# Children's Congenital Heart Services



# **Specialised Services**

# MINUTES Clinical Implementation Advisory Group 28<sup>th</sup> November 2012

Regus London Westminster, St James, 50 Broadway, London, SW1H 0RG

Attendee	Representing	Role	
Professor Deirdre Kelly	Chair	Professor of Paediatric Hepatology at Birmingham Children's Hospital NHS Foundation Trust	
Ms Anne Keatley- Clarke	Children's Heart Federation	Chief Executive, Children's Heart Federation	
Professor Basky Thilaganathan Mr Carl Davis	Royal College of Obstetrics and Gynaecology ECMO representative	Professor of Fetal Medicine, St George's Healthcare NHS Trust Consultant Paediatric and Neonatology Surgeon, Yorkhill Hospital, Glasgow	
Mr David Barron	Society for Cardiothoracic Surgery of Great Britain and Ireland	Consultant Congenital Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust	
Dr David Mabin	Royal College of Paediatrics and Child Health	Consultant Paediatrician with Expertise in Cardiology, Royal Devon & Exeter NHS Foundation Trust	
Ms Donna Kirwan	Fetal Anomaly Screening Programme	National Projects Officer, NHS FASP  Lead Nurse, East Midlands Congenital Heart Centre, University Hospitals of Leicester NHS Trust	
Ms Elizabeth Aryeetey	Royal College of Nursing		
Dr Graham Stuart	Congenital Heart Services Clinical Reference Group	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust	
Dr Ian Jenkins	Paediatric Intensive Care Society	Consultant in Paediatric Intensive Care & Anaesthesia, University Hospitals of Bristol NHS Foundation Trust	
Mr James Ford Mr Jeremy Glyde	Grayling Secretariat	Managing Director of Public Sector Programme Director, Safe and Sustainable National Specialised Commissioning Team	

Mr John Richardson on behalf of: Mr Michael Cumper	Somerville Foundation	National Director, Somerville Foundation	
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	
Mr Michael Wilson	NHSCB	Interim Programme Director for Implementation of the JCPCT decision	
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	Clinical Psychologist specialising in Paediatric Cardiology, Great Ormond Street Hospital for Children NHS Foundation Trust	
Ms Teresa Magirr	Health and Social Care Board, Northern Ireland		
Dr Tony Salmon	British Congenital Cardiac Association (President)	Consultant in Paediatric and Adult Congenital Cardiology, Southamptor University Hospitals NHS Foundation Trust	

# **Apologies**

Name	Representing	Role	
Dr Alan McGee	British Congenital	Consultant Paediatric Cardiologist,	
	Cardiac Association	Royal Brompton & Harefield NHS	
		Foundation Trust	
Fiona Smith	Royal College of	Adviser in Children and Young	
	Nursing	People, Royal College of Nursing	
Gail Fortes-Mayer	NHS Specialised	Assistant Director, Specialised	
	Commissioning	Commissioning, Midlands and East	
Jo Sheehan	NHS Specialised	Acting Director of National	
	Commissioning	Specialised Commissioning, National	
		Specialised Commissioning Team	
Kathy Collins	The NHS in Scotland	Nursing & Quality Adviser, NHS	
		National Services, Scotland	

Dr Poothirikovil Venugopalan	Royal College of Paediatrics and Child Health	Hon Secretary of Paediatricians with Expertise in Cardiology Special Interest Group	
Dr Vimal Tiwari	Royal College of General Practitioners	General Practitioner	

	Action

# 1: Welcome, introductions and apologies

The Chair opened the meeting.

Apologies had been received as noted above.

The Chair introduced Mr Wilson from the Programme Team. Mr Wilson will be taking over as the main contact and providing Secretariat support. All communications should now be directed to Mr Wilson.

# Clarifying Names and Terminology

The name of the group has been changed from the Implementation Advisory Group to the Clinical Implementation Advisory Group.

The Programme Board have agreed that the work will be called 'children's congenital heart services'. Dr Gill noted that in the last discussion it was felt it would be better to use the term 'congenital heart services'. Mr Wilson explained that the Programme Board had decided to include the word 'children's' to accurately reflect the scope of the work they were doing, which had been established by the JCPCT decision. The Chair stated that a definition could be included detailing what was meant by children, which would include the fetus up to transition to the adult service. She did not think there should be a specific age defined for transition but should say it covered up to the point an individual transferred to the adult service. Mr Hamilton noted that the paediatric team would be responsible for the transfer and the Chair summarised that the phrase, 'Through transition up to transfer' be used.

Dr Gill noted that, although he understood there were two separate reviews, his Society's view was that they provided care for children and adults with congenital heart disease (CHD). To implement a change just for fetus to transfer meant ignoring the risks associated with a process that was not integrated. The Chair stated that their scope did not extend to adults but that this concern had been noted as a risk to be managed. Mr Wilson noted that the scope of the programme was for children's services and this was what the JCPCT had reached a decision on. The review of adult services had not yet reached a decision. This Group needed to implement the JCPCT decision and they could not wait for the decision on adult services to do this, but should be mindful of the links between the services. Mr Glyde stated that they would not know until 2014 which centres were designated as adult CHD services. So, although they were working towards an integrated congenital heart service, currently the only decision related to the paediatric service. It was acknowledged that this was not the ideal position but this Group were experts being asked to advise commissioners on clinical issues related to implementation. Reconciling the two separate reviews would be part of this task. The Chair said that this Group could

advise commissioners that the work was unfinished unless the link was considered.

Professor Thilaganathan asked whether they could use the term 'congenital heart services' and then define their scope, rather than having a slightly misleading title and then defining children as being the fetus up to adult transition. The Chair said this issue could be taken back to the Programme Board. Mr Hamilton noted that the Programme Board were senior to this Group and if they felt the term 'children's congenital heart services' was more appropriate it might well be.

DK

The Chair summarised that the term 'children's congenital heart services' would continue to be used for the time being, whilst being clear in their definition of children. The risks of a non-integrated service would be highlighted, and look at how to advise on specifics in this area. Mr Wilson noted that risk 8 in the Risk Register related to this issue and needed to be checked for accuracy.

MW

#### **ACTIONS:**

- 1.1. DK to discuss name of programme with programme board
- 1.2. MW to review wording of risk 8 in the Risk Register

# 2: Minutes of the Previous Meeting and Report of Facilitated Session

#### Minutes of the Previous Meeting

The minutes were approved with corrections, as follows:

clarification of the spelling of 'fetus'

on page 6 - 'nurses have not been prepared' to be changed to 'not able', on page 8 - 'access to expertise was the same' to be changed to 'access to expertise should be the same'.

MW

Mr Richardson noted that Mr Cumper was clear he did not want the minutes to be approved and had said, 'I do not believe they reflect the discussion about the importance of the effect on prenatal or adult services and that any decisions over implementation needed to take full account of the needs of a life-long service. The Somerville Foundation will be voting against accepting these minutes'. This was duly noted.

Dr Gill noted that members of his Society had asked to see the minutes. The Chair stated that everything was put on the website once approved and individuals could be directed to this. The link for this would be sent out to be circulated. A corrected version, not marked as confidential, would also be emailed out and could be sent on to Society members.

MW

#### Summary of Opportunities and Risks Workshop

The Chair noted that the importance of mapping onto work already done was key, including current networks and the need for a strong communication plan distinct from Safe & Sustainable. Mr Hamilton stated that an error remained in this document where it said, 'Transition of care to the newborn', which should read, 'Transition of care to adulthood'.

Ms Kirwan asked whether item 3.2 on page 4, 'Networks should focus on the whole service not just the surgical centre' was referring to maternity, including ultrasound services and fetal medicine uses. The Chair confirmed that it meant the whole service. The comments in this document were taken directly from the meeting but individuals should highlight if they felt their own comments were not

reflected.

#### **ACTIONS:**

- 2.1 MW to amend minutes as outlined and circulate
- 2.2 MW to circulate link to website
- 2.3 MW to agree process to ensure all approved documents appear on the website
- 2.4 All to review summary of Opportunities and Risk Workshop and send any comments to MW

# 3: CIAG Ways of Working

The Programme Board had been established and the draft programme initiation document circulated. Four CIAG meetings a year would not be able to implement all the work and so subgroups had been agreed. Further groups, or links with established groups, may be required to ensure the right advice was implemented.

A draft paper on ways of working had been put together by Mr Wilson. This proposed forming a smaller executive group to oversee CIAG's work, supported by the programme team. Each member of this group would chair a specific piece of work, which would be run on a 'task and finish' basis. Dr Stuart would be asked to report on the Clinical Reference Group. Mr Barron said that he was uncomfortable with the concept of an executive group as they would be seen as an elite group making decisions on behalf of the others. The Chair said that the work could not be done by a group as large as CIAG meeting four times a year. The role of the executive group would be to oversee CIAG's work on behalf of the whole group, rather than having any separate authority or decision making role. This was agreed.

DK

The Networks Sub-group had been set up to define a network. Two groups on standards would be established: Standards Working Group for Children's Cardiology Centres and Standards Working Group for District Children's Cardiology Services.

Mr Hamilton noted that there were currently no representatives on CIAG working in district children's cardiology centres. Dr Fortune noted that he worked at a cardiology centre and that Dr Vengopalan worked at a potential district service.

The Clinical Outcomes Working Group did not yet have a chair. Discussion needed to occur with NICOR over whether a separate group was required or whether representation from them would be sufficient.

DK

The executive group currently did not have a surgical representative or a nursing representative.

Dr Gill said that it was necessary to have a patient representative on the executive group. The Chair noted that everyone on the executive group would be leading a workstream and if there was a patient representative there would need to be a role for them. Ms Keatley-Clarke noted that she was a patient representative and did not want excessive work and would not be able to provide clinical advice herself.

Professor Thilaganathan asked why there were two different standard working groups for different centres. Following discussion of the pros and cons of one group versus two it was agreed that there would be a single standards group, with

DK

a Chair who had the time to draw on both aspects and draw relevant people onto the group.

Mr Richardson noted the long expressed concern about the effect on the adult service of implementing children's services first. Therefore it may make sense to have a subgroup looking at the implications on the adult service. The Chair noted the need to manage the potential impact of changes to children's services on adult services and stated that this would be achieved by shared membership between the programme board and CIAG and the adult review rather than setting up a sub-group at this stage. CIAG representatives agreed that there were enough members who were also on ACHD and could provide feedback and raise necessary issues.

Dr Jenkins felt that they also could not separate out networks and standards in two groups as it would be impossible to work on networks without the standards. Dr Martin thought that the standards were already pretty much written and the focus was on implementing them through the network, so there only needed to be one group.

The Chair stated that the networks group would establish the pathway for commissioners. There would also need to be more detailed work for standards.

Dr Fortune felt that separating these issues was artificial. Mr Wilson believed that the networks group had a distinct role in establishing the functionality of a network and producing guidance on the governance, model, resourcing and staffing required. The focus would be on how networks would work rather than the clinical care delivered. Dr Gill added that establishing the function of a network was urgent and to ask one group to do this and set standards would involve too much work to be carried out quickly.

The Chair summarised that they would continue to have a networks group and a single standards group.

#### **ECMO**

Mr Davis raised the issue of ECMO as, if Leicester closed and their paediatric cardiology surgeons moved away, their ability to provide paediatric ECMO would be dubious. This workload would therefore have to be spread across England. He hoped that solutions could be reached in the workshops in early 2013 to feed back to CIAG. All centres would be asked to do cardiac ECMO and there was a question over whether they should be asked to take on respiratory ECMO as well. Whether all centres would do this or just a subset could be decided.

#### Nursing Representatives

The Chair reiterated that there was no nursing representative on the executive group and asked whether this was deemed acceptable. Ms Aryeetey said that the children's cardiac nurses work would continue through Fiona Smith. These individuals regularly teleconferenced and the key for them would be about implementation. They could feed into CIAG rather than be on the executive group.

The Chair summarised that there would be a small executive group, which would not be decision making but focusing on getting work delivered. Representation would be from: the Networks Group, the single Standards Group, Paediatric Transport Group, the Clinical Reference Group, and a surgical representative.

Chairs of the Networks and Standards Groups were to be decided, as were Terms of Reference and work patterns. Mr Wilson would provide support to the subgroups. Notes of the action points would be circulated but would not go on the website.

#### **ACTION:**

- 3.1 DK to establish executive group
- 3.2 DK to discuss with NICOR the need for a Clinical Outcomes Subgroup
- 3.3 DK to create one standards sub-group for District Children's Cardiology Services and Children's Cardiology Centres

# 4: Terms of Reference (Revised)

These had been revised in light of the discussion at the previous meeting, but needed to be more concise.

MW

Mr Davis said that they should be less specific and make reference to the relocation of children's respiratory ECMO services from Leicester rather than specifying that they moved to Birmingham. Mr Wilson noted that this direction had come from the Secretary of State. Mr Barron explained that Birmingham had shown they had capacity and could deliver the service if required.

#### Programme Objectives

Objective 5 would become objective 1 as it was intrinsic to their work. Objective 2 would then be to ensure that, 'Seven managed children's congenital heart networks are established covering the whole population of England, each including a congenital cardiac surgical centre', rather than, 'Each led by a congenital cardiac surgical centre'. Objective 3 would relate to the new model of care. Objective 4, regarding children's respiratory ECMO would be rephrased. Suggested wording was, 'Will be provided by Birmingham Children's Hospital' rather than, 'Will be relocated to'. Objective 5 was that transition to the new system would be managed safely and efficiently.

Dr Stuart asked about the link between congenital heart networks with the new strategic clinical networks. Mr Wilson said that this issue would be examined by the Networks Group. Mr Glyde said the crucial difference was that strategic networks would be disbanded once their job was complete. However, networks from Safe & Sustainable would be there forever.

Dr Stuart said that there was overlap with the development of dashboards with the Clinical Reference Group (CRG). There was also CCAD, which was a process where surgical outcome measures were looked at. All of these things needed to be brought together so there was one process. Dashboards were required as part of specialised commissioning to show the various quality patient experience measurements.

Dr Gill asked whether the point on implementing Referral Pathways implied that children's congenital heart networks would be geographically different from the adult networks. He noted that the ACHD group was not working on this assumption. Mr Wilson stated that there was no presupposition either way but the interface between the children's and adults' service needed to be considered and managed.

Mr Hamilton asked whether they needed a cardiologist working in children's cardiology centre as a representative. Mr Phillips noted that the usual representative from Wales would fill this role.

#### **ACTIONS:**

#### 4.1 MW to amend Terms of Reference to reflect comments

# 5: Principles of Implementation (Revised)

The Chair noted Mr Cumper's concern about the use of the term 'children's congenital heart services' rather than 'congenital heart services'.

#### **Patient Choice**

The issue of patient choice in designated surgical centres was raised. Mr Glyde stated that patient choice was enshrined in the JCPCT decision. The group discussed the practicalities of this issue. The Chair stated that they did not need to decide on practicalities but should agree that the principle was a patient could go to any designated centre.

#### Communication

Mr Wilson proposed the language was changed from 'clinicians and nurses' to 'clinical staff'.

# Children's Congenital Heart Networks

Mr Wilson said that Operational Delivery Networks were principally about the delivery of service.

Mr Davis said on point 7 they should include a comment about the importance of links with fetal, maternal and adult congenital services.

Dr Stuart noted that there was a description of the children's heart networks but not the relationship between children's heart networks. A mechanism for this should be established. The Chair said that they should add a bullet point saying, 'Communication will be through the congenital heart network board'.

Point 14 should be changed from, 'Would not be neglected' to, 'Would be strongly supported'.

Mr Davis asked whether being released to undertake training was classed as a recruitment and workforce issue. Mr Wilson explained that they were using the phrase 'people transition' to ensure all aspects were covered.

#### MW

#### **ACTIONS:**

# 5.1 MW to amend Principles of Implementation to reflect comments

# 6: Working Group Reports

#### i)Networks Subgroup Report

Terms of Reference and definitions had been agreed. The network would be based on a patient pathway from the pregnant mother at risk to transition to adult services.

# ii) Standards Sub-Group Report

The two standards groups would be merged as discussed previously. Once a chair was selected they would appoint the membership and agree Terms of Reference.

# iii) Clinical Reference Group Report

Dr Stuart explained that the aim of CRGs were to ensure that products of specialised commissioning, such as dashboards, had clinician support and approval. This role had been redefined at the end of 2011. A series of products relating to innovation had been agreed, and definitions of CQUINs, QIPPs and dashboards were produced.

Concerns remained regarding short deadlines for complex work. Not all meetings were well attended and it had been difficult to produce a QIPP when the legal decision on Safe & Sustainable had not yet been reached. Ms Kirwan reported that she sat on the fetal medicine CRG, which had also produced a CQUIN. A linkage between the CHD stream and the fetal medicine stream should be made to ensure women were treated appropriately.

# iv) Retrieval Group Report

Dr Jenkins explained that the Retrieval Group had been redefined as the Transport Group. Discussions were ongoing with Embrace regarding the transport of neonates and children. Two meetings had occurred with national commissioners. The scope of the group was neonatal, paediatric and aeromedical transport. The predominant discussion so far had been about whether the strategy should be aimed at neonates and paediatrics jointly or separately. There had been a disparity of views on this issue.

The Chairs of the CRGs for paediatric intensive care and neonatal intensive care were now liaising on this issue. It was considered preferable to have one set of standards and specifications for babies and children rather than two separate and slightly disjointed specifications. However, a unified set of standards did not mean that there would be one model of care. In fact, it was seen as a good idea to have different models of care but working towards the same standards and specification. The Chairs of the paediatric IC CRG and neonatal IC CRG would both attend the next Transport Group meeting.

Further consideration was being given as to how to transport children to nearer their home following treatment.

The Chair asked whether the reason transport teams could not have all the equipment for both neonates and paediatrics in one vehicle was due to cost. Mr Davis replied that it was in fact about the transport team themselves, who would be specialised in one of the fields rather than the equipment. Dr Jenkins explained that previously all transport had come from intensive care units but this had evolved into a standalone transport service. This change had benefitted from economies of scale and tailored teams for specific transfers.

# 7: Programme Board 7.11.12 report

The Programme Board had met for the first time. Its membership was agreed. The Chair was currently the only clinician on the Board but another would be invited if necessary.

# i) Programme Initiation Document (PID)

The job of the PID was to be clear about the work being done, how it was being taken forward and what was not being done. Particular points to highlight involved the governance and structure of the programme. The PID also set out the resources required to deliver the programme. All terminology included in the document would be clarified following decisions made in this meeting.

The beginnings of a Programme Plan were included, having been drawn from conversations, documentation and the decision making case. The next step would be to turn this into a full Programme Plan. The current proposal was for a small group to work on this issue and spend dedicated time on it. CIAG members could either volunteer to join the workshop group or provide comment on the proposals made by it.

Ms Aryeetey raised concern about the benefits: some points were tangible and easy to measure against baselines but there were others that did not currently exist and would be impossible to measure. The Chair noted that if any CIAG members had suggestions on how to strengthen this aspect of the document it would be helpful.

Mr Richardson reiterated the points raised in Mr Cumper's letter about the necessity of linkages between children and adult services.

Ms Kirwan stated that on page 11, regarding benefits and measures, the box should be populated saying that early diagnosis included ultrasound and timely referral of women to specialised services in fetal medicine or cardiac services.

Dr Stuart said that he was unclear what happened if a unit did not meet the red designation standards. He noted that currently there were a significant number of centres who did not have four cardiac surgeons, as required. Mr Wilson stated that they recognised that not all centres could meet all the standards at the moment. The standards were meant to be a stretch rather than a reflection of the current situation. The new system would ensure that where centres were not meeting standards there was a plan in place to address this.

Mr Davis noted that there had been no discussion of outcomes that were non-mortality related and that the outcomes group would need to consider looking at longer term developmental outcomes.

Mr Wilson noted that the PID was a working document and even once signed off it would continue to be updated. Any further comments should be emailed through to him.

Regarding the Programme Plan, Mr Wilson reiterated that it would be helpful for those involved in the delivery of the service to be involved. The Chair suggested that Mr Wilson wrote to CIAG members prior to the next meeting to encourage people to look at and consider the Programme Plan.

The risk register was reviewed. High level comment was sought on whether all risks had been encapsulated and whether suitable mitigating actions were listed.

Mr Wilson noted that risk 8 was regarding the linkage at a service level with the adult services. Mr Hamilton stated that it was unknown at the moment whether there would be any surgeons who operated on adults only. Mr Barron said that there was no plan for this strategy and it was likely that the surgeons operating on

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MW

children would also operate on adults. There had been no general expression of interest in specialising on adults except from one surgeon in the North West and this was not considered a sustainable proposal.

Ms Aryeetey said that there was a risk regarding the loss of children's cardiac intensive care nursing skills through de-designation.

Dr Mabin said that there was a risk about the lack of knowledge about units with paediatricians with special expertise at DGH level. This therefore led to a lack of knowledge about the implications for training, recruiting, retaining and funding. The Chair asked for this point to be considered in the Standards Group. Mr Wilson said that he had hoped this point was covered by risk 19 and he had tried to group all staff together rather than including separate risks for each one.

Mr Davis raised the issue of the impact of the changes to paediatric ECMO on adult ECMO. Mr Wilson asked for this point to be sent to him in writing. Mr Wilson also highlighted that it may not be part of the scope of this group to address the point.

CD

Dr Stuart raised a concern that the process might not improve care for teenagers. Professor Thilaganathan said that the fetal medicine CRG would recommend a number of designated fetal medicine centres. A risk of children's congenital cardiac services implementation was that it might result in removal of fetal cardiology from the designated fetal medicine centres, which would be counterproductive and retrograde step. Professor Thilaganathan suggested that networks must maintain co-location of fetal cardiology within the CRG recommended fetal medicine centres in order to provide effective care for women at risk of fetal congenital cardiac disorders.

The Chair asked for every additional risk to be emailed through to Mr Wilson.

# CD/EA/ DM/GS/BT

# iii) Communications and engagement plan

Mr Ford stated that the current communication situation was focusing mainly on the IRP and the JR. A draft plan was being amended following initial discussion on communications for implementation. This would be circulated at the next meeting. The Chair said that the Programme Board had agreed that there needed to be a different communication plan for the implementation phase, clearly separated from the decision phase, as the key messages and engagement style with stakeholders would be different. Engagement with professions was very important and it was for the CIAG to say how they should inform people of the implementation work. To date there had not been much communication about implementation as there had not been much progress.

JF

#### **ACTIONS:**

- 7.1 Comments re the PID to be emailed to MW
- 7.2 MW to amend the PID in light of comments received
- 7.3 MW to write to CIAG members to ask them to review the Programme Plan
- 7.4 CD to write to MW re ECMO
- 7.5 Comments and additional risks to be emailed to MW
- 7.6 MW to amend Risk Register in light of comments received
- 7.7 JF to circulate draft Communications Plan at next meeting
- 8: Safe and Sustainable Update

#### Judicial Review (JR)

Mr Glyde explained that a JR had been requested by a private company established by a campaign group with a relationship with Leeds.

At an initial hearing the campaign group had applied to delay the legal challenge until after the Secretary of State made his decision on the IRP. The JCPCT had said that a delay would prejudice the interests of children. The Secretary of State had said the JR should be heard first and that he would not make a decision before the court ruled on whether the process had been lawful. The court had therefore granted an expedited hearing, which would happen in early February with a judgement likely in early March.

There would be an opportunity to appeal against the JR decision and if this were to happen the appeal would probably be heard around June/July.

#### Independent Reconfiguration Panel (IRP)

The Secretary of State had asked the IRP to advise him by 28 February on the JCPCT's decision. It was currently assumed that all legal challenge would be resolved by the end of March 2013.

# 9: National workshop 16.10.12 update

The national workshop was considered to have been useful and positive. It had established the style that would be used to implement the process. Information and views had been received, which were close to what had already been identified in the Implementation Advisory Group.

Dr Salmon said that whilst another high level workshop may have a role, individual units also needed to talk to each other about the future.

#### 10: Charities workshop 10.09.12 report

Ms Keatley Clarke explained that national groups had been present as well as a group of informed parents. All groups accepted the standards and wanted them implemented as soon as possible. Concerns had been expressed about when they would be implemented, the lack of certainty, and how delays impacted on existing services. There were reports of uncertain referral patterns of new patients and questions over whether they should be referred to centres that would not be offering surgery in the future. Good clinical leadership with consistent messages was required.

# 11: Any other business

None

#### 12: Future meeting dates

A date for the meeting in February would be circulated later and there would be an attempt to establish dates for the whole of 2013.

# **ACTION:**

# 12.1 MW to circulate future meeting dates

MW