Taking Organ Utilisation to 2020
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FOREWORD

In July 2013 the UK was set a challenge – to match world class performance in organ donation and transplantation by 2020. We knew that this would not be easy, but the commitment and enthusiasm for meeting the challenge has led to unprecedented results. The number of deceased donors has increased significantly and a record number of patients have received transplants.

However, we still have some way to go particularly in relation to organ utilisation.

A documented change in donor demographics represents a test of decisions in organ utilisation and in many areas of organ usage; we fare well by international comparison. Yet there is variation in decline rates between and within centres, leading to inequity of patient access across the UK.

This strategy sets out the improvements that could be made across the donation and transplantation pathway to ensure that as many organs as possible are safely transplanted. It focuses on two key areas – organ acceptance and organ utilisation. Neither of these fall within NHS Blood and Transplant’s remit, but I am aware of our duty to ensure that the transplant teams have the information and support they need to feel confident in accepting more organs. I remain very grateful to members of the Organ Advisory Groups in promoting action in this area.

The last 4 years has demonstrated the remarkable improvements that can be made when the organ donation and transplant communities work together to achieve a common purpose. I am confident that, through continued collaboration and commitment, we can match world class performance in organ utilisation by 2020, to save even more lives.

John Forsythe
Medical Director for ODT in NHSBT
EXECUTIVE SUMMARY

The UK strategy ‘Taking Organ Transplantation to 2020’ sets out an ambitious series of actions and targets for maximising the potential for organ donation and transplantation in the UK, with the overall aim of matching world-class performance in organ donation and transplantation.

Work to deliver the recommendations within the strategy has been underway since 2013 and much progress has been made with the numbers of deceased organ donors and transplants increasing most years.

The delivery of some of these recommendations has led to challenges in other areas. For example, referrals of potential donors have increased exponentially and patients who would not previously have been considered possible organ donors are now referred. While many have gone on to donate organs that have resulted in successful transplantation, the donor demographics have changed over time and increasingly marginal organs are being offered. Donors are older, more overweight and with higher co-morbidity compared with donors from years past.

There are two areas in deceased donation that require greater focus:

i. Organ acceptance: There are a significant number of organs – particularly hearts, lungs and pancreas – that are declined by all Transplant Units. There is also variation in decline rates both between and within centres, leading to inequity of patient access across the UK. Some of this variation is inevitable due to a range of factors, such as waiting list demographics and local protocols. However, international comparisons suggest that the UK could have a higher acceptance rate without impacting on risks to patient safety.

ii. Organ utilisation: There are many organs that are accepted by a transplant team, but then rejected after the organ arrives on the unit. These organs are then offered on to other units. The risk of discarding the organ increases with the number of declining centres, partly due to prolonged cold ischaemic time. If an organ is no longer suitable for transplant and if a family has given consent/authorisation for research, the organ can be used for research.

There are already steps in place to address both organ acceptance and utilisation. However, more can and should be done to improve practice and enable a greater number of people to have their lives saved or transformed through organ transplant.
Future work in these areas will focus on delivering the following aims and outcomes:

<table>
<thead>
<tr>
<th><strong>Aim: To match world class performance in organ donation and transplantation</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Who</strong></td>
</tr>
<tr>
<td>NHS hospitals and staff (donation)</td>
</tr>
<tr>
<td>NHS Blood and Transplant (allocation and offering)</td>
</tr>
<tr>
<td>NHS hospitals and staff (acceptance)</td>
</tr>
<tr>
<td>NHS hospitals and staff (organ retrieval)</td>
</tr>
<tr>
<td>NHS, NHS Blood and Transplant, Professional Bodies (infrastructure)</td>
</tr>
</tbody>
</table>
THE CHALLENGES

NHS Blood and Transplant, working together with the Organ Donation and Transplantation clinical communities of the United Kingdom, has delivered a steep increase in the numbers of organ donors and a record number of consequent transplant procedures.

**Figure 1: Organ Donation and Transplantation rates, 2006-2016**

The majority of the increase in organ donor numbers has come from those who are confirmed dead following cardio-respiratory arrest, known as donation after circulatory death (DCD).

**Figure 2: DBD and DCD Donation Rates, 2006-2016**
Because of this and other factors such as increasing age, co-morbidity and BMI, the organs that have been used for transplant purposes in the last few years have been of a more marginal nature compared with organ transplants performed a decade ago. For an individual patient on a transplant waiting list, the balance of benefit versus risk in proceeding with the transplant, even from more marginal donors, is still in favour of transplantation for the majority of patients. However, there is a change in that balance of risk because of the increasing marginality of organs. As a result, the decision (by clinician and patient) about whether or not to accept an organ is more complex than it was historically.

There are many factors that may be considered to make an organ more marginal for the purposes of transplantation. These factors vary between different organs.

**Donation after Circulatory Death**

At first, as DCD donation was introduced, organs removed from a donor who died following circulatory arrest were seen as more marginal because of the damage that possibly occurred to the organ during deterioration of the body immediately prior to death.

Accumulating evidence suggests that organs from DCD donors have very similar long term outcomes to DBD donor organs. Of course there is variation for different organs of the body. Until recently it was thought that the heart from a DCD donor could not be used, for what would seem obvious reasons. Even this has been challenged by early success in pilot projects. In addition, complications following liver transplantation seem to be higher after DCD donation – yet UK data suggests that there are benefits to many patients on the waiting list by accepting a DCD liver transplant rather than remaining on the transplant list and waiting for a liver from a DBD donor.

**Age**

Large international studies have demonstrated that the long-term outcome following transplantation is significantly correlated with the age of the donor at the time donation occurs. An exception to this is transplantation of the lung, where there is little correlation between the outcome and the age of the donor, until donors are over the age of 65.

**Figure 3: UK patient survival after first adult lung-only transplant, 01/04/2007–31/03/2011**
In the United Kingdom, it is clear that the donor population is now significantly older than a few years ago. It is of interest to note that the UK donor population is still much younger than that of Spain (see Figure 4 below).

Age and DCD are two common factors that are cited by clinicians as reasons to consider a particular organ more marginal in 2016 compared with 2010. However, there are others such as history of smoking, fat deposits in the liver (steatosis), history of high blood pressure, increasing BMI, history of arterial disease etc.

International comparison demonstrates that the donor demographics are different. However, there is evidence that whilst there may be higher acceptance rates in other countries, there is also a higher discard rate, particularly for older donors. Therefore, the UK’s rates of organ acceptance may be more reasonable than it first appears.

**Figure 4: UK and Spain all donors by age group (% total)**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>UK</th>
<th>Spain</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14</td>
<td>2.7</td>
<td>1.6</td>
</tr>
<tr>
<td>15-29</td>
<td>11.1</td>
<td>4</td>
</tr>
<tr>
<td>30-44</td>
<td>17.5</td>
<td>10.2</td>
</tr>
<tr>
<td>45-59</td>
<td>33.7</td>
<td>31</td>
</tr>
<tr>
<td>60-69</td>
<td>31</td>
<td>22</td>
</tr>
<tr>
<td>70-79</td>
<td>22.6</td>
<td>12.1</td>
</tr>
<tr>
<td>≥80</td>
<td>9.8</td>
<td>0.9</td>
</tr>
</tbody>
</table>

**Figure 5: Discard rates for kidneys from deceased donors, 2014, by donor age**

<table>
<thead>
<tr>
<th>Country</th>
<th>No. kidneys retrieved</th>
<th>% adult deceased donor kidney transplants from a DCD</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>N=2,986</td>
<td>24% overall</td>
</tr>
<tr>
<td>US</td>
<td>14,754</td>
<td>19% overall</td>
</tr>
<tr>
<td>UK</td>
<td>2,432</td>
<td>10% overall</td>
</tr>
<tr>
<td>Australia</td>
<td>700</td>
<td>6%</td>
</tr>
</tbody>
</table>

Source: ONT – Spain data, OPTN – US data, ANZ – Australia data, NHSBT – UK data
The spectrum of response

In a Transplant Unit, there may be different protocols for who makes or contributes to the decision to accept or decline a particular offer of an organ for transplantation, sometimes for a specified recipient and sometimes for use in any eligible patient within that transplant centre. The duty transplant surgeon is nearly always involved but there is variable inclusion of the transplant physicians or the patient in the initial decision to move forward to a transplant. Consequent on this decision, the patient will be called into the Transplant Unit and the organ will be transported as quickly as possible to allow the procedure to occur.

There is strong evidence of clinician variability in the response to different levels of risk represented by more or less marginal donor organs. This is only natural. There is an accepted level of conservatism or aggression in all clinicians, partly arising from their own personalities, their experience, and the resources available to them, and the patient outcomes from their recent similar decisions. The rate of turning down donor organ offers, often referred to as decline rates, therefore varies from clinician to clinician and across Transplant Units. However, in the field of transplantation one might expect that this spectrum would be relatively tight across the United Kingdom given the similarity of donor organ offers and the state of health of patients on the waiting list across the country.

There is also a surprisingly wide spectrum of decline rates, with a significant centre difference across the United Kingdom. This can be partly explained by individual clinician acceptance of risk, local factors and size of waiting list. However, the full explanation is as yet unknown.

Figure 6: Adult standard criteria DBD donor kidney offer decline rates for kidneys that resulted in a transplant, 1 April 2013 and March 2016
ACHIEVING THE OUTCOMES

In any clinical community there is always a spectrum of action for any particular intervention. Some may argue that the decline rates seen across the United Kingdom are an example of such behaviour. Others would point to the fact that the spectrum of decline rates is wide and some donor/recipient matches, turned down by certain clinicians, would be accepted, almost without question, by other clinicians and with no evidence of any worse outcomes for their patients. Therefore the consensus of opinion seems to be that, while there will always be a spectrum of acceptance/decline, especially in present circumstances of marginal organ donation and great need, work should be carried out in order to see whether the spectrum could be narrowed.

It should be stressed that there is no intention to apply pressure to a particular clinician or patient to take unacceptable levels of risk. Rather, the intention would be to demonstrate average or consensus behaviour to see whether or not that reduces the width of the clinical spectrum seen at present, with the aim that all Units adopt best practice and mirror the behaviour of those Units who have the lowest decline rates yet also have excellent outcomes for patients.

Outcome 1: Excellence in the assessment and management of potential donors means that as many organs as possible are available for transplant.

Donor referral
A large amount of work has been done to increase the referral of potential donors, particularly DCD donors. This programme has been very successful, but has had the unintended consequence that some patients were referred who, after exploring their condition/past medical history, could not realistically donate some or all of their organs. However, the system encouraged all organs with no absolute contra indications to be offered until all centres had declined. This delay causes some concern amongst critical care staff who believe that it imposes additional burdens on patients, their families and critical care resources.

There are a number of conditions that can be listed as recognised contra indications to donation so that certain potential donors are excluded at an earlier stage. This is appropriate for the patient and much kinder to the family involved, not to mention that it is beneficial to critical care staff in their management of patients. It will also encourage transplant clinicians to carefully consider each organ that is offered for transplant and examine each organ that is eventually retrieved to provide greater reassurance that the organs are usable.

Donor optimisation – Ante-Mortem Interventions for DCD donation
There are a range of actions that could be taken to preserve organs for transplantation prior to the donor’s death, but at a stage where death is imminent. These are referred to as ‘ante-mortem interventions’. There are a range of procedures that could be undertaken, from minor activities such as taking additional x-rays, through to administering additional drugs to reduce the risks of blood clots forming in the organs and then to more invasive procedures, such as trans-oesophageal echo (TOE) and elective ventilation. Several of these are common practice in other countries and evidence demonstrates that they improve the number and quality of organs available for transplant. However, current legal guidance limits this possibility in the UK.
Place of withdrawal
There is some evidence that more organs can be successfully retrieved from DCD donors if withdrawal of life sustaining treatment occurs in theatre, rather than in the intensive care unit. This approach reduces warm ischaemic time and therefore the likelihood of successful organ retrieval.

Cardiothoracic donor management
Evidence from UK pilot projects suggest that the number and quality of donated hearts from DBD donors are increased if a member of the retrieval team – a ‘Scout’ – attends the donor at an early stage after brainstem death is declared to support donor management and assessment.

The data from the pilot project has been peer-reviewed, with the recommendation that “There is a strong support and overall suggestive evidence that the Scout concept may significantly improve heart transplant numbers, and this needs to be somehow continued and institutionalised.”

Actions to achieve Outcome 1:
1. Establish a rapid and appropriate screening pathway to exclude inappropriate DCD donors.
2. Subject to a change in the current legal guidance regarding ante-mortem interventions, pilot new approaches for ante-mortem donor management.
3. Take all possible steps to minimise warm ischaemic injury in proceeding DCD donors, including withdrawal of life sustaining treatment in the operating theatre suite where this is likely to improve retrieval and transplant outcomes.
4. In line with recommendations from the Cardiothoracic Advisory Group, National Organ Retrieval Group and external peer reviewers, introduce a UK-wide Scout facility.

Outcome 2: Donated organs are effectively matched with the most appropriate recipients and then offered in a timely manner.

The Hub
The process for offering organs is complex and organs are often offered to some centres that, realistically, are very unlikely to utilise them. The process can also be very lengthy, which increases the risk of organs being lost due to withdrawal of family consent/authorisation, or increased ischaemic times.

This needs to be improved, so that the offering process is rapid and more effective. There needs to be an improved process that enables offering processes to be implemented in a timely way, supporting the more careful matching of donor organ offers to suitable recipients. This will save time in offering and make the donation process shorter as a result. It may also increase organ utilisation through offering organs intelligently e.g. HIV donor organs to HIV positive patients. This new process will be supported by an intelligent, responsive IT infrastructure – known as ‘The Hub’.

1 Cardiothoracic Scout Project: Report from External Review, 2016, L. Potena, A. Zuckerman
Length of the offering process

The process from referral to organ retrieval can be very lengthy for a range of reasons. It is not possible to isolate one specific reason for this extension and it is not isolated to donor characterisation; potential donors are older and more complex which does often require longer to safely characterise, however, there have also been changes in organ offering and allocation, increases in patients listed for urgent hearts and more complex recipient procedures leading to delays in retrieval. Some of the potential reasons for the extension are improvements in transplantation such as more possible types of transplant and in DCD the ability to now donate almost the same organs as in DBD and not just liver and kidneys as was the case in previous years. These timescales are extending year-on-year. Also, the time period between referral to formal approach is often consciously prolonged to allow family conversations and understanding.

All of the above factors have compounded to increase the period between approach and retrieval. These timescales are increasing year on year.

Figure 7: Average times of DBD donation process by financial year

<table>
<thead>
<tr>
<th>Financial year</th>
<th>Time from referral to formal approach</th>
<th>Time from approach to retrieval operation start</th>
<th>Time from retrieval operation start to kidney perfusion with recipient’s blood</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011/12</td>
<td>6:30</td>
<td>14:03</td>
<td>14:52</td>
<td>37:35</td>
</tr>
<tr>
<td>2012/13</td>
<td>8:00</td>
<td>15:05</td>
<td>14:45</td>
<td>41:55</td>
</tr>
<tr>
<td>2013/14</td>
<td>11:15</td>
<td>16:51</td>
<td>14:15</td>
<td>45:42</td>
</tr>
<tr>
<td>2015/16</td>
<td>12:04</td>
<td>19:45</td>
<td>14:06</td>
<td>49:39</td>
</tr>
</tbody>
</table>

Average time interval (hh:mm)

Figure 8: Average times of DCD donation process by financial year

<table>
<thead>
<tr>
<th>Financial year</th>
<th>Time from referral to formal approach</th>
<th>Time from approach to withdrawal of life sustaining treatment</th>
<th>Time from withdrawal of life sustaining treatment to retrieval operation start</th>
<th>Time from retrieval operation start to kidney perfusion with recipient’s blood</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010/11</td>
<td>4:00</td>
<td>9:36</td>
<td>0.28</td>
<td>12:36</td>
<td>28:57</td>
</tr>
<tr>
<td>2011/12</td>
<td>3:45</td>
<td>10:17</td>
<td>0.26</td>
<td>11:28</td>
<td>27:55</td>
</tr>
<tr>
<td>2012/13</td>
<td>3:33</td>
<td>11:50</td>
<td>0.26</td>
<td>12:01</td>
<td>30:29</td>
</tr>
<tr>
<td>2013/14</td>
<td>4:31</td>
<td>12:58</td>
<td>0.26</td>
<td>11:43</td>
<td>32:53</td>
</tr>
<tr>
<td>2014/15</td>
<td>4:46</td>
<td>14:40</td>
<td>0.26</td>
<td>11:25</td>
<td>34:26</td>
</tr>
<tr>
<td>2015/16</td>
<td>5:20</td>
<td>16:49</td>
<td>0.26</td>
<td>11:17</td>
<td>37:32</td>
</tr>
</tbody>
</table>
Table 1: Change in donation process time 2010-2016

<table>
<thead>
<tr>
<th>Financial year</th>
<th>Average length of DBD process (hours)</th>
<th>Average length of DCD process (hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010/11</td>
<td>39</td>
<td>29</td>
</tr>
<tr>
<td>2011/12</td>
<td>38</td>
<td>28</td>
</tr>
<tr>
<td>2012/13</td>
<td>42</td>
<td>30</td>
</tr>
<tr>
<td>2013/14</td>
<td>46</td>
<td>33</td>
</tr>
<tr>
<td>2014/15</td>
<td>47</td>
<td>34</td>
</tr>
<tr>
<td>2015/16</td>
<td>50</td>
<td>38</td>
</tr>
</tbody>
</table>

For the family, sitting with their relative, the process will appear even longer. For them it begins with the news of the admission of their family member, the time in critical care and possible multiple interventions. Given the traumatic time and emotional stress on family members, the length of the donation process can sometimes be too much of an added burden and leads to some families withdrawing their consent/authorisation – particularly in relation to DCD donation.

Assessing a potential donor’s past medical history is vital to ensuring that any organ donated would be safe. However, this does not always need to be a lengthy process.

There is a subset of patients who, at initial assessment, will clearly be donors. In these circumstances there should be a rapid assessment (Enhanced Retrieval Process), followed with more speedy retrieval procedures. This new approach will help to shorten the process and will be popular with ICU clinicians, retrieval teams and, most importantly, donor families. A more rapid process is also beneficial for ICU clinicians so that clear decisions are made quickly and ICU bed usage is more efficient. This rapid approach is likely to optimise the quality of organs that are retrieved from such donors and thereby improve organ utilisation.

**Named organ recipients**

NHSBT already uses algorithms to support the matching of donated organs with named recipients particularly for kidneys, where work is being undertaken to improve the allocation process and match donor and recipient quality. This helps to ensure that the best possible use is made of donated organs. This service needs to be developed to increase the numbers of organs that are offered for named recipients across all organ types.

**Actions to achieve Outcome 2:**

1. Develop and improve the IT infrastructure, to support the timely, accurate matching of donor organ offers to suitable recipients.
2. Increase the numbers of organs offered to named recipients in allocation algorithms.
Outcome 3: Surgeons have the information and guidance to enable them to safely accept and transplant as many organs as possible, with patients being able to take an active role in the decision.

Patient involvement in organ acceptance

Patients have in-depth discussions with their clinicians regarding what levels of risk they are willing to accept regarding donated organs. For example, whether a patient who is waiting for a lung transplant would be willing to accept the lungs of a donor who had smoked. These discussions could lead to patient-specific criteria for organ matching. Discussions would need to be repeated at suitable intervals as a patient’s level of acceptable risk may change as their circumstances change.

The final decision regarding whether an offered organ is suitable for a potential recipient lies with the surgeon, who has to consider the condition of the offered organ, the condition of their own patient and any restraints the patient may have placed on organs they would be willing to accept. This means that the surgeon has to carefully balance the risk of accepting a marginal organ against the risk that they may not be offered another organ for a long period of time or potential death whilst on the waiting list. Where possible, a surgeon will speak to their transplant team and their patient regarding a specific offer before the final decision is made, but time constraints mean that this is not always possible. Patients are not routinely made aware of the organs that have been offered specifically for them and declined by their unit on their behalf.

More needs to be done to support patient involvement in these complex decisions. Patient groups should be consulted regarding what more could be done. A pilot should be established to explore the benefits of enabling patients on the transplant waiting list to access information about any organs that had been offered for them, but declined by the Transplant Unit. This will help inform the discussion between transplant surgeons and their patients regarding the acceptance criteria. The outcome of the pilot will be used to inform next steps.

NHSBT (ODT) Support to clinicians who accept reasonable risk

NHSBT monitors short-term patient outcomes following organ transplantation through centre specific cumulative sum (CUSUM) analyses. These are undertaken monthly or quarterly depending on organ type. These ‘within centre’ analyses enable prompt detection of any changes in mortality rates, providing external assurance and enabling centres to compare current outcomes with their own past performance to assist in internal auditing. CUSUM monitoring compares current outcome rates with an expected rate and has been applied to transplantation centres for a number of years. This data does not lead to any widespread call for surgeon-specific results as it is recognised that results depend on the whole team.

There is evidence that, after well-publicised incidents in transplantation, there has been some move to avoid higher risk procedures. This risk-averse behaviour goes against the overall picture of good outcome figures and disadvantages patients on the waiting list that may benefit from a ‘more risky’ transplant procedure.

For example, the Montgomery versus Lanarkshire case led to dramatic changes in consent/authorisation to medical intervention, with a shift in consent/authorisation of the patient from ‘what a reasonable group of clinicians would want to be known’ to ‘what a reasonable patient would want to be known’.

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2 Montgomery (vs) Lanarkshire Health Board, 2015
NHSBT is not, ultimately, responsible for the consent process that is carried out in a Transplant Unit. However, it can support the efforts of the British Transplantation Society to provide professional leadership on best practice and to help ensure that the process of consent/authorisation is laid out adequately to transplant clinicians in a description of best practice. This will also enable NHSBT to give stronger support to those clinicians who take appropriate risk.

There is a range of guidance and support offered from NHSBT to transplant surgeons and their teams in making decisions regarding accepting organs for transplant. This ranges from guidance and advice from the Solid Organ Advisory Groups and published on the ODT microsite, ad-hoc advice about specific issues and support/ liaison with press. These documents are kept under regular review to ensure that they are updated and remain fit for purpose.

**Improving organ declines data**

A package of projects is required to improve the detail of information that we hold on referrals, the timing of transport and reasons for organs being declined by one or more centres. This would improve understanding – nationally and locally – about the rates of declines and benchmarking to identify areas that need to be addressed, to help ensure that no transplantable organs are discarded. This package could include:

1. Dissemination of data from surveys of transplant surgeons.
2. Work with the Chairs of the Solid Organ Advisory Groups to review any existing ‘standard criteria’ for organs either in the UK or where possible in comparison with international data. New criteria should be developed for any organs where there are no ‘standard criteria’ in place. These definitions should be publicised and then used to support monitoring of organ declines/utilisation and support best practice.
3. Examine comparative data on outcomes of declined organs that were used elsewhere and deaths on waiting list after declined offers.
4. Map time from organ arrival in Transplant Units to time of subsequent decline and using this data, identify where improvements can be made to provide an efficient, streamlined process, enabling organs to be offered on in a more timely manner.
5. Feedback from the NHS England Transplant Unit Peer Review.

As part of the Peer Review process, NHS England has advised Transplant Centres to hold monthly clinical review meetings regarding organ utilisation and decline rates. This data would support these local discussions.

**Analysis of discarded organs**

A significant proportion of retrieved deceased donor organs are discarded each year in the UK, ranging from 10-12% of kidneys, to approximately 50% of pancreases. While in most cases the reasons for discard are clear and acceptable, in many instances there are concerns that these organs have been discarded inappropriately.

Registry analyses of these organs do not provide sufficiently detailed data for clinicians to judge whether organs have been discarded appropriately or not. To address this, a review of sample of discarded deceased donor kidneys was undertaken. The assessment identified weaknesses in the offering and allocation processes, leading to the introduction of the UK Kidney Fast-Track Scheme3.

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3 Callaghan et al, Clin Transplant, 2014
Building on this work, regular evaluations of a sample of discarded organs will be performed to provide valuable data on clinician decision-making, and to ensure that organ offering, allocation, assessment and transport pathways are optimised.

Dissemination and discussion of data

Transplant Units are provided with data on the outcome of organs that they have declined and have been implanted elsewhere. The aim is to provide information on the outcome of any organs that one Unit may have deemed unsuitable for transplantation for patients on their waiting list, but were accepted and transplanted by another Unit, which can then inform future practice.

The data that is disseminated is drawn from the NHSBT central data collection and is not robust. In addition, the data is not always received by the most relevant people and those with the ability to support and influence change at a local level. These issues need to be addressed.

Once improved, this data should be disseminated to Trusts, to support them in identifying where there is best practice and any issues to be addressed along the donation and transplantation care pathway. This could include outcomes from higher-risk organs, which were declined by one or more Units before being accepted and transplanted.

NHSBT should work with the Solid Organ Advisory Groups to review specific instances where the reasons for decline are unclear. The definitions and exact triggers would need to be agreed on an organ-specific basis, but could include the following circumstances:

- A highly sensitised patient (one who has a high level of anti-HLA antibodies) where the relevant testing suggests that transplantation would be possible, and a standard donor organ has been offered (i.e. not a high risk marginal kidney).
- A long waiting patient and a standard criteria organ has been offered.
- Any offer of an organ from an ‘ideal donor’ that is declined.

Once a data-set is agreed, abdominal organ Transplant Unit Directors should be issued a letter providing the details and asked for clarification regarding the reasons why the organ had been declined. The returns will inform future practice both nationally and locally.

For CT organ declines, where there are a small number of centres, there should be regular national reviews to discuss the reasons behind declines of ‘ideal donors’. The outcomes of these meetings would be used to inform future acceptance policy, as well as supporting best practice at a local level. The meetings should be led by the CT Advisory Group and representatives from all Units would be required to attend.
Actions to achieve Outcome 3:

1. In discussion with clinicians and patient groups, identify how to improve patient involvement in difficult decisions about organ acceptance.

2. In liaison with the British Transplantation Society, improve and raise awareness of best practice regarding consent.

3. NHSBT will work with the BTS to raise awareness of the support already available from NHSBT to surgeons and explore whether this needs to be strengthened, so that surgeons feel better able to take considered/controlled risks in the utilisation of offered organs. The effectiveness of this approach will be kept under review to assess whether surgeons feel that support offered by NHSBT has improved.

4. NHSBT will collate and disseminate an evidence-base on the use of higher risk organs using UK Transplant Registry analyses.

5. A retrospective audit of reasons for decline as held on the central NHSBT database and that held locally by Units, to inform improved data collection and dissemination. Building on the outcome of the audit, improve data collection on organ declines to remove any inaccuracies, so that it can better inform local decisions and actions.

6. Build on the current data routinely provided through senior management to NHS Trusts regarding organ donation activity and where a Trust also includes a Transplant Unit, include comparative data on organ acceptance and declines.

7. Introduce a standard clinical governance package, which should be made available for every Transplant Unit to inform local action. The package should include:
   a. Regular decline (monthly) review meetings
   b. Decline reviewed in relation to waiting list mortality for that unit
   c. Annual review of discarded organs

8. There will be a national annual review of discarded organs, to share learning and understanding regarding the potential loss of organs.

OUTCOME 4: Retrieval teams attend donors at the most suitable time and organs are preserved to maximise the potential for successful transplantation.

Information Sharing

There are a small number of local initiatives to improve the data available – in real time at the time of retrieval – regarding organ quality. These include the ability to send live images and readings between the retrieval and transplanting centres, which in turn has locally led to an increase in organ utilisation\(^4\). These initiatives should be further developed, to deliver improvements in:

- Patient safety, patient outcomes and organ utilisation, through improved data regarding organ quality at the retrieval/offering/acceptance/examination stages.
- Quality governance, through improved ability for early identification and resolution of issues with: (i) retrieval teams regarding organ damage etc; (ii) transplant teams regarding discard rate.
- Support the ongoing training of retrieval surgeons, through the early identification and management of any performance issues.

\(^4\) European Society of Cardiology, Al Attar N et al, 2015
Monitoring damage rates

Transplant Units frequently quote the damage of organs at the retrieval stage as one of the main reasons for declining organs. All Transplant Units are asked to formally record any incidence of organ damage due to the retrieval process. The evidence from NHSBT from clinical governance reports suggests that a relatively small number of organs are discarded each year due to organ damage.

Figure 9: Number of organs (abdominal and cardiothoracic, DBD & DCD) not transplanted due to damage as a proportion of all organs retrieved\(^5\)

There is clearly some disparity between what is perceived as damage, what is recorded as damaged and what is reported to NHSBT as damage as a result of the retrieval process. This needs to be addressed so that a clear evidence base can support and inform any further action to minimise the risk of organ damage at the retrieval stage.

Novel means of perfusion and preservation

Novel methods of organ perfusion, preservation and resuscitation have the greatest potential for increasing the number and quality of organs that can be transplanted. For example, the DCD hearts service evaluation enabled an additional 22 hearts to be safely transplanted.

The Research, Innovation and Novel Technologies Advisory Group (RINTAG) has been established to guide, order and coordinate projects so that the most effective means of using these novel technologies may be identified as quickly as possible and make recommendations to NHSBT and UK Commissioners on the suitability of any further innovations for service evaluation in the UK.

Going forward, RINTAG will continue to monitor progress with research and novel technologies and, where clinical trials and service evaluations prove successful, work with NHSBT, Commissioners and the relevant solid organ Advisory Groups to develop business cases for wider roll out across the UK.

\(^5\) Where grade of surgical damage reported (6% missing for reasons such as not received with intent to transplant, transplanted abroad, went for research or genuinely missing)
Enhanced retrieval process

Currently, with the exception of super urgent organs, all organs are offered in line with an agreed protocol. This supports and enables equity of access to donated organs for those on the waiting list, but means that organs are occasionally lost as a donor quickly becomes unstable, or does not facilitate an enhanced, rapid retrieval process for those donors where there is little doubt that an organ would be accepted or the family may withdraw consent/authorisation due to concerns regarding the length of the process.

Actions to achieve outcome 4:

1. Develop an improved system to support the sharing of real-time data and digital imaging, to inform surgical decision after acceptance of an organ but prior to the organ being dispatched.
2. Audit of discarded organs that may have been damaged during the retrieval process.
3. RINTAG will provide rigor to the donation, retrieval and transplantation research programmes and advice to NHSBT and Commissioners regarding how innovation may improve future service provision.
4. Establish an enhanced retrieval service, which will provide rapid attendance in circumstances where:
   - Following initial patient assessment, donation will clearly proceed.
   - Organs are likely to be accepted but the donor is unstable or the family says the process is too long.

Outcome 5: Innovation and best practice is recognised, rewarded and shared. Barriers to maximising the potential for safe organ transplantation are quickly identified and addressed.

Dissemination activity

NHS Blood and Transplant undertakes a range of activities to support the dissemination of information with the transplant community, patient groups and others. Actions already in place include the Associate Medical Director’s Monthly Bulletin, which provides updates and the latest developments. The ODT microsite provides a wealth of information for donation, retrieval and transplant teams, as well as patients. However, it is apparent that not all of those who need to access this information regularly do so and the information provided would benefit from being strengthened. Also, there may be benefit in a forum to bring the donation and transplant communities together to discuss and address issues along the care pathway and share lessons learned.

There is no regular meeting that brings together Transplant Units, the donation community and ODT staff, outside of the special session at the BTS Annual Congress and/or the NHSBT National Donation and Transplantation Congress held approximately every two years. It is important to hold such a meeting with each of the organ-specific Transplant Units, in order to engage the relevant community and support change. The meetings should bring together all the stakeholders, including surgeons, physicians, nurses and patients.
**Review of Barriers to Utilisation**

There has been a growing body of feedback from UK Transplant Units that, following the significant improvements in organ donor numbers, they are feeling increased strain. The extra work required in dealing with higher risk donors means that each transplant requires a greater quantum of work than before. It is quite possible that the strain on resources produces an effect on decline rates, either directly or subliminally. There is some evidence of this, with decline rates being greater after midnight.

It is acknowledged that the responsibility for commissioning transplant services lies with the UK Commissioners and there is an established programme in place to monitor and respond to resource requirements. This includes the Peer Review programme as well as individual commissioning meetings.

However, NHSBT should take action to understand the pressures on Transplant Units and whether there is any impact on organ utilisation. This could then be used as an evidence base to inform next steps.

**Recognising talent**

Any successful clinical service relies on attracting new staff and talent. For transplantation, there is a growing concern that there is a difficulty in appointing and retaining staff, partly due to the high pressures of the role and the unsociable hours. It may also partly be due to the perception that transplantation is no longer the exciting field of practice that it once was and as a result, staff are not attracted to the profession. More needs to be done to recognise and reward new talent and innovation in the field of organ transplantation.

**Actions to achieve outcome 5:**

1. A meeting with each organ transplant service community will be held to review data on declines and organ utilisation and share best practice.

2. NHSBT to survey all Transplant Units to explore what, if anything, should be done to improve the infrastructure and resources to support organ utilisation.

3. NHSBT will work with the British Transplantation Society to establish a scheme for recognising talent in the field of organ transplantation.
## ANNEX – SUMMARY OF AIMS AND ACTIONS

**Aim:** To match world class performance in organ donation and transplantation

<table>
<thead>
<tr>
<th>Who</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>NHS hospitals and staff (donation)</td>
<td>Excellence in the assessment and management of potential donors means that as many organs as possible are available for transplant.</td>
</tr>
<tr>
<td>NHS Blood and Transplant (allocation and offering)</td>
<td>Donated organs are effectively matched with the most appropriate recipients and then offered in a timely manner.</td>
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<tr>
<td>NHS hospitals and staff (acceptance)</td>
<td>Surgeons have the information and guidance to enable them to safely accept and transplant as many organs as possible, with patients being able to take an active role in the decision.</td>
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<tr>
<td>NHS hospitals and staff (organ retrieval)</td>
<td>Retrieval teams attend donors at the most suitable time and organs are preserved to maximise the potential for successful transplantation.</td>
</tr>
<tr>
<td>NHS, NHS Blood and Transplant, Professional Bodies (infrastructure)</td>
<td>Innovation and best practice are recognised, rewarded and shared. Barriers to maximising the potential for safe organ transplantation are quickly identified and addressed.</td>
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<td><strong>Outcome 1: Excellence in the assessment and management of potential donors means that as many organs as possible are available for transplant.</strong></td>
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<tr>
<td>1.1 Establish a rapid and appropriate screening pathway to exclude inappropriate DCD donors.</td>
<td>NHSBT</td>
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<tr>
<td>1.2 Subject to a change in the current legal guidance regarding ante-mortem interventions, pilot new approaches for ante-mortem donor management.</td>
<td>NHSBT</td>
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<td>1.3 Take all possible steps to minimise warm ischaemic injury in proceeding DCD donors, including withdrawal of life sustaining treatment in the operating theatre suite where this is likely to improve retrieval and transplant outcomes.</td>
<td>Clinical Leads for Organ Donation</td>
</tr>
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<td>1.4 In line with recommendations from the Cardiothoracic Advisory Group, National Organ Retrieval Group and external peer reviewers, introduce a UK-wide Scout facility.</td>
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<td><strong>Outcome 2: Donated organs are effectively matched with the most appropriate recipients and then offered in a timely manner.</strong></td>
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<td>2.1 Develop and improve the IT infrastructure, to support the timely, accurate matching of donor organ offers to suitable recipients.</td>
<td>NHSBT</td>
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<td>2.2 Increase the numbers of organs offered to named recipients in allocation algorithms.</td>
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### Outcome 3: Surgeons have the information and guidance to enable them to safely accept and transplant as many organs as possible, with patients being able to take an active role in the decision.

| 3.3 | In discussion with clinicians and patient groups, identify how to improve patient involvement in difficult decisions about organ acceptance. | NHSBT; Transplant Units |
| 3.4 | In liaison with the British Transplantation Society, improve and raise awareness of best practice regarding consent. | NHSBT; British Transplantation Society |
| 3.5 | NHSBT will work with the BTS to raise awareness of the support already available from NHSBT to surgeons and explore whether this needs to be strengthened, so that surgeons feel better able to take considered/controlled risks in the utilisation of offered organs. The effectiveness of this approach will be kept under review to assess whether surgeons feel that support offered by NHSBT has improved. | NHSBT; British Transplantation Society |
| 3.6 | NHSBT will collate and disseminate an evidence-base on the use of higher risk organs using UK Transplant Registry analyses. | NHSBT |
| 3.7 | A retrospective audit of reasons for decline as held on the central NHSBT database and that held locally by Units to inform improved data collection and dissemination. Building on the outcome of the audit, improve data collection on organ declines to remove any inaccuracies, so that it can better inform local decisions and actions. | NHSBT; Transplant Units |
| 3.8 | Build on the current data routinely provided through senior management to NHS Trusts regarding organ donation activity and where a Trust also includes a Transplant Unit, include comparative data on organ acceptance and declines. | NHSBT |
| 3.9 | Introduce a standard clinical governance package, which should be made available for every Transplant Unit to inform local action. The package should include:  
  - Regular decline (monthly) review meetings.  
  - Decline reviewed in relation to waiting list mortality for that unit.  
  - Annual review of discarded organs. | NHSBT; Transplant Units |
| 3.10 | There will be a national annual review of discarded organs, to share learning and understanding regarding the potential loss of organs. | NHSBT; Transplant Units |
### Outcome 4: Retrieval teams attend donors at the most suitable time and organs are preserved to maximise the potential for successful transplantation.

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• Following initial patient assessment, donation will clearly proceed.  
• Organs are likely to be accepted but the donor is unstable or the family says the process is too long. | NHSBT; NORS Teams |

### Outcome 5: Innovation and best practice is recognised, rewarded and shared. Barriers to maximising the potential for safe organ transplantation are quickly identified and addressed.

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NHS Blood and Transplant

NHS Blood and Transplant (NHSBT) saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England. We are the organ donor organisation for the UK and are responsible for matching and allocating donated organs.

We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells. Their generosity means each year we’re able to supply around 1.9 million units of blood to hospitals in England and around 4,200 organ and 5,800 tissue donations, which save or improve thousands of lives.

For more information
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Call  0300 123 23 23