

NHSBT Board
26 January 2017

Taking Organ Transplantation to 2020: a review of progress

1. Status – Public

2. Executive Summary

The 2020 Oversight Group (with membership from all four UK Health Departments, NHSBT, professional bodies and voluntary sector stakeholders) reviewed the strategy, *Taking Organ Transplantation to 2020*, in November 2016.

The Oversight Group concluded that the aim of the strategy, to match world class performance in organ donation and transplantation, was still the right ambition but there were varying degrees of confidence in the likelihood of meeting all the measures by 2020. The Group therefore developed a supplementary action plan which it is hoped will increase the number of organ donors and transplants across the UK.

3. Action Requested

The Board is asked to:

- **Note the progress being made to meet the challenges set in the *Taking Organ Transplantation to 2020* strategy**
- **Approve the supplementary action plan to increase the number of organ donors and transplants across the UK.**

4. Purpose of the paper

This paper is to brief the NHSBT Board and the four UK Health Departments on progress in meeting the aims of the strategy *Taking Organ Transplantation to 2020* and sets out the additional actions that have been agreed to boost the numbers of donors and transplants up to 2020.

5. Background

In June 2013 the UK published a new strategy, *Taking Organ Transplantation to 2020*, with the objective of matching world class performance in organ donation and transplantation. The strategy identified four outcomes to achieve and measures by which these would be assessed. Shown in figure 1.

Outcomes & Measures

- 1 Action by society and individuals will mean that the UK's organ donation record is amongst the best in the world and people donate when and if they can. **Consent rate – 80% by 2020**
- 2 Action by NHS hospitals and staff will mean that the NHS routinely provides excellent care in support of organ donation and every effort is made to ensure that each donor can give as many organs as possible. **Deceased organ donors per million population – 26 pmp by 2020**
- 3 Action by NHS hospitals and staff will mean that more organs are usable and surgeons are better supported to transplant organs safely into the most appropriate recipient. **Patients transplanted pmp – 74 pmp by 2020**
Increase organ utilisation – 5% by 2020
- 4 Action by NHSBT and Commissioners means that better support systems and processes will be in place to enable more donations and transplant operations to happen.

A 2020 Oversight Group was formed, chaired by Elizabeth Buggins and with membership from: all four UK Health Departments; NHSBT; transplant commissioners; professional bodies and stakeholder representatives. Given the challenges in changing public behaviour an associated Stakeholder Group, chaired by Professor Gurch Randhawa, was established to harness the efforts of a wide range of stakeholders in promoting organ donation.

In November 2016 the Oversight Group met to review progress, assess whether the UK is on track to achieve the aims and agree any further actions that are required. It was noted that although donor numbers had increased in years 1 and 3, there had been fewer donors in year 2 and progress in year 4 (current year) is behind plan. Sadly transplant numbers have not kept pace with expectations, due largely to increases in donors after circulatory death and to increasing donor age and co-morbidity. As a result the number of organs transplanted from each donor is lower than hoped. ¹

Progress against each of the outcomes is as follows:

Outcome 1: Public Behaviour

Despite increasing the number of people joining the NHS Organ Donor Register, more people reporting awareness of the issue and more people recently having conversations with their family after registering, the UK consent rate has only increased by 4% and at 62% is well behind our aim of 70% for 2016/17. It is particularly disappointing that there has been no

¹ The review focussed on the deceased donor strategy: review of the living donor strategy will take place separately.

sustained improvement in consent from the black and Asian communities where need for matched organs is significant. The organ donation behaviour change strategy outlined the level of investment necessary to achieve a behaviour change of this magnitude. With a tenth of the recommended budget we have trialed a number of initiatives over the last year to identify which have the most impact. We will report to the Board in March setting out the proposed spend and the marketing and campaign plans for 2017/18.

Outcome 2: Donor Hospital Performance

Generally donor hospital clinicians are more consistently testing and referring potential donors and making sure that trained specialists are involved in approaching families. This does not mean, however, that there are no missed opportunities. Between April and September 2016 we estimate that about 700 opportunities were missed when best practice was not followed. While it is very unlikely that all would have led to a transplant, when dealing with only about 5,500 potential donor opportunities annually, we cannot afford to miss a single opportunity.

Outcome 3: Transplant Centre Performance

Sadly for those on the transplant waiting list, the rate at which organs are converted to transplants has not increased. Whilst the donor profile is increasingly challenging, there is considerable variation across centres in organ acceptance, disadvantaging patients registered with centres which turn down a significant proportion of offers. Although a high percentage of organs are placed through fast track schemes, the current system adds delay. This may have a negative impact on the organ and results in avoidable delays for donor and transplant hospital. There was some evidence that capacity in transplant centres may be affecting organ utilisation but this is difficult to quantify. There are also some areas for optimism: normothermic regional perfusion appears to show promise of increasing the numbers of livers that are transplantable and a service evaluation has demonstrated that hearts from Donors after Circulatory Death can safely be used to increase the number of heart transplants.

Outcome 4: improvement to systems and processes

In two areas considerable progress has been made. Specialist Nurses now collect and transmit all donor characterisation data using a specially designed mobile application, Donorpath, and the first step towards creating a central organ donation and transplantation Hub has been taken, with the release of an improved cardiothoracic allocation scheme on a new platform. Despite this the time taken to offer and place organs has increased considerably causing distress to some donor families and problems for both donor hospital and the transplant centres. Although a step change in the offering process is dependent on a fully functioning Hub, interim improvements need to be made.

6. Assessment of the 2020 Oversight Group

The Oversight Group reaffirmed that the aim to match world class performance was still a reasonable ambition but there were concerns that this might take longer than hoped without additional actions. It was agreed that

the key measurement was the number of transplants but all elements of the system need to be optimised to increase transplant numbers.

The group considered what additional actions should be taken to:

- Engage with the public
- Ensure no opportunities are missed in hospitals
- Make the best of new opportunities
- Ensure the system has the sustained capacity to meet the strategic aims.

A full plan of additional detailed actions is attached at appendix 1. The engagement of all participants in developing the plan should ensure that it is supported and implemented. Some of the key ideas included:

- Develop a UK -wide social media plan to engage with the public and a complementary plan to engage with NHS staff and with politicians.
- Engage with forensic pathologists, coroners, procurators fiscal and the Association of Chief Police Officers (ACPO) to secure operational support for organ donation and develop professional guidance.
- Publish league tables showing missed referral of potential donors to encourage 100% referral and make sure no opportunity is missed.
- Publish and implement a detailed organ utilisation strategy.
- Develop an operational plan and business case for Normothermic Regional Perfusion (NRP) for livers from donors who donate after circulatory death and pursue options for funding a DCD Heart transplant programme across the UK.
- Explore fast tracking organs sooner rather than after five offers as now. (A Rapid Improvement Event is being held in January 2017 to identify options for reducing the length of the clinical pathway).
- Explore options for developing a transplant unit scorecard to assess capacity and performance of all units in relation to deceased donation and renal units for live donation.

Once the supplementary action plan has been approved, it will be publicised widely under the strapline 'no missed opportunities' and monitored alongside the other actions in the strategic plan.

Conclusion

A review of the strategy *Taking Organ Transplantation to 2020* concluded that more would need to be done to achieve the UK's ambition of matching world class performance by 2020. A plan has been developed and once agreed, this will be implemented, urging everyone involved in donation and transplantation to *miss no opportunity to make a transplant happen*.

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Appendix 1.

Actions of the outline plan

Aim to match world-class performance in organ donation and transplantation

The *Taking Organ Transplantation to 2020: A UK Strategy* Oversight Group carried out a mid-point review of the strategy on 30 November 2016. In addition to the specific actions recorded in the strategy, new actions have been identified by the Oversight Group and are outlined here in this new chapter.

Outcome 1 Action by society and individuals will mean that the UK's organ donation record is amongst the best in the world and people donate when and if they can.	
Specific Actions	Responsibility
Develop single conversation brand/hashtag to be used by <i>everyone</i> . Test immediately and socialise it with stakeholders.	NHSBT
Write an engagement plan for the following groups: NHS staff, the public, politicians.	NHSBT
Develop a celebration event that is family led, with mixed communities and with politician support. Consider linking with the Order of St. John Award.	NHSBT
Facilitate a series of public debates.	NHSBT
Explore linking with hospital coffee shops to provide cardboard cups or sleeves with appropriate branding (and barcode to scan to the website), to support the normalisation of organ donation.	NHSBT
Explore the creation of 'pamper packs' for families of hospital patients, containing appropriate branding (e.g. phone chargers that can be returned, toothpaste), to support the normalisation of organ donation.	NHSBT
Discuss and create a social media strategy to maximise opportunities.	NHSBT, UK Health Departments

Outcome 2 Action by NHS hospitals and staff will mean that the NHS routinely provides excellent care in support of organ donation and every effort is made to ensure that each donor can give as many organs as possible.

Specific Actions	Responsibility
Respond to consultations on 'Never Events' and consider the introduction of a new 'Never Event' on referring all expected deaths in ICUs to the Organ Donation Service.	NHS England
Investigate the possibility of the equivalent of 'Never Events' in Scotland.	National Services Division Scotland
Explore the introduction of a CQUIN for referral of expected deaths in ICU to the Organ Donation Service and determine if this should be mandatory.	NHS England with NHSBT support
Seek to incorporate referral of expected deaths to the Organ Donation Service as part of End of Life Care practices on CQC inspections.	Professional bodies, NHSBT
Engage with forensic pathologists, coroners, procurators fiscal and ACPO to secure operational support for organ donation and develop professional guidance.	NHSBT, Professional bodies
Undertake a detailed comparison of the Spanish and UK organ donation systems and determine if any changes are required to the UK model.	NHSBT
Publish league tables of missed referrals by Trust/Board and hospital level.	NHSBT
Revise the information, layout and dissemination of the Trust/Board organ donation performance reports so they have greater impact.	NHSBT
Routinely provide case studies for Morbidity and Mortality and Multi-Disciplinary Team meetings.	NHSBT
Explore providing branded pens (and other suitable merchandise) en mass to all hospitals, to support the normalisation of organ donation.	NHSBT

Outcome 3 Action by NHS hospitals and staff will mean that more organs are usable and surgeons are better supported to transplant organs safely into the most appropriate recipient.

Specific Actions	Responsibility
Develop a business case and an operational plan for Normothermic Regional Perfusion (NRP) for DCD livers.	NHSBT
Pursue options for funding a UK DCD Heart retrieval and transplant programme.	UK Health Departments
Determine how to make transplant surgery an attractive choice for surgeons.	BTS
Explore new technologies and the role of Scouts.	NHSBT
Monitor information from Peer Review of transplant services and investigate barriers to utilisation to ensure a robust service to deliver the measures of the <i>Taking Organ Transplantation to 2020 Strategy</i> .	NHSBT, Commissioners

Outcome 4 Action by NHSBT and Commissioners means that better support systems and processes will be in place to enable more donations and transplant operations to happen.

Specific Actions	Responsibility
Explore options for developing a transplant unit scorecard to assess capacity and performance of all units in relation to deceased donation and renal units for live donation.	NHSBT, Commissioners
Explore options to go to fast track offering more rapidly to reduce time spent offering.	NHSBT
Achieve a sustainable employment model for designated/specialist requesters.	NHSBT