#### NHS BLOOD AND TRANSPLANT ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

### NATIONAL ORGAN DONATION COMMITTEE (NODC) AT 10:30AM ON TUESDAY, 5<sup>TH</sup> JUNE, 2018 AT CHARTERED INSTITUTE OF ARBITRATORS 12 BLOOMSBURY SQUARE, LONDON WC1A 2LP

#### PRESENT:

Dr Dale Gardiner (Chair) National Clinical Lead for Organ Donation Performance & Business Manager, ODT, NHSBT Miss Joanne Allen Ms Liz Armstrong Lead Nurse, Service Development, ODT Mr Andrew Broderick **Donor Assessment Programme Lead** Regional CLOD - Yorkshire Ms Helen Buglass Miss Chloe Brown Statistics & Clinical Studies, NHSBT Dr Paul Carroll **Regional CLOD - Eastern** British Association of Critical Care Nurses Representative Ms Sarah Clarke Mr Anthony Clarkson Assistant Director, Organ Donation & Nursing Regional CLOD - South Wales Dr Katja Empson Prof John Forsythe Associate Medical Director, ODT (part meeting) Donation Committee Chair (Non-Clinical Donation Rep) Ms Amanda Gibbon Dr Pardeep Gill Regional CLOD – South East Regional CLOD - Northern Ireland Dr Paul Glover Independent Lay Member, ODT, NHSBT Mrs Margaret Harrison Ms Alison Ingham Regional CLOD - North West Ms Sally Johnson Director of Organ Donation and Transplantation Mr Craig Jones Independent Lay Member, ODT, NHSBT Dr Tim Leary **Regional CLOD - Eastern** Mrs Lesley Logan Regional Manager - Scotland Mrs Sue Madden Statistics and Clinical Studies - NHSBT Dr Alex Manara **Regional CLOD - South West** Ms Olive McGowan Asst. Director, Education & Governance, ODT (part meeting) Dr Iain MacLeod Regional CLOD - Scotland Ms Susan Richards Regional Manager – Midlands & South Central Regional Manager - London Ms Rachel Rowson Ms Marian Ryan Regional Manager - Eastern/South East Ms Angie Scales Deputy for Dr Kay Hawkins, NODC Paediatric sub-group Dr Ian Tweedie Regional CLOD - North West Dr Andre Vercueil Regional CLOD – London (part meeting) **Dr Angus Vincent** Regional CLOD - Northern Ms Fiona Wellington Head of Operations for Organ Donation, ODT, NHSBT Mr Colin Wilson British Transplantation Society representative

#### IN ATTENDANCE:

Mrs Liz Armstrong Ms Anne Walsh Mrs Kathy Zalewska Deputising for Head of Transplant Development, ODT Clinical & Support Services, ODT Clinical & Support Services, ODT

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			Action
1.	D Gardiner welcomed everyone		
		to the meeting.	
	APOLOGIES		
		tensive Care Society Representative	
		CoA Representative	
		itish Society of Neurological Surgeons representative ational Clinical Lead for Governance, ODT	
		egional Manager – North West/Yorkshire	
		egional Manager – Northern & Northern Ireland	
		hair – NODC Paediatric sub-group	
		aculty of Intensive Care Medicine representative	
		ead of Referral and Offering/TSS representative ead of Health Informatics, NHSBT	
		egional CLOD – Scotland	
		egional Manager – South Wales & South West	
		egional CLOD – South Central	
	Dr Argyro Zoumprouli Re	egional CLOD – South East	
	DECLARATIONS OF INTERES	ST IN RELATION TO THE AGENDA	
	There were no declarations of ir	nterest in relation to the agenda.	
2.		IELD ON 27 <sup>th</sup> FEBRUARY, 2018 – NODC(M)(18)1	
2.1	Accuracy	1220 ON 27 TEBROART, 2010 - NODC(M)(10)1	
		d on 27 <sup>th</sup> February 2018 via telecon were confirmed as	
		ardiner agreed to investigate the possibility of holding	
	one digital meeting per annum.		D Gardiner
2.2	Action Points NODC(AP)(18)1		
	AP1 – Matters Arising – E Lea	rning: Defer to minute 4.3	
		-	
	AP2 – Matters Arising – Pregr	-	
	AP3 – Matters Arising – Ante-	mortem interventions: Refer to minute 4.2	
	AP4 – DCD Heart Retrieval: U	pdate on retrieval protocols	
		e joint abdominal thoracic NRP protocol had been	
		ments before being submitted to the next DCD heart	
		The UK is the world leader in DCD heart majority of DCD heart transplants having been carried	
		nchester and Harefield also transplanting. Both	
	Newcastle and Glasgow	are also drawing up their own protocols with	
	Glasgow developing a b	usiness case.	
	AP5 – Length of donation pat	hway: Completed – slides shared with members.	
	AP6 – Organ Donation Hospit	al Annual Awards: Refer to minute 4.4.	
	AP7 – Impact of Emergency D	Department Strategy	
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	Work is in hand to look at engaging with the College to relaunch the strategy on the College of Emergency Medicine website or as part of an on-line education resource. K Empson, J Featherstone and D Gardiner will be liaising with national education CLODs on how to engage Emergency Department trainees using existing resources.	
3.	MATTERS ARISING	
	Members noted an email received from Dr Paul Murphy, outgoing Chair of NODC, and acknowledged his unique contribution to the Committee and UK Deceased Organ Donation.	
	<b>Scout pilot:</b> SMT had agreed the principle of a national scout service but the implementation model could not be supported financially against competing priorities. The Workforce Transformation Board was asked to look into a cost neutral option and in the interim all cardiothoracic centres (except Birmingham) will continue to offer the scouting service.	
4.	STANDING ITEMS	
4.1	Performance	
	<ul> <li>ODT Performance Report: End of year 2017/18 – NODC(18)12</li> <li>J Allen summarized the key points from the report: <ul> <li>1,574 deceased donors (956 DBD, 619 DCD), an 11% increase on last year</li> <li>In 2017/18 there were 24.1 deceased donors pmp; target for 2020 is 26 donors pmp</li> <li>4,035 patients received a solid organ transplant from a deceased donor in 2017/18, a 9% increase on last year</li> <li>257 fewer missed referrals (27% decrease) and 118 fewer occasions where a SNOD was not present (26% decrease)</li> <li>65% increase in the overall consent rate (72% DBD; 60% DCD)</li> <li>1.24 million new ODR opt-in registrants during 2017/18</li> </ul> </li> <li>During April there were 144 deceased donors, making it the third highest month ever with an 80% DBD consent rate in April.</li> <li>Comments on the report: <ul> <li>There appears to be a gradual increase in consented donors with no organs transplanted which raises concerns over capacity. The BTS is holding a transplanted which raises concerns over capacity. The BTS is holding a transplantation sustainability summit on 12<sup>th</sup> June which will look at the 'pinch points' in the clinical pathway and what needs to be done to address those</li> <li>The increasing age and BMI of the donor population also bring challenges as there are not the technical innovations to allow every donor's organs to be transplanted; however, the PITHIA trial will allow biopsies to be taken at donor hospitals to provide more information on donor organs</li> <li>The new offering policies for lung and for liver, both of which offer on a named patient basis, have led to increased numbers of offers</li> <li>A review of NORS Team demand and capacity is taking place in response to a rise in donor numbers</li> <li>The organ utilisation project is identifying and investigating declines for high priority recipients</li> </ul> </li> </ul>	

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Data on organ survival in recipients is included within the annual activity report and, as part of the utilisation strategy, work is taking place with the BTS to make more information available to both patients and clinicians. A meeting has also been held with the Winton Centre for Risk and Evidence Communication in Cambridge looking at how best to communicate numerical data to the public in a fair and balanced way.	
<b>Regional donors per million population (pmp) – NODC(18)13</b> A report on regional donors pmp was received for information and highlighted wide variation across the Organ Donation Service Team (ODST) regions. Based on the 2017/18 pmp target, eight teams were green, one amber and three red. Of those eight teams four were already achieving the 2020 target of at least 26 donors pmp.	
The report also highlighted potential, eligible, approached, consented/authorised and actual donors pmp by ODST region. Members felt the data indicated both structural and behavioural differences and questioned whether the data could be correlated with data on ICU bed capacity.	
<b>Expectations for investigating missed opportunities for 2018/19</b> During 2018/19 the focus remains on missed opportunities, with a particular focus on referral and SNOD involvement. The Committee supported a graded response relating to regional need and felt it would be useful for Regional Managers to share with each other a bullet point summary of their region's processes for monitoring missed opportunities. Any messaging should include positive as well as negative messaging.	
Discussion occurred around SNOD involvement and the need for the SNOD to be actively involved rather than merely present in the room at the time of discussion. It was noted that on those occasions where the donor has already opted out it is less likely that a SNOD will be asked to attend if they are busy. This level of detail is not easy to extract from the PDA data and members felt there should be the facility to record on the PDA where and why the decision on SNOD attendance was made. This would be included as part of the work of the NODC Statistics Working Group.	
<b>Length of donation process data – NODC(18)14</b> Average times of both the DBD and DCD donation processes were submitted for information.	
Length of donation pathway	
<ul> <li>All agreed actions arising from the Stakeholder Group review of the donor pathway have been completed. Decisions are now being made on the next steps:</li> <li>Monthly review of data broken down by team</li> <li>Focusing on DBD donations, providing data, by ODS Team, on the proportion of times that the transplant occurred between midnight and 7 am to allow teams to review the data and consider what could have been done better Members felt it would be beneficial to also consider the timings for DCD donations</li> </ul>	
<ul> <li>Consider focusing on median time from approach to start of operation for DBD and from approach to withdrawal of life sustaining treatment for DCD</li> </ul>	

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	<ul> <li>Looking at what can be done to improve the SNOD part of the pathway (timely referral, attendance, reduction in what the SNOD undertakes). This will involve visiting the SNOD teams to add clarity and reassurance on the role of the SNOD</li> </ul>	
	Submitting reports to both SMT and NODC	
4.2	Policy	
	Antemortem Interventions DH have withdrawn the 2010 legal guidance on NHBD and passed on responsibility to the relevant professional bodies. Work now needs to begin with the professional bodies to update guidance.	
	<b>Pregnancy</b> Clarification is still required on the process for organ donation and end of life care in women who are pregnant. The SNOD workforce finds itself in a difficult situation as the agreed process does not support SNODS to approach families to ask for bloods or urine for pregnancy testing. FICM have discussed the issue and concluded that testing for pregnancy is in the patient's best interest and should be occurring irrespective of donation. However, practice is known to vary and it is clear that not all ICUs carry out blood tests for pregnancy on women of childbearing age on admission.	
	<ul> <li>NODC made two recommendations:</li> <li>1. Exclusion of the potential for pregnancy should be mandatory before deceased donation occurs.</li> <li>2. A pregnancy test should be a blood assay not urine.</li> </ul>	
	O McGowan agreed to raise at ODTCARE the issue of whether blood testing for pregnancy could be incorporated as part of the normal SNOD donation process.	O McGowan
	Safety in DCD – NODC(18)15 Members received a proposal on DCD and noted that this was a confidential paper not for onward circulation. The proposal outlined clinical actions which should be incorporated into relevant MPDs and education and training for SNODs, CLODs and organ retrieval staff. Members agreed the proposed actions subject to minor changes and clarification of who is responsible for each step in the process. This will now be submitted to CTAG for approval.	D Gardiner
	<ul> <li>Recommended changes: <ul> <li>Add comment about ceasing oxygen/ventilation (if arch of the aorta not already clamped)</li> <li>Make it clear at each stage who is responsible (CT NORS Team or SNOD)</li> <li>Amend point 5 – surgeons cannot confirm death (donor ITU anaesthetic team should administer analgesia and confirm death, not the NORS team anaesthetist)</li> <li>Ensure RM or RCLOD are aware of any instances of this nature</li> </ul> </li> </ul>	

	<b>Application of neurological criteria inpatients on ECMO – NODC(18)16</b> Members received draft supplementary guidance outlining how the criteria for the diagnosis of death using neurological criteria can be satisfied when the patient is on ECMO. Once approved by the FICM/ICS Standards Committee, NODC will endorse the supplementary guidance such that if death is confirmed using this guidance then donation after brain stem death testing would be supported. Following this, the Advisory Groups will be informed.	
	<b>Organ Donation Committees – Rapid Improvement Event – NODC(18)17a &amp; b</b> Arising from a report by medical students on the functioning of organ donation committees a two-day rapid improvement event was held in April on strengthening the effectiveness of the Organ Donation Committee. A GAP analysis was conducted which identified eight themes where action is required. Actions have been assigned to individuals and a series of teleconferences have been scheduled to monitor progress.	
	Quarterly monitoring of the impact of deemed consent in Wales – NODC(18)18 Members received the quarterly report on the effect of Welsh Legislation on consent/authorisation rates for information. At this stage there is insufficient statistical evidence to conclude whether deemed consent in Wales has led to an increase in consent rates compared to England.	
	<ul> <li>Update on opt-out legislation</li> <li>England is developing a formal Government response to the public consultation of deemed consent and progressing with legislation</li> <li>Scotland is developing deem authorisation legislation based on consultation responses</li> <li>Northern Ireland held a public consultation on what more could be done to raise awareness of organ donation and responses are being reviewed</li> <li>Wales published a '2 Years On' report of progress made and lessons learned following the introduction of deemed consent legislation</li> <li>Jersey has enacted deemed consent legislation but is awaiting clearance from Privy Council before implementing</li> <li>Guernsey is considering the introduction of deemed consent legislation</li> <li>Isle of Man has launched a public consultation to introduce deemed consent legislation</li> </ul>	
4.3	Education	
	<ul> <li>The PDT strategy is currently being written and this will form the 1, 3 and 5-year plan for medical education</li> <li>Deceased donation course: Clinician and SNOD faculty development is evolving. Administrative burdens to local SNODs and SNOD teams have been dramatically reduced but with close contact remaining. Delegate attitude to SNOD involvement is being measured and will contribute to further analysis. Accreditation is still being explored. Tendering for the SIM centres has commenced with completion anticipated by Autumn 2018</li> <li>Discussions are ongoing to incorporate an emphasis on hospital engagement within the CLOD induction course</li> <li>The content of the annual 1-day Chair Induction course will alter in response to changes arising from the Chair RIE. An on-line e-learning resource will be developed, along with a system of mentoring and regional opportunities for practice sharing</li> </ul>	

4.4	<ul> <li>There is now an education 'holding page' on the ODT clinical website and work can now commence on migrating the Deceased Donation website to this area</li> <li>Collaborative work will continue to support further development of the paediatric SIM.</li> <li>The ambition is to have a joint Organ Donation and Transplantation Congress with the British Transplantation Society every two years in order to facilitate shared learning and network building. The event earlier this year was well evaluated and a response is awaited from the BTS on linking up on a more formal arrangement for March 2019. It is anticipated that there will be a joint Congress/BTS day with a sole Congress day. Details of costs are awaited but it is anticipated that funding will be made available to supplement the attendance of SNODs, CLODs, and Chairs. Volunteers would be sought to help develop the programme.</li> <li>Promotion</li> </ul>	
	<ul> <li>Organ Donation Week – NODC(18)19 A presentation on 2018-19 Strategic priorities, including details of Organ Donation Week from 3<sup>rd</sup> – 9<sup>th</sup> September 2018, was received for information. </li> <li>St John Awards Award ceremonies are currently held in the Autumn but in 2019 it is planned to move these to the Spring following feedback from donor families that as the ceremonies are held in the evening they would prefer them to be held when the evenings start to become lighter in the Spring. Scotland may retain the Autumn date as this ceremony is held during the day and is linked to Organ Donation Week. Members had no objection to the change in the other UK countries.</li></ul>	
	<ul> <li>Organ Donation Hospital Annual Awards A working group had met to discuss the awards scheme and members were given an outline of the decisions from that group:  <ul> <li>First annual awards should be held at the joint BTS Congress and built into the programme for the joint day</li> <li>A request for nominations will be included in the Medical Director's Bulletin and a nomination form will be created</li> <li>Nominations have been requested in the following categories: Exceptional individual Exceptional newcomer Exceptional team Excellence in innovation or research Excellence in performance </li> </ul></li></ul>	
	members, will meet in February 2019 to decide on the award winners. There may be more than one winner for each category, ie donation team or retrieval team. Members questioned whether awards should be split between level 1 & 2 hospitals and level 3 and 4 hospitals due to differences in levels of experience. It was emphasised that there needs to be a degree of subjectivity when deciding on winners rather than basing decisions purely on data. There was also concern that nominations will only come from those who can be bothered to do so for someone they know. It was emphasised that individuals or teams will be able to self- nominate.	

5.	WORKING GROUP REPORTS	
5.1	NODC Statistics Working Group	
	<ul> <li>Terms of Reference – NODC Statistics Working Group – NODC(18)20 The Terms of Reference were agreed.</li> </ul>	
	• Investigating the recent increase in DBD donor numbers – NODC(18)21 S Madden presented a paper which further explored recent trends based on additional data. The data indicated that smaller hospitals had contributed to 50% of the increase. This data will be further reviewed at the NODC Statistics Working Group	
	Specialist Requesters – NODC(18)22     Discussion of this paper was delayed until next NODC.	
	• Five-year Level 1 Statistics (for information) – NODC(18)23 The data was received for information. RCLODs were asked not to circulate the data until the re-levelling letter (see below) had been issued.	
	• <b>Re-levelling hospitals (for information) – NODC(18)24</b> The previous re-levelling of Hospital Boards/Trusts took place in 2016 with a view to repeating the re-levelling after two years. Trusts/Boards are being notified of their new level as at 2018 and, once dates have been set for new level meetings, letters will be issued to Trusts/Boards. Increased UK donation activity has led to an increased threshold for each category expect Level 1.	
5.2	Paediatric NODC	
	A Scales reported on progress with the paediatric and neonatal strategy. Discussion on the final draft is taking place and the final document will be submitted to both SMT and the Board in the next few months. Members noted that Dr Kay Hawkins, Chair of the NODC Paediatric sub-group would be retiring at the end of June and NHSBT would be seeking a new Chair for the sub-group. On behalf of the Committee, D Gardiner expressed thanks to Dr Hawkins for her work as the inaugural Chair of the sub-group.	
5.3	Research	
	<ul> <li>DePPaRT DePPaRT is a Canadian led research trial with participation from the UK, the Czech Republic and the Netherlands. Nottingham has now opened as a trial recruitment site.</li> <li>Hypothermia trial</li> </ul>	
	• Hypotherma that D Gardiner and D Harvey met with Prof Chris Watson with a view to undertaking this trial as a formal research proposal following on from a study which took place in New England in 2015. The aim is to improve delayed graft function in transplanted kidneys from DBD donors. From a donation community aspect this would involve the network of hospitals interested in donation research.	

	• Uterine transplantation A team from Imperial College NHS Trust, supported by Oxford University Hospitals NHS Trust, are working up a proposal for a deceased donor programme. Retrievals would be undertaken by Oxford with Imperial managing patients post-operatively. Funding has been agreed and REC/HRA approval obtained for this programme; however, a letter is still awaited from Oxford confirming support for the programme and that there will be no additional costs for NHSBT. Imperial have advised that they are also interested in working up a living donor programme. There is renewed interest in the live programme as retrieval techniques have advanced enabling a retrieval operation of 4 - 5 hours as opposed to 12 hours, presenting a more acceptable risk. Additionally, a team at Guy's and St Thomas' are planning to develop a living donor uterine transplant programme although funding has yet to be agreed for the programme. Progress on both programmes is being monitored by RINTAG.	
	• Olfactory bulb retrieval for spinal injury research St George's Hospital has successfully carried out the first olfactory bulb retrieval from a DBD donor with positive feedback from all stakeholders involved. Agreement is currently in place for a further two retrievals to be supported.	
6.	SPECIAL ITEMS	
6.1	Donor Referral and Assessment	
	A Broderick gave a presentation on Donor Referral & Assessment Transformation including the new design for an on-screen DonorPath process. This aimed to capture all data and reduce the time of the donation process. The process had been piloted in two regions with a third region about to join the pilot. Following discussion, it was suggested that a form of guidance on completing the form should be made available to clinicians.	A Broderick
6.2	Potential Donor Audit Development Project	
	Members took part in a SWOT analysis of the current PDA form, the outcomes of which would be used to inform a review of the PDA.	
7.	ANY OTHER BUSINESS	
	A brief report on the ODT Hub Programme and ODT Hub Operations was circulated for information. Members were asked to address any comments/queries to A Broderick to pass on to J Newby	
	<ul> <li>Members were encouraged to join a monthly webinar with colleagues in Canada. If interested, details could be obtained from D Gardiner.</li> </ul>	
	• Future meetings: D Gardiner suggested amending the meeting schedule for NODC to two face-to-face meetings and one telecon meeting per year. The plan would be to meet again face to face in November 2018, following which the next meeting would probably take place via GoTo or Skype.	
8.	DATE OF NEXT MEETING	
	Tuesday, 6 <sup>th</sup> November, 2018 at Chartered Institute of Arbitrators, 12 Bloomsbury	