

**MINUTES OF THE
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUB GROUP
HELD ON WEDNESDAY 25TH SEPTEMBER 2019**

One Park Crescent, Marylebone, London W1B 1SH

PRESENT:

Reinout Mildner	(RM)	Chair, National Paediatric CLOD, PNODC Chair and PICU Consultant Birmingham Children's Hospital
Susan Archibald	(SA)	Specialist Nurse - Organ Donation, Scotland, Representing Scotland (Dialled in)
Omer Aziz	(OA)	Paediatric CLOD, PICU Consultant Bristol Children's Hospital
Hannah Bartlett Syree	(HBS)	Team Manager, South Central ODT Team, NHSBT
Joe Brierley	(JB)	Paediatric CLOD, PICU Consultant PICU Great Ormond Street Hospital
Cherry Brown	(CB)	Senior Communications Officer – Media and PR, NHSBT
Ben Cole	(CB)	Lead Nurse – Family Aftercare, ODT, NHSBT
Caroline Davison	(CD)	Paediatric CLOD and PICU Consultant & Anaesthesia, St George's University Hospitals
Sue Duncalf	(SD)	Regional Manager North West & Yorkshire, ODT, NHSBT
Jill Featherstone	(JF)	National Professional Development Specialist, Medical Education Lead, NHSBT
Dale Gardiner	(DG)	National CLOD, NHSBT
Jane Gill	(JG)	CLOD, Neonatologist NICU, University Hospitals of Leicester
Riaz Kayani	(RK)	Paediatric CLOD, PICU Consultant, Addenbrookes Hospital
Yemi Jegede	(YJ)	Paediatric CLOD, PICU Consultant Kings College Hospital, London
Stephen Large	(SL)	Consultant Cardiac Transplant Surgeon, Papworth Hospital, Cambridge
Tracey Long Sutehall	(TLS)	Associate Professor, School of Health Sciences, University of Southampton
Sue Madden	(SM)	Senior Statistician, NHSBT
Ajit Mahaveer	(AM)	Consultant Neonatologist, Central Manchester University Hospital
Alex Mancini	(AM)	Pan London Lead Nurse for Neonatal Palliative Care
Dawn McKimm	(DM)	Team Manager Northern Ireland, ODT, NHSBT
Simon Messer	(SM)	Cardiac Surgical Specialist Trainee, Papworth Hospital, Cambridge
Catherine Penrose	(CP)	Paediatric CLOD PICU Consultant, Leeds General Infirmary
Stewart Reid	(SR)	Paediatric CLOD, PICU Consultant & Anaesthesia, Belfast
Angie Scales	(AS)	Lead Nurse: Paediatric and Neonatal Donation and Transplantation NHSBT
Jon H Smith	(JHS)	Paediatric CT Anaesthesia / ECMO, Freeman Hospital
Simon Steel	(ST)	Paediatric CLOD, PICU Consultant & Anaesthesia, Sheffield Children's
John Stirling	(JS)	NORS Workforce Transformation Program Lead, ODT Commissioning, NHSBT
Lisa Tombling	(LT)	Specialist Nurse Organ Donation, Northern Representative
Joanna Wright	(JW)	Consultant Neonatologist, Leeds Teaching Hospital

IN ATTENDANCE:

Ambreen Iqbal	(AI)	Clinical & Support Services, NHSBT
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Item	Title
1.	Welcome, Introduction and Apologies
1.1	<p>R Mildner welcomed everyone to the meeting and noted the apologies given for this meeting. Apologies have been received from Suzanne Browne, Anthony Clarkson, John Forsythe James Fraser, Michael Griksaitis, Debbie Macklam, Stephen Marks, Teressa Tymkewycz, Fiona Wellington, Carli Whittaker, Michelle Jardine, Chris Kidson, Nagarajan Muthialu Naga Kishore Puppala, Simon Raby and Simon Robinson.</p> <p>Additional attendees were welcomed to the meeting: Dr Tracy Long - Sutehall - University of Southampton, Stephen Large - Royal Papworth Hospital and Simon Messer - Royal Papworth Hospital.</p>

		ACTION
2.	Review of previous minutes and action points	
2.1	The minutes of the previous meeting were accepted as a true and accurate record of the meeting. All actions have either been completed or appear on the agenda.	
3.	Matters arising	
3.1	Neurological Determination of Death Testing Forms	
	<p>Members received a draft version of the Neurological Determination of Death Testing Forms. The Clinical Standards group are in the process of ratifying the forms and have requested to amend the wording to state “when not to test” in the preconditions. D Gardiner informed members that the ICS and FICM have approved the adult Neurological Determination of Death Testing guidance. There following minor differences were noted:</p> <ul style="list-style-type: none"> - Donor characterisation has been removed from the extended form - Further clarity has been provided regarding hypoxia injury. <p>Members agreed to review the paediatric forms and ensure uniformity is achieved in both the Adult and Paediatric guidelines. R Mildner, A Scales and D Gardiner to review the Guidance.</p>	R Mildner/ A Scales / D Gardiner
3.2	Coroner Update	
	<p>Professor Forsythe has written to the Chief coroner addressing some of the challenges around paediatric donation, particularly the high level of decline by coroners in paediatric DBD cases. The Chief coroner was made aware of the National Strategic plan to consider the challenges that are observed in cases where the donor is a child. The complexities of the legislation and requirements around child death, particularly in cases where a cause of death is unknown, unexpected or possibly caused by a non-accidental injury are fully appreciated. R Mildner highlighted the reoccurring crisis in hearts available for transplantation for children, particularly in younger infants where size matching is critical. Therefore, members agreed for R Mildner to liaise with J Forsythe and consider how NHSBT can re-engage with the Chief Coroner to resolve the issue of high Coroner / Procurator Fiscal refusal rate for paediatric organ donation.</p> <p>J Brierly has been liaising with paediatric forensic pathologists and members were supportive of exploring this avenue further at a meeting in November. J Brierly to feedback to A Scales and R Mildner.</p> <p>C Penrose described changes in local practice working with Coroner, police and pathologist to find ways of accommodating their needs and concerns. This has allowed donation to proceed on occasions.</p> <p>Y Jegede informed members of a Pan-London meeting discussion regarding coroners and pathologist. There was consensus that the regional team should consider establishing a working relationship with the local police teams and consider the protocols required to support proceeding to donation. Y Jegede to feedback the outcome and actions arising from future meetings.</p> <p>A Mahaveer requested consideration for consent in neonates to be included in the chief coroner work.</p>	R Mildner / J Forsythe J Brierly Y Jegede
4	PNODC Membership and Terms of Reference - NODC PSG(19)2	
4.1	The membership list and Terms of Reference were noted for information. Members acknowledged the necessity to ensure that the membership of PNODC enables delivery of the strategic plan and includes appropriate representation from stakeholders. It was emphasised as this committee has ownership of the National Paediatric and Neonatal Deceased Donation Strategy therefore should act as an overseer of this strategy.	

	Several requests for amendments were suggested and noted, TOR to be updated and a final version presented for agreement at the next meeting.	R Mildner																					
5	Paediatric SNOD regional role description - NODC PSG(19)3																						
5.1	The Paediatric regional SNOD role description is in the process of agreement. This item has been deferred to discuss at the next meeting.	A Scales																					
6.	Paediatric Donation and Transplantation Annual Data Report 18-19 NODC PSG(19)4																						
6.1	<p>S Madden presented a paper outlining the Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2018 to 31 March 2019.</p> <p>In the year 1 April 2018 to 31 March 2019, there were 1,075 paediatric deaths audited for the PDA. Of these deaths, 94 and 183 patients met the referral criteria for DBD and/or DCD, respectively and 98% and 84% were referred to a SNOD. Of the 94 patients for whom neurological death was suspected, 73% were tested and there were 67 and 145 eligible DBD and DCD, respectively.</p> <p>Of the families approached, consent/authorisation was ascertained for 73% eligible DBD donors and 51% of eligible DCD donors. Of these, 83% and 64%, respectively, became actual solid organ donors. No families overruled their loved one's known wish to be an organ donor.</p> <p>On 31 March 2019, there were a total of 180 paediatric patients on the transplant list. In the year 1 April 2018 to 31 March 2019, 270 paediatric patients received a transplant. The number of paediatric patients on the transplant list at the end of the year increased by 50 patients compared with the end of 2017/18. There were 15 fewer paediatric patients transplanted during 2018/19 when compared with 2017/18.</p>																						
7	Data Reports, Analysis and Statistical Resources																						
7.1	<p>S Madden tabled a paper detailing the Paediatric Statistical Resources which have been agreed as being available following the strategy recommendations.</p> <p>The PICU reports include PDA activity for all UK PICU and paediatric cardiothoracic ICUs. The Paediatric reports include activity for all patients under 18 years old. Archived versions of all published reports are also available on the clinical website.</p> <p>In addition to that noted below there will be 6 monthly PDA data available from neonatal units, it should be noted that this data is currently limited to audited units.</p> <p>Members noted the Paediatric reports in the table below.</p> <table border="1"> <thead> <tr> <th>Paediatric reports</th> <th>Distribution</th> <th>Frequency</th> </tr> </thead> <tbody> <tr> <td>1. Annual paediatric PDA report</td> <td>https://www.odt.nhs.uk/statistics-and-reports/paediatric-activity-reports/</td> <td>Annual</td> </tr> <tr> <td>2. PICU benchmarking slide set</td> <td>https://www.odt.nhs.uk/statistics-and-reports/trustboard-level-benchmarking/</td> <td>Annual</td> </tr> <tr> <td>3. Paediatric website summary data</td> <td>https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/paediatric-care/</td> <td>Annual</td> </tr> <tr> <td>4. PICU meeting booklet</td> <td>https://www.odt.nhs.uk/statistics-and-reports/trustboard-level-benchmarking/</td> <td>Every 2 years</td> </tr> <tr> <td>5. ODST team performance reports</td> <td>https://www.odt.nhs.uk/statistics-and-reports/regional-reports/</td> <td>Biannual</td> </tr> <tr> <td>6. ODST regional collaborative slide sets (PICU specific data from Spring 2019)</td> <td>Regional ODSTs</td> <td>Biannual</td> </tr> </tbody> </table>	Paediatric reports	Distribution	Frequency	1. Annual paediatric PDA report	https://www.odt.nhs.uk/statistics-and-reports/paediatric-activity-reports/	Annual	2. PICU benchmarking slide set	https://www.odt.nhs.uk/statistics-and-reports/trustboard-level-benchmarking/	Annual	3. Paediatric website summary data	https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/paediatric-care/	Annual	4. PICU meeting booklet	https://www.odt.nhs.uk/statistics-and-reports/trustboard-level-benchmarking/	Every 2 years	5. ODST team performance reports	https://www.odt.nhs.uk/statistics-and-reports/regional-reports/	Biannual	6. ODST regional collaborative slide sets (PICU specific data from Spring 2019)	Regional ODSTs	Biannual	
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	7. Quarterly PICU PDA data by hospital	Angie Scales	Quarterly	
	8. PICU performance report (To be finalised)	(To be agreed)	Quarterly	
8	Performance Report Draft - NODC PSG(19)5			
8.1	A Scales advised members that various performance reports are generated by NHSBT to provide a monthly breakdown of performance in relation to ODT strategic objectives. There was consensus of proposing and adapting a similar report for capturing Paediatric data. A draft National Paediatric ICU – Organ Donation Performance Report was received. Members were supportive of this initiative and are requested to feedback any comments to A Scales by end of November.			All
9	Research bid proposal – Paediatric Organ Donation from Paediatric Units: Investigating Potential, Practice, Preferences and Perceptions (PODPPP) - NODC PSG(19)6			
9.1	<p>It was noted that children will wait for a heart transplant on average 2.5 times longer than an adult on the urgent heart waiting list and in order to increase OD there are several elements that require further exploration. T Long Sutehall presented a research proposal to the committee and sought their participation and engagement.</p> <p>Members noted the following research questions:</p> <p>RQ1: What assets and barriers underpin the donation climate in Paediatric Intensive Care Units (PICU) in the UK?</p> <p>RQ2: What are the experiences, expectations consequences and outcomes for parents approached to consider POD and what factors shape their decision making?</p> <p>RQ 3: What form of behavioural intervention could lead to a sustained change in the donation climate of PICUs so that POD rates increase?</p> <p>Members are requested to submit their expression of interest to Tracy Long Sutehall - T.Long@soton.ac.uk .The deadline for submission of bid is 27th November 2019.</p>			All
10	Paediatric Heart Transplantation			
10.1	Concerns have been raised around the shortage of donor hearts for children with end-stage heart failure. Over the last few years cardiomyopathy diagnosis has led to huge demands of transplant centres and few donors are available to meet clinical demand. R Mildner informed members that NHS England are in the process of raising awareness of the changing criteria for accepting children organs for the purpose of transplantation. R Mildner to discuss this at the next PICS meeting.			
10.2	DCD heart			
	<p>S Messer gave a presentation outlining a DCD proposal which could potentially be introduced in paediatrics centres. The Papworth team have developed a small perfusion device that can provide ex-vivo perfusion of DCD hearts with no lower age criteria. The results of the established DCD heart transplant programmes provide a strong case for DCD heart transplantation to be incorporated into existing heart transplant programmes worldwide. The committee is supportive of this development to improve transplantation and the transplanting centres were advised to submit any project proposals to RINTAG for discussion and approval. S Messer to circulate a modified version of the presentation slides to this committee.</p> <p>R Mildner to liaise with J Forsythe and discuss setting up a small working group to determine how to proceed with this initiative.</p>			S Messer R Mildner
11	Media Plan			
11.1	<p>C Brown gave a comprehensive media release update detailing current and future projects.</p> <p>Media release – Sunday 29th September – children waiting for a heart transplant It was reported that the first media release will focus on the fact the waiting list for hearts is high, has grown 130% in a decade.</p>			

	<p>The story is being finalising and links back to the law change and key messaging around conversation and paediatric donation. Two further case studies will be featured, a teenager waiting for a heart explaining her story in her words and the mum of a baby waiting for a heart sharing their situation. Angie Scales, our paediatric lead, is the spokesperson and quotes from Caroline Dinenage, the new minister and the Children’s Heart Federation will also be included.</p> <p>The activity for World Heart Day will focus on children, with social media, stakeholder support, charities and hospital involvement and we will have internal and website news on the need for more young donors to help those children waiting for hearts.</p>	
12	Strategic plan – Workstream Updates	
12.1	<p>A Scales reported that the workstream leads are currently developing clear actions to support recommendations of the strategic plan.</p> <p>A presentation update was received from each workstream coordinator.</p> <p>C Penrose has agreed to join the operational workstream with B Cole.</p> <p>A Scales informed members that the Professional Development Team have agreed to support and fund a multidisciplinary leadership course in Child and Infant Deceased Donation.</p> <p>(Current Planned Dates: December 5th, 2019 in Birmingham and March 24th, 2020 in Bristol)</p> <p>The course is aimed at:</p> <ul style="list-style-type: none"> • CLODs covering PICUs • Paediatric Regional Lead SNODs • SNODs covering PICUs • Specialist Requestors • Family liaison staff in PICUs <p>A Iqbal to circulate details of the course to the committee.</p> <p>Work stream updates to be provided at every meeting. Presentation slides can be found here.</p>	A Iqbal
12.2	RAG rating for Strategy	
	<p>A Scales presented a snapshot of the Red, Amber and Green (RAG) rating system. The rating tool will act as a framework for identifying high priority areas and actions within the strategy. Most of the actions have a year timeframe. It was reported that the change in legislation had an impact on the timings of completion for some of the actions. A further update will be provided at the next meeting.</p>	A Scales
13	Regional Feedback	
	<p>Scotland</p> <p>S Archibald reported work to incorporate palliative care networks in Scotland is underway. This will be called PELICAN. All the palliative care teams are involved and have agreed the importance of the inclusion of organ and tissue donation options when planning end of life care.</p> <p>Northern Ireland</p> <p>Members were informed of the full-time paediatric CLOD appointment Stewart Reid. PICU capacity remains a challenging issue in their children hospital.</p> <p>Midlands</p> <p>Dr Anju Singh (Consultant neonatologist) is the new CLOD at Birmingham Women’s and Children’s Hospital</p> <p>South East / London</p> <p>Members were informed of a recent useful paediatric meeting. The meeting comprised of sharing examples of best practice from clinical members and discussing issues around paediatric donation.</p>	

	<p>Yorkshire Rachel Barber undertook a simulation training course in Manchester which was well received. J Wright is running a local neonatal deceased simulation in Leeds.</p> <p>South West O Aziz is the Paediatric CLOD for Bristol and has been working on the engagements with level 3 neonatal units. O Aziz also featured a radio broadcast focusing on BAME communities and promoting organ donation. A meeting took place with Michelle Jardine PICU Consultants in Cardiff and also the Paediatric CLOD for Wales, discussions were focused around ensuring education resources are up to date and correct.</p> <p>South Wales A Scales gave an update on behalf of M Jardine.</p> <p>The number of referrals and donors from PICU remain low.</p> <p>The following targets below have been identified following the Paediatric and Neonatal deceased donation strategy launch in June.</p> <ul style="list-style-type: none"> - Brains stem testing in neonates - Highlighting potential tissue donation - Withdrawal in theatre for donation after cardiac death - Donors to have the option of going to our local hospice after donation <p>Welsh Government runs the Welsh Transplantation Advisory Group (WTAG). They are focussing on Paediatric donation over the next year to support the Paediatric and Neonatal deceased donation strategy.</p> <p>South Central Following previous discussion around regional representation and capacity issues, the South-Central team are in the process of appointing a second paediatric CLOD in Oxford.</p>	
14.	Any Other Business	
14.1	<p>Following previous discussion around DCD heart donation, it was stressed that the proposal will need to be operationalised appropriately and safely as not all SNODs are familiar with DCD heart donation.</p> <p>D Gardiner advised members that Simon Elmore (the Kids & Teens Coordinator) works for Transplant support and has expressed an interest in working together to help bridge the donation / transplantation gap.</p> <p>R Kayani informed members about the Winston Churchill Memorial Trust runs who the Churchill Fellowships, a unique programme of overseas research grants. Applications for next year's Fellowships will open around April 2020, accommodation, travel and subsistence costs are funded by the organiser. A further update will be given at the next meeting.</p>	R Kayani
15.	Next Meeting	
15.1	The next NODC Paediatric Sub Group will take place on: Wednesday 12th February 2020, 11:00 – 15:30 at the Copthorne Hotel Birmingham Paradise Circus, Birmingham, B3 3HJ	