

Should Consent Be Required for Deceased Organ Donation?

Thomas Burton*

ABSTRACT: The current legal framework in the UK governing deceased organ donation has adopted the doctrine of consent as its central guiding principle. Under the Human Tissue Act 2004, appropriate consent must be given for the removal of organs from a cadaver to be lawful. However, this position requires justification; consent is not a free-standing principle, but must exist in relation to a potential right violation. In healthcare, the need for consent has been grounded on the protection of the patient's rights to autonomy and bodily integrity. These rights are not present in the context of deceased organ donation, and therefore consent should not be required. Instead, we should adopt a system of routine retrieval with opt-out based on the best interests of the donor. This recognises the fact that both the deceased and their relatives can have strong interests regarding the use of the body after death, which, although not sufficient to ground a right, must be taken into consideration. A system of routine retrieval with opt-out would also result in more organs for potential recipients, and reduce the decision-making burden on families.

KEYWORDS: Organ donation; Consent; Best interests; Opt-out; Posthumous interests.

SUMMARY: 1. Introduction. – 2. The role of consent. – 3. Posthumous interests and harms. – 4. The role of relatives in deceased organ donation. – 5. Alternative systems. – 6. A new proposal. – 7. Conclusion.

1. Introduction

Since the first successful kidney transplant in 1954, the field of organ transplantation has advanced at an astonishing pace. It is now possible to transplant an ever-increasing list of organs and tissues, and the long-term success of these procedures continues to improve. In 2013/14, there were 1320 deceased donors, resulting in 3505 organ transplants¹. For many of these recipients, these transplants are either life-saving or have a dramatic impact on their quality of life. However, with the success of this rapidly expanding field of technology has come a problem: an increased demand for viable organs that cannot be met by the current system of organ procurement in the UK. As a result, many lives are lost each year that could potentially have been saved if more organs were available².

* BSc(Hons), BMBS, MA. This essay is a revised version of a dissertation submitted as a requirement for the MA Medical Ethics and Law, King's College London, England. This essay has been subjected to a double blind peer review.

¹ NHS BLOOD AND TRANSPLANT, *Organ donation and transplantation: Activity report 2013/14*, 2014, 6.

² 456 patients died whilst on the active transplant list in 2013/14 (NHS BLOOD AND TRANSPLANT, *op. cit.*, 2). However, it is estimated that the true number of deaths because of a shortage of organs is likely to be much higher; 1000 deaths per year (or three deaths per day) is often quoted (BMA, *Building on progress: Where next for organ donation policy in the UK?*, 2012, 8).

In response to this problem, strategies to increase the supply of available organs are constantly being sought. However, there is no avoiding the fact that these organs are obtained from human beings, albeit, human beings that are no longer alive in the case of deceased organ donation³. Nevertheless, cadaveric organ donors were once people with interests and rights. Therefore, in the context of deceased organ donation, there can be seen to be two broad, and often conflicting, considerations: those that seek to promote the interests of the persons in need of an organ (recipient-focused); and those that are concerned with the interests of the individual whose organs could be donated (donor-focused). The first category is heavily influenced by utilitarian thinking; it aims to maximise the amount of good done for the most people by advocating policies that prioritise the number of lives saved or improved. In contrast, donor-focused policies are often deontological or rights-based in their approach. They seek to protect the interests or rights of the individual from the needs of others, even at the expense of saving more lives. Most deceased organ donation policies fall somewhere on a spectrum between these two extremes, seeking to reach a compromise between saving as many lives as possible, whilst at the same time avoiding the violation of individual rights.

In 2008, the Organ Donation Taskforce (ODT) published their report addressing the question of how the supply of organs could be increased, including whether legal reform is warranted⁴. At the time, the ODT advised against a change in the law in the UK to an opt-out system, and instead recommended a number of infrastructure and organisational changes within the current legal framework to improve the efficiency of the current system. Since their report in 2008 and the implementation of the recommended changes, the situation has somewhat improved in terms of the number of available organs for donation. From 2009/10 to 2013/14, the total number of deceased donors has consistently increased⁵, as has the number of people registered on the Organ Donor Register (ODR)⁶. In addition, the number of people on the active transplant waiting list has simultaneously fallen each year⁷. Clearly the situation in the UK appears to be improving. However, the fact still remains that the supply of available organs is unable to meet the demand. Similarly, the decrease in the number of people on the waiting list is unlikely to reflect a true drop in demand for organs as many more people would be added to the list if more organs were available⁸. Assuming that saving lives, or at least prolonging the lives of those who wish to continue living, is a good that we should aim for, there is an incentive to increase the number of available organs.

In this paper, I will address the question as to whether consent should be required for deceased organ donation⁹. In order to do so, I will first summarise the current legal framework in the UK regarding or-

³ I am assuming here the acceptance of the current medico-legal definition of death, including brainstem death, which remains controversial in some quarters. However, this is an issue outside the scope of this essay.

⁴ ORGAN DONATION TASKFORCE, *The potential impact of an opt out system for organ donation in the UK. An independent report from the Organ Donation Taskforce*, 2008.

⁵ NHS BLOOD AND TRANSPLANT, *op. cit.*, 4.

⁶ NHS BLOOD AND TRANSPLANT, *op. cit.*, 117.

⁷ NHS BLOOD AND TRANSPLANT, *op. cit.*, 4.

⁸ BMA, *op. cit.*, 8.

⁹ The scope of this paper will be confined to deceased (or cadaveric) organ donation in the context of adult donors for therapeutic purposes. Although some of the issues discussed within this paper may also be relevant in the contexts of living organ donation, donation for research purposes, or donation from minors, further discussion would be required before the conclusions drawn here could be applied to these areas as well.

gan donation and the emphasis on consent. I will then question the justification for this approach, including a discussion of the doctrine of consent and how it can be undermined, and an examination of the interests/rights that are relevant in this context, including those of the deceased themselves and the family. Lastly, I will appraise two different approaches to deceased organ donation – conscription and opt-out – before proposing a new approach based on an adapted best interests test.

2. The role of consent

2.1. The Human Tissue Act 2004

The law concerning deceased organ donation in the UK is contained within the Human Tissue Act 2004 (HTA 2004), covering England, Wales¹⁰, and Northern Ireland, and the Human Tissue (Scotland) Act 2006.¹¹ The HTA 2004 replaced the Human Tissue Act 1961¹², the Human Tissue Act (Northern Ireland) 1962, the Anatomy Act 1984, and the Human Organ Transplants Act 1989¹³, and aims to provide a «consistent legislative framework for issues relating to whole body donation and the taking, storage and use of human organs and tissues»¹⁴. It also established the Human Tissue Authority, which publishes codes of practice as one of its statutory functions¹⁵. The driving force behind this reform in the law was largely a response to the widespread public outcry when it came to light that children's organs had been retained without the knowledge of the parents at both the Bristol Royal Infirmary and the Alder Hey Children's Hospital in the 1990s. Subsequent inquiries into the practices of post-mortem human organ and tissue retention at the time highlighted that legal reform in English law concerning these matters was long overdue.¹⁶ As Margaret Brazier noted: «There is little dissent

¹⁰ However, the Welsh Government recently passed the Human Transplantation (Wales) Act 2013, which introduces an opt-out system of consent to deceased organ donation and will come fully into effect on 1st December 2015. I will discuss this new piece of legislation later.

¹¹ Although there are several differences between these two Acts, for the purposes of this essay, I will focus my discussion on the English version, and only highlight aspects of the Scottish version that are relevant to my discussion. One such difference is the use of 'authorisation' in the Scottish Act in place of 'appropriate consent' which I will come to later.

¹² In fact, the 1961 Act was mainly concerned with the regulation of transplantation therapy, with only a small part covering post-mortem examinations. Some are critical of this conflation of the different uses of human tissue in the law, such as therapy or research, despite the clear distinction in the public consciousness, and that it is a «matter for regret that the opportunity was not taken to legislate for the first time on a distinct conceptual plane». (J. MASON J, G. LAURIE, *Mason and McCall Smith's Law and Medical Ethics*, Oxford, 2011, 549).

¹³ However, the removal of human material from living persons will continue to be governed by the existing common law, particularly relating to informed consent and battery, see Human Tissue Act 2004 Explanatory Notes s. 9.

¹⁴ HTA 2004 Explanatory Notes, s.4.

¹⁵ HTA 2004 s.26. So far, 9 codes of practice have been published: 1) Consent; 2) Donation of solid organs for transplantation; 3) Post-mortem examination; 4) Anatomical examination; 5) Disposal; 6) Donation of allogenic bone marrow and peripheral blood stem cells for transplantation; 7) Public display; 8) Import and export; 9) Research. This highlights the expansive nature of this field and the constant need for the Human Tissue Authority to update its guidance.

¹⁶ See: Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-95, *Learning from Bristol* Cm 5207, 2001; and *The Royal Liverpool Children's Inquiry Report* (Redfern Report), London, 2001.

from the view that law reform is urgent. The confused and tangled web of different statutes and outdated common law principles must be clarified, preferably in a single Act of Parliament»¹⁷. In response to these inquiries, the Government published the Human Tissue Bill 2003, and, after several amendments, the HTA 2004 received Royal Assent on 15th November 2004¹⁸.

The HTA 2004 adopts the doctrine of consent as the fundamental principle underlying the lawful removal and use of human organs¹⁹. Accordingly, 'appropriate consent' must be obtained in order for the removal of organs or tissue from a human body for the purposes of, among other things, transplantation²⁰. For adults, appropriate consent can be obtained in three ways: 1) if the deceased themselves consented to donation prior to their death, by registering on the organ donor register (ODR) or by carrying an organ donor card²¹; 2) if the deceased's wishes are not known, then someone appointed by the deceased can consent on their behalf²²; 3) if neither 1) nor 2) are possible, then consent can be sought from someone in a qualifying relationship²³; The HTA 2004 defines qualifying relationships and the ranking in which they should be sought²⁴; those higher in the hierarchy should be approached first, if possible, and their consent or refusal is binding upon members lower down the order²⁵. Relationships within the same ranking are accorded equal priority²⁶. If there is more than one person of equal highest ranking present, the consent of any of them is sufficient²⁷. As Emily Jackson points out, this has the potential to create friction among family members that are in disagreement:

«This means that if the deceased has both an estranged spouse and a new partner, the consent of the estranged spouse would be sufficient, even if the current partner objects. Similarly, where the deceased has no spouse or partner, but several children, any one of them can give consent, even if all of the other children are opposed to organ retrieval»²⁸.

The Act itself does not specify exactly what form the consent should take nor what is required in order for the consent to be valid, except in the case of anatomical examination or public display in which written consent is required²⁹. However, it is assumed to be explicit consent, as opposed to im-

¹⁷ M. BRAZIER, *Medicine, Patients and the Law*, London, 2003, 479.

¹⁸ Scotland later enacted the Human Tissue (Scotland) Act 2006 in response to similar pressures.

¹⁹ HUMAN TISSUE AUTHORITY, *Code of Practice 1: Consent* (Version 14.0), 2014, para.26.

²⁰ HTA 2004 s.1.

²¹ HTA 2004 s.3(6)(a).

²² HTA 2004 ss.3(6)(b)(ii) and 4.

²³ HTA 2004 s.3(6)(d).

²⁴ HTA 2004 s.27(4). The full hierarchy is as follows: a) Spouse or partner; b) Parent or child; c) Brother or sister; d) Grandparent or grandchild; e) Child of a brother or sister; f) Stepfather or stepmother; g) Half-brother or half-sister; h) Friend of long standing. Interestingly, although most familial relationships are covered within this list, including nephews and nieces, aunts and uncles are not.

²⁵ HTA 2004 s.27(6).

²⁶ HTA 2004 s.27(5).

²⁷ HTA 2004 s.27(7).

²⁸ E. JACKSON, *Medical Law: Text, Cases, and Materials*, Oxford, 2013, 580.

²⁹ HUMAN TISSUE AUTHORITY, *op. cit.*, para.61.

licit or inferred³⁰. Furthermore, the Human Tissue Authority provides guidance as to what constitutes valid consent via its codes of practice. Whether it is the individual themselves who is consenting, or a nominated representative or person in a qualifying relationship, the decision-maker should be aware of the nature and purpose of the intended activities³¹.

Lastly, section 5 of the HTA 2004 establishes offences where organs are removed without appropriate consent, unless the person 'reasonably believes' that either appropriate consent was obtained or that it was not required for the activity performed³². This builds on the existing common law regarding lawful removal of bodily material, governing the use of such material after removal as well. As such, «the offense uses the doctrine of consent to provide individuals with greater protection over the subsequent use of relevant material removed from their body than that which is conferred under the common law»³³.

The attraction of adopting consent as the fundamental principle underpinning deceased organ donation is obvious; it has arguably become the defining principle within medical law and provides strict legal safeguards for individuals³⁴. However, is this position justifiable? Should consent be required for deceased organ donation?

2.2. The role of consent in medical law

In *Schloendorff v New York Hospital*, Cardozo J famously stated that: «Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without the patient's consent commits an assault»³⁵. The idea that a competent adult must give consent for any treatment to be lawful is a fundamental principle of medical law and continues to be strongly reiterated by the courts³⁶. Touching another person without

³⁰ DEPARTMENT OF HEALTH, *Proposals for new legislation on human organs and tissue*, 2003, 2: «Explicit consent to be the fundamental principle underpinning the lawful removal, storage and use of bodies, body parts, organs and tissue».

³¹ HUMAN TISSUE AUTHORITY, *op. cit.*, para.35: «For consent to be valid, the person should understand what the activity involves and, where appropriate, what the risks are»; para.106: «Where no decision was made by the deceased, when seeking consent from a nominated representative or from a person in a qualifying relationship, full and clear information should be provided about the purpose for which consent is being sought. This should allow them to make a properly considered decision. This information should include the nature of the intended activities and the reasons for them».

³² HTA 2004, s.5(1).

³³ R. HARDCASTLE, *Law and the Human Body: Property Rights, Ownership and Control*, Oxford, 2007, 108.

³⁴ G. DWORKIN, *The Theory and Practice of Autonomy*, Cambridge, 1988, 90: «Consent serves as a check on the power of those agents (political or medical) who are making decisions that affect one's interests in significant ways. Consent makes it more likely that welfare will be maximised because costs are borne only by those willing to pay them and are therefore presumably worth it to those individuals. Consent preserves the autonomy of the individual because his right to self-determination, his control of his body and his possessions, can be abrogated only with his agreement».

³⁵ *Schloendorff v New York Hospital* (211 NY 125 (NY CA 1914) 126).

³⁶ Lord Steyn in *Chester v Afshar* [2004] UKHL 41, para.14: «The starting point is that every individual of adult years and sound mind has a right to decide what may or may not be done with his or her body. Individuals have a right to make important medical decisions affecting their lives for themselves: they have the right to make decisions which doctors regard as ill-advised».

their consent is prima facie unlawful, resulting in an action in battery or assault³⁷. This is in recognition of the right to bodily integrity that has long been protected by English law³⁸. In order for consent to be valid, it must fulfil certain stipulations: the person giving consent must have capacity; the consent must be given voluntarily; and the individual must be adequately informed of the nature and purpose of the proposed procedure. The term 'informed consent' is often used to denote this.

The importance of the doctrine of informed consent in medical law is intrinsically linked to the principle of autonomy³⁹. Respect for individual autonomy, together with concern for the individual's welfare, are necessary in order to show respect for persons, which defines how we should treat those who matter morally⁴⁰. Autonomy allows us to dictate our own lives, shaped by our own values and interests; concern for welfare promotes an environment in which autonomy can flourish. For some, concern for welfare is necessarily held to be subordinate to autonomy; «it is not simply a good in itself»⁴¹. When concern for welfare ceases to enhance an individual's autonomy, but rather hinders our ability to make our lives our own, it is no longer legitimate. As Gerald Dworkin explains:

«One way of showing respect for a person is by seeking his willing acceptance of a plan of treatment. Seeking consent is an expression of respect for autonomy in the way that apology is an expression of regret. To fail to seek consent, as in the case of therapeutic privilege, is necessarily an insult to autonomy even though motivated by pure benevolence»⁴².

The principle of autonomy has come to wield considerable influence within modern political and moral discourse⁴³. Indeed, some have argued that autonomy «deserves ultimate respect because it is taken as the ground for both moral treatment and moral responsibility»⁴⁴. It has been invoked as one of the four fundamental principles guiding the discipline of medical ethics⁴⁵, and is regarded by some as the «first among equals»⁴⁶. However, invoking the right to respect for autonomy is not without its difficulties. First, there is the question of what exactly is meant by respect for autonomy; how is autonomy to be understood and what is required of others in order to give it due respect? Are there

³⁷ See: *R v Tabassum* [2000] 2 Cr App R 328 (CA); and *Appleton v Garrett* [1995] 34 BMLR 23.

³⁸ G. FLETCHER, *Basic Concepts of Legal Thought*, Oxford, 1996, 109: «When individuals consent to undergo medical operations... they convert what otherwise would be an invasion of their person or their rights into a harmless or justified activity».

³⁹ J. HARRIS, *Law and regulation of retained organs: the ethical issues*, in *Legal Studies*, 22, 2002, 529: «The centrality of consent in health care is a function of the importance accorded to autonomy; and autonomy itself is part of our concept of the person because it is autonomy that enables the individual to 'make her life her own'».

⁴⁰ J. HARRIS, *Law and regulation of retained organs: the ethical issues*, cit., 529.

⁴¹ J. HARRIS, *Law and regulation of retained organs: the ethical issues*, cit., 530.

⁴² G. DWORKIN, *op. cit.*, 120.

⁴³ For example, the right to autonomy is clearly enshrined within the European Convention on Human Rights, Article 8: Right to respect for private and family life (*Pretty V United Kingdom* [2002] 35 EHRR 1).

⁴⁴ R. RHODES, *Physicians, assisted suicide, and the right to live or die*, in M.P. BATTIN, R. RHODES, A. SILVERS (eds.), *Physician-Assisted Suicide, Expanding the Debate*, London, 1998, 169.

⁴⁵ T. BEAUCHAMP, J. CHILDRESS, *Principles of Biomedical Ethics*, Oxford, 2009.

⁴⁶ R. GILLON, *Ethics needs principles – four can encompass the rest – and respect for autonomy should be "first among equals"*, in *Journal of Medical Ethics*, 29, 2003, 307.

limits to autonomy? The problem is that autonomy is used by different authors to convey a variety of meanings and there does not appear to be a consensus view on its use⁴⁷. The danger, therefore, is that the interpretation of what autonomy entails, its limits and what it demands of others, will be influenced by the argument that the author is seeking to promote. For example, as we have already seen, John Harris understands autonomy as a liberal and powerful construct, which enables us to make our lives our own; to shape our lives by the choices we make. For him, concern for welfare is necessarily subordinate to autonomy⁴⁸. John Keown, on the other hand, argues that individual choice can only be respected when it accords with fundamental moral values and promotes human flourishing. There must be limits to its scope; it is not absolute⁴⁹.

Regardless of these problems, the priority that is conferred to the protection of these two principles, autonomy and bodily integrity, in English law cannot be in any doubt. The courts have consistently reiterated the right for a competent adult to refuse medical treatment, «notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent»⁵⁰. Furthermore, this right has been upheld even in situations when the refusal of treatment will likely result in death⁵¹. This would suggest that, in English law at least, respect for autonomy is able to override concerns for another's welfare⁵².

2.3. Threats to the doctrine of consent

According to Roger Brownsword, there are two kinds of threat to the integrity of the principle of consent⁵³. The first, and more familiar one, is the threat of undervaluation, where consent is «reduced to a bureaucratic process... as a lazy justification»⁵⁴. He gives the examples of presumed, deemed, or implicit consent, which are not in fact consent. The other, more insipid, threat is that of overvaluation, in which consent is «viewed as *the* key to ethical and legal justification»⁵⁵. In this sense, communities can become fixated on consent and treat it as an independent value⁵⁶. When this happens, the claim is often invoked that whether an act is right or wrong hinges on the presence, or absence, of consent.

⁴⁷ G. DWORKIN, *op. cit.*, 6. Autonomy is often related to ideas of liberty, self-rule, freedom, dignity, integrity, individuality, self-assertion, and knowledge of one's own interests to name but a few.

⁴⁸ J. HARRIS, *Euthanasia and the value of life*, in J. KEOWN (ed.) *Euthanasia Examined: Ethical, Clinical and Legal Perspectives*, Cambridge, 1995, 11.

⁴⁹ J. KEOWN, *Euthanasia, Ethics and Public Policy*, Cambridge, 2002, 53-5.

⁵⁰ Lord Donaldson MR in *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, p102. Also see Lord Goff in *Airedale NHS Trust v Bland* [1993] AC 789, p864: «the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so».

⁵¹ *Re B (Adult: Refusal of Treatment)* [2002] EWHC 429 (Fam).

⁵² See: Lord Mustill in *Airedale NHS Trust v Bland*: «If the patient is capable of making a decision on whether to permit treatment... his choice must be obeyed even if on any objective view it is contrary to his best interests».

⁵³ R. BROWNSWORD, *The cult of consent: fixation and fallacy*, in *The King's College Law Journal*, 15, 2004, 223.

⁵⁴ R. BROWNSWORD, *op. cit.*, 224.

⁵⁵ R. BROWNSWORD, *op. cit.*, 224.

⁵⁶ D. PRICE, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework*, Cambridge, 2010, 104: «There is a tendency toward perceiving consent as a "free-standing ethics or

This claim inevitably leads to one (or both) of two fallacies: the fallacy of necessity and the fallacy of sufficiency. The fallacy of necessity arises when the secondary claim is made that where there is no consent, an act must be wrong. However, as Roger Brownsword points out, what makes an act unjustified is the violation of a right⁵⁷, not the absence of consent per se. Furthermore, it does not follow that there can be no other justification for the act other than consent. The fallacy of sufficiency results from the claim, based on the initial false premise that whether an act is justified hinges solely on the presence of consent, that where consent is present, an act is justified. This claim fails on two accounts. Firstly, it does not hold that if there is consent, there can be no wrong. For example, if there are two consenting parties, there can still be harm caused to a third party. Secondly, it also does not follow that if there is consent and no private wrong, that this excludes the possibility of a public wrong.

2.4. The role of consent in deceased organ donation

It is clear that it must first be determined what right is being violated, and therefore whether consent is required, not the other way around. In competent adults, the doctrine of consent protects the rights to autonomy and bodily integrity. But what rights are being violated in the instance of organ retrieval from the deceased? Do the dead have these rights? Certainly, the dead cannot be autonomous, which raises the issue of whether a person's autonomy can be violated after the person has ceased to exist. And even if their autonomy can be violated, this raises the equally controversial question of the possibility of posthumous harms. For some, these differences are too significant to afford the protection of consent to the deceased⁵⁸.

Furthermore, there is the question of whether the deceased can have their bodily integrity violated. In some sense, it would appear that they can. For example, if individuals are not treated according to their religious or cultural beliefs that require the dead to be buried whole, or intact⁵⁹. In fact, «bodily integrity after death is for very many people a more fundamental value than protection from a pinprick in life»⁶⁰, which would be protected by the principle of consent. However, even if this is so, this interpretation of bodily integrity in the dead is a far cry from the idea of bodily integrity in the living; «the interest in bodily integrity is clearly changed by death, even if it does not disappear, as we can see when we consider that while people cannot consent to being dismembered while alive, they can consent to being dismembered after death»⁶¹. It is not clear that this changed idea of bodily integrity requires the same level of protection that consent provides to the living.

These differences between the use of consent in its traditional sense and its use within the discussion of deceased organ donation have led some to call for the adoption of a different term. The notable

justificatory standard", the view that there is a wrong merely on account of an absence of consent *per se*. Morally speaking, consent may make things right but its absence in and of itself does not make things wrong».

⁵⁷ Roger Brownsword approaches the question from a human rights perspective.

⁵⁸ A. JONSEN, *Transplantation of fetal tissue: an ethicist's viewpoint*, in *Clinical Research*, 36, 1988, 215: «consent is ethically important because it manifests and protects the moral autonomy of persons... [and] it is a barrier to exploitation and harm. These purposes are no longer relevant to the cadaver, which has no autonomy and cannot be harmed».

⁵⁹ M. BRAZIER, *Retained organs: ethics and humanity*, in *Legal Studies*, 22, 2002, 558.

⁶⁰ M. BRAZIER, *Retained organs: ethics and humanity*, cit., 565.

⁶¹ T. WILKINSON, *Last rites: the ethics of research on the dead*, in *Journal of Applied Philosophy*, 19, 2002, 34.

example is of Scotland's use of 'authorisation' instead of consent in the Human Tissue (Scotland) Act 2006, which was based on the recommendation by the Scottish Review Group on Retention of Organs at Post Mortem⁶². These concerns were shared by the Nuffield Council on Bioethics, especially regarding the different amounts of information required to fulfil informed consent:

«Decisions about deceased donation should be based on the known wishes of the donor, so far as this is ascertainable. In ethical terms, the permissibility of such donation should be understood to be on the basis of the authorisation, or willingness to donate, of the deceased, rather than on their consent. We distinguish "authorization"/"willingness to donate" from "consent" in these circumstances, on the grounds of the potentially different informational requirements involved. In contrast to those consenting to donate during life, those authorising donation after death do not expose their health to any risks, and the minimum informational requirements for donors are correspondingly lower»⁶³.

It is important to notice here that there is already a weakening of the requirements for valid consent that normally apply⁶⁴. Arguably, there is a very real risk that the overvaluation of consent and its treatment as a detached and free-standing principle is exactly what has happened with the law regarding deceased organ donation contained within the HTA 2004⁶⁵. In order to justify the requirement of consent, we must determine what rights are being violated. This begs the question of whether the dead can have any interests on which to ground a right, a complex issue which I will now turn to.

3. Posthumous interests and harms

3.1. Posthumous interests

Can the dead have interests? If so, in what sense are the dead harmed if these interests are not respected? Are these interests sufficient to afford the deceased rights? Although to some it may seem absurd to attribute interests to those who are no longer living, it is common for the wishes of the dead

⁶² SCOTTISH REVIEW GROUP ON RETENTION OF ORGANS AT POST-MORTEM, *Final Report*, 2000.

⁶³ NUFFIELD COUNCIL ON BIOETHICS, *Human Bodies: Donation for Medicine and Research*, 2011, 5.

⁶⁴ UK DONATION ETHICS COMMITTEE, *An Ethical Framework for Controlled Donation After Circulatory Death*, 2011, para.3.1.1: «Putting a name on the Organ Donor Register does not require the same level of informed consent as for other medical procedures, when a health professional will describe what is going to happen and why, and answer any questions the patient may have before they sign the consent form. While this is a matter of concern for some, there is also the fact that many people who put their names on the register take the view that what happens to their body after death is not something they wish to think about in any detail».

⁶⁵ R. BROWNSWORD, *op. cit.*, 230: «The Explanatory Notes to the Human Tissue Bill betray an element of back-to-front thinking in this respect (no doubt, reflecting similar thinking in the Bill itself). Consent is presented as 'the fundamental principle underpinning the lawful storage and use of human bodies, body parts, organs and tissue and the removal of material from the bodies of dead persons' (para 4). The question of compliance with the European Convention on Human Rights, particularly with Article 8 arises much later (see para 67). However, the first question should be whether rights (under Article 8 or otherwise) are implicated in the storage and use of human bodies, body parts, organs and tissue. If so, this is why consent is required; if not, consent is a mere courtesy».

to be afforded a degree of respect by most cultures⁶⁶. Perhaps organ donation should be viewed in the same light. Furthermore, people often think that it is important that the bodies of the deceased are treated with respect and dignity; it would be considered improper to desecrate their remains despite the fact that the individual concerned is no longer able to be harmed physically by the treatment. And simply stating that the dead cannot be wronged because they are unaware of the harm caused is also not sufficient. For example, if someone slanders me behind my back, but I remain unaware of the insult, it would still be thought that that person had wronged me. Awareness of the harm does not seem to be necessary for the wrong to occur. In the same way, it does not seem acceptable to no longer attribute any respect to the dead simply because they are no longer able to voice their interests.

That being said, there does appear to be a contradiction between the way in which we feel the deceased should be respected and the acknowledgement that many of the justifications for attributing respect to a person are no longer present in the dead. For one thing, the dead are no longer *persons*. They cannot be autonomous and no longer have any welfare for us to be concerned about. Why then should we respect the wishes of the now deceased? A more plausible way of thinking about posthumous interests is to accept that the dead do not (or cannot) have interests⁶⁷. but «the living have interests in what happens to their dead body»⁶⁸. To use Ronald Dworkin's terminology, these interests are "critical" interests, which persist after death, and are important in determining whether our lives have gone well⁶⁹. For example, I might have an interest in what happens to my estate after I die, or that my family are adequately cared for. I might be a keen environmentalist and want the world to be a better place for future generations. I might have an interest in being remembered in a positive light after I die and not have my reputation defamed. In this sense, it may be possible for people to have wishes whilst alive that we should continue to respect after they have died; pre-mortem interests that persist after death. Therefore, in the context of organ donation, I might have wishes regarding the use of my body that I believe should be respected after I die.

3.2. Posthumous harms

If we do assign pre-mortem interests to the living that persist after death, a further problem is encountered in terms of what harm is caused if these wishes or interests are not respected. Essentially, the problem of posthumous harm can be distinguished into two broad difficulties. Firstly, there is the issue of who is harmed after death when the person whose interests have been neglected is no more (the "no-subject" issue). Secondly, the objection of "backward-causation" (harm cannot occur retrospectively). According to David Price, it is possible for harm to be caused by the defeating of the right to exercise control over one's body after death⁷⁰. Therefore, although the dead no longer have any

⁶⁶ For example, we honour people's decisions regarding the inheritance of their estate or their burial wishes.

⁶⁷ For if someone in PVS cannot have interests, then surely the dead cannot also have interests of any kind. See: Lord Mustill in *Airedale NHS v Bland*, p.894: «The distressing point, which must not be shirked, is that the proposed conduct is not in the best interests of Anthony Bland for he has no best interests of any kind».

⁶⁸ S. McGUINNESS, M. BRAZIER, *Respecting the living means respecting the dead too*, in *Oxford Journal of Legal Studies*, 28, 2008, 297.

⁶⁹ R. DWORKIN, *Life's Dominion*, London, 1993, 215.

⁷⁰ D. PRICE, *op. cit.*, 60.

surviving welfare interests, «our previously formulated desires regarding the posthumous use of the corpse would appear to be intimately connected to our essential “selves” in the broadest sense».⁷¹ But can the deceased really be harmed? Probably not in the traditional sense, but if it is possible for the dead to have persisting interests, as I have argued they have, then it must be possible for the dead to be wronged when these interests are neglected⁷². One way in which the deceased may be wronged is to use their bodies for inherently unacceptable uses. This view usually incorporates the idea of the inherent dignity of all human beings, and attributes the duty to respect this dignity to the dead⁷³. As the Nuffield Council on Bioethics states: «The most widely accepted reasons, however, often stress that these sort of action fail to respect others or to accord them dignity, that they injure human beings by treating them as things, as less than human, as objects for use»⁷⁴. Therefore, «removal of tissue from a corpse may constitute degradation unless it is *either* governed by a direct or indirect therapeutic intention *or* part of accepted funerary rites»⁷⁵.

3.3. Balancing living and posthumous interests

But what moral weight should be given to these persisting interests? And how do they compare with the interests of the living should they come into conflict? According to John Harris, the interests of the dead are necessarily weak and subordinate to the interests of the living⁷⁶. He argues that respecting post-mortem wishes is not to respect the autonomy of the dead, but rather because reciprocity is required if we want our own wishes to be carried out when we die, a social contract of sorts. Therefore, it does not follow that their autonomy has been violated when their wishes are not respected. Harris bases his argument in part on the idea of person-affecting interests⁷⁷. Posthumous interests are not person-affecting; the ‘I’ no longer exists. Instead, post-mortem preferences are other-regarding, rather than self-regarding, and must be balanced against the interests of others⁷⁸. For Harris, these persisting interests post-mortem are necessarily subordinate to person-affecting interests:

⁷¹ D. PRICE, *op. cit.*, 62.

⁷² C. HAMER, M. RIVLIN, *A stronger policy of organ retrieval from cadaveric donors: some ethical considerations*, in *Journal of Medical Ethics*, 29, 2003, 198: «Clearly the dead person cannot be harmed: all that remains of him is his material body. To avoid this problem we must think of the person not simply in terms of his present condition but from an objective and timeless perspective».

⁷³ LAW REFORM COMMISSION OF CANADA, *Procurement and Transfer of Human Tissues and Organs* (Working Paper 66), 1992, 182: «The duty to respect the dead body is a duty not to violate its intrinsic dignity and humanity».

⁷⁴ NUFFIELD COUNCIL ON BIOETHICS, *Human Tissue: Ethical and Legal Issues*, 1995, para.6.7.

⁷⁵ NUFFIELD COUNCIL ON BIOETHICS, *Human Tissue: Ethical and Legal Issues*, cit., para.6.29.

⁷⁶ J. HARRIS, *Law and regulation of retained organs: the ethical issues*, cit., 535: «The appropriate principle should be that their wishes when alive as to post mortem affairs should be respected subject to reasonable demands of public interest».

⁷⁷ Defined by Derek Parfit as: «This part of morality, the part concerned with human well-being, should be explained entirely in terms of what would be good or bad for those people whom our acts affect». (D. PARFIT, *Reasons and Persons*, Oxford, 1984, 394).

⁷⁸ J. HARRIS, *Law and regulation of retained organs: the ethical issues*, cit., 537. Dworkin also refers to ‘external’ preferences, which are subordinate to ‘personal’ preferences. (R. DWORKIN, *Taking Rights Seriously*, Cambridge, 1977, 234).

«When they are alive you can harm (or benefit of course) both the individual and her interests. Once she is dead only her interests remain to be harmed. This is why the damage to the persisting interests of the dead must be set against the damage to the persisting interests of the living, damage which, in the case of the living, also affects the persons whose interests they are. This double damage will for all practical purposes always give the edge to the interests of the living»⁷⁹.

There is a sense in which post-mortem interests can be person-affecting, but this refers to those persons who would benefit from the decision of the deceased (for example, the recipients of any organs donated), and those who would be adversely affected, such as the distressed and grieving family⁸⁰.

The idea that posthumous interests can be subordinate to the interests of the living is also supported somewhat by our intuitions. James Delaney and David Hershenov illustrate a scenario where an individual has made it very clear that they wish to be interred in a mausoleum after death and left forever undisturbed. This individual soon dies. After burial, a visitor to the cemetery, who is aware of the deceased's wishes, is threatened by fire. Their only avenue of escape is to seek shelter in the mausoleum and use the deceased individual's body to protect themselves from the flames, resulting in the corpse becoming badly burnt. Many people would probably agree that this is acceptable, despite the fact that it is completely against the expressed views of the dead⁸¹. In contrast, most people would not think that it would be morally acceptable to use an innocent living bystander as a human shield to save your own life.

The problem with Harris' account is that it fails to appreciate the strength of some individual's interests regarding the treatment of their bodies after death. For certain religious and cultural groups, respect for the dead can be just as profound, if not more so, as the respect afforded to the living⁸². In these groups, it is not clear that their posthumous interests should automatically be subordinate to the demands of the living. Instead, the strength of these competing interests would need to be subjected to a cost-benefit analysis. For example, in regards to the scenario described above, it would appear that the actions of the visitor were only justified because their life was in imminent danger; not because the wishes of the dead were worthless. It would be possible to think of scenarios where the interests of the living would not be sufficient to outweigh the dead's. For example, if the visitor wished to enter the mausoleum and disturb the corpse purely for their own curiosity. In addition, it is also possible that some people have such strong views about the respect that should be afforded to the dead, that they would subject themselves to the flames rather than cause offence to the deceased.

Roger Brownsword asserts that consent is only required when there is the potential for a right to be violated; otherwise obtaining consent is simply extending a 'mere courtesy'. Therefore, in order to require consent for deceased organ donation, it must be established what right is being violated, as well as to whom has these rights. I have argued that it is possible for the deceased to have interests,

⁷⁹ J. HARRIS, *Wonderwoman and Superman*, Oxford, 1992, 100-101.

⁸⁰ J. HARRIS, *Law and regulation of retained organs: the ethical issues*, cit., 538.

⁸¹ DELANEY J, HERSHENOV D, *Why consent may not be needed for organ procurement*, in *The American Journal of Bioethics*, 9, 2009, 4.

⁸² M. BRAZIER, *Retained organs: ethics and humanity*, cit., 550.

albeit that these are more accurately construed as pre-mortem interests (or wishes) that persist after death. However, these interests are not sufficient to ground a right. Firstly, posthumous interests are other-regarding rather than self-regarding. Secondly, it is not clear how the deceased would be harmed if these interests are not respected. Lastly, and most importantly, posthumous interests can be outweighed by the interests of the living, unlike rights which are above utilitarian balancing⁸³.

Some argue that we should treat wishes regarding the use of our bodies posthumously in the same regard that we allow individuals to decide how their estate is to be utilised after their death; to treat our bodies like wills⁸⁴. In this way, an individual would gain the protection of property rights in their body, including how to dispose of their organs after death, and would therefore require others to gain the consent of the individual before using them for their own ends. However, there remains a problem with this account: although material goods can be considered property, human bodies cannot, at least not in the eyes of the law⁸⁵.

4. The role of relatives in deceased organ donation

The other principal decision-makers that are able to give consent to deceased organ donation under the HTA 2004 are relatives of the deceased. In this we see one of the most striking deviations from the traditional rules on who can give consent for adult persons. Normally in situations where the person concerned lacks capacity, others may make decisions on their behalf. However, proxy decision-makers are not able to give consent, but rather are constrained to acting in the person's best interests. Under the HTA 2004, however, persons in a qualifying relation to the deceased are able to give appropriate consent to allow organ donation to take place, or to refuse to give consent. In fact, often it is the family of the deceased who are the ultimate decision-maker rather than the deceased themselves⁸⁶. Therefore, rates of organ donation are very much dependent on the rates of consent (or refusal) amongst family members, which vary considerably with knowledge of the deceased's wishes⁸⁷. Furthermore, because the legislation is enabling, and permits rather than requiring donation to proceed, occasionally the deceased's wishes are overridden by the family. This is despite the fact that «they do not have the legal right to veto or overrule those wishes»⁸⁸. In these instances, not only was

⁸³ R. DWORKIN, *Taking Rights Seriously*, cit., 198-205.

⁸⁴ M. BRAZIER, *Retained organs: ethics and humanity*, cit., 564.

⁸⁵ The 'no property principle', although it is possible for others to own bodies or body parts which have acquired some attributes from the exercise of work or skill (the 'work or skill exception'), see *R v Kelly* [1998] 3 All ER 741 CA. Also, see: R. HARCASLE, *op. cit.*, for an exhaustive analysis of the many nuances in the law concerning ownership and property rights in the human body.

⁸⁶ D. PRICE, *op. cit.*, 133: «It must be appreciated that in most explicit consent systems, including those in the UK, North America, Australasia, and most parts of Asia, it is the *relatives* that constitute the gateway to organ donation, i.e. it is not a pre-requisite for the deceased person to have consented to donation. It is the relatives who make the ultimate decision».

⁸⁷ In 2010/11, in regards to donation after brain death, the overall refusal rate by relatives was 35%; when the individual's wishes were known this dropped to just 6%, but rose to 50% when the individual's views were not known. Similarly, with donation after circulatory death, the overall refusal rate was 49%, dropping to 20% when the deceased's wishes were known and rising to 61% when they were not. (BMA, *op. cit.*, 23-4).

⁸⁸ HUMAN TISSUE AUTHORITY, *op. cit.*, para.84.

the opportunity to save a potential life via donation thwarted, but to add insult to injury, the deceased's known wishes were also overridden⁸⁹.

The other concern regarding the enablement of decision-making powers in relatives is that there is no legal obligation to reflect the deceased's wishes⁹⁰. This is despite the fact that the Explanatory Report to the Council of Europe's Additional (Transplantation) Protocol states:

«Unless national law otherwise provides, such authorisation should not depend on the preferences of the close relatives themselves for or against organ and tissue donation. Close relatives should be asked only about the deceased person's expressed or presumed wishes. It is the expressed views of the potential donor which are paramount in deciding whether organs and tissues may be retrieved»⁹¹.

The same essential policy is also enshrined in the HTA 2004. However, there is nothing in the HTA 2004 that disenfranchises relatives from vetoing. Part of the problem is surely that only 41% of people inform their relatives about their wishes concerning donation⁹². Furthermore, research has shown that even close relatives are generally poor judges of what another individual would have wanted⁹³. If this is the case, then what is the justification for allowing relatives to be involved in the consent process? Firstly, considering that only about 30% of the population is registered on the ODR, there is the concern regarding the detrimental impact on donation rates if only the deceased can consent to donation. Essentially, relatives provide an extra opportunity (and often the only opportunity) to obtain consent. Secondly, there is the acknowledgement that the individual concerned is no longer alive, whilst the grieving family very much are. This can have a huge impact on the medical staff in practice.

A commonly cited reason for giving relatives the power to give or refuse consent to organ donation is the importance of avoiding the potential distress caused to the already grieving family if their wishes are ignored⁹⁴. Margaret Brazier believes that this potential impact on bereaved relatives is sufficient to «build a case that families are entitled to be protected from conduct which may injure them»⁹⁵. Clearly, distress to relatives is to be avoided if possible, but how should this avoidance be treated. Is it simply a value with a certain moral weight that should be weighed up in a cost-benefit sum of moral considerations? Or does it have enough moral weight to form the basis to a right to be protected

⁸⁹ In 2010/2011, 6% of families refused donation despite the deceased having had consented (BMA, *op. cit.*, 11).

⁹⁰ UK DONATION ETHICS COMMITTEE, *op. cit.*, para.1.4.9: «Within the 'third party' category, although most consent providers will be influenced by the donor's wishes, there is no requirement in the Human Tissue Act for the consent, or lack of it, to reflect the donor's wishes».

⁹¹ COUNCIL OF EUROPE, *Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin: Explanatory Report*, 2001, para.102.

⁹² D. PRICE, *op. cit.*, p.81.

⁹³ A. WRIGLEY, *Proxy consent: moral authority misconceived*, in *Journal of Medical Ethics*, 33, 2007, 527-31.

⁹⁴ HUMAN TISSUE AUTHORITY, *op. cit.*, para.85: «Healthcare professionals should also consider the impact of going ahead with a procedure in light of strong opposition from the family, despite the legal basis for doing so. For example, healthcare professionals may consider that carrying out an anatomical examination would leave relatives or family members traumatised (or lead to their objections), despite the deceased person having consented to this whilst alive».

⁹⁵ M. BRAZIER, *Retained organs: ethics and humanity*, cit., 567.

from such conduct, which I have argued is necessary for it to entail the protection afforded by the principle of consent?

If the avoidance of distress is a moral consideration then it is more plausibly construed as an interest to be weighed up in a cost-benefit sum. It would seem unlikely that there could be a right against being caused distressed in all circumstances⁹⁶. As Tim Wilkinson notes, a doctor telling someone that their relative is dead, might cause distress, but does not necessarily violate any right⁹⁷. Similarly, the distress relatives may experience at not having their wishes respected in regards to organ donation, whilst unfortunate, is not sufficient to ground a right⁹⁸. Even if it could be argued that relatives should be given the right to decide based on the avoidance of distress, it is not clear why that right should only be enjoyed by the family of the deceased, and not others who might similarly be adversely affected by any decision, notably the potential recipient of any organ donated and their family. Brazier supports the involvement of family members in the decision of organ donation by stating that the right to say yes or no should rest with the people most directly concerned⁹⁹. However, it is by no means clear who is meant by those most directly involved. As Harris puts it:

«We can see that recognising these needs cannot have the priority assumed for them, these needs must, of needs, compete with the similar needs of other families, needs not to be needlessly bereaved for want of donor organs for their relatives for example»¹⁰⁰.

This has led some to be particularly scathing in their criticism of the involvement of relatives in the consent process¹⁰¹.

5. Alternative systems

5.1. Conscription

I have argued that neither the deceased themselves, nor their relatives, have rights that can be violated in the context of deceased organ donation, but rather interests that may be taken into consid-

⁹⁶ Although there it may be more plausible to argue for a right to not be caused distress in more limited and specified circumstances, such as the right to not be subjected to inhumane and degrading treatment, which is likely to involve a degree of distress on the part of the individual concerned.

⁹⁷ T. WILKINSON, *Individual and family decisions about organ donation*, in *Journal of Applied Philosophy*, 24, 2007, 34.

⁹⁸ F. KAMM, *Morality, Morality: Death and Whom to Save From It*, Oxford, 1998, 211: «Neither caring most, nor the fact that they will be comforted by keeping or giving an organ, would seem to be a strong enough basis for a moral and legal right to decide».

⁹⁹ M. BRAZIER, *Retained organs: ethics and humanity*, cit., 569.

¹⁰⁰ J. HARRIS, *Law and regulation of retained organs: the ethical issues*, cit., 540.

¹⁰¹ For example, COUNCIL FOR PUBLIC HEALTH AND HEALTH CARE, *Farewell to non-commitment: Decision systems for organ donation from an ethical viewpoint* (Monitoring Report Ethics and Health), The Hague, 2008, 67: «The fact that next of kin are granted the right to decide in so many countries, sometimes contrary to the statutory regulations, is not based on an adequate moral justification but on the sole fact of their presence on the scene and the special consideration for their circumstance required at that moment».

eration. Therefore, consent should not necessarily be required for deceased organ donation to proceed. The question then becomes what system should be adopted instead. One candidate that would seem to be supported by my discussion so far is conscription of organs, which is advocated by some authors¹⁰². Aaron Spital highlights four advantages of a system of conscription: 1) more organs would be made available, resulting in more lives saved; 2) the system would be less complex and so therefore cheaper; 3) it would reduce the decision-making burden for families; 4) it would result in a more equitable sharing of costs and benefits amongst members of the community. He accedes that there are potential disadvantages to this proposed system, including violation of autonomy, harming the deceased and their family by ignoring their wishes, and public outrage, but that these would be outweighed by the good that would be achieved in terms of lives saved¹⁰³.

Emson makes an argument for conscription on the basis that organs should be a public resource after a person has died. We should regard the body as being borrowed from the biomass to which it will later return. According to him, the right to determine what will happen to our bodies after death was only justifiable when there was no further practical use for the remains. However, this claim can no longer be «morally sustained in the face of what I regard as the overwhelming and pre-emptive need of the potential recipient»¹⁰⁴. In a similar vein, Robert Truog asserts that organs should be viewed as personal property of the living person, but which become a societal resource after death¹⁰⁵. Is it possible to ethically justify this position? One way is to simply perform a cost-benefit analysis and conclude that the benefits of conscription far outweigh the burdens¹⁰⁶. However, opponents of conscription maintain that others do not have a right to our body parts no matter how great the need, and even after death. As Daniel Sperling points out:

«More generally, it will be argued that members of the human community have elementary interests which must not be sacrificed or overridden for the sake of collective welfare or other goals in society. One such interest is the interest in having one's body left alone unless proper authorization is given»¹⁰⁷.

Others have attempted to create a duty to donate organs based on the principle of the rule of rescue. This rests on the presumption that refusing to act to save another's life, when the cost to the person in a position to act is significantly less, is morally wrong. James Nelson goes even further than this; not only is there a duty to provide organs to others, but people also have a duty to «reconsider and possibly

¹⁰² A. SPITAL, J. TAYLOR, *In defence of routine recovery of cadaveric organs: A response to Walter Glannon*, in *Cambridge Quarterly of Healthcare Ethics*, 17, 2008, 337-43.

¹⁰³ A. SPITAL, C. ERIN, *Conscription of cadaveric organs for transplantation: Let's at least talk about it*, in *American Journal of Kidney Diseases*, 39, 2002, 612-14.

¹⁰⁴ H. EMSON, *It is immoral to require consent for cadaver organ donation*, in *Journal of Medical Ethics*, 29, 2003, 126.

¹⁰⁵ R. TRUOG, *Are organs personal property or a societal resource?*, in *The American Journal of Bioethics*, 5, 2005, 14-16.

¹⁰⁶ J. HARRIS, *Wonderwoman and Superman*, cit., 102: «it seems clear that the benefits from cadaver transplants are so great and the reasons for objecting so transparently selfish or superstitious, that we should remove altogether the habit of seeking the consent of either the deceased or relatives».

¹⁰⁷ D. SPERLING, *Posthumous Interests: Legal and Ethical Perspectives*, Cambridge, 2008, 117.

reconfigure their attitudes about themselves and others insofar as those attitudes threaten their inclinations to be organ providers»¹⁰⁸. The problem with this view in the context of deceased organ donation is deciding on how to weigh-up the cost to the potential donor and their family. It could be argued that those individuals with strong religious or cultural objections to organ donation, or families that would be severely distressed if their relative's organs were removed against their wishes, could be seen to suffer a great cost or burden if their wishes are overridden. Similarly, it seems to go too far to suggest that people should necessarily reconfigure their views to one that Nelson himself supports, that of donation, when people may have equally strong views about respect for the dead.

Ultimately, despite the suggested merits of a system of conscription and the good that it would potentially achieve in terms of lives saved, it is unlikely to be legally adopted in the UK. Firstly, it is unlikely to gain public support if the wishes of individuals and their families are completely ignored. Secondly, there is the issue of whether a system of organ conscription would be able to withstand the inevitable appeals that would be made to Articles 8 and 9 of the European Convention on Human Rights. The right to respect for private and family life and the right to religious freedom protected by these articles «may suggest the necessity for some latitude to be given»¹⁰⁹. I will now assess a system that does afford some latitude: a system of opt-out organ donation.

5.2. Routine retrieval with opt-out

I have shown that the current system of deceased organ donation in the UK is one of explicit consent, sometimes referred to as an opt-in system. However, there are repeated calls from some quarters for a change in the law to one where organs can be retrieved unless the individual has formally objected to donation during their lifetime, so-called opt-out systems¹¹⁰. This model of donation is already operated in other jurisdictions. Most of these are referred to as “soft” or “weak” opt-out systems, in which the family of the deceased is also given the opportunity to express their wishes¹¹¹. In contrast, ‘hard’ or ‘strong’ opt-out systems only allow the individual themselves to register an objection and therefore prevent their organs from being retrieved¹¹². Wales has recently passed legislation to introduce a soft opt-out system in the form of the Human Transplantation (Wales) Act, which received Royal Assent on 10th September 2013. Under the Act, the law regarding deceased organ donation would function very similarly to other existing opt-out systems¹¹³. Furthermore, relatives of the

¹⁰⁸ J. NELSON, *Hippocrates' Maze: Ethical Explorations of the Medical Labyrinth*, New York, 2003, 119.

¹⁰⁹ D. PRICE, *op. cit.*, 48-9.

¹¹⁰ The BMA for example (BMA, *op. cit.*).

¹¹¹ In France, for example, relatives are always asked to give consent (B. TEO, *Is the adoption of more efficient strategies of organ procurement the answer to persistent organ shortage in transplantation?*, in *Bioethics*, 6, 1992, 127).

¹¹² For example, Austria (Austrian Federal Law of 1 June 1982, section 62a).

¹¹³ Human Transplantation (Wales) Act 2013 Explanatory Notes, para.3: «The Act provides that, in the absence of express provision in relation to consent, consent will be deemed to have been given in most cases. This means that, after death, a person's consent will be deemed to have been given unless they had expressed a wish for or against donation».

deceased will be involved in the decision-making process¹¹⁴. It is clear that the intention for involving relatives is to provide information relevant to the deceased's wishes regarding donation rather than providing a relative veto *per se*.

There are obvious difficulties inherent to an opt-out system of deceased organ donation. First, there is the practical consideration of ensuring that everyone is aware of the law and the consequence of not registering a formal objection. It is assumed that everyone who has not registered an objection is willing to donate, rather than that they are unaware of the law. There is particular concern that this would disproportionately affect the more vulnerable members of society, such as the less educated or minority groups, who are also less likely to support donation in the first place¹¹⁵. It is possible that this issue could be addressed with wide-ranging informational campaigns to ensure as many people are aware as possible, although it would have to be acknowledged that there would still be those that would remain uninformed of the change.

5.3. The fiction of presumed consent

A more theoretical problem exists regarding the justification for adopting such a scheme, which revolves around the synonymous use of the term "presumed consent" by some commentators¹¹⁶. The reasoning behind this is as follows: in a system of opt-out, we can *presume* that the individual consented to organ donation if they fail to take the opportunity to register an objection. There are several problems with this premise. First, there is the question of whether presumed consent constitutes consent at all. Some are very clear that it does not¹¹⁷. Indeed, it is sometimes viewed as a way of dressing-up a regime in the language of consent and respect for individual autonomy to make it more appealing, when in reality the organs are being treated as a public resource and justification other than consent is being employed¹¹⁸. This is particularly pertinent when the idea of opting-out is presented in societies that are strongly committed to the rights of the individual¹¹⁹.

¹¹⁴ Human Transplantation (Wales) Act 2013 Explanatory Notes, para.4: «The Act therefore creates a default position where adults are considered (deemed) to have given their consent unless they object. However, consent will not be deemed where a relative or friend of long standing objects on the basis they knew that the deceased would not have consented to their organs and tissues being donated for the purpose of transplantation».

¹¹⁵ M. JACOB, *Another look at the presumed-versus-informed consent dichotomy in post-mortem organ procurement*, in *Bioethics*, 20, 2006, 296.

¹¹⁶ For example, I. KENNEDY, R. SELLS, A. DAAR ET AL, *The case for 'presumed consent' in organ donation*, in *Lancet*, 341, 1998, 1650-2. However, the term is rarely used by jurisdictions that have laws endorsing an opt-out system. Interestingly, the Welsh Government chose to use the term 'deemed consent' rather than presumed consent, although in theory there appears to be very little difference (DEPARTMENT FOR HEALTH, SOCIAL SERVICES AND CHILDREN OF THE WELSH GOVERNMENT, *Explanatory Memorandum to the Human Transplantation (Wales) Bill*, 2012, para.12: «But if they choose not to do so, despite having had the opportunity, then they will be treated as though they had no objection to being a donor (or in other words their consent will be deemed)»).

¹¹⁷ C. ERIN, J. HARRIS, *Presumed consent or contracting out*, in *Journal of Medical Ethics*, 25, 1999, 366: «Presuming consent is an affront to the moral principle that is the foundation of consent itself»; R. VEATCH, J. PITT, *The myth of presumed consent: Ethical problems in new organ procurement strategies*, in R. Veatch (ed.), *Transplantation Ethics*, Washington, 2000, 167-74.

¹¹⁸ As Hugh McLachlan puts it: «To say that it can reasonably be presumed that we consent to donate our organs if we do not specifically say that we do not consent is absurd. It is a deceitful piece of sophistry. There

Furthermore, as Hugh Upton explains, it is doubtful that presumed consent is a distinct form of consent, but rather a term used to denote other forms of consent. When people use the phrase presumed consent, they are really referring to either tacit consent, where it is believed that consent was given, or counterfactual consent, where there is no reason to believe that consent has not been given or refused. According to Upton, to ensure that tacit consent had been given would require such exhaustive practices, such as ensuring that everyone concerned was aware of the situation and the consequence of their inaction, that it would be preferable to attain explicit consent (assuming that explicit consent is superior to tacit). Counterfactual consent, on the other hand, is a more limited proposal in which the belief is not expressed that consent would be given but rather that we can think of no reason why the individual concerned would mind. Therefore, «substituting the term “presumed consent” would be misleading and that it is unlikely that the conditions for tacit consent would be met in practice»¹²⁰.

Instead of presumed consent, Ben Saunders attempts to justify an opt-out system using David Estlund’s idea of “normative consent”¹²¹. This concept claims that if it is wrong to withhold consent to something, proceeding without consent may be morally justified¹²². Saunders uses this theory to support an opt-out system of cadaveric organ donation: if it is wrong for an individual to refuse their consent to donate, then their consent is not required. His argument rests on the assertion that it is wrong for most people to refuse to donate their organs after death, as well as the principle that if we can prevent something bad, at little to cost to ourselves, we ought to do so. He suggests that this would give us two types of person who would opt out: «those who do so permissibly, because having their organs used would be costly to them, and those who do so wrongly, because their reasons do not in fact justify them leaving others to die»¹²³. Individuals with strong religious convictions against donation could opt-out because the large burden to themselves of donating are given as an example of a justified reason for refusing consent. However, the obvious problem with this principle is deciding what level of burden would be sufficient to outweigh the duty to donate? And who would decide this? Unfortunately, Saunders does not offer any answers to these questions. Furthermore, his argument is still framed in the language of consent, which I have shown is unnecessary in this context.

might be a good utilitarian case for having an opt-out rather than an opt-in system of organ donation. However, this would mean that there is a case for using our organs even in the absence of our consent. If consent matters in this area, then only the explicit consent of the people concerned can justify the using of their organs after their deaths. If consent does not matter and the use of their organs can be justified without it, then consent does not matter. We should not appeal to the bogus notion of presumed consent». (H. McLACHLAN, *Presumed consent is no consent at all*, retrieved from www.bmj.com/rapid-response/2011/11/01/presumed-consent-no-consent-all (last visited 22/06/2014)).

¹¹⁹ This can be observed in the Institute of Medicine report on organ donation: «Routine removal is broadly communitarian, whereas presumed consent - like expressed consent - is largely individualistic, even though it may include a role for the family». (INSTITUTE OF MEDICINE REPORT, *Organ Donation: Opportunities for Action*, Washington, 2006, 206).

¹²⁰ H. UPTON, *Presumed consent and organ donation*, in *Clinical Ethics*, 7, 2012, 142.

¹²¹ B. SAUNDERS, *Normative consent and opt-out organ donation*, in *Journal of Medical Ethics*, 36, 2010, 84-7.

¹²² D. ESTLUND, *Democratic Authority: A Philosophical Framework*, Princeton, 2008, 117-35. An example of wrongful refusal given is if one’s room-mate who never allows you to play your radio. As they are being unreasonable, it is permissible to play your radio sometimes without their consent.

¹²³ B. SAUNDERS, *op. cit.*, 86.

The conflation of opt-out and presumed consent is an unfortunate error on the part of authors who use the term and has led to much unnecessary confusion. It has been simultaneously used by both advocates and opponents of an opt-out system in order to either justify or reject the proposals, respectively, rather than addressing the key issues at stake. It would be better if the term presumed consent was abandoned as a fiction altogether, allowing some clarity to return to the debate over the merits or drawbacks of an opt-out system. I have argued that the use of consent is not strictly required in the context of deceased organ donation. In fact, its use is inappropriate and undermines the very principle of consent. Therefore, there is no longer any need to adhere to the notion of consent and attempt to dress-up alternative regimes in this language to make them more appealing.

5.4. Does an opt-out system improve donation rates?

The question as to whether adopting an opt-out system of organ donation would improve donation rates is important because most arguments supporting a change to this system are based, at least in part, on the premise that it would¹²⁴. There are two possible avenues by which to answer this question: 1) compare the rates of donation in countries that have an opt-out system with countries that have a system based on explicit consent; 2) compare the rates of donation in the same jurisdiction before and after a change in the law. However, this research remains problematic to conduct and it is often difficult to separate between factors that affect donation rates between countries. Therefore, the analysis of the data is notoriously difficult and differing conclusions are often drawn from the same set of results.

A review commissioned by the ODT identified four major studies without major methodological flaws that compared countries with opt-out systems and those without, and five studies that compared donation rates within the same country before and after the implementation of an opt-out system¹²⁵. The evidence from these studies suggests that opt-out legislation is associated with an increase in organ donation rates¹²⁶. However, this remains controversial. The ODT found «no convincing evidence that it would deliver significant increases in the number of donated organs»¹²⁷. In fact, concerns were raised that the rate of donations may even be reduced¹²⁸. Furthermore, Spain, which is often cited as having the most successful organ donation programme in terms of its donation rates,

¹²⁴ This is clearly the purpose behind the recent passing of the Human Transplantation (Wales) Act 2013. «The principle aim of the legislation is to increase the number of organ donors through the introduction of a soft opt-out system.» (DEPARTMENT FOR HEALTH, SOCIAL SERVICES AND CHILDREN OF THE WELSH GOVERNMENT, *op. cit.*, para.21).

¹²⁵ ORGAN DONATION TASKFORCE, *The potential impact of an opt out system for organ donation in the UK: A report from the Organ Donation Taskforce. Supporting Information: Annex I*, 2008, 24-9.

¹²⁶ ORGAN DONATION TASKFORCE, *The potential impact of an opt out system for organ donation in the UK: A report from the Organ Donation Taskforce. Supporting Information: Annex I*, cit., 66. One of the methodologically-sound studies comparing between countries, for example, showed an increase of 25-30% in organ donation rates (A. ABADIE, S. GAY, *The impact of presumed consent legislation on cadaveric organ donation: a cross country study*, in *Journal of Health Economics*, 25, 2006, 599-620).

¹²⁷ ORGAN DONATION TASKFORCE, *The potential impact of an opt out system for organ donation in the UK. An independent report from the Organ Donation Taskforce*, cit., 34.

¹²⁸ Perhaps in light of the introduction of a system of opt-out in Brazil, in which so many people opted out, that the law had to be repealed to avoid a dramatic reduction in available organs (M. JACOB, *op. cit.*, 296).

only saw an increase in organ transplants after it made changes to its transplant infrastructures, many years after the introduction of opt-out legislation¹²⁹. However, as Romelie Rieu points out, it may be that the positive effect of the opt-out policy was only seen after the infrastructure was in place to accommodate it; «while architects of the new infrastructure may claim full responsibility, the opt-out policy may be a necessary precondition»¹³⁰.

5.5. Does an opt-out system respect an individual's wishes?

One of the main objections to opt-out systems is that it would result in the removal of organs from people who did not wish to donate, and therefore violate the principle of respect for individual autonomy. However, as Michael Gill points out, while this should be avoided if possible, «it is morally no worse than not removing organs from the bodies of people who did want them removed, and that a policy of presumed consent will produce fewer of these unfortunate results than the current system»¹³¹. Gill bases his argument on the fact that opinion polls often demonstrate a higher support for organ donation than is represented in organ donor registers¹³². Therefore, some people do not have their organs removed despite having a wish to donate. Assuming that mistaken removals and mistaken non-removals are morally equivalent, then there would be fewer mistakes in a system where the default corresponded to what the majority of the population agrees with. He rejects the argument made by critics of opt-out systems that it is morally worse to mistakenly remove organs than to mistakenly not remove organs by distinguishing between two models of autonomy: the “non-interference” model of autonomy and the “respect-for-wishes” model of autonomy¹³³. The first model is strongly related to the idea of bodily integrity; it is wrong to invade a person’s body without permission to do so. The respect-for-wishes model states that in order to respect autonomy we should treat a person’s body in accordance with their wishes. The first is appropriate for the competent living; the second is appropriate for the deceased. As Gill states:

«To refrain entirely from interfering with the body of a person who is brain-dead will not allow the person to exercise the capacity to determine for herself what happens to her, as the person no longer possesses that capacity. The best we can do with regard to respecting her autonomy is to treat her body in the way that she most likely wanted it to be treated»¹³⁴.

It is certainly true that mistakes are not the sole preserve of opt-out systems. Under an opt-in system, it is often the case that the relatives make the decision as to whether to donate or not because

¹²⁹ M. QUIGLEY, M. BRAZIER, R. CHADWICK ET AL, *The organs crisis and the Spanish model: Theoretical versus pragmatic considerations*, in *Journal of Medical Ethics*, 34, 2003, 223.

¹³⁰ R. RIEU, *The potential impact of an opt-out system for organ donation in the UK*, in *Journal of Medical Ethics*, 36, 2010, 538.

¹³¹ M. GILL, *Presumed consent, autonomy, and organ donation*, in *Journal of Medicine and Philosophy*, 29, 2004, 37.

¹³² 70-90% in support of organ donation is often quoted (BMA, *op. cit.*, 8).

¹³³ M. GILL, *op. cit.*, 44.

¹³⁴ M. GILL, *op. cit.*, 45.

the deceased's wishes are simply unknown. And even if they are known, the family is still usually involved in the process. However, there is no guarantee that the wishes of the deceased will be respected by the family, either through ignorance or disagreement, both by refusing donation when the deceased wishes to donate or agreeing to donation when the deceased was adamantly against it. Arguably, «an opt out system where objections can be registered and must be respected, would enhance individual autonomy for those who do not want to be donors»¹³⁵.

6. A new proposal

I have argued that consent, as it is normally understood, should not be required for deceased organ donation because neither the deceased individual nor the family have rights which would be violated and require the justification of consent. However, both these parties *might* have interests that require consideration. The dead *might* have pre-mortem interests that persist after death, both regarding the use of their organs and to the welfare of their family, and relatives *might* have an interest that they are not caused distress by having their wishes neglected. The emphasis on *might* is deliberate. Not everyone will necessarily have interests regarding the use of their bodies after they die. Some may be indifferent because of the simple fact that they will no longer exist. Some individuals may not have strong views either way regarding organ donation, or at least not feelings sufficiently strong to motivate them to register as a donor. This leads us with three class of people: those who express a wish to donate; those who express a wish to not donate; and those who do not express a wish either way. This last group would contain a mixture of people who wish to donate and who wish not to donate but have not registered their views, as well as some people who may be indifferent as to what happens to their organs.

According to the current law in the UK, consent must be given before donation can proceed. If an individual's wishes are not known, then someone else must provide that consent, usually the family. However, families are often hesitant to consent if they are also unaware of what the deceased wanted. In this situation, organ retrieval cannot take place. Here, I believe lies the problem. Polls suggest that approximately 70% of the population agrees with donation when asked, but only 30% are on the ODR. The issue is not the 30% who disagree with donation, but the middle 40% who agree with donation but do not register their intention as such. A system of routine organ retrieval with an opt-out clause would address this problem, based on an adapted model of the best interests test.

If an adult lacks capacity to make decisions, and therefore is unable to give consent to a proposed action, then the decision as to whether the intervention should proceed must be made in the best interests of the individual¹³⁶. Others cannot consent for the incompetent adult, unlike with the HTA 2004, which allows appropriate consent to be given by a qualifying relative. Why then not also use a best interests test for deciding whether organ donation should proceed in deceased individuals? Clearly, it is beyond doubt that the dead lack capacity. There are at least two obvious reasons why the best inter-

¹³⁵ V. ENGLISH, A. SOMMERVILLE, *Presumed consent for transplantation: a dead issue after Alder Hey?*, in *Journal of Medical Ethics*, 29, 2003, 151.

¹³⁶ Mental Capacity Act 2005 s.1(5): «An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests».

ests test would seem inappropriate in this context. Firstly, there is the question of whether the dead can have best interests on which to decide upon. Although the dead clearly lack capacity, unlike the incompetent living, they also lack any personhood whatsoever; they have ceased to have welfare concerns and can no longer be harmed. However, although the deceased may not have interests in the traditional sense (or experiential interests, to use Dworkin's terminology), I have already argued for the existence of pre-mortem interests that persist after death. Although the dead cannot be harmed, it is still possible for them to be *wronged*. If the dead do have these interests then it may be possible to judge what is in their best interests. Then the question becomes: could organ donation ever be in the best interests of the deceased? And if so, what factors would need to be taken into consideration?

Section 4 of the Mental Capacity Act 2005 contains the factors that must be taken into account when deciding what is in the best interests of a person lacking capacity. This includes the person's past wishes and feelings¹³⁷, and the views of carers and families as to what would be in the best interests of the individual¹³⁸. It has also clearly been established that the best interests test is far more expansive than simply medical best interests; it also includes an individual's social, cultural and religious interests¹³⁹. The easiest way to see how it could be in the best interests of a person to donate their organs is if they have a clearly expressed, known wish to donate¹⁴⁰. Conversely, if someone was known to have a wish not to donate, then it could be said to not be in that person's best interests to donate¹⁴¹. However, the harder question arises when the wishes of the deceased are not known either way; could it still be in their best interests to donate?

Harris argues that in the absence of an advance directive or known wishes to the contrary, the presumption should be that the deceased should want to act altruistically; that it could not be in the interests of the deceased to «make more probable the deaths of other people»¹⁴². This view does find some support in polls that suggest that the majority of the population support donation¹⁴³. However, it could also be argued that an individual would have an interest in their family not being distressed, which may support a role for relatives to be involved in the decision-making process. It is entirely plausible that someone would consider this a greater concern than even their own wishes being respected. In fact, some people may have very little interest in what happens to them after they die, and are content to allow the full decision-making powers to lie solely with the family. In this situation, it would not be in the best interests of the deceased to proceed with donation if the family are strongly opposed and would be severely distressed if their wishes were overridden.

But what if the family are undecided, or unwilling to take responsibility for any decision made? In this situation, where there is no clear objection from either the deceased, or the family, then the default should be that organ donation can proceed. Without any evidence to the contrary, it should be as-

¹³⁷ Mental Capacity Act 2005 s.4(6).

¹³⁸ Mental Capacity Act 2005 s.4(7).

¹³⁹ *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FLR 549; *Re Y (Mental Patient: Bone Marrow Donation)* [1996] 2 FLR 787.

¹⁴⁰ For example, by being registered on the ODR.

¹⁴¹ Although, unfortunately, there is no current way to express refusal of donation in the UK.

¹⁴² J. HARRIS, *Law and regulation of retained organs: the ethical issues*, cit., 540. He also believes that this should apply to the relatives as well.

¹⁴³ BMA, *op. cit.*, 8.

sumed that it is in the best interests of the individual to act altruistically. Changing to this position may also make it easier on relatives, «who, at a time of emotional upheaval and bereavement, may not relish being asked to decide in the absence of any indication of the wishes of the deceased»¹⁴⁴. I acknowledge that this use of best interests may be too expansive for some. However, this interpretation of best interests would only be applicable in the unique context of deceased organ donation, and would have no bearing on the way best interests is understood in the incompetent living. It is also likely that not everyone who objected to organ donation would register their objection, resulting in organs being taken against the wishes of the deceased. However, as already discussed, there would be fewer mistakes than under an opt-in system. Furthermore, this system could be made more robust if a more sophisticated register was implemented; one that recorded both wishes to donate and wishes *not* to donate organs.

7. Conclusion

The current legal framework in the UK governing deceased organ donation places the doctrine of consent as its central principle. However, adopting this model requires justification; consent is not a detached and free-standing legal concept that dictates whether an act is right or wrong in and of itself. Before utilising the doctrine of consent, it must first be determined what (and whose) rights are being violated. In the context of healthcare, I have shown that consent is required to protect a person's rights to autonomy and bodily integrity; rights that are no longer present in the deceased. However, it is possible for individuals to have pre-mortem interests that persist after death, and these individuals may be wronged if these interests are automatically overridden. Furthermore, families of the deceased may have strong convictions regarding organ donation and may be distressed if these views are ignored. Nevertheless, although these are moral concerns that should be taken into consideration, they are not a basis on which to ground a right. Therefore, consent should not be required in the context of deceased organ donation. In addition, not only is the current legal position unjustified, but it is also failing to provide enough organs for the current demand, resulting in the avoidable loss of life. The time has come for legal reform.

The conscription of organs is undoubtedly the best option for maximising the number of organs available for transplant. However, this system fails to take account of the interests of relevant parties, which for some groups may be sufficient to rule out donation, and arguments based on the duty to donate, normative consent, or cadaveric organs as a public resource fail to adequately justify this position. It is also unlikely to ever receive public support. A more promising approach is that of an opt-out system. However, the language of presumed consent should be abandoned as a fiction that is both misleading and unwarranted. Instead, I have proposed a position where the best interests of the deceased donor are taken into consideration. When the intentions of the deceased are known, any decision regarding donation should be in accordance with their expressed wishes. In those individuals that feel indifferently towards organ donation, or where their views are not known, the wishes of the relatives may be of relevance if acting against these wishes would cause them significant distress. This is because it would be in the best interests of the deceased individual to avoid suffering

¹⁴⁴ V. ENGLISH, A. SOMMERVILLE, *op. cit.*, 150.

being caused to their loved ones. If the family is also undecided, the default position should be to donate. If there are not known to be strong convictions either way, from either party, then it should be viewed to be in the best interests of the donor to act altruistically.

Chapter 8