NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION DIRECTORATE

THE 1st MEETING OF THE NHSBT PATIENT ENGAGEMENT MEETING
ON 20th OCTOBER 2026 16.30 – 18.00
Virtual
Via MS Teams
MINUTES

Present:

Name of attendee	Initials	Place of work / Centre represented
First name (Chair)	JP	Associate Medical Director – Patient Engagement

	ITEM	ACTION
1.	**Welcome, Introductions and Apologies**	
	JP welcomed all attendees to the Patient Engagement Meeting. The aim of this meeting is to provide an opportunity for patients, carers and the public to hear about the vital work the organisation does to save and improve more lives, and to foster effective engagement, collaboration and transparency between the Organ and Tissue Donation and Transplantation – Clinical Team and patients, carers and the public. This meeting will be held each month, and the NHSBT Patient Partners will be instrumental in co -designing agendas. This meeting will replace any previous patient engagement meetings in the interest of providing equitable and consistent engagement across all groups of transplant patients.	
2.	**Organ donation and transplantation activity**	
	Organ donation and transplantation activity presented by LM, Head of Organ Donation and Transplantation Studies. PDF ACTIVITY 13 Oct 2026.pdf The latest weekly organ donation figures are available on the NHS Organ Donation website - NHS Organ Donation – statistics about organ donation	
3.	**Organ donation recovery plan**	

	Presentation by Ben Hume (Assistant Director – Strategy, Transformation & Business Development)  Organ Donation Recovery Plan .pdf Deceased donation rates have declined in recent months current consent rates are Donation after Brain Death (DBD) 66% & Donation after Circulatory Death (DCD) 52%. The UK transplant waiting list continues to rise, with over 8,700 people currently waiting for a lifesaving transplant. This is the first time the NHSBT has implemented an urgent response plan for organ donation. The plan includes working with NHS Trusts throughout the UK to increase donation opportunities and improving society's support for organ donation. The urgent response plan aims is to increase donation opportunities, recover performance and ensure more patients receive the life-saving transplants they need. The urgent response plan will introduce measures to stabilise and recover organ donation, including: • Identifying and referring more potential donors - ensuring every possible opportunity is recognised • Improving testing for neurological death, reducing delays and uncertainty • Accelerating actions to improve consent rates • Maximising every viable donation opportunity in hospitals • Speeding up improvements across the donation pathway Alongside these urgent measures, NHSBT is developing a long-term transformation programme to ensure the donation and transplant system remains sustainable. This includes adapting to the changing donor population, expanding DCD, using innovative techniques to make the best use of organs that are available, and strengthening the living donation programme In addition, NHSBT will work closely with the UK's Health Departments to understand the economic benefits of transplant. Ultimately, this helps commissioners decide where best to invest the NHS funds.	
4.	**Advisory Group Updates**	
	<u>Cardiothoracic Advisory Group – Hearts (CTAG – H)</u> <u>Lucy Ryan (LR) and Trevor Collins (TC) Patient Partners</u>	

	LR is one of two NHSBT Patient Partners supporting the work of CTAG Hearts, working alongside TC. She received her heart transplant at Great Ormond Street Hospital 33 years ago and now receives care at Royal Papworth. Since her transplant, LR has graduated in Performing Arts, and has worked across hospitality, customer service, charity and advocacy. She balances her Patient Partner role with caring responsibilities and work as a voice actor. LR has also competed in the British and World Transplant Games, winning medals, and hopes to compete again in Belgium next year. Together, LR and TC connect with patients, carers and families across UK transplant centres. They support anyone affected by heart transplantation, both before and after transplant, including paediatric recipients and their guardians. Lucy considers it a privilege to represent the heart transplant community. LR and TC can be contracted via their NHSBT emails lucy.ryan@nhsbt.nhs.uk and trevor.collins@nhsbt.nhs.uk. Recognising that email may not be accessible to everyone, LR and TC welcome suggestions for alternative contact methods. LR and TC biographies and role summary have been shared with transplant centres and the wider heart transplant community. LR and TC acknowledged Ellie Johnson, Senior Transplant Coordinator at Queen Elizabeth Hospital Birmingham for inviting them to a virtual patient support meeting. They welcome further opportunities to meet patients and clinical teams. LR and TC are working with Sally Rushton, the Lead Statistician for Cardiothoracic Transplantation at NHSBT to develop a one-page heart transplant infographic, which will be shared with the community for feedback. LR hopes to visit every transplant centre during her three-year term to better understand patients' experiences. <u>Cardiothoracic Transplant Advisory Group (CTAG – Hearts) - Update</u> The Cardiothoracic Transplant Advisory Group (CTAG Hearts) meets twice a year, bringing together NHSBT, clinicians and Patient Partners to discuss key issues in heart transplantation. At the September 2026 meeting, discussions included: • Assessment and Recovery Centres (ARCs): Enabling further assessment and recovery of organs that may not initially be suitable for transplantation.	

	• Organ donation consent: Consent rates recently fell to 54%, before rising to 57%, against a target of 60%. Rates remain below targets for donation after brainstem death (67% against 69%) and donation after circulatory death (51% against 56%). • As DCD heart transplantation increases, NHSBT is increasing DCD heart retrieval capacity and training. Three teams are currently undertaking DCD heart retrievals, with a fourth team expected to join the DCD heart retrieval teams in January 2027. • Transplant centres are working more closely together to share knowledge and improve practice. <u>Changes to Heart Allocation Policy</u> Historically, adult donor hearts have been offered to adult recipients first, followed by children under 16 if no suitable adult recipient is identified. However, approximately 97% of heart donors are adults, while children account for 15–18% of the waiting list, raising concerns about equity. Following six months of modelling and consultation, a fixed term working group recommended an interim policy change. The modelling suggests the interim policy change could enable an additional 6–9 paediatric transplants each year, with minimal or no impact on adult recipients. Further work is underway to make allocation fairer for everyone awaiting a heart transplant, with ongoing monitoring of the changes. <u>Cardiothoracic Transformation Programme</u> The Cardiothoracic Transplant Transformation Programme is reviewing the entire cardiothoracic transplant pathway patient, and public representatives are supporting the work of the programme. Some service improvements are underway, while other areas remain in development. <u>Freedom of Information Requests</u> NHSBT has received a high volume of Freedom of Information requests about Cardiothoracic Transplantation, this is impacting on the statistics team. Patients are encouraged to contact their transplant centre first with any questions and queries that may have. If they cannot obtain an answer, they can contact Lucy and Trevor, who can raise the issue with the CTAG – Heart Chair.	

	LP and TC will be meeting the CTAG – Heart Chair every six weeks to discuss heart transplantation issues and can raise unanswered questions on the community's behalf. Lucy and Trevor welcome questions, experiences and feedback from the heart transplant community to help shape the future of transplant care. <u>Pancreas Advisory Group – PAG</u> <u>Kimberley Gahagan (KG) and Sian Emmett (SE) Patient Partners</u> KG introduced herself as one of two NHSBT Patient Partners supporting the work of the PAG, working alongside SE. KG is currently awaiting her second simultaneous kidney pancreas transplant after her first transplants sadly failed. Kimberley is passionate about quality improvement and contributing towards positive change in transplantation. KG has a long history of patient advocacy that stems back to her childhood, but more recently, she has represented patients at information events and an event at the Scottish Parliament with Kidney Research UK. KG values and recognises the need for different perspectives and believes effective patient representation requires working collectively to improve outcomes, and the importance of building trust and enabling open communication. <u>Pancreas Advisory Group (PAG) - Update</u> A Pancreas Summit held earlier this year due to: • Declining deceased pancreas donor numbers • Increasing reliance on DCD donors resulting in lower pancreas utilisation • Interactions between the national kidney and pancreas offering schemes • Variation between transplant centres in organ utilisation practices • Workforce fragility • The need for better collaboration between solid organ pancreas, and islet cell transplant programmes Work is underway to address the above issues and will be supported by our Pancreas Patient Partners.	
5.	**Questions and Answers**	
	Q Will pre-submitted questions be answered and what format will these questions be answered? **A** Lots of pre-meeting questions were submitted, and this will give a flavour of patients wish to hear in future meetings. The plan is to theme	

	them, and signpost individuals where possible to relevant areas of the NHSBT website where information is already available. **Q** Are deceased donor kidneys offered according to ethnicity? **A:** All deceased donor kidney offers are matched between donor and receipt based on their 'HLA unacceptable' which considers what a potential recipient cannot accept. Rare HLA types get set priority in the kidney offering scheme. Ethnicity is not part of the organ allocation systems as this is a protected characteristic therefore cannot legally be included in an organ offering scheme. **Q:** What is the guideline about transplant recipients contacting the family of donors? **A:** Information on the correspondence process between donors and receipts is available here – https://www.nhsbt.nhs.uk/organ-transplantation/resources/writing-to-your-donors-family/ A Questions and Answers sheet has been devised to accompany these minutes and responds to Q and A's posed in the chat that were not responded to on the day of the meeting.	
6.	Date of next meeting to be confirmed, will take place in November	