NATIONAL ORGAN DONATION COMMITTEE (NODC)
MINUTES OF THE THIRTEENTH MEETING HELD ON TUESDAY 28TH FEBRUARY 2017
CHARTERED INSTITUTE OF ARBITRATORS, 12 BLOOMSBURY SQUARE, LONDON

PRESENT:

Dr Paul Murphy (**Chair**)	National Clinical Lead for Organ Donation
Miss Joanne Allen	Performance & Business Manager, TSS, NHSBT
Ms Liz Armstrong	Head of Service Development
Mrs Sarah Beale	Service Development Manager, ODT
Prof Stephen Bonner	RCoA Representative
Dr Katja Empson	Regional CLOD– South Wales
Dr Dale Gardiner	Deputy National Clinical Lead for Organ Donation
Ms Amanda Gibbon	Donation committee Chair
Dr Pardeep Gill	Regional CLOD – South East
Dr Paul Glover	Regional CLOD – Northern Ireland
Ms Monica Hackett	Acting Regional Manager – Northern Ireland
Dr Kay Hawkins	Chair, paediatric subgroup of NODC and Paediatric Intensive Care Society Representative
Ms Sally Johnson	Director Organ Donation and Transplantation
Dr Zahid Khan	Intensive Care Society Representative
Mrs Lesley Logan	Regional Manager – Scotland
Dr Justin McKinlay	Regional CLOD – Yorkshire
Dr Alex Manara	Regional CLOD - South West, and representative of Faculty of Intensive Care Medicine
Ms Sue Madden	Statistics and Clinical Studies - NHSBT
Miss Susan Richards	Regional Manager – Midlands & South Central
Ms Marian Ryan	Regional Manager – Eastern, London & South East
Prof Jonathan Thompson	Regional CLOD – Midlands
Dr Ian Tweedie	Regional CLOD – North West
Dr Angus Vincent	Regional CLOD – Northern
Dr Charles Wallis	Regional CLOD – Scotland
Dr Malcolm Watters	Regional CLOD South Central
Ms Fiona Wellington	Head of Operations for Organ Donation

IN ATTENDANCE:

Mr Ratan Gor	Medical Student, Imperial College London
Ms Catherine Green	Clinical & Support Services, ODT
Mr Geeth Silva	Medical Student, Imperial College London
Mrs Claire Williment	Head of Transplant Development, ODT
Mrs Kathy Zalewska	Clinical & Support Services, ODT

Item	Title	Action
1.	**Welcome and introduction** Dr Murphy welcomed everyone to the meeting. Apologies were received from: Mr Gareth Brown, Mr Roberto Cacciola, Dr Paul Carroll, Dr Maria Cartmill, Mr Anthony Clarkson, Dr Catherine Coyle, Ms Rebecca Curtis, Prof John Dark, Mrs Sue Duncalf, Prof John Forsythe, Prof Arpan Guha, Dr Edmund Jessop, Ms Caroline Lewis, Dr Sian Lewis, Dr Ian Macleod, Mr Joe Magee, Prof Derek Manas, Ms Lorna Marson, Ms Trish McCready, Ms Roseanne McDonald, Ms Olive McGowan, Prof David Menon, Ms Triona Norman, Mr Brodie Paterson, Dr Nilesh Parekh, Prof Rutger Ploeg, Mr John Richardson, Mrs Anne Sheldon, Mr Anthony Snape, Dr Andre Vercueil, Mr Phil Walton, Ms Sarah Watson, Ms Julie Whitney, Dr Mike Winter, Ms Esther Wong, Dr Argyo Zoumprouli	
2.	**Review of previous minutes and action points from the last National Organ Donation Committee held on 14th June 2016** The minutes of the last meeting were approved as a correct record. All outstanding action points had been completed or were covered within the agenda.	
3.	**Matters arising** There were no separate matters arising.	
3a.	National Donation and Transplantation Congress 2016 S Beale reported that the Congress went well with overall positive feedback. There were 400 delegates for both days and the congress app was introduced for the first time. There is still an on-going issue with accommodation in Warwick and with traffic leaving the venue. Following discussion, members felt that the Congress was a good educational event for both CLODs and SN-ODs. The Committee agreed to pursue options for a future Congress in 2018, taking into account available funding.	**S Beale**
3b.	Scout Pilot C Williment updated the Committee on this pilot and on the report from the external peer review. The report would be submitted to CTAG for formal discussion, following which it would be considered at NRG in June. Members questioned whether there were alternatives to Scout and whether this was the best approach for standard practice in the UK. In response to a question on the remit of the pilot, it was confirmed that this was an evaluation of effectiveness of the role rather than of cost effectiveness. Alternative models were not considered within the remit but reviewers drew on their experience of other models outside the UK when undertaking the review.	

3c.	DCD heart transplantation C Williment reported that the programme has resulted in 35 DCD hearts retrieved and 31 transplanted to date with mortality rates in line with DBD heart transplantation. The business case for the programme had been submitted to the Department of Health for consideration of continuation. The programme is expensive due to equipment costs and alternatives may need to be considered. The Committee expressed disappointment at the possibility of the programme discontinuing as it had proved to be very promising. In response to a query on out-of-zone requests for DCD heart retrieval it was confirmed that in these instances the request should be supported where appropriate and referred to the Regional Manager on-call to determine whether it is safe to proceed.	
3d.	Specialist Requestor Update F Wellington updated members on the new role that has been implemented in Yorkshire, London, Midlands and the North West. So far, data shows improved consent and authorisation rates, with a positive impact on 24-hour working. Feedback from members was generally positive with a view that gathering more data over a longer period is important to determine effectiveness.	
3e.	ODT Hub S Johnson reported that the cardiothoracic allocation scheme is on the new platform with the aim that the remainder will be delivered by the end of the year. A new business case is going to the board in March which proposes the following: o Deliver an electronic waiting list for livers that will be accessible for transplant centres on mobile devices. o Create an allocation scheme for livers and multi-organ offering. o Expand and bring the referral process into the Hub.	
3f.	Statement on the early management of patients with devastating brain injury A Manara reported that the Statement has been approved by relevant stakeholders. Next steps are as follows: o Ratification at the Joint Standards Committee of ICS and FICM. o Decide how it will be audited and where it will be published.	
3g.	ED Strategy D Gardiner updated members on the strategy which has been launched in five Collaboratives. The aim of the strategy is to identify and reduce the number of patients who are dying in ED and who meet referral criteria. A checklist is being developed for collecting data which will be used by Regional CLODs and Regional Collaboratives to support implementation of the strategy.	
3h.	RINTAG Issues C Williment reported on the following: **Uterine transplantation** RINTAG requested assurances on this project which have not yet been received. Once received, work will take place with SN-ODs and CLODs to determine protocols.	

	Olfactory bulb sampling RINTAG are awaiting feedback from the two teams undertaking this work to determine the best method moving forward. P Murphy requested that the Birmingham protocol be circulated to the Committee.	**C Williment**
4	**Standing Items**	
4a	<u>Latest 2016/17 performance</u> Jo Allen reported on NHSBT's record for January 2017: o 345 patients received a transplant thanks to 132 deceased donors and 193 families or patients who gave consent. o YTD 1636 families or patients consented; 1182 deceased donors and 1127 utilised donors where at least one organ was transplanted. 3110 patients have received a deceased donor transplant over the last 10 months. o January's overall consent rate was 69% (75% DBD and 64% DCD) which is 1% higher than the previous year. o Consent rates for regions stand at: Northern Ireland 100%, Eastern, North West and South East >70%, South Wales and South West >80%. o Northern Ireland, South East, South West, South Wales had 100% SN-OD involvement. o YTD Scotland achieved 109 deceased donors (more than what they achieved in all of 2015-16). o Mandatory training compliance is 85% and PDPR compliance is 91%. o 68 patients received a transplant from a living donor. The number of missed opportunities was listed to emphasise the continuing potential to improve performance. In January: o 84 patients met referral criteria but were not referred (3 DBD and 81 DCD) which would equate to 747 missed referral opportunities (41 DBD and 746 DCD) over a twelve month period. o 21 occasions where neurological death was suspected but tests not performed. o Families were approached without a SN-OD on 3 occasions when the patient was on the ODR and 23 occasions when the patient was not on the ODR. o There were 6 occasions where the family overruled the patient's decision to donate, in line with the monthly average for Q3. o There were 5 full coroner refusals and 21 partial refusals. Members raised questions around performance to which J Allen responded with the following: o There remains a positive association between DCD referral and the number of utilised DCD donors, implying that there remains a donation potential with those DCD donors who are not currently referred. o Efforts are being made to address the disappointing rates of organ utilisation, including the launch of an NHSBT utilisation strategy at the BTS Congress in March 2017.	
4b.	<u>2017/18 Strategic targets</u> J Allen reported on the revision of the original targets and members noted the current targets from 2017 to 2022. Individual targets for each centre will follow once these have been collated.	

4c.	<u>Reports from Statistics & Clinical Audit</u> S Madden presented the data to members which was noted. 4c(i) DCD approach rates accounting for DCD screening: This paper was produced to evaluate the proportion of patients who were excluded from the donation process via DCD exclusion or kidney screening, and consequently not approached by SN-ODs/medical or nursing staff, in order to calculate a more appropriate DCD approach rate. Members concluded that non-approaches to patients who have been excluded should not be reported and it was agreed that the calculation should be recalibrated to reflect this. 4c(ii) Five year trends in PDA data: Members agreed that they would like to receive this information on an annual basis. Centres could use the information at meetings where individual missed opportunities could be reviewed. 4c(iii) Reporting missed opportunities in the donation process: Following queries made by members, it was agreed that S Madden would amend the tables and send to one team initially to test the effectiveness of sending the information on a monthly basis to each team. 4c(iv) Matching Best Performance analysis The aim of the 2020 strategy and the current performance was noted by the committee. D Gardiner asked that members disseminate this paper within their regions. 4c(v) Monitoring the impact of deemed consent in Wales At this stage, there was insufficient evidence to determine the effect of introducing a system of presumed consent in Wales.	**S Madden** **S Madden**
4d.	<u>Paediatric sub-group of NODC</u> K Hawkins reported on the progress of the sub-group who met in November: o There is now a section on the ODT website covering organ donation from children of all ages, including guidance on donor optimisation. o The National Paediatric Organ Donation Care plan was launched successfully at Congress. o Angie Scales has been placed in a secondment role for 12 months as National Lead for Paediatric and Neonatal Nursing. o The auditing of all neonatal units continues and work is taking place with NHSBT to determine the best way to continue this work.	
4e.	<u>National Paediatric and Neonatal Symposium</u> K Hawkins reported that the symposium is fully booked with all 140 spaces filled. Members interested in attending the symposium were encouraged to register in the event that someone drops out.	

4f.	Education and training J McKinlay described the e-learning package being developed in Leeds. One module has been completed with an aim to develop a further seven. This could be delivered within two years if a secondment could be allocated to this work. Discussion took place around the best platform for accessing the learning. In previous instances 'learn-pro' was used which allowed different Trusts to access the training from a central space. Members were encouraged to contribute their existing presentations to aid in development of content. The project was met with unanimous support and it was agreed that J McKinlay should work with O McGowan to progress this.	**J McKinlay**
5.	**Pregnancy, end of life care and organ donation** P Murphy updated on the outcome of a request to the UK Health Departments regarding organ retrieval from donors who are pregnant, together with actions subsequently taken by NHSBT. The view of the UK Departments is that organs should not be retrieved from pregnant donors and that decisions to withdraw mechanical ventilation should be referred to the Courts, regardless of the gestational age of the foetus. NHSBT subsequently sought independent guidance from Counsel which had differed somewhat. However, given the sensitivity of the issue, NHSBT has: 1. written to all donation teams advising that organ retrieval should not be considered from female donors of child bearing age who are known to be pregnant. 2. written to the Health Departments requesting that they initiate a dialogue with relevant professional bodies such as the Intensive Care Society and Faculty of Intensive Care Medicine. Members noted the complexity of the situation and the potentially far-reaching effects that it could have on the wider medical community. P Murphy concluded that he will continue this work by seeking clarity on the situation from health departments.	
6.	**CLOD review – update from Level Meetings 1-3** D Gardiner updated the committee with the CLOD review objectives and thanked members for their SWOT analysis at the previous meeting. S Beale and D Gardiner will produce a report on this within three months which will detail the layout and current distribution of CLODs in terms of their type of employment, relationship with their hospital and their expanded roles. It was noted that the success of the model rests with the regional CLODs and whether they have the capacity to develop the role.	**D Gardiner/ S Beale**
7.	**Ante-mortem interventions** C Williment reported the findings and recommendations of the Ante Mortem Interventions Steering Committee, which in summary were: 1. ante mortem interventions such as heparin could be of benefit to organ donation and transplantation, although the evidence was weak. 2. ante-mortem interventions such as heparin are, in principle, acceptable to most clinicians, donor families and members of the public who are supportive of donation, particularly for one-off drug treatments and simple investigations. This advice has now been presented to the Health Departments.	

	Following this evidence from the steering group, the next steps now rest with Ministers who have the following three options: o Take no action. o Amend current legal guidance to allow ante mortem mortems to be introduced. o Formally withdraw their legal guidance and hand over responsibility for further developments in this area to relevant Professional Bodies. A decision is yet to be made but members agreed the importance of any new guidance which P Murphy will take forward.	**P Murphy**
8.	**Diagnosis of death in DCD donors** D Gardiner reported on the growing number of ACCPs in ICUs. Members agreed that they would accept an ACCP confirming death if they are trained and competent. Following discussion, it was decided that more work is required to develop this. D Gardiner would establish a working group to submit a recommendation to the next meeting of NODC in June.	**D Gardiner**
9.	**Research: the role of NODC** D Gardiner thanked the staticians for producing world-class reports and stated that it would be useful to share this work. J Thompson will investigate how this could be shared and structured and report back at the next NODC meeting.	**J Thompson**
10.	**Hospital Promotion** S Beale identified the three pilots currently being supported by our Marketing department: o Photo wall mounts which tell a local donation story – up to three can be funded per hospital and nine trusts have completed this so far. Some Trusts had difficulty locating a high resolution photograph of the donor. A good place for the wall mount is near ICU as it acts as a sensitive prompt for organ donation for both staff and families. o Hardback wipeable book - this is 20 pages in length, ethnically representative and includes stories from both donor and recipient families. Prototypes were sent to ICS Patients and Relatives Committee and the Donor Family Network for feedback. o Lift-wraps – This was offered to 11 Trusts around the country of which nine have accepted this so far. Two wraps will be provided per hospital: one in ICU and another in an area of high-footfall. More details on the effectiveness of this campaign to follow with the aim for completion by May.	
11.	**Order of St John Award** D Gardiner thanked those involved in the awards and commented on the great success of the ceremonies. It was recommended that in instances where a family member was upset because they did not receive an award as they had not signed the form as next of kin, they could receive a plaque instead. This would remedy a potentially sensitive situation. Members agreed that the report should be published.	**D Gardiner**

12.	**Reviewing the Organ Donation Committees** R Gor and G Silva presented their project to the Committee and asked for their support. The project was met with enthusiasm from members who invited the students to observe their meetings. A three-phase approach was outlined: o Send out an online questionnaire to SN-ODs, CLODs, and Chairs. They will then use this in conjunction with quantitative analysis of audit over the past five years. o Attend meetings as observers to determine how committees work and the level of work involved. o Collate the information to a written paper which will outline recommendations to help meet current needs.	
13.	**Any other business** Regional Stretch Goals – Members commented on the success of this work and agreed that the next set of goals should be determined regionally prior to the next NODC meeting to ensure they can report back. It was agreed that outcomes from the length of donation process work should be considered. P Murphy to liaise with O McGowan and J Forsythe on collaborative planning. S Madden reminded the Committee that the Trust Report Survey is closing in two weeks and to therefore fill out the survey if they have not already done so. Donor re-imbursement – there is a need to investigate a reduction in spending to allow more funding for DCD hearts, DCD liver perfusion, donor characterisation. There was a final note to say that the funding from the Department of Health is flat so if further projects are needed then income will have to be generated from within.	**CLODs/RMs** **P Murphy**
14.	**Dates of next meetings** Tuesday 6th June 2017, 11:00–16:00,12 Bloomsbury Square, London WC1A 2LP Tuesday 3rd October 2017, 11:00-16:00, Venue TBC	
	Close	