Consultation on the future delivery of Congenital Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland

CONSULTATION RESPONSE FORM

I am responding:
As an individual

As a health and social care professional

On behalf of an organisation

(please tick one option)

About you or your organisation:

Name: Mrs Maeve Hully
Job Title: Chief Executive
Organisation: Patient and Client Council
Address: The Ormeau Baths, Ormeau Avenue
Belfast BT2 8HS
Tel: 0800 917 0222
E-mail: maeve.hully@hscni.net

Consultation Questions related to recommendations in Section 4 above

1a. Do you agree with an “all island” model for the provision of this service?

Yes _______
No _______

If ‘no’ please comment below:

Children and families are undoubtedly concerned about any shift in service away from the Belfast Health and Social Care Trust. It is important that with any new model of service provision, children and families must be assured that the service is safe and capable of responding in a timely manner. In addition it will be important to ensure that travel and patient transport arrangements are available and effective. Communication systems must be clearly agreed and patients and their families should have a lead clinician as their individual point of contact.
1b. As part of an “all island” model a Governance Committee/Clinical Network vehicle, comprised of clinicians, service commissioners, service providers, patient representatives and departmental officials from Northern Ireland and the Republic of Ireland, to oversee the model has been proposed. Do you have any suggestions on how this could work?

Comment:

| Families or their representatives need to be involved at every level and aspect of the service development and implementation. It is better that there are a number of patient representatives on each governance forum and not a single person. These individuals need to be supported and attention should be given to the practical logistical support to enable them to contribute effectively. |

2. Do you agree with the establishment of a Family Advisory Group with representatives from both jurisdictions?

   Yes   ____√____
   No     ______

If ‘no’ please comment:

If ‘yes’ please comment on how you think this might work best:

| Family representatives should be included on both clinical networks and in governance arrangements and in every aspect of the service. They should be involved in the development of the terms of reference and the development of arrangements for establishing this group. |
3. Do you agree with the establishment of a central database for both jurisdictions to collate and analyse information on outcomes, resource utilisation for review by a Governance Committee/Clinical Network and other interested parties?

   Yes  √
   No

If ‘no’ please comment:

   Information on outcomes should be made publically available and should eventually be published on HSC Information Portal.

If ‘yes’ please comment on how you think this might work best:

4. Do you agree that professional staff from Northern Ireland and the Republic of Ireland should be deployed across the different hospitals in both jurisdictions?

   Yes  
   No

If ‘no’ please comment:

   Staffing arrangements must ensure continuity of care for the children and their families.

If ‘yes’ please comment on how you think this might work best:

   

   

3
5. It has been recommended that the paediatric cardiac surgery capacity in Our Lady's Children's Hospital Crumlin (OLCHC) in Dublin should be increased with specific investment in paediatric cardiac services. Do you agree that such investment should be made?

Yes ________
No ________

If 'no' please comment:

It is not within the remit of, nor appropriate for the Patient and Client Council to comment on investment decisions such as this one.

If 'yes' please comment on how you think this might work best:

6. Do you agree that the telemedicine links between the Belfast Trust and OLCHC should be improved to facilitate the transfer of clinical information?

Yes ________√________
No ________

If 'no' please comment:

If 'yes' please comment on how you think this might work best:

The Patient and Client Council would wish to see the implementation of best practice with regards to use of new and emergency technology in this area. In particular there is opportunity to reduce the burden of travel for patients and their families particularly in respect of some consultation and review appointments.
The International Working Group has recommended the cessation of all paediatric cardiac surgery and interventional procedures in the Belfast Trust with a refocus on lower complexity adult congenital cardiac surgical and interventional procedures.

a. Do you agree with the IWG's clinical view that paediatric surgery and interventional procedures in the Belfast Trust should cease?

Yes ________
No ________

If 'no' please comment:

Please provide any further evidence that you think the IWG should have considered in their review of the service:

b. Do you think that the Belfast Trust should re-focus on the provision of services to adult congenital patients as proposed?

Yes ________
No ________

If 'no' please comment:

It is important that services are maintained locally as far as possible and that those children and young people who are already known to the Belfast Health and Social Care Trust can expect continuity of care.
8. It is proposed to enhance patient and family services in Dublin, including the role of Family Liaison co-ordinators? Do you agree that this is appropriate?

Yes ____
No ______

If ‘no’ please comment:

If ‘yes’ please comment on how you think this might work best:

Family liaison will be vital to ensure patients and their families know exactly what is happening and how they are to be supported in the community and reviews. Families should have a named key clinician who will provide them with advice and support.

9. It has been proposed to expand the role of the Clinical Nurse Specialists and Advanced Nurse Practitioners and that they should work in an integrated way to provide patient and family support. Do you agree with this proposal?

Yes _____√____
No ______

If ‘no’ please comment:

If ‘yes’ please comment on how you think this might work best:

The Patient and Client Council welcomes the development of a multidisciplinary approach.
10. Do you agree that there should be regular meetings between the paediatric and neonatal transport services from Northern Ireland and the Republic of Ireland?

Yes ___ √ ___
No ______

If ‘no’ please comment:

[Blank space for comments]

If ‘yes’ please comment on how you think this might work best:

The Patient and Client Council recommends strong communication links and integrated working relationships in order to ensure a seamless service for patients and their families.

The Patient and Client Council recommends strong communication links and integrated working relationships in order to ensure a seamless service for patients and their families.

11. It is proposed to further upgrade the paediatric transport services and consider the development of a mobile extra corporeal life support (ECLS) service. Do you agree that this is appropriate?

Yes ___ √ ___
No ______

If ‘no’ please comment:

[Blank space for comments]

If ‘yes’ please comment on how you think this might work best:

It is important that these arrangements are able to respond in a safe and timely way.
12. An expansion of the current 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, is proposed. This would involve ensuring robust telemedicine links between Belfast Trust and OLCHC. Do you agree that this is appropriate?

Yes √
No ______

If ‘no’ please comment:

If ‘yes’ please comment on how you think this might work best:

This is vital to ensure continuity of care and to enable a joined up service supporting positive patient outcomes

13. An expansion to the current monthly multi-disciplinary team meeting of the paediatric cardiac teams from the Belfast Trust and OLCHC is proposed, to include safety event reviews as well as mortality and morbidity reviews. Do you agree that this is appropriate?

Yes √
No ______

If ‘no’ please comment:


If ‘yes’ please comment on how you think this might work best:

This activity is essential for continued quality development and improvement of the service. Family representatives should be involved in the process.

14. Do you agree that an annual “all island” symposium on congenital heart disease management should be held, to include an annual report, governance review and planning for resources?

Yes  ______ √____
No  ______

If ‘no’ please comment:

If ‘yes’ please comment on how you think this might work best:

Ensuring that venues are as accessible as possible to families would be a key feature of this activity. In addition information on outcomes and service development should be published and accessible to the public.
Please provide any further comments about the 14 recommendations in the space below:

<table>
<thead>
<tr>
<th>It is vital that transport and IT systems are in place which gives families access to safe and responsive services. The Patient and Client Council recommends that there is clear accessible information:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• about the service</td>
</tr>
<tr>
<td>• transport arrangements</td>
</tr>
<tr>
<td>• family liaison service</td>
</tr>
<tr>
<td>• who is responsible for what</td>
</tr>
<tr>
<td>• how after care/reviews are to be managed</td>
</tr>
</tbody>
</table>

Each patient and their family should have a clear treatment plan and a named clinician who will take responsibility for co-ordination of same and follow up.

As this service is provided on an All-Ireland basis, there will a requirement to implement a single process to enable patients and their families to raise concerns and if necessary, to make a formal complaint. Referral should also be made to the complaints support service provided by the Patient and Client Council.