

Safe and Sustainable

Paediatric Cardiac Surgery Services



Specialised Services

Minutes from the Safe and Sustainable Networks Group
MWB Victoria, 10 Greycoat Place, London SW1P 1SB
9 November 2012

Attendance:

Name	Constituency	Role
Professor Deirdre Kelly		Chair of the Implementation Advisory Group
Danny Beales	Children's Heart Foundation	
Dr Peter-Marc Fortune	Paediatric Intensive Care Society	Paediatric Intensivist
Jeremy Glyde	Safe and Sustainable	Programme Director, National Specialised Commissioning Team
Ann Jarvis	Safe and Sustainable	Chief Operating Officer, South of England SCG
Angie Johnson	RCN	Matron, Paediatric Cardiology
Dr Ari Kannivelu		Consultant Paediatrician Cardiology
Dr Rob Martin	BCCA	Paediatric and Adult Congenital Cardiologist
Dr Sara O'Curry	British Psychological Society	Chair-Elect, Paediatric Network
Professor Basky Thilaganathan	Royal College of Obstetrics and Gynaecology	Professor of Foetal Medicine
Michael Wilson	Safe and Sustainable	Interim Programme Director for Implementation

Apologies:

Leslie Hamilton	Society for Cardiothoracic Surgery in Great Britain and Ireland (Immediate Past President) and Vice Chair of Steering Group	Consultant Cardiac Surgeon, Newcastle-upon-Tyne Hospitals NHS Foundation Trust
Dr Tony Salmon	British Congenital Cardiac Association (President Elect)	Consultant Paediatric Cardiologist, Southampton University Hospitals NHS Trust
Dr Graham Stuart	British Congenital Cardiac Association	Adult Cardiologist, University Hospitals Bristol NHS Foundation Trust

PAEDIATRIC CARDIAC SURGERY SERVICES STEERING GROUP – 9 November 2012

<p>1: Introductions and apologies</p>	<p>The Chair opened the meeting and gave apologies as above.</p>	<p>Chair</p>
<p>2: Networks and pathways</p>	<p>Update Mr Glyde reported on two forms of ongoing challenge to the JCPCT's decision. A judicial review had been launched by a private limited company in Leeds. The intention was to ensure this case was heard as soon as possible. The second challenge had come via the IRP, which would be revisiting each of the current surgical units, except Oxford. Mr Glyde stated that he could not explain the criteria that the Panel would follow, because they would not disclose this. The IRP process would conclude on 28 February and deliver its advice to the Secretary of State for his decision. The Chair reported that plans for implementation were pressing ahead despite the challenges to the process. The workshops carried out had highlighted the necessity for strong clinical leadership, clarity in commissioning, national standards, and the importance of the networks and network Boards, which should map onto existing networks. Mr Wilson stated that the Programme Board at its first meeting had considered its Terms of Reference and a number of other key documents, including the programme initiation document and the opening risk register. A first draft was under discussion and should be signed off at the December meeting. That meeting would also discuss a first look at an actual programme plan.</p> <p>Networks The Chair emphasised the need for clarity from clinical leaders on the definition of the network, and encouraged all members to reflect on whether they had enough time available to embark on this work, and whether they could involve others. It was crucial that a skeleton framework existed by December or January. Mr Wilson would be available to provide help and support. Professor Thilaganathan observed that there were many misrepresentations and</p>	<p>Chair</p>

	<p>misunderstandings about networks. For example, surviving centres were inviting decommissioned centres to network meetings, which could create instability and insecurity. In order to avoid destabilising hardworking clinicians, it would help if the appropriate person within this group were able to communicate to clinicians across the UK the timeframe and supports for implementing this process.</p> <p>Ms Jarvis stated that there were many types of networks. The NHS Commissioning Board had talked about two types: strategic clinical networks, and operational delivery networks (ODN), which delivered care on the ground. The ODN model was envisaged for paediatric cardiac, paediatric neuroscience, burns and major trauma. ODNs would vary in terms of clinical areas and geographical coverage, but would also have common elements. The ODNs were seen as a clinical networking environment, but in coming years there might be a more financial model with lead centres subcontracting to other centres. One Trust would be designated as a nominal lead, but the team could be selected from all members of the ODN. The current focus was on describing common characteristics of ODNs, and on funding. Dr O'Curry stated that clarity around the money would be very helpful at this stage.</p> <p>The Chair stressed that the lead centre would not automatically be the surgical centre. Dr Fortune agreed, noting that such an assumption might present a conflict of interest for senior network leaders. Ms Jarvis commented that in general the ODN model tended to make the most specialised centre the leader. However, she agreed it was not a prerequisite. Clinical leadership should come from the best person for the job, but in general it tended to be a 'hub and spoke' model.</p> <p>Dr Fortune noted that the focus here was on cardiac surgery, but the surgical centre was only a tiny part of the whole experience for the child. The cardiology centres should be treated as equal partners. He suggested 'likely to fall within a cardiology centre' would</p>	<p>MW to distil the learning from other networks and research literature</p>
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	<p>be good language. Dr Martin felt it would be difficult for a non-surgical centre to lead a network; the models already in use in many places usually had the surgical centre leading the networks. It was important that the surgical centre had overall lead, but in partnership with the other centres. The Chair suggested it might be too soon to be prescriptive on this issue.</p> <p>Ms Jarvis suggested that this group should work on identifying primary deliverables for the network, particularly the non-surgical deliverables. Dr Kannivelu stated that the purpose of the network was to improve patient experience and patient outcomes. If this purpose was understood, the surgical centre would probably provide leadership, but some patients did not require surgery and leadership would stay within the non-surgical centre. Where infrastructure was concerned, he agreed the surgical centre was likely to lead. For a long time, cardiac patients had had to rely on the tertiary centre, with little knowledge and understanding on the peripheries in District General Hospitals (DGHs) and among GPs. The key for the network was to identify gaps, disseminate information and have clear pathways for these complex patients.</p> <p>Dr Martin noted that at this point they were not delivering a similar standard of care in DGHs as in children's cardiology and surgical centres. Improving this would require adequate paediatrician and nursing support locally. Even well-set-up centres did not have enough nursing support to DGHs. The Chair asked about multi-disciplinary support, which was often missing at the DGH. Dr Fortune noted that the same was true of non-surgical cardiology centres. That equity and quality for children was vital. Mr Beales stated that the key benefit to parents was care closer to home, where suitable. Unfortunately, this was often patchy and variable in quality. The role of the lead centre must be in spreading expertise and ensuring gaps were addressed.</p> <p>Dr Kannivelu suggested learning from other well-established clinical networks, such as paediatric oncology. The Chair noted that</p>	<p>MW and A Jarvis to discuss ODN model and feed back to group</p> <p>A Johnson to consult with colleagues and provide input to Mr Wilson</p> <p>MW to contact Graham Stuart and find out any recommendations made</p>
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	<p>Scotland also had a cardiology network. Dr Fortune stated that retrieval networks set up across the country worked across very similar regions and had shared services. They needed to map onto these networks.</p> <p>Ms Jarvis felt it was worth learning from networks that had achieved similar aims, such as oncology, Bristol/Cardiff and Southampton/Oxford. The Chair stressed that they wanted to know what lessons had been learned in these networks, including communication, funding, and staffing. Dr Martin stated that the Bristol/Cardiff network had been a clinically led network for the most part.</p> <p>Professor Thilaganathan noted that neonatal networks set up to manage tertiary neonatal services had disappeared, but had been successful in managing a very similar remit to the current one, supported with NHS toolkits.</p> <p>Dr Kannivelu asked whether these networks extended into the peripheries and DGHS, including a peer review process. For oncology, there were formally written, pre-identified pathways specifying which parts of the care would be delivered locally.</p> <p>Dr Martin stated that network meetings for Bristol/Cardiff had started only recently, and were relatively informal. The only formally managed network he knew of was Leeds.</p> <p>Ms Johnson stated that there had been a pot of money available in Leeds, which had helped to support it. Dr Fortune agreed that this had also been the case with retrieval networks.</p> <p>The group agreed that they were essentially fitting into the ODN model as Ms Jarvis had described it. Dr Fortune asked about the possibility of independent financial resource. The Chair responded that this was what they had in mind.</p> <p>Ms Johnson stated that the nurses in the Bristol/Cardiff network had a strong core of leadership, and the specialist nurses in Cardiff had been there a long time. This was not the case in the Oxford/Southampton network.</p> <p>It was agreed that they would try to ‘flesh out’ the ODN model with a cardiac flavour.</p>	<p>BT to put his comments in writing and forward to MW</p> <p>Hannah Weaver to circulate RM’s document</p>
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	<p>Pathways</p> <p>Professor Thilaganathan stated that the pathway started with a suspected diagnosis, usually at 20 weeks, and whoever led it, it needed to provide equitable services throughout the network for women with a suspected diagnosis. 60-70% of congenital heart defects were picked up prenatally; for every one that was picked up, four or five women were referred for scanning with suspected cases. Their planning therefore needed to include resources for suspected abnormalities as well. Fetal cardiologists tended to see women from high-risk backgrounds earlier in the pregnancy, but they should plan for 20-week referrals. Suspected abnormalities were referred to their local tertiary service. Moreover, where there were cardiac abnormalities, there were often coincidental foetal abnormalities to be excluded and managed. Therefore, fetal cardiology services needed to be colocated within the fetal medicine services for that region. Geographically, there were more than enough foetal medicine centres to cover this.</p> <p>Dr Martin stressed the link between fetal medicine centres and fetal cardiologists in refining the diagnosis. The pathway would vary by location; some might see a cardiologist early on, but in Exeter, for example, the local fetal specialists would see them first and refer them on, with telemedicine to specialised service centres. A management plan would be drawn up for the child.</p> <p>The Chair suggested the group should indicate a preferred way of managing this. Ms Jarvis responded that the Clinical Reference Group had a responsibility to make recommendations on this, but she did not know if they had done so; she felt the group could recommend a best practice pathway, but did not have an independent governance role.</p> <p>Ms Johnson asked what a mother's journey would be over a wider geographical area. Dr Martin stated that if a cardiac abnormality was diagnosed in Wales, it would be done at</p>	<p>BT to forward guidelines to MW</p>
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	<p>the Cardiac Centre in Cardiff. Once a diagnosis was made of a significant abnormality, the family would come over to the surgical centre to talk about the appropriate place for delivery and postnatal management.</p> <p>Dr Kannivelu stated that in the West Midlands, cases of suspected abnormalities would be sent to the regional foetal medicine centre, and a foetal cardiologist would provide scans within that centre. They could then involve their colleagues if necessary. Usually babies were delivered in local units; only rarely did they need to be delivered close to their surgical centre. Professor Thilaganathan felt the models of delivery were very similar, but the core to the model was that when women were referred up from a DGH with a suspected problem, the foetal medicine and foetal cardiology services should be colocated.</p> <p>The Chair asked whether they would expect foetal medicine to sit in the district cardiology centre. Professor Thilaganathan stated that at the moment, the recommendations were that foetal medicine centres should be at tertiary level. Whatever a network did, it must support the collocation of these two services.</p> <p>The Chair asked about in utero cardiac surgery. Dr Martin stated that there were very small numbers of interventions. The key stage was peribirth and there were already accepted pathways for this. Dr Martin stated that he had forwarded a document to Hannah Weaver on delivery of care in district centres. 50% of those who needed surgery in the first year might need further interventions as they grew up.</p> <p>Dr Kannivelu commented that peribirth interventions largely fell under neonatal networks and their standards. Below level 2, no antenatal diagnosis of complex congenital heart disease would be delivered. Most of these babies would need immediate interventions, and would probably be delivered at level 3. Dr Fortune commented that one-third would not have been prenatally diagnosed. Dr Kannivelu noted that some were concerned about the loss of</p>	<p>A Johnson to send work by nurses' group on specialist nurse roles to MW</p> <p>AK, RM and A Johnson, SOC and PMF to forward</p>
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	<p>skills from having all such babies diagnosed at level 3, since those born without diagnosis would have to be managed where they were.</p> <p>Dr Fortune stressed the parallel pathway for undiagnosed cases. Professor Thilaganathan noted that the level of antenatal diagnosis was closer to 50% nationally. Dr Kannivelu stated that the most severe abnormalities and those most in need of surgery were more often picked up antenatally.</p> <p>Ms Johnson stated that there should be specialist nursing support, although it did not necessarily need to be a cardiac fetal nurse it could be a cardiac specialist nurse. Dr O'Curry stated that the psychological support pathway ran parallel to this pathway, as agreed by the National Cardiac Reference Group. The service could be provided at any point. Dr Fortune noted that it was not uniformly available. Dr O'Curry agreed that most of the workforce was in surgical centres. Funding for MDTs was always difficult to obtain. Dr Fortune noted that pragmatically, it had to be available but could not always be colocated. Ms Jarvis recommended that they describe the 'What?' rather than the 'How?', because local contexts differed.</p> <p>Dr Kannivelu noted that some patients might opt for termination or palliative care post-delivery, and the holistic care could be very patchy. Professor Thilaganathan stated that prenatally it was already taken care of, but there was an issue with postnatal care. Dr Martin noted that the Clinical Reference Group had also discussed access to postnatal palliative care.</p> <p>Mr Glyde asked about the parallel pathway for cases not diagnosed antenatally, and the current models of care for those children. Dr Fortune stated that those children presented acutely and would be managed by DGH paediatricians initially, who would rapidly involve the regional retrieval services. The most acute diagnoses presented within the first two months. Mr Beales remarked that the newborn infant examination programme</p>	<p>information to MW</p>
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	<p>would be a step forward and would also have its own pathways.</p> <p>The Chair asked how primary care fitted into the pathway. Dr Martin stated that they would be referred either to a paediatrician or directly to paediatric cardiologists. The majority went through paediatricians and would go back to GPs for prescriptions. Late diagnoses came through GPs, who were very much part of the process in terms of prescribing and supporting families.</p> <p>DGHs would now have expert cardiologists; Dr Martin felt that these were already quite well-set-up. There should be a paediatrician with expertise in cardiology wherever there was an in-patient paediatric service, and two in bigger DGHs. However, there was currently not enough training to provide this nationally. The JCPCT had defined it as hospitals with maternity units with at least 3,000 live births per year.</p> <p>Dr Fortune noted that children could be stuck waiting to come into a centre, but other children could also be disadvantaged by a child stuck in a tertiary centre not being able to step down to a DGH bed. The Chair agreed that this was critical. Professor Thilaganathan added that DGHs were meant to have obstetricians with expertise in fetal medicine. However, often the person who was due to provide this was only available one day per week. The national foetal medicine guidelines were clear that if local expertise could not see the woman within 48 hours, a referral to the local tertiary centre was mandated. Dr Fortune stressed that it was not only DGHs to cardiac centres, but cardiology into cardiac surgical.</p> <p>Dr Kannivelu noted that over time, small units would vanish, and the expectation of having two PECs per unit was reasonable, with the tertiary centre as backup. It was the responsibility of the PEC in the individual unit to identify the pathway to be followed in his or her absence. With suspected heart disease, they did not wait for PEC availability and would have conversations directly with the tertiary centre.</p> <p>The Chair asked about transition to adult services. Dr Martin stated that most children</p>	
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	<p>would be transitioned where they were seen on a routine basis, normally by the DGH. It depended on the nature of the patient whether they needed a GUCH specialist. Currently, from 16 onwards, the transfer across to adult services would begin, done jointly with an adult congenital heart disease specialist and a local cardiologist. They needed to link into the adult network.</p> <p>Dr Kannivelu noted the difference between 'transfer of care' and 'transition of care'. More and more GUCH consultants were trying to provide outreach services. They needed to acknowledge that visiting cardiologists were doing outreach in most DGHs. The Chair summarised this approach as 'Two ways in, two ways out.'</p> <p>The Chair asked whether patients always came through a cardiology centre. Dr Martin remarked that if a major defect was diagnosed that was life-threatening and required urgent surgery, the child would go directly to the surgical centre. If it was something that needed more detailed evaluation and treatment but not immediate surgery, it could be done at the children's cardiology centre or stay in the local centre if there was expertise.</p> <p>Dr Fortune stated that only a tiny percentage needed to go directly to surgery. It could be valuable for a family to have a cardiac centre as a staging post, and it might be safer to go to a cardiology centre if it was closer. .</p> <p>Mr Wilson stated that the distribution of non-surgical cardiology centres might not allow this pathway to be followed everywhere. In Bristol, children coming from the Southwest would go directly to Bristol. However, this was the cardiology centre colocated with the surgical centre. The Chair asked about a child born in Truro. Ms Jarvis suggested that in the absence of a decommissioned surgical centre, there could be a cardiology centre, for example in Plymouth.</p> <p>Mr Glyde noted that the pathway needed to reflect the fact that large populations would live closer to a surgical unit than a cardiology centre, at least at the outset of</p>	
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	<p>implementation. Mr Wilson commented that they also needed to look carefully at whether there was a case for these cardiology services in other places as well as decommissioned surgery centres.</p> <p>Dr Kannivelu felt that antenatal diagnosis and, in its absence, local expertise were helpful in identifying where a child needed to be. Dr Fortune commented that many cardiac babies did not go to surgery for many days. It was very rare for babies to go instantly to surgery.</p> <p>Dr Martin commented that few centres in the South West would have enough throughput to keep up their expertise. The Chair noted that the standards for the cardiology centres would define the throughput levels. They needed to be open-minded if other centres wanted to make a bid, provided that they met the standards. Ms Jarvis commented that they did not want to dilute the strong message about maintaining clinical expertise.</p> <p>Ms Johnson stated that the mother would need to have a meeting with the surgeon, and she asked where that would take place. Professor Thilaganathan noted that typically the women would travel to meet the surgeon, since it was difficult to take surgeons out of operating lists. Dr Martin stated that this could be done via telemedicine.</p> <p>Mr Wilson asked about the role of the specialist nurse. Ms Johnson responded that it was not standard across the services. It was agreed that Ms Johnson's group would do further work on defining the role of the specialist nurse, especially with parents in negotiating the pathway, acting as advocate and navigator. Ms Johnson stated that there were two models for providing specialist nurse support. Dr Martin noted that specialist nurse support for surgical and cardiology centres was reasonably well-established; at the DGH level access was often very limited.</p> <p>Ms Johnson stated that there was not a specialist nurse at every clinic, as was already written into the standards. Ms</p>	
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	<p>Johnson would provide a consensus about what was known and recommended, and where the gaps were.</p> <p>Dr Kannivelu asked whether the specialist nurse should be linked to the patients or linked to the units. In his region there would be an assigned liaison nurse from the tertiary unit, who formed the link for that patient even when the patient had moved to the local area, including linking with community nurses. The liaison role was not specified in the standards.</p> <p>It was agreed that Dr Kannivelu, Dr Martin and Ms Johnson would look at the standards and agree on them, and forward to Mr Wilson.</p> <p>Dr O’Curry would also send her standards to Mr Wilson.</p> <p>Dr Fortune would send information from the retrieval networks to Mr Wilson.</p> <p>Mr Glyde asked whether there were particular co-morbidities of which the group needed to be mindful. Dr Martin felt it was essential to manage co-morbidities. Mr Wilson suggested that in developing templates for networks, they needed to be aware of the need to make links outside the network. Dr Martin felt they were in the standards for the surgical centres.</p>	
<p>3: Terms of Reference and Timeline</p>	<p>The Chair asked the group to consider the draft Terms of Reference that had been circulated to them. She suggested changing the term ‘antenatal screening’ to ‘defined pathway from suspected diagnosis at antenatal screening’.</p> <p>Mr Wilson had been tasked with coming up with job descriptions for network directors and clinical leads.</p> <p>It was agreed that a ‘first pass’ draft of the work arising from this discussion would be presented at the Clinical Advisory Group meeting in November.</p>	<p>Chair</p>

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	<p>Ms Jarvis noted that one of the key pieces of feedback from the workshops had been that people needed direction and would welcome it within a reasonable timescale. The Chair stressed that if anyone could not commit to the time demands of this project, they should let her know.</p>	
<p>4: Any Other Business</p>	<p>It was also agreed that they would aim to meet again no later than the second week of December, and that some meetings could be held by teleconference if necessary. Dr Fortune noted that some individuals might also be invited to join by teleconference even if the main group met in person.</p>	