

# North South Inter-Parliamentary Association

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**Briefing Paper for the sixth meeting of the  
North-South Inter-Parliamentary Association**

## **Paediatric Congenital Cardiac Surgery**

**5<sup>th</sup> June 2015**

**Background briefing prepared by the Research and Information Service (RaISe) of the  
Northern Ireland Assembly and the Library & Research Service of the Houses of the  
Oireachtas (*Tithe an Oireachtais*)**

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## Key points

Congenital Heart Disease (CHD) refers to any defect of the heart present from birth and includes structural defects, arrhythmias, and cardiomyopathies.

Paediatric cardiac procedures are defined as any cardiac or intrathoracic great vessel procedure carried out in patients under the age of 16 years. Adult congenital cardiac procedures are defined as those performed for a cardiac defect present from birth.

Worldwide, the incidence of CHD in full-term live-born infants is estimated at 4-9 per 1,000 and is the most common congenital condition diagnosed in newborns. In Northern Ireland (NI) the incidence of CHD ranges from 8-10 per 1,000 live births and in the Republic estimates are between 5-6 per 1,000 live births.

CHD Services have been undergoing review and redesign across the UK and internationally over the past two decades. The international consensus demonstrates that, as far as possible, congenital heart surgery and interventional cardiology is best provided by specialist teams large enough to sustain a comprehensive range of interventions, meet recognised international standards of case volume standards and medical staffing levels.

In NI, in recent years, there has been a number of clinical and operational reviews of CHD services, accompanied by strong lobbying, public and political interest. There have been recent reviews of paediatric services in Ireland but none have specifically reviewed CHD.

On 9<sup>th</sup> December 2013 the then Health Ministers in NI and Ireland, Edwin Poots MLA and Dr James Reilly TD, jointly announced the appointment of a team of international clinicians (IWG) to carry out an independent assessment and recommend the optimal model for a Cardiology, Cardiac Surgery and Interventional Cardiology service for CHD to meet the respective needs of Ireland and NI.

The IWG Report highlighted shortcomings in both jurisdictions, for instance the service in NI does not meet case volume standards and the Dublin-based service has a medical staffing level, in both intensive care and cardiology, that is significantly lower than in comparably sized UK and European centres.

The key surgical recommendation was that provision of paediatric cardiac surgery and interventional cardiology services would cease in Belfast and surgical care of all paediatric patients would be transferred to Our Lady's Children's Hospital, Crumlin. On 14 October 2014, the then Health Minister for NI, Jim Wells, and the Health Minister for the Republic, Leo Varadkar, stated that both Ministers had agreed to accept all of the IWG's recommendations and were committed to their full implementation.

The new model is being taken forward in stages with the immediate impact being that more children from NI are likely to receive elective surgery at a specialist centre in England until appropriate capacity is in place in Dublin. Interventional paediatric cardiology ceased in Belfast from April 2015.

The model includes an all-island CHD Network, established on 1 April 2015. The network comprises a Cross-Jurisdictional Oversight Group with responsibility for oversight of the implementation of the IWG recommendations and all-island Clinical Network Board with responsibility for the operational, clinical management and delivery of the service.

## 1. Introduction

Congenital Heart Disease (CHD) services have been subject to close scrutiny and review over the last 10 to 20 years, particularly within the UK. In Northern Ireland (NI), the issue has a long and emotive history, involving numerous clinical and operational reviews, strong lobbying by charities and parent groups and consistent public and political interest. Although there have been recent reviews of paediatric services in Ireland, none of these specifically reviewed CHD in the Republic.

Reviews of Congenital cardiac services in the UK commenced with Professor Ian Kennedy's Review into children's heart surgery in Bristol between 1984 and 1995 (published in 2001). During the Bristol Heart Inquiry, Mr Kennedy collected 900,000 pieces of evidence and examined operations spanning a ten-year period.<sup>1</sup> The report called for children's heart surgery to be undertaken in fewer specialist centres. This was followed up in 2003 by recommendations from the Paediatric and Congenital Cardiac Services Review Group also backing fewer larger centres.

The call for fewer larger centres was reiterated by the Royal College of Surgeons in 2007, and in 2008 the Safe and Sustainable review for England was set up and also chaired by Professor Kennedy.<sup>2</sup>

A number of reviews of the services in NI have also been undertaken, starting with the 2010 clinical review by Mr David Barron and Dr Asif Hasan<sup>3</sup> and culminating in the International Working Group Report (IWG) (2014) (see Sections 3, 4 and Appendix 2).

There have been a number of reviews of paediatric services in Ireland (Appendix 2), though none have specifically reviewed CHD. The most recent review of paediatric

<sup>1</sup> <http://www.bristolpost.co.uk/Bristol-Heart-Inquiry-Fresh-review-children-s/story-21280761-detail/story.html>

<sup>2</sup> NHS Specialised Services, *Safe and sustainable: a new vision for children's congenital heart services in England – consultation document*, March 2011

<sup>3</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, October 2014, page 3  
<http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

and neonatology services in the Republic (July 2013) had its origins in the Health Service Executive's (HSE) Clinical Programme for Paediatrics and Neonatology<sup>4</sup>. It identified ten pillars for the services and a number of these are relevant to the delivery of CHD services (see Appendix 2).

On 9<sup>th</sup> December 2013 the then Health Ministers in NI and Ireland, Edwin Poots MLA and Dr James Reilly TD, jointly announced that they had appointed a team of international clinicians (IWG) to carry out an independent assessment and recommend the optimal model for a Cardiology, Cardiac Surgery and Interventional Cardiology service for CHD to meet the respective needs of Ireland and NI.

On 14 October 2014, the Health Ministers Jim Wells and Leo Varadkar stated that both Ministers had agreed to accept all of the IWG's recommendations and were committed to their full implementation following any necessary consultation.<sup>5</sup>

The key surgical recommendation of the IWG was that provision of paediatric cardiac surgery and paediatric interventional cardiology services would cease in Belfast and surgical care of all paediatric patients would be transferred to Our Lady's Children's Hospital, Crumlin (OLCHC). Also recommended was a refocusing of the Belfast program to elective, lower complexity, adult congenital cardiac procedures.

Interventional cardiology ceased in Belfast from April 2015 and NI children will, in future, receive this service in Dublin delivered as part of an all-island clinical network.<sup>6</sup> The new model will be taken forward in stages and the immediate impact is that from January 2015 more children from NI are likely to receive elective surgery at a specialist centre in England until appropriate capacity is in place in Dublin.

Due to this successful joint agreement for paediatric CHD services, this paper presents the all-island Paediatric Congenital Cardiac Surgery model as a good practice example of what can be achieved with co-operation to provide an all-island service to diagnose and treat relatively rare conditions, when it is recognised that neither jurisdiction alone can maintain a service which meets international standards.

This research paper provides:

- An introduction to CHD (including antenatal detection rates and incidence);
- Details of the IWG report and recommendations;
- Details of the all-island clinical network;

In addition, an appendix gives the historical context leading to the IWG Report.

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<sup>4</sup> <http://hse.ie/paeds/>

<sup>5</sup> Oral Statement to the Assembly by Health Minister Jim Wells MLA – 14 October 2014 – Outcome of October Monitoring Round and Paediatric Congenital Cardiac Services, <http://www.dhsspsni.gov.uk/oralstatement141014>

<sup>6</sup> As above.

## 2. Congenital Heart Disease

CHD refers to any defect of the heart present from birth and includes structural defects, congenital arrhythmias, and cardiomyopathies. Acquired heart disease develops after birth, for example, rheumatic heart disease.<sup>7</sup>

Paediatric cardiac procedures are defined as any cardiac or intrathoracic great vessel procedure carried out in patients under the age of 16 years. Adult congenital cardiac procedures are defined as those performed for a cardiac defect present from birth.<sup>8</sup>

The diagnosis and treatment of complex heart defects has greatly improved over the past few decades. As a result, almost all children who have complex heart defects survive to adulthood.<sup>9</sup>

In considering care for children with CHD a number of overarching considerations have been identified as important to the development of services<sup>10</sup>:

- The relative rarity of the conditions;
- The association between volume of surgical activity and clinical outcomes;
- The need for a complex infrastructure of facilities and equipment;
- The need for a multidisciplinary range of specialists and technical expertise;
- The changing profile of the CHD population as more children with CHD live longer into adulthood; and
- Increasingly stringent standards of care as practice and treatment develop.

### 2.1 CHD – Antenatal Diagnosis

Antenatal diagnosis of CHD has improved in recent years, although this is not consistent across the UK and Ireland. Around a quarter of cases are detected by antenatal ultrasound scans. The values shown in Table 1 are the percentage of eligible cases<sup>11</sup>, over a four year period, that were successfully diagnosed in the antenatal period.

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<sup>7</sup> National Congenital Heart Disease Audit Report 2010-2013, Section 2.1, page 4, [http://www.ucl.ac.uk/nicor/audits/congenital/documents/annual-reports/nchda2010\\_13](http://www.ucl.ac.uk/nicor/audits/congenital/documents/annual-reports/nchda2010_13)

<sup>8</sup> As above, page 3,

<sup>9</sup> As above, page 4,

<sup>10</sup> Evidential Base and Clinical Practice Aspects of Congenital Cardiac Services, DHSSPS, Chief Medical Officer, 2013, page 1, <http://www.dhsspsni.gov.uk/congenital-cardiac-services.pdf>

<sup>11</sup> Eligible cases – numbers do not include deaths during pregnancy or termination of pregnancy, or perinatal deaths or deaths in infancy in infants with congenital heart malformations who did not have a procedure.

**Table 1 Antenatal Detection Rates of Congenital Heart Disease**

	2009-10	2010-11	2011-12	2012-13
England	35%	38%	40%	42%
Ireland	Data not available for this period	22%	37%	33%
N Ireland	40%	32%	36%	34%
Scotland	10%	8%	26%	22%
Wales	34%	30%	37%	47%

SOURCE: Fig. 7 National Congenital Heart Disease Audit Report 2010/13

## 2.2 Statistics – Incidence of Congenital Heart Problems

Worldwide, the incidence of CHD in full-term live-born infants is estimated between 4 and 9 per 1,000 and each year there are about 1.5 million new cases worldwide. It is the most common congenital condition diagnosed in newborns.<sup>12</sup>

### Northern Ireland

NI has a population of 1.8 million with 0.35 million children aged 14 or less. Estimates of the live birth prevalence of CHD in NI are between 8 and 10 per thousand live births with approximately half of this number requiring cardiac surgical procedures<sup>13</sup>.

A 2013 Report by the Chief Medical Officer for NI noted<sup>14</sup>:

- In NI, between 200 and 250 babies will be born in NI each year with such a condition; and
- It is estimated there are around 2,800 adults with congenital heart disease per 1 million population which equates to around 5,000 people in NI (with steady birth rate and increasing survival the population of adults with CHD will increase by 5% per year); and
- NI incidence figures have generated some 50 interventional cardiology procedures and 140 cardiac operations on children, and around 40 interventional cardiology procedures and 50 cardiac operations on adults each year.

<sup>12</sup> Congenital Heart Disease in Children, Patient.co.uk, PatientPlus, [http://www.patient.co.uk/doctor/Congenital-Heart-Disease-\(CHD\)-in-Children.htm](http://www.patient.co.uk/doctor/Congenital-Heart-Disease-(CHD)-in-Children.htm)

<sup>13</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, October 2014, page 3 <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

<sup>14</sup> Evidential Base and Clinical Practice Aspects of Congenital Cardiac Services, DHSSPS, Chief Medical Officer, 2013, page 2, <http://www.dhsspsni.gov.uk/congenital-cardiac-services.pdf>

Each year approximately 140 children under the age of 16 years and 30 adult patients require surgery for congenital heart conditions in NI.<sup>15</sup>

To illustrate the range and prevalence of the main congenital cardiac conditions, Appendix 1 shows the estimated number of cases of each condition in NI based on 25,000 births per year.

### **Ireland**

Ireland has a population of 4.59 million with 0.98 million children aged 14 or under:

*Estimates of the live birth prevalence of congenital heart disease in the Republic of Ireland are between 5 and 6 per thousand by both the Eurocat data and the extrapolation to the entire Republic of Ireland. This incidence is in the same order of magnitude (overall incidence 8/1000 live births, incidence of defects requiring surgery or intervention is 3.5-4/1000 live births) as in essentially all studies of various populations throughout the world.<sup>16</sup>*

Paediatric cardiac surgery in the Republic of Ireland is carried out in Our Lady's Children's Hospital Crumlin (OLCHC). There are currently three paediatric cardiac surgeons with a combined surgical volume of about 400 cases a year. Adult congenital services are provided by the paediatric congenital team of cardiologists with surgery undertaken at the Mater Hospital. Women diagnosed antenatally and assessed as high risk are delivered at the Coombe Maternity Hospital close to OLCHC.

## **3. International Working Group 2014 Report and Recommendations**

To assist with understanding the work of the International Working Group (IWG), it is informative to consider the historic context of this issue. Concerns surrounding the quality and potential safety of paediatric CHD services have existed across the UK, including NI, for many years. A number of reviews of CHD services and paediatric services have been undertaken in the NI and the Republic.

Five recent reviews of paediatric services in Ireland were shared with the IWG, none of these had specifically reviewed CHD services in the Republic. The Paediatric Congenital Cardiac Service in NI has been extensively reviewed, particularly since 2010, and five of the recent reviews informed the IWG's deliberations.

<sup>15</sup> Review of the Paediatric Congenital Cardiac Service, Belfast HSC Trust, July 2012, <http://www.hscboard.hscni.net/pccs/Paediatric%20Congenital%20Cardiac%20Service%20Review.pdf>

<sup>16</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, page 3, October 2014, <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

**Appendix 2** summarises the previous reviews of CHD and paediatric services that helped to inform the subsequent work and recommendations of the IWG.

As stated earlier, on 9<sup>th</sup> December 2013, the then Health Ministers in NI and Ireland, Edwin Poots MLA and Dr James Reilly TD, jointly announced that they had appointed an IWG to carry out an independent assessment and recommend the optimal model for a Cardiology, Cardiac Surgery and Interventional Cardiology service for CHD to meet the respective needs of Ireland and NI<sup>17</sup>

In a joint policy statement on 14 October 2014, the Ministers Jim Wells and Leo Varadkar stated that both Ministers had agreed to accept all of the IWG's recommendations and were committed to their full implementation following any necessary consultation.<sup>18,19</sup>

The IWG Report highlighted that neither centre was delivering a service which met international standards of both case volume and consultant staffing: the service in NI does not meet the case volume and the Dublin-based service has a medical staffing level, in both intensive care and cardiology, that is significantly lower than in comparably sized UK and European centres.<sup>20</sup>

Overall, the IWG proposed an **all-island congenital cardiac service** (a total of 14 inter-dependent recommendations) with a combined population base of 6.4 million (1.3 million children and 400-500 paediatric congenital cardiac surgical cases per year). This reaches service volume thresholds that are sustainable and capable of meeting international standards.

The "*clinical and physical resources of the two jurisdictions were to be considered as one pool of resources ...a 'network' solution for patients with congenital heart disease in both jurisdictions*"<sup>21</sup>. In summary, the 14 recommendations are<sup>22</sup>:

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<sup>17</sup> Official Report (Hansard), Northern Ireland Assembly, Monday 9 December 2013, Vol 90, No 3, <http://www.niassembly.gov.uk/assembly-business/official-report/reports-13-14/>

<sup>18</sup> Oral Statement to the Assembly by Health Minister Jim Wells MLA – 14 October 2014 – Outcome of October Monitoring Round and Paediatric Congenital Cardiac Services, <http://www.dhsspsni.gov.uk/oralstatement141014>

<sup>19</sup> Varadkar welcomes publication of the Report of the expert International Working Group on the Assessment of Cardiology and Cardiac Surgery for CHD in Northern Ireland and the Republic of Ireland, Department of Health, Ireland, Press Release, 14.10.2014, <http://health.gov.ie/blog/press-release/varadkar-welcomes-report-of-the-expert-international-working-group-on-the-assessment-of-cardiology-and-cardiac-surgery-for-congenital-heart-disease/>

<sup>20</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, October 2014, page 8 <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

<sup>21</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, pages 8-10, October 2014, <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

<sup>22</sup> As above, pages 8-10.

1. Establish an all-Island governance committee to: (a) oversee the operations of the personnel, facilities, and institutions involved in the care of patients (of all ages) with CHD; and (b) to develop plans for improvements in the areas of personnel, resource management and capital investments for facilities dedicated to the management of children and adults with CHD.
2. Establish a Family Advisory Group with representation from both jurisdictions that will meet at least quarterly and include clinical nurse specialists and other family support staff to provide direct input to the Governance Committee.
3. Establish an all-Island database covering all CHD patients - procedural outcomes, follow-up data, and resource utilisation.
4. Facilitate the flow of nursing/physician personnel between the two jurisdictions, where shortages exist, and deploy consultant staff across jurisdictions for situations that do not require extended periods of care;
5. Expand the paediatric cardiac ICU capacity in Dublin to at least 10 fully staffed beds.
6. Expand and upgrade telemedicine links between the Republic and the Belfast HSC Trust paediatric cardiology facilities with ongoing IT support.
7. Cease the provision of paediatric cardiac surgery and paediatric interventional cardiology services in Belfast and transfer surgical care of all paediatric patients to OLCHC. Refocus the Belfast program to elective, lower complexity adult congenital cardiac surgical and interventional catheterisation procedures.
8. Provide enhanced patient and family services in Dublin for those who do not reside in the Dublin metropolitan area, with Family Liaison Coordinators to provide assistance on non-clinical matters.
9. Integrate the activities of Clinical Nurse Specialists (CNS) and advanced practice nurses (APN) in Belfast and Dublin to provide patient/family support, to manage the transfers of patients between Belfast and Dublin, and to co-manage clinics. Expand roles of Clinical Nurse Specialists and advanced practice nurses in the ambulatory clinics and in the transport teams.
10. Require quarterly meetings between the paediatric and neonatal patient transport services in the two jurisdictions to facilitate safe transfers between outlying areas and the centres in Belfast and Dublin, and transfers between the centres.
11. Upgrade the paediatric transport services in the Republic and consider building on the expert inpatient Extracorporeal Life Support (ECLS) services in Dublin to form a mobile ECLS service.
12. Expand weekly case conferences for patients requiring or interventional catheterisations at OLCHC, incorporating cardiologists, adult congenital cardiologists and surgeons from Belfast HSC Trust (in person or by teleconference).
13. Extend the current OLCHC monthly multi-disciplinary team mortality and morbidity conference to include cardiologists, cardiothoracic surgeons, intensivists and anaesthetists from both jurisdictions.
14. Mandate an annual "all-Island" symposium on CHD management, including an assessment of results of the current service arrangements.

With regard to the decision process around recommendation 7 (the surgical element), the IWG considered four options and judged them by seven criteria as outlined in the terms of reference.<sup>23</sup> In producing its recommendations, the IWG considered previous reviews, current case volumes, visited facilities, and interviewed the surgical team at the Belfast HSC Trust and OLCHC:

*The option of maintaining a paediatric case volume at Belfast was considered to be a sub-optimal solution as the result would be maintenance of two programs, each with volumes well below the current levels recommended under the UK Safe and Sustainable standards.....*<sup>24</sup>

The Ministers agreed that the IWG recommendations proposed an achievable model but it did not prescribe the detail about “*how the transfer should occur, or when surgery in Belfast should cease, or how Dublin’s capacity can be increased, or what happens with these patients in the meantime.....our Departments are working together closely.....to plan how to make that model a reality*”.<sup>25</sup>

The IWG perception was that there was a willingness at political level, clinical level, policy and management level, and parental level to make an all-island solution work.<sup>26</sup>

The Children’s Heartbeat Trust, a key NI charity involved in the various NI reviews of services, stated<sup>27</sup>,

*We recognise and acknowledge the speed with which the process has moved under the current and previous Health Ministers since the Working Group reported last Autumn. There is still an interim period of up to 15 months while the new all-Island structure is put in place and during that time families still face the upheaval of travelling to England for surgery. Ministers from Belfast and Dublin need to work to reduce that time period as much as possible. We will also be seeking assurances that when*

<sup>23</sup> Recommendations extracted from - Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, page 11, October 2014, <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

<sup>24</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, page 17, October 2014, <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

<sup>25</sup> Oral Statement to the Assembly by Health Minister Jim Wells MLA – 14 October 2014 – Outcome of October Monitoring Round and Paediatric Congenital Cardiac Services, <http://www.dhsspsni.gov.uk/oralstatement141014>

<sup>26</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, October 2014, page 8 <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

<sup>27</sup> Minister of Health announces acceptance of all IWG recommendations, Children’s Heartbeat Trust, <http://www.childrensheartbeattrust.org/news/minister-of-health-announces-acceptance-of-all-iwg-recommendations/>

*emergency surgery is required in Dublin during that interim period it will be available.... Our overriding priority as we began this campaign was to ensure that the treatment provided to children with congenital heart disease was the most appropriate, clinically and in terms of family support. At the start of this process we were promised an improved service, now we need to see this being delivered without delay.*

#### **4. The Way Forward – All-Island Clinical Network**

The new model is being taken forward in stages and the immediate impact is that from January 2015 more children from NI are likely to receive elective surgery at a specialist centre in England until appropriate capacity is in place in Dublin. Interventional cardiology ceased in Belfast from April 2015 and NI children will, in future, receive this service in Dublin delivered with Belfast cardiologists working as part of an integrated team.<sup>28</sup>

In their joint policy statement, the Ministers highlighted the following short/medium and long-term actions<sup>29</sup>:

##### **Short-term (October 2014-April 2016):**

- An extension and expansion of the current Service Level Agreements to provide for agreed provision of emergency and urgent surgical and interventional cardiology care to children from NI;
- Expansion of paediatric ICU, other inpatient and associated facilities at Crumlin to facilitate growth of elective surgical capacity; and
- Enhancement of access for clinicians and support staff to both Belfast and Dublin.

##### **Medium-term (April 2016 to April 2019):**

- Provision of emergency, urgent and elective surgery and interventional cardiology on all-island basis in Dublin in line with the IWG recommendations; and
- Provision of lower complexity adult congenital cardiac surgical and interventional catheterisation procedures and associated surgical interventions which may arise on an all-island basis at Belfast in line with the IWG recommendations.

<sup>28</sup> Oral Statement to the Assembly by Health Minister Jim Wells MLA – 14 October 2014 – Outcome of October Monitoring Round and Paediatric Congenital Cardiac Services, <http://www.dhsspsni.gov.uk/oralstatement141014>

<sup>29</sup> Joint Policy Statement by the Minister of Health and Social Services and Public Safety Northern Ireland, Jim Wells and the Minister of Health in the Republic of Ireland, Leo Varadkar on the report of the expert International Working Group (IWG) on the Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, 14 October 2014, <http://www.dhsspsni.gov.uk/policystatement141014>

**Long-term (from April 2019):**

- Upon completion and commissioning of the new children's hospital in Dublin, all paediatric congenital heart-disease services will move to the new site.

On 3rd March 2015 the Ministers published the framework setting out the single all-island CHD Network, established on 1 April 2015. This comprises a **Cross-Jurisdictional Oversight Group** and **all-island Clinical Network Board**.

The **Cross-Jurisdictional Oversight Group** has responsibility for oversight of the implementation of the IWG recommendations. The all-island **Congenital Heart Disease Network Board** is working to implement the IWG recommendations and be responsible for the operational, clinical management and delivery of the service.<sup>30</sup>

The initial Action Plan to be implemented by the Network Board is phased to reflect the need to build-up capacity at OLCHC. In the interim current Service Level Agreements will remain in place between service providers in NI, the Republic and England.

In order to facilitate the development of this network, including the Belfast cardiology hub, there is a commitment of £1million from the DFP Change Fund to invest in the network. The DHSSPS is also committing a further £200,000 for 2015/16 to invest in the network.<sup>31</sup>

The contribution of the Republic for the all-island model is primarily related to infrastructural and staffing resources, both within the hospital and through liaison with the national paediatric patient retrieval (specialist ambulance/ emergency aeromedical support) service<sup>32</sup>:

*A new €4.5m 25 bed Children's Heart Centre has been developed at Crumlin from external fund-raising. Work was completed at the end of summer 2013. The hybrid interventional catheterisation suite (on which the sod was turned on 5 February 2015 by Minister Varadkar) is a further key infrastructural development taking place prior to the completion of a single national children's hospital campus. The modular design of the new lab is intended to facilitate the transfer of the equipment from Crumlin to the new children's hospital in due course. All necessary planning permission and design works are in place, with construction scheduled to be completed by the end of 2015. A budget of €5.6m has been allocated by the HSE for this project (construction and fit-out), with €4m assigned in 2015.*

*The hospital, through cardiac stabilisation funding, is appointing an additional*

<sup>30</sup> Wells Updates Assembly on Paediatric Congenital Cardiac Services, DHSSPS News Release, 3/03/15, <http://www.northernireland.gov.uk/news-dhssps-030315-wells-updates-assembly>

<sup>31</sup> Wells Updates Assembly on Paediatric Congenital Cardiac Services, DHSSPS News Release, 3/03/15, <http://www.northernireland.gov.uk/news-dhssps-030315-wells-updates-assembly>

<sup>32</sup> Email communication from Miriam Joyce, Assistant Principal Officer, Acuter Hospitals Policy Unit, Department of Health, Ireland, 28/04/15

*cardiologist which will assist with the general waiting list in cardiology. Crumlin is also working with a cardiac consultant in the Mater to agree dates for him to provide RFA (ablation) procedures at Crumlin, working with the existing consultants...*

#### 4.1 The Framework<sup>33</sup>

The framework outlines the **all-island Clinical Network**. It builds on existing services and draws them together in a network of care comprising partnership, service integration and formal arrangements.

The framework recognises the need for standards, targets, quality assurance, risk management, clinical and social care arrangements and communication/engagement - detailed proposals and implementation in respect of these are to be matters for the CHD Network Board.

**The Cross Jurisdictional Oversight Group (CJOG)** has responsibility for oversight of the implementation of the recommendations in order to provide information and assurances to both Ministers. Its roles and responsibilities include:

- Authorisation of the initiation of the project for the new service model;
- Agreement of overall CHD all-island clinical network structure;
- Network Board and membership; and
- Oversight of change/ action in the delivery of the implementation plan for CHD.

The CJOG membership will be comprised of the Chief Medical Officers and senior administrative management of the Departments of Health in Northern Ireland and the Republic:

**The Congenital Heart Disease (CHD) Network Board** will be chaired by Dr Len O'Hagan (CEO of the Royal College of Physicians of Ireland) and comprised of patient representatives, clinicians and key service providers and commissioners. There will be specialist expertise/skills, programme and project support, policy advice and input where appropriate.

The Children's Heartbeat Trust welcomed that it<sup>34</sup>,

*will be represented on that Board and we will continue to represent the views of children and their families. It is positive that there will be family representation at all levels in the new structure.*

<sup>33</sup> Framework for All Island Clinical Network for Congenital Heart Disease, 3/03/15, <http://health.gov.ie/blog/publications/framework-for-all-island-clinical-network-for-congenital-heart-disease/>

<sup>34</sup> Minister of Health announces acceptance of all IWG recommendations, Children's Heartbeat Trust, <http://www.childrensheartbeattrust.org/news/minister-of-health-announces-acceptance-of-all-iwg-recommendations/>

The Network Board will concentrate initially on services for paediatric and young adult patients, and progress to adults with CHD. The Board will be responsible for ensuring the delivery of the phased implementation plan and will be accountable to the CJOG. It will work with the support of a Core Team, comprised of a Network Manager, Clinical and Nursing leads and deliver its work programme assisted by any working groups it deems necessary.

The Network Board is expected to meet monthly to monitor and report progress. It will report directly to the CJOG, providing update reports on progress and identifying risks/barriers to achieving a successful outcome, along with measures to mitigate against these.

The Network Board is tasked with setting out clear standards and the effectiveness of the clinical network will be measured, in part, by the definition of the standards and adherence to them. Following establishment of the clinical network, the Board will publish an annual report on the service provided by the clinical network and organise an annual symposium.

## 5. Conclusion

CHD Services have been undergoing review and redesign across the world over the past two decades. The international consensus demonstrates that, as far as possible, congenital heart surgery and interventional cardiology is best provided by specialist teams large enough to sustain a comprehensive range of interventions, meet recognised international standards of case volume standards and medical staffing levels.

In NI, the issue has involved numerous clinical and operational reviews, strong lobbying by charities and parent groups and consistent public and political interest. Although there have been recent reviews of paediatric services in Ireland, none of these specifically reviewed CHD in the Republic.

With regards to the current situation in NI and the Republic, in December 2013 the then Health Ministers in NI and Ireland, Edwin Poots MLA and Dr James Reilly TD, jointly announced the appointment of a team of international clinicians (IWG) to carry out an independent assessment and recommend the optimal model for a Cardiology, Cardiac Surgery and Interventional Cardiology service for CHD to meet the respective needs of Ireland and NI.

The IWG Report highlighted shortcomings in both jurisdictions, for instance the service in NI did not meet case volume standards and the Dublin-based service had a medical staffing level, in both intensive care and cardiology, that was significantly lower than in comparably sized centres elsewhere.

The key surgical recommendation was that provision of paediatric cardiac surgery and interventional cardiology services should cease in Belfast and surgical care of all paediatric patients should be transferred to Our Lady's Children's Hospital, Crumlin (Dublin). On 14 October 2014, the then Health Minister for NI, Jim Wells, and the Health Minister for the Republic, Leo Varadkar, stated that both Ministers had agreed to accept all of the IWG's recommendations and were committed to their full implementation.

Due to this successful joint agreement for paediatric CHD services, this paper concludes that the all-island Paediatric Congenital Cardiac Surgery model represents a good practice example of what can be achieved with co-operation to provide an all-island service to diagnose and treat relatively rare conditions.

The new model has recently commenced and is being taken forward in stages with the immediate impact being that more children from NI are likely to receive elective surgery at a specialist centre in England until appropriate capacity is in place in Dublin. Interventional paediatric cardiology ceased in Belfast from April 2015.

The model includes an all-island CHD Network, established on 1 April 2015. The network comprises a Cross-Jurisdictional Oversight Group with responsibility for oversight of the implementation of the IWG recommendations and all-island Clinical Network Board with responsibility for the operational, clinical management and delivery of the service.

## Appendix 1

The prevalence of the main congenital cardiac conditions and the estimated cases of each in NI based on 25,000 births per year:

Defect	Median prevalence per 100,000 live births (lower quartile, upper quartile)	Prevalence per 100,000 live births	Estimated cases in NI per year (based on 25,000 births per year)
Complete atrioventricular septal defect (CAVSD)	34 (24, 40)	277	70
Ventricular septal defect (VSD)	Over 4000 (if series involving echocardiography at birth included)	197 (echocardiography not used to screen)	49
Pulmonary stenosis (PS)	53 (35, 84)	65	16
Persistent (patent) ductus arteriosus (PDA)	57 (32, 78)	50	13
Coarctation of the aorta (COA)	36 (29, 49)	35	9
Tetralogy of Fallot (TOF)	35 (29, 58)	31	8
Transposition of the great arteries (TGA)	30 (23, 29)	30	8
Atrial septal defect (ASD)	56 (37, 106)	28	7
Aortic (valve) stenosis (AS)	26 (16, 39)	20	5
Pulmonary atresia (PA)	8 (8, 15)	21	5
Hypoplastic left heart (HLH) syndrome	23 (15, 28)	14	4
Interruption of the aorta arch (IAA)	[not cited]	8	2
Total anomalous pulmonary venous connection (TAPVC)	9 (6, 12)	9	2

Source: Evidential Base and Clinical Practice Aspects of Congenital Cardiac Services, DHSSPS, Chief Medical Officer, 2013, page 13, <http://www.dhsspsni.gov.uk/congenital-cardiac-services.pdf>

## Appendix 2 - History of Reviews of Services Prior to the IWG Review and Recommendations

To assist with understanding the new all-island model (detailed in Sections 3 and 4 below), it is informative to consider the historic context of this issue. This appendix briefly summarises the previous reviews of CHD and paediatric services that helped to inform the subsequent work and recommendations of the IWG.

### Ireland

Five recent reviews of paediatric services in Ireland were shared with the IWG but none of these had specifically reviewed CHD services in the Republic.

#### Reviews in brief<sup>35</sup>:

In 2008, the Health Service Executive (HSE) commissioned a report, “Right Care, Right Place, Right Time”, with clinical advice provided by Professor Ian Murdoch (Evelina Hospital, London), Dr Kevin Morris (Birmingham) and Professor Des Bohn (Toronto). Their report reviewed the paediatric intensive care services in the Republic and recommended the number of beds/medical staff required to deliver a ‘robust’ Paediatric Intensive Care Unit (PICU) service for Ireland.

In May 2012, Professor Murdoch and Dr Morris revisited the service, publishing “Clinical review of Paediatric Critical Care Services”, which looked at progress in the four years since the 2008 report, taking into account the stalled build of the new children’s hospital (originally planned for 2012). They made a number of recommendations including:

- Moving to a 5 day cardiac operating schedule;
- Triage of “general” PICU activity towards the Children’s University Hospital Temple Street PICU; and
- Delivery of a consultant led transport service which should be integrated within the PICU at OLCHC.

In February 2014, the College of Anaesthetists of Ireland published “Providing Quality, Safe and Comprehensive anaesthesia services in Ireland – a review of manpower challenges”. It recommended that for Paediatric Intensive Care, referring to “Right Care, Right Place, Right Time”, there should be between 12 and 18 full time paediatric intensivists (at the time there were 3).

The most wide-ranging review was the *Review of Paediatric and Neonatology Services and Framework for Future Development*. (July 2013).<sup>36</sup> The review had its origins in

<sup>35</sup>Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, page 3, October 2014, <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>, pages 5-6,

the HSE's Clinical Programme for Paediatrics and Neonatology (established June 2011). The two national leads of the clinical programme engaged in a consultation process involving a formal site visit to all 23 paediatric centres across Ireland.

The review avoided centre-specific analysis but focused on broad themes. It identified ten pillars or principles. Several of the 'Pillars' are particularly relevant to the development of the paediatric cardiac service<sup>37</sup>:

- Pillar 4 - emphasised the need for a consultant delivered paediatric service and expansion of consultant numbers through formal manpower planning;
- Pillar 7 - advised urgent expansion of the retrieval service for newborn and paediatrics to a 24/7 service, including the appointment of additional consultant intensivists; and
- Pillar 9 – required national minimum service standards for paediatric departments and collection of minimal datasets (the review revealed a lack of standard datasets needed to support a national model of care).

## Northern Ireland

The Paediatric Congenital Cardiac Service in NI has been extensively reviewed, particularly since 2010, and five of the recent reviews informed part of the IWG's deliberations. The main points from these reviews are now briefly outlined.

In 2010 there was an external clinical governance review by Mr David Barron and Mr Asif Hasan (UK consultant cardiac surgeons<sup>38</sup>). Their report made recommendations regarding sustainability and the limits of the Belfast service in performing complex surgical procedures. It recommended that Belfast become a Paediatric Cardiology Centre working in close liaison with Dublin as the surgical centre.<sup>39</sup>

In 2012, a Royal College of Surgeons of England report noted no concerns regarding the standard of cardiac surgery in Belfast. However, it raised concerns around the split-site functioning on the Royal Hospital site; caring for children in an adult ICU;

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<sup>36</sup> Review of Paediatric and Neonatology Services and Framework for Future Development, Clinical Strategy and Programmes Directorate, HSE, Royal College of Physicians of Ireland, July 2013, <http://www.hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatologyprogramme/Workplan/revision/framework.pdf>

<sup>37</sup> As above.

<sup>38</sup> Birmingham Children's Hospital and Freeman Hospital, Newcastle

<sup>39</sup> Review of the Paediatric Congenital Cardiac Service Belfast Health and Social Care Trust, 2 July, 2012, HSC Board, HSC Public Health Agency, Independent Review Panel led by Sir Ian Kennedy, page 4, <http://www.hscboard.hscni.net/pccs/Paediatric%20Congenital%20Cardiac%20Service%20Review.pdf>

staffing capacity in relation to PICU; and the inability to provide Extracorporeal Life Support (ECLS) as a backup.<sup>40</sup>

By 2012, the services in Belfast had been recognised for over a decade as being vulnerable, given the numbers of patients being treated per year. In this context, the then Minister, Mr Edwin Poots, announced (in March 2012) the HSC Board's external review by an expert panel led by Professor Sir Ian Kennedy.<sup>41</sup>

This Review concluded that there were many excellent features in the NI service. However, as with the 2010 review, it was the surgical element that was again considered unsustainable with "*no realistic prospect of the Belfast Trust being able or suitable to meet the demands of the Northern Ireland surgical caseload without assistance from other surgical units*".<sup>42</sup>

Five options were considered including the recently agreed all-island model to cease surgery in Belfast and plan to transfer all surgery to Dublin, while continuing to send children to England until capacity is built in Dublin.<sup>43</sup>

The expert panel highlighted that a partnership with OLCHC (Dublin) provided an opportunity for a networking arrangement that could see Belfast Trust's cardiologists delivering their service at OLCHC.<sup>44</sup>

The HSC Board then established a Paediatric Congenital Cardiac Services (PCCS) Working Group to determine a preferred option for services in Belfast. It ran a 12-week consultation solely on the development of a framework to be used to determine a preferred option. It made recommendations in relation to a final service specification, together with eight possible options for delivery (plus criteria and weightings to assess/score the options).<sup>45</sup>

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<sup>40</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, October 2014, page 4, <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

<sup>41</sup> 'Safe and Sustainable' – In 2010 Professor Sir Ian Kennedy chaired an independent expert panel which assessed all 11 of the hospitals in England that provide children's heart surgical services as part of the *Safe and Sustainable* review, which was the largest review of a single clinical specialty in the history of the NHS.

<sup>42</sup> Review of the Paediatric Congenital Cardiac Service Belfast Health and Social Care Trust, 2 July, 2012, HSC Board, HSC Public Health Agency, Independent Review Panel led by Sir Ian Kennedy, page 6, <http://www.hscboard.hscni.net/pccs/Paediatric%20Congenital%20Cardiac%20Service%20Review.pdf>

<sup>43</sup> Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland, International Working Group Report, October 2014, pages 9-15, <http://www.dhsspsni.gov.uk/iwg-report141014.pdf>

<sup>44</sup> As above, page 7

<sup>45</sup> Future Commissioning of paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland – Identification of a preferred option, HSC Board, April 2013, pages 4-5, <http://www.hscboard.hscni.net/pccs/PreferredOptionDocument.pdf>

The eight options were - Paediatric Cardiac Surgery and Interventional Cardiology commissioned primarily from: <sup>46</sup>

- (i) Belfast;
- (ii) Dublin (no surgery or interventional cardiology in Belfast);
- (iii) provider(s) in GB (no surgery or interventional cardiology in Belfast);
- (iv) providers in Belfast and Dublin on an all-island basis;
- (v) providers in Dublin and GB (no surgery or interventional cardiology in Belfast);
- (vi) providers in Belfast, Dublin and GB;
- (vii) Belfast with clinical teams from elsewhere in GB or Ireland undertaking the surgery; and
- (viii) 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.

The majority of the PCCS Working Group members identified **Option 2 (Dublin only)** as the preferred option, provided it was delivered within an acceptable timeframe.<sup>47</sup>

However, not all Working Group members agreed with Option 2. In particular, the two Working Group members associated with the Children's Heartbeat Trust concluded (at that time) that they were not able to support an option that removed paediatric cardiac surgery from Belfast. Their minority report was included at Annex 2 of the PCCS report.<sup>48</sup>

In 2013 The Chief Medical Officer (CMO) for NI and the four paediatric cardiologists in Belfast looked at the paediatric cardiac surgery service in NI, focusing on two options only, retention of cardiac surgery in Belfast or an all-Island solution. The logistical difficulties of the first option were acknowledged - the CMO gave the view that on the balance of the evidence, operative caseload was unlikely (even drawing on appropriate areas in the Republic) to gain numbers consistent with good outcomes, therefore the all-island solution was favoured.<sup>49</sup>

<sup>46</sup> Future Commissioning of paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland – Identification of a preferred option, HSC Board, April 2013, page 13, <http://www.hscboard.hscni.net/pccs/PreferredOptionDocument.pdf>.

<sup>47</sup> As above, page 47

<sup>48</sup> As above, pages 66-67

<sup>49</sup> Evidential Base and Clinical Practice Aspects of Congenital Cardiac Services (2013), <http://www.dhsspsni.gov.uk/congenital-cardiac-services.pdf>