# Cautionary Tales
## in Organ Donation and Transplantation

NHS Blood and Transplant

*Issue 12, July 2016*


## Introduction

Every part of our lives is impacted on by technological advancements, from the newest mobile phone to the next 3D television. Health care is no exception; however we will all be aware that it is a lot easier to change a SIM card in a new phone than implement a new IT system within a NHS organisation. Every day in the health sector, information is collected, managed, used and shared. Safe patient care depends on a fast and accurate flow of information. Whilst changes within the ODT IT systems may be complex, information delivery is crucial; IT is invaluable in all parts of the donation process, from donor registration to allocation and offering.

Getting it right ensures that we minimise manual processes wherever possible to reduce risk – which in turn makes transplantation safer for recipients. Most of you will have heard of the ODT Hub project and due to the vast impact of changes in this project, John Asher, National Clinical Lead for Health Informatics, has provided a summary and update to the project in this edition

Much of the learning from relevant incidents reported has been linked into the IT changes taking place as part of the ODT Hub. It therefore continues to be crucial in ensuring wider learning, changes and better outcomes to continue to report via the follow link:

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

Reporting an incident does not necessarily mean that anything has been done wrong, it is not a complaint nor a way of attributing blame. By reporting, lessons can be shared with those involved and the wider community as needed and often simple issues can lead to large improvements in the processes.

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## The ODT Hub Project

The field of transplantation has seen dramatic changes in the last decade with the planned 50% increase in organ donation having been realised, improving access to transplantation but at the cost of increasing complexity as the accepted criteria both to donate and to receive an organ have broadened.

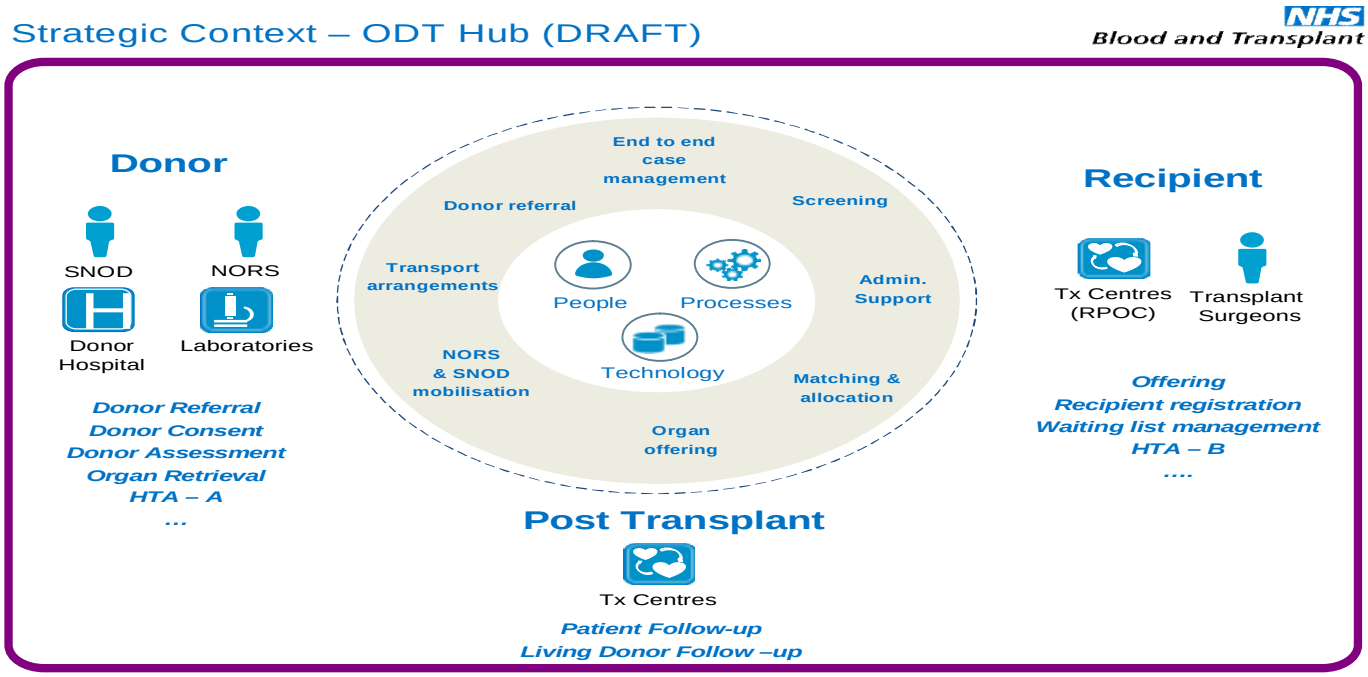
The further expected increase in organ donors and transplants coming from the TOT2020 strategy will produce challenges as well as opportunities, and in response NHSBT has developed a plan to improve the efficiency of both its internal logistics and its service interface with the transplant centres. This plan, modelled on the operations of the better OPOs in the United States, has been called the National Hub. The American experience suggests this should speed up the clinical pathway, improve efficiency and increase the number of transplants.

The main components of the plan are a transformation in working practices together with an improved IT system to support these changes. The major transformation is that, in addition to the existing functions of the Duty Office, the Hub will take all organ donation referrals and coordinate the dispatch of both Specialist Nurses in Organ Donation and NORS retrieval teams.

A specialist nurse advisor will be on call for the Hub, which may lead to the right questions about a donor being asked earlier in the process, so that a more granular level of detail can be included in the information provided to transplant centres at the time of organ offering.

Although much of the change is to improve the internal efficiency of ODT, and particularly the overstretched Duty Office, potential changes for clinicians include the opportunity to develop patient-specific matching criteria (to eliminate all those inappropriate named-patient offers) and online tracking of progress with a retrieval and

transport (to reduce unnecessary preoperative fasting and facilitate planning of emergency theatres in the transplant centre).



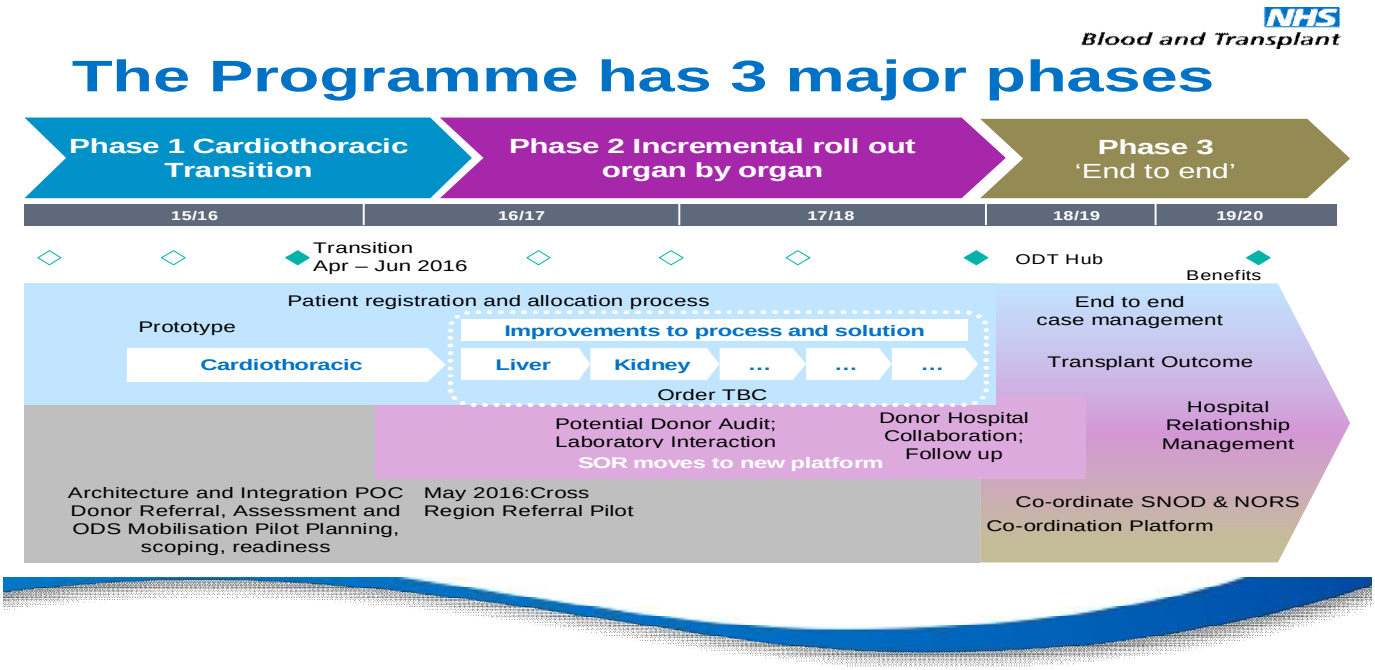

## The story so far

The National Hub project plans need to be implemented in a phased way alongside existing processes, so the full transition will take around five years, and is still dependent on continued funding from the four UK health departments.

The cardiothoracic pathways are the first to be developed in the Hub, as this would fit in with the plans for national heart offering and would provide an opportunity to create the necessary changes to implement a super-urgent heart offering scheme.

Once the cardiothoracic pathways have been developed, the liver pathway is expected to be next, allowing the new liver allocation scheme to go live.

On the donation side there are to be changes with an improved system for the SNOD to record organ donor information via a new application called DonorPath created with the developers of EOS mobile. The new system is expected to go live this summer and should provide better communication to transplant centres.



## Communication of new clinical information

You will remember that in January's edition of Cautionary Tales we discussed the incident that led to the national quarantine of perfusion fluid due to possible Candida contamination. Within this there were a number of key recommendations and learning points - the case can be found here: http://www.odt.nhs.uk/odt/governance-and-quality/cautionary-tales/ .

Following on from this there has been another case of Candida detection in transport perfusion fluid reported to NHSBT. Similar to the last case, the pancreas was retrieved and therefore the detection of Candida in the transport fluid was not in itself surprising.

This case did highlight some learning regarding the dissemination of new clinical information in a timely way. Both accepting transplant centres and the tissue bank completed transport fluid cultures, all of which cultured Candida. One centre informed the Duty Office via email, one did not inform the Duty Office, SNOD Team or other centre and one informed the SNOD team utilising an incorrect email address. In this case, as all centres had detected Candida, the clinical teams had the information to decide any prophylactic treatment - so luckily no harm done.

This however does highlight the importance of ensuring good communication of any new significant information. In order for centres to make an informed decision regarding clinical care new information is required in a timely way. In the case highlighted above none of the three centres informed the Duty Office, which is a 24/7 contact, via telephone of the positive result. Emails are not necessarily picked up in a timely way, and the Duty Office is no exception – we all know that usually if something is urgent then we pick up the telephone.

The second point this case highlighted was again the importance of communication of breaches of the gut. All parties are in agreement that any breach during retrieval is communicated to accepting centres and documented in the medical notes and on the HTA A form. This case raised the importance that in circumstances where breach of the gut occurs, recipient/tissue centres should be informed to enable informed decision making and treatment planning.

### Learning point

- Any new clinical information should be highlighted to the Duty Office via telephone. Best practice is that written details are also forwarded to allow onward dissemination, however a verbal conversation will ensure confirmation of receipt and that information is disseminated in a timely way
- When positive ***fungal*** cultures are grown from transport fluid, these should be communicated as new clinical information as above to allow for this information to be disseminated to other recipient centres who received organs from the same donor
- It is vital that any concerns of a breach of the gut during any part of the pathway is communicated to any accepting recipient/tissue centres


## Fast track offers

In a health care world of competing demands on ICUs, EDs and theatres there is an ongoing balance between ensuring that as many transplantable organs as possible are transplanted and that the process is timely and realistic for local hospitals and donor families.

One of the recent changes to aim to work within both these competing demands was the streamlining of the fast track offers. The benefits of fast track is that it allows all centres the opportunity to accept an organ for transplant, meaning it is more likely to be transplanted, whilst reducing the time to offer. Fast track is not a new system, however previously the Duty Office were required to contact all centres that had not responded to the fast track offer once it had expired to confirm either acceptance or decline. In general if a centre made no contact with the Duty Office it meant they did not wish to accept – so the Duty Office made an unnecessary call, and the Recipient Centre point of contacts were disturbed unnecessarily. Therefore following a lean event with all stake holders the decision was made for kidney, pancreas and liver fast track offers to become a 'presumed decline'.

For this system to work there are key aspects that are required from all sides. The NORS Teams and SNODs need to be fully aware of the time scales involved in fast track and should ensure that they confirm with the Duty Office at the end point of the fast track whether any centres have expressed an interest in acceptance. No organ should be deemed untransplantable until the fast track period has expired. The Duty Office therefore also need to be clear on the times of when an offer is made and the expiry time.

The recipient centres also have a requirement to ensure that fast track offers are responded to within the time period. If no response is received then a presumption will be made that the organ is declined.

In a recent case these processes were not followed and regrettably a potentially transplantable organ was not transplanted. If all involved had followed the steps above this organ would have been sent to the accepting centre with the aim of being transplanted.

### Learning point

- No organ should be deemed untransplantable until the full fast track time period has expired
- Recipient centre points of contact need to ensure that fast track offers are responded to within the time period when there is an interest of acceptance. The time period commences when the Duty Office sends out the initial offer

## Living Donor Follow-up and Registry Data

A case has recently been reported of a tumour being identified in the remaining kidney of a previous living donor several years after donation. This case highlighted the contribution of the Living Donor Registry in providing information about donor outcomes and the importance of accurate reporting.

Following its identification, a search of the registry was requested by the clinical team in order to identify other reported cases of either benign or malignant renal tumours in previous living donors. We identified a low incidence: 4 cases out of a total 12,711 donors (0.03%) since the start of the registry in November 2000. This information is reported as free text in the 'Health Issues since last visit' section on the follow-up form and in each case, clarification from individual centres was needed to understand more about the type of tumour, outcome and treatment.

This recent incident serves as a timely reminder of the importance of life-long follow-up and completeness of registry data. The LDKT 2020 Strategy Implementation Group has produced a framework to improve the quality and consistency of living donor follow-up and submission of registry data, soon to be published. The 'toolkit' provides options for arranging life-long donor follow-up and responsibilities for data collection. Centre specific data on follow-up returns to the Living Donor Registry will be published annually from July 2016 so that centres can benchmark their own performance.

## Learning point

- When reporting 'free text' health issues, please include the following information, where known, to ensure that NHSBT can improve the consistency and accuracy of information searches based upon relevant criteria:
    - The nature of the health issue and, if organ specific, please specify (I.e. kidney, liver, etc.)
    - For tumours, please specify type, histology and size of tumour
    - Date of diagnosis (to the nearest month)
    - Treatment and/or management
    - Outcome of treatment and planned follow up