NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

NATIONAL ORGAN DONATION COMMITTEE (NODC) MEETING AT 10:30AM ON TUESDAY 6 NOVEMBER 2018 AT CHARTERED INSTITUTE OF ARBITRATORS, 12 BLOOMSBURY SQUARE, LONDON WC1A 2LP

Present:

Dr Dale Gardiner (Chair)	National Clinical Lead for Organ Donation
Miss Joanne Allen	Performance & Business Manager, ODT, NHSBT
Ms Cliona Berman	Team Manager, London
Dr Jeremy Bewley	Intensive Care Society Representative
Mr Andrew Broderick	Donor Assessment Programme Lead
Miss Chloe Brown (CBr)	Statistics & Clinical Studies, NHSBT
Ms Joanne Chalker	Regional Manager, South West & South Wales
Mr Anthony Clarkson	Interim Director, Organ Donation & Transplantation, NHSBT
Mr Andrew Davidson	Regional CLOD, Yorkshire
Dr Katja Empson	Regional CLOD, South Wales
Ms Jill Featherstone	National Professional Development Specialist, Medical Education Lead
Prof John Forsythe	Associate Medical Director, ODT
Ms Amanda Gibbon	Donation Committee Chair (Non-Clinical Donation Rep)
Dr Pardeep Gill	Regional CLOD, South East
Dr Paul Glover	Regional CLOD, Northern Ireland
Ms Monica Hackett	Regional Manager – Northern & Northern Ireland
Ms Sarah Hanner-Hopwood	Marketing and Campaigns Manager, NHSBT
Mrs Margaret Harrison	Independent Lay Member, ODT, NHSBT
Ms Alison Ingham	Regional CLOD, North West
Mr Craig Jones	Independent Lay Member, ODT, NHSBT
Dr Rob Law	Regional CLOD, Midlands
Dr Tim Leary	Regional CLOD, Eastern
Mrs Lesley Logan	Regional Manager, Scotland
Mrs Sue Madden	Statistics & Clinical Studies, NHSBT
Dr Alex Manara	Regional CLOD, South West
Ms Trish McCready	British Association of Critical Care Nurses Representative
Ms Olive McGowan	Asst. Director, Education & Governance, ODT
Ms Susan Richards	Regional Manager, Midlands & South Central
Ms Rachel Rowson	Regional Manager, London
Ms Marian Ryan	Regional Manager, Eastern/South East
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
Ms Fiona Wellington	Head of Operations for Organ Donation, ODT, NHSBT
Mrs Claire Williment	Head of Transplant Development, ODT, NHSBT
Dr Argyro Zoumprouli	Regional CLOD, South East

In attendance

Miss Heather Crocombe	Clinical & Support Services, ODT
Miss Caroline Robinson	Manager, Clinical & Support Services, ODT

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<tr><td></td><td></td><td>ACTION</td></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td>1</td><td>Welcome, Apologies, Declarations of Interest
Apologies
Prof Stephen Bonner RCoA Representative
Ms Helen Buglass Regional CLOD, Yorkshire
Dr Maria Cartmill British Society of Neurological Surgeons Representative
Prof John Dark National Clinical Lead for Governance, ODT
Mrs Sue Duncalf Regional Manager, North West/Yorkshire
Dr Iain MacLeod Regional CLOD, Scotland
Prof David Menon Faculty of Intensive Care Medicine Representative
Ms Jacki Newby Head of Referral and Offering/TSS Representative
Mr John Richardson Head of Health Informatics, NHSBT
Mr Colin Wilson British Transplantation Society representative

Declarations of Interest in relation to the Agenda
There were no declarations of interest in relation to the Agenda.</td><td></td></tr>
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<tr><td>2</td><td>Review of previous Minutes & Action Points NODC(M)(18)2 and NODC(AP)(18)2
The minutes of the previous meeting were deemed to be an accurate reflection of that meeting, except for:
<u>Performance</u>
• <u>65% increase in the overall consent rate</u> should be amended to read <u>65% overall consent rate</u>

<u>Action Points</u>
To be discussed during the meeting</td><td></td></tr>
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<tr><td>3</td><td><u>Standing Items</u>

4.1 Performance
Jo Allen presented the Organ Donation and Transplantation UK & Regional Performance Summary ODT Performance Report NODC(18)10

Latest Performance – Key Points (Apr – Sept 2018)
• 771 deceased donors: 50 extra (7% increase)
• 1912 transplants: 22 extra (1% increase)
• 43% decrease in missed referral opportunities
• 10% decrease in occasions where SNOD not present
• 30% decrease in ODR overrides
• 67% consent rate (3% increase)
All comparisons with same six months last year

Measure 1 – Consent/Authorisation Rate (%) Key Points
• Overall consent rate 67% YTD (Apr to Sept 2018)
• Up 10% since Strategy was published (2012/13)
• Increasing trend in number of consents

Measure 2 – Donor Numbers – Key Points
• 771 deceased donors YTD (target of 816 for a six-month period)
• 50 more than same six months the previous year
• 144 per month needed for second half of the year
• 169 January 2018</td><td></td></tr>
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- 147, 144, 143 in March April & May 2018
- Activity October 2018 is a concern

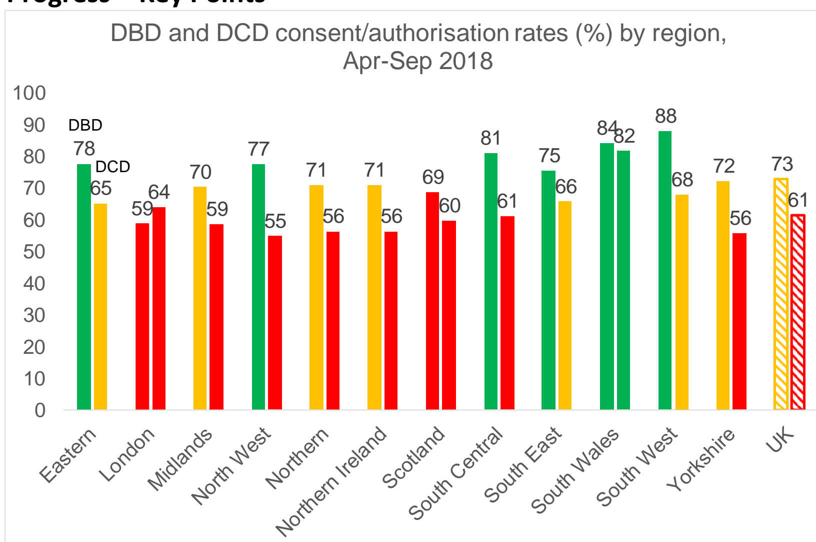
Ongoing Improvement Theme – Miss No Opportunity – Key Points
Following excellent improvements in 2017/18, DCD referral and SNOD presence rates continue to increase:

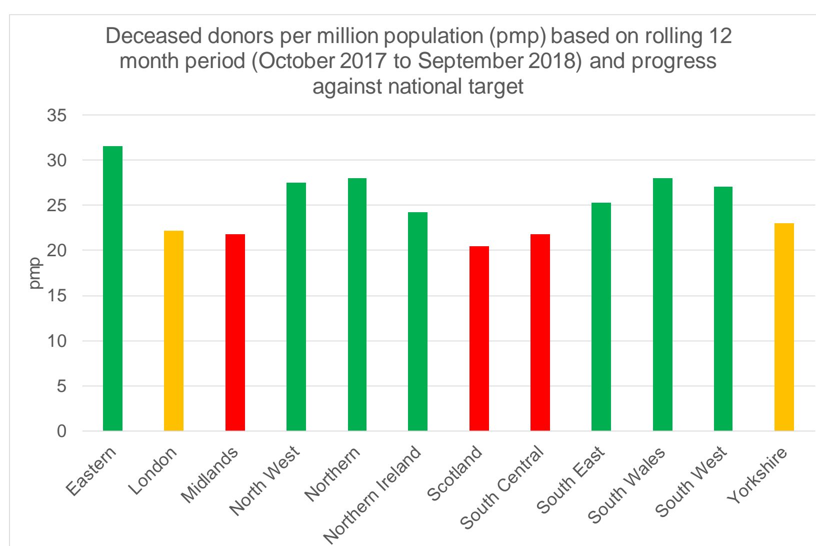
- 93% DCD referral rate YTD
- 87% DCD SNOD presence rate YTD

DBD and DCD Missed Opportunities YTD

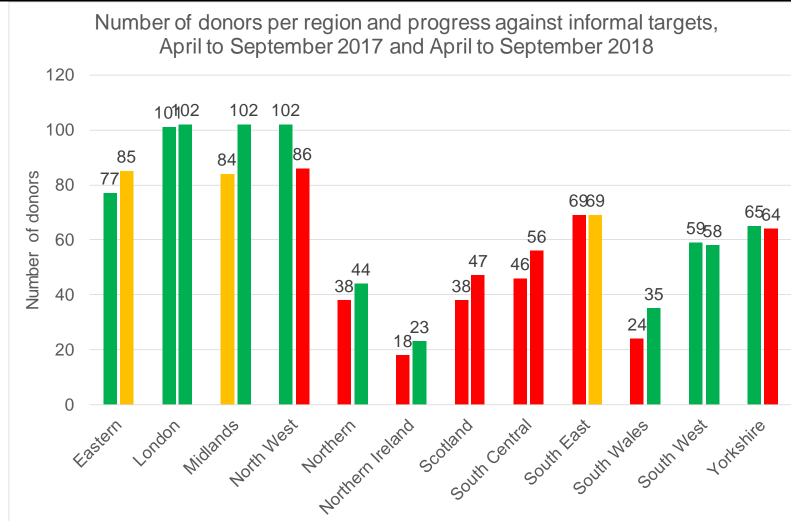
- 190 missed referral opportunities (43% decrease)
- 151 occasions where a SNOD not present (10% decrease)
- 7 more DBD occasions where a SNOD was not present
- 24 fewer DCD occasions

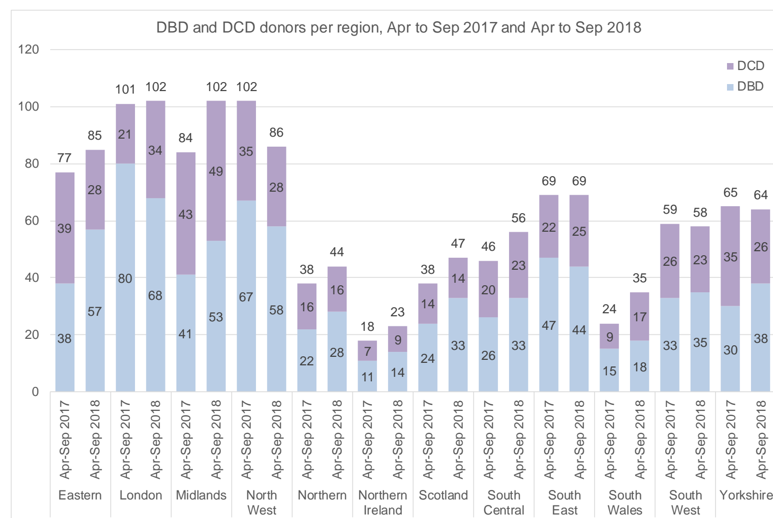
Regional Progress – Key Points





ACTION





Discussion

AG expressed discomfort at the thought of having to have a target for living donors, better to measure success eg. of paired pooled kidney donors. Needs to be measured but without a target.

JF: Countrywide there are huge discrepancies in eg. living donor numbers, consent rates, always useful to investigate detail.

DG: We are close to the target of 26 per million which would be a great achievement. However, despite heading for this 26 target, the number of organs used per donor is not increasing. JF: we are looking in great detail into lung under-utilisation. This could be due to resources but remains to be seen.

USA is quoting 32/33 donors per million population, Spain is quoting 47. There remains more which can be achieved.

GV: some staff are not on the same page/on board when it comes to donation potential – daily battle.

AV: Three consented DBD donors waited more than 36 hours – resources and capacity always a problem.

		ACTION
	Eastern is the only team that has hit 32 donors per million population. We need to understand what we can learn from Eastern. CB advised that DBD is constant and steady, DCD is still needing work. MR: Her area plan is to drive DCD consent rates. Message will need to be delivered more clearly through CLOD network as well as SNOD network. TL: Some regions are struggling with SNOD recruitment. Is there something we can do nationally to support areas with lower numbers of nurse recruitment and retention? FW: ran an open day to recruit specialist nurses, few appointments as potential applicants didn't have the relevant expertise or experience.	
	Length of the Process Update & Bedside Nurse Proforma NODC(18)11 OMcG: Pilot is to commence in Salford in December. JC: Was tasked with looking at improvements that could be made in Intensive Care Units. Intentionally basic document has been prepared and circulated to bedside nurses. Key point is that when SNODs arrive on a unit they should have access to medical notes. No further tests being requested besides those which would ordinarily be carried out in Intensive Care Units. Alongside this document will be an *aide memoire* regarding consent to be used by nursing staff. This document will be a national one. FW to make some amendments to document and distribute. Any feedback to Jo Chalker. AG felt that the document sounded slightly apologetic and perhaps should be more strongly worded and authoritative. TL stated that bedside nurses aren't keen to do the extra work included, accessing and printing paperwork etc, using up more of their time. TL said that we shouldn't be apologising for this as it will create extra work but is extremely important work.	**FW/JC**
	Update Level Meetings January 2019 Level 4 meeting planned for January has unfortunately had to be cancelled due to low sign up. Therefore Level 3 and 4 Meetings will be amalgamated. DG asked that Teams be encouraged to prepare their posters for the meeting– A3 size - great way to get the word out. Registration closes end November and Managers should be encouraging their staff to sign up. If the CLOD can't come a representative should still be sent from hospitals. An updated list will be circulated to Managers, so they can see who hasn't signed up	**CB**
	Workforce Project Update There are two phases to this Project, one of which has started, and which is set to end in April 2019. The project will result in the creation and implementation of regional clusters. South West and South Wales recently implemented, Eastern & South East implementing January 2019, by autumn 2019 all teams will have specialist requesters in some shape or form. Plan is to rid units of 24-hour SNOD working patterns. Phase 2 will look at more creative ways for SNODS to work. Final phase April 2019 onwards. Designated email address that SNODS and team managers have access to, should they have specific questions (ODT.Workforcetransformation@nhsbt.nhs.uk) **4.2 Policy** **Pregnancy**	

		ACTION
	Advice received from DH 18 months ago regarding retrieval of organs from pregnant females. It was hoped that routine pregnancy testing occurs for all women of childbearing age on Intensive Care Units; but this does not appear to be the case. The DH legal advice was considered by the BMA Ethics Committee meeting in October and the BMA's advice should be with OMcG shortly. **Opt-Out Legislation - Wales NODC(18)12** This paper reviewed quarterly consent/authorisation rates for the four UK nations since the introduction of a system of deemed consent in Wales from 1 December 2015. A formal evaluation of the effect of introducing an opt-out system in Wales based on accumulating data in England and Wales over the same time period was also presented. DBD and DCD consent rates were analysed separately. **Conclusions** • In the first nine months of 2018, overall consent/authorisation rates for the four UK nations were similar, ranging from 63% in Scotland to 73% in Wales. • For the first time the quarterly monitoring has shown statistical evidence of an increase in the DBD consent rate in Wales compared to England (powered to detect a 10% difference); there is no evidence of a similar trend in the DCD consent rate. • Quarterly monitoring will continue to ensure the improvement in the DBD consent rate in Wales is maintained. • A multivariate analysis is also required to determine whether the observed increase in DBD consent rates in Wales is as a result of the introduction of deemed consent, having accounted for other factors known to influence consent rates. DG added his congratulations to the Welsh team that the Welsh opt out legislation has now resulted in statistical evidence on improvements. **Scotland** LL is attending a meeting next week when any final amendments will be made to the proposed Scottish Bill with a view to publishing it in March 2019. There will then be a year's public consultation. New legislation (deemed authorisation) should come into effect May 2020; though a two-year implementation period may be introduced by Scottish Parliament. Ante-mortem interventions and duty to enquire are points which need to be elucidated in more detail. **England NODC(18)13** Firstly, CW wanted to thank JF for the work that he has done in order to provide reassurance to various groups during the course of the opt-out process, which has been a fantastic help. **Deemed Consent Legislation** **Key Points** **England** Government response published, includes new items: • Introducing a new button on the ODR to support faith/belief declaration – in place by December 2018 • Faith specific support materials to be included on ODR website	

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Bill passed by Committee with unanimous support and passed third reading. Bill now in the House of Lords.

Working with DHSC and NHS Digital to:
• Integrate the ODR with the new NHS APP. Full Push and Pull facility by April 2019
• Develop/deliver Communication Strategy to support change in legislation

Next Steps
• Lords debate scheduled for 23 Nov 2018; would then require further stages.
• If fully approved by House of Lords without amendments, the bill could be enacted March 2019
• Liaise with faith groups, seek views on proposals for ODR/new faith specific material

Implementation
1. Operational
- Guidance/Codes of Practice/internal documentation
- Capacity (SNOD, Hub, DRD, NORS, ODR etc)
- Hub
- Stakeholder engagement
- Training
2. ODR/Hub
- Faith Declaration
- Integration with NHSApp
3. Communications
- Publicity campaign
- Faith specific information

Jersey, Isle of Man and Guernsey are also moving to introduce deemed consent. Jersey’s Act is in place but not yet implemented.

CW asked that NODC keep engaged in the opt-out process and to ensure that we keep the public onside.

DG asked if CW could produce some slides that could be adjusted to match each UK nation, to be used at the respective regional collaborative meetings. CW to prepare.

ACCP’s confirming death in DCD NODC(18)14
NODC approved the following three recommendations:
1. <u>In principle NODC does not oppose ACCPs diagnosing death in DCD</u>
Discussion/points made:
• ACCPs already diagnose death on wards in some hospitals for expected deaths
• Junior doctors also diagnose death (some with very little training)
• AM made the point that this should be used once ACCPs and junior doctors have been trained to a particular level – not all ACCPs have received training in diagnosing death.
• Certification of death (which is the paperwork required for registering a death not the diagnosis) currently needs to be by a certified practitioner and will remain so.
• GV asked if the wording was a bit soft and perhaps we should be saying that ACCPs diagnosing death is entirely appropriate. That way potential donations wouldn’t be lost eg. in Plymouth
</td><td>CW</td></tr>
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		ACTION
	• Qu: if there is a death in the middle of the night and an ACCP certifies death, can DCD donation proceed? Ans DG: This should not be occurring. • CB highlighted the fact that there could be an issue with the Coroner if an ACCP certifies death • Discussion to continue and we must have a clear steer on the situation. **2. Prior to approving this possibility, NODC will require a statement from FICM/ICS supporting ACCPs diagnosing death, and specifically in the context of DCD** • DG is in discussion with FICM/ICS representatives. Email and verbal communication is that they would not support ACCPs diagnosing death for DCD *at the current time.* But this has been raised at the Legal and ACCP subcommittees for further discussion and consideration. **3. If such a statement were made, NODC would work with FIC/ICS to identify what additional training requirements are necessary to approve an individual ACCP diagnosing death in DCD.** **Update on DBD Donor Optimisation Bundle NODC(18)5** DG advised that the Extended Care Bundle is now being widely used and has been well received. CW made the point that the Optimisation Bundle is a great document to work from and agreed that it is being widely used. NODC approved a change in the vasopressin advice in the bundle to: • "Commence vasopressin (0.48 – 4 units/hour) where vasopressor required, wean or stop catecholamine pressors as able" • The ICS Standard Medication Concentration 2016 document recommends Vasopressin (Argipressin) 20 units in 50 mls = 0.4 units/ml. To achieve 0.48 units/hour a pump can be set at 1.2 mls/hr. • This change was introduced because if the ICS concentration is used, the old guidance asked for (0.5 – 4 units/hour), which can only be achieved by setting the pump at 1.25 mls /hr. Pumps only work to once decimal point. This has caused confusion in the past. **Changes to the potential Donor Audit NODC(18)16** AB presented an overview of the UK Potential Donor Audit Review **Background** • The UK Potential Donor Audit was introduced in 2003 to establish and maintain a clear understanding of the potential for Organ Donation throughout the UK. The audit tool and data set have undergone a number of changes over time in response to the changing needs of stakeholders and strategic directives. • It is now a key tool used to improve and benchmark performance. • The review commenced in May 2018 with a PDA review group established to undertake the review through consultation with stakeholders and analysis of data requirements **Progress** • Following the review process, the PDA data set team have proposed a new data set which can be reviewed (and data entry simulated) using the following working prototype: https://form.jotformeu.com/82144294460354 **NODC is asked to approve the proposed PDA data set** • Following approval at NODC the data set will be reviewed by ODT SMT and approval will be sought to proceed with the design of the IT solution • Solution design will commence in November/December 2018	

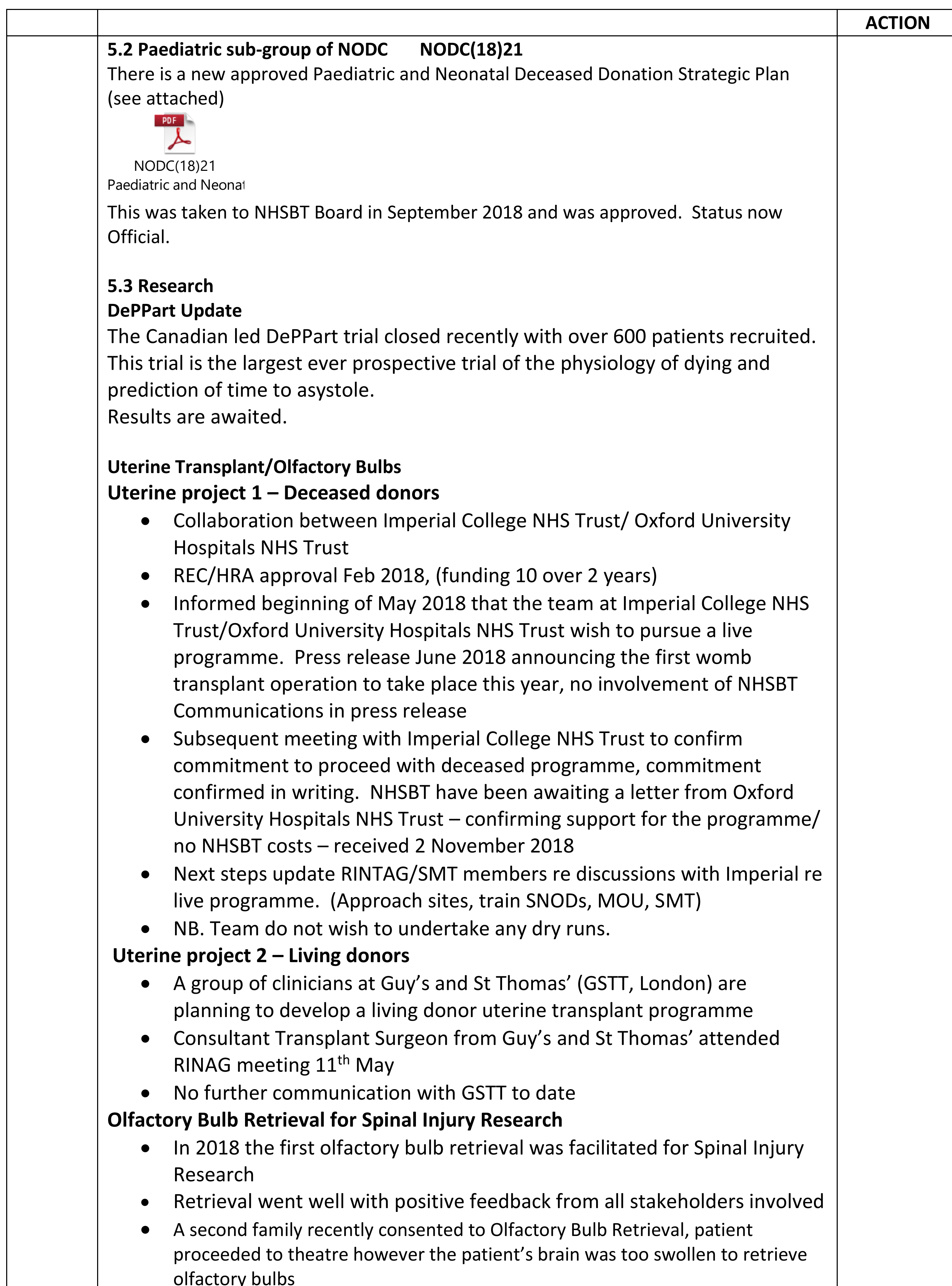
		ACTION
	• Solution agreement in Spring 2019 • Development of the agreed solution to commence Spring 2019 • Updated PDA solution to go live Summer 2019 NODC approved this new data set **4.3 Education Report and Update NODC(18)17(a) and (b)** A tender process is currently under way to secure the best facilities to support SIM training for both SNOD and ICM trainees to ensure all SIM training delivered remains world class **SNOD Cohort Training** • Eight cohorts of SNODS have now been trained over the last three years, 87% of whom have completed full training within the six-month period • This award-winning cohort training has been recognised on an international platform and attracted an award for "Innovation in Donation and Transplantation" from the North American Transplant Coordinators Organisation (NATCO) **Specialist Requester (SR) Training** This is evolving as the SR service is rolled out **Shared Professional Practice Course (SPPC)** The use of Forum theatre has been a welcome initiative allowing a dynamic way of sharing good practices across the UK as well as across the specialist requester/SNOD roles. **Mentorship Course** Supports training of established SNODs to enable trainees to be supported by team members in Trust, out on call and within their teams. **Influencing Skills** Run by PDS team and Organisational Development to help people understand their own communication style and different personality types. **Regional PDT** members support national teaching programmes and shadow on call work. Train incoming Specialist Nurses and Specialist Requesters. **Medical Education** PDT medical education strategy for 1, 3 and 5 years feeds into the overall education strategy **The Deceased Donation Course** A modified tender process will allow for future flexibility of delivery sites Pre and post course data evidences the positive impact of having a SNOD join family conversations at all stages. **CLOD Induction** Currently two per year **Chair Induction** Currently one day per year but a second course could be added to support attendance from more new Chairs **KPIs** Development of KPI data for medical evaluation is ongoing **Website and e-learning** Work continues to migrate the Deceased Donation website to the microsite **Paediatrics** Collaborative work continues to support development of paediatric organ donation education	

		ACTION

	4.4 Promotion
	July/August
	• Paid media run in July/August to support the increased noise around organ donation (release of Organ Donation and Transplantation Activity Report, launch of the Government BAME campaign, opt out announcement, Transplant Games)
	• Activity: radio, digital audio, social media prospecting and retargeting, BAME podcasts, BAME paid media partnership with Capital Xtra, digital OOH in Birmingham (Transplant Games) and operation donation events
	• **BAME media partnership** – with Capital Xtra, Capital and PopBuzz. Educate, motivate and empower young people, especially from BAME communities about organ donation so they commit to be donors
	    o Activity delivered across Capital Xtra & Capital – co-branded video content, educational trails, direct messaging trails, digital hub and editorial content
	    o Activity delivered across PopBuzz – 4 pieces of content, 8 social posts and co-branded video content
	    o Results – Capital – over delivered against all benchmarks (reach, impacts, page views, dwell time) The page on the digital hub had over 8,000 page views. The benchmark for page views is 3-3.5k and the pages usually include a competition to draw people in, just shows how engaging the content was.
	    o Results – PopBuzz – Levels of engagement surpassed benchmarks, with one of the articles achieving an engagement rate of 11.84%, the benchmark is 1%.
	    o The key benefit of a media partnership is that the media owners know their audience extremely well and they develop content in the tone of voice and language of the audience which makes it extremely engaging as can be seen from the results
	• **BAME podcasts** – Had trails on two BAME podcasts, Wanna Be & Global Pillage. Delivered over 170,000 impressions. Had to measure channel however the benefit is that the presenter delivered the trails in a language and tone of voice that will resonate with the audience.
	• **Radio** – purpose to drive awareness and conversations. Stations chosen to target our three main audiences; over 50s, DEs and BAME (17-34 years). Delivered a reach of over 15million to our target audience
	• **Social media** – ran adverts on Facebook, Twitter & Instagram targeting the over 50s and DEs. To drive awareness, conversations and registrations (from retargeting).
	    o Prospecting phase – delivered over 2.7m video views. Over delivering on the majority of benchmarks set
	    o Retargeting users who engaged with the adverts – over 1,500 sign ups (however still waiting on data for Twitter from Carat so will be higher)
	    o Retargeting users who have just registered to encourage them to share their decision – over 340,000 video views
	• **OOH adverts** – in 7 key sites in Birmingham city centre – potential to reach 2.5 million adults
	• **Operation donation** – Two events at England vs India Test cricket match to engage with a mainly Asian audience. Achieved 117 sign ups and potentially engaged with 250 people
	• **Partnerships** – with 7 county cricket clubs across England, content and announcements at matches. Long term partnership with The Barat Army (Indian Cricket Supporter group) for England v India test series, and ongoing for opt out comms.	

		ACTION
	• **Transplant Games** – Largest ever with over 1000 athletes taking part. Secured over 30 case studies, media reach includes 44 broadcast and 25 national pieces of coverage. • **Teaching resources** – promotion of updated resources to teachers and head teachers via email at the end/start of old/new school terms. Promotion ongoing, updating resources for legislation in Spring. Held education workshop with key charity stakeholders to work together more closely and identify aps in content across young people. **Content** Developed many more case study videos, particularly with BAME patients and donor families. Developed large set of animations explaining the basics of organ donation to address lack of knowledge. Worked with Lesley on SNOD animations for use with potential donor families. **Organ Donation Week** Over 52,000 online sign ups during the week which is a 75% uplift on the week prior to ODW and a 3% uplift compared to ODW 2017. Activity delivered: • **Paid media** – radio and digital audio, podcasts (x7), social media advertising across Facebook, Twitter & Instagram – 2.4 million video views and 4,400 sign ups. We also ran Twitter First View (the first ad users see when they log on to Twitter on Tuesday 4th September) This activity alone generated 6.7 million impressions, 2.3 million video views, and 88,000 tweet engagements – This is an increase of 1.53% impressions and 33.88% increase engagement compared to 2017. • **Partnerships** – support from 64 partners with a combined reach of 25.6 million (includes sports clubs, emergency services, healthcare, employers – Asda, BA, Virgin) • **Stakeholders** – 350 posts on social media from 127 stakeholders with a combined reach of almost 6.4 million. Plus 9 social post from MPs reaching almost 300,000 • **Influencer activity** – 38 posts from 21 influencers with a combined reach of almost 7.3 million. • **Social media** – own channels = 164 posts across the week, with 128,000 social engagements and 300,000 video views. The best performing posts, as usual, were real life stories (Max Johnson video and the Great Ormond street post). Across the week there were over 8,000 mentions on social media of organ donation week which generated 45.6 million potential views. • **Media & PR** – report not yet received • **Operation donation** events – 8 events to support ODW resulting in 682 sign ups **Tell and Ask** Tools on the end of transaction page to enable family conversations. Currently in build, tool will offer messaging via email, SMS, WhatsApp and Facebook messenger (all being scoped for feasibility). Will also offer tips on face to face conversations, downloads of digital donor cards and a sharing section for real life stories. Will be offering a faith and belief based version with downloadable donor cards and specific content to meet faith needs. **Opt out comms** Budget given by DHSC for the creative development, required now in order to be ready for Spring. Messaging focus groups taking place this week both north and south of	

		ACTION
	England to ascertain peoples' comprehension and narrow down the messaging approach. Research started also on an awareness tracker, 54% of respondents were aware of the change, higher than we expected. Hope that messaging will encourage donation as well as inform of legislation changes. Multichannel media and marketing campaign will start in Spring providing Bill passes through Parliament. Will be in phases across vast number of channels in order to reach everyone (target tbc) in England. Budget and therefore channels still TBC from DHSC.	
5	**Working Group – Subgroup Reports**	
	5.1 NODC Statistics Working Group **Specialist Requesters NODC(18)19** **Key Points:** • SR role formally introduced in the North West, London, Midlands and Yorkshire teams in autumn 2016. In the first 18 months, the SR consent rate was slightly lower than the national SNOD rate, 70% compared to 71% • SR rates were lower than SNOD rates in three of the four teams, North West team had better SR rates. SR consent rates were significantly higher than SNOD consent/authorisation rates for DCD donors and patients with no known decision to donate at the time of approach • Having considered other factors that affect family consent (ODR status, ethnicity and donor type), the presence of an SR from North West or Yorkshire was 1.7 times more likely to result in family consent DG: Que: Why does having a specialist requester seem to make such a difference in the North West? Ans: They have a very well-established and full quota team and a very low staff turnover. As this team is showing such good results it may be that in a year or two's time, other teams may be at the same level and showing great results. **Time to family approach NODC(18)20** **Background** • UK Devastating Brain Injury consensus statement published December 2017 • Consensus statement recommended that patients who had been intubated with DBI be admitted to critical care for a period of observation • Suggestion was that acceptance of DBI consensus statement would increase time from hospital/critical care admission to time of approach for organ donation and influence family decisions to consent for donation **Statistic based findings** • It does not appear that the introduction of the DBI protocol has impacted the median times from hospital/critical care admission to approach for DBD or DCD eligible donors. No evidence in regional variation in time between hospital/critical care admission and approach across twelve teams • For eligible DCD patients the median time from hospital/critical care admission to time of approach is higher for the family consented group compared to non-consented group – difference is not significant • For eligible DBD patients the median time from hospital admission to approach is similar for family consented and non-consented. Time for critical care admission to approach is slightly higher but difference is not significant	



ACTION

5.2 Paediatric sub-group of NODC NODC(18)21

There is a new approved Paediatric and Neonatal Deceased Donation Strategic Plan (see attached)

NODC(18)21 Paediatric and Neonat

This was taken to NHSBT Board in September 2018 and was approved. Status now Official.

5.3 Research

DePPart Update

The Canadian led DePPart trial closed recently with over 600 patients recruited. This trial is the largest ever prospective trial of the physiology of dying and prediction of time to asystole.

Results are awaited.

Uterine Transplant/Olfactory Bulbs

Uterine project 1 – Deceased donors

- Collaboration between Imperial College NHS Trust/ Oxford University Hospitals NHS Trust
- REC/HRA approval Feb 2018, (funding 10 over 2 years)
- Informed beginning of May 2018 that the team at Imperial College NHS Trust/Oxford University Hospitals NHS Trust wish to pursue a live programme. Press release June 2018 announcing the first womb transplant operation to take place this year, no involvement of NHSBT Communications in press release
- Subsequent meeting with Imperial College NHS Trust to confirm commitment to proceed with deceased programme, commitment confirmed in writing. NHSBT have been awaiting a letter from Oxford University Hospitals NHS Trust – confirming support for the programme/ no NHSBT costs – received 2 November 2018
- Next steps update RINTAG/SMT members re discussions with Imperial re live programme. (Approach sites, train SNODs, MOU, SMT)
- NB. Team do not wish to undertake any dry runs.

Uterine project 2 – Living donors

- A group of clinicians at Guy's and St Thomas' (GSTT, London) are planning to develop a living donor uterine transplant programme
- Consultant Transplant Surgeon from Guy's and St Thomas' attended RINAG meeting 11th May
- No further communication with GSTT to date

Olfactory Bulb Retrieval for Spinal Injury Research

- In 2018 the first olfactory bulb retrieval was facilitated for Spinal Injury Research
- Retrieval went well with positive feedback from all stakeholders involved
- A second family recently consented to Olfactory Bulb Retrieval, patient proceeded to theatre however the patient's brain was too swollen to retrieve olfactory bulbs

		ACTION
	• One further case will be supported followed by a meeting with the St Georges researchers to agree how we can continue to support them with their Spinal Injury Research. **INOAR – I**ncreasing the **N**umber of **O**rgans **A**vailable for **R**esearch • INOAR subgroup of RINTAG made recommendations to RINTAG and SMT November 2017, with regards to increasing the numbers of organs available for research • Recommendations included that the QUOD licence should be extended to support removal of specific organs for generic research purposes (transplantation/healthcare). This would remove the requirement for 'specific' consent for individual research projects. Phase 1 of the implementation of INOAR will include the removal of the heart, lungs and diabetic pancreas for research and after implementation and evaluation other organs may be included in further phases • No implementation date yet as actions to develop and deliver INOAR project still in progress. **QUOD, Heart Bx and BAL** • SNODs will be trained in 2018 to take consent for the collection of heart biopsies (from hearts not accepted for transplantation) and BAL sample (from lungs accepted or not accepted for transplantation – CT in attendance) in addition to the current QUOD samples. NB. the BAL in the case of a DCD MUST be taken post-mortem and the bronchoscope will be brought to the donor hospital by the CT NORS team • NORS teams are currently being trained to undertake heart biopsies - go live date is planned for early 2019	
5	**Afternoon Discussion: Developing the next Strategy NODC(18)22** **Attendees divided into Groups to have discussions around the following questions:** **Q1. How can we maximise changes in legislation?** • Learn from Wales (communications) • Sign on the ODR (not a conversation with family) • Explain deemed consent/authorisation • Schools mandatory • Education • Teaching • Duty to enquire – why leave to SNOD • Must know if opted out • BAME national role models • Nationally coordinated day to change their status on Facebook/Twitter • Being bold and be brave (escalate plan for override - what is the message) • Age of deemed consent/authorisation • Marketing (learn from Wales), role of family • SNODs as change agents for legislation • Change in culture (eg plastic shopping bags) • Review education strategy for CLODs and SNODs • Loss of UK DEC - re-establish • Active choice/'mandated choice' • Learning from other countries with presumed consent • Information of donation in the hands of every UK citizen / once in lifetime	

Q2. How can we optimise the length of the donation process?

- Referral
- Testing (if opted in send results; role of legislation/codes of practice)
- Offering (centralised, whole country; not piecemeal one after another centre)
- Retrieval (dependent on offering; NORS team under-resourced?)
- Manage family expectations of the length of the time in advance/early
- DCD? Aim to next day (on family return to hospital)
- Change of expectation – family and staff
- Different DBD/DCD
- Change NORS composition – self-sufficient NORS team
- Hospitals provide a theatre (Bring their own theatre)
- Targeted approach – goal to extubate at a certain time (sign post better); then we manage to achieve this and expectations
- Family support SNOD role
- Recognition of lack of capacity and increased demand
- If donation is to be expected

Q3. What should the following roles look like in 2025?

SNOD

- (Nurses?, types of roles: specialist requesters, hospital engagement SNODs, offering SNODs, organ optimisation and theatre SNODs)
- Not necessarily a nurse
- More SNODs/career structure
- Split role family/clinical
- Offering via hub – SNODs family/optimisation

CLOD

- (Does every hospital need a CLOD?)
- Personally involve in donation (less strategic)
- More shared practice across regions/communication
- Not every hospital needs
- Level 4 not a doctor
- If donation expected – won't need number of CLODs
- Regional CLODs with regional committees (less local); reinvest SNOD
- Senior clinician as part of their remit

ODC Chair and ODC

- (What role should they play?)
- Do away with local hospital/cluster
- Benefits non-clinical person
- Salaried Chairs – honorarium
- Not in favour regionalisation; local accountability
- Increase local ODC powers
- Oversight/link to Board
- More autonomous peer review

Q4. Where is intensive care going?

How might this effect deceased donation?

- Regionalised specialised services – sick patient
- Available family support officer at point of entrance
- Future of NHS – we need to adapt to meet ever expanding need; no increase in resources
- Unrealistic public expectation
- More level 2 admissions/use
- Aging/fatter
- Limitation

		ACTION
	• Electronic systems hospital by hospital – difficult **Q5. Targets in the next strategy?** • Do we want a target? • 30 donors pmp? • At five years? • Waiting time on list as a target? • Another target? • Targets do drive behaviours • More on organ utilisation • Transplanted • Retrieval targets – length of the process • Maintain/improve donor PMP (small increases) • Not a consent target • More on ODR • Waiting times • If pmp = 30 (if can show how we get there – if we can did not work this time) • Target minimise missed opportunities • Is it organisationally stressful to have a target – reduce emphasis	
6	**Any Other Business** None	
	For information • NHSBT ODT Hub Programme document	
	Goodbye and Thank You Ian Tweedie is retiring. DG thanked IT for the work he has carried out over the last 3 years and said that he has made a huge difference. Paul Glover is also moving on as he has been promoted. Again, DG said that his work has made a huge difference and that he will pass on NODC's thanks when he sees him next.	
	Date of next meeting: Proposed Dates: **13 February 2019 (Skype)** **25 June 2019** **12 November 2019**	HC to send invites and book venues

Organ Donation & Transplantation Directorate