

## **Workshop to discuss the development of a new strategy for increasing deceased organ donation and transplantation rates, 17<sup>th</sup> July 2012**

### **Report of Discussion**

#### **Background**

In January 2008 the Organ Donor Taskforce (ODTF) published its report setting out 14 recommendations which, if implemented in full, should enable the UK to increase the number of deceased organ donors by 50% from a baseline of 809 donors. All four national governments endorsed the recommendations, participated in the ODTF Programme Delivery Board and provided resources to enable the recommendations to be implemented. Nearly four years later the recommendations have largely been implemented. Deceased donor numbers are up by 34% and we recognise that this increase is predominantly made up of an increase in DCD donors and that donors in general are becoming older and heavier. There is still a significant gap between the need and availability of organs for transplant.

A new strategy is needed to ensure that as many people as possible in the UK receive the transplant they need. This strategy will build on what has been achieved so far and incorporating new initiatives, such as the living donor strategy. It is vital to develop the strategy in collaboration with the transplant and organ donation community, as much of the implementation of the strategy will require their active support.

#### **Process for developing a new strategy**

Stage 1 – Evidence Gathering (January – May 2012): Development of a report detailing the current and future potential for organ donation and transplantation, which will be used to inform stakeholder discussion.

#### Stage 2 – Comprehensive stakeholder engagement (May – July 2012):

Engage with all stakeholders to explore the challenges and opportunities for organ donation and transplantation and seek views on what the strategy should contain.

Stage 3 – Developing the strategy (August – December 2012): Building on the advice provided, work with national and international experts to identify the priorities and interventions that have the most potential to increase the UK transplant rates. This will form a draft strategy, which will be accompanied by a high level timetable and some key measures of progress against each of the objectives and will be shared with our stakeholders for comment. (We anticipate that this will be in November.)

Stage 4 – Approval process (January – March 2013): Put the draft strategy with the NHSBT Board and UK Health Departments for approval.

#### Stage 5 – Publish (April 2013)

#### **Stakeholder engagement workshop**

The workshop was attended by around 50 people, representing patients, donor families, voluntary sector, professional organisations, faith groups, UK Government Health Departments, and regulatory bodies.

The event started with a presentation outlining the current and future potential organ donor and transplantation rates and setting 'the big questions' for delegates to discuss.

Delegates were then seated in groups - according to whether they were 'clinical' or 'non-clinical'. The discussion in each group was facilitated and captured by an independent market research company – Opinion Leader. The report overleaf provides their summary of the discussion and the advice provided by stakeholders at the event.

All discussion groups were given the option to discuss any of the 6 'big questions':

1. How do we get the best outcome for those listed for a transplant? (Best practice in transplantation)
2. How do we maximise use of every offered organ? (Donor management, offering, retrieval and transport)
3. How do we make sure every eligible donor is given the opportunity to donate? (Perfect practice every time)
4. What should we do to increase the pool of appropriate potential donors? (Total hospital approach)
5. How do we make organ donation a normal part of UK culture? (Donor behaviour change)
6. What changes do we need to make to infrastructure, working practices, training, IT etc?

If you have any further comments or ideas that you would like to put forward, or would like to see the portfolio of evidence again, please go to:

[www.organdonation.nhs.uk/ukt/newsroom/statements\\_and\\_stances/statements\\_and\\_stances.asp](http://www.organdonation.nhs.uk/ukt/newsroom/statements_and_stances/statements_and_stances.asp)

This site will be open until the 24<sup>th</sup> September 2012.

# NHS Blood and Transplant: Organ Donation and Transplantation Strategy

## Summary of Feedback from Events on Tuesday 17 July 2012



This document provides a two page summary of the issues discussed at the NHS Blood and Transplant event held on 17 July 2012 to discuss future strategy. Discussion followed a presentation of progress results which raised questions for future delivery of donor and transplantation services.

### **Refusal of Consent**

There was detailed discussion of refusal of consent for organ donation on all tables. It was strongly felt that reasons for refusal needed to be better understood so that doctors and nurses were better equipped approach donor families. Suggestions were made as to how this family refusal may be dealt with in the future. These included ensuring that families were aware of a potential donor's wishes prior to their being admitted to hospital/ dying and providing hospitals with a way of tracing the wishes of a donor, perhaps via the donor card. This card would be distributed to a donor after they registered to donate their organs after death, and could contain a space for the signature of a family member or next of kin to corroborate that they understand the donor's wishes. There was a strong view that donors should be encouraged to have open discussions with members of their family prior to their being admitted to hospital (or, preferably, at the point of their decision to register). It was frequently observed that people were uncomfortable discussing death and events following a loved one's death. Greater openness here was seen as essential to promotion and acceptance of organ donation, encouraging families to feel less hostile about consenting to organ donation.

Another suggestion was that families ought to be approached about donation as far in advance of the event as possible (prior to death where possible), so that they were able to digest their relative's wishes and arrive at an informed decision. One way of doing this might be to embed discussions about organ donation in end of life care plans. Another way might be to integrate donor services more closely with hospital bereavement services generally, so that discussion of donation could be factored into bereavement discussions.

This fed into another suggestion made by participants: the importance of having specially trained staff, capable of understanding and reacting to the needs of each donor family. One participant from a religious group, for instance, said it was important that SNODs received faith training, so they were equipped with the cultural knowledge necessary to broach the subject of donation with a family of a particular faith. It was also suggested that staff should be able to empathise and respond to the needs of different families in different situations, providing them with as much or as little information as they needed at the time. (It was not always felt that discussions with donor families were responsive in this way.) If a family was feeling distressed, for example, they might not want to be given the details of what happens during organ donation and retrieval. In this respect, members of staff should not adhere to codes and guidelines alone, but know what is and is not appropriate for different patients and their families.

### **Public Education**

A second issue that was raised by both clinical and non-clinical participants was that of education of members of the public. By targeting youngsters even before the age of ten, it was thought that this would 'normalise' the issue of talking about death and organ donation,

and might even encourage them to discuss the issue at home with their family. Additionally it was thought that there were many misunderstandings and misconceptions about organ donation that, if addressed, might improve the public's perceptions of organ donation. Some members of the public were thought to associate organ donation with 'body bags', or assume that retrieval took place whilst patients were still alive (through ventilation), while others were seen as harbouring suspicions that if their health were ever at risk, a clinician may not offer them the best treatment in order to 'get their hands on their organs'.

By explaining the process, an individual would go through prior to organ donation (and death) these concerns might be allayed. This would have the additional benefit of allowing people to make an informed choice about donating organs, and to discuss the subject freely with others. One participant spoke of an organ donor who elected to have his organs removed but not tissue, which meant that his heart was retrieved and the valves were not. Those close to him felt the donor could not have understood this distinction and therefore must have made an inaccurate choice. Education was thought to be essential to encouraging individuals to become donors. Simply enforcing an opt-out system, for example, would not stimulate discussion or improve understanding of the process of organ donation, and ignorance would remain as to what was actually involved.

Sending clinicians into schools to talk about donation was seen as a way of changing attitudes over time. Young people would tell their parents what they had heard, be involved in making decisions about donation of their parents' organs in the future and, ultimately, decide whether they wanted to donate their own organs on death. As a result, promoting organ donation in schools was seen as having a long-term impact. Some clinicians also felt there should be better education on donation within hospitals, to ensure managers and clinicians working across hospital services were focused on promoting and ensuring high levels of donation.

### **Consistency of Performance**

Discussion also focused on the importance of ensuring consistency in performance throughout the organ retrieval and transplant process (i.e. in carrying out brain stem tests, obtaining consent, and carrying out successful transplant procedures) across all centres. It was suggested that an independent regulatory body should be established to develop and uphold a code of practice or set of guidelines which all centres were bound to follow. This body should monitor the performance of centres with regard to the number of brain stem tests being carried out (some clinicians thought brain stem tests should be mandatory for all potential donors), the refusal rate of family members, and the success rate of transplants.

Similarly, there was support for cash incentives being offered to hospitals that did meet certain criteria, in the form of money to fund additional Intensive Care Unit beds (which was seen as of paramount importance to some clinicians), and preferential treatment when organs became available for patients (although the reaction to this was mixed, with some clinicians strongly rejecting the idea). The focus of this regulatory body would not, initially, be to change public attitudes/mentalities towards organ donation, but to ensure existing and known potential donors are sufficiently identified and managed first and foremost.

There seemed to be a fairly even divide between those who felt changing public opinion and encouraging people to become donors ought to be the first step and those who thought it would make greater sense to address inefficiencies in procedural and infrastructure. Similarly, there were mixed responses to proposals for increasing the number of potential donors. Some believed that an opt-out system would raise awareness of the issue of organ

donation and stimulate discussion to an extent that members of the public would engage with it, while others were more sceptical. Many clinicians stated that improvements in transplant rates in Spain (which has an opt-out system) had been achieved through improvements in donor management and end-of-life care, with evidence showing that opt-out registration made no noticeable difference to donor levels. Some had moral objections to enforcing donor registration on society. Offering incentives to potential donors and their families also received mixed reactions. Some queried whether this was morally right and whether the NHS could foot the bill for this. Some clinicians, however, seemed to think an incentive of £2,000-£3,000 paid through vouchers (and perhaps contributing to funeral expenses) might improve consent levels.

### **Optimising Use of Donor Organs**

Clinicians commented that the data supplied to surgeons about the state of an organ and the risk involved in transplanting it into a patient was often out of date and insufficient. Transplant surgeons currently take responsibility for weighing up whether or not each transplant procedure – and the organ – is viable. Some were of the view that standardisation in the way this information is delivered was necessary and it was also suggested that the teams collecting and delivering this information should also be consistent. One way of ensuring this would be to have independent donor teams working nationwide to deliver donor organ information in a robust, reliable and standardised way. This (operating alongside improved regulation) would allow a common set of indicators for organ quality to be developed and maintained, which would take some of the pressure off the individual judgment of the surgeon.

Discussion of independent, nationwide donor teams also fed into suggestions for how current donor teams could be better utilised. Numbers of donor teams were seen to vary between different trusts / regions and staffing levels were seen as restrictive. Clinicians felt that this (along with low staffing levels) resulted in low levels of utilisation. It was suggested that donor teams could be focused on a smaller number of hospitals (with donors brought to these) to optimise utilisation. It was also argued that a national, independent, organisation could be established, providing five or six donor teams nationwide, to achieve better optimisation.

In addition, if surgeons had the technology to receive information about an organ that had become available more quickly (perhaps on a tablet or other mobile device), this would increase the overall time available for the donation and transplantation process and alleviate any rush at time-critical points. It was also suggested that greater consideration should be given to using less-than-perfect organs and that donor and transplant teams could be less risk-averse in selecting organs. Surgeons could consult potential recipients before a less-than-perfect organ became available, to ascertain their willingness to receive the organ. This might increase optimisation in borderline cases and could only proceed where the surgeon was willing to consider use of the organ.

Finally, there was extensive discussion of the need for better funding for ICUs in order to deliver better results. It was believed there should be an increase in ICU beds nationally, given current levels of demand. Alongside this, donation and transplantation needed to be given a higher profile within hospitals, via better incentives for organ retrieval and transplantation in hospitals. At present, it was agreed that hospitals had the wrong attitude towards donation and that donors were not being optimised, mainly due to the need for ICU beds. Overall, better reimbursement for hospitals, slowing the rush to identify ICU beds, was seen as necessary here.