Children's Congenital Heart Services



Specialised Services

MINUTES

Networks Sub-Group (Clinical Implementation Advisory Group) Tuesday 15th January 2013 Room 6LM1, Stephenson House, 75 Hampstead Road, London, NW1 2PL

Attendee	Representing	Role	
Ann Jarvis	Chair	Acute Portfolio Director (Specialised Commissioning) Medical Directorate, NHSCB	
Angie Johnson	Royal College of Nursing	Matron, Paediatric Cardiothoracic Services, Freeman Hospital, The Newcastle upon Tyne Hospitals NHS Foundation Trust	
Dr Ari Kannivelu	Paediatricians with Expertise in Cardiology Special Interest Group	Consultant Paediatrician (Cardiology), The Shrewsbury and Telford Hospital NHS Trust	
Professor Basky Thilaganathan	Royal College of Obstetrics and Gynaecology	Professor of Fetal Medicine, St George's Healthcare NHS Trust	
Professor Deirdre Kelly	Clinical Implementation Advisory Group	Professor of Paediatric Hepatology at Birmingham Children's Hospital NHS Foundation Trust	
Dr Graham Stuart	Congenital Heart Services Clinical Reference Group	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust	
Dr Peter-Marc Fortune	Paediatric Intensive Care Society	Consultant Paediatric Intensivist and Clinical Director of Critical Care, Central Manchester University Hospitals NHS Foundation Trust	
Dr Ravi Gill	Association of Cardiothoracic Anaesthetists	Consultant in Cardiac Anaesthesia and Intensive Care Medicine, Southampton University Hospitals NHS Foundation Trust	
Dr Rob Martin	British Congenital Cardiac Association (President Elect)	Consultant in Paediatric and Adult Congenital Cardiology, University Hospitals of Bristol NHS Foundation Trust	
Dr Sara O'Curry	British Psychological Society	Consultant Clinical Psychologist specialising in Paediatric Cardiology, Great Ormond Street Hospital for Children NHS Foundation Trust	
Michael Wilson	NHSCB	Interim Implementation Programme Director	
Debbie Hodges	NHSCB	Interim Implementation Project Officer	

Apologies

Apologica				
Name	Representing	Role		
Jeremy Glyde	NHSCB	Programme Director, Safe and Sustainable, National Specialised Commissioning Team		
Mr Leslie Hamilton	Society for Cardiothoracic Surgery of Great Britain and Ireland (Past President)	Consultant Cardiac Surgeon and former Deputy Chair of Safe and Sustainable Steering Group, The Newcastle-upon-Tyne Hospitals NHS Foundation Trust		
Dr Tony Salmon	British Congenital Cardiac Association (President)	Consultant in Paediatric and Adult Congenital Cardiology, Southampton University Hospitals NHS Foundation Trust		

	Action
1: Introduction and apologies for absence	
The Chair opened the meeting. Apologies had been received from Jeremy Glyde, Mr Leslie Hamilton and Dr Tony	
Salmon.	
2: Minutes of the previous meeting	
The minutes of the previous meeting were approved.	
3: Action log and matters arising The Chair caked for undertee on the amber and red items on the action log	
The Chair asked for updates on the amber and red items on the action log.	
Action 4 - Capture learning on nurse network functions and practice from Cardiff and Southampton	
Deferred until the next meeting after the nurses workshop.	AJo
Action 7 - Hannah Weaver to circulate RM's document on delivery of care in district centres	
Dr Rob Martin confirmed that the documentation had been circulated. Michael Wilson said he did not recall receiving a copy. Dr Rob Martin said that he would	
send Michael Wilson a further copy. Subject to this, this action was considered complete.	RM
Action 10 - Nurses' group to complete further work making recommendations	
on specialist nurse roles	
Deferred until the next meeting after the nurses workshop.	AJo
Action 11 - Conduct baseline assessment of specialist nurse staffing and roles compared to the standards, by unit	
This item would no longer be addressed by the group but would be picked up by	
local commissioners as part of the programme plan.	
Action 12 - Develop recommendations for nurse liaison role Deferred until the next meeting after the nurses workshop.	
Action 13 - Retrieval network guidelines to be sent to Michael Wilson Received - the item was therefore closed.	

Actions 15&16 (2.1/2.2) - Suggested revised wording re the reference to specialist nursing to be sent to Michael Wilson

Angie Johnson agreed to provide this in order to allow the minutes to be finalised.

AJo

Action 17 (3.1) - Feedback from 16th January workshop re nursing network roles

Deferred until the next meeting after the nurses workshop.

AJo

Action 18 (3.2) - Comments on the pathway for prenatal diagnosis of suspected cardiac defects to be sent to \mbox{MW}

No comments had been received.

There was a discussion about the guidelines on prenatal diagnosis. Dr Graham Stuart informed the meeting that the NHSCB was consulting on the Fetal Service Specification until 25th January. Professor Thilaganathan stated that the Fetal Maternal Child Health Group of the National Screening Committee (NSC) would provide a simplified version of the guidelines on prenatal diagnosis within six months. The pathway developed by the group should be reviewed against the specification and updated guidance as they are finalised.

Action 19 (3.3) – Children's Acute Transport Services (CATS) documents to be circulated to group members

Received - the item was therefore closed.

Action 22 (5.1) - PID to include a list of agreed job descriptions and competencies for Network Director, Clinical Lead and Lead Nurse Considered as an agenda item.

Action 25 (10.1) – To ascertain whether the Oxford and Southampton Network wished to send a representative

Dr Tony Salmon to recommend.

TS

Action 27 (11.1) – Dates of future meetings to be circulated

The Chair confirmed that dates of future meetings had been circulated.

ACTIONS:

- 1. Angie Johnson to capture learning on nurse network functions and practice from Cardiff and Southampton
- 2. Dr Rob Martin to resend document on delivery of care in district centres to Michael Wilson
- 3. Angie Johnson to complete further work making recommendations on specialist nursing roles
- 4. Angie Johnson to send revised wording re reference to specialist nursing to Michael Wilson to enable minutes from previous meeting to be amended
- 5. Angie Johnson to feedback following nurses workshop
- 6. Dr Tony Salmon to make a recommendation for a representative from the Oxford and Southampton Network

4: Terms of Reference (revised)

Michael Wilson provided members with an updated version of the Terms of Reference indicating changes made since the previous meeting.

Mr Wilson advised the meeting that the sections on programme scope and objectives had been discussed during work in a variety of groups and that this was now standard information appearing on all terms of reference for the programme.

Mr Wilson talked through the amendments since the last meeting.

Dr Peter-Marc Fortune sought clarification on the scope in relation to ECMO as he had heard it reported that it was intended that all surgical centres should provide ECMO. Michael Wilson to seek clarification from Jo Sheehan.

MW

Dr Graham Stuart observed that the introduction to the terms of reference referred to services in England and there was no mention of Wales. It was agreed that the terms of reference should be shared with and agreed by a representative from Wales.

MW

Professor Kelly stated that as she was no longer chairing the group she would attend only 'by invitation'.

Subject to these amendments and ensuring consistent wording with those of the programme board the group agreed to sign off the terms of reference.

MW

ACTIONS:

- 1. Michael Wilson to seek clarification from Jo Sheehan with regards to the current position on ECMO
- 2. Michael Wilson to agree with a representative from the NHS in Wales the references to Wales in the terms of reference
- 3. Michael Wilson to amend terms of reference as agreed

5: Network Specification update

Draft proposals on CCH network specification & NHSCB specification

Michael Wilson had produced a revised version of the draft proposals on CCH (Children's Congenital Heart) network specification document presented at the last meeting reflecting comments received.

This work was then needed by the NHS Commissioning Board (NHSCB) for incorporation into the commissioning specifications that were to be issued alongside other Operational Delivery Networks (ODNs). Michael Wilson had therefore worked with the NHSCB to produce another document to meet this need. This document had been completed and had now been sent out to area teams. Due to the tight deadline (21st December), the paper had been sent out without the formal approval of this group, but approval had been given by Caroline Taylor (Senior Responsible Owner) and Professor Deirdre Kelly.

The Chair explained that the NHSCB was seeking to have formally commissioned ODNs in place for April. In the case of children's congenital heart networks however this would not be possible given the on-going judicial review, and area teams had been instructed to introduce them at the appropriate time. She confirmed that 0.1% of CQUIN (Commissioning for Quality Innovation) funding would be available this

year for ODNs but that in future network costs would be picked up in tariff.

Dr Graham Stuart asked for clarification on the processes involved in allocating the money. The Chair explained that the way in which the funding was distributed between ODNs would be determined at a local level by the NHSCB area teams to reflect local priorities. Funding would be provided to the network host organisation. Networks would need to agree their work programme with commissioners.

Dr Peter-Marc Fortune pointed out that the NHSCB specification described repatriation as the responsibility of transport teams, but that currently provision of repatriation as well as retrieval was only provided by one service in the North East.

Dr Ari Kannivelu asked whether Paediatric Cardiology would be a mandatory ODN. The Chair confirmed that the network model would be mandatory by 2014 but the start date will be confirmed in local areas.

In reviewing appendix 5 & 6, Professor Kelly observed that transition services were not mentioned in the Service Description/Care Pathway in Appendix 6 and Dr Stuart observed that transition was omitted from Appendix 5 under Purpose and Care Pathway. It was agreed that in appendix 5 (the group's specification document) the following amendments would be made:

- 'Purpose' include a phrase to the effect of 'to ensure the safe and effective transition of care to adult services'
- Section 2.1 amend to include Transition Services
- Section 2.1 amend the paragraph commencing 'The network will ensure that' to read 'The network will ensure that children's congenital heart services have appropriate links with all district and tertiary paediatric services, including laboratory services'.
- Section 2.1 amend the last sentence, 'pathway of care' to 'pathway of transition'
- Section 9 Paediatric Intensive Care to be added as an additional network and 'tertiary paediatric' to be replaced by 'other tertiary paediatric networks.'

The Chair advised that while Appendix 5 could be amended Appendix 6 cannot.

Dr Sara O'Curry observed that informing mental health services and social services was not captured in section 2.1. Professor Kelly indicated that the Standards Group would be the logical place to discuss the sharing of information and agreed to speak with Dr Tony Salmon about this.

Dr Graham Stuart asked to whom the network would report and how the networks would interact with each other. It was noted that this was covered in sections 2.2 and 4.0 of Appendix 5.

ACTIONS:

- 1. Michael Wilson to amend the draft proposals on CCH network specification to reflect comments received
- 2. Professor Deirdre Kelly to discuss with Dr Tony Salmon whether the Standards Sub-group is the correct forum for discussing the sharing of information

MW

DK

6: Children's Congenital Heart Networks: Key roles

Michael Wilson presented the paper outlining the roles identified in Safe and Sustainable specific to the network infrastructure. The information had been extracted from the JCPCT documentation and a paper produced by the Royal College of Nursing.

It was noted that the JCPCT had provided information on the Lead Nurse and the Children's Cardiac Specialist Nurse roles. The other key roles of Clinical Lead and Network Director had not been discussed in detail.

Dr Rob Martin observed that the role of 'Paediatrician with Expertise in Cardiology' had been omitted from the document. Dr Graham Stuart observed that the document was somewhat confusing because it included the Children's Cardiac Specialist Nurses, which are not network roles but are key to the working of the network. The same was also true of the Paediatricians with Expertise in Cardiology Special Interest roles. Professor Deirdre Kelly stated that these roles would be covered in the Standards Sub-group. Following further discussion it was agreed that the group should focus on those roles that allow the network to work effectively rather than clinical roles.

The Chair raised the question of how prescriptive the group wished to be with regards to the roles. Professor Kelly said it was important to be prescriptive in terms of the support allocated for the individual roles. The group, in her view, should be clear on clinical and nursing leadership and also ensure that adequate managerial and administrative support was made available.

Professor Deirdre Kelly observed that the Clinical Lead would have a significant role in setting up the network.

Dr Peter-Marc Fortune raised questions about the language used to describe the Clinical Lead. In his view, the role should be open to both doctors and nurses. Professor Kelly agreed that the Clinical Lead could be any discipline but questioned whether if this was a nurse would there then also be a need for a Lead Nurse. In her view the person in this role should be someone with knowledge of patient care. Angie Johnson's view was that a Lead Nurse was desirable as he or she could take responsibility for ensuring the education levels of the specialist nurses across the networks were maintained. This was particularly important because the nurse workforce was so large.

The Chair stated that the role of Clinical Lead was an important role as this person should have clinical credibility as well as leadership and political skills. Michael Wilson observed that the Safe and Sustainable documentation specified that the Clinical Lead be an experienced consultant. As such, the group would need to work through the Clinical Advisory Implementation Group (CIAG) and the Programme Board to reframe the role in a way that was open to both medical and nursing practitioners. Professor Thilaganathan observed it was not necessary to identify what profession the Network Lead be drawn from.

It was agreed that the group wished to recommend that the Network Clinical Lead could be either a suitably experienced doctor or nurse, and that every network leadership team would need to include both a network lead nurse and a network lead consultant, depending on the profession of the appointed Network Clinical Lead.

Professor Thilaganathan highlighted the importance of physician, nursing and managerial input into the network. Dr Ari Kannivelu asked whether the role of the Network Director was a managerial post. It was confirmed that this would be managerial. Professor Deirdre Kelly stated that in her view, networks do not work without management support as they just become clinical forums. It was agreed that appropriate managerial and administrative support would be vital, but that further discussion was needed on whether it was necessary to specify a network director role or to specify the support that would be needed as part of the specification that host organisations would need to meet.

Angie Johnson said that she was supportive of the discussion of nursing roles undertaken in the document. She hoped that the nursing group would sign off the nursing job descriptions in the meeting on 16th January.

The Chair asked if the requirement that the Lead Nurse be a senior member of the clinical team at the tertiary centre excluded any individuals. Angie Johnson clarified that this was about the levels of knowledge required for the role. It would be impossible to lead the team without knowledge of the specialist surgical centre. If the lead nurse was employed elsewhere in the network they would need to work closely with the surgical centre team and lines of accountability would need to be made clear. The Chair asked that the paragraph that begins 'As a senior member of the clinical team' should be reworded to ensure that no-one was excluded. It was suggested that the purpose of the role be amended to state 'The role of the Lead Nurse is to provide professional and clinical leadership and support to nursing staff across the network' taking out within the Specialist Surgical Centre.

Dr Graham Stuart also suggested taking out 'at the Specialist Surgical Centre' in the next sentence, however he was advised by Michael Wilson that this is the wording in the Safe and Sustainable document. It was agreed though that rather than saying 'As a senior member of the clinical team', it should read 'a clinical team'. The Chair suggested that the differences between the group's view and that of the JCPCT be discussed by the full CIAG and if agreed drawn to the attention of the programme board to ensure that any decision is fully informed and formally made.

Dr Graham Stuart asked what the funding arrangements were for centres other than the lead centre within the network. The Chair said the funding would flow with the patient; it was not currently the intention to designate the lead centre as the primary contractor.

Dr Sara O'Curry asked that the reference in section 3.4 to the attendance of psychologists being required during appointments with Paediatric Cardiologists be amended to read 'access to psychologists.'

Actions:

- 1. Michael Wilson to amend the document, Children's Congenital Heart Networks: key roles, to reflect comments made
- 2. Ann Jarvis to advise the programme board of the differing views of the group to those of the JCPCT

7: Pathway Description

MW

AJa

Michael Wilson presented the pathway description and stated that it had been drawn from Safe and Sustainable, the Fetal Anomaly Screening Programme and narrative drawn up by the Clinical Reference Group.

The Chair stated that it was a document to note and Professor Deirdre Kelly asked whether the group felt everything was included.

Professor Basky Thilaganathan stated that the document insofar as it touched on the fetal issues was sufficient.

Professor Kelly questioned the prescriptive nature of the Points of Entry section, given that referrals were sometime accepted from EU and overseas organisations. The group considered that it was not necessary to reference this in the document.

The group agreed the document.

8: Nursing update

Angie Johnson informed the group that a meeting of nurses would take place on 16th January. It was hoped that it would be possible to sign off work on the key nursing roles and job descriptions following this meeting. Ms Johnson would put this work together and send it on to Michael Wilson in time for the next meeting of this group. Professor Kelly explained that different aspects of the work would need to come to this group, the Standards Group and the Clinical Implementation Advisory Group.

AJo

Professor Kelly stated that the Clinical Outcomes Sub-group has not yet been set up but asked that the meeting on 16th consider some potential nursing outcomes for the work of the network. The Chair advised that Ms Johnson avoid issues of compliance with standards.

AJo

Actions:

- 1. Angie Johnson to collate work from the nurse workshop and send to Michael Wilson
- 2. Angie Johnson to consider some potential nursing outcomes for the work of the network with the nurses at the nurses workshop

9: Any other business

Professor Kelly asked how Dr Peter-Marc Fortune would ensure that his work on transport services fed into the group. His view was that the best way was through his presence and contributions within the meetings.

The Chair advised the group that an audit of current retrieval providers against the standards was being undertaken which would provide helpful information. Work was also underway on PICU capacity and potential changes, which would also provide insight.

10: Date and time of next meeting

Monday 25th February 2013 - 15.00–17.00, Room 6LM1 Stephenson House, 75 Hampstead Road, London NW1 2PL