UK Organ Transplant Capacity

Executive Summary

This report sets out the findings from discussions held between UK Transplant Units¹ and NHS Blood and Transplant's Medical Director for Organ Donation and Transplantation regarding capacity to meet the continuing increase in organ transplantation.

Recent years have seen record numbers of solid organ donors and transplants and the number continues to increase. Work is ongoing to build on this success, so that the number of organs available for transplant can continue to increase further. When combined with the development and increased use of innovations and novel technologies, the demand on Transplant Units has never been greater.

It is clear from the discussions that Units are feeling this pressure. All the Units expressed concerns regarding their ability to continue to keep pace with the growing numbers of organ donors. Evidence collected as part of the discussion and centre engagement suggested that in the previous 12 months, over 80 organs had been declined due to capacity issues within transplant centres. A further 61 organs had been declined due to issues with offering and retrieval, such as missing or inaccurate data.

Building on the feedback and advice received from the Transplant Units, the following recommendations are made:

1. All Trusts with a transplant programme should have explicit support mechanisms for maximising organ utilisation potential.

It was apparent that those Units which had put in place high-level support within the Trust for the transplant programme experienced the least difficulties in securing the necessary resources, particularly operating theatre and intensive care access.

2. The data shared with and between Trusts should be improved, to better support surgical decisions.

Whilst the feedback was that the data provided from NHSBT was useful, there were a range of ways in which this could be improved. This included the data both provided to and from NHSBT being more relevant and meaningful reflecting what is happening on practice eg improved reason coding for organ declines. There should also be improved dissemination of data within Trusts and transplant teams.

3. Improve the pathology and microbiology support infrastructure

The lack of availability of pathology services has a significant impact on the utilisation of organs, resulting in surgeons having to decline organs that may in fact have benefitted their patients.

¹ 28 Centres participated, out of a total of 30 Centres. See Annex A for list of participants.

4. Improve support for transplant surgeons who take appropriate risk. Given the changing donor demographics and the increasing number of extended criteria organs, surgeons increasingly have to consider the use of higher risk organs. The guidance on consent should be improved and there should be better support for transplant surgeons who take appropriate risk.

All the Units advised on potential changes that could be made to NHSBT's systems and processes to inform and improve the organ transplant care pathway. A summary of these are provided at Annex A.

The recommendations within this report strengthen and build on the existing national strategies – Taking Organ Transplantation to 2020 and Taking Organ Utilisation to 2020.

Aim

The aim of the work was to assess what actions NHSBT could take to support organ utilisation and help ensure that UK Transplant Units can meet further anticipated increases in deceased donor numbers.

Approach

All UK Transplant Units were invited to participate in a 1-hour teleconference to discuss barriers to accepting organs for transplantation. The discussion followed 'Chatham House rules', with responses being anonymised. The structure of the discussion followed the plan laid out at Annex B.

Key issues/ best practice raised

i. Criteria for listing

There was general agreement that the criteria for listing were equitable and the majority of Units abided by the various organ specific criteria. The national guidelines were helpful and prevented the risk of 'gaming'. However, there was felt to be some lack of equity between adult and paediatric patients regarding listing for heart transplants.

ii. Donation

Some Units suggested that there is an increasing disconnect between the organ donation and transplanting teams and there would be benefit in bringing the two communities together more frequently – at both national and local levels – to share information and learning.

Some Units suggested that it would be of benefit to amend the time of treatment withdrawal and organ retrieval to ensure that the transplanting team is ready. This is already in place to support cardiothoracic (CT) transplantation and should be introduced for liver transplantation to increase the likelihood of a successful graft.

Lack of 24 hour histopathology services was flagged by many Units as a barrier to organ utilisation. Many pathology services relied on good will and local informal arrangements. This lack of a comprehensive service has led to a number of previous organ declines.

iii. Offering

There was some concern that data on the Electronic Offering System (EOS) was misleading/ inaccurate/ incomplete and led to organs being declined without proper justification. For example, one entry on EOS stated '? Encephalitis', with no evidence to support the suggestion.

There was concern that data available on EOS was sometimes changed without alerting the transplant team. This leads to late declines of offered organs and rapid offering requirements.

Most Units stated that the data provided during the offering process should include real time data and photos. The Scout service had helped to provide this for CT donors, but did not cover abdominal organs. The provision of this data would help inform clinical decisions and minimise risks to patients.

There was disagreement between Units regarding the ability to find out how many other Units had declined an offered organ. Some Units thought that this was inappropriate and led to surgeons relying on the decisions of others, rather than the data provided. Others believed that this information acted as a warning to check the data in more detail in case there was particular information they had missed. A potential solution would be to provide this information as part of a governance check after the organ had been accepted.

Some Units requested additional data not routinely provided that the SN-OD would have access to, such as Polymerase Chain Reaction (PCR) results.

Several Units expressed frustration at the offering process for a range of reasons. Sometimes offers are made at a very late stage while other times offers are too early and there are insufficient data to make an informed decision. One Unit noted there are local cost implications of c£10k when the offering process is lengthy, due to the requirement to hold theatres open..

Several Units noted that the current reliance on manual donor data entry is unsafe and outdated. One Unit noted that they had moved to a completely electronic system for sharing information. This reduced the risk of errors and improved data sharing.

iv. Acceptance

Some Units had strong collaborative approaches to organ offer acceptance, whereby colleagues were always available for a second opinion. One team noted that there were also arrangements for a surgeon to accept an organ on behalf of a colleague who would then be undertaking the operation.

Some Units expressed frustration that the fast-track system led to organs being accepted but then not actually being allocated to the Unit.

One Unit noted difficulties with EOS. In some instances, data was changed on EOS after acceptance but this change was not flagged to the accepting surgeon. Also, some ambiguous wording led to organs being inappropriately declined (e.g. notes included '? encephalitis' or '? Herpetic rash'. Later both were negative, but once the suggestion is written in to EOS it is difficult for surgeons to accept a potentially high-risk organ.

v. <u>Retrieval</u>

'The beat of the retrieval drum drives the transplant service.'

The timing around organ donation was perceived as a barrier to utilisation. In particular, several Units stated that this uncertainty led to a difficulty in organising their own staff and theatres. This in some instances meant that elective surgery was cancelled unnecessarily, as there were delays in the retrieval and transportation of organs which were not effectively communicated to the transplanting team. This in turn leads to a loss of good-will and enthusiasm for the transplant programme at a local level. One Unit noted that this places more risk on fragile renal patients and they advised was contrary to guidance from the Confidential Enquiry into Perioperative Deaths

(CEPOD) and guidance on emergency surgery. It was acknowledged, and welcomed, that ODT is already working on this issue.

Perfusion was also flagged as an issue. Some Units explained that reports of perfusion of organs were unreliable. For example, notes would record 'poor perfusion', when the organ was well perfused and vice-versa. Also, the timing of machine perfusion was not noted, so that the ischaemic times were unclear and therefore adversely impacting on acceptance rates.

Some Units expressed concern that organs were being damaged during retrieval. Livers and pancreases seemed to be of particular concern. One Unit indicated that 50% of pancreases they received were damaged, leading them to develop training in transplanting damaged organs. Another Unit gave an example of a split liver where the lobe had been so damaged that it had to be discarded. There was also concern that the rates of damage were increasing, but that this was not being accurately and meaningfully recorded and thus the statistical reports were not sufficiently robust.

Many Units advised that there was no effective way for retrieving and transplanting teams to share information, which led to inappropriate declines/ acceptance. Comments included:

- Data and information at the time of retrieval is poor and often misleading, with little or no ability to provide accurate, real-time information.
- Feeding back to retrieval teams regarding the organ and sharing lessons learned.
- Timescales for both removal and perfusion or organs, as well as likely arrival time at the transplanting hospital.

vi. <u>Transport</u>

Several Units expressed concern regarding the travel time and the lack of certainty about when organs will arrive. This causes problems with reserving theatre space and cancelling other surgery, as well as managing the team's time.

Some Units were concerned regarding the 'blue-lighting' of organs. One said that it was unclear in what circumstances this was allowed. Another Unit advised that all DCD organs should be blue-lighted, due to ischaemic times.

vii. Quality and governance

Most Units felt that the quality and governance systems were both helpful and appropriate. However, several thought that more could be done to support dissemination of outcomes and sharing of lessons learned.

Several Units raised the issue of variation in risk appetite between and within Units, particularly for marginal organs, but views were split between whether the CUSUM system helped or hindered surgeons to accept extended criteria organs.

viii. Reduce disincentives in the system

Several Trusts stated that they were penalised for cancelling elective surgery to carry out a transplant, particularly when that elective surgery was a type where targets for time to treatment had been set. It was commented that Trust senior managers do not have transplant or donation numbers as a priority in the same way as other metrics in health care delivery. This leads to reduced access to theatre and a negative culture within the Trust towards the transplant programme, transplant competes for resources on an uneven basis.

ix. Communications

Units that do not also have retrieval teams commented that the progress of the retrieval, or lack of progress, was not always well communicated, resulting in difficulty in booking general resource and access to theatre.

Most Units were aware of the ODT website and found the data available helpful, although the navigation needed to be improved. Work is currently underway to address this issue and improve the ODT website.

Similarly, most Units were aware of the Associate Medical Director Communications Bulletin and found the data provided helpful. There were mixed responses regarding how the bulletin was utilised. Some teams used it as a basis for discussion at team meetings, others simply circulated the document for information to their teams.

Most teams also found the monthly reports on organ utilisation to be helpful. Many teams used this data to inform their own local discussions regarding organ acceptance and the data had helped to inform local changes in practice. There were several examples of good practice regarding the use of the data. This included one Unit who provided the donor data blind in quarterly audit meetings as case studies to discuss whether the final decision was the correct one and share any lessons learned amongst the Unit. Another team used the data to inform discussions with their Trust's Quality Assurance and management teams.

Several Units advised that it would be helpful to have the organ utilisation data regarding the outcome of organs more frequently and over a longer period.

Several Units noted that the Annual Reports published by NHSBT were helpful in informing both local and national practice.

x. Local issues

All Units expressed concern regarding the resource available for the transplant programme. Specific issues were:

 <u>Access to theatre.</u> Most teams had restricted access to theatre, particularly out of hours. This is exacerbated when the Unit is within an Acute Trust/ Trauma Centre. This meant that they were unable to accept more than 1 offered organ within a 24-hour period. A small number of Units who had very strong support from the Trust stated that theatre access was classed as a local 'never event' and should never be a cause for declining an offered organ. It was clear that strong support from senior management in a Trust led to less difficulties in competing for resource for the transplant multi-disciplinary team. In other trusts, this support was less visible. This means that patients are, to some extent, subject to a 'post-code' lottery.

- <u>Access to pathology services.</u> Most Units expressed concern at the access to pathology services, particularly out of hours. This impacts particularly on the acceptance of marginal organs. For highly sensitised recipients, where full cross-matching is required, it leads to prolonged cold ischaemic time and therefore risks organ quality.
- <u>Access to ICU beds.</u> One Unit stated that they have particular issues for pancreas, with at least 7 organs declined due to issues with ICU access.

Several Units noted that Peer Review reports had been helpful in highlighting resource/ safety/ sustainability issues and, it was hoped that this would lead to securing additional resources/ commitment from the Trust.

Many Units raised concern regarding staffing levels. This included:

- <u>Ability to recruit and retain surgical staff within the transplant team.</u> Most surgeons have other surgical commitments within in the Trust. As a result, some Units are unable to undertake more than 1 procedure within a 24hour period. Also, there is little or no recognition for the fact that 50% of the work is out of hours.
- <u>Access to theatre staff out of hours.</u> Most teams stated that they relied heavily on good will and a few people who are willing to go 'above and beyond' their requirements to support the transplant programme.
- <u>Stress and fatigue.</u> Most Units reported that staff across the transplant programme are increasingly stressed and fatigued. There are several compounding factors to this, such as frequent calls during the night with organ offers and the frequent out of hours working, alongside other clinical commitments. One Unit explained that they had addressed this locally by ensuring that surgeons have no elective commitments when on-call.

Several Trusts noted that there was a very strong, visible support for the transplant programme from the Trust's senior management, which meant that they avoided the barriers around theatre access etc. experienced by other Trusts. One Unit noted that in their Trust an organ decline due to capacity issues was regarded as a local 'never-event'. Several Units noted that their Trust viewed their transplant programme as one of the most important, founding principles and again this meant that there were no issues around capacity. It was noticeable that the Units who were experiencing the most difficulties regarding theatre and/ or ICU access were also those Trusts where there was a lack of senior support for transplantation.

xi. Additional Points

Novel Technologies: Some teams noted that the move to increased innovation and novel technologies was causing issues for teams. In particular, Normothermic Regional Perfusion (NRP) was being increasingly utilised but there are no clear national guidelines available. Variation in funding: One Trust expressed concern that the funding for a range of interventions, such as bridging ECMO, varied across the UK and this led to another form of post-code lottery, with the resulting impact on patient outcomes.

IT: A small number of Units expressed concerns regarding IT capability, which meant that they still had to rely on faxes rather than e-mails.

Organ Declines

The table below outlines the estimated numbers of organs declined due to resource issues.

Reason	No. Organs declined in the last 12 months
Information at offering or retrieval	50
quality of organ retrieval	20
Theatre availability	59
Operating staff	11
ITU beds	21
Total	161

The following caveats should be noted:

- 1. The organ decline does not mean that the organ was discarded. It is likely that the organ was offered on and accepted by another Unit.
- 2. The Unit representative was asked for their estimations on organ declines in the previous 12 months to the discussion. Some representatives provided definitive figures, whereas others provided their own estimates.

Advice from Transplant Units The table below summarises the advice from Transplant Units about where improvements could be made.

Issue	Action
Building on best practice	
There are fewer barriers to organ transplantation in those Trusts where there is visible high-level support for the transplant programme.	Increase and publicise incentives for visible, high-level Trust support for transplant programmes and/or work with Commissioning teams to build this into contractual commitment for those Trusts/Hospitals with a transplant unit
Utilise peer review reports to deliver local improvements	Continue with Peer Review
Criteria for listing	
Inequality of access for paediatric CT cases.	Develop a national waiting list for CT paediatric patients.
Donation	
Long time from asystole to perfusion (c.15 mins) leads to organ deterioration (especially ischaemic biliary complications after liver transplant)	Need to start withdrawing in, or close to, the theatre, rather than ICU
Offering	
Insufficient/ inaccurate data at the time of offering	Work with Units, Duty Office and SN-ODs to identify what more can be done to improve data available at the time of offer.
	Include real-time data and photos during the offering process.
	Include recipient name; number; days on the waiting list and whether they are sensitised.
The timing of the offering process is inappropriate	Continue with current work to optimise the timing of the offering process
Acceptance	
Risk-averse behaviour following Cardiff case	NHSBT should do more to promote best practice in organ acceptance amongst surgeons and provide visible support to surgeons when challenged. NHSBT should raise awareness within the public regarding the risks and uncertainties surrounding organ transplantation.

Issue	Action				
Retrieval					
Extended time taken for organ retrieval	 Continue with work to optimise the retrieval timescales. Continue with move to increased use of machine perfusion to support longer ischaemic times. 				
Organ damage at the time of retrieval	 Improved audit Ability to feedback to NORS teams on the outcome of organs. Discarding organs due to damage at the time of retrieval should be a never event. 				
Transport					
Poor communication about anticipated arrival time	Ability for Units to have up to date information about when organs are likely to arrive. Ideally through real-time tracking data.				
DCD kidneys often have prolonged cold ischemic time	There should be clear rules about when it is appropriate to 'Blue-light' organs				
Quality and Governance					
CUSUM Triggers	 Review the current CUSUM triggers to ensure they are still appropriate. Identify ways to improve dissemination of lessons learned to support changes in practice both nationally and locally. 				
Reduce disincentives in the system					
Disincentives in the system – particularly regarding cancelling elective surgery	Identify and remove any national disincentives.				
Communication					
Dissemination of data on organ declines and outcomes	 Explore how the data disseminated to Units could be further improved, particularly in relation to the outcome of declined organs. This includes both longer-term outcomes and more data regarding the recipient (e.g. length of time on waiting list, recipient age, whether the recipient was on the elective or urgent waiting list etc.). Consider providing the data with improved benchmarks covering re-graft rates, graft failures etc. 				

Issue	Action			
	• Explore how the data could be better presented, potentially with a 1-page cover sheet.			
Dissemination of additional data	Consider how calculated reaction frequency for waiting lists could be disseminated to Units.			
Local barriers				
Access to theatre, particularly out of hours	Provide national guidance on access to theatres, make clear as part of CUSUM monitoring?			
Access to ICU beds, particularly for pancreas	There should be a formal report to NHSBT every time an organ has been declined due to Theatre or ICU capacity			
Access to histopathology and H&I services, particularly out of hours	Continue with work underway to address this issue. In addition, explore whether there are any differences in acceptance rates between normal working hours and out of hours.			
No recognition that 50% of work is out of hours leads to difficulties with recruiting surgical staff.	Follow examples set by other areas for best practice in out of hours provisions.			
Variation in surgical 'risk-appetite' within and between teams.	Build on work underway regarding guidance and best practice.			

Annex A – Participants

Abdowing	Condictheresis
Abdominal	Cardiothoracic
Belfast	Glasgow
Birmingham	Harefield
Bristol	Newcastle
Cambridge	Papworth
Cardiff	
Edinburgh	
Glasgow	
Guy's and St Thomas'	
Hammersmith	
Kings	
Leeds	
Leicester	
Liverpool	
Manchester	
Newcastle	
Nottingham	
Oxford	
Plymouth	
Portsmouth	
Royal Free	
Royal London	
Sheffield	
St George's	
All	
Great Ormond Street Hospital	

Annex B – Agenda and Papers Provided

- 1. <u>Local barriers:</u> Are there any local barriers to organ utilisation and if so, is there anything that NHSBT could do to help overcome them?
- 2. <u>NHSBT Barriers:</u> Are there any barriers to you being able to accept an organ due to:
 - a. Criteria for listing
 - b. The donation process
 - c. The offering process
 - d. The acceptance process
 - e. The retrieval process
 - f. The organ transportation process
 - g. Quality and Governance support

If so, what could be done to overcome these barriers?

- 3. <u>Disincentives:</u> In your opinion, are there any disincentives in the current system which impact on organ transplantation (e.g. is your Trust penalised for cancelling elective surgery to enable a transplant to proceed?).
- 4. <u>Data:</u> Are you aware of the various sources of information from NHSBT available to transplant units:
 - a. AMD Comms
 - b. ODT Website
 - c. Monthly data on organ offering and acceptance

If so, do you have any suggestions for how these could be improved? Should any additional data be circulated and if so, how frequently?

The following data would also be helpful to have, although it is acknowledged that it may not be possible for Units to provide this during the discussion.

- 5. WTE staffing levels for the following staff (current and anticipated future):
 - Consultant Surgeon
 - Surgical Fellow Surgical Trainee
 - Consultant Anaesthetist
 - Anaesthetic Fellow
 - Operating Department Practitioners (includes scrub nurse and transplant technician)
 - Recipient Coordinator
 - Physician
 - Lab staff
 - Audit Officer
- 6. How many times in the last 12 months have you had to decline an organ due to lack of:
 - information regarding the organ at either initial offering or retrieval stage
 - Quality of the organ retrieval
 - Surgical staff
 - Anaesthetist availability

- **Operating Department Staff**
- Theatre availability
- ITU beds
- Ward beds .
- Lab services

TRANSPLANT TARGETS TO 2020/21 - FOR INFORMATION (February ODT SMT)

Purpose of the paper

The high level ODT strategic targets have already been agreed and also provided for information at this meeting. This paper breaks down the targets for the different organ groups, for information.

Targets

The targets in Table 1 are the donors and transplants required to meet the following Strategy targets by 2019/20 and an initial assumption has been made that the number of donors and transplants will be maintained into 2020/21:

- 26 donors pmp
- 74 transplants pmp ٠
- 85% of abdominal organs from DBD donors to be transplanted
- 35% of hearts and lungs from DBD donors to be transplanted
- 65% of abdominal organs from DCD donors to be transplanted
- 12% of lungs from DCD donors to be transplanted

Table 1 Deceased donor and transplant targets to 2020/21						
		2016/17	2017/10	2010/10	2010/20	2020/2
		2016/17	2017/18	2018/19	2019/20	2020/2
ស	DBD donors	855	956	1020	1048	104
Donors	DCD donors	585	664	708	728	72
Ğ	Total donors	1440	1620	1728	1776	177
	Pancreas	43	47	50	52	Ę
nts	Liver	772	863	921	946	94
DBD Transplants	Kidney	1327	1494	1600	1653	16
DBD	Kidney & Pancreas	194	216	230	235	2
Tra	Heart	208	228	239	241	2
	Lung	211	239	258	268	2
S	Pancreas	8	9	10	10	
ant	Liver	163	187	200	207	2
DCD Transplants	Kidney	900	1039	1122	1173	11
a ji	Kidney & Pancreas	37	41	43	44	
Ļ	Lung	37	41	43	43	
	Pancreas	51	56	60	62	
ts	Liver	935	1050	1121	1153	11
lan	Kidney	2227	2533	2722	2826	28
dsu	Kidney & Pancreas	231	257	273	279	2
rar	Heart	208	228	239	241	2
Total transplants Total transplants Hear Lung	Lung	248	280	301	311	3
<u> </u>	Total	3900	4404	4716	4872	48