

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

**THE TWENTY- SIXTH MEETING OF
THE ADVISORY GROUP CHAIRS COMMITTEE
AT 2:00 PM ON WEDNESDAY 27 FEBRUARY 2019 AT CORAM CAMPUS
41 BRUNSWICK SQUARE, LONDON, WC1N 1AZ**

PRESENT:

Professor John Forsythe (Chair)	Medical Director – ODT, NHSBT
Ms Liz Armstrong	Head of Transplant Development, NHSBT
Ms Lisa Burnapp	Lead Nurse Living Donation, NHSBT
Mr John Casey	Chair, Pancreas Advisory Group
Professor John Dark	NORS Clinical Governance Lead
Dr Jan Dudley	Chair, Kidney Advisory Group (Paediatric Sub Group)
Professor Peter Friend	Chair, Multi-visceral & Composite Tissue Advisory Group
Mr Ben Hume	Assistant Director, Transplantation Support Services, NHSBT
Professor Derek Manas	Deputy Chair, Liver Advisory Group
Ms Lorna Marson	Deputy Chair, Kidney Advisory Group
Dr Gail Mifflin	Medical and Research Director, NHSBT
Dr Reinout Mildner	Chair, Paediatric National Organ Donation Committee
Mr Jeremy Monroe	Non-Executive Director, NHSBT
Ms Lisa Mumford	Head of ODT Studies, NHSBT
Mr Gabi Oniscu	Chair, Research, Innovation & Novel Technologies Advisory Group
Professor Rutger Ploeg	Chair, National Retrieval Group
Dr Douglas Thorburn	Chair, Liver Advisory Group
Mr Rajamiyer Venkateswaran	Deputy Chair, Cardiothoracic Advisory Group - Hearts
Ms Claire Williment	Head of Legislation Implementation - ODT, NHSBT

IN ATTENDANCE:

Ms Caroline Robinson (Minutes)	Clinical and Support Services Manager
Ms Hannah Westoby	PA/Secretary, Clinical and Support Services

		ACTION
1	WELCOME & APOLOGIES	
	Apologies were received from: Ms Joanne Allen, Performance and Business Manager, NHSBT Mr John Asher, Medical Informatics Lead – ODT, NHSBT Titus Augustine, Deputy Chair, Pancreas Advisory Group Mr Marius Berman, Incoming Joint Chair, National Retrieval Group Mr Anthony Clarkson, Director of ODT at NHSBT Mr Chris Callaghan, National Clinical Lead for Organ Utilisation (Abdominal) Mr Ian Currie, Incoming Joint Chair, National Retrieval Group Dr Dale Gardiner, Chair, National Organ Donation Committee Professor Jayan Parameshwar, Chair, Cardiothoracic Advisory Group Ms Karen Quinn, Assistant Director UK Commissioning Mrs Laura Stamp, Lead Nurse – Recipient Co-ordination Professor Chris Watson, Chair, Kidney Advisory Group	
1.1	DECLARATIONS OF INTEREST – AGChC(17)10	
	There were no declarations of interest.	
2	MINUTES OF PREVIOUS MEETING: 11TH APRIL 2017 - AGChC(M)(17)1	

		ACTION
2.1	It was noted that it was some time since this meeting had been held as issues to be raised had been covered in other Advisory Group meetings. The minutes of the previous meeting on 5 th December 2017 were approved	
3	ACTION POINTS & MATTERS ARISING	
3.1	Action points - AGChC(AP)(17)1 AP1 – <u>Preparations for new allocation/offering schemes: Recipient-specific matching criteria and reasons for decline</u> - The offering schemes are becoming more reactive and recipient specific matching criteria are being built in	CLOSED
	AP2: <u>Improving the recording of reasons for organ offer decline</u> - Lack of information previously noted has been tightened up and this is now being fed into the Advisory Group meetings.	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 and L Armstrong presented the key issues in the meeting:	
4.1	<u>Increasing the Number of Organs Available for Research (INOAR)</u> – Operational and IT challenges have resulted in delays and delivery is now expected this summer. There is now project management oversight a couple of days per week, SNODS are being trained and a further progress report will be given later this year.	
4.2	<u>Olfactory Bulb Retrieval</u> – Following 3 initial retrievals at St Georges, RINTAG has approved 3 further retrievals. Action: L Armstrong will draft a letter to NORS leads regarding these 3 further retrievals.	LA
4.3	<u>Uterine Retrieval and Transplantation (deceased donation)</u> – ODT SMT approved a decision for one region to be identified for initial rollout of UTx with roll out thereafter. Dan Harvey and Angie Scales will work with Imperial and Oxford Hospitals to develop the programme.	
4.4	<u>Pithia/QUOD Hx Bx and BAL</u> – This has now gone live. Gavin Pettigrew congratulated for the work of him and his team.	
4.5	<u>Kidney Photographing Project</u> – The go live date is set for March 2019 and SNOD training commenced in January. Photos will be sent to accepting centres with the hope that this will improve utilisation.	
4.6	<u>Digital</u> – To help progress ODT projects, monthly telecons are now taking place with Digital.	
4.7	<u>Secure Area of the ODT Microsite</u> – passwords are being developed for stakeholders and it is hope that this will be a valuable resource for clinicians and a useful contact list.	
4.8	<u>Aide Memoire</u> – This will record the most recent SaBTO recommendations and is now in development.	
4.9	<u>Communicating Risk and Consent in Organ Transplantation</u> – The combined work of BTS, ODT and the Winton Centre over the last 12-18 months will be further discussed at a meeting on 28 February and a paper will go to SMT, ET and the Board in March 2019 to gain support for the project and timely digital resource. Action: L Armstrong to circulate links and slides showing work underway to attendees of this meeting	LA
4.10	<u>London Kidney and Pancreas Transplant Collaborative</u> – following the success of the first collaborative last November in London, it is planned to carry out more regional meetings in a similar way.	

		ACTION
4.11	<u>European Day for Organ Donation and Transplantation (EODD)</u> – The UK will host the 2019 EODD on 12 th October and CD-P-TO on 10 th and 11 th October. A good showing from the British Transplantation community is important and key speakers will be asked to take part. The key themes are Donation after circulatory death, perfusion techniques and increasing donation among hard to reach communities.	
4.12	It was noted that Laura Stamp will commence maternity leave on 1 st April and Katie Morley from Papworth Hospital is now in post to cover this	
5.	UPDATE ON ORGAN DONATION LEGISLATION	
5.1	<p><u>England</u> – The bill has passed its 3rd reading and will now go forward for Royal Assent. If Parliament falls due to Brexit, the bill could still fall as it will require the Queen's signature. Secondary legislation is expected shortly for novel transplantation and a great many responses are needed to this consultation regarding research and rare forms of transplantation particularly.</p> <p>Action: Chairs to add this to the agenda for all advisory groups coming up or inform members directly</p> <p>HTA is revising its codes of practice and meetings are taking place with faith and BAME groups. Phil Walton has been appointed as Implementation Project Lead, Cathy Miller will be Education Lead for SNODS, CLODS and the wider community, Claire Williment will be the Accountable Executive and J Forsythe will be the Responsible Officer. There is no confirmation of any funding yet, but some reassurance has been given that this will not be an issue. Some benefits have been realised already with the faith declaration now active on the ODR, integration planned with the NHS app from April and an overall improved faith engagement and relationship. It was noted that Transplant commissioners need to be aware of increased capacity needed for retrieval teams and better technology. Overall, there is a need to bring all relevant parties together to discuss what is needed.</p>	AG Chairs
5.2	<u>Scotland</u> – A significant vote has approved the report stage of the Bill. Implementation is planned for June/July with the implementation going live in winter 2020.	
5.3	<u>Jersey and Isle of Man</u> – Jersey now has approved legislation. The Isle of Man hopes to approve legislation this coming month with implementation to become live later this year.	
5.4	It was noted that there is still no move towards any change in Northern Ireland, but the Republic of Ireland is now considering new legislation.	
6.	PATHOLOGY	
	Issues around organ quality and unexpected findings in donors (eg lymph glands, pigmented skin) were discussed. It was agreed that communication is now much better, but there are governance issues due to a lack of timely histological investigation. There is a lack of on call pathologists and it was noted that Jo Martin from the Royal College of Pathologists has suggested to identify an on-call rota in one large Trust.	
7	UPDATES FROM ADVISORY GROUP CHAIRS	
7.1 /7.2	<p><u>CTAG Heart and Lungs</u></p> <ul style="list-style-type: none"> Recruitment of the Deputy Lung Chair will take place in March A review of the lung transplantation outcomes has shown there is no change in the waiting list and it is felt this could be due to organ utilisation or donor quality issues Lung and heart transplantation figures are down (8% heart; 17% lung) which is a worrying trend. Now that the scout programme is not to be funded, a meeting will take place in April to discuss issues for retrieval services. It is noted that with the retirement of older surgeons and other surgeons choosing to work abroad or in different areas, there are 	

		ACTION
	<ul style="list-style-type: none"> concerns around recruitment and commitment to transplantation. Issues with TA-NRP are to be reviewed. 	
7.3	<p><u>Liver</u></p> <ul style="list-style-type: none"> The NLOS has now been active for 9 months. Its effectiveness will be measured over a long period with outcomes 5 years from listing. At present this is only for DBDs and no increase in mortality has been noted. Primary offer acceptance is lower than anticipated and there is a high fast track rate with an increase of offers to each centre so the reasons for this are now being assessed. Refinements in CUSUM has led to more triggers likely and helpful reports from centre leads re adverse outcomes. Capacity issues have been raised in one centre. There is no provision for how this will be managed and what happens to patients at this centre. This will be discussed at the next advisory group meeting. 	
7.4	<p><u>Pancreas</u></p> <ul style="list-style-type: none"> Adaptations in the PAOS are being made for highly sensitised patients and those who need both kidneys and pancreas transplants. The aim is to increase pancreas utilisation as it has one of the highest decline rates. A review of organ damage will take place too to see why decline rates are so high. It was noted that declined organs could be used for islets. In the islet sub group KPIs are ongoing to look at islet isolation. 	
7.5	<p><u>Kidney</u></p> <ul style="list-style-type: none"> The Kidney Offering Scheme will go live later this year. L Mumford will present at BTS in March on the scheme C Callaghan will be looking at reasons for kidney declines/utilisation and what a reasonable level of activity should be <p>Action: Agreed that this needs to come from AG Chairs. This will be included on the agenda for the next AG Chairs meeting.</p> <ul style="list-style-type: none"> Gavin Pettigrew was commended for getting the Pithia scheme up and running For Paediatric Kidneys, there are inconsistencies between centres on decline reasons. There will be observation to analyse how national consent forms are used. It is hoped they will become part of the BTS/NHSBT portfolio and any feedback is appreciated. A harmonisation and standardisation project will look at immunosuppression treatment in paediatric kidney transplantation 	CR
7.6	<p><u>MCTAG</u></p> <ul style="list-style-type: none"> Discussion is ongoing regarding intestinal follow up which is not so good at present along with what happens when a paediatric patient becomes an adult. It has been noted that there is a low volume of referrals and inequity of access due to lack of an integrated intestinal programme to feed into transplantation to ensure optimal referral. 	
7.7	<p><u>NODC</u></p> <ul style="list-style-type: none"> Feedback is welcomed for the strategy to assess the process for paediatric NODC. <p>Action: R Mildner will share the press release with BTS</p>	RM
7.8	<p><u>RINTAG</u></p> <ul style="list-style-type: none"> Monitoring is taking place of the offering scheme Decline rates are being audited along with face transplants and DCD Hearts. NRP now has two more centres (making four in total). 	
7.9	<p><u>NRG</u></p> <ul style="list-style-type: none"> NORS standards have been completely revised Perfusion solutions will be available whatever the outcome with Brexit. For capacity, an 8th virtual team will be established made up of part-time 	

		ACTION
	<p>people. There is now a move away from the closest available team to a nominated 1st or 2nd team on call.</p> <ul style="list-style-type: none"> • Reviews of the workforce have been concluded • The proposed scout programme will not take place at present • Work on electronic HTA A & B forms is now completed • Perioperative training is being developed for training and accreditation and a meeting will take place in April to discuss and revise the whole process of accreditation. • At the Masterclass in January the Royal College of Surgeons gave reaccreditation for a further 3 years. 	
8	<p>RECIPIENT CO-ORDINATOR REPRESENTATIVE ON THE SOAG</p> <p>In L Stamp's absence, L Armstrong stated that an event for Recipient Co-ordinators and Lay Members had taken place and they will be encouraged to attend the advisory group meetings.</p> <p>Action: J Forsythe to consider support for a face to face meeting of Recipient Co-ordinators.</p>	JF
9.	<p>DECLINE REASONS</p> <p>Reasons for declines given historically are not good. Choices are being offered in drop down boxes to improve information and it was agreed that further discussion is needed to sub-define categories and that more detail is better than less. Immunological factors also need to be included for consideration. It was noted that drop down boxes do offer more freedom.</p> <p>Action: Decline reasons needs to be high on the agenda for all advisory groups. L Mumford will send out information to all with cc to JF and appeal to respond with any suggested changes</p>	AG Chairs LMu / JF
10.	<p>PLANNED NHSBT AUDITS</p> <p>It was agreed that the planned audits agreed at ODT CARE in February 2019 should be discarded and the following were agreed:</p> <ul style="list-style-type: none"> • Pancreas Utilisation: Reasons for lack of compliance with explanting at organ retrieval • Accreditation: Do we send out certified competent surgeons to retrieve organs in the UK <p>Action: CR to put this on agenda for ODT CARE in April.</p>	CR
11	<p>ANY OTHER BUSINESS</p>	
11.1	<p>JF acknowledged the work of J Dark and R Ploeg over many years as they retire from this group and other NHSBT activities. J Dark has been a source of valuable advice and a wise head to ODT's activities and R Ploeg's work has led to the creation of the Masterclass and advancements in retrieval. Agreed by all the group present</p>	
12	<p>DATE OF NEXT MEETING:</p> <p>The next date of the Advisory Group Chairs will be in September/October 2019 Further details of venue and confirmation of the date will be circulated in due course.</p>	

February 2019