Patient Engagement Meeting 20th October (Q and A's from the meeting chat)

Is it fair to say that the biggest hurdle with DCD consent is just how tough it is for families to navigate both the withdrawal of care and donation all in one go?

The Potential Donor Audit completed by the Specialist Nurses collect information about reasons for Donation after Circulatory Death reasons for declines. There are several reasons for declines, the highest reasons this year to date are:

- Family did not want surgery to the body
- Family felt the length of the donation process too long
- Family felt patient has suffered enough
- Family not sure if the patient would have agreed to donation

There is currently a research study funding by the NIHR, understanding delays in Organ Donation after Circulatory Death in the UK. More information can be found here:

Understanding Delays in Organ Donation after Circulatory Death in the UK: An Ethnographic Study - NIHR Funding and Awards

Once the research study is complete, we can invite Dr Jessie Cooper the Chief Investigator to share her findings.

More useful information can be found on our website Home - NHS Organ Donation

Why do you think there has been a move away from promoting the benefits of donation? Can we reverse that trend?

Our website includes a page re Organ transplant stories so that people can read about people who have got their confidence, their independence, and their lives back thanks to an organ or tissue transplant.

Organ transplant stories - NHS Organ Donation

There are ways that you can share your experience that could help to inspire and encourage people to donate.

Personal stories that show what it's like waiting for an organ and how a transplant can change lives are extremely powerful. So are stories of organ and tissue donation told by families who are proud that their loved one has saved and transformed lives.

Real stories of donation and transplant can encourage people to become organ and tissue donors.

If you are interested in sharing your story, please email your contact details and a brief summary of your story to pressoffice@nhsbt.nhs.uk

As part of the recovery plan, is there any scope to make use of extended criteria for donors ?

If the 90-day plan gets us back to 120 donors a month, that is roughly where we were last year, with a record waiting list. What is the plan to get above that, and is a plan that has been running since 2020 while donation declined still the right one, or is it time for one that accepts more risk, in how organs are accepted and how the pathway is run?

As well as the work going on to look at the low donation rates, there is already work going on to address the organs that are donated to see how we can ensure we make the best possible use of all available organs.

The Secretary of State established a group called the Organ Utilisation Group (OUG). In 2023 the OUG published their report, 'Honouring the gift of donation', with several recommendations. You can read more about this in detail using the link above.

As an example of some of the outcomes of these recommendations is Recommendation 3 which included the requirement to establish organ-specific Clinical Leads for Utilisation (CLUs) at every transplant centre. This is now established in every transplant centre. CLUs are senior surgeons or physicians working in transplant centres who aim to promote the best use of organs offered and are empowered to report and address barriers to organ utilisation.

Some of their roles include

- improving organ utilisation across solid organs, implementing new interventions to deliver improvements at both a local and national level
- disseminate best practice in organ utilisation and improve equity of access across all centres
- ensure additional activity can be sustained within local transplant centres, as visions of increasing donation rates and organ utilisations are realised
- drive improved organ utilisation through organ utilisation research

The CLU scheme began in November 2020 and has gone from strength to strength since this time. For each organ there is also a national lead CLU and a leadership team who work with the CLU network to share best practice and optimise organ utilisation (OUDT). The lead CLUs also run an Offer Review Scheme. This scheme looks at organs that have been declined each week. Organ Lead CLUs review the decline data and liaise with the transplanting centre to understand the circumstances and reasons leading to the decline. The offer decline reports are shared with centres to encourage learning, help identify missed opportunities and reduce barriers to transplantation.

Great presentation, Ben. Could you please share your slides and email address so we can contact you with any follow-up questions? There were a lot of detailed findings, and it would be great to have some time outside of the meeting to go through them.

Slides shared as per minutes on Home - Organ transplantation - NHS Blood and Transplant

What is the guideline about transplant recipients contacting the family of donors?

https://www.nhsbt.nhs.uk/organ-transplantation/resources/writing-to-your-donors-family/