

A global pandemic is not a good time to introduce ‘opt-out’ for organ donation

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Abstract

Following several international examples, England introduced a system of deemed consent for organ donation in May 2020. This had been planned for over a year. However, the unprecedented circumstances of the COVID-19 pandemic raise issues that make the timing of this change unfortunate. The planned public awareness campaign has thus far been overshadowed by media coverage of the pandemic, and will likely continue to be, creating a situation in which a significant portion of the population may be unaware of having become potential organ donors. Further, the immediate impact of the new policy is likely to be significantly weakened by the suspension of the majority of organ donation and transplant activity. In this article, we first outline the details of the new model introduced in England, before considering the impact of the pandemic on transplantation services. We put forward three ethical reasons why, given the unprecedented circumstances, the change should have been postponed. We argue that (1) COVID-19 dominating headlines will prevent widespread awareness of the change, thereby undermining the autonomy of those who do not wish to be donors; (2) a lack of transplant activity during the pandemic will make the impact of the change difficult to measure; and (3) trust in the new system may be damaged given controversial decisions regarding Do Not Attempt Cardiopulmonary Resuscitation orders and the allocation of scarce intensive care resources. These reasons combined make for a shaky start at best and present a risk of the new system failing to achieve its desired and essential effect of increasing the number of voluntary organ donors.

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Introduction

A model of deemed consent for organ donation¹ (commonly known as ‘opt-out’) came into force in England on 20 May 2020 under the Organ Donation (Deemed Consent) Act 2019 (DCA 2019).² In adopting deemed consent, England has followed the earlier example of Wales, where the Human Transplantation (Wales) Act 2013 introduced a similar consent model. As is usually the intention when a country introduces deemed consent, the purpose of the DCA 2019 is to increase the number of organ donations and, in turn, the number of organ transplants taking place each year. However, the circumstances in which the DCA 2019 came into force bring into question its ability to achieve its desired effect.

The COVID-19 pandemic has ushered in unprecedented circumstances not only in England but throughout the world. It was extremely unfortunate that the already planned introduction of deemed consent should fall within such a difficult period. With the media understandably prioritising coverage of pandemic developments, the public awareness campaign planned to accompany the introduction of deemed consent has thus far been overshadowed and will likely continue to be indefinitely. The result of this is that we now find ourselves in a situation whereby a significant proportion of the population may be unaware of the new system and the fact that they are now potential organ donors. In the absence of sufficient public awareness, the autonomy of such individuals may be undermined, as being unaware of the new system prevents them from exercising their right to opt out. Beyond the rights of individual potential donors, the new deemed consent system is unlikely to have a significant immediate impact on transplant numbers because the majority of organ donation and transplant activity in England was suspended at the height of the first wave of COVID-19 and is only gradually returning to normal levels.³

In this article, we first outline the details of the new model introduced in England, before considering the impact of the COVID-19 pandemic on transplantation services. We put forward three ethical reasons why, given the unprecedented circumstances, the change should have been postponed. We argue that (1) COVID-19 dominating headlines will prevent widespread awareness of the change, thereby undermining the autonomy of those who do not wish to be donors; (2) a lack of transplant activity during the pandemic will make the impact of the change difficult to measure; and (3) trust in the new system may be damaged given controversial decisions regarding Do Not Attempt

1. The term ‘donor’ may not be appropriate where consent is not explicit. However, we proceed with the term in recognition of its prevalence.

2. Section 3(6)(6B) Human Tissue Act 2004 (HTA 2004), as amended by section 1(4) DCA 2019.

3. With the possibility of a second wave, transplant activity may again be suspended.

Cardiopulmonary Resuscitation (DNACPR) orders and the allocation of scarce intensive care resources. These reasons combined make for a shaky start at best and present a risk of the new system failing to achieve its desired and essential effect of increasing the number of voluntary organ donors.

Organ Donation (Deemed Consent) Act 2019

The DCA 2019 (also known as ‘Max and Keira’s Law’⁴) received Royal Assent on 15 March 2019 and came into force in England⁵ on 20 May 2020. It acts to amend the provisions of the Human Tissue Act 2004, under which the use of an individual’s organs for transplantation required the expressed consent of either the donor themselves, a representative nominated by the donor prior to their death, or a person who stood in a qualifying relationship,⁶ in that order of succession.⁷ Under the DCA 2019, in the absence of a formally recorded objection, any person aged 18 or over who is not in one of the excluded groups⁸ is deemed to have consented to donation ‘unless a person who stood in a qualifying relationship to the person concerned immediately before death provides information that would lead a reasonable person to conclude that the person concerned would not have consented’.⁹ The question of the reasonable person’s conclusion is a matter for clinical discretion, essentially requiring the person in a qualifying relationship to convince the relevant member(s) of the healthcare team that the deceased would not have wanted to be a donor.

In moving to a system of deemed consent, England has followed the earlier example of Wales where such a system has operated since 2015. The success of the Welsh system has been questioned following data released one year after the law came into effect, with the recorded increase in donation being safely within the pattern of annual fluctuation.¹⁰

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4. This is an acknowledgement of the two children widely considered to have inspired the move to deemed consent. The donation of Keira’s heart saved the life of Max. See NHS Blood and Transplant, ‘Keira’s story – Max and Keira’s Law’. Available at: <https://www.organdonation.nhs.uk/helping-you-to-decide/real-life-stories/families-who-donated-their-loved-ones-organs-and-or-tissue/keiras-story-max-and-keiras-law/> (accessed 21 July 2020).
 5. The DCA 2019 extends to both Wales and Northern Ireland, but amendments therein to the HTA 2004 are such that deemed consent for transplantation only applies in England. See section 3(6)(6A) HTA 2004, as amended by section 1(4) DCA 2019. The DCA 2019 does not affect Scotland; in Scotland, the Human Tissue (Scotland) Act 2006, as amended by the Human Tissue (Authorisation) (Scotland) Act 2019, governs this area of law.
 6. Qualifying relationships are ranked from ‘spouse, civil partner or partner’ to ‘friend of longstanding’. See section 27(4) HTA 2004.
 7. Section 3 HTA 2004 (as enacted).
 8. A person is excluded if they were not ordinarily resident in England for at least 12 months immediately before their death or if they had lacked capacity to understand the effect of the DCA 2019 for a significant period before their death. See sections 3(9) and 3(10) HTA 2004, as amended by section 1(5) DCA 2019.
 9. Section 3(6)(6B) HTA 2004, as amended by section 1(4) DCA 2019.
 10. J.A. Parsons, ‘Welsh 2013 Deemed Consent Legislation Falls Short of Expectations’, *Health Policy* 122 (2018), pp. 941–944.

It is, then, right to question the impact that can be expected in England. Nonetheless, the concerns we discuss here relate to the appropriateness of the change in policy specifically during the pandemic regardless of whether deemed consent has the longer term potential to reduce the shortfall of organs for transplantation. Despite the concerns we will discuss, the Government appeared to show no hesitation ahead of the switch to deemed consent. Interestingly, this contrasts with Scotland where the decision was quickly made to delay the coming into force of the Human Tissue (Authorisation) (Scotland) Act 2019 – which makes similar provisions for deemed consent in Scotland – until March 2021 due to the pandemic and resulting concern that in the circumstances of the pandemic it may not be possible to implement it successfully and deliver on its stated aims.¹¹

Introducing opt-out during a pandemic

Awareness and autonomy

The requirement of consent within medicine is grounded in respect for autonomy, and this is similarly true of consent for organ donation. Consent can potentially be obtained in several ways. In opt-in systems, people indicate their willingness to donate by joining an organ donor register. In the absence of such action, family members may be asked to decide whether, given what they know about their relative, the deceased would have wanted to become a donor. In either scenario, the aim is to reflect the known wishes or ‘reconstructed’ wishes, and therefore respect the autonomy of, the potential donor. This same aim also arises in deemed consent systems. For consent to be validly ‘deemed’, the autonomous wishes of donors and non-donors must be respected. For deemed consent systems to operate effectively and ethically, staff facilitating organ donation need to be confident that a person’s lack of recorded objection to organ donation does actually mean that they would have wanted to become a donor.¹² The ability, within soft deemed consent systems,¹³ of those in qualifying relationships to the potential donor to demonstrate objection goes some way to protecting that patient’s autonomy, but this is limited

11. Organ Donation Scotland, ‘Human Tissue (Authorisation) (Scotland) Act 2019 – Update’. Available at: <https://www.organdonationscotland.org/news-events/human-tissue-authorisation-scotland-act-2019-%E2%80%93-update> (accessed 22 June 2020). Interestingly, a duty is placed on Scottish Ministers to promote awareness. See sections 1(d) and 1(e) Human Tissue (Scotland) Act 2006, as amended by section 2(1) Human Tissue (Authorisation) (Scotland) Act 2019. This may be a contributing factor in the decision to postpone the introduction of deemed consent in Scotland.
12. Human Tissue Authority, ‘Code of Practice F: Donation of Solid Organs and Tissue for Transplantation. Part Two: Deceased Organ and Tissue Donation’. Available at: https://www.hta.gov.uk/sites/default/files/HTA%20Code%20of%20Practice%20F%20Part%20Two%20-%20Deceased%20Organ%20and%20Tissue%20Donation_0.pdf (accessed 23 June 2020).
13. The distinction between so-called ‘soft’ and ‘hard’ deemed consent systems is based on the role of those in qualifying relationships to the deceased. Under a ‘soft’ system, which the DCA 2019 introduces, those in qualifying relationships can voice what they perceive to be

by the fact family members do not always know the wishes of the deceased.¹⁴ Indeed, this is why the public awareness campaigns around organ donation have, in recent years, encouraged discussion of our preferences for or against organ donation with those close to us.¹⁵

Many accounts of autonomy require that a person be sufficiently informed to be regarded as autonomous with respect to a particular choice. Beauchamp and Childress, for example, suggest that ‘a substantial degree of understanding’ is one of three criteria of autonomous action.¹⁶ Informational requirements for organ donation to proceed are generally low (for example, someone can register to become an organ donor without having to demonstrate an understanding of the differences between donation after circulatory death and donation after brainstem death), so there is debate to be had about how informed choices about organ donation should be.¹⁷ However, it is reasonable to assert that for a lack of objection to be deemed to reflect a choice about organ donation, a person must at least be aware that this is the case. Saunders has applied this idea specifically to deemed consent systems of organ donation and argues that such a model constitutes consent provided that (1) the change of system has been clearly communicated to citizens so that inaction can feasibly be interpreted as consent and (2) the process for opting out is not unreasonably costly.¹⁸ Sunstein argues that defaults such as deemed consent may in fact enhance our autonomy by not requiring us to waste our ‘limited bandwidth’,¹⁹ which is part of the reason for England’s move to deemed consent as detailed in the DCA 2019 explanatory notes: ‘around 80% of people [say] that they support organ donation “in principle,” and would be willing to donate their organs and tissue after they have died’.²⁰ Although Saunders’ criteria are not without some objections,²¹ it seems fundamental that any donation system that claims to facilitate and

the views and preferences of the deceased. In a ‘hard’ system, however, they are afforded little to no input.

14. F. Ghorbani, H.R. Knoddami-Vishteh, O. Ghobadi, et al., ‘Causes of Family Refusal for Organ Donation’, *Transplant Proceedings* 43 (2011), pp. 405–406.
15. NHS Blood and Transplant, ‘Why Share Your Decision?’. Available at: <https://www.organdonation.nhs.uk/tell-your-family-and-friends/why-share-your-decision/> (accessed 23 June 2020).
16. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press, 2001).
17. See S-J.R. Brown, ‘Organ Donor Registration in the UK: The Need for Informed Consent for Ante-mortem Interventions to Facilitate Organ Donation’, *Medical Law International* 19 (2019), pp. 113–135.
18. B. Saunders, ‘Opt-out Organ Donation Without Presumptions’, *Journal of Medical Ethics* 38 (2012), pp. 69–71.
19. C.R. Sunstein, ‘Autonomy by Default’, *American Journal of Bioethics* 16 (2016), pp. 1–2.
20. Explanatory Notes to the DCA 2019, para 5. This explanatory note provides no context or source of the 80% figure.
21. D. MacKay, ‘Opt-out and Consent’, *Journal of Medical Ethics* 41 (2015), pp. 832–835.

promote personal choice over organ donation²² should give people sufficient information to make and record their choices.²³

Requiring individuals to actively register their objection entails a lesser respect for autonomy than the reverse.²⁴ Citizen inaction resulting in state action, then, requires a higher level of justification if it is not to go against the autonomy of those citizens whom oppose the action in question. Therefore, the ‘understanding’ condition outlined by Saunders is essential. Understanding constitutes that higher level of justification, as citizens recognising the need to register any objection create a situation in which one can justifiably deem consent in the absence of such objection. For a system of deemed consent to constitute respect for autonomy, then, sufficient efforts must be made to ensure widespread understanding and awareness of the change to the system.

The importance of awareness regarding the change to deemed consent is even tacitly acknowledged in the DCA 2019 itself, whereby those who lack capacity to understand the impact of the Act are excluded from its reach.²⁵ Further, the Government’s response to the public consultation on deemed consent in 2018 stated the desire to ‘raise awareness of these important issues and support the public to make informed decisions’ and noted the intended launch of a communication campaign in 2019.²⁶ While the campaign has begun, the large increase in media coverage anticipated in the weeks preceding the change was ultimately muted.

Unsurprisingly, headlines are currently populated almost entirely by policy and data concerning COVID-19. For other significant news to gain any exposure is difficult, as even where they are reported they are not of great concern to the general public at a time when they are more concerned about the availability of personal protective equipment and the development of a vaccine.²⁷ Testament to this is the introduction of telemedicine in the provision of early medical abortion which took place in England, Scotland and

22. NHS Blood and Transplant, ‘From 20 May 2020 the Law Around Organ Donation in England Is Changing’. Available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/18291/organ-donation-law-in-england-factsheet-updated-010520.pdf> (accessed 23 June 2020).

23. D. Shaw, ‘Presumed Evidence in Deemed Consent to Organ Donation’, *Journal of the Intensive Care Society* 19 (2018), pp. 2–3.

24. E.J. Gordon, ‘International Perspective on Organ Donation’, in D.N. Weisstub and G.D. Pintos, eds., *Autonomy and Human Rights in Health Care: An International Perspective* (Dordrecht: Springer, 2008), pp. 235–255.

25. Section 3(9)(b) HTA 2004, as amended by section 1(5) DCA 2019.

26. Department of Health & Social Care, ‘The New Approach to Organ and Tissue Donation in England: Government Response to Public Consultation’. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/731913/govt-response-organ-donation-consent.pdf (accessed 23 June 2020).

27. One notable exception is the global protests in relation to the Black Lives Matter movements. However, this was always more likely to garner media coverage as it was a global event, whereas the move to deemed consent is a national matter.

Wales in March 2020.²⁸ That such a significant story should gain such little traction is surprising, especially given the initial mistake of the Department of Health and Social Care in England which resulted in two consecutive U-turns on this policy.²⁹ With a policy as controversial as telemedical abortion failing to make headlines, it seems unlikely that the introduction of deemed consent will achieve the level of public awareness that has been promised by the Government and is ethically required.

There is also a concern given increasing death rates amidst the pandemic. Current guidance excludes from donor consideration those who have had a confirmed positive test for COVID-19 and have not recovered³⁰ and those who meet the Government's possible COVID-19 definition.³¹ However, the potential donor pool will be populated by those who have died from more severe conditions as a result of late presentation; there have been reports from clinicians that patients have been reluctant to attend hospitals, resulting in them later presenting in a far worse condition and therefore being more likely to die.³² These patients may become donors under the new system where transplant activities are continuing, though they may be unaware of the new policy. With less family involvement in care due to visiting restrictions, it is less likely that those who would have objected to donation will have that view voiced by someone in a qualifying relationship.

Assuming the accuracy of the DCA 2019's explanatory note, which documents that 80% of people support organ donation, this still leaves 20% who might object to donation being deemed to consent. In the absence of widespread awareness and appropriate safeguards to allow them to express their objection, this is a clear violation of autonomy.³³ Such safeguards come in the form of a register for objections and 'intensive, sustained educational efforts to inform individuals and families of their right to opt out'.³⁴ As such, the absence of the intended public awareness campaigns fails to sufficiently respect

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28. E.C. Romanis, J.A. Parsons and N. Hodson, 'COVID-19 and Reproductive Justice in Great Britain and the United States: Ensuring Access to Abortion Care during a Global Pandemic', *Journal of Law and the Biosciences* 7(1) (2020). DOI: 10.1093/jlb/ljaa027.
 29. E.C. Romanis and J. Parsons, 'Access to Remote Abortion Services Should Not Be Temporary', *BMJ Opinion*. Available at: <https://blogs.bmj.com/bmj/2020/04/02/elizabeth-chloe-romanis-jordan-parsons-access-remote-abortion-services-should-not-temporary/> (accessed 23 June 2020).
 30. A patient is deemed recovered 28 days after a full clinical recovery. Even if a patient is recovered, the clinical team must discuss this before considering the patient as an organ donor.
 31. NHS Blood and Transplant, *COVID-19 Assessment and Screening Flowcharts* (2020).
 32. BMA Media Team, 'BMA Doctors Tell of Patients Being Neglected and Their Condition Worsening due to Covid'. Available at: <https://www.bma.org.uk/bma-media-centre/bma-doctors-tell-of-patients-being-neglected-and-their-condition-worsening-as-bma-research-indicates-millions-of-patients-in-england-have-had-surgery-and-appointments-cancelled-due-to-covid/> (accessed 21 July 2020).
 33. Council on Ethical and Judicial Affairs, American Medical Association, 'Strategies for Cadaveric Organ Procurement: Mandated Choice and Presumed Consent', *Journal of the American Medical Association* 272 (1994), pp. 809–812.
 34. Op. cit.

autonomy in the move to deemed consent. Even in the first 24 hours of deemed consent in England, claims of a lack of notice ahead of the change have circulated on social media, suggesting attempts at widespread awareness have thus far been unsuccessful.

This issue is not just of theoretical ethical concern. Any instance of organ donation going ahead contrary to a person's wishes (whether recorded or unrecorded) should be regarded as forced organ 'donation'. Deemed consent arguably increases the chances of this happening in comparison with express consent, and a deemed consent system that has not been effectively communicated to *all* potential organ donors increases the chances of it happening further still. This will be unintentional in individual cases, but on a political level it should be acknowledged for what it is: COVID-19 was obviously going to dominate headlines and detract from the public awareness campaign in relation to deemed consent, but the Government clearly decided that unknown countervailing considerations outweigh the importance of ensuring that organ donation is an informed choice. This alone is grounds to temporarily reverse the change until after the pandemic so that a public awareness campaign can be effectively executed.

Reduced transplant activity

Realistically, governments only get one attempt at introducing deemed consent. Given that a lot of the increase in donation rates associated with deemed consent is related to the publicity, 'big splash', and public conversation about organ donation that a move to the new system generates, it is important to make the most of this unique opportunity. While the sudden spike in transplantation activity that some hope for is unlikely, at least a modest increase might be considered necessary to justify the policy change and garner public support moving forward. However, the specific circumstances of this pandemic give us good reasons to think that the impact of opt-out will be severely compromised.

First, transplant activity has been significantly reduced during the pandemic. In preparation for an anticipated surge of patients infected with COVID-19, hospitals throughout the country underwent varying levels of restructuring with staff redeployed to ensure sufficient staffing levels in intensive care units (ICUs). In addition, there have been mixed reports of the impact of COVID-19 infection on transplant recipients,³⁵ justifying caution in resuming operations. This combination of surge protection and infection risks has led to many transplant centres either temporarily suspending operations or reducing them. As of 22 June 2020, the majority of UK transplants are closed for pancreas and islets transplants³⁶ and kidney transplants and suspended at 10 of 24 centres.³⁷ Most

35. J. Huang, H. Lin, Y. Wu, et al., 'COVID-19 in Posttransplant Patients – Report of 2 Cases', *American Journal of Transplantation* 20(7) (2020), pp. 1879–1881; L. Zhu, X. Xu, K. Ma, et al., 'Successful Recovery of COVID-19 Pneumonia in a Renal Transplant Recipient with Long-term Immunosuppression', *American Journal of Transplantation* 20(7) (2020), pp. 1859–1863.

36. As of 22 June 2020, two of eight centres offering pancreas transplants are open, and two of seven for islets transplants.

37. NHS Blood and Transplant, 'Transplant Centre Closures and Restrictions: Current UK Transplant Centre Closures or Restrictions as a Result of COVID-19'. Available at:

centres have remained open for life-saving heart, lung, and liver transplants, and all of those that closed temporarily have reopened.³⁸ However, where transplants are going ahead, clinicians are advised to consider cases on an individual basis and decisions may be taken on consideration of urgency and local resources.³⁹ As such, even where centres are open they are not operating at their usual capacity as low risk patients are having operations indefinitely postponed. Similar actions were taken by transplant programmes globally, such as in Canada where the advice from the Canadian Blood Services and Canadian Society of Transplantation was to consider suspending deceased kidney transplants and, for all other transplants, account for hospital capacity.⁴⁰

Second, along with the reduction in the number of transplants, there has been a large drop in the number of donations amidst the pandemic. Comparing the period of 1 April 2020 to the end of June 2020 with the same period in 2019 shows a significant drop in deceased donors from 365 to 195.⁴¹ Whether this reduction is a consequence of reduced demand, or difficult decisions about priorities for resources towards the end of life that would be required for organ donation to proceed, it is clear that organ donation and transplantation have become much rarer during the pandemic. One presumes, however, that the reduced number of organ donors is not due only to a reduced number of *potential* organ donors. Rather, organ donation is, alongside transplantation, a lower clinical priority at present than dealing with the crisis COVID-19 has caused. Given the potential risks to immunosuppressed recipients at this time, this decision seems entirely justifiable, but there are knock-on consequences in terms of its impact upon deemed consent.

Given the reduced donation and transplantation activity thus far in the pandemic and the reasons for this, the change to deemed consent is not likely to have any measurable impact on the very point it is intended to. As such, despite the best efforts of those working in transplantation and organ donation, we should expect the introduction of deemed consent to be somewhat underwhelming. When assessments are made a few months after the policy change to consider its initial impact, the data are likely to make for disheartening reading; it is unlikely we will see record rates of organ donation and a sudden reduction in transplant waiting times. Instead, we will probably see lower rates of donation than we ordinarily would, and, in the short term, an increase in transplant

<https://www.odt.nhs.uk/deceased-donation/covid-19-advice-for-clinicians/transplant-centre-closures-and-restrictions/> (accessed 22 June 2020).

38. Although liver transplants are, at the time of writing, only proceeding for urgent cases, with centres closed to elective patients.
39. NHS Blood and Transplant, 'COVID-19 Bulletin, 17th March 2020'. Available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/18021/covid-19-bulletin-1-17-03-2020.pdf> (accessed 23 June 2020).
40. Canadian Blood Services and Canadian Society of Transplantation, 'Consensus Guidance for Organ Donation and Transplantation Services During COVID-19 Pandemic'. Available at: https://profedu.blood.ca/sites/ansi/files/20200504_covid-19_consensus_guidance_final.pdf (accessed 23 June 2020).
41. NHS Blood and Transplant, 'Donation and Transplantation Monthly Activity Report. June 2020 - data as at 10 July 2020'. Available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/19022/monthly-stats.pdf> (accessed 07 August 2020).

waiting times as patients who have been suspended from waiting lists due to COVID-19-related risks will again become eligible.⁴² Not only will there be little positive news to report, but the data are unlikely to be useful in measuring the impact of deemed consent due to myriad other factors at play. The big ‘public conversation’ around organ donation has not been had, but even if it had happened, the reality of donation/transplantation rates following the change – that is, the negligible at best impact – would become a point of confusion and potential frustration among the general public.

Furthermore, given the likely reduced impact of implementing deemed consent during the pandemic, it seems probable that the impact of postponing the policy change would have been minimal. If we are not already making full use of all the potential organ donors that we do have – which, for the reasons we have highlighted, is a reasonable response to the unprecedented circumstances – then it becomes difficult to defend the position that there is an urgency for implementing a policy designed to get more of them.

Public trust during crises

A final issue that speaks against the decision to implement deemed consent during the pandemic is that of public trust. Although it has been argued that withdrawing consent to donation as a consequence of a loss of trust in the transplantation system is not a morally appropriate response,⁴³ it has been found that, in reality, concerns about unethical recovery of organs are a significant barrier to donation.⁴⁴ Voluntary organ donation systems rely on the goodwill of the public to thrive, and relatively minor events can have dramatic consequences in terms of donation rates. Indeed, this line of reasoning is often used to justify the controversial ‘family veto’ in organ donation. Unfortunately, there are aspects of the pandemic in the United Kingdom that may raise some concerns in relation to trust, with potential knock-on consequences for organ donation.

Early fears about the impact of COVID-19, and indeed much of the early academic ethics response,⁴⁵ focused heavily on scarce ICU beds, the idea that these would have to be rationed, and that patients with certain pre-existing conditions or characteristics would not receive particular types of treatment. Fortunately, in the UK at least, additional capacity was created, and existing capacity managed sufficiently well, to ensure that there remained an excess of ICU beds. Although a surplus of beds transpired, resource scarcity has been a prominent feature throughout the pandemic to date, emphasised by limited availability of personal protective equipment available to National

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42. V. Sharma, A. Shaw, M. Lowe, A. Summers, D. van Dellen and T. Augustine, ‘The Impact of the COVID-19 Pandemic on Renal Transplantation in the UK’, *Clinical Medicine* (2020). DOI: 10.7861/clinmed.2020-0183.
 43. A. Dufner and J. Harris, ‘Trust and Altruism – Organ Distribution Scandals: Do They Provide Good Reasons to Refuse Posthumous Donation?’, *Journal of Medicine and Philosophy* 40 (2015), pp. 328–341.
 44. J.D. Newton, ‘How Does the General Public View Posthumous Organ Donation? A Meta-synthesis of the Qualitative Literature’, *BMC Public Health* 11 (2011).
 45. E.J. Emanuel, G. Persad, R. Upshur, et al., ‘Fair Allocation of Scarce Medical Resources in the Time of Covid-19’, *New England Journal of Medicine* 382 (2020), pp. 2049–2055.

Health Service (NHS) and care workers. The public is more aware than ever of the finite nature of scarce medical resources. Around the time that strained ICU resources and rationing were dominating the news, an incident occurred where patients with certain conditions registered at a Welsh general practice surgery were written to and asked to complete a DNACPR form.⁴⁶ Although careful end of life planning for such patients may have been entirely appropriate, the unexpected letter encouraging completion of such a form caused distress to some of the patients concerned. These aspects of COVID-19 may quite reasonably give some people the perception that those with certain conditions or characteristics may not have access to the same ‘life saving’⁴⁷ resources as others.

These issues occur against a backdrop where there exists a lot of false information about organ donation. For example, a message disseminated on social media has perpetuated the myth that there is a deadline to opt out of organ donation. NHS Blood and Transplant have set up a web page correcting some common misconceptions.⁴⁸ The first misconception that they address is the notion that efforts to save life will be constrained by the fact that the patient has been identified as a potential donor. A meta-synthesis of qualitative literature in relation to deceased organ donation found that mistrust of the medical profession was a common cause of anxiety.⁴⁹ NHS Blood and Transplant have another web page combatting so-called ‘fake news’ on social media,⁵⁰ so there are clearly concerns about the possibility of factually inaccurate public perceptions impacting upon the new deemed consent system. We are concerned that a public worried about access to appropriate care and treatment at the end of life, coupled with misinformation on social media, could continue to feed the myth that treatment will somehow be compromised for those registered as or deemed an organ donor, potentially causing some people to register an objection.

Conclusion

In principle, we do not oppose moving to deemed consent organ donation systems, assuming that such moves are conducted in the right way and in the right circumstances. Our arguments in this article are not intended as a criticism of those working in organ donation and transplantation, as we appreciate that COVID-19 has presented them with

46. BBC News, ‘Coronavirus: GP Surgery Apology Over “Do Not Resuscitate” Form’. Available at: <https://www.bbc.co.uk/news/uk-wales-52117814> (accessed 23 June 2020).

47. We are not criticising the appropriateness of these decisions – we fully appreciate that admitting patients with no chance of meaningful recovery to ICU is unlikely to be in their best interests.

48. NHS Blood and Transplant, ‘Get the Facts About Organ Donation’. Available at: <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/get-the-facts/> (accessed 23 June 2020).

49. Newton, ‘How Does the General Public View Posthumous Organ Donation?’.

50. NHS Blood and Transplant, ‘Fake News Alert! There Is no Deadline to Opt Out’. Available at: <https://www.organdonation.nhs.uk/get-involved/news/fake-news/> (accessed 23 June 2020).

numerous challenges that they have worked relentlessly to overcome. Instead, we question the decision at a governmental level to push ahead with the implementation of deemed consent in such extreme circumstances, especially when another government – that of Scotland – has recognised the problematic state of affairs and delayed the same policy change. In England, we are now regrettably in a position where the possibility of postponement has passed, so we must move to making the most of a compromised situation. Most importantly, this must start with an ongoing commitment to effectively communicate the transition to a deemed consent system to *everyone* to whom it applies. The impact of COVID-19 should be taken into account when doing this: adverts on bus stops or in hospital lifts, or posters in general practices are unlikely to have the same reach given that people are still being encouraged to stay at home if possible. Given that every household in the UK was written to in relation to social distancing measures, we wonder why similar efforts have not been made to provide information about deemed consent. This is not just important in terms of ensuring that deemed consent has as big a positive impact upon donation rates as it can but also for ensuring that the new system meets the most fundamental of ethical requirements: that people are sufficiently informed to know that they need to opt out if they do now want their organs donated.


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