

**1<sup>st</sup> Meeting of the PCCS Working Group held on  
Friday 10 August 2012 at 10am in the  
5<sup>th</sup> Floor Meeting Room, HSC Board Headquarters,  
Linenhall Street, Belfast**

<b>Present:</b>	Mr Dean Sullivan (Chair)	HSC Board
	Ms Teresa Magirr	HSC Board
	Dr Miriam McCarthy	Public Health Agency
	Dr Brian Armstrong	Belfast Trust
	Dr Frank Casey	Belfast Trust
	Ms Lynne Charlton	Belfast Trust
	Sarah Quinlan	Children's Heartbeat Trust
	Julie Greenaway	Parent Representative
	Aidan Kearney	Parent Representative
	Irwyn McKibbin	Heartbeat NI
	Ms Maeve Hully	Patient and Client Council
	Dr David McManus	NIAS Trust
	Dr Damien Armstrong	Western Trust
	Mr Tom Robinson	DHSSPS

<b>Apologies:</b>	Dr Patricia Donnelly	Belfast Trust
	Mr Alastair Graham	Belfast Trust
	Dr Steve Robinson	Belfast Trust
	Ms Rosie Byrne	Belfast Trust
	Ms Pat Cullen	Public Health Agency
	Ms Margaret Rose McNaughton	DHSSPS
	Dr Paddy Woods	DHSSPS

**Item**

**1. Welcome and Introductions**

**Action**

Dean Sullivan welcomed those present and introductions were made.

With regard to the membership of the group, Dean Sullivan highlighted that the HSC Board and PHA are keen to ensure the process is as inclusive as possible to include appropriate involvement of parents and parent groups on the Working Group. It

was suggested that each of the parent groups would be invited to nominate two people to sit on the group and that at least two of the four nominations should be parents.

It was agreed that both parents groups would consider the proposal with members and respond in advance of the next meeting.

Parent Groups

Parental involvement on the working group will be supported by more detailed engagement outside of the meetings with parents which it is intended will be facilitated by the Patient and Client Council.

Maeve Hully noted that the need to ensure clarity on the expectations of engaging with parents and families. It was agreed that the nature of such engagement during pre-consultation and consultation phases would be clarified.

It was agreed that the agendas and notes of the Working Group meetings would be made available on the HSC Board website.

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Dean Sullivan noted that a key product from the Working Group would be a draft consultation document that is submitted to the HSC Board and onwards to Minister for approval. This will subsequently be issued for public consultation and at that stage there will be further opportunity for engagement with parents and families.

In order to ensure the integrity of the working group, it was agreed that any queries to members regarding the role or work of the group must be channelled through the chair of the group in the first instance.

All members

## **2. External Review findings and conclusions**

Dr Miriam McCarthy provided an overview to the review and the findings from the report of the review panel.

- The report followed the visit of the review panel in

**April when meetings were held with clinicians and parents**

- **The report included the following key messages:**
  - **Children in NI are well served by a dedicated and experienced team of consultant paediatric cardiologists and nurses. There are many excellent features in the current service that present opportunities for the development in the future of a model children's cardiology centre;**
  - **There are no immediate safety concerns with the current arrangements for the provision of paediatric cardiac surgery but that the surgical element of the service was not sustainable. Belfast Trust is already adopting a risk management approach with complex cases being referred elsewhere.**
  - **The review emphasised the unsustainability of current service arrangements and recommended that the potential safety risks be addressed within a period of six months.**
  - **The report set out a number of generic options for future service provision that will be considered by the Working Group.**
  - **The assessment of service was against Safe and Sustainable standards which had been used in England and Scotland.**
  - **In a number of areas the Trust compared very well against the standards but fell short of minimum requirements in other areas such as numbers of procedures and surgical staff.**

**To set this in context it was noted that work currently underway in England as part of the Safe and Sustainable review is recommending a reduction in the number of units undertaking paediatric cardiac surgery.**

**In terms of the current numbers, it was noted that there are currently around 25,000 births per year in NI and that around 1% (250 – 300) babies are born with cardiac congenital abnormalities. The paediatric**

cardiology service receives around 1,200 new referrals each year and only a small proportion of children require cardiac surgery (approximately 130 per annum).

In 2011/12, there were 140 procedures with 91 being performed in Belfast Trust and 49 being undertaken outside Northern Ireland. It was pointed out that NI has been transferring to other centres for a number of years.

Irwyn McKibbin highlighted that the wider Safe and Sustainable review process did not include representation from NI. It was agreed that clarity would be sought on whether an invitation had been extended to the organisations in NI.

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### **3. Ministerial statement and DHSSPS correspondence**

The review report was published on 1 August 2012 with a Ministerial statement published on the same date.

The Department wrote to the Board on 6 August 2012, to formally commence the process outlining the requirement that the Board and PHA establish a Working Group and the proposed outputs from the group.

The correspondence indicates that a draft consultation document is required for the Minister by September 2012. This will need to go to the HSC Board meeting on 13 September and therefore needs to be finalised at the beginning of September.

Subject to Ministerial approval by the end of September, the document will then be issued for a 12 week consultation period. This will be followed by a review of consultation responses which will again be presented to the Minister with a view to have a decision on the way forward early in 2013.

As a separate exercise, but in parallel with the Working Group, the Board is asked to undertake a

robust analysis of the current paediatric retrieval and transport system for the Northern Ireland population.

#### 4. Working Group

A copy of an initial draft Terms of Reference (TOR) for the Working Group was tabled. This set out the objectives of the group as per the letter from the DHSSPS.

It was agreed that members of the group would be given the opportunity to consider the draft TOR and respond with comments to Paul Cunningham by close of play on Monday 13 August 2012.

All members

The TOR will, as appropriate, be revised and reissued in advance of the next meeting with a view to agreeing the final version at the meeting on 17 August.

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Dean Sullivan outlined the intention that the process is open and transparent and that moving forward with the work of the group all options are considered for interaction with as many stakeholders as possible.

Dr Frank Casey referred to surgery required for patients over the age of 16. Dr Miriam McCarthy noted that a NHS consultation on future service provision for adult congenital cardiac patients had recently closed. The outcome of this consultation is due to be reported in coming months. The Working Group will be focussing on services for children but will consider the implications for other services as per the correspondence from the DHSSPS.

It was acknowledged that there is a need to ensure that all relevant stakeholders are consulted as part of the process and this should be reflected in a Project Initiation Document. It was agreed that this should also include pregnant women.

## **5. Next Steps**

As outlined earlier in the meeting, the Working Group has been tasked with developing a consultation document to include:

- A service specification for commissioning paediatric cardiac surgery and interventional cardiology;
- Clear criteria against which the service for children from Northern Ireland should be assessed;
- The implications of the criteria on potential service models

In response to a query from Sarah Quinlan, Dean Sullivan advised that all potential options including the generic options set out in the report would be considered.

Discussion took place regarding areas for inclusion in the service specification and assessment criteria:

- Access to services
  - There was debate about commissioning from a single provider but it was felt that this needed to be balanced against the need for the resilience of having a small number of providers and the requirement to have the ability to refer to specific providers for specialist work.
- Parent and Family support
  - There was discussion around the practicalities associated with the current arrangements for accessing services elsewhere and it was agreed that these would need to be considered irrespective of the future model of care. An update on this will be provided to a future meeting.
- Quality and safety of service provision
  - It was noted that this was an overriding requirement
  - The need for the provision of a service that can be delivered on a 24/7 basis throughout

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the year was highlighted

- The need to ensure that any unit providing care is able to demonstrate the quality of care through robust data which permits benchmarking with other providers.
- **Transportation**
  - Issues were highlighted regarding the current arrangements associated with accessing services outside of NI.
  - It was noted that transport and retrieval would be addressed through a separate piece of work that would be undertaken in parallel
- **Clinical requirements**
  - The need to ensure workforce skills and retention of staff within paediatric cardiology was highlighted. Belfast Trust will provide comments on this issue.

Belfast Trust

It was agreed that a first draft of the service specification, criteria and options would be provided in advance of the next meeting.

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6. Any other business

There were no other issues raised.

7. Dates for future meetings

It was agreed that meetings would be held on a weekly basis for the remainder of August to be reviewed thereafter.

The details for the next three meetings are as follows:

Friday 17 August 2012, 12 – 2pm

Friday 24 August 2012, 12 – 2pm

Friday 31 August 2012, 12 – 2 pm

The venue for all meetings will be the 5<sup>th</sup> Floor Meeting Room, HSC Board headquarters, Linenhall Street, Belfast.