

Manuscript version: Author's Accepted Manuscript

The version presented in WRAP is the author's accepted manuscript and may differ from the published version or Version of Record.

Persistent WRAP URL:

<http://wrap.warwick.ac.uk/168093>

How to cite:

Please refer to published version for the most recent bibliographic citation information. If a published version is known of, the repository item page linked to above, will contain details on accessing it.

Copyright and reuse:

The Warwick Research Archive Portal (WRAP) makes this work by researchers of the University of Warwick available open access under the following conditions.

Copyright © and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable the material made available in WRAP has been checked for eligibility before being made available.

Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

Publisher's statement:

Please refer to the repository item page, publisher's statement section, for further information.

For more information, please contact the WRAP Team at: wrap@warwick.ac.uk.

Title Page

Title

A proposal to support making decisions about the organ donation process

Corresponding author

Dr Greg Moorlock

Warwick Medical School

University of Warwick

Gibbet Hill Campus

Coventry

CV4 7AL

United Kingdom

Author List

1. Dr Greg Moorlock, Warwick Medical School, University of Warwick, Coventry, UK
2. Professor Heather Draper, Warwick Medical School, University of Warwick, Coventry, UK

Word count: 4459

Key words

Organ donation, best interests, autonomy, transplantation, consent

Abstract

In this paper we propose a novel approach to permit members of the public opportunity to record more nuanced wishes in relation to organ donation. Recent developments in organ donation and procurement have made the associated processes potentially more multi-staged and complex than ever. At the same time, opt-out legislation has led to a more simplistic recording of wishes than ever. We argue that in order to be confident that a patient would really wish to go ahead with the various interventions and procedures that now accompany organ donation, more nuanced information than a simple 'yes' or 'no' may be required. This is of particular importance for donation after circulatory death, where some interventions to facilitate donation occur when the patient is still alive. We propose the implementation of an online form to allow people to record more nuanced wishes in relation to donation, including an indication of competing wishes and how these should be weighed into decision-making. We argue that this approach will promote autonomous decision-making for the public, potentially reduce difficulties that family members encounter at the time of organ donation, and should make medical staff more confident that they are truly acting according to the wishes and best interests of their patients.

INTRODUCTION

In recent years, developments such as pre-mortem interventions to facilitate organ donation after circulatory death, normothermic regional perfusion and ex-situ machine perfusion have significantly changed what happens to donors and their organs. While the processes associated with donation have become more complex, the opportunities to indicate a willingness to become donors have been simplified. In the United Kingdom, most devolved nations (England, Wales and Scotland) have moved to systems of deemed consent, and Northern Ireland is moving to deemed consent in Spring 2023. An absence of objection can now be regarded as willingness to donate.

Maintaining simplicity in an organ donation system is generally desirable, insofar as presenting the public with numerous complex options may deter them from making decisions, or potentially create confusion and an unwillingness to donate. But this mismatch between the simplicity of the donation registration system and complexity of donation processes has ethical implications.

In this paper, we argue that these ethical implications are undesirable and potentially lead to patients being treated in ways that are not clearly in accordance with their best interests, or their wishes about donation. We will propose a way forward, similar to the existing ReSPECT form used in end-of-life planning, which would provide patients with the opportunity to express greater nuance and precision in relation to their organ donation wishes. Our proposal is not targeted at decisions about donation per se, but rather the processes that accompany donation (although we accept that this may sometimes have an impact upon donation going ahead). We argue that, if done appropriately, this need not be considered to increase complexity in the donation registration system and would increase the likelihood of patients' wishes being accurately respected, thereby also reducing some challenges faced by families and clinicians at the time of organ donation. We situate our discussion within the UK context, but our arguments will apply to other countries where complex decisions are made regarding donation and the processes that accompany it at a time when the potential donor is unlikely to be able to express their views.

BACKGROUND

Transplantation has always embraced new developments, and technology to support and facilitate organ donation has significantly advanced in recent years. Dying, death and organ retrieval inevitably cause injury to organs, so technological approaches to minimising or even reversing aspects of this damage are of benefit to transplantation. Ex vivo machine perfusion, where organs are connected to machines that flow fluids through them, allows more time to assess the function of the organ. In some cases, it permits the organ to 'recondition' so that some organs that were previously considered higher risk for recipients, or simply untransplantable, may now be transplanted with greater confidence.[1] In situ normothermic regional perfusion allows for oxygenated body-temperature blood to be perfused through organs while still in the donor's body (after death has occurred). Measures are implemented to ensure that this perfusion does not risk restoring any limited function to the heart or brain, and the process typically lasts around 2 hours.[2] The process improves transplant outcomes for the eventual recipients of the organs.[3]

These technological developments may be used in conjunction with more routine interventions prior to death that are necessary to facilitate or optimise donation/transplantation. This has particularly been the case for DCD donors, and has been the subject of much ethical and legal discussion.[4,5]

Pre-mortem interventions currently tend to be limited to relatively minor things such as additional blood tests or measures to stabilise a dying patient's condition prior to withdrawing life-sustaining treatment, but could theoretically include more involved interventions aimed at optimising organ quality while the patient is alive.

The UK-wide strategy for organ donation and transplantation identified key areas for action, including aiming for "optimal organ utilisation in every organ group, benefitting from new technologies and techniques" and to build "a pioneering culture of research and innovation in donation and transplantation in the UK".[6] Recent research has highlighted issues with consent in relation to interventional research with organ donors,[7] so it is important to give consideration to how some of these issues may be resolved.

It is no longer the case that organ donation is a relatively linear process of organs being retrieved from the dead donor, stored and transported at a low temperature, and then transplanted into a recipient. Organs may spend extended periods of time inside the dead patient, or may be connected to machines for days prior to transplantation, and some actions to facilitate or optimise donation may take place while the patient is still alive. To add complexity to this, some aspects of these developments remain relatively experimental and involve elements of research. All of these factors combine to make for a potentially complex set of decisions at a time when the patient is unlikely to be able to express their wishes. It is surprising, then, that there is currently little opportunity for patients to formally record their wishes in relation to these decisions.

ETHICAL IMPLICATIONS

The principle of respect for autonomy (understood in broad terms as others respecting one's wishes about what happens to oneself) is challenging to apply to dead people because posthumous wrongs/harms are difficult to convincingly explain,[8] but respect for individuals' wishes is nonetheless built into organ donation systems. It is widely considered that, to be ethical, organ donation should be voluntary. This is a feature of organ donation systems worldwide, whether opt-in, opt-out or reciprocity-based like that seen in Israel. Where forced organ donation has occurred, it has been almost universally condemned. We will take as our starting point that whether or not organ donation proceeds (if it is clinically appropriate) should be in alignment with the patient's wishes.[9]

UK residents are able to express their wishes about organ donation in different ways. In nations currently with deemed consent systems, someone is presumed willing to donate unless they register an objection. Willing donors therefore need do nothing to indicate willingness. There remains an option, however, for willing donors to positively express their wishes via opting-in (and in Northern Ireland, this is currently how all willing potential donors formally record their wishes). This provides an opportunity to express some nuance in one's wishes, as one can select precisely which organs one would be willing to donate (no such nuance is available when one opts out). Some nuance is also incorporated into deemed consent legislation, so that organs for novel transplants (such as uteruses) are excluded, and patients who lack capacity to understand the consent system will not have consent deemed. People are given control over whether they donate, and what they donate, but there is no opportunity to record wishes in relation to *how* one donates, nor the strength of those wishes.[10]

Because the organ donation process has become more complex it is not obvious that a willingness to donate some or all of one's organs necessarily translates into a willingness to undergo (or for one's organs to undergo) all of the steps and interventions that may now, or in future, be a part of

donation. Some of these processes are aimed at optimising donated organs, so may be considered 'optional' and not strictly necessary for donation to proceed. There is a danger that organ donation may go ahead involving processes that are not in accordance with the donor's wishes. For example, a potential donor may be broadly in favour of donation, but uncomfortable with the idea of their organs being hooked up to a machine for days, or they may be uncomfortable with the idea of blood flow returning to their organs in their own body posthumously. If it is important to respect a patient's wishes over whether their organs are donated, their wishes for *how* their organs are donated should arguably also be respected.

Patient wishes are even more important for DCD. Potential DCD donors are alive at the time that many decisions about organ donation are made, but in most cases the patient lacks capacity to make decisions, bringing them under the protection of the Mental Capacity Act 2005 in England and Wales, Adults with Incapacity (Scotland) Act 2000 or Mental Capacity Act (Northern Ireland) 2016. Decisions must therefore be made in the best interests (or 'overall benefit' depending upon specific legislation) of the patient. Determining the best interests of a patient when it comes to organ donation is difficult. The fact that someone has not opted-out of organ donation does not necessarily mean that they would be willing to undergo the pre-mortem interventions required to facilitate donation. The fact that someone has opted-in to organ donation may give stronger evidence of the patient's wish to become a donor, but does not give evidence of the strength of the patient's wish to donate. Application of relevant legislation to DCD donation has clarified that donation can be in a patient's best interests if that patient wanted to donate, and that treatment to facilitate donation may also be in that patient's best interests.[11] But to accurately determine this, a doctor would need to know about the patient's other interests and how they would weigh these against their wish to become a donor. For instance, a patient may wish to donate but not if it were to distress their loved ones. Or a patient may wish to donate, but not if it required a significant delay in withdrawing life sustaining treatment, or involved pre-mortem interventions that carried particular risks. Weiss et al found that the majority of authors in their scoping review did not view a previously expressed willingness to donate as including consent for pre-mortem interventions,¹² although a qualitative interview study found that some NHS staff thought differently.[10] Either way, further evidence of wishes with regard to these aspects would be valuable. Brown has argued that current policy in relation to DCD pushes the idea of best interests to its limits and that informed consent standards should become a part of donor registration.[13] She highlights the lack of specific consent for pre-mortem interventions and suggests that doctors may face challenges determining patients' wishes. Our proposal will be more modest than Brown's suggested systemic change to incorporate informed consent standards into organ donation registration, but we share her concerns about decision-making. The lack of a routine formal opportunity for potential donors to consider and then express the strength of their wish to become an organ donor, and to describe other countervailing considerations, means that decisions about best interests are sometimes essentially guesswork.

Although pre-mortem interventions have been the focus of much ethical debate due to the fact that the donor is still alive, our discussions are also important for post-mortem interventions. Doubtless many donors are willing for their donations to be facilitated by new technology to further push the boundaries of transplantation, but it would be wrong to assume this of all donors. Some donors may perceive more experimental interventions to be riskier, and instead wish for their organs to be used in lower risk ways. Some donors may fully support ground-breaking research and wish for their organs be used in its furtherance, even if it means their organs may ultimately not be transplantable. Donors may have differences senses of what costs to their families are outweighed by successful

transplantations. But without a routine opportunity for potential donors to consider and express their preferences in relation to donation research, respect for patient autonomy is potentially undermined, and we may create additional challenges for this type of research.

PROPOSAL

Many UK institutions have implemented the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) approach.[14] The ReSPECT form,[15] and the process via which it is completed, provides personalised recommendations about a person's future treatment and care when they are unable to make their own choices. The brief form includes the option to state things such as 'What I most value' and 'What I most fear/wish to avoid'. There is a scale upon which one can mark one's position between 'Living as long as possible matters most to me' and 'Quality of life and comfort matters most to me', followed by a section where a clinician can recommend 'Prioritise extending life' *or* 'Balance extending life with comfort and valued outcomes' *or* 'Prioritise comfort'. The details of the form are not crucial for this discussion other than to give a sense of what such a form can potentially capture. Interestingly, the ReSPECT form gives no specific consideration to organ donation (although as an aside, we think that it should), and as a consequence could hinder donation if some of its content was in tension with donation processes. The exclusion of organ donation may be deliberate rather than an oversight, given that ReSPECT forms are often used for patients with terminal/degenerative conditions which may prohibit much donation anyway, but nonetheless it is a notable omission.

We propose an equivalent to the ReSPECT form, explicitly for the purposes of providing additional information about a patient's organ donation wishes. An appropriately designed form would give patients who use it an opportunity to express how their wish to donate their organs should be balanced against other potentially competing wishes, would allow patients to express which procedures pre- and post-death they would be willing to undergo, and express their preferences in relation to interventional research. Designing this form would need input from patients, healthcare professionals and policy-makers, but indicatively it could ask (using sliding scales akin to the ReSPECT form) how a person weighs optimising their donated organs against risks to themselves, or how they weigh organ donation against an intervention-free death, and potentially even how much they wish for their family members to be involved in decision-making about organ donation. The form could be an optional extra for patients when they register an organ donation decision online and simple for patients to update should their wishes change. Given the increasing complexity of organ procurement processes, having such a form for the purposes of organ donation could offer some benefits.

It could be argued that the existing ReSPECT form could serve this purpose, as it allows patients to express values/preferences at the end of life. Although the ReSPECT form and its processes are technically available to anyone, it is primarily aimed at those with complex health needs or people nearing the end of their lives: it therefore caters for a particular population of patients, specifically a population for whom organ donation is less likely to be a possibility. The existing form overlooks organ donation completely, and focuses heavily on quality of life, quantity of life and CPR decisions. Using the ReSPECT form to guide decision-making about organ donation would require a significant reframing of its purpose and target userbase, and may add length and complexity to a form that is already frequently poorly completed by clinicians.[16]

ETHICAL ADVANTAGES

There are four key benefits to our proposal. First, our proposal promotes patient autonomy. Second, it is more likely to result in decisions being made that accurately reflect the patient's best interests. Third, it presents a clearer situation to relatives and alleviates some of the decision-making burden. Finally, it provides clarity for clinicians so that they can be confident that they are making the right decisions.

The proposed form would promote autonomy in two respects. First, it creates a wider domain of decisions over which patients can exercise choice. Potential donors would be able to specify what they would be willing, or would be willing to permit their organs, to undergo in order to achieve successful donation.

Second, it increases opportunities to educate potential donors about donation, thereby helping them to make more informed choices. An online form could be accompanied by interactive materials explaining the pros and cons of the various technological options that may now accompany donation. Completing the form could remain optional but could help interested patients to make more nuanced and informed choices about what happens at the end of their lives. Without contrary evidence, we should not assume that the public knows what donation may involve or what research and innovation may hold for the future of transplantation. Not everybody would wish to know more about the intricacies of donation, and some people may be willing to give a blanket 'yes' or 'no' to everything involved in donation. But the increasingly complex nature of donation, with components that patients may or may not wish to be involved with, suggests that giving patients additional information and control will maximise opportunities to both respect and promote autonomous decision-making.

Most importantly, our proposed form would give potential donors an opportunity to clearly express the importance of organ donation to them, and which burdens they are willing to shoulder to become an organ donor. As discussed, someone not opting-out of organ donation may be considered evidence of a wish to become a donor. Someone opting-in to organ donation would also be evidence of a wish to become a donor. Assuming that somebody opting in has a stronger desire than someone who has simply not opted out would reflect flawed reasoning. Opting-in arguably gives stronger evidence of a desire to donate, but says nothing about the strength of the desire or how this should be weighed against other factors. Simply knowing that somebody wanted to become an organ donor does not provide much guidance when determining whether organ donation is in their best interests: all it provides is one known wish amongst potential other known and unknown wishes. Without knowing the weight afforded to each of these wishes by the patient, establishing whether donation is in their best interests (without further discussion with family members, or making fairly heroic assumptions) is not possible. A well-designed form would allow potential donors to express the relative value they afford to their donation wishes, thereby increasing the likelihood of decisions being made that accurately reflect these.

The advantages are not restricted to people who could become organ donors. A key message of recent UK organ donation campaigns has been to communicate one's donation decision with one's relatives.[17] Partly this is because it increases the likelihood of one's decision being respected, but it has also been suggested that it makes the situation for one's relatives easier if they have a clear sense of what one wanted.[17] Our proposed form would make explicit the patient's wishes, in a way that is likely to be difficult to achieve via an informal conversation over the dinner table. Shaw previously proposed video 'personalised organ donation directives' to inform relatives of one's willingness to donate,[18] but our proposal goes beyond this, by providing nuance and value to one's potentially conflicting wishes. This benefit also extends to the staff involved in organ donation.

Having additional information to guide their decisions should increase their confidence that they are making the right decisions for that particular patient.

POTENTIAL DISADVANTAGES

Our proposal does, however, have potential downsides. A key feature of the ReSPECT form is that it has accompanying processes. The plan recorded on the form is reached via discussions between patient and healthcare team, and can be an important part of advance care planning. Implementing a similar approach for organ donation would be resource intensive, and it is not obvious when would be an appropriate time for such discussions to be had. Although there may be arguments in favour of a wider use of ReSPECT forms, they are generally used with patients approaching the end of their lives or who are foreseeably anticipated to risk losing capacity. While equivalent processes for our proposed form may offer some advantages, we suggest that they are not strictly necessary: online materials could serve a similar purpose, and a form without processes is preferable to no form.

A further potential disadvantage is that such a form could potentially become outdated should a patient's wishes change, and therefore potentially hinder respect for their autonomy. It is currently the case, however, that a person's organ donor register status may not reflect their latest wishes, and nor might their family's perceptions. While there is the potential for such a form to become outdated, it would at least provide a starting point and an additional snapshot of concrete information about the patient's wishes to aid discussions and decisions.

There are some putative reasons why scope for patients to have additional input over the specifics of organ donation is not already facilitated:

- i) some of these decisions are considered clinical decisions and patient input is not required;
- ii) providing people with more information, or too much choice about organ donation will discourage donation;
- iii) it may exacerbate existing inequalities related to organ donation and advance care planning;
- iv) giving patients additional choice would require 'bespoke' donation processes for each patient

While it is true that decisions about whether, for instance, ex situ machine perfusion is appropriate for a donated liver is largely a clinical decision, it also remains true that it is something that a potential donor may feel that they have a stake in, and something that might influence their willingness to donate. Someone feeling that they should have input into a decision does not mean that they should have input, but if that decision has a substantive impact upon another decision within their legitimate control, then their views do gain some significance. For example, a potential donor may be willing to donate but only if ex situ machine perfusion is not used. Although this could be construed as conditional donation and fall into murky ethical territory,[19] it is not significantly different from someone agreeing to donate some but not all organs.

Whether giving people more information or too much choice would discourage them from donating is an empirical question, but does not speak decisively against our proposal. If giving patients more information leads them to make different decisions, then arguably they should be provided with that information to make a sufficiently autonomous decision in the first place. If providing patients with too much choice discourages them from donating (in that they become confused by the options and this dissuades them), then the choices could be presented differently or in more understandable ways. Given our proposed form is an optional extra for those wishing to record more nuanced

wishes, it seems unlikely that those with no interest in these options would pay much attention to it anyway.

There is a risk that our proposal may see variable uptake, that awareness and engagement may vary, and that this may potentially exacerbate inequalities in end-of-life care planning. For example, uptake of advance care planning has been found to be low amongst older people from cultural or ethnic minorities,[20] and there are long-standing inequalities related to organ donation and transplantation in the UK.[21] Our proposal could be viewed as undesirable if it risks increasing or perpetuating these inequalities. This does not provide a compelling argument against our proposal, however, but rather speaks to the importance of targeted campaigns to increase awareness, engagement and uptake amongst those groups who may currently be lacking in these regards. These sorts of campaigns should already be happening as part of the move to deemed consent.

Finally, it is plausible that having more precise information about patient's wishes could make the donation process more complex. Rather than a consistently applied process, each patient may require a 'bespoke' process based upon the individual factors/processes that they would or would not accept. This may add complexity and may require additional planning (if a patient is not willing for their organs to undergo machine perfusion further down the line, then different recipients may be more appropriate for those organs, for example). Additionally there is a risk that wishes recorded via our proposal may conflict with wishes recorded via other advance care planning tools, thereby potentially clouding decision-making. But these are not compelling reasons to oppose our suggestions. Clinical differences already dictate individualised approaches to donation, so our suggestion may not make things more complex than they already are, and greater clarity of the patient's wishes may aid navigating this complexity. A well-designed form could accommodate potential conflict, and ask patients how they would like their organ donation wishes to be weighed against previously recorded wishes elsewhere. If it is important to respect patients' wishes at the end-of-life then the system should adapt to accommodate this, rather than baulking at extra complexity.

APPLICATION WITHIN A UK CONTEXT

We have suggested a proposal to provide more nuanced information about patient wishes and values regarding processes associated with organ donation. Implicit in our argument is a view that decisions should respect patients' wishes, and it could be argued that a system of deemed consent is not the best way to achieve this, particularly given the non-ideal timing of the implementation of deemed consent in England.[22] Our proposal would, however, work effectively within the UK's deemed consent systems: we would envisage our proposed form being used by those opting-in and registering a positive wish to donate, although it could also be accessible to those who have not opted out. It would seem sensible, however, to understand completion of the form as effectively indicating opting-in (and the form could be designed to make this explicit), as there would be no reason to complete it if one did not want to donate.

Rather than acting as a binding advance decision, we would envisage the purpose of this form being to add to the information available to aid decision-making regarding organ donation, with the aim of increasing the likelihood of decisions being made that reflect what the patient would want were they able to make the decision for themselves. Other information may also be available from relatives, or via other advance care planning tools, but this form would make explicit the patient's own preferences in the specific scenario of potential organ donation.

CONCLUSIONS

We have argued that a form similar to the ReSPECT form specifically for the purposes of organ donation may offer benefits to potential organ donors, their families and medical staff involved in donation. A simple 'yes' or 'no' to cover all aspects of donation may be sufficient for some patients, but there are practical and ethical imperatives to offering patients opportunity to record more complex preferences. It is perverse that, as organ donation/procurement has become more complex and multi-staged, the means of expressing one's wishes has become more simplistic via opt-out legislation. Our proposal would give those who wish to make more nuanced decisions the opportunity to do so, and would also provide a vital opportunity to establish not just evidence of a wish to donate, but the strength of that wish relative to other considerations. This latter aspect has been given inadequate consideration in key guidance, potentially resulting in decisions being made that are not consistent with a patient's best interests.

Acknowledgments

The authors thank the two anonymous reviewers for their helpful and constructive comments.

Competing Interests

The authors confirm that they have no competing interests.

Funding

The authors have received no funding for this work.

¹ de Meijer VE, Fujiyoshi M, Porte RJ. Ex situ machine perfusion strategies in liver transplantation. *J Hepatol* 2019;70(1):203-5.

² NHS Blood and Transplant NRP Implementation Group. UK Protocol for Normothermic Regional Perfusion (NRP) in controlled Donation after Circulatory determination of Death. 2021. Available at: https://scts.org/_userfiles/pages/files/transplant/ukprotocolfornormothermicregionalperfusionversion13100421.pdf Access date: April 2022

³ Padilla M, Coll E, Fernández-Pérez C, et al. Improved short-term outcomes of kidney transplants in controlled donation after the circulatory determination of death with the use of normothermic regional perfusion. *Am J Transplant* 2021;21(11):3618-28.

⁴ UK Donation Ethics Committee. An Ethical Framework for Controlled Donation After Circulatory Death. 2011. Available at: https://www.aomrc.org.uk/wp-content/uploads/2016/04/Ethical_framework_donation_circulatory_death_1211-3.pdf. Date accessed: April 2022

⁵ Coggon J, Brazier M, Murphy P, et al. Best interests and potential organ donors. *BMJ* 2008;336(7657):1346-7.

⁶ NHS Blood and Transplant. Organ Donation and Transplantation 2030: Meeting the Need. 2022. Available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/23463/meeting-the-need-2030.pdf>. Date accessed: April 2022

⁷ Cooper J, Harvey D, Gardiner D. Examining consent for interventional research in potential deceased organ donors: a narrative review. *Anaesthesia* 2020;75(9):1229-35.

⁸ Taylor JS. Death, posthumous harm, and bioethics. New York: Routledge 2012

⁹ Albertsen A. Against the family veto in organ procurement: Why the wishes of the dead should prevail when the living and the deceased disagree on organ donation. *Bioethics* 2020;34(3):272-80.

¹⁰ Gathani, A., Moorlock, G., Draper, H. pre-mortem Interventions for Donation After Circulatory Death and Overall Benefit: A Qualitative Study. *Clin Ethics* 2016;11(4):149-158.

¹¹ Department of Health. Legal issues relevant to non-heartbeating organ donation. 2009. Available at: https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_109864.pdf Date accessed: April 2022

-
- ¹² Weiss MJ, van Beinum A, Harvey D, Chandler JA. Ethical considerations in the use of pre-mortem interventions to support deceased organ donation: A scoping review. *Transplantation Reviews*. 2021;35(4):100635
- ¹³ Brown, S-J. Organ donor registration in the UK: the need for informed consent for ante-mortem interventions to facilitate organ donation. *Med Law Int* 2019;19(2-3):113-135
- ¹⁴ Hawkes CA, Fritz Z, Deas G, et al. Development of the recommended summary plan for emergency care and treatment (respect). *Resuscitation* 2020;148:98-107.
- ¹⁵ ReSPECT Form Version 3, available at: https://www.resus.org.uk/sites/default/files/2020-09/ReSPECT%20v3-1-formSPECIMENFINAL_0.pdf Date accessed: April 2022
- ¹⁶ Eli K, Hawkes CA, Fritz Z, et al. Assessing the quality of ReSPECT documentation using an accountability for reasonableness framework. *Resuscitation Plus* 2021;7:100145
- ¹⁷ NHS Blood and Transplant 'Talk to your loved ones' - <https://www.organdonation.nhs.uk/talk-to-your-loved-ones/>
- ¹⁸ Shaw D. Personalized organ donation directives: saving lives with PODDs. *Critical Care* 2014;18(3):1-2.
- ¹⁹ Wilkinson TM. What's not wrong with conditional organ donation?. *J Med Ethics* 2003;29(3):163-4.
- ²⁰ de Vries K, Banister E, Denning K, et al. Advance care planning for older people: The influence of ethnicity, religiosity, spirituality and health literacy." *Nursing ethics* 2019;26(7-8):1946-1954.
- ²¹ Randhawa G, Gardiner D. Tackling organ donation among minority ethnic communities in the UK-a whole systems approach. *British medical bulletin* 2022;p.ldac008.
- ²² Parsons JA, Moorlock G. A global pandemic is not a good time to introduce 'opt-out' for organ donation. *Med Law Int* 2020;20(2):155-166.