

Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland

The International Working Group (IWG) visited Belfast and Dublin from April 7- April 11, 2014 under the terms of the Project Initiation Document¹ with the Terms of Reference outlined on page two of this report. The IWG consisted of Dr. John Mayer, Dr. Adrian Moran, Dr. John Sinclair, and Dr. Patricia Hickey.

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John F Sinclair MB ChB FRCA is a Consultant Paediatric Cardiac Anaesthetist at the Royal Hospital for Sick Children Glasgow where he has practiced since 1992. He was also a paediatric intensivist until 2012 and was in administrative charge of the PICU from 1999 to 2005. He was a member of the multidisciplinary working group which produced the current Paediatric Intensive Care Society, "Standards for the Care of Critically Ill Children". His undergraduate and medical training were at Aberdeen University and his post graduate training was in Glasgow Royal Infirmary and Toronto Sick Children's Hospital. He worked as a Consultant Anaesthetist in Glasgow Royal Infirmary before taking up his post in the Royal Hospital for Sick Children.

Patricia Hickey PhD, MBA, RN, FAAN is vice president of cardiovascular and critical care services and associate CNO at Boston Children's Hospital. She is assistant professor of paediatrics at Harvard Medical School and holds faculty positions at Boston College, Northeastern University in Boston and Jiao Tong University, Shanghai. Dr. Hickey has extensive experience developing paediatric cardiac surgery programs and consulting globally including in Shanghai, Beijing, Guatemala City, Buenos Aires, London, and New Delhi. She is on the executive committee of the International Quality Improvement Forum for Reducing Pediatric Mortality from CHD and received the USA President's gold volunteer service award from President Barack Obama in 2013. The group reviewed several briefing documents specifically generated by the Department of Health (DOH) and the Health Service Executive (HSE) in the Republic of Ireland and by the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland for the IWG.

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The list of all references, including additional information provided that was requested after the site visit, is attached at the end of this document.

In addition, the IWG met with the Ministers of Health of both jurisdictions and their policy teams, the Chief Medical Officers of both jurisdictions, senior hospital management, clinical physicians and nursing leaders, patient transport providers and representatives of patient groups in both jurisdictions. The IWG also attended a number of presentations in both jurisdictions and received printed materials from these presentations. These materials provided population and birth rate data in both jurisdictions and provided recent levels of surgical procedures, interventional and diagnostic catheterisation procedures, outpatient visits, and waiting times in both jurisdictions. The IWG also personally interviewed a number of physician and nursing personnel in both jurisdictions. The IWG reviewed and considered the options, criteria, and weighting methodology used in the report on Future Commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland (April, 2013). This assessment was undertaken under the terms of the Project Initiation Document² with the terms of reference enumerated below as defined by the DOH and the DHSSPS.

Terms of Reference:

- 1) To examine the current and projected need for cardiology and cardiac surgery for congenital heart disease in both jurisdictions and on an all-Island basis
- 2) To describe existing services and provision in both jurisdictions and on an all-Island basis
- 3) To outline the options for service configuration and supporting governance arrangements which will support a model or models of care that meets the population health needs and other requirements of both jurisdictions
- 4) To evaluate and score these models according to explicit criteria as set out below:
 - a. Safety
 - b. Sustainability
 - c. Access
 - d. Medical/Professional training and staffing
 - e. Physical and capital resources
 - f. Relationship to primary, secondary and emergency transport services
 - g. Research collaboration and academic links
- 5) To engage in appropriate consultation with stakeholders including family representatives and patient groups as well as key health professionals\providers and health professionals from related relevant specialties
- 6) To provide to the oversight group set out below interim contact reports and first draft assessment report for quality assurance by the Departments
- 7) To recommend a model based on the foregoing to both Ministers within six months of establishment.

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The Current Position & Rationale for Change.

United Kingdom and Republic of Ireland Context

Congenital cardiac services have been subject to close scrutiny within the British Isles over the last 20 years. Professor Sir Ian Kennedy's inquiry into children's heart surgery in Bristol between 1984 and 1995 reported in 2001 and concluded that paediatric cardiac surgery services at Bristol were "flawed, failed to progress and were simply not up to the task, with shortages of cardiologists, surgeons and nurses, and a lack of leadership, accountability, and teamwork." He subsequently chaired the Safe and Sustainable review of congenital cardiac services, which visited the paediatric cardiac centres in England, and was invited to benchmark the two other UK paediatric cardiac services in Scotland and Northern Ireland, although they were not part of the formal review process. Although this Safe and Sustainable review of congenital cardiac services did not directly consider the Republic of Ireland, the IWG concluded that this review provided important context for the current reviews of the programs in Belfast and Dublin.

It is recognised that the complexity of surgery and interventions for congenital cardiac disease increasingly requires the concentration around the patient of a wide range of expert technical skills and resources. Many professional bodies in the British Isles have now produced standards, with recommendations regarding case numbers, minimal staffing levels and the support services required to provide viable services in the second decade of the 21st century. While the actual number of cases required to ensure a safe and sustainable congenital cardiac service is still being debated, there is a recognition internationally that there is a threshold below which a congenital cardiac service becomes unsafe and unsustainable.

In December 2013 Mr. Edwin Poots, the Minister for Health, Social Services and Public Safety in Northern Ireland, and Dr. James Reilly T.D., Minister for Health in the Republic of Ireland, jointly announced that they had appointed an international team to carry out an independent assessment of current and future needs of cardiology and cardiac surgical services for congenital heart disease on the island of Ireland.

Northern Ireland and the Republic of Ireland Context

Belfast

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 congenital heart disease in NI are between 8 and 10 per thousand live births with approximately half of this number requiring cardiac surgical procedures.

The congenital cardiac surgical service in Belfast is based in the Royal Belfast Hospital for Sick Children. Congenital cardiac surgery is carried out in the adjacent Royal Victoria Hospital, an adult hospital, by a Belfast based cardiac surgeon on a temporary basis, supported by colleagues from Dublin. About 150 -160 children with congenital heart disease are referred per year for cardiac surgery from the Belfast cardiology service, and these cases are currently distributed among 4 institutions, including Belfast Trust, OLCHC (Dublin), Birmingham Children's Hospital, and Evelina Hospital (London).

Five recent reviews of services in NI were shared with the expert team. In 2010 a clinical governance review by Mr David Barron and Mr Asif Hasan (both established UK consultant cardiac surgeons) recommended that Belfast become a Paediatric Cardiology Centre working in close liaison with Dublin as the surgical centre.

In 2012 the Royal College of Surgeons of England service review report, by Mr. David Barron, Dr. Tony Salmon and Ms. Sally Williams found no concerns *per se* regarding the standard of cardiac surgery carried out by the surgeon in Belfast at that time (Mr. Woods). However, they raised concerns around the split-site functioning on the Royal Hospital site, caring for children in an adult ICU, staffing capacity in relation to PICU, and the inability to provide ECLS as a backup, all of which were viewed as no longer acceptable for a congenital cardiac surgery service.

In 2012 Professor Sir Ian Kennedy was invited to undertake a review of the paediatric congenital surgical service in Belfast using a modified version of the 'Safe and Sustainable' review methodology. The outcome of this review included a recommendation that the unsustainable nature of the paediatric congenital cardiac surgical service at the Belfast Trust presents potential safety risks that must be addressed within clearly defined time limits and that the implementation of alternative arrangements which would seek to retain even some paediatric congenital cardiac surgery at the Belfast Trust is high risk.

In 2013 the Health and Social Care Board established a Paediatric Congenital Cardiac Services Working Group to determine a preferred option for services in Belfast. They identified as the preferred option, *option two* (services commissioned primarily from Dublin) of the eight options considered, with the acknowledgement that with this option there would be no congenital cardiac surgery or interventional cardiology in Belfast.

In March 2013 the four paediatric cardiologists in Belfast looked at the future of the overall paediatric cardiac surgery service in Northern Ireland, focusing on two options, retention of cardiac surgery in Belfast and an all-Island solution. Much of this document explores the second option, recognising the logistical difficulties of option 1 and set out a proposed model for the future delivery of paediatric cardiac services with the development of BHSCT into a properly resourced Children's Cardiology Centre.

Workforce and Facilities in Belfast:

All paediatric and adult congenital cardiac services are provided in Belfast at the Royal Victoria Hospital and the adjacent Children's Hospital. The number of births/year in Northern Ireland was reported to be approximately 25,000/year, and the estimated number of new babies with congenital heart disease is estimated to be approximately 200/year (8/1000 live births), although not all have defects that will require surgery or interventional catheterization procedures. The data provided were that in the year April 2012 to March 2013 there were 155 cardiac surgical procedures carried out on patients from Northern Ireland each year, either in Belfast or in referral centers. Of these, 61 surgical cases were carried out in Belfast. Between April 2013 and March 2014, the paediatric cardiac outpatient activity was reported to be 1,113 new patient visits and 2,570 return visits. The adult congenital heart disease service reported that they are currently following a patient population of 4,000, which resulted in 156 new out patient visits and 762 return visits. A total of 44 patients in this population underwent surgical procedures

There are four WTE consultant paediatric cardiologists (1/450,000 population) and three consultant adult cardiologists with an interest in adults with congenital heart disease (1/600,000 population and 1/ 1,000 adult congenital heart disease patients). There is one *locum tenens* cardiac surgeon and one visiting consultant surgeon who comes to Belfast from Dublin two days per month, when there are surgical cases to be done.

The paediatric cardiac surgery cases are carried out at the Royal Victoria Hospital cardiac surgery facility, and the patients remain in the cardiac surgical intensive care unit at least for the first night

after their procedure. The patients are then transported by ambulance to the Children's Hospital for further convalescence in the Clarke Clinic.

Dublin

The Republic of Ireland (RoI) 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 (10). 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 world³.

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. Five recent reviews of paediatric services in the Republic of Ireland were shared with the expert team, although it should be noted that none of these specifically reviewed Congenital Heart Disease in the Republic of Ireland.

In 2008, the HSE commissioned a report, "Right Care, Right Place, Right Time", which was produced by DNV Consortium, with clinical advice provided by Professor Ian Murdoch (Evelina), Dr. Kevin Morris (Birmingham) and Professor Des Bohn (Toronto). Their report looked in detail at the paediatric intensive care services in the Republic of Ireland and made detailed calculations on the number of beds and medical staff required to deliver a robust PICU service for the children of Ireland in the new children's hospital which was planned for 2012.

In May 2012 Professor Ian Murdoch and Dr. Kevin Morris revisited the service, producing a report "Clinical review of Paediatric Critical Care Services"⁴. The 2012 clinical review looked at how far the two PICUs, at OLCHC and Children's University Hospital Temple Street (CUHTS) in Dublin, had come in the four years since the previous report, taking into account the stalled build of the new children's hospital. It made a number of recommendations including: moving to a 5 day cardiac operating schedule, triage of "general" PICU activity towards the CUHTS PICU and delivery of a consultant led transport service which should be integrated within the PICU at OLCHC as an urgent priority. They also recommended the ECLS service should be fully funded, with enhanced roles for nurses and that an ANP (Advanced Nurse Practitioner) programme for PICU and transport should be developed.

In July 2013 a wide-ranging review of paediatric and neonatology services was published in order to underpin the future care of children and young people in Ireland. This report had its origins in the HSE's Clinical Programme for Paediatrics and Neonatology. It identified ten pillars or principles. Pillar four emphasises the need for a consultant delivered paediatric service and the need to expand consultant numbers. Pillar seven was to develop a retrieval service for newborn and paediatric retrieval. For Paediatric retrievals, additional consultant intensivists should be appointed to ensure a robust service model capable of delivering a co-ordinated, responsive and effective service. A partial paediatric retrieval service was initiated in December, 2013 following the appointment of a full-time consultant paediatric intensivist to lead the program.

³ Fyler DC, Prevalence Ch 18, Nadas' Pediatric Cardiology, Hanley & Belfus, Inc. Philadelphia, 1992 pg 273-280

⁴ Index of documents, #7

In February 2014 the College of Anaesthetists of Ireland published “Providing Quality, Safe and Comprehensive anaesthesia services in Ireland – a review of manpower challenges”. Their executive summary included recommendations that the number of anaesthetists should increase to 11/100,000 population (currently 8/100,000) and minimum standards to prevent the erosion in standards that may occur with insufficient manpower.

Consultant recruitment has become problematic following the 2008 contract restrictions. With regard to Paediatric Intensive Care the College quotes “Right Care, Right Place, Right Time” from 2008, saying there should be between 12 and 18 full time paediatric intensivists by 2012 (currently there are 3).

Workforce and Facilities OLCHC.

A new purpose built “state of the art” facility for paediatric cardiac patients, the Children’s Heart Centre, opened in November 2013 with a 25 bedded dedicated inpatient infant and child cardiac unit with support accommodation and services.

PICU

The 23 PICU beds at OLCHC provide intensive care to more than 1000 children from the Republic of Ireland and Northern Ireland per year and the PICU submits data to the UK and Ireland Paediatric Intensive Care Audit Network (PICAnet). Over half of the PICU admissions are related to children with congenital heart disease (51%, 2010-12). The adjusted Standardised Mortality Ratio for 2010 - 2012 was 1.167 which lies within 95% confidence intervals of the mean.

The newly built 17 bedded PICU was opened in 2011 and has 10 PICU and 5 HDU staffed beds and two currently unstaffed beds since 2012. The older cardiac PICU is a stand-alone 8 bedded unit on a separate floor which is limited in space and consistently runs with a very high percentage occupancy, 89% occupancy in 2011 and 90% occupancy in 2012; overall PICU occupancy rates across all 23 beds was 86% in 2013.

Consultant staffing

There are 2 whole time equivalent (WTE) PICU consultants supported by 10.78 WTE anaesthetic consultants who also cover 7 operating theatres (one of which is a dedicated cardiac theatre), 2.5 cardiac catheterisation sessions per week, MRI, CT scan, acute pain service and weekday off site radiotherapy sessions. The consultants run two separate out of hours rotas to cover PICU and Theatres. Currently there is no separate cardiac anaesthetic or transport on call rota.

The IWG also noted that the current number of consultant staff in paediatric cardiology at OLCHC (5) was providing consultant services at OLCHC and was also providing outreach services for patients in clinics outside of Dublin. At OLCHC these consultants provided 1,628 new patient visits and 3,458 return visits in 2013. The current waiting list is reported at 2,682 patients. In addition, these consultants interpreted approximately 125 transoesophageal echocardiograms, 14,144 transthoracic echocardiograms, 9,426 EKGs and 171 cardiac MRI studies. The number of consultant paediatric cardiologists was significantly below (<50%) the level of other congenital heart disease institutions in the UK by several measures, including indexing by number of congenital heart disease hospital discharges or by numbers of cardiac surgical procedures performed.

The IWG also reviewed the Paediatric Cardiology section of the Census of Consultant Physicians in the UK 2012 document and noted that there was a recommendation by the British Congenital Cardiac Association of one paediatric cardiologist per 500,000 population (51). Given the 30-35% higher fertility rate in the Republic of Ireland compared to the UK and to the European Union and given the relatively constant incidence of congenital heart disease per 1,000 live births, the ratio of paediatric cardiologists per total population should be as much as 30% higher than the British

Congenital Cardiac Association recommendation of one paediatric cardiologist per 500,000 population.

The current cardiology consultant to population ratio for the Republic of Ireland is one per 900,000 population, although the IWG was informed that two additional consultants are scheduled to start work in 2014, which would bring the ratio to slightly greater than one paediatric cardiologist per 657,000 population. In addition, the consultant cardiology staffing levels for adults with congenital heart disease in the Republic of Ireland was reported to be one consultant paediatric cardiologist for the entire population of adults with congenital heart disease. This staffing level was also well below that in Northern Ireland (1/1,000 adult congenital heart disease patients). The IWG was informed that the Republic of Ireland has no national strategy or policy for adults with congenital heart disease⁵The IWG noted that there were no paediatric cardiology electrophysiology specialists (heart rhythm disorders specialists) in either jurisdiction, and that there will be an increasing need for this specialty, particularly as the adult congenital population increases. By way of reference, the IWG noted that in the US there are more adult aged patients who were born with congenital heart disease than there are children under 18 years.

New Children's Hospital in Dublin:

The IWG was informed that a unified Children's Hospital Group Board was established in August 2013, and that plans were underway to consolidate the three children's hospitals in Dublin into a single new 469 bed facility. The IWG was further informed that capital funding had been allocated for this new facility, but that there has been some controversy over the selection of a site for this facility resulting in one change in site having occurred. The time frame for this new facility was presented as 2018.

Current Clinical Outcomes in Belfast and Dublin:

Surgical outcome data from both Belfast and Dublin were provided to the IWG. The outcomes in Belfast that were achieved occurred under the arrangements of a two-person surgical team, comprised of a senior surgeon who carried out procedures and provided supervision and operative assistance to the Belfast *locum tenens* surgeon. This arrangement has resulted in selection of relatively low-risk surgical procedures, and the VLAD chart that was supplied indicated that the expected-to-actual mortality rate was >0, indicating a lower than expected mortality rate. Similar data was provided from OLCHC. The overall complexity of the patients undergoing surgery for congenital heart disease at OLCHC was considerably greater compared to the patients undergoing surgery in Belfast. Over the 10 months from February, 2013 through December, 2013, the VLAD chart supplied showed that the expected-actual mortality rate varied from -2 to 0 for the first 5 months and rose to +4 for the last 6 months of 2013. The overall survival rate at OLCHC was 97.8% with an expected survival of 97.7%. These mortality rates are in line with international norms for paediatric cardiac surgery.

Rationale for Change

In accordance with terms of reference #1 and #7, the IWG proposal is to develop an all Island congenital cardiac service, an "international" service between the UK (NI) and the Republic of Ireland. With a combined population base of 6.4 million with 1.3 million children and 400-500 paediatric congenital cardiac surgical cases per year in the combined jurisdictions, this service reaches service volume thresholds that are sustainable and capable of meeting international standards.

As evidenced by recent reviews neither centre is currently delivering a service which meets current international standards of both institutional case volume and consultant staffing: the service in

⁵ Index of documents, #4

Northern Ireland does not meet the case volume threshold 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 centers. By working together as a single all island networked service, a combined service would have the critical mass required to command facilities and attract staffing and requisite support resources.

The IWG perception was that there is a real willingness at a political level, at a clinical level, at a policy and management level, and at a parental level to make an all Island solution work. The construction of a new children’s hospital in Dublin is occurring at a serendipitous time. Investment from both sides of the border in the congenital cardiac services at the new children’s hospital in Dublin will mean that all the children with congenital heart disease on the island of Ireland will benefit. The improved paediatric and neonatal transport and telemedicine infrastructure within the proposed cardiac clinical managed network with Belfast will have positive knock-on effects for children throughout both jurisdictions in Ireland. The IWG envisions several ways in which improvements in paediatric cardiac services could occur in both jurisdictions. Prior experience in other countries indicates that the concentration of surgical and interventional paediatric congenital cardiac cases will almost certainly be associated with improved clinical outcomes for these patients. Other examples include the following: Improved quality and more rapid remote interpretation of echocardiograms carried out in areas of Ireland outside Dublin using the already developed telemedicine infrastructure in Belfast; Use of the well-developed Northern Ireland neonatal and paediatric transport service for patient in northwestern Ireland (e.g Donegal); Improved training of cardiac ultrasonographers for deployment outside the centers in Belfast and Dublin utilizing the established training program for ultrasonographers in Belfast; Improved ability to recruit and retain paediatric and adult congenital heart disease specialists by creating centers with a critical mass of patients to promote the development of greater expertise.

Recommendations

The IWG considered the program for the care of patients with congenital heart disease from the perspective that the clinical and physical resources of the two jurisdictions were to be considered as one pool of resources and should be considered a “network” solution for patients with congenital heart disease in both jurisdictions. Our recommendations build on the strengths of the paediatric cardiac services in each jurisdiction while recognising and attempting to improve on their respective weaknesses.

Our recommendations are to be considered as a whole. We believe that these recommendations are interdependent, requiring changes in practice in both Belfast and Dublin. They cannot be easily separated without threatening the viability of an all-Island solution based on the formation of an all-Island network of congenital heart disease providers and institutions. The major recommendations are first summarised in outline form, and the rationale for each of the recommendations is subsequently explained.

Summary of recommendations:

1. Establish an all-Island governance committee (GC) to:
 - 1) oversee the operations of the personnel, facilities, and institutions involved in the care of patients of all ages with congenital heart disease, and
 - 2) 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 congenital heart disease, with terms of reference agreed by the respective health authorities in Northern Ireland and the Republic of Ireland. The Governance Committee should meet on at least a monthly basis to address all operational and policy issues. The IWG suggests two alternatives for the chairmanship

role for this group. One alternative is to have the chair position rotate between the two jurisdictions on an annual or bi-annual basis. A second alternative is to have the two jurisdictions jointly appoint an independent chair, although the identification of the characteristics of an “independent” chair are unclear.

a. Recommended members are as follows:

1. Patient representative (Ms. Sarah Quinlan)
2. Dr. Frank Casey (consultant paediatric cardiologist Belfast HSCT)
3. Dr. Paul Oslizlok (consultant paediatric cardiologist, OLCHC)
4. Dr. Christopher Lockhart (Consultant Adult Congenital Heart Disease Cardiology, Belfast HSCT)
5. Mr. Lars Nolke or Prof. Mark Redmond (Consultant Cardiothoracic Surgeons, OLCHC)
6. Dr. Brendan O’Hare (Consultant Anaesthetist, OLCHC)
7. Ms. Geraldine Regan (Director of Nursing, OLCHC) or Ms. Rachel Kenna (Deputy Director of Nursing OLCHC)
8. Clinical Nurse specialist from Belfast HSC (Heather Jackson)
9. Advanced Practice Nurse specialist from OLCHC
10. Dr. Michael McBride, Chief Medical Officer, Northern Ireland
11. Dr. Tony Holohan, Chief Medical Officer, Republic of Ireland
12. Dean Sullivan Director of Commissioning Health and Social Care Board
13. Mrs. Eilish Hardiman, CEO Children’s Hospital Group

b. Scope of authority of the Governance Committee: To effectively influence or control the deployment of capital and personnel resources for the management of patients with congenital heart disease in both jurisdictions. At a minimum, the Governance Committee should review all expenditures and savings of resources from the “all-island” solution.

2. Establish a Family Advisory Group with representation from both jurisdictions that will meet at least quarterly that will include clinical nurse specialists and other family support staff to provide direct input for the Governance Committee.

3. Require establishment of a central all Ireland database in which all congenital heart disease patients are entered with provision for entry of procedural outcomes, follow-up data, and resource utilization. As much of this data is currently being collected for reporting to NICOR, the major task will be to consolidate this information for the Governance Committee and other interested parties to review.

4. Enable and facilitate the flow of nursing and physician personnel between the two jurisdictions where shortages exist and deploy consultant staff across jurisdictions for situations where the services provided do not require extended periods of care for a given episode or visit.

5. Expand and update the paediatric cardiac ICU capacity in Dublin to at least 10 fully staffed beds. The IWG noted that during one earlier time, the HDU beds for the paediatric ICU had been moved to a different location allowing the cardiac patients to be housed in the new PICU facility. If a similar reassignment cannot occur to accommodate the cardiac patients in the same space as the rest of the PICU, then the IWG recommends proceeding with plans to build a new cardiac PICU adjacent to and on the same level as the newly built PICU or adjacent to the new cardiac ward and catheterization laboratory at OLCHC without delay.

6. Expand and upgrade telemedicine links between the Republic of Ireland and the Belfast Trust paediatric cardiology facilities and provide ongoing information technology support. The IWG recommends that specific IT personnel be budgeted and earmarked for this effort.

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 and on surgical situations resulting from adult congenital cardiology interventional procedures.

8. Provide enhanced patient and family services in Dublin for all patients and families who do not reside in the Dublin metropolitan area, including assistance with travel, lodgings, meals and other considerations of a practical nature. Information packs (hard copy and/or web-based/Apps should be available for patients and families, particularly those from outside the Dublin metropolitan area, with Family Liaison Coordinators to provide assistance on non-clinical matters in both jurisdictions.

9. Integrate the activities of Clinical Nurse Specialists (CNS) and advanced practice nurses (APN) in Belfast and Dublin to provide patient and 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 (clinical and EMT support groups) in the two jurisdictions to facilitate safe transfers between outlying areas and the centers in Belfast and Dublin, and transfers between the centers.

11. Continue to upgrade the paediatric transport services in the Republic of Ireland and consider building on the expert inpatient ECLS services existing in Dublin to form a mobile ECLS service.

12. Continue with and expand weekly case conferences for patients requiring congenital heart surgery or interventional catheterisations at OLCHC, incorporating cardiologists and adult congenital cardiologists and surgeons from Belfast Trust either in person or by teleconference. Ensure that telemedicine links between Belfast Trust and OLCHC are robust and support simultaneous high-fidelity viewing of all diagnostic images in both locations and free communication among participants in both locations. The focus of the conference should be on surgical cases scheduled for the next week, but this short-term case management conference should also include contingency planning both for elective case cancellations due to intercurrent illness (reserve list) and for expected deliveries of patients with prenatal diagnoses of critical congenital heart defects.

13. Extend the current OLCHC monthly MDT mortality and morbidity conference in which all interventional catheterisation and surgical cases with complications are reviewed to include cardiologists, cardiothoracic surgeons, intensivists and anaesthetists from both jurisdictions. This conference should also include safety event reviews, including “near misses” and other system related problems.

14. Mandate an annual “all-Island” symposium on congenital heart disease management, including an assessment of results of the current service arrangements. This annual review and consequent annual report of congenital heart disease management throughout both jurisdictions should be reported to the Governance Committee and serve as the basis for data-driven benchmarking against other international services and future planning for personnel and physical plant resources.

Options considered:

The IWG considered four options. Option 1 represents the all-Island solution as outlined in the recommendations of the IWG. Option 2 represents the continuation of the current delivery system, with surgical consultants from Dublin providing assistance in Belfast and with selective referral of certain types of cases from Belfast to UK centers. Option 3 is an expansion of current links with centers in the UK with discontinuation of the service level agreements with Dublin. Option 4 is to expand the case volume and complexity of services in Belfast by multiple mechanisms, including recruitment of patients from outside Ireland. These options were adapted from those previously considered by the Northern Ireland working group, and they represent what the IWG judged to be the most feasible of the eight options that this group had previously considered.

Option	Safety	Sustainability	Access	Medical Professional Training and Staffing	Physical and Capital Resources	Relationship to Transport Services	Research collaboration and academic links	Total possible score
Weight	100	97.5	95	83.75	65	57.5	63.75	4500
Scores 0,1, or 2								
1-All Island proposal	1,2,2,2	2,2,2,2	2,2,1,1	1,2,1,2	1,1,2,1	1,1,2,2	1,2,2,2	
	700	780	570	502.5	325	345	446.25	3668.75
2-Maintain current Belfast Dublin SLA and Belfast UK SLA	0,0,0,0	0,0,0,0	2,1,2,1	1,1,1,1	1,1,1,1	2,1,2,2	0,1,1,1	
	0	0	570	335	260	402.5	191.25	1758.75
3-Expand Belfast relationships with UK centers	1,1,1,1	2,2,2,1	1,1,1,0	1,1,1,2	1,1,1,1	1,2,1,1	2,1,1,1	
	400	682.5	285	418.75	260	287.5	318.75	2652.5
4-Expand Belfast volume and capacity	0,0,0,1	0,0,1,0	2,1,2,1	1,1,0,1	1,0,2,0	1,2,2,2	1,1,1,0	
	100	97.5	570	251.25	195	402.5	191.25	1807.5

Explanation of table: As outlined in the terms of reference and based on the scoring system previously used in consideration of options by the Northern Ireland working group entitled “Future commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland,” the IWG considered each of the eight options and judged that only four of these options warranted further consideration. The seven criteria by which each of the options were judged were outlined in the Terms of Reference for the IWG. Each of the four members of the IWG independently provided weights for each of the 7 criteria, and the average of these 4 individuals’ weightings is listed in the row labelled “weight.” Each member of the IWG then gave a score of 0, 1, or 2 for each of the criteria. The average of the four scores were then multiplied by the average of the weightings for each criterion. The products of the average weightings and the average scores were then added together to yield a total score for each option.

Rationale:

Introduction:

The IWG undertook this review with the understanding that its charge was to examine the current and projected need for cardiology and cardiac surgery for congenital heart disease in both jurisdictions and on an all-Island basis and to develop a model or models of care that meet the population health needs and other requirements of both jurisdictions. Four options as outlined in the above table were considered.

The IWG concluded that in the existing two separate paediatric cardiac delivery systems there were significant strengths and weaknesses, but that these individual jurisdiction strengths and weaknesses were, for the most part, complementary and non-overlapping. Neither system meets all

of the needs of the congenital heart disease patient population in its own jurisdiction. As a result, the strengths in one jurisdiction have the potential for addressing weaknesses in the other jurisdiction. Therefore, an “all Island” approach offers the potential for a combined approach to result in higher quality and greater cost effectiveness than either jurisdiction would be able to achieve acting alone. This option received the highest score among the four options considered by the IWG.

Service arrangements other than the “all Island” solution were judged to be less acceptable because of a reduced ability to provide timely and safe patient access, to be sustainable and cost effective, and to address several of the non-medical needs of patients and their families that were described to the IWG by the patient groups. The proposed model will require some capital investments in both jurisdictions and will depend on the willingness of medical and nursing personnel to continue to make service to patients’ needs their primary priority, with support by the political, policy and managerial structures of both jurisdictions. Investment in both physical plant, particularly a new Cardiac Intensive Care Unit at OLCCH with increased capacity, and in establishing high capacity and high fidelity data links across both jurisdictions will be necessary, and collaboration, including cross jurisdictional provision of certain medical services, will be required. The assessment of the IWG was that there was a willingness and commitment to this priority of improving the care provided to this congenital heart disease patient population that was shared by all at both the leadership and provider levels that we encountered.

Recommendation 1:

Establish an all-Island governance committee (GC) to:

- 1) oversee the operations of the personnel, facilities, and institutions involved in the care of patients of all ages with congenital heart disease and
- 2) 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 congenital heart disease, with terms of reference agreed by the respective health authorities in Northern Ireland and the Republic of Ireland. The Governance Committee should meet on at least a monthly basis to address all operational and policy issues.

The IWG believes that the creation of this GC with the shared responsibility and accountability for ensuring the successful operation of the congenital heart disease services in both jurisdictions is an essential element of an all-Island approach to the provision of these services. We envision that this GC will initially act as the driver to steer the service towards an integrated all-island solution. It will identify and solve problems that will inevitably arise ensuring that an all-island approach is implemented.

It will be essential that this GC have some authority over a pool of resources contributed by both jurisdictions, as determined by the Terms of Reference to be agreed by both jurisdictions, in order to act in the best interests of this congenital heart disease patient population. The ability to be able to direct resources will be essential to both bind the Governance Committee together with a common purpose and to provide the GC with the ability to have more than an advisory role in their interactions with related entities in both jurisdictions.

The IWG reviewed the Framework Document for an All Island Clinical Network. In this document, the network is given a number of responsibilities for meeting standards and targets and maintaining a quality assurance programme, but there is no mention of mechanisms to acquire or manage the deployment of resources to fulfil these responsibilities. The IWG recognizes that there are a variety of institutional and governmental responsibilities that the Ministries of Health and the involved healthcare institutions bear, and that the proposed clinical network must function within existing organizational structures and constraints. While the concept of a clinical network contains several

elements embodied in our recommendation for an all Island Governance Committee for congenital heart disease services, the IWG strongly recommends that in order to maintain a core sense of purpose and a focus, this governance committee must have the operational mechanisms to address resource needs and allocations of resources. The IWG considered several approaches to provide this level of “ownership” by the Governance Committee for the services to patients with congenital heart disease, and the IWG suggests that these are not mutually exclusive.

1. Create an annual budget supported by both jurisdictions for these combined services including both supply and personnel costs and capital expenditures. Make a commitment that resources that are not expended can be “rolled over” into the following fiscal year and re-deployed by the Governance Committee.
2. Designate a subgroup of the Governance Committee to serve as the representatives to any and all bodies that will make resource allocation decisions that affect the functions of the Congenital Heart Disease Clinical Network.)
3. Develop a methodology to measure the resources utilized in the care of patients with congenital heart disease throughout both jurisdictions.

The meeting site will be up to the GC, but the IWG recommends that the meetings be alternately scheduled in Dublin and Belfast or at a site midway between the two clinical sites. The suggested composition of the GC is an attempt to provide balance between the two jurisdictions and to ensure that other interested parties also have a role in the operations of services for congenital heart disease. It will be essential that one of the charges of this GC will be to review outcomes of all congenital heart disease services in both jurisdictions. None of the other alternatives that the IWG considered would establish an organisational structure that would have accountability for the care of this patient population and would have any ability to direct resource allocation to improve their care.

Recommendation 2:

Establish a Family Advisory Group with representation from both jurisdictions that will meet at least quarterly that will include clinical nurse specialists and other family support staff to provide direct input for the Governance Committee. The IWG believes that the formation of such a group will be an essential feature of an all Island approach as it will give an on-going voice to the patients and families with congenital heart disease and will serve to provide early warning of problems with how the system is functioning. The Advisory Group can also serve as an important focus for philanthropy to provide support for families and for some capital investments. The Family Advisory Group can also serve as important advocates and spokespersons for the all-Island congenital heart disease network. This group can use a variety of mechanisms, including multidisciplinary case conferences and opportunities for patient advocacy groups to discuss issues that have arisen, particularly when care of patients results in significant geographic or psychosocial dislocations for families.

Recommendation 3:

Require establishment of a central all Ireland database in which all congenital heart disease patients are entered with provision for entry of procedural outcomes, follow-up data, and resource utilization.

The IWG believes that reliable data, when carefully collected and analysed, will be the strongest driver for improvement and change in the care of congenital heart disease patients. Therefore, the IWG strongly recommends that a central database be established to include all congenital heart

disease patients, including both paediatric and adult patients, from both jurisdictions with provision for entry of procedural outcomes, longitudinal follow-up data, and resource utilisation. The benefits of an all-island database, as described, would enable proper long-term follow-up on long term outcomes, would facilitate service planning, audit and evaluation, and provide capacity for research and knowledge improvement. The experience of some members of the IWG with similar databases is that it is the collection and feedback of outcomes data, both clinical and resource utilization, that is necessary to drive innovation and improvement. The existing data collection for NICOR reporting, and hospital administrative reporting systems, such as HIPE and HIS, will serve as the base dataset, but the IWG recommends that additional data, particularly on resource utilization be added. This database will also serve to provide data on the numbers and types of patients that will become adults with congenital heart disease and thereby allow planning for resources that this patient population may require in the future. This dataset will be jointly owned and maintained by the Governance Committee, and it will be a critical source of information to direct the decisions of the GC. The IWG recommends that expert data analytical personnel be dedicated to assist and advise the GC on the interpretation of the clinical outcomes and resource utilization data.

Recommendation 4:

Enable and facilitate the flow of personnel between the two jurisdictions in the following areas where shortages exist but where services provided do not require extended periods of care for a given episode or visit. Three examples envisioned by the IWG include: 1) Provision of anaesthetic services for patients undergoing congenital heart operations or catheterizations in Dublin in order to increase the case capacity at OLCHC and 2) Provision of intraoperative transoesophageal echocardiography support for patients undergoing surgery at OLCHC, since intraoperative TOE (TEE) is becoming the standard for patients undergoing congenital heart surgery. Provision of each of these services is limited to the time that the patients are in the operating room. 3) Staffing of adult congenital heart disease clinics in the Republic of Ireland by cardiologists from the Belfast Trust. The IWG anticipates that other similar opportunities will be identified by the Governance Committee. As outlined in more detail in the context section of this document, the assessment of the IWG is that there are significant shortages in the number of consultant paediatric cardiologists, paediatric anaesthetists, and paediatric intensivists at OLCHC, and a similar shortage of adult congenital cardiologists also appears to exist in the Republic of Ireland. In each of these types of services, the duration of the service is generally limited to the day of service.

On examination of the workforce data from a number of perspectives, the IWG made the general observation that the number of paediatric cardiologists, paediatric anaesthetists and paediatric intensivists in the Republic of Ireland is far below that of comparable International centers. For example, based on a comparison with staffing levels for UK congenital heart disease centers based on the number of congenital heart operations, the Republic of Ireland should have 12 paediatric cardiologists for the volume of patients they are managing as opposed to the current 5. The paediatric and adult congenital cardiology staffing in Northern Ireland seemed to be more appropriate for the existing workload. By the criteria of the British Congenital Cardiac Association of one consultant paediatric cardiologist per 500,000 population, the Republic of Ireland should have nine consultant paediatric cardiologists. The shortfall in adult congenital heart disease cardiologists in the R of I seems to the IWG to be even greater.

The IWG specifically proposes that the following inter-jurisdictional personnel-sharing activities be implemented as part of the “all Island” approach for the management of patients with congenital heart disease:

- a. One of the two cardiac anaesthetists who currently provide anaesthesia for paediatric cardiac cases in Belfast should provide anaesthesia for paediatric cardiac cases one or more days/week at OLCHC. By doing so, expanded cardiac theatre usage at OLCHC will be facilitated, and expertise and familiarity with the anaesthetic considerations in patients with congenital heart diseases will be

maintained. This familiarity and comfort with the anaesthetic management of patients with congenital heart disease will be advantageous to allow these patients to be cared for in Belfast when non-cardiac procedures are required. The Manion report (8) observed that there has been chronic understaffing at a consultant level of paediatric anaesthetists and paediatric intensivists in Dublin. Utilisation of cardiac anaesthetists from the Belfast Trust will serve to address some of this shortage of staff. Conservatively, there is a shortfall of at least 5 anaesthetists and 6 intensivists at OLCHC which are necessary to allow development of separate cardiac surgical and transport emergency cover. The IWG has considered the concern that the paediatric anaesthetists in NI have other responsibilities in the Belfast Trust, but the IWG notes that these paediatric anaesthetists are currently providing services for the paediatric patients who are undergoing cardiac surgery in Belfast. The IWG envisions that their services will simply be delivered in Dublin with the advantage that their case experience will be enhanced by exposure to a more complex spectrum of cases, which will then enhance their ability to provide anaesthetic care for non-cardiac procedures when cardiac patients require such non-cardiac procedures in Belfast.

b. Adult congenital heart disease consultants from Belfast should hold clinics in Dublin at the Mater Misericordiae Hospital and in other currently un-served areas of the Republic of Ireland to provide more opportunities for Republic of Ireland patients to be seen in a more timely fashion and to thereby shorten waiting times. The IWG was informed that funds are already committed in Dublin for a consultant adult congenital cardiologist, but that the position is unfilled. Utilisation of the three adult congenital heart disease consultants from the Belfast Trust will help to address this personnel shortfall. In addition, the Governance Committee should consider directing the care of adults with congenital heart disease from Donegal and one or more additional northwestern counties to receive their care in Belfast or in outreach clinics staffed by adult congenital heart disease consultants from Belfast. The IWG recommends that at least one consultant with specialized training in electrophysiology should be added to the group of consultants providing both paediatric and adult congenital cardiac care.

c. Paediatric cardiologists from Belfast should work with OLCHC staff to provide intraoperative transoesophageal echocardiography services at OLCHC one or more days/week. The IWG was informed that intraoperative transoesophageal echocardiography was not routinely available at OLCHC, and the paediatric cardiologists from the Belfast Trust could help to provide this service, which has become a standard of care in the intraoperative management of patients undergoing congenital heart surgery in most US and UK centers.

d. Paediatric cardiac surgeons from OLCHC should hold bimonthly clinics in Belfast to see pre-operative patients, post-operative follow-up patients, and to provide backup support for adult congenital heart surgery cases and complex adult congenital interventional catheterisation procedures.

e. One designated paediatric cardiologist from Belfast should participate in cardiac catheterisation procedures at OLCHC with an on-site paediatric cardiologist.

The IWG noted that the opportunity to participate in cardiac catheterisation procedures was an important element in the retention of current paediatric cardiology staff at the Belfast Trust and that paediatric cardiologists in Belfast currently participate in the cardiac catheterisation procedures in Belfast with the adult congenital heart disease cardiologists at Belfast Trust. The increased opportunities for catheterisation experience for the Belfast Trust paediatric cardiologists will thus be important for professional satisfaction and for maintaining the level of catheterisation care in Belfast for adults with congenital heart disease.

f. The current Paediatric cardiology trainees in the Belfast Trust should have regularly scheduled rotations at both OLCHC and Belfast to take advantage of the training opportunities in both facilities. The IWG observed that the paediatric training program at Belfast Trust has a long and successful history and that the program would be improved by having its trainees exposed to an increased in-patient clinical caseload that would be experienced at OLCHC.

g. The IWG recognizes that these recommendations will require the approval of the professional regulatory bodies and of the institutional sponsors of these trainees, and that issues related to human resources, registration, and insurance must be addressed. The IWG is confident that any administrative issues can be overcome if there is commitment at the Ministries of Health and at the level of professional bodies to do so.

Recommendation 5:

Expand and update the paediatric cardiac ICU capacity in Dublin to at least 10 fully staffed beds. Proceed with plans to build a new cardiac PICU adjacent to and on the same level as the newly built ICU or adjacent to the new cardiac ward and catheterization laboratory at OLCHC without delay.

The IWG opinion is that the existing facilities for cardiac ICU patients at OLCHC cannot supply optimum support to the existing patient population from the Republic of Ireland. The IWG was informed that within the last year over 30 elective cardiac surgical cases were cancelled due to non-availability of cardiac ICU care at OLCHC, although it is acknowledged that this is not solely a capacity issue and that, as with all acute units, beds may become unavailable for a variety of reasons. Upgrading of the cardiac PICU cannot wait until the proposed new children's hospital in Dublin is built. Reconfiguration of current cardiac PICU and main PICU facilities adjacent to the newly built ICU facility at OLCHC or at another location in close proximity to the new cardiac in-patient unit and catheterization laboratory should be implemented without delay. The IWG noted in a prior report by Murdoch and Morris in 2012,⁶ that during temporary closure of the existing cardiac ICU at OLCHC, it had been possible to move the patients requiring HDU services to another location with cohorting of all ICU level care in the newly built facility. Use of a similar strategy could reduce the need to build an entirely new Cardiac ICU, but there must be a minimum of 10 dedicated cardiac ICU beds to accommodate the anticipated patient volume. Movement of all paediatric cases from Northern Ireland to OLCHC will place additional strain on the facilities and staff at OLCHC, and the alternative of rapid implementation of the existing plans to build a new paediatric cardiac ICU facility adjacent to the existing ICU facility at OLCHC with appropriate nursing and consultant staffing would be another (preferred) plan. It will be essential to increase the cardiac ICU capacity to accommodate the increased number of patients to be cared for from Northern Ireland. The IWG was impressed at the ability of the OLCHC administration to combine private and public resources to address facility shortcomings in the cardiac program and for the general intensive care unit.

Recommendation 6:

Expand and upgrade telemedicine links between the Republic of Ireland and the Belfast Trust paediatric cardiology facilities and provide ongoing information technology support for transfer of imaging and other data across jurisdictions. The IWG recommends that specific IT personnel be budgeted and earmarked for this effort.

The assessment of the IWG is that the infrastructure to support remote acquisition of echocardiographic and radiographic images exists in Northern Ireland, and that there is interest among the Belfast Trust paediatric cardiologists to expand the number of images being read remotely, particularly foetal echocardiograms. The IWG was less certain about the data transfer capabilities in the Republic of Ireland, but given the shortage of paediatric cardiologists in the Republic of Ireland, the IWG assessment was that the provision of remote echocardiography interpretation services, including foetal echocardiography, would be of significant benefit to Republic of Ireland patients. In addition, the current Belfast Trust training program for echocardiography technicians should be extended to comparable personnel from the Republic of Ireland.

The upgrade of telemedicine links is essential to allow the following:

a. to allow echocardiograms carried out in areas outside both Dublin and Belfast to be promptly read and interpreted (reference laboratory model) - this may provide a basis for expanding services to other areas of the UK. Given current staffing and case workload, this service should be provided in Belfast.

⁶ Index of Documentation, #7

b. to enhance the ability of paediatric cardiologists in Belfast to continue to serve as a research center. The Governance Committee should consider how the experience and expertise of the existing research center in Belfast can be leveraged to improve all paediatric cardiac clinical research on the Island of Ireland.

c. to enhance the ability of paediatric cardiologists in both jurisdictions to interact on a weekly basis and to participate in the decision-making for patients with congenital heart disease in both jurisdictions.

Recommendation 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 and on surgical situations resulting from adult congenital cardiology interventional procedures.

The IWG carefully considered the previous reports on Future Commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland (31)(April, 2013), the Proposed Model for Future Delivery of Paediatric Cardiac Services (6) (March, 2013), the Review of the Paediatric Congenital Cardiac Service, Belfast Health and Social Care Trust-(42) July 2012 (Ian Kennedy Report). The IWG also reviewed the current case volumes, viewed the facilities, and interviewed the surgical team at the Belfast 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 and with the resulting impact on the capacity for improvement. In regard to the current surgical program in Belfast, the IWG concluded that the current system of paediatric cardiac surgery in one facility (Royal Victoria Hospital) with transfer of patients to the Children’s Hospital on the first or second postoperative day was inherently unsafe and clearly not sustainable.

As a result of the limited caseload in Belfast, the current *locum tenens* surgeon at Belfast Trust has not had the opportunity to acquire the skills and experience necessary for independent sole practice for neonatal or complex paediatric or complex adult congenital cases. Given the population and birth rate in Northern Ireland, the prospects for rapid acquisition of the necessary experience and expertise are low. The reported difficulties in attracting a consultant level paediatric cardiac surgeon to Belfast are evidence that the current and projected case volumes will be unlikely to support such a recruitment.

The strengths of the program at the Belfast Trust lie in the large volume of “adult” cardiac surgery for acquired heart disease and the associated experience with this population. In addition, many of the cardiac surgery cases for adults with congenital heart disease are at the less complex end of the spectrum (with the exception of patients with single ventricle heart defects), and these cases should be able to be safely cared for by the existing adult cardiac surgical staff and *locum tenens* surgeon. The IWG recommends careful attention to case selection for adult congenital heart disease patients to be scheduled for either interventional catheterization or surgery in Belfast.

The IWG also carefully considered the issue of “emergency care” for congenital heart disease patients in Northern Ireland. The IWG noted that all of these cases are currently transferred away from the Belfast Trust for surgical care. In particular, the IWG considered the impact of the discontinuation of the paediatric cardiac surgical services at the Belfast Trust on the provision of paediatric cardiac catheterisation services and the ability to provide balloon atrial septostomy for patients with D-transposition of the great arteries with intact ventricular septum. According to the data provided to the IWG, there are approximately 25,000 live births per year in Northern Ireland. The incidence of all patients with D-transposition of the great arteries (including those with ventricular septal defect) is approximately 2-4 per 10,000 live births, and therefore 5-10 children will be born each year in Northern Ireland with D-transposition. Of these about 2/3 will have an intact ventricular septum so that there will be 3-7 D-TGA/IVS patients born who could potentially need a balloon atrial septostomy, but only 2-4% will have a highly restrictive ASD or an intact atrial septum and need an emergent balloon atrial septostomy⁷. Based on these data, the IWG estimates that in Northern Ireland, a single newborn with D-TGA/IVS in NI would be in need of an urgent/emergent balloon atrial septostomy once every 3.5-10 years. This incidence could be further reduced with prenatal diagnosis and delivery of the newborn in Dublin (50% of D-TGA patients are correctly identified prenatally in France at the current time), the need for an urgent balloon septostomy would be reduced to less than one case every 10 years. Should either jurisdiction alone or in partnership with the other create the capacity for remote institution of ECLS and transport on ECLS (a mobile ECLS service) as part of the upgrade of its paediatric transport services (as is currently underway in the Republic of Ireland), the risk for this subset of neonates with TGA/IVS and a highly restrictive ASD could be further reduced. This mobile ECLS service would also be available for non-cardiac neonates with disorders such as meconium aspiration, diaphragmatic hernia, and other forms of neonatal respiratory distress. Given the small number of infants likely to require these ECLS services outside of the congenital heart surgery center, based on the data regarding transposition patients outlined above, and the resources required to develop such a mobile ECLS transport capacity, the IWG recommends that these resources be utilized in other areas of congenital heart disease management to enhance the existing physical and personnel resources for managing the more common forms of congenital heart disease.

The IWG also considered the Safe and Sustainable standards that have been proposed by the NHS in London, particularly in regard to the issue of the requirement for adult catheterisation congenital services to be provided in or adjacent to facilities where there are paediatric cardiac surgical and paediatric cardiac catheterisation procedures being done. The Belfast adult congenital cardiology group advocated a “network” solution that would allow catheterisation and adult congenital heart surgery to continue in Belfast. The IWG’s proposed all-Island solution will help to establish such a network, by supporting the current consultant staffing that exists in the Republic of Ireland. The existing relationships between the Belfast Adult Congenital cardiology group and UK centres could be maintained as well, but the IWG envisions that over time, the need for these relationships will be reduced as the experience and expertise of the all-Island combined adult congenital heart disease service increases.

The IWG recommendation that the congenital heart disease management in Belfast be re-focused on adults with congenital heart disease requires that both recommendations 4d and 4e are implemented. First, the participation of the Belfast paediatric cardiologists in catheterisations at OLCHC will serve to maintain some level of expertise that would be applied to adults with congenital heart disease undergoing catheterisations in Belfast. Second, there would be surgical availability for backup on at least two days per month when one of the paediatric cardiac surgeons from Dublin will

⁷ Index of Documentation, #50

be in Belfast for clinics. In addition, the anticipated complications that might arise from the majority of the adult congenital interventional catheterisation cases can be safely supported by the existing cardiac surgical services in the Belfast Trust Royal Victoria Hospital in Belfast.

Recommendation 8:

Provide enhanced patient and family services in Dublin for all patients and families who do not reside in the Dublin metropolitan area, including assistance with travel, lodgings, meals and other considerations of a practical nature. Information packs (hard copy and/or web-based/Apps) should be available for patients and families, particularly those from outside the Dublin metropolitan area, with Family Liaison Coordinators to provide assistance on non-clinical matters in both jurisdictions.

As illustrated in the above model, and consistent with the OLCCH institutional values of quality, dignity, community, advocacy, and unity, patients and families from within and outside the Dublin metropolitan area should feel confident, respected, valued, inspired and cared for. In order to function as a valued referral center, a family support program should be implemented to provide assistance with:

Family housing and accommodation /utilities

Banking and business (email, phone, copy/print/fax)

Childcare and schooling

Dining

Directions (inside and outside of hospital)

Navigating the hospital

Pharmacy

Shopping (grocery, recreation)

Transportation (rental car, escort to and from locations)

to ensure patient families have as positive an experience before, during and after their hospital stay as is possible.

In addition to engagement in the Family Advisory Group (Recommendation 2), the family advocacy networks in Ireland have expressed interest and should be engaged in supporting families and in the development of a formal “family to family” program to provide short-term support from trained mentors to patients and/or parents who are facing a challenging diagnosis as well as long-term support from diagnosis or age specific specialty groups e.g. a cardiovascular teen program that provides an adolescent perspective to the hospital and creates projects for teens including a teen advisory committee (since ~33% of patients with congenital heart disease are adolescents, it is important to acknowledge their perspective and opinions).

The IWG recognizes that there may be a variety of existing or future resources that will be required to fulfil this recommendation and that the identification and coordination of these resources will be an important responsibility of the Family Advisory Group, working with existing social service and other resources in both jurisdictions. The IWG is unclear about the sources of funding to support these non-medical expenses, but support for these types of expenses will be very important for the success of the program in the eyes of those patients and families who have to travel any significant distances to reach OLCCH regardless of their jurisdiction of residence.

Recommendation 9:

Integrate the activities of advanced practice nurses in Belfast and Dublin to provide patient and family support and to manage the transfers of patients between Belfast and Dublin and to co-manage clinics. Expand the roles of advanced practice nurses in the ambulatory clinics and in the transport teams.

For the past decade in Ireland, registered nurses are required to complete a baccalaureate degree in nursing for entry into practice, which has resulted in a highly educated and professional nursing

workforce. From our observations, the supply of nurses is good, and the enthusiasm and willingness of nursing staff and leaders to assume increasing levels of responsibility with appropriate competency training and education is apparent. The CNS nursing group from OLCCH Dublin and from the Belfast Clark unit have demonstrated success in supporting patients and families before the admission process, longitudinally over time, and after discharge. Formalising a partnership of the nurses on these teams will bolster effective communication and true collaboration between both institutions and ultimately advantage families who will experience a patient and family centered care delivery model.

For the all-island solution to be implemented effectively, there is opportunity to expand the roles to nurses and extend the inter-professional team. Paediatric nurse practitioner-managed cardiology clinics and nurse-led paediatric transport teams are strategic solutions for improving patient access and facilitating high quality patient care while gaining high levels of patient satisfaction. These care delivery models have demonstrated success in the domains of access, quality of care and patient / family satisfaction in the United States⁸ and United Kingdom and should be seriously considered for the all – island Ireland solution.

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One advanced practice nurse from Belfast and one from Dublin could coordinate the care for patients pre and post surgery and facilitate an optimal experience between the two cities for families needing to navigate both systems. Advanced practice nurses could extend the medical teams for ambulatory clinics as well as for the transport teams which currently only consist of physicians. Given the shortage of paediatric physicians, advanced practice nurses can work collaboratively to extend the services beyond the capacity currently available. Full job descriptions for advanced practice nurses are attached for your consideration.

Recommendation 10:

Require quarterly meetings between the paediatric and neonatal patient transport services (clinical and EMT support groups) in the two jurisdictions to facilitate safe transfers between outlying areas and the centers in Belfast and Dublin, and transfers between the centers.

An essential component of an all-Island approach to the management of patients with congenital heart disease is a smoothly functioning system for the transport of patients to the facility and caregivers with the expertise and resources to provide the best care possible. The IWG was provided data that indicates that in Northern Ireland during the last year, transport of ductus dependent congenital heart disease patients as well as other paediatric patient transfers had been safely accomplished using both land and air vehicles, including patients requiring artificial ventilation.

The current Irish Neonatal Transport Programme has been in operation for 12 years and undertakes 300 neonatal transports each year. Up to December 2013, this service operated 8 hours per day, but since December 2013 it has commenced working on a 24 hour basis. The IWG would support the findings of the 2013 Review of Paediatric and Neonatology Services and Framework for Future Development that “the development of a national retrieval service for paediatric patients is a key priority in terms of patient safety and risk but will require significant added resources” and concur with their opinion recommending the development of an Advanced Nurse Practitioner transport role.

The IWG was informed that progress has been made in the expansion of both neonatal and paediatric patient transport and that a medical director for paediatric transport service has been

⁸ Evangelista, Connor, Pintz, Saia, O’Connell, Fulton and Hickey (2012) *Paediatric nurse practitioner managed cardiology clinics: patient satisfaction and appointment access*. Journal of Advanced Nursing.

appointed for the Republic of Ireland with funding for a senior registrar. A service level agreement is in place between the HSE and the Air Corps of Ireland for air transports.

Recommendation 11:

a. Continue to upgrade the paediatric transport services in the Republic of Ireland

b. Consider building on the expert inpatient ECLS services existing in Dublin to form a mobile ECLS service. If a mobile ECLS service is established, it will be critical to ensure that ambulance and transport services are capable of transporting patients on ECLS from areas outside the Dublin metropolitan area (in both of the jurisdictions) to OLCHC. It is the view of the IWG that the need for mobile ECLS services will be very uncommon, if used only for the care of the very small number of congenital heart disease patients who will need mobile ECLS. See Recommendation 7.

c. The IWG recognizes that there are currently separate transport services for neonates and for paediatric patients and that development of a mobile ECLS service will require significant personnel and capital resources. If this mobile ECLS capability were to be considered as part of the continued development of paediatric and neonatal transport capability, then that would require a second set of resource allocation decisions that would likely have to be made outside the Congenital Heart Disease Network. Under any circumstance, the Governance Committee will have to establish a close working relationship with all of these transport services, and should plan for a quarterly review of these services as part of its agenda.

Recommendation 12: Continue and expand weekly case conferences for patients requiring congenital heart surgery or interventional catheterisations at OLCHC, incorporating cardiologists from Belfast Trust either in person or by teleconference.

The focus of this weekly conference should be redefined so that it focuses more on cases scheduled to be carried out in the upcoming week. This conference will be essential in providing a consistent approach to patient management that will incorporate the experience and expertise of all physicians and surgeons in the “network.” This short-term case management conference should also include contingency planning both for elective case cancellations due to intercurrent illness (reserve list) and for expected deliveries of patients with prenatal diagnoses of critical congenital heart defects. This group will also be an important early source to identify issues to be addressed by the Governance Committee. The smooth functioning of the all Island network approach to congenital heart disease management will depend heavily on how well this group functions. The IWG recognized the essential role of smoothly functioning high speed, high capacity data links between Belfast and Dublin in assuring that this conference will meet the needs for clear communication and ongoing participation by providers in both jurisdictions. Attendance at this meeting is crucial to the ongoing success of this all Island network. The IWG recommends that this conference be led each time by a surgeon and either a cardiologist from Dublin or from Belfast.

Recommendation 13:

The IWG recommends the extension of the current OLCHC monthly MDT mortality and morbidity conference in which all interventional catheterisation and surgical cases with complications are reviewed. This conference should continue to include cardiologists, cardiothoracic surgeons, intensivists and anaesthetists and should include participation by professionals from both jurisdictions. This conference should also include safety event reviews, including “near misses” and other system related problems. This conference will serve as an opportunity for self-critical improvement and as a mechanism to continue to provide transparency and to build trust and mutual respect among all of the participants.

Recommendation 14:

Mandate an annual “all-Island” symposium on congenital heart disease management, including an assessment of results of the current service arrangements. This annual review and consequent annual report of congenital heart disease management throughout both jurisdictions should be reported to the Governance Committee, and serve as the basis for data-driven benchmarking against other international services and future planning for personnel and physical plant resources. It will also serve as an additional opportunity to build trust and mutual respect among all of the providers in the all-Island network.

Limitations of the IWG analysis:

The IWG was not provided detailed information on the current expenditures for the care of patients with congenital heart disease (both children and adults) in either jurisdiction. The IWG understands that current cost accounting systems in both jurisdictions may not allow cost analyses by patient group, i.e. for patients with congenital heart disease. It is the IWG recommendation that this data be obtained retrospectively, or at least gathered prospectively so that the working of the Governance Committee can take these factors into account in planning for future investments and expenditures. The IWG did note in data provided from Northern Ireland that the cost per case for patients referred to UK centers and to Dublin were higher for those referred to Dublin, although there is no adjustment for diagnosis or severity of illness. However, there may be significant contractual differences in the service level agreements between the Belfast Trust and the centers in the UK and Dublin, and this topic will require consideration in the agreements between the two jurisdictions as the recommended all-Island plan for patients with congenital heart disease is implemented.

Sequence of Next Steps

A. Essential first steps

1. Cross credentialing:

Belfast Cardiac anaesthesiologists, paediatric cardiologists, adult congenital cardiologists

2. Standardised process for cross jurisdictional issues involving patients and families

Patients and families: birth certificates, passports, insurance, housing, transportation, meals, death certificates, payments: Avoid families becoming embroiled in the paperwork and financial issues.

Nursing staff : Navigator

3. Establish IT links between OLCHC and Belfast Trust to enhance weekly case conferences

4. Confirm membership and staffing of Governance Committee and establish meeting schedule- Establish processes and mechanisms to gather data on resource utilisation for the management of congenital heart disease in both jurisdictions. Governance Committee will have to establish personnel schedules, especially for personnel providing services in Dublin.

5. Establish Patient Advisory Group and select members from both jurisdictions

6. Establish nursing liaison group with membership from both jurisdictions to manage patient transfers

7. Establish the Governance Committee and initiate meetings. Clarify the roles and responsibilities of the GC with careful attention to the recommended scope of influence over resources to be deployed for the management of congenital heart disease in the two jurisdictions

B. Short term (within first 3 months):

1. Finalise plans for ICU expansion at OLCHC and begin construction or renovation depending on site selected. Unit should open within 12 months.

2. Staff exchanges and joint conferences begin, including first meeting of governance committee

3. Begin work to allow Belfast paediatric cardiology trainees to receive credit for rotations at OLCCH and to establish a joint training program.
4. Recruitment of new staff and maintenance of existing staff (physicians and nurses).

C. Vision for the future

1. Research
 - Genetics
 - Neuro-developmental outcomes
2. Further planning for unified children's hospital in Dublin

Index of Documents

1. Healthatlas (2014) Congenital Cardiac Surgery – Comparative Access Map. Ireland, Healthatlas.
Document Name: retrieval access isochrone map - journey times.pdf

2. HSE/RCSI (2013) Review of Paediatric and Neonatology Services and Framework for Future Development. Dublin, Ireland. HSE.
Document Name: HSE Review of paediatric neonatology services 2013.pdf
Authors: DR John F. Murphy & Prof Alf Nicholson

3. Our Lady's Hospital, Crumlin (2013) OLCHC Paediatric Intensive Care Unit 2011-2012 Combined 2nd and 3rd Annual Report. Dublin, Ireland. OLCHC.
Document Name: PICU 2011-2012.pdf

4. *Donohue, Dr S, 2014* - Tertiary Services for Adults with Congenital Heart Disease in the Republic of Ireland
Document Name: Tertiary Services for Adults with Congenital Heart Disease in the Republic of Ireland.doc

5. *Donohue, Dr S, 2014* - AMENDMENTS & ADDITIONS to THE OVERVIEW OF TERTIARY PAEDIATRIC SERVICES FOR CHILDREN WITH CONGENITAL HEART DISEASE
Document Name: AMENDMENTS.doc

6. Belfast Health and Social Care Trust, (2013) Proposed Model for Future Delivery of Paediatric Cardiac Services. Belfast, Northern Ireland.
Document Name: Congenital Paed Cardiac Service - Proposed model Mar 2013v13.doc

7. Murdoch, Prof. Ian and Dr. Kevin Morris (2012) Clinical Review of Paediatric Critical Care Services.
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8. College of Anaesthetists of Ireland (2013) Providing Quality, Safe and Comprehensive Anaesthesia Services in Ireland. Dublin, Ireland. College of Anaesthetists of Ireland.
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Document Name: JTCVSx 2013 Devlpmt diagnosis procedure based model 30 day outcome.pdf

13. NHS/NIHR (2013) A mortality risk model to adjust for case mix in UK paediatric cardiac surgery. London, England. NHS/NIHR

Document Name: Mortality risk model casemix adjustment UK paed CThSx.pdf

14. RCSI/RCPI/RCSI/ICSI (2014) REGULATIONS RELATING TO THE TRAINING, EDUCATION AND EXAMINATION OF CANDIDATES FOR DIPLOMA of the IRISH BOARD of INTENSIVE CARE MEDICINE (DIBICM). Dublin, Ireland. RCSI

Document Name: DIBICM Regs.pdf

15. British Congenital Cardiac Association (2009) Requirements for Provision of Outreach Paediatric Cardiology Service. London, UK. BCCA

Document

Name:

Requirements_Outreach_clinic_Paediatric_Cardiology_Service_BCCA_Oct_2009.pdf

16. NHS (2012) The Scottish Adult Congenital Cardiac Service. Clydebank, Scotland. NHS.

Document Name: Scottish Adult Congenital Cardiac Service 2012.pdf

17. A range of reference and briefing material was sent to Dr Mayer and the other members of the IWG team in the period March to August 2014

Document Name: IWGRefListAug14.docx

18. Minor factual changes notified to Dr Mayer in August 2014 in relation to the IWG draft report

Document Name: IWGRepAmendAug14.docx

19. Activity & Cost Estimates for Congenital Cardiac Services in Belfast for the years 2011/12, 2012/13, 2013/14: Source Belfast HSC Trust 2014

20. Agreement for the provision of Paediatric Congenital Cardiac Surgery & Interventional Cardiology Services: Service Level Agreement between Health & Social Care Board & Guys and St Thomas' NHS Foundation Trust, January 2014: Source Health & Social Care Board 2014

21. Agreement for the provision of access to Paediatric Congenital Cardiac Surgery & Interventional Cardiology Services in Our Lady's Childrens Hospital Crumlin for Infant & children with critical cardiac illnesses/ life threatening emergencies: Service Level Agreement 2014. Source Health & Social Care Board 2014

22. Agreement between Health & Social Care Board & Guys and Our Lady's Childrens Hospital Crumlin Republic of Ireland, January 2014: Source Health & Social Care Board 2014

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25. Birth Numbers, population and travel times from Local Government district to major centres in Northern Ireland and the Republic of Ireland. Source – CSO and NISRA 2012: Published by Institute of Public Health 2014

26. Cardiac Safe & Sustainable Review: NI Paediatric Cardiac Surgery Service – Completed Self-Assessment Template April 2012. Source Belfast HSC Trust

27. Childrens Cardiac Transport Services: A briefing note. Source Northern Ireland Ambulance Service (NIAS) 2014

28. Clinical Governance Review of the Paediatric Cardiac Surgical Service for Northern Ireland by Mr David Barron & Mr Asif Hassan 2010: Source Belfast HSC Trust 2014

29. Congenital Heart Disease CCAD Outcome Data for Belfast Trust 2010-2013: National Institution for Cardiovascular Outcomes Research (NICOR) 2014
30. Costs of Childrens Ambulance Services: Source Northern Ireland Ambulance Service (NIAS) 2014
31. Future Commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the Population of Northern Ireland: A Post Consultation Document February 2013. Source – Health & Social Care Board 2013
32. Future Commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the Population of Northern Ireland: Identification of a Preferred Option April 2013. Source – Health & Social Care Board 2013
33. NI Deanery Out of Programme Guidelines 2013: Source NI Medical & Dental Training Agency 2014
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37. PCCS Cath Lab and Surgical Activity 2013/14 by Location and level of urgency: Source Belfast HSC Trust 2014
38. PCCS Expenditure by Average Case per Location in 2013 in Belfast, Dublin, England. Source – Health & Social Care Board 2014
39. PCCS Risk Adjusted Outcome Data for 3 year period 2011/2014: PRIAS National Database 2014
40. Provision of Information to the Congenital Cardiology and Cardiac Surgery Expert Assessment Group: Letter from Chief Medical Officer for Northern Ireland to HSC Chief Executives March 2014: Source DHSSPS 2014
41. RCS Report on an Invited Review of Paediatric Cardiac Surgery Service in Belfast HSC Trust June 2012: Royal College of Surgeons 2012
42. Review of the Paediatric Congenital Cardiac Services in Belfast HSC Trust: A Safe & Sustainable Review Kennedy et al 2012. Including HSCB and PHA Explanatory Comments. Source Health & Social Care Board 2014
43. Royal Belfast Hospital for Sick Children - Consultant Paediatric Anaesthetic Resources 2014: Source Belfast HSC Trust
44. Royal Belfast Hospital for Sick Children: PICU Bed Occupancy 2011- 2014: Source Belfast HSC Trust 2014
45. A Strategy for the Belfast Trust Adult Congenital Heart Disease (ACHD) Service, Lockhart et al March 2014: Source Belfast HSC Trust 2014

46. A Strategy for the Belfast Trust Adult Congenital Heart Disease (ACHD) Service: Supplementary Paper on Networked Surgical Support for Congenital Heart Surgery in Belfast April 2014: Source Belfast HSC Trust 2014

47. Support for Paediatric Congenital Cardiac Surgery & Interventional Cardiology in Northern Ireland: Service Level Agreement between Belfast Trust and Our Lady's Childrens Hospital Crumlin January 2014. Source Belfast HSC Trust 2014

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Spreadsheets:

1 - Hospital & Age Data, 2012

2 - Detailed Diagnosis Data, 2012

3 - Age & Diagnosis Data, 2012

4 - Cases by Hospital 2009-2013

5 - Cases by Age Groups 2009-2013

6 - Cases by Age Groups & Daycase Inpatient Status 2009-2013

7 - Cases by County of Residence 2009-2013

8 - County of Residence by Hospital, 2009-2013

9 - County of Residence by Hospital, Grouped

10 - Hospital by County of Residence

11 - Principal Procedures, 2009-2013

12 - Principal Procedures by DRG Partition