

**NHS BLOOD AND TRANSPLANT  
ORGAN AND TISSUE DONATION AND TRANSPLANTATION  
THE SIXTEENTH MEETING OF THE NHSBT  
CARDIOTHORACIC PATIENT GROUP (CTPG)  
ON WEDNESDAY 7 DECEMBER 2022 FROM 10:30 TO 13:30  
MINUTES**

**PRESENT**

Robert Burns	CTAG Patient Group Co-Chair
Andrea Barrett	Patient Representative (Zoom Hearts)
Hugh Brazier	Cardiomyopathy UK, DCM Patient Freeman Hosp, LVAD
Trevor Collins	Heart Transplant Recipient, Royal Papworth Hospital
Rebecca Curtis	Statistics and Clinical Research, NHSBT
Ellie Davies	Cystic Fibrosis Trust
Catherine Exley	Dean of Population Health Sciences Institute, Newcastle
Andrew Fisher	NIHR BTRU Rep, Deputy Director, Freeman Hospital, Newcastle
Steve Griffith	Birmingham VAD Patient / British Society for Heart Failure Rep
Joanna Heath	Children's Heart Foundation
Helen Hoskin	Sheffield Teaching Hospitals NHS Foundation Trust
Jessica Jones	CT Patient Representative / Organ Utilisation Programme, NHSBT
Emma Johnson	Parent of Heart Transplant Recipient and Organ Ambassador, NHSBT
Ellie Johnson	Transplant Co-ordinator, Birmingham
Beverley Jones	Manchester ROA NHS Hospitals Foundation Trust
Stephen J Kee	Freeman Heart and Lung Transplant Association
Peter Knox	Harefield Transplant Club
Rachel Leonard	Recipient Co-ordinator, Royal Brompton and Harefield Hospital
Jan Lockett	Heart and Lung Transplant Patients, Birmingham
Alan Lees (AL)	Patient Representative, Harefield Transplant Club, Harefield Hospital
Zoey Malpus	Psychologist, PACT
Derek Manas	Medical Director, OTDT, NHSBT
Amanda Norris-Woods	Harefield Transplant Club
Kirsty McGovern	Golden Jubilee Hospital, Glasgow
Nkechi Onwuka	Statistics and Clinical Research, NHSBT
Jas Parmar (JP)	Chair CTAG Lungs, NHSBT (Royal Papworth)
Janka Penther (JPe)	Harefield Transplant Club
Sian Russell	Population Health Sciences Institute, Newcastle University
Lucy Ryan (LRy)	Heart Transplant Patient / Heart Transplant Families UK
Linda Sharp	Professor of Cancer Epidemiology, Newcastle
Lewis Simmonds	Statistics and Clinical Research, NHSBT
Adrian Sims (AS)	Heart and Lung Patient (awaiting transplant)
Laura Stamp	Lead CT Recipient Transplant Co-ordinator, NHSBT
Michael Thomson (MT)	Patient Representative, Golden Jubilee National Hospital
Annette Tremlin	Heart Transplant Families UK
Rajamiyer Venkateswaran (RV)	Chair CTAG Hearts, NHSBT (Manchester)
Julie Wilcock	Transplant Coordinator, Harefield
Claire Williment	Accountable Executive – Organ Utilisation Programme; Legislation Implementation, NHSBT
Michelle Woods	General Manager, Somerville Heart Foundation
Rosie Pope	Patient Parent, Harefield

**IN ATTENDANCE**

Cherrelle Francis Smith	Advisory Group Administrator, OTDT, NHSBT
Caroline Robinson	Advisory Group Support Officer, OTDT, NHSBT (Minutes)

1	Welcome and Introductions	ACTION
	<ul style="list-style-type: none"> <li>• R Burns welcomed all to the meeting.</li> <li>• <u>Apologies</u> were received from Liz Armstrong, Lynsey Beswick, Emma Billingham, Andy Bright, Charlotte Carney, Lynda Ellis, Shamik Ghosh,</li> </ul>	

	<p>Kathryn Green, Chris Hannah, Margaret Harrison, Ged Higgins, Fiona Kennedy, Adele Lambert, Linda Nesbitt, Sally Rushton, Tara Smith, Claire Walter</p> <ul style="list-style-type: none"> <li>R Burns paid tribute to Patient Group member, Maggie Gambrell who has died recently. Maggie recently celebrated 20 years since her heart transplant and her 30<sup>th</sup> wedding anniversary and was also Games Lead at Papworth for nearly a decade. Commiserations are offered to her family from all in CTAG and the Patient Group with thanks for her work promoting organ donation and transplantation.</li> </ul>	
<b>2.</b>	<b>Declarations of Interest - CTPG(20)08</b>	
	<ul style="list-style-type: none"> <li>Declarations of Interest in Relation to the Agenda were circulated.</li> <li>T Collins stated that as a heart transplant patient at Papworth, he is on a steering committee for the NHSBT NIHR Signet secondary trial which offers donors either a statin or placebo prior to donation of the organ to measure viability, longevity and overall outcomes. <i>See also Item 11</i></li> <li>The Agenda and Minutes from this meeting will be posted on <a href="http://www.odt.nhs.uk">www.odt.nhs.uk</a>. Copies of papers for the meeting are available on request from <a href="mailto:advisorygroupsupport@nhsbt.nhs.uk">advisorygroupsupport@nhsbt.nhs.uk</a>.</li> </ul>	
<b>3.</b>	<b>Minutes and Action Points from Previous Meetings</b>	
3.1	<p><u>Minutes of previous Patient Group meeting Accuracy and Action Points - CTPG(22)20</u></p> <p>The Minutes of the previous Patient Group meeting on 22 June 2022 were circulated and accepted as a true record. Action Points from the last meeting were noted as follows:</p> <ul style="list-style-type: none"> <li>AP1 – <u>Item 3.3 - Sherpapak</u> – At the last meeting R Venkateswaran, Chair of CTAG Hearts, agreed to discuss ice box commissioning with E Billingham at NHSBT. Sherpapak is an alternative to an ordinary ice box for organ transportation, maintaining a constant temperature throughout transit. Some transplant centres believe use of Sherpapak would improve cold ischaemia times, but others would like to see more confirmation of the benefits. Although a trial has not taken place, Sherpapak is now used widely in the USA where it has been shown to reduce hospital and ICU stays. A paper has now been published showing reduction of PGD requiring ECMO and work is ongoing regarding potential funding of this in the UK. It was noted that it would be helpful if NICE could assess this.</li> <li>AP2 – <u>Item 6.2 – Routine Blood monitoring</u> – <i>See Item 10</i></li> <li>AP3 – <u>Item 7.1 – Outcome Data</u> - S Rushton agreed to look at longer survival rate periods and this is shown in the paper circulated for today's item on Activity and Outcome Data – <i>See Item 7.1</i></li> <li>AP4 – <u>Item 9.4 – Psychology Support for Patients</u> – <i>See Item 9</i></li> </ul>	
<b>4.</b>	<b>NHSBT – Medical Director's Report and NHSBT Updates</b>	
4.1	<p>D Manas gave the following update:</p> <ul style="list-style-type: none"> <li><u>Funding</u> - Unlike other areas of the NHS, OTDT's funding at NHSBT comes from a grant in kind from the Department of Health. There has been flat funding for the last 3 years which is challenging, particularly given the rise in inflation.</li> <li><u>DCD Hearts</u> – the underspend is being used to fund this programme for 2022-23 but there is no long-term funding beyond this yet. Cardiothoracic Centre Directors have written to the Department of Health to emphasise how important DCD Hearts along with NRP are for increasing heart transplantation numbers.</li> <li><u>Lung Summit</u> – Lung transplantation is a particular concern currently so a summit will be held on 22 February 2023 to look at ways to improve numbers of transplants, workforce issues and commissioning of the service – <i>See Item 4.2</i></li> <li><u>Organ Utilisation</u> – Work is ongoing to improve the culture within units to utilise more organs. The individual Clinical leads for Utilisation (CLUs) have</li> </ul>	

	<p>made a difference and utilisation rates have improved but there is no funding in place for their work to continue currently. Consent rates have gone down mainly due to opt out, well-publicised problems within the NHS and donor families becoming fatigued by the donation process so it is a priority for NHSBT to improve these areas where possible. A review of organ retrieval will take place, particularly workforce issues and the retrieval service will be changing from the New Year onwards to prioritise all retrieval taking place at night. <i>See Item 4.4</i></p> <ul style="list-style-type: none"> <li>• <u>Research streams</u> – An update on NIHR BRTU will be given later in the meeting – <i>See Item 10</i>. D-CERT (electronic transfer of donor characterisation) is now complete. Other projects include Xenotransplantation collaborative working with NHS England and developing an early recovery after surgery programme.</li> <li>• <u>Lay members</u> – NHSBT is fortunate to have a group of very experienced skilled lay members who sit on the advisory groups for solid organs, and they are now meeting more regularly and being used more in some of the working and subgroups as well as other projects taking place.</li> </ul>	
4.2	<p><u>Minutes of CTAG Lungs Meeting – 28 September 2022 – (CTAGL(M)(22)02) – CTPG(22)21</u></p> <ul style="list-style-type: none"> <li>• The Minutes were circulated prior to the meeting.</li> <li>• J Parmar reported that the main topic was the current crisis in lung transplantation. Transplant numbers have dropped significantly compared with pre-pandemic years. Prior to the pandemic, a lung summit was held to recognise issues affecting transplantation. These were made worse by COVID and include workforce resource, retrieval issues, ICU and post-transplant care. It is also likely that heart transplantation is prioritised by teams over lungs. A new Lung Summit will be held on 22 February focussing on better utilisation of organs and engagement with retrieval and surgeons and ways to replenish the numbers of implanting surgeons (to include training and curriculum changes) and the use of novel technologies such as the 10-degree fridge which prolongs the potential viability of organs.</li> </ul>	
4.3	<p><u>Minutes of CTAG Hearts Meeting – 9 November 2022 – CTAGH(M)(22)02 – CTPG(22)37</u></p> <ul style="list-style-type: none"> <li>• The Minutes from the CTAG Hearts meeting are circulated with these Minutes.</li> <li>• <u>DCD Hearts</u> - R Venkateswaran reported that DCD Hearts funding is secure until the next financial year and there is good support from all UK devolved nations in continuing this work. A supporting letter from all cardiothoracic centres has also been sent.</li> <li>• <u>Heart Allocation</u> - Changing the heart allocation policy to ensure that those patients who need transplantation most has been explored in a subgroup. Data shows that almost 82% of all registrations on the Urgent Heart Allocation Scheme need continuous inotrope treatment. These patients have been divided into 3 categories in any future heart allocation scheme. The aim is to have a national waiting time, although ischaemic times matter in making any change.</li> <li>• <u>Adjudication for early re-transplant</u> - The policy is not clear currently regarding when adjudication is needed for early re-transplantation. Currently, patients that have had a previous transplant may not be registered on the urgent or super-urgent list until 3 months have elapsed. It was agreed that as numbers of those needing re-transplantation are small it is appropriate that these patients should go through adjudication for transparency, information sharing and education and would therefore be subject to CUSUM.</li> <li>• <u>Risk adjusted survival</u> – It was noted that the 6 CT centres in the UK are not making the same decisions about donor risk and recipient risk and there are differences between risk adjusted and unadjusted outcomes from several centres. The model presented at CTAG Hearts which was included in the annual report, is an improvement on what was available previously from both</li> </ul>	

	a statistical and clinical perspective and there will be another review in 5 years' time. Further information is available on the ODT website.	
4.4	<p><u>Update from Organ Utilisation Group – CTPG(22)22 –</u></p> <ul style="list-style-type: none"> <li>• C Williment reported that the remit of this group was to deliver improvements in numbers of organs utilised and transplanted for children and adults in England. The group looked at workforce issues, investment and infrastructure as well as innovation. As there are no transplant centres in Wales or N Ireland, all the devolved nations sat on the group. Once the report is approved by the new minister Neil O'Brien, it will be published, and the group disbanded. Honouring the gift of donors is very important so involvement with trust boards to embed innovation and to place the UK as a world leader in donation and transplantation has been important.</li> <li>• While donor numbers have increased and the transplant list has gone down over recent years, there are now indications that the waiting list is going up again. The group looked at the whole care pathway including inequities of access, ethnicity, geographical issues, theatre access, team availability and resource.</li> <li>• On-line workshops, surveys, patient specific surveys, patient focus groups and the lack of psychological support, effects on families, contraception and family planning all formed part of the group's work. As well as positive comments about the care they received, patients who had successful transplantations and felt well, often experienced personal problems and issues with their families. All those who took part are thanked.</li> <li>• The published report will have 6 chapters, each with a series of recommendations. It is hoped to set up an oversight group within the Department of Health that will include, NHSBT, NHS England, other UK commissioners and the British Transplantation Society (BTS) and as well as the Royal Colleges to take actions and to empower the patient voice.</li> </ul> <p>D Manas emphasised that the new strategy is to put patients at the heart of what NHSBT does. While NHSBT does not commission transplantation, it does have a role in governance and outcome and the work of the OUG highlights the role that Trust Boards need to take to meet KPIs to monitor these issues.</p>	
<b>5.</b>	<b>Patient Chair Update</b>	
5.1	<u>Patient Chair Report - CTPG(22)23</u> - A report from R Burns was circulated prior to the meeting.	
5.2	<p><u>Feedback Report – CTPG(22)24</u> - Eight patient support groups which are a mixture of national, local patient, charity and professionally led have reported feedback over the last 6 months. Two items were highlighted at the meeting:</p> <ul style="list-style-type: none"> <li>• <u>COVID</u> is the biggest issue. While most of the country moves to a post-pandemic culture, many patients still feel very vulnerable and are still sheltering. COVID therapies and treatments for these people vary across the UK. There is widespread disappointment about the current decision from NICE not to recommend Evusheld. Sotrovimab has been the first line treatment although this is not being offered universally as the latest circulating variant is highly resistant to it, and it is noted that recent data indicates that having 4 vaccines reduces risk of death or hospital admission from Covid.. <i>See Item 7.1</i></li> </ul> <p><b>ACTION: R Burns and A Barrett to contact NHS England's COVID delivery team to feedback patient challenges with accessing Covid therapies in a timely manner.</b></p> <ul style="list-style-type: none"> <li>• <u>Access to primary care</u> – patients find it difficult to make appointments with GPs, including for blood tests needed for their secondary care monitoring. There are also communication issues with difficulties ensuring blood test results completed in primary care are communicated to transplant centres. <i>See Item 10</i></li> </ul> <p>All the issues in the report will be communicated to the two CTAG meetings every 6 months.</p>	<b>R Burns A Barrett</b>

5.3	<p><u>Sentinel Skin Flap Project – CTPG(22)25</u> – This study is being rolled out for lung transplant patients. Information on the study was circulated and anyone interested in participation can let R Burns know.</p>	
6.	<p><b>ODT Patient Information Website</b></p>	
	<p>J Parmar gave an overview of the ‘<i>Information for Patients</i>’ part of the ODT website <a href="https://www.odt.nhs.uk/information-for-patients/">https://www.odt.nhs.uk/information-for-patients/</a> On this page visitors will find the ‘<i>Visit the Organ Transplantation website</i>’ <a href="https://www.nhsbt.nhs.uk/organ-transplantation/">https://www.nhsbt.nhs.uk/organ-transplantation/</a></p> <p>On this page there is specific information and videos for each organ and patient support group. L Stamp stated that contact details for the transplant teams are to be added. All Patient Group members are encouraged to use this tool and to feedback their experiences and any ideas for future development of this part of the website.</p>	
7.	<p><b>Activity and Outcome Data</b></p>	
7.1	<p><u>Long-Term Survival Post-Transplant - CTPG(22)26</u> - N Onwuka showed 2 slides indicating long term survival post heart transplant which were circulated prior to the meeting:</p> <ul style="list-style-type: none"> <li>• The first graph showed all long-term survival in the period 1 April 1995 to 31 March 2015. This indicates median survival of 12.9 years.</li> <li>• The second graph shows median survival following 1 year’s post-transplant in the same period which indicates median survival of 15.9 years.</li> <li>• After 25 years there are 78 transplant patients who are still living.</li> <li>• In the future, long term lungs and paediatric survival will also be mapped.</li> </ul> <p><b>ACTION: N Onwuka / S Rushton to produce long term survival charts for Lung and paediatric hearts</b></p>	<p><b>S Rushton / N Onwuka</b></p>
7.2	<p><u>COVID-19 Vaccine Effectiveness Analysis</u> – R Curtis gave a presentation regarding vaccine effectiveness for solid organ transplant recipients which has been put together by her along with Lisa Mumford from the Statistics and Clinical Research team at NHSBT and senior clinicians working in organ transplantation. Limitations included:</p> <ul style="list-style-type: none"> <li>• There is only knowledge regarding reported positive SARS-CoV-2 tests reported</li> <li>• NHSBT does not collect data on hospitalisations so therefore UKHSA helped with this part of the analysis</li> <li>• NHSBT cannot account for person behaviour</li> <li>• Information is based on what is recorded on the UK Transplant Registry</li> <li>• Recipients move through phases at different times</li> <li>• Most recipients were vaccinated during a period of low SARS-CoV-2 circulation</li> </ul> <p>There was a cohort of nearly 43,000 recipients in the study. Issues considered were:</p> <ul style="list-style-type: none"> <li>• <i>Does vaccination reduce incidence of testing positive for SARS-CoV-2?</i> – 2 types of vaccination were considered: the Astra Zeneca vaccine and mRNA vaccines (Pfizer and Moderna) – the study found that vaccination does not reduce incidence of testing positive.</li> <li>• <i>Does vaccination reduce incidence of hospitalisation or death from SARS-CoV-2?</i> – The study found that vaccination was associated with a reduction in risk of hospitalisation for those receiving 3 or more vaccine doses and the greatest protection was 4 doses, specifically mRNA x 4.</li> <li>• <i>Does vaccination reduce risk of death after a positive test for SARS-CoV-2?</i> – the dataset looked at positive only cases from 7 December 2020 to 28<sup>th</sup> April 2022 and death is defined as within 28 days of a positive test. The survival rate here was much higher for those who had received 4 doses, specifically 4 mRNA doses (Pfizer or Moderna).</li> </ul> <p>The slides are not circulated as the information is due to be submitted for publication with a lot more specific data on specific organ types. It was also noted that for those whose antibody protection is low, specialist white blood cells also offer significant protection alongside vaccines. A joint NHSBT/BTS statement can be found at:</p>	



	<a href="https://www.organdonation.nhs.uk/get-involved/news/latest-nhs-advice-on-covid-19-vaccine-for-patients-and-recipients/">https://www.organdonation.nhs.uk/get-involved/news/latest-nhs-advice-on-covid-19-vaccine-for-patients-and-recipients/</a>	
<b>8.</b>	<b>Items Raised by Representatives</b>	
8.1	<p><u>Evusheld as a preventative treatment – CTPG(22)27 –</u>  Emma Johnson (mother of patient, Max Johnson) gave a presentation, circulated prior to this meeting, expressing disappointment at the government's decision not to give Evusheld as an intervention against COVID, particularly for those for whom vaccines do not appear to be working despite many other countries using it, including every other G7 country. There is also concern about a perceived lack of transparency in making this decision as it is unclear what data was considered and who was on the advisory panel. Concern is exacerbated by the lack of availability now of sotrovimab which it is felt is less effective against the Omicron variant. NICE have added CTPG as a formal stakeholder in the consultation for Evusheld (ID6136). CTPG gave delegated authority to R Burns and E Johnson to provide the response on behalf of the group.  <b>ACTION: R Burns and E Johnson to respond to NICE consultation when launched.</b></p>	<b>R Burns / E Johnson</b>
8.2	<p><u>NICE consultation on therapeutics for people with COVID 19 – CTPG(22)28 –</u> The updated proposed response from the CT Patient Group was circulated. The group approved the response which R Burns would upload to NICE today.  <b>ACTION R Burns to upload approved response to NICE</b></p>	<b>R Burns</b>
8.3	<p><u>World Transplant Games 2023 – CTPG(22)29 –</u> L Ryan who received her heart transplant 30 years ago gave an overview of the World Transplant Games which will take place next year in Perth, Australia. The British Transplant event is held annually in different cities around the UK. Anyone who is signed off as medically well enough can compete and the first one since 2019 took place in Leeds this year. Those who do well enough in their events may be considered for the World Games and next year there will be a team of 150 British transplant participants. The aim is to raise the profile of this event and the benefits of life post-transplant, to encourage communication about donation and joining the Organ Donor Register. As the estimated cost per competitor is £4000 there is a lot of sponsorship and fundraising needed.</p>	
<b>9.</b>	<b>Psychology Support for Transplant Patients- CTPG(22)30</b>	
	<p>R Burns reported on the work he has done with the Psychological Association for Cardiothoracic Transplant (PACT). Three themes were identified and presented at the CT Patient Group in June:</p> <ul style="list-style-type: none"> <li>• A national patient survey of psychological care for adult CT transplant and VAD patients</li> <li>• A review against current service standards</li> <li>• A psychology needs analysis</li> </ul> <p>This work demonstrated that there is insufficient psychology provision in CT transplant centres. The results are shown in the paper circulated. Since the meeting, R Burns has continued to lobby the CTAG Chairs, and a formal paper was presented at both Hearts and Lungs meetings. Several local charities have made contact to express their concerns and the issue has been discussed with CT Centre Directors and Commissioners. The issue is complicated by problems with recruitment; Harefield has 2 vacancies but there have been no applicants. This is symptomatic of the overall strain on NHS resources and recruitment problems. It was noted that Manchester has trainee placements, and it is hoped this will help to fill some posts. D Manas commented that while the provision of support is inadequate currently, CT psychological support is better than for other solid organs. While social workers have taken on the role of providing some psychological support, this support has been lost in many centres. It is acknowledged that specialist psychological therapy is what is needed which comes through a different training route.  <b>ACTION – R Burns to work with the CTAG Chairs to audit the current dedicated social work provision across the transplant centres.</b></p>	<b>R Burns / J Parmar / R Venkateswaran</b>

<b>10.</b>	<b>Update on Progress from Routine Bloods Working Group</b>	
10.1	<p>Routine Bloods CTPG Dec 22 – <b>CTPG(22)31</b> – This working group was formed to look at issues facing post-transplant patients who need routine blood monitoring on a regular basis. Three meetings out of the four planned have now been held with a group consisting of clinicians, GPs, pharmacy, pathology, patients from all over the country and alongside all transplant centres looking at:</p> <ul style="list-style-type: none"> <li>• Results of a patient survey and the tests associated with measuring immunosuppressant levels.</li> <li>• Tests that are done locally (FBC, U&amp;Es etc) and the process of requesting these and getting results returned to transplant centres</li> <li>• How results are reported to patients and how centres monitor tests are being done in a timely manner.</li> </ul> <p>The recommendations from these meetings will be discussed in the final meeting later in December and will then go to the next CTAG Hearts and Lungs meetings. Further information is in the papers circulated for this meeting.</p>	
10.2	<u>Appendix One</u> – <b>CTPG(22)32</b> was circulated prior to the meeting	
10.3	<u>Appendix Two</u> – <b>CTPG(22)33</b> was circulated prior to the meeting.	
<b>11.</b>	<b>Launch of National Institute of Health Research Blood and Transplant Research Unit (NIHR BRTU) – CTPG(22)34 and CTPG(22)36</b>	
	<p>Professor Andrew Fisher, a lung transplant physician at the Freeman Hospital and Professor in Transplant Surgery at Newcastle University gave a presentation on this project which is circulated with these Minutes.</p> <ul style="list-style-type: none"> <li>• NIHR BTRU is a partnership between Newcastle University, Cambridge University and NHSBT aiming to increase organ donation and utilisation to perform more organ transplants and improve long term outcomes.</li> <li>• Since the collaboration started in 2015, the project has been awarded £19M in funding, has published 70 research articles, trained 60 younger clinicians and scientists in transplant research, had 17 collaborations with industry and recruited 50 members to its patient and public research panel. 12 PhDs have been awarded.</li> <li>• When a competition was launched in 2021 to award a new BTRU, the joint collaboration was successful in getting a further £4M for the next 5 years.</li> <li>• The unit works across Freeman, Papworth and Addenbrookes Hospitals as well as the research elements within Cambridge Heart and Lung Institute, Newcastle Medical School and Newcastle Centre for Life where organ perfusion is performed.</li> <li>• The themes being explored are involvement of public and patient groups in training and capacity issues, organ donation and utilisation and improving long term outcomes after transplantation.</li> <li>• Further information on these and cross-cutting themes are given in the presentation.</li> </ul>	
11.1	<p><u>PROMS and PREMS in Solid Organ Transplants</u> – <b>CTPG(22)35</b> – Linda Sharp and Catherine Exley gave a presentation on their work to improve and tackle inequalities through the experience of patients and their families. The work measures Patient Related Outcomes and experiences (PROMS and PREMS) by looking at what's already available and being used, how well it's working and what can be learned from this to increase donation rates and reduce inequalities.</p> <ul style="list-style-type: none"> <li>• A PROM is a patient reported outcome measure that takes account of a person's view of their health status. A questionnaire measures quality of life, symptoms, side effects of a condition or treatment, or the impact of a disease and its effect on a patient's life and how people function physically, emotionally or socially.</li> <li>• A PREM is a patient reported experience measure focussing on a patient's perceptions of their experience of healthcare looking at quality of care (information, interactions with staff, communication and timeliness)</li> <li>• In the first 2 years, it is hoped to engage with patients' and families' experience of transplantation and quality of life following transplantation. Patient groups and their transplant centres will be involved.</li> </ul>	

	<ul style="list-style-type: none"> <li>This will be mapped against evidence generated about PROMs and PREMs so that it can be embedded into everyday practice.</li> <li>One or more topics will be chosen to pilot.</li> </ul>	
<b>12.</b>	<b>Any Other Business</b>	
	NAD	
<b>13.</b>	<b>Date and Structure of Next Meeting</b>	
	Further information will be sent regarding the CTAG Patient Group meeting for 2023 when it is available. Although there will be only one meeting during the coming year due to resource constraints, R Burns will continue to engage with patient groups and report back to CTAG Heart and Lungs meetings.	

<b>ACTIONS FROM THIS MEETING</b>		
<b>AP1</b>	<b><u>Item 5.2 – Feedback Report from Patient Chair</u> - R Burns and A Barrett to contact NHS England’s COVID delivery team to feedback patient challenges with accessing Covid therapies in a timely manner.</b>	
<b>AP2</b>	<b><u>Item 7.1 - Long-Term Survival Post-Transplant</u> - N Onwuka / S Rushton to produce long term survival charts for Lung and paediatric hearts</b>	
<b>AP3</b>	<b><u>Item 8.1 - Evusheld as a preventative treatment</u> - R Burns and E Johnson to respond to NICE consultation when launched.</b>	
<b>AP4</b>	<b><u>Item 8.2 - NICE consultation on therapeutics for people with COVID 19</u> - R Burns to upload approved response to NICE</b>	
<b>AP5</b>	<b><u>Item 9 - Psychology Support for Transplant Patients</u> - R Burns to work with the CTAG Chairs to audit the current dedicated social work provision across the transplant centres.</b>	