

NATIONAL ORGAN DONATION COMMITTEE (NODC)
MINUTES OF THE THIRTEENTH MEETING HELD ON TUESDAY 6TH JUNE 2017
The Old Library, Chartered Institute of Arbitrators, 12 Bloomsbury Square, London WC1A 2LP

PRESENT:

Dr Paul Murphy (Chair)	National Clinical Lead for Organ Donation
Miss Joanne Allen	Performance & Business Manager, ODT, NHSBT
Ms Liz Armstrong	Head of Service Development
Mrs Sarah Beale	Service Development Manager, ODT, NHSBT
Ms Lisa Burnapp	British Transplantation Society Representative
Dr Paul Carroll	Regional CLOD - Eastern
Dr Maria Cartmill	British Society of Neurological Surgeons Representative
Mr Anthony Clarkson	Assistant Director – Organ Donation & Nursing, ODT, NHSBT
Dr Katja Empson	Regional CLOD – South Wales
Prof John Forsythe	Associate Medical Director, ODT, NHSBT
Dr Dale Gardiner	Deputy National Clinical Lead for Organ Donation
Ms Amanda Gibbon	Non-clinical Donor Champion
Dr Pardeep Gill	Regional CLOD – South East
Dr Paul Glover	Regional CLOD – Northern Ireland (part meeting)
Ms Monica Hackett	Acting Regional Manager – Northern Ireland
Mrs Margaret Harrison	Lay Member, ODT, NHSBT
Ms Sally Johnson	Director Organ Donation and Transplantation
Dr Iain MacLeod	Regional CLOD - Scotland
Dr Alex Manara	Regional CLOD - South West
Ms Sue Madden	Statistics and Clinical Studies - NHSBT
Ms Jacqui Newby	Head of Referral & Offering/TSS Representative, ODT, NHSBT
Dr Nilesh Parekh	Regional CLOD - Midlands
Miss Susan Richards	Regional Manager – Midlands & South Central
Mr John Richardson	Head of Health Informatics, ODT, NHSBT
Ms Marian Ryan	Regional Manager – Eastern, London & South East
Ms Angie Scales	National Paediatric & Neonatal Specialist Nurse, ODT, NHSBT
Dr Ian Tweedie	Regional CLOD – North West
Dr Andre Vercueil	Regional CLOD - London
Dr Angus Vincent	Regional CLOD – Northern
Dr Charles Wallis	Regional CLOD – Scotland
Dr Malcolm Watters	Regional CLOD – South Central

IN ATTENDANCE:

Mr Ratan Gor	Medical Student, Imperial College London (part meeting)
Ms Susan Manu	Medical Student, Imperial College London (part meeting)
Mr Nishil Patel	Medical Student, Imperial College London (part meeting)
Mr Geeth Silva	Medical Student, Imperial College London (part meeting)
Mrs Claire Williment	Head of Transplant Development, ODT
Mrs Kathy Zalewska	Clinical & Support Services, ODT

Item	Title	Action																																				
1	<p>WELCOME AND INTRODUCTION</p> <p>P Murphy welcomed everyone to the meeting. Apologies were received from:</p> <table border="0"> <tr> <td>Prof Stephen Bonner</td> <td>RCoA Representative</td> </tr> <tr> <td>Prof John Dark</td> <td>National Clinical Lead for Governance, ODT</td> </tr> <tr> <td>Mrs Sue Duncalf</td> <td>Regional Manager – North West/Northern/Yorkshire</td> </tr> <tr> <td>Prof Arpan Guha</td> <td>Regional CLOD – North West</td> </tr> <tr> <td>Dr Kay Hawkins</td> <td>Paediatric Intensive Care Society Representative</td> </tr> <tr> <td>Dr Zahid Khan</td> <td>Intensive Care Society Representative</td> </tr> <tr> <td>Mrs Lesley Logan</td> <td>Regional Manager – Scotland</td> </tr> <tr> <td>Ms Trish McCreedy</td> <td>British Association of Critical Care Nurses Representative</td> </tr> <tr> <td>Ms Olive McGowan</td> <td>Asst Director of Education & Excellence, ODT, NHSBT</td> </tr> <tr> <td>Dr Justin McKinlay</td> <td>Regional CLOD – Yorkshire</td> </tr> <tr> <td>Prof David Menon</td> <td>Faculty of Intensive Care Medicine Representative</td> </tr> <tr> <td>Mr Brodie Paterson</td> <td>College of Emergency Medicine Representative</td> </tr> <tr> <td>Ms Amanda Small</td> <td>Lead Nurse Service Delivery, ODT, NHSBT</td> </tr> <tr> <td>Prof Jonathan Thompson</td> <td>Regional CLOD – Midlands</td> </tr> <tr> <td>Mr Phil Walton</td> <td>Regional Manager – South Wales & South West</td> </tr> <tr> <td>Ms Fiona Wellington</td> <td>Head of Operations for Organ Donation, ODT, NHSBT</td> </tr> <tr> <td>Dr Mike Winter</td> <td>Medical Director, NSD Scotland</td> </tr> <tr> <td>Dr Argyro Zoumprouli</td> <td>Regional CLOD - South East</td> </tr> </table>	Prof Stephen Bonner	RCoA Representative	Prof John Dark	National Clinical Lead for Governance, ODT	Mrs Sue Duncalf	Regional Manager – North West/Northern/Yorkshire	Prof Arpan Guha	Regional CLOD – North West	Dr Kay Hawkins	Paediatric Intensive Care Society Representative	Dr Zahid Khan	Intensive Care Society Representative	Mrs Lesley Logan	Regional Manager – Scotland	Ms Trish McCreedy	British Association of Critical Care Nurses Representative	Ms Olive McGowan	Asst Director of Education & Excellence, ODT, NHSBT	Dr Justin McKinlay	Regional CLOD – Yorkshire	Prof David Menon	Faculty of Intensive Care Medicine Representative	Mr Brodie Paterson	College of Emergency Medicine Representative	Ms Amanda Small	Lead Nurse Service Delivery, ODT, NHSBT	Prof Jonathan Thompson	Regional CLOD – Midlands	Mr Phil Walton	Regional Manager – South Wales & South West	Ms Fiona Wellington	Head of Operations for Organ Donation, ODT, NHSBT	Dr Mike Winter	Medical Director, NSD Scotland	Dr Argyro Zoumprouli	Regional CLOD - South East	
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2	<p>REVIEW OF PREVIOUS MINUTES AND ACTION POINTS – NODC(M)(17)1 & NODC(AP)(17)2</p> <p>The minutes were agreed and approved as a correct record.</p> <p>AP1 National Donation Congress: Planning is ongoing.</p> <p>AP2 RINTAG issues: The Birmingham protocol has been circulated to Committee members.</p> <p>AP3 DCD approach rates accounting for DCD screening: Refer to minute 3.</p> <p>AP4 Reporting missed opportunities in the donation process: Ongoing</p> <p>AP5 Education and training: Carried forward to the next meeting.</p> <p>AP6 CLOD review – Update from level meetings 1 – 3: Refer to minute 7 below.</p> <p>AP7 Ante-mortem interventions: Refer to minute 3.</p> <p>AP8 Diagnosis of death in DCD donors: This was agreed as an acceptable activity for ACCPs in ICUs assuming that appropriate training was given within the context of DCD donation. However, nothing exists in writing or in competency materials with regard to this. It was suggested that this might be more appropriate for inclusion in the DCD consensus statement.</p> <p>AP9 Research – The role of NODC: J Thompson would be asked to report at the next meeting on the investigation into how statistical reports could be shared and structured.</p> <p>AP10 Order of St John Award: Completed - The report has been published.</p> <p>AP11 - Regional Stretch Goals: Regional stretch goals should be set at the collaboratives taking place this week and next. The focus should be on maximising referral and collaborative requesting. Regional Managers/Regional CLODs were asked to circulate their goals to the group.</p>	<p>C&SS</p> <p>C&SS</p> <p>RMs/RCLODs</p>																																				

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3	MATTERS ARISING	
3a	<p>Pregnancy Clarity on the issue of organ retrieval and withdrawal of life-sustaining treatments from potential donors who are pregnant is still being sought from the Department of Health. The lack of any case law or primary legislation on this issue has made it difficult to reach consensus and if agreement cannot be reached it is likely that a joint application will need to be made to the Courts to rule on the matter. Members will continue to be updated on developments at future meetings.</p>	
3b	<p>Ante-mortem interventions The Ante Mortem Interventions Steering Committee submitted its findings and recommendations to the Department of Health but any decision was delayed due to the purdah arising from the announcement of a General Election. The Department plans to withdraw the current guidance on ante-mortem interventions and NHSBT will work with the relevant professional bodies to create new guidance to replace the existing. Agreement will need to be reached on how and when this happens.</p>	
3c	<p>Devastating brain injury guidance The guidance is awaiting ratification by FICM. The SICS had expressed concerns about auditing and talks have taken place with ICNARC around outcome data and how to include this within the SMR.</p>	
3d	<p>DCD heart retrieval All four Health Administrations have stated that they are unable to support the DCD heart programme at present due to the high disposable costs associated with the use of the Transmedics Heart Care system. However, whilst unable to meet these additional costs, NHSBT will continue to support all other aspects of the three DCD heart retrieval programmes currently in operation (Harefield, Papworth and Manchester). It was noted that 10% of heart transplants are now undertaken using DCD hearts and that other centres wishing to join the programme will need to work with existing centres to gain experience of a minimum of three DCD retrievals. It was also reported that Harefield were keen to extend their retrieval programme into the South Central region.</p>	
3e	<p>Proposals for a future national meetings The Senior Management Team at ODT are keen to further develop collaboration with the British Transplantation Society (BTS) rather than continue to support further donation-specific national events. Following initial discussions it is possible to deliver a donation-devoted session at the BTS Congress in Brighton in March 2018, followed by a more fully collaborative meeting the following year. Alternative options for a National Donation Congress in either March or September 2018 are also being considered at either Birmingham or Warwick Universities. A proposal is to be submitted to SMT for a decision.</p>	
4	STANDING ITEMS	
4a	<p><u>Latest 2016/17 performance – NODC(17)15</u> J Allen summarised the headlines from the ODT Performance Report for March 2017:</p> <ul style="list-style-type: none"> • Another record year - 3.6% increase in deceased donors and 5.1% increase in deceased donor transplants • A decrease in the number of patients on the transplant waiting list (182 fewer patients at 31st March 2017) • Non collaborative requesting continues to be an issue with 28 such approaches, only one of which resulted in consent. It was noted that there is no pattern to when and where this is taking place. Further work needs to take place on what measures 	

Item	Title	Action
	could be taken to address this and members were asked to include this within their stretch goals. These data will be included in the missed opportunities reports.	
4b	<p><u>Missed opportunities reporting & draft letter – NODC(17)16a & 16b</u> Members received an example report and draft letter for missed opportunities. It is hoped to include a comments box as well as the reasons for not approaching (although this can be picked up from the PDA), with those DCD patients who have been screened out having been removed. A paper is being submitted to SMT to set out the intention and purpose of the report which will be placed in the NHSBT G drive on a monthly basis for Regional Managers to forward on to RCLODs. This could also be forwarded to Chairs of Organ Donation Committees if required. Each collaborative will need to manage the data as some instances may have been reviewed and identified as not being a missed opportunity. It was noted that although these data can be provided there is not sufficient resource to record any modifications to the original PDA dataset.</p> <p>S Johnson and A Clarkson agreed to write to RCLODs & RMs, copied to Donation Committee Chairs and CLODs, re the launch of the report which would be split by Trust / Health Board. Members felt that Trusts should be given a 6 months' grace period before any missed opportunities are challenged. After that time the template letter highlighting any missed opportunities should include an action for completion by the CLOD for follow up.</p>	S Johnson/ A Clarkson
4c	<p><u>Specialist Requestor report – NODC(17)17</u> A Clarkson reported on consent and authorisation rates of the Specialist Requestor (SR) role which was introduced in four Organ Donation Services Teams. Comparing activity between Specialist Requestors and SNODs within these teams shows that in two of the teams the consent rates are higher for SRs than for SNODs but lower in the other two teams. There is, therefore, insufficient evidence to determine whether the SR role has improved consent rates since it was introduced. This role will continue to roll out as resources allow.</p>	
4d	<p>Action plan for non-collaborative requesting Refer to minute 4a above.</p>	
Reports from Clinical Audit and Statistical Studies		
4e	<p><u>Monitoring the impact of deemed consent in Wales – NODC(17)18</u> Members received a paper from S Madden summarising the effect of Welsh Legislation on consent/authorisation rates for Quarter 5. It was noted that at this stage there is insufficient evidence to conclude whether deemed consent in Wales has led to an increase in consent rates. Quarterly monitoring of consent/authorisation rates for the four nations of the UK will continue. Scotland is currently considering the possibility of a soft opt out system but this has yet to be confirmed.</p>	
4f	<p><u>Draft annual Potential Donor Audit (PDA) report – NODC(17)19</u> Draft PDA information for the financial year 1st April 2016 to 31 March 2017 was reported. Once finalised, the report will be circulated to NODC members and then await input to the ODT website which is currently being migrated to a new site.</p>	S Madden
4g	<p><u>PDA definitions – NODC(17)20</u> Details of updated PDA definitions were received. The following were noted:</p> <ul style="list-style-type: none"> • The change to approach rate metric is not included. S Madden/J Richardson need to raise a change request to change the PDA to capture this data. • Neurological death in neonates is excluded. The reason code needs to be changed in the actual application before changing in the definitions. 	

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4h	<p><u>Paediatric subgroup update</u></p> <ul style="list-style-type: none"> Annual Report on Donation in Transplantation in Paediatrics 2016/17: This presents PDA data and transplantation data for the financial year 2016/17. There is no significant change from last year. The report is run for all patients under 18 years of age so captures data on older children cared for on adult ICUs. However, similar reports are already produced to demonstrate the challenges specific to PICUs. Consent is one of the main challenges (65% DBD and 28% DCD). Brain stem death testing guidance for patients under 2 months old: This is to support those not familiar with testing and is in the final stage of ratification with RCPCH, BAPM and UKPICS. Work is ongoing on exploration of a mechanism to establish a full data set from neonatal units across the UK. Paediatric and neonatal strategy: This is a key area for focus and a skeleton strategy report is being developed. This document will set out recommendations for paediatric and neonatal donation and will help to develop the best practice guidance documents. The next stage is stakeholder engagement and establishment of workstreams with a view to completing by March 2018. <p>Members asked that the final draft document be submitted to NODC .</p>	A Scales
5	EDUCATION	
5a	<p>New roles and appointments</p> <p>D Gardiner reported that SMT had approved additional educational support, two new CLOD roles, and continued support for the ICM simulation courses, with an ambition to deliver six courses per year. Interviews for the national roles will take place within the next couple of months.</p> <p>A Gibbon highlighted the need to strengthen induction training for Donation Committee Chairs at a regional level and it was noted that induction training for CLODs and Committee Chairs would form part of the new medical education roles.</p> <p>J Forsythe reported on a recent meeting with the Chief Coroner to discuss the education of coroners and coroners' assistants in relation to organ donation. For the first time NHSBT will be involved in the mandatory training programme for coroners and will also be heavily involved in the education of coroners' assistants. In addition, it was suggested that coroners be invited to St John Awards ceremonies.</p>	
5b	<p>Update on toolkit for diagnosis of death using neurological criteria</p> <p>S Beale reported that work on the audio visual tool for the website is currently behind the target delivery date. Subject to approval from Clinical Governance around appropriate consenting of the family, it is hoped to add the BSD testing of a patient to the tool. To date three hospitals have given support at Chief Executive level for filming to take place.</p>	
6	<p>DONATION COMMITTEE REVIEW</p> <p>Members received a presentation from the students who were undertaking a project reviewing the Organ Donation Committees, the aims of the review being:</p> <ul style="list-style-type: none"> To review the roles and structure of the Committees To review time management, effective delivery of improvement and accountability To deliver recommendations on the roles, responsibilities and structure <p>Methodology:</p> <ul style="list-style-type: none"> Literature review Data analysis Surveys & interviews Formulation of a framework Recommendations 	

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	<p>Six key findings:</p> <ul style="list-style-type: none"> • Lack of formal training of Chairs • Lack of influence in Trusts - Chairpersons who were also on the Trust Board found it easier to influence • Poor attendance by members • Misalignment of communication between NHSBT and Organ Donation Committees • Limited sharing of information – there is no platform for Chairpersons to meet outside of meetings • Variation in funding of Committees <p>Short term recommendations (internal):</p> <ul style="list-style-type: none"> • Monitoring of attendance at meetings • Internal promotion • Administrative support • Utilisation of the framework <p>Short term recommendations (external):</p> <ul style="list-style-type: none"> • Publish a report from the Committee for annual review by the Trust – should include attendance; progress on actions/goals; achievements • Annual assessment • Regular feedback • External promotion <p>Long term recommendations (internal):</p> <ul style="list-style-type: none"> • Establish a mentorship scheme • Share best practice <p>Long term recommendations (external):</p> <ul style="list-style-type: none"> • Guidelines for Chair recruitment • Influence • Chair training programme • Review of funding <p>Other suggestions arising from the survey and interviews included the nomination of an ODC of the year, on a regional basis; and development of an on-line platform or newsletter for Chairs.</p> <p>The team thanked those who had participated in the survey and interviews as well as S Johnson and D Gardiner for their support. The results of the review project will be written up into a report and circulated.</p>	
7.	<p>CLOD REVIEW – UPDATE FROM LEVEL MEETINGS 1-3 – NODC(17)21</p> <p>A review of the CLOD role has been undertaken in order to ensure that the CLOD role is able to fulfil the <i>Taking Organ Transplantation to 2020</i> strategy ambitions. This review has involved a SWOT analysis of the CLOD role, discussion at a stakeholder meeting, and testing at a Level 4 meeting together with a paediatric Go To meeting. Members were asked to verify the data in the draft report relating to CLOD numbers (Appendix A) and PA reimbursement in each region. Any comments needed to be received by the end of June, following which the document would be submitted to SMT in July for endorsement.</p>	<p>RCLODs</p>

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	<p>Comments:</p> <ul style="list-style-type: none"> The document should clarify the outcomes that are sought rather than the expectations of the review to ensure there is no mismatch of expectations Feedback from CLODs is important for Chairs and could be included within this. Chairs should be included on interview panels for new CLODs. <p>Members thanked D Gardiner and S Beale for their work on this review.</p>	
8.	LENGTH OF DONATION PATHWAY	
8a	<p>Project overview – NODC(17)22</p> <p>Members received a presentation summarising the work to date on reducing the length of the organ donation and retrieval pathway, and a letter to P Murphy asking NODC to consider how they could contribute to shortening the section of the pathway that falls within their remit. This included:</p> <ul style="list-style-type: none"> Early referral Asking donation clinicians/MDT to provide or facilitate GP information/access to historical records Withdrawal of life-sustaining treatment either in theatre or close to theatre BSD tests performed early in the day Donor characterisation testing performed prior to consent/authorisation in patients who are on the organ donor register <p>Members were supportive of the proposals and noted that some of the changes were already being implemented on the retrieval and transplantation sections of the pathway. All changes will be monitored to measure their impact on pathway timings.</p>	
8b	<p>Letter re Donation related actions – NODC(17)23</p> <p>Refer to minute 8a above.</p>	
9.	<p>DONOR REIMBURSEMENT</p> <p>Work is taking place with colleagues within NHSBT Finance on looking at ways to realign donor reimbursement to Trusts. The plan is to rebadge this as donor recognition funding under a simplified process involving a reduction in the amount paid. It is anticipated that the change will come into effect from next April, subject to agreement by the Departments of Health sustainable funding groups.</p> <p>The funding will be awarded at the beginning of the financial year as a lump sum with the request that this be directed to the Organ Donation Committees. This could give accountability to the Committees, and Committee Chairs will have the opportunity to discuss this with their Trust Accountable Officer.</p>	
10.	<p>HOSPITAL PROMOTION</p> <p>Marketing update – NODC(17)24</p> <p>S Beale gave a summary of progress with three pilot projects for permanent promotional materials:</p> <ul style="list-style-type: none"> Lift wraps & wall-mounted displays – Lift wraps promoting organ donation and transplantation to members of the public visiting the hospital have now been installed in ten hospitals whilst wall-mounted displays telling inspirational stories about organ donation and transplantation have been installed in 30 hospitals. A family information booklet developed in conjunction with the Donor Family Network and other donor families will be sent out to regional SNOD teams shortly and it is hoped that these can be placed in ICU waiting areas to provide families of patients who are critically ill with information about the benefits of organ donation and transplantation. 	

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	<p>All three pilots will be evaluated using a combination of surveys, ODR data, monitoring of social media and comparing hospital consent rates.</p> <p>Plans for Organ Donation Week A schedule of the promotional materials available for Organ Donation Week was provided for information.</p>	
11.	<p>ANY OTHER BUSINESS</p> <ul style="list-style-type: none"> • D Gardiner referred to the Canadian DePPart study. Research ethics approval and NIHR portfolio approval has been obtained for a trial to take place in Nottingham, led by D Harvey. Further details will be reported at future meetings. • S Johnson reported that NHSBT had been made aware of a website (Organ Tree Ltd) which offers payment for deceased organ donation. A statement has been added to the NHSBT website disassociating NHSBT with this organisation and making it clear that giving or receiving payment or reward for organ donation in the UK is illegal. The company is based in the Republic of Ireland and is being investigated by the Human Tissue Authority. It is hoped to issue a press release warning of the dangers of entering into any financial arrangement with this or any other service operating on a similar basis. • A new Lead for Recipient Co-ordination has recently been appointed and will, as a priority, seek to increase the proportion of organ recipients who write thank you letters to their donors' families. Donor records will monitor the number of letters sent from recipients within each centre. 	
12.	<p>Date of next meeting</p> <p>The next meeting will be held on Tuesday 14th November 2017, 10:30 – 15:30, at the Radisson Blu Edwardian, Grafton, 130 Tottenham Court Road, London W1T 5AY</p>	
	Close	

July 2017