MINUTES
Clinical Implementation Advisory Group – Networks Sub-Group
December 11th 2012
Room 115, MWB Victoria, 10 Greycoat Place, London, SW1P 1SB

Attendee	Representing	Role
Professor Deirdre Kelly	Chair	Professor of Paediatric Hepatology at Birmingham Children's Hospital NHS Foundation Trust
Anne Keatley-Clarke	Children's Heart Federation	Chief Executive, Children's Heart Federation
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 Ari Kannivelu	Paediatricians with Expertise in Cardiology special interest group	Consultant Paediatrician (Cardiology), The Shrewsbury and Telford Hospital NHS Trust
Angela Johnson	Royal College of Nursing	Matron, Paediatric Cardiothoracic Services, Newcastle 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	Clinical Psychologist specialising in Paediatric Cardiology, Great Ormond Street Hospital for Children NHS Foundation Trust
Dr Tony Salmon	British Congenital Cardiac Association (President)	Consultant in Paediatric and Adult Congenital Cardiology, Southampton University Hospitals NHS Foundation Trust
Dr Graham Stuart	Congenital Heart Services Clinical Reference Group	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Michael Wilson	NHSCB	Interim Programme Director, CCHS Implementation

Apologies

Name	Representing	Role
Jeremy Glyde	Safe and Sustainable	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, Newcastle-upon-Tyne Hospitals NHS Foundation Trust
Ann Jarvis	NHS Specialised Commissioning	Chief Operating Officer, Specialised Commissioning, South of England
Professor Basky Thilaganathan	Royal College of Obstetrics and Gynaecology	Professor of Fetal Medicine, St George's Healthcare NHS Trust

	Action
1: Introduction and apologies for absence The Chair opened the meeting. Apologies had been received from Jeremy Glyde, Mr Leslie Hamilton, Ann Jarvis and Professor Baskan Thilaganathan. The Chair asked whether members of the Group had any conflicts of interest to declare. There were none.	
2: Minutes of the previous meeting Ms Johnson asked that the reference on page 7 of the minutes to specialist nursing support be amended to state that this support could be provided by either a paediatric specialist cardiac nurse or a fetal nurse. The Chair asked Ms Johnson to submit an amended form of wording in writing to Mr Wilson. Dr Martin stated that he did not remember the context in which he had stated that he 'saw links in the surgical centres', as per page 10 of the minutes. The Chair clarified that this had probably been intended to refer to links to managing co morbidities, but should be amended for ease of reading. Subject to these amendments, the minutes of the previous meeting were approved. **ACTIONS:** **1 AJ to send suggested revised wording to MW** **2 MW to revise the minutes as discussed**	**AJ** **MW**
3: Action log and matters arising The Chair noted that Ms Johnson was scheduled to undertake a large amount of work and asked whether she would require assistance. Ms Johnson noted that it was difficult at present to have a constructive conversation with all centres, but that there was to be a meeting of nurses on 16th January at which the topics of networks and the role of specialist nurses were to be discussed. She would feedback to the Group following the meeting. In reference to action point 5, Dr Stuart stated that the CRG (Clinical Reference Group) had included fetal cardiology as a part of the service specification. However, no dashboards or CQUINs (Commissioning for Quality Innovation) had yet been produced. These products would be produced according to a preset timescale, which stated that dashboards would be established soon and that CQUINs and QIPPs (Quality Improvement Program Planning System) would be established within the next 12 to 18 months. The service specifications had now been written, although they had not yet received formal confirmation. Dr Stuart noted that there was to be a meeting the following day on this topic. It was agreed that diagnosis of suspected cardiac defects in utero would be an important part of the pathway. The Chair noted that this had been previously discussed and that Mr Wilson had been sent some information regarding how to manage patients' entrance into this pathway without being overly prescriptive. Members of the Group were invited to submit any further ideas as to how best this could be done. It was noted that a document endorsed by the BCCA British Congenital Cardiac Association) dealing with district cardiology children's services had been circulated, as per action point 7. In reference to action point 13, Dr Fortune noted that the North-West and North Wales Paediatric Transport Services (NWTS) guidelines had contained the information the	**AJ** **All**

Group had wanted, but that he had only had sight of those on the previous day. Certain documents from Children's Acute Transport Services (CATS) had also been informative, and Dr Fortune stated that he would forward these to members of the Group if they wished. Due to confusion with some of the acronyms, the Chair stated that it might be beneficial to append glossaries to future minutes. Dr O'Curry stated that she had sent a document enumerating standards that were already available to Mr Wilson, although this had not been listed on the action log. **ACTIONS:** 1. **AJ to feedback to the group following the nurses meeting in January** 2. **All to send comments on the pathway for prenatal diagnosis of suspected cardiac defects to MW** 3. **P-MF to circulate Children's Acute Transport Services (CATS) documents** 4. **MW to ensure that any acronyms used in future minutes are defined**	**P-MF** **MW**
4: Terms of Reference (Revised) The Chair reported that following discussion, the Programme Board had agreed that the work would continue to be referred to as 'Children's Congenital Heart Services'. The Programme Board had also agreed that for consistency all documentation should use the same language as that used in the consultation document. The Chair also stated that no reference to age would be contained within the Terms of Reference for patient transition. It was agreed that the terms of reference for the group should be reviewed in light of these decisions, and would then be considered complete. It was agreed that the Group would attempt to conclude their work by 1 April, although this date would not be binding. **ACTIONS:** 1. **MW to review terms of reference to ensure consistency with other documentation.**	**MW**
5: Networks The Group received three pieces of work on network effectiveness which had been submitted by Mr Wilson. The Chair invited comments from group members. <u>Key Personnel and Competencies</u> Ms Johnson noted that none of the documents described in detail the role of the Lead Nurse within the network. There was a discussion about whether the position of Lead Nurse was in fact a network role. Ms Johnson stated that the Safe and Sustainable documentation there had been references to a Lead Nurse role with responsibility for ensuring leadership across networks. The Chair noted that, when the Group had been putting together the PID (Project Initiation Document) for the Programme, it had been stated that it would contain job descriptions for Network Directors and Clinical Leads. She asked that additionally the final document contain a list of agreed competencies for these roles, and the same for the position of Lead Nurse. Ms Johnson observed that a list of competencies for Lead Nurses had been attached as an appendix to the 'Safe and Sustainable' documentation. The Group concurred regarding the importance of establishing guidelines for key roles. Group members also stated that it would be vital to establish what workload individuals in these roles could expect, what competencies and experience these individuals	**MW**

should possess and what sort of compensation should reasonably be offered in exchange for their services.

Ms Johnson stated that, although Lead Nurses might be employed by a single surgical centre, they would have responsibilities across the network including promoting education across DGHs, (District General Hospitals) facilitating linkages between cardiology and surgical centres, and establishing equality of care.

The Chair noted that it had been agreed that the lead centre within a network did not necessarily have to be a surgical centre.

Representation on Network Boards

Guidelines from the RCPCH (Royal College of Paediatrics and Child Health) had indicated that each key professional group should have representation on the network board. Dr O'Curry stated that the Lead Nurse would fulfil that role for nursing, but that other professionals would also wish to be represented on the board. The Group agreed that it was important to define who should be present on these boards. Dr O'Curry's view was that, at a minimum, professionals in the areas of dietetics, occupational therapy, physiotherapy, and speech and language should have representation. The Chair and Dr Stuart noted that it would be important for psychology to be represented on the board as well.

Time Commitments

The Group discussed the issue of the amount of time Lead Nurses would need to devote to their roles. It was observed that they would need to spend a significant amount of time in other units to foster and maintain linkages across the network. It was generally accepted by the Group that it would be reasonable to expect Lead Nurses to devote at least one day per week to this.

Draft Proposals on CCH (Children's Congenital Heart) Network Specification

This document was discussed in some detail as Ann Jarvis had asked if a reasonably comprehensive draft could be submitted by 21st December.

Mr Wilson noted that the timetable being followed was a single timetable that encompassed all operational delivery networks (ODNs), which, in most cases, were already in existence.

It was agreed to amend the second paragraph in the first section to state that all travel, not just 'travel to the Specialist Surgical Centre', should only take place when essential.

Dr Martin asked whether the document should enumerate one of the CCH network's purposes as being the decommissioning of previous surgical centres. The Chair replied that this was important to note, but that this would be better suited for the section in the document dealing with the networks' scope.

The Chair asked the Group whether the networks' purposes should include the collection and analysis of outcomes data. It was agreed that they should.

Dr Kannivelu asked whether it was entirely accurate to refer to the scope of these networks' responsibilities as 'congenital heart diseases'. The Chair agreed that this label was potentially slightly misleading, but stated that it was not going to be altered at this stage of the process. It was agreed that the word 'multidisciplinary' should be inserted between the words 'coordinated' and 'approach' in the document's third paragraph. Subject to these amendments, the Group confirmed that they were happy with the purposes of the networks as stated in the document.

With regards to the section on scope, the Group discussed whether this should be defined as encompassing acquired heart disease, or whether adopting such a remit

could potentially exclude inherited diseases. It was agreed that inherited diseases should be explicitly included. It was agreed the 'network care pathway' should be referred to in the section on 'scope'.

It was agreed that the networks' components should include fetal care, district general hospitals, cardiology centres, specialist surgical centres, and transition to adult services, and that the networks should be explicitly given responsibility for making sure that care standards were met. The Group discussed which constituencies should be represented on these networks' boards, and agreed that there should be a representative from the area of adult congenital cardiology drawn from the adult congenital networks' personnel.

Ms Keatley-Clarke asked whether community representatives would be represented on these boards, with responsibility for liaising with schools and ensuring parents' engagement. It was asked whether it would be feasible to establish a requirement that networks took responsibility for community engagement without mandating who on the board would have this responsibility, or whether a specific member of the board should be deputised for this, such as the paediatrician with expertise in cardiology or the specialist nurses within the network.

The Group debated the question of how the profile of community medical services could be raised, as they presently appeared to be receiving less attention than high-technology services, and whether there would be enough nurses within the networks to provide an appropriate level of support. It was decided that Lead Nurses should take responsibility for ensuring adequate specialist nurse support across their communities, and that district clinics should identify at least one local liaison nurse amongst their staff.

The Group confirmed that the provisions within the draft document for PICUs were acceptable. It was noted that there would be a series of meetings in January with representatives of ECMO (Extracorporeal Membrane Oxygenation) practitioners and support staff, the outcomes of which would be relevant to the Group's final recommendations. The Group resolved to make no detailed recommendations on ECMO until the January meeting had concluded.

It was agreed that the final document would contain two lists: one of the key individuals within the networks, who would need to be represented on the networks' boards, and those other individuals and constituencies with whom the boards would need to liaise. The Chair asked whether it would be beneficial for the boards to maintain a relationship with NIHR (National Institute for Health Research) networks, and whether the final document should instruct boards to do so. The Group agreed to add a responsibility to 'support innovation and research development' to the networks' purposes.

It was noted that networks would need to ensure that there was sufficient local expertise in district general hospitals to enable post-operative patients to receive the care they needed before being discharged. Lead and specialist nurses would play a major role in ensuring this. It was also agreed that the document should contain some reference to networks' responsibilities to provide adequate end of life care.

The role of other specialised services in relation to the networks was discussed. The Chair stated that these would probably be included in the list of stakeholders with whom the networks were to liaise. It was also observed that it would be valuable for the final document to make explicit references to the areas that were out of the networks' scope, although liaison with specialised services would be within their scope.

The Chair asked whether group members were content with referral between centres mostly taking place on the basis of geographic proximity. Ms Johnson observed that

not all referral in the existing system was done on the basis of proximity. Dr Stuart asked that the reference to networks that contained a cardiac surgical service on Page 2 of the document be removed, as all networks would contain one. The Group noted that the boundaries of the networks would be developed further. It was observed that, although it was not desirable for two different networks to hold clinics in the same hospital, this might continue to be the case for some time while the new system was implemented. Further work also needed to be done on establishing paediatric retrieval pathways. The Group discussed the topic of accountability and commissioning. It was noted that the final document might benefit from an overview of the role of Local Area Teams (LATs). In response to a question from Dr Martin, the Chair explained that some networks would not have a LAT within their boundaries, while others might have multiple. Mr Wilson further explained that there would be 27 LATs, of which 10 had been nominated to take the lead on implementing specialised commissioning functions. It was asked whether resource money would be distributed centrally. The Chair stated that she believed network boards would be given a budget, which would be allocated to the lead centre within the network. The Group noted that, in order for the 'Accountability and Commissioning' section to be comprehensive, there would need to be a provision for collective upstream reporting that encompassed all networks. It was agreed that, although the document contained a reference to the 'Safe and Sustainable' consultation document stating that specialist surgical centres should lead networks, this would not be mandated. It was also observed that it might be beneficial for the document to establish a minimum expected time commitment for members of these networks' Boards. It was agreed to add a reference to the importance of peer review in the document's 'Accountability' section. It was also agreed that CQUINs should fund the lead host provider within a network, although they would be responsible for determining how this arrangement would operate. It was agreed that the phrase 'other multi organ specialised services' should be added to the list of external relationships that the networks would be expected to maintain. Following discussion, it was agreed to amend, distribute for comment and then, following feedback produce a final draft of appendix 7. **ACTIONS:** **1. MW to include a list of agreed job descriptions and competencies for Network Director, Clinical Lead and Lead Nurse in final PID** **2. MW to produce a final draft specification and guidance on CCH Networks**	**MW**
6: Nursing Ms Johnson explained that representatives from the nursing community had been meeting regularly at the RCN (Royal College of Nursing) offices in London, and that their next meeting would be in January. At this meeting, it was intended that representatives would discuss the role of specialised nurses within the networks, as well as broader issues relating to how the networks would function.	
7: Pathway Description It was decided that a detailed discussion of the optimal pathway should be postponed until the next meeting and that this pathway should not be too rigid. **ACTION:** **1. MW to produce a draft document outlining the pathway**	
8: Programme Board 7.12.12 Report	

The Chair noted that she had already spoken on the topic of the Programme Board's report, but stated that the Board had met in the previous week and had welcomed Ms Keatley-Clarke as a patient representative. A discussion had taken place regarding the networks' Terms of Reference and Programme Initiation Document. A meeting was due to take place the following Friday to do further work. A newsletter was scheduled to be published in January, which would outline the case for change, and would be branded as both a 'Safe and Sustainable' and a CCHS (Children's Congenital Heart Services) document.	
9: CIAG Report The Chair gave a short report of the recent meeting of CIAG (Clinical Implementation Advisory Group) (at which most members of the networks group had been present).	
10: Any other business Dr Salmon informed the Group that NHS staff in Southampton and Oxford were currently putting together proposals for a joint network group, to be led by Alison Sims. He stated that he would ask Ms Sims whether a representative of this network wished to attend a meeting of the Group. The Chair asked to be kept updated regarding progress in this area. The Chair noted that it would be useful for the Group to receive regular updates as to how the new systems were working in practice, particularly with regard to communication and cooperation between centres. Dr Kannivelu asked for the list of members in the Group's Terms of Reference to be updated to include his name. The Chair agreed to arrange this and apologised that he was not already included. Ms Keatley-Clarke noted that there had been an influx of calls over the previous day relating to Roger Boyle's comments on the perceived failure of networks. Dr Boyle had stated that cancer and burns networks appeared to be being closed down 'by stealth', regardless of whether they were working or not. Mr Wilson noted that Dr Boyle's views related primarily to strategic clinical networks, which had not been discussed at this meeting of the Group for reasons of clarity. The Chair also noted that Dr Boyle had primarily been concerned with adult networks, not paediatric ones. **ACTIONS:** **1. TS to ascertain whether the Oxford and Southampton network wished to send a representative on the networks group** **2. MW to add Dr Kannivelu to the list of members in the Terms of Reference**	**TS** **MW**
11: Date and time of next meeting The date of the next meeting was set as 15 January 2013. The Chair agreed to distribute provisional dates for future meetings. **ACTION:** 1. **Provisional future meeting dates to be circulated**	**MW**