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Why did England change its law on deceased organ donation in 2019? The dynamic interplay between evidence and values

Lorraine Williams¹ , Jennifer Bostock¹, Jane Noyes², Leah McLaughlin², Stephen O'Neill¹, Mustafa Al-Haboubi¹ , Paul Boadu¹ and Nicholas Mays¹

¹Health Services Research and Policy, London School of Hygiene and Tropical Medicine, London, UK and

²Bangor University, Bangor, UK

Corresponding author: Lorraine Williams; Email: lorraine.williams@lshtm.ac.uk

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Abstract

In the three years since the law on adult deceased organ donation consent in England changed to include an opt-out system, there has been no discernible change to donation rates. The lack of a positive impact on donation rates was predicted by many of those who took part in debates before and during the passage of the Bill through Parliament. This invites the question as to why England moved to an opt-out system for organ donation despite equivocal evidence of likely benefit and opposition from expert health professional organisations. To address this question qualitative analyses of Parliamentary debates on organ donation was undertaken. This revealed a shift from a dominant position, which gave primacy to the evidence of likely effects, towards a more normative position where a deemed consent option was viewed as the ‘correct thing to do’ and the limited and conflicting evidence viewed in a positive light. By 2017, following Wales’s move to an opt-out system, together with continued lobbying for similar changes for England by professional and patient groups, alongside sustained public popularity for organ donation, the balance of opinion had shifted towards a system where deemed consent would become the default position for most English adults

Keywords: deemed consent; policy

1. Introduction

In England, and other similar countries, there has been increasing concern about the gap between the demand for, and the availability of, organs for donation after death, leading to people dying whilst on an organ transplant list (McHale *et al.*, 1995). The system of consent to organ donation contributes to this situation. In 2019, influenced to some degree by overseas experience and a similar law change in Wales in 2015, England changed its laws on adult consent for deceased organ donation from a soft ‘opt-in’ system to a soft ‘opt-out’ system. The soft opt-in system, in place in England until 2019, relied on individuals registering or recording their wishes to be a donor, or if they had not made such a wish known, their family were asked to give consent on their behalf. A soft opt-out system involves the individual registering or expressing their organ donation decision to donate or not, or doing nothing, in which case consent to donate can be ‘deemed’ on the assumption that the individual had expressed no objections to being an organ donor in life. The ‘soft’ aspect of the consent system refers to the inclusion of close family members, friends or nominated representatives in discussions with nurses specialised in deceased organ donation to support (or not) deceased donation.

The Organ Donation (Deemed Consent) Act, England was passed by Parliament in 2019 and implemented in May 2020 (Gov.UK, 2019). The UK Government's rationale for supporting this law change was that, although it was estimated that the majority, up to 90%, of the public supported deceased organ donation, this was not reflected in the numbers registering their decision to be an organ donor after death, and demand for organs continued to exceed supply (DHSC, 2017). In 2017 approximately 37% of the population in England had 'opted-in' on the Organ Donation Register (ODR); the organ donation (OD) consent rate was relatively low (63%) and family refusal rates for deceased donation were relatively high (36% compared with 25% in Greece and 13% in Spain) (NHSBT, 2017). It was reasoned by proponents of a change in the law that by adopting a system whereby most adults are presumed organ donors, unless they have expressed otherwise during their lifetime by 'opting out', deceased donation consent rates should increase, as seen in other countries with similar 'opt-out' systems, since the potential donor pool would be increased. Also, it was assumed that it would be much more likely that family members would support their relative's organ donation decision if it had been clearly conveyed to them during life (such as by registering their decision on the ODR or by telling them). However, three years after the law change was implemented in England, thereby allowing to some degree for the disruption that Covid-19 had on the deceased donation system, donation numbers had not increased, and family support had declined. In the post-pandemic year 2022/2023 the consent rate for deceased organ donation in England was 66%, which was 3% lower than the 2020/21 rate of 69% (NHSBT, 2022b). There was concern about the decreasing consent rate from families of donors where consent was to be 'deemed', compared with families of donors who had expressed consent (NHSBT, 2023b).

These statistics are not so unsurprising since the adoption of deemed consent for deceased organ donation has long divided opinion in the clinical community and beyond (McHale *et al.*, 1995; Beecham, 1999; Randall and Downie, 2012; Rudge and Buggins, 2012), resulting in a series of Parliamentary meetings and debates on changing the laws on consent over a period of fifteen years (see Table 2 [suppfile Table 2]). Since 1999 the British Medical Association (BMA) has consistently advocated for a change in organ donation consent law in the UK (Beecham, 1999; Silvert, 2000; BMA, 2012). In one of its briefings to Parliament during the debates on the opt-out Bill (2017–19), it stated that 'increasing evidence from systematic reviews of international data [shows] that opt-out is one of a number of factors that is positively associated with higher donation rates', arguing that a move from a default opt-in system to a default 'opt-out system with safeguards', their preferred term for presumed consent, would greatly improve donation rates (BMA, 2019). The BMA continues to hold this position (English *et al.*, 2019; BMA, 2023). Similar sentiments were echoed earlier by the Chief Medical Officer for England, Sir Liam Donaldson, when recommending improvements to the organ donation system including the creation of presumed consent with an opt-out option (Donaldson, 2006). One international study found deceased donation rates were higher in opt-out countries than in opt-in (Shepherd *et al.*, 2014), but could not demonstrate that it was the law, or the systems that support the law, that had the greatest impact, or that determines the difference between countries.

However, opinion among other health professionals, ethicists and legislators were more sceptical, or clearly opposed to opt-out legislation, including from those closely connected with intensive care and organ transplantation (Bramhall, 2011; Royal College of Surgeons, 2013; Fabre, 2014; Barber *et al.*, 2018; Rudge, 2018). Those opposing cited the lack of good evidence that opt-out would lead to increased donations (House of Lords European Union Committee, 2008; Rudge and Buggins, 2012; Hall and Parkin, 2016; SMC, 2017). They also made an ethical case – that opt-out would likely erode public trust in the organ donation system, one that had to be rebuilt after the Alder Hey Children's Hospital scandal of the 1990s, where it was found that a pathologist had removed and retained organs of deceased babies without family consent (Bauchner and Vinci, 2001; Gov.UK, 2001).

In 2006 the UK government established an Organ Donation Taskforce, comprising clinical and managerial experts in the field of organ donation and research, to identify barriers to organ donation and make recommendations for improvement. Its report, published in January 2008, made 14 recommendations for improving the donation system in the UK, including establishing a national team of clinical leads and specialist nurses to work with the National Health Service (NHS) to strengthen the organ donation system, with a target to increase organ donation rates by 50% over the next five years (DHSC, 2008). As well as accepting and implementing all recommendations, and in response to the range of views on opt-out consent systems, the Government subsequently asked the Taskforce to 'examine the potential impact on organ donation of introducing an 'opt-out' or 'presumed consent' system in the UK, having regard to the views of the public and stakeholders on the clinical, ethical, legal and societal issues, and publish its findings' (Johnson, 2008). The Taskforce's second report, published at the end of 2008, stated that 'there was no convincing evidence that it would deliver significant increases in the number of donated organs' and that 'moving to an opt-out system... carries a significant risk of making the current situation worse' (Buggins, 2008, p. 5). Risks identified were: 'undermining the concept of donation as a gift; eroding trust in NHS professionals and the government; negatively impacting on donation numbers; and would be costly to implement' (Buggins, 2008, p. 34). The Report suggested that organ donation rates could be improved by implementing the Taskforce's recommendations for system reform without recourse to changing the law (DHSC, 2008). The Taskforce further recommended that a review should be undertaken in five years' time (2013) to examine achievements in donation rates following implementation of the 14 recommendations.

Although organ donation rates rose steadily after 2008, indicating that the target of a 50% rise in organ donation was likely to be met, there were variations between the different countries in the UK, with Wales performing less well than England (NHSBT, 2009). In response, in 2011, the devolved Welsh Administration indicated its intention to pursue an opt-out system of organ donation (Griffiths, 2011) and carried out a public consultation (Gov.UK, 2012) which eventually led to the passing of the Human Transplantation (Wales) Act 2013 (Gov.Wales, 2013), which included deemed consent with a soft opt-out option. The law included a duty on Welsh Ministers to report annually for five years on how the law change was being promoted and resourced.

Encouraged by the change in Wales, the BMA and other patient and public groups, such as the National Kidney Federation and The British Heart Foundation, continued to lobby for similar law changes. There were also concerns that organ donation laws between England and the rest of the UK countries should be aligned. Additionally, sections of the English popular press, in particular the Mirror Group's campaign for an opt-out system in England in support of a heart transplant for a nine-year old boy called Max, (MGN, 2019) led to further Parliamentary questions and debate on changing the law in England. This resulted in the Government undertaking a twelve-week national consultation in 2017 in England on moving to an opt-out system (Gov.UK, 2018). Prominent relevant organisations, such as the Nuffield Council on Bioethics, questioned the rationale for this, citing a dearth of supporting evidence (SMC, 2017) and the more pressing need to counter myths and misunderstandings about organ donation practice in the UK (Prout, 2018). Nevertheless, the Organ Donation (Deemed Consent) Act, England (Gov.UK, 2019) was introduced in Parliament as a Private Members' Bill in 2017; achieved cross-party support; passed into law in 2019; and went live in May 2020. Scotland enacted a similar law change soon after and Northern Ireland followed in 2023.

This paper examines the views and evidence that informed the decision to change the law in England from one 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), despite limited supportive evidence of its likely positive impact on increasing organ donation, and opposition from significant health professional organisations such as the Intensive Care Society and the Royal College of Surgeons of England, through an analysis of the debates before, during and immediately after the law change.

2. Methods

We undertook a documentary analysis of Westminster Parliament's official Hansard Reports (UK Parliament, 2023) for all activity relating to organ donation consent between 2004 and 2022, using search terms such as organ donation opt-out, and presumed, or deemed consent. We also reviewed related documents and reports mentioned in the debates. These included Parliamentary briefing papers, key position papers and reports from stakeholders: clinical and those representing patient groups.

One member of the research team (LW) identified and analysed 23 published transcripts of organ donation debates and meetings taking place in the House of Commons or the Lords between 2004 and 2022. These comprised: four readings of organ donation presumed consent Bills presented, but withdrawn, or which did not proceed beyond first or second readings in the House of Commons in 2004, 2009 and 2017; five debates on strategies to increase organ donation taking place in Westminster Hall and the Commons between 2008 and 2017; ten debates and meetings relating to the Private Members' Bill first presented in 2017 that became law in 2019; and four motions and questions about organ donation initiatives, regulations and strategies. One hundred and thirty-eight responses from 117 individuals were analysed, some contributing to more than one debate, representing those in favour of presumed consent/opt-out and those against, plus those who supported presumed consent in principle but who expressed some concerns or reservations. The debates are summarised in [Table 1](#).

LW uploaded transcriptions of the Parliamentary debates and meetings to a qualitative analysis software package (NVivo 12) and analysed the data thematically using the Framework Method. Framework (30) is an approach to the analysis of qualitative data designed specifically for use in applied policy and practice research (31). LW read and re-read transcripts to enable familiarisation of the data. A deductive approach to coding was used, using predefined categories and codes to capture the range of views expressed relating to whether and on what basis the law should be, or might be changed. These were then indexed and charted within an analytical matrix of cases and categories. Further interpretation and discussion within the research team during regular meetings was carried out to identify patterns, themes and relationships. Related documents (i.e. those cited and used in the debates) were categorised by type and level of support for presumed consent (i.e. arguments presented in support of a change in the consent laws, arguments against) to complement and aid synthesis.

2.1. Study rigour

We presented our interim findings and interpretations at an event in April 2023 with members of the Commons and Lords involved (e.g., those leading and speaking in organ donation debates in the lead-up to the law change in 2019), as well as other commentators. Participants were asked whether the findings were expected or not, given their previous positions on deemed consent, and their opinions on the implications of the findings for future policy on deceased organ donation. The meeting was recorded with consent and ethical approval was obtained from the London School of Hygiene and Tropical Medicine's Research Ethics Committee (Ref: 26427 – 3. 17/02/23) and used as a final marker of rigour in the analysis.

2.2. Reflexivity

This analysis was undertaken as part of a wider mixed-methods evaluation of the impact of opt-out on the entire organ donation system in England. The research team had varied backgrounds and were experienced in policy, health and social care services, methods and law and included lay representatives and mixed ethnicities. Two of the team had led an evaluation of opt-out in Wales. During regular team meetings, team members made transparent their potential biases concerning the topic and the interpretation of evidence. As the Act was introduced as a Private Member's

Table 1. Characteristics of debates, motions, and questions relating to organ donation opt-out/deemed consent

Title of debate/meeting	Date/lead	Transcripts analysed from Houses of Commons, Lords and Westminster Hall	Total	
			docs	Total no. speaking
Organ Donation (Presumed Consent & Safeguards) Bill	2004 (Siobhan McDonagh – Lab)	Presentation and first reading in Commons (withdrawn after first reading)	1	2
Organ Donation (Presumed Consent) Bill	2009 (Jeremy Browne – LD)	First and second readings in Commons (did not continue to third reading)	2	4
Bill to enable persons in England to withhold consent for organ donation	2017 (Paul Flynn – Lab)	First reading in Commons– did not proceed to second reading due to prorogation and General Election)	1	1
Organ Donation (Deemed Consent) Bill	2017 (Geoffrey Robinson – Lab)	Readings in Commons and Lords × 6; Committee meetings in Commons and Lords × 2; meeting in Commons to agree funding × 1; Meeting in Commons to discuss impact assessment × 1	10	82
Debates on opt out system of organ donation	2008 (Dawn Primarolo) 2011 (Paul Uppal – Con) 2011 (Glyn Davies – Con) 2014 (Andrew Griffiths – Con) 2017 (Dan Jarvis – Lab)	2008 debate in Westminster Hall 2011 (Paul Uppal) in Commons 2011 (Glyn Davies) in Westminster Hall 2014 debate in Westminster Hall 2017 debate in Commons	5	40
Motions/questions on organ donation initiatives/strategy	2011 (Duncan Hames, LD) 2020 (Lord Bethel, Con) 2021 (Dan Jarvis, Lab) 2022 (Andrew Mangall – Con)	2011 Question on OD initiatives in Commons 2020 motion to approve OD regulations presented in Commons 2021 Question on success of OD law change in Commons 2022 Motion on OD strategy presented in Westminster Hall	4	9
			23	138
Lab = Labour Party, LD = Liberal Democrat Party, Con = Conservative Party. Responses from 117 individuals (82 from the House of Commons, 35 from the House of Lords) - some individuals spoke on more than one occasion.				

Bill, and not by a political party – subsequently receiving cross-party support to pass the Bill into Law – there were not considered to be any obvious political conflicts of interest. We also engaged with Parliamentarians and key decision-makers from all political persuasions.

3. Findings

Three positions were identified among those debating opt-out systems of organ donation: (1) Optimism – that the law change will save more lives; (2) Rational scepticism – changing the law would be unlikely to make much difference to organ donation rates and would be too risky; (3) Pragmatic optimism – agreement that the law change would not be a panacea on its own but would likely help to increase donation with other changes and safeguards in place. Though all three positions were present in the debates from 2004 onwards, the first two (optimism and rational scepticism) came to dominate the debates in the lead up to the readings of the Bill in 2017. Thereafter, during meetings and debates in 2018 and 2019, the debate became more marked by those with a ‘pragmatic optimist’ view. According to this, objections to a change in the law could be accommodated as long as it was made clear that the law would be implemented in its ‘soft’ form; i.e. family members of the deceased would always be consulted to confirm and support their relative’s actual or deemed organ donation decision; donation would not go ahead if the family objected; and other safeguards would be put in place to exclude the deemed option for specific organs and tissues, such as novel transplants and groups, children, non-residents and those lacking capacity to consent. Figure 1 illustrates the three positions and key timelines of Parliamentary debates, significant reports and emerging evidence.

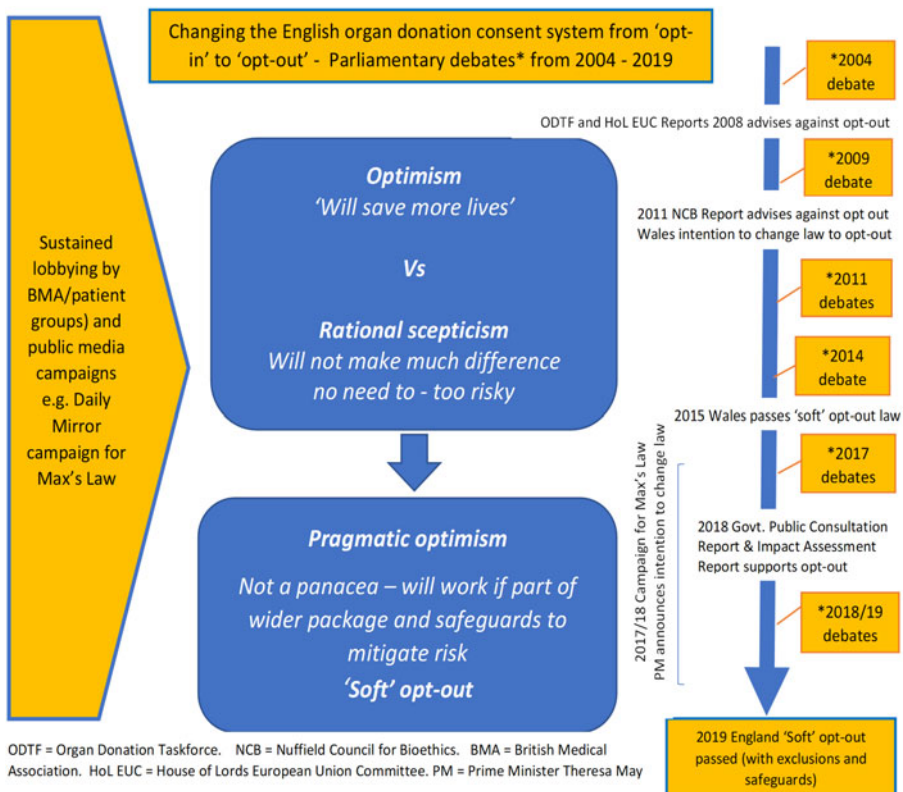


Figure 1. Debate on changing the law to an opt-out system including an option of presumed consent.

3.1. Optimism: deemed consent will save more lives and reduce suffering

A central theme in the arguments in favour of deemed consent was the belief that this would ‘save people’s lives’ as it would allow more organs to become available. Expressions such as ‘people are dying whilst waiting for an organ to become available’ and ‘demand for organs is outstripping supply’ were repeated regularly among members proposing and supporting a deemed consent option. The sense of duty to do something was strong among these speakers.

In all debates, these members spoke frequently of the evidence of a lack of organs available for donation and of high public support for organ donation – some members citing surveys where, despite up to 90% of people in favour of organ donation, this was not converting into a commensurately high level of willingness to ‘opt-in’ on the ODR. (NHSBT, 2023a) It was, as described by one Member of Parliament (MP), an opportunity for politicians from all parties, to work together to save lives:

‘For goodness’ sake, instead of going along as we are... serving the few rather than the many and talking about our various political differences, let us realise that this is an area in which we politicians **can save lives** and lift the burden of anxiety from families waiting for organs’. (Paul Flynn MP, Westminster Hall Debate on Organ Donation, Nov 2011).

For these Parliamentarians, the current system of opt-in was viewed as not working, or not working well enough. It was also noted that, apparently, similar countries with opt-out laws had better donation rates than the UK (House of Commons Debates: 20 Nov 2008; 17 June 2014; 23 Feb 2018; 26 Oct 2018). There was a perception that, by moving to an opt-out system, the organ donation pool would increase as it was rationalised that people would be encouraged to specifically indicate in life if they did not want to donate by telling their relatives and/or by opting out on the ODR. Doing neither would indicate implicit consent to donation.

However, for some Parliamentarians, evidence or assumed evidence that an opt-out system including presumed consent would increase organ donation was viewed as less important than it being simply the right thing to do. As one MP noted:

‘...logic tells us that, [with deemed consent], it is likely that more organs will be donated. **Even if that was not the case, and even if, as has been said, it made no difference whatever, are we not right to try?**’ (Kevin Brennan MP, Westminster Hall Debate on organ donation 2011).

Throughout debates, particularly during early readings of the 2017–2019 Deemed Consent Bill, Parliamentarians reasoned that opt-out would better reflect the national sentiment, which was supportive of donating organs, signalling the UK as a ‘compassionate society’. Affective reasoning was frequently employed in arguments to support the change in law, such as by giving personal examples of how organ donation could help their constituents. Many of these were stories of the pain and privations individuals (often children and young adults) endured whilst waiting for a suitable donor, and of the benefit of organ donation to the recipient and their family. One Member, in a description of their young constituent’s experience on kidney dialysis, said:

‘...this Facebook post hits home: ‘Today 1608 days with total kidney failure. Today 19,296 hours spent on Dialysis. Today waiting for the precious call, a match has been found’ ... when we think of such children...it is very hard not to support the Bill today?’ (Andrea Jenkins MP, House of Commons Second reading of the Bill Feb 2018)

This type of response was common in key debates, such as those on the Second Reading of the Bill in the House of Commons in February 2018, whereby Members would have had the opportunity to read parliamentary briefings (Barber *et al.*, 2018) and consider the evidence. Large

proportions of Members (in one Reading 17 out of the 42 Members speaking) presented examples of their constituents', friends' or family members' need for organ donation as the sole reason for their support for the Bill. Many of those in support of deemed consent drew selectively on evidence that best supported their argument, particularly the evidence of opt-out systems working successfully to increase consent and donation in other apparently similar countries. For many, the solution was simple and intuitive; changing the law to an opt-out system, as in Wales, 'would [likely] add thousands of names to the organ donation register', therefore potentially saving 'hundreds of lives' (Dan Jarvis, House of Commons Third Reading of Bill, Oct 2018), and would also have wide public support.

The urgency of the issue was a concern for many, leading to statements such as 'we cannot afford to do nothing' as 'people were continuing to die' whilst on the transplant waiting list. Even those who expressed some reservations, accepting that the evidence was promising but not wholly conclusive, were 'willing to go with an act of faith' to address the problem (Julian Knight MP, House of Commons Third Reading of Bill 2018), or to forgo personal ethical concerns for the sake of the 'greater good', as expressed in this quotation:

I'm not entirely comfortable with the principle of the state taking control of bodies without express permission, but I think that that option is far less bad than the situation whereby hundreds of lives are unnecessarily lost every year effectively through inertia' (Mike Wood MP, House of Commons Second Reading of Bill, Feb 2008)

3.2. Rational scepticism: Law change is unlikely to make much difference to rates of organ donation and is a potential risk

A rational sceptic is defined as 'one who questions the validity of particular claims of knowledge by employing or calling for statements of fact to prove or disprove claims, as a tool for understanding causality' (Shermer, 1997, p. 17). Those arguing from this position focused mainly on two areas: that there was limited and conflicting evidence that the law change would lead to an increase in deceased donations; and that it could have negative outcomes by harming trust between the public and the medical profession. These arguments were more frequent during earlier debates, for example, those occurring in 2008, 2011 and 2014 – before the Readings of the Organ Donation (Deemed Consent) Bill 2017–19 [see [suppfile_Table 2](#)].

Those arguing against implementing a deemed consent option cited the evidence supplied by the 2008 Organ Donation Taskforce (Rithalia *et al.*, 2009) which recommended against changing the law on the grounds that the evidence did not wholly support such a change or was conflicting (Figure 1). Members, including Government Ministers summarising organ donation debates prior to 2017, reasoned that the organ donation system changes that had been put into place in response to the Taskforce's recommendations in its first report (Buggins, 2008), such as setting up a dedicated national and regional team to promote and support organ donation, were already having some impact in meeting the 2013 target of a 50% organ donation increase. From this perspective, this group of Parliamentarians argued that any further changes to the system, such as a change in the law, were not necessary, would be expensive to implement and could even be disruptive, for example, by giving the public the impression that the 'state was taking organs' rather than these being given as a gift. Some argued that this might even reduce the organ donation pool, through more people opting out on the ODR. Lord McColl, when reflecting on the position in Wales since its introduction of opt-out, argued that 'over 180,000 people, all of whom were previously potential donors, have now withdrawn and...lost to the system' meaning that 'It is no longer possible for clinicians to talk to [some] families about donation, when previously they could all have been approached' (Lord McColl, House of Lords Committee debate, Feb 2019). Improving current organ donation systems generally, as in the Task Force recommendations, was viewed to be the most appropriate way to increase donation rates, and Members argued

for this in debates, even those who had reservations, by supporting a ‘wait and see’ approach: ‘*let’s get to 2013 then see where we are*’ (Paul Uppal, 9th November 2011).

A concern for some was that the case for change was based on a misconception of how the current opt-in organ donation system worked in practice. The popular, although incorrect perception, leading to, as Members suggested, large public support for a change in the law, was that only those on the ODR were approached for donation:

‘Many people support presumed consent because they intuitively feel that it must make a difference. Opinion polls show support, and it is not surprising that they do. When people are going around saying that the change to presumed consent will increase the number of organs available, others will automatically say that they are in favour, but the reality is not what they think. There is a misconception that, if a citizen does not put their name on a centralised register, their organs can’t be used for transplantation’ (Glyn Davies, Westminster Hall Debate, Nov 2011)

Up until 2019 practice in the English opt-in system meant that health practitioners were encouraged to refer all potential candidates for donation, irrespective of their name being on the ODR or not. Thus it was argued that changing the law would not necessarily change consent protocols and practice, though it might change the conversation with relatives. Here too, it was argued that the change in conversation from ‘consent’ to ‘support’ risked alienating families. As one MP noted:

‘...Asking, ‘Do you wish to object?’ is no easier than asking ‘Please may I do this?’ but the latter is far kinder and gentler’ (David Wilshire MP, House of Commons 2004).

Those arguing from this position stressed the importance of awareness raising (rather than law change), so that people would be encouraged to let their closest relatives and friends know of their organ donation decision so that this could be supported.

The risk of the law change damaging the relationship of trust between clinicians and their patients, and between the medical profession and/or NHS and the public was discussed during all debates. One Minister suggested that this was more important than the potential for opt-out improving donation rates:

‘..the Taskforce did not completely write off [deemed] consent. It noted that it ‘may deliver real benefits’, but the stronger concern, which outweighed that possibility, was that it ‘carries a significant risk of making the current situation worse.’’ (Dawn Primarolo, Minister of State for Public Health, House of Commons debate Nov 2008)

3.3. Pragmatic optimism: law change is on balance worth pursuing, but will not be a panacea, it may not work on its own and it will need safeguards

In later debates (2018 onwards), a compromise position gained support as arguments on both sides of the debate became more open to a middle of the road position, and a sort of pragmatic consensus, or acquiescence, emerged. There was acceptance that changing the law to include a deemed consent option, while not a ‘silver bullet’ on its own, might help address organ donation shortages if implemented as part of a package of measures designed to raise awareness and develop a culture in which organ donation would become the norm. Concerns about the potential risks, identified and debated previously, were to be largely mitigated through a series of suggested safeguards, such as: a requirement to include the deceased’s family and close friends in any decision making; to ensure adequate staff training, and to put in place regulations to ensure ethical practice of the medical profession so that public trust was maintained. Creating a culture of acceptance of organ donation was viewed as particularly important:

‘...how we can make sure that the Bill is as successful as it can be... making sure that we educate people from a very young age, so that they see organ donation as a positive thing that they want to do... to help other people’. (Michelle Donelan, House of Commons Second Reading of Bill 2018).

Evidence of perceived ‘success’ of the Welsh opt-out system at the time, with consent rates continuing to rise following implementation, was also deployed in favour of an English law change. The reported positive public response in Wales, and the fact that there had not been the predicted public backlash, were listed as reasons for supporting the Bill, even among those who had expressed reservations in earlier debates:

‘I used to be sceptical about opt-out systems but the proposal in this legislation, which has been demonstrated to work in Wales, strikes the right balance, giving people power and control while making sure that they can make a positive choice if they are well informed’ (Lord O’Shaughnessy, House of Lords Committee, Feb 2019)

Some Members, concerned about the continued lack of organs to meet demand, framed their support as a step towards creating a compassionate culture where organ donation would become normalised. These Parliamentarians viewed the law change, with its accompanying communication campaigns, as a means to stimulating debate on organ donation and, as one Member asserted, ‘*will do absolutely no harm*’ (Dame Cherry Gillan, House of Commons Second Reading 23 February 2018). Others, who in earlier debates had been concerned that the law change might adversely affect faith groups, particularly those that require ‘bodily integrity’ after death, softened their concerns and supported the Bill after assurances that any expressed decisions to opt-out would be respected, and that families of the deceased potential donor would always be consulted. One Peer quoted a letter presented by the Parliamentary Under Secretary of State for Mental Health and Suicide Prevention, Jackie Doyle-Price (Doyle-Price, 2018), assuring faith groups that a faith option would be included within the ODR which would include the text:

‘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’; and that ‘appropriate agencies will engage with faith and minority communities in developing guidance that addresses those concerns’ (Baroness Deech, House of Lords Second Reading Nov 2018).

The letter also confirmed that, if family members could not be contacted, donation would not take place (even in cases where the deceased had opted in on the ODR). However, others questioned whether this commitment should be contained within the legislation rather than in a ‘side letter’.

3.4. ‘Making it work’: coming to a consensus supporting a very soft approach

During the various debates, participants began to influence one another over time and identify ways that could conceivably make an opt-out system work alongside the current opt-in system in England, given that both systems needed to operate simultaneously as not all potential donors would meet the eligibility criteria for deemed/presumed consent. Figure 1 and Table 2 [suppfile_Table 2] illustrate the shift in the dominant Parliamentary narrative. Before the introduction of the 2017 Bill, there had been eleven Parliamentary debates, motions, and questions on changing the organ donation law to an opt-out/deemed consent system for adults who met the eligibility criteria since Tom Watson, MP, had introduced his original Bill in 2002. These discussions were first introduced to Parliament via a number of Private Members’ bills and related debates but had remained largely binary, based on conflicting ethics and evidence. Parliamentarians discussed the pros and cons of changing the law to an opt-out system, using

rival interpretations of the emerging evidence. Those supporting opt-out would refer to the evidence of higher donation rates in other seemingly similar countries with opt-out laws. Those against, or expressing concerns, would highlight the evidence of other opt-in countries with higher donation rates than England (e.g., the US) and the fact that Spain's apparent success was not necessarily attributable to its opt-out laws, rather its better organised and resourced organ donation system. Participants in later debates, from 2017 onwards, described by many as having strong cross-party support, appeared more accepting of the case for the law change. As one commentator noted, they exhibited more 'reluctant acceptance' (C. J. Rudge, Personal communication, 2023) of the principle of the law change for eligible adults and its limitations, for example, agreeing that it would not be a quick fix and would need to be supported by a strong and continuous public awareness campaign, as well as other safeguards.

'...it is absolutely right to say that this Bill, in itself, is not a panacea, but it is an important contribution. It will help start the debate and deliver—in the way that has been shown in Wales—profound changes, we hope, in levels of donation' (Lord Oates, – House of Lords Second Reading, Nov 2018)

Some questioned or refuted interpretations of the evidence of the Organ Donation Taskforce Report, stressing the ambiguity of the term 'may' as used in its findings, suggesting that opt-out could have the potential to be effective if implemented alongside other supportive measures. This was further supported by updated evidence reviews and reports, which concluded in favour a soft form of opt-out for England and Scotland (Niven and Chalmers, 2018; DHSC 2018a, 2018b). Even those who were vocal in their opposition in earlier debates reluctantly accepted the popularity of the Bill within both Houses, and its likelihood of passing, so, whilst expressing their reservations, did not oppose it, but instead argued for system improvements as part of a reform package alongside the law change:

'...we accept fully the head of steam, as it were, behind the Bill and will certainly not oppose it. Nonetheless, we ask that...three very important considerations are taken into account... there should be very good communication...adequate resources should be made available for the implementation of this new system....[and] more effective use should be made of potential donors, in ways highlighted by the transplant pathway. Only then do we believe that the pressing need for more organ donations will be met' (The Lord Bishop of Carlisle, House of Lords Second Reading, Nov 2018)

Research team discussions with some of those involved in the Lords debates confirmed that their intention were to make the law change work through providing greater clarity around persons, organs and tissues that fell under the law (and any that were excluded). They relied on advice from Department of Health officials and lawyers to ensure this '*...so as far as possible, you know, the Bill should be watertight*' (Lord Hunt, meeting to reflect on law change, April 2023).

3.5. Interpretations of the successes of the law change

After implementation in 2020, Ministers made statements on the impact of the law change, particularly in light of its enactment during a global pandemic. It was initially viewed very positively, as families were seen to be supporting deemed consent. For example, around the first anniversary of the law change, Matt Hancock, the then Secretary of State for Health and Social Care, announced that it was '*already having an impact*' (Kidney Care UK, 2021; NHSBT, 2021), and the Minister for Care announced that the opt-out donation system '*is saving hundreds of lives ...as [deemed consent] accounted for 29% of the 1021 donations that took place last year*' (Helen Whately, House of Commons, May 2021). In 2022, similar statistics were presented to

the public as a success (NHSBT, 2022a), despite the fact that many of the deemed consents would probably have appeared as ‘family consent’ under the previous opt-in system, so were not necessarily a reliable indicator of the impact of the new law. However, in the same year, Ministers began to frame success differently as ‘more people opting in’ on the ODR and a ‘less than anticipated’ number opting out’ (Hansard Parliament UK, 2022). Overall consent/authorisation rates for deceased donors were, in fact, down from 69% in 2021 to 66% in 2022. (NHSBT, 2022b) This was likely to be why Government Ministers became more cautious, reporting family consent rates as being ‘*a good figure – much better than where we were – but there is still a lot of room for improvement*’ (Maria Caulfield, Parliamentary Under-Secretary of State for Health and Social Care, House of Commons, Feb 2022 (Hansard Parliament UK, 2022), also see Table 2 [suppfile_Table 2]).

4. Discussion

For approximately 15 years (from 2002 until 2017), the issue of whether England should change from an opt-in to an opt-out system of deceased organ donation was debated in a range of parliamentary fora, until, in 2017, the Government notified its intention to implement a ‘soft’ opt-out system by backing a Private Members’ Bill to make amendments to the Human Tissue Act (2004) in relation to consent. The current analysis has shown that this came about through a gradual shift from more binary arguments in early debates, based principally on conflicting ethics and evidence, to an emerging consensus around what could be termed a position of ‘pragmatic optimism’ in support of a ‘soft’ opt-out system of deceased organ donation deemed consent. This pragmatic position recognised that the law change was only likely to be acceptable and workable in a ‘soft’ form: that is, by continuing to involve families of the deceased in any organ donation decisions, and by minimising potential risks by excluding certain groups and ‘novel’ organs, where family consent would still be required. The change was not seen by its supporters as a panacea but would need to be underpinned by a package of measures, especially greater publicity. It was also understood that the law change would likely take some time to have effect.

A number of external factors can be identified that help to explain this shift among Parliamentarians, notably: the example presented by Wales’s decision to move to ‘soft’ opt-out (despite it being difficult to interpret trends in the Welsh data due to small numbers); and public and media support for the principle of default opt-in (albeit possibly in part based on a misunderstanding of the status quo).

The knowledge that Wales was intending to implement its own opt-out law change from 2011 was a key factor in shifting the debate in England (and the other UK countries) towards considering the same. The apparent increase in organ donation consent rates in Wales after the law change was referenced by the English media and in Parliamentary debates in 2017, despite small numbers limiting the interpretability of the data and the absence of any sign of an increase in organ donation or transplant rates in Wales (an example of framing effect bias, see below). In addition, public support for the law change in Wales remained high, and there was no public backlash, a reassurance to those concerned about this anticipated risk.

Public and media support for the change in law was clearly highly influential with Parliamentarians. Faherty and colleagues, in their recent analysis of English media portrayal of organ donation at the time, found that most press coverage, namely online content of UK national and local newspapers and specialist publications, was supportive of organ donation and of changing the law, emotively portraying organ donors and recipients as superheroes worthy of full public support (Faherty *et al.*, 2022). There was a clear shift in Government rhetoric and activity following the Mirror Group’s campaign for opt-out, framing the debate as ‘saving Max’s life’, even though deemed consent would not apply to people under 18 in England. The Daily Mirror, a popular UK tabloid newspaper, claimed the law change, named ‘Max and Kiera’s law’ after the child recipient and donor, as its own victory (MGN, 2019), winning awards for

its efforts, and inspiring other UK countries to follow suit. For example, Northern Ireland named its opt-out law as Dáithí's Law, after a five-year-old child on a heart transplant waiting list. The attendance of both Max's and Kiera's family at significant Parliamentary debates on both the Second and Third Readings of the Bill in the Commons and Lords, may have increased pressure on sceptical Parliamentarians not to speak against the Bill, due to the sensitivities of those present.

It is also clear that participants in debates were more likely to accept and deploy evidence that supported their general position and to refute evidence that contradicted it. There were clear signs of confirmation bias in the debates, especially among those arguing in favour of the opt-out. There was little or no dispute among participants on the evidence of the need for more organs; all agreed that donation rates were not rising fast enough to meet demand. The differences lay in how a greater number of organs could be achieved, with some arguing for the continuation of measures aimed at strengthening the existing donation system and raising public awareness (the 'wait and see' approach that prevailed until 2014) and others supporting a change to the law on consent. The 'pragmatic optimistic' position that emerged later was an amalgam of the two.

The debates also display evidence of framing effect bias (Tversky and Kahneman, 1981). This is when decisions are influenced by the way the information is presented, or framed, in a positive or negative way, leading to an emotional response. Glyn Davies, MP, (among others) pointed this out during one of the early debates in November 2011, arguing that people would intuitively be more likely support the option of deemed consent if it was presented simply as being about 'saving more lives.' Similarly, later debates consisted largely of members expressing their support for organ donation per se (largely equating supporting organ donation in general as automatically supporting the law change), with very little discussion of the likely effectiveness of changing the law or of any possible negative effects. This is particularly evident in statements of those leading the debates and from Ministers commenting and summing up.

Another rather different explanation for the law change relates to an occupational bias among Parliamentarians in favour of using legislation to solve problems, since they are familiar with, and can control legislative change. Those arguing strongly for the law change recounted their experiences of organ donation, as either advocates for their constituents or others on waiting lists for transplants or having personal experiences of donation or transplant. This was particularly noticeable in supporting statements in both Houses on Second Readings of the Deemed Consent Bill where Members declared their involvement with patient groups, especially groups benefitting from more deceased organ availability, and/or individuals lobbying for law change. The evidence presented in support favoured other countries which had better donation rates on the assumption that these were the result of opt-out systems. Yet cross-country comparisons are challenging to interpret as countries differ in their population compositions, death rates (including statistics on road traffic deaths, a major factor in the supply of deceased organs suitable for transplantation) as well as in their cultural and religious sensitivities (McHale *et al.*, 1995).

There was also some misconception and misinterpretation of what was proposed in the Bill and the evidence to support it which may have contributed to the votes in favour of changing the law. Some Parliamentarians alluded to this by reminding their colleagues that not all deceased organs were obtained from those on the opt-in register, pointing out that a wider group of families of potential donors were already approached under the opt-in system. Another misperception was to present the law change as being a complete shift from an opt-in system to an opt-out system, thereby ignoring the fact that, in practice, the law change would provide an *additional* deemed consent pathway, alongside other previous consent processes. This was possibly encouraged by the title of the Bill which included 'deemed consent'. This may well have contributed to the incorrect impression that there would be a single route to deceased donation with opt-out replacing opt-in. In reality, the 2019 Act introduced a dual 'opt-in and opt-out' system in which family members of the deceased would have a potential veto whichever route was involved. Thus, instead of making the system easier to navigate, it probably made it more complex for those

requesting and taking consent. Figure 2 [suppfile_Fig. 2] illustrates the consent pathways after the law change, showing deemed consent, in blue, as one of seven potential donation consent pathways.

One could argue that these specifics were not necessarily intended for debate as there had been Government-led consultation with stakeholders before the main legislative debate, as well as an ex-ante assessment of any impact the law change would have on the donation system as a whole. Parliamentarians were therefore deliberating primarily on the principle and ethics of England moving towards a system whereby deemed consent for deceased organ donation would become the default position for adults who had not indicated otherwise. The perceived ‘successes’ of recent opt-out systems such as that in Wales, in terms of numbers of consents deemed, clearly influenced the debates but were not fully interrogated. For example, there was no counterfactual evidence available to show whether family members would be more likely to consent in a system of deemed consent than in an opt-in system.

There was, especially in later debates, some greater recognition of the imperfect nature of the empirical evidence supporting an opt-out system, but Members were still able to rationalise their support for changing the law as something that they ‘couldn’t afford not to do’ as ‘people were dying on waiting lists’ – it ‘being right to try’; and something they, as Parliamentarians, could do now in the belief that it would, in time, be helpful. Action bias, a tendency favour action over inaction (including legislating), even without sufficient reasoning in support, may also have been a factor. This bias towards intervening was also likely to have been bolstered by the ‘high confidence’ with which the Government’s Chief Scientific Advisor presented their judgement in the official Impact Assessment (DHSC, 2018b) that the law change, in any event, would not reduce organ donation rates.

In his analysis, focused on the extent to which the law change was evidence-based, medical ethicist Parsons reaches similar broad conclusions to the current analysis, arguing that, in his view, whilst the law change can be seen as ethically defensible from a logical perspective – in that moving to a default position of deemed consent would best reflect the in-principle attitude of the majority of the population – there was not enough good evidence of likely benefit to support the law change (Parsons, 2023). Our findings support Parsons’s high-level thesis but illustrate the nuances involved in the debates. While there was highly imperfect evidence throughout, it was interpreted and deployed differently over time. This was accompanied by some misconceptions and biases which mainly worked in favour of the law change. Parliamentarians tended to assume that deemed consent would increase organ donation in and of itself whereas all the evidence suggested that the law is at most a marginal contributor and a lot more relates to establishing a ‘pro-donation’ culture and system. The identification of safeguards associated with a ‘soft’ opt-out helped alleviate the concerns of sceptics sufficiently to enable the Bill to pass on the grounds that it could ‘do no harm’ and might conceivably be beneficial.

5. Conclusion

The above analysis of Parliamentary debates has revealed the shift from a dominant position, which gave primacy to the evidence of likely effects, towards a more normative position in which the deemed consent option was viewed as the ‘correct thing to do’, and the limited and conflicting evidence viewed in a generally positive light. By 2017, the balance of opinion had shifted towards a system where consent to donate organs would become the default position for most adults, leading to little opposition and large cross-party support for the change in law. There are a number of reasons why this shift took place despite imperfect evidence of likely benefit in terms of increasing consent rates, and considerable scepticism from medical experts. One reason was to ensure that the law better reflected popular opinion: that most people would be happy to donate their organs after death. This was amplified by UK media rhetoric. Another reason was to demonstrate a response to the pressing need for more organs for donation,

and therefore reflected an underlying belief that it would somehow save more lives, even though the evidence for this was always unclear. This can be seen as an example of the symbolic function of legislative change, seen in many areas of public policy when there is pressure (in this case from the media and the example of Wales) for government to be seen to be doing something about a high profile social problem (Aubert, 1966).

Much weight was also given to perceived ‘successful opt-out countries’ such as Spain, signalling a degree of confusion between correlation and causation. 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. For those initially opposed to the law change because of insufficient evidence of its likelihood of increasing consent and donation rates, this indicated a shift to a position of acquiescence. Others were more hopeful, viewing the law change as one step towards creating a more positive culture towards donation, particularly as it was accompanied by dedicated resources, in terms of largely extra funding for publicity and evaluation. Early evidence of a reduction in family consent/authorisation rates in England since implementation in April 2020 casts some doubt on the emergence of a positive culture. However, it is too soon to tell what lies behind this. It may be that the new system is too complex to implement, or that a ‘soft’ opt-out results in extensive family vetoes, thereby blunting any impact of the shift to deemed consent. Part of the picture may be the residual impact of the COVID-19 pandemic – the publicity campaign that had been planned for the immediate aftermath of the law change was severely affected by the pandemic – or a combination of all of these factors. The current analysis is part of a larger evaluation of the of the law change addressing these and other questions.

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