**NHS BLOOD AND TRANSPLANT**
**ORGAN DONATION AND TRANSPLANTATION DIRECTORATE**

# NATIONAL ORGAN DONATION COMMITTEE (NODC) MEETING AT 10:00AM ON TUESDAY 25 JUNE 2019 COPTHORNE HOTEL, BIRMINGHAM

**Present:**

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| Dr Dale Gardiner (Chair) | National Clinical Lead for Organ Donation |
| Miss Joanne Allen | Performance & Business Manager, ODT, NHSBT |
| Ms Cliona Berman | Team Manager, London |
| Mr Stephen Bonner | Royal College of Anaesthesia Representative |
| Mr Chris Booth | Regional CLOD – North West |
| Ms Jackie Brander | Lead Nurse – Service Delivery |
| Mr Andrew Broderick | Donor Assessment Programme Lead |
| Ms Maria Cartmill | British Society of Neurological Surgeons Representative |
| Ms Jo Chalker | Regional Manager – South Wales & South West |
| Mr Anthony Clarkson | Director, Organ Donation & Transplantation, NHSBT |
| Mr Gordon Crowe | Regional Manager – North West & Yorkshire |
| Ms Susan Dashey | Regional CLOD - Midlands |
| Mr Andrew Davidson | Regional CLOD – Yorkshire |
| Dr Katja Empson | Regional CLOD, South Wales |
| Dr Pardeep Gill | Regional CLOD – South East |
| Ms Monica Hackett | Regional Manager – Northern & Northern Ireland |
| Ms Susan Hannah | Regional Manager – Scotland Organ Donation Services Team |
| Mrs Margaret Harrison | Independent Lay Member, ODT, NHSBT |
| Dr Dan Harvey | National Innovation and Research CLOD |
| Ms Alison Ingham | Regional CLOD – North West |
| Dr Ben Ivory | National Education CLOD |
| Dr Tim Leary | Regional CLOD - Eastern |
| Mrs Sue Madden | Statistics & Clinical Studies, NHSBT |
| Dr Reinout Mildner | National Paediatric CLOD – Chair of Paediatric Subgroup of NODC |
| Mr Stephen Park | Assistant Director Communications, ODT |
| Ms Katy Portell | Ambassador Programme Manager, ODT |
| Ms Susan Richards | Regional Manager – Midlands & South Central |
| Ms Marian Ryan | Regional Manager, ODT |
| Mr Dominic Trainor | Regional CLOD – Northern Ireland |
| Mr Angus Vincent | Regional CLOD - Northern |
| Mr Phil Walton | Project Lead – Organ Donation and Nursing |
| Dr Argyro Zoumprouli | Regional CLOD – South East |
| Dr Charles Wallis | Edinburgh |

**In attendance**

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| Mrs Lizzie Abbot-Davies | Clinical & Support Services, ODT |

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| 1 | **Welcome, Apologies, Declarations of Interest**<br>Dr Andre Vercueil — Regional CLOD – London<br>Mrs Lesley Logan — Regional Manager – Scotland<br>Professor John Forsythe — Associate Medical Director, ODT<br>Ms Amanda Gibbon — Organ Donation Committee Chair Representative | |

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| | Ms Julie Whitney — Lead Nurse Service Delivery, NHSBT<br>Dr Alex Manara — Regional CLOD – South West<br>Ms Fiona Wellington — Head of Operations for Organ Donation, ODT, NHSBT<br>Ms Sue Duncalf<br>Mr Craig Jones — Lay Member Representative<br>Ms Sarah Clarke — BACCN Representative<br>Ms Olive McGowan — Assistant Director Education and Governance<br><br>**Declarations of Interest in relation to the Agenda**<br>There were no declarations of interest in relation to the Agenda. | |
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| 2 | **Review of previous Minutes & Action Points NODC(M)(19)1 and NODC(AP)(19)2**<br><br>The minutes were agreed to be an accurate representation of the previous meeting.<br><br>**Action Points:**<br><br>Bedside Nurse proforma - NODC(AP)(19)1 – Aide Memoire to use for referrals so key information is given, e.g. what bloods to take, what can be done in advance, what to do ahead of the SNOD arrival etc. Currently collating feedback and this should be done by Thursday and will be distributed as a document – CLOSED.<br><br>**AP1: Length of the Process Update: Get hospital data to pilot sites –** on agenda<br><br>**AP2: Opt Out Legislation: Look at how many transplants successfully happened from Welsh donors who died in England –** on agenda<br><br>**AP3: Approve New Memorandum of Understanding between NHSBT and hospital Trusts/Boards: Review document and make necessary changes to include wording about best quality of care and missing no opportunities within the performance indicators. –** on agenda<br><br>**AP4: Promotion: Speak to C Williment and A Ttofa regarding media requests relating to Opt Out –** on agenda<br><br>**AP5: Look into challenge from hospital regarding Hep C virology and report back**. – discussed at collaborative. Surprise Hep C virology was found in a hospital, discussion on best actions in this situation, and new guidance is now being written and this will be brought to a future NODC meeting. | |
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| 3 | <u>**Standing Items**</u><br><br>**3.1 Performance**<br>• ODT Performance Report<br>• Performance NODC discussion<br><br>Performance slides were shared. . Last year was a record year for donors, however, the waiting list didn't fall. However, the weekly report shows that, compared to this time last year, performance is down -9.8% overall<br><br>D Gardiner invited NODC members to discuss the reasons beind the decreasing donor numbers and whether this reflected a proposed reduction in the number of eligible | |

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| | donors. It was suggested that it could be explained by statistical variation, there are peaks and troughs and we are currently seeing another trough. However, the rolling 12 month average is also down. It would be interesting to look at the subgroup of patients admitted who were potential donors and see how many were trauma and how many were neurological injury. It is unclear if the drop in performance is due to the donor pool or not and it would be useful to drill further into the data and see what happens in the next 6 months.<br><br>The reduction of performance could be a function of good reasons or addressable reasons. Good reasons – less death due to the fact that hospitals are better at intensive care and there is more aggressive early intervention. Addressable reasons include patients being moved to another part of the hospital and potentially devastating injuries being missed. Some patients who have died in the emergency unit are being identified as potential donors, even though some died in ways that meant they couldn't be considered. ICUs are accepting patients much more readily and it's possible this has an impact on the overall numebrs somehow. The activity report will be published next month.<br><br>A lot of investment has been put into opt-out which may result in static donor numbers if the eligible donor pool continues to fall. SNOD presence is up to 92% but this is vulnerable to what the eligible pool is – the aim is to bridge the gap with opt out like in Wales. There are already local, regional and national actions to involve specialist nurses early in the process and letters are sent to investitigate all missed opportunties (referral and SNOD involvement).<br><br>It was suggested that the biggest gains to the donor pool will come from consent rates. A discussion followed regarding the amount of donors that are falling off in the offering / retrieval step, it would be useful to know haw many times consent was given and the organs were actually retrieved after consent. Last year saw the highest number of consents but only 1600 donations – more and more people are consenting but this doesn't necessarily work in correlation to donation numbers.<br><br>There is a meeting this afternoon with the CQC to discuss their role in monitoring donation processes. The group agreed that it is a good idea to engage them actively.<br><br>A Clarkson put forward the idea of a Perfect Week – a dedicated period of time where the aim is to have perfect practice within that week and run debriefs afterwards. The group discussed this idea and whether the amount of effort to run this would be acceptable. The amount of effort needed to increase the referral rate percentage is difficult to identify – if it raises from 95% to 96%, all the donors in that final percent may be non-proceeding. It was agreed that arranging this would take a lot of effort and it may be best to consider running it within NHSBT operationally (Hub) at first and then include the wider community at a later stage.<br><br>• Length of the process update – NODC(19)13<br><br>To aid interpretation of the process following approach, time from referral to formal approach is presented before 0 on the graphs. North West has good results – trying to mobilise SNODS along with the SRs so they work in tandem to reduce the amount of time. | |

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| | There was a discussion about whether approach is being delayed – there is a danger that by the time approach is made, the family has already had enough. The new PDA will help with this – early referral may not mean the rest of the process is faster. It was suggested the graphs are trying to show too much, and the final section (operation end to kidney perfusion) is not relevant for NODC. it was recommended that SMT should see the entire graph, but it would be good if NODC can see the graph ending when the operation ends. It would also be useful to have more information about the impact on theatres between Monday – Friday, 8am – 4pm. | |
| | • New PDA update | |
| | There are plans for the Potential Donor Audit to change platforms from EOS and go onto Donor Path. Currently testing the end-to-end process and this will result in the PDA being stored in the new database. Planning to release this in quarter 4 of this financial year. The target is interactive reports in graph type formats where it's possible to look at everyone's anonymysed data. Sharepoint is working for external users. Key outcomes are for PDA to be more explicit regarding Wales to allow us to understand who has opted out. Referral and SNOD involvement – need to know more about the donation conversation. This will be recorded withing the system to help with missed opportunities. A Broderick will send the form to NODC members. | **A Broderick** |
| | • Declined offers due to logistical reasons | |
| | No update at this time. | |
| | **3.2 Policy**<br>• Pregnancy | |
| | The BMA Ethics Committee has given specific advice regarding pregnancy and donation. NHSBT have decided to support the BMA Ethics Committee advice and O McGowan has drafted a letter regarding this. | |
| | The BMA recommendations state that <u>if it is not</u> in the best interest of the pregnant woman to continue with life prolonging treatment, there is no legal reasons it should be continued, and donation does not raise any further ethical or legal issues in this scenario. The view of the BMA is that the death of the woman leads to the death of the foetus, not the act of donation. The woman's intention to donate should be respected and the death of the foetus is foreseen but not intended. Donation would follow once foetal death is confirmed. | |
| | Any donor referral for a pregnant woman should be escalated to the manager on call and all recommendations should be incorporated into practice and SNOD policy. | **A Manara** |
| | It can be complicated to confirm when a foetus has died, and advice needs to be worked out for this. D Gardiner will ask A Manara to liaise with obstetric colleagues regarding this and report back to NODC. | |
| | A policy became live 6 months ago – in any potential female donor of child bearing age (12-55) bloods will be taken to test for pregnancy. There have since been some requests from SNODS to change the policy – if the patient has had an evident hysterectomy, is it possible not to test in that situation. After a brief discussion, all | |

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| | members agreed that the policy can be amended to reflect this.<br><br>• Update on *Strengthening the effectiveness of Organ Donation Committees*<br><br>C Berman provided an update – currently waiting on marketing to send over a PDF of the Organ Donation Committee Book. All documents are ready to go up on the clinical site. The new chairs handbook will also go up on the landing page of the clinical website**.**<br><br>• Update on *Memorandum of Understanding between NHSBT and hospital Trusts/Boards*<br><br>Memorandum has gone out and some people have already signed and returned it. D Gardiner has dealt with one query. There has been some feedback – there were quite a lot of changes from the previous version, it would be useful to have a summary of changes to be sent out when the document is re-issued.<br><br>• Update on FICM end of life care guideline<br><br>No update at present.<br><br>• Endorsement of updated diagnosing Death using Neurological Forms – NODC(19)14a & NODC(19)14b<br><br>Neurological forms – there were a few minor changes needed. It was decided that NODC will not officially endorse on the form but are planning on endorsing the forms in principle. Endorsement comes from ICS and FICM.<br><br>A key clinical change is wording in the section 'Red Flag' groups. There was a discussion about moving from 2 forms to 1 but after talking to different groups it was decided that 2 forms are very useful, so there remains a long and short version.<br><br>There was a discussion regarding the 'key question' on page 4 of the long form. It currently states: 'the key question the two doctors must answer is if the observed coma or apnoea is due to cardiorespiratory instability.' C Wallis suggested this be rephrased to say 'the doctors must exclude the possibility that cardiorespiratory instability is the cause of observed coma and apnoea' instead. NODC agreed for the wording to be changed.<br><br>It was also suggested that the suggested cardiovascular goals section on the same page of the long form could be dropped. NODC agreed for this to be taken out.<br><br>Once the forms have been amended, they will go to the ICS Standards Committee and then on to FICM.<br><br>• Summary of Fatwa from Mufti Mohammed Zubair Butt – NODC(19)15<br>• Fatwa implications for deceased donations – NODC(19)22<br><br>NHSBT have liaised with Mufti Zubair to create a Fatwa on donation. It is an important piece of work and represents the hard work of many people. However, it is important to clinically understand the implications of the Fatwa; therefore, D Gardiner has | |

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| | produced a document which he summarised.<br><br>The positives from the Fatwa is that it supports donation and transplantation. Many Muslims say they cannot have desecration of the body, the Fatwa says that donation is not a desecration, but it is saving lives and is a positive gesture.<br><br>The part that concern NODC is the deceased donation implications. DBD is not permitted until there has been irreversible cardiorespiratory arrest. However, this should not be interpreted as endorsement of DCD. The theoretical concept of DCD is supported, but the practice is not. UK DCD practice (and UK diagnosis of death practice in general) does not satisfy the Mufti's criterion of 'elective irreversibility' – not capable of being resuscitated.<br><br>It was suggested that NHSBT should provide a platform or framework for further dialogue and debate for scholars to agree on the point of elective reversibility with guidance from clinical intensivists. SNODS should carry on as they do now and not use the Fatwa in conversations with Muslim families unless raised by them.<br><br>It was agreed that the Fatwa should be circulated to aid Muslim communities in their discussions about donation. This is not an official document, it is the point of view from one scholar. NHSBT is hoping more Fatwas come from other scholars. The British Islamic Medical Society is also supportive of donation and transplantation.<br><br>NODC members were asked to relay this back to their SNODS. There is more work to be done, D Gardiner and A Clarkson will investigate this further.<br><br>**3.3 Education**<br><br>• Medical Education update<br><br>B Ivory provided an update. Currently running 6 deceased donation courses, which are 2-day residential courses. 7 centres are running these now and there is evidence that these courses are changing attitudes in intensive care trainees. The course is also suitable for paediatric training. The Paediatric leadership training course is in the development stage, hoping to tun the first one by the end of the year.<br><br>CLOD inductions will be run every year as a 2-day residential course – all CLODS need to attend within a year of their employment.<br><br>A lot of hospitals have less registrars and more ACCPs – ACCPs are not currently able to diagnose death for DCD but discussion is ongoing with FICM. The national course is not designed for ACCPs, but their growing education need does need to be addressed in time.<br><br>These courses are reliant on volunteer faculty from both CLODS and SNODS, B Ivory asked that the attending RCLODS raise this with their CLODS to see if anyone would be able to help in future.<br><br>• Congress 2019 – summary – NODC(19)20<br><br>D Gardiner provided a summary which included a financial breakdown. Pleased with RCLOD/CLOD attendance and the numbers of no shows down from previous Congress. | **D Gardiner /A Clarkson** |

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| | The current plan is in 2 years' time, do it again with BTS. NODC members agreed this was a good idea.<br><br>**3.4 Promotion**<br><br>• Marketing update (for information)<br><br>K Portell provided an update on Donation Ambassadors – there is still a small group in the Midlands and 18 in the London regions. Now working on restructuring and finessing the programme. K Portell spent a couple of weeks recruiting in the Northern regions and the plan is bring on 40-45 across 3 regions. Max's mum Emma Johnson is coming on board as an ambassador. The new ambassadors will be trained throughout July and August and they will be up and running by organ donation week. | |
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| 4 | **Working Group – Subgroup Reports** | |
| | **4.1 NODC Statistics Working Group**<br><br>• Specialist Requester review update – NODC(19)16<br><br>For the period since the SRs were introduced in the North West, SR consent rates were the same or higher than SNOD consent rates in five of the eight teams. However, only the SRs in the North West team had a significantly higher consent rate than their SNOD counterparts. The North West team, who have one of the highest proportions of SR approaches, have some of the shortest median times from approach to both retrieval and WLST.<br><br>D Harvey will put this report in the peer review literature.<br><br>**4.2 Paediatric sub-group of NODC**<br>• Paediatric & Neonatal Strategy update<br><br>R Mildner provided an update. A new paediatric and neonatal strategy has been launched, and there is a national meeting on Friday to start working on the priorities.<br><br>Currently working on training and education. A leadership course will be coming online in the next 6-12 months and the aim is to get as many trainees through the national courses as possible and to encourage people to continue running these courses. A new acronym has been created for a trainee representative to Paediatric NODC – TROD.<br><br>Most regions have a Paediatric CLOD, but each PICU may not have their own CLOD. The aim is to create a Paediatric lead for each region. This might be part of the person's normal recognition as a CLOD or it could be an unpaid position depending on the structure of the region. This person would be a point of contact up to R Mildner and from him to the rest of the region.<br><br>R Mildner and A Scales plan to attend collaboratives in the next few months to answer questions regarding the strategy. | **D Harvey**<br><br>**R Mildner / A Scales** |

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| | **4.3 Research**<br>• Donation Research Strategy – NODC(19)17<br>• INOAR<br>• Uterine transplant<br>• RINTAG and ODT Research Annual Report – NODC(19)21<br><br>Uterine transplant – Plan within Imperial and Oxford for a pilot scheme to offer uterine transplantation for an initial 10 cases. SNOD training will hopefully roll out in September for the pilot to go live early November.<br><br>INOAR – this is a new system for allocating organs given over for research. This has been beset by IT problems, but these are being resolved and the hope is that this will improve allocation for research and utilisation rate. This is wrapped up in QUOD and is documented in the RINTAG research report which contains a summary of all the work that currently exists.<br><br>Strategy paper – this will be discussed more in depth at the strategy meeting tomorrow. Members were asked to read over the document ahead of the meeting to discuss further. The paper outlines 4 or 5 different strategic paths that could be taken to improve capacity.<br><br>A short discussion was had about Consent for Interventional Research. There are 2 research consents – general consent, e.g. happy for tissues that cannot be used in transplants to be used in research purposes yes/no, and specific consent which is taken for more complex research interventions. A recent review of consent for interventional research shows the process is poorly understood and little researched. Research nurses go through additional training to take research level consent, SNODS don't have the same level of training but are given specific research training during the induction programme. There is a nested study within the proposed 3T study – plan to use research nurses to take that consent and some centres will have SNODS do it and then compare the experiences.<br><br>Consent for interventional research to go on the Agenda as separate item for the next meeting. | |
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| 5 | **Opt Out Legislation**<br><br>• Wales<br><br>Opt Out was introduced 3.5 years ago. Wales celebrated a fantastic year last year with 87 donors in total. There is a new wave of communication strategy, so it doesn't fall off the radar and they are working hard to share the experience their Specialist Nurses have had.<br><br>• Scotland<br><br>The bill was passed on 9th June and Royal Assent will be happening on 12th July. There will be a 12-month public awareness campaign and, in conjunction with the Scottish Implementation Group, will be rolling out training and education. 4 education CLODS will be put in place. | |

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| | There are ongoing discussions with Scottish lawyers regarding pre-death procedures – this is due to the difference in Scottish legislation which uses the term 'benefit' rather than 'best interests' – and these terms are not legally equivalent.<br><br>• Northern Ireland<br><br>The Department of Health have published a document to raise public awareness of donation, but it is a long way off legislative change.<br><br>• Monitoring plan for England – NODC(19)18<br><br>Members were asked to comment on the proposed anlyses to monitor the impact of opt-out legislation in England and determine if it is agreeable to proceed.<br><br>The baseline consent rate assumes a continuation of current trends without opt-out legislation. This will be a 5 year period prior to the enactment of opt-out. Stats teams will allow for a 1 year bedding in period before testing the consent rates. Initial tests will be carried out after 12 months and then it will be tested again after 24 months.<br><br>The figures forecast that if nothing is done, the numbers are going up however it was suggested that the proposed increase was unreaslistic and it was suggested instead that this be compared to the numbers from the end of last year. After a short discussion it was agreed that 2017/18 would be used as the baseline year as this is what is used in the Department of Health but more sophisticated analysis will occur concurrently. Stats team will bring back to NODC a final proposal for this. The group agreed that DBD and DCD will be analysed spearately, as it was in Wales.<br><br>• Operational Preparation for England<br><br>There are currently 31 workstreams to bring forward legislation across 5 countries – England, Scotland, Isle of Mann, Jersey and Guernsey. Jersey will go live on Monday (1st July).<br><br>There has been good progress already – the NHS app is live and functioning and there is a section where a person can record their donation decision. Credit to the ODR team that have delivered this.<br><br>Additional funding has been received from Department of Health for additional SNODS which are currently being recruited. There will be 12 additional SNODS spread evenly across the teams and they will be ready by the time the legislation goes live.<br><br>There are currently a lot of opt outs that need to be dealt with on an individual basis but there is no back log.<br><br>Encourage members to disseminate the novel transplant consultation to their colleagues – this looks at what should and should not be included under deemed consent. Under consideration currently is research.<br><br>There are some risks and issues from a programme point of view, there is no funding beyond the current financial year, and we are not signed up with the Government yet with what we are going to deliver in terms of opt out. | |

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<tr><td></td><td>There are additional things to be aware of in terms of England and Jersey. A consultation document, code of practice from the HTA, will be released this week. This is a handbook that applies to how you clinically approach opt in/opt out. This will be cascaded through the clinical community.<br><br>Visited each individual regional team for regional collaboratives which have been very positive and will be visiting the collaboratives in Autumn and again in Spring. Will be speaking to the SNODS/CLODS at the Autumn collaborative in England about the HTA code of practice. It was suggested that the Spring collaborative be booked for late February / early March, just before the opt out launch in April.<br><br>BACCN has invited NHSBT to deliver sessions on Opt Out. There will be a plenary session and workshop sessions with the ICS SOA December 2019. The plan is to showcase deemed consent conversations through role play.<br><br>• Marketing plan for England – NODC(19)23<br><br>Department of Health asked NHSBT to run a campaign in the 12 months preceding opt out and allocated funds to cover this - £11m over 2 years. Main objective it to make people aware of the change in law and understand what it means.<br><br>The campaign has been well received, it makes people aware of the law change but also encourages people to opt out, can track some spikes in opt outs to some false social media posts. Must be careful to keep eye on opt outs - vast amount from BAME communities and geographically the majority are from London. There is a potential for this to have an impact on the ability to get consent in London.<br><br>The separate legislations all have exclusions.<br><br>Given the investment received, it is likely that we will reach 60% of public awareness in the first year and build on that in the second year. In terms of reach, this will reach everybody, but will they will need to see something several times for it sink in. One third of England have opted in on the register and we know the demographics roughly of those opted in. Advertising will be targeted at those hard to reach groups, those most likely to not be opted in.<br><br>Brexit is suffocating news, it’s difficult to break through therefore paid advertising is very important. We have done well in getting airtime and coverage in the media.<br><br>Something we need to consider is once app is up and running how effective this is going to be. There are still other opt in avenues, e.g. DVLA / Boots but the app means NHSBT won’t need to write to individuals regarding their decision to opt in.<br><br>DG checked the website and noted that there is nothing about DCD or DBD and it’s almost impossible for the public to find out about the different types of donation. Should it be more at the forefront of the clinical website? K Portell put forward that it’s rare for ambassadors to have in depth conversations about death but it would be useful for this information to be accessible. Understanding the process debunks myths but there doesn’t appear to be a lot of thirst in the public for these questions. Should people be able to consent to DCD but not DBD it they wish to? It was agreed that there should be more information available as it is the family that end up making the decision. There is a potential option to have a link on the clinical website to the other</td><td></td></tr>
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| | site, so the public can dig deeper into DBD / DCD if they want to. S Park's team will investigate this. | **S Park** |
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| 6 | **Any Other Business**<br><br>• Letter to D Gardiner re: DC Review for information – NODC(19)19<br><br>Donor characterisation has evolved organically over many years and there is no one system. NHS England has agreed to transfer funding over to NHSBT. This will take a couple of years to implement.<br><br>AC informed members that in England, organ donation will become part of the national curriculum from 2020. There has been a consultation on health section of the curriculum, it has now been agreed to include donation including stem cell. | |
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| 7 | **For information** | |
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| 8 | **Date of next meeting:**<br>12th November 2019 - London | |

**Organ Donation & Transplantation Directorate**

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