NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

NATIONAL ORGAN DONATION COMMITTEE (NODC) MEETING AT 10:30AM ON TUESDAY 12 NOVEMBER 2019 AT CORAM, 41 BRUNSWICK SQUARE, LONDON WC1N 1AN

MNUTES

Present:

Dr Dale Gardiner (Chair)	DG	National Clinical Lead for Organ Donation
Mr Stephen Bonner	SB	Royal College of Anaesthesia Representative
Dr Chris Booth	CB	Regional CLOD, North West
Ms Jackie Brander	JB	Lead Nurse, Service Delivery
Dr Helen Buglass	HB	Regional CLOD, Yorkshire
Ms Jo Chalker	JC	Regional Manager, South Wales & South West
Mr Gordon Crowe	GC	Regional Manager, North West & Yorkshire
Mr Andrew Davidson	AD	Regional CLOD, Yorkshire
Dr Katja Empson	KE	Regional CLOD, South Wales
Prof John Forsythe	JF	Associate Medical Director, ODT
Ms Amanda Gibbon	AG	Organ Donation Committee Chair Representative
Mrs Monica Hackett	MH	Regional Manager, Northern and Northern Ireland
Mrs Margaret Harrison	MHar	Independent Lay Member
Dr Dan Harvey	DH	National Innovation and Research CLOD
Dr Ben Ivory	BI	National Education CLOD
Mr Roddie Jaques	RJ	Statistics & Clinical Studies, NHSBT
Mr Craig Jones	CJ	Lay Member Representative
Dr Iain MacLeod	IML	Regional CLOD, Scotland
Mrs Sue Madden	SM	Statistics & Clinical Studies, NHSBT
Dr Alex Manara	AM	National Quality CLOD
Dr Reinout Mildner	RM	National Paediatric CLOD – Chair of NODC Paediatric Sub-Group
Ms Bethan Moss	BM	Team Manager, South Wales, ODST
Ms Katy Portell	KP	Ambassador Programme Manager, ODT
Mr Dominic Trainor	DT	Regional CLOD, Northern Ireland
Dr Andre Vercueil	AVe	Regional CLOD, London
Mr Angus Vincent	AVi	Regional CLOD, Northern
Ms Julie Whitney	JW	Lead Nurse Service Delivery, NHSBT
Ms Sarah Whittingham	SW	Team Manager, Yorkshire, ODST
Mrs Claire Williment	CW	Head of Legislation Implementation Programme, NHSBT
Mr Colin Wilson	CWil	Freeman Hospital Newcastle

Apologies:

Miss Jo Allen	JA	Performance & Business Manager, ODT, NHSBT
Mrs Liz Armstrong	LA	Head of Transplant Development, NHSBT
Ms Cliona Berman	CB	Team Manager, London
Mr Anthony Clarkson	AC	Director, Organ Donation & Transplantation, NHSBT
Ms Rebecca Curtis	RC	Statistics & Clinical Studies, NHSBT
Ms Sue Duncalf	SD	Regional Manager, North West
Ms Jill Featherstone	JF	Medical Education, SNOD Lead
Dr Pardeep Gill	PG	Regional CLOD, South East
Dr Tariq Hussain	TH	Regional CLOD, London
Ms Patricia McCready	PMC	BACCN rep

Ms Olive McGowan	OMG	Assistant Director of Education and Excellence
Mr John Richardson	JR	Acting Assistant Director – Transplantation Support Services
Ms Rachel Rowson	RR	Regional Manager, London
Dr Charles Wallis	CW	Edinburgh
Ms Fiona Wellington	FW	Interim Assistant Director, Organ Donation and Nursing
Dr Argyro Zoumprouli	AZ	Regional CLOD, South East

In attendance:

Miss Heather Crocombe	HC	Clinical & Support Services, ODT

Decisions made at NODC 19(3)

1. NODC accepted the initiative from NHSBT for a UK deceased donation referral rate of 97.5% by April 1 2020, though doubt about achievability was expressed.
2. NODC expressed concern that the initiative from NHSBT to decrease SNOD non-presence by 50% by April 1 2020, while the ultimate aim, is both unachievable and potentially counter-productive in the short term.
3. NODC supported the ongoing implementation of the bedside aide-memoire as it is a key action aimed at reducing the length of the process. NODC wondered how widely it is being used.
    a. Action - JC will review and update NODC on implementation.
4. NODC endorsed FICM's recent document approving ACCPs diagnosing death in DCD (outside of Scotland).
    a. Action - Chair to write to NRG informing them of this.
    b. Action - BI to continue to work with FICM to create the relevant education package and governance procedures for ACCP sign off.
5. NODC expressed concern that stakeholder feedback from the recent process of NHSBT procurement for medical and nursing simulation was very negative.
    a. BI to lead a formal survey of feedback on the procurement process for medical simulation (to discuss with Olive McGowan (not present) to see if similar survey is desired for SNOD simulation). Chair asked MHar to assist with this.
6. NODC expressed concern that the length of the deceased donation process has worsened, and is now the worst it has ever been, despite efforts to reduce. NODC supported the division of the pathway into areas of responsibility in the hope that this will lead to sustained improvements.
7. NODC supported AM's recommendations on diagnosing foetal death but considered NODC was not empowered to recommend criteria for diagnosing death.
    a. Action - AM to take his recommendations to the Royal College of Obstetrics and Gynaecology to ask for their formal advice.
8. NODC was pleased that there is now an Organ Donation Committee Chair's page on the clinical website, but concern was expressed that the page was difficult to navigate to and not well

signposted. It was also identified by NODC that the whole Deceased Donation section of the clinical website needs updating.

a. Action - Chair will explore options with education team of moving the Chair's page within the clinical website.

b. Action – Chair will discuss with education team about reviewing deceased donation section of the clinical website.

9. NODC accepted AM's recommendations on NRP. These are:

    a. In abdominal NRP the descending thoracic aorta must be occluded, and a large bore cannula inserted in the ascending aorta before NRP is commenced. If flow is noted in the ascending aorta the retrieval team must check the adequacy of occlusion of the descending aorta and if necessary, reposition the clamp or intraluminal balloon. If the flow continues the recommendation is to stop NRP immediately and in situ hypothermic (cold) perfusion and organ recovery initiated. It is hoped that this protocol will be accepted and adopted by all abdominal retrieval teams in the UK.

    b. The above approach is also recommended when abdominal NRP is combined with cardio-thoracic direct (hypothermic) procurement and perfusion.

    c. The recommendation for TA-NRP is to continue to clamp the aortic arch vessels but to also open the distal ends to atmosphere to allow diversion of flow. More experience and data are required before more widespread adoption of the technique.

10. NODC endorsed the statement, 'While the principle remains that deceased organ donation is an anonymous altruistic gift there should not be artificial barriers placed between donor family and transplant recipient contact.'

11. NODC supported the actions to date and planned, to remove artificial barriers between donor family and transplant recipient contact.

12. NODC acknowledged the statistical paper 'Reasons for Family Not Supporting Organ Donation' but asked that the breakdown of reasons comparing DBD vs DCD be added.

    a. Action – Statistics team to add DBD vs DCD table, and then share with NHSBT ODT SMT.

13. NODC was unable to recommend that it should become an expectation in the UK that a Moment of Honour be held during the organ donation process to acknowledge and honour the gift that the donor and their family are giving to others. The Chair recommended that those wishing to implement a Moment of Honour should take a regional perspective rather than individual hospitals all doing something different.

14. NODC was unable to agree on the best way of monitoring the impact of deemed consent/authorisation in England and Scotland.

Details of discussion at NODC 19(3)

<table>
<tr><th>No.</th><th>Title</th><th>Action</th></tr>
<tr><td>1.</td><td>Welcome and Apologies
DG welcomed everyone to the meeting and gave details of apologies received as shown above.

Declarations of Interest NODC(19)24
There were no declarations of interest in relation to the Agenda</td><td></td></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td>2.</td><td>Review of previous Minutes NODC(M)19(2)
The Minutes of the NODC Meeting that took place on 25 June 2019 were deemed to be a true and accurate reflection of that meeting.

NODC Membership List NODC(19)25
DG asked any attendees whose job title/contact details have changed to contact HC in order that we can keep the Membership List fully up to date, and asked attendees to look at who attends NODC from their region – it would be ideal if the meeting numbers could be reduced where possible so that NODC can continue to be represented by a wide range of different stakeholders.</td><td>All</td></tr>
<tr><td>3.</td><td><u>Standing Items</u></td><td></td></tr>
<tr><td>3.1</td><td>Performance
ODT Performance Report NODC(19)26
(including Rest of the Year performance focus, updating Regional Deep Dives)
See paper for details, but key points:

• Sept 2019 was the third highest donor month ever (150 deceased donors)
• Donors per million population (pmp) increased throughout Q2, returning to March 2019 level (24.3pmp)
• 8 more donors YTD, despite 58 fewer eligible donors compared with the same 6 months last year)
• 137 donors now needed per month in order to beat last year, but 161 donors needed per month to reach target
• Transplants pmp is still a major concern
• 40 fewer patients benefitted YTD, despite 8 more donors
• 347 transplants per month now needed to beat last year
• ODR opt-in overrides are a real concern
• 60 YTD (almost double the 31 YTD last year)

<u>Discussion Points:</u>
1. Are there any ways clinically to help with missed referral opportunities? Certain regions have higher missed referrals than others.
2. The aim is to achieve a 97.5% referral rate by April 2020 (when the TOT2020 strategy concludes)

• NODC supported this initiative.
• But if may be unrealistic to expect rapid change. Hospitals are already under considerable winter pressure. Is now the right time</td><td></td></tr>
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to be pushing for more referrals when hospitals are going to be busier?
- An increased focus is needed on referral of ALL potential donors – Refer all, miss none.
- RM/CLODs should continue to meet regularly, provide good weekly data and review missed referrals in real time as much as possible (SM made the point that Statistics & Clinical Studies currently collect data monthly so if weekly data collection is required, this is something that regional teams will need to undertake)

3. The aim is to achieve a 50% reduction in non-SNOD presence rate by April 2020 (when the TOT2020 strategy concludes).
    - NODC expressed concern that while this was the ultimate aim, in the short term it was both unachievable and potentially counter-productive.

A SaBTO update has just been circulated confirming which organs can be retrieved/transplanted from flu-affected patients.

Transplant Projections NODC(19)27
This paper was submitted to today's meeting by Statistics & Clinical Studies, NHSBT, for information only.

Updates to *Aide Memoire* (Bedside Nurse Checklist)
Updated *Aide Memoire* is now live except for in Scotland. This has already been cascaded to Units and JC is looking to make this available digitally to make it more accessible. Use of the Aide Memoire is unclear. JC has received no feedback so far, although there is apparent anxiety about the *Aide Memoire* being left on Units and where it should more appropriately be stored.

Update New PDA
It is still the plan that this will go live for English opt-out in spring 2020. The database structure is being worked on and Statistics & Clinical Studies are in the process of building their new programme for data collection. During the second phase, it is hoped to make the PDA more interactive using Power BI.

Responsibility for each aspect in the length of the process update
Six-Monthly Report NODC(19)32
See paper for details, but key points:

Median times for the key lengths within donation control have increased:
- Approach to first kidney matching run
- First kidney matching run to first NORS Team departure

This is the opposite to that which was planned and hoped for.

Only South Wales and the South West have improvements in their times.
This matter was put before the Chief Executive at a meeting on 12 November 2019 with an explanation as to why this is such an important issue and why it needs resolving ASAP.

	One possible contributory factor to median times increasing is the number of SNODs who are now involved in the process. This needs to be overcome and potentially the “links in the chain” need reducing. The point was made that when you are going through the process and when the potential donor family is exhausted, there should be a way to get to a quick retrieval (by analogy, pressing a ‘red button’) to draw the process to an end. SM, DG, Statistics & Clinical Studies to get together to unpick their parts of the process (from referral to first kidney matching run) to try to figure out where time can be saved.	**SM/DG/Stats**
3.2	**Policy** **Pregnancy – Update and in DCD diagnosing the death of the foetus NODC(19)33** *In February 2019, the Department of Health and Social Care (DHSC) stated that it was not in a position to provide clinical or legal advice on organ donation or the withdrawal of life sustaining treatment in pregnant women. Instead, the Department recommended that NHSBT continue to work with the BMA and other relevant stakeholders to reflect professional advice in NHSBT’s practices and procedures.* Guidance from the BMA’s Medical Ethics Committee, were: • The best interests of the pregnant woman are the sole consideration when deciding whether life-prolonging treatment should be continued or withdrawn • If a woman wished to donate after the withdrawal of life sustaining treatment, the donation pathway would be DCD, so long as organ recovery did not commence until after the death of the foetus • When death has been confirmed using neurological criteria, there is no legal or ethical obligation to continue ventilation in order to keep the foetus alive • The legality of cross-clamping the aorta during DBD organ recovery remains unclear. At present, DBD should not be undertaken until a test case is taken to the Court of Protection and receives a judgment • Donation in pregnancy should only proceed after the withdrawal of life-sustaining treatment (Maastricht 3 DCD) or after circulatory arrest in a brain-dead patient (Maastricht 4 DCD). Organ recovery must only proceed after the death of the foetus. NODC supported AM’s recommendations on diagnosing foetal death but considered NODC was not empowered to recommend criteria for diagnosing death. Action - AM to take his recommendations to the Royal College of Obstetrics and Gynaecology to ask for their formal advice. **Update Hep C Donations** There have been ten Hep C+ donors so far.	

	Update Peri-Mortem Interventions professional statement with ICS/BTS This is ongoing. This project is being co-led by ICS/IFICM and NHSBT. There was a productive meeting held in November with intensive care and transplant professionals, patient groups and ethics/legal experts to discuss the updated statement. The meeting feedback notes are in the process of being typed up and DG will feed back. **Opt-Out Legislation** **Wales** Opt-out in Wales is now well established and is very much business as usual. Consent rates are slightly lower than this time last year and JC is looking into why/the situation is being monitored. **Scotland** On 11 June Scottish parliament passed the Human Tissue Authorisation Scotland Act 2019 followed by Royal assent on 18 July replacing the current opt in model to an opt out system The Scotland Opt Out Implementation Group is taking forward the new legislation changes with 12 work-streams and working collaboratively with national Opt Out Team to be ready for Autumn 2020. The 2019 Act has introduced a statutory legal framework governing the authorisation and carrying out of medical procedures before death for the purpose of successful transplantation known as pre death procedures classified as Type A or Type B. Following a year of informal discussions the Scottish Government has moved to formal consultation on what medical procedures should be listed within regulations as Type A - Type A is considered more routine within the context of facilitating transplantation blood tests for eg blood samples, x-rays. This Consultation closes on 11 Dec 2019. Type B are likely to be less routine or novel and may require additional authorisation before being undertaken. No time line or consultation has yet taken place, and this will be taken forward in the secondary legislation in due course. The Scottish Government has also recently sent a draft guidance document to support understanding of legislation on deceased organ and tissue donation in authorisation requirements for donation and pre death procedures, with response required by 19 Dec 2019 The Training plan and dates have been agreed and will be taken forward from March-August (Cascade Model) next year which has a detailed breakdown of five categories of relevant personnel to be trained to include awareness sessions across Scotland. The authorisation form is being finalised this week to be sent to the Scottish Lawyers and once agreed will be sent to SDTG in Dec for sign off and associated quality training documents will be reviewed in line with the training plan.	**DG**

	The Duty To Inquire in the legislation has placed emphasis that most recent views about donation and pre death procedures must be sought from nearest relative before undertaking any preliminary gathering/sending blood samples. An expressed decision can only be in writing (or recorded if registering verbally on the ODR) and if given orally will not be recorded as an opt in but as deemed authorisation. Currently working with Opt Out Leads and JR with a meeting organised for 11 Dec to discuss PDA and Donor Path. Awareness campaign planned for next year which will involve a mail drop. **England** Learning from Wales Awaiting a note of key points from Claire W **Update Progress towards ambitions in *Strengthening the effectiveness of Organ Donation Committee*** The Key Resources for Committee Chairs are now available on the Clinical website. **NODC was pleased that there is now an Organ Donation Committee Chair's page on the clinical website, but concern was expressed that the page was difficult to navigate to and not well signposted. It was also identified by NODC that the whole Deceased Donation section of the clinical website needs updating.** **Action - DG will explore options with education team of moving the Chair's page within the clinical website.** **Action – DG will discuss with education team about reviewing deceased donation section of the clinical website.** **Monitoring Opt-Out Going Forward NODC(19)35** This paper described the proposal for monitoring the impact of the new opt-out legislation in England and Scotland following its implementation in 2020. Members were asked to comment on the proposed analyses to monitor the impact of opt-out legislation and agree how to proceed. Proposed Analyses • Fixed sample tests comparing the DBD and DCD consent rates in England under opt-out legislation with estimated baseline consent rates in England, based on a continuation of current trends without opt-out. (This method aims to detect a 10% increase in DBD and DCD consent rates, and will compare consent rates over the monitoring period at 12 and 24 months post implementation of opt-out legislation; • Sequential analyses comparing the DBD and DCD authorisation rates in Scotland under opt-out legislation with estimated baseline authorisation rates in Scotland, based on a continuation of current trends without opt-out. This method allows for small numbers and aims to detect a 10% increase in DBD and DCD authorisation rates, and will compare accumulating data on a quarterly basis following a 12-month bedding-in period post implementation of opt-out legislation; • Detailed multivariable analyses comparing changes in the chance of consent/authorisation in England and Scotland over the various stages of	

implementation, and established opt-out legislation, adjusted for all relevant risk factors; and

- Quarterly reporting of ODR registrations and consent/authorisation rates for all four UK nations will be ongoing. These reports will include funnel plot comparisons on the consent/authorisation rates by nation.

NODC was unable to agree on the best way of monitoring the impact of deemed consent/authorisation in England and Scotland.

Normothermic Regional Perfusion – Maintaining Isolation of the Cerebral Circulation NODC(19)36

One of the greatest challenges in the practice of DCD is to limit the damage caused to organs by warm ischaemia. Techniques that can limit warm ischaemia and provide post-mortem organ reperfusion have the potential to improve transplant outcomes. Organ reperfusion after death can be provided through normothermic regional perfusion (NRP) in situ or ex situ machine perfusion of individual organs. Both techniques are being increasingly used to improve organ assessment and transplant outcomes.

Retrieval teams however need to ensure that the organ recovery process does not have the potential to inadvertently restore brain perfusion.

A Joint UK and Canadian group with representation from both donation and cardiothoracic/abdominal transplantation worked collaboratively to address the question: *What additional reassurance can we provide that brain perfusion is not restored during in situ NRP?*

Please see paper for details on the key principles in deceased donation (and the dead donor rule), UK death using circulatory criteria and restoration of brain perfusion, as well as Recommendations to help support the safe development of *in situ* NRP techniques that have the potential to improve transplant outcomes. There is also a need for an expanded evidence base to show that *in situ* NRP techniques achieve better outcomes than *ex vivo* machine perfusion.

JF wanted to thank AM for looking into this matter in such detail – it is much appreciated.

The point was made that it would be helpful for AM to come to either RINTAG or the new implementation meeting, to get feedback on this and answers to the questions contained within the paper.

NODC accepted AM's recommendations on NRP.
These are:

1. **In abdominal NRP the descending thoracic aorta must be occluded, and a large bore cannula inserted in the ascending aorta before NRP is commenced. If flow is noted in the ascending aorta the retrieval team must check the adequacy of occlusion of the descending aorta and if necessary, reposition the clamp or intraluminal balloon. If the flow continues the recommendation is to stop NRP immediately and in situ hypothermic (cold) perfusion and organ recovery initiated. It is hoped that this protocol will be accepted and adopted by all abdominal retrieval teams in the UK.**

	2. The above approach is also recommended when abdominal NRP is combined with cardio-thoracic direct (hypothermic) procurement and perfusion. **3. The recommendation for TA-NRP is to continue to clamp the aortic arch vessels but to also open the distal ends to atmosphere to allow diversion of flow. More experience and data are required before more widespread adoption of the technique.** **Establishing a "Moment of Honour" for the donor at the time of organ retrieval NODC(19)37** *The Moment of Honour is a time that is taken during the organ donation process to acknowledge and honour the gift that the donor and their family are giving to others.* Having taken a survey of UK practice, it is apparent that some units do this already, others do it occasionally, and the centres that don't do it would be very keen to do so. The teams who do the Moment of Honour as routine have found this to be positive for all involved. It was the hope that ODT would work alongside the National Advisory Groups within the UK to write a Standard of Practice (SOP) with minimum recommendations as to how the Moment of Honour could be undertaken across the UK. In practice, surgeons overall are supportive, however, some have raised a potential issue with it in that surgeons generally need to detach in order to be able to carry out the clinical work. Some members of NODC were deeply concerned by this admission. *Qu. What happens to the families of a patient who doesn't want to donate? Should a moment of honour also happen for them?* DG suggested that any withdrawal of life sustaining treatment on ICU could be accompanied by a Moment of Honour, it just needed local leadership and practice. *Qu. What happens if the family of the patient doesn't want a Moment of Honour?* *BM/SW* were clear that, of course, Moments of Honour only occur with family agreement. **NODC was unable to recommend that it should become an expectation in the UK that a Moment of Honour be held during the organ donation process to acknowledge and honour the gift that the donor and their family are giving to others. DG recommended that those wishing to implement a Moment of Honour should take a regional perspective rather than individual hospitals all doing something different.** **This topic to return onto the Agenda for NODC June 2020.** **Removing artificial barriers between donor families and transplant recipients making contact NODC(19)38**	 **HC**

	A founding principle in the UK is that deceased organ donation is an anonymous altruistic gift, yet many donor families and transplant recipients will make contact, some even physically meeting. Feedback from donor families is that they enormously value contact from the organ recipients who benefitted from the donor's gift. Yet, even where there is a desire on both parties for contact, NHSBT is aware that artificial barriers often prevent or delay this contact, much to the eventual frustration of both parties. While the principle remains that deceased organ donation is an anonymous altruistic gift, there should not be artificial barriers between donor families and transplant recipient contact. A lot of work has taken place within ODT to try to alleviate some of the barriers and this paper outlines the work carried out so far, the findings from this work and the actions to remove artificial barriers. Please see paper for full details. **1. NODC endorsed the statement, 'While the principle remains that deceased organ donation is an anonymous altruistic gift there should not be artificial barriers placed between donor family and transplant recipient contact.'** **2. NODC supported the actions to date and planned, to remove artificial barriers between donor family and transplant recipient contact.** DG thanked BC for all the hard work that he has put into this project.	
3.3	**Education** **Medical Education Update** **ACCPs diagnosing death NODC(19)28 (a-d)** BI presented details of the new Leaning Tool for Diagnosing Death for DCD Donation for ACCPs, together with the Written Assessment required to be taken, replies to the Written Assessment and instructions for the setting up of the ACCP assessment station. The aim of this Advanced Critical Care Practitioner (ACCP)DCD competency are to: • Enable ACCP training to a nationally agreed standard by FICM and NHSBT for the diagnosis of death in the context of DCD organ donation • To describe the core theoretical knowledge, practical skills and professional judgment required of an ACCP in the diagnosis of death in the context of DCD organ donation. This learning tool has now had Board approval. Training will be a one-day training package. The Faculty of Intensive Care Medicine, the ACCP Committee and BI have worked together to produce this training package. BI has also written the examination paper which will have an 80% pass rate. If after reading the Training package anyone wishes to comment, or if any questions arise, please contact BI directly.	

	Scotland will not be included in this training, as only a doctor can diagnose death in Scotland for the purposes of deceased organ or tissue donation. DG gave his thanks to both BI and the Faculty of Intensive Care for completing this large complicated piece of work. **NODC endorsed FICM's recent document approving ACCPs diagnosing death in DCD (outside of Scotland).** **Action - DG to write to NRG informing them of this.** **Action - BI to continue to work with FICM to create the relevant education package and governance procedures for ACCP sign off.** **Congress 2021** DG is asking for some volunteers to help lead on this. DG will find out where the 2021 Congress is being held and further details and will advise. **Reflection on procurement process for simulation centres to run the national deceased donation course and SNOD simulation training days** The procurement process had previously been very easy to deliver, whereas feedback from the recent process is seen as arduous, has created more work and has caused some bad feeling and loss of goodwill. **NODC expressed concern that stakeholder feedback from the recent process of NHSBT procurement for medical and nursing simulation was very negative.** **Action - BI to lead a formal survey of feedback on the procurement process for medical simulation (to discuss with Olive McGowan (not present) to see if similar survey is desired for SNOD simulation). DG asked MHar to assist with this.**	**DG** **BI**
3.4	**Promotion** **Community Ambassador Programme** KP gave an update on the Ambassador Programme: • Five centres have adopted the Programme so far • 17 ambassadors signed up • 165 volunteer hours spent so far at events etc. • 1800 conversations taken place with the public • Requests for speakers are being received • KP is part of the workstream for the opt-out team • An End of year Report will be produced • Ambassadors stating how a situation has impacted them personally has been found to have a more profound effect than just giving statistics etc. • Ambassadors can tailor information to their target audience/community • The intention is for this to become a national Scheme. NODC was very supportive and encouraging for this programme. NODC considered it vital that this programme be expanded and incorporated into the next UK donation and transplantation strategy.	
4.	**Working Group/Sub-Group Reports**	

4.1	**NODC Statistics Working Group NODC(19)29** Due to ever-increasing demand for statistical work within NHSBT and the limited staff resource, the Statistics Team have been under considerable pressure to continue to deliver their statistical service. Within the area of donation there have been some high priority projects – opt-out legislation and the development of the new PDA. A new starter has now joined the team, working three days a week in the donation area, which is beginning to alleviate some of the pressure. A list of the current priorities within the donation team was agreed by members of the NODC Statistical Subgroup (SSG). This list was presented to and approved by ODT Senior Management Team (SMT) in August, as below: • Supporting and evaluating opt-out legislation • Delivery of new PDA and new PDA reporting tool • Routine monthly KPI reporting and regular reports • Investigating donation performance dips and developing new reports • All other new projects and *ad hoc* requests Please see Table 1 in the paper showing Regular donation reports within Statistics and Clinical Studies, and Table 2 showing Current donation workload priorities within Statistics and Clinical Studies. **Reasons for Family Not supporting Organ Donation NODC(19)30** Data were obtained from the national Potential Donor Audit (PDA) on all family approaches of eligible DCD and DBD patients between 1 January 2013 and 31 August 2019 on reasons why the patient's family decided not to support donation. **Please see Table 1 of the paper (Trends in Reasons for Family not Supporting Donation) and Table 2 of the paper (Summary of Reasons for not Supporting Donation)** **<u>Summary of Findings</u>** • The proportion of cases reporting *Patient previously expressed decision not to donate* as the reason for family not supporting donation has increased from 18% to 24% between 2014 and 2019 • The six most common reasons for families not supporting donation were unchanged between the periods 2013/15 and 2016/19 • In 2013/15 there were 313 (7.8%) of cases where the patient's ODR opt-in decision was overruled. In Jan 2016 – Aug 2019 it was more common for *Strong refusal – probing not appropriate* to be given as the reason for not supporting donation • There are differences in the reasons for not supporting donation when comparing the patient's ODR status and the SNOD presence, but no real difference when comparing SR and SNOD presence. A pamphlet is being produced which can be handed to families to set out a Step by Step process of their relative's hospital stay/journey. This needs to be done sensitively but would give a better explanation to families as to what to expect. North West team will be launching a pilot for this and will feed back. **NODC(19)30** also needs to be put before ODT SMT.	

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<tr><td></td><td>Paediatric Sub-Group of NODC NODC(19)31
Annual Report on Deceased Donation and Transplantation in Paediatrics
presented to NODC for information
Please see paper for full details, but summary/key points:
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
Of the families approached, consent/authorisation was ascertained for 73% eligible DBD donors and 51% 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.
Over the last five years, the testing rate has remained consistent at 73% and there have been improvements in referral, SNOD presence and consent rates for both DBD and, more notably, DCD donation
At 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.
Uterine Transplantation
There is a planned go-live in London at the end of November 2019. There is likely to be press interest and there is a media plan to cope with this.

Olfactory Bulbs
There was nothing new to report on Olfactory Bulbs</td><td></td></tr>
<tr><td>5.</td><td>Any Other Business
Dates were confirmed for 2020 NODC Meetings:
Feb 6 (via Skype)
Jun 22 (face to face, London)
Nov 10 (face to face, London)</td><td></td></tr>
<tr><td>6.</td><td>Date of next meeting: 6 February 2020 (via Skype)</td><td></td></tr>
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