

**Meeting of the PCCS Working Group held on Friday
12 April 2013 at 12.30 pm 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 Nigel Campbell	SE LCG / Primary Care
	Dr Miriam McCarthy	Public Health Agency
	Denise Boulter	Public Health Agency
	Dr Brian Armstrong	Belfast Trust
	Dr Frank Casey	Belfast Trust
	Rosie Byrne	Belfast Trust
	Sarah Quinlan	Children's Heartbeat Trust
	Julie Greenaway	Children's Heartbeat Trust
	Dr Nigel Ruddell	NIAS

Observers:	John Mone	HSC Board
	Jackie Johnston	DHSSPS
	Karena McErlean	Parent
	Joanne Clifford	Parent
	Orla McElroy	Parent
	Sam Marshall	Parent
	Nadine McGaffin	Patient

Item:

1. Apologies

Action

Dr David McManus, NIAS
Irwyn McKibbin, Heartbeat NI
Clare Caulfield, Heartbeat NI
Maeve Hully, Patient and Client Council

2. Minutes of previous meeting held on 29 March 2013

Sarah Quinlan sought the following amendments to
the minutes from the meeting held on 29 March 2013:

Page 2 – after the second paragraph under section 3.1 it was agreed that the following line would be included: *'The Children's Heartbeat Trust's view was that the ultimate decision on this matter would be at Ministerial level in both jurisdictions'*

Page 3 – third paragraph – the line beginning Dean Sullivan noted... should be revised to state *'It has been previously advised...'*

Page 5 – Any other business – Sarah Quinlan asked that it be recorded that *'Dean Sullivan confirmed that, as indicated at the previous meeting on 22 March 2013, the Minister was provided with the post consultation paper agreed by the Working Group and the HSC Board. No recommendation has been made to the Minister at this time in relation to a preferred option.'*

Sarah Quinlan queried more generally the robustness of the minuting process. In response it was noted that the minutes from each meeting are circulated in draft format for comments by all members. Dean Sullivan highlighted that all minutes since the Working Group's establishment have been seen in draft and agreed by the Working Group.

Other members of the Working Group were asked for comments in respect of the process for agreeing the minutes from the Working Group meetings; members indicated they were content with the process.

3. Matters Arising

3.1 Letter from Belfast Trust

Dean Sullivan noted that, further to discussion at the last meeting, the response from the Belfast Trust regarding the requirements and timescales for expanding capacity to accommodate additional activity had been circulated with the papers for the meeting for information.

3.2 E-mail from Irwyn McKibbin, Heartbeat NI.

Dean Sullivan referred to e-mail correspondence from Irwyn McKibbin following discussion at the previous meeting. Two specific issues were raised.

The first issue related to a comment from Children's Heartbeat Trust recorded in the previous minutes on page 4. It was noted that the comment had been taken out of context and that the minutes from the meeting on 29 March would be revised to read as follows: *'Sarah Quinlan asked that the Children's Heartbeat Trust view be recorded that the charity's assessment against the safe and high quality criterion was that any option that does not include a surgical service in Belfast cannot meet this criterion.'*

Dean Sullivan will follow this up with Irwyn McKibbin.

The second issue raised in the e-mail related to the identification of a preferred option. The Heartbeat NI representatives on the Working Group were unable to attend today's meeting but wanted to advise that the preferred option from Heartbeat NI was that while they would prefer to see most activity take place in Dublin, for the sake of parental choice, there should be an avenue left open for surgery to take place in GB.

3.3 Proposed Model for Future Delivery of Paediatric Cardiac Services

Further to discussion at the previous meeting, Dr Casey presented a paper on behalf of the Belfast paediatric cardiology team which presented two aspects. The first part of the paper indicated the preferable option from clinicians perspective, namely a model with surgery on two sites in Belfast and Dublin on an all-island basis with the key components for service delivery being a substantial expansion in the number of children receiving surgery in Belfast and cover available on a 24/7 basis in Belfast (and Dublin). The paper went on to set out the detail of a proposed service model centred around a surgical

service provided in Dublin on the basis that the key components necessary to deliver a two-centre model are not currently available in Belfast.

It was noted that there the proposals included a requirement to further enhance services for children in Northern Ireland with congenital heart disease.

Dean Sullivan noted that irrespective of the preferred option, the HSC Board acknowledges that enhancement of the model of paediatric cardiology service provision for Northern Ireland will be a key priority.

4. Draft Preferred Option Paper

The latest draft of the preferred option paper was circulated with the papers for the meeting.

Dean Sullivan noted that a number of minor amendments had been made to sections 1 – 4 to reflect comments made at the last meeting. The document circulated also includes a first draft of section 5 which sets out an initial qualitative assessment of the higher scoring options to facilitate discussion.

The Working Group members present did not highlight any amendments to sections 1 – 4.

With regard to section 5, it was noted that two options scored significantly higher than the others. Namely, Option 2 (Dublin only) and Option 5 (Dublin and GB).

It was agreed during discussion at previous meetings, that whilst the scoring of the options is important, the Working Group would also take appropriate account of qualitative issues in identifying a preferred option.

The Working Group considered the issues presented in section 5 in identifying a preferred option. Discussion took place regarding issues in respect of access, clinical linkages and service resilience.

Dr Casey noted that in his experience parents will take account of clinical advice in terms of the most appropriate centre for treatment. He added that patient choice is an important issue but stated that the preference for clinicians would be to develop linkages and relationships with one centre recognising that small numbers of patients will, due to their clinical condition, be required to travel to other centres.

On the basis of the scoring exercise and the consideration of the issues set out in section 5, the consensus view of the Working Group was that Option 2 (Dublin only) would be the preferred option.

Julie Greenaway noted that as a parent, any option without a surgical service in Belfast was not satisfactory.

Dean Sullivan noted that the current position is that at most around 110 procedures is the maximum possible level that could be undertaken in Belfast. He further noted that even this maximum level of activity was materially below the required number of procedures to deliver a safe, sustainable and high quality service for children from Northern Ireland.

The Children's Heartbeat Trust representatives on the Working Group referred to issues previously raised in respect of access for emergency cases and as such they indicated that they would not be in a position to agree a document recommending Dublin as the preferred option. Also as previously discussed the charity felt that a Belfast / Dublin solution needed to be fully explored to Ministerial level.

The charity advised that they intended to submit a minority report which sets out their views. Dean Sullivan agreed to accept such a report.

In terms of next steps, it was agreed that the preferred option document would be updated to include Option 2 as the preferred option. This will be circulated to

Working Group members on Monday 15 April for comments by Wednesday 17 April 2013.

Section 6 (Equality and Human Rights considerations) and Section 7 (Next Steps) will then be circulated to the Working Group on Thursday 18 April in advance of discussions and agreement at the Working Group meeting on Friday 19 April 2013.

Julie Greenaway asked Dr Casey about the care pathway for a child with an emergency (e.g. blocked shunt) if surgery were not available in Belfast. Dr Casey advised that such cases were rare but required immediate action. He referred to a recent case being transferred to Dublin for treatment.

Dr Casey noted that in such circumstances accessing care within a clinically appropriate timescale may be challenging for emergency cases and it is essential that robust care pathways, transport arrangements etc are in place.

5. Any other business

There was no other business raised.

6. Date of next meeting

The next meeting of the PCCS Working Group will be held on Friday, 19 April 2013 at 12.30pm in the 5th floor meeting room, HSC Board headquarters.