The change in law around organ donation

Cathy Miller
Implementation Lead
Education and Governance
Purpose

Current progress and plans
Deemed consent - when and where
Considerations for surgeons
Changes to consent form
Organs and Tissues - included and excluded
Deemed consent conversation - SNOD role
Identify any resource/training requirements
Why is change needed?

- Change the culture and balance of presumption
- Consent rates not kept pace with ODR
- Learning from experience in Wales

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<thead>
<tr>
<th>Country</th>
<th>2015</th>
<th>2018</th>
<th>Change</th>
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<tbody>
<tr>
<td>England</td>
<td>61%</td>
<td>67%</td>
<td>+6%</td>
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<tr>
<td>Scotland</td>
<td>54%</td>
<td>63%</td>
<td>+9%</td>
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<tr>
<td>N. Ireland</td>
<td>59%</td>
<td>64%</td>
<td>+5%</td>
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<tr>
<td>Wales</td>
<td>58%</td>
<td>73%</td>
<td>+15%</td>
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Consent for donation after brain death: 83%
# Primary Legislation

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<thead>
<tr>
<th>Region</th>
<th>Current</th>
<th>Future</th>
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<tbody>
<tr>
<td>England</td>
<td>Opt-In</td>
<td>Opt-Out</td>
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<tr>
<td>Scotland</td>
<td>Opt-In</td>
<td>Opt-Out</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>Opt-In</td>
<td>Opt-In</td>
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<tr>
<td>Wales</td>
<td>Opt-Out - 2015</td>
<td>Opt-Out</td>
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<tr>
<td>Isle of Man</td>
<td>Opt-In</td>
<td>Opt-Out</td>
</tr>
<tr>
<td>Jersey</td>
<td>Opt-Out - 1st July 2019</td>
<td>Opt-Out</td>
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<tr>
<td>Guernsey</td>
<td>Opt-In</td>
<td>Opt-Out</td>
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- **Legal basis for consent/authorisation**
- **Potential Enactment and 'Go Live' dates**
  - **Scotland**: Enacted: Summer 2019. Go Live: Summer 2020
  - **N. Ireland**: n/a
  - **Wales**: Enacted: June 2018. Go Live: Summer 2019
  - **Isle of Man**: Enacted: March 2019. Go Live: To be confirmed
  - **Jersey**: Enacted: June 2018. Go Live: Summer 2019
  - **Guernsey**: Enacted: To be confirmed, potentially 2020. Go Live: To be confirmed
Primary Legislation Progress in England

Bill started in the House of Commons

House of Commons

1 2 C R 3

House of Lords

1 2 C R 3

Consideration of amendments

Royal Assent

2017

March 2019
Secondary Legislation

• Exemptions to deemed consent:
  • Novel (e.g. face; uterine)
  • Rare (e.g. limb)
  • Material for use in ATMPs research
• Commencement Orders
• Procedural SIs

Scotland:
• Pre-Death Procedures
Secondary Legislation-Inclusions

It is intended that the following organs and tissues will be covered by opt-out:

- heart
- lung(s)
- kidneys
- eye
- nervous tissue
- artery/veins/blood vessels
- bone
- muscle
- tendon
- skin

- Liver, including liver cells ('hepatocytes'), unless used for an Advanced Therapy Medicinal Product (ATMP)
- pancreas including pancreatic cells (called ‘islets’), unless used for an ATMP
- intestinal organs (small bowel, stomach, abdominal wall, colon, spleen)
- rectus fascia (tissues that encases abdominal muscles)
Progress in Scotland

2018

June 2019
General Principles

• Soft’ opt out – family will continue to be consulted
• Decision rests with the individual – opt in or opt out
• Shifts focus on what the individual would have wanted, rather than what the family want to happen.
Deemed Consent
Inclusion/Exemption

WILL apply to
ADULTS who

- Ordinarily resident in England for at least 12 months
- Died in England

WILL NOT apply to:

- Anyone under the age of 18 in England or 16 in Scotland
- People who lack mental capacity to understand the new arrangements and take the necessary action
- If a donation decision has been made
Supporting Guidance

- Human Tissue Authority Code of Practice F
- To support implementation in England: consultation period between July - September 2019
- Chief Medical Officer Guidance in Scotland
Next steps

- Secondary Legislation on exemptions to the Law – Novel transplants
- HTA Code of Practice
- Enactment: March 2019
- Go Live: Spring 2020

- Secondary Legislation
- CMO Guidance
- Go Live: Autumn 2020

- Continue Legislation process
- Enacted: Spring 2020?
- Go Live: Late 2020?
Engagement
Public

• ‘Pass It On’ campaign launched in England in April 2019
• Key messages:
  • the law is changing in spring 2020
  • donation is your decision
  • record your decision on the NHS Organ Donor Register
  • pass your decision on, as family will still be consulted about the option for donation
• Planned bursts of heightened activity, with highest concentration in the months before ‘Go Live’
• NHS Pack available to help drive local awareness.

www.nhsbt.nhs.uk/pass-it-on
Paid media
Future activity

- Real life stories - Transplant who are competing @ WTG
- Pass it On - law change
- Real life stories - Donor families
- BAME - myth-busting
- Radio - Pass It On 30” radio advert & 60” live reads on select community radio stations
- Full page Pass It On print ads & ½ page editorial in community print publications observing Diwali

- World Transplant Games
- Organ Donation Week
- [Icons for social, radio, TV, VOD, cinema, OOH, print, search]
Paid media

Activity to date
Real life story videos featuring transplant recipients / patients waiting (18 July – 15 August 2019)

Users served with either a 10” or 30” video advert encouraged to ‘watch more’ and click through to the website

Here you can:
• watch the full video
• are directed to find out more about the law change
• encouraged to record a decision
Organ Donation Week 2019

2 – 8 September

- ‘Pass It On’ campaign – opportunity to inform the public about the upcoming change in the law around organ donation, as well as address myths and concerns around organ donation, and sharing real life stories to show the positives of organ donation and transplantation

- Paid media advertising – social media and radio advertising

- News story – focused on the role of the family and the need for people to share their organ donation decision, as well as the change in the law and what this means for people.

- New content – real-life story videos, law change animations, myth busting clips with clinicians addressing the concerns and barriers to donation in black, Asian and minority ethnic communities

- Lots of activity across our social media channels @NHSOrganDonor

- Support from partners, stakeholders, celebrities and influencers

- Community and hospital events
Organ Donation Week 2019
NHSBT teams

Focused engagement of staff/teams directly impacted by the change:

• Sessions held at each regional Organ Donation Services Team meetings
  • Explain the law changes and plans
  • Opportunity to raise questions/concerns
  • Ideas about implementation
• Tissues & Eye Services: Programme of activity with legislation – a regular agenda item
• Legislation Leads/Champions in each Organ Donation Team and across Tissues & Eye Services
• Plans to carry out regular operational temperature checks
Additionally, in respect of the broader NHSBT workforce:

- Survey of all staff to help gauge awareness – 500 responses received, used to formulate plans
- Business cards distributed to all NHSBT sites with key messages for staff
- Campaign leaflets and pull up banners
- Yammer
  - Regular postings on main page
  - Opt Out specific page
  - Encourage everyone to post
- 4 page ‘Connect’ article Sep/Oct 19
- Team Talk – Monthly update on progress and opportunity to raise queries
- Further workshops and meetings planned over the next year to raise awareness (e.g. Regional Collaboratives; Team Meetings etc)
## Internal activity

<table>
<thead>
<tr>
<th>Key Activity</th>
<th>Deliverable</th>
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<tbody>
<tr>
<td><strong>Launch of Campaign</strong></td>
<td>All-staff email and letters to clinical partners</td>
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<tr>
<td></td>
<td><em>Connect Magazine</em></td>
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<td></td>
<td><em>Team Talk</em></td>
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<tr>
<td></td>
<td><em>Yammer</em></td>
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<tr>
<td></td>
<td><em>Link (new site)</em></td>
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<tr>
<td><strong>Opt out page on Link and Yammer group</strong></td>
<td>Both pages active and updated regularly</td>
</tr>
<tr>
<td><strong>New letters (articles within existing newsletters)</strong></td>
<td>Front line teams (BD, TAS, Transport, ODT, TES)</td>
</tr>
<tr>
<td><strong>Front-line sense check and distribution of resources (leaflets, posters)</strong></td>
<td>Email front line teams and gauge public interest</td>
</tr>
<tr>
<td><strong>Business style card for Drivers, now available to staff at all sites</strong></td>
<td>Available to all front line teams and available on iProcurement</td>
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<tr>
<td><strong>Team Talk – include monthly update</strong></td>
<td>Monthly briefing delivered via email and presented by Directors and Ads via Skype or call</td>
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<tr>
<td><strong>Internal posters with 2-3 main questions highlighted from feedback (for ODT)</strong></td>
<td>Posters to ODT team bases</td>
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<tr>
<td><strong>Connect magazine features</strong></td>
<td>Feature and updates in every copy leading up to spring 2020</td>
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<td></td>
<td><em>Including 4-page spread in Sep/Oct 2019 issue</em></td>
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<td><strong>Yam Jam</strong></td>
<td>Q&amp;A on Yammer with workstream leads</td>
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<tr>
<td><strong>Internal FAQ</strong></td>
<td>Frequently Asked Questions available on Opt Out Intranet Link Page – devised from staff feedback</td>
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<tr>
<td><strong>Internal survey or Yammer Poll</strong></td>
<td>Yammer poll or Survey Monkey</td>
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<tr>
<td><strong>Organ Donation Week</strong></td>
<td>All-staff email and letter to partners. Share media and campaign coverage internally. Share staff activity.</td>
</tr>
<tr>
<td><strong>Did you know … (fact based posts on Yammer to give clarity around some facts)</strong></td>
<td>Yammer post with infographics. Encourage workstream leads to share facts and updates on Yammer</td>
</tr>
<tr>
<td><strong>Screensavers</strong></td>
<td>Set of four screensavers to run throughout Organ Donation Week on all PC and devices across NHSBT</td>
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Internal coverage
NHS/ICU Teams

- Attendance at National Conferences
- ‘Champions’ in each team to help raise awareness and disseminate messages
- NHSBT Advisory Groups kept informed and consulted
Implementation plans
Portfolio of Projects/Workstreams
The programme is structured into 5 projects under NHSBT management:

<table>
<thead>
<tr>
<th>ICT</th>
<th>Communications</th>
<th>Operations</th>
<th>Scotland</th>
<th>Tissues</th>
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<tbody>
<tr>
<td>Faith</td>
<td>Insight &amp; awareness</td>
<td>Organ Donation &amp; Nursing</td>
<td>Scotland</td>
<td>Tissues</td>
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<tr>
<td>NHS App **</td>
<td>Paid media</td>
<td>Internal Comms</td>
<td>Hub &amp; Info. Sers</td>
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<tr>
<td>ODR/CR</td>
<td>Media &amp; PR</td>
<td>BAME/Faith</td>
<td>Education &amp; Governance</td>
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<td>Materials &amp; Digital Content</td>
<td>Charity, political &amp; NHS stakeholders</td>
<td>ODR/Enquiries</td>
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<td>Social media</td>
<td>Partnerships</td>
<td>NORS</td>
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<td></td>
<td>Targeted mailing</td>
<td>Young people/U18s</td>
<td>Advice To HTA</td>
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<td>Ambassadors</td>
<td>Legislative Procedure to Government</td>
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<td></td>
<td>Celebrities &amp; Influencers</td>
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** DHSC business case
- Faith business case
- NHS App Integration business case
- Communications business case
- Operations business case
- DTS CPB / business case
- Scottish Government Business Case
Creating the ‘Deem Team’

- Workshops to bring together the implementation teams, including OWD session about setting culture for the programme
- Programme support to bring together plans, monitor resources and pressures
- Formal Programme Board and Project Boards
- Informal weekly calls to bring teams together
- Clear structure for escalation of issues/ problems/ concerns
Training
Education/Training

Module 1
- Legislation
- Human Tissue Authority Codes of Practice
- Consent manual

Module 2
- Conversation
- Forum theatre and shared practice

Module 3
- Consolidation
  - Combine theory, practice and reflection ready for implementation
  - (+/- Potential Donor Audit training)

Module 4
- Evaluation
- Implementation
- Outcome
- Impact

Also training other teams:
- Donor Records Departments
- Information Services
- Hub Operations
- National Call Centre
- Recipient Coordinators
- National Organ Donation Retrieval Team
- Regional Collaborative members

Digital Learning
- Blockbuster style-legislation quiz
- Videos depicting best practice
Impact on Clinical Practice

- Due to go live with the extra NORS abdominal team
- No change to the current consent form that surgical teams review
- Section C has been future proofed when Jersey went live with deemed consent - to capture deemed consent in England and other territories.
- No technical changes were made – just to the paper form

*What training/resources would be helpful for surgical teams?

Section C
For Countries and Territories where Deemed Consent applies
The patient named in Section 2 is deemed to have given their consent to deceased organ and/or tissue donation under the applicable legislation*.

Please insert Country/Territories .........................

Healthcare Professional signature             

*What training/resources would be helpful for surgical teams?
Change in donation practice and consent conversation

- Planning between SNOD/SR, Consultant and bedside nurse
  - Understand if deemed consent applies and plan the breaking bad news and approach

- Donation conversation-positive approach-benefits of organ donation
  - The way organ donation works now in England...is people have a choice to opt in or opt out
  - Because Mary had not opted-out, Mary is considered to want to help others by being an organ donor
### Timeline: April 2019 – March 2020

<table>
<thead>
<tr>
<th>Apr</th>
<th>May</th>
<th>Jun</th>
<th>Jul</th>
<th>Aug</th>
<th>Sep</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
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</thead>
<tbody>
<tr>
<td>25th April Campaign launch</td>
<td>British Transplant Games</td>
<td>World Transplant Games</td>
<td>Organ Donation Week 2-9 Sep</td>
<td>European Organ Donation Day</td>
<td>Training Moratorium</td>
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<td>Training on HTA codes</td>
<td>Training on new donation conversation</td>
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<tr>
<td>Review all active ODT Quality documents</td>
<td>Meet all SNOD teams + PDS / Quality etc</td>
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<td>BACCN Conf</td>
<td>ICS Conf</td>
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<tr>
<td>Provide materials for SNODs/CLODS</td>
<td>Regional Collaboratives</td>
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<tr>
<td>Regional Collaboratives</td>
<td>New PDA development / testing &amp; delivery</td>
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<tr>
<td>HTA Code of Practice Consultation</td>
<td>HTA Code of Practice</td>
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Benefits
Benefits - culture

- ‘Max and Keira’s Law’ – Puts emphasis on the patient’s saved and recognition of donors
Benefits – retrieval and transplantation

• English Government commitment of 700 additional transplants as a result in the change in law.

• Ministers are clear that the retrieval and transplant services need to be resourced to keep pace with the increase in donors.

• Working closely with UK Commissioners to help ensure that resources are in place.
Operational readiness

- Aiming to recruit 27 additional SNODs in England and 3 Team Managers
- Recruited 4 additional Specialist Requestors in Scotland
- Additional staff already recruited in to the ODR, Stats and Information Services Teams
Benefits – Ministerial commitments

‘…we will make sure that there are enough highly trained staff to make the most of the changes resulting from this Bill. Our current estimate is that 27 more nurses would be required but, of course, if that number were to rise, we would make sure that they are fully trained and fully financed for the future.’

Lord O’Shaughnessy, Health Minister

‘We will make sure that the system is funded as it should be. I assure noble Lords that we are working closely with NHS Blood and Transplant on its operational costs, which we will fund.’

‘Our ambition is to reach 80% of the population of England, so we are very ambitious. It is important that we do this. As I said, the Government intend to spend around £18 million on communications in 2020-21.’

Baroness Manzoor on behalf of DHSC

…there will always be a personal discussion with the family at the bedside, and special consideration will be given to a person’s faith and the views of their loved ones...

Jackie Doyle-Price, Minister
Benefits - collaboration

Parliament

Patient Groups

NHS

Faith

Regulators

Ethics

Media
Benefits – media coverage

**Guardian**
This change in the law on organ donation will save hundreds of lives
Cole Moreton

**Mirror**
Organ donor ‘opt in’ law to be passed
Top transplant surgeon calls for change to law NOW to save lives

**Metro**
As Max and Keira law is set to be passed, here’s everything you need to know about organ donation
Benefits – NHS app

• Integration with the NHS App in place December 2018
• Full ‘push and pull’ facility enables people to see their own ODR record
Benefits – faith/beliefs

• Faith/ Beliefs Declaration introduced in December 2018

• Supported by revised faith pages on the website and faith-specific organ donation cards
Ways you can help

We have a big challenge ahead to make sure that as many people as possible are aware of the changes before they come into effect in spring 2020 and that is why we need your help.

• use the **toolkit** and **downloadable resources** we have developed for the campaign

• talk about organ donation and encourage your friends and family, **blood donors and patients** to take the conversation home

• follow our social media channels and share our content with your friends and family

• display the campaign materials
Thank you

What questions do you have?