From Better to Best: Improving the availability of organs for transplant

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2020 Strategy Oversight Group Chair
Presentation outline

• Progress 2004 - 2014
• 2020 Strategy and work underway
• Outcomes and financial case for continuing investment
• Ethnicity, donations and access to transplants
• Living donation
• A plea!
Deceased and living donors

Number of deceased and living donors in the UK, 1 April 2004 - 31 March 2014

- DBD donors
- DCD donors
- Living donors

Year
Number
664 637 634 702 609 611 624 1062 1046 1055 1101 1146

5 November 2014 APPG
Deceased donor kidney programme

Deceased donor kidney programme in the UK, 1 April 2004 - 31 March 2014,
Number of donors, transplants and patients on the active transplant list at 31 March

5,486 people are currently actively waiting for a kidney transplant
Deceased and living donor kidney transplants pmp worldwide

Taking Organ Transplantation to 2020

44 pmp in 2011

Source: Council of Europe – Transplant Newsletter 2013

c600 extra kidney transplants per year if we matched best in the world (61 pmp)
Time on the kidney transplant list

Waiting list at 31 Dec 2005

70% waiting < 3 years

Waiting list at 31 March 2014

75% waiting < 3 years
UK 2020 Strategy
Aim of the UK Strategy

To match world-class performance in organ donation and transplantation

Delivery of the strategy is dependent on:

Evolution of NHS services and clinical practice

Revolution in public behaviour so UK citizens consent to organ donation

Participation by 4 UK Governments, NHSBT, donor hospital staff, transplant centre staff, Professional Bodies, voluntary sector.
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

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

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

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
Outcome measures

1. Consent Rate – 80% by 2020

2. Deceased Organ Donors per million population – 26 pmp by 2020

3. Increase Organ Utilisation – 5% by 2020

4. Patients Transplanted per million population – 74 pmp by 2020
Outcome 1 - current initiatives

• Public Behaviour strategy approved for England: key themes include:
  • Increase ODR registrations by 50% with focus on over 50s, D&E socio-economic groups & BAME citizens
  • To stimulate conversations and debate about donation, particularly through leveraging the ODR as a marketing tool
  • To present donation as a benefit to families in the end-of-life and grieving process
• Funding of £1.5million being sought for years 1 & 2 of programme as part of wider ODT funding discussions
• Support for increasing registration through Govt websites led by Grant Shapps and Jane Ellison
• Options for donation incentives to be considered by UKDEC
• Human Transplantation (Wales) Bill proceeding with £2m to be spent on communication strategy
Outcome 2 - Current Initiatives

• **ODT National Hub** – NHSBT working with specialist agency to build business case for funding. Will build a new Operations Hub and supporting IT to: triage donor referrals, dispatch specialist nurses & retrieval teams, enable faster organ offering and acceptance and better organ allocation.

• Project to work with Coroners and Police underway

  — Portfolio of evidence gathered – further evaluation required
  — Survey on relationships between staff and coroners about to be launched
Outcome 3 - Current Initiatives

• Analysis of data from Scout project inconclusive as to impact – will be taken forward as part of NORS Review

• Peer Review system:
  — NHS England/NHSBT collaboration: expected to peer review heart and lung transplantation in 2014/15
  — Extend to kidneys, livers etc in subsequent years

• UK DEC consulting on an ethical framework for DBD donation.

• New perfusion technologies: assessment model being developed & funding for limited service evaluation being sought which is expected to enable 50+ extra transplants.
Outcome 4 – Current Initiatives

• NORS Review underway – recommendations expected early 2015

• NHSBT Workforce Strategy and SNOD role review in progress: will soon proceed to pilot new models of donor triage & family liaison specialist role.

• New consent training programme for Specialist Nurses being rolled out

• Accredited training programme for retrieval surgeons in development: working with Royal College of Surgeons and Dutch Transplant Service

• Project to reduce use of paper forms for transplant follow-up, working with the UK Renal Registry, underway.
• The Oversight Group oversees delivery across all of the strategy
• The strategy is shared by the four Governments, NHSBT and others involved in the organ donation and transplantation pathway
• An 'oversight' group is needed to hold all those responsible to account for delivery of their areas of the strategy
Key responsibilities of members

• Working collaboratively with stakeholders
• Advising on the implementation of the strategy
• Speaking on behalf of, and with the authority of, the organisation they represent
• Championing the strategy within their organisation and disseminating key messages from the Group
• Lead on the development and delivery of implementation plans within their own organisation
• Ensuring that the implementation plans of the organisation they represent are aligned with, and do not jeopardise, the work of others with a role in implementation
Future Challenges

• Is transplantation a commissioner priority in a financially constrained environment?

• National political leadership needed to support behaviour change

• NHSBT Operational Funding – ongoing discussion with four administrations regarding funding model.

• Funding for major developments still to be secured:
  — Public Behaviour Strategy (England)
  — Workforce & Role Redesign Strategy
  — New Perfusion Technologies
  — ODT National Hub and IT systems
Financial benefits of kidney transplantation
Kidney: Net benefits (preliminary results)

Net benefits in a given year = Cost of dialysis - Cost of transplant

Caveat: These are preliminary results provided by the Health Protection Analytical Team at the Department of Health. Further work is underway and therefore these results are likely to change.

Taking Organ Transplantation to 2020
Outcomes, activity and transplant list
## One-year first kidney graft survival rates (%)

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<td>92</td>
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### Ethnicity of kidney donors, transplant recipients and patients on the active transplant list

#### 2005/06

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<th>Donors</th>
<th>Transplant recipients</th>
<th>Active transplant list patients</th>
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<td></td>
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<td>(%)</td>
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<tr>
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<td>(97)</td>
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#### 2013/14

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<th>Active transplant list patients</th>
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<td>(94)</td>
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2013/14 eligible and actual BAME donors

- Eligible donors: 4691
  - Eligible BAME donors: 395

- Actual donors: 1320
  - Actual BAME donors: 71

But more than 1700 BAME patients are on the active kidney transplant list.

Even if every BAME family said yes to donation, that would not meet the need of BAME families on the transplant list.

A real call for living donation is therefore critical.
UK 2020 Living Donor Strategy
Living donor kidney transplantation 2020

“To match world class performance in living donor kidney transplantation”
Objectives: LDKT 2020

1. Increase LDKT activity; state of the art donor care
2. Embed principle of ‘transplant first’ and improve equity of access to LDKT
3. Ensure the National Living Donor Kidney Sharing Schemes (NLDKSS) are clinically and cost effective
**Outcomes: LDKT 2020**

1. NHSBT, commissioners and all UK health departments will work together to ensure that there are no financial disincentives to support a fully integrated UK-wide LDKT programme.

2. NHSBT, commissioners and clinicians will ensure that appropriate infrastructure, systems and processes are in place to maximise the number of transplants achieved from all suitable living kidney donors.

3. NHSBT, clinicians, commissioners and other authorities will ensure that outcomes of LDKT are monitored and that information is accurately interpreted and utilised to support state of the art donor and recipient care.

4. NHSBT and clinicians will ensure that all suitable recipients have an opportunity to consider the option of LDKT before dialysis or to minimise waiting time if dialysis is unavoidable, regardless of where they live in the UK.

5. NHSBT, society and individuals will ensure that awareness of LDKT is effective across all sectors of society in all four UK countries.
Measuring success: LDKT 2020

- Global benchmarking
- Effective commissioning across the UK
- Timely assessment and surgery
- Effectiveness of National Living Donor Kidney Sharing Schemes
- Standardisation of antibody incompatible transplantation
Conclusions and key messages
Good progress but lots more to do
   Financial situation of NHS may restrict opportunities to develop & particularly to promote organ donation

Ask of the APPG
   To ensure that organ donation and transplantation remains a priority

Currently some 55,000 UK citizens walking around with a transplanted organ
   If strategies successful, this is expected to increase to 74,000 by 2020. A huge opportunity for the UK!
The LDKT and TOT2020 strategies seek the support of community, patient groups and charities to contribute to its implementation alongside NHSBT, the UK Health Departments and Commissioners.

- 5,486 people are actively waiting for a kidney. Increasing consent rates is a key aim of the TOT2020 strategy. The support of the kidney community is essential to help achieve this.

- Living donation also plays a vital role in saving and improving lives. Its unique contribution offers more patients the possibility of a successful transplant.

- Living donation has an important role amongst all groups but particularly in the BAME community. Even if every family of an eligible BAME deceased donor said yes to donation, it would not meet the need of BAME patients on the list.
Individuals, charities and patient groups can help make sure the public and politicians are aware of the benefits of transplantation.

As well as meeting the needs of patients, other clear drivers are:

• Reduced dialysis (for kidney patients) which saves the NHS a lot of money

• Enabling people to be economically and socially active, contributing to their families and the country
Thank you

Any questions?