

**Meeting of the PCCS Working Group held on Friday 16
November 2012 at 12 noon in the 5th Floor Meeting Room
HSC Board Headquarters, Linenhall Street Belfast**

Present:	Dean Sullivan (Chair)	HSC Board
	Teresa Magirr	HSC Board
	Philip Moore	HSC Board
	Sally Kelly	HSC Board
	Dr M McCarthy	Public Health Agency
	Dr Brian Armstrong	Belfast Trust
	Rosie Byrne	Belfast Trust
	Sarah Quinlan	Children's Heartbeat Trust
	Irwyn McKibbin	Heartbeat NI
	Clare Caulfield	Heartbeat NI
	Maeve Hully	Patient and Client Council
Observer:	Margaret Rose	DHSSPS
	McNaughton	
	Dr Heather Livingstone	DHSSPS

Item: **Action**

1. **Apologies**

Dr Nigel Campbell, SE LCG / Primary Care
Dr David McManus, NIAS Trust
Dr Frank Casey, Belfast Trust

2. **Notes of Previous Meeting**

The minutes of the meeting held on Friday, 19
October 2012 were agreed as an accurate record
subject to the first line of the second paragraph on
page 5 being amended to read as follows:

*It was accepted that any member attending a public
meeting in any capacity remains a member of the
Working Group.*

3. Matters Arising

The Working Group were advised that further to discussion at the last meeting, a formal response to the e-mail from Sarah Quinlan on 17 October 2012 had been issued. It was agreed that this would be circulated to Working Group members.

HSC Board

Dean Sullivan noted any remaining items arising were covered under item 4 of the agenda – Communication process update.

4. Communication process - update

4.1 Public Meetings / Focus Groups

Philip Moore noted that an update on the communication process had been shared with the Working Group on Wednesday, 7 November 2012.

In summary it was advised that the dates and venues for the five public meetings and 3 focus group events with parents and families have been confirmed. With regard to the public meetings, it was noted that a press release was issued, the Board has included details on its website and adverts have been placed in local press. The Board has also notified around 600 stakeholders of the dates and times of the public meetings.

All parents who have expressed an interest in attending the focus group events have been notified of the dates. It was noted that not all parents have responded and a reminder e-mail will be issued.

Parenting NI

Members agreed that if fewer than 5 people had confirmed attendances at a focus group 48 hours ahead of the event, then the event may be subject to cancellation.

It was agreed that the Board would forward the details of the three events to Sarah Quinlan and Irwyn McKibbin to share with other members of their groups

with a view to increasing the attendance at the events. HSC Board

As previously discussed a fourth focus group event with older teenagers will be held. The Board is in the process of finalising the arrangements for this event but it was advised that this will be held in Belfast on Wednesday, 19 December 2012. Belfast Trust colleagues will be contacting the teenagers directly with invitations to attend.

4.2 Consultation Update

Dean Sullivan informed the Working Group that 22 responses to the consultation document had been received by the Board.

4.3 Public Consultation Presentation

A copy of the presentation that will be used at the Public Meetings and Focus Group events was shared with the papers for the meeting.

A number of minor amendments were identified and it was agreed that these would be incorporated into the final version of the presentation.

HSC Board

It was also suggested that a glossary of key terms used in the presentation would be drawn up.

HSC Board

5. Visits to potential providers

At the last meeting, it was agreed that it would be useful to have additional information from potential providers in advance of the proposed visits.

The Board has written to each provider requesting more detail and responses are due to be received today. The dates for the visits will be confirmed over the next week.

HSC Board

It was noted that Secretary of State for Health in England (Jeremy Hunt) has asked the Independent Review Panel to review the decision in respect of the

provision of Paediatric Congenital Cardiac Services that was made by the Joint Committee of Primary Care Trusts.

In response to a query from Sarah Quinlan, Dean Sullivan noted that this review was related to the decision regarding the number and location of centres that would provide services in the future and was not a review of the Safe and Sustainable standards. It is felt therefore, without prejudice to the outcome of the consultation process, it would still be reasonable to visit those centres of the seven initially identified in England that had responded positively to the correspondence from the HSC Board on behalf of the Working Group.

6 Meeting with HSE - Update

Dean Sullivan advised that a meeting had taken place with representatives from the HSE and Our Lady's Children's Hospital Crumlin (OLCHC) on Friday, 9 November 2012. There were representatives from the HSC Board, PHA, Belfast Trust and DHSSPS at the meeting.

In previous correspondence OLCHC had indicated that they would be in a position to provide the urgent / emergency activity required for NI immediately, but would not be in a position to provide the elective activity required until August 2013, and could not commit to the provision of the level of interventional cardiology activity needed.

At the meeting on 9 November, updates were provided on each of these areas:

- Urgent / emergency activity – OLCHC could continue to support this, although it was noted that there have been pressures in recent weeks due to the number of emergency cases from NI;
- Elective activity – The position remains that there would need to be an increase in infrastructure in Dublin to allow the level of

- elective activity to be provided;
- **Interventional Cardiology – Constructive discussions took place regarding this area of activity and it was indicated that if a decision was made by the Minister for the option that provided activity in Dublin, this might be undertaken by staff from Belfast Trust using the Dublin infrastructure.**

The other main area identified was in respect of the provision of data to CCAD (national outcomes database). Dublin will have feedback on one year's data in January 2013. Steps are being taken to submit further information from previous years onto the database as soon as possible.

7. Patient Experience Workshop

It was agreed that the patient experience workshop that has been discussed at previous meetings would take place during January 2013 once the consultation process has been completed.

This workshop will be an opportunity for parents to present the practical experience issues associated with parents and children travelling outside NI for treatment e.g. booking flights and accommodation, reimbursement issues etc.

Teresa Magirr noted that a range of issues have already been flagged up by parent representatives at the Paediatric and Neonatal Transport Project Team meetings.

It was agreed that the workshop should be attended by parents, Belfast Trust and HSC Board/PHA.

8. Any other business

There was no other business raised.

9. Date for future meetings

It was noted that further meetings are already scheduled for Friday, 30 November and Friday, 14 December 2012.

It was agreed that meetings would be scheduled for each Friday during January and February 2013.

Meetings will take place between 12 noon and 2pm. Although it was noted that one longer meeting will be required at the start of January 2013, to work through the post consultation response to the Minister.

Subject to approval of this document by the Minister a further longer meeting will be required mid-February for the Working Group to apply the final criteria and weightings to the final set of options.

The venue for each of the meetings will be the 5th Floor Meeting Room, HSC Board Headquarters.