

**Meeting of the PCCS Working Group held on Friday  
4 January 2013 at 12.30 pm in the 5<sup>th</sup> Floor Meeting Room  
HSC Board Headquarters, Linenhall Street Belfast**

<b>Present:</b>	Dean Sullivan (Chair)	HSC Board
	Teresa Magirr	HSC Board
	Philip Moore	HSC Board
	Dr Miriam McCarthy	Public Health Agency
	Dr Frank Casey	Belfast Trust
	Dr Brian Armstrong	Belfast Trust
	Rosie Byrne	Belfast Trust
	Dr David McManus	NIAS
	Sarah Quinlan	Children's Heartbeat Trust
	Julie Greenaway	Children's Heartbeat Trust
	Irwyn McKibbin	Heartbeat NI
	Maeve Hully	Patient Client Council
<b>Observers:</b>	Margaret Rose	DHSSPS
	McNaughton	
	Dr Heather Livingstone	DHSSPS
	Karena McErlean	Parent
	Sam Marshall	Parent
	Nadine McGaffin	Service User

**Item:**

**Action**

1. Apologies

Pat Cullen, PHA  
Dr Nigel Campbell, Primary Care/ SE LCG  
Dr Damien Armstrong, Western Trust  
Clare Caulfield Heartbeat NI  
Jackie Johnston, DHSSPS

2. Consultation Update

Dean Sullivan advised that 603 responses were received by the close of the consultation at 5pm on Friday 21 December. A further 44 responses were

received after the closing date up to close of play on 24 December 2012.

The Working Group agreed that all 647 responses would be included in the post consultation analysis.

### **3. Draft post consultation document**

An initial outline draft of the post consultation document with an early indication of the themes that have been identified by respondents on the Service Specification, Options and Criteria/Weightings was circulated with the papers.

It was noted that the aim of this stage of the process is to identify particular changes that may be required to each of three areas being consulted on with a view to presenting a revised framework to the Minister for consideration. It is not the intention that a preferred option be recommended at this point.

Dr Frank Casey indicated that it would be useful to have the responses analysed by an independent organisation (rather than by Board/PHA staff) to provide assurance on the robustness of the analysis process. Sarah Quinlan added that an independent analysis would be important in terms of public confidence. In this regard she referred to the recent article in the News Letter.

Dean Sullivan responded that this had not been included in the original Project Initiation Document and felt that such a step should not be required. Nonetheless, in response to the issues raised by Working Group members, Mr Sullivan advised that he would consider whether it might be possible to secure some independent scrutiny in the assessment of responses. In addition he noted that, as previously discussed, members of the Working Group would have the opportunity to review the individual responses to ensure that all key areas are picked up during the analysis process.

Dr McManus suggested that copies of the responses be made available to Working Group members to review in advance of discussions at the next meeting.

Dean Sullivan advised that an electronic copy of the responses would be made available by close of play on 4 January 2013 and that upon request hard copies of the responses would be made available to Working Group members (requests have already been received from Sarah Quinlan and Dr Casey).

Dean Sullivan noted that the responses were for Working Group members only and were not for onward circulation.

4. Notes of Previous Meeting

It was noted that the minutes were revised following comments received from Sarah Quinlan.

The revised version circulated with the papers for the meeting were agreed as an accurate record following clarification of the issues referred in section 8.1 to by Dr McCarthy and Dr Casey.

5. Matters Arising

Dean Sullivan noted the matters arising were covered by the other items on the agenda.

6. Update on visit programme.

Dean Sullivan advised that the remaining visits to units outside NI have been arranged for the next few weeks. This visits will take place as follows:

- Liverpool, 7 January;
- Southampton, 14 January;
- Newcastle, 23 January
- Dublin, 28 January (provisional)

Attendance for the visits to the units in England have been confirmed. It was noted that Irwyn McKibbin and

Sarah Quinlan would be attending the visit being planned for Dublin.

7. Patient Experience Workshop

The Patient Experience Workshop will take place during the week commencing 4 February 2013. The workshop will be arranged for a venue in the Antrim area.

The Board will confirm the date in the next week and invitations will be issued.

8. Any other business

8.1 Endorsement of standards in England and Wales

Sarah Quinlan advised that the Children's Heartbeat Trust had written to a range of professional organisations in the UK regarding endorsement of the Safe and Sustainable standards.

A number of organisations have responded indicating that they had not specifically endorsed the standards for application in Northern Ireland.

Dean Sullivan stated that the HSC Board was aware that this was the case and that this was not unusual but added that the organisations represented clinicians across the UK. He added that the consultation allows the opportunity for the public to comment on the applicability of standards to Northern Ireland.

8.2 Services for Teenagers and Adults with CHD

Julie Greenaway, enquired whether the visits that had taken place to date had included a visit or analysis of the teenage/ adult congenital cardiac service provision available. Dr McCarthy advised that while the visits had not specifically addressed this issue, each of the units visited indicated that they had the flexibility to manage children and young people up to

their late teens.

Dr Casey referred to the need to have robust arrangements in place for teenagers and adults with CHD who require surgery within the same timeframe as any revised arrangements for children.

As indicated at previous meetings, Dean Sullivan confirmed that the HSC Board would not take any decision that doesn't improve the balance of services for the population of Northern Ireland.

### **8.3 Transport arrangements**

Dr Casey noted that the current transport arrangements for children who need to be transferred to other units is mainly provided by a private organisation. Dr Casey went on to refer to discussions at previous meetings of the Working Group around the parallel work being taken forward on transport services.

Dean Sullivan confirmed that clarity on the transport arrangements would be provided within the same timescales as the outcome of the consultation process and the outcome would be available before a final decision is made on a preferred option.

### **9. Date of next meeting**

The next meeting of the Working Group is scheduled to take place on Friday, 11 January 2013 at 12.30 pm. The venue for the meeting will be the 5<sup>th</sup> Floor Meeting Room, HSC Board Headquarters.