NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

NATIONAL ORGAN DONATION COMMITTEE (NODC) MEETING
AT 10:30AM ON WEDNESDAY 13 FEBRUARY 2019
VIA SKYPE

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
Miss Chloe Brown	Statistics & Clinical Studies, NHSBT
Mr Anthony Clarkson	Director, Organ Donation & Transplantation, NHSBT
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
Ms Monica Hackett	Regional Manager – Northern & Northern Ireland
Mrs Margaret Harrison	Independent Lay Member, ODT, NHSBT
Ms Alison Ingham	Regional CLOD – North West
Mrs Lesley Logan	Regional Manager – Scotland
Mrs Sue Madden	Statistics & Clinical Studies, NHSBT
Ms Rebecca Curtis	Statistics & Clinical Studies, NHSBT
Dr Alex Manara	Regional CLOD – South West
Ms Trish McCready	British Association of Critical Care Nurses Representative
Dr Andre Vercueil	Regional CLOD – London
Ms Fiona Wellington	Head of Operations for Organ Donation, ODT, NHSBT
Dr Argyro Zoumprouli	Regional CLOD – South East
Dr Reinout Mildner	National Paediatric Clinical Lead Organ Donation
Mr Mark Roberts	Head of Commissioning Development, ODT
Mr Phil Walton	Regional Manager – South Wales and South West
Ms Julie Whitney	Lead Nurse Service Delivery, NHSBT
Dr Katja Empson	Regional CLOD, South Wales

In attendance

Miss Heather Crocombe	Clinical & Support Services, ODT
Mrs Lizzie Abbot-Davies	Clinical & Support Services, ODT
Mr William Olsen	Transplantation Support Services, ODT

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1	**Welcome, Apologies, Declarations of Interest** Mr Craig Jones Independent Lay Member, ODT, NHSBT Dr Malcolm Watters Regional CLOD – South Central Ms Olive McGowan Asst. Director, Education & Governance, ODT Dr Rob Law Regional CLOD – Midlands Dr Tim Leary Regional CLOD – Eastern Dr Iain Macleod Regional CLOD – Scotland Angus Vincent Regional CLOD – Northern **Declarations of Interest in relation to the Agenda** There were no declarations of interest in relation to the Agenda.	
2	**Review of previous Minutes & Action Points NODC(M)(18)3 and NODC(AP)(19)1**	

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	The minutes were agreed to be an accurate representation of the previous meeting. J Allen commented that it is not necessary to reproduce slides within the minutes as these are included in the papers. **Action Points:** **AP1 Length of the Process update & Bedside Nurse Proforma NODC(18)11 –** on agenda **AP2 Update Level Meetings January 2019 –** on agenda **AP3 Policy: Implementation** – on agenda	
3	**<u>Standing Items</u>** **4.1 Performance** • ODT Performance Report **NODC (19)2** J Allen provided an update. For January, there are now 1330 deceased donors which is 32 more than the same 10-month period last year. 150 donors per month are needed in February and March to hit targets. The number of organs utilised per donor isn't shifting and this is getting a strong focus at SMT. Liver and pancreas data will be available at the next meeting. Consent rates are still at 67% and there is a large variation between all the teams. February was a low month last year, with 129 donors, and January this year was the second highest month with 156 donors. The activity is looking like last year's and it is hoped that this will be another record year. The fall in organ utilisation and number of transplanted organs is under careful monitoring, each unit is now asked to review any declines of organs. Following the last SMT meeting, declines that end in discards will now be looked at. NHSBT plans to have a policy put in place where any time a decline is made for a named patient, the patient will be told if the transplant was turned down due to lack of resources. This has received strong support from patient groups. Massive improvements have been made in all parts of the pathway. Missed opportunities are looked at monthly and missed referral opportunities will have more of a focus going forward. There is still more to be done to get up to 26 donors per million population. There was a short discussion about how end of life care can affect whether consent is given for donation. Having a SNOD in the room doesn't prove correlation with consent. The consensus was that if there is good end of life care then the chances of getting consent are much higher. • Length of the Process Update – **NODC (19)3** D Gardiner highlighted page 12 of the performance report, specifically, the proportion of occasions were DCD operations ended between midnight and 7am. This measure has been getting worse. R Curtis provided an update on the length of process. There is regional variation, which can be explained by different teams in different areas, different response times.	

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	Overall, we would expect this to be closer together than the report suggests. R Curtis asked the group for any comments. The group discussed how it is difficult to pinpoint any one reason why there is such a variation. The report gives regional teams something to go away with to process in their own areas. It was suggested that breaking down the process further would be helpful, for example, the time from commencing the offering to the start of the retrieval operation would be useful data. R Curtis confirmed that this could be built into the report for the next version. C Booth is currently part of the pilot scheme and requested baseline data for the hospital to compare to as they need to know how things are changing. R Curtis will liaise with O McGowan regarding getting hospital data to pilot sites. L Logan commented on the DCD timelines going up in Scotland. This is a consequence of a high proportion of DCD patients having NRP, the length of time in theatre has gone up. L Logan couldn't explain the offering length of time and will go back to her team to investigate. • Update Level Meetings January 2019 D Gardiner provided an update and thanked Tracey Jones and C Berman for their help. Three meetings were held in January. The fourth meeting for Level 4 was cancelled due to lack of attendees and a combined Level 3 & 4 meeting was run instead. We will use the vacated spot to run a Paediatric NODC invitational meeting instead. This was the first time the Level meetings were held in Birmingham and the overall feedback was positive. The venue, facilities and food received very positive feedback and 48% of attendees marked the meeting overall as very useful (the highest category) compared to 35%, 2 years ago. There were 130 posters from the meetings, D Gardiner will put these together in a poster booklet. A Gibbon stated that the data booklet put together by Stats was very helpful and they would look to re-do them in 2 years' time. Attendees were asked how frequently the meetings should be held, the majority felt every 2 years. 71% of attendees believed that the Trust and Boards should be re-levelled every 2 years. There was a short discussion about whether the meetings should take place every 2 or 3 years. It was agreed that the group would not decide yet, but it won't be done again in 12 months. **4.2 Policy** • Pregnancy J Forsythe provided an update. The BMA Ethics Committee has produced a report, and this has gone back to the Department of Health to see if this can now be operationalised. J Forsythe has not yet had a response. • Referral Crib Sheet – **NODC (19)4a & NODC (19)4b** These crib sheets were shared at the level meeting and received good feedback. They will start to be used in J Chalker's regions in South Wales and the South West. There was a concern that the form would reduce the willingness to refer, but this needs to be	**R Curtis / O McGowan**

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	monitored. The form is designed to make the referral a more straightforward interaction. It is important to start getting the GP information, lack of access to the GPs is a source of stress and getting the information early is helpful.
	
	A query was raised whether it would be possible for SNODS to get access to System 1 to be able to get to the GP records. This is different all around the country, there may be local or regional solutions but there is no national system. A Clarkson has had a discussion with NHS Digital about gaining access to these records and this may be possible to get in the future. Some GPs have contacted the BMA asking about their legal obligation to provide information to NHSBT, there is an action for D Gardiner and O McGowan to contact the Royal College of General Practitioners and work on getting a letter sent out to GPs to give reassurance that it's ok to send NHSBT the requested information.
	
	D Gardiner asked the group whether they are happy to go ahead with the pilot. The plan is to begin a 6-week test, get the feedback and make any necessary tweaks and then roll out the proforma nationally. The group agreed for the pilot to go ahead.
	
	• Opt Out Legislation
	  ○ Wales – Quarterly Monitoring **NODC (19)5**
	  ○ Scotland
	  ○ England
	  ○ Marketing Plan for England
	
	S Madden gave an update on the quarterly monitoring in Wales. In 2018, overall consent /authorisation rates for the four UK nations ranged from 64% in Scotland to 75% in Wales. Further analysis is required to determine whether the increase in DBD consent rate in Wales is a result of deemed consent.
	
	There was some concern there was a discrepancy in the data as North and South Wales were recording opt-out cases differently. The data has been looked at again and where it is unclear if the family were informed or approached, it has been recorded as having been approached for the purposes of analysis, so the data is comparable with England.
	
	It was suggested that it would be worth looking at consent rates of Welsh donors who die in England as most North Wales donors die in Stoke / Liverpool etc. This could be difficult due to National Allocation Schemes, but it could be possible to look at whether there has been an increase in transplants from those donors and worth exploring whether transplants resulting from Welsh donors have increased. A point was made that organs retrieved in Wales may well be transplanted all over the UK, and it would involve looking for specific organs. For the purposes of the paper, it would be better to look at how many transplants successfully happened. KPI charts specify utilised donors, S Madden will pull out these figures for the paper.
	
	L Logan provided an update on Scotland. The government bill has been presented in parliament and they launched a report 10 days ago supporting the bill. It will next be debated around Easter time and all parties should support it making the transition to the next stage smoother. The English and Scottish bills are happening reasonably separately, Department of Health meetings are holding things together. All countries are aware of the issue of a donor dying over the border but until all the legislation is in place across the UK this can't easily be addresses.
		S Madden

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	A Vercueil gave an update on England. A meeting was held with Department of Health lawyers yesterday and it will be going to the House of Lords on 19th February. Work has started on the secondary legislation; the final draft will be ready mid-March alongside the public consultation document. J Forsythe added that a huge amount of work has gone into making sure all amendments were withdrawn prior to committee stage at the House of Lords. Commitments have been made at the dispatch box regarding extra resources for donation and transplant sides for this to be a success. The secondary legislation will look at novel technologies / rare transplants etc. and a decision was made to make a full consultation on this. External stakeholders have been informally consulted and they are in support. A Ttofa provided an update on the marketing plan. To support operational implementation of Opt Out, there will be a robust communications campaign targeted at everybody over 18 in England, and over 16 in Scotland, about the change in the law. If the bill goes through the House of Lords with no amendments, it will then go onto Royal Assent and they will be in position to launch the campaign in April. The English campaign will involve non-personalised household mailing, BAME / Faith group awareness raising activities etc. People need to be aware of the choices they need to make before the implementation of the law. There will be an NHSBT stand at Congress which will have a marketing bit for Opt Out, but the content depends on whether the Minister has signed off on the creative approach by Congress. • **Approve following documents and actions to *Strengthen the effectiveness of Organ Donation Committees*** o Non-functioning committees **– NODC (19)6** o Role Descriptions **– NODC (19)7a & NODC (19)7b** o New Chair's Handbook **– NODC (19)8** o Website A definition of a non-functioning committee was created due to the MOU's desire that donor recognition funding should only be going to hospitals with a functioning organ donation committee. It was suggested that the wording of '6 monthly meetings' within the main minimum requirements section could be misinterpreted and it should say 'biannual' instead. This will be amended. M Harrison queried how the decision is made that a committee is non-functioning. It was suggested that a SNOD / CLOD could bring this to the attention of the region, from there the regional chair / CLOD / Manager would look to see if the definition is met. The regional CLOD would then write to the medical director with an action plan. **Role Descriptions** – it wasn't clear what a Chair should do and who they should be. We want to allow a variety of backgrounds for the Chair and not limit who they could be but provide a structure. This will be shared with hospitals as a word document, there will be space at the top for the logo of the hospital. The document states what is expected of the Chair. C Jones sent a comment regarding the person specification for the ODC chair - you've currently got 'experience of analysing data' as desirable but given the responsibility to interrogate the trust's performance fata, shouldn't this competency be rated 'essential'? There was a short discussion of this point and it was agreed that this should be left as 'desirable' as some Chairs are from donor families and won't have this kind of experience. The Chair would not be expected to attend a meeting on their own to	

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	interrogate data, they would be together with a SNOD. It was also suggested that the requirement of having worked within the NHS be taken out of the job description and be replaced with evidence of working positively with a team instead. Chairing and leading meetings is an essential skill – if a donor family member is keen to be involved, they could be put in as a deputy for 6 months before becoming the chair. **Regional Chair for Organ Donation Committee** – Scotland and the Midlands have recruited into this position. There had been debate over the job title, as there will not be a regional organ donation committee. This person will be a representative from the ODC chairs to the region. F Wellington stated that the feedback from Midlands / Scotland is that this role is very beneficial and provides support to the collaborative. The challenge in some regions is to get people with the right skills to take on the role, having a job description helps set those expectations. Core expectations - It's hoped that there would be a meeting with the Regional CLOD and manager in an NHSBT office where they would talk through each committee and how things are going. The minutes would be uploaded to the region. C Berman stated that a template should be ready soon and everyone should use the same template to record the organ donation committee minutes. These will be stored in every region's performance folder and act as a way of ensuring people are meeting the core minimum requirements. The group supports the documents with the modification to the local chair one. **New Chair's handbook** – gained the group's general support for direction and travel from NODC. This will be part of the welcome package that goes out to new chairs and will be available on the new website. If members have something specific to point out, please email D Gardiner. There was a discussion surrounding the use of the term 'organ recovery'. It was suggested that 'recovery' to a layperson means the organ getting better, whereas, 'retrieval' is much clearer about what happens in theatre. The group decided to go ahead with the terminology as is, 'organ recovery'. J Allen suggested a glossary would be helpful to remind people about the different acronyms, D Gardiner agreed, and this will be included on the website as well. **Website** – Deceased donation area will link people to the best practice guidance. The new landing site will include some introduction, pictures, introduction to the handbook, role descriptions and a link to book onto an induction as a Chair. Something launchable will be ready for Congress. In summary – the group agreed that there is support for the definition of a non-functioning committee as written. The job roles are agreed with the small changes discussed and there is widespread support for the new Chair's handbook. The group agreed with continuing to develop the website as a landing page. • **Approve a new Memorandum of Understanding between NHSBT and hospital Trusts/Boards - NODC (19)9** J Whitney provided an update – significant changes have been made and 2 sections, Clinical Lead and Organ Donation and Committee, have been added in. Part 2 identifies each CLOD role and talks about expanded roles. This has been brought to NODC for comment and approval on those 2 sections. The desire is for this to come into force on 1st April.	

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	There was a discussion regarding this document. J Allen suggested that it's worth having working about best quality of care and missing no opportunities within the performance indicators. J Allen will review and make changes as necessary. It was suggested that the document be pushed to medical directors and CLODs for review. The group agreed that they are happy with the document and editorial changes can be made. **4.3 Education** • Medical Education update J Featherstone provided an update – a new centre (Newcastle) was used for the deceased donation course and this was very well received. There was a good mix of experience from the CLODS coming through. The Chair digital page will be developed ahead of Congress. There has been a delay in the new learning platform and an alternative will be sought if it is delayed any further. Permission has been granted to develop a one-day paediatric specific course. J Featherstone will work collaboratively with A Scales. One centre has decided not to go for the bid due to problems with the tendering process which does have some implications. There has been some reputation damage and the SNOD tendering is causing similar issues. There was a short discussion about possibly combining training courses. There are no plans to combine training at present as this would be too much pressure on junior SNODs. However, the idea is that paediatric intensive care trainees will go on the course for everyone and then go on a paediatric specific one. • Congress 2019 – update 265 people are currently booked in for the NHSBT spaces. The programme is set, Day 1 is joint with BTS and there will be joint NHS/BTS awards on Day 1. Day 2 will be an NHSBT day and all sessions have Chairs and speakers. There was an issue with people receiving emails telling them not to book travel before receiving a confirmation email. If anyone has any trouble, please let D Gardiner know. **4.4 Promotion** Work is being done to have shareable content at the end of the ODR website and how to integrate this with messaging platforms. The desire is to deliver this by the end of the quarter. A new phase of advertising is going out in the next month directed at BAME communities, specifically social media ads aimed at Black and Asian communities. Short term projects will be finished by the end of June and A Ttofa will circulate a link to the recent Radio 4 programme regarding organ donation and faith communities. Awareness of the change in the law in England was measured in October at 54% but only 34% in January. There needs to be a focus on making sure awareness is raised as much as possible prior to the implementation of the Opt Out legislation.	**J Allen**

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	Intensive Care consultants are keen to work with NHSBT in running workshops where they can talk about deemed consent. This would be the best way to meet as many consultants at one time, including those who aren't already involved in transplantation. Regarding media requests relating to Opt Out, F Wellington will take an action to speak to C Williment and A Ttofa.	**F Wellington**
5	**Working Group – Subgroup Reports**	
	5.1 NODC Statistics Working Group • Planned improvements to the Regional Collaborative slide set – **NODC (19)10** Overall the changes being made to the slide sets are as follows: the colour scheme will be changed to organ donation pink. Font size and chart colour schemes will be considered carefully to ensure they are clear. Five-year bar charts will be used, like trust reports. Approach rates and consent/authorisation rates where SNOD present/not present will be removed from the slide sets. Percentages will always be rounded to the nearest whole number. An introduction slide will be added, the text of which will be defined by the group. Further changes to be introduced are: kidney offer decline rate data and heart and heart-lung donor data will be removed and a contents slide, chart displaying current number of donors per million of the population, new 'Useful Links' slide and blank slides will be added. The aim is that all changes will be introduced for the Spring 2019 production of these slides. The group agreed to the changes. • Summary of consented DCD donors with no known death date – **NODC (19)11** S Madden provided a reportConcerns have been raised that there is no known date of death for some patients consented for organ donation. The number of consented patients with no known death date is small, 2% between 2016 and 2018. The small numbers involved indicate it should be possible to follow up all cases. Members were asked to consider a suitable follow up process for cases where no death date has been recorded. The group discussed the paper and it was agreed that there is a duty of care for the consented donor to know when the date of death was. Some of this may be down to a data entry issue, the information is known but not put into the system in the correct way. For example, if a patient is consented to be a donor but doesn't die in the expected timeframe and is transferred to a ward and dies later, could they be being recorded as having died in ICU to capture consent. S Madden, P Walton, C Berman, A Manara and D Gardiner will have a telecon to discuss this further. **5.2 Paediatric sub-group of NODC** • Paediatric & Neonatal Strategy R Mildner provided an update. The strategy has been written and will be formally launched at Congress in March. Thanks to D Gardiner and A Scales for this. There is a NODC Paediatric meeting at the end of the month to start planning the implementation. The new Chair of NODC Paediatric is looking at the current membership as it hasn't been reviewed since it launched.	

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	A Paediatric level meeting is being held on 14th May, the hope is to have people from Paediatric ICUs come to Birmingham, to have a shared meeting to discuss strategy. Work is being done on having a more formal approach to neonatal donation. NHSBT is not funded to formally cover it, liaising with them to see how to progress with this. Advertising for paediatric role will involve the paediatric team. They will come up with generic questions for the interviews. **5.3 Research** • Hypothermia trial • DePPart update • Uterine transplantation / Olfactory bulb Hypothermia Trial – an application has been submitted to the HTA (Health Technology Assessment). Currently awaiting news as to whether this will get funded. DePPart update – Currently on hold while we go through a substantial amendment with the NIHR Technology Assessment Programme. Novel technologies – In discussion about draft Peri=Mortem in Potential Donors Guidance document. Uterine transplantation has been signed off by SMT. This will be launched with deceased donors in the London area. There are some concerns about the comms related to this. The advice is to wait until the end of the pilot project (3 transplants). F Wellington and D Harvey will have a catch up regarding this offline. Olfactory bulbs are on the back burner for now.	
6	**Any Other Business** The St John Awards have been moved to Spring. To date, and consistent over many years, 2/3 of families will accept an award and of those who accept, 2/3 will attend a ceremony and the other 1/3 receive their award by post. An annual report will be shared with the group as soon as it's available. F Wellington provided an update on a workshop held to look at SNOD recruitment. The key output was to widen the person specification. The aim is to recruit nurses with critical care experience and widen the pool to include nurses with applicative care or transplant backgrounds. The next round of recruitment goes live in April which will be for an additional 27 SNOD posts. A query was raised regarding the MOU as it doesn't mention Tissues. F Wellington confirmed that the MOU should include Tissues from a multi-organ donor perspective but not tissue donors only. F Wellington will pick this up with J Featherstone. A Ingham provided a quick update on a case where surprise Hep C Virology turned up. The Hospital is challenging NHSBT policy when it comes to explaining to the next of kin. A Ingham will look into this and report back to the group.	**A Ingham**

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	D Gardiner asked all members to email with any comments on the Skype meeting, what went well etc.	
	For information BBC Radio 4 programme as part of the current fatwa series: https://www.bbc.co.uk/programmes/m0002b9x A dedicated programme that follows the development of the fatwa, interviews Mufti Mohammed Zubair Butt, who has been developing the updated fatwa. BBC Asian Network Covers the development of an updated Fatwa on organ donation following broadcast of the BBC Radio 4 programme. Starts at 1:40 mins for 17 mins. https://www.bbc.co.uk/sounds/play/m0002dd4	
	Date of next meeting: **25 June 2019, face-to-face London. (Moved to Birmingham)**	

Organ Donation & Transplantation Directorate