NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

THE TWENTY-FIRST MEETING OF THE NHSBT CTAG(L) LUNGS ADVISORY GROUP ON WEDNESDAY 15 NOVEMBER 2023 – Via Microsoft Teams
MINUTES

Attendees:

Jasvir Parmar	**CTAG Lungs Chair**, Royal Papworth Hospital
Amit Adlakha	Cons. Intensivist/Lung Transplant Physician, Royal Free Hospital
Zakyeya Atcha	Consultant, Public Health Medicine
Richard Baker	Associate Medical Director - Clinical Governance, OTDT, NHSBT
Adam Barley	Specialist Nurse Service Delivery, North-West
Jim Barnard	Consultant CT Transplant Surgeon, Manchester
Malcolm Brodlie	Respiratory Physician, Newcastle
Robert Burns	Co-Chair, CTAG Patient Group
Heather Chapman	Pharmacist, Royal Papworth Hospital
John Dark	University of Newcastle
Andrew Fisher	Deputy Director BTRU, Freeman Hospital, Newcastle
Diana Garcia Saez	Specialty Doctor Cardiothoracic Surgery and Transplantation, Harefield
Dale Gardiner	Associate Medical Director – Deceased Organ Donation, NHSBT
Shamik Ghosh	CTAG Lay Member Representative
Margaret Harrison	CTAG Lay Member Representative
Rachel Hogg	NHSBT Statistics and Clinical Research
Ian Currie	Associate Medical Director, Retrieval, NHSBT
Rebeka Jenkins	BTRU Clinical Research Fellow
Gareth Jones	Consultant Nephrologist, Royal Free Hospital, London
Delordson Kallon	CTAG BHSI Representative
Jim Lordan	Physician Centre Representative, Freeman Hospital, Newcastle
Haifa Lyster	Pharmacist, Royal Brompton and Harefield Hospital
Debbie Macklam	Head of Service Development, OTDT, NHSBT
Derek Manas	Medical Director – OTDT, NHSBT
Gerard Meachery	Joint Centre Director, Freeman Hospital, Newcastle
Maria Monteagudo-Vela	Consultant CT Surgeon, Royal Brompton and Harefield Hospital
Michelle Murray	CT Transplant, The Mater Hospital, Dublin, Rep of Ireland
Aaron Ranasinghe	Queen Elizabeth Hospital, Birmingham
Ben Rimmer	Faculty of Medical Sciences, Freeman Hospital, Newcastle
Miguel Reyes Roque	Statistics and Clinical Research, NHSBT
Rachel Rowson	Regional Manager, London Organ Donation Team
Stephanie Russell	Specialist Nurse Service Delivery, Royal London Hospital
Karthik Santhanakrishnan	Centre Director, Wythenshawe Hospital
Lewis Simmonds	Statistics and Clinical Research, NHSBT
Helen Spencer	Centre Director, Great Ormond Street Hospital
Ulrich Stock	Consultant surgeon, Royal Brompton and Harefield Hospitals
Louit Thakuria	Consultant in Critical Care, Hammersmith Hospital
Debra Thomas	Physician Centre Representative, Royal Papworth Hospital
Richard Thompson	Physician Centre Representative, QEH, Birmingham
Rajamiyer Venkateswaran	Chair CTAG Hearts; Consultant CT Surgeon, Wythenshawe Hospital
Sarah Watson	NHS England
Daniel White	CTAG Recipient Co-ordinator, Papworth
Julie Whitney	Head of Service Delivery, OTDT Hub, NHSBT

In attendance:

Caroline Robinson	Advisory Group Support, NHSBT (Minutes)

Item	APOLOGIES AND WELCOME	Action
	• J Parmar welcomed everyone to the meeting. • Apologies were received from Waqas Akhtar, Ayesha Ali, Liz Armstrong, Lynne Ayton, Sam Baker, Colin James Begg, Martin Carby, John Dunning, Vicky Gerovasili, Ben Hume, Pradeep Kaul, Stephen Pettit, Tracey Rees, Philip Seeley, Raynie Thomson, Craig Wheelans	

1	**DECLARATIONS OF INTEREST**	
	There were no declarations of interest raised at the meeting. • ***It is the policy of NHSBT to publish all papers on the website unless the papers include patient identifiable information, preliminary or unconfirmed data, confidential and commercial information or will preclude publication in a peer-reviewed professional journal.*** • ***Authors of such papers should indicate whether their paper falls into these categories.***	
2	**MINUTES AND ACTION POINTS OF THE CTAG LUNGS MEETING HELD ON 26 JULY 2023 – CTAGL(M)(22)01 and CTAGL(AP)(22)01**	
2.1	The Minutes of the previous CTAG Lungs meeting held on 26 July 2023 were accepted as a true record.	
2.2	The Action Points from the previous CTAG Lungs meeting on 26 July 2023 were discussed as follows:	
2.2.1	National Proforma	*See Item 10.2*
2.2.2	Workplan/Strategic Aims	*See Item 10.2 and 4.1*
2.2.3	CLU Update – a) Centre reps have been asked to gauge what anaesthetic review patients receive for transplantation and to include clearer information in consent documentation and patient information leaflets – see Item 10.5. b) A full CLU update will be given at the CTAG Lungs Spring meeting 2024.	**a) ONGOING** *b) See Item 10.5*
2.2.4	ISOU - It was noted that if the retrieval time is moved, scouting could help with pulmonary function which deteriorates over time. J Parmar was keen that scouting both physical and virtual be a work stream for the OUG. Although scouting is not a priority in organ utilisation work, it was agreed J Dunning should discuss the pathway work being undertaken by I Currie who will provide an update at the next meeting.	**ONGOING**
2.2.5	Super Urgent Lung Monitoring report - It was agreed that S Rushton would look at longer term survival by urgency group in the next report in Autumn 2023 and into survival from listing.	**COMPLETE** *See Items 8.2 and 9.2*
2.2.6	Lung Summit **-** Recommendation 1 – 'All Cardio Thoracic Transplant Centres (CTTCs) must adopt the principle that no single clinician can decline an organ' – Has been rephrased to include senior co-ordinator alongside clinician.	**COMPLETE**
2.2.7	Lung Summit **-** Recommendation 2 - All CTTCs must explore the possibility of purchasing a the 10-degree fridge – the word 'purchasing' has been replaced with 'using'	**COMPLETE**
2.2.8	Lung Summit **-** Recommendation 15 - Clinicians should be given information about contract funding for the transplant and retrieval services in an open and transparent manner to maximise the use of resources for direct patient care - Centre Directors have discussed this in detail.	**COMPLETE**
2.2.9	CUSUM Change Proposals - It was agreed that *Option E, No Change* to the current CUSUM monitoring process for lung transplantation would be adopted for the present. D Manas / R Baker/J Parmar to work with CT community regarding better messaging around CUSUMs and to re-share the policy.	**COMPLETE**
2.2.10	TransplantPath **-** Each individual who needs to use TransplantPath and who meets the criteria will need to complete the registration form, in full, to ensure a username is issued. The original form has now closed and access should be requested through Microsoft Forms The deadline for account requests is now 24 November. Queries should be addressed to TransplantPathTeam@NHSBT.nhs.uk	**COMPLETE** *See Item 6.1*
2.2.11	Donor lung utilisation – national figures - V Gerovasili will present granularity on the data at the next CTAG Lungs meeting in Spring 2024.	**ONGOING**
2.2.12	Lung Allocation – A spread of priorities has been identified: • For both patients and clinicians, reducing waiting times was the lowest priority. • For those patients surveyed, post-transplant survival is a higher priority. • For clinicians, reducing waiting list deaths was a marginally higher priority. • Overall, priorities for both patients and clinicians were broadly similar. A small working group will look at how a new routine allocation policy can be implemented**.**	**COMPLETE** *See Item 8*
2.2.13	Selection and Allocation policy updates - The age criteria for allocation of accepted lungs of up to 70 years for DBDs and 65 years for DCDs, (extended to 75 for both if donor did not smoke for 10 years or more or was a lifetime non-smoker) were discussed. Following discussion by Centre Directors post-meeting, it is agreed more data on outcomes is needed before changing the criteria. R Hogg to examine the outcomes in older donors.	**ONGOING**
2.2.14	Update on BTRU - R Jenkins, ODT Clinical Research Fellow is invited to this meeting of CTAG Lungs to give a presentation on work for BTRU.	**COMPLETE** *See Item 10.1*

2.2.15	HHV8 – **CTAGL(23)54 -** J Parmar has drafted information to go into the patient information booklet so recipients have appropriate details in advance of transplant. This was circulated to CTAG Lungs members prior to the meeting.	**COMPLETE**
2.2.16	CTPG Psychology & Social Work Update - The disparity of specialist social work support at centres has also been raised. An audit of current provision was undertaken, and results are still outstanding from Birmingham, Harefield, GOSH and Sheffield. J Parmar has raised this issue with Centre Directors.	**COMPLETE**
2.2.17	Anaesthetic reviews with transplant patients – Centres are asked to examine whether their anaesthetic review procedures are adequate or whether a national approach to ensure this is done better is needed. Centres are also asked to consider if this is something that should be included in the listing process prior to addition of a patient to the waiting list and whether this should be included in the forthcoming service specification review. S Watson to look at Peer Review Standards to see if this is included.	**COMPLETE** *See Item 10.5*
2.2.18	Donor age and lung transplantation – Centres need to consider whether DCD offers after age 65 years are considered due to poor utilisation of older donor organs. It is agreed it is Important to know the outcomes of transplantation for those between 65-74 and whether donors are nearer 65 or 74. The transplant co-ordinator's role in this is critical.	**COMPLETE** *See Item 8.4*
3.	**MEDICAL DIRECTOR'S REPORT**	
3.1	Developments in NHSBT – D Manas reported the following: • Finance – remains very tight and has not changed for 3-4 years. The lack of sustainable funding means that applications need to be made for additional money. New means of funding novel technologies which are now standard practice are needed. • DCD Hearts are funded until the end of the financial year after which a new application will be needed. The aim is still to get sustainable funding as numbers will drop by one third if there is no continuation of funding. DCD Heart Allocation and mOrgan subgroups have also been set up. • There is no funding for ANRP, machine perfusion or ARC's. There is now a plan to look at CLOD and Donor Recognition monies to see where savings can be made to fund other projects (eg PACs development). • EVLP – Following an EVLP proposal from Papworth, a meeting has taken place with NHSE on how this can be developed and rolled out nationally. It was noted that other centres need the opportunity to contribute their expertise. • CLU Funding – this is secured until mid-2024. Lead CLUs are funded from NHSBT. • Living Donation for Liver Transplantation – Funding is available to set up a national programme. • Histopathology – money has been secured for this service. • CT Review – Plans are in place for an external review supported by the Department of Health. It is not yet clear how this will take shape. The Terms of Reference and remit still need planning, but it is now considered an urgent matter due to current issues within transplant teams. This will consist of 3 people (Heart, Lung and Chair). • Recommendations from the Lung Summit – Plans on how these can be implemented will be circulated to CTAG Lungs. • RINTAG – is being discontinued in its current form and will be replaced by an R&D Steering Committee to be chaired by Lorna Marson. RINTAG will be an operational and feasibility subgroup of this. • CUSUMs – a recent Lung CUSUM signal at Harefield is currently being reviewed. • At a global summit in Santander the resilience of transplant teams was discussed alongside donation, TA-NRP and how to make projects a reality across the world.	
3.2	ISOU – • 4 meetings of this DH group have been set up to date and subgroups on trust engagement, innovation including ARCs, patient and stakeholder are in progress to put forward recommendations for the future. • Transplant Oversight Group (TOG) – this group involving NHSE and NHSBT has had an initial engagement meeting to look at joint working. This will be a recurring meeting. **ACTION: S Watson to circulate the Terms of Reference.** Overall, more engagement with DH is needed to explore where mandate lies for particular areas.	**S Watson**
3.3	New Appointments – • Anya Adair has taken over as the new Liver Lead CLU from Raj Prasad	

	• Varuna Aluvihare succeeds Doug Thorburn as Liver Advisory Group Chair with Steve Masson as Deputy Chair. • Tracey Rees, Scientific Officer has retired and a new appointment will follow. • Lisa Burnapp will retire and return, working 3 days a week from beginning of April. Support for L Burnapp will also be appointed along with a short-term project manager for OUG to engage with the DH and NHSE. • A Band 7 Transplant Development Support Officer has been appointed. • Workforce – Issues with workforce, especially in CT units and paediatric renal transplantation have been highlighted at ISOU.	
4.	**ISOU and SCORE**	
4.1	Workplan/Strategic Aims – A meeting has been held to discuss how the 18 recommendations from the Lung Summit will be managed. **ACTION: J Parmar to circulate a document to show where responsibilities/workstreams lie**	**J Parmar**
4.2	Activity – **CTAGL(23)55** – this presentation from D Gardiner was circulated but not discussed at the meeting.	
4.3	Sustainability and Certainty in Organ Retrieval (SCORE) overview – D Macklam gave a presentation highlighting the work of SCORE which will look at issues of an ageing workforce, impacts of Brexit and COVID, finite funding, staff sickness and changing, more complex healthcare needs. presentation. SCORE is: • A programme of work to bring improvements to the whole pathway. • It aims to provide certainty and support for sustainability. • A change in culture will be needed to move away from *'as fast as possible'* to *'certainty'* across the pathway. • It aims to identify and deliver improvements over a 10-year period. The 5 key areas identified for initial work are: • To increase certainty of donor potential through better donor screening to reduce non-proceeding donation. • To achieve financial sustainability by re-aligning costs within affordability, and to identify system inefficiencies. • To increase efficiency and achievability of retrieval by defining an optimal retrieval model • To commission a framework for perfusion technology to stabilise and sustain DCD and ANRP service. • To enable the NORS workforce to be sustainable so future recruitment is an attractive prospect. The 7 working groups are set up and running; Donation, NORS Service Model, Support Services and NORS workforce make up the operational groups and Communication and Stakeholder Engagement, Business Care and Commissioning will make up the support and working groups. It is hoped the first stage of approval will be in November before moving onto more detailed design and implementation prior to the deadline of March 2025. Contact SCORE@nhsbt.nhs.uk for more information.	
4.4	SCORE NORS Modelling Workstream – I Currie and S Beale lead this group which numbers 30-40 people (although it is difficult to get CT representation). Key points in the presentation shown are: • Reperfusion of the organ overnight increases mortality. • It is not known why abdominal organs are now being transplanted overnight as this is difficult from the workforce point of view, ITU practice and family decisions have not changed over the 10-year period 2011 to 2021. • The period from family decision to first offer however, has changed with a 6-hours increase in time. This is likely due to greater complexity of donors requiring more information, and more difficulties in getting information. Records are now electronic rather than on paper. • The time of the first offer is now 6 hours later and now takes place after midnight. • In addition, the time from first offer to mobilisation is now 2 hours later. • In 2011, 90% of abdominal cross clamp happened between midnight and midday. In 2021, there are two peaks – one overnight and one longer period during the day. • By 2021 reperfusion is taking place across the 24-hour period rather than at 10, 11 or 12 or mid-afternoon. • In conclusion, a lot of transplantation is taking place across the 24-hour day as opposed to night-time retrieval. Times to avoid/times for transplant –	

	• The data shows that starting a transplant between midnight and 6 am is unpopular. After 6 am, there is more support for starting a transplant. • There is general acceptance for doing retrievals across the 24 hour day (apart from between 4-6 am) • For CLODs, the time that is most acceptable is 6-10 pm • For SNODs, there is acceptance of working across the 24 hour period, but more acceptance during the daytime. • Enabling certainty for families about the proposed timescales is desirable. In summary, the aim would be to do more transplants in the daytime. Modelling shows no major issues for being able to do this and trusts are commissioned to offer a 24 hour service.	
4.5	Service Specification Update – S Watson highlighted that the service specification defines standards trusts need to follow for commissioned services and now needs updating to reflect the modern service. The current specification dates from 2017 for Lungs. While there is some crossover with the external CT review, it is important to progress with this work now. The heart and lung specifications will be done in sequence and NHSE will work with work with each centre to discuss services in virtual meetings. This will be put into the work programme from next April and patients will be involved in this process to complete the draft service specification over 6 months.	
5.	**GOVERNANCE REPORTS**	
5.1	Clinical Governance Report - **CTAGL(23)76** – This report was circulated prior to the meeting. • There are around 60 incidents reported per month (700 per year) • R Baker highlighted INC7728 where pulmonary arteries and veins were cut flush with the lung and there was no left atrial cuff. This precluded the use of arterial PA cannula that usually requires a simple purse-string suture. Following repair and reconstruction, the lungs were suitable for EVLP research study. • Several cases have highlighted the need to share NHSBT Organ Donation Management Team On-Call Contact Details with transplant centres. Any questions or concerns regarding proceeding donors/cases should be directed in the first instance to the Team On call 24hrs a day via a pager 07623512222. The Management Team will liaise with staff directly involved and escalate to NHSBT Directors-on-Call if required.	
5.2	CUSUM Monitoring of 90-day outcomes post lung transplantation – **CTAG(23)56** – There have been no signals in lung CUSUM transplantation reporting over the 6 months since the last CTAG Lungs meeting.	
5.3	Explaining how CUSUMs work – R Hogg gave an overview of CUSUMs and how they work. • CUSUM stands for Cumulative Sum • CUSUMs informs centres how outcomes can change over time. • They facilitate central oversight of Clinical quality • They prompt detection of any increase in mortality to enable remedial action to take place. • There is no risk adjustment as this would affect granularity of the data and could hide bad practice at centres. The baseline is the time used to calculate expected mortality (currently Jan 2015 to 31 Dec 2018). The monitoring period is the time period used to monitor post-transplant survival (currently starting 1 Jan 2018) and this increases monthly. The CUSUM is based on deaths over a 90-day period in the baseline period and there are different rates for adults (9.2%) and paediatrics (10.3%). If there is a trigger: • The Medical Director is informed along with the Chair of the relevant Advisory Group and the Commissioners. • If this appears to be a short run of unrelated failures, no further action is required • If there is cause for concern an external review is initiated • Overall CUSUM is designed to be a learning process for centres and not a punishment. Full details of how CUSUM works is under Policies on the ODT website and is circulated with these Minutes.	
5.4	Group 2 Transplants – There are no Group 2 transplants to report	
6.	**OTDT HUB UPDATE**	
	J Whitney stated that working groups have been set up with representation from CTAG Lungs to look at how changes to offering and acceptance may be affected by night-time	

	retrieval, day-time offering. Further information and potential models will be presented at the next CTAG Lungs meeting in the Spring.	
6.1	Transplant Path **–** R Thomson was unable to attend the meeting. TransplantPath is now scheduled to go live in Feb/March 2024. All those who need access should now have passwords but if there are any outstanding account requests, the deadline is **24th November.** Please use the link Microsoft Forms to request access as the original form has now closed. the software aims to be intuitive and enables inclusion of up to 5 images and 15 seconds of video. Any queries should be directed to the email TransplantPathTeam@NHSBT.nhs.uk or raynie.thomson@nhsbt.nhs.uk	
6.2	NHSBT PACS Proposal – **CTAGL(23)57** – In W Akhtar's absence, R Rowson gave an update on this proposal to create a transplant repository of information that can be viewed for a set period of time (to be decided). Donor recognition funds are being used to fund the trial in London and SE which to go live on 1 December, and this will sit with the CT group initially. This web-based PACs system will operate in a similar way to the Stroke service with two individuals identified to access images at the point of offer. The overall aim is to improve organ utilisation. Images will be shared for 1 month after which they may be accessible via individual trusts. Any imaging remains the property of the trust. Operationally, user guides will be available. Any queries about the proposal going forward should contact w.akhtar@rbht.nhs.uk	
7.	**LUNG UTILISATION**	
7.1	CLU Update – Due to V Gerovasili's absence, an update will follow at the CTAG Lungs Spring meeting.	
8.	**LUNG ALLOCATION**	
8.1.1	Lung Allocation Working Group (11.05.23) - **CTAGL(23)58** –J Parmar stated this group was set up to see how lungs are currently allocated and processed and how this can be improved. The group has met 4 times to discuss detailed work by A Fisher and S Kennedy at Newcastle who has been working on a simulation engine to test ways of managing lung allocation. There has been excellent support also from the patient group on a survey indicating what they think are priorities. Following discussions with L Mumford it is agreed that it would be useful for the Lung Allocation group to meet again early in the New Year to discuss the next steps. **ACTION: a) C Robinson to circulate invitation in January for the meeting b) Centres to identify 2 x lung patients (waiting list and post-transplant) to join the Lung Allocation Working Group**	**a) C Robinson** **b) R Burns**
8.1.2	Lung Allocation Research Executive Summary – **CTAGL(23)59** – This executive summary has been produced and was circulated prior to a meeting with the NHSBT Stats team and outlines the findings of the simulation engine work suggesting a pathway towards implementation.	
8.2	Review of lung allocation data – **CTAGL(23)60** – This report was circulated prior to the meeting and looks at data up to the end of July 2023. • There were 1289 non-urgent registrations in the period. • There were 242 urgent registrations and 39 super-urgent registrations representing 2% of all registrations. • There was a lower proportion of non-urgent registrations which ended in transplant compared to urgent and super-urgent. • There was a significant difference for survival from listing between the urgency categories. Those listed on the urgent list have a significantly worse outcome for two years survival from listing; 55% in the urgent category had a two year survival compared with 69% for non-urgent patients. It is noted that patients with pulmonary fibrosis experience worse outcomes for removal from the waiting list and subsequent mortality. A query was raised about whether median waiting times by disease could be included in the annual report. This is not done currently in order to be consistent across all organ reporting. Full details are shown in the report circulated.	
8.3	Potential for 14-day removal review – this was not discussed at the meeting.	
8.4	Adjustment of Donor Age – **CTAGL(23)73** – The paper was circulated prior to the meeting. • In January 2018, the lung donor offering criteria was extended up to 74 years and 364 days for DBD and DCD donors where the donor was a lifetime non-smoker or had not smoked for 10 years. • Prior to this the upper age limit was 64 for DCD donors and 69 for DBD donors • Since the age criteria was extended there have been 416 donors offered for lung donation (7 per month) • Only 13 (3%) were utilised in the 5-year period considered.	

	• For donors aged >65 most were declined without NORS attendance. • When NORS attended, 51% of DBDs and 33% of DCDs proceeded to donation. 90% of recipients of lungs from donors aged >65 were alive at 30 days. It has been agreed that the upper age limit will now be removed, and the previous age limits reinstated. This change will be implemented in the coming months.	
9.	**STATISTICS AND CLINICAL RESEARCH REPORTS**	
9.1	Summary from Statistics and Clinical Research – **CTAGL(23)61** – this paper was circulated for information.	
9.2	Long term conditional survival – **CTAGL(23)62** – This paper reporting on long-term survival post-lung transplant nationally and on centre specific basis was circulated prior to the meeting. Transplants between April 1996 and March 2016 were included in the analysis. Full details are given in the report. This is the first time this data on long term survival has been shown and the Patient Group are grateful to see long-term outcomes. • The median survival time following adult lung transplantation is 6.2 years. • Excluding those who died within the first-year post-transplant, the median rises to 8.4 years. In the most recent transplant era (ie, 2011/12-2015/16) the median rises to 6.5 years and 8.4 years conditional on surviving the first year. • The International Society for Heart and Lung Transplantation reported a median of 6.5 years for transplants between 2002-09. The UK estimates are 6.2 years. It was noted at the meeting that comparisons with other countries are difficult as patients in the UK tend to be older and there is ongoing instability in the surgical workforce. Very often patients are sicker with more co-morbidities making transplant a more complex undertaking. The most comparable countries are probably the Netherlands and France who have similar donation/recipient mixes, and this could be something to incorporate in reports in future. • 3 patients nationally have survived for >25 years following lung transplantation. It was agreed it would be useful to include this information in the annual report.	
9.3	NHSBT Annual Report – this is available on the ODT website.	
10.	**STRATEGIC DEVELOPMENTS FROM THE CHAIR**	
10.1	Update on BTRU – **CTAGL(23)63** – R Jenkins, Clinical Fellow at NHSBT gave a presentation on the work she has been doing on Patient Reported Measures in Solid Organ Transplantation. The process measures looked at patients' reported experiences on healthcare delivery: • There have been some reflections that generic PROMS were being used across the board. Whether these are appropriate or whether specific ones should be used will be a focus of future work. • Broad PREMS are for larger patient groups with robustly developed measures, Coordination of a transplant specific, but nationalised collection using robustly developed measures is proposed. Not all measures are created equally, and a lot of work goes into making sure they are robustly developed and tested. The work includes: • A systematic review of quality-of-life measures for solid organ transplant recipients using internationally agreed standards and criteria. More input is needed from patients and multidisciplinary professional groups in the development and validation of the work learning from in depth interviews with solid organ transplant recipients and looking at the lived experience. • For PREMS a co-ordinated national approach is needed so a scoping review is being undertaken to see what measures already exist. To date it appears there aren't many in existence, so an in-depth qualitative phase is planned leading to a pilot across the country. • The aim is to integrate this alongside the outcome measures and existing data sets from the UK Transplant Registry. There is now increased capacity within BTRU to make sure CT is going to be run in parallel with the developments in kidney rather than sequentially which is what was initially planned.	
10.2	National Proforma update – L Thakuria gave a demonstration of how this form on 'Refer a Patient' will work. Following consultation around the UK, this proposal was taken to ALTP to get feedback and suggestions from colleagues on its development. • The form is a faithful representation of the paper form used previously and helps referring centres to manage referrals as real-time messaging between centres is possible. • An NHS email is needed to submit any information through the portal.	

	• Earlier drafts had mandatory fields, but after discussion with colleagues it was felt that forcing completion of these fields was too onerous. If there is a gap in any information, centres are advised to request further details via the real-time messaging function. • The proforma has been purchased at Harefield who also put money into the development cost. • Centres can use for a year and then there is an annual subscription cost. A bulk discount is available for multiple centres. There are some minor amendments to make, but hopefully the form will be live to use in the next few weeks. S Watson confirmed that she will put in a business case for this at NHSE and will discuss this further with centres.	
10.3	London Collaborative Buddying up – G Jones, renal physician and the lead of the pan London Collaborative attended to talk about the benefits of working collaboratively. • Collaboratives are a regional collective of healthcare professionals engaged in quality improvement. • The aim is build resilience and improve the patient journey. The pan London Kidney Collaborative started in 2019 and was initially an organ sharing scheme to provide mutual aid across centres. When the pandemic started and London kidney units closed, the collaboratives provided an opportunity to discuss protocols and how to move the transplant programme to the independent sector to keep transplantation going. After the pandemic, the idea of collaboratives was discussed for other parts of the UK and these are now also in the Northern region and Coventry/Oxford. Work is ongoing to develop this process within Liver transplantation. For CT, it was agreed that there is potential to develop this idea for protocol development, pathways and unified care. For lung transplantation, which potentially has more complex patients needing end to end care and long term follow up were suggested rather than just the transplant episode. If there are questions on the collaborative process, please contact gareth.jones14@nhs.net	
10.4	10-degree fridge data – **CTAGL(23)64** – The paper circulated details proposed fields to be added to the HTA-B form to record use of the 10 degree fridge across centres. This has not previously been collected. The fields proposed are: • 10 degree device preservation used – yes / no *If yes, below questions are required:* • Type of preservation – MOReS / Fridge / Other • If other please specify (free-text box) • Lungs in device – left only / right only / pair • Time placed in device – date/time field • Time left lung removed – date/time field • First lung side – left / right • Time second lung removed – date/time field • Second lung side – left / right Changes will be made to the form to incorporate these.	
10.5	Anaesthesia assessment – An anaesthetic assessment for patients going onto the list and the anaesthetist's attendance at MDT meetings was discussed at the last meeting. In an update, centres reported as follows: • Papworth – an anaesthetist is now joining Friday morning clinics and will be assessing waiting list patients. It is hoped they will join MDT in future. • Manchester reported that the anaesthetic assessment is a dynamic process and a patient's condition may change between going on the waiting list and going forward for transplant and are discussed at MDT. • GOSH – has been doing an anaesthetic assessment for the last 4-5 years and this has been incorporated into listings meetings and is appreciated by patients and their families. • Newcastle has a rotational anaesthetist who joins the MDT. If the patient is to be listed, an in-person physical assessment prior to consent will be completed where any anaesthetic requirements will be noted. It was reiterated that patients believe an anaesthetic assessment is a core standard and part of the service specification and that the anaesthetist should be represented at MDT meetings.	
10.6	Update from pharmacists and co-ordinator group re-routine bloods – **CTAGL(23)78** - D White gave an update on the work he has been doing with H Lyster, H Chapman and one of the Senior sisters at Newcastle which is based on the recommendations from the Patient Support group. The focus is on shared management guidelines rather than shared	

	care guidelines. It was noted some centres have not repatriated their prescribing back to the transplant centre as GPs were prescribing transplant specific prescriptions. • The focus of the work was the responsibilities of each party for the monitoring of immunosuppression levels and other biochemical and haematological markers. • Included in the appendices are some draft letters that centres can format to their own trust standards to send out to GP practices. All centres are invited to view the document circulated with these Minutes and to feedback to D White with any comments.	
11.	**REPORTS FROM RELATED GROUPS**	
11.1	Retrieval Advisory Group (08/06/23) – **CTAGL(23)65** – • Plans are ongoing to change current practice so lungs can be transported in perfadex rather than saline. • The next RAG meeting will be on Thursday 30 November at the Royal National Hotel in London.	
11.2a	CTAG Patient Group report - **CTAGL(23)66** – This report was circulated prior to the meeting. A feedback exercise was repeated recently and issues remain similar to previously. There is an increase in concern re access to clinical teams for advice (organ and centre specific).	
11.2b	CTAG Patient Feedback Report - **CTAGL(23)67 –** this paper was circulated prior to the meeting	
11.2c	CT Patient Group Minutes (25/10/23) – **CTAGL(23)68** – these are circulated for information.	
11.2.1	Osteoporosis in the Cardiothoracic Transplant population (with a focus on lungs – **CTAGL(23)69** – This report circulated prior to the meeting, arose following concerns raised by a patient regarding late diagnosis of osteoporosis and fragility fractures for transplant patients. The Patient Group undertook a survey to look at this issue. • 207 surveys were completed, (203 adult, 4 paediatric). • The overall adult sample size was 4.61% with returns from every centre included. The number of paediatric returns too low to make a meaningful analysis. • 42% (39% heart, 48% lung) of transplant recipients and 45% of pre transplant patients reported that they had a diagnosis of osteopenia or osteoporosis. • 28% (23% heart, 38% lung) of transplant recipients and 25% of pre transplant patients reported that they had suffered a low impact (fragility) fracture. • 24.6% (50) of the post-transplant patients reported taking osteoporosis treatments, these were bisphosphonates (44) or the monoclonal antibody Denosumab (6). • Post-transplant, 34% (62) patients were not taking Vitamin D. Of these, 89% (55) patients reported they had never had, or were not aware of, a prior Vitamin D blood level check. • Post-transplant patients were also asked when they last had a DEXA scan to assess their bone mineral density. • The patient survey further assessed if post-transplant patients without a prior DEXA scan had knowledge of a FRAX or Q fracture assessment. Of this group of 40 post-transplant patients only one had knowledge of an individual fracture risk assessment, which they stated had been undertaken by their GP. In response to the above and centre specific data included in the paper, all centres present at the meeting confirmed that they are aware of the risks and patient information leaflets have information on osteoporosis. DEXA scans did not happen during the pandemic and in some centres, the service has not yet been re-established. However, all patients are given appropriate medication at the time of transplant and post-transplant as well as calcium and Vitamin D supplements. It was suggested that the sample size is perhaps too small and a survey with a larger response may provide more comprehensive information to identify potential serious issues.	
11.2.2	Social Work Audit Results – **CTAGL(23)70** – • R Burns stated that concerns regarding provision and variability of specialist social work support for patients was raised at CTPG in December 2022. • The 9 centres providing CT care for transplant patients were asked to complete an audit proforma regarding social work provision within their service. The results of this are in the paper circulated prior to the meeting. The Patient Group makes the following recommendations: • Commissioners and providers take action to ensure services meet current service standards and specifications. This will require some services investing in social work provision.	

	• In the upcoming service standard revision, social work provision is a core profession required within the MDT team at 1WTE per 400 patients. (For CF this is 1 WTE per 125 patients) • It is not considered appropriate for other professionals to cover social work as they do not have the necessary skills and contacts. • The CTPG Co-Chair has formally written to commissioners outlining concerns about the lack and variability of specialist Social Work provision and the negative impact this has on patients.	
11.2.3	COVID 19 and Shingles vaccine - **CTAGL(23)71** – This update on COVID 19 treatments and access to the shingles vaccination was circulated prior to the meeting. From 1 September, those immunosuppressed patients aged >50 became eligible for a shingles vaccination and these are available via primary care and pharmacists.	
11.3	CT Centre Directors' meetings (last one 20/10/23) – **CTAGL(23)72** – J Parmar stated that there are workforce issues in two centres particularly, with the Centre Directors leaving the NHS. It is therefore important to work collaboratively to support each other in these difficult times.	
11.4	Report from Recipient Co-ordinators – there was no update at the meeting.	
12.	**FOR INFORMATION**	
12.1	NHSBT ICT Update for Advisory Groups – there was no report at this meeting.	
12.2	QUOD Update – **CTAGL(23)74** – The latest report for October 2023 was circulated prior to the meeting	
13	**ANY OTHER BUSINESS**	
13.1	Key points from today's meeting for cascade to centres – The following headlines are to be cascaded to teams: • ISOU **(**Implementation Steering (Group) for Organ Utilisation) has been established with a number of subgroups under the aegis of the Department of Health. • Transplant Oversight Group (TOG) has been established involving NHSE and NHSBT and has had an initial engagement meeting to look at joint commission. • Sustainability and Certainty in Organ Retrieval (SCORE) aims to change the philosophy from as *fast as possible* to *certainty.* o To increase certainty of donor potential through better donor screening to reduce non-proceeding donation. o To achieve financial sustainability by re-aligning costs within affordability, and to identify system inefficiencies. o To increase efficiency and achievability of retrieval by defining an optimal retrieval model o To commission a framework for perfusion technology to stabilise and sustain DCD and ANRP service. o To enable the NORS workforce to be sustainable so future recruitment is an attractive prospect. o Shift from night-time implants- working groups to examine impact and feasibility. • Refreshing the lung transplant service specification • No CUSUM triggers in current time period. • TransplantPath - request for registrations by the 24th November(further information from TransplantPathTeam@NHSBT.nhs.uk or raynie.thomson@nhsbt.nhs.uk) • PACS study for review of images for C/T donor going live in December for further information contact w.akhtar@rbht.nhs.uk • Lung allocation group to convene in January for further discussion. • Decrease in donor age DBD to 70, DCD to 65 • PROMS and PREMS developed as part of BRTU. • National Proforma, using refer a patient platform- requires small amendments, NHSE happy to consider a business case. • 10 Degree fridge data to be collected via HTA B form. • Anaesthesia assessment centres are encouraged to ensure that these are offered to all patients. • Harefield and Birmingham are forming a collaborative, Newcastle/Manchester and RPH are joining together. • Conditional survival now to become part of the regular report.	

	• Osteoporosis post-transplant centres are encouraged to consider this in all post-transplant patients.	
13.2	SIGNET trial update – **CTAGL(23)75** – J Dark circulated an update on the SIGNET trial prior to the meeting. SIGNET is an NIHR funded prospective randomised study investigating a single dose of simvastatin given to adult brain stem dead donors and is the largest donor intervention study in the world. The trial is making good progress and all centres were thanked for their participation. Donor centres are not blinded, but retrieval teams and recipient teams are. The trial will run for another two years and it is likely that there will be a request for an extension. Centres are asked to contact J Dark john.dark@newcastle.ac.uk if they are doing a randomised study of a service evaluation affecting transplant recipients. **ACTION: J Dark to contact H Giele henk.giele@nds.ox.ac.uk re SENTINEL trial.**	**J Dark**
13.3	Date of next meeting – The next meeting will be held in d further information will follow.	

Date of next meetings
CTAG Hearts – Weds 17 April 2024 – Further information to follow
CTAG Hearts Meeting – Thurs 16 May 2024 – via Microsoft Teams - Further information to follow.