submitted to CCAD	29
Reduced access for emergency and urgent cases compromises right to life	21
Families should be given higher weighting	18
Review in England was not meant for NI / no NI rep	14
Transport should be included	13
Process to develop criteria flawed	11
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed	11
Need to consider teenagers/young people and adults	10
CCAD data vital	7
More criteria should be given equal weighting with patients as a priority	7
Should be about safe high quality services when needed in Belfast	6
Criteria needs refined for NI	6
Document if not user friendly	5
Poor succession planning led to difficulties replacing Mr Gladstone	4
Not clear on what the term weighting meant	3
Improve facilities in Belfast	3
Clinical linkages/local training prospects need further explanation	2
Criteria not relevant to PCCS - developed to meet government targets	2
Are NI Children valued less?	2
Weightings biased towards sustainability	2
Option meets criteria or doesn't - could use two stage approach to assess options	1
Effective use of resources should be higher	1
Money should not be included	1
Standards in England have not been uniformly applied / centres do not meet all standards	1
Child most important element	1
Potential to lose experienced staff (cardiology) if no surgery in Belfast	1

Decisions being made by people with no experience of CHD	1
Child does not appear in criteria	1
More emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres - Criteria	1
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)	1
Disregard Sustainability	1

OTHER COMMENTS

Q10. Please provide any other comments, evidence or information that you wish to share.

Comment	Number of Responses
Quote re family/friend experience	195
More emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres	123
Support provided by family is important but not available if surgery outside Belfast / impact on siblings	113
Children are used to Clarke clinic/continuity of care within range of specialities in Belfast Trust	111
Quote re personal experience	103
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)	95
Reliability and/or timeliness of access to Air Travel	76
Concern regarding arrangements for timely intervention for urgent / emergency cases	43
Timescales for review in NI rushed / not consistent with England / Process and timescales flawed	38
Concern over expecting sick children to have to travel outside NI	27
Retrieval team to be available within 3 hours / 3 hours by road	25

Transport is an issue	23
Unique geography / population size of NI	18
Document hard to understand / template difficult to complete	16
Finance/budget issue	15
Ideal solution would be Belfast/Dublin	13
NI can not meet all standards a service is still needed	12
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed	12
Standards in England have not been uniformly applied / centres do not meet all standards	9
Need to keep at least one surgeon in Belfast	9
Reviewed 10 years ago - why review again?	9
Surgery elsewhere not cost effective	8
Not providing service for vulnerable babies if they have to travel on commercial airline	7
Issue of travel for mother immediately post natal	7
Take same approach as Scotland	7
Need to retain service to ensure keep and attract 1st class professionals	6
Disproportionate impact on mothers	5
Needs of children should be prioritised	5
Issues raised regarding the aftercare in Birmingham	5
Rights of children have not been considered	5
Practical arrangements around travel to other locations	4
Panel responses at public meetings were not satisfactory	4
Does Dublin/other centres have the capacity to take on additional cases	4
Only commissioners are opposed to service staying in Belfast	3
Accept most complex cases need surgery elsewhere	3
Children's welfare paramount	3
Increasing number of teenagers and adults with CHD	3
Call for Minister to prioritise needs of children by retaining services in Belfast	2
Service in Belfast deemed vulnerable	2
Post surgery complications while away from home	2
The NI review should be delayed until outcome of JCPCT review known	2

Review in England was not meant for NI / no NI rep	2
Some wording in the consultation document was insensitive	2
Not all cases diagnosed antenatally - robust plans needed for these cases	2
Major challenges following retirement of Mr Gladstone	2
Will there be any consultation on the solution?	2
Children being treated as 2nd class citizens	2
The service in Belfast can be sustainable without 400 procedures or other services should also close	1
Current services for inter hospital transfer by road and air of infants and children are robust and continue to deliver a high quality service	1
Aeromedics working with Woodgate have clinically effective service able to respond to urgent/emergency requests on 24/7 basis with no adverse incidents reported	1
Suggestion re: contacting the Congenital Cardiac Service Provider in Jackson, Mississippi regarding the service they provide	1
Is there a recommended form of transport	1
Clarification sought on who pays for travel	1
Is accommodation elsewhere suitable?	1
Accountability/responsibility if proposed solution does not protect children	1
Durability of NI and poor road infrastructure	1
Sustainability appears to equal cost savings	1
There are good examples of networks elsewhere	1
Impact of the proposals on range of patient groups and waiting time for services	1
Impact of the proposals on patient safety and transport arrangements	1
Belfast cannot remain a stand alone centre	1
Would require access to 24/7 SLA with provider for road transfer	1
Service in Belfast not sustainable	1
Preference for single surgical service of island of Ireland	1
Review has made access to appropriate treatment more difficult	1
Service requires reconfiguring, support and investment	1
Team of experienced cardiologists and support team	1

already in Belfast	
Option 4 preferred	1
More important than flags issue	1
Consultation unfair to parents	1
Children should not be discriminated against	1
Workforce planning required to ensure that the nursing capacity & capability will meet the needs of any new service	1
Junior medical staff should be available to PICU on a 24/7 basis	1
Clarity required regarding the handover over arrangements for patients	1
Focus should be on entire patient journey not just the surgical element	1
Effect on employment/employers	1
Future is not possible because of closure	1
Risk to pregnant women's health	1
Public meetings well organised/facilitated	1
Confidence that decision will improve overall provision of services for CHD for NI	1

Annex 5

Summary of comments from Public Meetings and Focus Groups

SERVICE SPECIFICATION

Q3. Are the proposed standards set out in the draft specification appropriate?

Change Proposed
Develop a tailored set of standards for the population of Northern Ireland
Revise the number of procedures to be delivered by a service in Northern Ireland

Q4. Are there other areas which should be considered?

Additional areas
More emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres

Comments received in respect of the service specification questions

Comment
Review in England was not meant for NI / no NI rep
Retrieval team to be available within 3 hours / 3 hours by road
Unique geography / population size of NI
Reliability and/or timeliness of access to Air Travel
Need to consider teenagers/young people and adults
Emergency Cases - concerns about the transfer of newborns and their fitness to travel
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)
Timescales for review in NI rushed / not consistent with England / Process and timescales flawed
Standards in England have not been uniformly applied / centres do not

meet all standards
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed
Potential to lose experienced staff (cardiology) if no surgery in Belfast
NI can not meet all standards a service is still needed
Support provided by family is important but not available if surgery outside Belfast / impact on siblings
Standards not accepted in Scotland
Not all cases diagnosed antenatally - robust plans needed for these cases
Funding issues
Issue of travel for mother immediately post natal
Service safe in NI
If Working Group don't agree on a recommendation for the Health Minister, who makes the decision
Role of liaison nurses needs to be developed for transfer of patients
Didn't explore detail of network arrangement with Dublin
Transport issues need to be considered
Service must be able to respond to emergencies at any time
Is England safer?
More expensive to provide a service outside NI
Access to information / package of support particularly for those having to travel
What professional bodies endorsed the standards for NI
Congenital Heart Disease is most common birth defect
Figures include interventional cardiology
Not consulting on diagnostic caths
Report not about safety
Are NI children less important?

OPTIONS

Q5. Are the options for future service provision appropriate?

There were no changes suggested to the options proposed.

Q6. Are there other options which should be considered?

Additional options proposed
Bring consultants from other centres to Belfast to undertake surgery

Increase capacity in Belfast to make sustainable/Centre of Excellence/bring children to Belfast from elsewhere

Comments received in respect of the options questions

Comment
Prefer Option 4 (Surgery in Belfast and Dublin)
Options with no surgery in Belfast not appropriate
Prefer Option 1
Options about location rather than service/children focused
Surgical Services outside NI will mean some mothers are unable to transfer with their child immediately after giving birth
Reliability and/or timeliness of access to air travel
Enhance and retain service in Belfast
Emergency Cases - concerns about the transfer of new borns and their fitness to travel
More emphasis on the impact for families particularly the emotional, practical and financial issues associated with the potential of travelling to other centres
Preference for surgical service linked to Dublin which would enable Paediatric Cardiologists to undertake interventional cardiology in Belfast when required
Issues about travelling home with a sick child following surgery on a commercial flight.
Does Dublin/other Centres have the capacity to take on additional cases
Are all six options safe?
Medical notes should travel with patient
Feeling of isolation in other centres
Surgeons from Belfast could operate elsewhere to maintain skills
Surgical team required to provide a service not just the surgeon
Review team didn't support all island model

CRITERIA / WEIGHTINGS

Q7. Are the assessment criteria relevant for considering the most appropriate option for future service provision?

Change proposed
Safe and Sustainable should be separate/sustainability should be lower

Q8. Are the associated weightings appropriate?

Change proposed
Criteria 2 (Emergencies and Urgent Cases) should be increased and/or same as safety
Criteria 4 (Accessibility) should be increased and/or same as safety
Criteria 6 (Use of resources) should be lower

Q9. Are there other criteria which should be considered?

There were no other criteria proposed

Comments received in response to the questions on criteria / weightings

Comment
Why has Dublin not previously submitted to CCAD
Safety paramount
Process to develop criteria flawed
Families should be given higher weighting
Criteria and or Weightings need to be refined for NI
Criteria conflicting
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)
Sustainability should be lower
Safety should be evidence based
Medical and support care key to mental strength of patient and family
Ranking of criteria needs to be reviewed
Primary Criterion should be outcome from surgery
Criteria and weightings were agreed by Working Group

OTHER COMMENTS

Q10. Please provide any other comments, evidence or information that you wish to share.

Comment
Support provided by family is important but not available if surgery outside Belfast / impact on siblings
Quote re personal experience
Potential impact on other services available for children if no surgery in Belfast e.g. paediatric cardiology, cath lab and other specialist paediatric services (deskilling)
Timescales for review in NI rushed / not consistent with England / Process and timescales flawed
Reliability and/or timeliness of access to Air Travel
Children are used to Clarke clinic/continuity of care within range of specialities in Belfast Trust
Transport is an issue
Unique geography / population size of NI
Finance/budget issue
Standards in England have not been uniformly applied / centres do not meet all standards
Surgery elsewhere not cost effective
S&S under review in England / Decision of Joint Committee of Primary Care Trusts is currently being reviewed
Accountability/responsibility if proposed solution does not protect children
Accept most complex cases need surgery elsewhere
Post surgery complications while away from home
Retrieval team to be available within 3 hours / 3 hours by road
Document hard to understand / template difficult to complete
Sustainability appears to equal cost savings
The NI review should be delayed until outcome of JCPCT review known
Not all cases diagnosed ante-natally - robust plans needed for these cases
Does Dublin/other Centres have the capacity to take on additional cases
Major challenges following retirement of Mr Gladstone
Increasing number of teenagers and adults with CHD
Option 4 preferred
Visits to England premature / waste of resources
Perception that decision already made

Minister's decision should be on basis of evidence presented
Consistency of panel membership at public meetings/impartiality
Process biased against Belfast
Process not consistent with Transforming Your Care
Need to listen to views of parents
Document very clear and easy to understand / sound framework for assessing future service model
Need to consider future needs/new procedures and technologies
Communication with parents in the short term whilst decisions are made is important
Clinical and family views are crucial
Panel's job is to reflect parents views

Annex 6

Changes to Service specification for paediatric cardiac surgery and interventional cardiology services for the population of Northern Ireland

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~~ draw on ~~are~~ those developed by the Safe and Sustainable process but have been amended to reflect the specific needs of the Northern Ireland population. ~~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 provide enough staff to provide a consistent and robust 24-hour emergency service within legally compliant rotas, including cover by consultant paediatric cardiologists ~~be staffed by a minimum of 4 full-time consultant congenital cardiac surgeons~~ • Each surgeon in the team must perform a minimum of 100 and ideally 125 paediatric cardiac surgical procedures a year • The service ~~must~~ should be working towards performing a minimum of 400 and ideally 500 paediatric cardiac surgical procedures a year, consistent with Safe and Sustainable standards ~~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. The providing centre should be in a position to accommodate all children and young people who require to be carded for in a paediatric environment.

Also, ~~and~~ appropriate transitional arrangements ~~will~~ should be in place for patients who require surgery as adults. Ideally the providing centre should have links or arrangements for ensuring the provision of services for adults with congenital heart disease.

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 paediatric cardiac surgery or interventional / diagnostic investigations or procedures access requirements are:

- Emergency cases i.e. those requiring immediate treatment, the totality for time for the patient journey from the clinical decision being made that a child requires emergency intervention to the time that the child is in the centre where surgery takes place should be consistent with clinically indicated timescales to meet the needs of the child and achievable ideally within three hours and not taking longer than four hours.

- ~~and u~~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.

- For those neonates in the regional neonatal intensive care unit who require patent ductus ligation, arrangements must be in place for this group of patients to undergo surgery in Belfast. This must be provided by a specialist surgical team dispatched from the centre providing the paediatric cardiac surgical service for Northern

Ireland. The team should be suitably equipped in terms of staff and equipment

- 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~~ multi-disciplinary team discussion for every child requiring surgery irrespective of the provider. There should also be 24/7 access for the Belfast team to consultant surgical advice and support. ~~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 or diagnostic investigations / 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.~~

For those children and families that are required to travel for treatment, there should be a seamless pathway that ensures continuity of care and ongoing advice and support as required. Specifically, 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. Where possible accommodation should also be available for siblings in the eventuality of a child having a lengthy stay in a centre outside Northern Ireland.

Changes to options for the future provision of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland

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.
7. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery.

8. Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with an increase in the number of procedures in Belfast by bringing children from elsewhere to make the local service sustainable / a Centre of Excellence.

<u>Changes to criteria and associated weightings for the assessment and scoring of options for the future provision of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland</u>

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.	**The option ensures that the services commissioned are:** • **safe~~, sustainable~~ and of high quality, consistent with prevailing professional standards;** • **compliant with CCAD control limits.** *(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.)*	**50**
2.	**The option ensures emergency and urgent procedures can be undertaken within clinically indicated timescales.** *(Rationale: Each year about 20 emergency and urgent procedures are required for Northern Ireland children and it is important that the future*	**~~30~~50**

	model of service is able to respond within a timeframe to optimise outcomes for each child.)	
3.	**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.** *(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.)*	**~~20~~35**
4.	**The option ensures that services are sustainable / deliverable with:** • **The service is deliverable and able to be sustained 365 days a year** • **The service sufficiently resilient to respond to expected and unexpected absences among key clinical staff** • **The service able to recruit and retain key clinical personnel** • **The service able to train/mentor staff, particularly doctors in training.** (Rationale: A priority for the HSC Board as commissioner is to ensure that the service is available at all times.)	**35**
~~3~~5.	**The option ensures the required volume of activity can be delivered reliably and consistently, in accordance with extant NI waiting time standards (currently 9 weeks for diagnostics, 9 weeks for outpatients and 13 weeks for inpatients/daycases), from early**	**~~30~~25**

	2013. *(Rationale: Each year a total of some 110[1] surgical, ~~and~~ up to 50 interventional cardiology and up to 60 appropriate diagnostics 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.)*	
~~5~~6.	**The option ensures, through partnership working, the continued provision of medical and diagnostic paediatric cardiology services and other paediatric and cardiac services in Belfast and takes account of the need for multi-disciplinary training.** *(Rationale: Medical and diagnostic services for children with heart disease will continue to be provided in Northern Ireland. It is important than any future provider of surgical and interventional procedures is in a position to provide appropriate support and collaboration with the local service.)*	**~~20~~25**
~~6~~7.	**The option ensures the effective use of resources.** *(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.)*	**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.