

**Meeting of the PCCS Working Group held on Friday
25 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 |
| | Sally Kelly | HSC Board |
| | Dr Nigel Campbell | Primary Care/SELCG |
| | Dr Miriam McCarthy | Public Health Agency |
| | Dr Frank Casey | Belfast Trust |
| | Mr Alastair Graham | 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 |
| | Maeve Hully | Patient and Client Council |

| | | |
|-------------------|------------------------|-----------|
| Observers: | John Mone | HSC Board |
| | Jackie Johnston | DHSSPS |
| | Dr Heather Livingstone | DHSSPS |
| | Joanne Clifford | Parent |
| | Gerald Clifford | Parent |
| | Karena McErlean | Parent |
| | Jim O Neill | Parent |
| | Samantha Marshall | Parent |
| | Dr Terrence Logan | PHA |

Item:

Action

1. Apologies

Philip Moore, HSC Board
Dr David McManus, NIAS

2. Minutes of Previous Meeting – 18 January 2013

Due to technical IT issues, the minutes of the previous meeting were only issued earlier today. It was agreed that Working Group members would be given the

opportunity to review the content with a view to signing these off at the next meeting.

3. Matters Arising

Dean Sullivan noted the main issue for discussion at today's meeting was the post consultation document which is included on the agenda.

The other issue arising from the previous meeting was in respect of the feedback on the analysis of public meeting transcripts and focus group reports

Alison McNulty updated the Working Group on her review of the process for analysis the transcripts of the public meetings and the reports from the focus groups. It was noted that the approach taken was similar to that used for analysing the written responses. A couple of minor issues were identified in respect of interpretation of the comments, as a result, revisions to have been made to the comments recorded. Alison confirmed that the process and methodology applied was robust.

In response to a query from Sarah Quinlan, it was confirmed that the public transcripts and focus group reports would be made available for Working Group members. Copies of the documents, redacted to remove any personally identifiable information will be included on the Board's website and hard copies or copies in other formats will be made available to members of the public on request.

4. Draft Post Consultation Document

Dean Sullivan referred to the draft post consultation document that was circulated with the papers for the meeting and outlined that intention to go through this in detail at today's meeting with a view to identifying any immediate issues that required to be amended. He noted that there would be the opportunity for Working Group members to review the document in more detail over coming days and respond with any

other comments no later than lunchtime on Wednesday 30 January 2013.

It is intended that a final draft will be issued to the Working Group by lunchtime on Thursday 31 January for discussion and sign off at the next meeting that is scheduled to be held on Friday 1 February 2013.

Review of the draft post consultation document:

Section 1, Background – The Working Group did not identify any changes to this section of the document.

Section 2, Consultation Process – The Working Group did not identify any changes to this section of the document.

Section 3, Process for analysing input to the consultation process – Dean Sullivan noted that this section had been included following the discussion at the previous two meetings regarding the need to ensure that the process for analysing the written responses, the transcripts from public meetings and the reports from the focus groups was transparent, objective and robust. It was noted that the information presented could potentially be included in the previous section (Consultation Process).

Following discussion, the Working Group agreed that this should be a separate section in the document. The Working Group did not identify any changes to this section of the document.

Section 4, Summary of Written Responses – The content of this section of the document is based on the information presented at the last meeting. It was noted that a sample of the patient experience issues raised by respondents is still to be included in this section. This will be included at the end of this section of the document.

Sarah Quinlan stated that it might be useful to supplement the information included in this section

with some charts. The Working Group agreed that this would be explored.

Maeve Hully stated that it might be useful to highlight some of the key messages from the information presented in this section. It was agreed that an Executive Summary to the document would be prepared to include the key areas highlighted by respondents.

Section 5, Summary of Response from HSC organisations and individual professionals – As with section 4, the content of this section of the document is based on the information presented at the last meeting. This section follows the same format as section 4.

It was agreed that there would be some further analysis of this information with a view to including an indication of the number of respondents that made each comment.

Sarah Quinlan also noted that some responses in this category stated that options 2, 3 and 5 should be ruled out and asked that this be included.

Section 6, Summary of issues raised at Public Meetings and Focus Groups – This section has been updated since the previous meeting to include the substantive list of additional issues raised at the public meetings and focus groups. A full list of all the issues raised at these events is included as annex 4.

Section 7, Proposed changes to the Service Specification, Options and Criteria / Weightings – This section outlines the key issues for consideration as identified at the previous meeting and proposes changes to the Service Specification, Options and Criteria / Weightings on the basis of the issues raised.

Maeve Hully noted that in terms of presentation, the document goes straight from the comments and input received to the consultation to a section on proposed

changes. It was suggested that the list of issues to be considered in respect of the Service Specification, Options and Criteria / Weightings be set out in a separate section.

The Working Group agreed that this would be useful. The current section 7 will become section 8 and a new section '*Issues for Consideration by the Working Group*' will be added to the document.

In terms of section 7 as presented in the document being considered at the meeting, a number of comments were made and amendments identified.

Service Specification

A list of seven issues was identified for consideration. The Working Group did not identify any additional issues. As outlined earlier in the meeting, there would be the opportunity for Working Group members to review the document in more detail over coming days and respond with any other comments / issues no later than lunchtime on Wednesday 30 January 2013.

Issue 1 (Revision of standards to tailor for NI population/geography) – Sarah Quinlan queried whether the 400 procedures referred to were across a service or was the intention that these are delivered in one location.

Dean Sullivan advised that the standard is related to activity in a centre i.e. one site. As discussed at the previous meeting this relates to the wider issue of the staffing required to deliver a service on a 24/7 basis and the recommended levels of activity for each surgeon within this service. Revised wording for the Service Specification had been suggested on this basis.

Dr Casey indicated that the revised wording in the amended Service Specification at annex 5 was more appropriate. It was suggested that with a view to reaching agreement on this issue that the word must

be working towards a minimum 400 procedures ... be replace with should.

The Working Group agreed to the revision above in relation to the Service Specification.

Issue 2 (Access to services - Emergency transfers and retrievals) – Dean Sullivan noted that the Service Specification had been amended on the basis of discussions at the last meeting, specifically to split the transfer time requirements for emergency and urgent cases. Dr Casey agreed to consider the specific wording around the appropriate timescales for emergency cases for inclusion in the final Service Specification. In the interim, it was agreed that the reference to 'true' emergencies be removed from the wording.

The revised wording will then be considered at the next meeting.

Issue 3 (Patent ductus ligation) – The proposed additional wording in respect of this issue refers to the service being delivered on an outreach basis. Sarah Quinlan queried if this wording was relevant if a surgical service was available in Belfast. It was noted that if this was the case, technically the service would still be provided on an outreach basis across the different hospital facilities on the Royal Hospital site.

The Working Group agreed to the proposed wording on this issue.

Issue 4 (Inclusion of wording on diagnostic catheterisation) – The Working Group agreed to the proposed wording on this issue.

Issue 5 (24/7 access to consultant surgical advice)- The Working Group agreed to the proposed wording on this issue.

Issue 6 (Improving arrangements for parents/families) – The Working Group agreed to the proposed wording

with a further extension to include specific reference to practical, emotional and financial support.

Issue 7 (Age group of patients) – The Working Group agreed to the proposed wording without the final paragraph on the current activity.

The amendments will be made to this section of the document and the proposed Service Specification to reflect the discussions above.

Options

There were two additional options identified by a significant number of respondents. The Working Group agreed that these would be added to the original list to give eight options in total.

Julie Greenaway referred to the significant number of responses that indicated a preference for option 4 and suggested that this be included in this section. The Working Group agreed that this was an important issue but felt that it would be more appropriate for this to be included in the executive summary.

No other areas were identified by the Working Group for inclusion in this section.

Criteria

Two issues were identified for consideration.

Issue 1 (Split criterion 1 - Safe and Sustainable) - The Working Group agreed that in light of the significant number of responses that had suggested this amendment that it would be appropriate for these areas to be considered separately and that the number of criteria be increased from 6 to 7.

Proposed wording for the new sustainability / deliverability criterion was included in the draft document. It was agreed that Working Group members would consider this and respond with any

comments by lunchtime on Wednesday 30 January 2013.

Issue 2 (Amend criterion 3 to include reference to diagnostic catheterisation capacity) – The Working Group agreed that it would be appropriate to include a reference to the potential need for the providing centre to deliver diagnostic catheterisation activity.

Sarah Quinlan suggested that reference is also made to activity for older teenagers and adults. Working Group members noted that this issue had been appropriately reflected in the Service Specification.

Weightings

The responses to the consultation identified three issues for consideration:

- **Criterion 2 (Emergencies and Urgent Cases)** weighting should be higher and/or the same as safety
- **Criterion 4 (Accessibility)** weighting should be higher and/or the same as safety
- **Criterion 5 (Clinical Linkages)** weighting should be higher

It was noted that these areas needed to be considered in the context of the number of criteria being increased from 6 to 7.

The Working Group discussed the proposed ranking of the revised criteria and then the weighting associated with each. The Working Group agreed that it would be reasonable to apportion equal weightings to safety and quality and emergency / urgent cases. The Working Group agreed that geographic accessibility did not justify an equivalent weighting. Following a detailed discussion on this issue, the final proposed list of criteria (with the weighting in brackets) is as follows:

- **Safety and quality (50);**

- Emergency / urgent cases (50);
- Accessibility (35);
- Sustainability / deliverability (35);
- Volume / Waiting Times (25);
- Partnership working / Clinical Linkages (25); and
- Use of resources (10)

Section 8, Equality Considerations – With the revisions referred to above, this will become section 9 of the revised document. A draft of the equality section of the document will be finalised over the coming days and forwarded to Working Group members for consideration in advance of the next meeting.

Section 9, Conclusions and next steps – With the revisions referred to above, this will become section 10 of the revised document. Working Group members present did not identify any changes to this section of the document.

As outlined above a revised final draft of the post consultation document will be circulated to Working Group members by lunchtime on Thursday 31 January for discussion and sign off at the next meeting.

5. **Update on visit programme**

Dr McCarthy provided feedback on the visit programme to other paediatric cardiac surgery centres. It was noted that visits have taken place to Evalina, Great Ormond St, Alder Hey, Southampton and Freeman's Hospital.

The visit to Our Lady's Hospital in Dublin will take place on Monday 28 January and the visit to RBHSC will take place during the week commencing 11 February 2013.

Dr McCarthy highlighted that there had been consistency in terms of the team that has visited each

centre with Board, PHA, Parent and Belfast Trust representation at each visit.

As outlined previously, the visits were exploratory and this was made clear to each of the centres that were visited.

The visits provided an excellent opportunity to meet with the clinical teams all of whom were enthusiastic about strengthening links with Belfast.

The visits included discussions with parents where possible and a visit to parent accommodation.

Irwyn McKibbin commented that the standard of parent accommodation varied across centres and also noted that some centres demonstrated excellent support was provided to parents.

6. Any other business

6.1 Patient Experience Workshop

Alison McNulty advised that the invitation to the workshop had been issued earlier today to those parents on the circulation list from the focus group meetings. The invitation has also been shared with Sarah Quinlan and Irwyn McKibbin to share with other parents.

It was confirmed that the workshop will take place on Tuesday 5 February from 6.30pm in the Dunsilly Hotel, Antrim.

7. Date of the next meeting

The next meeting of the Working Group is scheduled to take place on Friday, 1 February 2013 at 12.30 pm. The venue for the meeting will be the 5th Floor Meeting Room, HSC Board Headquarters.