
Evaluation of the Organ Donation (Deemed Consent) Act 2019 in England

Lay report

August 2024



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1. What did we do?



The Policy Innovation and Evaluation Research Unit based at the London School of Hygiene & Tropical Medicine was commissioned before the pandemic to undertake an evaluation of the implementation of the changes, in partnership with Bangor University. The research took place between October, 2020 and September, 2023.

The project comprised:

- a review of Parliamentary debates leading up to the law change;
- a media content analysis of the public's responses to media articles ahead of the law change;
- analysis of intensive care and routine NHS Blood and Transplant (NHSBT) potential donor audit data;
- surveys and interviews with health care professionals involved to varying degrees with deceased organ donation;
- interviews with the public;
- interviews with relatives and close friends who had been approached about organ donation after their relative or friend had died; and
- a comparative analysis of Spain's consent processes and documents;
- a high level of patient and the public involvement throughout the evaluation.

Given the timings, all components looked at the impacts of COVID-19 on the organ donation and wider health care system.

Below is a summary report of the main findings followed by recommendations for policy and practice.

2. Why did we do it?



Organ donation is the supply of an organ or tissue to allow a lifesaving or life-changing transplant to be performed. Consent to deceased organ donation has been widely cited as the biggest single barrier to making more organs available for transplant in the UK. To address this issue between 2013 and 2023 each of the devolved nations and territories in the UK moved to ‘soft’ opt-out systems of consent to deceased organ donation.

The new system in England from May 2020

Organ donation in the UK is managed by a specialist agency separate from the rest of the NHS called NHS Blood and Transplant (NHSBT). This is a nurse-led specialist service. One of the main roles of these specialist nurses is approaching families about organ donation after their relative sadly died.

Under the new ‘soft’ system in England, all adults aged over 18 years are considered to have consented to organ donation (deemed consent). People can register an opt-out decision on the organ donor register and tell their family members if they do not want to be a donor. The law does not apply to people under 18, people who do not voluntarily live in England and people who lack mental capacity. Only certain organs, tissues and their use are covered by the ‘soft’ opt-out system. Excluded organs and tissues and their use still require family or another type of consent (e.g. first person). The law is ‘soft’ as families can still, in practice, override the decision the deceased person made in life.

The official goals of the law change in England were to:

- Increase the consent rate to deceased organ donation;
- Increase the number of deceased donors;
- Increase the number of transplants from deceased donors.

Contents of the rest of this report

The material that follows is chronological, covering: the lead up to implementation; what happened from multiple perspectives; learnings from organ donation consent processes of other countries; a discussion bringing together the results; and implications and recommendations for policy and practice.

3. Why did England change its law on deceased organ donation in 2019?

In May 2020, England changed the law on organ donation from a system in which individuals were encouraged to express their consent for organ donation (opt-in), to one in which most adults are deemed to have given their consent for organ donation unless expressed otherwise (opt-out).

Based on analysing debates in Parliament, we found that:

- Over 15 years of debate, the narrative on deceased organ donation changed from a focus on evidence and likely success of an opt-out policy, towards a more positive overall attitude. Regardless of mixed evidence, deemed consent was increasingly viewed as the 'right thing to do'.
- Wales's implementation of an opt-out policy, lobbying from patient groups, and UK media rhetoric, all contributed to winning extensive cross-party support for a change in the law so that organ donation would become the default for citizens.
- While much weight was given to the perceived success of opt-out countries, especially Spain, there were misconceptions in the debates as to how organ donation actually works in the UK, and therefore how the legislation was expected to work in practice.

Parliamentarians wanted a law which better reflected what they saw as popular opinion: that most people would be happy to donate their organs after death. This law also aimed to address the critical shortage of organs available for transplant. The argument that the law change 'would not make the situation worse', thereby being a quick win and 'good news story', with minimal risk if implemented as a 'soft' opt-out appeared to be influential in gradually growing support for change among Parliamentarians, despite mixed evidence of any real impact.

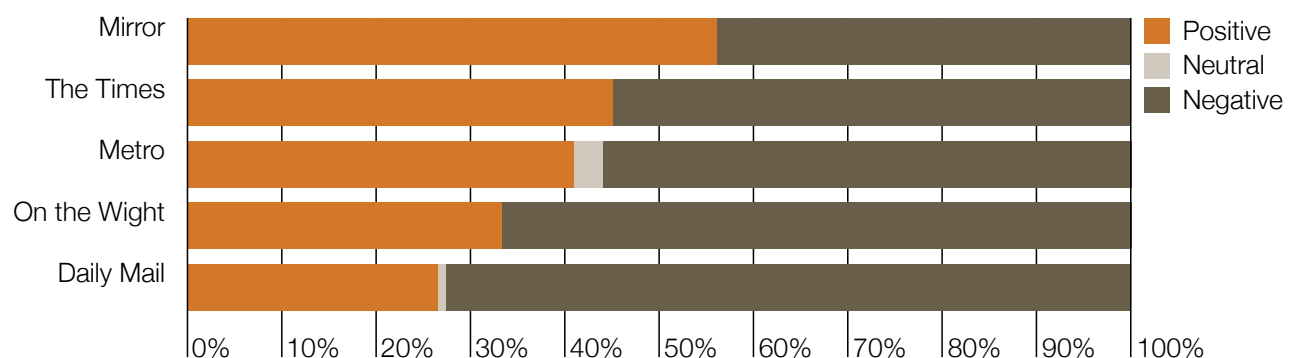
4. What did the media have to say about the 'new' law?

The switch to a 'soft' opt-out system of organ donation was preceded by a national media campaign. We aimed to learn more about how the changes were communicated, how people responded and any discrepancies between key messages and how they were interpreted by the public.

We analysed 286 leading UK online news sources and reader-generated content from 2019-2021.

- We found that most conventional media coverage on both organ donation and the law change was positive, with little variation over time or between publications.
- Complementary media campaigns to the government-led media campaign leading up to implementation created a consistent narrative that organ donation is a moral good with donors described in heroic terms and transplantation described as a miracle.
- However, analysis of reader-generated content in response to media coverage was mixed towards organ donation in general, and mostly critical of the law change, and tended to focus on the loss of individual freedom to the state and lack of trust in the organ donation system.

Tone of reader-generated comments for law change



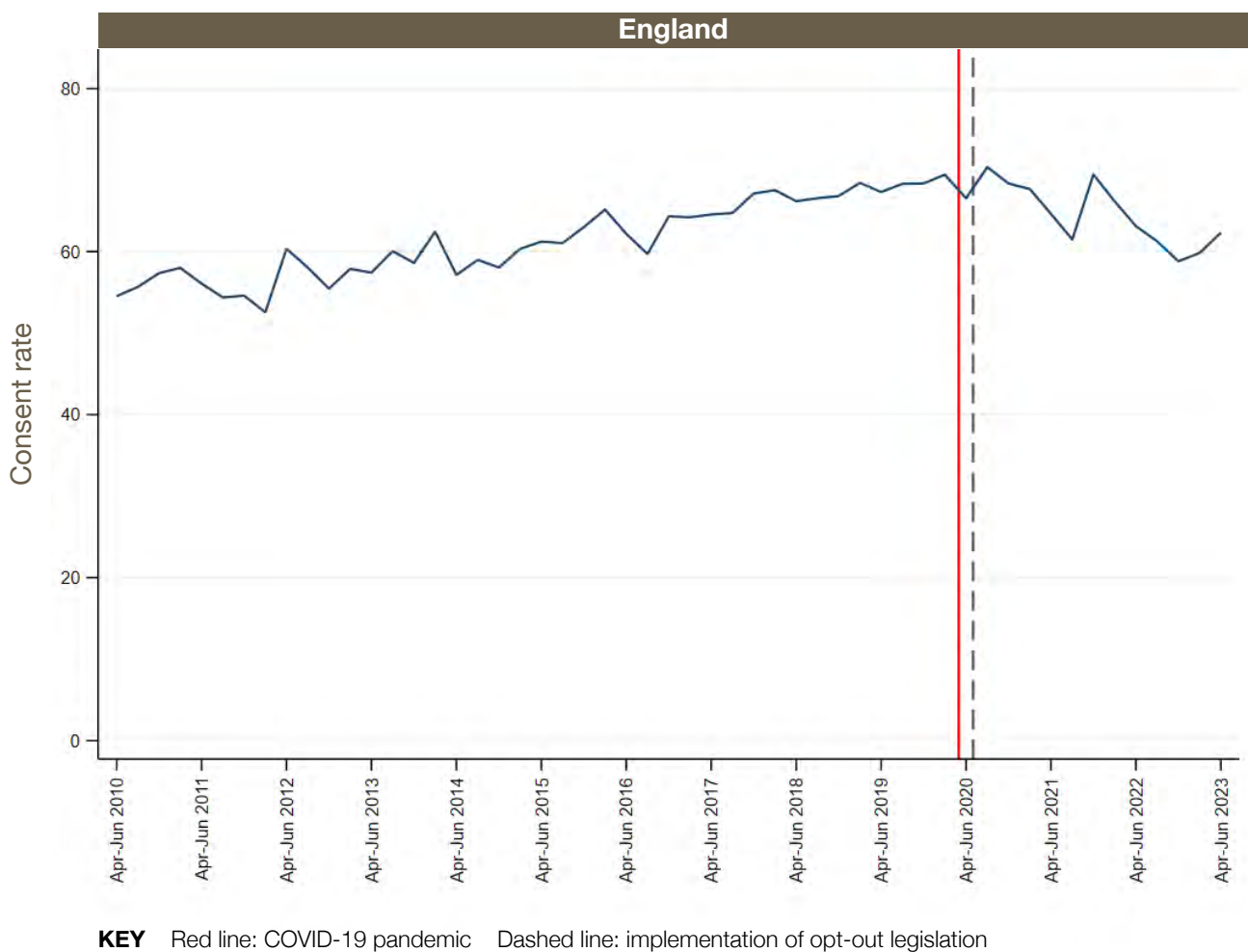
- There was much less sympathy towards members of ethnic minorities waiting for organs who might benefit particularly from the law change if more organs became available.

The discrepancies between the tone of the articles and the readers' comments suggests that some members of the public were much less trusting and supportive of the law change than Parliamentarians and the mainstream mass media.

5. What's been happening with organ donation in England, Scotland and Wales?

Wales and Scotland had changed to 'soft' opt-out systems in 2015 and 2021. England changed in 2020. All three countries aimed to increase consent and transplant rates with their law change. We looked to see whether this had happened.

England's consent rate



Consent rates increased significantly in the decade before the law change in England. However, this trend was interrupted by major fluctuations during the COVID-19 pandemic. While the UK organ donation system shows signs of recovery from the pandemic, donation rates, the number of eligible potential donors and consent rates remain below their pre-pandemic levels. These findings are more likely to be the result of the pandemic rather than the switch to deemed consent.

The COVID-19 headline:

The pandemic makes straightforward interpretation of trends difficult, but there is no evidence so far that the law change in England has boosted the consent rate which was its intention.

6. What did the public think and do about organ donation before and after the law changed? And does ethnicity make any difference?

We aimed to learn more about the impact of the law change on attitudes and views likely to be relevant to consent to deceased organ donation between different population subgroups.

We analysed surveys of the public on attitudes towards organ undertaken from 2015 to 2021 (19,011), and the change in law from 2018 to 2022 (45,439). We also interviewed thirty members of the public with a particular focus on ethnic minority and faith perspectives.

- Changing the law has had little impact on the general public's support for organ donation, which has remained high and stable at around 80% in favour. Furthermore, it does not appear to have influenced people's willingness to become deceased organ donors, but this proportion is lower. Fifty-six percent of the population would be prepared to give their organs after death.
- The number of people registering on the organ donor register has stagnated.
- Of those registered, 89% have opted in and are predominately white; about 10% have opted out and are predominately non-white.
- Harmful misinformation campaigns targeted at certain ethnic minorities encouraged people to opt-out of organ donation.
- The intention of the Act, to give decisions to individuals to make while they are alive, is not straightforward for some ethnic minority families where decisions are shared or delegated in a hierarchy.
- There is a very low level of understanding about what deceased organ donation is, how it comes about, and how this aligns with important end of life rituals and processes in some ethnic minority communities.
- The presumption of consent left gaps in all people's knowledge. They wondered what they needed to do while alive, what would happen if they or their relative who died was eligible for organ donation and, critically, what they would do if they did not know what their relative who died had wanted.

The implementation of the opt-out law seems to have had no effect so far on general public attitudes and consent preferences in England, including within minority ethnic groups.

7. What did doctors and nurses feel about trying to use the new law during the COVID-19 pandemic?

Healthcare professionals were (re)trained leading up to the law change which was implemented in May 2020 in the middle of the COVID-19 pandemic. We aimed to learn more about the perceptions of health care professionals, specifically their experiences of implementing the new 'soft' opt-out system.

We undertook two surveys of 244 and 738 staff and interviews with 59 healthcare professionals directly and indirectly involved in organ donation, early and later into implementation.

- COVID-19 had affected every aspect of implementation for staff. Many staff were redeployed or left their jobs.

"I do think we're coming out the other side [of the pandemic]. I do think the nation's returning to some kind of normal, but I think the hospitals and the staff are still terribly broken. And it feels like it's just something that's going to just explode, if I'm honest with you. The staff are broken, so everyone else has moved on but then there's no recognition for the people who worked right the way through it. It's now like, "Well you're not meeting these targets, you're not doing this, you're not doing that.""
(Health Care professional)

- Although supportive in principle, many staff were unconvinced that legislative changes alone would increase consent rates.
- The law gave the specialist nurses no new tools to navigate the complexities of speaking to the acutely bereaved or influencing family behaviours in regard to deceased organ donation.

"I think law is a scary word for people. Using the word law to people suggests there is going to be some sort of consequence should you not do it, so it becomes almost a threat. And on balance at a time of somebody's acute grief that's quite strong I think."
(Specialist nurse)

- NHS clinicians too felt that NHSBT's standard operating procedures were not always helpful in what were often highly varied family contexts, and complex family discussions and negotiations.
- Nothing got any easier for staff managing these complex and sensitive end of life care processes in a permanently overstretched and understaffed service as a result of the law change.

"When I come out of that room and I can't get consent, nobody cares, it's so frustrating, the reality is I'm the only one out here searching for organs, if I don't get them people die, its that simple really, I wanted it [law change] to help, it hasn't"
(Specialist nurse)

Implementing the law change at the height of the pandemic, when many staff were retrained and redeployed elsewhere, meant that implementation strategies were ineffective, diluted or did not happen.

8. How are bereaved families affected by the new law?



Families of potential donors are among the people most affected by changes in legislation. While they remain essential for organ donation to proceed, according to the 2019 legislation, they are no longer the decision makers. Their role is to support the decision their relative made during their lifetime. We aimed to learn more about the experiences, behaviour and decisions of families who were approached about organ donation after their relative died.

We interviewed 103 family members and friends representing 83 potential donor cases who were approached about organ donation in the hospital after the person died.

- Thirty-one out of 83 (37%) cases fully supported the organ donation, 41 out of 83 (49%) supported retrieval of some organs, tissues and procedures but not others, and 11 out of 83 (13%) cases declined completely.
- Irrespective of whether the deceased registered via the Organ Donor Register, talked about it with their family or the consent was deemed (i.e. the deceased person was presumed to have no objection to organ donation under the new legislation), most families still felt that they were the decision makers.
- The 'soft' opt-out system was not yet making decisions or experiences any easier for families at the bedside.

“Families are complicated aren't they, death causes tensions, brings out the worst and the best in people, and there are countless things to organise in death I can't see how this [law change and introduction of deemed consent] is likely to infiltrate or help such matters to be honest”. (Family member)

- Families did not see deemed consent as a genuine choice (because it did not necessarily require the deceased to make an active decision) unlike a decision on the Organ Donor Register which was generally viewed as a clearly positive decision in support of organ donation.

If I made a decision to donate I wouldn't think anybody would have the right to override that. But you've got to have gone on and filled the appropriate form out, or whatever it is you have to do, and then if you've done that a husband or a child can't override that, no, that is wrong.” (Family member)

- Families frequently asked themselves if their relative would have wanted to have surgery rather than whether the person who died wanted to save lives.
- Families struggled to comprehend the highly complex, multiple-step process of organ donation that they were presented with at the bedside.

“No its not nice, I mean it felt like he was still alive and here we were talking about taking body parts from your loved one, but they said obviously it was his wishes so I thought we will just have to go with that.” (Family members)

- Families consistently relied on the specialist nurses for guidance, support and reassurance, and appreciated and needed the high quality care that they provided.

Despite a change in legislation, family members' attitudes and behaviour often did not appear to align with the principle implicit in the Act to benefit people requiring transplants.

9. Spain has a similar system – so what can we learn from Spain?



Spain also operates an opt-out system yet has almost twice the organ donation rate per million population compared to the UK. The Spanish approach was also mentioned in the debates leading to the law change in England. We aimed to identify both differences and similarities in the consent policies, documents and procedures between the two countries to see how important the law might be compared with other factors in explaining the difference in donation rates.

- Families are as involved in deceased organ donation conversations in Spain as they are in England.
- According to Spanish experts, the Spanish system has simpler and more locally tailored consent documents, which reduce the time bereaved families have to spend enabling organ donation.
- There are more pathways leading to organ donation in the Spanish system, and more robust legal protections for the decisions of individuals made in life.
- England appeared more focussed on establishing last known decisions and the specialist nurses are encouraged to remain impartial. The Spanish system aims to establish the willingness of the deceased in general to help others, as well as their willingness to donate their organs.
- In Spain, organ donation is more ingrained as an integral part of end-of-life care, with many health care professionals aware of it and encouraged to be involved.
- The Spanish system has more resources to facilitate organ donation in end of life care e.g. more intensive care bed capacity.

10. What do we think should happen now?



The evaluation has shown that deemed consent is not generally viewed by anyone as being equal to a decision explicitly made and recorded by the deceased during their life. In this context, deemed consent has made the donation process even more uncertain and ambiguous as families are being given mixed signals as to whether they are the decision makers or not. Given the traumatic circumstances which often precede deceased organ donation, the (very) 'soft' opt-out policy adopted in England is thus unlikely to help families at their most vulnerable support organ donation decisions.

There are multiple agencies and stakeholders which already work together to deliver organ donation and transplant services in the UK. Our recommendations try to reflect this highly complex and dynamic system. These are summarised below with further details including steps that need to be taken and by whom in the complete full report available online, here: <https://piru.ac.uk/projects/current-projects/evaluation-of-changes-to-organ-donation-legislation-in-england.html>

The main recommendations are:

- To introduce new public ongoing media campaigns crafted to be more supportive of organ donation as a benefit to transplant recipients. Communications need to emphasise the changed role of the family as well as improving public understanding of the circumstances likely to bring about deceased organ donation and the processes involved.
- To give decisions on the organ donor register greater legal status to further legitimise and protect individuals' decisions and increase support for the changed role of the family. There also need to be regular reminders embedded in day-to-day life to those on the organ donor register so that decisions are kept up-to-date, thereby helping the specialist nurses in their roles.
- To shorten and simplify the documents and processes that the family have to complete so that they only cover the essentials needed to ensure the safety and effectiveness of transplanted organs.
- To provide more training to implement deemed consent rather than the previous model of explicit consent to organ donation.
- To clarify the concept of deemed consent and increase public understanding of the principle so that family members come to consider it as a legitimate pathway for their deceased relative.
- To institute a more positive philosophy of deceased organ donation, embedding organ donation in end of life care and developing practice more in line with the spirit of the opt-out legislation.

Taken together, these recommendations are designed to reassure healthcare professionals that discussing organ donation, supporting potential donors' personal choices, and helping families to endorse these decisions are integral parts of their role. It would also help families see the benefits of organ donation and most importantly the consequences of denying potential beneficiaries lifesaving and life improving treatments. If families were more reassured that they were supporting what their relative wanted (e.g. by more up-to-date entries on the organ donor register), then the ambitions of the Act might be easier to implement in the real-world context of deceased organ donation.

Finally, we need to acknowledge that the UK NHS consistently operates over and above maximum capacity. More intensive care resources would help increase organ donation rates. NHSBT and in particular the specialist nurses are essential to the organ donation service which is currently operating in a context that is permanently overstretched and consistently understaffed.

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A very special thank you to every person who took the time to participate in this research and help us learn.

Declarations

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Further information

You can find a more detailed report of the evaluation on the website: <https://piru.ac.uk/projects/current-projects/evaluation-of-changes-to-organ-donation-legislation-in-england.html> as well as updates and any follow on research and dissemination.

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