NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

THE TWENTY- SEVENTH MEETING OF
THE ADVISORY GROUP CHAIRS COMMITTEE
AT 10:30 AM ON WEDNESDAY 2 OCTOBER 2019 AT WEST END DONOR CENTRE, 26 MARGARET STREET, LONDON, W1W 8NB

PRESENT:

Professor John Forsythe (Chair)	Medical Director – ODT, NHSBT
Mr John Asher	Medical Informatics Lead – ODT, NHSBT
Mr Titus Augustine	Deputy Chair, Pancreas Advisory Group
Ms Lisa Burnapp	Lead Nurse Living Donation, NHSBT
Mr Chris Callaghan	National Clinical Lead for Organ Utilisation (Abdominal)
Mr John Casey	Chair, Pancreas Advisory Group
Mr Ian Currie	Chair, Retrieval Advisory Group
Dr Jan Dudley	Chair, Kidney Advisory Group (Paediatric Sub Group)
Professor Peter Friend	Chair, Multi-visceral & Composite Tissue Advisory Group
Professor Paul Johnson	Chair, Pancreas Islet Steering Group
Professor Derek Manas	Deputy Chair, Liver Advisory Group
Mr Jeremy Monroe	Non-Executive Director, NHSBT
Ms Katie Morley	Lead Nurse – Recipient Co-ordination
Ms Lisa Mumford	Head of ODT Studies, NHSBT
Dr Jayan Parameshwar	Chair, Cardiothoracic Advisory Groups (Heart and Lungs)
Mr John Richardson	Acting Associate Medical Director, Transplantation Support Services, NHSBT
Professor Douglas Thorburn	Chair, Liver Advisory Group
Dr Andre Vercueil	Regional CLOD, London
Professor Chris Watson	Chair, Kidney Advisory Group
Professor Stephen Wigmore	Chair, British Transplantation Society
Ms Claire Williment	Head of Legislation Implementation - ODT, NHSBT

IN ATTENDANCE:

Ms Caroline Robinson (Minutes)	Clinical and Support Services Manager

		ACTION
1	**WELCOME & APOLOGIES**	
	Apologies were received from: Ms Liz Armstrong, Head of Transplant Development, NHSBT Mr Anthony Clarkson, Director of ODT, NHSBT Dr Dale Gardiner, Chair, National Organ Donation Committee Dr Gail Miflin, Medical and Research Director, NHSBT Dr Reinout Mildner, Chair, Paediatric National Organ Donation Committee Mr Gabriel Oniscu, Chair, Research, Innovation & Novel Technologies Advisory Grou Ms Karen Quinn, Assistant Director UK Commissioning	
1.1	**DECLARATIONS OF INTEREST – AGChC(17)10**	
	There were no declarations of interest.	
2	**MINUTES OF PREVIOUS MEETING: 27 FEBRUARY 2019 - AGChC(M)(19)1**	
2.1	The Minutes of the previous meeting on 27 February 2019 were approved.	

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3	**ACTION POINTS & MATTERS ARISING**	
3.1	**Action points - AGChC(AP)(17)1** AP1 – Project Update: Olfactory Bulbs – Liz Armstrong - 3 retrievals have taken place at ST Georges. RINTAG membership have agreed to allow 3 more retrievals to be facilitated. St George's Research Team are being more selective regarding cases as only 1/3 successful Olfactory Bulb retrievals have taken place.	
	AP2 – Project Update: Communicating Risk and Consent in Organ Transplantation – Liz Armstrong - Project request forms from the Business Transformation Team are to be completed in order to review resource required to complete 2 elements of the project: • Patient Information • Transplant Risk and Consent Tools (TRCT) We are aware that Transplant Risk and Consent Tools need to be considered alongside evolving guidance, Medical Device Directive is due to be replaced by the European Union Medical Device Regulation 2020.	
	AP3 – Update on Organ Donation Legislation – Following the Bill in England passing its 3rd reading, AG Chairs agreed to update members at forthcoming advisory groups	**CLOSED**
	AP4 – Reasons for Kidney Declines/Utilisation – see item 9 below	
	AP5 – Feedback for Strategy for Paediatric NODC – R Mildner to report on sharing press release with BTS	**CLOSED**
	AP6 – Recipient Co-ordinator Representative on the SOAG – It was confirmed that a face to face meeting for Recipient Co-ordinators had taken place	**CLOSED**
	AP7 – Reasons for Decline of Organs – see Item 9 below	
	AP8 – NHSBT Audits – Audits for Pancreas utilisation and Training and Registration were discussed at ODT and added to the programme for the coming year.	**CLOSED**
3.2	**Matters arising not separately identified**	
	There were no 'Matters Arising' discussed at this meeting.	
4	**PROJECT UPDATES**	
	An update of current projects was circulated prior to the meeting. In addition to the areas covered in the report, the Chair highlighted the current UK position regarding the use of organs from Hepatitis C Viraemic donors for Hepatitis C Negative recipients. It is believed that this strategy will increase the number of organs available for transplantation and reduce the morbidity and mortality of patients on solid organ transplant waiting lists. It was noted that the Welsh and Scottish governments have already agreed funding for this scheme and that notification has this week been received that NHS England will agree the same funding. Participating centres are being evaluated by a LAG working group, particularly regarding the policy, consent issues, what any centre coming on board needs to have in place and how the scheme will be monitored. It was emphasised that at present, this is only offered through the fast track process and as not all centres are involved in fast track, further consideration is needed to decide how the scheme will progress further. Waiting list tools are currently being developed by Hub Operations.	
5.	**UPDATE ON ORGAN DONATION LEGISLATION**	
5.1	England – The HTA consultation has closed and a workshop will take place shortly with SNODs and CLODs to review the Code of Practice. The DHSC are reviewing the responses to their consultation on exemptions to deemed consent. Those who contributed to the consultations were thanked for their input. It is anticipated that the legislation will be debated in Parliament early in the new year. The 'go-live' date is Spring 2020.	

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5.2	Scotland – the Government were in the process of drafting secondary legislation – one for exemptions and another for pre-death procedures. It is likely that 'go-live' will be in Autumn 2020.	
5.3	Jersey and Isle of Man – Jersey's go live date was 1 July 2019. It is likely that The Isle of Man will 'go-live' at the same time as England. While the populations of these areas are small, the first deemed consent has already taken place in Jersey.	
5.4	Guernsey has not yet started their Bill process. Northern Ireland have introduced legislation to mandate promotion of organ donation but has no plans to change the legal basis of consent.	
5.5	It was noted that training and raising awareness with everyone regarding the implications of the new legislation is now imperative and the Chair offered thanks to C Williment and her team for all their hard work.	
6.	**PATHOLOGY**	
	D Manas gave an update on recent issues. Following recent incidents regarding QUOD and PITHIA, meetings have been held to look at what lessons can be learned. There was also an update on the Pathology FTWU. Several options have been put forward, all of which require funding, some more than others. The favoured option requires the PITHIA digital platform to be used and the BMS staff in each PITHIA enrolled lab to be on-board; this is the next phase of the work to be done. Hopefully there will be a business case ready for the SMT by January 2020. The Chair thanked D Manas for moving the process on so quickly.	
7	**UPDATES FROM ADVISORY GROUP CHAIRS**	
	The Chair thanked all the Advisory Group chairs for their continuing hard work. Those present gave a brief summary of headlines from their recent meetings:	
7.1	CTAG Heart and Lungs (J Parameshwar) • A lung summit will take place on 31 October. Overall, lung numbers are up in the first 6 months of this year. • Heart numbers fell last year and there has been a further fall this year. • There has been one 30-day CUSUM trigger following heart transplantation since the last meeting. This is being investigated at present. • NHSE and NHSBT have put together interim funding to support DCD heart transplantation. A bid from all heart transplant centres has been submitted and approved, subject to a few changes. A board to implement the programme is being formed with representation from each centre.	
7.3	Liver (D Thorburn) • The NLOS has now been active for 18 months. The waiting list mortality has fallen slightly with similar post-transplant outcomes for DBD donors compared with the period prior to implementation. Its effectiveness will be measured over a long period with outcomes 5 years from listing. It has been noted that fast track DBDs have increased and work is ongoing to reduce this. Fast track DCD is stable. • It has been established HCC patients do not have competitive transplant benefit scores against patients with chronic liver disease. This will be discussed formally in LAG with a view to an adjustment in the offering scheme. It has also been noted that new additions to the waiting list are receiving transplants quicker than those who were on the list when the scheme was implemented. For DCD patients' outcomes have remained broadly the same as they were prior to the implementation of the scheme. Mark Hudson was thanked for his input as Chair of the monitoring committee who meet and review outcomes data 3 monthly.	
7.4	Pancreas (J Casey / P Johnson) • The revised Pancreas Offering Scheme has now gone live to fit in with the	

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	Kidney Scheme. Lisa Mumford and Claire Counter were thanked for their work putting the two schemes together to go live at the same time. • The pancreas imaging project has now started. • A working group has been set up to look at declines and the reasons for these over the last few years. • Two short term working groups have been set up to look at a) optimising long term outcomes and b) quality of life. It has been agreed that the SIK working group will be implemented.	
7.5	<u>Kidney</u> (C Watson / J Dudley) • The Kidney Offering Scheme has now gone live. Unfortunately, when the KOS went live the Liver scheme stopped for a few days due to IT issues, but this has now resumed working normally. • Declined offers remains a concern. In part it is hoped that the new offering scheme will reduce declines. C Callaghan is also writing to centres to ask for explanations as to why good grafts are declined in order to shed more light on the underlying reasons • In response to reports of bleeding, it was agreed to downsize the Pithia punch biopsy for pathology to 2mm; the QUOD biopsy size has also been reduced. Members at KAG agreed that the transplanting surgeon should close the biopsy site, not the retrieving surgeon. • In paediatrics, a project to align centres' immunosuppression regimens is underway. The effects of the NKOS on offering of kidneys to children will be monitored with interest.	
7.6	<u>MCTAG (P Friend)</u> • The first uterus transplantation will take place next year with a living donor. This is being done through charitable funding rather than through the NHS. • There is some uncertainty regarding the status of abdominal fascia – whether this should be treated as an organ or as a tissue. This has implications with respect to HTA regulations and direct communication with the HTA has been initiated.	
7.7	<u>NODC (D Gardiner / A Vercueil)</u> • An update was circulated prior to the meeting by D Gardiner. NODC is now holding 3 meetings per year (2 x face to face and 1 via Skype) • A Vercueil highlighted that while donor numbers had been down earlier in the year, this figure is now 3 above the YTD target last year. • PDA Version 2 will come out in Spring 2020. • Supporting joint work with ICS/BTS and NHSBT is ongoing on a Perimortem Interventions Professional Statement.	
7.8	<u>RINTAG</u> (G Oniscu) • There was no update at the meeting. Post meeting, G Oniscu reported that the INOAR process is nearing completion. IT processes are now being finalised so we can go live by the end of year.	
7.9	<u>RAG</u> (I Currie) • The inaugural meeting of the Retrieval Advisory Group (formerly National Retrieval Group) was held this week. All NORS leads are now being invited to participate in these meetings, as well as a wide range of personnel involved in the retrieval process. • Issues around movement of organs under a blue light was discussed as there is no current legal dispensation for blue light transport. Urgent transfer of specific organs will require a strong governance structure. Discussions with the Department of Transport are ongoing, with an aim to shape secondary legislation in 12-18 months' time. • The Novel Technologies Implementation Group (NTIG), a subgroup of RAG, has been established and will oversee the rollout of DCD Hearts, NRP and other novel technologies from the research arena to clinical retrieval practice. • Organ Damage Monitoring FTWU (chaired by D Manas) looks at better	

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	classification of retrieval damage to organs. It is planned to use CUSUM techniques to feedback to teams, using organ loss as the significant event. • The Workforce Sustainability Group has been established and is drawing on staff across the UK to share best practice. The three workstreams, Mustering and KPIs, Sustainable Rotas and Recruitment and Retention, are aiming to improve work and work patterns. • Retrieval delays may put super-urgent liver recipients at risk. A project has arisen at RAG to examine such delays. It is planned to develop a 'super-urgent' offering and retrieval pathway to prevent delays when a super-urgent liver recipient is waiting.	
8	**RECIPIENT CO-ORDINATOR REPRESENTATIVE ON THE SOAG**	
	K. Morley stated that the first annual face to face meeting for the Advisory Group representatives took place and this proved very worthwhile. The group would like to meet every 6 months. The role profile has been assessed and a few minor changes made: • It was agreed that questions raised through the Representative should be communicated to the group Chair before the actual meeting and not brought up in AOB. • It was agreed a tenure of 5 years was appropriate and therefore those who have been in post longer should go out to advert. • The group will commence work on trying to establish Recipient Co-ordinator core competences for all organs.	
9.	**KIDNEY DECLINE/UTILISATION**	
	C Callaghan reported on the projects he leads on. Organ imaging pilots for Kidney/Pancreas are active and an audit will be undertaken to see if they are being used as designed. Liver imaging will be introduced in time. It appears that in some cases organs are currently being declined from higher quality donors. Offer Review Schemes for kidneys and pancreases were discussed. This approach will be rolled out to livers, after work with Doug Thorburn and Rhiannon Taylor is completed, and after discussion at LAG. The ORS Oversight Committee for kidney offers was described, including using 'Amber' responses to generate CUSUM curves for centres' utilisation data. The next layer of projects that need support from NHSBT are now being considered. The meeting recognised that C Callaghan is taking on most of the work for this project himself and that it was important to identify where additional admin / clinical support could help. **Action: C Callaghan to report back on any admin / clinical needs he has**	**CC**
10	**ADVISORY GROUP BUDGETS**	
10.1	The Chair raised the issue of the rising cost of meetings. It was noted that membership of groups has been growing in number and meetings held in central London venues are increasing in cost perhaps due to the need to use West End hotels to find larger rooms. A meeting will take place shortly with the third-party supplier NHSBT has to use to find venues to see how we can improve the service they offer. Using venues in other parts of the UK (eg Birmingham and York) were also suggested and it was noted that these are currently used for some meetings. The optimum number of people that ensures a meeting is effective was also discussed. It is proposed that each advisory group is given their budget at the beginning of the financial year for its meetings, working groups and sub groups. Some savings can be made by encouraging members to book travel or accommodation early, using admin support at NHSBT to help with travel arrangements and ensuring membership lists are up-to-date and appropriate. It was also suggested that Chairs pass on information on potential meeting room hire within their own hospital trusts to their advisory group admin support that could prove to be more cost-effective options for consideration than commercial venues,	

		ACTION
	(particularly in Birmingham and London). **Action: CR/JF to circulate further information** **Chairs to pass on information on any accommodation at hospital trusts that can be investigated.**	**CR/JF** **ALL**
10.2	The Terms of Reference for this advisory group meeting were last updated in 2014. Some changes to this, reflecting recent developments were presented at the meeting to bring the information up-to-date and these were approved. These will now be uploaded to the ODT website. **Action: C Robinson to ensure the updates are added to ODT website**	**CR**
11	**NHSBT FUTURE STRATEGY UPDATE**	
	J Richardson gave an update on ongoing work to develop a new Strategy for ODT. Ben Hume is heading up this project and several events are being organised around the UK to identify important themes for the future. The aim is to be innovative as well as realistic. Advisory Group Chairs are asked to participate where this is convenient and anyone who needs further information on forthcoming events, should contact J Richardson for details.	
12	**NHSBT TRANSPLANT PROJECTIONS FOR THE UK**	
	L Mumford presented a paper indicating donor and transplant projections for the UK for the next 5 financial years This has been developed with consideration to historic trends in organ utilisation, initiatives to increase organ utilisation and the expected impact of introducing opt-out legislation. Projections are a likely scenario based on current evidence, but all were asked to bear in mind that reality could prove to be different. The Advisory Chairs were asked to note that the information is presented for this group only and this should not be circulated elsewhere at present.	
13	**CONTACT AND OFFERING WORKSHOP FEEDBACK**	
	J Whitney presented a paper detailing the outcomes of a workshop held in August reviewing the contact between ODT, the Transplant Centres and the organ offering process. The workshop identified 16 themes some of which require an IT change to be incorporated into a longer-term plan. Advisory Group Chairs were asked to ratify the following short-term plans that can be implemented in a 3 months period: • All named patient offers will be made directly via a single phone number as point of contact to reduce the risk of missed messages and delays. Fast track and group offers will continue to be sent via Page One service until an alternative solution is found. It was agreed that a backup number would be needed in the pilot in case of issues such as a recipient co-ordinator being on call. • Pilot the use of transplant centres emailing Hub Operations using a structured form to request more time or to decline an organ. It was agreed that a Microsoft form would be trialled to ensure reasons for decline are given. • Centres in group or fast track offers that have previously declined an organ for all recipients due to donor related reasons will not be included in subsequent offers to avoid multiple disturbances overnight. It was noted that there are issues around DCDs becoming DBDs and/or changes of staffing in transplant centres that need to be considered along with capacity issues. If a decline is for logistical reasons the centre will be included in subsequent offers. • Group and fast track offers should be considered by all centres as a full offer with an accept/decline response given to Hub Operations within 45 minutes of the offer being made to avoid the offer process being extended by an individual centre. It was noted that the 45 minutes start when the	

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	match list goes out. • Advisory Groups are asked to review provisional offering by organ group where there is no added value as this ties up phone lines and causes additional workload for Hub Operations. • Advisory Group Chairs are asked to consider whether, should a NORS retrieval surgeon regard an organ as not transplantable, this should be offered onto all other centres or not. The issues of differing experience (eg junior surgeons) or subjective views were discussed. It was agreed that a photograph would help with decision making. • Advisory Groups Chairs are asked to review the number of organs accepted and transplanted if the organ has been declined for the same donor related reason by 3 or more centres. It was agreed that there was an important safety aspect here and that it was essential that centres had enough information to make an appropriate decision • Transplant co-ordinators have identified that the number of simultaneous offers and frequency of these is an issue. An audit is planned following implementation of other actions and this will be reported back at an Advisory Chairs meeting. • Transplant centres have also reported that key information is not included in fast track offer messages and it is recommended that advisory groups (LAG, PAG, KAG) are asked to review this. **Action: Any transplant centres interested in piloting improving current issues are asked to contact J Whitney**	**ALL / J Whitney**
14	**ODT ORGANOGRAM**	
	An organogram put together by John Stirling of all the current advisory group meetings was circulated prior to the meeting. AG Chairs are asked to look at this and to update C Robinson with any additional sub groups or working groups that are taking place. **Action: All Chairs to inform C Robinson of additional groups that are not currently included in the organogram**	**ALL**
15.	**ANY OTHER BUSINESS**	
15.1	J Asher reported that funding for the Hub will end next year. The medical team and Advisory groups are asked to identify any IT support that they are likely to need, especially those areas where they are anticipating that the Hub can deliver so that he can collate these for development into an IT strategy. **ACTION: All to consider any IT needs and report these to J Asher**	**ALL**
16	**DATE OF NEXT MEETING:**	
	The next date of the Advisory Group Chairs will be in June/July 2020 to tie in with the revised date of the Transplant Policy Review Committee. Further details will be circulated in due course.	

October 2019