FRAMEWORK FOR ALL ISLAND CLINICAL NETWORK
FOR CONGENITAL HEART DISEASE

1 Policy Context

With the Ministers acceptance of the recommendations of the International Working Group (IWG) report on an all island model for congenital heart disease, a framework of governance which can facilitate the work required and recognise the cross jurisdictional responsibilities is required. An All Island Clinical Network to manage the all-island service delivery model offers a way of doing this which builds on existing services and draws them together in a network of care which is service user focused and locally responsive. The basic concepts of such a network are of partnership, service integration and formal arrangements. They may be defined as linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, to ensure equitable provision of high quality, clinically effective services.

Information in respect of the CJOG, the Congenital Heart Disease Network Board and its possible subgroups, standards and governance are addressed in this paper and a chart of the framework is presented at Appendix 1. Whilst the need for standards, targets, quality assurance, risk management, clinical and social care arrangements and communications / engagement requirements is acknowledged, detailed proposals and implementation in respect of these are a matter for the Congenital Heart Disease Network Board.

2 Cross Jurisdictional Oversight Group (CJOG)

- The CJOG has the overarching responsibility for oversight of the Implementation of the recommendations of the IWG report for an all island service for patients with congenital cardiac disease 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;
  - 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 of Ireland, viz.:
To reflect the principle in recommendation 1 of the IWG report, the CHD Network Board will be comprised of patient representatives, clinicians (doctors, nurses and specialists), key service providers and commissioners, with specialist professional expertise and skills, programme and project support, policy advice and input from improvement workstream leadership where appropriate. The Network Board will reflect the phased approach to the implementation of an all-island model, concentrating initially on services for paediatric and young adult patients, and progressing to adults with Congenital Heart Disease; engagement with those involved in the care of adult CHD patients will be sought as work progresses.

The Membership will therefore be comprised of:

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<th>Name</th>
<th>Organisation/Role</th>
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<tr>
<td>Dr. Len O’Hagan, CBE DL (Chair)</td>
<td>CEO, Royal College of Physicians of Ireland</td>
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<tr>
<td>Ms. Eilish Hardiman</td>
<td>CEO Childrens Hospital Group</td>
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<tr>
<td>Mr. Lorcan Birthistle</td>
<td>Chief Executive, OLCHC</td>
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<tr>
<td>Dr Cathy Jack</td>
<td>Medical Director, Belfast HSC Trust</td>
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<tr>
<td>Dr Eddie Rooney</td>
<td>Chief Executive, Public Health Agency</td>
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<tr>
<td>Mr. Dean Sullivan</td>
<td>Director of Commissioning, Health and Social Care Board</td>
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Framework for CHD Network

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<tr>
<th>Name</th>
<th>Organisation/Role</th>
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<tr>
<td>Ms. Helen Byrne</td>
<td>Health Service Executive</td>
</tr>
<tr>
<td>Ms. Sarah Quinlan</td>
<td>Chief Executive, Children’s Heartbeat Trust</td>
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<tr>
<td>Mr. Irwyn McKibbin</td>
<td>Heartbeat NI</td>
</tr>
<tr>
<td>Ms. Margaret Rogers</td>
<td>Heart Children Ireland</td>
</tr>
<tr>
<td>Network Team</td>
<td>Dr. Frank Casey, Senior Consultant Cardiologist, Belfast Health and Social Care Trust</td>
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<td></td>
<td>Dr. Paul Osliizlok, Consultant Paediatric Cardiologist, Our Lady’s Children’s Hospital Crumlin Dublin</td>
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<td></td>
<td>Ms. Brenda Creaney, Executive Director of Nursing, Belfast Health and Social Care Trust</td>
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<tr>
<td></td>
<td>Ms. Tracey Wall Assistant Director of Nursing, Our Lady’s Children’s Hospital Crumlin Dublin</td>
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<tr>
<td></td>
<td>Network Manager (to be recruited shortly)</td>
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While recognising existing individual accountabilities, the members of the Network Board will work in partnership to ensure the delivery of an all island service for children and adults with congenital heart disease. In addition it will have the key responsibility to ensure the delivery of the phased implementation plan as recommended in the IWG report and to account to the CJOG in doing so. Following the initial implementation of services in respect of children and young people, participation in the work of the Network will be sought from those involved with the provision of adult CHD services.

The Network Board 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 to advise on and drive the implementation of the recommendations of the expert group (IWG) report (covering, inter alia, clinical advisory, family advisory and infrastructure / resources requirements). The terms of reference, of working groups will be developed by the CHD Network Board (the Board). These terms of reference must comply with the objectives of the Network. Working groups must carry out their work underpinned by a strong programmatic approach, thorough
assessment of workforce needs and challenges, robust financial analysis and effective communications.

Any working groups formed will be comprised of co-chairs, as appropriate, (who will be members of the Network Board) and other members to be approved by the Board. The Co-Chairs of each working group will identify the other members required for each group with necessary skills and experience necessary for the successful conduct of its work and submit the proposed members’ details to the Board for ratification.

The Network Board will continuously monitor, and adapt as necessary, the role and parameters of the clinical network, suggest workstreams for the working groups to ensure appropriate phasing and coordination. This will include reviewing / revising membership, roles and functions of the Network Board’s working groups as these develop to ensure that they continue to be fit for purpose. The Network Board and its working groups will liaise with other parts of the service as required, for example in the co-ordination of general paediatric, adult and obstetric services.

The Network Board is expected to meet monthly to monitor and report progress. Core team members may be required to be in attendance at CJOG meetings. The Network Board will report directly to the CJOG, providing update reports on progress and identifying risks or barriers to achieving a successful outcome, along with measures to militate against such risks / barriers.

Following establishment of the clinical network, the Network Board will publish an annual report on the service provided by the clinical network and organise an annual symposium.

4  Standards

The Network Board must set out clear standards which seek to:

- improve care and contribute to continuous quality improvement,
- ensure the safety of service users, carers and staff
- ensure high quality clinical and corporate governance
- ensure access to and use of appropriate information including data driven benchmarking against other international services and for future service planning
- establish key service performance indicators in respect of specific treatment requirements,
- promote access to and use of international evidence-based research and best practice
- demonstrate user involvement
- promote clear, effective communication, both internally and in all external interactions
• contribute to continuous professional development
• mitigate against identified risk
• address critical incidents in a robust and timely manner
• ensure that structures and processes for the adequate review of service and care delivery within the Network are established and adhered to.

The effectiveness of the clinical network will be measured in part by the definition of these standards and adherence to them.

5 Governance

The establishment of the clinical network as the preferred means of service delivery does not remove or dilute the statutory governance requirements placed on service commissioners or service provider organisations. The clinical network will work across traditional structural boundaries and therefore require careful management particularly at the interfaces between its various organisational components. Whereas it is inevitable that a significant level of informal communication will continue between the various parties involved, and that informal engagement between officials / commissioners / service providers and service users is a positive hallmark in the genesis and continuation of these processes, the role of such communication should be facilitative in nature and will, in no way, replace the responsibilities and accountabilities of the CJOG and the individual members of the Network Board. The clarity of where decisions are recommended, agreed, informed and consulted on needs to be mapped out early in the programme of work.
Framework for CHD Network

Appendix 1

Minister
DHSSPS (NI) / DoH (RoI)

Cross Jurisdictional Oversight Group (CJOG)

Congenital Heart Disease (CHD) Network Board

Clinical Advisory Group
Family (Patient Experience) Advisory Group

Infrastructure & Resources Group (Including ICT & data analysis requirements)

CHD Network Core Team

Data flow & Imaging
National project group