

**MINUTES OF THE  
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUB GROUP  
HELD ON TUESDAY 9<sup>TH</sup> MAY 2017**

1st Floor BJA Library Royal College of Anaesthetists, Churchill House,  
35 Red Lion Square, London

**PRESENT:**

Kay C Hawkins	(KCH)	Paediatric Clinical Lead for Organ Donation (Chair)
Caroline Davison	(CD)	CLOD St George's University Hospitals NHS Foundation Trust
John Forsythe	(JF)	Associate Medical Director, NHSBT
Jayne Fisher	(JF)	Team Manager, Yorkshire
Reinout Mildner	(RM)	CLOD Birmingham Children's Hospital
Ajit Mahaveer	(AM)	Consultant Neonatologist, Central Manchester University Hospital
Debbie McGuckin	(DM)	Senior Commissioning Manager - ODT
Angie Scales	(AS)	Lead Nurse: Paediatric and Neonatal Donation and Transplantation NHSBT
Jon H Smith	(JHS)	Paediatric CT anaesthesia / ECMO, Freeman Hospital
Riaz Kayani	(RK)	CLOD and PICU Consultant, Addenbrookes Hospital, Cambridge
Catherine Penrose	(CP)	CLOD Leeds General Infirmary
Louise Bruce-Tresnan	(LBT)	Deputising for Cherry Brown, Corporate Communications
Yemi Jegede	(YJ)	CLOD, Kings College Hospital, London
Simon Steel	(ST)	CLOD and PICU Consultant & Anaesthesia, Sheffield
Sue Madden	(SM)	Senior Statistician, NHSBT
Joanna Wright	(JW)	Consultant Neonatologist, Leeds Teaching Hospital
Caron Watts	(CW)	Advanced Neonatal Nurse Practitioner Doncaster and Bassetlaw Teaching Hospitals, Representing the Neonatal Nurses Association,
Simon Robinson	(SR)	CLOD, Leicester
Hannah Bartlett – Syree	(HBS)	Professional Development Specialist, NHSBT
Neil Healy	(NH)	Specialist Nurse - Organ Donation, Scottish Representative NHSBT
Michael Griksaitis	(MG)	Consultant Paediatric Intensivist & CLOD, Southampton Children's Hospital
Nagarajan Muthialu	(NM)	Consultant Cardiothoracic Surgeon, Great Ormond Street Hospital for Children
Judith van der Voort	(JvdV)	Paediatric Clinical Lead organ Donation, Consultant Paediatric Nephrologist and Paediatrician
<b>IN ATTENDANCE:</b>		
Ambreen Iqbal	(AI)	Clinical & Support Services, NHSBT

Item	Title	
<b>1.</b>	<b>Welcome introduction and apologies</b>	
1.1	<p>K C Hawkins welcomed everyone to the meeting and noted the apologies given for this meeting. Apologies have been received from Sarah Beale, Paul Baines, Paul Murphy, Anthony Clarkson, Rebecca Curtis, Sally Holmes, Stephen Marks, Dawn McKimm and Esther Wong, Joe Brierley, Cherry Brown, Michelle Jardine.</p> <p>Welcome extended to those attending for the first time including Caron Watts: Kay Hawkins clarified if she would be representative for British Association of Perinatal Medicine BAPM in addition to the Neonatal Nurses Association.</p> <p>Judith van der Voort for her position and representation of Wales.</p>	
		<b>ACTION</b>
<b>2.</b>	<b>Review of previous minutes and action points</b>	
2.1	The minutes of the previous meeting were agreed as a correct record. Representation from the Paediatric Intensive Care Society (PICS) has been confirmed; however it was suggested to invite a nurse from PICS.	K Hawkins

3.	<b>Matters arising</b>	
3.1	<p><b>Coroner update</b>  J Forsythe informed the Committee that he had met with the Chief Coroner last year. Detailed discussion took place around issues relating to organ donation and other areas of concern that either party may have. Following a positive meeting, it was acknowledged that organ donation should not have an impact on how coronial matters are taken forward. It was agreed to continue to build up a portfolio of cases to share information and learning. S Madden advised that the statistical teams are working with M Stevens to produce reports on Coroners jurisdiction which will include the number of organs donation, transplants and refusal rates.</p> <p>An invitation was extended to one of the South Central team managers to attend and present at the Coroners' continuation training Mass Fatalities event in May. H Bartlett to send details to J Forsythe. Communication amongst the Coroner and the SNODs still remains a priority and members are encouraged to continue to build effective working relationships with their local coronial service.</p> <p>M Stevens, Specialist nurse: Research and Service Delivery has been involved in training around 700 coroners' officers</p>	H Bartlett
3.2	<p><b>Banners and leaflets - NODC PSG(17)1</b>  Members discussed the new paediatric leaflet; the leaflet was launched at the national symposium. A Scales to confirm availability and ordering for external stakeholders. Consensus was reached that the Trusts would also be keen to introduce multimedia advertisement as well as display banners in the paediatric units represented.</p> <p>A Scales suggested that it would be useful to have paediatric banners available for hospitals with Paediatric Intensive Care Units for promotional activities such as Organ Donation Week. J Fisher, C Brown, L Tresnan and S Steel to take this forward and aim for a deadline of six weeks.</p>	A Scales
3.3	<p><b>NHSBT website update</b>  J Forsythe commented that the ODT website is currently in the "wireframe" testing phase to lay out content and functionality on each page taking into account user requirements. It was recognised that the data available on the website needs to be easily accessible and user friendly.</p> <p>The aim of this wireframe is to provide a visual understanding of each page and seek member's approval before the creative phase gets under way. The website will be accessible in due course. Feedback has been sought for each component of the new website. A Iqbal to send A Scales a link to use the wireframe.</p>	J Fisher/ C Brown, L Tresnan, S Steel
4.	<p><b>Media update</b>  L Bruce -Tresnan provided an update of forthcoming media campaigns. The first of which is a Ramadhan campaign and the release of the transplant activity report which will be published in June/July and will be combined with some strong media stories.</p> <p>The organ donation week will be launched in the first week of September, this provides an opportunity for the organ donation and transplant community to promote organ donation nationally and locally.</p> <p>It was noted that a circulation list should be created to ensure members receive regular e-bulletin of new events, announcements and updates within NHSBT. A Scales to liaise with C Brown to set up a circulation list to share proactive paediatric stories and include team managers, SNODs and CLODs. It was agreed to delegate the dissemination responsibility to the NODC PSG groups.</p>	A Scales/ C Brown

<p>4.1</p>	<p><b>Neonatal Audit update</b>          Following detailed discussion at the last meeting, strong emphasis was made for the need to audit across all level 3 neonatal units. A business case is due for completion; a few options have been proposed to ensure we capture auditing of all 64 level 3 neonatal units. An agreement on how this data will be captured will be concluded by the next meeting. A Scales reported that at this stage we are aiming for solely data collection, there is no performance indicator measure for the neonatal units currently.          A Scales reported results on data collected between April 2016 – March 2017 outlining infants recorded as 0 or 1 month in neonatal units and PICU, A Mahaveer has been looking at the data collected by Badgernet and will work with A Scales to establish how the data collated in NICUs may be used to assist in the PDA data collection.          A Mahaveer to feedback at the next meeting.</p>	<p>A Mahaveer / A Scales</p>
<p>4.2</p>	<p><b>Paediatric level meeting data report - NODC PSG(17)2</b>          The Paediatric level meeting data report was noted for information. The classification of hospital levels is now based on actual donors rather than potential, it was agreed that the PICUs would benefit from further benchmarking and discussion around challenges that are particular to them and therefore a telecom was held to discuss this. Data was presented as previously circulated. J H Smith had a query around data presented on page 2 - 3. S Madden to verify the figures.</p>	<p>S Madden</p>
<p>4.3</p>	<p><b>Scotland Update</b>          N Healy advised that the Scottish government working group is currently working on three work streams:</p> <ol style="list-style-type: none"> <li>1. Antenatal, Obstetric and fetal medicine</li> <li>2. Neonatal and paediatric donation</li> <li>3. Crown Office Procurator Fiscal Agreement on organ and tissue donation with Scottish Donation Transplant Group.</li> </ol> <p>Scotland is currently completing the neonatal potential donor audit within all level 3 units.</p> <p>They are currently in the stage of developing some patient information leaflets for families where there is an antenatal diagnosis of serious abnormality. The first meeting of work stream one is due to be held this week.          N Healy to feedback and send a draft of the proposed leaflet to K Hawkins and A Scales for comments. A Scales queried if this leaflet would be available to share when agreed. N Healy to explore this with the Scottish Government.</p> <p><b>Wales Update</b>          J van de Voort updated that following recent appointment as the Paediatric Clinical lead for organ donation have met with the regional CLODs and SNODs. It was noted that there has not been a donation in the PICU, however are in the process of establishing working relations with our Specialist nurses in organ donation. J van de Voort will be meeting with the neonatal network and starting the clinical data audit retrospectively starting from 1<sup>st</sup> April. It is proposed to audit units in Swansea and Cardiff.</p> <p><b>Northern Ireland Update</b>          It was acknowledged that there was no representation from Northern Ireland at the meeting, no update available.</p>	<p>N Healy</p>

5.	<b>Education and training</b>	
5.1	<p><b>Brain stem testing video</b></p> <p>The paediatric brain stem death testing element of the six big wins project was filmed recently using a paediatric and infant mannequin. It is anticipated that this will provide a useful educational tool that can be used as best practice for the diagnosis and confirmation of death. The completion of the final elements of the project has been delayed by consent issues related to filming of the adult brain stem testing.</p> <p>The videos will be accessible on the NHSBT website. The guidance forms for neurological determination of death have been adapted and are in the final stages of ratification with RCPCH and UKPICS before being widely accessible.</p>	
5.2	<b>Symposium Update</b>	
	<p>The symposium event was held in March and attended by 150 delegates. It was a very positive event and was well received by all attendees. Delegates expressed interest in holding a similar event regularly. Gratitude was extended to attendees as well as those involved in the organising committee.</p>	
6.	<b>Ongoing Work streams</b>	
6.1	<p><b>Annual Report on Donation and Transplantation in Paediatrics 2015/2016 and associated publication</b></p> <p>The annual report on donation and transplantation in paediatrics will be available shortly for 2015/2017. Publication is due for imminent submission.</p>	
6.2	<p><b>Annual Report on Donation and Transplantation in Paediatrics 2016/2017 - NODC PSG(17)3</b></p> <p>S Madden gave an update on the annual report on donation and transplantation in Paediatrics. This report presents Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2016 to 31 March 2017 and summaries of the following are provided:</p> <ul style="list-style-type: none"> <li>- POTENTIAL DONOR AUDIT</li> <li>- TRANSPLANT LIST</li> <li>- TRANSPLANT ACTIVITY</li> </ul> <p>The dataset used to compile this report includes all audited paediatric deaths in UK Intensive Care Units (ICUs) and Emergency Departments as reported by 8 May 2017. Paediatric patients have been defined as all patients under 18 years of age. Neonatal patients who die in a neonatal unit have been excluded from the report and patients who die on a ward have not been audited.</p> <p>This report summarises the main findings of the PDA over the 12-month period, in particular the reasons why patients were lost during the donation process. Data on the paediatric transplant list and transplant activity have been obtained from the UKTR. Organ specific paediatric definitions are provided with the data.</p>	
6.3	<p><b>Brainstem death testing forms</b></p> <p>The brain stem death testing forms are in the final stages of ratification with RCPCH and UKPICS. K Hawkins ensured the committee were fully aware of the donor optimisation care bundle and that it is available on the NHSBT website and also on the MOHAN app.</p>	
6.4	<p><b>Careplan update</b></p> <p>The minor changes agreed at the last meeting have been made to the Care Plan, circulation has been delayed due to the ratification of the brain stem death testing guidance forms. Circulation without these forms attached was requested by some members of the committee. A Scales to circulate as requested.</p>	A Scales

6.5	<p><b>Future Workstream</b>  <b>Paediatric and Neonatal Strategy - NODC PSG(17)4</b>          A Scales presented the Paediatric and Neonatal Skeleton Strategy report and asked for any comments/questions from the committee. It was noted that this will be a document to set out recommendations for paediatric and neonatal donation and a step towards developing the best practice guidance documents. The committee is asked for their engagements in stakeholder events to be held in September/October.</p>	
7.	<p><b>Any other business</b></p>	
7.1	<p><b>Length of the organ donation and retrieval process</b>          J Forsythe reported a workshop was held in January looking at ways to reduce the length of donation process. The length of the organ donation process and times of different events in the donation pathway are a crucial measure. It was recognised that the assessment is prolonging the process and earlier notification is encouraged to speed up the procedure. A letter has been disseminated to all transplant units outlining and seeking approval on actions towards developing a new protocol to shorten the length of donation and retrieval processes. J Forsythe to provide an update at the next meeting.</p>	
7.2	<p><b>DCD in children – NODC PSG(17)5</b>          J H Smith discussed the possibility of introducing DCD Heart transplantation in the paediatric community. Members welcomed recent reports of successful DCD heart transplantation in adults and expressed the view that the committee support pursuing a similar strategy in our paediatric population. Members acknowledge that there will be a financial and operational impact to achieve this.</p> <p>The issue of funding consumables has been a major discussion point. Further developments will be disseminated to the committee as available. Guidance on referrals was recently agreed by the NHSBT SMT and has been disseminated to SNOD teams.</p> <p>J H Smith was thanked for raising the item which produced a useful and informative discussion.</p>	
8.	<p><b>Next Meeting</b></p>	
8.1	<p>The next NODC Paediatric meeting will be held on Tuesday 26<sup>th</sup> September, 11:00 – 15:00, London (Venue to be confirmed).</p>	