

# **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

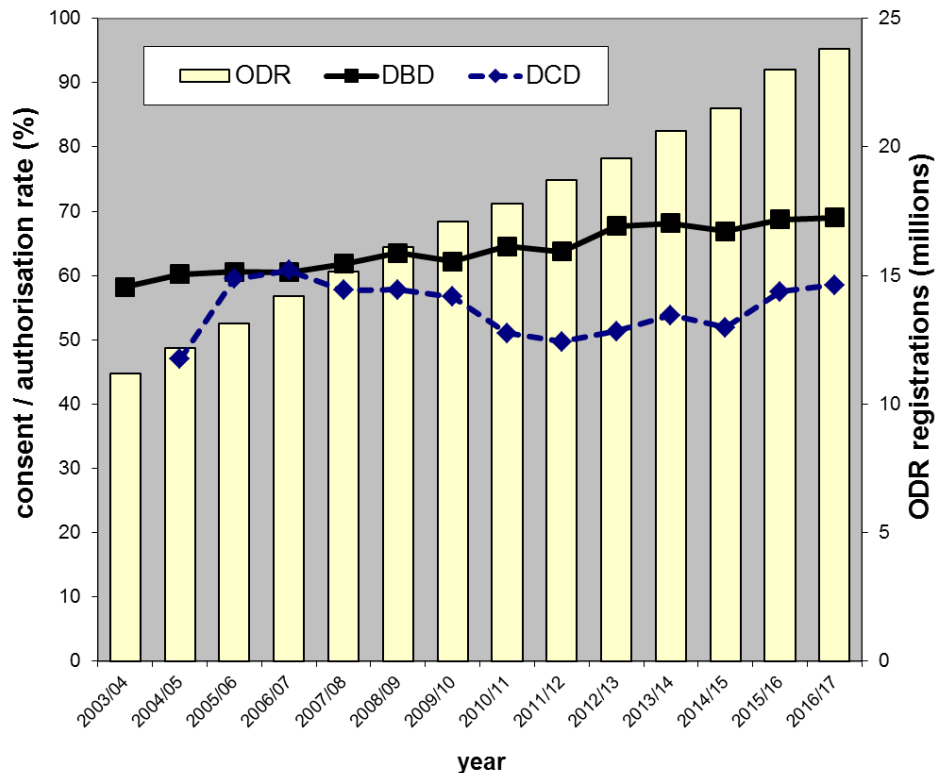
Organs and Tissues-included and excluded

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

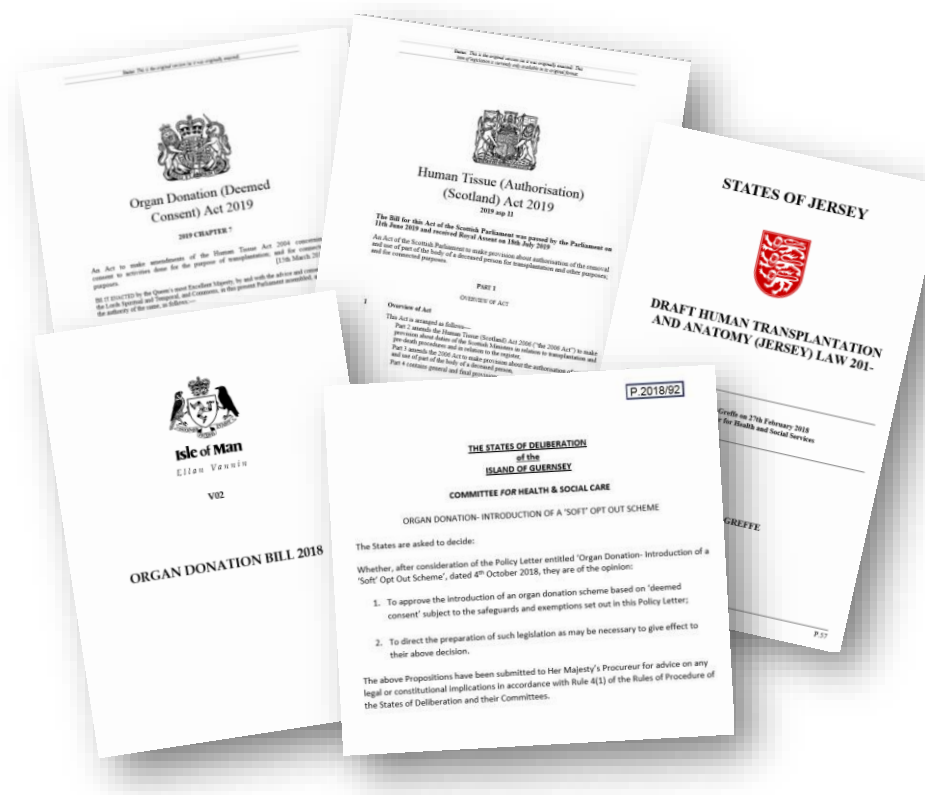


Country	2015	2018	Change
England	61%	67%	+6%
Scotland	54%	63%	+9%
N. Ireland	59%	64%	+5%
Wales	58%	73%	+15%

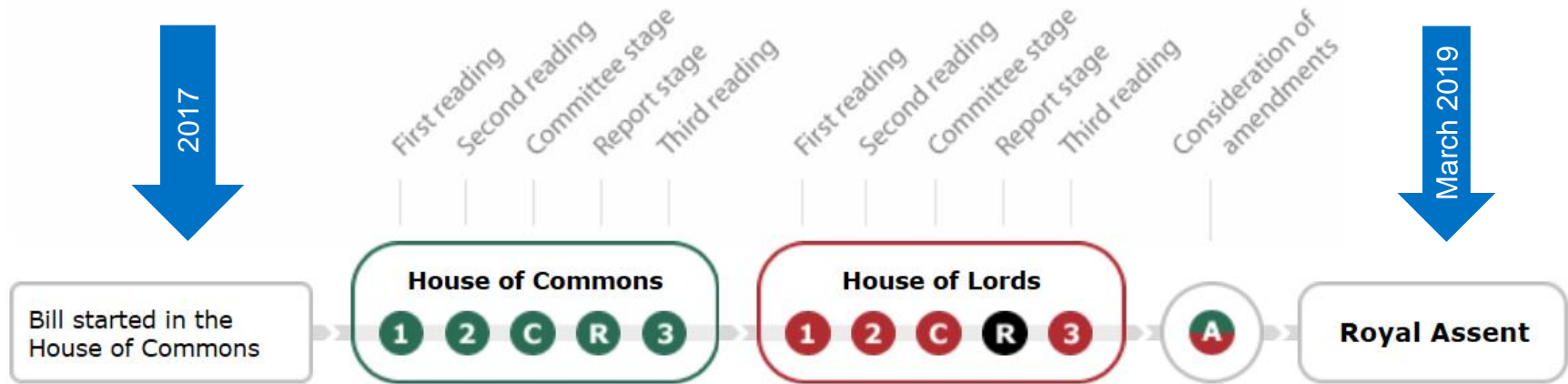
Consent for donation after  
brain death: 83%

# Primary Legislation

	Legal basis for consent/authorisation	
	Current	Future
England	Opt-In	Opt-Out
Scotland	Opt-In	Opt-Out
N. Ireland	Opt-In	Opt-In
Wales	Opt-Out - 2015	Opt-Out
Isle of Man	Opt-In	Opt-Out
Jersey	Opt-Out – 1 <sup>st</sup> July 2019	Opt-Out
Guernsey	Opt-In	Opt-Out



# Primary Legislation Progress in England



# 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

## Organs and tissues to be excluded from the new system of organ and tissue donation in England (known as “opt-out” or “deemed consent”)

Published 29 April 2019

**Consultation on the Draft Human Tissue (Permitted Material: Exceptions) (England) Regulations 2019**

### Contents

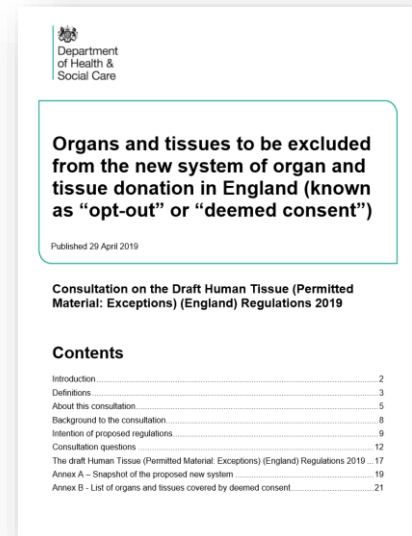
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# Secondary Legislation-Inclusions

## Blood and Transplant

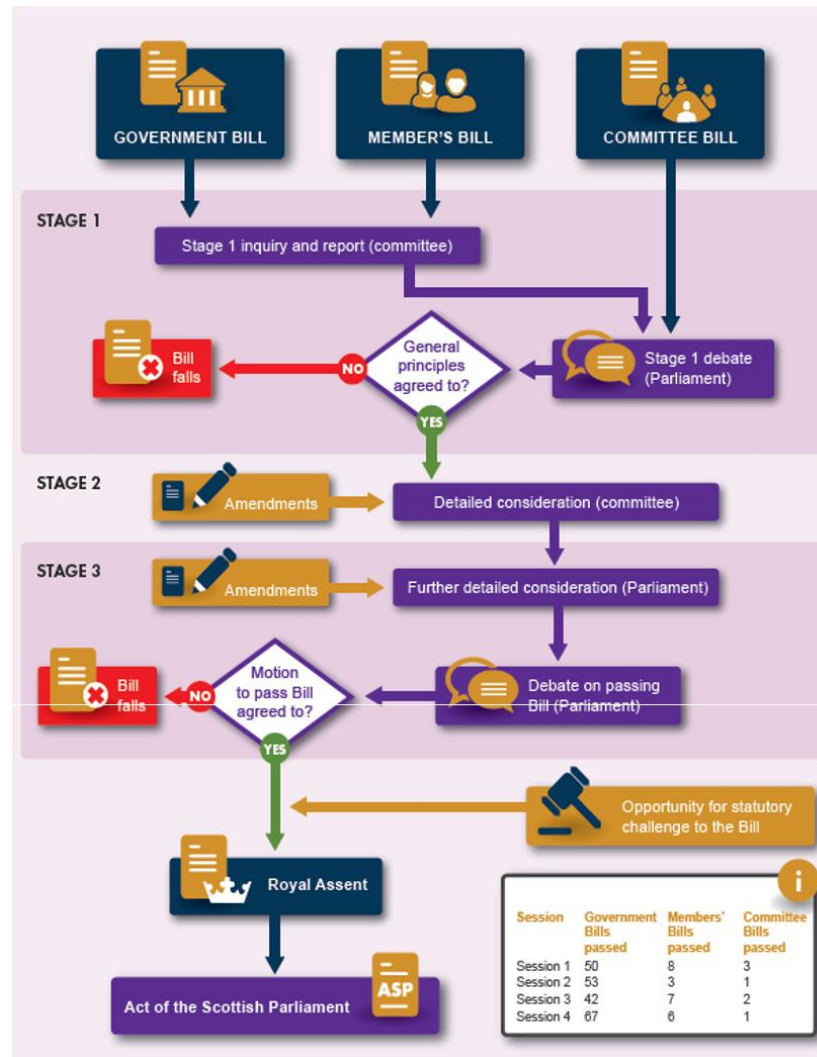
- It is intended that the following organs and tissues will be covered by opt-out:

- 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

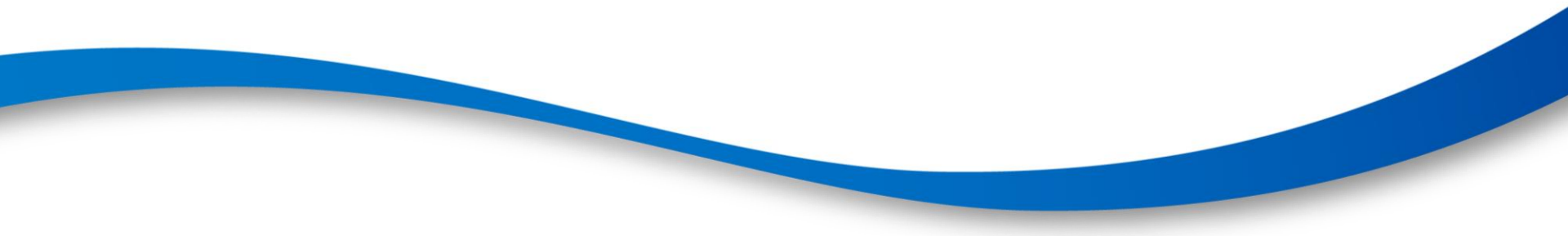
2018



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:

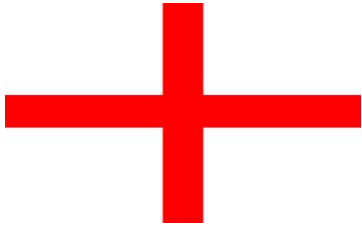
- Anyone under the age of 18 in England or 16 in Scotland
- People who lack mental capacity to understand the new arrangements and take the necessary action
- If a donation decision has been made

# 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?

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# Engagement

# Public

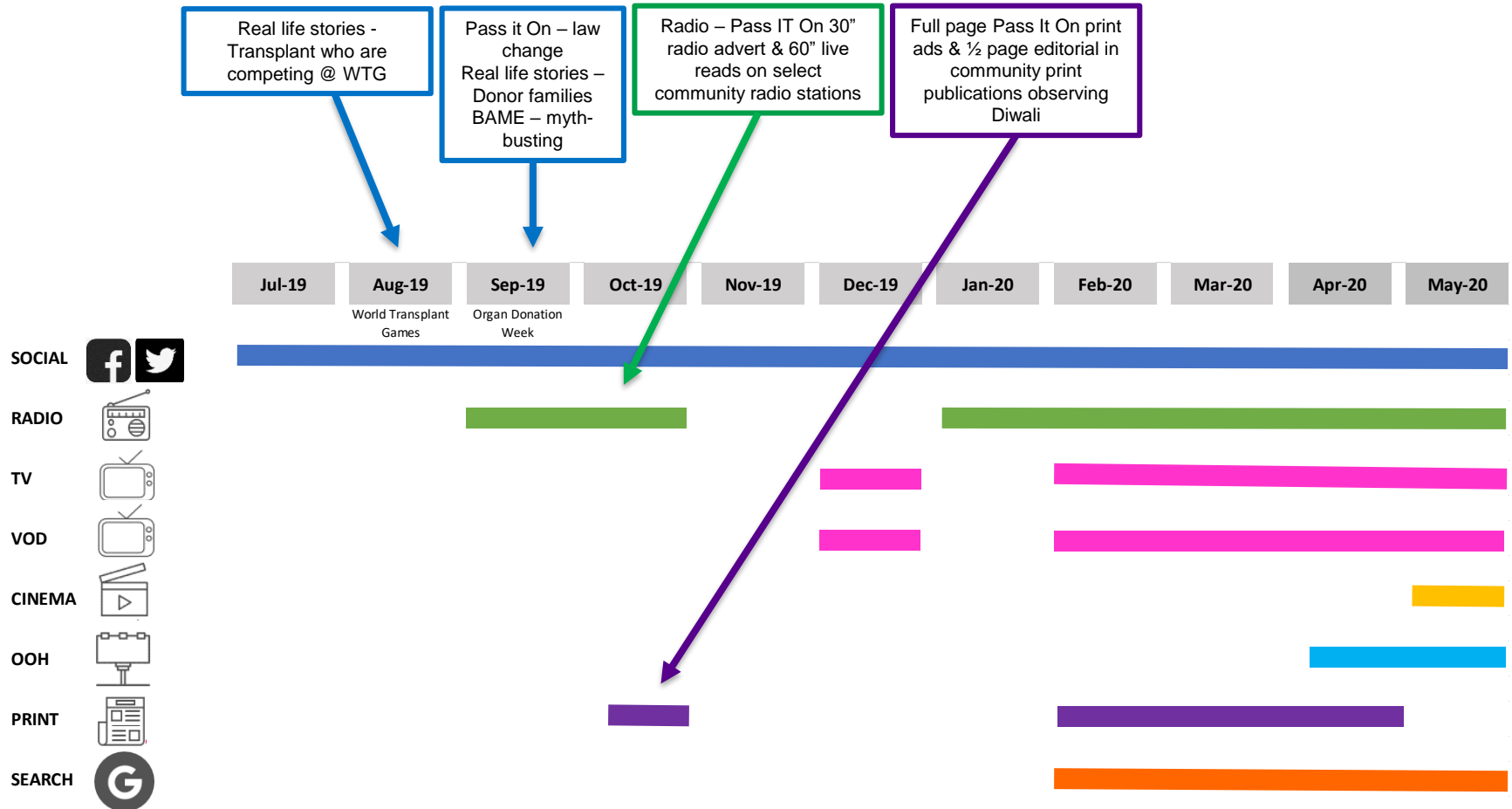
- 'Pass It On' campaign launched in England in April 2019
- Key messages:
  - the law is changing in spring 2020
  - donation is your decision
  - record your decision on the NHS Organ Donor Register
  - pass your decision on, as family will still be consulted about the option for donation
- Planned 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](http://www.nhsbt.nhs.uk/pass-it-on)



# Paid media

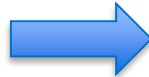
## Future activity



# Paid media

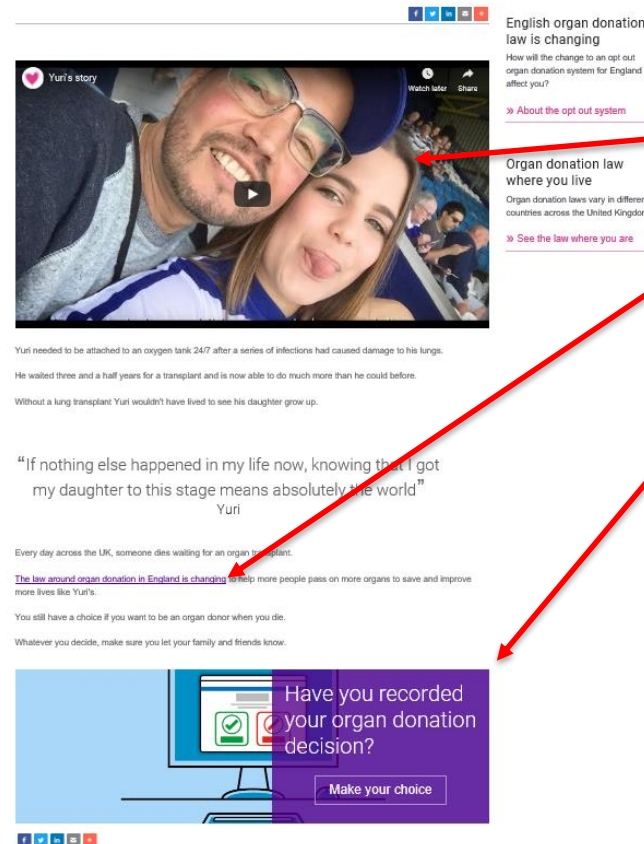
## Activity to date

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



### Yuri's story

Londoner Yuri owes his life to an organ donor.



Here you can:

- watch the full video
- are directed to find out more about the law change
- encouraged to record a decision

Users served with either a 10" or 30" video advert encouraged to 'watch more' and click through to the website



# 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

Blood and Transplant



## How organ donations and transplants saved this remarkable student's life three times

Artist Linzi Saunders, from Sunderland, is supporting Organ Donation Week and urging people to discuss their wish

By Hannah Graham  
30th SEP 2019

SHARE f t i n r e c o m m e n t

RECOMMENDED



"Thank you for my new donor card - you're welcome to recycle the lot once I've crowd-surfed out of here!"

- Mary Anne Hobbs, DJ

## one Transplant Games



As the World Transplant Games take place on Tyneside, tells the story of athletes whose lives have been transformed by transplant surgery.

## NHS appeals for West Midlands families to talk about organ donation

By Kyle Moore 3rd September 2019

SHARE f t i n r e c o m m e n t

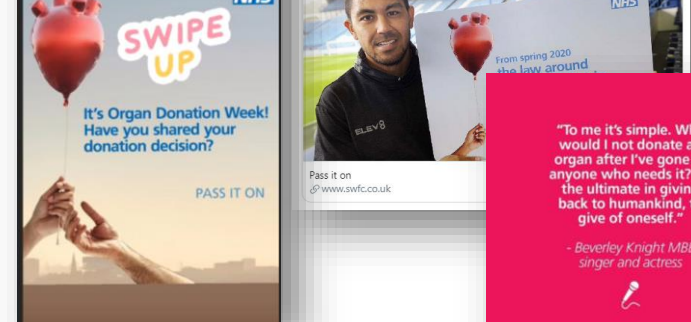


During Organ Donation Week (September 2 to 8) NHS Blood and Transplant are urging locals in the region to talk to their families about organ donation to increase the number of people whose lives can be saved or transformed by an organ



The Owls are supporting @NHSOrganDonor's #PassItOn campaign.

The law around organ donation in England is changing, all the information you need is here #swfc



## Evening Express Organ Donation Week: Donors can save lives

by Emma Morris 02/09/2019, 6:00 pm



"To me it's simple. Why would I not donate an organ after I've gone to anyone who needs it? It's the ultimate in giving back to humankind, to give of oneself."

- Beverley Knight MBE singer and actress



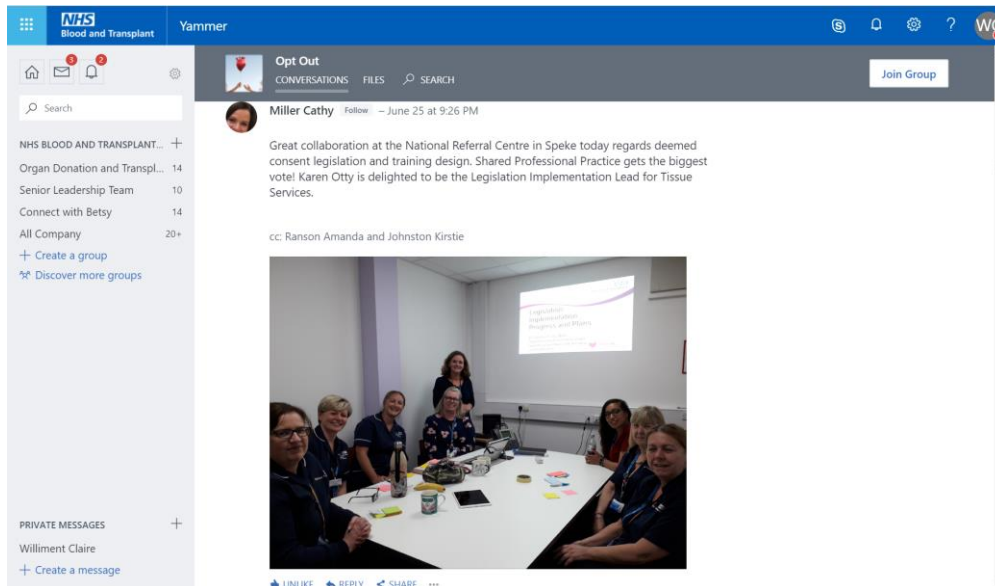
"I was told my last option was a lung transplant. I had researched organ donation and realised there is a shortage of black and Asian donors. I was devastated and thought this going to be the end."

"I've now been able to start travelling to the places I've wanted to see and live the life I've wanted to for the last four years. I never thought I would get the transplant so I want to use it well! It is life changing." bit.ly/2ldnJW



### 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



# NHSBT teams cont...

### 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

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



# 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



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# Implementation plans



# Portfolio of Projects/Workstreams

The programme is structured into 5 projects under NHSBT management:



**Blood and Transplant**

ICT	Communications		Operations **	Scotland	Tissues
Faith **	Insight & awareness		Organ Donation & Nursing	Scotland	Tissues
NHS App **	Paid media	Internal Comms	Hub & Info. Sers		
ODR CR	Media & PR	BAME/Faith	Education & Governance		
	Materials & Digital Content	Charity, political & NHS stakeholders	ODR/ Enquiries		
	Social media	Partnerships	NORS		
	Targeted mailing	Young people/U18s	Advice To HTA		
		Ambassadors	Legislative Procedure to Government		
		Celebrities & Influencers			

## \*\* 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



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# Training

# Education/Training

## Module 1

- **Legislation**
- Human Tissue Authority Codes of Practice
- Consent manual

## Module 3

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

Also training other teams:

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

## Module 2

- **Conversation**
- Forum theatre and shared practice

## Module 4

- **Evaluation**
- Implementation
- Outcome
- Impact

## 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

## **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

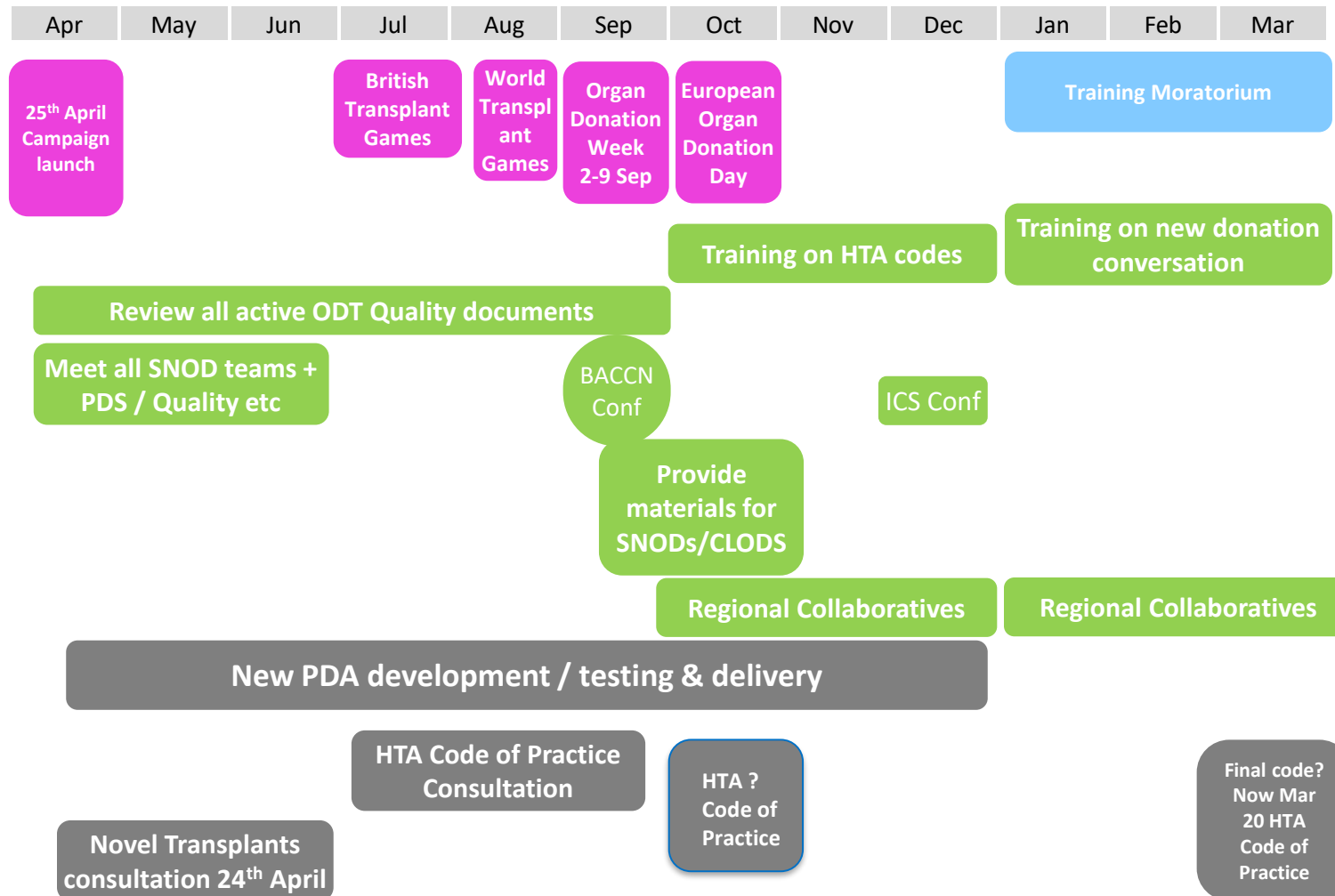
**\*What training/resources would be helpful for surgical teams?**



# 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

## Blood and Transplant



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# Benefits



# Benefits - culture

- 'Max and Keira's Law' – Puts emphasis on the patient's saved and recognition of donors

NEWS ▾ POLITICS ▾ SPORT ▾ FOOTBALL ▾ CELEBS ▾ TV ▾ FILM ▾ ROYALS ▾ WEIRD NEWS ▾ TECH ▾ MONEY ▾ TRAVEL ▾ FASHION ▾ MUMS ▾ COMPETITIONS ▾ MORE ▾

News ▾ Politics ▾ Organ donation

## Organ donor Bill: Max and Keira's Law clears final hurdle in landmark victory

Presumed consent could now come into force as early as this year In a victory for campaigners and the Mirror

SHARE





2925 SHARES

4 COMMENTS

By [Martin Bagot](#) Health And Science Correspondent
15:20, 26 FEB 2019
UPDATED 15:25, 26 FEB 2019
NEWS

Max's new law is expected to come into effect in days (Image: Julian Hamilton/Daily Mirror)

The law has since been named in honour of Max's nine-year-old heart donor Keira Bell (Image: Daily Mirror)

# 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



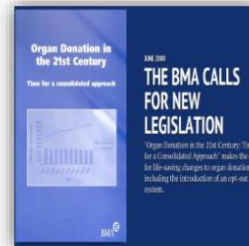
Department  
of Health &  
Social Care

## Patient Groups

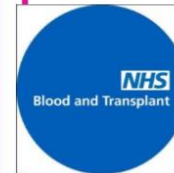


## Ethics

NUFFIELD  
COUNCIL ON  
BIOETHICS



## NHS



## Media



## Faith



## Regulators





## Benefits – media coverage



### Max's law to help organ patients within days

## GREATEST GIFT OF ALL

**EXCLUSIVE**  
By Erin Cardiff and Nicola Small  
AT first glance it is just another snap of folk in their finery at a bit of a do. But everyone here is extraordinary – they have either received the gift of life or cared

for a tragic loved one whose organs have saved others. Their courage has resulted in 23 lives being saved. These 22 heroes were united at a Gift of Life Ball organised by campaign group Share Your Wishes. Their aim is to promote the Organ Donation Bill, which is set to receive Royal Assent in days and will



PATIENT: Max



As Max and Keira law is set to be passed, here's everything you need to know about organ donation

### Mirror

## Organ donor Bill: Max and Keira's Law clears final hurdle in landmark victory

Presumed consent could now come into force as early as this year

SHARE 2923 SHARES



## Organ donor 'opt in' law to be passed



### Mirror

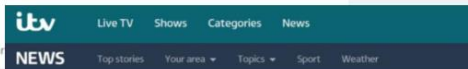
## Top transplant surgeon calls for change to law NOW to save lives

EXCLUSIVE: Prof Lorna Marson says the legislation meaning a person's consent to donation come soon enough

SHARE 1927 SHARES

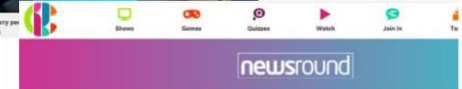


Prof Marson says too many people die from organ donation law change (BBC)



### ITV REPORT

## Organ donation opt-out law which assumes consent set to pass in England



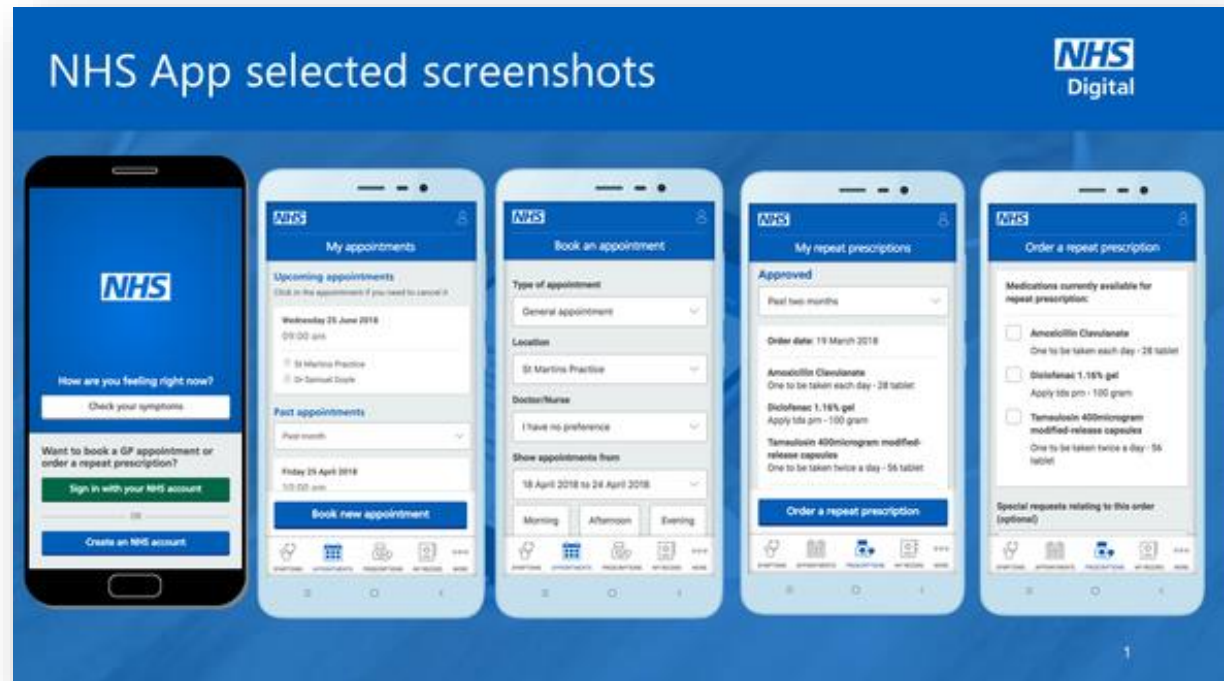
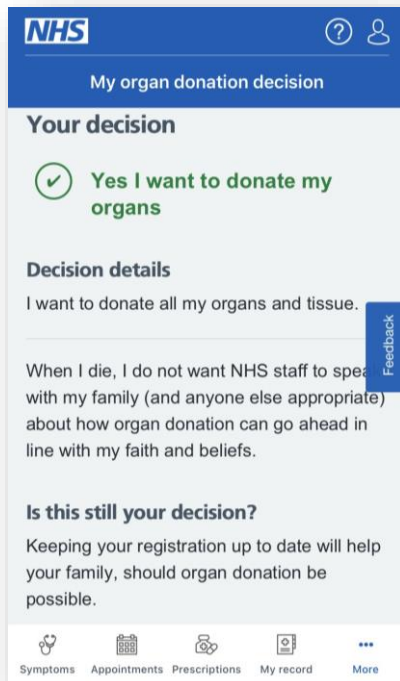
### Max and Keira's new law: How organ donation in England is expected to change

© 27 Feb 2018 Last updated at 18:53



# 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

## Faith/beliefs

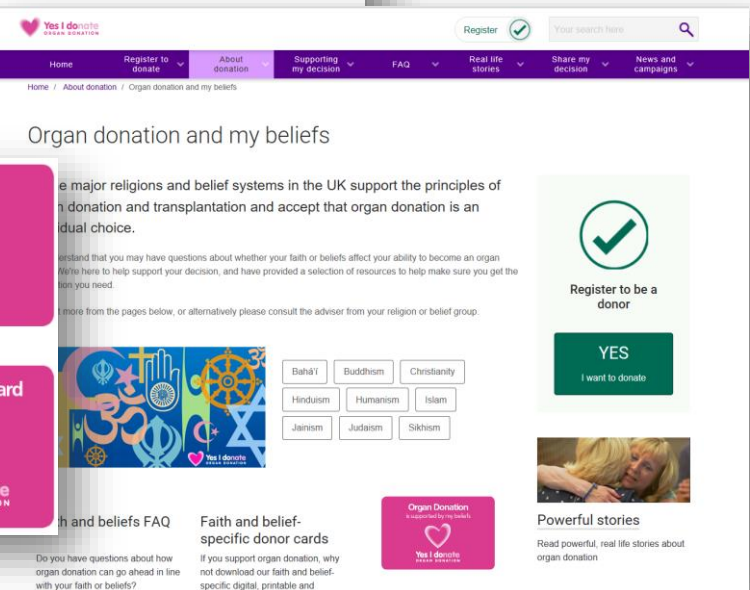
I would like NHS staff to speak to my family and anyone else appropriate about how organ donation can go ahead in line with my faith or beliefs.

Yes - this is applicable to me

No - this is not applicable to me

Prefer not to say

Record whether you want our specialist nurses to discuss your faith or beliefs with your family when they approach them about organ donation.





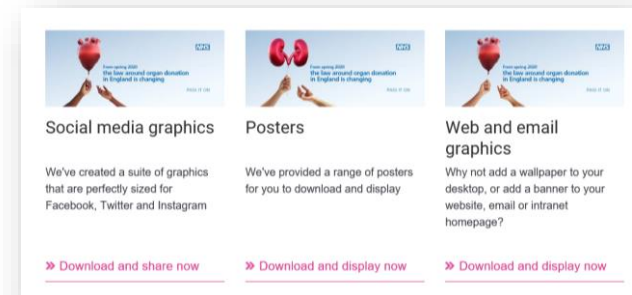
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# Resources

# 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?**