



# Premature presumptions about presumed consent: why Parsons' comparison is mistaken

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In his recent paper<sup>1</sup>, Parsons argues that Scotland's approach to implement deemed consent for organ donation is preferable to England's for three reasons:

1. Scotland's stronger approach to deemed consent helps overcome the family veto.
2. Scottish legislation imposes a duty on Government ministers to promote transplantation, and this is preferable to the English legislation which does not.
3. Scotland postponed deemed consent due to COVID-19, whereas England did not.

In my view, each of these assertions is incorrect and in this paper I will explain why.

## I. FAMILY VETO

Parsons' first claim is that by 'slightly reducing' the influence of people in qualifying relationships, the Scottish approach is better equipped to overcome the family veto. So how does the Scottish system slightly reduce the influence of those in qualifying relationships? When considering whether donation should go ahead, a person's organ donor register status (whether they have opted in/out) is used as a strong guide. As both England and Scotland use 'soft opt-out', a patient's recorded wishes will be checked with those in a qualifying relationship (broadly speaking, family members, or long-standing friends). The English and Scottish systems both allow people in qualifying

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1 Jordan A. Parsons, *Deemed consent for organ donation: a comparison of the English and Scottish approaches*, 8(1) J. LAW BIOSCI., lsab003 (2021). <https://doi.org/10.1093/jlb/lsab003>

relationships to provide information to suggest that the potential donor's most recent wishes differ from their organ donor register status, presumably to enhance the likelihood of following a patient's most recent donation wishes. Parsons suggests the two systems differ in their handling of situations where nobody in a qualifying relationship is contactable. Although it may be lawful to proceed, The English system's Code of Practice states that donation should not proceed if it is not possible to confirm a person's wishes with someone in a qualifying relationship. No Code of Practice is yet publicly available for the Scottish system, so Parsons is not comparing like-with-like. He is instead comparing legislation with a Code of Practice. If English and Scottish *legislation* are compared, one would conclude that these situations are resolved similarly: they both permit consent to be deemed when potential donors have not opted out. In time, a Scottish Code of Practice or equivalent may be published that supports Parsons' argument, but currently this is conjecture.

This aside, Parsons' argument remains unconvincing for other reasons. He suggests that the Scottish system is preferable because it actually deems consent and this helps to overcome the family veto. The family veto can be interpreted variously, but a particularly morally problematic occurrence is when someone's known donation wishes are overruled on the basis of their family's wishes. It is reasonable to think that it may be desirable to minimize this type of veto. However one understands the family veto, in order to reasonably consider it a veto the family must be involved in the decision. Parsons' assertion that the Scottish system helps overcome the family veto is therefore mistaken: the purported advantage of the Scottish system only occurs when family are uncontactable, so applies when it cannot be an instance of a family veto. Parsons may respond suggesting this is 'family veto by default' or 'passive family veto', but this is unconvincing. If uncontactable family members support donation the veto framing is incorrect, as the decision does not reflect their wishes. And sometimes there will exist no person in a qualifying relationship: it is incoherent to claim that this is a veto, as someone who does not exist cannot veto something. The two systems' responses to these scenarios are entirely unrelated to the family veto, so Parsons' argument misfires. Parsons describes the Scottish approach as reducing the influence of those in qualifying relationships, but this cannot be correct: those who are uncontactable do not have any influence in either England or Scotland. Their views cannot be obtained to influence the decision.

Parsons may adapt his argument to suggest that the Scottish system is preferable because it deems consent in a broader range of circumstances than the English system, but broader deeming of consent may be undesirable. Indeed, the Human Tissue Authority in England has clearly judged what Parsons considers to be desirable to be undesirable. The cited Code of Practice clarifies that the policy of not proceeding with donation in these circumstances exists not because of the family veto, but because of commitments made during the passage of the Act through Parliament.<sup>2</sup> It could be argued that the Scottish system is preferable because similar commitments were perhaps not made in the Scottish Parliament, but this argument is not attempted by Parsons.

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2 Human Tissue Authority, *Code of Practice Part Two: Deceased organ and tissue donation*, at para 91.

## II. DUTY ON MINISTERS

Parsons' second point is that the Scottish system includes within its legislation a duty on ministers to promote transplantation and raise awareness of deemed consent. The English system of deemed consent has no such requirement. Parsons correctly suggests that public awareness is an essential part of deemed consent being ethical. If people do not wish to donate, they need to know that they must act to ensure that their, presumably autonomous, wishes are respected. Parsons appears to assume it advantageous for ministers to have responsibility for ensuring that awareness-raising occurs. It is unclear, however, that incorporating this into legislation is necessary or even beneficial.

The key objective is presumably that awareness-raising does occur, and we can see that it *is* occurring in England. The initial impact assessment of implementing deemed consent planned for the costs of raising awareness, and more recently an NHS Blood and Transplant (NHSBT) report<sup>3</sup> suggests £11.5 million has been committed, with the option of extending the campaign if necessary. There clearly is a commitment to ensuring that awareness is raised, and the financial backing builds this into NHSBT's future plans. Promoting organ donation is part of NHSBT's general responsibilities and raising awareness of deemed consent falls under this. The NHSBT Directions 2005 state that the Secretary of State directs NHSBT to 'promote, by advertising, marketing and otherwise, the donation of organs and tissues with a view to maintaining an adequate number of organs', and to 'secure the provision of such education and training in any matter related to its functions.'<sup>4</sup> Introduction of deemed consent in Wales added an additional responsibility to 'acquire, record, update and keep information about persons who do not wish to donate organs and tissues for transplantation', and this responsibility now applies in England. Taken as a whole, this suggests that NHSBT have responsibility for promoting donation, informing the public and operating the system of deemed consent, and they have been given specific financial support for this.

Parsons claims there is no formal recognition of the ethical importance of public awareness within the English system but this is plainly incorrect. 'Formality' is open to interpretation, but formal recognition of things can exist outside of legislation. The commitment of financial resources to raise awareness suggests formal recognition of its importance. Alternatively, the awareness targets set by NHSBT and the Government may be considered to constitute formal recognition. An NHSBT report suggests that their target awareness level of the law change in 2019/20 was 60%.<sup>5</sup> In the same document, NHSBT highlight a key focus on raising awareness amongst BAME groups. The Government also set a target of achieving awareness amongst 80% of the English population. NHSBT state that they cannot be held accountable for delivery of the 80% target due to funding constraints that place a high reliance on cross government

3 NHS Blood and Transplant, *Board Meeting March 2019—Organ Donation Consent Legislation—Progress Report*, <https://nhsbtbde.blob.core.windows.net/umbraco-assets-corp/16165/organ-donation-consent-legislation-progress-report-march-2019.pdf> (accessed Mar. 5 2021).

4 National Health Service, *NHS Blood and Transplant Directions*, <https://nhsbtbde.blob.core.windows.net/umbraco-assets-corp/22129/nhsbt-directions-2005.pdf> (accessed Mar. 5 2021).

5 NHS Blood and Transplant, *NHSBT Board Meeting May 2020—Organ Donation Consent Legislation and Public Awareness Campaign—Update* <https://nhsbtbde.blob.core.windows.net/umbraco-assets-corp/18858/11-organ-donation-consent-legislation-and-public-awareness-campaign-update-may-2020.pdf> (accessed Mar.

partnerships, but this is not due to a lack of formal recognition.<sup>6</sup> Although not written into English legislation, the importance of raising awareness is recognized by the existence of these targets, and resources and strategies have been put in place to meet them.

The important outcome is that awareness-raising occurs and that the public are suitably informed. Parsons suggests that Scotland's approach is preferable to England's, because of recognition of the importance of public awareness to the ethical defensibility of deemed consent. He appears to assume that Scotland's form of 'formal recognition' will produce increased public awareness, but cites no evidence for this. Awareness-raising is built into the English approach, but in different ways. It is simply too early to tell whether the Scottish approach is preferable in this regard, so Parsons' claim is surely premature.

### III. COVID-19 RESPONSE

Parsons' final comparison is the impact of COVID-19 on deemed consent implementation. He suggests that the English response was to have no response, whereas Scotland delayed its planned introduction of deemed consent. His claims that implementing deemed consent during the COVID-19 peak was unwise because the transplantation landscape was unstable, and that it was also a bad time to raise awareness, seem reasonable, but available evidence now suggests it is wrong to suggest that England did not change its approach.

There was a carefully considered response to the challenges posed by COVID-19 in England.<sup>7</sup> Meeting minutes reveal a phased approach to implementing changes, whereby training and awareness-raising would be undertaken when teams were ready (in light of COVID-19 pressures). All engagement roadshows were cancelled, for example, and Parsons would be right to regard this as a threat to the ethical basis of the system. The same minutes reveal other important information though. For example, that 'given the challenges arising . . . it is unlikely that transplants will proceed under deemed consent',<sup>8</sup> and that '[w]here there isn't a recorded or known decision, we will support families to make a decision on behalf of the patient'.<sup>9</sup>

Parsons draws a correct link between lack of awareness of deemed consent and potential violations of autonomy, suggesting that safeguards are necessary. It is clear though that appropriate safeguards to autonomy *were* in place in England: deeming consent was optional, and donation decisions were explored with families to allow a decision to be made on the patient's behalf. Parsons claims that Scotland's choice to delay introducing deemed consent acknowledged the importance of respecting the autonomy of potential donors, and that this makes the Scottish system preferable to the English. Parsons' preference is, however, based on empirically false claims. Although a different approach was taken in England, the end was the same: to respect autonomy. The English response to COVID-19 and deemed consent acknowledges the impor-

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6 NHS Blood and Transplant, *supra* note 3, at 3.

7 NHS Blood and Transplant, *supra* note 5, at 1.

8 NHS Blood and Transplant, *supra* note 5, at 3.

9 NHS Blood and Transplant, *supra* note 5, at 4.

tance of donor autonomy, and consent will not have been deemed where considered inappropriate. Parsons' preference for the Scottish approach is again questionable.

#### IV. CONCLUSION

I have argued that Parsons' arguments for favoring the Scottish implementation are flawed. The purported difference between the two systems in relation to uncontactable people is unconfirmed and is unrelated to the family veto. It is incorrect to assert that the lack of legal duty on Ministers in the English system means there is no formal recognition of the importance of public awareness and donor autonomy. Finally, the suggestion that England's response to the COVID-19 challenges was to plough on regardless is incorrect. It may yet transpire that the Scottish approach is preferable to that of England. It is, however, simply too early to say.