NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION

THE MINUTES OF THE TWENTY SECOND MEETING OF THE PAG ISLET STEERING GROUP AT 10:30AM ON 3 JUNE 2025 VIA MICROSOFT TEAMS

John Casey	**Chair & Clinical Director, Edinburgh Transplant Centre**
Aneta Ogah	Newcastle Representative
Carla Rosser	OTDT H&I Lead, NHSBT
Claire Counter	Senior Statistician, Statistics & Clinical Research, NHSBT
David Van Dellen	Manchester Representative
Gareth Walker	Edinburgh Isolation Facility
Jenni Banks	Statistician, Statistics & Clinical Research, NHSBT
Jim Shaw	Chair, UKITC and Newcastle Representative
Joanne Berridge	Lead Biomedical Scientist
Julie Whitney	Head of Service Delivery - Hub Operations, NHSBT
Laura Barton	Programme Manager, NHSBT
Lora Irvine	Edinburgh Isolation Facility
Malcolm Greenwood-Morgan	Manchester Representative
Nicky Moyse	Newcastle Representative
Paul Johnson	Oxford Director Islet Isolation and Transplant Programmes
Rebecca Spiers	Oxford Isolation Facility
Rhiannon Wallis	Statistician, Statistics & Clinical Research, NHSBT
Ruth Chrisman	H&I Representative
Sandra Campbell	Newcastle
Sapna Marwaha	Lay Member
Sarah Watson	NHSE Commissioning Manager- Highly Speciality team
Steve White	PAG Chair

In Attendance	
Lawna Pugh	Clinical & Support Services, NHSBT

Apologies	
Kay Carruthers, Arash Akbarzad-Yousefi, Guo Cai Huang, Denise Bennett and Aileen Feeney.	

		ACTION
1.	**Declarations of interest in relation to Agenda:** No declarations of interest were noted.	
2.	**Minutes of PAGISG 28/11/2024**	
2.1	**Accuracy** There was one completed request at PAG to amend item 7.2 – the minutes have now been ratified.	

2.2	**Action Points** There were no action points for PAG-ISG.	
2.3	**Matters Arising, not separately identified** There were no matters identified for discussion at the meeting.	
3.	**Clinical Islet transplantation**	
3.1	**Update from each centre** <u>Newcastle - S Campbell provided an update:</u> Newcastle completed 2 transplants in 2024; both are on the priority waiting list. There are 7 patients on the waiting list currently, with no SIK (Simultaneous Islet and Kidney transplant) listed. Pancreas for islets were accepted for priority patients; however, there were no laboratories available. It has been difficult to test due to staff shortage and sickness, but with the new diabetes centre opening in July testing will be easier. There has been benefits with additional referrals, set up with the MDT team (Multi-Disciplinary Team). Newcastle is in the process of setting up IAK (Islet After Kidney) for some patients and requesting referral teams to re-refer after 6 months. – J Shaw added it has been a difficult period. The IAK (Islet after kidney) programme met with nephrologists and discussed planned renal transplants, particularly live donor kidneys who consider IAK as a completion procedure and steroid free induction for all patients with diabetes. <u>Manchester - M Greenwood-Morgan provided an update:</u> There are 23 patients listed and 10 SIK listed, 6 of which are for islets alone. In 2024 there were 4 SIK and 1 in 2025. Referrals for kidney alone has been received and Manchester are requesting referral centres to refer everything. Similar issues like Newcastle lab capacity are an issue. <u>Oxford – P Johnson provided an update:</u> Oxford completed 7 transplants over the last year as well as 11 TPIAT (Total Pancreatectomy with Islet Auto transplantations). <u>Kings – Y Cheah provide an update:</u> Kings reopened last year so were not as active. There were 2 patients listed for islet transplantation and 4 IAK referrals with 3 for islets alone. Referrals for (IAT/ TPIAT) are monthly from being involved in the auto Islet programme. Royal Free patients were referred but then decided to continue ongoing care with Royal Free. Kings are working with Guys to develop the SIK programme. – P Johnson added that Royal Free are not actively adding new patients for Islets. – S Watson shared that NHSE has not received formal notification from Royal Free and have notified the London region regarding the contractual arrangements and will investigate this with formal correspondence to the CEO. – C Counter had received confirmation from M. Rosenthal that Royal Free were not doing islet transplants and therefore remove them from the fast-track offers. – P Johnson confirmed that Kings would be the main centre in London and refer to Oxford for patients outside the catchment area. – J Casey requested to ensure all clinicians know where to refer patients. **ACTION: C Counter to forward Royal Free email to S Watson – action complete.** <u>Edinburgh – J Casey provided an update:</u>	

	There have been 13 transplants in 2025 with 3 SIK. Currently there are 25 patients on list (half SIK). There are similar issues as other centres, with patients trying to transplant within a very short window, which has increased the waiting times. Edinburgh are starting to look at the registry for live donor transplants and offer beta cell replacement if appropriate.	
3.2	**Referral patterns to each centre** J Casey shared that referrals is part of the summit outputs and if there is anything else to encourage referrals or look at patters. – J Shaw added referrals are still not happening and to look at the summit outputs for anything missing - this can then be republished when the inclusion criteria widen. Hybrid closed loop is not being rolled out which is a challenge for centres and this will slow referrals. – P Johnson asked to remember the issue of capacity and projected referral numbers are needed.	
3.3	**Sustainability and Certainty in Organ Retrieval (SCORE)** J Whitney shared the key highlights of SCORE and the Spring update 2025 link: https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/36568/score-spring-2025-update.pdf All face-to-face roadshows are complete. Virtual engagement is to be arranged for renal centres in summer/autumn 2025. The digital offering needs to be established first. Modelling work shows that the labs receiving pancreas for isolation would be arriving around 7-8am depending on geographics and flight timing etc. although this will all be part of the planning calls the day before retrieval. Centre specific data will be shared. Currently the team are shadow stating the live activity, so some centres may be contacted to ensure there is accurate data as well as identifying any blockers before going live, which will be in the next financial year. – R Spiers asked if the digital accept/decline policy extend to the labs. – J Whitney explained the centres will contact the labs and there maybe access to transplant path – the SCORE team can work with labs. – J Casey asked how islets will be offered. – J Whitney explained this is out of scope at this stage, but there will be an option to upload photos and possible give them to a lab.	
4.	**Islet Isolation**	
4.1	**Isolation statistics** C Counter presented PAGISG(25)01 (this paper circulated prior to the meeting) and noted that the data could not be separated for what the pancreas was being isolated for and figure 1 has a footnote - 'released under licence with low islet yield'. Further discussion took place with the following points noted: – J Shaw asked what the appetite was for taking anything that meets release criteria (even if less than 4000 IEQ per kg) for a first transplant. – J Casey added it's a much broader decision and if the lab is happy, it will be considered as it is not based purely on numbers per kilo.	

	– D Van Dellen added Manchester would also include the recipient in the decision, and it is a broader discussion which depends on the day.	
4.2	**Update from the UK Islet summit** J Casey noted PAGISG(25)01 (this paper circulated prior to the meeting). The outputs have been circulated with a follow up to itemise areas which need focus on. Supporting the isolation labs to have a sustainable 24/7 service is vital for the UK, meetings are being arranged to discuss this. Another action plan is to focus on the COBE replacement - the labs are meeting to discuss this further. Further discussion took place with the following points noted: – S Watson asked what the model of care for the service should be and how best to take forward. – J Casey/S White explained it is critical to deliver lab services in UK and that it is well funded. Also, the service specification needs updating. Scotland and England funding model could be unified. – J Shaw added for long term or lifelong care there is no resource outside the centres for this. – J Casey agreed and shared that in Scotland there is no expectation to provide long term care. After 6 weeks the referral centres take over, and this is within the funding structure. – S Watson shared that funding in the UK has not shifted around the model of care. If patients are seen locally, they can charge a tariff. – P Johnson urged to mirror the joint beta cell replacement and the need for expertise in a regional hub. – J Casey agreed that a hub and spoke model would increase a better working relationship between transplant centres and diabetologist. – J Shaw added it would take some work to get local diabetes teams on how to manage this and this needs to be looked at as part of the Service specification.	
4.3	**Report of Islet Isolation Sub-Group Meeting** L Irvine provided an update from the ISG Lab subgroup with the following points noted: – Newcastle experienced an issue with perfusion of autologous pancreas with surgeons performing this, not the lab team. L Irvine/R Spiers offered training so the lab team can do this themselves. – Concerns with poor low yield of autologous pancreas within a diabetic range – what is the clinical advice. o S White commented that all patients go through the MDT team and therefore should be accepted. Using a different enzyme has also improved the yield. – Oxford are working on the implementation of the Roche enzyme for younger donors. – Delivery of Roche enzyme is an issue and Edinburgh are currently using Nordmark. – Endotoxin testing was causing an issue obtaining valid positive control results, but recent results have improved control results within the valid range. – Leicester had an issue with DNA build up during prep for an accurate count. Some centres use Pulmozyme to break this down. – There has been a consumable, and reagents supply issue, and all centres are looking into contingency suppliers. – Newcastle reported issues with pin prick holes in the blood warmer bags which may have been due to too much pressure.	

	– Autologous process with different approaches for purification if over the threshold was discussed. In Edinburgh this would be a clinical decision. – All labs HTA inspections went well. – It would be preferable for those aged 51 – 55 inclusive that NRP is performed, though this may not always be known at the point of offer" to "DCD donors aged between 51-55 years inclusive should only be accepted for islet isolation if NRP is performed, though this may not always be known at the point of offer. Once NORS team leave base it will be known if NRP has been performed, however there can be a long wait between, so calling NHSBT Hub Ops before declining another pancreas will confirm if NRP has been performed. – The tech sub-group for the COBE replacement will assess the Prism machine option, although there has been delays to delivery. G Walker confirmed they are still trying to get the units in the UK and evaluate the unit before proceeding use for clinical organs. Other viable options are being looked into as the COBE will no longer be available after December 2025. P Johnson requested to test clinical grade pancreas as time is running out. Edinburgh/Oxford have enough COBE bags to maintain the service. Further discussion took place with the following points noted: – R Spiers explained the issue with the labs receiving multiple phone calls overnight and being offered the same pancreas, which was previously declined. – P Johnson also has the same issue which is having an impact on staff. – R Spiers can do some mapping/ gathering data. – L Irvine explained the decline can be an HTA regulatory policy. – J Whitney added data will be very useful and if there is clear and accurate reasons to why the organ cannot be used for islets isolation, this can be highlighted so staff in Hub Ops do not offer on. **ACTION: R Spiers to gather data on offer calls over the weekends and share with J Whitney.**	**R Spiers**
5.	**Islet Transplantation**	
5.1	**Islet transplant activity and outcome** C Counter presented PAGISG(25)03 (this paper circulated prior to the meeting) with the following points noted: JC expressed how good it is to see this data on a 6 monthly basis. The 2 eras in Figure 3 (page 10) there's a trend in graft survival, although it's not significant but want to keep a watch on it. C Counter clarified the data is not broken down to whether patients had a top up or not.	
5.2	**Pancreas/Islet Utilisation** D Van Dellen presented PAGISG(25)3.1 (this paper circulated prior to the meeting) which was to review offer declines and organ discards from apparently 'higher quality' deceased pancreas donors. Actions on the paper for discussion is the top 3 points below, and to review at 6 -12 months. HQD definition (must meet all the criteria to be HQD): 1. DBD and DCD 2. Aged 30-60 inclusive 3. BMI 26.0 to 35.4 inclusive	

	– J Casy commented the CLU initiative was set up for higher quality organs and this did not include islets. Now with increased declining donor number and an increase in DCDs this need to be investigated. – R Spiers asked if the transplant centre accepts and the lab declines, where would the letter go. – D Van Dellen clarified in that scenario the letter will usually go to the lab, but it usually goes to the centre head due to overlap. Only approx.10% of cases generate a letter. – P Johnson supports this as long data is analysed prior to the letter. **All members agreed to support criteria.**	
5.3	**Auto transplant update/data collection** S White met with J Whitney and will be updated after discussions with Hub Ops.	
6.	**Standard listing criteria**	
6.1	**Islet transplant listing exemptions request and outcome of previous applications to appeals panel** J Casey shared that 2 requests where circulated and approved.	
6.2	**Standard listing summary** R Wallis presented PAGISG(25)04 (this paper circulated prior to the meeting). No comments noted.	
6.3	**Update to Patient Selection policy and Supplementary Registration form** J Shaw shared a paper and highlighted it was agreed at PAG this should now be the NICE definition for pump use of disabling hypoglycaemia. The following changes were highlighted: • Definition to be applied for pancreas alone • Add in C-peptide less than 200 pmol/l • Add on the form 'Patient has trialled Hybrid closed loop therapy where feasible'. • Additional question 'Patient has trialled Hybrid closed loop where indicated and appropriate Yes/No'. • Remove criteria for patients listed for Islet after kidney transplant to be same as for patients listed for pancreas after kidney transplant Further discussion took place with the following points noted: – C Counter confirmed that changes can be implemented if agreed. – S White/J Casey agreed to not involve exemptions committee and keep monitoring. – J Shaw added it was only conceptual changes in the service specification. – P Johnson agreed to support changes and have stricter wording on optimal medical treatment to include hybrid closed loop rather than the word 'feasible'. – J Casey added it's important to not exclude patients who don't want to have hybrid closed loop.	
7.	**Governance / Clinical Incidents**	
7.1	**Quality/damage** C Counter presented PAGISG(25)05 (this paper circulated prior to the meeting). No comments noted.	

7.2	**Organ offer summary** R Wallis presented PAGISG(25)06 (this paper circulated prior to the meeting). No comments noted.	
8.	**Report from Pancreas Advisory Group meeting** No update or comments noted.	
9.	**Report from UK ITC and the UKITC Research Steering Group (including update of MRC-QUOD extension)** J Shaw provided an update adding it was a great bringing a wider community together and introducing innovation like potential stem cell derived transplantation within the NHS, biomarkers and immunosuppression reduction etc. – P Johnson asked how the negotiating was working with the UK immunotherapy group – J Shaw added there have been good collaborative discussions, for new therapies and there is an appetite to bring groups together. There is concern that beta cell replacement therapy should be under a separate group. The next meeting will possibly be late summer 2025. The group may want to move towards using NHSBT national registry for stem cell transplants as soon as it stops being a trial. **ACTION: Add standing agenda item – 'How to manage emerging cell therapies for diabetes' OR 'Clinical adoption of advanced therapies for diabetes' – Title TBC**	**Complete**
10.	**Update on islet data applications** C Counter confirmed there are no new application.	
11.	**Any other business** No comments noted.	
12.	**Future Meeting Dates:**	
	Joint PAG and PAGISG Face 2 Face Meeting will be held on Thursday 9th October 2025, The Wesley Hotel, Euston House, 81-103 Euston Street, London, NW1 2EZ **Pancreas Forum** Thursday/Friday 26th/27th June 2025, Cambridge Venue TBC **IPITA Conference** 16 – 18 June 2025 Pisa	