



Department
of Health &
Social Care

ISOU Digital Workshop - 18 November 2025

Published 26 March 2026

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Executive Summary

The ISOU Digital Workshop, convened by the Department of Health and Social Care's Implementation Steering Group for Organ Utilisation (ISOU), brought together NHS England (NHSE), NHS Blood and Transplant (NHSBT), clinicians, patient and carer representatives and stakeholders from across the transplant landscape. The event aimed to address Recommendation 7 of the Organ Utilisation Group (OUG) report: to transform data provision within transplantation services through digital approaches, ensuring equitable, timely and accurate access to critical information throughout the donation-to-transplantation pathway and beyond.

The OUG was established to maximise opportunities for organ transplantation and regain the UK's global leadership in the field, despite challenges such as increasing donor and recipient complexity, COVID-19 pandemic-related pressures, and inequalities in access and outcomes. The OUG's 2023 report highlighted that fragmented, inconsistent and poor-quality data, coupled with limited sharing between centres, undermined clinical decision-making and patient experience. It called for a shift to integrated, user-centred digital systems, standardised data collection, and robust patient feedback mechanisms, including Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs).

At the workshop, delegates explored the current state of digital infrastructure, identifying significant barriers such as inadequate Wi-Fi, outdated technology, limited system interoperability, and inconsistent systems access for key staff like Specialist Nurses in Organ Donation (SN-ODs). These issues often lead to inefficiencies missed opportunities for donation and increased burden on patients and clinicians. Patients are often left to manage fragmented information themselves, and incomplete data means clinicians may not be able to make the best quality clinical decisions. The group agreed that empowering patients requires accessible, trustworthy digital tools and equal access must be central to resource design.

Opportunities for improvement focused on the creation of a Single Patient Record (SPR) for integrated access across care settings, the digitisation and unification of data systems, and the adoption of national data standards to ensure secure information flow. Delegates highlighted the importance of including genomic and compatibility data, and of future-proofing systems to support advanced analytics and artificial intelligence in matching donors and recipients. The need for a central, plain-language repository for patient information, linked to every clinic letter, was also emphasised.

To deliver these improvements, the workshop advocated for co-production of solutions with patients, organisational collaboration, and sustained investment in

digital infrastructure and change management. Regional collaboration and open data sharing, supported by commissioners, were seen as key to spreading best practice and reducing non-clinical reasons for donor organs being declined. Clinical Leads for Utilisation (CLUs) were identified as central to driving data accuracy, tool adoption, and ensuring that insights inform action at all levels.

In conclusion, the ISOU Digital Workshop reaffirmed the urgent need for a digitally connected, patient-centred transplant pathway, aligning closely with the move from an analogue past to a digital future as set out by the government in Fit for the Future: The 10 Year Health Plan for England, published by in July 2025. Delegates called for clear governance, standardised processes, and ongoing monitoring to ensure that innovation delivers real improvements in equity, experience and outcomes for all patients on the transplant waiting list. The workshop outcomes and recommended actions will inform the next phase of digital transformation, with responsibilities delegated to relevant organisations upon approval by the DHSC.

Actions:

- Collaboration between NHSBT and NHSE colleagues on the digital data provision initiatives to facilitate data standardisation and connectedness between digital infrastructures.
- Collaboration between NHSBT and NHSE colleagues to ensure that the unique challenges of the transplant pathway are addressed, including day-to-day issues such as SN-ODs' access to hospital IT systems, as well as the planning and implementation of the SPR.
- NHSE SPR colleagues to consider using the transplant pathway as a pilot project in the roll out the SPR.
- NHSE SPR team colleagues recommended to prioritise supporting the timely transfer of hospital prescribed medications on to GP records.
- NHSBT statistics and digital colleagues to work with patients to improve data accessibility, including relocation of OTDT guidance and data to a more user-friendly location on the NHSBT website.

Background and Context

Organ Utilisation Group (OUG) was established by the Department of Health and Social Care (DHSC) in England and chaired by Professor Sir Stephen Powis. Its purpose was to develop recommendations to maximise opportunities for organ transplantation and ensure a world-class healthcare system that delivers equity, excellence, and innovation for patients on the transplant waiting list. The Group also aimed to identify and overcome barriers to transplantation, regaining the UK's position as a global leader in transplant innovation and ensuring no viable opportunity for a successful transplant was missed.

At the time of its formation, organ donation rates had improved significantly, with donor numbers rising by 56% over the previous decade. However, while transplant rates have also increased, they have not kept pace with donation. Factors such as the increasing age and co-morbidities of donors and recipients posed challenges for successful organ utilisation.

The COVID-19 pandemic added further strain, with the first wave prompting rapid improvements in transplantation services but also causing a reduction in donors and temporary unit closures. This led to a five-year high in the number of people on the transplant waiting list. National audits and joint NHSBT/British Transplantation Society summits highlighted the significant inequalities and variations between units, affecting access to treatment and patient outcomes. These disparities were linked to local resource limitations and uneven access to innovative technologies, resulting in inequities across geographic, socio-economic, and ethnic groups.

It was agreed that a review of the organ transplantation infrastructure was needed to optimise existing resources and better meet patient needs. The final report, published in February 2023, included a section on data provision within transplant services. The OUG report noted that patients and clinicians said that poor-quality and inconsistent data often increased stress and hindered decision-making, particularly on topics such as diet and medication. Limited data sharing across the care pathway, coupled with the absence of information from non-transplanting centres restricted opportunities for transplantation and made it challenging to monitor variations in access and care. The feedback mechanisms focused predominantly on negative outcomes, which discouraged teams and fostered risk aversion. Furthermore, it was noted that evaluation should not be limited to clinical outcomes, incorporating PROMs and PREMs was vital to ensure services meet patient needs.

The report included the recommendation:

The provision of data must be transformed using digital approaches to provide access to complete, accurate and standardised data and information to everyone who needs it at critical decision points throughout the donation to transplantation pathway.

The report included the following actions to support the successful delivery of this recommendation:

- The information and data sources required at each stage of the transplant care pathway for different users must be identified and provided.
- Assessment must be made of the feasibility of creating a user-centred 'portal' that integrates all data and information, with priority being given to the user-group and/or stage of the pathway that will drive the biggest improvements to organ utilisation.
- The availability and use of tools to support patients and clinicians in their discussions about transplant options and potential impact on patient outcomes (for example, waiting times) must be improved.
- Data terminology, collection and secure transfer processes must be standardised across the UK to ensure completeness, accuracy and accessibility of data, including access to patient data for multiple transplant centres.
- Building on existing knowledge and infrastructure, the minimum data sets required along the patient pathway must be identified and provided.
- Data collection processes must be established to ensure completeness, quality and integrity of clinical and donor and/or recipient self-reported data at point of capture.
- The relevant data in donation and transplant pathways must be digitised to enable efficient and accessible flow of data from point of recording to point of access by:
 - digitising paper-based data collection and data transfer processes, starting with pathways that have the greatest impact on organ utilisation
 - creating personal health records for patients on the transplant waiting list, transplant recipients and living donors
 - developing patient and donor-focused applications that allow for self-reporting along with access to key information

- modernising existing legacy digital tools and processes
- ensuring there is appropriate capacity, capability and multi-year funding in place to deliver effective digital transformation

To implement the OUG recommendations, the Department of Health and Social Care established the Implementation Steering Group for Organ Utilisation (ISOU). The ISOU was co-chaired by Professor John Forsythe and William Vineall and founded to deliver the OUG vision for maximising the number of people whose lives could be saved through the gift of organ donation via:

- Bringing together those with a role in leading implementation of the OUG recommendations (including patients, lay representatives and devolved government representatives),
- Prioritising and aligning implementation activity
- Providing updates on progress (including to Ministers)
- Monitoring implementation activity
- Identifying and addressing issues with implementation

Aim of the event

The ISOU Digital Workshop brought together NHS England, NHS Blood and Transplant, clinicians, patient representatives and stakeholders to explore the current issues with data provision in the transplant pathway, opportunities for improvement and explore how to implement the Organ Utilisation Group's 7th recommendation.

A copy of the programme for the event is provided at Annex A.

Outcome

The content of the ISOU Digital Workshop was reported via ISOU to the DHSC, summarising the discussion, required actions and action owners to address recommendation 7 of the Organ Utilisation Group (OUG) report. Once cleared by Ministers at the DHSC, actions would be delegated to the relevant organisations.

Attendees and involved organisations

There were 23 delegates representing organisations across the transplant landscape including the clinical workforce, NHS Blood and Transplant, NHS England, Patient Representatives, and the DHSC. Abhay Pradhan, Head of Analytics at the London Stock Exchange Group (LSEG) also attended as an external contributor, as described in the section below.

A list of organisations represented at the meeting is provided at Annex B.

Approach

The programme and approach for organising the event and delegate invite list was co-produced with NHSBT, NHSE and patient representatives.

The workshop started with presentations to set the background to the event and context. This included a 'look out to look in' presentation by Abhay Pradhan from the LSEG. Delegates were sat at a 'horseshoe' style table to discuss current actions underway and opportunities for improvement in data provision and how these improvements can be delivered. An online survey tool was used throughout the workshop to record reflections and feedback on the questions asked. Discussion was captured via the nominated scribe, Microsoft Teams transcript and the online reflection/feedback tool.

Presentations

Delegates were provided with a series of talks and presentations to set the context and perspective of data provision in transplant services, including:

- The Organ and Tissue Donation Perspective
- The Transplantation Perspective
- The Patient Perspective
- NHS England Perspective – Data and Analytics
- NHS Blood and Transplant Perspective – Digital Architecture

Slides presented at the workshop are provided at Annex C.

Summary of Group Discussion and Next Steps

The Digital Future: views from the London Stock Exchange Group

The Head of Analytics at the London Stock Exchange Group (LSEG), Abhay Pradhan, opened the presentation series of the ISOU Digital workshop and discussed the critical role of trusted data in both the finance and health sector. He highlighted how the LSEG relies on robust governance, shared responsibility, and industry best practices to ensure data quality and trust. Pradhan explained that while AI brings analytical opportunities, it introduces risks like bias and privacy concerns, underscoring the need for ongoing human oversight. Delegates discussed the value of treating data as a strategic asset, investing in IT infrastructure, standardising data, and innovation in the healthcare system.

Theme 1: Where are the opportunities for improvement?

Presenter and delegate feedback

Opportunities for improvement from an organ and tissue donation perspective were shared, highlighting inadequate WiFi coverage in Intensive Care Units, outdated technology, and limited inter-hospital connectivity as significant barriers to efficient healthcare delivery during the donation and retrieval process. It was noted that clinical staff often face challenges accessing digital systems, especially when moving between hospitals and trusts. This is particularly true for Specialist Nurses in Organ Donation (SN-ODs), who are often considered external contractors and therefore frequently have limited access to IT systems. Delegates acknowledged that communication between SN-ODs and hospital teams could be more proactive when a patient's prognosis is poor, to give more time for highly sensitive, less rushed discussions with potential donor families about the possibility of their loved one becoming a life-saving donor. This discussion concluded with a call to prioritise digital infrastructure, empower SN-ODs with systems access, collaborate across NHSBT, DHSC and hospital trusts and embed change management into every digital investment.

From an organ transplantation perspective, delegate discussion identified several opportunities for improvement, including the provision of accurate, comprehensive and timely donor and recipient data. The current system often leaves clinicians without access to all relevant data, forcing lower quality clinical decisions such as unnecessary excessive risk taking or risk avoidance, which can negatively impact

patient care. Delegates noted that opportunities lie in shifting towards a unified digital system for patients and clinicians, enabling near real-time access to personalised data, including pre- and post-transplant medical data, two-way communication and digital decision aids.

Delegates noted there are opportunities to improve donor-recipient matching through better integration of genomic data from both patients and donors and sharing this information between laboratories and the Organ and Tissue Donation and Transplantation (OTDT) national transplant database (NtXD). Implementing advanced compatibility technologies, such as high-resolution Human Leukocyte Antigen (HLA) typing for deceased donors, combined with the ability to digitally capture this data nationally, would provide more complete and clinically relevant data for matching donor organs with recipients. Delegates discussed how modernising these systems will help address risks associated with outdated technology, such as health inequalities, transcribing errors, and missed opportunities for optimal donor-recipient matching, and will position the UK to deliver safer, more efficient, and more equitable transplant care.

Patients often encounter inconsistent and fragmented information about transplantation, which can lead to confusion, anxiety, and inequality. Many are required to manage their own data and updates, a task that is especially challenging for those who are unwell or less digitally confident. This situation places additional responsibility on patients and may result in errors and misunderstandings. Delegates discussed a key opportunity for improvement is to create a central, accessible repository of patient information, written in plain language and linked in every clinic letter, so that patients can easily find the information they need.

“Specialist Nurses in Organ Donation (SN-OD) often struggle to access staff or contractor Wi-Fi networks in hospitals, as they are not employed by the Trust or Health Board. Although their devices have mobile connectivity, poor 4G or 5G signal within the hospital means they must either move to areas with better reception or pay for patient Wi-Fi. Even when Wi-Fi is available, coverage in crucial areas like the intensive care unit or operating theatre is frequently inadequate. As a result, SN-ODs may need to relocate to find a reliable connection just to submit essential data, which is both time-consuming and especially challenging overnight when parts of the hospital are secured.”

- John Richarson, NHSBT Assistant Director - Organ & Tissue Donation

“As a transplant patient, it’s unsettling to realise that the advice you receive can depend on where you’re treated. I discovered that, in some units, patients are routinely told not to eat blue cheese after their transplant, while in others it’s never mentioned. When such basic information isn’t consistent, it makes you question what else might be missing. Clear, accessible and uniform information is vital for patients to feel confident and safe in managing their health.”

- A liver transplant patient at an ISOU Patient Engagement sub-group visit.

“Too often, I’ve had to chase blood test requests between my specialist hospital, GP, and local hospital, with results frequently going missing. Like many other patients, I have ended up driving a four-hour round trip to the specialist hospital just to ensure the results will not be lost. If test requests and results could be managed digitally, for example via QR codes sent to a phone and uploaded automatically, it would save time and frustration for everyone involved.”

- Dan Peel, lung transplant recipient and ISOU patient representative

Theme 2: What actions are underway or planned?

Presenter and delegate feedback

The NHS Single Patient Record (SPR) is a broad transformation effort to connect health records across care centres. Rather than functioning as a standalone app or website, the SPR will serve as an interconnected system that brings together a range of health information, including patient records, genomics and research data, so clinicians and patients can access these resources through connected services. Clinicians will have real-time access to patient information, and future plans include more patient input and remote monitoring. Delegates discussed that the focus of the SPR is within England and there are no immediate plans to expand to other devolved nations. Pilot projects are expected by the end of 2026/27. A call to consider the uniqueness of the transplant pathway in design and implementation of the SPR was heard and taken back to the SPR team.

NHS Blood and Transplant (NHSBT) is digitising pathways by consolidating systems onto fewer, modern platforms and reducing duplication. They are building a central, standardised collection of data, known as a Data Lake, which will bring together data from different sources and ensure it is consistent and accurate, supporting analytics and AI use. NHSBT is also hoping to integrate this with the wider NHS through the SPR and Federated Data Platforms (FDP). This will enable data sharing between NHSBT, hospitals and GPs, improving efficiency and data quality. The adoption of national standards will ensure data can flow securely and in real time across organisations, reducing manual data entry and supporting collaboration across the healthcare system.

Theme 3: How can we deliver improvement?

Empowering patients through data and choice - summary of key workshop reflections

In the workshop, delegates highlighted that empowering patients requires accessible, trustworthy digital tools and clear information. Delegates explored provision of data through mobile apps to guide patients navigating transplant choices, with features such as shared care plans and culturally sensitive support. The integration of clinical and pathway data into the NHS app was discussed as a means of creating a single, dependable source of information for patients. The group emphasised the importance of capturing PROMs and PREMs as well as targeted surveys and direct channels for feedback, as mechanisms to ensure patient voices directly influence service improvements, thereby promoting greater transparency and accountability.

Significant barriers remain to accessing information, particularly for less-heard voices. These include challenges in accessing reliable information, limitations in digital infrastructure, language and cultural barriers, and the diversity of data sources. In addressing these issues, the group explored the co-production of resources between patients and clinicians, and an awareness of the costs and connectivity difficulties faced by patients in rural communities. Crucially, delegates noted that GDPR is designed to empower individuals, not restrict their access to essential health information

“As someone who is immunosuppressed, I have often had to act as the link between my GP and hospital team. I was once prescribed a macrolide antibiotic in primary care, which can dangerously increase levels of immunosuppression. The issue was only avoided because I recognised the risk myself. Patients should not have to rely on their own vigilance to prevent avoidable harm; effective sharing of medical information between GPs and hospital services is essential.”

- A transplant patient

Building a Connected Digital Infrastructure - summary of key workshop reflections

Building a connected digital infrastructure to improve organ utilisation will depend on modernising legacy systems and digitising paper-based processes. Delegates commended existing connected digital system initiatives such as the roll out of Epic (an electronic health record software) in some trusts and the London Care Record which allows links between primary, secondary, and tertiary care in London. It was noted that new developments should ensure compatibility with wider NHS systems and help patients navigate different platforms without the need for multiple logins for their various conditions and hospital visits. The group emphasised the importance of GDPR being centred around people’s needs and explored whether AI could digest paper-based records to facilitate digital transformation. However, challenges were acknowledged including limited interoperable digital infrastructure, scarcity of legacy system expertise, and a culture resistant to change. The group concluded there is a need for organisational collaboration and the co-production of resources, including with patients.

Innovation Across the Transplant pathway - summary of key workshop reflections

The group emphasised that by strengthening digital data recording and forging links between donor and potential recipient data, NHSBT can better match donor organs to patients, which may reduce the frequency of declined offers. The group discussed impact measurement for innovation initiatives. Patient feedback, gathered through surveys, focus groups and direct engagement, were acknowledged to be essential for understanding whether these changes improve lived experience. Quality of life measures, PREM and PROM feedback, and analysis of health inequalities provide a balanced view of whether digital adoption is achieving its goals. The need for

equitable deployment of these tools across organ types, age groups, and ethnicities, remains a challenge.

Involvement of Trusts in modernising the digital pathway

The group highlighted the importance of treating data as a shared asset for the entire healthcare system, rather than confining its use to individual hospitals or Trusts. In the context of organ donation, access to a donor's comprehensive health record reduces the need to reach out to grieving families and supports informed decision-making at the point of care. Delegate discussion focused on the necessity for Trusts to collect data that drives action, such as monitoring cases, matches, and offers that may not result in donation. Delegates also observed that regional collaboration is enhanced by shared terminology and digital solutions. Ongoing communication and transparent data sharing would contribute to the dissemination of best practices and help decrease the number of non-clinical donor organ declines. Furthermore, the group recognised the role Clinical Leads for Utilisation (CLUs) can play in improving data accuracy, promoting the adoption of digital tools, and raising data-related matters at the Board level.

Actions

- Collaboration between NHSBT and NHSE colleagues on the digital data provision initiatives to facilitate data standardisation and connectedness between digital infrastructures.
- Collaboration between NHSBT and NHSE colleagues to ensure that the unique challenges of the transplant pathway are addressed, including day-to-day issues such as SN-ODs' access to hospital IT systems, as well as the planning and implementation of the SPR.
- NHSE SPR colleagues to consider using the transplant pathway as a pilot project in the roll out the SPR.
- NHSE SPR team colleagues recommended to prioritise supporting the timely transfer of hospital prescribed medications on to GP records.
- NHSBT statistics and digital colleagues to work with patients to improve data accessibility, including relocation of OTDT guidance and data to a more user-friendly location on the NHSBT website.

About this publication

Microsoft 365 Copilot was used to assist with editing and improving clarity. All content was reviewed, validated and approved by Department of Health and Social Care officials who remain responsible for the final text.

	Patient Communication	<p>Richard Battle, Consultant Clinical Scientist, Scottish National Blood Transfusion Service (SNBTS)</p> <p>Jessica Jones, ISOU Patient Engagement sub-group Co-Chair; ISOU cardiothoracic patient representative</p> <p>Maria Ibrahim, Resident Doctor, Royal Preston Hospital</p>
11:30-11:40	Tea & Coffee break	
11:40-12:10	<p>What actions are currently underway or planned?</p> <p>NHS England</p> <p>NHS Blood and Transplant</p>	<p>Henry Holms</p> <p>Single Patient Record Tech, Systems, and Data Lead</p> <p>James Fishwick, Chief Architect, NHS Blood and Transplant</p>
12:10 - 13:00	<p>Workshop – how can we deliver improvements?</p> <p>Empowering Patients Through Data and Choice</p>	All

	Building a Connected Digital Infrastructure	
13:00-13:30	Lunch	
13:30-13:40	Reflections from NHSBT & NHSE	NHSE-TBC James Fishwick, Chief Architect, NHS Blood and Transplant
13:40-14:20	Workshop – how can we deliver improvements? Discussions focused on: Innovation Across the Transplant pathway Involvement of Trusts in modernising the digital pathway	All
14:30-14:45	Next steps, thank you and close	John Forsythe, Co-Chair of ISOU, Department of Health and Social Care

Annex B - Participants attended from the following organisations

- Department of Health and Social Care
- NHS Blood and Transplant
- NHS England
- North Bristol NHS Trust
- Guy's and St Thomas' NHS Foundation Trust
- Nottingham University Hospitals NHS Trust
- Royal Preston Hospital
- Scottish National Blood Transfusion Service
- London Stock Exchange Group

Annex C - Slides presented at the workshop



Department
of Health &
Social Care

ISOU Digital Workshop

To address recommendation 7 of the Organ Utilisation Group (OUG) report concerning the provision of data.

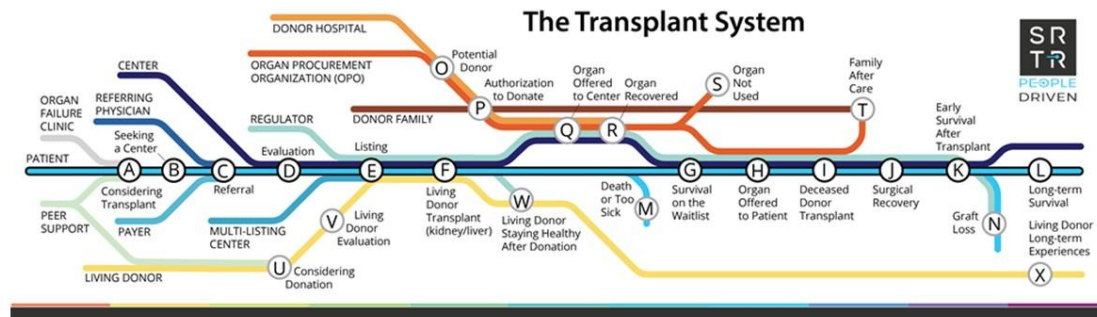
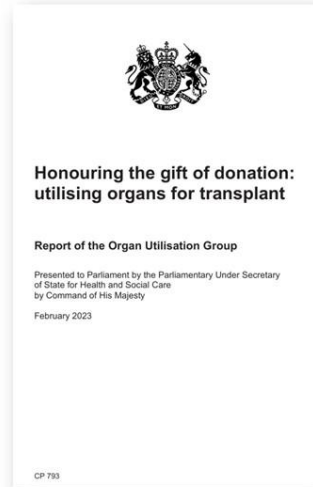
18th November 2025

Welcome and aims

John Forsythe, Co-Chair of ISOU, Department of Health and Social Care

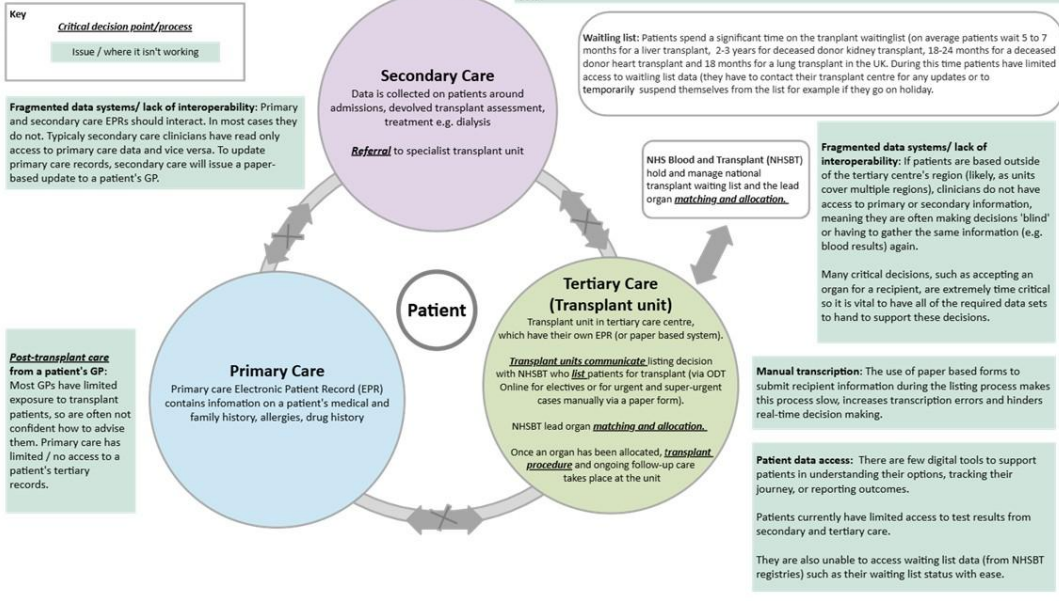
Organ Utilisation Group Rec. 7

The provision of data must be transformed using digital approaches to provide access to complete, accurate and standardised data and information to everyone who needs it at critical decision points throughout the donation to transplantation pathway.

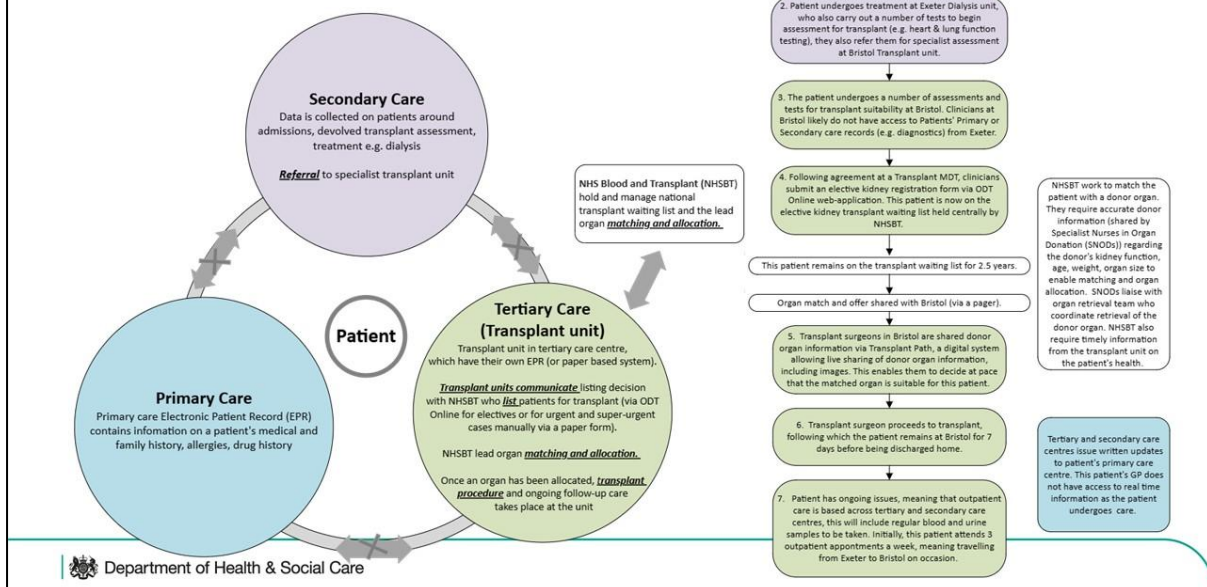


<https://www.srtr.org/about-srtr/the-task-5-initiative/>

Transplant recipient data flow and issues



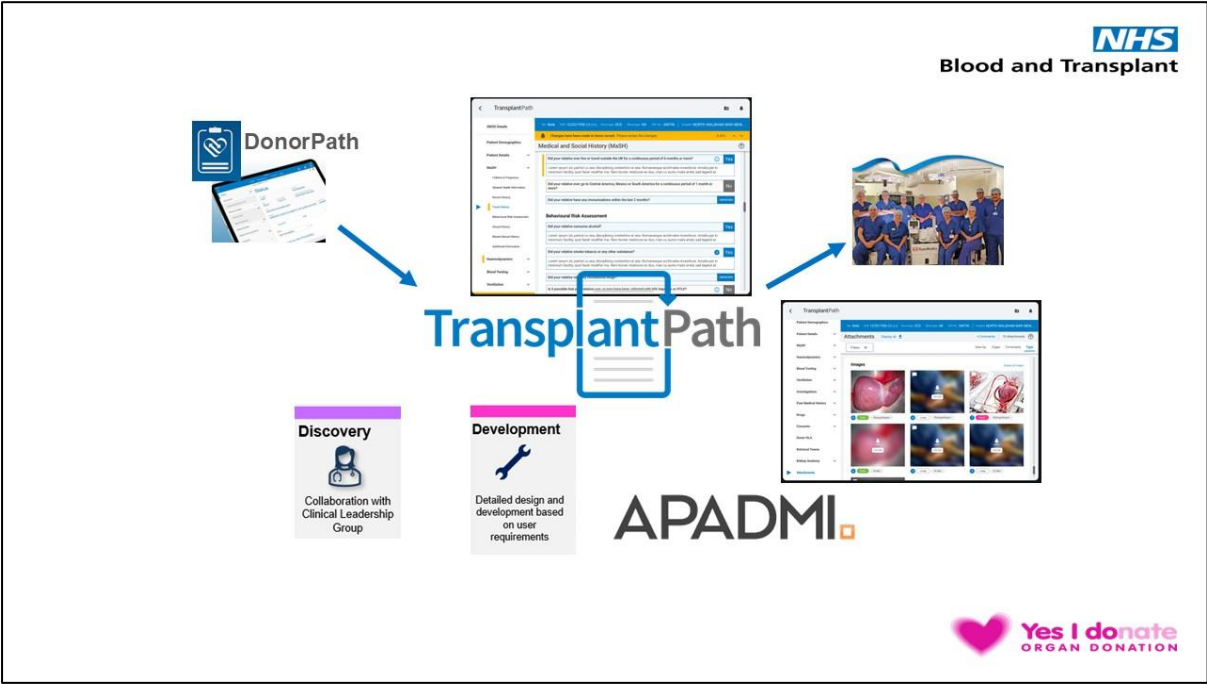
Kidney transplant recipient example pathway & data flow

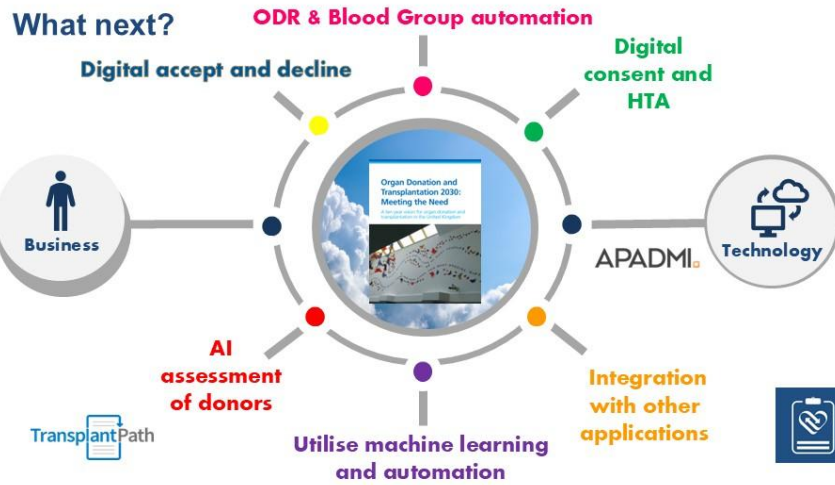


Where are the opportunities for improvement?

Organ Donation

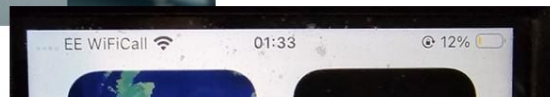
Where are the opportunities for
Improvement?





Hospital Wi-Fi – The Hidden Bottleneck

- Poor connectivity costs UK healthcare staff 122 hours per year
- Fragmented Wi-Fi infrastructure causes dead zones
- Upgrade to medical-grade Wi-Fi and explore Wi-Fi 6 / Private 5G



System Interoperability – Breaking Down Silos



Fragmented IT systems create data silos



Lack of interoperability leads to inefficiencies and errors



Adopt UK Core FHIR standards and APIs for real-time data exchange



SNOD System Access in Hospitals



SNODs face inconsistent access to hospital systems



Delays in donor referral and consent processes



Enable secure remote access and standardise workflows



Ability to Meet the Need for System Change



Funding alone doesn't solve barriers



Leadership instability and resource shortages hinder progress



Invest in change management and workforce training



Call to Action



Prioritise digital infrastructure as enablers of patient safety



Empower SNODs with system access



Embed change management into every digital investment



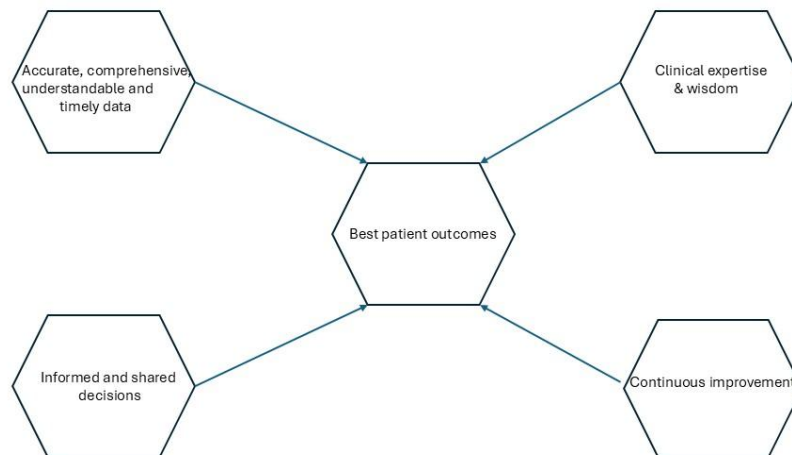
Collaborate across NHSBT, DHSC, and hospital trusts



Digital opportunities for better patient outcomes

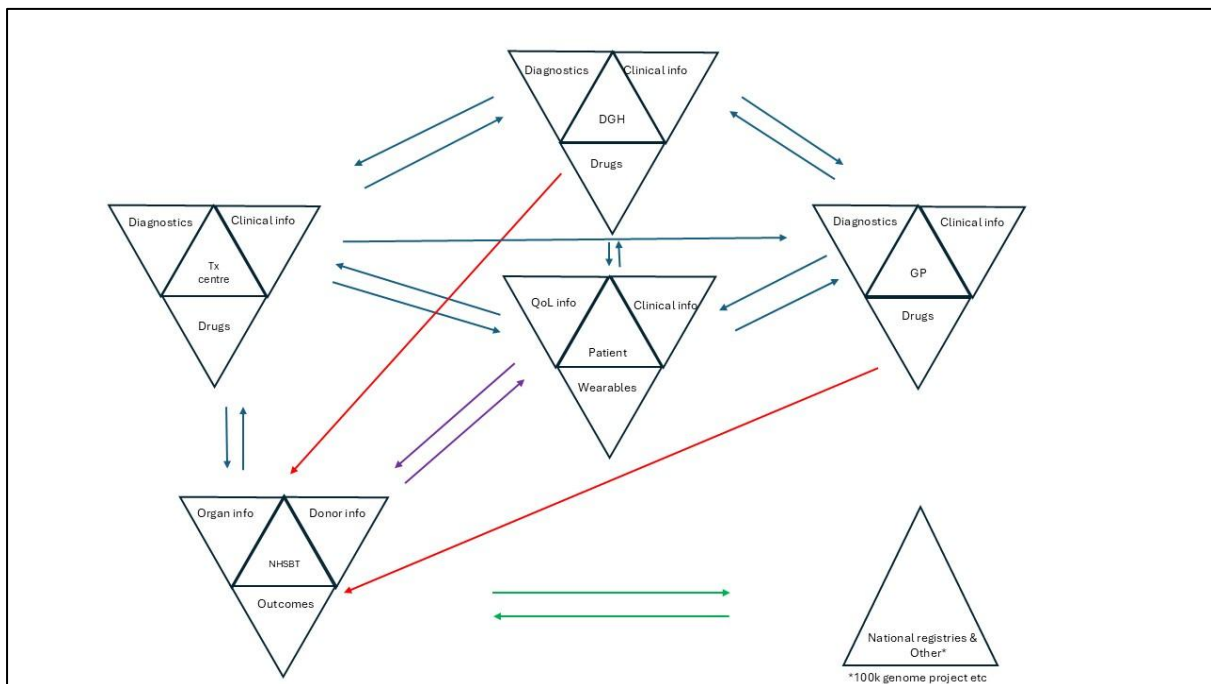
Dr Rommel Ramanan
Deputy Medical Director OTDT/NHSBT
Consultant Nephrologist North Bristol NHS Trust

The pillars for best quality clinical decisions



Organ transplantation decisions

- Comprehensive donor data
- Comprehensive, up to date, recipient data
- Data driven organ matching algorithms
- Outcome data and continuous improvement



The aspiration

- NHS/NHSBT app on patient's phone with (near) real time pre and post transplant information enabling two-way comms with all care professionals + digital decision aids
- Single digital portal with all data (historic and longitudinal) on organ donor/organ recipient accessible to clinicians and NHSBT + NHSBT app on clinician phones with digital decision aids
- Linked data sets + two-way communication with patients for continuous improvement

ISOU Digital Workshop Nov 2025

Advancing Compatibility Assessment in Transplantation

A reminder – OUG recommendation 9 (Innovation)

- As part of the ISOU response to recommendation 9 a sub-group was set up with the mandate to evaluate and **make recommendations concerning new ways for laboratory transplant compatibility assessment and related technologies – implementation 5-10 years**
- Recommendations published December 2024 and consisted of three themes.
- Theme 1 “Better Matching – Latest Technology”
 - **This included digitalisation recommendations**

Theme 1 Recommendations

1) Implementation of Advanced compatibility Technology

Integrate latest laboratory technology to improve donor-recipient matching and transplant success rates. **(In progress)**

2) IT Infrastructure Upgrades

Upgrade NHS IT systems to support complex data processing for advanced transplant technologies (e.g. Centre LIMS, NTxD).

3) Data-Driven Transplant Outcomes

Utilise improved transplant data to enhance patient outcomes and ensure equitable access.

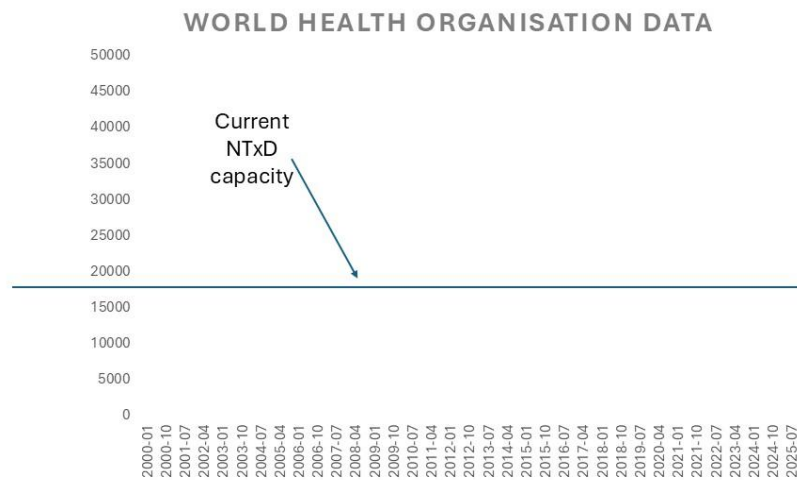


How does the UK compare at present?

Capability	United Kingdom (NTxD)	Europe (Eurotransplant)	United States (OPTN)	Australia (OrganMatch)
Virtual crossmatching (allocation)	✓	✓	✓	✓
High Resolution Data	✗	✓	✓	✓
All clinically important compatibility variables (HLA)	✗	✓	✓	✓
WHO derived data	✗*	✓	✓	✓ (indirectly)

*WHO data updates no longer supported

Compatibility variants and NTxD capacity



Risks and Impact

Risks –

- **Donor –**
 - Disadvantage ethnic minorities
 - Health inequalities
 - Poorer donor experience
- **Patient –**
 - Poorer patient outcomes
 - Disadvantage ethnic minorities
 - Health inequalities
 - Poorer patient experience

Impact

- Inability to implement best practice
- Poor use of precious donor organs
- Resource heavy (manual processes which should be digitalized)
- Prolonged transplant waiting times

Drivers for change

- **Reduce risk / resource implications** of current system
- **Reduce risk to transplant patient**
- ISOU H&I **subgroup innovation recommendations dependent upon change**
“Availability of high-resolution compatibility datais essential to derive alternative organ allocation algorithms to improve long term patient outcomes and/or reduce inequity due to ethnicity or other demographic factors”
- **NHS 10-year plan** digitalisation ‘Fit for the future’
 - NHS transplant compatibility/allocation digital infrastructure is a ‘global laggard’
 - Change will ‘liberate front line staff from bureaucracy and admin’

Confidence Through Consistency: Why Information Equity Matters

Jessica Jones | Co-Chair, ISOU Patient Engagement Sub-group,
ISOU CT Patient Representative

The Patient Voice



PATIENTS NOTICE THE
CRACKS BEFORE ANYONE
ELSE DOES



REPORTS OF INCONSISTENT
INFORMATION BETWEEN
CENTRES

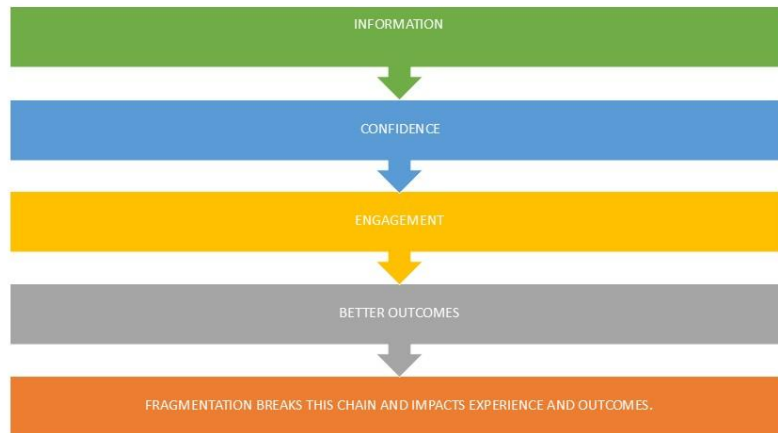


PATIENTS HEAR DIFFERENT
ADVICE FROM PEERS AND
ONLINE



VARIATION UNDERMINES
CONFIDENCE AND SAFETY

Information as a Building Block



The
Problem:
Fragmented
and Hidden
Information

Good NHSBT/ODT information
exists but is buried online

Centres create their own
materials – rarely aligned

Patients end up managing data,
results, and updates themselves

The burden of managing
information falls on patients.

Consequences



Confusion and anxiety when advice conflicts



Those most digitally confident benefit most → widening inequality



Variation consumes time for both patients and teams



Information inconsistency has become a quiet driver of inequality.

The Opportunity

Create one national, co-produced, central repository.

Regularly reviewed, accessible, and in plain language.

Link the repository in every clinic letter → Any patient can open any letter and find trusted information.

Central updates ensure consistency and accuracy.

System Benefits



Safer care, fewer misunderstandings.



Reduced duplication between centres.



Supports mental health and confidence.



Builds equity and efficiency across the system.

The Call to Action

Consistency must be non-negotiable

Every digital tool should link to shared, co-produced content

National standardisation of patient information.



Closing

Imagine a future where every patient,
no matter where they are, receives the
same clear, trusted information- every
single time. That's not just access;
that's empowerment.

By making information equity a reality,
it doesn't just build trust- it has a
material impact on lives and outcomes.

Enhancing Organ Utilisation in Transplantation: The Role of Effective Patient Communication

Maria Ibrahim
ISOU Digital Workshop
18th November 2025

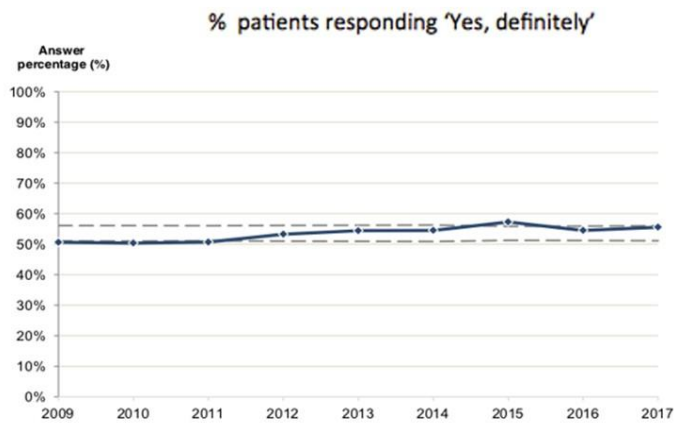
Introduction

To make good decisions we need good evidence which must be clearly communicated

'To inform and not persuade'

Information should be useful and trustworthy

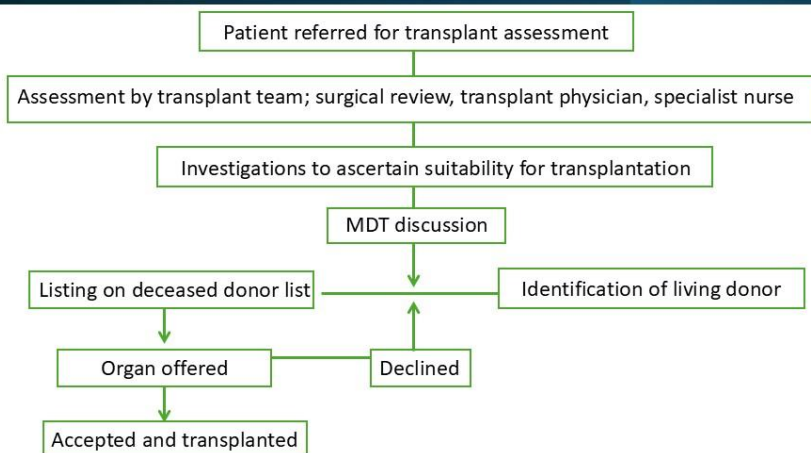
Were you involved as much as you wanted to be in decisions about your care and treatment?



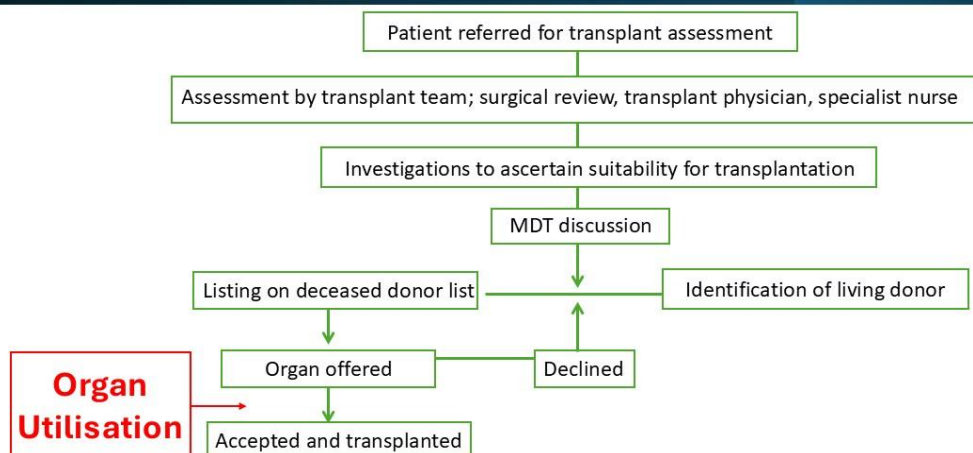
Number of respondents: 2009 (67,580), 2017 (70,759)

NHS Inpatients Survey, CQC

Kidney transplant recipient journey



Kidney transplant recipient journey



Risk communication

- The first urn has **10** marbles in it, **1** of which is red
- The second urn has **100** marbles in it, **8** of which are red

Which bowl would you like to choose from?

Daniel Kahneman: Thinking, Fast and Slow

Risk communication

- Which of the following represents the biggest risk?

1 in 100 or **1 in 1000** or **1 in 10**

Galesic & Garcia-Retamero, 2010

Risk communication

Chances of Survival

Vs

Risk of Death

Risk communication

- Provide understandable information
 - Denominator neglect
 - Framing

Risk communication

- Provide understandable information
 - Denominator neglect
 - Framing
- Information to be given in a variety of ways
 - Impaired vision
 - Illiteracy and innumeracy
 - Multilingual

Risk communication

- Provide understandable information
 - Denominator neglect
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- Accessible at different time points for patients

Risk communication

- Provide understandable information
 - Denominator neglect
 - Framing
- Information to be given in a variety of ways
 - Impaired vision
 - Illiteracy and innumeracy
 - Multilingual
- Accessible at different time points for patients
- Communicate uncertainty

Current methods of communication in the UK

- Face to face consultations - consent clinics
- Leaflets
- Annual reports
- Infographics
- Risk-communication tool

Risk communication tools



Lung Risk Communication Tool

To help decision making when considering a lung transplant.

[» Access the tool](#)

Kidney Risk Communication Tool

To help decision making when considering a kidney transplant.

[» Access the tool](#)

Ron Stratton Liver Risk Communication Tool

To help decision making when considering a liver transplant.

[» Access the tool](#)

Heart Risk Communication Tool

To help decision making when considering a heart transplant.

[» Access the tool](#)

Pancreas Risk Communication Tool

To help decision making when considering a pancreas transplant.

[» Access the tool](#)

<https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/risk-communication-tools/>



[< Instructions for use](#) [About NHSBT Kidney Risk Communication Tool](#) **[Kidney Risk Communication Tool](#)** [Contact](#) [>](#)

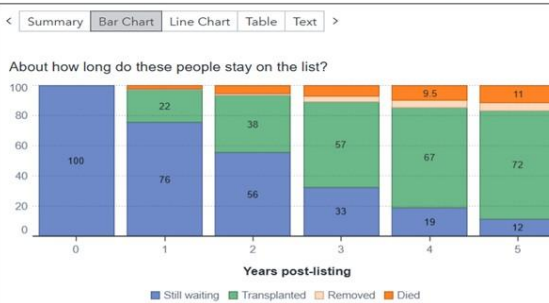
Please select your centre:

[< Waiting time](#) [Deceased donor patient survival](#) [Deceased donor graft survival](#) **[Living donor patient survival](#)** [Living donor graft survival](#) [Background information](#) [How to use](#) [>](#)

Please select patient characteristics:

i Age at registration 50-59	i Sex Male	i Ethnicity White
i Blood group O	i Graft Number First kidney transplant	
i Matchability score 1-3 Easy	i On Dialysis at registration? Yes	
i Highly sensitised cRF>=85%? cRF <85%	i Primary renal disease - diabetes? No	

Results for a patient who entered the same information as you



Risk communication tools - ODT Clinical - NHS Blood and Transplant

NHS Blood and Transplant

< Instructions for use About NHSBT Kidney Risk Communication Tool **Kidney Risk Communication Tool** Contact >

Please select your centre:

< **Waiting time** Deceased donor patient survival Deceased donor graft survival Living donor patient survival Living donor graft survival Background information How to f >

Please select patient characteristics:

i Age at registration: 50-59
i Sex: Male
i Ethnicity: White

i Blood group: O
i Graft Number: First kidney transplant

i Matchability score: 1-3 Easy
i On Dialysis at registration?: Yes

i Highly sensitised cRF >=85%?: cRF <85%
i Primary renal disease - diabetes?: No

Results for a patient who entered the same information as you

< Summary Bar Chart **Line Chart** Table Text >

About how long do these people stay on the list?

Years post-listing	Still waiting (%)	Transplanted (%)	Removed (%)	Died (%)
0	100	0	0	0
1	~75	~25	0	0
2	~55	~45	0	0
3	~35	~65	0	0
4	~19	~81	~0.5	~0.5
5	~10	~90	~1	~1

Risk communication tools - ODT Clinical - NHS Blood and Transplant

NHS Blood and Transplant

< Instructions for use About NHSBT Kidney Risk Communication Tool **Kidney Risk Communication Tool** Contact >

Please select your centre:

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Results for a patient who entered the same information as you

< Summary Bar Chart Line Chart Table **Text** >

Select number of years post listing

0 1 2 3 4 5

At 4 years post listing:
 19 out of 100 people will still be waiting on the list
 67 out of 100 people are likely to receive a transplant
 4.6 out of 100 people may be removed from the list
 9.5 out of 100 people may die on the list

Risk communication tools - ODT Clinical - NHS Blood and Transplant

Emerging tools



Overall aim is to deliver and test a clinically-viable clinical decision support tool

1. Model Development - train explainable machine learning models that predict patient outcomes when organ offers are accepted or declined.
2. Integration and regulatory
3. Assess impact: Randomised, prospective clinical trial in three UK transplant centres (Oxford, Coventry and Newcastle)

Transplant communication tools

Country	Communication tool	Patient facing?
US	Kidney Transplant Decision Aid	Yes
	Transplant Models	Perhaps
	iChoose Kidney	Yes
Australia	Waitlist Navigator Tool	Yes
	SimKap	No
Canada	My Transplant Coach	Yes
Netherlands	Kidney Failure Decision Aid	Yes

Kidney Transplant Decision Aid

Introduction	Dialysis vs. Transplant	Living vs. Deceased Donor	Kidney Quality (KDPI) vs. Infectious Risk Kidneys	Deceased Donor Kidney Quality	Increased Infectious Risk Kidneys	Questions for Your Doctor
<input type="button" value="Calculate Your Risks"/>						

Kidney Quality (KDPI) vs. Infectious Risk Kidneys

What are high / low quality deceased donor kidneys and what are infectious risk kidneys?



Kidney Quality

All deceased donor kidneys considered good enough to transplant are given a score (0-100), called the Kidney Donor Profile Index (KDPI). The score is calculated based on 10 factors that help predict how long the kidney will last, the factors are:

- Age



Infectious Risk Kidneys

Some kidneys are donated from people considered at "increased risk" for infectious diseases such as HIV and Hepatitis B and C. The donors have tested negative for these infections, therefore the risk is very low. This category is different from the quality, or KDPI, as these kidneys are likely to be high quality.

Living Kidney Donor Risk Index (LKDPI)

This model predicts recipient risk of graft loss after living donor kidney transplantation based on donor characteristics, on the same scale as the KDPI ...

Massie AB, Leanza J, Fahmy LM, Chow EK et al. A Risk Index for Living Donor Kidney Transplantation. *Am J Transplant.* 2016 Jul;16(7):2077-84

ESRD Risk Tool for Kidney Donor Candidates

This model is intended for low-risk adults considering living kidney donation in the United States. It provides an estimate of 15-year and lifetime incidence of end-stage renal disease...

Grams ME, Sang Y, Levey AS, Matsushita K, Ballew S, Chang AR et al. Kidney-Failure Risk Projection for the Living Kidney-Donor Candidate. *N Engl J Med.* 2016 Feb 4;374(5):411-21.

Infectious Risk Donors

When a patient with end stage renal disease (ESRD) on the waitlist for a kidney is offered an Infectious Risk Donor (IRD) kidney, they need to decide whether they will accept the IRD kidney and the associated infectious risk, or if they will decline it and continue to wait for the next available infectious-risk free kidney ...

Chow, E. K. H., Massie, A. B., Muzaale, A. D., Singer, A. L., Kucirka, L. M., Montgomery, R. A., ... & Segev, D. L. (2013). Identifying appropriate recipients for CDC infectious risk donor kidneys. *American Journal of Transplantation*, 13(5), 1227-1234.

Transplant Candidacy for Patients 65+

This prediction model is intended for adults with ESRD on dialysis aged 65 and above; it provides the predicted probability of 3-year survival after kidney transplantation (KT). Patients with predicted 3-year post-KT survival in the top quintile are deemed "excellent" candidates ...

Grams, M. E., Kucirka, L. M., Hanrahan, C. F., Montgomery, R. A., Massie, A. B., & Segev, D. L. (2012). Candidacy for kidney transplantation of older adults. *Journal of the American Geriatrics Society*, 60(1), 1-7.

Pediatric Transplant: Living or deceased donor first?

Most pediatric kidney transplant recipients live long enough to require retransplantation. The most beneficial timing for living donor transplantation in candidates with one living donor is not clear...

Van Arendonk, K. J., Chow, E. K., James, N. T., Orandi, B. J., Ellison, T. A., Smith, J. M., Colombani, P. M., & Segev, D. L. (2012). Choosing the Order of Deceased Donor and Living Donor Kidney Transplantation in Pediatric Recipients: A Markov Decision Process Model. *Am J Transplant*, 9(2):360-6.

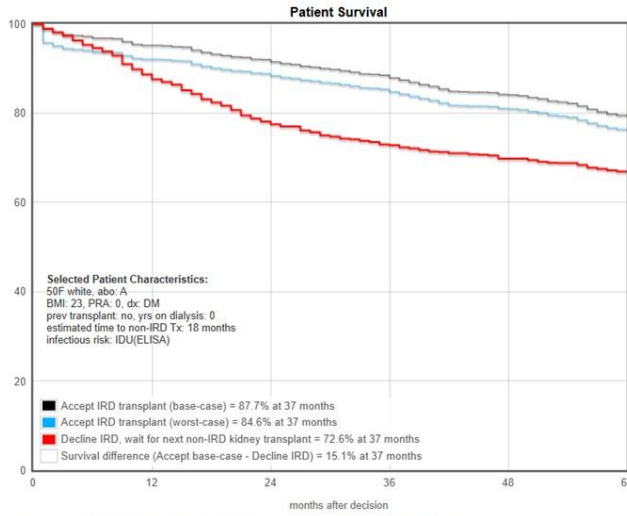
Postdonation Risk of ESRD in Living Kidney Donors

Risk estimation is critical for appropriate informed consent and varies substantially across living kidney donors.

Massie, Allan B., et al. "Quantifying Postdonation Risk of ESRD in Living Kidney Donors." *Journal of the American Society of Nephrology* (2017): ASN-2016101084.

<http://transplantmodels.com/>

Johns Hopkins IRD Kidney Transplant Calculator



Recipient Characteristics:

Age: (20-75)

Gender:

ABO:

Ethnicity:

BMI: (19-39)

PRA: (0-100)

Renal failure diagnosis:

Previous transplant:

Years on waitlist:

Estimated time remaining until non-IRD transplant

*: This is time in addition to the time the patient may have already waited. eg: if a patient has spent 1 year on the waitlist, and the estimated time remaining until a non-IRD transplant is 18 months, the patient is expected to have waited 30 months since listing, before a non-IRD transplant.

Donor Characteristics:

Infectious Risk Behavior:

Serology Testing Used:

base-case estimate: mortality risk (if seroconverted) increased by 4.12% HIV, 3.42% HCV per year
 worst-case estimate: mortality risk (if seroconverted) equivalent to immediate (100% chance) death

<http://transplantmodels.com/>

SEX

Male
 Female

AGE AT DIALYSIS START

Years

RACE

White
 Black or African-American
 Other

ETHNICITY

Hispanic
 Non-Hispanic

TIME ON DIALYSIS

Select a **Dialysis Type** above to access these options.

< 6 months 6-12 months
 > 1-2 years > 2-3 years
 > 3-5 years > 5-7 years
 > 7-10 years > 10-14 years
 > 14 years

PATIENT HISTORY

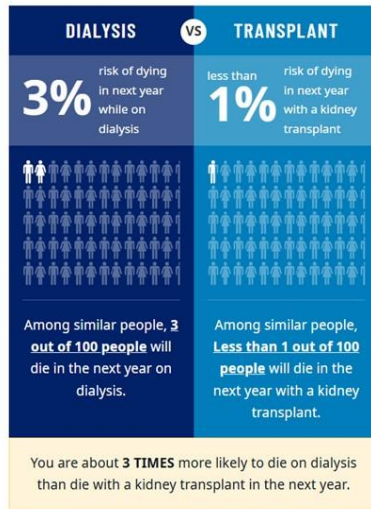
Select all that apply:

Hypertension
 Diabetes
 Low Albumin (Less than 3.5 g/dL)
 Cardiovascular Disease

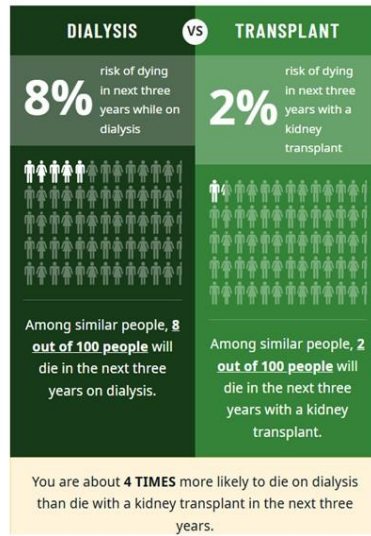
VIEW AS

Mortality Risk
 Survival Benefit

1-Year Mortality Risk



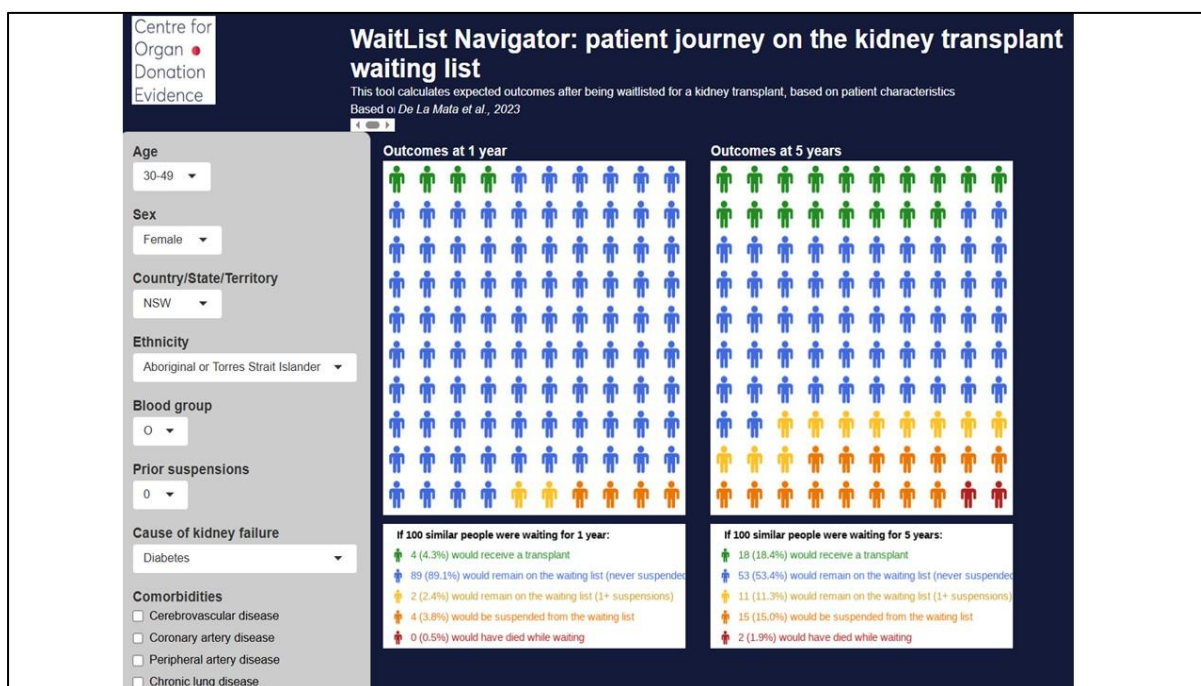
3-Year Mortality Risk



iChoose Kidney | Emory University | Atlanta GA

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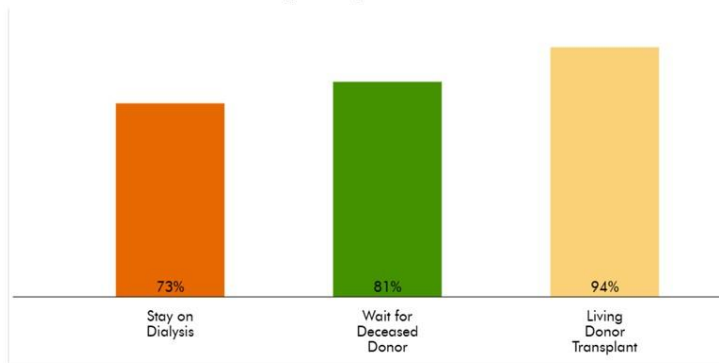


Launch My Transplant Coach



Height: Feet Inches
 Weight: Pounds

My Transplant Coach



Graph 1: Patients with your characteristics

[NEXT SCENE](#)


This graph demonstrates the percentage of patients with your characteristics who are alive in 5 years if they chose to remain on dialysis, are placed on a local waiting list and possibly receive a deceased donor kidney transplant, or who receive a living donor transplant.

[EMAIL GRAPHS TO ME](#)


- 1
- 2
- 3
- 4
- 5
- G1
- 6
- G2
- 7
- 8
- 9

Transplant communication tools


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Starting the process of SDM


1 Team talk and option talk




The nephrologist explains the patient's diagnosis and treatment options using the **hand-out sheet**. Each hand-out contains a weblink and unique log-in code for the interactive website.


During the process of SDM


2 Decision support



The patient reads the information in the **interactive website** and lists his/her goals, considerations and treatment preferences.


Concluding the process of SDM

3 Decision talk

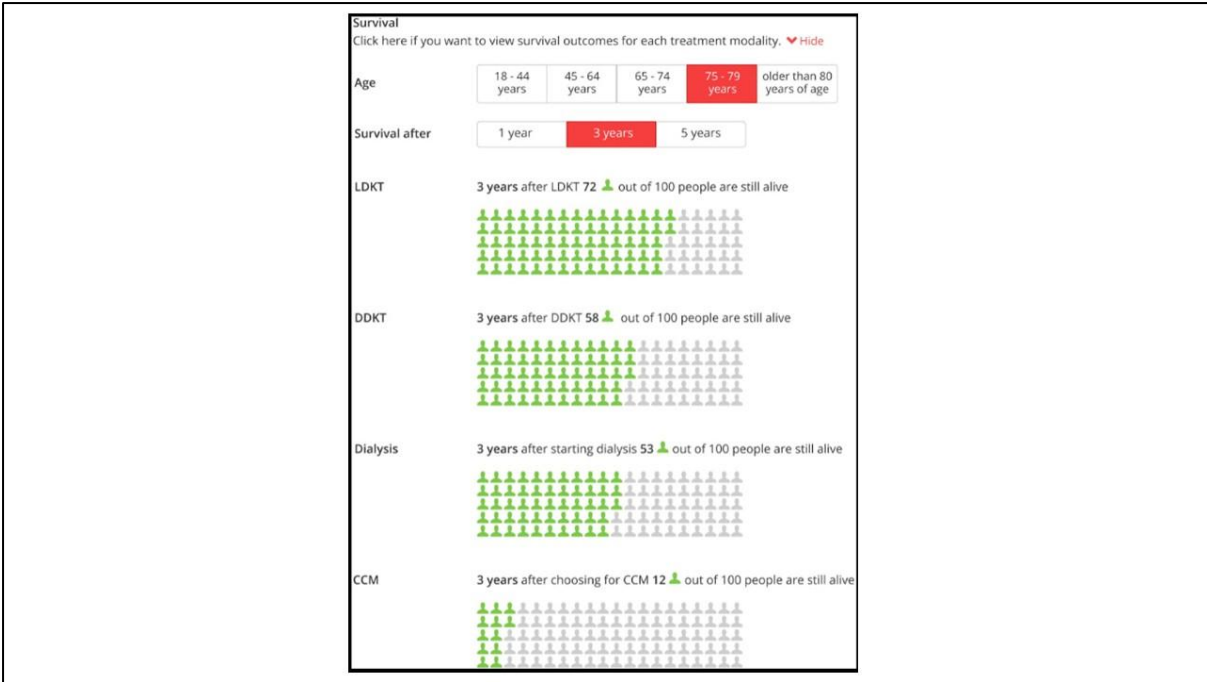


Patient and nephrologist discuss the patient's goals, consideration and preferences, supported by the **personal summary sheet**. Together they make a shared treatment modality decision.

[BMC Nephrol. 2022 Jul 6;23\(1\):236. doi: 10.1186/s12882-022-02853-0.](https://doi.org/10.1186/s12882-022-02853-0)

Development of an online patient decision aid for kidney failure treatment modality decisions

© ZoraKeuzelLab



AI tools

Mission Team Sign Up Investor

Empowering Transplantation Decisions with Precision AI. ↓

Revolutionizing patient care through intelligent, data-driven clinical decision support. Developed with clinicians for clinicians.

“Digital extension of senior expertise”

<https://www.viska.ai/>

Future potential

THE LANCET
Digital Health

Development and validation of a machine-learning model to reduce futile procurements in donations after circulatory death in liver transplantation in the USA: a multicentre study

Rintaro Yanagawa, Kazuhiro Iwadoh, Toshihiro Nakayama, Daniel J Firl, Chase J Wehrle, Yuki Bekki, Daiki Soma, Jiro Kusakabe, Yuzuru Sambommatsu, Yutaka Endo, Kliment K Bozhilov, Jenny H Pan, Masaru Kubota, Koji Tomiyama, Masato Fujiki, Magdy Attia, Marc L Melcher, Kazunari Sasaki

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Organ donation



New AI tool could cut wasted efforts to transplant organs by 60%

Machine learning model predicts whether donor is likely to die within the timeframe that liver remains viable

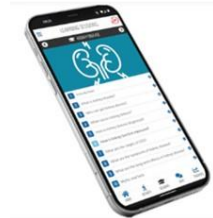
Future potential

- Individualised patient journey mapping
- Transparency
 - Organ offers
 - Reason for decline
 - Centre performance
- Improved prediction modelling
- We need to ask patients what they want!

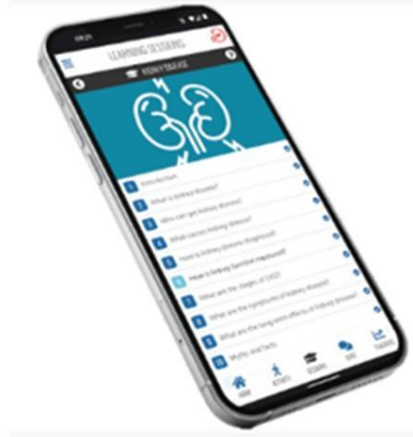


Summary

- Effective communication
- Patient engagement
- Individualised
- IT infrastructure support
- Optimising organ utilisation vs increasing utilisation rates



Thank you



maria.ibrahim@nhsbt.nhs.uk

Tea and Coffee break (10 mins)

11:30 – 11:40

What actions are currently underway or planned?

NHS Blood and Transplant

James Fishwick, Chief Architect, NHS Blood and Transplant

What actions are currently underway/planned



What do we plan to do?



Digitise pathways

Remove manual processes and digitise end-to-end clinical and operational pathways.



Modernise technology

Reduce tech debt and build modern, modular platforms to support safe, scalable transformation.



Unlock and connect data

Bring NHSBT data together into a single, standardised data lake to support data insights, TREs and AI.



Integrate our systems

Connect systems so data flows securely across NHSBT, hospitals, GP and transplant centres.



Use AI and automation

Deploy practical AI solutions to improve decisions, reduce workload and automate everyday tasks.

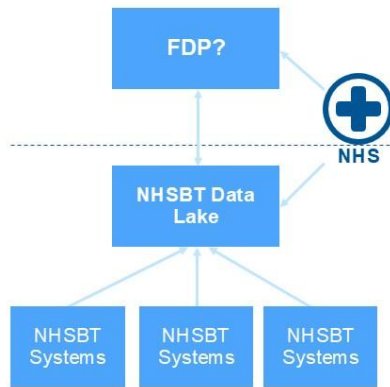
Modernise technology



- Standardise to fewer, strategic platforms
- Build modular architecture
- Reduce technical debt
- Improve resilience
- Enable faster delivery



Unlock and connect data



Federated Data Platforms (FDP)

FDP could **potentially** bring together multiple data sets from NHSBT, hospitals, GPs and transplant centres.

NHSBT Data Lake

Aims to bring data from all systems into one Data Lake in standard data formats. This enables:

- Single trusted source of data for analytics
- Secure TREs
- AI and machine learning applications
- Real-time predictive insights



Integrate our systems



Use cases

- Donor Suitability Assessment:** Integrating with hospital EPRs to access donor information and reduce manual data entry.
- Follow-up Care:** Connecting follow-up data across systems to replace isolated, paper processes.
- Patient Registration:** Capture registration data across multiple systems avoiding paper and manual data entry.
- GP Data Integration:** Connecting with primary care systems for comprehensive patient information.

Actions

- NHS ID Adoption:** Implementing NHS ID across all our systems to enable seamless data sharing and improve patient safety.
- FHIR Standards & APIs:** Implementing FHIR and APIs to enable real-time, secure data exchange between NHSBT and NHS systems.



Use AI and automation

AI Framework

- AI Policy
- Clinical, ethical and legal compliance
- Data and security
- Transparency and explainability
- AI skills
- AI technology standards
- AI and Algorithm register

AI Delivery Team

- 3-4 team members who can deliver working solutions
- Access to the tech, data, standards, policy and governance needed to deliver at pace

AI Use Cases

- **OrQA** – phase 1 done, now adding to transplant path
- **Triage and assess patients**
- **Support consent conversations** using Google Translate base AI solution
- **Plan retrieval teams** using ML algorithms
- **Co-pilot and Agents** to automate everyday tasks



Workshop - Empowering Patients Through Data and Choice

All

What digital tools could help patients understand transplant options and outcomes (e.g. waiting times, centre performance)?

How can we ensure patient-reported outcomes (PROMs) and experiences (PREMs) are captured and used to improve services?

What barriers exist to accessing digital information, especially for less-heard voices?

Workshop - Building a Connected Digital Infrastructure

All

How can we modernise legacy systems and digitise paper-based processes to improve organ utilisation?

What are the main barriers to retiring or integrating legacy systems, and how can we overcome them?

Lunch break (30 mins)

Reflections

James Fishwick, Chief Architect, NHS Blood and Transplant

NHSE

Workshop - Innovation Across the Transplant pathway

All

How can NHSBT enhance the donor to transplant pathway with digital innovation?

What digital support is needed to implement Organ Utilisation Strategies effectively?

How can we measure the impact of digital innovation on patient experience and clinical outcomes?

Workshop - Involvement of Trusts in modernising the digital pathway

All

What data do hospitals need to monitor and improve organ utilisation locally?

What role should Clinical Leads for Utilisation (CLUs) play in driving digital transformation?



How can hospitals collaborate regionally to share best practices and reduce non-clinical declines – and what digital tools would help?

Next steps, thank you and close

All