# **Cautionary Tales** in Organ Donation and Transplantation

NHS <u>Blood and Transplant</u>

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### Introduction

Most of us will have noticed a renewed national focus on building cultures of safety and improvement across NHS organisations, and greater proficiency at learning when things go right as well as when things go wrong; spreading good practice. Clinical Governance is a dynamic process that is never 'finished', and each of us involved in organ donation and transplantation can make a positive contribution to improving quality and patient safety.



It can be easy to forget the importance of when things go well. To enable learning from good practice the 'Learning from Excellence' webpage will be live shortly. It has been fully developed and is just undergoing final checks before it is added onto the ODT microsite; this will allow everyone across the organ donation and transplantation pathway to submit. We will of course share once it is available.

Back in 2017, we shared a serious complex case relating to CMV transmission that led to the death of a patient. This highlighted not only the significant impact CMV can have on immunosuppressed recipients, but also the need for clarity and vigilance around processes, testing, results and timely treatment. The first of the reports in this bulletin is a reminder that we need to learn when things go wrong and ensure that processes are in place to ensure patient safety.

We have seen an increase in incident reporting, and we would encourage everyone to continue to report when things wrong so we can share the learning across the community.

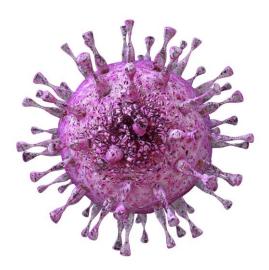
https://www.organdonation.nhs.uk/IncidentSubmission/Pages/IncidentSubmissionForm.aspx

## **Cytomegalovirus Transmission**

It is not uncommon to transplant Cytomegalovirus (CMV) positive organs into CMV negative recipients; however, to enable the transplant to proceed safely, the standard is that this is done with the full awareness of both recipient and donor statuses to ensure any appropriate prophylaxis is commenced. There have been two recent cases that have highlighted how important an accurate knowledge of CMV status can be.

The first highlighted the potential impact when the CMV status of BOTH the donor and the recipient is not confirmed.

Prior to admission for transplantation a patients CMV



status was documented as equivocal. On admission pre transplant they had repeat bloods taken, which included CMV, however these results were not checked prior to transplant. The patient received a kidney transplant from a CMV positive donor; they did not receive CMV prophylaxis.

Approximately a month later the recipient became unwell and were admitted as an in-patient. The pre-transplantation bloods were checked and the CMV status was noted as negative, not equivocal. They were diagnosed with CMV infection and commenced on appropriate treatment. Unfortunately, they lost their graft and subsequently, sadly died.

Following on from this case there were significant learning points within the transplant centre, some of which it was felt beneficial to share:

- The key learning was a change in protocol of CMV prophylaxis. CMV equivocal status recipients are now all treated as negative until confirmed otherwise.
- Pre-transplant bloods will be taken ahead of the initial pre-transplant workup clinic.
- Patient blood results are formally discussed at the Transplant MDT meeting.
- An admission proforma has been developed for transplant patients including recipient and donor clinical details including virology status so that differences are clear.

The above steps have been included to ensure that there is a focus on the CMV status of any potential recipients prior to transplantation to enable appropriate prophylactic treatment.

In the second case, the CMV result from the donor's record was incorrectly transcribed onto the transplant centre records; whilst the donor was CMV positive the status was recorded incorrectly in the recipients notes as CMV negative. The recipient was CMV negative. As it was believed both the donor and recipient were negative, the recipient was not identified as being at high risk and consequently did not receive the standard CMV prophylaxis treatment.

Post discharge the patient developed a CMV viremia which was not immediately acted on when the result was available. Whilst they had regular outpatient follow up it was unclear if the change to CMV status (with an increasing viral load) was immediately noted. The CMV viremia was subsequently diagnosed however the patient had a complex clinical picture. It was difficult balancing the therapeutic benefits of immunosuppression and its impact on managing the CMV infection due to fluctuating kidney transplant function. Despite all efforts, the recipient died of a CMV related infection.

The below actions were identified and completed by the transplant centre:

- To reduce the risk of the incorrect recording of CMV blood results a secondary independent check of this information has been put into place.
- The clinical follow up process for recipients with complex medical needs now have transplant consultant nephrologist level and multi-disciplinary team overview to ensure early diagnosis and appropriate treatment.

#### Learning point

- These cases demonstrate the importance of having robust and timely systems for management of blood results. Obvious vulnerabilities such as manual transcription of results should be avoided where possible, and where this is not possible steps should be in place to mitigate the risk.
- Equivocal or inconclusive results for microbial serology should be treated by default as negative in the recipient and positive in the donor until unequivocal results become available.
- Some of the other actions raised above may be transferrable to other centres.

## Medical and Social History Vs Core Donor Data Form



Donor information is gleaned from several sources; medical professionals, medical notes, physical assessments and often most importantly family conversations. A potential donor's family are asked very specific questions to gain information and this has always been collated onto a specific form; the Medical and Social History Form (MaSH) (previously known as the 'Patient Assessment Form' or 'PA1'). Previously the Specialist Nurse – Organ Donation (SNOD) transcribed the 'important' information from this onto the Core Donor Data (CDDF) set.

Following a Coroner Inquest recommendation, this form with all the information is now visible to transplant centres when considering offers. This means that no information is transcribed from the MaSH form onto the CDDF. It also ensures it is clear who has provided the information; the MaSH form stipulates 'Information obtained from relatives/significant others'. There have been a number of cases reported relating to centres not reviewing the MaSH form and so being unaware of key pieces of information. As both forms may contain differing information, it is important that both are fully

reviewed at the point of organ offer to ensure acceptance is made with the knowledge of all information.

There have also been concerns raised by transplant centres around the fact the information can sometimes differ between the MaSH form and the CDDF.

There may be occasions where there is information present on the MaSH form but not on the CDDF and vice versa. This will usually be because there has been different information gleaned from different sources and as such differences are not uncommon. The SNOD should clarify any significant discrepancies (such as previous malignancies), however if there are any concerns these should be discussed with the SNOD prior to acceptance.

## Learning point

- The MaSH and CDDF collate information from different sources and so there may be different information present. Any concerns should be raised with the SNOD at the time of offer.
- As both forms may contain differing information, it is important both are fully reviewed at the point of organ offer to ensure acceptance is made with the knowledge of all information.