

**MINUTES OF THE
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUBGROUP
HELD ON WEDNESDAY 23rd SEPTEMBER 2020
VIA MS TEAMS MEETING**

PRESENT:

Reinout Mildner	(RM)	Chair, National Paediatric CLOD, PNODC Chair and PICU Consultant Birmingham Children's Hospital
Omer Aziz	(OA)	Paediatric CLOD, PICU Consultant Bristol Children's Hospital – South West
Hannah Bartlett-Syree	(HBS)	Team Manager, South Central ODT Team, NHSBT
Ben Cole	(BC)	Lead Nurse – Family Aftercare, NHSBT
Jan Bengtsson	(JB)	Consultant Paediatric Intensivist and CLOD PICU Consultant Newcastle RVI
Sarah Box	(SB)	Regional Paediatric SNOD Lead - South West
Cherry Brown	(CB)	Senior Communications Officer – Media and PR, NHSBT
Chloe Brown	(CB)	Senior Statistician, NHSBT
Helen Buglass	(HB)	Regional CLOD, Yorkshire (Representing Dale Gardiner)
Colin Faichnie	(CF)	Team Manager Scotland ODT Team, NHSBT
Jill Featherstone	(JF)	National Professional Development Specialist, Medical Education Lead, NHSBT
Laurence Fry	(LF)	Regional Paediatric SNOD Lead – North West
Jane Gill	(JG)	Co-CLOD, University Hospitals of Leicester - Midlands
Margaret Harrison	(MHar)	Lay Member, NHSBT
Sally Holmes	(SH)	Education and Professional Development Manager, Professional Development Team, NHSBT
Michelle Jardine	(MJ)	CLOD, Cardiff PICU – South Wales
Riaz Kayani	(RK)	CLOD, PICU Consultant, Addenbrookes Hospital - Eastern
Louise Mahon	(DM)	Regional Paediatric SNOD Lead – South East
Mairi Mackenzie	(MM)	SNOD NHSBT – Scotland (Representing Susan Archibald)
Alex Mancini	(AM)	Pan London Lead Nurse for Neonatal Palliative Care
Rachel Rowson	(RR)	Regional Manager - London - Organ Donation Team
Marian Ryan	(MR)	NORS Workforce Transformation Project Lead, ODT Commissioning NHS Blood and Transplant
Angie Scales	(AS)	Lead Nurse: Paediatric and Neonatal Donation and Transplantation, NHSBT
Sue Madden	(SM)	Senior Statistician, NHSBT
Emma Schoorl	(ES)	Regional Paediatric SNOD Lead - London
John Stirling	(JS)	Interim Head of Operations, OTDT, NHSBT
Lisa Tombling	(LT)	Regional Paediatric SNOD Lead - Northern
Jon H Smith	(JHS)	Paediatric CT Anaesthesia / ECMO, Freeman Hospital
Carli Whittaker	(CW)	Paediatric Critical Care Society (PCCS) Nurse Representative Nottingham University Hospitals NHS Trust
Rachel Wiseman	(RW)	Regional Paediatric SNOD Lead – Yorkshire
Joanna Wright	(JW)	Consultant Neonatologist, Leeds Teaching Hospital

IN ATTENDANCE:

Ambreen Iqbal	(AI)	Clinical & Support Services, NHSBT
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Item	Title
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1.	Welcome, Introduction and Apologies
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| 1.1 | R Mildner welcomed everyone to the meeting and noted the apologies given for this meeting. Apologies have been received from John Richardson, Joe Brierley, Rachael Barber, Anju Singh, Petra Shroff, Claire Murphy, Dale Gardiner, Claire Murphy, Gail Melvin, Naga Kishore Puppala, Catherine Penrose, Claire Williams, Debbie Macklam, Ajit Mahaveer, Nagarajan Muthialu, Nikki Crowley and Chris Kidson. |
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ACTION

2. Review of previous minutes and action points

- 2.1 The minutes of the previous meeting were agreed and approved as a correct record subject to one minor change: Minute 3.2 POD PPP update: Amend 'NIRH' to read NIHR'.

All actions have either been completed or appear on the agenda.

The Neurological Determination of Death Testing Forms is now available on the website.

Action point 6: Social Media family contact

A Scales reported that meetings took place with the Comms team and currently is in the process of liaising with GOSH to set up a working group to explore more formal advice. A further progress update will be delivered at the next meeting.

A Scales

3. Matters arising**3.1 Coroner / Forensic Paediatric Pathology update**

Deferred to the next meeting.

3.2 Coroner Update Appendix to Integrated Care Plan - NODC PSG (20)6

Members noted a Coroner appendix complementing the Integrated Care Plan for managing coronial/ legal or safeguarding issues. R Mildner briefed members on the order of liaison with key professionals to obtain permission to proceed with organ donation where a child is a potential organ donor confirmed by SNOD and is subject to a safeguarding investigation. Following discussion, there was consensus that the Coroner should be the first point of contact, acknowledging the existing good working relationship established with the Coroner. Members recognized that there will be geographical deviation across regions, therefore suggesting an order may not be feasible. There was consensus to consider each case independently and utilize local intelligence. It was suggested to highlight the importance of having discussions with a SNOD and for this to be incorporated into the document. There will be variation between local situation, R Mildner will incorporate comments received and update the document.

R Mildner

A Scales will share this with the SNODs group next week and feedback any further suggestions.

A Scales

3.3. POD PPP update (Paediatric Organ Donation from Paediatric Units: Investigating Potential, Practice, Preferences and Perceptions)

Following previous discussion, it was noted that a bid has progressed to stage two of the application process. A final decision will be taken in October 2020. A further update will be provided at the next meeting.

A Scales

3.4 Paediatric DCD heart update

Papworth continue to work alongside NHSBT through appropriate research protocols to approve their modified mOrgan machine for clinical use with the aim to support DCD heart retrieval from children and smaller infants. This process is ongoing and currently resides with the designated individuals in the three centres identified.

4 PNODC Membership TOR /circulation and attendee list -final agreement and expectations – NODC PSG(20)7

- 4.1 Members noted the final Membership and Terms of Reference.

R Mildner highlighted the need to ensure that representation from each region is achieved to enable effective delivery of the strategic plan. It was noted that only one representative for a region attends this meeting, and the regional representative is accountable for sending a deputy where required. It was noted that every region now has a designated paediatric CLOD and SNOD.

Amend the title Paediatric Intensive Critical Society (PICS) to the Paediatric Critical Care Society.

R Mildner

5 Clinical Statistics Update

5.1 Annual Report 2019- 2020 - NODC PSG(20)8

S Madden presented a paper outlining the Potential Donor Audit (PDA) and UK Transplant Registry (UKTR) information on the financial year 1 April 2019 to 31 March 2020 and summaries of the following are provided:

- Potential Donor Audit
- Transplant List
- Transplant Activity

In the year 1 April 2019 to 31 March 2020, there were 1,125 paediatric deaths audited for the PDA. Of these deaths, 93 and 223 patients met the referral criteria for DBD and/or DCD, respectively and 98% and 83% were referred to a SN-OD.

Of the 93 patients for whom neurological death was suspected, 74% were tested and there were 65 and 180 eligible DBD and DCD, respectively.

Of the families approached, consent/authorisation was ascertained for 68% eligible DBD donors and 46% of eligible DCD donors. Of these, 89% and 58% respectively, became actual solid organ donors. No families overruled their loved one's known wish to be an organ donor.

Over the last five years, the testing rate has remained consistent at around 73% and there have been improvements in referral and SNOD presence for both DBD and, more notably, DCD donation. R Milder recognises that the testing rate remains in the low 70 compared to adults and work is in progress to consider peer reviews. It was noted that all PICU will be requested to review all mortality rates and identify reasons for not testing. It was queried if the findings from the peer review could have a positive impact on the PDA data and if this can be included in the current report. S Madden advised the routine reports cannot be amended; however, a standalone report can be produced on an adhoc basis.

At 29 February 2020, there were a total of 198 paediatric patients on the transplant list. In the year 1 April 2019 to 31 March 2020, 230 paediatric patients received a transplant. The number of paediatric patients on the transplant list at 29 February 2020 increased by 18 patients compared with the end of 2018/19. There were 40 fewer paediatric patients transplanted during 2019/20 when compared with 2018/19.

AS highlighted the reduction in decline rates by coroner / procurator fiscal noted in period compared to 2018-19.

The report will be available on the OTDT website.

5.2 Benchmarking Data 19-20 NODC PSG(20)9

Members noted the benchmarking data on paediatric patients in PICU during 2019 – 2020. The report summarises audited deaths which proceeded into becoming a potential donor in PICU during 2019 – 2020. It was noted that NHSBT is in the process of appointing a Clinical Lead for Organ Utilisation and it is hopeful that will could have a positive impact. The CLUs would be appointed for a short term period and would be responsible for carrying out a local assessment of organ utilisation and creating the framework which will support the unit in meeting the anticipated increase in organ offers resulting from England's opt out legislation in the COVID-19 context.

6 Clinical

6.1 Surge Planning – NODC PSG(20)10

Members noted the COVID-19 Second Surge Planning document drawn up by Clinical Team within OTDT. The document outlines plan and consideration in response to a potential second surge and is available to review on the OTDT website. It was noted the NORS was maintained at 100% of normal availability during the peak of the COVID-19 crisis.

The document provides advice on:

- PPE
- Donor and recipient testing
- Retrieval
- Waiting list management

6.2 **DNN on ECMO guidance - NODC PSG(20)11 a - d**

R Mildner informed members of the supplementary guidance, endorsed by the Faculty of Intensive Care Medicine, the Intensive Care Society Standards Committee and the NHS England Severe Respiratory Failure Network for adults and children older than 16 years. Members also noted three papers outlining the management of a potential paediatric donor via ECMO. D Gardiner and colleagues from FICM are setting up a small working group to review existing literature and the adult guidance. Members wishing to submit an expression of interest to join this working group are requested to contact R Mildner.

All

6.3 **10-point checklist**

O Aziz reported following a near miss incident, a ten-point check list has been produced. The ten-point check list is available for any visiting SNODs to be aware and understand the paediatric and neonatal systems to ensure they are well equipped to support and facilitate donation in a PICU setting. Members agreed to incorporate the check list into the care plan, the document is also being considered as a controlled document by the Regional Lead SNOD group.

S Box

6.4 **Role of Paediatric retrieval service in organ donation**

O Aziz informed members that early in the year, a donation was facilitated in the South West region. It was noted that during the current pandemic circumstances, there is a likelihood that withdrawing life sustaining treatment take place in a district hospital and it was felt that discussion around organ donation needs to be considered. A local SOP is in draft and will be incorporated into the regional retrieval service policies.

7 **Media Update**

7.1 C Brown gave a comprehensive media update detailing recent, current and future projects.

It was reported that COVID 19 has dominated for the press office and there is no significant key progress to report. The utmost urgent activity has continued during the pandemic and the coverage around organ donation was fair and balanced. The media continued to support individuals with information on a reactive basis.

The following events were noted:

- On 20 May 2020, the law around organ donation in England was changed to help save and improve more lives.
- The transplant activity report was released in July.
- In light of the COVID-19 pandemic, organ donation week was digitally focused, encouraging stakeholders, partners, local campaigners and colleagues from the organ donation community to support the campaign on their online and social channels.
- World Heart Day - activity planned to raise awareness of the need for more heart donors to help those waiting. A press release will be sent out highlighting that there have been more heart transplants, particularly for children, during COVID, than there was in the same 6 months last year. However, the waiting list remains stable with hundreds of people waiting for a heart transplant, including dozens of children. The release shares the stories of two children who have received hearts during COVID, a baby and a teenager.
- It is hoped to do a follow up in the Sunday Mirror on Baby Ethan Eaves who was urgently waiting for a heart transplant and received his heart during this Summer.
- Christmas Campaign will focus on sharing paediatric stories and highlighting the number of people facing Christmas waiting for a transplant, including children.

There is also a lot of social media activity planned, including emotive case study stories and key messages and stats.

8 Strategic plan – Workstream Updates

- Progress Data
- Structural
- Operational
- Educational
- Neonatal

8.1 A Scales provided members with an update and a presentation on the Strategic plan workstream.

Following previous discussions, it was agreed to determine a more efficient way of measuring progress of each workstreams and tasks that came out of the strategy.

The following **structural** actions were noted: 9 of structural workstream are in progress.

- Appropriate and relevant performance measures
- Timely review of cases
- Clear regional and local responsibilities – SNOD / CLOD
- Clear support structure for all individuals involved in OD where a child is the donor

The following **operational** actions were noted: 9 of educational workstream are in progress. A risk assessment will be discussed with the SNOD group and it was agreed to extend the notification triggers and trial this in three regions.

- Overview of EOLC Pathways / Protocols / Care Guides
- Review of Identification and Referral Triggers
- Appropriate Post Donation Care of Paediatric Donor Families
- Increase in Organ Utilisation (under 5 years)

The following **educational** actions were noted: 12 tasked were allocated, 1 completed and 9 are still in progress.

- Review of SNOD to ensure specific support is given
- Review of clinical staff training in paediatric organ donation – *a webinar is run for all SNODS and requesters as part of the Continuing Professional Development*
- Ensuring all training incorporates a wide range of appropriate tools and resources
- Virtual platforms developed
- Peer review process – *working closely with clinical colleagues to ensure this is continued as part of their annual appraisal.*
- Endorsement of standardised forms for determination of death by neurological criteria – *The forms have been endorsed and updated in May 2020.*

The following **neonatal** actions were noted: 7 tasks allocated, 4 in progress.

- Support where there is potential
- Understand fully the need for these organs and potential there maybe – *focus on need for organs under 5 years of age*
- Managing expectations and messaging
- Safe determination of death using neurological criteria

It was reported that awareness and discussion regarding neonatal donation has improved amongst the SNODs community.

9 Any Other Business

9.1 Regional Update:

Scotland - No representative present at time of request to feedback

Northern - In the process of establishing effective working relationship with SNODs and Freeman and planning to approach the DGHs. The team has approached pathologist regarding limited donation. A decrease in the number of coroner's refusal nationally was noted, a meeting is yet to be arranged with the coroner. Work is in progress to expand teaching for new trainees. The proposal to collaborate with neonatal units is still pending and will be considered in due course.

Northern Ireland - No representative present.

North West - Since April 2020 achieved 100% referral rate for DCD and DBD. Concerns were expressed regarding a DCD heart donation not proceeding as the patient was over 30kgs but under 50 kg. It is hoped that once the modified mOrgan machine is rolled out, lower weight paediatrics can become DCD heart donors. Audit collection has commenced in NICU at Saint Mary's Manchester.

South Wales – There were 11 potential donors, achieving 100 % referral rate.

Midlands – The Midlands team is engaging collaboratively with the regional SNOD Leads and a neonatal and paediatric SNOD has recently joined the team. Concern was expressed regarding organ utilisation in small infants. The chair noted wider questions that need to be addressed, including the need to evaluate the existing post donation care with the aim to improve bereavement support in palliative care settings.

Eastern

It was noted that paediatric activity was maintained throughout COVID 19. Concerns were raised regarding specialist requestors not having any paediatric experience. A Scales highlighted that work re training is ongoing to help provide greater awareness, education and training for specialist requestors and SNODs.

South Central

Work is in progress to collaborate with regional teams. Paediatric donation and referral activity continued throughout the pandemic.

South West – O Aziz shared experiences relating to social media and national press and the challenges that were experienced. The South West team liaised with A Scales and the Comms team to ensure the situation was managed collaboratively.

O Aziz continues to work with the BAME community to facilitate more discussion around organ donation and this is predominantly in collaboration with some adult intensive care colleagues throughout the country.

South East - There is no significant activity to report and it has been very quiet during the COVID period. Concerns were raised regarding staffing shortages for in-house SNODs, however it was reassured that this did not have any impact on the PICUs.

London

The region has continued to receive paediatric referrals and donors throughout the pandemic.

The highest paediatric donor rate was achieved last year.

A paediatric network has been set up within London, Eastern and South East regions. The meeting was attended by colleagues from each PICU unit and considered different aspects of the strategy. It is hoped that paediatric CLOD representation is achieved across all PICUs.

Yorkshire

Continued to receive around 90% referrals through the pandemic.

The Yorkshire Organ Donation Services Team have reconvened training programmes virtually for nursing staff and medics, secured invites for paediatric MDT meetings in Leeds and commenced audit in Leeds NICU.

10. Next Meeting

- 10.1 The next NODC Paediatric Subgroup will take place on Wednesday 10th February 2021, 11:00 – 14:00 via Microsoft Teams Meeting.