

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

**THE MINUTES OF THE FORTY SIXTH MEETING  
OF THE PANCREAS ADVISORY GROUP  
AT 10:30AM ON 1 MAY 2025  
VIA MICROSOFT TEAMS**

Steven White	PAG Chair
Andrew Sutherland	Edinburgh Transplant Centre Representative
Arthi Anand	BSHI (H&I) Representative
Chris Callaghan	NHSBT Associate Medical Director, Organ Utilisation
Claire Counter	NHSBT Senior Statistician
Colin Wilson	Newcastle Transplant Centre Representative
Edward Sharples	Oxford Transplant Centre Representative
Elker Doruk	Cardiff Transplant Centre Representative
Gail Defries	Cambridge Pancreas Transplant Coordinator
Georgios Papadakis	Guys Transplant Centre Representative
James Shaw	UK Islet Transplant Consortium
Jenni Banks	NHSBT Statistician, Statistics and Clinical Research
John Casey	PAG-ISG Chair
Julie Whitney	NHSBT Head of Service Delivery – ODT Hub Operations
Laura Barton	NHSBT Programme Manager
Lewis Simmonds	NHSBT Statistician, Statistics and Clinical Research
Lora Irvine	SNBTS Islet Cell Production Manager
Martin Drage	Guy's Transplant Centre Representative
Neil Russell	Cambridge Transplant Centre Representative
Paul Johnson	Oxford Director Islet Isolation and Transplant Programmes
Rhiannon Wallis	NHSBT Statistician, Statistics and Clinical Research
Rommel Ravanan	NHSBT, Transplant Innovation & Interim AMD for Research & Development
Sarah Watson	NHSE Commissioning Manager Highly Speciality team
Victoria Prior	Edinburgh Recipient Coordinator
Yee Cheah	KCH Transplant Centre Representative
Zia Moinuddin	Manchester Transplant Centre Representative

<b>In Attendance</b>	
Lawna Pugh	NHSBT Advisory Group Administration Officer
Sam Tingle	Herrick Society presenting DECIPHER Trial

<b>Apologies</b>	
David van Dellen, Sanjay Sinha, Rebecca Spiers, Tahmid Siddique, Anand Muthusamy, Liz Armstrong, Ian Currie, Alistair Lumb, James Hunter, Hussein Khambalia, John Richardson, Aileen Feeney, Mohamed Elzawahry and Argiris Asderakis.	

		<b>ACTION</b>
<b>1.</b>	<b>Declarations of interest in relation to Agenda:</b> No declarations of interest were noted.	

<b>2.</b>	<b>Minutes:</b>	
2.1	<p><b>Accuracy</b> The Minutes of the PAG-PAGISG(M)(24)02 (this paper circulated prior to the meeting) meeting held on 28.11.24 were approved with one change to item 7.2. The first sentence should read <i>'Most centres have experienced issues with the <b>COBE</b> bags, which have since been issued with a safety notification and the rotation seals of the bags.</i></p>	
2.2	<p><b>Action Points - PAG(AP)(24)02</b> the following action points were discussed:</p> <p><b>AP1 Referral Patterns and AP13 NPOS Annual Review</b> There has been no progress made with NHSE due to organisational changes. Centres are looking into referrals for patients who may be considered suitable for islet transplantation with Type 1 diabetes and secondly for those patients who have Type 2 diabetes and maybe suitable for SPK, numbers are lower than other countries.</p> <p>R Ravanan agreed with S Watson suggestion to arrange a meeting with the Medical Advisor of NHSE Specialised Services (J Palmer). This will help raise the profile and highlight the referral issues for both pancreas and islets.</p> <p><b>ACTION: S Watson to arrange a call with D Manas, S White and J Casey.</b></p>	<b>S Watson</b>
2.3	<p><b>Matters Arising, not separately identified</b> There were no matters arising.</p>	
<b>3.</b>	<p><b>Medical Director Report</b> R Ravanan provided an update on behalf of D Manas:</p> <ul style="list-style-type: none"> <li>• <u>ToR</u> - A planned review of ToR (Terms of Reference) for all Advisory Groups, including the terms of office for members of the group (ongoing).</li> <li>• <u>New appointments:</u></li> <li>• Carla Rosser is the new H&amp;I Chief Scientific officer NHSBT</li> <li>• D Garcia was thanked for her work as national lead CLU. V Gerovasili takes over that role in the interim.</li> <li>• The Deputy Director post is being advertised on NHS Jobs</li> <li>• Andy Morley Smith was welcomed as the new Heart CLU lead.</li> <li>• <u>Patient Engagement Group</u> – A new AMD is being appointed to lead this new group representing patient interests for all organs. This will replace the current Patient Groups for Heart and Lungs, Liver and Kidney.</li> <li>• <u>Funding</u> - Following the spending review, baseline funding is confirmed by the NHSBT Board for DCD hearts, CLUs and NRP.</li> <li>• <u>ARCS</u> - Part of the spending review funding was allocated to preliminary set up ARCS. Although the funding will not be enough to set up an ARC it will provide the foundation to set up a programme board to write a business case for long term funding.</li> <li>• <u>Histopathology</u> - The business case for this is now with NHSE and funding has been identified to ensure progress is made. A delay is now anticipated following the recent announcement regarding the dissolution of NHSE. <ul style="list-style-type: none"> <li>– S Watson added that with so many projects paused due to funding. NHSE are trying to raise this as a higher priority.</li> </ul> </li> <li>• <u>Organ donation consent rates</u> – This is 60% currently which is significantly lower than previously recorded. A review of consent practices will take place in June's summit, at how various steps of the pathway can be improved to increase consent rates.</li> </ul>	

	<ul style="list-style-type: none"> <li>• <u>Utilisation</u> – results indicate the highest results ever recorded at 2.56 organs per donor. Thanks to colleagues, even though donor numbers have dropped transplant numbers have not due to improved organ utilisation.</li> <li>• <u>ISOU</u> – Patient engagement, innovation (including H&amp;I and Xenotransplantation, Trust engagement, Commissioning, Workforce and ARCs sub-groups have all reported. NHSBT are waiting to hear back from the minster if those</li> <li>• recommendations are accepted.</li> <li>• <u>OUG</u> - Workforce, specifically, to try and develop the workforce template for organ donation and transplantation - the summit is Wednesday, 7th of May.</li> <li>• <u>EVLP</u> - This work has commenced at Papworth with planned collaboration with Birmingham. Funding for 9 applications were received 3 of which have been funded.</li> <li>• <u>HHV8</u> – Guidance from NHSBT and BTS is now available on both the websites.</li> </ul> <p><b>ACTION – R Ramanan to share paper to be circulated with minutes.</b> <b>N.B. Action complete</b></p>	<b>R Ramanan</b>
4.	<p><b>Sustainability and Certainty in Organ Retrieval (SCORE)</b> J Whitney shared the key highlights of SCORE:</p> <p>All face-to-face roadshows are nearly complete with mostly positive feedback. All transplant centres understand there will be a change coming down the pathway, with some centres varying in readiness. The main concern is access to daytime theatre, multiple organs arriving at the same time and screening calls for the Specialist Nurse. kidney and pancreas offer will mainly be during the day depending how centres manage that. Logistics and flights are also a key theme, NHSBT will send summaries of feedback to all centres along with local data.</p> <p>ANRP and DCD Hearts with baseline funding approved need to be reprofiled to see if this makes a difference to the SCORE programme. The team are already ahead of the changes, which will be communicated if there are any.</p> <p>A Commissioners meeting in April 2025 was held, which presented SCORE and the impact to centres. Centres are asked to contact their commissioners locally for support in the first instance.</p> <p>The digital accept/decline is progressing, and the discovery work has been completed, with all the recommendations accepted and funding agreed. The delivery phase has started to enable modelling. April/May 2026 is the aim, but digital changes need to be implemented first, which needs a period of embedding before PAW (Planned arrival window). Digital changes will enable uploading of images and use in TransPlant path. This is being shadowed currently to understand any complexities, which will provide heat maps.</p> <p>S Watson relayed that NHSE can support and asked all centres to share information at hospital level so it all links up.</p>	
5.	<b>Governance</b>	
5.1	<p><b>Incidents for Review: PAG Patient Safety Report (formerly Clinical Governance) report</b> No update was provided in the absence of S Sinja.</p>	
5.2	<p><b>Summary of CUSUM Monitoring following Pancreas Transplantation</b> There were no CUSUM signals in the last 6 months. The updated expected rates of 1% for patient mortality and 6.5% for pancreas graft failure will be implemented from June.</p>	

	<p>The monitoring period will move forward so it's separate to the data used to create those expected rates.</p> <ul style="list-style-type: none"> <li>• S White asked if a CUSUM will capture kidney failure after PAK (Pancreas after Kidney) transplant. Numbers are so few it may not be useful.</li> <li>• J Casey agreed it would be good to look at kidney outcomes after PAK. This would pick up earlier losses.</li> </ul> <p><b>ACTION: C Counter to look at data for short term graft outcome for kidney following PAK within 30 days.</b></p>	<b>C Counter</b>
5.3	<p><b>Pancreas Damage and Quality</b> R Wallis presented PAG(25)03 (this paper circulated prior to the meeting) with the following points noted:</p> <p>N Russell highlighted that colleagues who have attended the retrieval course, have been told that donor duodenum flushing is no longer being taught.</p> <p><b>ACTION: N Russell to send protocol on perfusion fluid preference to S White who will circulate to other centres for agreement.</b></p> <p><b>ACTION: S White will discuss at RAG to reinstate flushing and use UW perfusion fluid.</b></p>	<b>N Russell</b>  <b>S White</b>
5.4	<b>Annual Utilisation Report</b>	
5.5	<p><b>Pancreas transplants by PDRi score</b> L Simmonds presented PAG(25)04 (this paper circulated prior to the meeting) which was created due to pancreas and donation rates lowering and understand the reasons.</p> <p>The PDRi score has increased in recent years and fits with the US outcome. The US models give large weighting to whether the donor was a DCD or not, as DCD retrievals are lower in the US which may skew the data. This could be something to look at taking the UK model forward.</p>	
5.6	<p><b>Update Solid Organ Pancreas Clinical Leads in Utilisation</b> C Callaghan provided an update on behalf of D V Dellen that baseline funding is now secured for lead and local CLUs.</p>	
5.7	<p><b>Update on High Quality Organ Offer Declines</b> C Callahan presented on behalf of D Van Dellen PAG(25)06 (this paper circulated prior to the meeting). The final table in the paper was highlighted in 2025 three letters were issued to centres. As donor offers have lowered, centres are accepting offers which would not have been accepted previously.</p> <ul style="list-style-type: none"> <li>• C Callahan asked if there is still support of islets being brought into some type of higher quality donor offer review schemes.</li> <li>• S White, J Casey, L Irvine supported the request, along with P Johnson who added to ensure governance is the same.</li> </ul> <p><b>ACTION: J Casey (call arranged) to discuss with D V DELLEN.</b></p>	
5.8	<p><b>DCD Working Group update</b> A Sutherland updated that complex simulations are required to obtain the data to move this forward, however, there have been some issues with programming – there will be an update at the Autum PAG.</p> <p><b>ACTION: Add to Autum PAG/ISG agenda – N.B. Action complete.</b></p>	<b>L Pugh</b>
6.	<b>Pancreas Transplant Activity</b>	

6.1	<p><b>Fast Track Scheme review</b> C Counter shared PAG(25)07 (this paper circulated prior to the meeting) with the following points noted:</p> <ul style="list-style-type: none"> <li>• S White asked Islet centres (Table 2 in the paper) the actual number of islet transplants from DCD donors is few (1 in the last 5 years) and does the group still think it's worth DCD organ offering for islet isolation.</li> <li>• J Casey added that NRP pancreas are more accepted, so would prefer to keep this in.</li> </ul>	
6.2	<p><b>Transplant List &amp; Transplant Activity</b> C Counter shared PAG(25)08 (this paper circulated prior to the meeting) with the following points noted:</p> <ul style="list-style-type: none"> <li>• S White asked to look at recent data with the effect on the waiting list.</li> <li>• C Counter explained that the Annual Organ report shows median waiting times for specific cohorts that enable the calculation of a median waiting time.</li> <li>• C Counter explained that the risk communication tool gives estimates of waiting times based on recipient and donor demographics.</li> <li>• N Russell asked to include for DCD whether NRP was used or not.</li> <li>• DCD not NRP does not affect centres decisions in accepting.</li> </ul> <p><b>ACTION: C Counter to look at including the proportion that were NRP DCD pancreas.</b></p>	<b>C Counter</b>
6.3	<p><b>Transplant Outcomes</b> C Counter presented PAG(25)09 (this paper circulated prior to the meeting) with no comments noted.</p>	
6.4	<p><b>DECIPHER Trial</b> S Tingle presented PAG(25)10 (this paper circulated prior to the meeting) requesting the collaboration of PAG for:</p> <ul style="list-style-type: none"> <li>• Aiding in defining consensus definitions for post-pancreas transplant pancreatitis, and early pancreas graft function/DGF. Generated definitions will be validated during the trainee-led cohort study phase of DECIPHER.</li> <li>• Enabling access to UK Transplant Registry data, which will enable the DECIPHER study team to assess the impact of these early complications on long term outcome.</li> </ul> <p><u>PAG agreed to support the trial, with the suggestion of longer follow up time than stated in the paper.</u></p> <p>The DECIPHER trial would need to link the application data, which needs approval by ODT CARE.</p> <p><b>ACTION: C Counter to check approvals and discuss with L Mumford and D Manas.</b></p>	<b>C Counter</b>
7.	<p><b>Islet Transplantation:</b></p>	
7.1	<p><b>Islet Transplant Summit and Fixed Term Working Group</b> L Barton presented PAG(25)11/12 (this paper circulated prior to the meeting) and explained that the Summit held in 2024 was to gain understanding of the current challenges. This was regarding capacity and workforce in relation to the laboratories, as well as technology, commissioning models and funding streams. To capture the summary output an Islet Transplantation fixed term working group has been created. Six main priorities were noted with technology being the priority to tackle first and then the future commissioning model and how this would look.</p>	

	<p>NHSBT and OTDT research teams have confirmed that validation sets will be required. Edinburgh have all the approvals in place and with HTA regulations. Kings and Oxford will also need to understand their own validations in due course.</p> <p>With regards to current and future state mapping S White, J Casey and L Barton will be visiting five centres to work with the teams to understand what the current provision is in more detail.</p> <ul style="list-style-type: none"> <li>– P Johnson expressed the need for data on clinical grade organs and can also transplant the islets from these. Seven organs are required for testing which means potentially 15-20 organs.</li> <li>– J Casey highlighted the lack of PRISM machines, which will cause a delay, and cost is also a concern.</li> </ul>	
7.2	<p><b>Report from the PAG Islet Steering Group</b></p> <p>J Casey updated the group of the next meeting due to be held on 3rd June 2025. Highlights are the Islet summit and Fixed term working group which provide insights, with technology being an issue.</p> <p>Other key points are the increase in the number of simultaneous islet/kidney (SIK) transplants, showing a distinct benefit to kidney transplant recipients, who receive replacement Islets and how to manage that.</p>	
7.3	<p><b>Islet Isolation Outcomes</b></p> <p>L Simmonds presented PAG(25)13 (this paper circulated prior to the meeting) with the following points noted:</p> <p>L Irvine and P Johnson noted that Figure 1 could possibly be a misclassification.</p> <p><b>ACTION: C Counter to classify SIK different from islets transplant within the data.</b></p> <p>C Counter added that the policy update to increase the age of DCD donors offered for islet transplantation to &lt;56 years will change at the end of May 2025.</p>	<b>C Counter</b>
7.4	<p><b>Islet Transplant Activity &amp; Outcome</b></p> <p>L Simmonds presented PAG(25)14 (this paper circulated prior to the meeting) with the following points noted:</p> <p>J Casey added that there has been an increase for priority transplants recently and what was the reasons.</p> <p><b>ACTION: C Counter to look at a more recent cohort for any changes.</b></p>	<b>C Counter</b>
<b>8.</b>	<b>Standard Listing Criteria:</b>	
8.1	<p><b>Summary Data</b></p> <p>R Wallis presented PAG(25)15 (this paper circulated prior to the meeting) with the following points noted:</p> <ul style="list-style-type: none"> <li>– J Casey noted that only three units registered patients in that year, with no registrations in an entire region in a year, is inconceivable. This report is a good starting point.</li> <li>– Y Cheah shared that several centres in the UK are getting increased referrals for diabetes technology, which is reducing the issue of hypoglycemia. People are being given various options and there are a growing number of centres offering Hypoglycemia Awareness Restoration Therapy (HART), which is a physiotherapy educational programme, which is a cost-effective way of reducing severe hypoglycemia.</li> <li>– N Russell added that their center had very few people referred with pancreas alone, who are hypo aware and the kidneys are fine.</li> </ul>	

	<ul style="list-style-type: none"> <li>– P Johnson added this is why it was especially important that heat maps are available for the whole country, and the summit will provide this.</li> </ul>	
8.2	<p><b>Identify new criteria for registrations</b></p> <p>J Shaw presented a slide on Expanded Indication. After the Summit the priority at this stage is to look at the NICE definition of hypoglycaemia and update the wording so, it is fit for purpose. Further discussion took place with the following points noted:</p> <ul style="list-style-type: none"> <li>– A Sutherland commented there is a problematic patient group with recurrent Diabetic ketoacidosis (DKA) and if this is an indication for islet transplants.</li> <li>– J Shaw added it does feel a barrier is being made for this group and the messaging needs to shift.</li> <li>– S White agreed that there is scope to expand the definitions.</li> <li>– J Casey agreed with the definitions and to share with nephrologists.</li> <li>– C Counter noted that a wording change to the data collection and supplementary form would be easier.</li> <li>– J Shaw the only refinement to the definitions would be recorded as dangerous hypos and remove the stipulation to islet after kidney (IAK) and will obtain a consensus on it.</li> <li>– P Johnson agreed to modernising definitions and may want to expand to other criteria and indications in due course. Also to ensure the definitions meet with international and diabetology.</li> </ul> <p>N Russell asked where the lines are drawn.</p> <ul style="list-style-type: none"> <li>– M Drage felt islets come from pancreas not used for solid organ transplants.</li> <li>– S White agreed that the number of pancreases being directed to isolation centres has reduced due to redefining the policy. Also, the number of islet transplants apart from SIK. Equity of access is vital for all patients regardless of whether they have renal failure or not.</li> <li>– J Casey reiterated the offering scheme is reviewed regularly and if there was a negative impact on solid organ transplantation donation this would have been picked.</li> <li>– J Shaw added it has always been equitable in terms of organ use, but there is inequitable access to those with problematic diabetes.</li> </ul> <p><b>ACTION: Review listing criteria with J Shaw, C Counter and J Casey.</b></p>	<b>C Counter</b>
9.	<p><b>Any Other Business</b></p> <p><b>Waiting times:</b></p> <p>A Sutherland raised an issue which has been raised previously. A patient on the kidney list and who's been on dialysis for five years (due to complications) who would then benefit from a kidney/pancreas transplant. If they are activated on the SPK list, they lose the time from dialysis.</p> <p>C Counter clarified that time spent on the kidney only waiting list can be transferred to the pancreas or islet registration when the patient is activated on the SPK or SIK list. Centres must remember to let Information Services know, and ask for the waiting time to be transferred, at the time of activation on the pancreas or islet list.</p> <p>[Post meeting note: Prior to the implementation of the new Scheme in 2019 there were discussions about time from dialysis being used within the Pancreas Offering Scheme, but it was agreed at PAG in April 2018 that waiting time from dialysis would not be used within the Pancreas Offering Scheme, due to pancreas and islet alone patients being disadvantaged.]</p>	

	<p>C Counter also clarified that those SPK or SIK patients with a kidney waiting time from dialysis or registration of over 7 years or matchability score 10 or sensitisation of 100% cRF would be in Tier A of the Kidney Offering Scheme rather than Tier A of the Pancreas Offering Scheme.</p> <p><b>ACTION: CC to send flow chart to coordinators which was issued in Sept 2019.</b></p> <p><b>HHV8</b> N Russell shared the issues with HHV8 which has been raised in the liver community. This is being discussed in the pancreas consent team and asked if this is being discussed in the wider pancreas community. A pancreas was transplanted which had HHV8, although the recipient managed to clear it.</p> <p>S White shared that he had reached out to the centres, although none had an issue relating to SPK.</p> <p>C Callaghan added that this is mainly affecting livers patients. All other organs only have a brief mention of HHV8 on the patient facing website as agreed within NHSBT.</p> <p><b>O Blood group patients</b> V Prior raised concerns with O blood group patients moving to Tier A of the pancreas offering scheme where patients are ranked by matchability score (highest to lowest) and then waiting time. Those with lower matchability scores are dropping down the matching run when a patient with a higher matchability score but lower waiting time joins Tier A. This means patients wait longer if they do not have a high matchability score.</p> <p><b>ACTION: V Prior to share this case with S White</b></p>	<p><b>C Counter</b></p> <p><b>V Prior</b></p>
<b>10.</b>	<b>FOR INFORMATION ONLY</b>	
10.1	Summary from Statistics & Clinical Research	<b>PAG(25)16</b>
10.2	Transplant Activity Report	<b>PAG(25)17</b>
10.3	QUOD Report	<b>PAG(25)18</b>
10.4	Management of BK Virus Infection and Disease following Kidney Transplantation: <a href="#">UK Guideline on Management of BK Polyomavirus (BKPyV) Infection and Disease Following Kidney Transplantation - British Transplantation Society</a>	<b>See Link</b>
<b>11.</b>	<p><b>Future Meeting Dates:</b> <b>Joint PAG and PAGISG</b> Face 2 Face Meeting will be held on Thursday 9<sup>th</sup> October 2025, The Wesley Hotel, Euston House, 81-103 Euston Street, London, NW1 2EZ</p> <p><b>Pancreas Forum</b> Thursday/Friday 26<sup>th</sup>/27<sup>th</sup> June 2025, Cambridge Venue TBC</p> <p><b>IPITA Conference</b> 16 – 18 June 2025 Pisa</p>	