

**Meeting of the PCCS Working Group held on Friday 19
October 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
	Dr M McCarthy	Public Health Agency
	Dr Nigel Campbell	SE LCG / Primary Care
	Dr F Casey	Belfast Trust
	Dr Brian Armstrong	Belfast Trust
	Rosie Byrne	Belfast Trust
	Dr David McManus	NIAS
	Sarah Quinlan	Children's Heartbeat Trust
	Julie Greenaway	Parent Representative
	Irwyn McKibbin	Heartbeat NI
Observer:	Margaret Rose McNaughton	DHSSPS

- | <u>Item:</u> | <u>Action</u> |
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| 1. <u>Apologies</u> | |
| | Pat Cullen, Public Health Agency
Dr Damien Armstrong, Western Trust
Maeve Hully, Patient Client Council |
| 2. <u>Notes of Previous Meeting</u> | |
| | The minutes of the meeting held on Friday, 5 October
2012 were agreed as an accurate record. |
| 3. <u>Matters Arising</u> | |
| | Dean Sullivan noted that many of the items arising
were covered under item 4 of the agenda –
Communication process and update paper. |

3.1 Summary of the proposed events/meetings

Summary paper attached for noting.

Sarah Quinlan and Irwyn McKibbin reported that approximately 30 parent representatives have indicated an interest in participating in the Focus Groups. It was agreed to extend the deadline for a further week.

Parent Groups
HSC Board

Philip Moore will seek to confirm dates and venues within the next week as this would be helpful in advising parents when seeking nominees.

HSC Board

The suggested locations of Omagh, Belfast and Craigavon for the 3 Focus Group meetings were agreed by the Working Group as suitable.

If it was necessary to schedule a further date it was agreed this could be accommodated.

There are 5 Public Meetings proposed to be held in Belfast, Derry, Ballymena, Enniskillen and Portadown. Dates and venues to be confirmed.

The Patient Experience Workshop is set up to draw on the quality of service and patient experience of parents and children and explore the whole patient journey for patients referred to another provider outside NI. Date and venue to be confirmed.

HSC Board

3.2 Correspondence received from Dr Frank Casey and Sarah Quinlan

Dean Sullivan made reference to correspondence received from Dr Casey and Sarah Quinlan. Copies were shared with the Working Group.

Dean Sullivan addressed the issues raised in Dr Casey's correspondence.

Dr Casey expressed reservations about the proposal for visits to be carried out to 7 specialist centres in

England and Scotland. In particular Dr Casey reported that only 2 of the centres have 4 surgeons and undertake at least 400 procedures.

Dean Sullivan acknowledged the issues raised by Dr Casey and advised that the HSCB and PHA representatives had also been considering the best way to proceed on this matter. He highlighted that it was the intention to visit to those units who had expressed an interest in forming a network with NI, without prejudice to the outcome of the consultation, as documented in the Project Initiation Document and discussed at previous Working Group meetings. The visits are intended to be information gathering to permit robust information on the deliverability of potential service options to be provided to the Minister to inform his decision-making.

As the HSC Board had received positive responses from 5 of the units approached it has been agreed to only visit those 5, which would not include Glasgow, Birmingham or Bristol. There will be 4 visits in total as it is expected that the 2 units in London will take place on the one day.

A further separate visit will be made to Dublin.

Dr Casey also suggested that it would be helpful to receive more detailed information on capacity etc. in advance of the visits.

It was agreed that further information would be sought from each of the units and in particular members accepted that a copy of the units report of the Safe and Sustainable visit, coupled with an update on developments and staffing since then would be very informative.

HSC Board

The Working Group agreed to move ahead with the visits as outlined above, with the core team consisting of HSC Board, PHA representatives, a representative from Heartbeat NI and clinical representatives from the Belfast Trust carrying out the visits.

HSC Board

Dean Sullivan addressed the issues raised in Sarah Quinlan's email correspondence.

The decision by the Children's Heartbeat Trust not to participate on behalf of the Working Group in either the Public Meetings or the visits to the units in the UK was noted.

Mr Sullivan advised that he would respond in writing to her email of 17 October. In regard to Sarah's concern about the timing of visits and the potential of such visits pre-empting a Ministerial decision, Dean advised of the need to undertake the visits in parallel with the consultation process and set out in the PID and agreed by all members of the Working Group.

3.3 Format of Public Meetings / Focus Groups

Members agreed that the purpose of the public meetings is to permit public engagement as part the consultation. A panel of individuals, comprising Working Group members, will attend to summarise the issue, to set out the main components of the consultation document and to seek views on the matters contained in the consultation questions.

Sarah Quinlan expressed concerns that given the remit of the charity to provide support to parents and families affected by congenital heart disease in Northern Ireland, it would be disingenuous to sit on a panel at public meetings and feel constrained in the opinions and views they could voice. Sarah stated that the charity's first responsibility was to reflect the views of the parents and families they represent.

Sarah also noted that after taking legal advice the charity would not be participating in any of the visits to centres in England as they had serious concerns that the timing of such visits, with an ongoing public consultation was inappropriate.

Dean Sullivan acknowledged the request from

Children's Heartbeat Trust regarding not participating as panel members at the Public Meetings.

Nonetheless, members expressed some concerns if Working Group members were to participate as members of the audience as this would have the potential to cause confusion.

It was accepted that any member attending a public meeting in any capacity remains a member of the Working Group. It was suggested that it would be appropriate to have someone independent of the consultation process to facilitate the event. Philip Moore will follow this up.

HSC Board

Suggested Panel members to include HSC Board members, Irwyn/Clare, representation from the Patient Client Council and clinical and management representation from Belfast Trust.

Format will include

- a presentation providing a description of paediatric cardiac surgery, interventional cardiology and an overview of current services;**
- a summary of each of the areas within the consultation document and feedback on each question;**
- A Q&A session.**

The Working Group agreed that any media in attendance would not be permitted to film or record during the meeting.

The Working Group agreed that it would be beneficial to have a counsellor available at the Public meetings.

It was agreed that the format for the Focus Group sessions needs further refinement. It was suggested that these events would last around 90 minutes with 12 – 14 in attendance with minimal representation from the Working Group. It was suggested 1 member from the Working Group with an independent

facilitator.

4. Next Steps

The following next steps were agreed:

- Write to 5 units and confirm dates of visits;
- Philip Moore to update the paper to reflect location, venue and time of public meetings (8pm start), focus group and workshop;
- Philip Moore to draft a detailed programme for each public meeting
- Confirm with parent groups on the indicated numbers for the focus group meetings;
- HSC Board to complete presentation for use at Public meetings.

5. AOB

5.1 Meeting with Dublin Unit

A meeting is scheduled to take place on 9 November 2012 in Dundalk with representatives from HSE. A senior official from the HSC Mr G O'Dwyer, has been identified to liaise with DHSSPS and HSC Board. Mr G O'Dwyer will attend the meeting on the 9th November.

6. Date of next meeting

The next meeting of the Working Group will take place on Friday, 16 November 2012 between 12 noon and 2pm. The venue for the meeting will be the 5th Floor Meeting Room, HSC Board Headquarters.

Meetings will continue to take place fortnightly thereafter, with further dates scheduled for Friday, 30 November and Friday 14 December.