

**Meeting of the PCCS Working Group held on Friday
14 December 2012 at 12.30 pm in the 5th Floor Meeting Room
HSC Board Headquarters, Linenhall Street Belfast**

Present:	Dean Sullivan (Chair)	HSC Board
	Philip Moore	HSC Board
	Dr M McCarthy	Public Health Agency
	Dr Nigel Campbell	SELCG/Primary Care
	Alison McNulty	Parenting NI
	Dr Brian Armstrong	Belfast Trust
	Dr David McManus	NIAS
	Sarah Quinlan	Children's Heartbeat Trust
	Clare Caulfield	Heartbeat NI

Observers:	Jackie Johnston	DHSSPS
	Dr Heather Livingstone	DHSSPS

<u>Item:</u>	<u>Action</u>
1. <u>Apologies</u>	
	Pat Cullen, PHA Dr Frank Casey, Belfast Trust Dr Damien Armstrong, Western Trust Maeve Hully, Patient Client Council Irwyn McKibbin, Heartbeat NI
2. <u>Notes of Previous Meeting</u>	
	The minutes of the meeting held on Friday, 30 November 2012 were agreed as an accurate record.
3. <u>Matters Arising</u>	
	Dean Sullivan noted the matters arising were covered by the other items on the agenda.

4. Communication process - update

4.1 Public Meetings / Focus Groups

Dean Sullivan advised that all five of the public meetings had taken place and that around 180 people had attended the events.

The three focus groups with parents have taken place with around 25 participants in total at the events.

The meeting with teenagers and young adults is due to take place on Wednesday, 19 December. It was noted that there are still only two confirmed attendees for this event. Further discussion is taking place between the Parent Groups and Belfast Trust with a view to increasing attendance at the event.

Alison McNulty from Parenting NI, who facilitated the three focus group meetings with parents, joined the meeting to give an initial feedback from the events in advance of a formal report being provided to the HSC Board. Alison gave a detailed summary of the key themes that were raised and it was noted that these were fairly consistent with the messages being conveyed at the public meetings.

The final report from Parenting NI will be made available to the HSC Board by Wednesday 19 December 2012. It was noted that the parents who attended the focus groups would be given the opportunity to see the report before it is shared any further.

Dean Sullivan thanked Alison McNulty for the very useful support provided in facilitating these events.

4.2 Consultation Update

Dean Sullivan informed the Working Group that 94 responses to the consultation document had been received by the Board to date.

5. Draft Structure for the post consultation document

An initial draft of the post consultation document was circulated with the papers for the meeting to provide an early indication of the structure of the final document. Dean Sullivan advised that the intention was for the final document to be provided to the January meeting of the HSCB Board. The proposed structure of the document was agreed.

It was noted that there would be opportunities to discuss the updated draft of the document, with a summary of the responses, following the period of consultation at the Working Group meetings on 4 and 11 January 2013.

6. Patient Experience Workshop

The Working Group was advised that, further to discussion at the last meeting, it is intended that the Patient Experience Workshop will take place during January 2013. On the advice of Working Group members it was agreed that this would be an evening event during either the week commencing 14 January or week commencing 21 January.

It was also agreed that Parenting NI would facilitate the event that will include parents, the Board, and Belfast Trust (liaison staff).

7. Update on the Paediatric and Neonatal Transport Work

A short update paper on the progress that has been made with the Paediatric and Neonatal Transport work was shared with the Working Group.

Dean Sullivan advised that the final report from the Project Team would be shared with the Working Group in due course.

In response to a query from Sarah Quinlan, it was noted that the stakeholder standards identified by the

representatives on the Transport Project Team would either be considered for inclusion in the service specification for a transport service and as appropriate considered at the patient experience workshop.

8. Any other business

8.1 Issue raised at Belfast Trust Public Meeting

Sarah Quinlan expressed concern that, in response to questions at one public meeting about the timeline of the Kennedy review, there was reference to the higher than expected number of deaths among children undergoing surgery for Tetralogy of Fallot and this may have caused anxiety among attendees.

Dr McCarthy explained that while the panel was acutely aware of parents needs and sensitivities, it had been necessary to answer all questions, particularly those asked repeatedly, as fully as possible. She also advised that information on the higher than expected number of deaths was in the public arena and had been referenced in a Ministerial statement.

Sarah Quinlan expressed a view that it would have been helpful for Dr McCarthy to have provided at the public meeting more information including detail on the outcome of the Royal College of Surgeons review.

Dean Sullivan noted that the specific question was on the background to and the short timescale for the Kennedy Review and with input from both Dr McCarthy and Dr Casey a detailed response was provided.

9. Date of next meeting

The next meeting of the Working Group is scheduled to take place on Friday, 4 January 2013 at 12.30 pm. The venue for the meeting will be the 5th Floor Meeting Room, HSC Board Headquarters.