

Should conditional deceased organ donation be permitted? Identifying legal and ethical considerations

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Abstract

Increasing the availability of suitable organs is essential for life-saving transplant surgery. We highlight the importance of consent to deceased organ donation and discuss whether a 'blanket ban' on attaching conditions to a donation is appropriate by analysing relevant legal, ethical, and clinical considerations. The introduction highlights key issues in this area and defines the different kinds of conditional donations. We focus on conditions that seek to limit 'who' might receive an organ. The article outlines the current approach to conditions attached to the donation of organs. We identify key models of conditional organ donation: (a) no conditions allowed; (b) permit all conditions; and (c) permit some conditions. The third model of permitting some conditions includes permitting conditions except those contrary to equality and non-discrimination law, or permitting conditions as exceptions, or permitting conditions, but only as advisory. We demonstrate that there is room for disagreement about the permissibility of each model and argue that there is potential for reforming the law in this area to achieve the appropriate balance between protecting the personal autonomy of donors with the wider interests of protecting the organ allocation system.

Keywords

Gift of life, organ allocation, deceased organ donation, conditional donation, decision-making process

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Introduction

Although the wealth of literature on consent in medical law continues to grow, the legal and ethical challenges arising from conditions placed on consent to deceased organ donation ('conditional donation') require further attention in light of the increasing emphasis placed on patient autonomy and choice. We argue that law reform in this area would depend on the kinds of values that the healthcare system seeks to protect and we identify five models of conditional donation. Healthcare and legal professionals, patients, and families should engage in a dialogue about options for reform to increase the availability of life-saving organs.

While consent is a fundamental pillar in medical ethics, patient consent often depends on a range of factors which includes clinical, ethical, and personal reasons. The importance of taking into account personal factors when providing a patient with the information they need to give fully informed consent is generally accepted as part of a patient's personal

autonomy.¹ All organs are associated with varying degrees of risk (such as transmission of disease, risk of non-function, rejection, or delayed complications) and the risks associated with declining an offered organ have to be balanced against the risks of death or illness while waiting for another offer. A ‘patient-centred’ approach acknowledges that there may be issues which are significant to an individual even if they are not important to the average person. For example, the risk of very minor loss of muscle control in the non-dominant hand might not concern most people but potentially be devastating to a concert pianist. These person-specific concerns deserve respect, as part of personalised care, for both recipients and donors particularly in the context of transplantation medicine.

The significance attached to autonomy, particularly in the sensitive area of transplantation, raises the question of whether we should allow donors to choose to attach conditions on the use of their organs. Such conditions can be considered as ethically legitimate or illegitimate and lawful or unlawful. But what makes a condition ethically illegitimate? Should the law respect and accommodate donor preferences in attaching conditions to their gift?

The dominant view is that ‘The fundamental principle of all deceased organ donation is that it must be **unconditional**’.² Across jurisdictions, there is an imbalance between the number of organs available for transplant and the need for transplantation.³ Not permitting conditional donation may deter some people from making donations, which then reduces the donor pool, but permitting conditions might weaken the overall support for organ donation.

Organ donation is normally viewed as an altruistic gift⁴ that a person makes freely for the benefit of those in need of an organ transplant. It is a life-saving act. The gift of life metaphor is widely used in the context of donation of organs and other bodily materials such as blood. For example, Richard Titmuss emphasised that (blood) donors thought it was important that they were seen to be making an altruistic gift, rather than a sale or acting for selfish reasons.⁵ The reasons for donating and personal motivation continue to play a role in patient’s decision-making. The UK National Health Service Blood and Transplant (NHSBT), the body responsible, among other roles, for promoting organ donation and maintaining the organ donor register in the United Kingdom, explicitly uses the term ‘celebrate the gift of life’ in its public campaigns and materials to promote organ donation.⁶ However, the relationship between the notion of a gift and the legal

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1. See *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.
 2. British Transplantation Society (BTS), ‘Requested Allocation of a Deceased Donor Organ’, <https://bts.org.uk/wp-content/uploads/2016/09/finalguidanceen.pdf>.
 3. Raymond Vanholder, Beatriz Domínguez-Gil, Mirela Busic, Helena Cortez-Pinto, Jonathan C. Craig, Kitty J. Jager, Beatriz Mahillo, Vianda S. Stel, Maria O. Valentin, Carmine Zoccali, and Gabriel C Oniscu, ‘Organ Donation and Transplantation: A Multi-Stakeholder Call to Action’, *Nature Reviews Nephrology* 17 (2021), pp. 554–568.
 4. Organ ‘donation’ is a gift and, if it is not a gift, then it has not been donated, and has rather, just be taken, transplanted, or used. See ‘Benedict XVI on Organ Donation: A Unique Testimony of Charity’, 7 November, 2008, <https://zenit.org/2008/11/07/benedict-xvi-on-organ-donation/>.
 5. R. M. Titmuss, *The Gift Relationship: From Human Blood to Social Policy* (London: George Allen and Unwin Ltd, 1970). Titmuss was concerned about blood safety.
 6. ‘Celebrate the Gift of Life’, <https://www.blood.co.uk/news-and-campaigns/the-donor/latest-stories/celebrate-the-gift-of-life/>.

requirement of a patient giving consent is complex. Antonia Cronin and James Douglas have argued that ‘it appears, as far as the law is concerned, that “donation” of an organ is not a true gift but merely a consent to the process of organ retrieval and transplantation’.⁷ The patient is not given a say over how their organ is allocated, at least in the case of deceased donations. We discuss how the law and clinicians could respond to conditional donation and identify a broad framework of approaches that could be implemented in practice.

What is conditional donation and why is it important?

Defining conditional donation

In the broadest sense, all donations are conditional in that they operate within numerous constraints, including a legislative framework which places limits on organ donation.⁸ Simon Jenkins and Greg Moorlock define conditional donation as ‘any donation where the donor sets conditions’.⁹ This section clarifies the different kinds of conditions that a donor might want to attach to their donation. A potential donor might limit their consent to organ donation in terms of:

- a. *to whom* they are donating (either as directed donation to a specified individual or to a class of individuals),
- b. *which* organs (where consent covers some but not all donatable organs),
- c. the *use* of organs (donation for implantation and/or research purposes).

It is generally less controversial if an individual wants to limit *which* organs (or tissue) they are willing to donate and research shows that many people are uncomfortable with donating some bodily material such as their corneas.¹⁰ It is more controversial where an individual might want to attach conditions *to whom* the organs are donated. We will focus on this category of conditional donations which are often motivated by personal factors and might be based on benevolent reasons (the donor wants a particular individual or group to benefit from their donation) or malevolent reasons (the donor wants to exclude a particular individual or group because of wrongful discrimination based on race or ethnic origin).

7. A. J Cronin and J. F. Douglas, ‘Directed and Conditional Deceased Donor Organ Donations: Laws and Misconceptions’, *Medical Law Review* 18 (2010), pp. 275–301, 288.

8. See L. Frith and E. Blyth, ‘They Can’t Have my Embryo: The Ethics of Conditional Embryo Donation’, *Bioethics* 27 (2013), pp. 317–324.

9. S. P. Jenkins and Greg Moorlock, ‘Conditional Donation: Is It Justifiable to Have Different Policies for Different Kinds of Tissue?’ *Clinical Ethics* 18 (2023), pp. 375–384.

10. See A. M. Williams and K. W. Muir, ‘Awareness and Attitudes toward Corneal Donation: Challenges and Opportunities’, *The Journal of Clinical Ophthalmology* 12 (2018), pp. 1049–1059.

Living and deceased donation

Normally living organ donation is typically made to a family member or close friend and constitutes a form of directed donation. Living donors are motivated by the need to help a family member or a close friend and must give their explicit consent. Living donation is permitted where the donor is able to lead a healthy life with one of a pair of organs (kidney) or part of an organ (such as a liver or lung), and in the absence of coercion.¹¹ Non-directed living donations (also known as altruistic donations) are permitted in the United Kingdom, but are rare. Pooled donations especially for kidneys is permitted (this occurs where there is incompatibility between the kidney of the donor and recipient so Donor A donates a kidney to Recipient B and Donor B to recipient A). Cronin and Douglas have argued that ‘. . . two parallel donation/allocation regimes have evolved and are in operation with (in essence) an impartial justice rationale governing deceased donation and a partial autonomy-driven rationale underpinning living donation’.¹² Whether deceased donors *should* be afforded a similar degree of autonomy to living donors to direct their donation is discussed below.

Examples of different conditions Legitimate versus Illegitimate conditions

The different kinds of conditions that a person might attach to their consent could fall under two broad categories that include potentially ethically *legitimate* or *illegitimate* conditions. Many people would agree that ethically legitimate conditions include the desire to donate to a family or loved one to save their life. This may be regarded as legitimate where an individual indicates that if their loved one cannot receive the organ, they would still consent to it being donated to others in need. Illegitimate conditions include conditions that are based on criteria, such as race or sex, and which have the effect of excluding certain classes of recipients typically on discriminatory or prejudicial grounds.

Directed donations to individuals versus class conditions

A common view is that conditional donation to a specific person is *sometimes* permissible, whereas conditions that seek to restrict the *class of recipients* are unacceptable. Michael Volk and Peter Ubel argue that conditional donation is generally morally unacceptable, and that directed donation to an individual is acceptable only when the donor and recipient have had a pre-existing relationship.¹³ However, this distinction is worth exploring further.

Directed donation normally refers to a donation to a *specific individual* (the usual case for living donations), whereas conditional donation can include a *wide range of restrictions* attached to the consent of the donor and that might have the effect of excluding *classes* of

11. See Human Tissue Authority, Human Tissue Act 2004, Code F: Donation of Solid Organs and Tissue for Transplantation, Part One: Living Organ Donation (2023).

12. Cronin and Douglas, ‘Directed and Conditional Deceased Donor Organ Donations’, p. 278.

13. M. L. Volk and P. A. Ubel, ‘A Gift of Life: Ethical and Practical Problems with Conditional and Directed Donation’, *Transplantation* 85 (2008), pp. 1542–1544.

recipients. However, it is important to note that there is not necessarily a hard and fast distinction between the two. A donation to ‘my children’ or ‘my blood relatives’ might be permitted as a directed donation to a *specified group of individuals*. A donation to ‘anyone except supporters of the Conservative party’ is clearly a conditional donation because the focus is on excluding people. However, is a donation to ‘any graduate of King’s College London’ a directed donation to a group of individuals or a condition which seeks to exclude non-graduates? It is likely that directed donations are generally seeking to benefit an individual, while other conditions seek to benefit a group of individuals, and in effect exclude others who do not share the conditional characteristic.

There might be specific concerns where the directed donation is to someone not known personally. For example, where a person wishes to donate to an individual who has made a public appeal on social media (maybe owing to their popularity) or where the reason for the condition appears to be arbitrary. Research highlights the use of social media can lead to misinformation and discrimination.¹⁴ The issue here would not necessarily be the use of social media in and of itself, but the potential negative effects of not regulating biases produced by the use of such mechanisms for organ allocation decisions.

That generalisation might suggest that directed donations are likely to be less problematic, but as shown by the examples above, the ethical reasons for maintaining a strict dichotomy between the two (lawful directed living donations and unlawful directed deceased donations) is debatable.

Mandatory or expression of will

Another important distinction that could be drawn is between a condition which is mandatory or simply an expression of a wish or hope that is not intended to be binding. We draw on hypothetical examples to illustrate the ethical and practical issues arising from permitting and not permitting conditional donations. Let us assume that in hypothetical Example 1 ‘Parent A’ dies while their child is on a transplant waiting list. Parent A is declared dead using neurological criteria (‘Brain Stem Dead’), and the child has renal failure and is on the transplant waiting list. Parent B requests that one kidney from Parent A should be allocated to the child, but states that the donation is not conditional on the request being accepted. This is a non-binding condition which might still deserve to be upheld. In hypothetical Example 2, a potential deceased donor’s relative works in a transplant centre with close contact with patients who have received a transplant. The relative might request a condition that their donated organs are *not* used at the transplant centre at which their relative works at as they are concerned that the organ could be allocated to a recipient that the healthcare professional will care for. There might be unintended consequences of refusing a conditional donation with potential consequences including:

14. J. O. O. Ayorinde, K. Saeb-Parsy, and A. Hossain, ‘Opportunities and Challenges in Using Social Media in Organ Donation’, *JAMA Surgery* 155(9) (2020), pp. 797–798.

1. The risk of breach of anonymity of the donor and/or recipient, playing into how the relative and the clinical team interacted with the recipient;
2. The withdrawal of consent to donation and so losing several organs with several potential recipients harmed.

Both examples raise ethical questions about when and whether we ought to permit conditional donations. In order to distinguish between different kinds of cases of conditional donation, it might be beneficial to separate out concerns which relate to the *nature* of the condition (e.g. is it a race-based condition) and concerns which relate to the *practicality* of the condition (e.g. it would be too complex to determine who satisfied the condition). Thus, the nature of the condition requires an ethical evaluation of the condition: is it legitimate or not? The practicality of the condition is concerned with how feasible it is to realise the condition in reality. The former relates to identifying relevant principles to determine permissibility while the latter relates to its implementation.

Ethical issues arising from cases in practice

The example of a controversial case of conditional donation arose in the United Kingdom in 1998, when a donor had an apparent wish to donate their organs ‘only to a white person’ and whose family explicitly supported this request. However, it was deemed inappropriate to accept organs from deceased donors if there were *any conditions attached*. This view had then been incorporated into the guidelines from the Human Tissue Authority (see below). Subsequently, the Department of Health produced *The Report of the Investigation into Conditional Donation* which concluded that: ‘to attach *any* condition to a donation is unacceptable, because it offends against the fundamental principle that organs are donated altruistically and should go to patients in the greatest need’.¹⁵ Organs with conditions attached to them could not, therefore, be available for allocation.

The report’s conclusions were controversial. Antonia Cronin and James Douglas have argued that the report ‘. . . failed to take account of the fact that the UK organ-sharing scheme was then (and remains still, rightly or wrongly) a matter of cooperation rather than compulsion’¹⁶ and ‘had the opportunity to analyse the true legal position but discarded it in favour of asserting the NHS policy as if it were established law’.¹⁷

It is arguable that justice and equality might require the accommodation of *some* conditions. Martin Wilkinson questions whether conditional donations *should always* be considered as a *failure to act altruistically*.¹⁸ The report did not clarify why conditions, including morally repugnant conditions, are not altruistic. A donation to a disadvantaged group might be motivated by the desire to achieve positive outcomes, rather than be

15. Department of Health, *An Investigation into Conditional Organ Donation: The Report of the Panel* (London: Department of Health, 2000), pp. 1, 25.

16. Cronin and Douglas, ‘Directed and Conditional Deceased Donor Organ Donations’, p. 290.

17. Op. cit., p. 300.

18. T. M. Wilkinson, ‘What’s Not Wrong with Conditional Organ Donation?’ *Journal of Medical Ethics* 29 (2003), pp. 163–164.

motivated by hatred. Nor, arguably, did the report give sufficient weight to the impact of excluding conditional donation and increasing morbidity and mortality of those who are denied life-saving organ transplants.

The rationale behind prohibiting such (race based) conditions is based on the recognition that such discrimination is unethical and unlawful and cannot be justified even if the donation can save lives. Michael Volk and Peter Ubel explain that:

. . . accepting such a racially based donation requirement violates many fundamental principles of justice and equality. It violates some principles of justice purely on moral grounds – discriminating against a group of people based on morally irrelevant characteristics, failing to give all people equal opportunity, and furthering hardship to a group of people who are already treated harshly by society.¹⁹

Similarly, Guido Pennings argues that ‘when potentially life-saving resources are distributed, only a pure egalitarian distribution is in agreement with the principle of justice’.²⁰ Accordingly, the need to safeguard the integrity of the system is key.

The case of Laura Ashworth attracted public attention because an intended directed donation from a daughter, whose dying wish was to donate her kidney to her mother (Mrs Leake), was refused.²¹ Muireann Quigley commented that ‘the quick application of a policy that was actually intended to stop racially motivated conditions being attached to the donation process led to the wrong decision being made in Mrs. Leake’s case’.²² This led to calls to distinguish conditional donation from directed donation. In a case of directed donation, a donor may ask that an organ be given to a family member or a friend. In 2008, James Neuberger, with support from Baroness Finlay, proposed the concept of *directed* allocation where, under strict conditions, the donor family may ask that an organ be given to a family member or a close friend.²³ This proposal can be distinguished from the racist condition on the basis that directed donation to a family member or friend is considered ethically acceptable. Living donors are permitted in law to direct their donation. Neuberger’s proposal merely suggested extending this to *deceased donations*. In 2010, the Department of Health adopted this proposal and issued a policy that made a distinction between conditional donation and directed donation.²⁴ This is now reflected in the Guidance Produced by the Human Tissue Authority.

19. Volk and Ubel, ‘A Gift of Life’.

20. G. Pennings, ‘Directed Organ Donation: Discrimination or Autonomy?’ *Journal of Applied Philosophy* 24 (2007), pp. 41–49.

21. A. Jones, ‘Mother Denied Dead Daughter’s Organ Transplant’, *The Guardian*, 12 April, 2008, <https://www.theguardian.com/society/2008/apr/12/health.nhs>.

22. M. Quigley, ‘Directed Deceased Organ Donation: The Problem with Algorithmic Ethics’, 2008, https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4702080.

23. See J. Neuberger and D. Mayer, ‘Conditional Organ Donation—The Views of the UK General Public Findings of an Ipsos—Mori Poll’, *Transplantation* 85(11) (2008), pp. 1527–1529.

24. BTS, ‘Requested Allocation of a Deceased Donor Organ’.

Differences over the ethical issues around conditional donation often reflect a fundamentally different starting point. For some, the key issue is the importance of saving lives under an effective organ allocation system. For others, the key issue is autonomy and respecting the views of donors. For them, a fundamental issue arising from conditional donation relates to the extent that people should control what happens to their separated body parts. There are lively debates over the extent to which bodily material can be seen as property, which is ‘owned’ by its originator.²⁵ According to that view, it may seem natural that a person can attach a condition to a gift of bodily material, just as they can in relation to other property they have. Robert Truog argues that:

guidelines for allocating organs obtained from living donors should be modelled on the view that these organs are the personal property of the donor, whereas those for the allocation of cadaveric donors should be based on the view that these organs are a societal resource.²⁶

However, Jonathan Herring rejects the property model for body parts on the basis that bodies are interconnected and interpersonal,²⁷ and that the ownership model does not capture the reality of how people’s bodies are intimately connected with others. For those who do not accept that bodily material is property, there is more scope for attaching weight to *communal* interests which might emphasise that organs are a public good to be allocated in a manner that is fair and non-discriminatory rather than based on the values of any individual donor. It would be wrong to simplify the debate to those who emphasise property interests versus those who emphasise communal interests as other values are relevant to determining how we view the status of donatable organs. Some argue that to describe the body as property fails to capture the personal significance of the body and hence its dignity which is also evident in canon law in the special case of the relics of the saints which it is forbidden to buy or sell.²⁸

However, the significance of conditional donation is not purely connected to the debates around property ownership of body parts. A healthcare system that puts patients at the centre of decision-making and emphasises personal autonomy recognises the importance of allowing people to decide how their body parts should be dealt with, whether during their life or after. This is increasingly relevant in transplantation medicine where there is potential for different kinds of transplantation (vascularised composite allografts such as uterus, hand or face, and xenotransplantation). For example, Elizabeth Romanis and Jordan Parsons argue that, in the context of uterus transplantation (a non-life-saving procedure), it is particularly likely that people will want to direct their

25. I. Goold, K. Greasley, J. Herring, and L. Skene, eds., *Persons, Parts and Property: How Should We Regulate Human Tissue in the 21st Century?* (Oxford: Hart Publishing, 2014).

26. R. Truog, ‘Are Organs Personal Property or a Societal Resource?’ *The American Journal of Bioethics* 5 (2005), pp. 14–16.

27. J. Herring and P.-L. Chau, ‘Interconnected, Inhabited and Insecure: Why Bodies Should Not Be Property’, *The Journal of Medical Ethics* 40 (2014), pp. 39–43.

28. Code of Canon Law strictly prohibits the sale of relics: ‘It is absolutely forbidden to sell sacred relics’ (CIC 1190 §1).

donation to particular individuals,²⁹ and it is understandable why a donor might want to direct the donation to a specific individual but also to a group of persons (such as former cancer patients) in such cases. Therefore, there are several reasons as to why the law should potentially accommodate conditional donation as part of personal autonomy, gift giving, and the need to save lives.

Moving from the ethical issues to the legal, the law might respond to unethical or problematic conditions either by:

1. Not allowing the use of the organ if a condition is attached to it.
2. Upholding the condition and only allow its use where the condition is met.
3. Taking the condition into account in allocation, but not regarding it as binding so that reasonable steps would be taken to comply with the condition, but use of the organ under the normal rules could go ahead where that is not possible.
4. Ignoring the condition and using the organ regardless of whether the condition is met.

Further difficulties may arise if a condition is attached to some organs, but not other organs. Then it will need to be decided whether the above approaches only apply to the specified organ or to all organs. For example, if a donor attached a condition in relation to their liver, but donated their other organs without condition, would adopting policy 1, above, mean none of the organs could be used, or would only the liver be unavailable?

There is no consensus on the question of which option is more ethically defensible. For example, whether it is more defensible to not allow the use of an organ at all if a condition is stated or to allow for the use of the organ while ignoring the condition. While individuals are generally permitted to choose which specific organs they wish to donate, most jurisdictions do not permit conditional donations from deceased donors. One key reason for not permitting conditions is that it would depart from the concept of allocating organs according to agreed principles (such as greatest need or greatest benefit). In the context of organ donation, there is an ongoing tension between the interests of the person donating the organ and the broader societal interest in ensuring there is a fair and effective organ distribution system. Those who emphasise the interests of the individual donor might ask whether conditional donation is *always* unethical, if organ donation is a gift that is a voluntary act on the part of the donor such that some conditional donations could still be lawful. After all a person can leave a gift in their will for what may be perceived as bad motivations (e.g. leaving a gift to a dog home to spite a canine-hating relative). If we respect autonomy over other gifts, we might also wish to take this approach in the case of gifts of organs. Another argument is that organs should be treated as equivalent to property.³⁰ Yet, those who consider the use of organs in transplantation as part of a nationalised health system often argue that the system should be governed by the principle of

29. E. C. Romanis and J. A. Parsons, 'Directed and Conditional Uterus Donation', *The Journal of Medical Ethics* 48 (2022), pp. 810–815.

30. See Truog, 'Are Organs Personal Property or a Societal Resource?'

non-discrimination. Thus, conditional donation must be situated within the broader requirements of medical ethics that takes into account the integrity of the entire system.

The current legal position on conditional donation

The United Kingdom has now adopted an ‘opt-out’ model for organ donation. Wales enacted The Human Transplantation (Wales) Act 2013, which came into force on 1 December 2015. England implemented the Organ Donation (Deemed Consent) Act 2019 which stipulates that everyone consents to donation upon death, unless there is evidence to rebut this presumption.³¹ The presumption can be rebutted if someone registers their intention not to donate on the organ donation register or makes their views known to family and friends. Next, The Human Tissue (Authorisation) (Scotland) Act 2019 provides for a ‘deemed authorisation’ and came into effect on 26 March 2021. On 1 June 2023, the law on organ donation in Northern Ireland changed too. The opt-out consent model means that consent to organ donation is still required in all jurisdictions; however, it is now possible to rely on deemed consent in addition to explicit consent. The current consent system operates as a soft opt-out in practice whereby the role of the family remains important in the decision-making.

A significant portion of the population has taken action to record their intention. In Scotland and Northern Ireland, a majority of the population have taken action to register as potential donors (53%), and in Wales a majority have taken action either to opt in or opt out (45% + 6.4%), and in England, 44.7% have taken action (41% + 3.7%), but there is reason to believe this will improve and England too will achieve a majority of opting in.³²

Freedom to donate organs is regulated and curtailed. The current legal position under the Human Tissue Act 2004 (covering England, Wales, and Northern Ireland) appears to prohibit transplanting conditions which are subject to a conditional consent that seeks to restrict the class of would-be recipients. The Human Tissue Authority’s Code F (Part II) on Deceased organ and tissue donation sets out:

43. Consent may be limited in a variety of ways. The HT Act does not prevent an individual from placing limits on their consent via the imposition of conditions, for example, to participate in particular research studies or to donate specific organs and tissue and not others.

44. However, no organ should be transplanted under a form of consent which seeks to impose restrictions on the **class of recipient of the organ**, including any restriction based on a protected characteristic or based on language. This includes the recipient’s age, disability, gender, marriage or civil partnership, pregnancy or maternity, race (which includes colour, nationality

31. The Act which amended the Human Tissue Act 2004 came into force on 20 May 2020 and applies to everyone in England apart from those who fall within one of the ‘excluded groups’.

32. See <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/30188/activity-report-2022-2023-final.pdf> NHS BT, Organ and Tissue Donation and Transplantation: Activity Report 2022/23. See also J. A. Parsons, ‘Deemed Consent for Organ Donation: A Comparison of the English and Scottish Approaches’, *Journal of Law and the Bioscience* 8 (2021): lsab003.

and ethnicity), religion or belief (which includes philosophical belief), sex or sexual orientation, or political opinion. . . .³³ (our emphasis).

The Code explicitly prohibits conditions that impose restrictions on ‘the class of recipient of the organ’ and outlines that any restrictions based on a protected characteristic would breach the Equality Act 2010. The Code goes on to further specify that:

45. NHS Blood and Transplant (NHSBT) is the body that has legal responsibility for organ allocation across the UK. As a matter of policy, NHSBT does not accept organs from deceased donors where any restriction is attached. However, requested allocation of a deceased donor organ to a specific recipient can be considered if this is carried out in line with NHSBT policy . . .

46. It would be an offence to proceed with an activity for a scheduled purpose in the knowledge that a persisting condition on consent could not or would not be fulfilled, as valid consent would not be in place. Only the person who has attached the condition to the consent can put the condition aside.

In effect, the NHSBT policy prohibits individuals (and their families) from stipulating any conditions on deceased organ donation. Moreover, the Code is clear that NHSBT, rather than the donor, has the legal responsibility for *organ allocation*. NHSBT’s updated policy ‘Exceptional Donation Requests Policy’ emphasises that ‘The fundamental principle of all deceased organ donation is that the offer to donate must be unconditional’³⁴ because ‘there are two key principles which underpin the UK organ donation programme – the absence of conditionality and the requirement that patients are treated equitably’.³⁵ Exceptions are only permitted if certain conditions are met as specified in the policy, but they are not binding.³⁶

A living donor can *direct* donation although they can also make an undirected live donation.³⁷ In the case of a deceased donor, the direction can ‘be considered’ but only ‘in line with NHSBT policy’. Thus, there is a difference between *conditional* donation in the cases of deceased and living donors. However, it is important to note that living donation

33. Human Tissue Authority, Human Tissue Act 2004, Code F: Donation of Solid Organs and Tissue for Transplantation, Part Two: Deceased Organ and Tissue Donation (2023), p. 10.

34. NHS BT, POL322/1 – Exceptional Donation Requests Policy, Effective Date: September 15, 2023, para. 4, <https://nhsbtbe.blob.core.windows.net/umbraco-assets-corp/30851/pol322.pdf>.

35. Op. cit., para. 11.

36. Op. cit., para. 4 which includes appropriate consent/authorisation which is unconditional, there are no others in urgent clinical need of the organ, the deceased (or family) expresses a decision to donate to a specified named relative, and that relative is on the UK waiting list and transplant is clinically indicated for the intended recipient.

37. NHSBT, People Donating a Kidney Altruistically Peaks at Five Year High, January 20, 2020, <https://www.nhsbt.nhs.uk/news/people-donating-a-kidney-altruistically-peaks-at-five-year-high/>.

is usually a ‘requested’ donation linked with a private person with personal relationship.³⁸ Other (and more) altruistic forms for organ donation are based on the general demand and need for organs for transplant where there is not a necessary connection between the donor and recipient, and this means that the underlying principles for each case are different, and thus, there is not necessarily an inconsistency. Accordingly, the difference between permitting *directed* living donation, but limiting it in the case of deceased donors is valid because the interests of a living donor are weightier than the interests of a deceased donor. If a living person’s organ was used against their wishes, there is a risk that they would find that distressing, whereas a deceased person would be unaware if their organ was used contrary to their wishes. There may be pragmatic arguments too.³⁹ Some argue that if conditions were not permitted (in the case of deceased donation), most people would still donate regardless.⁴⁰ However, most live donations are directed to an identified relative, and if individuals are unable to place such conditions, the majority of people might be unlikely to donate. The obvious reason for live donation is to save the life of a loved one. In sum, the approach for directed living donations and conditional deceased donations differs due to different policy preferences.

Reforming the law: five models of conditional donation

The notion of organ giving as gift is closely tied to an opt-in organ donation system,⁴¹ but in an opt-out donation system, it is questionable whether a donation is ‘truly’ a gift or is actually a construct in cases where people have not expressed a view either way. Accordingly, consideration needs to be paid to *why* people might want to attach conditions and what *kind* of conditions the law should permit. We identify five models of conditional donation that include the following: (1) *no* conditions permitted; (2) *all* conditions permitted; or (3) *some* conditions permitted. Within the category of ‘some conditions’, we include three variations of this option: permit conditions *except* those contrary to equality and non-discrimination law; or permit conditions as *exceptions*; or permit conditions, but only as advisory/ non-binding. We draw on case study examples to highlight the legal, ethical, and practical considerations arising from the proposed models.

38. See Cronin and Douglas, ‘Directed and Conditional Deceased Donor Organ Donations’, p. 280.

39. On this issue contrast J. Harris, ‘Law and Regulation of Retained Organs: The Ethical Issues’, *Legal Studies* 22 (2002), pp. 527–549 and S. McGuinness and M. Brazier, ‘Respecting the Living Means Respecting the Dead too’, *Oxford Journal of Legal Studies* 28 (2008), pp. 297–316.

40. See American Transplantation Society (ATS), British Transplantation Society (BTS), International Transplant Nurses Society (ITNS) The British Organ Donor Society (BODY), Donor Family Network (DFN), ‘Conditional Organ Donation—The Views of the Patients and Health Care Professionals’, *Transplantation* 85 (2008), pp. 1532–1538.

41. See P. K. Prabhu, ‘Is Presumed Consent an Ethically Acceptable way of Obtaining Organs for Transplant?’ *Journal of Intensive Care Society* 20 (2019), pp. 92–97.

Model 1: no conditions

This first model would not permit any conditions on the basis that a national healthcare system is for everyone and that permitting conditions would directly affect organ allocation. This view holds that it is ethically unacceptable to attach any conditions at all to a decision to donate. A ban on all conditions is better defended by reference to the positive benefit of having an ethos of free donation, in addition to the practical benefit of simplifying allocation decisions and working with a national list based solely on need. Moreover, prohibiting conditional donation for deceased donors makes little difference in practice. In other words, a prohibition will not prevent people who feel passionate about organ donation from making a positive decision to donate. It might be argued that the law of deemed consent to organ donation means that conditional donation is not a pressing concern as those individuals who feel strongly about not donating their organs, and want to restrict their donation, can record their wishes on the organ donation register. The majority of people will take no action and organ donation will be legally possible.

A reason for discouraging conditions in general is because it creates difficulty, and ultimately if conditions are prohibited, then there might be more donors because of higher trust in the integrity of the system. Every patient who suffers from organ failure and are put on the waiting list should have a fair chance to receive an organ for transplant. Accordingly, the general population might reasonably expect the organ allocation system to be based on the principle of *equal access*. A nationally delivered health system is founded on the fundamental principles of fairness and giving effect to some conditions would run counter that principle. Fairness is, however, a famously illusive concept and difficulties in determining distribution of scarce resources persist.⁴² Yet, the fundamental principles of medical ethics would include a notion of fair allocation.

Moreover, the importance of enacting a simple system for urgent allocation of resources in healthcare should not be underestimated. For example, during the COVID pandemic, the Joint Committee on Vaccination and Immunisation (JCVI) in the United Kingdom recommended a priority system or vaccine roll out based mainly on age.⁴³ This was very divisive among different professional groups (such as the teachers), as well as representatives of ethnic minorities who argued for the inclusion of other factors which had been shown to affect risk of death from the virus. However, there was consensus on the JCVI that age was by far the most important determinant and that the information was easy to obtain (much more so than profession or race or ethnicity). Thus, a faster, simpler system saves more lives. Likewise, if a potential organ donor places a condition that the recipient must 'live in the London area' or must be a 'Pentecostal Christian', then these data must be gathered for all possible recipients. It may not be practically deliverable for the system if these data have not been collected and there is difficulty in determining who might qualify within a certain category as there is no consensus on how to definitively define racial or religious groups.⁴⁴ In contrast to a race condition, a

42. J. Herring, *Medical Law and Ethics* (Oxford University Press, 2022), chapter 2.

43. Local Government Association, Briefing – Vaccine Prioritisation, 10 February, 2021.

44. See *R (E) v Governing Body of JFS* [2009] UKSC 15.

conditional donation that specifies that ‘kidneys can be donated, but not the heart’ does not add an extra burden as allocation of each organ is generally treated separately as there are lists for specific organs.

Finally, if healthcare professionals are seen as complicit in promoting wishes at odds with fundamental values such as equality, and in effect, support choices that may be prejudicial within a national health system for all, it could cause reputational damage to the healthcare system especially at a time when trust generally is not high.⁴⁵ Therefore, the ‘no conditions’ model is similar to the current approach.

Model 2: permit all conditions irrespective of their ethical value

This section will analyse key inter-related arguments in favour of organ donation which include personal autonomy, moral agency, and the harm to the organ allocation system. The primary justification for permitting *all or any* conditions is to save more lives. However, permitting any condition means that the system would accommodate all kinds of conditions and reasons for those conditions. There is current debate about the ethics of permitting non-medical criteria in decisions about organ allocation. For example, Greg Moorlock et al. argue that using non-medical criteria for organ allocation might *sometimes* be justifiable in order to avoid waste.⁴⁶ Martin Wilkinson, commenting on the 1998 case outlined above in which conditional donation was rejected, argues that:

Attaching a condition might be ‘unacceptable’, but that does not yet give us a reason against *accepting* the offer. Perhaps the panel believes an offer that is itself wrong should not be accepted. As a general principle, that cannot possibly be correct. There must be some offers that should be accepted if they do a great deal of good even if the motives are slightly discreditable.⁴⁷

If people are allowed to decide how to dispose of bodily materials, then this should include conditions that others might find morally reprehensible especially since the gift can still be considered altruistic. Antonia Cronin and David Price argue that ‘we must be prepared to properly consider all of the possibilities that altruism presents to us and we must be able to coherently explain why some altruistic gifts are more equal than others’.⁴⁸

45. See G. Randhawa, ‘Developing Culturally Competent Approaches: A Reply to ‘Nurturing, Nudging and Navigating the Increasingly Precarious Nature of Cooperation in Public Health: The Cases of Vaccination and Organ Donation’ by Heidi J. Larson and Alexander H. Toledo’, *Global Discourse* 13(3–4) (2023), pp. 1–5. See also IPSOS, ‘Most Patients Feel That Trust in Healthcare Has Declined in the Past Two Years’, 10 November, 2022, <https://www.ipsos.com/en-us/news-polls/patients-trust-healthcare-declines>.

46. G. Moorlock, J. Ives, S. Bramhall, and H. Draper, ‘Should We Reject Donated Organs on Moral Grounds or Permit Allocation Using Non-Medical Criteria? A Qualitative Study’, *Bioethics* 30 (2016), pp. 282–292.

47. Wilkinson, ‘What’s Not Wrong with Conditional Organ Donation?’ pp. 163–164.

48. A. J. Cronin and D. Price, ‘Directed Organ Donation: Is the Donor the Owner?’ *Clinical Ethics* 3 (2008), pp. 127–131.

A core justification for permitting *all or any* conditions relies on personal autonomy. Arguably, attaching conditions to organ donation is a fundamental aspect of personal autonomy because individuals should be afforded the (moral) discretion to do as they wish with their body parts and this *ought to* include attaching conditions that are considered problematic. For example, Wilkinson argues that it can also be problematic to deny donors their *moral discretion to decide*.⁴⁹ Margaret Lock argues that although the gift of life metaphor represents organ donation as a personal choice, organ allocation is generally a very *impersonal* process whereby the identity of the donor is anonymised.⁵⁰ Therefore, it is at least arguable that the lack of choice to make a conditional donation contributes to an ‘impersonal allocation system’ that does not enable individuals to exercise their full autonomy.

However, personal autonomy as a core justification for acts has been questioned on the basis that it is over-inflated and often used to justify any desired position.⁵¹ Accordingly, personal autonomy fails to explain why we should permit *any* conditions, and why autonomy ought to trump other communal interests in decisions about organ allocation.

It might be that personal autonomy, when grounded in the notion that the organ is ‘the property’ of the owner/donor, provides a stronger justification for allowing conditions. However, English law does not currently uphold the property approach to body parts⁵² and even appears to strike down some gifts of money in wills which are contrary to public policy.⁵³ If body parts were considered to be, say, just like money, then a person could donate their body for, for example, ‘the use of people in Oxfordshire’. Of course, trusts very commonly specify beneficiaries and some trusts attach specific conditions, for example, to improve educational attainment in certain ethnic groups. The key issue, however, is whether the body and body parts *should* be treated as being like property. We argue that they should not because there are too many ethical concerns about treating the body like property.

Another argument in favour of permitting any condition is based on the notion that there is no good reason to treat deceased or living donation as *substantially* different since both are about organ donation. While living donation is usually directed to a specific person, deceased donation generally cannot be directed in this way (see Neuberger’s proposal in the section above) which arguably creates an inconsistency.⁵⁴ Some have argued that deceased donors and living recipients are treated inequitably whereby organ givers are often treated as ‘an invisible and discredited collection of anonymous suppliers of spare parts’ and organ recipients ‘are cherished patients, treated as moral subjects

49. Wilkinson, ‘What’s Not Wrong With Conditional Organ Donation?’ pp. 163–164.

50. M. Lock, ‘The Social life of Human Organs’ in M. Lock, ed., *Twice Dead: Organ Transplants and the Reinvention of Death* (University of California Press 2010), p. 318–320.

51. C. Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Oxford: Hart Publishing, 2009).

52. See Jonathan Yearworth & Ors v North Bristol NHS Trust [2009] EWCA Civ 37.

53. G. Williams, ‘The Doctrine of Repugnancy – I: Conditions in Gifts’, *Law Quarterly Review* 59 (1943), pp. 343.

54. Cronin and Price, ‘Directed Organ Donation’, pp. 127–131.

and as suffering individuals . . .'.⁵⁵ Arguably, allowing all donors to attach conditions would enhance the visibility of the identities of organ donors as moral agents in control of how they choose to gift a precious life-saving resource.

It could also be asserted that unethical conditions should be accepted because the harm of an unethical condition is not substantially relative to the benefit of saving more lives; this sits at the heart of the core principle of beneficence in medical ethics.⁵⁶ This assumes that permitting conditions will increase the number of organ donors because at least *some* people would rather not donate at all unless they can donate with conditions; empirical evidence may help establish whether allowing conditional donation will result in a net increase or decrease in the number of organs available.⁵⁷

However, subjective motivations should generally be irrelevant in determining the rules for the organ allocation system. The value to ascribe to individual autonomy (for instrumental or intrinsic reasons) must be balanced against the interests of the whole system. It would be too controversial to permit *all* conditions and might be impossible to deliver. Permitting *all* conditions to determine when a donation should be accepted might weaken the high-level support for organ donation which is typically understood to be a freely given gift (without conditions attached). Thus, if conditions were to be accommodated, it would need to be under a variation of some conditions permitted.

Model 3: permit some conditions

A compromise between permitting 'no' and 'all' conditions includes a position that permits *some* conditions. We will briefly analyse some general concerns raised by permitting some conditions before setting out three variations of the model.

First, there are real difficulties in determining what counts as acceptable conditions as some conditions are positive and well-intentioned while others are not. Members of the community might be disadvantaged under the health system and conditional donation might be seen as an act of solidarity. There are analogous examples where the recipient has to be from a specific background in order to be eligible for some trusts and scholarships, such as the Stormzy Scholarship for Black UK students at the University of Cambridge⁵⁸ and the Walcot Foundation Townsend Scholarship, open to students from ethnic minorities living in the London borough of Lambeth.⁵⁹ Where race is specified, it is generally to support people from a disadvantaged ethnic minority background. That said, in 2019, Winchester College turned down a large donation which would have funded a scholarship for white boys from disadvantaged backgrounds due to concerns about reputational damage even though it would have benefitted a group who perform

55. N. Scheper-Hughes, 'Bodies for Sale—Whole or in Parts' in N. Scheper-Hughes and L. Wacquant, eds., *Commodifying Bodies* (London: Sage, 2003), p. 4.

56. See J. Herring, *Medical Law and Ethics*, 8th ed. (Oxford, Oxford University Press, 2020).

57. See ATS, BTS, ITNS, BODY, DFN, 'Conditional Organ Donation', pp. 1532–1538.

58. Stormzy Scholarship for UK Black Students, <https://www.undergraduate.study.cam.ac.uk/fees-and-finance/financial-support/outreach-scholarships/stormzy-scholarship>.

59. Walcot Foundation Townsend Scholarship Programme, <https://www.walcotfoundation.org.uk/townsend-scholarships.html>.

worse at school than their counterparts from other ethnic groups.⁶⁰ Such examples demonstrate that debates about fair distribution are complex and that some conditions raise multi-faceted concerns about race and socio-economic status.

Second, permitting some conditional donations in the healthcare context raises questions for professional ethics and the management of healthcare systems which aim to uphold the core principles of medical ethics which includes justice.⁶¹ While there is not one single way to achieve justice, enabling a system which permits discriminatory conditions in allocation can undermine this ideal. Although organ donation and educational scholarships are both forms of gift giving, conditional donation can be distinguished given the unique challenges of healthcare professionals operating within a national healthcare system. If clinicians were required to implement a problematic conditional donation decision, it could lead to them refusing to do so, based on their right to freedom of conscience. Moreover, physicians are bound by several ethical and professional obligations.⁶² Unlike educational scholarships, many decisions relating to organ donation and allocation result in life or death for individuals. Whereas, if an individual fails to get an educational scholarship, the loss is not the equivalent to not being allocated an organ. Accordingly, conditional donations, if permitted, must be based on defined criteria.

Third, conditional donations involve a number of actors operating within a system of complex rules. Normally, although donors usually give money to an institution who administers the grant, people are free to give their assets, money, or gifts as they please. However, there is a deep tension in transplantation medicine because a national organ allocation system should be designed to benefit patients according to need and allocate according to need. Accordingly, there is a tension between one key goal (e.g. the distribution of resources according to need) and the freedom to donate (based on personal autonomy (e.g. the dispose of body parts as desired)). Therefore, the problem of permitting conditional organ donation stems from balancing those two goals. The need to involve the health care administrations and the clinicians in achieving the outcome the conditional donor also means the weight that can be attached on the personal autonomy of the donor should be limited.

A distinction could be made based on the intention of the donor, where restricting donation to a subgroup of people which aims to *exclude* unwanted people, with directing a donation to a specified group which may aim to support people from disadvantaged backgrounds. However, it is possible to frame some objectionable conditions in a positive way (e.g. only for use by the favoured group) or in a negative way (so not for use for the unfavoured group). This, it is very difficult to agree on how to distinguish between the positive and negative motivations of the potential donor.

60. See J. Eastham, 'Charities "Must Not Refuse Donations Because of Personal Views"', *The Telegraph*, 4 March, 2024, <https://www.telegraph.co.uk/news/2024/03/04/charity-trustees-must-not-refuse-donations-personal-views/>.

61. T. Beauchamp and J. Childress, *Principles of Biomedical Ethics*, 8th ed. (Oxford: Oxford University Press, 2019).

62. See General Medical Council, Professional Standards for Doctors, <https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors>.

Moreover, another challenge is that there is rarely time in the context of deceased organ donation to undertake a sensitive analysis of whether or not a race condition, for example, can be justified. Opening the door to controversial, and ethically questionable, kinds of conditional donation could fail to increase the number of donors and yet increase public stigma. However, this does not mean that it is impossible to devise a system which filters out those conditional donations that would lead to mistrust, discrimination, and public stigma. Our proposed three variations of the ‘some conditions’ model include: (1) permit all conditions *except* those that breach equality and non-discrimination laws; (2) permit some conditions as exceptions; and (3) permit some conditions but make them advisory and not binding and could pave the way forward for law reform.

Model 3A permit conditions except those contrary to equality and non-discrimination law

This model would allow *some* conditions except those conditions that breach equality law. Although there is debate about the dimensions of equality and its realisation in practice, with arguments that equality is ‘an empty ideal’,⁶³ the law does recognise the need for equality and minimum standards of protection against different forms of discrimination.⁶⁴ Under the Equality Act 2010, unlawful discrimination is associated with the following protected characteristics, as listed in section 4: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; and sexual orientation. This would provide a clear limitation to permitting conditions so that potential donors’ autonomy is respected, but within a clear framework that is based on equality law.

However, if such a model were implemented, it would still leave some room for conditional donations based on prejudice.

Example 1

Henry is in favour of organ donation as it accords with his views of being a good citizen. However, he does not want to donate to those who suffer from alcohol toxicity or drug use because he believes that consuming excess alcohol is irresponsible and is an act for which the person is at fault. He does not think his organs should be ‘wasted’ on bad citizens.

Example 2

Sharon is a fitness instructor and would not want to donate her organs to those who have been overweight and where this has resulted in organ failure. She thinks people should take responsibility for their health and fitness.

63. P. Westen, ‘The Empty Idea of Equality’, *Harvard Law Review* 951 (1982), pp. 537–596.

64. S. Fredman, *Discrimination Law, Clarendon Law Series* (Oxford: Oxford University Press, 2010).

The two examples illustrate cases based on prejudices that do not explicitly fall within the scope of equality law. In Example 1, Henry's conditional donation is based on his biased beliefs that stigmatise patients who suffer from alcohol-related disease and who constitute a significant number of patients in need of organ transplants. Georg Schomerus et al. demonstrate how stigma in liver transplantation continues to be a real problem where patients who suffer from alcohol-related disease are subject to moral judgement, and where those who do not have alcohol-related disease seek to distance themselves from those patients who suffer from alcohol-related disease.⁶⁵ Schomerus et al. subdivide stigma into 'public stigma, self-stigma, and structural stigma'⁶⁶ and note that 'population studies consistently show that a majority of respondents blame those with alcohol use disorder (AUD) for their condition, in contrast to other mental disorders like schizophrenia or depression and other behaviour-related medical diseases like diabetes'.⁶⁷ Public stigma, then, affects a patient's self-perception and willingness to fully discuss their problems due to the fear of judgement. Unfortunately, stigma also can occur in institutional settings where some healthcare professionals display negative attitudes towards patients who suffer from alcohol-related disease. Moreover, some argue that the abstinence rules for patients with alcohol-related disease are punitive and are based on form of stigmatisation.⁶⁸ Conditional organ donation, therefore, might add to current attitudes around stigma.

Similarly, in Example 2 above, Sharon's views stigmatise overweight persons. Under section 6 of the Equality Act 2010, disability is defined as follows:

Disability

(1) A person (P) has a disability if –

(a) P has a physical or mental impairment, and

(b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.

However, obesity is not protected as a ground *per se* in the Equality Act or in the European Union's Council Directive 2000/78/EC that created a general framework to combat all kinds of discrimination on grounds of religion or belief, disability, age, or sexual orientation in employment and occupation,⁶⁹ and which currently applies to its members.⁷⁰

65. G. Schomerus, 'The Stigma of Alcohol-Related Liver Disease and its Impact on Healthcare', *Journal of Hepatology* 77 (2022), pp. 1–9.

66. *Op. cit.*

67. *Op. cit.*, p. 2.

68. *Op. cit.*

69. Council Directive (EC) 2000/78 establishing a general framework for equal treatment in employment and occupation [2000] OJ L303/16 (Employment Equality Directive 2000/78, <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32000L0078>).

70. https://european-union.europa.eu/institutions-law-budget/law_en European Union, Law.

It is increasingly recognised that obesity can result in a patient suffering from disabilities.⁷¹ The World Health Organization recognised that obesity is a disease in 1948.⁷² Therefore, prejudice against those who are overweight, and in need of an organ transplant, has real negative consequences for patients. Volk and Ubel argue that justifying decisions about treatment and the allocation of resources on a notion of personal responsibility is problematic since it can be argued that everyone can be held to be responsible for some bad choices that they made:

Few people are not guilty of damaging their health in some fashion. Remember those extra cookies last night? The role of the liver transplant system is to benefit all patients as much as possible, not to act as judge.⁷³

Their view is that if we stretch the argument of personal responsibility and apply it to a range of everyday situations, it would mean that singling out one category of patients is unfair. One person eats too many cookies, another works too much, and yet another drinks too much fizzy pop – all of which are arguably unhealthy practices – and the point being that conditional donations based on a notion of personal responsibility and blame is simply too subjective. Accordingly, given the very real harm of stigma for patients, model 3A would accommodate some conditions that, although do not explicitly breach equality law, would still permit prejudice, and are accordingly ethically questionable. Therefore, this model is too wide in scope.

Model 3B: permit conditions as exceptions

This model would permit some conditions as exceptions as it recognises that not all conditions are unethical. As mentioned above, there is an important difference between conditions of inclusion and conditions of exclusion; one is generally offensive, and the other is generally seen to be reasonable because it is possible to be a donor, and yet, not to be entirely altruistic. In other words, a conditional donation is not necessarily altruistic as it may be that the donation is for a family member, but as everyone also benefits this might be deemed to be generally acceptable. Here, we first further unpick the issue of positive discrimination.

Example 3

Sarah would like to donate her organs to a disadvantaged minority group (Bangladeshi) because she is a member of that group and has learnt, through local community campaigns, that members of her ethnic group are in need of organ transplants. There has been a local call to action encouraging donation, and she now agrees to donation, but also believes that there is structural racism embedded in the healthcare system. She is now committed to donating her organs but only to someone within her ethnic group.

71. See WHO European Regional Obesity Report 2022, <https://iris.who.int/handle/10665/353747>.

72. W. P. T. James, 'WHO Recognition of the Global Obesity Epidemic', *The International Journal of Obesity* 32 (2008), pp. S120–S126.

73. Volk and Ubel, 'A Gift of Life', pp. 1542–1544. See also J. Herring, 'Rationing by Fault', *Theology* 121 (2018), pp. 112–116.

Sarah's conditional donation is a form of 'positive discrimination', which for some is defensible because it seeks to redress systematic and historic disadvantages faced by specific groups.⁷⁴ This stands contrast with the case discussed earlier where the donor wanted to donate to 'only white persons': the motivations are different although both conditions are based on race and would breach equality laws. However, since positive discrimination and action has a remedial function aimed at creating equal opportunities, it is *potentially* defensible as one way of achieving equality.⁷⁵ It might be worth understanding why a person wants to attach a condition to their organ donation. Some research suggests evidence of structural racism in the healthcare system⁷⁶ which requires ongoing action to understand patient perspectives. There is also evidence to suggest barriers in accessing the healthcare system due to geographical inequity.⁷⁷ Moreover, members of some ethnic minorities waiting for a kidney, heart, or lung transplant have a longer wait time to transplantation than white counterparts. That is because organ allocation is partly utility based, and this drives allocation on tissue matching (since a mismatch will reduce the survival of the transplanted organ). Tissue matching can be more challenging if there is a shortage of organs matching members of some minority groups. Such considerations do not apply to those organs (such as liver) where tissue type matching is not included in the allocation algorithm since tissue matching does not affect outcome.⁷⁸ Yet, many minority ethnic groups have a greater need for organ donation, but are less likely to agree to organ donation and more likely to opt out of organ donation.⁷⁹ This might lead to members of ethnic minority groups being motivated to donate to their group only.

Currently, the UK allocation system adopts a strict approach to ensure that there is no racism in the context of organ allocation. However, more work needs to be done in terms

74. See S. Fredman, 'Positive Duties and Socio-economic Disadvantage: Bringing Disadvantage onto the Equality Agenda', *European Human Rights Law Review* 3 (2010), pp. 290–304.

75. Op. cit.

76. Written evidence submitted by Professor Gurch Randhawa (MRS0068), <https://committees.parliament.uk/writtenevidence/2326/pdf/>. See also Fair Society Healthy Lives: The Marmot Review: Strategic Review of Health Inequalities in England post-2010, 2010, <https://www.parliament.uk/globalassets/documents/fair-society-healthy-lives-full-report.pdf> and Public Health England and UCL Institute of Health Equality, *Improving Health Literacy to Reduce Health Inequalities*, 2015, https://assets.publishing.service.gov.uk/media/5a80b62d40f0b62302695133/4b_Health_Literacy-Briefing.pdf.

77. This is based on the postcode acting as a surrogate for deprivation. See C. E. Graley, K. F. May, and D. C. McCoy, 'Postcode Lotteries in Public Health – The NHS Health Checks Programme in North West London', *BMC Public Health* 11 (2011), p. 738. And see Nuffield Trust, 'Poorest Get Worse Quality of NHS Care in England, New Research Finds', 2020, <https://www.nuffieldtrust.org.uk/news-item/poorest-get-worse-quality-of-nhs-care-in-england-new-research-finds>.

78. See NHS BT, 'The Need for More Black, Asian and Minority Ethnic Living Organ Donors', <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/black-asian-and-minority-ethnic-living-organ-donors/#:~:text=Kidneys%20are%20matched%20by%20blood,everyone%20waiting%20for%20a%20transplan.>

79. NHS BT, *Annual Report on Ethnicity Differences in Organ Donation and Transplantation Report for 2022/2023* (1 April 2018–31 March 2023), https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/31332/annual-report-on-ethnicity-differences-final-2022_2023.pdf, p. 5.

of trust-building to inform many non-white patients that most of the organs have been donated by white patients.⁸⁰ If that is better explained and trust is built from there, then it is less likely that people would want to attach such a condition. Understanding the history and evolution of how trust, familiarity, and fairness is built within communities, between communities, and between the state and communities is an important endeavour if we are to develop culturally competent approaches to achieving equity in health outcomes. There is now decades' worth of reports setting out the need to develop culturally competent approaches to cooperation in public health within the United Kingdom. The less-than-optimal implementation of these reports by successive governments has not engendered agency in familiarity, fairness, and trust between the state and the public.⁸¹ Thus, it might be helpful to address why some individuals would like to attach conditions that, although motivated by the desire to do good, raise difficulties in practice.

Example 4

Mary is a potential donor and very passionate about women's rights. She argues that her political and philosophical beliefs on feminism are not merely opinions, but have a profound impact on how she lives her life and her life choices. Accordingly, she would like to donate her organs to women only.

Mary might argue that her belief is part of her fundamental worldview and amounts to a philosophical belief as protected by the Equality Act 2010.⁸² Since not *all conditions are morally repugnant* such as where a condition is a religious preference, or a form of positive discrimination, or related to causes that individuals feel strongly about, does it follow that *some* conditions should be permitted? Mary's condition is a form of positive discrimination but is based on a protected characteristic (e.g. sex). Thus, there is a tension here between protecting equality law and carving out exceptions as forms of positive discrimination which is difficult to manage especially as it could include race and religion as justifiable exceptions. Thus, some key issues remain with permitting conditions as exceptions. However, this model could allow decision-makers some *discretion* in deciding and scrutinising some conditional donations and deciding whether or not to permit them. Of course, there is the issue of assessing the motivation and the question of complicity of healthcare professionals in taking part in a system that allows some conditions persist that would need to be clarified. For example, many people might find Mary's intended condition unfair. However, model 3B would make clear that conditional donations are not the norm, but an exception. As such, conditional donations which stipulate that a person will donate their organs, but not to someone with the 'X' ethnic origin, would be excluded as inherently morally repugnant, whereas a condition stipulating that donation must be to a child can be seen as morally virtuous. Nevertheless, detailed discussion about the

80. Op. cit.

81. Randhawa, 'Developing Culturally Competent Approaches', pp. 350–354.

82. See *Grainger plc v Nicholson* (2010) ICR 360 for the test of which beliefs might fall within the scope of the Equality Act 2010.

permissibility of positive discrimination geared to redressing a social disadvantage would be necessary to reassure the public of its potential benefits. If 'some conditions as exceptions' were to be permitted, it remains to be decided whether they should be strictly binding or whether the health authorities could simply make a reasonable effort to comply with the condition. Moreover, it would need to be decided how much weight should be attached to conditions and what should happen when they cannot be met.

Model 3C: permit conditions, but only as advisory

Under this model, it would be possible to accept the organ but potentially ignore the condition. For example, drawing on the justification of the personal autonomy of the donor could justify some cases where condition and motivation is not unethical. Suzanne Uniacke distinguishes between *compliance respect* and *consideration respect* where the former is determinative and the latter does not require compliance.⁸³ Accordingly, if a condition is considered acceptable, then reasonable steps could be taken to meet that condition, but if not, then it does not need to be complied with. This model requires a complex assessment of the various interests, subjective motivations, and the potential perception of harms associated with a condition. Yet, this challenge might not prove to be insurmountable if stable criteria are agreed upon.

Example 5

Katie is a devout Pentecostal Christian and believes that her moral duty is first and foremost to others within her religious group. She would only donate to members of her Church.

Proceeding with a donation according to Katie's condition would appear to be unlawful since the Human Tissue Act Code prohibits conditions that seek to restrict the class of recipients. Again, donating to a specific religious group might be seen as either discriminatory (negative) or as an act of faith (positive discrimination). However, if we return to the issue of property interests in body parts which included organs, Shaun Pattinson has argued that the Human Tissue Act 2004 *implies* some property interests in organs/body parts.⁸⁴ Pattinson submits that if the Act allows people to make decisions about their organs (section 3 requires appropriate consent) and to transfer their interest to another (third party as in accordance with section 4),⁸⁵ it suggests that individuals retain *some* autonomy over their organs. Accordingly, an argument can be constructed in favour of permitting some conditional donations, as in the case of Katie, based on her religious and personal autonomy.

83. S. Uniacke, 'Respect for Autonomy in Medical Ethics' in David Archard and Neil A. Manson, eds., *Reading Onora O'Neill* (London: Routledge, 2013), pp. 98–99.

84. S. D. Pattinson, 'Directed Donation and Ownership of Human Organs', *Legal Studies* 31 (2011), pp. 392–410.

85. Section 4 reads 'Nominated representatives (1) An adult may appoint one or more persons to represent him after his death in relation to consent for the purposes of section 1 . . . '.

However, as noted earlier, it remains that some conditions are not possible to meet or would be seen as unjust. Under this model, it is possible to ignore the condition, and this may be regarded as a form of a compromise, giving some weight to the autonomy of the donor and their wish, but ultimately, *balancing that interest against the public interest* to ensure a fair and effective donation regime. Such a view would, quite significantly, mark a shift towards individuals having more autonomy and authorship over body parts but with the important caveat that the discretion lies with the relevant decision-making bodies.

However, there might be a concern that such a proposal is too vague as it leaves the issue of conditional donation largely in the hands of a clinician who may have limited understanding of the ethical and legal issues. Perhaps guidance could be provided, which we might imagine would be along the following lines: where there is a suitable recipient who meets the condition and is high up the list the organ can be given to them, even if there was another even higher up the list who would have been given the organ had there been no condition attached.

A counter argument to this approach is that the donor's consent is not truly being respected or realised because it is treated as non-binding. Accordingly, to take the organ without the condition would undermine the original consent, which then begs the question as to why we should require consent at all if it can be undermined (in some cases)? Of course, that is precisely the perspective some have advocated for. However, if it is accepted that *consent matters*, then ignoring an intention to make a conditional donation means that sometimes there might not be 'true' consent because a person might not want their condition to be treated as a mere preference. However, a person could be informed that their conditional donation will be balanced against *other* considerations such that if a person is informed can state a preference and this preference may or may not be respected (but will be taken into account), then they have broadly consented to the following course of action irrespective of whether their preference may in the end not be upheld. It might be that the law allows a preference to be stated and that will be taken into account, but not necessarily upheld, and that this information is not communicated to the donor. So this would be a form of deemed (fictitious) consent in that case, but not consent where the donor is explicitly understanding this and agreeing to this.

Concluding comments: recommendations for future policy debates

This article outlined some key issues raised by deceased conditional donations. The issue is important since there is a shift towards personal autonomy in medical ethics whereby body parts are increasingly understood as having interests that ought to be *continuously* protected. Accordingly, conditional donation raises questions about how to increase donations, and realise the various interests in body parts in increasingly pluralistic societies, in addition to managing the collective interests of designing fair organ allocation systems for scarce resources to save lives. Whether the law should accommodate conditions depends on numerous factors including the extent to which there are good justifications in favour of a complex reform to the organ allocation system. Given the models we outlined above, there appear to be two broad rationales in favour of reform. The first

rationale is based on autonomy as an ethical principle: that conditional donations should be permitted as a fundamental part of personal autonomy so that individuals can decide how their organs and bodily materials are treated after their death. The second rationale is that conditional donations should be permitted for mainly pragmatic reasons and that more individualised notions of consent might persuade more people to donate their organs. If conditional donations were permissible, the question remains as to whether it would make any difference in practice. For some, the interest of saving lives carries far more weight than the (legitimate) interest of prohibiting morally objectionable conditions from being accommodated within the healthcare system. However, this argument depends on an assumption that giving effect to conditional donations will increase the number of organs available for transplant. This might occur but is by no means certain. For some, conditional donation is unjust and leads to inequity in the allocation system. Our article demonstrates that there is room for disagreement and potential for reforming the law and policies in transplantation.

We recommend that, in light of the lack of consensus on these issues, a working group should be set up to discuss the options and carefully engage with the issues to avoid the knee-jerk reaction of *automatically* rejecting all deceased conditional donations. The working group could include a committee with lawyers, clinicians, and ethicists to contribute to a framework for when and why conditions might be legally or ethically acceptable. A legal framework or statutory guidelines for decision-making that is based on the 'Some Conditions Models' outlined above might include criteria that conditions must meet to uphold key principles such as equality or integrity which would exclude race-based conditions or conditions that undermine the integrity of the allocation system. These issues of justice, allocation, and personal autonomy have wider significance for medical ethics and clinical practice. We emphasise the importance of trust when reviewing and implementing models of conditional donation and acknowledge that building trust is a dynamic process that requires time, effort, and resource investment.⁸⁶ The public need to feel confident in and trust both the message and the messenger. Moreover, the message needs to be culturally competent and come from trusted people since it is also worth considering the reality that 'it takes years to build trust, but only a second to lose it'.⁸⁷ Given the recent legal developments in the context of organ donation and deemed consent, our aim is to contribute to this timely debate by highlighting the challenges arising from our five models of conditional donations.

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86. Randhawa, 'Developing Culturally Competent Approaches', pp. 350–354.

87. Op. cit.

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