

**Meeting of the PCCS Working Group held on Friday
18 January 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	Primary Care/SELCG
	Dr Miriam McCarthy	Public Health Agency
	Pat Cullen	Public Health Agency
	Dr Frank Casey	Belfast Trust
	Dr Brian Armstrong	Belfast Trust
	Rosie Byrne	Belfast Trust
	Sarah Quinlan	Children's Heartbeat Trust
	Julie Greenaway	Children's Heartbeat Trust
	Irwyn McKibbin	Heartbeat NI
	Alison McNulty	Parenting NI
Observers:	Dr Heather Livingstone	DHSSPS
	Joanne Clifford	Parent
	Gerald Clifford	Parent
	Dr Terrence Logan	PHA
	Dr Matthew McCall	Medical Student

Item: **Action**

1. **Apologies**

Dr David McManus, NIAS
Dr Damien Armstrong, Western Trust
Maeve Hully, Patient Client Council
Jackie Johnston, DHSSPS
Margaret Rose McNaughton, DHSSPS
Clare Caulfield, Heartbeat NI

2. **Minutes of Previous Meetings**

The minutes of the meeting on Friday, 4 January 2013 were reissued to include amendments identified at the

last meeting. The revised version was agreed as an accurate record.

The minutes of the last meeting held on Friday, 11 January 2013 were also agreed as an accurate record.

3. Matters Arising

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

4. Update on analysis of consultation responses

Dean Sullivan presented an analysis of the consultation responses which included:

- An updated analysis of the 647 written responses to include quantitative data on the number of respondents who provided comments;
- An analysis of the subset of responses from HSC Organisations and individual professionals as agreed at the last meeting;
- An initial analysis of the additional issues / comments raised at the public meetings and focus group events;
- A series of issues for the Working Group to consider with regard to proposed changes to the Service Specification, Options and Criteria / Weightings as a result of the feedback received from the consultation process.

With regard to the updated analysis of the written responses, Sarah Quinlan noted that a number of comments appeared against more than one of the areas / questions. It was agreed that these would be cross referenced.

Dr Casey noted that a significant number of respondents had provided quotes on their personal experience and suggested that it would be useful to have a few examples of the issues that were raised included in the post consultation document. Working

Group members agreed that this would be a useful addition to the document.

A summary of the issues raised and comments made by the HSC organisations and professionals that responded was presented. Sarah Quinlan asked for a list of the individual responses that were included in this analysis.

It was noted that the majority of the issues raised at the public meetings and focus groups were also included in the written responses to the consultation. Nonetheless, a number of additional comments have been identified from the initial analysis of the transcripts from the public meetings and reports of the focus group events.

The detailed analysis of the additional issues raised will be included in the draft post consultation document. Alison McNulty advised that she had undertaken an initial review of the process for analysing the transcripts from the public meetings and focus group reports and that a further review would take place early next week once this process has been completed.

Dean Sullivan referred to the analysis of the input from the consultation process being substantially complete. A number of slides were presented with a range of issues that have been identified for consideration under the different areas being consulted on (i.e. Service Specification, Options, Criteria / Weightings).

The Working Group considered each of the issues presented and various amendments were proposed to each of the three areas.

Issues in relation to the Service Specification

A detailed discussion took place in respect of the following issues that were identified for consideration by the Working Group:

- Tailoring of standards to N.I. population/geography. Any change required to the draft Service Specification? and Should the Working Group revise the number of procedures to be undertaken in the providing unit?

Sarah Quinlan highlighted the issue around the number of procedures undertaken for the population of Northern Ireland and that the unique geography and population size needed to be taken into account.

Dr Campbell noted that the number of procedures required is linked to the quality and outcomes.

Dr McCarthy added that to deliver a 24/7 service, a minimum of four surgeons are required for the rota and that the number of procedures is then linked to each individual on the rota delivering an agreed volume to maintain skills.

Dr Casey noted that although higher volumes of procedures relate to better outcomes, the figure of 400 procedures is largely related to the number of surgeons required for a rota. It was acknowledged that the outcomes particularly for complex cases are better in units undertaking higher volumes of these procedures.

Dr Casey further noted that of the units in England providing a paediatric cardiac surgical service, only one would currently meet the requirement set out in the draft service specification.

Dr McCarthy suggested that the wording in the draft Service Specification might usefully be amended to include more focus on the delivery of a consistent and robust 24/7 service in which each surgeon undertakes at least 100 procedures, with the added requirement that the unit must be working towards the delivery of 400 procedures annually.

- **Should the Working Group amend section 3 of the Service Specification to reflect total transfer time for emergency retrievals?**

A significant number of respondents raised concerns in respect of the timescales associated with the retrieval / transport of children, specifically in emergency situations. A number of respondents were of the view that the specification should indicate the time for the totality of journey. Working Group members agreed that a time from the clinical decision being made to a child being in the unit where the surgery takes place would be more appropriate.

Dr Casey agreed to draft the wording for a standard for emergency cases and share it with the Working Group for comments.

Furthermore, the Working Group agreed that the current wording regarding the retrieval team being at the referring centre within 3 hours would remain in the specification.

- **Should the Working Group include a specific standard that any provider will provide a service for infants in a neonatal intensive care unit who require patent ductus ligation?**

One area that is not included at present within the draft Service Specification, but that has been raised in a number of the clinical responses and during the exploratory visits to units in England, is in respect of the arrangement for children who require patent ductus ligation. It was agreed that reference would be included in the Service Specification that the providing unit would need to be in a position to provide this service on an outreach basis, consistent with the arrangements being considered in other parts of UK.

- **Should the Working Group amend section 4 (clinical engagement) to include reference to support/advice being available 24/7 (to address the issue of decision making required re: septostomy**

etc)

The Working Group agreed that the current section on clinical engagement should be strengthened and made more explicit in terms of the requirements for Northern Ireland. At present reference is made to the need for MDT discussion for every child requiring surgery. It was agreed that this section should include a requirement for a provider to ensure that the Belfast team have access to 24/7 consultant advice.

Brian Armstrong indicated that this access should be two way, should the providing unit require any information from the staff in Belfast.

- Should the Working Group amend section 5 to improve arrangements for parents/families?

There was agreement from the Working Group that the section on arrangements for parents should be strengthened to highlight that a seamless process is required with the providing unit and that robust liaison arrangements are in place between the cardiology service in RBHSC and the unit providing the surgical service.

- Should the Working Group consider expanding the age group to be considered?

A significant number of respondents referred to the need to consider the ongoing needs for teenagers / young adults and adults. This has been discussed previously by the Working Group and although it was acknowledged that this cohort of patients was not included in the remit of this process, there was agreement that the wording of the specification be amended specifically. Reference will be made to the need for a provider to accommodate all children and young people who require to be cared for in a paediatric environment. Also, the statement around transitional arrangements will be expanded to indicate that ideally the provider should have links or arrangements for ensuring the provision of services

for grown ups with congenital heart disease (GUCH).

Issues in relation to the Options

The Working Group agreed that on the basis of the consultation responses received the following two additional options should be included:

- Bring consultants from other units to Belfast to undertake surgery
- Increase capacity in Belfast to make sustainable / Centre of Excellence / bring children to Belfast from elsewhere.

Issues in relation to the Criteria / Weightings

The issues identified for consideration in finalising the criteria and weightings were:

- Should the Working Group split criterion 1 into two parts to separate safety and sustainability?

The Working Group agreed that safety and sustainability should be separated into two criteria and that there would then be seven criteria in total.

Brian Armstrong suggested that sustainability should be linked to deliverability when amending the criteria. This was agreed by Working Group members.

- Should safety and access be considered under a single criterion?

Following discussion, the Working Group agreed that safety and accessibility should remain as two separate criteria.

- When the number and description of criteria are agreed:
 - What is the ranking of each in terms of importance?

- What is the weighting to be reflected for each criterion?

Dean Sullivan noted that the next point to consider was the ranking of each of the criteria. There was agreement that Safety and Emergency/Urgent were the most important and that effective use of resources was the lowest priority.

The revised ranking of the criteria proposed was broadly as follows:

- Safety and high quality
- Emergency / urgent cases
- Accessibility
- Sustainability / deliverability
- Volume / Waiting Times
- Partnership Working / Clinical Linkages
- Use of Resources

It was agreed that further discussion on the weightings associated with each criterion would take place at the next meeting.

5. Next Steps

Dean Sullivan advised that the draft post consultation document updated to reflect the outcome of the discussions at today's meeting, would be circulated for the next meeting. The document will include:

- Overview of consultation process
- Detail of responses to consultation
- Revised Service Specification
- Revised Generic Options
- Revised Criteria/Weightings
- Consideration of equality implications

As discussed previously the document will set out the proposed framework for making a decision on the future model for paediatric cardiac surgery. Once finalised this will be forwarded for Ministerial approval.

Subject to approval, the framework will then be used to develop a formal recommendation on the preferred option thereafter.

6. Patient Experience Workshop

Dean Sullivan confirmed that the patient experience workshop will be held on Tuesday, 5 February 2013 6-9pm, in the Dunsilly Hotel, Antrim. The venue is currently booked for between 30 and 40 participants.

The workshop will be facilitated by Parenting NI. Alison McNulty advised that Parenting NI will invite those parents on their database from the Focus Group meetings. Children's Heartbeat Trust and Heartbeat NI will notify their members of the date.

Brian Armstrong agreed to ensure that the cardiac liaison and transport liaison staff from RBHSC are invited to attend.

7. Any other business

7.1 Working Group visits to PCCS Units

Dr Casey extended an invitation for the Working Group to visit RBHSC as part of the series of visits to potential providing units. It was agreed that the visit would ideally be arranged to take place during the week commencing 28 January 2013.

8. Date of the next meeting

The next meeting of the Working Group is scheduled to take place on Friday, 25 January 2013 at 12.30 pm. The venue for the meeting will be the 5th Floor Meeting Room, HSC Board Headquarters.