



**Consultation response on the future delivery of Congenital
Cardiac Surgery and Interventional Cardiology**

23 January 2015

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 (but note below comments) _____

No _____

Whilst ideally we would have preferred a dedicated Northern Ireland service, we recognise that it has been determined that the long term sustainability will be secured by working on an all island basis.

We would however like to reiterate however that, as the 2012 external review of the PCCS found, procedures in Belfast have always been safe. We believe that important point was lost in the build-up to this new proposed model.

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:

We would stress that the all island model, including this Governance Committee, must have equitable involvement and feed-in from individuals and experts from both sides of the border. That applies especially to departmental and patient representatives which we trust will formally have 50/50 representation.

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

Yes _____

No _____

If ‘no’ please comment:

n/a

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

The Family Advisory Panel is absolutely essential if the service is to listen to the concerns or observations of patients. It must not be considered a device to placate parents; instead it must be given the prominent status it deserves.

We expect this Group will regularly provide feedback as to how they believe the system is functioning. We would ask that this feedback be given the required level of attention. We expect the comments of parents and services users, most especially their concerns, will be listened to and that formal responses will be issued.

Membership of this Group should, as far as reasonably practical, consist of fair representation of personnel from both sides of the border.

We trust that this group will suitably communicate their priorities to as many families as far as reasonably practical on a regular basis.

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 X
No

If 'no' please comment

n/a

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

It will no doubt be a major task consolidating all existing information so we trust that appropriate resources will be available to do this.

It is then essential that this database is maintained and updated on a very regular basis.

We expect the DHSSPS will have unrestricted access to this database and that relevant information such as waiting times and numbers of service users from Northern Ireland will be officially published regularly as per other statistical releases.

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:

n/a

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

We believe this is a logical proposal; however it must not be used as a pretext to gradually transfer the skilled nursing and physician posts entirely to Dublin.

We trust that families from Northern Ireland will still have the ability to meet the medical staff in Belfast before surgery takes place. It is therefore essential that Northern Ireland maintains the required skills base.

We are still concerned however that the cessation of paediatric cardiac surgery in Belfast will inevitably have an adverse impact on this.

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:

n/a

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

Whilst we do of course support increasing the capacity at Our Lady's Children's Hospital, we are totally unsatisfied that in the interim children from Northern Ireland are being transferred to England for treatment.

The previous Service Level Agreement between Belfast and Dublin should never have been allowed to come to an end until there was sufficient capacity in Crumlin. We believe that lapse of attention, either intentional or not, by the DHSSPS was reprehensible.

We firmly believe that increased expenditure in the OLCHC should not prevent continued investment in Belfast, both in capital costs and in staffing.

We would ask for the capital costs of this project to be identified and for both the political administrations in Belfast and Dublin to pledge to honour whatever contributions are required of them.

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:

n/a

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

We believe this will be a vitally important link between the Belfast and Dublin hospitals. We trust the latest innovations in telemedicine in the DHSSPS and the Department of Health in Ireland will be applied here.

7. 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:

We believe this is an entirely unnecessary proposal. Whilst we do accept that in this case OLCHC will take on the additional surgery, we believe this should not permanently prohibit the service taking place in Belfast. We believe an unequivocal cessation is unfair on future patients and their families.

As already referenced we also have real concerns about Belfast's ability to retain the existing skills base once surgery ceases.

If this proposal is adopted we would expect to see nothing less that significant enhancement and maintenance of non-surgical treatment in Belfast.

On a related note we would like to once again reiterate our disgust at the manner in which the announcement that surgery was to cease was made. The then Minister, Edwin Poots, showed blatant disregard to the very real concerns of the families by first making such the significant announcement in response to a Topical Question quite clearly 'planted' by a Party colleague.

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

We believe the distances beyond Belfast in which parents and patients will not be expected to travel will be difficult and may not have been entirely considered. People from the North Coast will be significantly inconvenienced by now having to bypass the centre in Belfast to travel to Dublin.

We also note that very often patients requiring emergency care will travel to the centre in Belfast before being transferred on to Dublin. In the case of Fermanagh as an example that could mean well in excess of a 4 hour journey.

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

Yes _____ **n/a**
No _____

If 'no' please comment:

Whilst we note this is the intention, we would make the point once again that an option or element of paediatric cardiac surgery should be maintained in Belfast.

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 _____ **X** _____
No _____

If 'no' please comment:

n/a

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

These roles will be essential in supporting families, especially those from Northern Ireland. We trust that these Liaison co-ordinators will make contact with families before they arrive in Dublin.

We believe that retaining sufficient staffing in Belfast will be absolutely necessary to provide the information and support to families about to be transferred.

In addition we expect additional costs incurred on families from Northern Ireland, not least travel and arrangements in regards to accommodation, will all be met by the DHSSPS.

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 X
No

If 'no' please comment:

n/a

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

Transfers must always be done in a smooth manner with no additional stress passed onto the patients or their families.

There should be continual contact between the clinical nurses on both sides of the Border.

We believe there is a further requirement of an extra specialist nurse, to be based in Belfast, who will support families travelling outside of Northern Ireland.

We trust that there will always be guaranteed specialist nurse available in every transport team and that the transfer will always be seamless.

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 X
No

If 'no' please comment:

n/a

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

These should be formal meetings in which any concerns or comments from both current and previous service users are considered.

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 X
No

If 'no' please comment

n/a

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

We believe the ECLS service must very regularly be located in Belfast. This is particularly important if the paediatric clinicians will generally be located in Dublin.

The DHSSPS must also ensure that there is a sufficient number of staff that have the required level of training in ECLS.

This mobile service would then be able to accompany children in the transfer to Dublin, if it is deemed that short-term extracorporeal support may be required.

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 X
No

If 'no' please comment:

n/a

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

Once again we trust the latest innovations in telemedicine in the DHSSPS and the Department of Health in Ireland will be available.

It is important to emphasis however that telemedicine must not replace all face-to-face meetings between cardiologists, surgeons and patients.

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 X
No

If 'no' please comment:

n/a

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

This information should be entirely available to the DHSSPS and then recorded by it in the usual manner.

We would expect that no less than the criteria for Serious Adverse Incidents in Northern Ireland will be applied when recording incidents.

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 ___X___
No _____

If ‘no’ please comment:

n/a

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

We trust that service users, both current and previous, will be welcome to attend this event.

We believe it will also present an opportunity for the Family Advisory Group and Governance Committee for instance to report on their work and findings for the year.

Please provide any further comments about the 14 recommendations in the space below:

The Ulster Unionist Party priority has always been keen to configure the service that best meets the needs of the patients and their families.

A situation of sending increasing numbers of children to England for treatment would have been indefensible; therefore we see the benefits of an all island model. We are disappointed however that it always looked as if the outcome of the location for the centre of surgery was always predetermined. That was no less the case than in this very consultation exercise during which the existing arrangements will have come to an end.

If paediatric cardiac surgery is removed from Belfast entirely it will present a number of significant challenges, a number of which we have mentioned in this response. However as important as retaining staff and our international reputation is; the biggest impact will be felt on families as they have no choice but to travel further from home for their child’s treatment.

The International Working Group has come up with a range of recommendations and, whilst we might not agree entirely with each of them, if the DHSSPS is to pursue their proposed model we believe that every other suggested improvement to the system should be implemented. There will be no excuse for a piecemeal approach by either jurisdiction.

In conclusion, A major opportunity which has once again been overlooked by the DHSSPS is the continued non-use of extensive pulse oximetry. We believe the Department must now move to introduce this cost effective and non-invasive screening test for all new born infants across Northern Ireland to screen for early detection of life threatening congenital heart defects.

For further information contact Mark Ovens at;

mark.ovens@party.niassembly.gov.uk

Or Tel: 028 905 21892