Health and Social Care Board

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

Identification of a Preferred Option

April 2013

Contents

1. INTRODUCTION

Overview – This section of the document summarises the background to the process, the establishment of the PCCS Working Group, the consultation document and consultation process, the analysis of input to the consultation process, the preparation of a post consultation document and proposed next steps following the identification of a preferred option.

Background

1.1 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.

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

1.3 Services were assessed against the *Safe and Sustainable* standards which have been used to assess children's cardiac surgical centres in England. 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.

1.4 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.

1.5 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. It was acknowledged that any change to paediatric cardiac surgery will, by extension, apply to interventional cardiology because it cannot be undertaken in the absence of surgical cover.

1.6 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.

Establishment of PCCS Working Group

1.7 In the above context 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 service model options could be assessed. Furthermore the DHSSPS 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 during the consultation.

1.8 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 includes commissioning, service providers, clinicians, parents and parent group representatives. Full details of the membership of the PCCS Working Group are attached as annex 1.

Consultation document and process

1.9 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.

1.10 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. 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.

1.11 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.

1.12 During the consultation process, the Working Group held five public meetings and four focus groups to facilitate input from stakeholders. A total of 176 people attended these events. 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.

Analysis of input to consultation process

1.13 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.

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

1.15 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.

Preparation of post consultation document

1.16 In January 2013, the Working Group prepared a post consultation document incorporating an analysis of written responses received during the consultation and feedback from the public meetings and focus group events, both specifically in relation to the service specification, options and assessment criteria, and more generally.

1.17 The post consultation document prepared and agreed by the Working Group set out proposed revisions to the service specification, list of options and criteria / weightings. These reflected comments received and suggestions made during the consultation process.

1.18 The post consultation document agreed by the Working Group set out the proposed commissioning framework. 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.

1.19 The post consultation document was agreed by the HSCB Board at it's meeting on 14 February 2013 and then submitted for Ministerial consideration.

Next Steps

1.20 The DHSSPS wrote to the HSC Board on 14 March 2013, confirming Ministerial approval to the post consultation document and the commissioning framework contained within. The correspondence from the DHSSPS asked that the HSC Board through the Working Group take forward the scoring of each of the eight options set out in the post consultation document with a view to providing a recommendation to the Minister on the proposed way forward for the future commissioning of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland. That is the focus of this paper.

1.21 In the following sections the Working Group set outs the:

- Methodology for identifying a preferred option
- Scoring of each option against criteria

- Identification of the preferred option
- Equality and human rights considerations associated with the preferred option.

1.22 The document then goes on to set out the proposed next steps and other relevant issues for Ministerial consideration.

2. COMMISSIONING FRAMEWORK

Overview – This section of the document sets out the final commissioning framework approved by the Minister. This includes a service specification, list of eight options and seven criteria / associated weightings.

2.1 The post consultation document agreed by the Working Group and subsequently approved by the HSCB Board and Minister set out the following commissioning framework, which includes:

- a final service specification,
- final list of options, and
- final criteria and weightings by which the options are to be assessed.

2.2 This final framework, as approved by the Minister, provides robust, specific and evidence based standards against which the HSC Board/PHA will 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 in Northern Ireland 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 required 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, have been agreed 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.

3. METHODOLOGY FOR IDENTIFYING A PREFERRED OPTION

Overview – This section of the document sets out the assumptions used to assess the eight identified options and the detail of each. The section also set outs the matrix in relation to each of the seven criteria to be used in scoring each option.

3.1 The Working Group agreed the following assumptions to be used in assessing each of the eight options:

- Each option to be scored against each of the seven criteria
- A preferred option would need currently to meet all criteria or be expected to meet all criteria within a reasonable timeframe
- Evidence / rationale must be available and documented to support any assertion that an option currently meets or is able in the future to meet a criterion
- Each option to be scored as a whole rather that on the basis of individual components
- Scores to be multiplied by the relevant weighting to calculate total marks awarded to each option.

3.2 The Working Group agreed the following matrix to be used in scoring the proposed options:

- 2 = option currently fully achieves the relevant criterion and is expected to continue to do so
- 1 = option does not currently fully achieve the relevant criterion, but could be expected to fully achieve the relevant criterion within a reasonable period (12 months)
- 0 = option does not currently fully achieve the relevant criterion, and could not be expected to fully achieve the relevant criterion within a reasonable period (12 months).

3.3 In addition, the Working Group agreed to the following detail with regard to the consideration of each of the eight options.

Option 1 – Services commissioned primarily from Belfast.

- 110 NI children cared for primarily in Belfast unit by the in-house clinical team
- Invasive cardiology procedures undertaken primarily in Belfast unit by in-house clinical team.

Option 2 – Services commissioned primarily from Dublin. With this option there would be no surgery or interventional cardiology in Belfast.

- 110 NI children cared for primarily in Dublin unit by Dublin clinical team
- Invasive cardiology procedures undertaken primarily in Dublin unit potentially by Belfast clinical team.

Option 3 – Services commissioned primarily from a provider(s) in GB. With this option there would be no surgery or interventional cardiology in Belfast.

- 110 NI children cared for primarily in a unit(s) in GB by the GB clinical team(s)
- Invasive cardiology procedures undertaken primarily in GB unit(s) potentially by Belfast clinical team.

Option 4 – Services commissioned primarily from providers in Belfast and Dublin on an all island basis.

- 110 NI children cared for primarily in Belfast unit by in-house clinical team supported by the clinical team from Dublin working across two units
- Invasive cardiology procedures undertaken primarily in Belfast unit by Belfast clinical team.

Option 5 – Services commissioned primarily from providers in Dublin and GB. With this option there would be no surgery or interventional cardiology in Belfast.

- NI emergency cases undertaken in Dublin unit, some NI planned activity undertaken in Dublin unit and balance of NI planned activity undertaken in GB unit(s) by respective unit staff
- Invasive cardiology procedures undertaken in Dublin and GB units potentially by Belfast clinical team.

Option 6 – Services commissioned primarily from providers in Belfast, Dublin and GB.

- NI emergency cases primarily undertaken in Dublin unit, NI planned activity split across units in Belfast, Dublin and GB, undertaken by respective unit staff
- Invasive cardiology procedures undertaken in Belfast, Dublin and GB units potentially by Belfast Team.

Option 7 – Services commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery.

- 110 NI children cared for primarily in Belfast unit by clinical team(s) from outside NI
- Invasive cardiology procedures undertaken primarily in Belfast unit by Belfast Team.

Option 8 – Services 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.

- 110 NI children cared for primarily in Belfast unit plus an additional 290 children from outside NI cared for in Belfast unit by expanded in-house clinical team
- Invasive cardiology procedures undertaken primarily in Belfast unit by Belfast Team.

3.4 The paragraphs below set out the scoring frame associated with each of the seven criteria.

3.5 Criterion 1 – Safe and High Quality

- 2 = the option currently ensures that the services commissioned are safe and of high quality consistent with prevailing professional standards and compliant with CCAD control limits
- 1 = the option does not currently ensure that the services commissioned are safe and of high quality consistent with prevailing professional standards and compliant with CCAD control limits, but could be expected to fully achieve the required standards within a reasonable period (12 months)
- 0 = the option does not currently ensure that the services commissioned are safe and of high quality consistent with prevailing professional standards and compliant with CCAD control limits, and could not be expected to fully achieve the required standards within a reasonable period (12 months).

3.6 Criterion 2 – Emergency / Urgent Cases

- 2 = the option currently ensures emergency and urgent procedures can be undertaken within clinically indicated timescales
- 1 = the option does not currently ensure emergency and urgent procedures can be undertaken within clinically indicated timescales, but could be expected to fully achieve the required timescales within a reasonable period (12 months)
- 0 = the option does not currently ensure emergency and urgent procedures can be undertaken within clinically indicated timescales, and could not be expected to fully achieve the required timescales within a reasonable period (12 months).

3.7 Criterion 3 – Accessibility

- 2 = the option ensures services are locally accessible (i.e. within Northern Ireland)
- 1 = the option ensures services are accessible without the need for air travel (i.e. on the island of Ireland)

- 0 = the option requires air or sea travel for patients and families to access services (i.e. within GB).

3.8 Criterion 4 – Sustainability / Deliverability

- 2 = the option is deliverable and sustainable 365 days/year, is resilient to expected and unexpected staff absences, and is able to recruit, retain and train key staff
- 1 = the option is not currently deliverable and sustainable 365 days/year, and/or resilient to expected and unexpected staff absences, and/or able to recruit, retain and train key staff, but could be expected to be deliverable and sustainable within a reasonable period (12 months)
- 0 = the option is not currently deliverable and sustainable 365 days/year, and/or resilient to expected and unexpected staff absences, and/or able to recruit, retain and train key staff, and cannot be expected to be deliverable and sustainable within a reasonable period (12 months).

3.9 Criterion 5 – Volume / Waiting Times

- 2 = the option currently ensures the required volume of activity can be delivered reliably and consistently, in accordance with extant NI waiting time standards
- 1 = the option does not currently ensure the required volume of activity can be delivered reliably and consistently, in accordance with extant NI waiting time standards but could be expected to do so within a reasonable period (12 months)
- 0 = the option does not currently ensure the required volume of activity can be delivered reliably and consistently, in accordance with extant NI waiting time standards and could not be expected to do so within a reasonable period (12 months).

3.10 Criterion 6 – Partnership Working / Clinical Linkages

- 2 = the option currently can ensure, through partnership working, the continued provision of medical and diagnostic paediatric and cardiac services in Belfast including multi-disciplinary training
- 1 = the option currently cannot ensure, through partnership working, the continued provision of medical and diagnostic paediatric and cardiac services in Belfast including multi-disciplinary training but could be expected to do so within a reasonable period (12 months)
- 0 = the option currently cannot ensure, through partnership working, the continued provision of medical and diagnostic paediatric and cardiac services in Belfast including multi-disciplinary training and could not be expected to do so within a reasonable period (12 months).

3.11 Criterion 7 – Use of Resources

- 2 = the option could be expected to be delivered at the lowest average cost per patient (including any associated travel costs) relative to other options
- 1 = the option could be expected to be delivered between the lowest and highest cost in terms of average cost per patient (including any associated travel costs) relative to other options
- 0 = the option could be expected to be delivered at the highest average cost per patient (including any associated travel costs) relative to other options.

4. SCORING OF OPTIONS AGAINST CRITERIA

Overview – This section of the document assesses and scores each of the eight options against each of the seven criteria. These scores are then summarised in Table 1 at the end of the section.

4.1 The Working Group assessed and scored each of the eight options against each of the seven criteria. The following paragraphs set out the Working Group's consideration of each option and associated evidence/rationale.

4.2 **<u>Option 1</u> - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast (110 NI children cared for primarily in Belfast unit by the in-house clinical team and invasive cardiology procedures undertaken primarily in Belfast unit by in-house clinical team).**

- <u>Safety and quality</u> – The Working Group considered option 1 against this criterion and concluded that this option is not currently able to meet the standards as set out in the service specification. The Working Group also concluded that this option would not be in a position to meet the standards within 12 months, because the service in Belfast serves a small population and provides a low volume service. **(Score = 0)**

- <u>Emergency / urgent cases</u> – The Working Group considered option 1 against this criterion and concluded that this option is not able currently to provide robust 24/7 cover and therefore would be unable to ensure that emergency and urgent procedures would consistently be undertaken within clinically indicated timescales. The Working Group also concluded that this option would not be in a position to ensure emergency and urgent procedures are consistently undertaken within clinically indicated timescales within the next 12 months. **(Score = 0)**

- <u>Accessibility</u> – Under option 1 the service would be available locally in Northern Ireland and the Working Group agreed that this would represent the most accessible solution for patients and families. **(Score = 2)**

- Sustainability / deliverability – The Working Group considered option 1 against this criterion and concluded that this option is unable to sustain and deliver a robust service 52 weeks a year because of staffing constraints and low activity levels. The Working Group also concluded that the option is not expected to be able to sustain or deliver a robust service in the next 12 months. **(Score = 0)**

- Volume / waiting times – The Working Group considered option 1 against this criterion and concluded that because of the small volume vulnerable service it is not clinically appropriate for this option to provide the level of activity required now or within 12 months. While option 1 can meet extant waiting times, the Working Group concluded it would only be able to do so for those less complex procedures considered clinically appropriate to be undertaken in a unit with a low volume of activity. **(Score = 0)**

- Partnership working / clinical linkages – The Working Group considered option 1 against this criterion and were of the view that professional and clinical linkages are in place now. **(Score = 2)**

- Effective use of resources – The Working Group considered option 1 against this criterion and concluded that based on the indicative costs per procedure and associated travel / accommodation costs of providing a service in different units, that a service in Belfast could be expected to be delivered at the lowest average cost per patient relative to other options. **(Score = 2)**

4.3 **<u>Option 2</u> - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Dublin. With this option there would be no surgery or interventional cardiology in Belfast (110 NI children cared for primarily in Dublin unit by Dublin clinical team and invasive cardiology procedures undertaken primarily in Dublin unit potentially by Belfast clinical team).**

- <u>Safety and quality</u> – The Working Group considered option 2 against this criterion and concluded that this option would be able currently to meet the standards as set out in the service specification. **(Score = 2)**

- <u>Emergency / urgent cases</u> – The Working Group considered option 2 against this criterion and concluded that this option would be able currently to provide robust 24/7 cover and therefore would be able to ensure that emergency and urgent procedures would be undertaken within clinically indicated timescales. **(Score = 2)**

  The Working Group recognised that there may be very occasional instances when a child needs definitive treatment in less than the agreed three-hour standard and that in such circumstances it may be challenging for them to access the unit in Dublin in a clinically indicated timescale. The Working Group also noted however that under the current arrangements, in which 24/7 cover is not provided in Belfast, there will be occasions when a child needing emergency treatment may have difficulties accessing the service in Belfast within clinically indicated timescales.

- <u>Accessibility</u> – Under option 2 the service would be available on the island of Ireland. The Working Group recognised that for the majority of the 110 families, access would be less convenient than Belfast. The Working Group's view was that the travel time for a child in NI to access services in Dublin would nonetheless represent reasonable access. **(Score = 1)**

- <u>Sustainability / deliverability</u> – The Working Group considered option 2 against this criterion and concluded that this option offers a deliverable and sustainable service now. **(Score = 2)**

- Volume / waiting times – The Working Group considered option 2 against this criterion and, informed by correspondence from the Health Service Executive, noted that the required volume of activity could not be delivered currently but could be delivered in the future when infrastructure and staffing constraints had been addressed. In this regard, the opening of a new ward area in autumn 2013, combined with recruitment of key clinical staff would contribute to an increase in capacity that would accommodate additional activity within 12 months. **(Score = 1)**

- Partnership working / clinical linkages – The Working Group considered option 2 against this criterion and were of the view that professional and clinical linkages are well established and these could be formalised to fully meet requirements within 12 months. **(Score = 1)**

  The Working Group acknowledged issues around the future recruitment and retention of paediatric cardiology staff as being a key requirement and noted the impact that there has been in other centres where surgical services have ceased. In this regard, the formalisation of partnership working and clinical linkages must include robust arrangements for staff training as part of an overall enhancement of the paediatric cardiology service for the population of Northern Ireland.

- Effective use of resources – The Working Group considered option 2 against this criterion and concluded that, based on the indicative costs per procedure and associated travel / accommodation costs of providing a service in different units, that a service in Dublin would be expected to be delivered at the highest average cost per patient relative to other options. **(Score = 0)**

4.4 **<u>Option 3</u> - 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 (110 NI children cared for primarily in a unit or units in GB by the GB clinical team(s) and invasive cardiology procedures undertaken primarily in GB unit(s) potentially by Belfast clinical team).**

- <u>Safety and quality</u> – The Working Group considered option 3 against this criterion and concluded that this option would be able currently to meet the standards as set out in the service specification. **(Score = 2)**

- <u>Emergency / urgent cases</u> – The Working Group considered option 3 against this criterion and concluded that, while this option could meet the requirement for urgent cases, the option would not be able to reliably ensure that emergency procedures would be undertaken within clinically indicated timescales. The Working Group also concluded that this position would be unlikely to change within the next 12 months. **(Score = 0)**

- <u>Accessibility</u> – Under option 3 there would be no service available on the island of Ireland. The Working Group concluded that this would be the least accessible solution for patients and families. **(Score = 0)**

- <u>Sustainability / deliverability</u> – The Working Group considered option 3 against this criterion and concluded that this option offers a deliverable and sustainable service now. **(Score = 2)**

- <u>Volume / waiting times</u> – The Working Group considered option 3 against this criterion and concluded that this option was fully able to deliver required activity / waiting times now. In this regard the Working Group referred to correspondence from a number of providers in England and from exploratory visits to units which indicated that the volume of activity could currently be accommodated and extant waiting times met. **(Score = 2)**

- Partnership working / clinical linkages –The Working Group considered option 3 against this criterion and were of the view that professional and clinical linkages are well established and these could be formalised to fully meet requirements within 12 months. **(Score = 1)**

  The Working Group acknowledged however that although possible to formalise linkages with unit(s) in GB, there was a need to consider the issues associated with the geography of Northern Ireland and the timescales involved in formalising the links.

  The Working Group acknowledged issues around the future recruitment and retention of paediatric cardiology staff as being a key requirement and noted the impact that there has been in other centres where surgical services have ceased. In this regard, the formalisation of partnership working and clinical linkages must include robust arrangements for staff training as part of an overall enhancement of the paediatric cardiology service for the population of Northern Ireland.

- Effective use of resources – The Working Group considered option 3 against this criterion and concluded that, based on the indicative costs per procedure and associated travel / accommodation costs of providing a service in different units, that if a service was not available in Belfast that the next least costly option in terms of average cost per patient would be a service provided in GB. **(Score = 1)**

4.5 **<u>Option 4</u> - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from providers in Belfast and Dublin on an all island basis (110 NI children cared for primarily in Belfast unit by in-house clinical team supported by the clinical team from Dublin working across two units and invasive cardiology procedures undertaken primarily in Belfast unit by Belfast clinical team).**

- <u>Safety and quality</u> – The Working Group considered option 4 against this criterion and concluded that this option is not currently able to meet the standards as set out in the service specification because one component part of the option serves a small population and provides a low volume service. The Working Group also concluded that there is no evidence to suggest that the necessary changes to clinical work patterns could be effected within 12 months and therefore the option would not be in a position to meet the standards within the next 12 months. **(Score = 0)**

- <u>Emergency / urgent cases</u> – The Working Group considered option 4 against this criterion and concluded that this option would be able currently to provide robust 24/7 cover and therefore, would be able to ensure that emergency and urgent procedures would be undertaken within clinically indicated timescales. Under this option emergency cases would be referred to Dublin for treatment. **(Score = 2)**

  The Working Group recognised that there may be very occasional instances when a child needs definitive treatment in less than the agreed three-hour standard and that in such circumstances it may be challenging for them to access the unit in Dublin in a clinically indicated timescale. The Working Group noted however that under the current arrangements, in which 24/7 cover is not provided in Belfast, there will be occasions when a child needing emergency treatment may have difficulties accessing the service in Belfast within clinically indicated timescales.

- <u>Accessibility</u> – Under option 4 the service would be available on the island of Ireland. The Working Group recognised that for those

accessing services in Dublin access would be less convenient than Belfast. The Working Group's view was that the travel time for a child in NI to access services in Dublin would nonetheless represent reasonable access. **(Score = 1)**

- Sustainability / deliverability – The Working Group considered option 4 against this criterion and concluded that this option was unable to demonstrate currently that it is deliverable and sustainable as one component part can not sustain and deliver a robust service 52 weeks a year. The option is also not expected to become deliverable/sustainable within the next 12 months. **(Score = 0)**

- Volume / waiting times – The Working Group considered option 4 against this criterion and concluded that this option is not able to deliver required activity / waiting times now because the small volume vulnerable service in Belfast means it is not considered clinically appropriate to provide all activity. The Working Group also noted the constraints with infrastructure and staffing in Dublin but considered the option could however deliver the required activity within 12 months. The opening of a new ward area in autumn 2013, combined with recruitment of key clinical staff would contribute to an increase in capacity that would accommodate additional activity within 12 months. **(Score = 1)**

- Partnership working / clinical linkages – The Working Group considered option 4 against this criterion and were of the view that professional and clinical linkages are well established and these could be formalised to fully meet requirements within 12 months. **(Score = 1)**

- Effective use of resources – The Working Group considered option 4 against this criterion and concluded that based on the indicative costs per procedure and associated travel / accommodation costs of providing a service in different units, that a service provided across more than one unit would be expected to be delivered at a higher average cost than a service provided in Belfast. **(Score = 1)**

4.6 **<u>Option 5</u> - 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 (NI emergency cases undertaken in Dublin unit, some NI planned activity undertaken in Dublin unit and balance of NI planned activity undertaken in GB unit(s) by respective unit staff and invasive cardiology procedures undertaken in Dublin and GB units potentially by Belfast clinical team).**

- <u>Safety and quality</u> – The Working Group considered option 5 against this criterion and concluded that this option would be able currently to meet the standards as set out in the service specification. **(Score = 2)**

- <u>Emergency / urgent cases</u> – The Working Group considered option 5 against this criterion and concluded that this option would be able currently to provide robust 24/7 cover and therefore would be able to ensure that emergency and urgent procedures would be undertaken within clinically indicated timescales. Under this option emergency cases would be referred to Dublin for treatment. **(Score = 2)**

  The Working Group recognised that there may be very occasional instances when a child needs definitive treatment in less than the agreed three-hour standard and that in such circumstances it may be challenging for them to access the unit in Dublin in a clinically indicated timescale. The Working Group noted however that under the current arrangements, in which 24/7 cover is not provided in Belfast, there will be occasions when a child needing emergency treatment may have difficulties accessing the service in Belfast within clinically indicated timescales.

- <u>Accessibility</u> – Under option 5 the service would be available on the island of Ireland for a proportion of patients. The Working Group recognised that for those accessing services in Dublin access would be less convenient than Belfast. The Working Group's view was that the travel time for a child in NI to access services in Dublin would represent reasonable access. The Working Group recognised for

those needing to access services in GB this would be a less accessible service which would require travel by air or sea. **(Score = 1)**

- Sustainability / deliverability – The Working Group considered option 5 against this criterion and agreed that this option offered a deliverable and sustainable service now. **(Score = 2)**

- Volume / waiting times – The Working Group considered option 5 against this criterion and concluded that this option was able to deliver required activity / waiting times now. It was recognised by the Working Group that now and in the next 12 months the necessary volume of activity could only be managed in a GB unit(s). **(Score = 2)**

- Partnership working / clinical linkages –The Working Group considered option 5 against this criterion and were of the view that professional and clinical linkages are well established with certain units and these could be formalised to fully meet requirements within 12 months. **(Score = 1)**

  The Working Group acknowledged that although possible to formalise linkages with unit(s) in GB, there was a need to consider the issues associated with the geography of Northern Ireland and the timescales involved in formalising the links.

  The Working Group acknowledged issues around the future recruitment and retention of paediatric cardiology staff as being a key requirement and noted the impact that there has been in other centres where surgical services have ceased. In this regard, the formalisation of partnership working and clinical linkages must include robust arrangements for staff training as part of an overall enhancement of the paediatric cardiology service for the population of Northern Ireland.

- Effective use of resources – The Working Group considered option 5 against this criterion and concluded that based on the indicative costs per procedure and associated travel / accommodation costs of providing a service in different units, that a service provided across

more than one unit would be expected to be delivered at a higher average cost than a service provided in Belfast. **(Score = 1)**

4.7 **<u>Option 6</u> - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from providers in Belfast, Dublin and GB (NI emergency cases primarily undertaken in Dublin unit, NI planned activity split across units in Belfast, Dublin and GB, undertaken by respective unit staff and invasive cardiology procedures undertaken in Belfast, Dublin and GB units potentially by Belfast Team).**

- <u>Safety and quality</u> – The Working Group considered option 6 against this criterion and concluded that this option is not currently able to meet the standards as set out in the service specification because one component part of the option serves a small population and provides a low volume service. The Working Group also concluded that there is no evidence to suggest that the necessary changes to local treatment capacity and clinical work patterns could be effected within 12 months and therefore the option would not be in a position to meet the standards within the required timeframe. **(Score = 0)**

- <u>Emergency / urgent cases</u> – The Working Group considered option 6 against this criterion and concluded that this option would be able currently to provide robust 24/7 cover and therefore would be able to ensure that emergency and urgent procedures would be undertaken within clinically indicated timescales. **(Score = 2)**

  The Working Group recognised that there may be very occasional instances when a child needs definitive treatment in less than the agreed three-hour standard and that in such circumstances it may be challenging for them to access the unit in Dublin in a clinically indicated timescale. The Working Group noted however that under the current arrangements, in which 24/7 cover is not provided in Belfast, there will be occasions when a child needing emergency treatment may have difficulties accessing the service in Belfast within clinically indicated timescales.

- <u>Accessibility</u> – The Working Group considered option 6 against this criterion. Under this option the service would be available on the island of Ireland for the majority of patients. The Working Group recognised that for those accessing services in Dublin access would

be less convenient than Belfast. The Working Group's view was that the travel time for a child in NI to access services in Dublin would represent reasonable access. The Working Group recognised for those needing to access services in GB this would be a less accessible service which would require travel by air or sea. **(Score = 1)**

- Sustainability / deliverability – The Working Group considered option 6 against this criterion and concluded that the option is unable to demonstrate that it is deliverable / sustainable as one component part can not sustain and deliver a robust service 52 weeks a year and is not expected to be able to sustain or deliver a robust service in the next 12 months. **(Score = 0)**

- Volume / waiting times – The Working Group considered option 6 against this criterion and concluded that this option is able to deliver required activity / waiting times now. **(Score = 2)**

- Partnership working / clinical linkages –The Working Group considered option 6 against this criterion and were of the view that professional and clinical linkages are well established with certain units and these could be formalised to fully meet requirements within 12 months. **(Score = 1)**

  The Working Group acknowledged that although possible to formalise linkages with unit(s) in GB, there was a need to consider the issues associated with the geography of Northern Ireland and the timescales involved in formalising the links.

- Effective use of resources – The Working Group considered option 6 against this criterion and concluded that based on the indicative costs per procedure and associated travel / accommodation costs of providing a service in different units, that a service provided across more than one unit would be expected to be delivered at a higher average cost than a service provided in Belfast. **(Score = 1)**

4.8 **<u>Option 7</u> - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Belfast with clinical teams from elsewhere in GB or ROI undertaking the surgery (110 NI children cared for primarily in Belfast unit by clinical team(s) from outside NI and invasive cardiology procedures undertaken primarily in Belfast unit by Belfast Team).**

- <u>Safety and quality</u> – The Working Group considered option 7 against this criterion and concluded that this option is not currently able to meet the standards as set out in the service specification. The Working Group also concluded that this option would not be in a position to meet the standards within 12 months, because the service in Belfast serves a small population and provides a low volume service. **(Score = 0)**

- <u>Emergency / urgent cases</u> – The Working Group considered option 7 against this criterion and concluded that this option is not able currently to provide robust 24/7 cover and therefore would be unable to ensure that emergency and urgent procedures would be undertaken within clinically indicated timescales. The Working Group also concluded that this option would not be in a position to ensure emergency and urgent procedures are undertaken within clinically indicated timescales within the next 12 months. **(Score = 0)**

- <u>Accessibility</u> – The Working Group considered option 7 against this criterion. Under this option the service would be available locally in Northern Ireland and the Working Group agreed that this would represent the most accessible solution for patients and families. **(Score = 2)**

- <u>Sustainability / deliverability</u> – The Working Group considered option 7 against this criterion and concluded that this option is unable to sustain and deliver a robust service 52 weeks a year and is not expected to be able to sustain or deliver a robust service in the next 12 months. **(Score = 0)**

- <u>Volume / waiting times</u> – The Working Group considered option 7 against this criterion and concluded that because of the small volume vulnerable service it is not clinically appropriate for this

option to provide the level of activity required now or within 12 months. While option 7 can meet waiting times, the Working Group concluded it would only be able to do so for those less complex procedures considered clinically appropriate to be undertaken in a unit with a low volume of activity. **(Score = 0)**

- Partnership working / clinical linkages –The Working Group considered option 7 against this criterion and were of the view that professional and clinical linkages are well established with certain units and these could be formalised between in reach clinical teams and related local services to fully meet requirements within 12 months. **(Score = 1)**

  The Working Group acknowledged that although possible to formalise linkages with unit(s) in GB, there was a need to consider the issues associated with the geography of Northern Ireland and the timescales involved in formalising the links.

- Effective use of resources – The Working Group considered option 7 against this criterion and concluded that based on the indicative costs per procedure and associated travel / accommodation costs of providing a service in different units, that a service in Belfast could be expected to be delivered at the lowest average cost per patient relative to other options. **(Score = 2)**

4.9 **<u>Option 8</u> - 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 (110 NI children cared for primarily in Belfast unit plus an additional 290 children from outside NI cared for in Belfast unit by expanded in-house clinical team and invasive cardiology procedures undertaken primarily in Belfast unit by Belfast Team).**

- <u>Safety and quality</u> – The Working Group considered option 8 against this criterion and concluded that this option offered the potential in terms of patient numbers to meet the standards as set out in the service specification. However, the Working Group concluded that there is no evidence to suggest that the necessary changes to patient flows and local treatment capacity could be effected within 12 months and therefore the option would not be in a position to meet the standards within the required timeframe. **(Score = 0)**

- <u>Emergency / urgent cases</u> – The Working Group considered option 8 against this criterion and concluded that this option offered the potential to ensure that emergency and urgent procedures could be undertaken within clinically indicated timescales. However, the Working Group concluded that there is no evidence to suggest that robust 24/7 cover arrangements could be established within 12 months and therefore the option would not be in a position to ensure emergency and urgent procedures are undertaken within clinically indicated timescales. **(Score = 0)**

- <u>Accessibility</u> – The Working Group considered option 8 against this criterion. Under this option the service would be available locally in Northern Ireland and the Working Group agreed that this would represent the most accessible solution for patients and families. **(Score = 2)**

- <u>Sustainability / deliverability</u> – The Working Group considered option 8 against this criterion and concluded this option is not currently deliverable. The Working Group recognised for this option to be deliverable there would need to be in addition to a significant

increase in patient numbers, a significant increase in capacity including physical infrastructure at Belfast Trust and clinical staffing levels. **(Score = 0)**

- Volume / waiting times – The Working Group considered option 8 against this criterion and concluded that while this option can currently meet waiting times it is only able to do so for less complex procedures considered clinically appropriate to be undertaken in a unit with a low volume of activity. The Working Group also concluded that there was no evidence that the necessary changes to patient flows and local treatment capacity could be effected within 12 months and so the option would not be in a position to meet the required volume of activity / waiting times within the required timeframe. **(Score = 0)**

- Partnership working / clinical linkages –The Working Group considered option 8 against this criterion and were of the view that professional and clinical linkages are well established with certain units and in the context of patients of Belfast accepting referrals from elsewhere these could be formalised to fully meet requirements within 12 months. **(Score = 1)**

  The Working Group acknowledged that although possible to formalise linkages with unit(s) in GB, there was a need to consider the issues associated with the geography of Northern Ireland and the timescales involved in formalising the links.

- Effective use of resources – The Working Group considered option 8 against this criterion and concluded that based on the indicative costs per procedure and associated travel / accommodation costs of providing a service in different units, that a service in Belfast could be expected to be delivered at the lowest average cost per patient relative to other options. **(Score = 2)**

4.10 On the basis of the consideration of each of the eight options against each of the seven criteria and the scoring awarded to each, table 1 below summarises the weighting scoring associated with each of the eight options.

Table 1 – Summary of scoring of the eight options for the future provision of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland

	Criterion	Safety and Quality	Emergency / Urgent	Accessibility	Sustainable / Deliverable	Volume / Waiting Times	Partnerships / Clinical Linkages	Use of resources	Total Score
	Weighting	**50**	**50**	**35**	**35**	**25**	**25**	**10**	
Option									
1	**Belfast**	0	0	2	0	0	2	2	140
2	**Dublin**	2	2	1	2	1	1	0	355
3	**GB**	2	0	0	2	2	1	1	255
4	**Belfast / Dublin**	0	2	1	0	1	1	1	195
5	**Dublin / GB**	2	2	1	2	2	1	1	390
6	**Belfast / Dublin / GB**	0	2	1	0	2	1	1	220
7	**Belfast with visiting surgeons**	0	0	2	0	0	1	2	115
8	**Belfast with children referred from outside NI**	0	0	2	0	0	1	2	115

4.11 Table 1 above highlights that two options scored significantly higher than the others, namely Option 2 (Dublin only with a score of 355) and Option 5 (Dublin and GB with a score of 390).

4.12 In addition, both of these options are able to deliver all non-financial criteria either currently or within the next 12 months. The following section of the paper considers in more detail the benefits and constraints of each option.

5. IDENTIFICATION OF A PREFERRED OPTION

Overview – The previous section highlighted that two options scored significantly higher than the others, namely Option 2 (Dublin only with a score of 355) and Option 5 (Dublin and GB with a score of 390). This section of the document considers in more detail, including consideration of qualitative issues, the benefits and constraints of each of these options and then identifies a preferred option for recommendation to the Minister.

5.1 In section 4, the Working Group detailed each of the eight options and the scoring for each option against each of the seven criteria. The rationale for a score was provided for each criterion and the Working Group gave careful consideration to the evidence that supported a particular score.

5.2 For each option a score of 0, 1, or 2, was assigned to all criteria. Scores were then multiplied by the appropriate weighting for each of the seven criteria. For each option the weighted scores for all criteria were added to provide a total score for each option.

5.3 In considering a preferred option the Working Group took account of the agreed methodology, including the agreed approach that a preferred option would need currently to meet all criteria or be expected to meet all criteria within a reasonable timeframe. In this regard it was noted that two options scored significantly higher than the others, namely: Option 2 (Dublin only with a score of 355) and Option 5 (Dublin and GB with a score of 390). In addition, both of these options are able to deliver all non-financial criteria either currently or within the next 12 months.

5.4 Option 4 (Belfast and Dublin) had a total score of 195. Notwithstanding this score, the Working Group was of the view from an aspirational perspective that an option with surgery being undertaken in Belfast and Dublin could potentially provide, in the longer term, an effective networked model of care, albeit that such a model could not meet the agreed commissioning standards on both sites. Consistent with this view, the majority of clinicians who responded during the consultation process indicated a preference

to retain paediatric cardiac surgery in Belfast as part of an all-island model. To effect this model would require a number of children from ROI to receive surgery in Belfast, and surgeons from ROI to provide support to the unit in Belfast to ensure 24/7 cover in both Belfast and Dublin.

5.5 The Working Group acknowledged that for many years an all-island model had been pursued and respective Departments, commissioners and providers had been closely engaged in this work. The deliverability of an all-island model had not however been realised, largely because of challenges in the staffing and sustainability of safe, high quality surgical services (including 24/7 cover) across two sites.

5.6 Working Group members discussed at length the potential feasibility of option 4 and in doing so took account of correspondence from the Health Service Executive (HSE) in Ireland, in which the HSE confirmed that it would not be feasible for children living in ROI to be referred to Belfast or for clinical staff from the centre in Dublin to support 24/7 cover on two sites.

5.7 In light of this position Working Group members acknowledged that expansion to the Belfast service associated with referrals from ROI was not deliverable. In that context the Working Group scored option 4 as a model of care in which 110 children would be cared for primarily in Belfast. On this basis, and with the resulting score of 195, option 4 was not pursued further, pending any change in the ROI position to include decisions at a Ministerial level.

5.8 More generally, the Working Group acknowledged that any preferred option must reflect an improvement for those using the service. In this regard both the Working Group and respondents to the consultation process recognised the quality of care provided by the Belfast Trust and the dedicated commitment of staff within the Trust.

5.9 However, the Working Group also noted that the current vulnerability of paediatric cardiac surgery services in the Belfast Trust meant that it was not possible to provide 24/7 care, to

routinely undertake all urgent / emergency procedures, or to accommodate the full clinical spectrum of surgery required by Northern Ireland children.

5.10 The Working Group emphasised that a preferred option needed to address each of these issues and to provide a model of care that would bring about measurable, deliverable and sustainable improvements.

5.11 Notwithstanding the numerical scores assigned to the two options with the highest scores - Option 2 (Dublin only with a score of 355) and Option 5 (Dublin and GB with a score of 390) - the Working Group was of the view that qualitative aspects needed to be considered with regard to the extent to which a particular option would best meet the needs of the Northern Ireland population.

Detailed consideration Options 2 and 5

5.12 Against the above background, the Working Group gave careful and detailed consideration to Option 2 (Dublin only) and Option 5 (Dublin and GB).

5.13 The Working Group acknowledged that in regard to safety and quality, emergency / urgent access and sustainability / deliverability, both options currently met the criteria.

5.14 There was detailed discussion on the matter of accessibility. Specifically the Working Group was of the view that Option 2 (Dublin only) was more accessible than Option 5 (Dublin and GB) and that ease of access for families needed to be given due account in determining a preferred option.

5.15 In regard to accommodating the necessary volume of activity, Working Group members acknowledged that Option 5 (Dublin and GB) was better placed currently to meet this criterion. However, Working Group members considered that within 12 months both Option 2 (Dublin only) and Option 5 (Dublin and GB) would both meet this criterion and therefore any advantage of Option 5 (Dublin and GB) would be of a short duration.

5.16 The Working Group expressed a view that when capacity was available in Dublin to respond to the need of the population of Northern Ireland, commissioning services from Dublin would represent a model of care within which children from Northern Ireland could access care within current waiting time standards.

5.17 In regard to partnership working / clinical linkages both options scored 1 against this criterion but Working Group members considered that the current partnership with Dublin was stronger than that with any GB provider and that this should be reflected in assessing the potential of each option to be a preferred option.

5.18 In regard to effective use of resources, the Working Group noted that Option 2 (Dublin only) would be likely to be a higher cost compared to Option 5 (Dublin and GB). The Working Group recognised that because of the different health service model in ROI and the higher levels of remuneration for clinical staff, the costs of undertaking paediatric cardiac surgery procedures was higher than GB.

5.19 While there was a small difference in the total scores between Option 2 (Dublin only) and Option 5 (Dublin and GB), Working Group members were of the view that qualitative issues not directly assessed under the agreed criteria should not be overlooked. In particular members wanted to ensure the following were given due consideration:

- The importance of providing patients and their families with a degree of choice in regard to the location of surgery
- The views of the public, expressed during the consultation period, that travel to GB can cause significant inconvenience to patients and families
- The importance of ensuring commissioned services are resilient for Northern Ireland children
- The relative ease with which cardiologists in Belfast could utilise cardiac catheterisations facilities in Dublin.

5.20 In regard to patient / family choice, Working Group members accepted that Option 2 (Dublin only) did not facilitate as much patient / family choice as Option 5 (Dublin and GB). Working Group members acknowledged that there may be circumstances in which such choice would be beneficial albeit that this issue would not be an over-riding requirement when considering the preferred option.

5.21 In regard to travel, Option 2 (Dublin only) was considered to offer more accessible services than Option 5 (Dublin and GB). Working Group members considered that accessibility was an important issue.

5.22 In regard to resilience, Working Group members acknowledged that Option 2 (Dublin only) would be less resilient than Option 5 (Dublin and GB) because of the inherently greater resilience with a two centre model. Working Group members did not consider that the issue of resilience was a priority in considering the preferred option. Working Group members did however recognise that as part of the commissioning arrangements the HSC Board may need to take measures to ensure that sufficient resilience was in place to respond to unexpected events.

5.23 In regard to clinical linkages, Option 2 (Dublin only) would facilitate more straightforwardly, clinical attendance at multi disciplinary meetings and would also allow the potential to provide access to cardiac catheterisation facilities. Furthermore Working Group members were of the view that under Option 5 (Dublin and GB) developing robust clinical linkages with a minimum of two providers would be more challenging, and could potentially undermine the ability to establish strong linkages with either centre.

5.24 Having considered and discussed the relative merits of Option 2 (Dublin only) and Option 5 (Dublin and GB), Working Group members concluded the following:

- While Option 5 (Dublin and GB) scores more highly, in 12 months time Option 2 (Dublin only) is likely to score at a

comparable level, as the volume of planned activity could be accommodated at that time

- Option 2 (Dublin only) provides a more accessible service than Option 5 (Dublin and GB) and minimises the inconvenience of travel for children and families
- Clinical partnerships could develop and progress more effectively under Option 2 (Dublin only) than Option 5 (Dublin and GB).

5.25 In taking account of the above, Working Group members identified Option 2 (Dublin only) as the preferred option for the future commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland, provided that this option could effectively be delivered within an acceptable timeframe. The Working Group recognised that under the Option 2 there will continue to be a small number of children for whom it would be more appropriate to refer to a unit in GB and that this should be accommodated through normal commissioning arrangements.

5.26 Not all Working Group members agreed with Option 2 (Dublin only). In particular, the two Working Group members associated with the Children's Heartbeat Trust concluded that they were not able to support this option or any other option that removes paediatric cardiac surgery from Belfast. A minority report in this regard is attached at Annex 2.

6. PREFERRED OPTION – EQUALITY AND HUMAN RIGHTS CONSIDERATIONS

Overview – This section of the document considers the equality and human rights issues associated with the preferred option, together with associated mitigating actions.

Introduction

6.1 As part of the consultation process on the future provision 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 approved in September 2012 was made widely available.

6.2 Unlike the majority of other consultation processes, at that stage the Working Group was not consulting on a preferred option; rather the focus was on the development of a commissioning framework to be used to determine a preferred option.

6.3 Following the consultation period and on the basis of the analysis of the input to the consultation process, the proposed commissioning framework to include a service specification, options for the delivery of services and criteria / weightings against which the services could be assessed were set out in a post consultation document. The post consultation document agreed by the Working Group, was approved by the HSC Board in February 2013 and by the Minister in March 2013. A copy of the document is available at: http://www.hscboard.hscni.net/pccs/PostConsultationDocument-14February2013.pdf

6.4 In the post consultation document, the Working Group set out the baseline profile of services for paediatric cardiac surgery and interventional cardiology and considered the potential impact on the Section 75 groups of any change to the profile of services as set out in the proposed eight options for future service delivery. The Working Group also considered potential issues in respect of Human Rights (including the UN Convention on the Rights of the

Child) associated with the proposed options. Finally the Working Group set out potential mitigating arrangements to address the issues identified.

6.5 The Working Group has now used the approved commissioning framework as set out in the post consultation document to score the eight options and has identified option 2 (services commissioned primarily from Dublin) as the preferred option for the future provision of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland. The Working Group acknowledged that with this option services would be commissioned primarily from Dublin and that there would be no surgery or interventional cardiology provided in Belfast.

6.6 The following paragraphs set out a further analysis of the equality and human rights issues on the basis of the preferred option.

Consideration of equality impacts of preferred option

6.7 The following paragraphs set out the Working Group assessment of the impact and mitigating factors as appropriate for each of the Section 75 groups of the preferred option i.e. *Option 2 - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Dublin.*

- Age –Up to 110 additional children (up to the age of 16) will need to travel to Dublin for surgery and up to 40 additional children will need to travel to Dublin for interventional cardiology, where previously they may have received care in Belfast. In addition, a number of children may have to travel to Dublin for diagnostic catheterisation. The Working Group recognised that for those children accessing services in Dublin, access would be less convenient for the majority of children than if a service was available in Belfast. However, the Working Group acknowledged that a significant proportion of children who undergo heart surgery currently travel from different parts of Northern Ireland to access the service in Belfast. The Working Group was of the view that access to services in Dublin

would represent reasonable access within clinically indicated timescales.

Mitigation: The HSC Board will ensure that appropriate support arrangements (in terms of, for example, travel, accommodation communication and language support) are in place for the patients and their parents, guardians or carers accessing services in Dublin. The HSC Board has commenced a process aimed at exploring 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. 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.

- Ethnicity – Evidence suggests there is a higher demand for paediatric heart surgery within the Asian population. Individuals of Asian descent comprise approximately 1% of the Northern Ireland population. It was highlighted that although this group is described as having a higher demand, due to the relatively small prevalence of this ethnic group it is not expected that there would be a disproportionate impact if the preferred option were to be implemented.

  There are additional needs arising amongst black and minority ethnic groups for interpreting and translation services.

  Mitigation: The HSC Board will ensure that appropriate support arrangements are in place for interpreting and translation support for this group as required.

- Gender – With the preferred option a small number of women (less than 10 per annum) will need to be transferred to Dublin ante-natally to give birth and / or a number of women will need to be transferred in the early post natal period where previously these women would have given birth in a maternity unit in

Northern Ireland. There may also be a 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.

Against a background of 25,000 births each year in Northern Ireland, this small number of women affected does not represent a disproportionate impact on this Section 75 group.

Mitigation: The HSC Board will ensure that appropriate support arrangements (in terms of, for example, travel, accommodation communication and language support) are in place for the patients and their parents, guardians or carers accessing services in Dublin. The HSC Board has commenced a process aimed at exploring 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. 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.

The HSC Board has also undertaken a robust analysis of current transport arrangements for children particularly in emergency situations. The implementation of the recommendations from this work will see the critical care road transport service for children extended to provide 24/7 cover.

- Marital Status - With the preferred option there may be an impact on couples, including same gender couples, and those who are single or lone parents, particularly where their child requires care in Dublin. Added travel, increased inconvenience and issues around employment, specifically if self-employed have all been highlighted. A number of children requiring paediatric cardiac surgery have protracted stays in hospital, often for several weeks or even months. A number of children requiring cardiac surgery and interventional cardiology already travel outside Northern Ireland for their treatment.

Mitigation: The HSC Board will ensure that appropriate support arrangements (in terms of, for example, travel, accommodation communication and language support) are in place for the patients and their parents, guardians or carers accessing services in Dublin. The HSC Board has commenced a process aimed at exploring 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. 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.

- People with dependants **–** With the preferred option there may be an 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.

  As outlined above, a number of children requiring cardiac surgery and interventional cardiology already travel outside Northern Ireland for their treatment.

  Mitigation: The HSC Board will ensure that appropriate support arrangements (in terms of, for example, travel, accommodation communication and language support) are in place for the patients and their parents, guardians or carers accessing services in Dublin. The HSC Board has commenced a process aimed at exploring 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. 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.

- People with a disability – With the preferred option there may be an impact on children with some disabilities who may be more likely to have congenital heart disease e.g. Down's syndrome. It has been highlighted that this is more common when the pregnancy occurs later in life. The absolute impact on the number of children born with congenital heart defects may be quite small because of the number of women in those groups is relatively small. These children will need to travel to Dublin for treatment where previously they would have received care in Belfast. However, as the proportion of children with disability requiring heart surgery will be small it is not considered that there is a disproportionate impact on this Section 75 group.

  Mitigation: The HSC Board will ensure that appropriate support arrangements (in terms of, for example, travel, accommodation communication and language support) are in place for the patients and their parents, guardians or carers accessing services in Dublin. The HSC Board has commenced a process aimed at exploring 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. 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.

  If particular support is necessary to address disability, the HSC Board will take full account of this and as far as possible accommodate the need.

- Political Opinion - It is not anticipated that there will be any impact on this group.

- Religion - It is not anticipated that there will be any impact on this group.
- Sexual Orientation - It is not anticipated that there will be any impact on this group.

Consideration of human rights impacts of preferred option

6.8 At the post consultation stage of the process, the Working Group undertook an assessment of the potential impact of the eight options on individual's Human Rights. The following paragraphs set out the Working Group's further assessment of the impacts on individual's Human Rights of the preferred option i.e. *Option 2 - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Dublin.* Table 2 summarises the assessment of the Working Group on which particular Human Rights Articles may potentially be affected.

Table 2 - 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	Yes

life, home and correspondence	
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

6.9 For each of the Articles where there is a potential impact, the Working Group considered the following:

- Article 2 – Right to life - All patients have the right to life and the preferred option must ensure that a safe and sustainable service is provided in accordance with individual patient needs. The independent review commissioned by the HSC Board 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 included 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 as set out in the agreed local service

specification. This is accepted and recognised as a necessity for those people who currently travel to GB / Dublin for treatment. The Working Group considered these issues in detail and was of the view that the preferred option would ensure the provision of robust 24/7 cover and therefore would ensure that emergency and urgent procedures would be undertaken within clinically indicated timescales and would meet current quality standards as set out in the agreed service specification. It is the view of the Working Group that the provision of services under the preferred option will protect the Article 2 rights of patients.

- Article 3 – Right to freedom from torture, inhuman or degrading treatment or punishment – Under the preferred option services in Dublin will be commissioned via a robust service level agreement that will ensure that all patients / parents / guardians / carers are treated with dignity and respect and are not subject to any degrading treatment during treatment, attendance for treatment or at any other time in the course of receiving services.

- Article 8 – Right to respect for private & family life, home and correspondence – Under the preferred option services in Dublin will be commissioned via a robust service level agreement. 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. It is acknowledged that patients / parents / guardians / carers may be apprehensive and/or inconvenienced as a result of the requirement to travel for treatment, with surgery being a significant and stressful event. The HSC Board will ensure, where necessary, that requisite support arrangements in terms of transport and accommodation are in place to support patients / parents / guardians / carers. This includes meeting the full cost of travel, accommodation and reasonable incidental costs. Where patients / parents / guardians / carers provide their own transport and / or accommodation all reasonable costs will be covered by the HSC Board. These arrangements will ensure

that parents / guardians / carers can remain with the patient whilst they are receiving services under the preferred option.

However, the overriding priority is that patients receive a high quality of care provided by skilled and professional teams. The preferred way forward under the preferred option will ensure that appropriate support is provided to patients / parents / guardians / carers who attend with patients including those in same-gender relationships, single parents and lone parents as well as to patients. The dignity of patients and their privacy and family arrangements will be respected throughout the delivery of services under the preferred option.

- Article 14 – Prohibition of discrimination in the enjoyment of the convention rights – The preferred option will ensure that services are delivered without discrimination on any ground through the provision of a robust service level agreement with the relevant provider(s) which will be monitored by the HSC Board.

- 1st protocol Article 2 – Right of access to education: The preferred option will ensure, so far as is reasonably practicable, that childrens' education is not unduly impacted where their treatment requires them to travel and remain in hospital in Dublin for a prolonged period outside Northern Ireland. In circumstances where pre-school / school age children are required to travel to Dublin, 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

6.10 As part of its consideration of Human Rights, the Working Group has given due regard to the UN Convention on the Rights of the Child (UNCRC) in identifying the preferred option. The Working considered this and felt that there were no additional material issues over and above those considered as part of the Human Rights assessment.

Other mitigating factors

6.11 It is the HSC Board's intention, to enhance emotional support for parents by ensuring that robust communication and liaison arrangements are in place between parents /guardians /carers, the Belfast Trust nurse liaison staff and the providing centres.

6.12 There is 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.

7. NEXT STEPS

Overview – This section of the document considers next steps and other relevant issues for Ministerial consideration.

Introduction

7.1 The consultation process 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.

7.2 The work resulted in the development of a post consultation document which set out the proposed commissioning framework against which the service model options for the future commissioning of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland were assessed.

7.3 The post consultation document was approved by the Minister in March 2013 and the Working Group was tasked with taking forward the scoring of options using the commissioning framework contained in the post consultation document.

7.4 The outcome of this process was the identification of option 2, namely - *Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from Dublin* as the preferred option for the future provision of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland. This option is subject to approval by the Minister.

7.5 The following paragraphs set out the steps that the Working Group considers need to be taken over the coming months to ensure the introduction of the preferred option is realised in a manner that provides safe, high quality and sustainable care during the transition period and thereafter. Also, as far as possible to ensure the preservation of continuity of care, particularly for those children

awaiting surgery. All such proposed measures are subject to Ministerial approval of the preferred option.

Refining Care Pathways

7.6 In determining a preferred option the Working Group acknowledged that the care pathways for children requiring paediatric cardiac surgery or interventional cardiology would need to be refined to reflect the element of their care to be provided in Dublin. It was recognised that while detailed care pathways needed to be agreed and should be the subject of multidisciplinary clinical discussions, the key components of refined care pathways would involve the following:

- For children who require elective (planned) surgery or interventional cardiology there should be an agreed referral mechanism, multidisciplinary team discussion on patient management and an agreed approach on follow up/reviews. Patients and parents should be provided with relevant information on the Dublin surgical centre and also provided with appropriate information and support in the eventuality of difficulties with transport, accommodation, etc.

- For newborns (neonates) in neonatal intensive care units who require surgical closure of patient ductus arteriosus (PDA) the infant should continue to be treated in Belfast but this will be under the care of the visiting surgical team from Dublin. This will ensure that such vulnerable infants have access to care from a specialist surgical team that meets the standards set out in the agreed service specification. Detail regarding the decision to perform surgery and the timing of such surgery will be tailored to the needs of the affected infant agreed between the Belfast based cardiologists/neonatologists and the Dublin surgeons.

- For the small number of babies with transposition of the great arteries (TGA) who require a septostomy, referral will be to Dublin for the septostomy and for surgical correction of their heart abnormality. This affects approximately eight infants each year. A proportion of infants with TGA may require emergency

treatment (i.e. within a few hours) and may need to undergo a septostomy in Belfast, with subsequent referral to Dublin for corrective surgery. To respond in such circumstances the retention of interventional cardiology skills including the skills of medical, nursing and technical staff should be retained in Belfast. To provide a responsive septostomy service a robust sustainable interventional cardiology rota should remain in place.

- For the very small number of other cardiac emergencies that may arise in a child with confirmed congenital heart disease, a care pathway should be developed and agreed so that patients and parents have the appropriate information to let them know the actions they should take and the most appropriate location to access care.

7.7 For any child requiring an emergency referral to Dublin, the care pathway should reflect the necessary transport/retrieval arrangements required to ensure safe transfer. In this regard the expansion of capacity, including staff in the paediatric intensive care unit (PICU) coupled with enhancements to paediatric and neonatal transport will help ensure the necessary measures are in place to support emergency transfers. Given the importance of the transport issue the Working Group is of the view that prior to the implementation of the preferred option it would be essential that appropriate arrangements to enhance existing transport services were in place, to include appropriate contingency arrangements.

<u>Enhancement of local Paediatric Cardiology Services</u>

7.8 The Working Group recognised that, regardless of the nature of the preferred option, there was the potential to expand and enhance the paediatric cardiology service in Northern Ireland both in Belfast and elsewhere. This was a matter that Sir Ian Kennedy commented on in the Safe and Sustainable review, indicating that the current cardiology service in the Belfast Trust had the potential to develop into a Children's Cardiology Centre.

7.9 As reflected in responses to the PCCS consultation in 2012 and subsequently discussed by the Working Group there is a need to ensure that paediatric cardiology services are maintained in Northern Ireland and continue to provide the ongoing medical advice and support required by children with heart disease and by their families.

7.10 Many responders to the consultation highlighted the excellent quality of care provided by the staff in Clark Clinic and the Working Group recognised that the high quality clinical care combined with the personal attention to families provided patient centred care. The ongoing cardiology care will continue to be vitally important if the surgical element of care were to be provided in another centre as set out in the preferred option.

7.11 It is the Working Group's view that the future arrangements for the provision of paediatric cardiac surgery and interventional cardiology for the population of Northern Ireland should be supported by the following associated changes to the existing arrangements:

- Development of more robust networks between RBHSC and paediatric units in acute hospitals in Northern Ireland. While clinical linkages are already in place, the Working Group's view is that these can be enhanced through, for example, the establishment of a forum for sharing best practice, documented care pathways, and agreed referral protocols.

- As part of a paediatric cardiology network the development of a specialist interest in cardiology role in acute hospitals across Northern Ireland should be explored among paediatricians. This would provide more locally accessible advice and would strengthen network arrangements across Northern Ireland. Similar measures are being discussed and explored in GB.

- In moving towards the preferred option, robust clinical linkages will be vital. Such linkages must be sufficiently robust to ensure that children from Northern Ireland can access interventional

cardiology procedures in a timely manner, with procedures undertaken by Belfast based paediatric cardiologists.

- For those children who need to travel for surgery or interventional cardiology, for referral, treatment and follow up, agreed care pathways must be developed such that there are clear clinical protocols and patient / family experience issues are fully addressed.

- In regard to patient / family experience it will be necessary to ensure that liaison arrangements are robust - to provide a responsive service to parents when they need to travel outside Northern Ireland and to provide support and advice on practical issues including travel, subsistence and accommodation.

- IT links must be sufficiently robust to support telemedicine, including patient assessment and provision of clinical advice via telelink. Paediatric cardiology in Northern Ireland has been at the forefront of telemedicine but there are areas in which there is scope for development, for example ensuring the compatability of IT systems such that data transfer can be readily accommodated.

- Improvement in the level of ante natal diagnosis of cardiac abnormality must be secured in Northern Ireland. While many structural abnormalities of the heart are diagnosed before birth, for some abnormalities this can be quite challenging. It is anticipated that enhanced training for those undertaking antenatal scans, regular audit and peer review may all contribute to an increase in prenatal diagnosis, as will incremental improvements in imaging.

- Improvement in the arrangements for the early identification of congenital cardiac disease in neonates, consistent with best practice and guidance from national bodies.

- Services for non-invasive diagnosis and treatment of children with cardiac conditions should be further developed in Belfast. This should include a cardiac MRI service. Children in Northern

Ireland have less access to cardiac MRI than other areas of the UK. Cardiac MRI has in recent years increasingly replaced diagnostic catheterisation and is viewed as more effective as it provides more dynamic images. It is also considered safer as it does not expose children to radiation.

7.12 It is the Working Group's view that all of the above measures are essential to strengthen current services and provide high quality care to all children who need diagnosis or follow up for a heart problem. These measures will also complement the new arrangements for the provision of the surgical component of care and will help ensure seamless services for those children who require to undergo heart surgery.

Implementation Structures

7.13 To take forward the implementation of the preferred option, the Working Group would expect appropriate project structures to be established to ensure that the revised arrangements are put in place within an appropriate timescale. Given the issues identified with the sustainability of the current service in Belfast it is essential that there is a defined timescale for this transition.

7.14 An implementation plan should be developed. This should include a detailed timeline for the introduction of the preferred option, and details of the arrangements to be in place during the transition period. It is proposed that the implementation plan may also detail any measures that are required to ensure the sustainability of paediatric cardiology in Northern Ireland.

7.15 During the period between approval of the preferred option and the revised commissioning arrangements being in place, the HSC Board and PHA should carefully monitor the service, including referrals, waiting times, surgical activity in Belfast and patient outcomes to ensure that any potential risks are identified and steps to mitigate those risks are introduced.

Annex 1

Paediatric Congenital Cardiac Services Working Group

Membership

Dean Sullivan (Chair), Director of Commissioning, HSC Board

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 Paediatric 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, PHA

Irwyn McKibbin, Heartbeat NI

Dr David McManus, Medical Director, NIAS

Philip Moore, Head of Communications, HSC Board

Sarah Quinlan, Children's Heartbeat Trust

Dr Steve Robinson, Consultant Anaesthetist, Belfast Trust

Observers

Margaret Rose McNaughton, Director of Secondary Care, DHSSPS

Dr Paddy Woods, Deputy CMO, DHSSPS

Mr John Mone, Non-Executive Director, HSC Board

Project Support

Paul Cunningham, Commissioning Lead, HSC Board

Annex 2

Children's Heartbeat Trust Report

The Children's Heartbeat Trust cannot support the recommendation as made by the PCCS Working Group to the Minister of Health. We do not have confidence that any recommendation that removes all children's heart surgical services from Northern Ireland can meet the necessary criteria of providing a safe and quality service, cater for emergency cases, or guarantee the essential maintenance of the specialist medical skills within Northern Ireland that all children with congenital heart disease (CHD) rely upon. At this point in the process, the Children's Heartbeat Trust wishes to record our main reasons why.

Safety & Quality centres upon providing a safe service to a child with CHD currently living in Northern Ireland. Any option which does not include a Belfast surgical service cannot provide this. A 24/7 emergency service is cited as a requirement for a safe and quality service. Without a surgical service in Belfast, the charity believes this cannot even partially be achieved. The proposed 24/7 Emergency and Urgent Transport Service for sick children is untested and must always be vulnerable due to variables inherent in land and air transport. Furthermore, there is no 24/7 transport service in place for neonates, the most vulnerable group of CHD patients and the group most likely to require emergency service. We cannot condone testing an untried and vulnerable service on babies and children with heart disease.

The charity also has serious concerns that any option that does not include Belfast will increase the risk of death for a patient needing an emergency operation. This is evident especially in the situation of an emergency balloon septostomy or acute occlusion of an aorto-pulmonary shunt. In these instances, a patient needs treatment immediately and an additional transfer adds a significant time delay and thus an unacceptably greater risk of a poorer outcome. The 3 hour clinically indicated timeline for treatment of emergency cases cannot be guaranteed for a child from the Royal Belfast Hospital for Sick Children accessing an emergency service

in Dublin. This timeline is very much a 'best–case' scenario and doesn't allow for occurrences such as non-availability of PICU beds in Dublin, delays in the transport team being available or actioned, or traffic.

Finally there is clear evidence that once a centre loses its surgical element that the continued provision of medical and diagnostic paediatric cardiac services greatly deteriorates. This is evident in that Children's Cardiology Centres in Manchester, Edinburgh and Cardiff no longer perform standard diagnostic catheterisations and are reporting difficulties in recruiting and retaining staff. Training opportunities in Belfast are unlikely to be attractive or even available - as demonstrated from a recent meeting of paediatric cardiology trainees in the UK where it was agreed that a paediatric cardiology trainee should not spend more than 6 months out of a 5 year training programme at a non-surgical centre. The resultant deskilling will directly affect the cardiology unit but will also indirectly diminish other specialties in the children's hospital which will gain much less experience of working with patients with CHD e.g. anaesthesia and intensive care. The consequent negative impact will not only be to the detriment of any child with congenital heart disease but also on the overall multi-disciplinary specialist care available through our Regional Children's Hospital.