

Islet Transplant Summit

Recommendations Report

December 2024



Summit Overview

The Islet Transplant summit was held on Tuesday 10 December 2024, at Mary Ward House in London. The purpose of the summit was to gain a joint understanding of the current challenges and the current service delivery model for islet isolation in the UK, specifically in relation to the laboratory role. The aim of the summit was to gain consensus on what the future model of islet isolation should be, specifically in relation to the laboratories, and what changes are required to deliver against this desired future state.

Attendees

The summit was organised by NHS Blood and Transplant (NHSBT), with support from commissioners from both England and Scotland. The organising Chairs of the event were:

- Professor Derek Manas, Consultant Transplant Surgeon, Freeman Hospital and NHSBT Organ & Tissue Donation & Transplantation Medical Director
- John Casey, Consultant Transplant Surgeon, Edinburgh Transplant Centre
- Steve White, Consultant Transplant Surgeon, Freeman Hospital and Newcastle University.

To promote a robust and thorough discussion, representatives from a broad spectrum of backgrounds with differing views and expertise were invited to attend. Attendees included:

- NHS Scotland Commissioner
- NHS England Commissioners – including representatives from Specialised Commissioning and Integrated Care Boards
- Highly Specialised Commissioner, UK Health Security Agency
- Recipient Transplant Coordinators
- Islet Coordinators
- Human Tissue Authority
- Laboratory Managers and Quality Managers (from each of the three Islet Isolation services)
- Clinical Leads for Islet Programmes
- Consultant Transplant Surgeons
- Consultants in Diabetes
- Head of Service Delivery, NHSBT
- Statisticians, NHSBT
- Organ Utilisation Programme Manager, NHSBT

Context and Discussion



Figure 1 Overview of Islet Transplantation Services in the UK

Current Provision

Across the UK there are 3 islet isolation laboratories (Oxford, King's College, and Edinburgh). The laboratories work with the 5 active transplanting centres (Oxford, King's College, Edinburgh, Newcastle, and Manchester). Due to workforce limitations there are a maximum of 2 laboratories operational at any time, where Oxford and King's College share a rota between them, including at the weekends, with an 24/7 on-call service for islet isolation. The Edinburgh service provides a regular service, but is not operational for isolation at the weekend.

The transplant community recognise the significant dedication and hard work of the isolation teams in the UK. They bring great passion and skill to their work, and whilst this report seeks to address the challenges faced by Islet Transplantation services, this in no way is attributable to the laboratory staff delivering islet isolation services. These teams are an asset, and every effort is required to support them in their roles, to deliver system-wide improvements.

There has been a three-fold increase in the islet transplant waitlist, from 2009 to 2024, with 63 patients waiting for transplant at the time of the summit. The median active and suspended (or total) waiting time increased from 450 days for registrations in 2008-2011 to 564 days for registrations in 2015-2019. The proportion of new islet registrations transplanted at three years post listing has reduced from 80% for registrations between 1 April 2010 to 31 March 2011 to 57% for registrations between 1 April 2019 to 31 March 2021. Although this decline could be due to multiple factors such as COVID-19 as well as increased number of registrations.

There is significant variance in individual transplant centre activity, and there is confusion regarding the funding model, and a recognised need to ensure that active centres are remunerated appropriately for their essential activity.

Service Resilience

Unforeseen circumstances led to the closure of the King's College Laboratory for islet isolation services between August 2023 and September 2024. This closure resulted in limited isolation lab availability and is associated with an increase in organ turndown for islet offers. **For the period of closure 18% of offers were declined solely to lack of lab availability (increase from 7% the previous year). As a result, a number of pancreas went unused as a result of this closure, and the closure of one facility demonstrated a significant impact on the islet isolation services as a whole on the UK.**

Laboratory Capacity and Workforce

The service delivered by each laboratory was recognised to be expert, collaborative, patient-centred, passionate and efficient. The highly experienced and knowledgeable staff spoke positively regarding their facilities and access to wider support (e.g. medical expertise), as well as their governance and

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Quality Control. **The laboratories' contributions to increasing organ utilisation are crucial and well understood by all.**

Despite the dedication of the laboratory managers and workforce, each laboratory reported similar significant challenges and limitations, which are preventing the delivery of a sustainable service.

These challenges include:



Technology

All three laboratories in the UK (and worldwide) utilise the COBE 2991 to undertake islet purification. The technology provider has confirmed that all servicing support for the COBE 2991 will be discontinued in December 2025. Further, the consumables have already been discontinued (June 2023) and are no longer able to purchase. **There is currently no certified replacement technology available in the UK for use in islet isolation, and there is therefore a real risk in relation to service continuity from December 2025.**

There are two potential alternatives available, which has the potential to positively impact on personnel and turnaround times, but each also has some drawbacks in relation to the current technology used. Each laboratory will be required to undertake a procurement exercise and then individually validate the technology prior to rolling out live. This is recognised as complex and time-intensive, but an essential exercise, for service preservation.

Further discussions on how best to ensure that validations can be undertaken within the required timescale, and how best to rapidly bring this technology online, will be led by the laboratories, with support from NHSBT's Pancreas Advisory Group, and Hub Operations, as well as the Human Tissue Authority.

Commissioning

The core components of commissioning and the value that it can offer to islet transplantation are well established. The Edinburgh laboratory is commissioned by NHS Scotland. The remainder of the islet transplant centres are commissioned by NHS England, specifically the Highly Specialised Commissioning Team.

For various reasons, including capacity and complexity, NHS England have been limited in their ability to undertake commissioning reviews with each individual transplant centre. Conversely, NHS Scotland work actively with Edinburgh, reviewing various data together to support the service and identify opportunities for improvement.

Further, due to the evolution of the service and the time lapse since last review, it was recognised that the service specification requires a significant update, with a focus on:

- Evidence
- Care pathway
- Monitoring and assurance
- Metrics

The summit attendees recognised there were challenges in relation to the current commissioning model, with a desire to move towards:

- Joint commissioning (UK-wide)
- Review of the funding and remuneration model
- Consistency in Quality Assurance and monitoring from Commissioners
- Performance and data driven approach

The Future of Islet Transplantation

Attendees recognised the innovation that the UK implemented in relation to islet isolation services, and there was widespread support for the need to jump forward again, to deliver the required number of transplants, and to do this in a timely way, to improve patients' lives and outcomes (including routine, and second and third grafts). **To deliver insulin independence to patients requires an uninterrupted islet isolation service.**

The discussion often focused on the efficacy of the referral pathway also, in recognition of the need to educate colleagues to improve understanding of the islet transplantation pathway and its outcomes. **Further work is required to improve referral pathways and activity, to understand how this can be better improved.**

There are many opportunities to drive future transplantation activity in the future, such as preservation technology and stem cell therapy, and we must focus on ensuring that our foundations are in place, so that we can maximise the number of transplantations we undertake, both now and in the future. This is of particular importance as we need to ensure provision for the increasing need for, and activity related to, Simultaneous Islet Kidney (SIK) transplantation.

Recommendations

Following robust discussion at the Islet Summit, the following recommendations are made:

1. Funding and Commissioning

- a) Refresh the service specification.
- b) Undertake bottom-up costing review and develop funding proposal (or business case, as appropriate).
- c) Develop metrics and KPIs (in conjunction with dashboard development in 6).

- d) Adopt joint commissioning approach across UK, review governance approach, and introduce regular commissioning reviews, with commissioners taking a Quality Assurance role.

2. Capacity and Demand

- a) Model future demand and capacity and develop proposal for future lab model (including consideration of SIK activity geography).
- b) Identify impact of SIK on activity.

3. Technology

- a) As priority, develop roadmap for ensuring service continuity over next 18 months with changes in technology, ensuring the availability of appropriate technologies are in place within required timescales.

4. Pathways and Protocols

- a) Deep dive into the referral pathway and identify opportunities for improvement.
- b) Once future provision model developed, develop resilience plans and protocols for national service continuity.
- c) Identify opportunities for standardisation across sites and implement accordingly.
- d) Review equity of access.
- e) Consider end-to-end pathway process mapping to identify opportunities for optimisation, to reduce complexities, timescales, and transport times.

5. Laboratory Staff and Training

- a) Develop a resilient and sustainable laboratory workforce model.
- b) Review the collaborative approach in place across the laboratories, and identify opportunities for improvement, in relation to training and education.
- c) Review joint lab manager meetings and identify opportunity to better support this forum, for sharing of best practice and learnings, and for future service planning.

6. Data and Outcomes

- a) Develop dashboard to support future service improvement (e.g. monitor yield from HQDs, split information by lab, include appropriate outcome data).
- b) Identify suitable approach to PREMS/PROMS, linking with existing workstreams where appropriate.

A small working group will be established, and will meeting throughout 2025, to deliver further recommendations in relation to the above.

Assurance regarding the completion of all of the recommendations will be overseen by the NHSBT Pancreas Advisory Group (PAG) going forward, and delivery and assurance plans may be requested from appropriate representatives, as appropriate.