

# Cautionary Tales

Sharing learning from events across the organ donation and transplantation pathway

ODT Clinical Governance Team

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We know that sometimes it isn't easy, but when things go wrong, we should embrace the opportunity to learn and strengthen where we can. We work in highly complex systems with multiple complex interactions between people, technology and workplaces. However, whilst we tend to focus on the things that go wrong, most things we do, we do right and we do well, and they can be learnt from as well.



Learning from excellence not only provides positive feedback to people, which is just nice to hear, it can also enhance learning through aspects such as increased self-efficacy and may improve relationships. The Clinical Governance Team review submissions received and triangulate learning with the incidents reported. If deemed beneficial, there are occasions where learning is explored further with those involved using appreciative enquiry. Below are a few comments from those who have received a 'Learning from excellence':



The Learning from excellence system is for everyone involved in the organ donation and transplantation pathway and we encourage people to submit reports via the online link:

<https://www.odt.nhs.uk/odt-structures-and-standards/governance-and-quality/learning-from-excellence/>

## Human Leukocyte Antigens (HLA) – Mixed samples

Human Leukocyte Antigens (HLA) are used to allocate donor kidneys to a well-matched recipient. HLA are proteins found on the surface of most cells in the body. They are highly variable in structure and form a part of your “genetic fingerprint”; this means the immune system sees donor HLA molecules with different structure as ‘foreign’ and this can cause the immune system to ‘attack’. A close match between the donor and the recipient HLA makes a successful transplant outcome more likely. This is especially true in kidney transplantation and so HLA matching forms the cornerstone of the national kidney allocation system.



Prior to completion of organ allocation, the potential donor’s blood sample is sent to the relevant H&I laboratory who then type the donor HLA. This information is then sent to Hub Operations to enable the appropriate allocation to a well-matched recipient.

In a recent case, the process above occurred as expected, the kidneys were allocated and subsequently transplanted.

Approximately 5 weeks later, the laboratory who performed the donor HLA typing were contacted by the laboratory from the centre who accepted a kidney to advise that they had repeated the HLA test, as part of their routine post-transplant protocol. On retesting they found a discrepancy in the HLA type, and it was different to the type that they had received from the original donor laboratory. The original laboratory retested the donor sample and found that they had issued an incorrect HLA type. The retested results confirmed the results provided by the second laboratory.

The relevant centres who had transplanted donor organs were then contacted to inform them of the discrepancy and they were provided with the correct, updated, result. Fortunately, there had been no acute organ rejection by either of the renal recipients.

On review of this case, it was confirmed that upon receipt of the initial sample prior to allocation, the on-call scientist had processed it as normal. However, the kit used for testing was unvalidated (CC files had not been run with a known result) and therefore the kit shouldn’t have been used, this was identified by the on-call scientist prior to analysis. The test was therefore discontinued and retested using a different validated kit. This was then processed as normal, and results issued.

However, when the recipient centre laboratory contacted the initial laboratory to inform them of the discrepancy, it was identified that an incorrect sample had been retrieved from storage when the second test was performed. The original donor sample was not used; therefore, the HLA type provided was for a different patient.

During the first test using the unvalidated kit, the original donor sample was tidied away in storage. One of the DNA samples was stored in the freezer and the other was stored in the fridge. When it was identified that the test needed repeating using a validated kit, the on-call scientist removed what was thought to be the donor sample from storage, but in error selected an incorrect sample from another patient.

Whilst in this case there was no direct patient harm, incorrect donor HLA typing has significant potential for causing harm and even graft loss. Local learning has taken place, but it would be beneficial to share this knowledge nationally:

## Learning points

- Unvalidated kits should be segregated from validated kits in the laboratory and clearly marked.
- All donor sample and aliquots should be retained for checking in an area where there are no historic samples, until all paperwork, results and samples can be checked during normal working hours.
- Clear guidance on what is required when a retest of the donor sample is necessary.
- This case also highlighted that there is no national agreement or recommendation of a timeframe for recipient centres to verify a donor HLA type. Some recipient centres, based on their own risk assessment, never verify the HLA type of donors, and some do but there is no set timeframe. This issue is being explored with relevant stakeholders.
- Re-affirms the importance of checking sample numbers and patient ID at critical steps in the process

## Recipient and Donor Family Correspondence

Since April 2022, the Donor Family Care Service (DFCS) have facilitated 2546 pieces of correspondence between donor families and recipients; 1796 from recipients and 695 from donor families. We know that many donor families get huge comfort from receiving letters and cards from recipients. We also know that writing these letters can be difficult for recipients for many reasons, and the DFCS receive letters and cards from recipients many years after they have received their transplant.



It was identified a few years ago that the process of ensuring that the right correspondence was sent to the right person could be strengthened. This led to the development of the 'Covering Information Sheet – Recipient Correspondence' to ensure that letters sent to DFCS have the right patient identifiable data (PID) for them to 'match' to the donor family. To ensure we minimise any risks, it is asked that any correspondence sent into DFCS has a completed sheet, the most updated can be found here:

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

DFCS aim to send on any correspondence as soon as possible. To ensure this is timely, please forward items as and when they are received so that families receive within a reasonable timeframe.

As mentioned, it is known that there can be a multitude of emotions when considering writing to a donor family. To support recipients, the below has some guidance:

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

There is also a leaflet available that can be given to recipients when appropriate, 'Writing to your donor family'. This is either available via the website or in a physical form. They can be ordered via the marketing team at NHSBT on [leaflets@nhsbt.nhs.uk](mailto:leaflets@nhsbt.nhs.uk) using the code OLC274.

### Learning points

- Many donor families receive great comfort in receiving letters and cards from donor families.
- There are a number of resources available to support the recipients writing to donor families, the links and details are above.

Anyone can raise a patient safety concern in relation to the organ donation and transplantation pathway via the online reporting form:

<https://www.odt.nhs.uk/odt-structures-and-standards/governance-and-quality/tell-us-about-an-incident/>

All reports received are reviewed by the ODT Clinical Governance Team and the person who completed the form responded to with any findings and, where appropriate learning to strengthen the process. These reports also enable wider trending to highlight any processes or concerns that may need a more detailed or wider review.

The Clinical Governance Team endeavour to respond to all reports within 90 days, often sooner, but if you are ever concerned you haven't had a reply, please contact:

[clinicalgovernance.odt@nhsbt.nhs.uk](mailto:clinicalgovernance.odt@nhsbt.nhs.uk)

If you have any feedback or suggestions regarding Cautionary Tales or Learning from Excellence, please let us know via email: [Jeanette.foley@nhsbt.nhs.uk](mailto:Jeanette.foley@nhsbt.nhs.uk)