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**In search of a system which
acquires the maximum
number of organs and is
consistent with a society's
values.**

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Abstract.

In 2008, the Organ Donation Taskforce was asked to consider the impact of introducing an opt-out system for organ donation in the United Kingdom. The Taskforce conducted a thorough investigation, which included information gathering from both the public and experts in the field of healthcare, ethics and law and a thorough appraisal of the countries currently operating an opt-out system. Having reviewed this evidence the ODT conceded that whilst the numbers of organs generated *may* increase under an opt-out system, conversely, because of the way the system actually works, they felt there was a risk that its introduction may cause a backlash amongst the general public resulting in a *decrease* in organ donations. They based their concerns around fears that such a system would remove the potential for spontaneous acts of goodwill, denying people the opportunity to give a gift, and may deny the opportunity for individuals to determine whether their organs should be donated, thereby precluding choice and the right to self-determination. This might ultimately compromise public trust in the system.

This thesis challenges the assumptions made by the Organ Donation Taskforce in respect of introducing an opt-out system. It casts doubt on their claims about compromising privacy interests and then looks to reconcile the potential issues which may arise under an opt-out system; these are preventing the choice to act altruistically and acting in such a way as to undermine public trust. Both of these may result in policy failure. It will advocate a system which addresses the issues raised by the ODT and acts to provide respect for self-determination; this is a soft opt-out system with a combined registry. Such a system would increase the supply of organs for those in need of a transplant, and remain consistent with a society's values in terms of demonstrating respect for individual choice regarding donation.

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List of Abbreviations.

BSDT	Brain stem death tests
BMA	British Medical Association
CD-P-TO Transplantation	Council of Europe European Committee (partial agreement) on Organ
DBD	Donation after Brainstem Death
DCD	Donation after Circulatory Death
DH	Department of Health
ESOF	End Stage Organ Failure
HC	House of Commons
HCP	Healthcare professional
HCSC	House of Commons Standing Committee
HTA	Human Tissue Act
IRG	Independent Review Group
NHS	National Health Service
NHSBT	National Health Service Blood and Transplant
NHSIN	National Health Service Innovations North
NCOB	Nuffield Council on Bioethics
ODT	Organ Donation Taskforce
PM	Post Mortem
PMP	Per million population
UK	United Kingdom

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Introduction.

In 2006 the Government set up the Organ Donation Taskforce (ODT), comprising medical professionals, National Health Service (NHS) managers, patients and patient representatives and ethicists. The ODT was charged with the responsibility of developing a set of recommendations to help increase organ donation within the current legal framework in the United Kingdom (UK)¹. These recommendations were introduced in the Taskforce's first report, '*Organs for Transplants*' (DH 2008). In 2008, prompted by a suggestion from the Prime Minister, Gordon Brown, the Department of Health (DH) asked the ODT to look into the impact of introducing an opt-out system in the UK. The ODT researched this particular system for organ donation thoroughly, publishing its findings and recommendations in its report: '*The Potential impact of an opt-out system for organ donation in the UK*', published later that year.

In this introduction I shall establish what an opt-out system is. From here I shall précis the concerns expressed by the ODT towards this method for organ procurement. I intend to use some of these as a platform on which to base my arguments advocating a soft opt-out system with a combined registry. I shall clarify my approach to this thesis before providing a brief overview of my intentions in respect of this, by way of a short summary of each of my chapters. These will focus upon specific areas which have been raised by the ODT, but will incorporate other legal and ethical objections to opt-out which have been raised. To conclude, a rationale for my decision to concentrate upon this very specific approach to managing the procurement of organs will be provided.

Under an opt-out system organs can be retrieved for transplant from a deceased individual unless they have registered an objection during their lifetime (Rithalia et al 2009a, p.2). An opt-out system can be further delineated into a soft and hard opt-out system. Under a hard opt-out system organ retrieval is allowed unless the deceased has explicitly registered an

¹ Except Scotland.

objection; relatives are not invited to express an opinion, and clinicians are under no obligation to act upon any objection expressed by relatives (Blasszauer 2003, p. 92). Under a soft opt-out system organ retrieval may take place unless an individual has registered an objection; however, what differentiates this system from a hard opt-out system is that relatives *do* have an opportunity to express an objection to procurement (BMA 2012). This default soft opt-out system is currently practised in a number of countries within the European Union; these include Spain, Croatia and Belgium (The Council of Europe European Committee (partial agreement) on Organ Transplantation (CD-P-TO) 2013).

The nature of this family involvement has been found to vary amongst different countries practising a soft opt-out system for organ procurement. For instance, in Spain, clinicians responsible for the procurement process must invite the opinion of relatives before organs are retrieved² (Monforte-Royo and Roqué 2012, p.299). In practice, the Spanish system provides relatives with the power to veto procurement where the wishes of the deceased are unknown. The Belgian system is different. Here, relatives may take the initiative to object to procurement on behalf of the deceased; however, clinicians are not legally required to inform the family of the intention to retrieve the deceased's organs (Michielsen 1996, p. 663). There is a combined registry, enabling individuals to opt in to or out of organ procurement. In the absence of a registered decision, a relative's veto will be upheld; however, if the deceased has opted in, then relatives do not retain the power of veto (Michielsen 1996).

In their report looking at the impact of an opt-out system in the UK the ODT concluded that, "what appears to be a simple idea to increase numbers may not in fact generate additional donors in sufficient numbers to justify the significant investment needed to put a new system into place" (2008, p.34). Having studied all of the evidence with an "open mind" (ODT 2008 p.6, p.34), the ODT suggested that whilst, on balance, opt-out could deliver "real benefits", such a system

² In Spain, in practice, consent is actually requested from the family.

carried too significant a risk (p.5). The main concerns expressed by the ODT with regards to introducing an opt-out system in the UK were that:

- The impact might have a damaging effect on the trusting relationship between the medical profession and the public (p.4, p.17);
- Introducing a register would be complex and costly and that it would require high levels of security to safeguard the register “due to the greater sensitivity of the information” (p.19);
- “Assuming consent from silence belongs to a paternalistic era” (p.5);
- It would detract away from the important changes to the infrastructure which had only just begun (p.34);
- It would threaten the elements of gift-giving and choice which could have a negative impact on donation rates and could make the current situation worse (p.34).

The Taskforce felt that in view of its findings the current opt-in system should be retained, under which individuals provide express consent for their organs to be retrieved posthumously, with the pursuit of their target of increasing organs donated by 50% by the year 2013 remaining the priority (DH 2008 p.3). They would then review the statistics in relation to donor numbers; if at that stage the 50% had not been reached with the changes in the infrastructure and the donor identification, alongside increased public awareness, then they would re-consider changing the law to a soft opt-out (ODT 2008 pp.5, 36). In April 2013 statistics released showed that the 50% target has been reached (NHSBT 2013a). However, despite the improvements in organ donor numbers, by advising the retention of the opt-in system for organ donation the Taskforce is failing both those waiting for a transplant, and society, who have given their opinions and shown their

favour towards an opt-out system and been rewarded with a system which does not properly reflect this.

In light of the ODT's findings I intend to argue that, on balance, and contrary to the ODT's recommendations, a change to a soft opt-out system would seem to be not only the most efficient system for addressing the widening gap between the supply of and demand for organs for transplant, but also such a policy could command public support. In view of this, I believe that a soft opt-out system with a combined registry, such as that practised in Belgium, best reflects the opinion of the majority of the public and their generosity, and will help to alleviate the suffering of more of those in need of a transplant than the present system is able to. Such a system gives priority to the needs of the living, whilst at the same time allowing for individuals to make a definitive decision about what happens to their organs post-mortem. I am putting forward this recommendation after studying the literature around the area of organ procurement closely. This has included the political, ethical and legal issues relating specifically to deceased organ procurement.

An opt-out system for organ procurement is not a new concept. It is practised in many countries and is often considered to be a more effective system for generating organs. Under the present opt-in system the UK now generates around 18.5 deceased donors per million population (pmp) (CD-P-TO 2013, p.36). The number of deceased donors pmp in Croatia and Belgium, which currently operate an opt-out system, are 34.8 and 30.2 respectively (CD-P-TO 2013, p.34). A change to a soft opt-out system has received support from the British Medical Association³ and, in recent years, from the Chief Medical Officer for England. Furthermore, in September 2013 Wales introduced the Human Transplantation (Wales) Act (HTWA). This will come into full effect in December 2015. Authorisation for transplant activities requires consent. In accordance with section 3 of the Act transplantation will be lawful if express consent is given or otherwise with

³ The soft opt-out system which the British Medical Association has long advocated (BMA 2012, p.46) mirrors that which is managed in Spain.

deemed consent. The subsequent sections (4, 5, 6 and 9) explain express and deemed consent where the person to whom the consent relates is an adult, an excepted adult (i.e. an adult to whom deemed consent cannot apply), a child or a living adult who lacks capacity (HTWA 2013). In essence this Act legislates for a soft opt-out system for organ and tissue procurement. The aim of this legislation is to increase the number of organs and tissues available for transplant in Wales (National Assembly of Wales 2013).

What I am proposing is not, in itself, a radical measure which is untested or untried. However, what is important about the concerns raised by the ODT in its report, and what sets this apart from other concerns which have previously been raised in relation to an opt-out system for organ procurement, is that it has had a direct influence on the retention of the current opt-in system in the UK to date. This presents a timely opportunity to examine some of the issues put forward in this report. It is for this reason that I have chosen to address some of these concerns. In doing this, I hope to be able to refute some of the Taskforce's claims and demonstrate that its arguments are not strong enough to dismiss a consideration for a change in our current system to a stand-alone soft opt-out system. With regards to those concerns which remain pertinent to a standalone soft opt-out system, I shall then argue for a political compromise in the form of a combined registry; this will accommodate the values which are considered important and worthy of inclusion in a policy governing deceased organ procurement in this country. The aim of this welfare policy is:

- To provide an organ procurement system which acquires the maximum number of organs and is consistent with a society's values.

A broadly utilitarian approach will be taken to argue for the adoption of this policy. Utilitarianism can be described as "a general theory about when actions and institutions are (instrumentally) desirable; and the idea is that they are so in view of their promotion of actual or expectable happiness, or better, actual or expected utility" (Brandt 1984, p.3). Devising policies

which focus upon the health and welfare of individuals can be seen as instrumentally desirable as they promote actual or expected happiness (understood as a subjective experience) (Duncan 2010, p. 177). An organ procurement policy falls within this category. When formulating an organ procurement policy, a careful, deliberate calculation of the risks and benefits is essential so that this policy will be instrumental in promoting overall actual or expectable utility.

If the only aim of this policy were to increase the supply of organs then a system of organ conscription, in which organs are routinely retrieved post-mortem, would be the ideal option to take. Organ conscription excludes the option of allowing the public to have some decision on whether their organs are retrieved. Such a system does not factor in individuals' interests and possible antipathy towards the removal of their organs posthumously. In line with the aim of this welfare policy, in terms of it being consistent with a society's values, the values may extend beyond simply extracting as many organs as possible. For instance, one of society's values may require the protection of individuals' interests in the form of their inclusion in decision-making around organ procurement. It is important to take this into account as, on the face of it, incorporating people's interests -often construed as rights - would seem to be inconsistent with a utilitarian approach.

Rights are justified claims which individuals and groups can make upon other individuals or society (Beauchamp and Childress 2009, p. 350). They are a prominent feature of today's society, often used to establish actions which are permissible and to validate a specific view of 'what may, must, and must not be done' (Wenar 2011). They can be invoked in legal, moral, natural and social forms, and pertain to a rule governed pursuit (Beauchamp and Childress 2009, p. 351). Individuals may appeal to 'rights' when challenging a system, the principles of which are grounded in netting social utility for the majority, but which may pay little heed to persons' needs or interests. This enables individuals to have the freedom to act without unwanted interference from government.

Arguably, there is some purpose to recognising legal and social rights in a utilitarian society, if doing so contributes towards the promotion of well-being resulting from respect for autonomy. The achievement of this particular policy, in terms of increasing the supply of cadaveric organs, relies upon the public to be cooperative. This sets it apart from most policies which will require public cooperation but which do not *rely* upon the public to act as the means to the end. In view of this, accommodating individuals' specific interests, in terms of privacy for instance, is arguably a necessary 'price' to pay for the success of the policy grounded in maximising welfare and happiness for the greater good, but which is wholly reliant upon public support.

Specific public deliberative events around organ procurement have provided a platform on which people have been able to exercise their views in this area, and express concerns and reservations around procurement (NCOB 2010; ODT 2008 Annex J). What is apparent from these events is that the public want to decide whether to donate their organs, and that altruism is an important feature of this policy. Having listened to people provide their opinion around policy provision in this area, it would be risky to now disengage with the public when reliance upon them is so high. It would therefore be prudent and productive to allow protection of persons' interests. As Scarre (1996, p.21) points out,

Other things being equal, we prefer that individuals should make their own decision on whether to sacrifice their personal interests for the public good: self-determination is rightly recognised as a good by many theories, whether or not it is regarded as a right.

From a utilitarian perspective, incorporating autonomous choices is in itself of no special moral interest; the happiness which results from this, in terms of enabling the opportunity to act, which may increase public confidence, should increase the likelihood of maximising overall happiness. Facilitating the opportunity to opt in or out of procurement is instrumental in

achieving this end; these are utilitarian grounds for inclusion of this in the policy. Moreover, politically it is a sensible approach to take, as it demonstrates acknowledgement of the European Convention of Human Rights which incorporates one's right to respect for privacy and family life (Article 8), freedom of thought, conscience and religion (Article 9) and freedom of expression (Article 10) (Council of Europe 2010, pp.10-11). A system which explicitly dismisses these human rights would open the policy to legal challenge. This would ultimately threaten the success and therefore the utility of the policy.

In addition to this, listening to public concern around organ procurement and addressing this may help to reconcile potential issues which may otherwise turn into objections. If the public do not trust the policy or those involved in its provision, then they may act in such a way that the policy fails in its promotion of actual or expectable utility, as many people will continue to die as a result of there not being enough organs retrieved. Conversely, if the public have confidence in the system, then this increases the chances of success in terms of promotion of utility, as more organs will be made available for transplant; this will ultimately maximise actual or expectable happiness, due to the benefits which transplantation brings, both to the recipient and their family and to society as a whole. In view of these points raised, I would like to point out that where I observe communitarian and libertarian lines of argument, ultimately I shall still taking a utilitarian line of defence, as by observing their arguments and taking them into consideration I shall reach my end goal of introducing a policy which may provide more organs.

With this approach in mind the thesis is divided up into 4 chapters, followed by a conclusion which includes an example of international practice proven to be very successful in terms of acquiring the maximum number of organs and being consistent with its society's values. A new organ procurement policy in this country could be based upon this model.

The first chapter will provide a brief background to the area of organ procurement and transplantation, including policy provision, past and present. I shall conclude this chapter by

introducing the specific issues raised by the ODT relating to the introduction of an opt-out system in the UK; these shall then be discussed in detail in the remaining chapters.

Chapter 2 will look at the provision of consent relating to ownership of one's body and organs. Whilst this topic has not been discussed in much detail by the ODT, it is something which was commented upon in the conclusion to the Taskforce's report when it discussed concerns about opt-out expressed by a "sizeable minority" (2008, p.27) of those involved in the public deliberative events. One of the opinions expressed by a member of the public, in relation to opt-out, was this: "at the end of the day people should decide what happens to their body, not their relatives or the State. I think people should determine their own destiny" (ODT 2008, Annex J, p. 24). The Taskforce inferred from this (and other comments presented alongside this) that:

many people felt that the system would take away individual choice...They felt that it would give the State too much control and '**ownership**' over people's organs, rather than giving individuals the right to choose what to do with their own bodies (ODT 2008, p.27).

It is not only the ODT which has raised the subject of ownership of one's organs. The Nuffield Council on Bioethics (NCOB) has discussed ownership and property of the human body, and parts thereof, in their recent report discussing the lengths to which society may go in the quest to help those who may benefit from human bodily material (NCOB 2011, p.vii). Property has also been discussed as part of the House of Lords European Union Committee Report (2008) '*Increasing the supply of donor organs within the European Union*'. In this report, the Committee considered the question of "who, if anyone, owned a body after death" (2008, p.160). The term ownership, in relation to a person and their relationship with their body, was also made reference to during the House of Commons' Standing Committee G reading of the Human Tissue Bill (HCSC 2004). It is also a term which has been used in the media associating the practice of an opt-out system with the State taking control of one's body.

Talking about the body and organs in terms of ownership would suggest that the body might be treated in the same way as other possessions described as property. But is it appropriate to view the body as property and to treat it in the same way as we treat property in legal terms? If it is, then treatment of the body may fall under property rights. I believe the issue of property matters to this discussion on organ procurement, since if there is a strong argument in favour of seeing the body as property, then in line with the law on property and rights of ownership, one could stipulate the need for consent to organ procurement. This is because the organs would be the property of the person, who would have a right to decide whether to give their organs or not. Consent, in this respect, may not be an act demonstrating respect for one's autonomy; it may be understood as a **legal** right associated with the terms and rules of property, and could be rationalised under the terms of trespass. It is important to consider arguments in relation to this when deciding whether consent should remain integral to the organisation of cadaveric organ procurement.

In Chapter 3 I shall consider the requirement of consent grounded in respect for autonomy. Demonstrating respect for autonomy is the traditional justification for gaining consent for clinical interventions. This has been closely linked to the idea that the body is something much more integral to our existence - an embodiment of our self. Any interests associated with this view, which does not condone the concept of the body being separate from the self, would fall under privacy rights. In accordance with this school of thought privacy rights ascribe to persons, property rights relate to objects. Looking closely at the arguments put forward by the ODT in favour of retaining an opt-in system (ODT 2008), their reasoning relating to self-determination would appear to accord most closely with privacy rights rather than ownership of the body and property rights. However, consent may also be upheld to prevent an invasion of bodily integrity, or to act as a waiver to legitimise what may normally warrant an unlawful act upon the body. In accordance with these privacy rights, consent is particularly appealing as a way of preventing harm being brought to bear on one's interests, which ultimately may result in harm to the person.

This shall be reflected upon during this chapter. I hope to show that whilst respect for self-determination is an important aspect of a cadaveric organ procurement policy, its recognition and provision need not rest solely upon a system of express consent.

Chapter 4 will begin by addressing the concerns raised by the ODT: that an opt-out system “might undermine the concept of donation as a gift” (2008, p. 34). Both the ODT and the Minister responsible for sponsoring the Human Tissue Bill voiced their strong support for an organ procurement system which should reflect the generosity of the public in their capacity to give something so special: the gift of life. The association between organ donation and gift-giving has long been endorsed by politicians, policy advisors and interested parties writing in the field. It would seem that organs should only ever be donated through choice, and this can only truly be achieved through a policy which encourages voluntarism. Whilst some would argue that opt-out represents a system which defaults to giving (BMA 2012; English and Somerville 2003), others might suggest that it in fact refers to a system which defaults to taking one’s organs (Marrin 2008). However, the arguments put forward by the ODT in favour of retaining an opt-in system for organ procurement and against introducing an opt-out system, centring on “the concept of a gift given freely” (ODT 2008, p.17), need to be tempered against the negative connotations relating to the concept of organs as ‘gifts’.

When devising a policy for organ procurement, what is important is having the opportunity to make an altruistic gesture. Consideration therefore needs to be given to the role altruism should play in an organ transplant policy. The remainder of chapter 4 shall look at how this may present an issue when devising a soft opt-out policy. I shall then consider how these potential obstacles may be resolved, so that the opportunity to act altruistically may be accommodated. In doing this I shall advocate a change to a soft opt-out policy with a combined registry. This has been shown to provide more organs for transplant, and allows for individuals to make an altruistic gesture should they wish to do so.

Trust is an important feature in the policy and practice of organ donation and transplantation, particularly since at the present time only human organs can be used for transplant. Trust can be understood to affect personal relations between an individual and a healthcare professional (HCP) as well as social relations between the public and those responsible for organising the delivery of healthcare in this area. There are examples of incidents which have resulted in diminishing trust on the public's part towards HCPs at the coalface, and managers of institutions within the NHS. Efforts on the part of the government to address these 'failings' have led to a far greater level of public involvement in managing the approach to care delivery. NHS England (2015) has declared:

Central to our ambition is to place the patients and the public at the heart of everything we do. We are what we want the NHS to be – open, evidence-based and inclusive, to be transparent about the decisions we make, the way we operate and the impact we have⁴.

In relation to the issue of trust, the ODT expressed concern that in an era when public trust is less forthcoming (2008, p.9) an opt-out system could result in fewer organs being donated if there is less confidence in this method for organising the retrieval of organs. These issues need to be addressed in order to provide a balanced argument for the introduction of a soft opt-out system with a combined registry. Chapter 5 will focus specifically on trust. Understanding and addressing the concerns of the public around issues relating to organ procurement, and a system for managing this, should allow for a change to a soft opt-out system with a combined registry to be built on trust.

The thesis will conclude with a look at the system introduced in Belgium which has successfully increased the number of organs procured. Their soft opt-out system with a combined registry has firmly placed the priority with the welfare of the living, whilst at the same time

⁴ Available at: <http://www.england.nhs.uk/about/>, viewed 16th March 2015.

acknowledging the importance of maintaining public support in order to turn favourable opinion into demonstrative action. Such a system is (instrumentally) desirable in view of its promotion of actual utility in terms of welfare provision.

There are other systems which may improve the numbers of organs made available for transplant; an example of this might be a market in organs. There are a number of reasons which I should like to put forward for choosing not to look at this option. Cogent and thought provoking arguments have been provided by philosophers in recent years around the sale of organs for transplant. These include introducing a strictly regulated market (Erin and Harris 2003, p. 137) to prevent an unfettered market (Radcliffe Richards et al. 1998, p.1950). A market in organs would have the potential to stop the exploitation (Wilkinson 2003, p. 132) which opponents express fear of. There is an apparent lack of logic when one considers that those who are paid to risk their lives (demonstrating a value for the risks they put themselves under), such as those from the armed forces (Savulescu 2003, p. 139), are often deemed to be heroes/heroines, yet those who would be paid to donate a kidney are castigated for being mercenary. Both are essentially acting for the welfare of others. It also seems strange that one is able to have a diseased part of their body removed; however, this level of acceptability does not extend to being able to sell an organ in order to be able to buy food to live, as the latter is deemed to be a degrading act (Brecher 1994, p.995; Chadwick 1989).

Undoubtedly such a system can be justified on utilitarian grounds that it will maximise utility in terms of welfare and happiness. This in itself makes such a system very appealing. However, from a practical perspective, the word count for this thesis is restricted. As a result of this, it would be difficult to provide a robust and compelling line of argument for more than one method for organ procurement. In addition to this, I believe I would struggle to advance the arguments which have been put forward by contemporary philosophers.

This thesis takes a practical approach to policy provision for organ procurement; therefore, choosing which method to focus upon has been guided by what would be permissible legally and therefore have real potential to be introduced. Whilst the arguments for a market in organs may indeed be very persuasive, from a legal perspective a line has been drawn under it, rendering its introduction at this time as extremely unlikely. NCOB noted in the mid ninety nineties that there was a growing body of international regulation and guidance prohibiting commercial dealings in organs and other human tissue (1995, p. 52). The principle of prohibiting payments for organs was established for the first time in Article 21 of the 1997 Council of Europe Convention on Human Rights and Biomedicine [CETS No. 164]. The article states “The human body and its parts shall not, as such, give rise to financial gain” (Council of Europe 1997). This principle was then re-affirmed in the 2002 Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin [CETS No. 186]. Article 22 of the Protocol states: “Organ and tissue trafficking shall be prohibited”. This principle is grounded in the belief that donation should be based upon altruism (Caplan et al. 2009, p.7). Principle 8 of the World Health Organisation’s, *‘Guiding Principles on Human Cell, Tissue and Organ Transplantation’* stipulates, “it should be prohibited for any person or facility involved in organ transplantation procedures to receive any payment that exceeds a justifiable fee for services rendered” (WHO 2010, p.7).

The Human Organ Transplants Act 1989 (UK) outlawed the commercial dealings in human organs for transplant; this included advertising the buying or selling of organs. This came about as a result of public concern raised following media focus around the trafficking of human organs (NCOB 1995, p.12). The Human Tissue Act (HTA) 2004 repealed the 1989 Act; however, section 32 of the 2004 Act expressly prohibits transplantation for profit (Cronin and Douglas 2010, p.287). In view of the firm stand taken against the provision of payment for organs, expressed and legislated for both here and within the European Union, it would appear that any practical discussion around increasing organ supply focussing on this as a potential measure are, for the time-being,

redundant⁵. It is for this reason that I shall not consider this option other than to express opinion around hypothetical issues raised by academics which may form part of the discussion during arguments raised in subsequent chapters. My aim in this thesis is to concentrate my arguments specifically on a soft opt-out system, which is legally viable and supports the inclusion of the public when implementing such a policy.

Throughout this thesis I shall employ the term 'organ procurement'. On occasion I shall also use the phrase 'organ donation' when I believe it fits more appropriately with the beliefs or arguments which are represented in the various discourses under examination.

⁵ A possible exception to this is the potential to introduce a system which provides financial recompense in the form of funeral expenses. This may be an acceptable compromise, allowing some compensation to be provided for those prepared to give their organs in death. This could be offered alongside an opt-out system, as happens in certain regions in Spain (BMA 2012, p. 60). Paying for funeral costs has been advocated recently by NCOB (2011, pp.ix, 9, 10, 111, 160, 174, 175, 222).

Chapter 1: Background to Organ donation and Transplantation.

1.1: The Value of Transplantation.

For most individuals health plays an important part in guiding the direction one's life might take. Maintaining good health can help us achieve many of our goals in life, and contributes towards our enjoyment and fulfilment, both in terms of work and pleasure. In the UK, in accordance with the egalitarian philosophy of the NHS, good healthcare should be available to all regardless of wealth (NHSIN 2009). Ideally then, if a person's health is compromised but can be treated, it might seem reasonable to suggest that as much as possible should be done to help restore that person's health. However, in reality, the provision of healthcare is constrained due to the limited budget available for resourcing the Health Service. As a result of limited funding the healthcare budget has to be divided up carefully (Lockwood 2006), and challenging decisions frequently need to be made in respect of the allocation of scarce resources. This financial support extends beyond supporting the physical health of individuals, and often requires consideration of their welfare needs which may be compromised as a result of their inability to work due to their ill health. Furthermore, this financial support may extend to the carers as well, especially those who stop working in order to care for their debilitated family member.

End stage organ failure (ESOF) is a life limiting condition. Organ donation and transplantation may successfully treat ESOF, preventing premature deaths and improving the quality of life for both the recipients and, potentially, for their carers. Successful transplantation today is the result of advances in surgical technique (Calne 2006), improved knowledge around the anatomy and physiology of graft survival and rejection (Friedman and Peters 2006), and the goodwill of society (Morris 2003). It is possible to retrieve organs for transplant from both living persons and from cadavers. Cadaveric organs can be retrieved from non-heart-beating (asystolic) donors and heart-beating donors (those declared brain stem dead (DH 1998)). Artificial ventilation, enabling continued circulatory support in brain stem dead patients, has provided the

potential for a number of major organs to be retrieved for transplant. These include: heart, lung, liver, pancreas, small intestine and bowel and kidneys (NHS Choices 2011a). In certain instances the liver can be split, resulting in two liver transplants. The result is that one heart-beating organ retrieval may result in up to eight transplants. This method of procurement also enables heart and lungs to be retrieved en-bloc and transplanted into one patient who, in turn, may be able to donate their heart for another patient requiring a heart transplant (Yacoub et al 1990). One can see from this that one heart-beating organ retrieval has the potential to help a number of people in ESOF requiring a transplant. Furthermore, looking at the organs which may be transplanted, it is clear to see that for some recipients this transplant will be lifesaving.

Sophisticated immunosuppressant therapy has led to a dramatic improvement in graft survival at one year, from 50% in the early era of transplantation (Calne 2006) to 85-90% in 2008 (NHSBT 2009a). Figures representing graft survival for most major organs demonstrate that a transplant recipient's life may be extended by up to ten years (NHSBT 2012a). This can be understood to benefit an individual both financially and in terms of quality of life. An example of these benefits can be found when examining the statistics relating to renal transplantation. Figures published by NHS Blood and Transplant (NHSBT) (2009b) show that the average cost of dialysis per patient is around £30,800 per annum. 3% of the total NHS budget is spent on renal failure services. The indicative cost of a renal transplant including induction therapy is £17,000 per patient, per transplant. Immunosuppression amounts to approximately £5000 per year. Calculating these figures against the cost of dialysis shows that renal transplantation could lead to a cost benefit in the second and subsequent years of £25,800 per year per patient. If all of these patients received a transplant, a saving could be made to the NHS of around £152million. These statistics represent a persuasive argument of the effectiveness of transplantation, both in terms of cost and value. Furthermore, a reduction in the pancreato-renal transplant waiting list is welcomed when faced with a growing number of individuals developing type II diabetes which can lead to renal failure (DH 2008, p.3).

From a health economic perspective organ transplantation, in almost all cases, is shown to be a cost effective use of resources (DH 2008, p. 7). This is an important consideration in a resource limited healthcare system, where finances need to be deployed in a way which achieves “the greatest amount of benefit and good” (DH 2008, p.22). Evidence points towards renal, liver and pancreas transplantation being cost effective (DH 2008, p.23). Measures have been taken to medically manage end stage cardiac and lung failure which may challenge the cost effectiveness of transplantation; however, as the effectiveness of immunosuppression continues to see recipients of these organs live longer due to improved graft survival, this challenge subsides owing to a greater Quality Adjusted Life Years (QALY) gain (DH 2008, p.23). This serves to promote utility in terms of welfare for the recipient and their family. The financial value of this, in terms of enabling the recipient and their family to return to work, promotes utility for society more generally. This is in terms of the extra income revenue which may then be generated by the transplant recipient, able once again to work, and net saving from the transplant itself which may be redirected to other healthcare requirements.

Increasing donor numbers will not just incur a financial saving, but will also improve the quality of life for those in ESO, thus acting to “address the burden of disease” (NICE 2011, p.8) which affects the individual and often their family. The target set by the ODT in 2008 to see an increase in the donor rate by 50% within a five year period was in view of the positive statistical and phenomenological evidence of the value of transplantation. Careful scrutiny of global initiatives which had led to similar positive results in terms of increased donors and reductions in waiting lists, particularly for those in end stage renal failure, encouraged the ODT to feel confident that with appropriate changes in the infrastructure these numbers could be achieved.

1.2: Policy Provision and Legislation for Organ Donation and Transplantation in the UK.

In the late 1950s policy provision for organ donation and transplantation in the UK was limited. The Anatomy Act 1832, regulating the use of cadavers for medical research and

dissection, did not provide for transplantation. The Corneal Grafting Act 1952 only dealt with the donation and transplantation of tissues (specifically eyes). The success of the first transplant prompted politicians to consider the potential advantages of transplantation: saving the lives of those in end stage renal failure, which, in turn, could improve productivity in the workplace by enabling these people to return to work (Kennedy 1988). Parliament needed to decide on a policy which would best recognise the need to increase organ procurement, without offending the public's generous role in the donation of organs (Kennedy 1979). The Government decided to offer a compromise. The Human Tissue Act 1961, repealing the Anatomy Act 1832 and Corneal Grafting Act 1952, provided the opportunity for an individual to opt in to organ donation, or, if the wishes of the deceased were not known, the alternative opportunity for the next of kin to opt out of organ donation if doubts were expressed about the will of the deceased. In practice, consent was sought from relatives where the express wishes of the deceased were unknown.

Subsection 1 (ii) of The Human Tissue Act 1961 required medical personnel to ensure that reasonable enquiry had been made to ensure that neither the deceased nor their surviving relative objected to the use of the deceased's organs for therapeutic purposes, medical education and research. In 2001 the publication of three reports⁶, requested by the Government, focussed upon the illegal and unethical activities which had occurred at the Royal Liverpool Children's Hospital (Alder Hey) and Bristol Royal Infirmary, relating to the removal, retention, storage and use of organs. Evidence from these reports pointed to the fact that section 1 (ii) of the Human Tissue Act had not been adhered to by certain medical personnel resulting in organs and tissues being used even though the parents of some of the children had refused consent to post-mortem tissue removal and examination.

⁶ *Learning from Bristol: The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995* (Kennedy 2001); *Royal Liverpool Children's Hospital Inquiry Report* (Redfern Report) (Redfern et al. 2001); *The Removal, Retention and use of Human Organs and Tissue from Post-mortem Examination, Advice from the Chief Medical Officer* (DH 2001). *The Isaacs Report* (HM Inspector of Anatomy 2003) also prompted a review of post-mortem examinations.

The events deeply affected those involved and led to a diminishing public trust with regards to this area of healthcare, and a feeling of scepticism, in particular towards organ donation for transplantation and for research based purposes (Alaszewski 2002). Recommendations from the reports that followed suggested that the Human Tissue Act 1961 should be amended promptly, to incorporate the requirement of fully informed consent for the lawful use of organs retained for post-mortem examination (DH 2001). A change in the law was the first vital step in demonstrating a commitment, on the Government's part, to respect and understand the needs of donors and their families, and the need to improve information for the public about the use of organs for therapeutic purposes⁷. These principles were reiterated in the DH's transplant framework, *'Saving Lives, Valuing Donors'*, published in 2003, encouraging a new era in which people would be valued, and all those wishing to donate being able to do so (DH 2003 p.2). It was hoped that these measures would help to re-build trust (Price 2005, p.818) and prevent further damage in respect of a decline in the numbers of organs offered for transplant.

In November 2004 the Human Tissue Act received royal assent, repealing the Human Tissue Act 1961, The Anatomy Act 1984 and the Human Organ Transplant Act 1989. The Act came into force in 2006. In the UK⁸, the Human Tissue Act 2004 legislates for an explicit consent/opt-in policy (Price 2005). In accordance with Part 1 of the Human Tissue Act 2004, section 1, 2, 3 and 4, "appropriate consent" is valid if it is provided by the living individual who is donating, or, as stated within an advance statement, or, failing this, by an appropriate person previously appointed to deal after death with the issue of consent, or in the absence of this the consent of a person who stood in a qualifying relationship to him immediately before he died. Provision, with respect to consent in this circumstance, is represented in part 2 section 27, subsection 4, in the form of a hierarchical list which should be adhered to by those seeking consent for the use of organs and tissues (HTA 2004). The Government hoped that the Human Tissue Act 2004 would encourage

⁷ Highlighted in the consultation document *'Human Bodies, Human Choices'* (DH 2002)

⁸ Except Scotland.

voluntarism and represent an appreciation of autonomy, altruism and gift-giving: qualities believed to underpin organ donation. Furthermore, a system in which consent remains the fundamental principle (ODT 2008, p.9) reflects current clinical standards in which gaining informed consent remains the cornerstone of all good medical practice. The patient, wherever possible, should play a fundamental role in the decisions which need to be made, thereby assuming a more powerful position, exerting more control over decisions regarding treatment and care (Brazier and Cave 2011; Brody 2001; O'Neill 2002). Under the current legislation, the public can continue to opt in by carrying an organ donor card, first introduced in 1971 (NHS Choices 2011b) or by joining the organ donor register (ODR), introduced in 1994. The ODR currently has over 21 million names on it (NHSBT 2015a) representing 32% of the population (ONS 2014).

The issue of informed consent has been debated in Scotland, with concerns initially expressed about the suitability of the term consent in the context of organ retention (Brazier 2002). The Scottish Independent Review Group on the Retention of Organs at Post Mortem (IRG) felt that its use could be misleading in this area of practice. Instead the term 'authorisation' was believed to be a more fitting term, confirming the right of decision in respect of organ retention as belonging with the deceased or their family (IRG 2001). This was then taken forward when the Human Tissue (Scotland) Act 2006 was drafted, which regulates activities concerning the removal, storage, use and disposal of human tissue (Scottish Executive Health Department 2006). The debate over the use of consent was deliberated at length in the run up to the enactment of the Human Tissue Act 2004. The DH questioned which term might be preferred to consent, which at the same time may infer a meaning considered to be markedly different from that of consent in ethical, practical and legal terms (DH 2002 pp.49,50). The conclusion of the discussions was that

consent should not be replaced since no other term was more preferable or accurate in its action in these circumstances⁹.

In 2006 the Organ Donation Taskforce was set up by the Government, its remit to develop recommendations to help increase organ donation within the current legal framework. At the time of the ODT's first report, *'Organs for Transplants'* (DH 2008), the number of donors pmp in the UK was 12.9 (Council of Europe 2007). The report identified the barriers to organ donation in the UK as: poor donor identification and referral, poor donor coordination and poor organ retrieval arrangements. By resolving these problematic areas, the ODT set the target of increasing the number of organ donors by 50% by 2013; this would increase the number of transplants by 1200, of which 700 would be renal transplants (DH 2008 p. 3). In order to achieve this target, the ODT looked to mirror the system employed in Spain, which throughout the world has consistently retained the highest number of donors pmp¹⁰. Spain currently has a dedicated organisation concentrating on the promotion and facilitation of organ procurement; coupled with this, coordinators -often medical professionals from intensive care units- have improved the referral rate and identification of potential donors (Miranda et al 2003)¹¹.

The amalgamation of the NHS Blood Service (which oversees blood and tissue retrieval) and UK Transplant (which oversaw organ donation and transplantation) resulted in a larger, more powerful and influential organisation that would be better able to utilise financial support added to the £4 million, given in 2000, to improve donor numbers and the retrieval process (DH 2003).

⁹The debate over the term 'consent' has recently been discussed by NCOB (2011) in its report, *'Human bodies: donation for medicine and research'*. The Council decided to opt for the term 'authorisation' rather than 'consent' when discussing decision-making specifically relating to cadaveric organ donation, believing it to be a more fitting reflection of the type of decision made by individuals with regards to donating one's organs in death. Harris (2002) has also suggested that consent could be said to be incongruous when linked with actions to be performed post-mortem, as normally, gaining consent includes the opportunity to withdraw the consent at any time, representing an active process. We cannot actively withdraw consent once dead, thus compromising this part of the consent process. So the terminology used in this area of practice remains a moot point.

¹⁰ At the time of the ODT's report the figure was 33.8pmp (Council of Europe 2007); this figure increased to 35.1 pmp in 2012 (CD-P-TO 2013).

¹¹ It is worth noting here that rather than move to an opt-out system, which would truly reflect the Spanish system, the Taskforce advocated retention of the opt-in system, stating this to be the method for procurement most consistent with "society's values" (ODT 2008, p.15).

More specialist nurses in organ donation (SN-OD) have been employed to ensure a presence in more intensive care units in the country with the result of earlier and more frequent donor identification (Rudge 2010). NHSBT (2014a) recommend that any patient that meets the criteria for a brain stem death test (BSDT), or whose circulatory death is deemed to be imminent, and for the decision regarding withdrawal of treatment appears to be appropriate, should be referred to the SN-OD (p. 4)¹². Donor champions have been introduced, who report directly to the hospital trust board, ensuring accountability for donation in the hospital (Rudge 2010). The number of hospitals undertaking non-heart beating donor programmes has also increased, adding to the number of heart beating donor organs available for transplant (NHSBT 2009a). Increasing the number of donors is clearly the fundamental driver in reducing the gap between the supply of organs and the demand for transplants.

Statistics released in 2013 showed that these infrastructural changes did help to secure the target of the 50% increase which the ODT set out in 2008 (NHSBT 2013a). However, the corresponding increase in the number of units actively participating in donation after circulatory death (DCD) programmes (DH 2008) also played a part in achieving the target, alongside the increase in the number of requests made for organs (23red 2014, p.5). Whilst the increase in deceased donors is encouraging, the biggest obstacle to donation remains relative refusal, at around 39% (NHSBT 2014a, p.5). Sanctioning such refusals appears to fly in the face of the aims of the Human Tissue Act 2004, advocating the right for individuals to decide what is done to their bodies in death. In reality, whilst the relatives retain a right to veto consent, the law continues to pay lip service to this principle.

Problems around relative and public reluctance may be accounted for, in part, by poor communication around the request process. When considering the process for requesting organ

¹² Figures taken from the UK Potential Donor Audit (PDA) in the financial year 2013-2014 (NHSBT 2014a) showed that the referral rate for donation after brainstem death (DBD) was 94% and for donation after circulatory death (DCD) was 71% (p.4) The reasons for non-referral included coroner refusal, medical contra-indications, clinicians deeming the patient to be medically unsuitable for donation and family refusal prior to testing for death (NHSBT 2014a, p.4).

donation, HCPs are in an 'onerous position' (Haddow 2004, p. 46). Clear information is required to enable families to understand their relative is dead. Reassurance can be achieved if certain information is repeated and clarified with family members. This can be difficult when there is pressure to continue all care for the patient and meet other patient needs as well. This can lead to a breakdown in communication, which can in turn lead to a loss of trust if family members feel as if their needs are not being sufficiently met or their questions are not answered. Haddow (2004) asserts that this can lead to non-donation (p.46). Timing of the request can also make a difference, with the suggestion that if the discussion comes before the BSDT or soon after, then this can cause anxiety (p.46). What this demonstrates is that donation at the coalface is a complex process; it requires clear, honest and open lines of communication and time for families to be able to come to terms with what has happened. The opportunity to understand the nature of the death and reconcile any fears they may have around donation serves to reassure families at a stressful time. Support from clinical personnel can help relatives to feel confident in the decision they make regarding donation.

The figures represented in the Potential Donor Audit¹³ (NHSBT 2014a) point to the positive impact a request made by a SN-OD can have, with a consent rate of 70% compared with 58% when the request for DBD is made by another HCP (NHSBT 2014a, p.6). Where the deceased's wishes have been registered the consent rate is even higher, at 93% compared with 55% when the deceased's wishes are unknown (NHSBT 2014a, p.6). All of this evidence suggests that what is required is training in communication for HCPs who are responsible for the care delivery of patients who may be eligible for organ donation. Collaboration with SN-ODs should enable clear lines of communication with family members and reassurance around issues which may be troubling and require resolution before consent can be given. This can then help to build confidence which may ultimately lead to a positive outcome for all involved in the potential donor

¹³ Commenced in 2003 to determine the potential number of solid organ donors in the UK, as part of a series of measures to improve organ donation (NHSBT 2015b).

process. It should be noted that the reasons for refusal as presented in the PDA¹⁴ suggest that refusal extends beyond poor communication. Moreover, these refusals continue to have a considerable impact upon numbers of donated organs made available¹⁵, leading to questions over whether the relatives' role should be so prominent in the decision-making process, or indeed whether they should have any role at all.

Coupled with this is the level of inertia from the public (Siegal and Bonnie 2006) to actively demonstrate their support for organ donation by signing up to the ODR¹⁶ or holding a donor card, even though opinion polls show that between 70 and 90% of those asked are in favour of organ donation (ODT 2008; Optimisa Research 2013; Rithalia et al 2009b). This will only compound an already difficult decision for relatives when faced with the question of whether to consent to retrieval. Looking at these statistics, respect for autonomy, generosity and altruism, which our present system relies so strongly upon, is still not optimising the potential deceased donor rate. This then begs the question as to whether there is another system of procurement which is able to provide for these values, whilst simultaneously further increasing the retrieval rate of organs for transplant.

1.3: An Alternative System for Organ Procurement.

Evidence from countries where organ procurement is practised shows that some type of consent or objection is necessary to enable this practice to proceed (Gevers et al. 2004). In general terms the management of organ procurement can be divided into opt-in and opt-out systems. Opt-in may also be referred to as contracting in or expressed consent, whilst opt-out may also be referred to as contracting out or presumed consent. Much debate has been provided

¹⁴ Reasons for refusal include objection by the deceased during their lifetime, family uncertainty of deceased's wishes, divided family opinion and concerns about organ allocation. Some families objected on religious/cultural grounds, whilst others stated that they did not want surgery to the body/ wanted the body to be buried whole. A small number expressed concern that the deceased had suffered enough, or had difficulty accepting the neurological test results. For one family refusal was grounded in the belief that patients' treatment may be limited to facilitate organ donation. For a full transcript of reasons for refusal please refer to the PDA report (NHSBT 2014a, p.6).

¹⁵ During the financial year, a total of 119 families overruled their loved one's known wish to be an organ donor (NHSBT 2014a, p.6).

¹⁶ Figures presented on page 21.

with regards to the permissibility and accuracy of the term 'presumed consent'. Whilst this is a point of interest, I shall not offer any form of discussion in respect of this; however, I shall adopt the term 'opt-out', as the ODT (2008) did when compiling its report looking into the practice. I shall do this based on the arguments presented by Montgomery (2013), representing the views of the Chief Medical Officer in 2007, who adjudged this system not to be about assuming or presuming that individuals consent, but that "it may be legitimate to take organs irrespective of consent" (Montgomery 2013, p. 10). Opt-out policies have been shown to yield a greater number of organs for transplant than opt-in policies (CD-P-TO 2013; Abadie and Gay 2006). With an opt-in system the default position could be interpreted as one of non-donation or presumed refusal (English and Somerville 2003), whereas an opt-out system maintains a default position of donation (BMA 2012).

At the request of the DH, the ODT researched the consequences of changing from an opt-in to an opt-out system for organ donation. In order to acquaint the reader with the various ways in which organ procurement can be managed, the ODT provided concise definitions of the different consent systems used globally. The table below, taken from the ODT's (2008) report, *'The Potential Impact of an Opt-Out System in the United Kingdom'* represents their definitions of the different consent systems in use around the world (p.10).

Option	Details
1: A 'hard' opt-out system	Doctors can remove organs from every adult who dies, unless a person has registered to opt out. This applies even if relatives know that the deceased would object to donation but had failed to register during life. An example of this system is that which is practised in Austria.
2: A 'hard' opt-out system which does not cover some groups	Doctors can remove organs from every adult who dies, unless a person has registered to opt out OR the person belongs to a group that is defined in law as being against an opt-out system. An example of this system is that which is practised in Singapore, where Muslims have chosen to opt out as a group.
3: A 'soft' opt-out system	Option 3a: Doctors can remove organs from every adult who dies, unless a person has registered to opt out OR the person's relatives tell doctors not to take organs. It is up to the relatives to tell the doctors because the doctors may not ask them. <u>With this soft opt-out system there is no need to consult relatives</u> . An example of this system is that which is practised in Belgium.
	Option 3b: doctors can remove organs from every adult who dies, unless a person has registered to opt out. It is good practice for doctors to ask the relatives for their agreement at the time of death. <u>With this soft opt-out system relatives should be consulted</u> . An example of this system is that which is practised in Spain ¹⁷ .
4: A 'soft' opt in system (current system in the uk)	Doctors can remove organs from adults who have opted in. It is up to each person to decide if they want to opt in. It is normal practice to let relatives know if the person has opted in and doctors can decide not to proceed if faced with opposition from relatives.
5: A 'hard' opt in system	Doctors can remove organs from adults who have opted in. It is up to each person to decide if they want to opt in. Relatives are not able to oppose the person's wishes.
6: A choice to opt in or opt out	Option 6a: People can register their choice to opt in or opt out.
	Option 6b: People must register their choice to opt in or opt out.

The Taskforce presented its findings in 2008. In this report the Taskforce stated that there were no fundamental ethical or legal barriers to a soft opt-out system, and that the interviews they had conducted with members of the public when gathering evidence for the report showed that 60% were in favour of a soft opt-out system (ODT 2008 p. 24). Recent figures presented in a systematic analysis on the impact of opt-out legislation on organ donor rates, which contributed

¹⁷ The inference here is that relatives should be consulted, imposing a duty upon the clinicians to approach relatives prior to the organ retrieval. In line with this approach taken to relatives' inclusion in the process, relatives should be able to initiate a refusal as well.

to the ODT's report, corroborate the figures presented by the ODT, with the highest figures from a survey showing 78% in favour of a change in the law (ODT 2008, Annex I). The ODT (2008) were, however, quick to counteract this level of expressed support with concerns that a small but "sizeable" number expressed strong opposition to a change in the law (p.27), stating that such a system could be "dehumanising" (p.5).

Furthermore, Rithalia et al (2009b) argued that whilst there was evidence from their systematic review to show that countries with an opt-out system did indeed have a higher donor rate pmp, they could not infer from this that such an increase would automatically occur "per se" (p.7), and that other considerations would need to be taken into account alongside a change in system. These should include any changes in infrastructure or action plans implemented alongside an opt-out policy, as well as availability of donors. So, for example, whilst Spain is cited as the most successful country with regards to organ procurement, its success is not associated with their soft opt-out system. It is attributed to the infrastructural changes which were introduced alongside the legislated policy; it is these that have resulted in the sustained high levels of organs procured.

The ODT looked specifically at the Spanish Model when reflecting upon the success of an opt-out system, resulting in their referring to the changes in infrastructure which had led to the rise in donor numbers, not the actual policy for procurement. However, it would be useful to consider the success of the country with the third highest retrieval system in the world: Belgium (CD-P-TO 2013), which operates a soft opt-out system with a combined registry. In 1984-5, under an opt-in system, the number of potential kidneys retrieved amounted to only 20 pmp (Michielsen 1996). In 1986 legislation was passed to change the organ procurement system from an opt-in to an opt-out. In 1987, in line with the policy, a centralised registry system was set up to allow individuals to register their wishes. During their lifetime, citizens are able to register an objection to organ procurement and they are also able to register an explicit consent to their

organs being procured (Michielsen 1996). When the wishes of the deceased are known their decision cannot be overruled; where a decision has not been made by the deceased the law provides relatives the right to refuse donation. Legally, these feelings must then be considered and respected (Michielsen 1996). This allows for relatives to be able to initiate some form of involvement in the donation process, and, more importantly, it also provides an opportunity for them to enlighten the transplant teams of any co-morbidities or social history which may be important when deciding upon the suitability of the organs for transplant. The cost of maintaining the register in Belgium, around the beginning of the century was 60,000 Euros annually (Gäbel 2003, p.997).

Changing the policy in Belgium had a marked effect on donor numbers. In the first three years following the change in the law kidney donation increased to 41.3 pmp (Roels et al 1991). The percentage of those who opted out in 1996 was 2% (Michielsen 1996, p.664). The donation rate for Belgium remains very high, with the figure of donors pmp standing at 30.2 for 2012 (CD-P-TO 2013, p.34)¹⁸. There is evidence provided by both Michielsen (1996) and English and Somerville (2003) pointing to clear statistical proof of this opt-out system improving numbers of donors. Both refer to a situation which occurred early on into the introduction of the opt-out system in Belgium. When the opt-out legislation was introduced Antwerp chose to retain an informed consent system; for the first year after the change the number of organs retrieved here remained unchanged. However, in Leuven, where they adopted the opt-out system, their numbers doubled over the first year (English and Somerville 2003; Michielsen 1996). There had been a good deal of publicity to inform the public of the change in the law, and much was made about the benefits of organ donation and transplantation; yet the numbers remained the same in

¹⁸ Spain remains first in terms of organs donated, whilst Croatia has now become the second most successful country in respect of this with 34.8 pmp (CD-P-TO 2013, p.34). Croatia has a soft opt-out system with an infrastructure system in place similar to that of Spain, the UK and Belgium for increasing awareness of potential donors and translating potential donors into actual donors (Živčić-Ćosić et al. 2013).

Antwerp, leading Michielsen to conclude that the publicity played little part in the improvement in numbers.

In the last decade Belgium instigated the Donor Action Programme (DAP)¹⁹; this has provided specific initiatives to improve donor rates, reflecting a similar system to that which is in place in Spain. As a result of these initiatives numbers further improved (Roels et al. 2008), with a demonstrable increase in the donor pmp which stood at 27 in 2007 (Van Gelder et al. 2008). It should be noted that the numbers which pre-date the DAP were still considerably higher than the figure in the UK today even with its infrastructural changes.

To strengthen their argument regarding the efficacy of opt-out systems for procuring higher numbers of organs for transplant, English and Somerville (2003) also highlight Denmark as an example, who until 1986 had one of the highest organ donor rates in Europe under an opt-out system. They then changed to an informed consent system and their numbers fell “by half” (p.151). There is also evidence represented by Abadie and Gay (2006) who have suggested that the subtle difference in approach and underlying ethos represented in an opt-out and opt-in system could make a difference to the number of donated organs. They provided evidence which showed that in a country with an opt-out system, where the default is one of donation, relatives were more likely to not object to donation, on the grounds that their deceased would have objected if they had felt strongly enough. Corresponding to this, in countries with an opt-in system relatives were more likely to object to donation, based on the idea that if the deceased had been in favour, they would have opted in (Abadie and Gay 2006, p.605). More recently, a study looking at the kidney transplantation rate from a sample of 44 countries representing both opt-in and opt-out organ procurement systems, showed that there was a higher number of renal

¹⁹ Details of this Donor Action Programme and results to date can be found at: <http://www.donoraction.org/>

transplants performed from deceased donor grafts in the countries with an opt-out system (Horvat et al. 2010)²⁰.

1.4: In Search of an Organ Procurement System which acquires the Maximum Number of Organs and is Consistent with a Society's Values.

An initiative which increases the supply of organs will, ipso facto, have one very important ethical argument in its favour: the potential to avoid death and relieve suffering (New et al. 1994, p. 61).

The benefits of transplantation, both in terms of value of life and cost effectiveness, present a powerful justification for persevering with transplantation. On the face of it, one could argue that the more organs we have the more transplants we can do, resulting in saving and improving more lives. In relation to this, if there is a system which has been shown to provide more organs, thereby maximising utility in terms of welfare, then this system could be regarded as a more successful policy than a system which provides fewer organs. It is important to remember that under European legislation policymakers are restricted in what type of policy they can introduce²¹. So whilst numbers do matter, achieving a rise in organs retrieved for transplant involves more than simply legislating for a system which organises procurement in such a way as to make organs available more easily than a system which relies upon voluntarism.

It is important to recognise that transplantation occupies a quite unique position in respect of resourcing requirements. Whilst undoubtedly money is needed to fund this area of healthcare, there is a greater reliance placed upon the public to help provide the organs in the first place, to allow for transplants to remain a viable option for the treatment of ESOF. We have to rely on each other for this policy to work. From this, one can see that it is not only the financial cost which requires consideration when deliberating over policy provision in this area of

²⁰ It should be noted that the authors of this study also highlighted their findings in respect of a decreased number of live donor renal grafts from opt-out countries, to temper the positive increase demonstrated in these countries from deceased donors.

²¹ Reference has been made to this on page 8.

healthcare, but also the potential personal cost. In respect of this, there are those who might contend that normative decision-making which invokes an impersonal and, arguably, crude utilitarian calculation in its approach to increasing the supply of organs ignores other important factors, such as the importance of public opinion, and certain values which are important to individuals.

1.5: The Importance of Public Opinion.

Whilst empirical data alone may not provide the answer to normative questions (Harris 2001) it can provide challenging debate in relation to practical appropriateness of some ethical claims. On occasion this data may serve to highlight concerns for ethicists and policymakers when instigating a policy or new piece of legislation (Sugarman and Sulmasy 2001, p.255). Disciplines involved in the field of ethical inquiry, specifically descriptive ethics, have conducted empirical research to provide descriptive facts about how society functions, the behaviour of people and, to an extent, the moral shaping of society. Empirical research, such as that involving public opinion, serves a valid purpose by providing an understanding of how important issues affecting society are perceived and accepted. The public's concerns may be overlooked if policymakers and ethicists only consider the specific ethical issues when devising a policy. Yet it is often the public that much of the issues under scrutiny will directly affect; no more so than in a policy which revolves around the procurement of the public's organs. A policy around increasing organ procurement has to be ethically acceptable to those orchestrating change, but also to the people on whom responsibility rests to ensure the policy succeeds. This can be achieved by listening to the public, and ensuring that information regarding the policy is both comprehensive and comprehensible. Levitt (2003a) points out that bioethicists do not listen to the public enough or pay enough attention to the practicalities of policy implementation (p.21), specifically when the public have such a decisive role to play. What is more, Warnock (2003) points out that when making policy decisions of this nature it is impossible not to consider the consequences of what will result from the policy, and how it may impact upon the public and their beliefs which, in turn,

may have a detrimental impact on the success of the policy. Listening to public opinion can enlighten policymakers; coupled with this, this opinion may provide the “raw material” helping ethicists to “fashion coherent sets of policies and principles” (Garrard and Wilkinson 2005, p. 87).

In addition to this, sharing information around the reasoning behind introducing a policy may lead to a level of congruence from the public. In this respect, when making difficult decisions which might be contentious, sensitivity and a careful avoidance of inflammatory language, which may be interpreted as arrogant or presumptuous, should also remain at the forefront of those charged with responsibility for making policies. When recounting her experiences chairing a committee examining the issues surrounding new fertility treatments, Mary Warnock (2003) described the committee’s painstaking attempts to avoid “riding roughshod over the moral scruples of a significant number of the public” (p.100). Clearly, the public need to be involved in some capacity when making policies that will directly affect them, but these policies also need to be presented in such a way as to prevent any potential alienating effect. It is important to strike a balance between what is deemed to be the right action to take, with what the public feel to be the right course of action. This is especially so when formulating a policy which relies so heavily on the public for their active support. An organ procurement policy is more likely to succeed when there is both an understanding on the part of the policymakers as to what the public feel, and an understanding on the part of the public of what the policymakers believe to be the right action to take in order to improve the well-being of society.

In respect of this, the public deliberative events which contributed to the ODT’s report on whether an opt-out policy should be introduced in the UK sought to achieve this level of participation from the public, ensuring their opinions fed into the report appropriately²² (ODT 2008, Annex J). From the evidence presented by the ODT, it would seem that what the public

²² Montgomery (2013) refers to the responsibility for the ODT, as set down in the terms of reference when undertaking their report on Opt-Out, which advised that due regard be given “to the views of the public and stakeholders on the clinical, ethical, legal and societal issues” (p.10). In view of this one can conclude that the public’s views were an important consideration, and contributed to the final decisions made by the ODT as to whether opt-out should be introduced in the UK; however, its decision was not based solely upon public opinion.

desire is respect for self-determination and choice in decision-making in this area (ODT 2008, p. 27; ODT 2008, Annex J, p.25, 33). If a policy does not reflect this, then it could be deemed ethically unacceptable even it does ensure that more organs are available when needed.

The importance of ownership of organs, and the right to retain control over what should happen to one's organs in life and death have been expressed by some members of the public during the ODT's deliberative events and deliberative workshops, as part of NCOB's research into the permissibility of using bodily material for medicine and research (NCOB 2010). The issue of ownership was commented upon and discussed by the ODT in its report, and explored in more detail in the report published by NCOB. In view of this, I would like to examine the subject of property. I believe this is an important area to explore, since the need for consent or authorisation has an integral role in matters of property and, as such, may be difficult to dispense with if the body is to be considered in such a way.

Chapter 2. The Relevance of Property Discourse in an Organ Procurement Policy.

2.1: Introduction.

When discussing the reason behind introducing an informed consent system for organ and tissue procurement in the UK²³, Rosie Winterton, the minister responsible for sponsoring the Human Tissue Act (2004), stated: “We are talking about the rights of individuals, not just those of the state. The state does not **own** a human body; nor do doctors or scientists. It is up to individuals to choose” (Hansard 2004, col. 989). An informed consent system was reinforced during the reading of the Human Tissue Bill 2003 in the House of Commons Standing Committee (HSCS) G in June 2004. Stephen Ladyman, former Labour MP for Thanet South, stated that the principles of the Bill were that: “we all **own** our own bodies, we are entitled to determine how material from our bodies is used; and we should have consented to the use of that material” (HCSC 2004). Consent was proposed both in terms of privacy rights and rights couched in property terminology.

In healthcare, it is normal practice to take consent from patients before a treatment or an investigation is commenced. The rationale underpinning consent is integral to the way we view the body. In healthcare, this is particularly important and requires a level of consistency in order for practitioners to act appropriately when treating patients. Yet there is a divergence of opinion amongst ethicists and legal commentators over the issue of the status of the body. This extends to practices such as live and cadaveric organ procurement. Members of the public have also aired strong views in respect of this. If references to ‘ownership’ can be linked to property, then consent may well remain an important proviso for organ procurement. If consent is important, then its ‘presumption’ could pose a challenge for those advocating either a system of organ conscription or one of presumed consent. However, in the countries where organs are routinely procured from the dead unless an objection has been registered, this system remains permissible

²³ Excluding Scotland.

both legally and ethically (ODT 2008). This is because although the default position is one of retrieval, the decision for organs to be removed post-mortem ultimately rests with the individual, provided in the right to objection. In accordance with this, the right to self-determination is the fundamental proviso, but this need not necessarily be applied through consent. This system seems to be justified using privacy rights.

One of the views expressed during the public deliberative events, conducted as part of the ODT's report looking into the impact of an opt-out system for organ donation, pointed towards concerns that under an opt-out system "assuming consent" could result in treating the deceased as "commodities" (Rudge and Buggins 2012, p. 142). This view appears to link an opt-out system with treating the body as property; moreover, the implication is that this would be demeaning. The inference would then be that an express consent system, such as the current opt-in, effectively prevents the possibility of this arising. Justification for this system would also appear to be grounded in privacy rights, demonstrating support for self-determination rather than ownership of the body. What is apparent is that from a theoretical perspective rights over the body *may* be expressed using both property and privacy terminology. This may have an important bearing upon how we legislate for organ procurement.

This chapter will look at the relevance of property discourse in relation to the body in the clinical context, from both a legal and ethical perspective; from this, whether it is a relevant and pertinent area for consideration when devising a policy for deceased organ procurement. I believe this is partly contingent upon whether the body can be viewed differently from the corpse. So, whilst justification for consent pointing towards privacy rights would seem to be the accepted approach to live organ donation, whether body parts once removed from the body, or the lifeless body, and parts thereof, can be viewed differently from the living body requires some attention. Theoretical and empirical evidence will be used to inform this discussion. This chapter will focus

upon discussions around these specific issues and whether consent need take centre stage for deceased procurement.

2.2: Property Discourse in the General Setting.

What difference would it make if the body were property? If the body is to be afforded protection under rules of property, then consent *may*²⁴ be a necessary requirement for any dealings with the body. This is because of the role consent plays when dealing with certain types of property. In lay terms property may be considered as ‘things’; however, in legal terms property is considered as a right in or to things (Nwabueze 2007). “To have property is to have a right in the sense of an enforceable claim to some use or benefit of something; whether it is a right to share in some common resource or an individual right in some particular thing” (Macpherson 1978 p.3). Macpherson differentiates property from a mere physical possession as the former allows one to have a claim- a right of ownership over the property. Private property provides rights and privileges in relation to one’s claim of ownership over the property; rules which have been constructed by society afford protection over these claims and privileges. One’s right in relation to private property includes the right to exclude others from using or entering the property without the consent of the individual.

There are different types of property: private property, State property (for instance, State owned buildings such as public libraries, museums, hospitals) and common property²⁵ (parks, bridle paths, streets) (Macpherson 1978). Consent is not always required when dealing with property. Rights in accordance with private property may require consent from the owner for others to use or enter into the privately owned piece of property; however, State and common property may allow use and entry without permission. Parks, for example, which the local authority may be responsible for, are often public property and no permission is required for

²⁴ I stress ‘may’ since consent is not an absolute requirement with all forms of property.

²⁵ A similar delineation is made by Grubb (1998) over property; he divides property into personal (private) and real (land) property.

public entry. Private property is not always completely 'private' either. If I own a house and have an acre of land behind the house, there may be a public pathway running through the land which the public will still be entitled to use. I may have private ownership rights relating my property, but the State controls the path that runs through my property. The State has the power to enforce public rights over common property for the benefit of society; the State is also responsible for enforcing the right of protection of the privileges associated with private property. Another example of the State's power over private property can be seen in the tax system. I do not have exclusive rights over all of the money I earn in my job. Some of it is owed as income tax and National Insurance contributions after I earn a certain amount of money. Therefore, it could be said that there are certain caveats to exclusionary control of private property, dependent upon what the private property is.

Consent may not always be required in the transfer of private property. If during my lifetime I own a piece of land, I shall have certain rights in respect of ownership regarding, for instance, access. My consent might be required for access onto the land as a result of this. When I die, since I shall not be able to keep it in death I may bequeath it to somebody in my Will, as I have the right to dispose of it as I wish. Bequeathing may involve the act of giving but it certainly does not involve the act of consent. Therefore, when making a last Will and testament I do not consent to my property being used by those I name in the Will. The body could be viewed of in a similar way, with respect to rights of access, in that whilst alive consent is required to access my body (generally). In death the body requires disposal; therefore somebody- normally relatives- will take ownership of the body in order to fulfil this. With regards to burial, I can stipulate what should happen to my body once dead; I can also request that my organs be retrieved for therapeutic purposes. However, decisions centring on disposal do not involve consent. Under the present system for organ procurement I may consent to my organs being used for transplant after death; however, there is no guarantee that this will in fact happen (if there is no suitable match

for the organs, or if the organs are deemed unsuitable for transplant, or if my relatives choose to veto my consent).

In respect of death and property, the State is also able to enforce certain financial claims via inheritance tax over 'my' property, depending on its value (HMRC 2011²⁶). My property may also be escheated if I have not left a Will, and have no relatives who may receive my property; this is governed by intestate law (Law Commission 2010²⁷). This shows that although I may possess certain items, these may end up becoming State property. With this in mind, it is worth considering the subject of property in relation to organ procurement.

2.3: Is Property Discourse Appropriate to Discussions around an Organ Procurement Policy?

When considering how the body is treated, privacy and property theories support similar expectations in respect of providing the right to possess one's own body, and the right to exclude others (Rao 2000, p.444). However, whilst privacy rights protect one from unwanted interference and property rights protect against trespass, their approaches to the body are very different. Property rights would regulate the use and treatment of the body as it would other objects of property; this, in theory, *may* allow the body, as an object, to be transferred, rendering the possibility for commodification. A commodity refers to an object that is instrumental but contains no intrinsic value, yet may command a monetary value; it can be replaced on a like for like basis or sold (Schweda and Schicktanz 2009). However, although privacy rights provide persons with an element of self-ownership, under the terms of privacy the body is not seen as separable from the self; it is not viewed as an object. In view of this, the right of transfer is therefore not an appropriate method under which to manage the rights an individual has regarding the body²⁸.

²⁶ Available from <http://www.hmrc.gov.uk/inheritancetax/intro/basics.htm#1> viewed 13th May 2011.

²⁷ Available from <http://www.justice.gov.uk/lawcommission/areas/intestacy-and-family-provision-claims-on-death.htm>, viewed 13th May 2011.

²⁸ That said, a possible exception to this may arise in the form of living organ donation. When one offers to donate a kidney for a live related/unrelated transplant this could constitute a form of transfer. On the face of it, it would seem that even if one is sympathetic to the privacy rights theory, there are opportunities, albeit few of them, in which an individual may have alienable rights over some parts of the body.

On the face of it, the property theory seems to be a pertinent discussion if considering a system for procurement which may include a market in organs. If ownership of the body is used to justify the use of consent for organ procurement, then whether this term is linked to property or privacy also has a very important bearing upon whether my argument for a change to a soft opt-out system is viable. I would like to consider the legal and ethical approach to the question of whether the body should be treated as property; doing this will help to clarify whether property discourse is an appropriate form of dialogue when devising a system for cadaveric organ procurement.

2.4: The Body as Property: the Legal Position.

Questions around whether the body should be treated in the same way as other property is treated are important and need to be asked, precisely because the body, having become such a valuable resource, prompts questions such as these. This was recognised in *Brotherton v Cleveland* 923 F. 2d 481 (1991), in which the Judge commented:

The importance of establishing rights in a dead body has been, and will continue to be, magnified by scientific advancements. The recent explosion of research and information concerning biotechnology has created a market place...the human body is a valuable resource. As biotechnology continues to develop, so will the capacity to cultivate the resources in a dead body.

Developments and advances in medicine have resulted in the perception of human organs and tissues as valuable 'assets'. They are not only valuable for the individual's existence when alive, but their value also extends beyond the existence of the individual's life span and on into the lives of others. In this way organs and tissues start to take on a new meaning, one which may be commensurate with objects which are instrumental but which, in themselves, may contain no intrinsic value (although this may be disputed when relating their value to the live 'owner' of

them), and, as such, may be replaceable. Their value can almost be compared with other items which we would commonly refer to as commodities.

From a personal perspective, if an individual believes her body to be her property, then within reason she should be able to do with it what she pleases. It can be protected as other possessions are protected under property rules; if she chooses to give her organs to others, then with her consent this should be able to happen (within reason). On this basis, consent would appear to be a logical measure to be taken when managing the use of bodily material for medicine and research. The introduction of certain organ procurement policies, such as opt-out, may then be problematic. The status of the body and organs does have an important bearing on how we legislate for organ procurement. The natural rights theory introduced by John Locke (1632-1704) built the foundations for private property (Ryan 1994). Locke believed:

...every man has a property in his own 'person'. This nobody has any right to but himself. The 'labour' of his body and the 'work' of his hands, we may say, are properly his. Whatsoever, then, he removes out of the state that Nature hath provided and left it in, he hath mixed his labour with it, and joined to it something that is his own, and thereby makes it his property (1690 II §27).

The relationship between man and his property was understood to be a natural one because the claim to property was seen as a natural right as at this time there were no rules or governmental powers to oversee the appropriation of property. In this way, property could be defined as a relation between the owner and the "owned object" (Bjorkman and Hansson 2006, p.210). The property in person allowed a man to extend his ownership through the skilful use of his person to add to a product; an example of this may have been tilling a field of crops, thereby cultivating land. Gaus (1994) makes the point that one's right to his own body could be understood as a basic right, and rights to external property could be derived from this "fundamental self-ownership" (p.221).

Historically, this notion of ownership of one's body and its parts, coupled with the value body parts have been shown to provide, have resulted in practices which have pointed to body parts being treated as commodities. This has provoked much disquiet. In English law, in the 1500s the companies of Barbers and Surgeons were united by Royal Charter in England and granted an annual right to take the 'Bodies of ffoure condemned persons yerely for Anatomies,' (American Association for the Advancement of Science 1900, p.251), permitting the use of the corpse for the purposes of dissection. Richardson (2001) argues that the body took on a utilitarian role: it helped to establish a deeper understanding of the workings of the body, and from there played a crucial role in pioneering techniques to improve health. This, in turn, resulted in increased social productivity. As such, the value in a corpse quickly rendered it a commodity.

Whilst the utility of the corpse grew, the number of bodies made available for dissection did not. Events took a sinister turn during the turn of the 19th century when evidence arose of body snatching to provide more corpses for post-mortem examinations (MacDonald 2009). Illicit activities resulted in public outcry. Richardson points out that the law did not view removal of a corpse from a grave as theft, or as a crime requiring harsh punitive measures. However, the vociferous nature of disgust demonstrated by the public about such behaviour towards the dead, their relatives, and to the community as a whole meant that the government had to act to provide some form of redress (Richardson 2001, p.85), fearing that lynch law may prevail if the public did not consider justice to be done for body snatching. This forced a revision of the statutory provision of bodies for anatomical examination and subsequently the introduction of the Anatomy Act 1832.

Under the Act, dissection was limited to those who had expressed a wish to donate their own or their relatives' remains for anatomical examination (MacDonald 2009, p.380), or those for whom no application for burial had been made (Richardson 2001). Unfortunately, whilst the Act did provide some protection from the previous illicit body snatching which had become rife,

Macdonald (2009) suggests that the Act, in effect, legislated for a system of presumed consent. To prevent an individual's corpse becoming available for dissection to medical schools at the discretion of the executor, responsible for the lawful disposal of the corpse, a person had to register an objection to dissection; in addition to this, relatives had to make a claim for the body within forty-eight hours of death. The Act did not provide sufficient power to anatomy inspectors to prevent the continuation of illicit dealings such as grave robbery, and the legislation itself rendered many members of the public still vulnerable to dissection post-mortem.

Furthermore, the Act did not include any formal wording around the negative property status of the human corpse (Richardson 2001, p.207). There was no provision made for ensuring that the transfer of a corpse to an anatomist should be made freely, thus preventing an explicit opportunity to outlaw the sale of bodies and their parts. This meant that specific decisions in regards to these acts remained under the jurisdiction of case law. Moreover, the Anatomy Act legislated for the use of whole corpses only; therefore medical schools were not accountable to the anatomy inspectors for body parts that they managed to procure (MacDonald 2009, p.388). In relation to the use of body parts, the law has evolved under the direction provided by court judgments.

Natural rights theory has been invoked in case law around the use of bodily material to render it as property, by adding a preservative or a chemical to tissue to manipulate it, thereby introducing a new meaning to it. Cases which are notable for the judgments made regarding the status of the body and body parts include *Doodeward V Spence* (1908)²⁹ in which Griffith C J held that:

a human body, or a portion of a human body, is capable of becoming the subject of property... when a person has by the lawful exercise or work or skill so dealt with a human body or part of a human body in his lawful possession that it has acquired

²⁹*Doodeward V Spence* 1908 6 CLR 406 (HCA)

some attributes differentiating it from a mere corpse awaiting burial, he acquires a right to retain possession of it³⁰

In English law, a natural rights approach to property rights, where work or skill is applied to body parts³¹, has been referred to in a number of cases. In *R v Kelly* [1999], which involved the theft of body parts for use in an art exhibition, the defendants appealed their innocence stating that there was no property in a body, and therefore they could not have committed a theft. The judge ruled against the defendants, inferring from section 4 of the Theft Act that:

Parts of a corpse are capable of becoming property if they have acquired different attributes through the application of skill (such as dissection or preservation techniques) for exhibition or teaching purposes. In future cases the exception may be extended to include body parts with a use or significance beyond their mere existence, even without the acquisition of different attributes. An example of this may include organs or body parts, intended for use in a transplant operation³².

This point, referring to dissection and preservation techniques, was again invoked in the case *re Organ Retention Group Litigation*³³, and the application of skill in another case, *AB v Leeds Teaching Hospital NHS Trust*³⁴, brought by aggrieved parents over the wrongful interference with the body of their child, including retention of body parts without the parent's permission. In both of these cases some 'qualifying work or skill' had been performed by the technicians when the organs were retained; this skill may have afforded a mere right of possession to continue the work for which they had been awarded the possessory rights (Hardcastle 2009, p. 36).

Statutory provision of property rights under the Human Tissue Act 2004 has also recognised property in relation to organ procurement, albeit in a limited and somewhat vague

³¹ *Dobson v North Tyneside Health Authority* [1997] 1 WLR 600 in which Gibson LJ stated: "a body may attain proprietary status following the application of skill"

³² [1999] QB 631

³³ [2004] EWHC 644 (QB), [2005] QB 506

³⁴ [2005] Q.B. 506

form. Section 32 of the Act prohibits commercial dealings in human material for transplantation; however, subsection 9(c) of section 32 provides an exception to this prohibition, in the form of material which is the subject of property because of an application of human skill. It is difficult to know exactly which circumstances the Act might be referring to; this has been noted and the Act criticised for its blatant lack of clarity in this respect (Brazier and Cave 2011; Hardcastle 2009).

It is interesting to note that in all of these legal examples, ownership or property is connected with the person retaining the organs/tissues, rather than with the person from whom the organ/tissue is extracted. These cases also refer to organs and tissues from deceased individuals. Discussions around this would appear to be at a tangent from those which concern the individual owning their body or describing it as property³⁵. Once removed from the person the organ or tissue may become an object for which property discourse may seem more appropriate. Whilst it remains within the person this would not seem to be a congruent line of discussion due to the place the organ/tissue has, both metaphorically and physiologically, with the person. In relation to this, perhaps advocates of natural rights, such as Locke, would seem to contribute better towards a discussion focusing on the ownership of body parts once removed from a body, which can then be treated or worked upon in a specific way, thus rendering some form of attachment to the technician as plausible. The theory does not seem to maintain such pertinence or relevance when focusing upon the individual and ownership of their body parts.

If this is the case, then the requirement of consent for organ procurement, contingent upon the body being regarded as property, would not seem to be a logical line of reasoning. Moreover, it should be noted that although Locke stated that “every man has a property in his own person”, he viewed persons as being entrusted with the body. Men had rights in relation to their body, but this did not constitute ownership. When speaking about ownership in the body

³⁵ This has been discussed in the case *Yearworth and Others v. North Bristol NHS Trust* [2009] 2 All E.R. 986. In this case the court held that the 6 claimants “had ownership of and, therefore, property rights in their sperm” (Harmon and Laurie 2010 p.479). However, the fundamental difference in this case is that the individuals in question were all alive. Generally, cases where body parts have been discussed, in terms of property and ownership, have centred on organs /tissues extracted from the deceased.

Locke referred to ownership ultimately residing with God: "Men being all the workmanship of one's omnipotent and infinitely wiser Maker- all the servants of one sovereign Master sent into the world by his order and about his business- they are his, whose workmanship they are made to last during his, not another's pleasure" (Locke 1690 II §6).

2.5: Rights to the Body utilising a Property Rights Approach: the Ethical Position.

Property matters to all of us, but it is libertarians who advocate the importance of it most fervently, believing the importance of property to be that it represents a symbol of one's liberty. Lee (1775, cited in Ely 2007, p.26) describes the right to property as "the guardian of every other right, and to deprive a people of this, is in fact to deprive them of their liberty". For some libertarians property is the embodiment of liberty (Gaus 1994). Narveson (1988) claims that *all* rights are property rights (p. 66); she intuitively feels that we own our bodies, possess them and have rights in relation to this, which accord with standard rights of ownership. For Narveson, these rights relate to bodily integrity and to liberty too, warranting protection from unwanted intrusion and/or bodily invasion. Viewing rights to the body in this way would necessitate a system of express consent governing the use of bodily material for medicine. An opt-out system would therefore simply not be acceptable.

However, Gaus (1994) refutes Narveson's view; he suggests that not all rights are liberty property rights. His examples are the right to bodily integrity and the right to religious worship (the more abstract and personal nature of these may implicate their protection be better served under the realms of privacy). Moreover, if our rights relating to the body are understood to be the same as our property rights in relation to the objects we 'own', then problems immediately arise when considering the extent of full ownership rights as well as the obligations corresponding with these rights. This is because the law allows us to dispose, transfer and control our property, and this assigns rights to us as individuals in respect of ownership of these possessions. Can rights to the body be afforded the same sort privileges?

Reflecting on the status of property and the importance we attribute to it in our lives, Harris (1996) states that there are two essential elements of property: one is protection from unwanted invasion without consent, and the second is the different and very open relationship property can invite. Provision, in respect of both of these, comes in the form of trespassory rules in relation to protection from unwanted invasion, and the concept of an ownership spectrum to illustrate and define responsibility and associated rights and privileges, in respect of ownership and control of different types of property (Harris 1996, p.59). The first he describes is at the lower end of the ownership spectrum; this is “mere property” (p.59). As owners of mere property we are afforded some general privileges and some powers regarding the control we can exert upon others in relation to their using it. In a similar vein to this Grubb (1998) describes a user entitlement: if a person owns a possession, she can do what she wants with it, and she has right of possession over the item that she owns.

At the upper end of the ownership spectrum one retains full blooded ownership (Harris 1996). This affords unlimited possession rights as long as these do not conflict with what Harris terms as “property independent prohibition” (1996, p.59). Grubb describes an exclusionary control that the possessor may have with property which she could be understood to have full blooded ownership of. A person is afforded protection from unwanted invasion of her property in accordance with the trespassory rules, as well as having exclusive rights in respect of what she does and how she may profit from that which she owns. Such privileges include dispositional liberties when owning a property, and these mean that the person may gift the possession to another or sell it (Grubb 1998).

In relation to property and ownership, Harris refers to a liberal society in which one of the fundamental freedoms is the “bodily-use freedom principle” (1996, p.62). Our relationship with our body is also of special significance in a similar way as some of our possessions are to us. I am therefore able to use my body as I want and I am the arbiter when it comes to decisions relating

to the use of my body and what is done to it. This is because it affects me as a person, and so (under normal circumstances) what happens to it, ergo to me, matters. However, as mentioned earlier, legal cases have suggested that although bodily parts can become property in accordance with Locke's fruits of labour theory, once separated from the body the rights of ownership, in respect of decisions as to what happens with the part, are not automatically the right of the individual from where the part has come³⁶.

Whilst alive, user entitlements allow me to do with my body what I want, within reason. However, there are certain acts which I cannot do. I cannot, for example, donate my heart whilst alive as this would result in my death; I am unable to perform sexual masochistic acts³⁷ which could bring about severe harm, even if I am aware of the harm and would still wish to consent³⁸. So, although the bodily-use freedom principle may exist, this shows that I am not entitled to full blooded ownership rights that I may have over my house, for example. I do have exclusionary rights, which mean that I am protected from bodily invasion such as assault, but I only have limited dispositional liberties. I can gift parts of my body, such as blood, or perhaps a kidney for transplant, as the risk of harm is relatively small; however, I cannot sell any of my organs³⁹.

³⁶ Please refer to *Moore v Regent of the University of California* 793 P 2d 479 1990 for detailed discussion and ruling over ownership of separated body parts.

³⁷ In *R v Brown* [1994] 1 AC 212 [1993] 2 All ER 75, the House of Lords were of the firm belief that "ritual physical abuse of the body for sexual pleasure remains criminal even when undertaken within the envelope of full and informed consent by the parties involved" (Mason and Laurie 2006, p.511).

³⁸ 'Dangerous' sports such as rugby, climbing, fencing may risk injury but do not directly lead to harm. These therefore differ from acts such as donation of a heart which leads to death, and sado-masochistic acts which constitute actual bodily harm. Here, the *actual* harm which results from the acts is not something for which consent can be legally invoked in defence thereof. Whilst morally one might argue that if these examples of masochistic and supererogatory acts do bring happiness then their consent should suffice, what might be difficult to prove would be whether their consent were entirely voluntary. In *R v Brown* [1993] 2 All ER 7 Lord Templeman stated that even when violence is intentionally inflicted and results in actual bodily harm, wounding or serious bodily harm the accused is entitled to be acquitted if the injury was a foreseeable incident of a lawful activity in which the person injured was participating. Surgery involves intentional violence resulting in actual or sometimes serious bodily harm but surgery is a lawful activity. Other activities carried on with consent by or on behalf of the injured person have been accepted as lawful notwithstanding that they involve actual bodily harm or may cause serious bodily harm. Ritual circumcision, tattooing, ear-piercing and violent sports including boxing are lawful activities.

<http://www.cirp.org/library/legal/UKlaw/rvbrown1993/>, viewed 30th April 2015.

³⁹ The law around organ selling has been discussed on pages 14 and 15.

Full blooded ownership rights to my body seem too extensive; however, rights associated with mere property seem to afford me too little in the way of control I have over what happens to my body. This demonstrates that the body does not seem to fit along the ownership spectrum as clearly as other items of property can. That is not to say that it cannot fit anywhere along it; the notion of this spectrum affords the opportunity for that which is being measured to fit anywhere along a continuous line. It seems reasonable to suggest that the body does not sit either at one end of the spectrum or the other. Harris suggests that we cannot ascribe the entitlements and privileges in respect of the body and the person in the same way as other objects of possession. This is probably to do with the relationship we have with our body. One view of this, represented by Judith Jarvis Thomson (1990), is that the body can be seen as distinctive from all other possessions and considered as our first property, with other items of possession taking second place.

However, I would suggest that the relationship we have with our body presents a quite different dimension from the concept 'ownership' which we may more often associate with other items or possessions that we own. Our relationship with our body may bear some similarities to our relationship with other items or objects that we own and which facilitate the rights featured on the Harris spectrum. On the other hand, it may be that any reference to 'ownership' is an attempt to represent our view of the way we perceive our self as being interconnected with our body. Using this interpretation, it would seem illogical to consider rights in relation to the body in terms of property rights, putting our body in the same category as we would a "tract of land or a library of books" (Campbell 2009, p.15).

However, if we view the body in terms of this interconnectedness, this then begs the question, how can I own something which *is* me? Perhaps reference to 'ownership' constitutes a form of defence. I refer to my 'owning' my body as a way of protecting against anyone else taking ownership of me. What would appear to follow from this is that if I do not own my body, then

somehow I may render myself vulnerable to being taken ownership of. Concern, in respect of this, has been expressed when considering the role of the State under a system of opt-out, and their taking 'ownership' or control of deceased people's bodies and their parts (NCOB 2011; ODT 2008). Arguably, 'ownership', when referred to in this sense, may misrepresent this relationship we have with our bodies, which we allude to when speaking of our defending our rights over our bodies. To conclude that if I do not own me then somebody else could is an illogical leap to make; Harris (1996) argues that this is a "non sequiter...from the fact that nobody owns me if I am not a slave, it simply does not follow that I must own myself. Nobody at all owns me, not even me" (p.71)⁴⁰. The reference to 'ownership' perhaps reflects the more accurate relationship we have with our bodies in terms of being responsible for it rather than 'owning' it in the more traditional sense. On this basis, viewing our body and our relationship with it in such a way as to require some rights in terms of access and exclusions, which the ownership spectrum may facilitate for other items of property, could be puzzling.

The problems highlighted by Harris in relation to ownership, and the point raised by Thompson in relation to the view of our body, both demonstrate that Narveson's intuitive feeling regarding our rights over our bodies may be ill thought out. Gaus regards our rights over our bodies as in fact being "highly revisionary" (1994, p.214) when considering the inappropriate relations of the body to standard liberal rights of transfer and alienable rights. In view of this criticism, at this point it is worth considering the social constructivist perspective on rights (Bjorkman and Hansson 2006). For social constructivists property rights cannot exist independently from the State. According to Rao (2000) the sophistication of property theory is that it functions in two ways; on the one hand, property rights limit the power Government has over persons, and on the other it enables Government to exercise power over said persons. Property rights are best understood as a set of legal relations between the owner and the non-owners of an object (Bjorkman and Hansson 2006 p.210). These relations can be tied together

⁴⁰ Harris relates this point to body parts as well.

into bundles of rights and obligations which may be modified to best suit the property being focused upon.

Property rights are often defined in terms of a 'bundle of rights' (Bjorkman and Hansson 2006 p.210). These bundles of rights are not complete and entirely free from constraint, hence the obligations which are tied into the bundle. However, their purpose is to protect one's right of possession, designating exclusive control of the possession to one individual (acting as the owner); this means that this control is not forfeited when not in physical possession of the said owned object. Honoré (1961) gave his very famous and often referred to account of "standard incidents of ownership"⁴¹ referring to these as "those legal rights, duties and other incidents which apply, in the ordinary case, to the person who has the greatest interest in a thing admitted by a mature legal system" (p.107). When discussing the term 'ownership' Honoré referred to his adopting the "'liberal'" account of "'full' individual ownership" of a thing (p.107). He regarded his standard incidents of ownership account as "the necessary ingredients of ownership" (p.112). These include: the right to possess, the right to use, the right to manage, the right to income of the thing, the right to the capital, the right to security, the rights or incidents of transmissibility and absence of term, the prohibition of harmful use, liability to execution, and the incident of residuary (p.113).

Honoré (1961) did not believe that his incidents of ownership should be applied to the body; he believed that a person could neither be owned nor 'have' his body or liberty; rather he had a right to bodily security and liberty. He reasoned that "here, the analogy with the ownership

⁴¹ Note that Honoré refers to "standard **incidents** of ownership" (1961, p. 112); in his work he refers to the "fashionable" use of bundles of rights (1961, p. 113). However, his tone suggests an attempt to distance himself from this sort of language, when he suggests that at least two of his incidents would need to be omitted from a bundle of rights; these being the incident of transmissibility (strictly speaking, although Honoré suggests that if there should be a revision of the term right then this may fall within it) and of absence of term. Further to this I would suggest that both the prohibition of harmful use and liability to execution would not have a place in a bundle of rights since these would appear to fall within the rights of the State to enforce protection of individuals and therefore legislate against harmful use of possessions, and to expropriate possessions should the individual find himself in debt.

of a thing is tenuous; thus, these rights are inalienable” (p.129)⁴². The relationship we have with our body is unique. The body itself is unique; its ability to function independently sets it apart from objects which cannot. An issue that would present if rights relating to the body were designated in the same way as the rights in accordance with full liberal ownership of a possession, is that this would render the body as open to transfer and able to be sold; this would “interfere with human freedom” (Honoré 1961, p.130). Therefore, with regards to rights over the body which may constitute a peculiar form of ownership, what may be required is a different set of the rules pertaining to this form of ownership; these would naturally deviate from other rights which relate to property. Any claim to rights would need to be carefully tailored so as to avoid endorsing the legal permissibility of acts such as rape and slavery.

In an attempt to organise a framework when discussing body ownership, particularly in the area of organ markets, Bjorkman and Hansson (2006) devised a bundle of rights influenced by the work of Honoré, utilising a socially constructive approach to property rights. Bjorkman and Hansson’s bundle of rights are specific to biological material. This bundle of rights would afford the same sort of protection as a bundle of rights for traditional objects of property, with a set of legally imposed sanctions to regulate conduct in this area. In accordance with the social constructivist approach one’s ownership of biological material would have certain rights and obligations associated with it, appropriate to the nature of the property in question and the type of ownership associated with this. Bjorkman and Hansson’s (2006, p.212) bundle of rights for biological material include:

1. The right to security in life. This includes the right of the person to keep a part of her body not have a part of her body removed;

⁴² This point has been echoed by both Rao (2000), stating that a person’s right to life and liberty are inalienable, and Gauss (1994), who has asserted that the body being ours justifies exclusive use of our bodies and the right to non-interference from this exclusive use; however, rights of exclusive use do not extend to transferrable rights (p.224).

2. The right to security after death. The right of a person that a part of her body is buried or disposed of in the way that she wishes;
3. The right to donate for removal in life. The right of a person to give up a part of her body without remuneration, to be removed in her lifetime;
4. The right to donate for posthumous removal. The right of a person to give up a part of her body without remuneration, to be removed after her death;
5. The right to sell for removal in life. The right of a person to give up a part of her body against remuneration, to be removed in her lifetime;
6. The right to sell for posthumous removal. The right of a person to give up a part of her body against remuneration, to be removed after her death;
7. The right to income. The right to receive the profits obtainable from the use of a biological material (such as the profits from a cell line). (This differs from a right to sell in referring to the profits obtained at points in time after the initial removal of the material.)

In accordance with this bundle of rights, if the body is to be identified as property, then items 2 and 4 may be particularly useful in allowing a person the right to donate organs after death. Whilst on the face of it these rights would appear to endorse a system of informed consent, one could argue that items 2 and 4 could be invoked to support a system of registered objection to organ procurement. The position Bjorkman and Hansson appear to take is that the bundles emphasise the individual's *right* to do what they want with their body as long as no harm is brought upon the body in the process. This again suggests that the choice over the body belongs with the person. What is perhaps more pertinent about this bundle of rights is that the rights refer to a part of the body. So, theoretically, whilst the whole body remains protected from transfer and alienability⁴³, and individuals are afforded privacy rights in respect of self-determination over what happens to the body, this need not necessarily extend to body parts once removed from the body.

⁴³ Therefore preventing the potential for commodification of the body and potential issues relating to slavery and rape.

It should, however, be noted that the removal of some parts of the body does not accord with this notion of rights talk requiring property-talk. For example, Kant argued that “to have something cut off that is a part but not an organ of the body, for example, one’s hair, cannot be counted as a crime against one’s own person—although cutting one’s hair in order to sell it is not altogether free from blame” (1797, §6:423). Furthermore, one has inalienable rights which serve to protect an individual from unwanted interference, or conversely, which serve to prevent an individual undergoing a significant risk to their health. Ownership of the body may still seem a clumsy and inappropriate label with which to describe our relationship with our body; however, body parts once removed are (or quickly become) inanimate and may be more aptly described as objects⁴⁴; at which point one could argue that they can then be owned.

Body parts can be described as an umbrella term for a plethora of parts, some of which play a more vital role in the function of the body than others. It may perhaps be acceptable to consider less vital organs as pieces of property⁴⁵? If this is so, then transfer for remuneration and alienability should no longer be an issue necessarily, as is presently the case under the Human Tissue Act, especially when one considers the utility of such an organ and the need for organs to redress the gaping margin between organ supply and demand. Perhaps protection of these parts could be provided for under property law and a moderated bundle of rights, such as that formulated by Bjorkman and Hansson (2006). Whilst such an argument may be applicable to living organ procurement, more pertinent to the discussion relating to cadaveric organ procurement and legislation governing this process is that if body parts outside of the body are deemed as lifeless objects, then perhaps the same could be said of a corpse and *all* of the internal organs in the lifeless body, as none play a part in terms of establishing functional capacity. If a corpse and its organs can be described as objects, then property rights would indeed remain a viable and

⁴⁴ An organ can work extra-corporeally if, for instance, it is provided with mechanical devices such as an extracorporeal membrane oxygenation machine (Great Ormond Street Hospital 2015) or an extracorporeal perfusion pump (Durandy et al. 2014). However, its ability to work independently (i.e. without any form of mechanical or electrical support) is not possible beyond an initial short period; as the organ dies its ability to work slows to a halt.

⁴⁵ See *R v Kelly* [1999] for legal judgment recognising this implication.

potentially *the* most appropriate method with which to regulate the management of their procurement⁴⁶. If this is the case, then once again there would remain a strong argument for the continued use of consent for these organs to be retrieved in death.

2.6: The Body versus the Corpse.

When dead, should body parts be recognised as objects akin to property, which it would therefore seem appropriate to seek consent for to permit the use of for transplant? Does death change the status of the body and its parts? Rao (2000) suggests that death delineates the status of the body between property and privacy. Whilst alive, the law currently protects the body in line with privacy rights, conferring limited rights of self-ownership and protection from interference or unwanted bodily invasion without some form of approval. Whilst alive, one cannot forcibly have an organ removed as this is judged to cause “revulsion to the judicial mind”⁴⁷. Although valuable, organs are not (yet) a commodity; the transfer of an organ is tightly regulated. Protection from this type of invasion stems from respect for the sanctity of the individual and the right to bodily security⁴⁸. The living body is not considered as an object of property ownership⁴⁹. However, dead bodies and severed parts are not sheltered by these privacy laws. Dead bodies are “divorced” from the soul (Rao 2000 p. 447); on this basis, autonomous decision-making regarding the body no longer exists. However, this does not automatically afford the State the right to enforce procurement. Rights relating to the dead body may therefore be served under the terms of property law. The removal of organs might be facilitated under the rules of property since the transfer and redistribution of property is permissible. According to Rao,

⁴⁶ Although the question of ownership would remain a moot point (which could be extended to an issue relating to Bjorkman and Hansson’s second and fourth right contained in their bundle of rights), as legally any focus around ownership of body parts has, until recently, lain with the recipient of the parts rather than with the person (or deceased) from whom the parts have been removed, as discussed previously on pages 44-46. The exception to this being Yearworth and Others v North Bristol NHS Trust [2009] which related to personal use of the sperm.

⁴⁷ McFall v. Shimp 10 Pa.D. and C3d91 (1978).

⁴⁸ Id. at 92.

⁴⁹ Although protection from interference could be interpreted as very similar to that of protection from unwanted trespass.

These therefore may be transferred because they are no longer intertwined with the person. The state can take control of these parts without loss of personal identity. Therefore to afford individuals a limited degree of autonomy over their bodies after death or separation from the person, these objects should receive at least some protection under the law of property (2000, p.460).

In accordance with Rao's theory, the corpse and its parts can be viewed of as objects due to the disembodiment which occurs as a result of death. Certainly, in legal terms discourse pertaining to the status of the corpse differs from that of the living. Relatives are responsible for providing a decent disposal of the deceased body for health and safety reasons; in accordance with this, they take ownership of the dead body in order to organise this. Furthermore, this right of ownership presently extends to the relatives having the opportunity to consent to their deceased's organs being retrieved for transplant. Under certain circumstances a post-mortem may be required by the State; this can be done without the relatives' approval and, in fact, in the face of their objection should this be raised. This demonstrates that the State retains some control over the corpse. Death results in a different approach to the body and the way it is managed.

If the corpse does become an object which, in turn, results in it being deemed permissible to regulate under property law, then perhaps one's decision over what should happen to one's organs could be organised alongside the bequeathal of other items of property in a Will. In which case, one could bequeath their body to the transplant community in the same way as they leave possessions to others as part of a Will⁵⁰. If so, in the absence of a Will, if the body were dealt with under the terms of intestate law, this may result in the body being left to relatives (in a hierarchical order). Would it be appropriate to leave a body to the family above and beyond the

⁵⁰ Currently the testator cannot give directions as to the disposal of his body in his Will. The rationale for this is that there is no property in the body and hence there is no right to direct the manner of its disposal following death (Pawlowski 2009, p.46). This is an interesting point; however, it does show how inconsistent the law actually is, since I am able to decide whether my body is buried or cremated; if my body is not property then how am I able to make this decision?

responsibility of burial? Unlike other items of property which may be valuable in sentimental and /or monetary terms, the body is unlikely to be accepted as either of these. The body has to be dealt with for practical reasons. It can no longer be the responsibility of the deceased, who would normally decide what happens to their body; therefore somebody has to take control. However, this does not necessarily mean that the person (relatives or the State) suddenly 'own' the dead body. Moreover, discourse relating to the Will and testament does not incorporate the use of or need for consent, as mentioned earlier in the chapter.

If in life I am responsible for my body, then I may be able to leave instructions as to how I would like the body to be disposed of when I die. This then becomes the responsibility of my relatives or the State. In this way they are responsible for the body just as I am during my lifetime. My responsibility does not assimilate to ownership. Surely the same logic applies in death as it does in life, with the role of relatives or the State being defined in terms of responsibility rather than ownership. In support of this, as part of their report on increasing the supply of donor organs in Europe, the House of Lords European Union Committee referred to the Human Tissue Authority's ⁵¹ view on the subject of ownership, taken from Halsbury's Laws of England⁵² which states that, "It is said that the law recognises no property in a dead body ...'" (House of Lords European Union Committee 2008, p.56).

Furthermore, viewing the corpse as an object or a disembodied self is not a view that is necessarily shared by the public. A qualitative study which Hadow (2005) conducted with 15 donor families highlighted that whilst some of the families involved⁵³ did appear inclined towards the notion of the body and the self separating in death, others⁵⁴ seemed more accepting of the notion that the body and the self are inseparable. This was expressed positively in respect of organ donation, in that the donation facilitated some form of continued existence of the

⁵¹ Which regulates activities concerning the removal, storage, use and disposal of human tissue.

⁵² A definitive encyclopaedic treatise on the laws of England

⁵³ Notably, the majority of these were from a medical background.

⁵⁴ Notably, those from a non-medical background.

deceased through their organs being transplanted and living on. This provided comfort to these families. However, there were also concerns highlighted by families following such a belief, of their inability to rid themselves of the fear that the organ retrieval would mutilate the deceased body, which they associated with a perceived harm to the deceased, as if the soul and body remained intertwined in some way (p.108). Haddow explains that for these families “this appeared to cause difficulties when considering the donation decision, leading some initially to refuse” (2005, p.108). This corresponds closely with Ai-Ling Lai et al’s belief that a tension exists between the concept of organ donation and the concept of death:

Organ donation lies at this uneasy intersection between the materialist, rationalised view of death- *‘when you’re dead, you are dead’* – and the more ambiguous transcendental view of the afterlife. While it perhaps offers potential donors the chance to transcend biological death- through the symbolic resurrection of “living on” in the donor recipient’s body- ...it leaves many unanswered questions about the status of the (dis)embodied self (2007, p.564).

Haddow’s study reveals that some relatives are simply not ready to dissociate the deceased body from the living person, even when they do understand that their loved one is dead. Not everybody is ready to make that transition from viewing the living body- and what it represents- to the dead body, and associating it with a lifeless object. This would suggest that whilst there is this doubt as to how we should treat the body or view it, we cannot simply start treating a corpse as if it were property. On this basis I would argue that any justification for consent for cadaveric organ procurement should not be based on the notion that when dead the body can become the subject of property law.

2.7: Conclusion.

The benefits of identifying the body as property may be that this affords rights and protection against trespass; it may also allow the right of transfer in death. However, there are

problems associated with this, in respect of the process which would naturally follow on from identifying the body in such a way; that is, that this would place governing it in the realms of property law, and with this might come the possible threat of commodification. Legal and ethical opinion on the body appears to ward away from viewing it as property. This view seems to be shared by the public. It would seem that the relationship we have with our bodies and the organs which form an integral part of the body serves to differentiate it from other items or possessions that we own. This appears to extend into death as well. The opinions expressed in the aftermath of the organ retention incidents bear this out. Paragraph 33 of the Bristol Royal Infirmary Inquiry Interim Report (Kennedy et al. 2000) stated that:

For the parents of the recently deceased child, human material, certainly substantial specimens such as organs and parts of organs and even smaller parts are still thought of as an integral part of the child's body and, thus, are still the child (p.9).

Even if a distinction could be made between the live body, the dead corpse and body parts once removed from the body, in terms of how it is viewed and regulated, property rights provide little in the way of respect for one's autonomy, which is an important feature in decision-making around cadaveric organ procurement. Whilst discussions by policymakers around organ procurement have included reference to ownership of our bodies, justification for consent has ostensibly been endorsed in terms of privacy rights. The ODT (2008) has recognised that the public wish to decide what happens to their body and, in light of the incidents surrounding organ retention and the reprisals which followed, consent is believed to be a fully justifiable method for retrieving organs for therapeutic purposes (DH 2008; ODT 2008). This appeal for the retention of consent is specifically directed towards privacy interests and respect for self-determination and not in terms of protection of property. So, whilst consent would play a fundamental role in an organ procurement policy if the body *were* considered as property and regulated under property laws, the justification for consent, thus far, has not been invoked using this line of reasoning.

Therefore, an opt-out system with a combined registry cannot be excluded on these grounds. In my next chapter I shall consider whether consent need to remain the “fundamental principle” (Human Tissue Authority 2014a, p.7) to demonstrate this respect for self-determination in terms of decisions around what happens to one’s organs post-mortem.

Chapter 3. Respect for Privacy Interests, Decision-Making and Cadaveric Organ Donation.

3.1: Introduction.

The aim of this policy is to provide an organ procurement system which acquires the maximum number of organs and is consistent with a society's values. The Ethics Working Group, which advised the ODT in its research around the impact of introducing an opt-out system in the UK, stated that whilst “moral decisions” should not be determined by “public opinion”, it did acknowledge that “for a significant change in policy to be effective it should not risk alienating significant numbers of people who see the change as inconsistent with their society’s fundamental values” (ODT 2008, Annex D, p.5). A policy which is consistent with a society's values is arguably an important value in and of itself. As a utilitarian, from a practical perspective, if incorporating society’s values increases the supply of organs and its exclusion may result in a decrease in organs, then that is reason in itself for its inclusion. In a liberal democracy, such as that which we have in the UK, with regards to the removal of their bodily organs and tissues, the provision for individuals to be able to exercise their autonomy would acknowledge strong public opinion demonstrating a desire for this. Promoting respect for autonomous choices in this policy will maximise happiness, and will, in all likelihood, produce a more favourable outcome in terms of organs retrieved if it engenders public support.

In this chapter I wish to look at whether respect for autonomy should be inextricably linked to consent for the purposes of cadaveric organ procurement. The ODT links individual autonomy to consent (ODT 2008, p.9), which it advises should underpin our procurement policy. Yet there is the issue under the current system that even if one registers their consent to organ procurement their wishes may be overruled by their relatives. This would appear to contradict respect for self-determination. In addition to this, whilst our opt-in system offers the opportunity for individuals to express their autonomous decision to donate, it does little to protect the wishes of those who may be opposed to their organs being retrieved. This interest should be protected

far more robustly than the present system is able to offer⁵⁵. The opt-out system provides this opportunity to express an objection. An opt-out system with a combined registry would afford protection to those opposed to procurement and facilitate the wishes of those wanting to donate.

Whilst some might argue that an opt-out system would not sufficiently protect those individuals whose objection is never registered and whose decision is never expressed to their relatives, the same can be said for those who are in favour of organ procurement under the current system, with regards to their willingness to donate. Those against opt-out would stress the much more serious and harmful implications of retrieving organs from one who objects to procurement, but whose wishes are ignored (albeit unwittingly) when compared with one whose organs are left intact against their wishes (again albeit unwittingly)⁵⁶. However, this rationale is based on a sophisticated philosophical theory centring on harm occurring as a result of interests being setback. This may, on the face of it, seem pertinent; however, when examining the arguments put forward it is actually a perplexing and quite abstract hypothesis to prove and therefore difficult to accept as a sufficiently convincing line of reasoning to demand a consent system or, therefore, to preclude an opt-out system.

When considering the importance of autonomy and its link to consent I shall examine the different definitions of this principle. An element of clarity is required in respect of this, so that when stipulating the need for respect for autonomy to underpin a deceased organ procurement policy one knows what this actually means. This chapter will also focus upon the need for consent to protect one's bodily integrity and prevent harm from occurring. Harms may include both physical harms, through the wrongful act of retrieving organs, and also the setback of interests which, some would argue, might occur if organs are taken from an individual who wished for their body to remain intact after death. Whilst these concerns may be linked to one's right to self-

⁵⁵ A point which has been made by NCOB (2011).

⁵⁶ It should be noted that in an opt-in system one who is against procurement but unable to stipulate their wishes may also succumb to the same fate as one who under an opt-out system has simply never actively expressed their objection.

determination, they are more broadly contingent upon one's right to bodily integrity. Whether based on autonomy or protection of bodily integrity, the need for consent has been invoked in support of respect for these privacy rights. It is this which I intend to examine and question. If my arguments for a change to an opt-out system with a combined registry are to be taken seriously, I have to be able to show that respect for self-determination and bodily integrity need not rely solely upon the exercise of consent.

3.2: The Importance of Autonomy and its Place in the Current Opt-In System.

Schicktanz (2007) describes the body as instrumental in acting as a "vehicle for decisions, choices and interests a person has" (p.3). However, alternative theories suggest that the body also plays an intrinsic role when making decisions which are critical to shaping one's life, including those decisions which will affect the way one chooses to live (Dworkin 1988; Dworkin (R) 2001; Feinberg 1986; Harris 2002). In accordance with this view, the description 'property' does not fit the body as neatly as other possessions which can be owned. It may be that on this account the right to decide what is done to the body is rationalised most appropriately in privacy rights. Rao (2007) states that privacy rights acknowledge the body "as integrally connected to the person, such that the invasion of the physical being endangers its essential personhood" (p.379). Respect for autonomy has come to be regarded with special importance in biomedical ethics and in law, and it is often used synonymously with demonstrating respect for self-determination. In recognition of the importance of the unique relationship we have with our body, the body is afforded special protection in law from both unwanted interference and harm.

Gerald Dworkin (1988) advocates respect for self-determination and individual autonomy in healthcare decision-making because he envisages the body in relation to the person as "irreplaceable and inescapable...Because my body *is* me, failure to respect my wishes concerning my body is a particularly insulting denial of autonomy" (p.113). More recently, The Nuffield Council of Bioethics (2011), when discussing the use of bodily material for medicine and research,

stated that respect for autonomy should continue to drive forward any policy made in this area. The Council stressed that autonomy is the “key value underpinning people’s entitlement to control their own bodies, either because of their relationship of identity between a person and their body, or because bodies are regarded as “part of” or as “belonging to” the individual person” (2011, p.120).

Respect for autonomy is connected to individuality, to choosing for ourselves what happens to us; our lives are shaped by these choices and decisions (Harris 2002). The principle of autonomy is a fundamental aspect of a functioning society and is important normatively in that it makes us ask how we should behave and how we should treat other members of society and their interests. This demonstrates the value of treating others as “independent sources of moral agency” (Dworkin 1988, p.110). People create their own life pathway shaped by interests which have been carefully developed over time through experiences, encounters and learning. These interests need to be acknowledged, and the rights of individuals to develop should be encouraged and, where possible, supported. Dworkin believes that exercising the capacity for autonomy enables an individual to take ownership of their life. Recognising this means treating others as having equal moral status. We need to respect that in exercising our own autonomy, when making decisions what we do affects others.

The importance of this and the right to self-determination have been expressed in the aftermath of the organ retention incidents, where consent of those affected was often not sought for post-mortem examination of their children, or their refusal of consent ignored (Redfern et al. 2001; Kennedy et al. 2000; DH 2001). However, whilst individuals will often place autonomy as the first principle, decisions are not normally made purely on the wants and personal desires of each person. On this basis, a number of moral commentators including Gillon (1985), Beauchamp and Childress (2009) and Dworkin (1988) have advised the need to temper the value of autonomy

against other important principles such as beneficence, non-maleficence and justice, especially in relation to healthcare.

Legal justification for observance of private interests and respect for autonomy are operationalised via a consent system⁵⁷ which yields a negative right of protection from assault. In legal terms this is to avoid acts which may be associated with either battery, in terms of unwanted touching or invasive contact, or negligent practice (Brazier and Cave 2011). In American law, rights which are “so rooted in the traditions and conscience of our people”, have been described as “fundamental” and “implicit in the concept of ordered liberty”⁵⁸. Rights, in respect of this, were first openly acknowledged by Justice Cardozo in the case *Schloendorff V Society of New York Hospital*, when he advocated 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 his patient’s consent commits an assault, for which he liable in damages”⁵⁹. Cardozo also acknowledged that interference with another’s bodily integrity could amount to trespass to the person or negligence⁶⁰.

The recognition of bodily integrity and the right of use of one’s own body bestows just such a fundamental right to protection in English law (Crisp 1990; Hardcastle 2009), with these rights being invoked in case law to support the right to self-determination in a clinical setting⁶¹. Being able to provide consent to most therapeutic interventions demonstrates recognition of the important role that self-determination occupies in the public eye, and suggests that we have ultimate control over our bodies in most instances. O’Neill (2002) points out that “increased recognition and respect for patients’ rights and insistence on the ethical importance of securing

⁵⁷ Where the individual is competent to provide permission; there are exceptions to this, for example, when a person is deemed to be mentally or physically incapable either due to mental instability, unconsciousness or a life threatening emergency, or due to a debilitating physical condition preventing the person from actively showing their decision.

⁵⁸ *Rochin v. California*, 342 U.S. 165, 169 (1952)

⁵⁹ *Schloendorff V Society of New York Hospital* 211 NY 125 (NY CA 1914) 126

⁶⁰ *Id.* at 92,93,105.

⁶¹ In *Chester v Afshar*, Lord Steyn reiterated Cardozo’s point verbatim, when he observed 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” [2004] UKHL 41; at 14.

their consent are now viewed as standard and obligatory ways of securing respect for patients' autonomy" (p. 2).

The importance of consent in this setting has extended beyond the decision-making that occurs between living persons; it has also been endorsed in legislation (Human Tissue Act 2004) governing the therapeutic use of living and cadaveric human tissue and organs. When considering a move away from this traditional consent system for cadaveric organs and tissues, the ODT stated that:

A move away from requiring explicit consent would put organ donation out of step with prevailing practices and would be inconsistent with the Human Tissue Authority's guidance on consent. It would also challenge commonplace assumptions about consent and individual decision-making at a time of greater expectation of individual autonomy among the public (2008, p.9).

The ODT (2008) argued that consent should remain the fundamental principle for organ procurement (p.9); the rationale for this is grounded in the right to choose whether to give one's organs for therapeutic purposes. When gathering evidence for its report concerning the impact of an opt-out system in the UK the ODT stated that it had received negative reaction from some members of the population asked about an opt-out system for organ procurement (ODT 2008; ODT 2008, Annex J). The ODT asserted that research pointed to current opinion adhering more closely towards autonomy and taking control of one's decision-making. Opinions gathered from some donor families highlighted that involvement in the decision-making process was important, enabling them to make a decision which they felt was often right "for them at the time" (ODT 2008, p.17). Coupled with this, the Taskforce felt that an explicit consent system would fit better with the general NHS agenda demonstrating a "move towards choice and personalisation agenda...which gives people a greater sense of control over what happens to them" (2008, p.9).

Taking one's silence to demonstrate a presumption of consent belonged to a "paternalistic era" (ODT 2008, p. 5).

NCOB (2011) also reflected upon the evidence provided by members of the public during their deliberative consultation on the use of bodily material for medicine and research (NCOB 2010). This demonstrated some concern that an opt-out system would result in the State taking control of decisions regarding organ procurement, rather than this being the responsibility of the potential donors (NCOB 2010, p.5). Rather than taking on the role of 'stewardship' (NCOB 2011, p. 4) (responsible for maximizing the health and well-being of society) some expressed apprehension that the State would "effectively gain control over... individuals' bodies, and that such a shift would be quite unacceptable" (NCOB 2011, p.148).

The Human Tissue Authority (2014a) stipulates that the positive act of consent should be the fundamental principle guiding the removal and use of organs; absence of refusal is not evidence of consent (Human Tissue Authority 2006, p.8). Under the Human Tissue Act (2004) consent is needed for the removal, storage and use of material from the deceased for transplantation (Human Tissue Authority 2014a, pp.16-17). Valid consent is defined as that which is given voluntarily, by an appropriately informed person who has the capacity to agree to the activity in question (Human Tissue Authority 2014b, p.15). In respect of capacity, the first of the five principles set out by the Mental Capacity Act 2005 stipulates that a person should be assumed to have capacity unless it has been established that he or she lacks capacity⁶². The person consenting to their organs being used should understand the nature and purpose of the proposed procedure, and understand and retain information relevant to the decision (Human

⁶² Capacity has been defined as the ability to make decisions regarding a particular matter at a particular time (Dimond 2008, p. xviii). Section 2.1 of the Mental Capacity Act 2005 defines lack of capacity as follows: For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

Tissue Authority 2014b, p. 15), including, where appropriate, what the risks are in order to arrive at a choice (Human Tissue Authority 2014a, p.8).

The ODT (2008) suggested signing a card or joining the ODR should act as proper informed consent as the term “is broadly understood”, although it was “clearly intended as an act of authorisation” (p.15). The provision of informed consent requires sufficient understanding of what it is the individual is expected to consent to. For example, a person needs to understand the risks as well as the benefits involved in a surgical procedure being offered, prior to their giving an informed consent, constituting sufficient capacity to interpret the information provided. The interaction which occurs to ensure that this may happen is generally personal and tailored to the patient’s needs. In relation to this, the issue remains as to how these requirements are sufficiently met under the present opt-in system. There is also the question of the level of understanding required by individuals prior to their asserting their right to decide whether to donate their organs or not. Coupled with this is the concern as to how those responsible for organ retrieval can ascertain that the donor had sufficient capacity or knowledge of the retrieval process to be able to provide a valid consent. Whilst the requirement of consent for live organ donation is congruent with clinical practice, it seems a little far-fetched a demand for cadaveric organ procurement, calling into question the appropriateness of express consent as a method for procuring organs from the deceased. Traditionally, capacity has played an important part when consent is required; however, this has been less of an issue when a refusal has been expressed⁶³. This may have important bearing on a system for cadaveric organ procurement.

Demonstrating respect for autonomy is important in a system which manages the procurement of organs for transplant. However, under the current system the decision does not ultimately rest with the individual. It also only provides for those who may agree to donation. Those who object strongly to their organs being donated in their death do not enjoy the same

⁶³ The exception to this being when a refusal is expressed by an individual under 18 years of age.

protection of their autonomous choice. Evidence from countries which practise an opt-out system for organ procurement stress that respect for self-determination is an implicit part of their agenda, facilitated through the right to register an objection. A soft opt-out system with a combined registry demonstrates respect for autonomy for those who wish to consent or object to donation; furthermore, this wish is taken as the final decision. This system appears to be more consistent with a society's values, due to its inclusion of those who wish to object. It therefore maximises utility as it provides more organs and it demonstrates respect for autonomy for a wider audience - something which the express consent system fails to do.

When thinking about decision-making for cadaveric organ procurement, it is important to acknowledge that there are various interpretations of autonomy which have been tendered in bioethical literature. Gerald Dworkin (1988) suggests that very often values such as freedom, rationality, ruling and responsibility are associated with the concept; he stresses, however, that with the diversity of opinion in this area, the only real "common denominator" amongst the different concepts is that autonomy is a "desirable quality to have" (1988, p. 6). It is worth providing brief consideration of some of these concepts of autonomy in order to weigh up which one most closely addresses decision-making in relation to deceased organ procurement.

3.3: Types of Autonomy.

From a historical perspective, the concept of autonomy plays a focal part in Kant's philosophical writings. Kant (1785) believed morality to be inseparable from rationality and freedom of will, or autonomy. In accordance with this, rational beings should regard themselves as subjects to the moral law. For Kant, the will to act in accordance with the moral law flowed automatically from the exercise of the completely rational will (Horn and Schönecker 2008). It is not that we *ought* to act in such a way to be moral, but rather that if we are rational, we simply *will* act in this moral way. One's autonomy of will brings together transcendental freedom (the ability to act in accordance with what is good, independent of one's desires or will of others) with

the imperative of reason. The autonomous agent therefore overcomes heteronomous designs and is governed by objective reasoning. According to Kant (1785, §4:440), “autonomy of the will is the property that the will has of being a law to itself”; it is “the sole principle of all moral laws and duties in keeping with them” (Kant 1788, §5:33).

The expectations of principled autonomy are far more demanding and all-encompassing than current interpretations of individual autonomy. Respect for individual autonomy includes the right to self-determination, independence, liberty, and freedom to act in a way which one feels best suits their needs (within reason); these components barely resemble the concept introduced by Kant. However, principled autonomy could provide the foundation for informed consent (O’Neill 2002, p.145). This is because of the very nature of principled autonomy: willing actions which can be universalised. What this may serve to prevent are behaviours associated with treating human beings unequally and with indignity. Certain acts would ultimately undermine the principle of treating human beings as ends in themselves and could therefore not be willed to become universal laws. Examples of these types of acts are coercion and deception. O’Neill (2002) suggests that if coercion and deception were universally willed, then some members’ capacity for action would be severely undermined or diminished altogether by others’ actions. Such actions disrespect persons and damage trust within society.

Whilst O’Neill supports the idea of principled autonomy underpinning informed consent, it should be noted that the practice of consent as a way of respecting autonomy is commonly understood to refer to one’s individual autonomy. It is important to look at this type of autonomy to understand how consent relates to autonomy, with particular reference to cadaveric organ procurement. Definitions of autonomy vary widely within contemporaneous philosophical writings. There are those which are rigorous and explicit in their detail; conversely, there are others which are so vague and inane that it is difficult to actually distinguish autonomous from ordinary day to day decisions.

Writers, such as Wolff (1970), believe that for one to regard herself as autonomous requires such a high level of independent thought and action that to accept the “commands of the others” one risks forfeiting this autonomy (p.14). This begs the question as to whether such a concept could ever be fulfilled in a community shaped by social obligations and laws. One might also question whether consent for most clinical interventions would be achievable if this were the way of demonstrating such a definition of autonomy. Moreover, when considering the terms of valid consent as represented by the Human Tissue Authority, it is difficult to know how the conditions of this consent could be verified when faced with a potential deceased organ donor.

This is not to say that it is not important for a person to be able to decide whether to donate organs post-mortem, and their decision correlate with some level of capacity and understanding. However, the amount of understanding and the type of decision in respect of organ procurement may not be best located within the practice of informed consent. Furthermore, the ODT’s acceptance of a signed donor card or registration with the ODT as a sufficient form of consent remains at odds with what the Human Tissue Authority actually stipulates as consent. These two apparently different approaches to consent could provide a source of confusion and a distinct lack of clarity when considering the weight of importance attached to this area of decision-making.

At the other extreme, there are those whose conception of autonomy is far more vague when it comes to detailing what might be required when making autonomous decisions, resulting in what Manson and O’Neill (2007) describe as focusing on “mere/sheer choices” (p.19). These are simply too vague to represent anything other than spontaneous, impulsive decisions, lacking thought or reflection (O’Neill 2002). To describe one’s expression of autonomy using this interpretation would be too minimalistic to fulfil the requirement of informed consent. This type of autonomy does not seem appropriate when considering end of life decisions, including disposal of the body and whether to donate organs post-mortem. Whilst it could be argued that a deep

understanding is not required, one is unlikely to act in quite such a flippant manner when contemplating what should be done at the end of life. A popular view is that the body and our relationship with it is something which should be taken seriously; decisions in respect of this should, at the very least, involve the individual. Where possible, the individual should be the final arbiter when decisions around the body are required. One might argue that deciding what will be done with one's body in death is the ultimate autonomous act. This would imply that a level of contemplation and reflection may be required when making end of life decisions. Such decisions reflect a capacity for autonomy.

3.4: Respecting the Capacity for Autonomy.

Interpretations of individual autonomy often include rationality, an ability to reflect and take charge of and be responsible for one's decisions. Individual autonomy may include acting in such a way that involves replacing a first order desire with a second order desire following a period of reflection. This involves a capacity to reason with oneself over these desires and take decisive action in respect of this. Decisions of this nature will often involve taking into consideration intrinsic and extrinsic factors which will help shape and determine the decision taken. This sort of autonomy requires that one is capable of reflection, the ability to rationalise one's understanding of what it is the decision is focusing upon, and the ability to alter one's preferences. Acting in such a way demonstrates the capacity for autonomy. Having discussed in detail these various components which correspond with an autonomous decision, Gerald Dworkin puts forward his concept of autonomy which is:

Putting the various pieces together, autonomy is conceived of as a second order capacity of persons to reflect critically upon their first order preferences, desires, wishes and so forth and the capacity to accept or attempt to change these in light of higher order preferences and values. By exercising such capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are (1988, p.20).

Gaining informed consent is the practice of respecting one's capacity to decide for oneself what should happen to their body. If a person is competent, then Dworkin believes that it is right and necessary to provide sufficient information to facilitate a proper evaluation when making an informed decision. This accords with the principle of individual autonomy. It shows respect for the notion that one retains control of their decision-making capacity. Informed consent therefore promotes autonomy and it acts to respect autonomy, in that it allows one to demonstrate one's volition to a proposed treatment. If a clinician fails to gain consent from an individual who is competent to give it, this represents "an insult to autonomy", even if the intention is a purely benevolent one (Dworkin 1988, p.120).

Gerald Dworkin's definition involves the capacity to reflect upon one's interests. In the clinical context, consent to some procedures could be understood to have life changing consequences for the person. Live organ donation could be considered to require the weighing up of one's critical interests, and may well involve the potential donor asking themselves why they are doing this and how it will affect their lives both in the short and long term. It may also include a consideration of other critical interests such as the relationship they have with the potential recipient, and the bearing this has on their decision to contemplate taking such a risk with their own health. These critical interests are so called because they help to shape one's life and one's identity as a person (Dworkin (R) 2001, p.192). They differ from those "experiential" interests (Dworkin (R) 2001, p.193) which are transient in nature; those which Manson and O'Neill (2007) might refer to as mere or sheer choices. So a link can be made between decision-making concerning live organ donation and respect for autonomy as described by Gerald Dworkin, which may involve consideration of critical interests as described by Ronald Dworkin.

On the face of it, it seems difficult to reconcile this definition of autonomy with a straightforward opt-out system due to its apparent inextricable link to the active nature of making the decision as to whether to donate one's organs. However, a combined registry could meet the

demands of this definition to some extent. One might also question whether informed consent and this definition of autonomy are consistent with the type of decision made by individuals deciding whether to donate organs posthumously. Whilst the decision to donate organs is undoubtedly very important, and as suggested for live donation, may involve weighing up interests which one deems critical, it is difficult to associate cadaveric organ donation, generally speaking, with critical interests. Empirical evidence from opinion polls and transplant statistics in the UK (NHSBT 2012a; ODT 2008, Annex J) suggest that for the majority of the population cadaveric donation is probably not considered a critical interest, or a process which involves weighing up other critical interests due to the impact it may have upon the individual's life⁶⁴. Public opinion, reported as part of the ODT's report on the impact of an opt-out system in the UK, suggested that many individuals were not sufficiently aware of organ donation or the different systems for organ procurement; many had thought little about it (ODT 2008, Annex J). If critical interests represent those interests which help shape one's life and are of real importance to a person, it is difficult to see from this evidence how a decision to donate organs post-mortem falls into this type of interest.

Respecting the capacity for autonomy may be too demanding when it comes to decision-making over cadaveric organ procurement. It does not seem to reflect the decision-making which is undertaken by the majority of the population, in terms of both consenting *and* objecting to organ procurement. A better interpretation of the nature of this type of decision-making might be respect for autonomous choices.

3.5: Respect for Autonomous Choices.

For an act to be considered an autonomous choice it must be intentional, understood and undertaken without controlling influences that determine the action (Beauchamp and Childress 2009, p. 101; Faden and Beauchamp 1986, p. 238). This correlates closely with self-rule.

⁶⁴ Figures provided on pages 21 and 25 show a poor conversion rate of those in favour to those providing 'express consent' via the ODR.

Autonomous acts must be voluntary acts; one must be free to be able to act in such a way, and one's right to privacy respected when making a decision which concerns one's self. One must have sufficient capacity to render the act intentional; however, capacity is gauged in the context of understanding the act.

When considering an autonomous choice in relation to providing an informed consent, Beauchamp and Childress suggest that "competence is more of a pre-supposition of informed consent rather than an element" (2009, p.121). Faden and Beauchamp and Beauchamp and Childress associate the expression respect for autonomy with respect for autonomous choices. If I respect another's autonomy, I should respect their autonomous choices. Taking this particular concept of respect for autonomy, one need not be completely autonomous to make decisions; autonomous persons can make non-autonomous choices and non-autonomous individuals can make autonomous choices. This is because there are different levels of autonomy and different levels of capacity ranging from complete to negligible degrees. Whilst an autonomous action requires intention and understanding and exclusion of external controlling influence, one need not infer from this that these components are absolute in nature (Beauchamp and Childress 2009). For instance, for the person consenting to a clinical procedure it would not be out of place to suggest that their capacity for 'full' autonomy may be impaired due to the nature of the condition requiring medical attention.

On the face of it, an opt-in system for organ procurement may appear to be the most appropriate method for ensuring that respect for autonomous choices is ensured. The opt-in system affords the opportunity for the individual to take control and exert one's authority by way of making the final decision; this is what binds consent to respect for autonomy (Beauchamp and Childress 2009). Providing consent demonstrates a deliberate act on the part of the agent; a system of opt-out may not accommodate this. When exercising one's autonomous choice to donate, the understanding need not be too extensive in order to make the decision to consent.

This level of capacity seems to be reasonable when making a decision about whether to donate organs post-mortem. The technical and complicated process undertaken in the lead up to organ procurement, as well as the actual procedure to remove organs, may be difficult to comprehend without any medical knowledge. Arguably, it is unnecessary to expect this level of understanding either, especially when most people willing to donate organs after their death are satisfied to know which organs could be removed, how the body will look afterwards, that all care will continue until completion of the procedure, and that, where possible, the organs will be put to good use. This may also better reflect the present feeling of the public concerning donation. This, as represented above, seems fairly apathetic and less indicative, in the main, of a strongly held individual commitment to posthumous donation, resembling a deep-seated desire. From the public's point of view what seems to be more important is that they have the opportunity to make the decision as to whether to donate.

When establishing a system for decision-making that allows for a sufficient level of understanding on which to base one's decision, registering an objection fulfils this expectation in the same way as providing consent does. Furthermore, an express consent system based on respect for autonomous choices does not appear to give any guidance over whether we can take organs or not when an individual has not deliberately opted in. The statistics would suggest this type of individual forms the majority of the population in this respect. Under the present opt-in system, in the absence of a decision it is then permissible to seek consent from relatives of the deceased. In fact, the relatives' decision is requested regardless of whether the individual has consented to organ donation or not. What this amounts to is a consent system which only really allows an individual to make an autonomous choice about offering their organs for transplant. Moreover, whilst the present system appears to support the provision of a deliberate act on the part of the agent, unfortunately little respect appears to be demonstrated to the decision when made. It merely serves as a starting point on which to base a discussion with relatives as to whether they would wish for the deceased's organs to be retrieved. It is questionable whether in

its current form this represents as convincing an act of authority as a refusal might, when such little weight is attached to the deceased's decision.

Unless the system provides a failsafe mechanism for guaranteeing that an individual's definitive wish to donate is respected such a system actually falls short of demonstrating proper respect for the autonomous choice, which public opinion suggests should be an important proviso of this policy. At least an opt-out system provides a more robust mechanism for protecting the autonomous choice, ensuring that the individual remains the final arbiter in this process. A combined system, such as that which is practised in Belgium, promises to provide exactly this type of respect for both a registered objection and a registered consent. Individuals are able to exert their control over what should happen to their organs post-mortem, safe in the knowledge that their autonomous choice will be respected. In accordance with public opinion around this issue, this would appear to reflect society's values in respect for self-determination. Such provision can be justified in a utilitarian policy as this approach to autonomy can be incorporated into a policy which aims to maximise welfare.

3.6: Self-Ownership, Sovereignty and One's Right to Self-Determination.

An alternative argument for the need for consent to organ procurement might be that it prevents the act from otherwise becoming a bodily trespass. In this way consent is justified as prophylactic (Archard 2008, p. 23). Consent remains an important proviso based upon the idea that to act without it constitutes a bodily trespass which, in itself, is wrong. One theory which may serve to underpin this is by connecting sovereignty to one's right to decide what should happen to their body. The association between sovereignty and personal decision-making extends back to John Stuart Mill, who asserted that one's conduct "which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign" (1859, p. 22). Feinberg (1986) forges a relationship between personal autonomy, self-rule and self-ownership. He discusses personal autonomy in terms of sovereignty over oneself and

one's body, and compares it with a State's sovereignty over its terrain (p.52). The body acts as the terrain belonging to the self; this extends one's domain to their breathing space. If a person is touched without consent, a violation or bodily trespass occurs; this constitutes a violation of the right not to be interfered with⁶⁵.

In terms of organ procurement, whilst this can be applied to live donation, it can also extend to cadaveric organ procurement, on the grounds that the severity of the trespass is inconsequential; no matter how trivial, a trespass is a trespass and this is wrong. One's sovereignty over their body confers the right to self-determination over what happens to the body. Feinberg (1986) defines this as personal autonomy, "my authority is a discretionary competence, an authority to choose and make decisions" (p.53). In this way, consent acts as a key to the lock enabling a physical intervention, the absence of which results in the tort of either battery or negligence. It bestows both positive rights upon individuals and negative obligations upon those wishing to have physical contact with another.

Consent, when linked to Feinberg's perspective of personal autonomy, acts to protect one's sovereignty over their body and their decision-making in respect of this. It demonstrates who is in charge. Feinberg states that personal autonomy encompasses more than protection from unwanted 'invasions' of the body and personal space; it extends to making decisions which impact upon one's life as a whole and the shape it takes. There is a similarity here between one's control over their body and a sovereign controlling their state. I may be sovereign over my body; however, legally and ethically this confers passive rights upon me in respect of what is done to my body. This does not then automatically extend to my doing things to my body or using my body to invade another's domain. This would seem to be a similar situation for a sovereign and their powers.

⁶⁵ One's personal space cannot be entered without consent; in this way, personal autonomy incorporates a right to privacy as well.

When considering a system for cadaveric organ procurement, on the face of it, respect for self-determination grounded in the right of sovereignty might be better represented by an opt-out system and a combined registry than a system of consent. Whilst alive, consent facilitates this right of being in charge of one's body; however, once dead the person is no longer in charge. On the face of it the sovereignty argument would appear to point towards a system of organ conscription if the State should act to benefit the needs of society. However, decision-making need not be dispensed with altogether; as has already been argued in this thesis, allowing this choice to be made by individuals is acceptable as this is more likely to maximise utility.

With this in mind, authorisation could be provided in a similar manner to that which one makes when one writes a Last Will and Testament. I could authorise for my organs, which I am sovereign over whilst alive, to be retrieved post-mortem. This provides a clear message to those who are responsible for the disposal of my body over what I would deem to be acceptable practice even after my death. This would show respect for personal and bodily integrity. However, the commitment to meet that wish for organs to be used may not necessarily be acted upon if the organs are not viable. Therefore, authorisation for cadaveric procurement is less strong than, for instance, a consent to live donation of an organ. Facilitating refusal of my organs being retrieved would seem to fit better with the passive right against trespass, preventing something happening to my body. A default system of opt-out establishes the State's role as steward, prioritising the needs of the living where no decision has been made, in line with the belief that once dead one's sovereignty over their body is relinquished. On this basis an opt-out system with a combined registry would appear to be acceptable, fitting with respect for autonomy grounded in the right of sovereignty.

Authorisation is the term NCOB (2011)⁶⁶ has accepted as most appropriate when referring to one's wish to donate organs posthumously. This provides a clear distinction in the type of

⁶⁶ Referred to in footnote 9 on page 22.

agreement which should be expected from a potential live donor and that which should be expected from an individual who agrees to cadaveric organ procurement, thus providing a clearer indication of what is required of the individual when making the respective decision⁶⁷. NCOB suggested that this terminology better reflected the level of risk associated with cadaveric organ procurement, actively differentiating this from the risk associated with live donation: “In contrast to those consenting during life, those authorising donation after death do not expose their health to any risks⁶⁸, and the minimum informational requirements for donors are correspondingly lower” (NCOB 2011, p.132). The risk here relates to potential physical harm; however, consent has been advised as the most appropriate method of decision-making for cadaveric organ procurement based upon avoiding potential harms which may occur, not from the physical harm which could ensue, but from the setback of interests which one may suffer ante-mortem as a result of a procurement taking place, if this is not what they would have wished for. The need for express consent appears to circumvent this potential issue.

This was a consideration included in the Ethics Working Group Report which provided supportive information for the ODT’s Opt-Out report (ODT 2008, Annex D). The working group suggested that it would be important to explore the potential harms and wrongs which may occur to persons even in death, should their organs be procured without their consent. Whilst they acknowledged that this is often a discussion centred upon by philosophers, they believed it could be “usefully employed ...to help capture the duties owed to potential and deceased and the exact costs associated with particular proposals” (ODT 2008, Annex D, p.3). The group suggested that a system could potentially harm or wrong a donor if there were insufficient information given to make an informed decision, the system was not able to provide appropriate support for the individual’s wishes, and their best interests were not sufficiently met. These are poignant

⁶⁷The same could be said for registering an objection to donation.

⁶⁸This point has also been made by Harris (2002) who asks how is it possible for consent to be an acceptable safeguard when referring to the deceased. What is it the dead individual is going to run the risk of suffering which the act of consent is used to protect against?

concerns when aimed at the potential for one's organs to be retrieved automatically unless an objection is registered. There are those who may object to procurement, but who for whatever reason have not registered this objection. In an opt-out system, if the organs are retrieved, then this *could* constitute a harm if one's interests are setback as a result of the retrieval.

For this to be the case an individual would have to believe in harm remaining a possibility even after death has occurred. Whilst this may seem questionable if one refers to post-mortem persons, it may be possible for it to affect a person and harm them ante-mortem. If they have strong feelings towards what happens to their body post-mortem, and they are unsure as to whether their body may be tampered with without their consent, organ procurement without an individual's explicit consent may result in a harm being wrought upon them whilst alive. The requirement of consent could be invoked to waive protection from the harm, based upon the idea that for some individuals the act of bodily trespass is intrinsically wrong. Consent to procurement (both for live and cadaveric acts) would waive the right of an individual and so "justify an act that would otherwise be unacceptable" (Manson and O'Neill 2007, p. 73).

In this way consent constitutes a social contract; as long as the person is willing for the act of procurement to be undertaken then no harm is done to them. For some people, if the removal occurs without consent, harm may occur due to a setting back of their interests (if, for instance, they have very strong feelings about their organs being removed in death). Consent appears to be the most effective way of preventing this harm from happening. In view of this, it is necessary to consider the relevance of arguments to do with potential harms resulting from interests being setback in order to reconcile this issue over whether consent is important for cadaveric organ procurement or not.

3.7: Interests and Harms.

The notion that one can be harmed after death is a contentious issue that has been debated at length. Before discussing the theory relating to interests and harms, it is important to

differentiate wrong from harm. Pitcher (1984) distinguishes a wrong from a harm in the following way: a wrong occurs when an individual is treated unjustly; for instance, if they are maligned or are spoken of badly or their trust is betrayed (p.184). The dead can be wronged “if their reputation is sullied, their achievements unjustly diminished” (Brecher 2002, p.113). Pitcher suggests that it may be more accurate to suggest that one’s name or their memory may be wronged once deceased if they are spoken ill of or a promise made to them prior to their death is broken. What harm amounts to is this: “an event or state of affairs is a misfortune for someone when it is contrary to one or more of his more important desires or interests” (Pitcher 1984, p.184).

According to Feinberg (1984), posthumous harm results from interests, which a person may consider to have important meaning, being thwarted or setback in the event of death occurring. Feinberg (1993) refers to death defeating these interests, thereby directly causing the setback to the interest. These interests may not lose their important meaning just because a person ceases to exist; therefore, if they remain unfulfilled in the event of a person’s death, this could constitute a thwarting of the interest, and this could result in the harm. The interest cannot be harmed, only the person (Scarre 2007, p. 112). Feinberg regards interests in the same way as one’s claims and obligations which survive a person’s death and which can result in harm if not properly respected. Pitcher’s interpretation of a harm after death takes a slightly different approach to Feinberg’s. In his discussion about the misfortunes of the dead, Pitcher describes a dead person in two ways: 1) an ante-mortem person: this is the person as was when alive and 2) a post-mortem person: the ‘person’ as she is now in death. Pitcher’s concept of an ante-mortem person being harmed by an unfortunate event after death is this:

...the occurrence of the event makes it true that during the time before a person’s death, he was harmed, harmed in that the unfortunate event was going to happen, if it does not happen then no harm comes (1984, p.187).

If it is known that an event will occur even at some stage later, this could be said to cause harm to me whilst alive as the ante-mortem person. An example of this may be that if I have a child who is diagnosed with a terminal illness for which there is no cure, not only will this harm my interests of seeing the child grow up and live a fulfilling and healthy life in my lifetime, but it will, according to Pitcher, also harm me if I die suddenly in an accident, leaving my child behind. My child still succumbs to the terminal condition, and because of this my interests are still setback and are still harmed. It is interesting to note that following this theory of interests being setback, which both Feinberg and Pitcher set out, death could actually fulfil an interest if that interest is to be relieved of suffering, or that interest is to donate organs post-mortem. In relation to deceased organ procurement, if adopting the Pitcher-Feinberg theory, an explicit consent system would appear to protect individuals from being harmed; without consent organs will not be procured, thereby preventing potential for harm. However, on that note, under the current consent system if one's wish to donate organs is vetoed by one's relatives post-mortem, then in accordance with the Pitcher-Feinberg theory it is the ante-mortem person's interest which is "squashed", and it is the living person that is harmed in respect of an "unfulfilled interest" (Scarre 2007, p. 112).

The Pitcher-Feinberg theory relates closely with the argument that a living person may suffer harm even if they remain unaware of the harmful action. This is because one does not need to actually perceive or experience the harmful action. Callahan (1987) opposes this view:

Lack of subject to be affected is sufficient, but not necessary, for lack of harm, while lack of negative effect on a subject is both necessary and sufficient for lack of harm. Thus if you go to some remote island and say terrible things about me while I am alive but this does not directly or indirectly negatively affect me in any way, you have not harmed me (p. 349).

Furthermore, Callahan refutes the idea that one is able to suffer a harm ante-mortem, as there is a lack of negative effect on a subject as the subject no longer exists post-mortem. This

objective perception of death is that the event results in the nonexistence of the person. This challenges the notion that “in some ways you do not cease to be a person after you are dead” (Brecher 2002, p. 115), as once dead one is “no longer the subject of experience” (Fabre 2008, p. 229). One’s cognitive, affective and executive capacities which make up a person (Fischer 1993, p.14) cease to exist. Therefore, one cannot be affected by posthumous events either well or badly, as they are not able to experience anything at all. On this basis, a dead body simply cannot *be* physically or emotionally harmed. Death can be described as a ‘real’ change affecting the integral nature of the body (Tomasini 2009, p.444). Even if organ procurement constitutes a harm, this harm will no longer exist in death if we follow this line of thought. As a result, requiring consent to waive the protection from the harm of procurement post-mortem simply does not apply. The deceased may leave behind a legacy, which out of respect for the dead may present an obligation to act in accordance with; however, the death of the individual nonetheless means that no physical harm can come to them once dead, even if they can be wronged.

The notion that the harm can somehow step back in time, adopting some form of backward causation to justify harms to an ante-mortem person is farfetched. Even Pitcher himself alludes to this when he says, “The view that an ante-mortem person can be harmed after his death is one that we all find, or can anyway be made to find, entirely plausible, if we don’t stop to examine it too closely” (1984, p. 185). His belief around intuitive feelings explains a lot about why we may feel that to speak ill of the dead or betray a trust may be wrong and may wrong the person, as was. However, it is difficult to take a leap further and reconcile this with the idea that an interest which is thwarted or unfulfilled at or after one’s death can actually harm the ante-mortem person. To legislate for protection against ante-mortem harms based upon the Pitcher-Feinberg theory of thwarted interests would be to subscribe to a metaphysical mystery tour moving forwards in time to cast a shadow of misfortune that “can reach back across the chasm even of a person’s death and darken his ante-mortem life” (Pitcher 1984, p.187). There is no way of proving the Pitcher/Feinberg theory objectively. To establish an opt-in policy which even

remotely refers to such a tenuous theory of upholding the interests of the deceased, the setback of which may otherwise lead to harm, would be absurd and, I would argue, irresponsible when it trumps the needs of the living and the harm they definitely *do* suffer as a result of not receiving an organ.

However, even if harm cannot be objectively proven to befall either a post-mortem 'person' or an ante-mortem person, what cannot be rationalised as easily is the strong feeling on the part of the public that they might be wronged should their wishes/interests not be considered in respect of organ procurement post-mortem. McGuinness and Brazier (2008) stress that instead of dismissing as irrelevant any objection to organ donation on the grounds of bodily integrity, on the basis that the dead can have no interests, such an interest should in fact be respected. They refer to these interests, which could be critical interests or merely preferential desires, as values; to dismiss them shows a disregard for one's personal integrity. Such values may be attached to preservation of bodily integrity in accordance with one's deeply held spiritual or religious beliefs. In relation to this, religious tenets which direct customs towards the disposal of the deceased may provide certain restrictions to organ donation, unless it happens in a specific time frame or at a specific time of day (Brazier 2002). Requiring consent may act to prevent harm or wrongdoing in relation to this. A system of objection to donation may not be effective in this respect, since those who may be opposed to procurement, but were for any reason unable to provide this objection, could suffer a setback of their interest which is important to them. Taking organs after death without consent may then constitute such harm. Following this line of argument, it would seem that only an explicit consent system would serve to protect those with very strong views regarding what happens to their body post-mortem. Without consent nothing should happen to one's body.

However, this public apathy to join the ODR or hold a donor card, as noted earlier in this chapter, would translate into fewer organs being retrieved under such an explicit consent system,

even though concurrent evidence suggests that the public favour organ procurement. When considering this, one might challenge whether the harm of 'fewer organs' being procured is greater than that done to the dead if people are compelled to 'hand on' their organs. There are two responses to this. Firstly, if the majority of the public are in favour of organ procurement, but for whatever reason many do not opt in, then an explicit opt-in system does not serve these people's interests. Following on from this, an opt-out system appears to reflect the views of the majority; when looking at numbers, then fewer would have their interests 'setback' under this system. The second response is that whilst this level of apathy exists the default position should be one that saves lives, since –other things being equal- life should trump individual's interests- especially ones which remain unknown.

McGuinness and Brazier's argument that a person's interests should be respected and protected in their death may coincide favourably with Brecher's line of thought that even after death a person remains, even though this is as a dead person (2002, p. 115). This leads onto the idea that "we do not cease entirely to be members of a particular community" (p.113). The obligation to remember the dead and to carry out their interests, where possible, applies to "those among us who have died whose lives made particular contributions to, had specific effects on us, who we are, whether collectively or individually" (p.117). The result of this is that the living may feel contractually obligated to uphold the deceased person's wishes, perhaps owing to a promise previously made, or as a mark of respect to the individual that once was and perhaps continues to hold a significant place in a family, which the obligation may be borne out of. Actions, in respect of this, may demonstrate this connection which continues between those who have died and those who live within the community or family. This reasoning would appear to support relatives having some level of involvement in the decision-making process around organ procurement.

I have argued that disrespect of this legacy, left behind when a person dies, may not constitute a setback of the deceased's ante-mortem interests which may negatively affect the deceased in the form of harm; however, it *may* negatively affect the living in the form of harm. In the same way, if a person's reputation is called into question after their death, the act may be considered wrong, but any harm which occurs will affect the living and those wishing to maintain the deceased's reputation as a mark of respect. It is not the deceased's interests which are the subject of harm but those who seek to preserve and uphold the person's reputation out of a sense of loyalty. In relation to organ procurement, our present system acts to prevent such wrongdoing and, arguably, harm from occurring. Relatives are asked to corroborate any decision expressed by the deceased, and are invited to provide consent for procurement to take place. Relatives are also able to divulge valuable information about the deceased's social and medical history; this may prove important when considering viability of the deceased's organs (Brazier 2002). This provides an opportunity for relatives to act in the best interests of the deceased as their advocate, thereby discharging their obligation to the deceased, whose wishes may have only ever been verbally expressed. However, as mentioned earlier, a problem which may arise from this is that relatives have the power of the final veto in respect of whether organs are retrieved posthumously. Therefore, one's active consent (arguably a strong interest) may be overridden by relatives under our current system. A tension exists between respecting the right to donate with respecting the right of the relatives to veto the deceased's decision.

3.8: Respect for Autonomy and the Role of the Relatives.

Historically, in English law property rights have been assigned to those whose obligation it is to respectfully dispose of the deceased body; responsibility for this has normally been given to executors and administrators of the deceased (Skegg 1984). Traditionally, the reasons for this have been twofold. Firstly, the health and safety of the public must be taken into consideration. In respect of this, dead bodies need to be disposed of to prevent unwanted putrefaction and potential for disease which could be spread to the public. In accordance with this, someone has to

be appointed to take charge of the deceased and ensure that burial takes place (Hardcastle 2009). Secondly, religious beliefs and social tradition have long encouraged the decent and dignified disposal of the deceased as a mark of respect for the dead in generic terms as well as for the specific individual (Dworkin and Kennedy 1993). It has been customary to assume that the relatives are best placed to honour such practice, resulting in the duty of organising the burial being passed on to them (Skegg 1984). However, this right of possession is for the purposes of disposal only (Grubb 1998; Mason and Laurie 2001).

Any strongly held convictions which drive relatives to act in a protective manner towards their deceased and take their responsibility seriously probably result from the emotional attachment forged between the deceased and the relatives in the deceased's lifetime (Callahan 1987). Doing the right thing for the deceased is borne out of respect for them as they were when alive. This may be why traditionally, in the absence of the deceased's wishes, relatives have been asked for their permission for their deceased's organs to be procured, based on the premise that they may be best placed to know what the deceased would have wanted. Death is a highly significant event for all those close to the deceased; because of this, the relative's opinions with regards to the disposal of the body are important. Providing families the opportunity to decide may constitute an appropriate substitution for the "unattainable autonomous decision of the deceased rather than as an alternative to it" (Boddington 1998, p. 76), demonstrating proper respect for the individual's autonomy (assuming the family are best placed to act in respect of this).

The events of Alder Hey and Bristol Royal Infirmary demonstrated the suffering felt on the part of relatives, unable to carry out their perceived duty in respect of protecting the deceased, and providing them with a burial they believed to be fitting for their loved one. In the aftermath of the improprieties around organ retention, the introduction of the Human Tissue Act served to advocate the importance of consent to protect one's right to self-determination, and to allow

relatives to share in the decision-making process to ensure that an individual's integrity remained protected. Enabling relatives to share in the decision-making process over cadaveric organ procurement has resulted in a broad acceptance in practice that relatives have some control when decisions are needed in respect of this.

With specific regard to cadaveric organ procurement, death is normally sudden and the relatives will often not be prepared for the event; this, in itself, will normally be the cause of much anguish on the part of the family. This could be heightened by proceeding with procurement in the face of their objection. Overriding the family's wishes could provoke consternation and despair; this could result in a backlash from the family. As a result the family could expose clinical personnel for their insensitive and disrespectful behaviour towards the family, using the media to bring their distress into the public eye. Such negative publicity could conceivably have a negative impact on the number of organs retrieved across the country. Overriding families who are understood to be acting in the best interests of the deceased could have a devastating impact on transplantation (Wilkinson 2005). In view of this, Wilkinson (2005) states that unnecessary and potentially damaging feelings of anguish should be avoided; this can be managed by continuing with families retaining the right of veto⁶⁹. Wilkinson's argument rests upon a practical premise; in clinical practice this is the reason why the family veto is accepted, even if it prevails over the deceased's wish to donate. However, some have criticised the hurried passing of the Human Tissue Act as "a 'knee jerk' response to public outcry" after the organ retention debacle (Zimmern 2007, p.314), resulting in the pendulum shifting too far towards showing deference towards relatives' rights.

Accepting the relative's veto in lieu of the deceased's (known) wishes shows a disregard on the part of clinical personnel for the law which stipulates that where the deceased's wishes are known the decision should be respected. It also begs the question of whose right the decision

⁶⁹ However, as he points out, this argument could also be applied to relatives wishing to consent to retrieval even though the deceased had objected.

about determining what happens to the body rests with. On the face of it, it would appear that whilst an opt-in system shows respect for an individual's right to self-determination, in practice relatives appear to be exempt from respecting this. Whether the State puts the wishes of the deceased second or the relatives do makes little difference if one is arguing that "respect for the living means respect for the dead too" (McGuinness and Brazier 2008, p.297). If putting the needs of the living over the wishes of the dead is deemed to be a blatant disregard for an individual's autonomy (ODT 2008), can our pandering to the threat of a backlash on the part of angry relatives whose veto is overruled not be considered to demonstrate the same sort of blatant disrespect for the individual's autonomous wish to donate?

It is interesting to note that during my lifetime, I am able, whilst competent, to write an advanced decision to refuse treatment (ADRT), which if invoked once capacity is lost may result in my death. If this ADRT is drawn up correctly, it must be upheld (MCA, 2005). Relatives have no right to overturn this, if it remains the only form of advanced planning (in terms of decisions relating to treatment refusal) organised by the individual. On the other hand, an advance statement of wishes, enabling an individual to declare their desires in relation to what should happen to them when they are in the terminal phase of their life, does not afford the same legal fortitude⁷⁰. One is unable to demand treatments. Similarly, one is also unable to demand that their organs be retrieved post-mortem for transplant. However, I can demand that something *not* happen, for example, that I not be given treatment and this must be respected. What this demonstrates is that we often treat the case where I say 'you must not do this' as different from the case where I say 'I would like you to do this'. In the case of organs, where the deceased has consented to donation all they have done is said that donation can be done. If they refuse donation, they say something stronger – that donation cannot be done. In the former case it might seem that all I am doing is giving permission, and it is not disrespecting my having given

⁷⁰ Information regarding can be found at:
http://www.endoflifecareforadults.nhs.uk/assets/downloads/supportsheet3_1.pdf

permission to block someone from acting. In the latter it is more likely that I am refusing permission, and it would be disrespecting my refusal of permission to allow someone to act.

A soft opt-out system appeals to affording this sort of respect. Under such a system the family could not overrule a refusal on the part of the deceased, but in the situation where no objection has not been registered (this will represent the majority of the cases) they could assert an objection if they were aware of the deceased's wishes or they felt strongly enough opposed to procurement. The soft opt-out system with a combined registry in Belgium facilitates this opportunity for relatives (Michielsen 1996). Such a system enables relatives to provide invaluable evidence about the deceased's medical or social history, and offer an objection on behalf of the deceased. However, the relative's decision does not supersede the registered wishes of the deceased. This would seem to demonstrate proper respect for self-determination. Under such a system, in the interests of the greater good organs would be retrieved from those who do not feel strongly enough to assert their interest in respect of organ procurement. However, this system would also serve to accommodate the interests of those who feel strongly enough to either object or consent to organ procurement and are able to register this, knowing it will be respected above all else.

Allowing relatives to be involved in the decision-making process with safeguards, such as not allowing their decision to override the deceased's registered wishes, will have a positive effect, since it will enable relatives to feel involved and able to advocate for their deceased, which they may feel is an important duty on their part. Practically, it also acts to provide a safeguard for transplantation, in terms of corroboration of social and medical history. This acts to maximise welfare. Politically, it is important to enable relatives to express an opinion; denying this opportunity (when there is no known view from the deceased) may result in a legal challenge mounted under the European Convention of Human Rights, Article 8: the Right to respect for private and family life. The legal Working group, set up to provide advice on the viability of an opt-

out system for organ procurement to the ODT, declared that “a ‘hard’ opt out system that did not seek evidence from families about the deceased’s own opinions or wishes could be open to a potentially successful challenge under the European Convention on Human Rights (ECHR)” (ODT 2008, p.12)⁷¹. As Wilkinson (2005) points out, it will also potentially become very difficult if a relative exposes the dismissal of their opinion made on behalf of the deceased. Negative publicity or a legal challenge would undoubtedly threaten the utility of the policy if the end result is a rise in the number of objections registered.

3.9: Conclusion.

The right to self-determination when clinical decisions are required is held up to be the pinnacle of good patient care in which shared decision-making resides. The introduction of the Mental Capacity Act 2005 serves to demonstrate a commitment towards putting patients first, protecting their right to self-determination or, where capacity fails, acting in their best interests. However, in respect of a policy for organ procurement this does not and ought not to mean that all roads should lead to consent. In relation to cadaveric organ procurement, the problem with our current system is that ‘consent’ seems to be unsuitable whichever way ones looks at it, and one that we cannot hope to fulfil the requirements of properly. Policymakers are trying to please too many parties, and in doing so have lost sight of the practicalities. On the one hand the system refers to ‘valid consent’ from individuals, whilst at the same time it allows relatives to override the deceased’s determined decision, thus potentially acting wrongly towards the deceased individual, who will have no further opportunity to stand firm with their wish. If the individual has taken the time and the responsible step of making their decision known, this should not then be overturned at the will of the relatives.

⁷¹ The legal group also advised that a register alone for recording decisions without involving families at the time of death, may be insufficiently compliant under the terms of the ECHR, since the organs may be retrieved from individuals who had not registered an objection decision for any number of reasons, including ignorance of the system, or physical or mental incapacity to object. In an opt-in system the deceased may have registered a wish to donate a long time ago and since changed their mind but not removed their name from the register (ODT 2008, p.12).

For most of the public, who do not appear to feel strongly enough to actively consent to cadaveric organ procurement, an opt-out system is no more disrespectful of autonomy than a consent system such as the one we have. Presently, we do still presume that it is permissible to retrieve organs from the deceased in the absence of their definitive consent, as long as a relative provides consent. It is difficult to know how this represents a more clearly defined respect for autonomy than a system which allows for one to object to their organs being retrieved.

Respect for persons has to be viewed by policymakers from a societal perspective as well as on individual basis. A policy which defaults to opt-out with a combined registry addresses the health of society *and* demonstrates a respect for self-determination. Whilst arguments against an opt-out system refer to the potential harm which may befall a deceased individual opposed to organ procurement, but whose wishes were never registered, this can be mitigated for by allowing relatives to assert such a refusal on the deceased's behalf. For a policy with such an important remit precedence should not be given to speculation of the potential but unproven harm which *may* occur over the known and definite harm which does occur. As Dufner and Harris (2015) argue, "a system of organ retrieval and allocation that increases supply and thereby saves lives, but that violates no rights or interests, is morally superior to an alternative that costs lives and protects no comparably important values" (p.7). Respect for self-determination means respecting our interests in terms of the autonomous decision we make (when it is made). The provision of consent (when adhered to) only meets this halfway; this coupled with the provision for objection promotes a more complete respect for self-determination. This is what a combined registry achieves.

Chapter 4: Organ Donation: providing an opportunity to make an altruistic gesture.

4.1: Introduction.

Consideration of potential systems for organ procurement and transplantation has generally led to three options. These are that: 1) organs can be taken, 2) organs can be sold, or, 3) organs can be given. When considering an opt-out system in the UK, The ODT ruled out any form of routine salvaging or hard opt-out system, stressing that such a system may contravene certain articles under the European Convention of Human Rights⁷² (ODT 2008, p.12). Coupled with this, the commercial trade of organs continues to remain unlawful, its prohibition most recently reinforced in the Human Tissue Act 2004. With the first two options rendered redundant by policymakers, traditionally this has navigated the discussion around procurement towards a system where organs are given.

The term 'gift-giving' is now commonly used to endorse the act of organ donation. Ministers, past and present, have spoken effusively of the public's generosity of spirit in donating the 'gift of life' to help others in need of a lifesaving transplant. Prior to the introduction of the Human Tissue Act in 2004, the Health Minister, Rosie Winterton, referred to organ donation as a "gift to society"⁷³. Policymakers have accepted that a successful transplantation policy largely relies upon the public to engage positively, both theoretically and practically, with the donation of organs. To encourage this process they have realised that discourse around donation has to be respectful and clear, yet influential. In view of this, a connection has explicitly been made with an act which most would feel good about taking part in. By linking organ donation to gift-giving policymakers have acted to persuade the public to relate an act which most would agree is not customary and which may, on the face of it, prompt feelings of discomfort with another act which

⁷² This would be in terms of not approaching the family for evidence of the opinions of the deceased.

⁷³ Available from: <http://news.bbc.co.uk/1/hi/health/3845365.stm> viewed 12th January 2012.

the majority of people are very familiar with and take pleasure from being involved in (Gerrand 1994).

In their report *'The Potential Impact of an Opt-Out System in the United Kingdom'* the ODT (2008) commented upon the “generosity of the British people – by the families of those who had donated organs and who spoke of organ donation as a gift, and by the many, many people who spoke of organ donation as an opportunity to fulfil either their own or their loved one’s choice to help others in need” (p.8). The message emanating from the ODT’s report was that an organ procurement policy should be underpinned by the freedom to exercise choice in terms of generosity, explicitly allying organ donation with gift-giving. These positive features of gift-giving, as presented by the ODT, make the argument for its inclusion in an organ procurement policy appealing. An opt-out system would potentially undermine this concept of donation as a gift (ODT 2008, p.34) by obviating the need for consent, thus denying one the opportunity and right to make an autonomous choice to be generous. Such a system might be perceived by some as “morally inferior to the positive altruism of gifting as represented by clearly opting in” (ODT 2008, Annex D, p.10); moreover, removing the gift element from organ donation could have a dehumanising effect (ODT 2008, p.30).

When emphasising the importance of describing this act as a lifesaving gift the ODT has neglected to consider that it may be fraught with difficulties when one takes into account the enormity of the gift. This often results in profound feelings of indebtedness on the part of many transplant recipients, simply unable to convey anything other than a deep sense of gratitude. The ensuing feelings of inadequacy, as well as exaggerated feelings of obligation on the part of the recipient towards the donor and, perhaps their family, often serve to create an asymmetrical relationship, unbalancing this utopian concept of social equality which ‘gifted’ organs can bring. NCOB (2011) suggest that it could be used to coerce or exploit some relationships.

From this one could argue that the use of the metaphor⁷⁴ ‘gift-giving’ and “the concept of a gift given freely” (ODT 2008, p.17) are troublesome and imprecise. What is required is the opportunity for altruism. Whilst some may view altruism and gift-giving as the same thing, research suggests that this is not the popular view, and the majority expressing an opinion in this area appear to separate out altruism from the act of gift-giving (NCOB, 2010; ODT, Annex J, 2008; Sque et al, 2003). However, evidence from public consultation events has shown that altruism remains an important value which the majority have expressed should continue to be a feature in an organ procurement policy. Because this policy is so reliant upon the public for its success, accommodating what appears to be a popular wish to have the opportunity to act altruistically would be a prudent measure. This should serve to contribute to the success of a policy which seeks to maximise the number of organs for transplant. Its inclusion would explicitly acknowledge the importance of individual decision-making, whilst at the same time meeting its obligation and responsibility towards a society of people, therefore retaining “a strong interest in the social production of giving” (Kierans 2011, p. 1475).

This chapter will begin with a discussion around the value and potential issues of relating gift-giving to organ procurement, leading onto the question as to whether it is the gift which is important, or, in fact, the act of giving which is important. What is needed is for altruism to play a part in an organ procurement policy. Explicit reference to gift-giving, which may bring with it problems, may not be required and which reference to altruism may not prompt. This may then open up the opportunity for moving away from a default opt-in system. The discussion will then reflect upon the importance of altruism when devising a policy for organ procurement. The present policy appears to be reliant on a strong altruism position; however, I shall argue that this need not be the case and that a weak altruism position reflects the views of society, in general, and may not serve to inadvertently shackle the opportunity for a policy to increase the supply of

⁷⁴ The term ‘metaphor’ is used as whilst one may wish to view giving their organs as a gift, cadaveric organ donation does not accurately represent this, as the individual is unable to actually give the organs at this time. However, ‘gift-giving’ provides a useful imaginative way to represent what some may feel stands for organ donation.

organs for transplant. This can be provided effectively under a default opt-out system, with the added advantage of a combined registry allowing those who feel strongly about giving a 'gift' to be able to explicitly opt-in.

4.2: The Value of Gift-giving.

The donation of blood and organs has been held in high regard since the first transplants were successfully performed, and it is commonly described as a lifesaving gift by those directly involved in policy provision in this area of health care and those directly involved in the organisation and management of organ donation⁷⁵. The phrase 'Gift of Life' was used after the first human organ grafts were transplanted in the 1950s (Murray 1987, p.32). The term has subsequently retained its sense of importance in relation to organ donation and remains pivotal to the process of organ procurement. Gift discourse has often been employed in medical and bioethical fields to engender a feeling of voluntarism, "in idealised altruistic terms to foster the promotion of organs, while preserving and enhancing social life and community values" (Kierans 2011 p.1475).

The work undertaken by Titmuss in 1970 around the practice of blood donation in the United States (US) and the UK points to a recognition of the value and importance of life (Campbell 2009), as represented through providing the gift of blood, contrasting this starkly with the materialistic practice undertaken in the US of the market transfer of blood. There is something quite disingenuous about allowing a market in blood and organ provision; where money is involved the motivation alters to help others, guided by the financial incentive (Sykora 2009). Retaining organ (and tissue) donation as a gift-giving process provides a buffer against the divisive and competitive nature of the economic market which seems to dictate so much in the way of social and welfare provision. Boas (2011) suggests that the "anthropology of the gift"

⁷⁵ The term is commonly used by the ODT (2008); it is also referred to regularly on the NHSBT website, in reports on organ donation regarding both statistics and initiatives. The following webpages provide a flavour of this: http://www.odt.nhs.uk/pdf/advisory_group_papers/NODC/transitional_steering_group_strategy_slides_june.pdf; http://www.odt.nhs.uk/pdf/Making_a_wish_come_true.pdf; http://www.odt.nhs.uk/pdf/introductory_remark.pdf; http://www.odt.nhs.uk/pdf/advisory_group_papers/NODC/donor_recognition_proposal.pdf.

unites with welfare politics, the result of which is the forming of “an economy of replaceable organs that is dissociated from the assumptions of capitalism on possessive individualism and the direct quid-pro-quo mode of market society” (p.1379). By making gift-giving the only acceptable form of provision of organs and representing organs as ‘gifts’ which are ‘priceless’ the ultimate anti-market culture is created (Wilkinson 2003, p.109). The act of giving an organ preserves a moral code of behaviour, whilst giving individuals the freedom to act in this way (Sykora 2009, p.14). Labelling organ donation as a ‘gift-giving’ process provides a very clear message that in a society in which so much is dictated by money and markets, there are some things which simply ought not to have a price placed upon them.

Gift-giving is often considered to be a voluntary and altruistic act. In relation to this, NCOB suggest that a ‘gift’ ‘implies a concern towards others’; they feel it can be ‘invoked synonymously with altruism’⁷⁶ (2011, p.125). The association between giving the gift of an organ and altruism might also suggest that acting in such a way is above and beyond that which is expected of you⁷⁷ (Wilkinson 2003, p.110). Acting at some cost to yourself represents “the act of generous sacrifice” (Joralemon 1995, p.348). It encourages a level of empathy towards human suffering; this motivates us to help alleviate it by giving something of ourselves. Explicitly presenting organ donation as giving a lifesaving gift asserts a powerful moral position, advocating a system of social solidarity underpinned by “moral, social, psychological, religious, legal and aesthetic ideals” (Titmuss 1997, p.124). As members of a community, the part individuals play in the success of this welfare policy necessitates recognition that one cannot survive in isolation and must take some responsibility in the continued existence of an interdependent society (Murray 1987, p.32). This creates a communal network of obligations: the group’s welfare being partly dependent upon

⁷⁶ According to the Council, altruism is “a selfless gift to others without the expectation of remuneration. For several decades, this understanding of altruism has been presented as the basis of blood and organ donation in the UK” (NCOB 2011, p.120).

⁷⁷ In contrast, there are those who believe that giving to help those who are worse off is something which we should all do, constituting a duty rather than a supererogatory act. This could extend to allowing organs to be procured post-mortem to help the living. One view might be that in death an individual’s organs are essentially wasted, and rather than see them disposed of they could be recycled to help those who are in need of a transplant (Emson 2003).

mutual cooperation (Lauritzen et al. 2001 p.30). Such an act of solidarity in combination with delayed reciprocity could be described as “the beauty of the gift without strings and solidarity without emphasis on reciprocity” (Zeiler 2014, p. 174).

4.3: The Emphasis on Gift-Giving in an Organ Procurement Policy.

In completing the publication of his study, *'The Gift Relationship'*, Titmuss suggested “examining the extent to which specific instruments of public policy encourage or discourage, foster or destroy the individual expression of altruism and regard for the needs of others” (1997, p. 59). A fundamental aspect of an organ procurement policy is to be able to relate to the public and allow them to relate to the importance of the donation of organs. By employing the metaphor ‘gift-giving’ as a social representation of organ procurement policymakers have encouraged the public to appreciate a previously unfamiliar and potentially uncomfortable image which may have been envisaged when thinking of organ procurement (Gerrand 1994). Gift-giving is normally associated with pleasure and happiness; by connecting organ donation to gift-giving the public have been able to view this in a more positive way and associate such an act with a feel good factor.

The term ‘gift’ and ‘gift relationship’ have been used in Government documents and policies concerning organ and tissue procurement in England and Wales to manipulate a definitive and lasting image. Introducing the transplant framework for England, *'Saving Lives, Valuing Donors'* (DH 2003), Rosie Winterton set out the Government’s position on the values underlying organ procurement when she said:

Organ and tissue donation is entirely dependent on the altruism of ordinary members of the public....We must build public confidence that the service is based on ethical principles and that their life saving **gift** is respected and received with gratitude (p.3).

The ODT (2008) implies that gift-giving can only be invoked to encourage donation as part of an opt-in system. NCOB (2011) appears to support this position stating that gifts are given “properly” as opposed to being taken “improperly” (2011, p.118). When one opts in to donation they actively choose to ‘give’; this contrasts starkly (on the face of it) with an opt-out system under which organs appear to be ‘taken’. One could infer from this that opt-in demonstrates ‘proper’ conduct whilst opt-out condones the (improper) taking of organs.

Fox and Swazey’s description of “the acutely ill patient” accepting the “priceless gift” from the donor (1978, p.5) is meant to conjure up an image of the enormity of the gift and the special relationship which is borne out of the donation process. It is this approach to organ procurement which the Government, both past and present, has continued to take forward in an attempt to encourage people to donate their organs. However, such an idealistic and sentimental perspective of ‘gift-giving’ fails to acknowledge the disingenuous aspects which may also accompany this social practice, and which appear to have been overlooked by policymakers keen to appeal to the public’s generous side.

4.4: Organ Donation as the ‘Gift of Life’: an Appropriate Discourse and Philosophical Approach to Take?

Much of the discourse around organ donation as a gift has connected the act simultaneously with a sacrifice. This may be because we view our organs as if representing symbols of ourselves. Following on from this, the donation of something which has such a special and unique meaning to the individual heightens the magnitude of the actual gift and what this act represents both to the donor and then to the recipient. The phenomenology of donation is therefore extraordinarily special and, as such, bears a close resemblance to a form of sacrifice as the gift of the organ donated is “wrought at great personal expense” (Mongoven 2003, p.90). Campbell (2009) suggests that in many cultures when a person dies their bodily organs take possession of “powerful symbolic significance” (p.25), an extension of the symbol that the body as a whole represents to the family of the person that once lived and was and is still loved. Whilst

organ procurement may be offered as a 'gift', this characterisation of the family dynamic illustrates how the actual act of organ procurement may simultaneously be viewed as a sacrifice.

Mongoven (2003) offers two explanations as to why this connection between organ procurement and sacrificial gift may be felt. "Motivational" sacrifice (p.91) defines the intention of the act of organ procurement as a benevolent act of giving, motivated by the wish to help those in need of a transplant; this 'gift' may be regarded as a willing sacrifice on the part of the donor. Organ procurement as a "cultic" sacrifice (p.91) refers to the actual surgical procedure of cutting the body and removing the organs (Sque et al 2008, p. 135). Cultic sacrifice is often rooted to religious symbolism; an example of this might be Christ's crucifixion which marks a paradigm case of organ donation understood as sacrifice (Mongoven 2003, p.91). An important symbolic association has also been made between the Eucharist -the blood and body of Christ- and the giving of (blood and) the body of the donor whose organs are procured. Both are connected in their purpose: saving those from harm. Moreover, the practice of organ donation tangibly creates a community among those who participate; the Eucharist and organ donation both represent the sharing of body and blood with the common purpose of the salvation of others (Mongoven 2003, p.91).

When viewed in this way organ procurement serves to inspire individuals guided by their religious belief to act in such a way so as to strengthen their community. Such behaviour resembles the act of a 'Good Samaritan' (Mongoven 2003, p.92); in a pluralist society this can act as a moral as well as religious motivation. This is something Childress (2001) also refers to when he discusses the strong sense of obligation and goodwill which Judaism and Christianity promote⁷⁸, translating into measures which can be taken to help and support members of the community. These religions view one's sacrifice of organ procurement as a gift of life, the result of which helps to strengthen a society, helping those most in need. Fox (1979) proposes that the

⁷⁸ This can be extended to the Islamic faith, with reference to compassion, human kindness and goodwill towards others advocated strongly in the Quran (Suzuki 2008, p.115).

gift of organ transplantation commands a deep and strong sense of transcendental purpose, suggesting that “truly redemptive gifts are divine ones....the gifts of life and death from God” (Fox 1979, p.120).

One may argue that in a pluralist society expressions of an overtly theologian nature may not resonate with most individuals’ beliefs around organ donation and the image or feelings it may conjure up; from this it may be questioned as to whether such a view need be considered particularly closely. However, NHSBT (2015c) has recently stressed that religion can act as a barrier preventing people from agreeing to organ donation because of a belief that one’s faith does not support the act. This can be felt particularly strongly by members of the Black, Asian, and minority ethnic who often describe their feelings in terms of the faith they follow (NHSBT 2015c; ODT 2008). NHSBT has described engagement with different religious and faith leaders as a “vital aspect of the strategic plan to raise awareness of organ donation and transplantation in the UK” which will involve working with faith groups “to increase awareness and build trust, whilst providing the information needed to dispel myths and encourage debate and discussion” (NHSBT 2015c).

Work conducted as part of the ODT’s (2008) report on the impact of an opt-out system included a detailed study of the different religious groups’ views concerning organ donation (ODT Annex M 2008). The ODT recognised the importance of their concerns as part of a public deliberative process around managing organ donation. In addition to this, the view put forward by many UK faith group leaders in a recent study endorses the current opt-in system which allows for this gift relationship to be celebrated. The majority of the leaders involved in this study questioned how any other system, in particular an opt-out system, can refer to organ procurement as donation or be linked to gift-giving when the actual act of gift-giving may inadvertently be removed. One of the Christian leaders expressly pointed to this when he stated

that “the gift relationship is a very important point in Christianity...a gift where you have no say whether you give it or not, is not quite a gift” (Randhawa et al. 2010, p.41).

However, a tension exists between the positive act of the sacrificial gift of organs with the body and its symbolic representation in its wholeness of the person who once lived (Morgan et al. 2013). The image conjured up by the retrieval process involving the cutting of the body may point towards the altogether more insidious aspects of sacrifice. This may serve to dissuade the public rather than motivate them towards ‘donation’. In chapter 3, I have argued that once deceased the donor is beyond physical suffering. In view of this, it could be argued that once dead the actual organ retrieval does not incur any suffering on the part of deceased. Moreover, it would seem absurd to suggest that there is any level of sacrifice felt when an individual pledges to donate their organs. However, this could be a particularly poignant observation when considering the circumstances which relatives most often find themselves in when an approach for donation is made, normally after a sudden and unexpected death. Relatives are often torn between what is ‘right’ and ‘good’ and what they imagine will harm their loved one, whose protection even after death they are charged with the responsibility of. This may unfortunately result in a higher refusal rate from families, unwilling to give consent due to the perceived suffering which they feel their loved one might endure when there is no evidence of an explicit desire to donate.

In addition to this, whilst opinion polls would suggest a favourable outlook towards organ procurement (NHSBT 2008), at the time of the deceased’s death the relatives are undoubtedly more concerned with what the deceased would have wanted and getting that right and not doing what is right by society. Their priority is thus focused upon what accords most closely with what their loved one believed, not what they believe under normal circumstances. Furthermore, for families of brain stem dead individuals, whilst the patient remains ventilated, for all intents and purposes, the individual will appear to be alive. The family will need to reconcile their uneasiness

with this perception and the reality of brain stem death if they are to agree to organ procurement.

Mongoven (2003) believes that it is these negative images which can result in families associating the donor process as a “live sacrifice” (p. 93). The idealistic notion of organ donation being regarded as a gift is suddenly replaced with the act being considered a burden- a sacrifice the family must bear- especially when faced with the knowledge that the deceased individual wanted to donate. What may be conceived as a ‘gift of life’ by the potential donor may seem inhuman to the family, whose decision it is to agree to procurement. Whilst the donor family gives very little, as they would have done nothing with the organs anyway, what is significant is their role in allowing the deceased’s organs to be retrieved, the act of donating on behalf of the deceased and what this represents to the family (Lauritzen et al. 2001). This harks back to the notion of the organs ‘symbolising’ the donor. It is this which makes the decision such a difficult one and one which might feel akin to sacrifice.

Reflecting upon this onus placed upon families, and corroborating this observation with their British studies of donor families, Sque et al. (2008, 2007, 2003) ask whether promoting organ procurement as a ‘gift of life’ provides an appropriate framework as it neither reflects accurately nor, as a result of this, demonstrates any real appreciation of the trauma and upset the donor family suffer when asked to consent to an organ retrieval. Organ procurement may present a useful paradigm for a form of personal sacrifice. However, it does not appear to represent the expense wrought by the family who have to balance the benefits of saving a stranger’s life (of which there is no guarantee) with the burden of relinquishing their responsibility for protecting the body of the deceased to facilitate the retrieval process (Mongoven 2003; Sque and Galasinski 2013; Sque et al. 2003). Some potential donor families have questioned whether donation should take place, citing concerns such as their lack of understanding of brain stem death (Long et al. 2008), that their loved one has suffered enough and that procurement may cause them pain

(Sque et al. 2008). On the basis of these concerns they are left wondering whether the body should be left intact (Sque et al. 2008). The analogy of the gift to organ procurement seems to be far removed from the families' minds when faced with the question as to whether they are willing to authorise the retrieval.

Since the final decision still commonly rests with the next of kin or closest member of the family (Farsides 2012, p.i74; Vincent and Logan 2012, p.i82), rendering them as gift 'distributor' (den Hartogh 2012), this prompts questions over the deceased's role in the donation process. Publicity campaigns around organ donation often marry together the generosity of spirit of the individual with a healthy respect for their right to make the autonomous choice to donate, "as if making the decision to sign the donor card (or join the ODR) and actually donating were equivalent" (Lauritzen et al. 2001, p. 35). However, our opt-in system allows the 'donor' a passive role ultimately, as at the time of the donation the 'gift' is not actually given by the donor. The deceased acts as a participant in the 'gift' process as "the gift object" (Siminoff and Chillag 1999, p.35). Joining the ODR or signing a donor card simply constitutes a pledging of one's organs to be used. What it does not do is allow the individual to give anything at that time or determine that retrieval will take place. At which point joining the ODR or signing a donor card, which is the most one can do, is not actually synonymous with gift-giving.

Childress (2001) disputes this suggesting that when an individual deliberately chooses to donate this renders their role in the procurement process as the 'donor'. Using empirical evidence of a mother's testimony of her deceased son's organ donation, he states that by consenting to her son's organ retrieval she acts as the source conveying his wishes to donate and "simply implementing his prior decision" (2001, p.4). The opt-in policy enables individuals to express a will for their organs to be given in death; this can then be facilitated via appropriate consent which is given on the deceased's behalf by their relative. In this way, whilst the law is "primarily individualistic...social practice is primarily communitarian, that is, it views the deceased individual

as part of a family” (Childress 2001, p.4). However, contrary to this interpretation of the present opt-in system, concerns have been voiced regarding the position policymakers actually take in their practical application of the legal process. Whilst the present system appeals, *prima facie*, to the individual’s freedom to decide whether to donate, “the actual procurement process relies on a group dynamic that is seriously at odds with the standard individualised decision-making” (Lauritzen et al. 2001, p.32).

Identifying organ procurement as a gift represents a challenge for transplant recipients who may have been overlooked by policymakers determined to preach the ‘gift of life’. Whilst many transplant recipients may talk about their donors as saviours, those who have given them a second chance at life (Joralemon 1995, p.343), promoting this concept of the organ donor making an “inestimably priceless gift” may also introduce a “complex exchange through which more than the organ is transferred” (Fox and Swazey 1978, p.5). Murray (1987) takes this further insinuating that “gifts may entangle people in relationships that will impose great but vague moral obligations...with ugly and manipulative potential” (p.30).

Gift-giving is often associated with obligations revolving around behaviour and reciprocation. In terms of organ donation, whilst the idea of reciprocity might be considered in a collective (societal) rather than an individual capacity, it is often something a transplant recipient may become very conscious of, especially in relation to the enormity of the gift (Shaw et al. 2012). This may present a twofold problem. Firstly, the recipient must come to terms with the idea that another’s death has led to their transplant being possible. The recipient must resolve any feelings of discomfort in relation to this in order to accept and enjoy the life it has provided for them. Secondly, this ‘priceless’ and ‘unique’ gift is invaluable. The recipient cannot repay such a gift and may feel that their gratitude for such a gesture of kindness is too meagre when considering the impact the transplant has on their life. Furthermore, although gratitude cannot be expressed to the deceased donor, this may not stop the recipient feeling a need to fulfil this integral part of the

gift-giving process and subsequently suffering profound guilt due to the inability to reciprocate (Fox and Swazey 1992; Shaw et al. 2012). As a result of this the recipient may feel a disproportionate sense of obligation towards the gift that is the organ itself, due to the circumstance by which the recipient has come to be given the organ. An added weight of pressure to 'ensure' that the organ does not fail has also been expressed by some recipients (Kierans 2011, p.1475). When rejection does occur these feelings of guilt and obligation combine; this can result in the recipient experiencing a sense of 'double loss' which can be too much to bear (Mongoven 2003, p.38).

Research suggests that this asymmetry between the donor/ donor family and recipient can have a psychologically damaging effect on the recipient (Kierans 2011; Lauritzen et al. 2001; Siminoff and Chillag 1999) as the end result of the donor process can be the rise of a "creditor-debtor position...binding one to another in a mutually fettering way" resulting in "the tyranny of the gift" (Fox and Swazey 1992, p.39). It is based upon this that Mongoven (2003) and Sque et al (2008;2007) assert that too much is played upon the metaphor 'gift' and the rhetoric associated with this, resulting in a burden for all concerned in the donor and transplant process, whilst Siminoff and Chillag (1999) believe that associating organ procurement with gift-giving is a "fallacy" (p.35). At this point one wonders whether organ donation as a 'gift' has any redeeming features. This pressure that can be felt by both recipients and donor families to conform to these socially orchestrated roles within the organ donor process can be manipulated even further by the tactical behaviour conducted by some HCPs specialising in the field of organ donation and transplantation (Shaw et al. 2012, p.34). Examples of exaggerating the gift metaphor⁷⁹ and using it explicitly to control compliance through the medium of guilt is not only destructive (Lauritzen et

⁷⁹ A particularly explicit manipulation of the gift metaphor was illustrated by one particular HCP in research conducted by Siminoff and Chillag (1999), who pointed out to a recipient that, "As a transplant recipient, you have been given a second chance at life through the selfless donation of another. An important way to hone, appreciate and protect that gift of life is to comply with your health team's medical instructions" (p.40).

al. 2001), but also serves to 'muddy' any of the altruistic undertones motivating the donation in the first place.

An overemphasis of the gift metaphor presents a danger that such a powerful symbolic representation of the dead body, reaffirmed with references of organ donation as a 'gift of life', will provide an elevated level of importance and exoticism to both the body and to organ donation. This naturally results in a level of exaggerated importance being attributed to organ donation; this may impact upon donor families and their impression of what it is they are actually consenting to. This could also risk heightening a recipient's sense of obligation in terms of the organ they have received. By making less of the gift metaphor, policymakers can stop romanticising it (Kuczewski 2002); consequently the obligations which are evidently felt by donor families and recipients may diminish. The introduction of an opt-out system, far from having the dehumanising effect (ODT 2008) resulting from the removal of the gift element from organ donation, may in fact provide a more humanitarian approach to procurement which serves to maximise the welfare of its (living) citizens. Furthermore, for those wishing to demonstrate an altruistic act of pledging their organs for transplant posthumously, a default opt-out system with a combined registry facilitates this. What lies at the heart of this debate is whether the default system of opt-out can demonstrate an acceptable altruistic position reflecting the public's disposition towards donation.

4.5: The Role of Altruism in an Organ Donation Policy.

Favourable public opinion towards organ procurement is reflected in numerous opinion polls and empirical studies which have been conducted nationally (Coad et al. 2013; NHSBT 2008; ODT 2008; ODT 2008, Annex J; Optimisa Research 2013; Sque et al. 2003). Support has been spoken of in terms of a desire to help where no financial recompense is provided, simply giving for giving's sake, thereby doing something good for somebody else (Long-Sutehall et al. 2012; ODT 2008, Annex J; Titmuss 1997) being able to do something good on behalf of the deceased as

a reflection of their altruistic nature (Long-Sutehall et al. 2012; Sque et al. 2003) and being able to give back (Titmuss 1997). Reciprocity, when considered in terms of the altruistic gesture of organ donation, can be understood to be experienced at a societal level rather than an expression of individual benefit. Public opinion, gathered from the deliberative public events for the ODT's report on opt-out, showed that increased awareness⁸⁰ resulted in an overall opinion that organ procurement has an important place in society as it serves to help those whose quality of life and/or survival depends on it (ODT 2008, Annex J). There was also strong feeling that the public should play a major part in this, managed under a system which may default to organ procurement, demonstrating a shift in favour from the current opt-in system towards a soft opt-out system (ODT 2008, Annex J, pp.5,43).

In order to maximise upon these benevolent expressions, it is important not to undermine or take away this option. A system for procurement is more likely to succeed if it includes an opportunity for individuals to act in such a way should they wish to do so. Although the public appear to favour an opt-out system, the fact that they wish to be able to act altruistically may not be effectively realised via a system where the only option available is to opt out. There are two positions which altruism might take in the management of organ procurement: a strong one and a weak one. Even with the option of a combined registry it is worth considering both of these in order to ascertain the position which best describes a soft opt-out policy.

The strong altruism position is that a system for procuring cadaveric organs should rely on altruism: people give their organs because they are motivated by the needs of others. On this basis, organs cannot be taken (even if this is to benefit others); they should be donated to the health service for no reward. The strong altruism position appears to require an opt-in system such as the one which presently operates in the UK, permitting individuals to pledge their organs

⁸⁰ Evidence from the deliberative events showed that initially there was a poor knowledge of organ donation and options available to register one's wish to donate, via the ODR (ODT 2008, Annex J). After initial opinion was sought, workshops were carried out educating these members of the public about organ procurement and the different systems available for the provision of organs for transplant. Their opinion was then examined again. The examples expressed here correlate with the informed opinion.

in their death. However, it should be noted that under the present opt-in system, in practice, where no decision has been made on the part of the potential donor (either by informing relatives of joining the ODR/signing a donor card) the strong altruism position is not always maintained even now. As has been pointed out in this thesis, often the donation process results from the generosity of the relatives to consent to the organs being retrieved, second guessing that the deceased would have wanted to donate. To have to rely on such a tenuous assertion which is neither verifiable nor robust renders the strong altruism position as rather weak in fact.

An effective opt-in system is dependent upon the recognition of interdependence and, from this, reliance upon human cooperation and reciprocity. According to Titmuss (1997) encouraged voluntarism, as expressed through the voluntary donation of blood (or organs), is important within society as it reflects the necessity of relying upon community members for support where money is unable to buy an individual's survival (p.311). The freedom of voluntarism is the bedrock of social cohesion in a largely liberalist society; fostering an altruistic attitude and "a desire to relate to, and help strangers in one's community" (Singer 1973, p.313-4) reaffirms a sense of mutuality among members of a community (Boas 2011; Mongoven 2003)

This points towards a theory of social solidarity, which according to Prainsack and Buyx (2011) "signifies shared practices reflecting a collective commitment to carry 'costs' (financial, social, emotional or otherwise) to assist others" (p.46). What underlines this approach to organ donation is the idea that 'we are all in this together'. Altruism is an important feature of this solidaristic approach to welfare policy provision. The example of social solidarity given by NCOB (2011) is that an individual gives blood out of desire to help others, but also an awareness that at some stage they may require this act of generosity from another (p. 121). An individual may never actually donate their organs. However, it is the altruistic act of pledging which upholds the values of social solidarity, that of "shared humanity or shared life which we can contribute towards and benefit from" (NCOB 2011, p.121). The desire to behave altruistically may be borne out of the

need to act upon a feeling of empathy. It may be that one's moral, religious or cultural beliefs underpin a deep seated need or obligation to help those who are suffering.

Under our current opt-in system this altruistic behaviour extends beyond the potential organ donor. Childress (2001) points out that a relative's consent can be described as altruistic, especially if they are acting against their own wishes as a mark of respect of their deceased's known wishes. The gesture can be considered altruistic in that they do not know who the recipient(s) will be, they receive no reward for the donation, and it is a voluntarily decision intended to help others (Healy 2004, p.393). One could say this is a real act of integrity on the part of the relative, who through no fault of their own is forced into a situation where they have to provide authorisation or objection to the retrieval process. Denying families the opportunity to act altruistically would potentially be to deny this 'duty' to advocate and this could, in itself, be damaging to those wishing to do good on behalf of the deceased, or as an expression of their own feeling of empathy and desire to help.

Whilst there are benefits to this approach of viewing an organ donation policy as celebrating a collective good in which altruism and reciprocity are the driving force, when considering the impact such a policy has on so many individuals one could question whether it is fair or appropriate to place the success of this policy purely upon altruism, as happens now. Fabre (2006) argues that a much more robust and arguably more forthright approach to this area of policymaking is required. In her view individuals should be *required* to provide help to those imperilled and to those who are unable to lead a life she describes as "minimally flourishing"(p.11), borne out of a principle that individuals should strive towards a just society in which each treats the other as a moral equal deserving of equal respect. What Fabre means by minimally flourishing extends beyond basic needs and requires that individuals are able to enjoy a life in which one is able to exercise capabilities which Fabre describes as "truly human" (p.24). These include being capable of relating to other human beings, enjoying aesthetic experiences,

engaging in intellectual activities of various kinds and developing and exercising a whole range of physical and manual skills (p.24). A just society should legislate for individuals to have “prima facie rights against the comparatively well off to the material resources” they require in order to be able to live a minimally flourishing life (p.39).

When an individual is unable to exercise these capabilities, those who are able to help, whose own minimally flourishing life is not then sacrificed, should have a duty to help. Those in need have a right to receive help to protect their “fundamental interest in leading a minimally flourishing life” (p.54), and Fabre argues that this should extend beyond a moral right and be legislated for in the form of a ‘Bad Samaritan’ law (p.41)⁸¹. To ensure support is provided in circumstances which do not render one imperilled, a civilian service should be introduced to engender a sense of community in a society which is motivated by what Fabre describes as “solipsism” (p.58). She feels that rather than this be a voluntary service which instils a sense of community and civic duty, in line with those better off helping those in need to enable them to live a minimally flourishing life, this should be provided for via a moral and legal mandate because those in need *need* help and they have a *right* to this (p.58).

To apply this to organ donation and transplantation, if an individual can help another who requires a transplant to be able to exercise these capabilities, then this surely justifies an introduction of a system in which organs are routinely confiscated. This routine procurement could, on the face of this justification, be extended to live procurement⁸². However, as Fabre points out, this may then threaten one’s own life and reduce their ability of even a minimally flourishing existence. With regards to cadaveric procurement this system of justice should apply. The nature of organ failure and the need for transplantation (in most cases) to live should behave

⁸¹ To provide a duty of justice Fabre argues that there is a need to show that performing a rescue entails providing a resource and also consists of providing a scarce resource (2006, p.47) and that one has a right to it.

⁸² A thought which has been explored and argued for previously by John Harris (1975) in his famous piece ‘*The Survival Lottery*’, although the basis for his argument is strictly utilitarian based upon maximising the numbers for the greater good.

the routine practice of procurement post-mortem⁸³. This argument is based, in part, upon this: that if one agrees that tax and inheritance tax⁸⁴ should be in place in order to help those in need, then this should extend to the donation of one's organs posthumously. If one is able to provide support via taxation based on this premise (helping those in need), then equally they should help provide support to those in need by donating their healthy organs from their dead body⁸⁵. Donation of organs must meet certain conditions; these include that one must be under some sort of duty to give, but this duty does not result in a change in nature of the organ, and that transferring does not alter the personhood of the donor⁸⁶ (Fabre 2006, p.73). Cadaveric donation meets both of these conditions. Just as an individual's money will be useful even when they are dead, so their organs may very well be too. On this basis, Fabre argues that the "medically poor have a right to the organs of the medically rich" (p.79) in order to lead a minimally flourishing life. Fabre mounts an individualistic defence of the right to organs.

Such a system would require the opportunity for individuals to register a conscientious objection; however, this would have to be strong enough to "destroy one's moral identity" (2006, p.89). So one is able to exert their right to deny the use of their organs posthumously, but the reasons for this must be sufficiently compelling to warrant its acceptance. This demonstrates a collective vision that society should behave in such a way (that is to help those in need) and that if an individual chooses to opt out of this, then they must be prepared to justify this publicly and show sufficient strength of conviction and rationality to allow such a view to be upheld. Whilst Fabre says that this is not to be used to justify opt-outs as one could simply opt out for any reason

⁸³ This concerns the aspect of procurement only; this does not extend to arguing for the recipient to have a *right* to the organ.

⁸⁴ If someone has property worth more than £325000 then inheritance tax is due. The rate is 40% of anything over £325000 but can be reduced to 36% if some is donated in one's Will to charity. <https://www.gov.uk/inheritance-tax/overview>, viewed 4th March 2015.

⁸⁵ One might argue that it is unfair to allow a family member to benefit from the riches of their deceased relative when one considers that others are not lucky enough to be able to enjoy such a benefit. The same can be said of organs. Why should one benefit from the organs of the deceased when they may not need them? Consider this when there are others who are not lucky enough to be able to benefit from such a donation if they do not have a deceased relative who can donate or whose organs or tissue match preclude donation. They still require the organs of the deceased in order to lead a minimally flourishing life.

⁸⁶ As discussed on page 84, Fabre believes that once dead, one is no longer the subject of experience.

at all, the problem with this particular system is how one would go about proving that their moral identity would be destroyed, and how would the public go about proving that one's moral identity would *not* be destroyed. At which point this does then start to look more like a hard opt-out system rather than organ conscription which normally speaking denotes a compulsory enlistment, denying the opportunity for objection.

Fabre's philosophical approach is a liberal egalitarian approach to justice in a society which comprises "mere aggregations of individuals" (Dawson and Jennings 2012, p.75) and is "driven by self-interest" (Fabre 2006, p.58). The type of society which Fabre alludes to is one in which a duty of justice behoves us to act in such a way as to facilitate a minimally flourishing life for all self-respecting persons. Fabre's approach is arguably a far more demanding approach to the way society should conduct itself (and be conducted) particularly when one compares this to social solidarity where the emphasis lies in strong social bonds -working together- where the public stand up beside one another driven by "sympathy and understanding" (Dawson and Jennings 2012, p.74). This requires commitment from the public and government in terms of "standing up for, standing up with and standing up as one" (Dawson and Jennings 2012, p.74) to represent and advocate for others so that the disadvantaged are helped, in a society which recognises "firm mutuality" (p.75) and commits to a strong sense of altruism, equality, civil discourse and tolerance of views.

When considering both of these approaches to organ procurement, ultimately the end aim is not dissimilar: those who are disadvantaged due to their ESOF require help and those that are able to help *should*. However, the approach and justification for this is very different as the discourse around this discussion displays. The concern with relying upon altruism can be applied to an approach which advocates a system of social solidarity. This is because it strives for a commitment on the part of the public and policymakers to act in a given way, and to view and feel strongly towards the values which are an implicit part of solidarity, expressed as altruism,

voluntarism and standing up beside each other. However, there are two problems with this; what is required in the first instance is to bring about this approach to social life. Arguably this does exist, but it is not necessarily the overwhelming ideology which most of the public or leaders naturally feel inclined towards. It may be that society is not necessarily driven by self-interest but a mixture of apathy and a certain level of uneasiness about thinking about one's impending death, which means the opportunity to actively behave altruistically towards other members of society does not come or come to be accepted automatically. On this point, Nagel's poignant observance of the public's behaviour appears to better reflect the fact that when left to our own devices we are unlikely to turn benevolence into beneficence. He suggests that this is because altruistic motives rely on "universal recognition of the reality of other persons; altruism is not remotely universal, for we continually block the effects of that recognition" (Nagel 1970, p146). Secondly, it will not always be clear that those who opt in are acting altruistically. Again, we assume that such an act is altruistic, but there is no way of proving this. It is an idealistic notion.

However, the harsher and arguably more extreme approach to organising organ procurement which Fabre proposes could, on the face of it, demonstrate just the sort of paternalism (even though the philosophy is indeed argued in terms of an individualistic defence of rights) which has previously been attacked by the ODT (2008) and would potentially thwart such a policy from succeeding, even if the premise on which it is based is the "wish to save another's life" (Fabre 2006, p.89). The public *may* interpret such a system as policymakers taking a hard line approach based upon the assumption that left to a system which relies upon voluntarism and altruism that self-interest would prevail; subsequent reactions could result in an increased number of conscientious objections (difficult to prove as already mentioned) which could then thwart any real success in terms of increasing the number of organs procured. In a society where individuals do wish their voices to be actively listened to whether this hard mandatory approach to healthcare provision which Fabre recommends would be condoned by the public is a very serious contention, and one which might ultimately undo the good which it aspires to achieve.

4.6: Incorporating Altruism into an Organ Procurement Policy.

From a practical viewpoint, the fact is that this opt-in system, even with the recommendations instigated by the ODT, is still not producing enough organs to treat the 7000 individuals awaiting a transplant. The number of donors has increased by 50% since 2008; however, this still falls far short of those countries operating under an opt-out system for organ procurement. In the UK we are practising under a system which is utterly reliant upon altruism in order to obtain a resource needed for prolonging people's lives. One could contend that this is unusual, basing this upon the fact that in other areas of healthcare we just do not do this. Healthcare is funded, in part, through public taxation. The value of the good we can do means that we do not think it is appropriate to fund healthcare by relying on the generosity and altruism of our fellow citizens. The body and organs are observed with a special importance; this concept naturally serves to differentiate organs from money in terms of appropriation for the good of others. Rationalising the routine salvaging of organs for the benefit of others might appear to be both logical and beneficial for society as a whole when we consider the good it can do. Despite this, our relationship with our bodies presents a problem in relation to routinely using the dead for the good of the living.

What is required is a calculation of different 'needs' in formulating a policy which will ultimately lead to the same end as that put forward by Fabre and those advocating a solidaristic approach to welfare. This will necessitate an element of paternalism on the part of policymakers. However, arguably this is their role in society. Scott and Seglow (2007) suggest that where the needs of those who are vulnerable are great enough, there is a moral requirement for the focus to transfer over from the agent to the recipient (p.89). They argue that, "it is too optimistic...for the welfare edifice to be built exclusively on foundations of altruistic fellow feeling. There are also important duties of social justice that citizens ought to meet, whether they are motivated to do so or not" (p.90).

The aim is to maximise the good for the greatest number within a pluralist society whose values and principles may differ. The public's intrinsic part in the success of the policy means that planning has to incorporate both individual needs *and* community needs (Upshur 2002). These can be expressed in the form of 'rights', but essentially serve as interests which each feels they require in order to live what perhaps Fabre describes as a minimally flourishing life. However, a delicate balance is required and careful planning which accommodates the ability to assert one's autonomous choice and act in a way which reflects the public's desire to help others in need⁸⁷.

Given the difference in numbers between those who opt in and those who support organ donation, it would seem that there are people who do not object to their organs being used but who, for whatever reason, are not sufficiently motivated by the good of others to actually do anything about opting in. The contrasting statistical picture suggests that there remains a strong level of apathy in terms of actively showing willingness to donate. Under an opt-in system organs from these people may be dismissed from use if there is no evidence of their actively opting in. However, it is not clear why it would be wrong to use them, given that the people whose organs they belong to, in accordance with evidence of favourable public opinion, may very well not object⁸⁸. A person in this category might take the position that they do not mind their organs being used, but they are not sufficiently motivated towards pledging their organs to the health service for therapeutic purposes.

A soft opt-out system allows for these people's organs to be used, whilst at the same time providing those who would not wish to donate the opportunity to register such an objection. What is apparent with this system is that it relies quite heavily upon the assumption that favourable opinion polls reflect the majority opinion in this country. This may not be the case. Coupled with this, there is a question mark over whether a description of these acts as altruistic is

⁸⁷ This is something often observed when charity events are organised which show considerable gestures of kindness and financial aid on the part of the public.

⁸⁸ Especially when one considers that this reflects current practice.

entirely accurate or whether it is in fact misleading and potentially manipulative. Wilkinson (2003) and Gerrand (1994) remark that in most instances we cannot be sure that one's motivation to donate really is altruistic⁸⁹. The timing of the act renders proving this almost impossible but for corroboration on the relatives' part. This seems to be a more difficult issue to reconcile if we have to consider organ donation as an altruistic act or we assume the strong altruistic position. One could argue that under the current opt-in system we presuppose that most individuals are altruistic and are willing to give. With either system there is an element of uncertainty and reliance upon an assumption over a person's wishes.

Proving one's intentions in respect of this would be a particularly perplexing task which, if required, may result in the downfall of a system reliant upon the strong altruistic position. The goal of the policy I am advocating is to increase the number of organs for transplant. Providing the opportunity for individuals to express their autonomous choice in respect of this is likely to increase the success in terms of achieving its aim, or at least reduce the likelihood of dissent over and above those that would wish to object for personal reasons. Whether an individual's decision not to object to procurement posthumously is altruistic does not really matter particularly. The motivation is not the driver, maximising utility is. Therefore, one's motives are of little consequence or value in such a policy; what is important is facilitating the opportunity to explicitly pledge. The weak altruism position would facilitate this.

The weak altruism position fits a culture which would support providing individuals with the option of giving one's organs altruistically. However, this system does not require that this is the only way in which organs can be obtained. A key difference between the strong and the weak altruism position is the position altruism takes in the rationale for the policy. So, with the strong altruism position the fundamental ethos underpinning a policy for organ procurement would be

⁸⁹ A point made on page 115.

that organs should be given and never taken. The weak altruism position permits organs to be taken unless the person objects.

An example of this type of altruistic position might be this: I own a piece of land which a public bridleway runs through, and on which I also have a number of apple trees. I am not against my apples being picked by passers-by as I am unable to pick them all, all of the time, and the remaining apples on my trees would rot if not picked. However, I am not motivated to pick these and take them to the local children's home. To observe consistent levels of verbal support for organ donation from the public, yet see so few convert to actual pledges, would appear to strike a very similar example of not being against organs being taken to help others, but not feeling motivated enough to actively pledge them. A system which incorporates a weak altruism position would seem to reflect this and, I would argue, appears to fit with many members of the public's views towards their organs being used posthumously.

The advantage of the weak altruism position is that it will readily accommodate those who wish to be altruistic. Facilitating this is congruent with public opinion, which refers to the importance of having the opportunity to decide whether to be altruistic. However, what distinguishes this particular position from the strong one is that a system based upon weak altruism does not exclusively rely upon philanthropy for the provision of organs. It enables one to be altruistic if they so wish, but defaults to a publicly favoured system in which organs will be routinely procured unless the individual opts out (incorporating the value of asserting autonomy) or the relatives of the deceased initiate a refusal.

According to Healy (2004) an individual's capacity to behave altruistically and the social organisation of organ procurement are not mutually exclusive; social organisations and policymakers facilitate the process of 'altruism' through their procurement policy. However, Scott and Seglow (2007) question whether genuine altruism can exist when altruism is configured into a policy and legislated for, thus "regularised" and "enforced" (p.89). Whilst on the one hand an opt-

out allows people who wish to be altruistic the opportunity to do so, conversely, a concern which has been raised is whether an opt-out policy could ultimately undermine the opportunity to behave altruistically if it is all but forced upon society, even where there is the option to opt out (ODT 2008). In relation to this, Keyserlingk (1990) refers to the potential for 'grudging' altruism to exist under an opt-out policy, felt on the part of those who do not wish to be seen to be selfish and therefore do not object to their organs being retrieved, or 'inadvertent altruism' by those who are not aware of the transplant policy (p.1006).

Whilst these forms of behaviour which Keyserlingk refers to may exist, these are not forms of altruism. It may be that the public choose not to opt out through ignorance; this cannot then be described as 'inadvertent' altruism. One may not be aware of the opt-out law and in death, unknown to them, their organs are taken. This has nothing to do with altruism, as if they are unaware of the policy how can they be motivated in any way to object or feel willing to accept the default position? Similarly, an individual may, through guilt or for reasons motivated by self-interest, choose not to opt out; however, rather than conforming to 'grudging' altruism this appears to resonate more closely with egoism.

With regards to the lack of awareness of the policy, this could indeed be a problem, especially if it does result in people's organs being retrieved who would otherwise have objected. However, as has previously been mentioned, this is a problem which is also pertinent to the present system. One way in which to tackle this issue would be to introduce a strong publicity campaign both in the consultation period and then around the implementation of the policy. This will be discussed in more detail in chapter 5. The point made around motives has been discussed, but suffice to say, under a system which takes a weak altruistic position whether someone does behave out of altruism or not is not an issue.

Leading on from this there is also the potential problem that opt-out may not actually facilitate the opportunity for those who wish to behave altruistically and pledge their organs. This

issue could be circumvented if my not opting out is motivated by my desire to donate and this constitutes an altruistic act on my part; at which point an opt-out system is not incompatible with altruism, albeit as a passive expression of the 'act'. There are examples of enabling individuals to demonstrate an altruistic gesture without their actually having to committing an act. For instance, there are certain organisations which will donate to a charitable organisation on the behalf of its members unless the person ticks a box or registers some form of objection to their contributing in such a way. Arguably, by omitting to do this they are contributing to the altruistic act⁹⁰. However, under an opt-out system, I have not acted in any way at all if I do not opt out, as not opting out is not something which I do and so, at the very least, I am unable to act altruistically in an opt-out system. I am merely able to omit from not objecting. When looked at it in this way, it seems difficult to accept that opt-out allows for one to act altruistically; one could argue that it actually deprives the public the opportunity of acting in such a way. Two potential issues emerge from this.

Firstly, an opt-out system might preclude a place for "pure altruists" wishing to play an active role in improving other people's lives and not "just being observers of them" (Scott and Seglow 2007 p.97). One might contend that accommodating those who wish to explicitly demonstrate their altruistic nature is to pander to some form of moral vanity or egoism on their behalf. However, such an accusation would be to overlook an individual's strong moral (or religious) integrity⁹¹ towards a duty of rescue. It would seem that both the opt-out system does and the current opt-in system *may* fail these individuals in terms of allowing their wish to act altruistically to take precedence.

⁹⁰ Although one could say that they are simply endorsing this rather than acting altruistically, as it is the organisation which is behaving in such a way.

⁹¹ This could be a conviction along the lines of that which Fabre describes when she discusses conscientious objection. For the example referred to here, this could be a strongly felt conviction which is as powerful to the individual as that which would compel one to object to donation (and be upheld in her system). Such interests have also been discussed in chapter 3 with particular reference to McGuinness and Brazier's (2008) points.

Secondly, whilst it might be justifiable to invoke a welfare policy which places high priority on meeting the needs of the vulnerable, and whilst an opt-out system may succeed in respect of this, such a system appears to crowd out altruism rather than incorporate it (Scott and Seglow 2007). This issue appears to have been acknowledged in Belgium; in an attempt to circumvent it legislators have described their organ procurement policy as representing “collective altruism” (Roels and Michielsen 1991, p.1473). However, whilst collective altruism may exist this may not actually be an appropriate example of it. If a town is subject to severe flooding and the residents from a neighbouring village help accommodate the residents of the houses that have been flooded, then this might be described as collective altruism. However, this depiction of collective altruism does not seem to mirror the term ‘collective altruism’ as used to describe the Belgian opt-out system or the values underpinning it. The Belgian system does enable personal acts of altruism, and the measures taken might appear to be a response to a need that has arisen in the same way as the need arises to support those whose houses have been flooded. However, rather than a spontaneous act of altruism or perhaps solidarity that the example illustrates, the Belgian government has legislated for this by prescribing a specific system to address the support required, as opposed to relying on spontaneous acts of altruism which perhaps mirrors the current opt-in system more accurately. What the Belgian system might be better described as advocating is one of collective beneficence translated from the public’s benevolent feelings about organ procurement.

In response to the first issue raised relating to being able to actively act altruistically, it is possible to facilitate this by incorporating a combined registry into the soft opt-out policy, such as the system which is employed in Belgium. Such a policy, according to Michielsen (1996) acknowledges that “...absolute priority is given to the will of the deceased” (p.663). It is important to stress that this registry acts to respect and protect an individual’s wishes if they have been registered. The registered decision cannot be overridden by anybody, as can happen under the current opt-in system in this country. The system which Belgium has introduced is the perfect

example of the compromise which policymakers have been faced with and have facilitated in order to meet the needs of all of those involved in a transplant policy. This policy seeks to maximise utility for all concerned under the constraints which such a policy is naturally faced with in terms of the small number of appropriate deaths which occur.

4.7: Conclusion.

Trying to implement a policy which can respect individualism, show deference towards the altruism involved in the act of donation, and meet the needs of the rising volume of individuals in need of a transplant appears to be a challenge which pulls policymakers in three different directions. Cronin and Harris (2010) point out:

...this powerfully draws attention to the sorts of consequences and (possibly insurmountable) difficulties that arise when a system of welfare regulation, which has at its core, principles of equity and impartial justice, is governed by a model of individual choice, authorisation and autonomy, which inherently relies upon altruism (p.630).

The current opt-in policy is underpinned by the right to self-determination and is totally reliant upon altruism for its success. However, I would suggest that when we consider the main aim of such a policy: to save and enhance the quality of the lives of those affected by ESOF, it would be reasonable to perhaps re-consider the balance of values which should drive such a policy. Altruism is an important feature of this policy; however, a more forthright approach is required by policymakers to maximise the welfare needs of a growing number of individuals who are dependent upon a transplant for their survival. A soft opt-out system with a combined registry demonstrates a positive attempt to improve the health and welfare of a growing population of those affected by ESOF whilst accommodating respect for autonomy, thus enabling those wishing to make an altruistic pledge the opportunity to do so.

In view of this particular policy, when calculating a successful strategy for maximising utility what needs be factored in is the public's role in achieving this. Success rests largely on public favour; therefore their opinion, as well as their opportunity to assert their autonomy, must be given careful attention. A system which does not facilitate this runs the risk of undermining public trust. The consequences of this could be very damaging. This will be the focus of the next chapter.

Chapter 5: Public Trust and Organ Donation.

5.1: Introduction.

Trust is central to the success of the NHS. The public need to trust NHS HCPs to do their job competently. They also need to have confidence in policymakers to structure policy provision proficiently around care and treatment. When incidents occur which call into question the competence of clinicians or introduce doubts in the minds of the public as to the credibility of institutions, the organisation itself, and those who manage the organisation, the consequences can be pervasive and enduring.

This thesis has explicitly argued for the introduction of an opt-out system with a combined registry. This is underpinned by the notion that providing as many organs as possible to help a growing number of people in ESOF will maximise welfare for the majority, as the effects of ESOF are far reaching, affecting family members, partners, and friends. It also has a deepening impact upon society in economic terms. A system which can provide a large number of organs will help to reduce the transplant waiting list, and this will have a positive impact upon individuals and society as a whole. When calculating the risks and benefits of a soft opt-out system reliance on the public remains at a premium for such a policy to work. Concerns around state ownership and negation of the right to self-determination in the form of positive consent have raised doubts as to whether such a system for donation can be trusted. Too much dissent could lead to a decrease in the number of organs retrieved. The public need to have confidence in the system in order for it to have any real chance of success.

Introducing a soft opt-out system could demonstrate an assumption on the part of policymakers that the public is well informed on the subject of organ donation, and that individuals will be forthcoming in registering their objection to donation. However, these numbers might be more forthcoming than desired under such a system if people fear that they may not receive such aggressive treatment in a life or death situation. Under such circumstances it might

be easier to register an objection than risk such a situation occurring (Siminoff and Mercer 2001, p.381). This demonstrates a sense of distrust in the healthcare system at an interpersonal level. Issues centring on organ retention without consent have been particularly problematic in the UK (DH 2001; Kennedy et al. 2000; Redfern et al. 2001), so such concern about distrust requires cautious consideration.

In relation to the issue of trust, the concerns expressed by the ODT (2008) in their report, *'The Potential Impact of an Opt-Out System in the United Kingdom'*, included:

- “The clinical Working group heard persuasive arguments from health professionals about **the potentially negative implications for clinical practice, especially the potential to damage the vital relationship of trust** between clinicians caring for people at the end of life, their patients and their families” (p.4).
- Setting up a register which would ‘command the trust of professionals and members of the public’ (p.4) would be expensive and complex.
- “**The public have become less trusting** and more questioning of authority over recent years. Trust, however, is key to the success of the organ donation system in the UK. If public trust is shaken, organ donor numbers are likely to fall rapidly and could take many years to recover. The need to maintain the confidence of the public has been a key consideration in the Taskforce’s deliberations” (p.9).

These concerns highlight the potential impact an opt-out system could have on the public’s trust, and the consequences of this in terms of decreasing numbers of donors. These issues need to be addressed in order to provide a balanced argument for the introduction of a soft opt-out system with a combined registry. This chapter will address this. The importance of trust will be discussed initially. From here analysis of previous events which have resulted in a loss of public trust will then follow to demonstrate the lasting impact this can have upon the

public's willingness to behave in a supportive manner. Understanding the concerns of the public provides an insight into this. For a soft opt-out system with a combined registry to have a real chance of success these concerns must be addressed and then, where possible, resolved.

5.2: The Importance of Trust.

Trust may have an intrinsic part to play in a functioning society; however, often it is difficult to actually know what trust is. Its meaning and the extent of its 'role' can differ depending upon the context of the situation or relationship. Kohn (2008a) proposes that trust is "an expectation, or a disposition to expect, that another party will act in one's interests" (p.9), the suggestion being that trust is often motivated by self-interest (Kohn 2008b). Kohn's description of trust also demonstrates a confidence in another, especially when there is a lack of certainty about another's future actions (Gilson 2003; O'Neill 2002). Often a decision whether to trust involves taking a risk. Weighing up whether to trust may include one's deliberation over what the risk of being trusting will be. On this point, Giddens (1990) refers to trust and risk being intertwined (p.35). It is frequently, although not exclusively, a two way process which can shape one's behaviour towards others. Giddens (1991) states that trust involves "the vesting of confidence in persons or abstract systems, made on the basis of a 'leap of faith' which brackets ignorance or lack of information" (p.244), denoting an air of vulnerability.

Trust can be quite specific, for instance, trusting a person to do something. This is usually restricted to a particular agreement, event or a transaction. However, trust can also be understood in a broader sense, especially when it does not relate to a specific set of circumstances. If an individual expresses trust in another to care for them in later life, this is a broader sense of trust. This denotes trustworthiness: "knowledge that the actor is trustworthy" (Hardin 2006, p.2) in respect of what it is they are being judged for their trustworthiness about on the part of the one trusted. Such reliance upon another *can* be an expression of 'absolute confidence' (Horsburgh 1960, p.343) in the individual to undertake this responsibility; however, it

should not be assumed that this *automatically* equates to unwavering confidence. One may weigh up the risks associated with entrusting their care to another and, on balance, decide that this is probably the best course of action to take.

Consider situations where trust is a prominent feature of decision-making. For instance, if A wishes to be an organ donor when she dies, she might ask her friend B to corroborate this decision, should the situation arise whereby he is able to advocate for her. This shows a level of trust on A's part towards B to fulfil her wish when she is unable to. In response to this request, if B expresses an air of revulsion at the thought of his organs being taken post-mortem, A might then make B promise that he will consent to her organs being donated when she dies. In doing this, A appears to be demonstrating a level of uncertainty as to whether B will do this, thus questioning whether he is trustworthy enough without adding in the obligation incurred via the promise. A needs to trust B enough to rely on him to undertake this responsibility; however, this example shows that one's confidence in the other shapes the amount of trust one feels towards them. What she is asking B to do is follow the promise, adding in an extra level of obligation to act on her wishes. A may have enough confidence in B to undertake smaller more practical tasks; however, fulfilling her strongly held autonomous wish to donate may leave A in some doubt as to whether B will act for her appropriately. This represents a level of mistrust on A's part that B will fulfil her expectations in a specified situation, although she may trust him in a broader sense.

When considering public trust in government what seems to resonate closely is the need for *confidence* in government, even if it is proportional. Individuals may need to feel sufficient belief or confidence in a political party that they will serve some of their interests, without relying strongly upon them to meet every one of their expectations and needs. This perhaps denotes trust in a broader sense- a general sense of confidence. A further example of trust is that which occurs between a shopkeeper and a customer. The shopkeeper has sufficient confidence in his customers to buy the products on offer and not simply take them. The customers trust that the

shopkeeper will sell the product he is advertising at a competitive price so as not to exploit the customer. This highlights trust in a specified sense. On the face of it, these different examples show that trust incorporates a multiplicity of meanings which can create “a measure of conceptual confusion, because confidence, reliability, faith, and trust are often used as synonyms” (Khodyakov 2007, p. 116). However, examining the properties which trust comprises in all of these scenarios demonstrates that whilst trust can be relative or absolute, the common denominator is confidence and reliance. Measures for these are difficult to quantify or qualify on a general basis as they are, more often than not, context specific, and therefore require consideration which is appropriate to the circumstances. So, for instance, gaining confidence to trust may require evidence, such as on the part of government, to gain the public’s trust, or an added obligation such as a promise to fulfil a request.

It is important to consider what human needs the concept of trust responds to (Simpson 2012, p.551). The examples show that trust responds to *our* needs and interests, representing a strong link with self-interest and cooperation. Will A’s interests be met by B, will the political party act in the public’s interests, and will the shopkeeper trade fairly and the customer reciprocate by buying the goods? These reflect a concern which is motivated by one’s own interests. Whilst self-interest might appear to be limiting in nature, and restrictive or short-sighted in terms of cooperation, this need not be the case. Trusting one’s neighbour may spread to building trust in a local community, so this becomes trusting *one’s* neighbour rather than trusting *my* neighbour. One person’s interests are often shared by others; looking after another’s interests can have reciprocal benefits. This can then spread across a community, representing a more diffuse trust. Neighbourhood watch schemes are a good example of establishing trust between members of a community (Perceptive Insight 2012); they can help provide a stronger community voice and make the community area a safer place (Slatter 2009). It is in the interests of the individual members of the community to build relationships with others from within that community in order to establish a safer area which each can then benefit from. This initially

entails trust and confidence in others that they have the same concerns and wish to do something to alleviate these, which may require group action as the problems cannot be individually resolved. Kohn (2008b) extends this to trusting others from different cultures- something which may well occur within local communities. Understanding and empathising with others from within a community can help towards finding a way of easing commonly felt difficulties. This may result in trust being the reward for self-interest 'properly understood' (Kohn 2008b, p. 29). One might also argue that neighbourhood watch is a result of precisely the opposite of trust: distrust, which may be felt by some towards other members of a community, or perhaps towards outsiders driving the perceived need for such a scheme to exist.

Horsburgh (1960) suggests that trust shows one's moral support towards another. Again, what appears to link the more abstract type of trust and a more intimate level of trust between individuals is reliance and confidence. The example of neighbourhood trust and trust between A and B also demonstrates vulnerability and taking a risk when deciding whether to trust. The weight of vulnerability and risk will differ according to the situation which the decision revolves around. However, vulnerability and risk are not always felt when one expresses trust. If A trusts that the concert for which she has bought tickets will take place, she is reliant on the organiser to act on their intention to perform at this given time; however, she is not taking any risks (unless the money she has paid for the tickets is non-refundable) and the circumstances do not render A vulnerable.

The different examples typify Simpson's (2012) view that "there is no single phenomenon that 'trust' refers to, nor that our folk concept has determinate rules to use" (p.551). It is commonly a tacit feature of many relationships, both personal and professional, and it strengthens the opportunity for a society to function, with the public entrusting their interests to government (Nacol 2011). Its importance and role is identified in theoretical discussions; however, it is not often actively invoked or referred to either explicitly or indirectly in everyday

practice until something goes awry. Nacol (2011) suggests that it is perhaps easier to understand trust and its importance retroactively: “We are able to understand the substance of trust, and the kinds of obligations, bonds and security it entails, in those moments when it is destroyed” (p.593). This then leads to a revision of the attitude the trusting party has towards those whose trustworthiness is under scrutiny. From this observation, one could argue that its role may not really be appreciated until it is lost. It prompts many philosophical questions due to the different nuances which it contains and, as Simpson suggests, “because it is so fertile a perspective from which to approach different topics related to the way we live together” (2012, p.566). It is important to consider its value in relation to different situations, and how it can contribute towards a successful organ donation policy.

Trust is often implicit between partners, family members and close friends; it helps to form and maintain meaningful relationships. This type of interpersonal trust has been described by Khodyakov (2007) as ‘thick trust’ (p.120), one that builds upon the basic trust which is experienced by children as they grow up and settle into a social setting, and which gradually facilitates social interaction as individuals mature and adapt to their personal social circumstances. Thick trust arises out of personal familiarity: feeling familiar about another individual to trust their competence in what they do. This may develop as one witnesses a display of moral standards which one might consider congruent with their own set of values, or who can learn from the standards which they are brought up to share (Kohn 2008a). It assumes trustworthiness, based upon characteristics such as benevolence and integrity (Skinner et al. 2014, p.208).

In the context of healthcare, trust has both intrinsic worth as well as instrumental value. Hall (2005) argues that trust has intrinsic value as it is at the “core of emotional and interpersonal aspects” of the clinician-patient relationship (p.156), enabling the relationship to have meaning, importance and substance (Hall et al. 2001, p.613). Trust is also instrumental in facilitating

cooperation. From an interpersonal perspective this is pertinent when one considers the relationship between the clinician and the patient. Trust can facilitate the sharing of information-vital for appropriate treatment and care planning; it can promote a feeling of safety which can result in compliance. It can expedite treatment, but is also the by-product of treatment.

Trust in the clinician-patient relationship can be strong, but this is partly owing to the vulnerability inherent in this relationship. The patient's psychological state demonstrates an acceptance of vulnerability based upon positive expectations of the intentions or behaviour of the clinician (Rousseau et al. 1998). This displays a belief that, as a professional, the clinician is expected to be competent (Skinner et al. 2014, p.208), honest, and able to demonstrate respect for the patient, in terms of maintaining confidentiality and remaining faithful to the patient's needs, acting to benefit them wherever possible (Hall 2002). In relation to this, Kohn (2008a) refers to 'thin trust' which is based on "reputations, norms, and assessments based on appearance and demeanour" (p.89). This is coupled with an emotional element of the relationship, with the patient assuming that the motivations of the clinician are 'benevolent and caring' (Hall 2002, p.474). The phrase 'leap of faith' (Giddens 1991, p. 244) appears a particularly poignant description when contemplating the patient's (and perhaps this extends to society's) level of expectation in relation to the clinician's role⁹². It also demonstrates the element of risk involved in placing trust in another to behave in the way you would wish them to, in so far as what is expected of them. The clinician correspondingly needs to trust that their patients will comply with the treatment prescribed. This reflects the need for trustworthiness.

Trust is an important feature in the policy and practice of organ donation and transplantation, particularly since at the present time only human organs can be used for transplant. Society must rely upon its own citizens to be willing to help alleviate another's (often a

⁹² In professional relationships, such as that of the clinician-patient, O'Neill (2002) argues that trust is context specific; it does not extend to trusting the clinician in anything other than providing clinical advice and treatment.

stranger's) plight. The public also need to trust that those involved in organ donation and transplantation will act professionally, to the same level that is expected of the clinician in terms of competency, respecting wishes, acting in their best interests and maintaining confidentiality. This professionalism extends to those involved in the donor process, the transplant and the testing of the organs for safe use. This level of trust generates risks and requires the clinical personnel to be trustworthy. Whilst the aforementioned thick trust is useful for interpersonal relations, it is thin trust which the public, as a collective, rely on and act in accordance with when dealing with people to whom they do not feel personally familiar. It extends beyond personal boundaries (Kohn 2008a, p.89) and is often taken on reputation or others' experiences whose opinions the individual may trust (invoking thick trust).

Under the current opt-in system this level of trust, and with it risk and trustworthiness, extends beyond the clinicians (and the general public) to the potential donor's family/ close friends, who may be asked to corroborate the deceased's wishes or advocate for them. The individual needs to be able to trust that their family member will act in accordance with their wishes should the situation arise. Again, this adheres more closely to thick trust. Thin trust can be applied to the potential transplant recipient having confidence that the transplant process is successful, and this will normally be via reputation and data to support its success in terms of graft survival. One can see from this overview that in relation to organ donation and transplantation trust incorporates a number of features (Yamagishi 2011).

When looking at policy provision, it is collective trust which plays a part here. The public need to have confidence in policymakers to devise policies which are for the good of society as a whole. Within healthcare the public need to trust those responsible for organising and managing the NHS to uphold its values: to meet the needs of all and to provide treatment, free at the point of delivery, based on clinical need, not the ability to pay (NHS 2014). The relationship between the public and government denotes a political trust which is a secondary symptom of, but not directly

related to the social trust which occurs between individuals (Hardin 2006, p.2). The expectations are quite different, more abstract and diffuse than those between individuals, even individuals who might be estranged. Gilson (2003) describes this situation between government and society as one in which the institution acts “not only as a guarantor of inter-personal trust, but also as the foundation of trust as a property of the overall social system, playing a critical role in the preservation of social order” (p.1457).

The public want a government to represent them in the sense of serving their interests (Hardin 2006, p.15). This invokes a sense of ‘active trust’, capturing the creative and processed aspect of trust that implies stepping into the unknown in the face of irreducible social uncertainty and vulnerability (Giddens, 1994). It incorporates a reflexive process of trust development (Skinner et al. 2014), which requires continuous communication and openness in order to result in a stable or, at least, continuous relationship (Möllering 2005, p.18). This type of trust is more closely related to one having confidence in government. Confidence is contingent upon the factors which relate closely to attributes found in an interpersonal context: competence, honesty, openness. However, because of the impersonal nature of the ‘relationship’ between individuals and policymakers (in the main) the definition of trust will not equate to that which one may describe in an interpersonal relationship, especially in terms of the two way beneficial process which interpersonal trust appears to involve. The asymmetry which this ‘relationship’ represents renders the public vulnerable due to power imbalances between public and the government.

Policymakers assume a great deal of power and responsibility when legislating and providing policies which should benefit a pluralist society. This presents certain hazards. Acknowledging that those who legislate and those who have executive power are often distinct, Locke (1690) described a ‘prerogative’ on the part of the executive, to have at their discretion the power to act for the good of society where the “municipal law has given no direction” (II §159). This recognises that there are many things that the legislators cannot “foresee, and provide by

laws, for all that may be useful to the community (II §159) “because also it is impossible to foresee, and so by laws to provide for all accidents and necessities that may concern the public...” (II §160). For members of the public trust may be the best way to deal with this uncertainty; however, it does carry a set of accompanying risks which result from entrusting what Nacol describes as ‘unchecked power’ (2011, p.593).

Reliance upon the public to generate organs for transplant means that policymakers need to garner public support. Trustworthiness, which can be expressed through institutions, practices and actions deemed to be reasonable for others to trust (O’Neill 2002, p.149), will help to achieve this, in part, as the public are more likely to be cooperative, contributing towards a successful policy. Such trust is demonstrated through the (general) acceptance of laws, regulations and codes of conduct that are in place to ensure that the conduct of the public (including policymakers) towards their fellow citizens is fair in both personal and professional dealings. Providing a clear sense of justice can help to build trust alongside sanctions for bad behaviour (Gilson 2003).

An important consideration when planning for an organ donation policy is that from the public’s perspective it is also about what motivates them to act. Individuals’ interests and why trust is important to them needs to be understood and taken as a starting point when looking at introducing a policy which will require their cooperation. Individuals tend to pursue interests which benefit them; cooperation is not a given (Kohn 2008a, p.24). Health and welfare benefits individuals and is therefore valued by the public (Gilson 2003). Citizens also need to trust each other, since this does not simply concern the policymakers benefiting them, but also that individuals will be willing to help (Parks et al. 2013). Understanding and empathising with a situation seems to prompt the public to behave kindly towards others⁹³. Reciprocity may act as

⁹³Examples of this are represented in Titmuss’ work and in expressions of willingness to help, as presented in the chapter 4 when discussing altruism.

the motivator for people to cooperate as such a system enables individuals to “contribute to the social good” (Gilson 2003, p.1461) which they benefit from.

There will naturally be individuals who will digress from the policy; however, as long as there is support or acceptance from the majority then these digressions can be accepted as part of the social fabric. Anticipating digressions, both on the part of the public, and from the public’s perspective on the part of the policymakers, shows that whilst we rely of trust we are also driven to act because of our mistrust. Self-interest and justice and fairness may prompt us to harbour a feeling of mistrust; this needs to be managed and reconciled as best possible for us to feel confident in allowing ourselves to build a trusting relationship with others.

Political trust or distrust develops secondary to the way in which certain political institutions perform, in general terms (Hardin 2006, p.3). When members of society feel that their interests are not being represented then this may lead to a feeling of distrust. Frequent disappointments and breaches of this trust serve to dent the confidence the public may have in government. Often these concerns are specific to different groups within society. An example of such a group might be ethnic minorities, who often feel segregated from the rest of ‘society’ and marginalised (Platt 2014). This can result from their needs and concerns not being appropriately addressed by government, institutions and authoritative figures. The result of this can be that groups form which trust each other (sometimes) but not others. “One section of a population finds grounds to agree, to cooperate, and to bond, by turning against another part of what might otherwise become a community” (Kohn 2008a p.19). The feeling of segregation leads to a lack of trust in authority. Behaviour can become fractious and antagonistic. General distrust in government may then permeate to policymakers and those responsible for delivering the care in accordance with policy provision. This may lead to a feeling of mistrust towards healthcare personnel as well as policymakers.

Evidence shows that within the donation and transplantation community, Black, Asian and some Ethnic Minority (BAME) communities are less likely to join the ODR or consent to their deceased relative's organs to be retrieved when compared with the rest of the population⁹⁴ (NHSBT 2014b). However, a significant percentage of those waiting for a renal transplant come from these communities (especially the Asian community) (NHSBT 2014b). One of the points raised by Cultural Working Group involved in the ODT's deliberative events was that the white population enjoy 'social resources' over time and are able to integrate organ donation more readily into their 'lifestyle' and general mind-set/way of thinking (ODT 2008, Annex M). Those from minorities do not enjoy the same level of resources and are therefore less able to integrate donation into their lives as readily. This has left them feeling socially isolated (ODT 2008, Annex M). This is coupled with the lack of open discussion around organ donation to share views and perceptions and to reassure widely held fears from all groups. One participant stated that policymakers need to "seriously engage with a political identity addressing concerns of trust, alienation and equality within the whole medical system, and not just organ donation, for those from an African Caribbean ethnic background" (ODT 2008, Annex M, p.7).

Ultimately, unless this mistrusting attitude is resolved the people who will most likely suffer are the citizens themselves. In light of this, it is important to consider the potential impact of an opt-out system on BAME communities. It *could* improve the number of organs available for racial minority groups; however, it *might* also cause a 'backlash' resulting from this mistrust, coupled with the fear of the State taking ownership of their organs; this might lead to increased refusals, and consequently fewer organs for ethnic minorities (Radcliffe Richards 2012).

Hall (2002) suggests that a breach of confidence which has a more calculative basis may result in disappointment when one's expected results are not achieved (p.494). However,

⁹⁴ Figures corroborating this statement can be found at: http://www.organdonation.nhs.uk/how_to_become_a_donor/black_and_other_minority_ethnic_communities/. This point regarding ethnic minorities and trust has been referred to in the previous chapter, on pages 102- 103.

confidence in the system may be easier to reconcile or less keenly felt as a result of being less intensive or personally felt. An example of this is the incident which was first brought to light in 2010; organs were mistakenly removed from deceased individuals without their consent after a data-handling error by the NHS. This error meant that 793,407 people on the UK donor register may have had their wishes about the use of organs for transplant wrongly recorded (Duff 2010, p.20). Despite information around this being negatively reported by the media⁹⁵, there was a subsequent rise in ODR registrations (NHSBT 2014c; 23red 2014, p.14).

5.3: Consequences of a Breach of Trust.

Breaches of trust can have a deleterious effect and a damaging impact upon relationships, both at a personal and professional level. The emotional context of the clinician-patient relationship, where vulnerability is an important feature, can lead to an increased threshold for forgiveness and patience on the part of the public towards clinical personnel. There is evidence of lenience in judicial decisions involving clinicians who have behaved negligently (Hall 2005). It is in both parties' interests to recover the trust. However, once trust is breached and the clinician is insufficiently repentant then the patient may react more negatively.

In the context of organ donation and transplantation, when events occur which may tarnish the reputation of donor and transplant teams a level of distrust can then occur, whereby the individual may have confidence in a negative expectation about the transplant team resulting in one not taking the risk of placing themselves in a vulnerable situation (Skinner et al. 2014, p.208). This can be damaging to the individual in need of a transplant, but this can be more pervasive in terms of its impact upon a general feeling of mistrust towards those involved in organ donation and transplantation, that they may not be honest or competent in their ability to act in the best interest of the those they are caring for. The consequence of mistakes or poor behaviour on the part of clinicians can have a more wide-reaching effect; this can result in strong public

⁹⁵ An example of one report is the BBC's article presented in 2010. This link provides the story as presented: <http://news.bbc.co.uk/1/hi/uk/8613791.stm>

reactions in response to an intense feeling of betrayal (Hall 2002, p.495). Kohn (2008a) suggests that this is because the public are “attuned to fairness” (p.43) and respond vehemently when they believe that poor or unfair conduct has occurred which may affect others.

There is historical evidence to support Kohn’s assertion in respect of this. What Richardson (2001) refers to as the “the prevailing belief in the existence of a strong tie between body and personality/soul for an undefined period of time after death” (p.7) has played a significant part historically in shaping the public’s trust and behaviour towards policymakers governing the treatment of corpses. The increased incidences of body snatching and murder which occurred in the 16th century led to public outcry (Richardson 2001), forcing a revision of the statutory provision of bodies for anatomical examination. The Anatomy Act 1832 was supposed to quell the fear and mistrust the public felt and remonstrated against in relation to such morally despicable behaviour. However, the Act’s provisions were of little comfort to poorer members of the public. As discussed in chapter 2⁹⁶, a system of presumed consent to procurement of the body came into practice (MacDonald 2009, p. 388). Whilst the public’s wishes were meant to be respected, in practice their wishes were never sought nor observed (Richardson 2001). This only fuelled the sense of betrayal and mistrust further and, according to Richardson, this has never been fully resolved.

Within the last fifteen years, the discovery and subsequent scrutiny over the conduct of clinical personnel involved in the betrayal of trust of a number of parents of deceased children, whose organs were taken without proper consent and used for research rather than being returned to the body after a post-mortem (PM) examination, most notably at Bristol Royal Infirmary and the Royal Liverpool Children’s Hospital, has only served to reignite these feelings of fear and mistrust. The avoidance of gaining consent for organ removal and usage after the PM for research purposes was justified by many of the medical personnel involved in organ retention by

⁹⁶ Pages 42-43.

way of the ambiguity of the wording of the Human Tissue Act 1961, pointing to an inadvertent legitimacy for such acts. Questions were raised at this time as to whether the Act had contributed to the incidents of organ retention which had wrought harm upon the public. The intention of the Act was called into question and whose good the law actually leaned towards (Cheung 2007).

Not only did this highlight a serious lack of open and honest communication and understanding between the medical establishment and the public regarding post-mortem examination and clinical research using human organs (Madden 2009; O'Neill 2002), but it also served to present a duplicitous approach from medical personal, which demonstrated what appeared to be an arrogant and disrespectful opinion of the importance of the public in advancing medical research. Such a malignant culture of power, coupled with an apparent misunderstanding of the public's integral role in the success of organ and tissue research, was reflected through an explicitly paternalistic approach taken when seeking consent for PM examination (Cheung, 2007). The individuals involved in organ retention viewed the body and its parts as a valuable resource in uncovering and helping to resolve difficult medical conditions. As such, the body retained a great deal of utility even in death. A utilitarian approach to the use of body parts was adopted to justify the retrieval and use of said parts to advance medical research and treatment options in the future. Unfortunately, the calculations of the harm suffered by the families involved in these scandals never appeared to be given serious consideration.

Ultimately it was this which contributed to the public's sense of distrust in the medical professionals' principles (ODT 2008, Annex E; ODT 2008, Annex M) and resulted in the public outcry, not dissimilar to that described by Richardson from the earlier century. The harms which became apparent, coupled with the public's reaction to the events which occurred, served to outweigh the potential benefits the use of the organs may have resulted in. The collective sense of distrust was a secondary symptom of the more intense feeling of betrayal of trust which was experienced by those directly involved in the organ retention debacle. A strong empathic reaction

from the public provoked a real feeling of solidarity; the collective outrage and alarming pace with which the lack of confidence in the NHS appeared to be growing forced the government to act quickly to address the concerns and reconcile the anguish and fear, borne out of the events which had taken place. Reducing this level of mistrust and distrust (Childress 2001) - the effects of which could easily spread and become the 'norm' - was vital.

The report, *'Human Bodies, Human Choices: the Law on Human Organs and Tissue in England and Wales- a consultation report'* (DH 2002), which included detailed opinion gathered from clinical experts and members of the public, including donors, donor families and transplant waiting list patients and transplant recipients, served to inform preparation for the Human Tissue Act 2004, governing the therapeutic use of human organs and tissues. The Act sought to rectify many of concerns expressed during this consultation process, as well as those highlighted in the Inquiries⁹⁷, conducted in response to the actions uncovered at Alder Hey and Bristol Royal Infirmary.

In light of these incidents and more recent events, such as the negligent care uncovered at Mid Staffordshire NHS Foundation Trust, demonstrating "serious failings... poor standards (of patient care) and a disengagement from managerial and leadership responsibilities" (Francis 2013, p.3), distrust has become a diffuse issue for governments to deal with over the last fifteen years. As Kohn (2008a) points out, "when public alarm arises in specifically medical contexts, where people feel that their lives are in professionals' hands, mistrust may rapidly flare in to a sense of betrayal" (p.7). The public have reciprocated, resulting in a diminished sense of public goodwill to help when asked. In terms of organ donation and PMs, in the early years after the organ retention Inquiries were published the number of consents to PMs were affected (Adam

⁹⁷Royal Liverpool Children's Inquiry Report (Redfern et al. 2001); *The Inquiry into the Management of Care of Children Receiving Complex Heart Surgery at the Bristol Royal Infirmary: Interim Report: Removal and Retention of Human Material Learning from Bristol: the report of the public inquiry into children's; heart surgery at the Bristol Royal Infirmary 1984 -1995* (Kennedy et al. 2000); *Report of the Independent Review Group on the Retention of Organs at Post-Mortem; The Removal, Retention and Use of Human Organs and Tissue from Post-Mortem Examination* (IRG 2001).

2001), and there were suggestions that it also contributed to a decreased number of organs and tissues for transplant (Curtis et al. 2001, p.1541) and healthcare research (Adam 2001, p.655), resulting in increased morbidity and mortality in this area of healthcare.

Measures have recently been taken to try to remedy what is perceived to be poor values displayed by a number of healthcare personnel across the NHS towards patients, in terms of welfare and safety. However, in view of these incidents which initially resulted in the diminished trust, especially those which centred on organ retention, Richardson (2001) notes that any change in the law for organ donation from opt-in, where consent is the explicit means to organ retrieval, to opt-out could result in the return to this sort of illicit behaviour with the removal of organs being poorly policed and the State effectively condoning illicit behaviour towards the treatment of the corpse, and at the same time a “systematic negligence towards public feeling” (Richardson 2001, p.415). Just as occurred after the introduction of the Anatomy Act 1832, Richardson warns that an opt-out system could effectively result in policymakers simply paying lip service to the public’s choices. Pond (2013) supports Richardson’s position stating that, “history has taught us that consent is the mainstay when it comes to bequeathing a body to science. Searching for consent removes the fear from dissection, and without the fear more people are willing to donate their bodies” (p.66).

If we are to heed the warning of Richardson, then the only system which would be appropriate would be an informed consent system. This is the system which O’Neill (2002) advocates. She believes that this system is the most effective way to ensure that clinicians responsible for organising organ retrievals and transplants remain trustworthy, especially if proper regulations are put in place to ensure that consent is provided in the appropriate manner to prevent coercion or deception. This coincides with the belief that informed consent upholds and safeguards the best interests of the public, a view represented by some of the participants

involved in NCOB's public consultation around the use of organs and tissues for donation and medical research (NCOB 2010).

The public need to have confidence that the system for storing and providing organs and tissues for therapeutic purposes is transparent, legitimate and well run. If they have confidence in this, then they may feel more able to entrust their deceased family member's organs to the NHS. Those who are suspicious of an opt-out system support the retention of opt-in believing that consent safeguards the best interests of the public. This is what cements trust; an opt-out system would undermine this. However, it is worth noting here that the evidence from many of the countries where a soft opt-out system operates shows that concern expressed by relatives *can* and often *does* result in donation not taking place⁹⁸. Confidence on the part of the public appears to be strong in these countries, with a low number of registered objections or relative refusals to donation.

The ODT (2008) expressed concerns around introducing a system of opt-out at a time when the public do not have great deal of trust in healthcare providers, managers and policymakers responsible for making decisions which will 'benefit' the public. It suggested that the public are far more willing to question authority (ODT 2008, p.9). The ODT's suggestion is supported by research conducted within the last ten years examining trust and government information, pointing to the decreasing level of confidence from the public towards the Government (Duffy et al. 2005). Many of the participants in Duffy et al.'s (2005) study around the public trust in government and public services spoke favourably about the NHS; however, less than half believed the NHS was providing a good service nationally. Moreover, an overall impression to come out of this research was that the government were failing to provide the 'right' policies for the NHS (Duffy et al. 2005, p.24). As Parks et al (2013) poignantly observe,

⁹⁸ Systems include Belgium, Croatia, Norway, Spain (European Directorate for the Quality of Medicines and HealthCare, Council of Europe and Organización Nacional de Trasplantes 2014).

policymakers need to focus closely upon this general feeling of distrust as a priority in order to work towards “a more consistent provision of publicly beneficial goods” (p.155).

The public are more cynical and therefore more inclined to be wary and perhaps distrustful of policymakers’ motives. In reference to this Kohn (2008a, p.74) points out that:

Democratic governments these days enjoy precious little of the deference, impressed upon people by the weight of traditional authority that curbed interference with their activities in earlier times. Politics, objective truth, and the public interest are only tenuously connected in the public’s view of the scheme of things. During public health alarms, it is perhaps not surprising that many people choose to believe the side the government is not on.

Introducing a policy where individuals *can* express an objection to organ procurement may result in numbers of organs retrieved being reduced in this climate of mistrust and cynicism towards the motives of government. With this in mind, policymakers have to be mindful of their actions and how they approach a policy which balances the aim of maximising the benefit for the greatest number (in terms of supplying as many organs as possible) with the concerns which the public may have about their role in the execution of such a policy.

5.4: Facilitating Policy Success.

Formulating a policy which is so reliant upon the public carries a risk due to the dependency it generates (Skinner et al. 2014, p.208). Policymakers must predict the success of such a policy based on their belief or confidence in the public to act in a given way. A policy can be understood to be successful if it meets the targets that have been determined by its proponents. Whilst an accurate prediction may not be possible, political scientists can look at ‘patterns of regularity’ to be able to gauge what might happen in the future (McConnell 2010, p.218). Arguably, policymakers in the UK would state that the current opt-in policy is successful in that it, alongside measures introduced by the ODT, has secured a year on year increase in the

numbers of organs procured for transplant. However, the policy is less successful when the patterns or relative refusal are considered, as these remain very high (NHSBT 2013b). Conversely, when looking at patterns of organs procured *and* relative refusal rates in European countries which practise donation under a soft opt-out system, both these figures are generally even more favourable (Shepherd et al. 2014). On the basis of these figures across Europe, one could predict that introducing such a system would succeed in producing more organs.

Public policies often have an “authoritative, legally coercive quality” (Anderson 2011, p.9) and demonstrate a very specific “authoritative allocation of values” (p.19). This establishes the normative aspect of legislation: how the public should act. The values normally represented in a public policy include “honesty, integrity, probity, public trust, the common good and discretion” (Geuras and Garofalo 2011, p.265). The present opt-in policy promotes generalised trust in citizenship. This incorporates values and norms such as truthfulness, attitudes of solidarity, a belief in fairness and ‘spontaneous altruism’ (Gilson 2003, p.1458). Whilst these values are laudable, the question, as asked in the previous chapter, is whether such an important healthcare policy should rely upon individuals actively ‘buying’ into these values for the policy to succeed in providing a large number of organs.

There are two very important factors to drive this policy forward and make it successful. Firstly, the values which underpin such a policy, incorporating what the goals of the policy are, and secondly, how these can be achieved, bearing in mind the need for public support to achieve this. The policy needs to be clear, transparent and focussed towards the public benefit. The values which represent the current policy are shared with those which underpin an opt-out policy: altruism, trust, solidarity. What serves to differentiate the two policies is the underlying focus placed upon society’s role in achieving success. Therefore, the point that only those supportive of the original goals are liable to perceive, with satisfaction, an outcome of policy success

(McConnell 2010, p.39), is pertinent, as this particular policy is complicated by the need for public assistance.

Speculation presented by the ODT regarding a potential undermining of trust resulting in a decrease of organs donated should not deter policymakers from introducing a policy which is believed to be in the best interests of the public. However, as Radcliffe Richards (2012) points out, public favour is required to make this policy work. Trust needs to be established as well as presenting a convincing policy known to be effective. Organ procurement will be guided by strong personal / intuitive values; these have to be factored in, as simply introducing the policy will not work if it overbears all of these concerns /personal values (Radcliffe Richards 2012). Sometimes attitudes are difficult to change; however, policymakers need to think about ways in which this can be addressed, as without a majority of the public engaging with the process of organ procurement an opt-out policy will be ineffective (Childress and Liverman 2006). The policy will not succeed if policymakers believe that simply allowing the right to self-determination is sufficient public involvement in the organ donor process. The omission of public involvement in the planning process of an opt-out policy may well result in a clear voice of dissent being used by the public after its inception, resulting in policy failure. Radcliffe Richards (2012) argues that public trust is essential-more important than increasing life expectancy of someone in organ failure. People's interests must be given "absolute priority" (Radcliffe Richards 2012, p.207). This could make policymakers far more cautious about introducing something which the public may feel encroaches upon their 'rights'. However, focusing attention predominantly upon this might serve to replace the goal of the policy with allowing the public to dictate the values underpinning it.

In relation to organ donation, attempts to assuage growing dissatisfaction and unrest from the public has resulted in a system which is overly protective of the public. This has led to questions such as whether the balance of power has tipped too far towards the 'rights' of the

living (Zimmern 2007), and whether the protection the current legislation provides for the living is really “of any value to them” (Radcliffe Richards 2012, p.212). The ODT’s Ethics Working Group (EWG) (Annex D) has suggested that there should be strategies to build support and trust (ODT 2008, Annex D, p.8); this needs to include trust in government, healthcare systems and practitioners (p.12). In such a climate what is essential is to address concerns; if this is not done, then it would appear that distrust is an inevitable consequence. Addressing people’s concerns, however, is not synonymous with rights. Policymakers need to act upon objective goals, not subjective demands.

5.5: The Importance of Public Opinion.

Policymakers need to strike a balance between achieving the goal of increasing organ supply with addressing the concerns and meeting the needs of the public. A compromise is needed which requires a careful and well calculated strategy. This will involve listening to the public and taking their opinion into consideration when formulating the policy. McConnell (2010) stresses the importance of speaking to the public, stating that it is “rooted in modern liberal tradition stretching from John Stuart Mill and his focus on educative benefits of participation” (p.130). Public opinion may not provide the answers to normative questions; however, scholars from other disciplines interested in bioethics feel that the public can highlight issues of concern, representing a challenge for scientists and ethicists to address constructively (Hoffmaster 2001; Kerr et al. 1998; Levitt 2003a, 2003b). It is the public that much of the issues under scrutiny will directly affect. Taking an interest in society’s concerns may lead to a level of congruence and may help to avoid problems which may otherwise arise further down the line (Pawson, 2006). Values that are conducive and understood by members of the public stand a better chance of working and shaping moral conduct.

The public might expect their views to be taken into account. If policymakers fail this expectation, what may ensue is a detrimental effect on trust “and consequently on commitment,

motivation and morale” (Yamagishi 2011, p.213). Engaging members of the public from a variety of different ethnic, religious and cultural groups at the deliberative stage can result in the expression of eclectic opinions to inform the decision-making process. This can facilitate a more meaningful address of public problems, demonstrating respect for diverse interests and values (Gastil and Levine 2005, p.3). If the public feel valued and their opinion not merely paid lip service to, this will increase the likelihood of a positive outcome, whereby the public can feel confident in the policy being introduced. Policymakers can use debate and negotiation, whilst preserving the original goal, to frame evidence in particular ways to integrate disparate interests (McConnell 2010, p.146).

The importance of trust and the use of organs for research and transplant has been voiced during both NCOB’s and the ODT’s public deliberative events (NCOB 2010; ODT 2008, Annex J). Many participants expressed a need to feel confident in the integrity of the HCPs involved in the procurement process that they would act honestly, responsibly, objectively and maintain their duty of care regardless of the expected outcome; this would help to improve the perception of organ donation and transplant practices (NCOB 2011; ODT 2008, p.26). This followed on from doubts which some participants raised in relation to these professionals’ principles when managing the care of the deceased, including the respectful disposal of the body, and honouring their wishes regarding donation (NCOB 2011, p.94), suggesting a hint of suspicion and lack of trust in health services.

Siegel et al. (2010) have warned that a fear of HCPs rushing an individual’s death if their wishes to donate are known, or that organs may simply be taken before death has occurred, have resulted in non-disclosure of wishes prior to death, placing responsibility with the family to provide consent to donation after death has occurred. This concern regarding rushing an individual’s death has also been raised in the Cultural Working Group’s report (ODT 2008, Annex M, p.6). These concerns point to questions relating to trust that HCPs will continue to act in the

individual's best interests at all times (Radcliffe Richards 2012). This has been echoed in recent public opinion research in which those involved questioned whether medical personnel would work as aggressively should the individual require lifesaving treatment, if they have previously made their wishes to donate known (Guttman et al. 2011). Some of those involved in the public deliberative events for the ODT (2008) also reported this fear: "you might not actually be dead, with doctors 'jumping in too quickly' before 'someone is definitely gone'", (p.17). This clearly demonstrates a climate of fear and mistrust that potential donors will not receive all care (Bard 2012, p.44), alongside questions about the public's understanding of organ donation (English and Sommerville 2003; Neades 2009). Fears such as these can be difficult to allay (Dufner and Harris 2015). The fear that with an opt-out system such behaviour on the part of HCPs would prevail may well result in larger numbers of individuals choosing to register an objection under such a system, defeating the object of the policy.

An issue highlighted by some members of the public which relates specifically to opt-out are that their wishes not to donate will not be respected even if they have registered their objection (ODT 2008), and that they will be treated as a means to an end (NCOB 2011)⁹⁹. This suggests that there is a fear that individuals will not be treated in a dignified manner. It would appear that those who have expressed these concerns around an opt-out system also believe that this inhibits the ability to make one's choice; they seem to be less trusting of this system than the present one and the motives of the policymakers in introducing such a system, and their integrity in ensuring it is managed properly. This may, in part, be as a result of how the current opt-in system works, in relation to having one's decision respected, where the relatives' veto is upheld even in the knowledge of the deceased's wish to donate. If the public are aware of this, then it is not surprising that they may question whether this sort of practice would be any different under an opt-out system.

⁹⁹ Echoing the sentiments expressed by Richardson (2001), discussed earlier in this chapter.

In terms of honesty and integrity, a further concern which has been expressed by NCOB (2011) and Radcliffe Richards (2012) is that an opt-out system might point to the State taking ownership of one's organs. As discussed in the chapter around property, discourse around body ownership, coupled with the fact that the body is now a valuable 'commodity' in medicine, means that people may want to have control over what happens to their body rather than simply having the right to prevent it being used. Only a system where positive consent is required would satisfy this demand. However, as has been discussed in the thesis, there is evidence from countries such as Belgium (Michielsen 1996; Neades 2009) where an individual's decision to opt out or opt in is taken as absolute, placing control over the decisions around the body firmly with the individual. Relatives' involvement in the decision-making process prior to the retrieval of organs is a practical measure, acknowledging that their role and relationship with the deceased continues after death, in respect of their responsibility to uphold the wishes of the dead alongside the provision of a dignified burial. An asserted objection will be respected if the deceased's wishes have not been registered, but relatives cannot override previously made wishes. Any change in the law in this country could mirror this stand which Belgium has taken. It is imperative to ensure that the public, especially those wishing to make a definitive decision, are aware that the law will uphold the autonomous choice of the public and that this must be acted in accordance with. The interpretation of the law must not be in any doubt or open to interpretation; this should prevent decisions being made which may override the deceased's choice.

The decision to retain an opt-in system would seem to be consistent with society's values if evidence showed majority opinion favoured this system. However, opinion polls and public workshops around organ donation, presented throughout this thesis, have demonstrated support for an opt-out system. This has been corroborated by more recent public surveys suggesting that 82% of the public would support a change to a soft opt-out system (BMA 2013). Whilst there may be a 'sizeable' minority (ODT 2008, p.27) opposed to opt-out, the system provides for their objection to be registered. However, Anderson (2011) suggests that policymakers can be affected

when an opinion ‘trends strongly’ on some matter; even if it is only expressed by a minority, this may prevail over a less committed majority (p.139). It is perhaps for this reason that when rationalising a continuation of the current opt-in system the ODT chose to take the “strongly expressed” opinion of the minority forward who opposed opt-out (p.27). Geuras and Garofalo’s point appears to reflect the actions taken by the ODT in this respect:

the perplexing and formidable ethical and policy challenges inherent in administrative practice are not easily resolved and, therefore, the tendency is to remain at the moral surface and permit general ethical misinterpretations and particular individual or group interests to hold sway (2011, p.106).

Whilst gauging opinion is very important, this needs to be balanced with the underlying goal of procuring a larger number of organs to help a growing population of people in need of transplant. Listening to the public and addressing their concerns does not equate to allowing them to dictate a policy. Those who have expressed concern, including those the ODT (2008) described as supporting opt-out “in theory” but still having “reservations around certain issues” (p.27), should be involved in the planning phase of a policy, facilitating the opportunity for their concerns to be openly addressed and where possible resolved. However, this should not prevent a move to an opt-out system. Again, it is important to stress that whilst there may be concerns the majority view appears to favour a move to opt-out. One could argue that the majority opinion should be more apparent in the final decision made, when introducing a policy which places so much weight of expectation on the public.

McConnell (2010) suggests that using evidence and taking a rational approach to inform policymaking can be a safer way “to ensure policy success” (p.128). Presently, evidence from the public deliberative events, coupled with evidence which suggests that opt-out is more effective in procuring organs than opt-in (Shepherd et al. 2014), shows that opt-out is favoured not only in terms of organs generated, but also by what the public are in support of, with regards to a system

for procurement. In expressing concerns that an opt-out would undermine trust, arguably, the ODT have pandered to a strong but vociferous minority, when there is no real strong evidence to suggest that this will happen if appropriate measures are put in place to allow for objections (and consents) to be respected. One could also question the effect such a decision may have had on the majority, whose opinion was sought and then, on the face of it, upstaged by a minority.

5.6: Addressing and Promoting Trust in an Organ Procurement Policy.

The effective implementation of any public policy requires that state action be seen as legitimate- and so be accepted and acceptable. Such legitimacy is reflected in the extent to which citizens tolerate the interventions of public organisations, accept these organisation's decisions when they are aimed at influencing citizen behaviour and co-operate with the organisations to achieve their goals

(Gilson 2003, p.1458).

Radcliffe Richards (2012) believes that when formulating an organ procurement policy what is required is a compromise instigated via a practical solution, with "the fundamental principles of good reasoning" (p.146) acting as the gatekeeper to shaping the policy. Issues around mistrust need to be taken seriously and then rationalised publicly to allay fears and reassure the public that the intention of this policy is to maximise organ procurement for the benefit of society. It is not about profiting from taking ownership of organs, or ignoring values such as altruism or respect for autonomy in order to achieve this benefit. A clear and transparent policy requires honesty as it helps to maintain "a cohesive, trusting civil society" (Geuras and Garofalo 2011 p.59). One could question whether a utilitarian policy might allow for a misrepresentation of facts to achieve the end target: to produce organs. In view of this, the public need to be satisfied that there is no hidden agenda, especially after the incidents around organ retention. What is pertinent here is to recognise that being trustworthy and appearing to be so are different; "if the aim is reassurance, simply being trustworthy is not enough on its own"

(Radcliffe Richards 2012, p.207). Reference to the previous incidents and reassurance that lessons have been learnt and changes to the way in which conduct is overseen and governed must be reiterated.

From a policymaker's perspective, the fall-out experienced after the conduct of HCPs at Alder Hey and Bristol Royal Infirmary was exposed demonstrates the significance of factoring this level of deceit and duplicity into a utilitarian calculation of maximising benefit in terms of retrieving more organs from the public. In order to prevent being discovered there is a need for deceptive practices to continue. Detection of this form of conduct could result in a breach of trust which would have damaging consequences in terms of the policy succeeding and confidence in government more generally. Evidence around the organ retention incidents and revelations of bad practice bear this out. Even the most hardened utilitarian would find it difficult to justify the use of deception as a means to justifying the ends when calculating risks such this, which are very real.

Honesty and transparency extend to separating out myths and emotional fears from moral objections (Hyde et al. 2012; Radcliffe Richards 2012). Harm and exploitation need to be prevented; in accordance with this, the main aim of this policy is to achieve as much good as possible whilst preventing harms. An example of a concern raised around harm and exploitation is the continued provision of treatment if the individual is known to be willing to donate organs (Hyde et al. 2012). It should be noted that these expressions of concern normally focus upon how aggressively a patient will be treated if it is known that they are willing to donate their organs (Arriola et al. 2005; Haustein and Sellers 2004; Hyde et al 2012), rather than the worry that an individual will be killed for their organs. Reassurance that treatment will not be deliberately withdrawn prematurely or withheld for the purposes of donation revolves, to an extent, around the principle which currently exists both morally and legally that it is wrong to kill. Legislation

around murder is not waived for the purposes of transplantation and the public need to be informed that this principle is not compromised.

One of the fundamental principles of medicine is to act in the interests of one's patients. The fourth principle of The Mental Capacity Act 2005 also stipulates that a decision made under the Act for a person who lacks capacity must be in their best interests. In respect of this the GMC (2010) require that decisions around futility of treatment must be made prior to any decision around withdrawal and withholding treatment¹⁰⁰. The British Transplantation Society and Intensive Care Society (2010) state clearly that should consideration be given over to the potential for an individual to donate their organs a strict de-coupling process must take place, with the decisions around futility of treatment being made before any decision around donation is introduced into the care plan of the individual¹⁰¹. Guidance is clear and unambiguous. On this basis one cannot be 'killed' for their organs; this would include altering a treatment regime to actively end an individual's life. These regulations, as well as legislation, will naturally constrain a policy which focuses on the retrieval of organs from cadavers (Radcliffe Richards, 2012). It is important for the public to be aware that donation and transplant conduct is governed for in this way to demonstrate proper protection from harm. Inadequate governance means that regardless of how well HCPs conduct themselves, confidence in them will still be questioned.

In addition to this, efforts have been made to engage families in the process of treatment withdrawal, by way of witnessed resuscitation and brain stem death testing, to provide an insight and facilitate a better understanding of the processes involved in making these vital decisions which ultimately lead to the declaration of death. Numerous studies have been conducted around

¹⁰⁰ The General Medical Council states that life prolonging treatment can be withheld or withdrawn from a patient who lacks capacity when starting or continuing treatment is not in their best interests, and this is because there is no obligation to give treatment that is futile or burdensome (GMC 2010, p. 80).

¹⁰¹ The British Transplantation Society and Intensive Care Society report, '*Donation after Circulatory Death*' (2010) states that withdrawal of life sustaining treatment on the grounds of "futility" is better described as "decisions relating to the best interests of the patient in withdrawing life-sustaining treatment" (p.4). These decisions should be made transparently and consistently regardless of the potential for organ donation. All Intensive Care Units (ICUs) and Emergency Departments (EDs) should have an explicit local policy based on nationally agreed guidance (p.4).

family witnessed resuscitation in this country; what is evident from these studies is that relatives feel reassured that the patient has received all possible care and that everything has been done to help the individual (Grice et al. 2003; McMahon-Parkes et al. 2009; Porter et al. 2014). Less work has been done around witnessing brain stem death testing; however, relatives are able to witness this in the UK (Ormrod et al. 2005; Pugh et al. 2000). Witnessing these tests has been shown to dispel some myths and genuine concerns that the patient is not receiving aggressive treatment prior to their death, and has provided appropriate confirmation that the person has indeed died (Ormrod et al. 2005, p.1004). The most recent British study, conducted across forty eight intensive care units in the UK, has shown that witnessing the tests led to greater acceptance by families that all treatment options had been exhausted, resulting in an acceptance of death (Dean and Booth 2009, p.282).

Whilst these studies may only represent a snapshot of public experience of treatment at the end of life, what it does show is that those who have witnessed resuscitation and brain stem death testing feel suitably reassured that the patient has been treated aggressively. The studies included here also point to the fact that efforts to facilitate witnessing of these events have been made across the country, suggesting that extensive work is being done to reconcile concerns in respect of this. In addition to the reassurance which may result from observing resuscitation and brain stem death testing, these acts also serve to help untangle what can be a complex process which otherwise often remains mysterious and “opaque to lay persons” (Dufner and Harris 2015, p.3).

The role of the HCP and their duty of care to act in the best interests of their patients should be reiterated and emphasised during any publicity campaigns. They need to be competent and trusted to act appropriately, in terms of carrying out accurate assessments, acting efficiently and carefully towards the donor and family, demonstrating proficiency and knowledge in their work (Childress and Liverman 2006, p.111). The body that monitors conduct in this area should be

an independent authority (such as the Human Tissue Authority) with the aim to oversee and audit an efficient and transparent system for organ procurement and transplantation. This is essential for the success of an organ procurement policy. If an institution and its members work efficiently and honestly, then people will trust them; if they do not, people will not (Kohn 2008a).

Cheung (2007) refers to establishing a transparent code which HCPs need to abide by and are held to public account if this is transgressed. Ethical codes act as a form of protection for the patient; as such, this may lead to their volunteering their trust from the outset of their relationship with the clinician (Gilson 2003)¹⁰². At the coalface, those working in the transplant community must be trustworthy. This will involve those practising in the area being vigilant of others around them and ensuring that any undue practices are stopped (Radcliffe Richards, 2012). This must be made explicit and the public reassured that measures will be taken to enforce these rules in order to build and then maintain confidence both in the system and in the workforce. This assumes that patients' trust is "somewhat contingent and can be affected, either directly or indirectly, through legal rules, which act to safeguard and establish trustworthy behaviour/approach to care" (Hall 2002, p.498), therein shaping attitudes.

In addition to this, information around conduct and clinical management which the public may be privy to needs to be clear and readily available (NCOB 2011). This would address concerns over the system used to collect and store data, and the infrastructure, expressed by some of the participants in the consultation informing the ODT's report. Individuals need to feel confident that their decision will be respected and that their choice protected, both in terms of it being acted upon and their choice being treated confidentially. One need only look at the recent issues which have arisen in terms of the Government's poor track record concerning data protection. There needs to be a failsafe system so data will not be lost, as if it is, people who have opted out might

¹⁰² However, it should be noted that too much attention can actually damage trust more, if too much is made of it. The intention of the law is to "hold physicians to a level of performance that it considers trustworthy" (Hall 2002, p.492), in terms of expectations of a reasonable physician (Bolam standard), not to ensure clinicians meet the exceptionally high standards which many members of the public may set. The law has been introduced to adopt a professional standard of care not to assuage the public though.

still have organs retrieved. Access to the system also has to be protected so that the wrong people (the media perhaps) cannot retrieve information regarding those who have chosen to opt out. With a potentially smaller register this should be more manageable than it has been under the current system¹⁰³.

The public want to see a fair distribution of their organs procured for transplant (Newton 2011; ODT 2008, Annex J). This may be difficult to satisfy for all members of the public, as their attitudes towards fairness and deserving recipients may differ widely. This links with the importance of making the public aware of the way in which procurement and transplantation is organised and that procurement is managed by a separate team from those who then carry out the transplant. The complex organ allocation system also needs to be communicated to the public in a clear and simple manner in order to prevent misconceptions which may negatively affect their decision to allow their organs to be procured. A policy which advocates fairness and justice in the distribution of organs across all sections of society, where there is no room for prejudice or segregation, should serve to reassure the public that all individuals play a part in the success of this policy. This needs to be rigorously regulated with strict penalties applied to those who breach the rules of distribution. Again, this points to a system where clinicians are absolutely accountable for their actions and their practices are monitored closely, in an earnest attempt to avoid the sort of distribution scandal which has recently occurred in Germany, resulting in a reduction in donor numbers of 40% in 2012 (Der Spiegel 2012).

Allowing the public to have an insight into the management of procurement and transplantation should encourage confidence in the process, thereby fuelling their willingness to be involved. When providing education around this area of healthcare, policymakers need to encourage group identity: a 'let's work together' approach, based on the idea that one individual

¹⁰³ When reporting on the error over ODR data collections, Sir Gordon Duffy noted that the ODR system had not been designed to fulfil the function for which it is now used, and technology for secure, interactive information management has advanced greatly since the ODR was originally set up (Duffy et al. 2005), alluding to the fact that accommodating the growing number of registrants safely and securely is a complex and therefore challenging task.

may not make much difference, but a community would, and this could have a big impact (Parks et al. 2013, p.154). This demonstrates an expression of community (Childress 2001) and a sense of solidarity (Parks et al. 2013, p.155) encouraging trust in the overall system. A bond forms in society when we think of ourselves as a 'collective'; this is more than just a sum of individual preferences (Kohn 2008a, p.56). Focussing on the public's integral role in helping to save lives will also appeal to providing a 'feel good factor' and a perception of responsibility which may resonate in times of need. Public appeals for donations and general help for people in crisis often result in enormous donations from the public¹⁰⁴. Kohn (2008a) suggests that individuals trust the NHS to provide blood (this could include organs and tissues) which they need because they trust that strangers will perpetuate this act of donating blood for other strangers' benefit (p.57). This is perhaps the best approach to take to both encourage the inclusion of people in allowing their organs to be procured and also the move from an opt-in policy to a soft opt-out. Advocating help on the basis that we may then directly or indirectly benefit from gestures of help may lead to what Kohn refers to as "the potential to stimulate and sustain cooperation across a network of strangers" (2008a, p.56).

Finally, communication remains key to the success of a public policy, both in the planning phase and once it has been introduced. Organ donation needs to be discussed openly and freely at 'grassroots level' to facilitate a frank exchange of beliefs and values (ODT 2008, Annex M). This would address some of the issues raised concerning segregation and lack of understanding of the many concerns which cut across a number of racial, cultural and religious values. In respect of this, Parks et al. (2013) point out that policymakers who "listen to the concerns of its citizens and provide accurate information in a transparent manner might often enhance not only institutional trust, but also a stronger commitment and willingness among people to make a positive contribution to urgent social dilemmas" (p.151). Open communication can facilitate a clearer understanding of public issues. From here reassurance can be given around 'myths' which have

¹⁰⁴ A point made earlier in this chapter 4 on page 117 (footnote 87) and in this chapter on pages 135-136.

remained prominent in some people's minds, and sincere concerns can be acted upon. The evidence from the ODT's public deliberative events shows that providing the correct information around donation and transplantation increased the participants' confidence in the system and resulted in a rise in the number supporting the introduction of a soft opt-out system (ODT 2008, Annex J). Not acting may prevent donation from occurring or a change in policy being a realistic proposal to put forward.

The ODT's workshops also served to prove that good and effective communication, both verbal and written, is a crucial feature in facilitating cooperation amongst members of society, with the effect stronger in 'larger groups' (Parks et al. 2013, p.135). In order to make public opinion meaningful, it is important to recognise that the public need to be suitably informed about what it is they are expected to provide an opinion about. In respect of this, Hardin (2006) points out that a poor use of language can be a hindrance to a successful outcome when gauging opinion which includes the consideration of complex concepts and deep-seated values. Specific terminology requires clear and unambiguous language to be adopted. This can be - and often is - a weakness of public surveys which seek to make generalised statements about the public, but base this on poor quality data collection. Having already considered the various dimensions of trust earlier in this chapter, when seeking the public's opinion around organ donation one of the most important issues to tackle would be to ask what their understanding of trust is. This way, if questions around trust relating to policy provision and decision-making at the coalface are raised, then clarification could be made, leading to a more significant discussion with more relevant answers provided. Without this one could argue that claims of a decline in trust and claims about citizen trust of government will remain "severely under-articulated" (Hardin 2006 p.13) and inappropriately represented.

Interviews recently conducted with HCPs from three countries¹⁰⁵ where opt-out currently operates yielded strong opinion around the importance of public knowledge and education in a successful organ donation policy (Neades 2009, p.273). The emphasis on the success of frequent public education and communication initiatives, looking specifically at issues which might affect the public, illustrates the utility of increasing public awareness in terms of building an acceptable policy which will produce more donations as a result of this recognition of the process. Neades (2009) points out that specific campaigns targeting groups such as school children, to help make them understand organ donation and allow them to talk about this with HCPs, has improved their knowledge and their acceptance of this system. Engaging this group of people has facilitated further discussion amongst families more widely, resulting in a greater level of familiarity with the system for organ donation. It has also prompted discussion around people's views from a personal perspective. The HCPs from the study felt that it was this education which had contributed to the "greater good and acceptance of" opt-out by the public (Neades 2009, p.273).

Shaping public opinion can be enhanced through the effective use of the media. Habel (2012) suggests the media can inform much of the public's knowledge in respect of politics and public affairs, and thus has some serious influence and ability to shape public opinion (McCombs 2004). This in turn can have important implications for public policy, in terms of affecting public confidence around policy provision, often as a result of questioning policymakers' motives and competence. The direction the media takes can often sway the public. This will be something which policymakers will be acutely aware of, and when formulating a policy which requires public support may help to engineer a policy in order to be able to predict its success more confidently.

Policymakers can influence public opinion via careful control of news items provided to media representatives (Anderson 2011, p.138). The media can act as a conduit of policy beliefs,

¹⁰⁵ The countries included in this qualitative study were Belgium, Portugal and Norway.

presenting narratives which are tailored to set out policy expectations (Shanahan et al. 2011). Mass media can also act as a good vehicle for providing simply imagery which can form a social representation for individuals who are previously unfamiliar with what the subject matter involves (Potter and Weatherall 1998). These media vehicles reach a significant number of people, and their portrayals of this area of healthcare can- and often do- influence individuals' attitudes and behaviour (Harrison et al. 2008, p.38). The media can also shape the public's understanding of scientific phenomenon through their representation and portrayal of those orchestrating the scientific events being reported upon; this can condition public trust in this area (Nowotny et al. 2001).

However, the negative aspects of media coverage can be to represent organ donation and transplantation in a misinformed and sensationalist manner. This is particularly true of portrayals presented by the entertainment industry; this can only add to fears the public might already harbour (Harrison et al. 2008, p.38; Morgan et al 2007). This form of entertainment works at cross purposes with social marketing organisations which seek to promote the benefits of organ donation (Harrison et al. 2008, p.40). The media can also scapegoat certain policy initiatives as a means of attacking a government and persuading the public to question the integrity of the government more generally. The media may not have a moral responsibility towards informing or educating the public, but they can influence public trust through their sensationalistic storylines and portrayals of legal and regulatory protections in this area (Hall 2002). This can have a troubling impact upon public opinion and can shape views around organ allocation and heighten fears around issues such as organ donation and the means by which this is governed. This can overshadow smaller, more localised coverage denoting the positive side of donation and transplantation; this generally does not reach out to as many members of the public as the entertainment programmes or tabloid newspapers. Any common misconceptions which appear in light of sensationalist stories from any media source should be addressed. At the same time this also affords the opportunity to highlight positive aspects of organ donation and transplantation

(Matesanz 2002) through powerful public narratives which may serve to influence public opinion towards support for a specific policy preference (Shanahan et al. 2011, p.374). These should be presented at national, not local or regional level.

Regular publicity campaigns around the organ donation system could continue to keep the public involved in the success of the policy and educated about ways in which to register an objection or willingness to donate. Secondary data from the 2010 Eurobarometer (n=29,288), research, which compared people's willingness to donate their organs in a representative sample from 19 opt-out and 10 opt-in consent countries from across Europe, demonstrated that the effect of consent on willingness to donate was moderated by people's awareness of their nation's organ donation legislation (Shepherd and O'Carroll 2013, p.1058). When people were aware of their nation's legislation the proportion of people who were willing to donate their organs was greater in opt-out (85.26%) than opt-in (80.72%) countries. By contrast, when people were not aware of their nation's legislation there was no difference in people's willingness to donate their organs in opt-in (58.63%) and opt-out (59.23%) countries (Shepherd and O'Carroll 2013, p.1061).

5.7: Conclusion.

From the policymakers' perspective trust can be calculated on what it sets out to achieve. Evidence shows that opt-out policies do produce more organs than opt-in policies. This is the goal of the policy. However, an opt-out policy will only succeed if the public are in favour of it. Evidence already shows that the general public's attitudes toward donation and transplantation can have a commanding effect upon surrogate decision-making around organ donation (NHSBT 2013b; ODT 2008; Siminoff and Mercer 2001). Public support for the underlying premise of the policy is needed, which opinion polls seem to suggest is present. In addition to this, policymakers need to actively listen to concerns which may run alongside favourable opinion. These concerns need to be addressed in order to demonstrate respect for public opinion and allow people to ultimately decide whether they wish to donate or not.

It is simply not enough to assert an authoritarian position declaring it to be for the good of the collective, overbearing any strongly felt beliefs which individuals may harbour. It will be self-defeating (Radcliffe Richards 2012). Due to the current political climate, coupled with previous events which have marred public trust in healthcare practice, there is a heightened level of mistrust and scepticism of policymakers' and institutions' true motives and aims. Individual interests must sometimes yield to collective needs. However, when such a situation arises policymakers should heed their responsibility in respect of public accountability. Public accountability requires being open to public deliberation and it obligates policymakers to be transparent, and justify the decision being made (Childress et al. 2002). This establishes a foundation on which trust can be built, even when difficult decisions may appear to infringe upon moral considerations such as liberty and privacy. The public need to have sufficient confidence in the purpose of the policy and the intentions of the policymakers to feel assured about the mechanism by which an opt-out system is managed. On this basis, Hall (2002) warns that "whether trust is regarded as an end in itself or as a means to some other end, trust is too important and pervasive for the law to neglect in any realm" (p.525).

Individuals wish to be involved in a decision-making process which directly affects them. Their contribution can highlight the risks involved characterised through expressions of concern: "risk characterisation is a decision-driven activity, directed toward informing choices and solving problems" (Stern and Fineberg 1996, p.155). Moreover, what needs to be taken into account is that people's opinions may well not coincide with the traditional harms and benefits approach which policy formulations are most often based upon (Radcliffe Richards 2012). That said, public opinion and public trust are not synonymous with public rights. Taking their opinion into account and addressing issues will be instrumental to the success of the system; however, it should not allow absolute dictation of a policy. Public fears need to be reconciled; however, they should not prevent a change in the current system which is for the benefit of society as a whole. A soft opt-

out programme is the method for procurement which has been shown to address the issue of supply most productively (European Directorate for the Quality of Medicines and HealthCare, Council of Europe and Organización Nacional de Trasplantes 2014). A combined registry facilitates the opportunity for individuals to express their autonomous choice most effectively, in that it provides for expressions of both objection and consent. Opinion will be useful in engineering an acceptable and effective policy, which then requires an equally effective marketing strategy so that public involvement contributes to policy success.

Conclusion: The Way Forward for Organ Procurement in the UK.

The subject of organ donation and transplantation is laden with emotion, and has provoked much in the way of passionate debate and strongly worded commentary both in favour and against its practice. Evidence shows the benefits of organ transplants in terms of cost effectiveness and the potential to prevent premature deaths. Currently, the only successful transplants come from allografts. Human beings are therefore the source of these transplants, and we have to rely on each other for this type of treatment to remain an available option. The fourteen recommendations made by the ODT in their first report, *'Organs for Transplants'* (DH 2008), have resulted in accomplishing the goal of improving the deceased donor rate in the UK by 50% by 2013 (NHSBT 2013a). Prior to achieving this target NHSBT had already published their strategic plan for 2012, in which they put forward a proposal to work towards achieving an increase in deceased donors to 60% by 2016-7 (NHSBT 2012b), implying that the present system for coordinating organ procurement would have remained unchanged even if the 50% target had not have been reached.

However, the fact remains that despite the success the changes in infrastructure have brought about, coupled with the financial incentive to push for donation after cardiac death to take place in the majority of hospitals, the rise in the number of donations after brain stem death has not increased at the same rate as donations after cardiac death. This means that there are still a significant number of patients who have not benefitted from the rise in donor numbers. In addition to this, the rise still leaves the UK far short of the number of donors when compared with some European countries, most notably those with an opt-out system. There is no denying that the infrastructural changes have had a very positive effect on the number of organs retrieved; however, a system which defaults to opt-out would only further improve upon this success, as has been demonstrated in Belgium. Having addressed the arguments around a move to a soft opt-out system, it is worth mentioning the interesting example of Belgium.

The ethos underpinning the Belgian Presumed Consent Transplantation Law and the centralised combined registry, introduced in 1986 and 1987 respectively, was deemed to be consistent with the majority view held by the public (Michielsens 1996; Roels et al. 1991). When explaining the rationale behind the introduction of this policy, Roels and Michielsens (1991) commented that, “ideally such legislation should be able to translate the altruistic attitudes of the public toward donation into efficient measures, with a maximum guarantee of the individual’s right of self-determination” (p.2514). The Belgian government believed that the new soft opt-out law, voted through the Senate and House of Representatives with a large overall majority (Michielsens 1996, p.664), succeeded in achieving these aims.

Whilst there is no legal sanction imposed upon medical professionals to actively invite relatives to express their opinion regarding the deceased’s donation, family members are able to volunteer their concerns or objection around the retrieval process. Squifflet (2011, p.3394) points out:

the Belgian law of presumed consent is not sufficient authority allowing the removal of organs after death... for those who did not make any decision during their life, even if they are presumed to be in favour of organ donation, patient rights’ law, transparency and common sense require informing family members

In the absence of a formal decision made on the part of the deceased, accepting the family’s refusal is commensurate with other human rights’ directives¹⁰⁶. In Wales, the soft opt-out system, which comes into effect later this year under the Human Transplantation (Wales) Act 2013, also enables relatives to offer evidence of the deceased’s (although not of their own) objection (Douglas and Cronin 2015, p.325).

¹⁰⁶ Squifflet’s point echoes the concerns raised by the ODT (see pages 91,92 & 94). Whilst Belgian legislation could make it lawful not to involve families, such legislation may be seen to be transgressing rights under the European Convention on Human Rights (referenced on page 94), which as members of the European Union, Belgians can then invoke (the same would apply in the UK).

Recognising that no transplantation policy can work effectively without the acceptance of the public, Roels and Michielsens (1991) believe that the Belgian model, where the official statement is that donation “is the rule” (Michielsens 1996, p. 666) can “perfectly combine collective altruism¹⁰⁷, self-determination and respect for the relatives with an efficient organ retrieval rate” (Roels and Michielsens 1991, p.2515). Whilst individual choice remains- ensuring dignity and respect for autonomy- what lies at the heart of it is that policymakers in Belgium have acted in the interests of society as a whole; implicit in this is the acceptance that this is what *should* underpin welfare policies. In essence, what this system recognises is the interdependence of society and the need to respect individual choice. The Human Transplantation (Wales) Act 2013 demonstrates that the Welsh Government has also chosen to adopt a policy for procurement which aims to “benefit the people of Wales by reducing the number of people dying whilst waiting for a suitable organ to become available and improving the lives of others” (LLywodraeth Cymru 2012, p. 5).

Reference has been made to the statistical evidence of the success that the soft opt-out system has had on organs procured¹⁰⁸. At the time of writing Michielsens (1996) observed that a transplant law is only able to provide “a legal environment which can influence the extent to which potential donors can be used” (p.665). He acknowledged that other factors such as road accidents, provision of critical beds and early detection of potential donors also played an important part in the provision of organs. The Donor Action Programme (DAP)¹⁰⁹ has been shown to further improve the donor rates (Roels et al. 2008). The soft out-out system and the infrastructural changes have had a very positive effect in increasing the supply of organs for

¹⁰⁷ I have raised the point in chapter 4 regarding the use of this term where I suggest that collective beneficence would be a more appropriate description for this system. Please refer to page 122 for the discussion around this.

¹⁰⁸ Figures are presented on pages 4 and 29.

¹⁰⁹ Discussed on page 30.

transplant since their introduction. These numbers compare very favourably against the UK's numbers¹¹⁰.

Transplantation can save lives; it can also improve the quality of a recipient's life. It is more cost effective when compared with medical treatment for ESOF. In addition to this, the UK economy would also potentially benefit from the reintroduction of many transplant recipients and their (former) carers back into the labour force. The impact of this can be very positive in terms of the benefit to the recipient's family. The net benefit of transplantation serves to show that such a policy will be advantageous to a far greater number of people than simply those who are affected by ESOF. When all of these features of this policy are taken into consideration this presents a strong utilitarian argument for introducing such a system into the UK. Moreover, Wales have shown that it is possible to introduce legislation which replaces "appropriate consent" from the Human Tissue Act 2004 with two concepts: "express consent" (which replicates "appropriate consent") and "deemed consent" (HTWA 2013). The Human Transplantation (Wales) Act 2013 restates certain sections of the 2004 Human Tissue Act directly related to consent for the purposes of transplantation. However, in order to maintain an effective cross-border regime, in terms of the operation of the UK-wide organ transplantation programme, there is an inevitable interplay with the 2004 Act. What this effectively demonstrates is that a soft opt-out system can be introduced without a great deal of hardship or complicated re-working of the current legislation.

A Soft Opt-Out System with a Combined Registry in the UK.

This thesis has set out to examine the possibility of moving from an opt-in to an opt-out system. In doing this the approach taken has started by specifically focussing upon the ODT's report, published in 2008, looking at the potential impact an opt-out system might have in this country. This report and the recommendations emanating from it have directly informed the

¹¹⁰ 18.5 pmp in 2012, compared with Belgium whose rate was 30.2 in the same year (CD-P-TO 2013, p.36).

present retention of the opt-in system. An important part of the thesis has therefore been to consider their reasoning behind rejecting a move. These reasons have been identified in the introduction, and then subsequently addressed in the chapters that follow.

The first issue which warranted close examination was consent. Since the introduction of the Human Tissue Act 2004 the explicit requirement of consent for deceased organ procurement has remained a moot point; this has been discussed in detail by both the ODT (DH 2008; ODT 2008) and, more recently, by NCOB (2011). Chapters 2 and 3 concentrated upon whether consent is necessary when legislating for cadaveric organ procurement. Two quite distinct reasons for invoking the need for consent in this area were discussed at length: the first is if the body is considered as property, the second is in accordance with privacy interests.

Property rights and the importance of consent relative to this are worth considering, since the ODT and policymakers have referred to an individual's 'ownership' of the body. Ownership can pertain to property. In chapter 2 the idea that property is an appropriate form of discourse when discussing issues relating to the body was reflected upon. This is because if it is an appropriate form of discourse, then it may be that consent cannot be dispensed with when formulating legislation around organ procurement. Legal statute and case law in this area have explicitly dismissed the notion that the body is property; however, this has not prevented some strong ethical arguments favouring one's view of the body in this way being brought to the fore. Careful examination of some of the most compelling of these arguments, specifically when relating this to invoking the need for consent to organ procurement, has led me to conclude that these are not convincing enough to wage a serious challenge to the current and consistently upheld legal position that the body and, ergo, organs are not items of property. If consent is required, it is not justified using this particular line of reasoning.

The ODT proposed that an organ procurement system based on consent was the most appropriate and ethically permissible method for demonstrating respect for autonomy and bodily

integrity, most commonly invoked in the form of privacy interests. The focus of the discussion in chapter 3 was therefore whether the application of consent really is the most acceptable method for demonstrating what the ODT described as individual decision-making, in an era moving towards “greater individual autonomy” and “...a choice and personalisation agenda within the NHS, which gives people a greater sense of control over what happens to them” (2008, p.9). This chapter considered arguments put forward in favour of retaining consent, based upon this premise. Whilst these arguments are indeed convincing in terms of asserting the importance of respect for self-determination, and the importance of enabling individuals to exert this freedom of choice, they do not point exclusively towards a system of consent.

These arguments can and have been used to show that what is important is that an individual is able to decide what happens to their organs posthumously. This can be done equally as effectively under a soft opt-out system. Respect for autonomy must remain an important feature of legislation around the procurement of organs, as this appears to be consistent with society’s value of respect for privacy interests- something which the public have spoken strongly of when asked for their opinion around organ procurement. In Belgium, the legislation extends absolute respect for autonomous choices registered; the decision made by the deceased cannot be overridden. Conversely, current UK practice permits relative refusal to be upheld even in the knowledge of the deceased’s wish to donate; this has been met with consternation and anger by many members of the public who feel that their last wish may be disrespected (ODT 2008 Annex J, pp.4,5,19,24,30,31). One of the concluding comments from a participant of the ODT’s public deliberative event was that, “People would like to see greater clarity about the role of relatives and many would like to see an individual’s wishes taking priority” (ODT 2008 Annex J, p.22). Such a betrayal of trust may be contributing towards the apparent apathy which exists under the current system of those actively opting in.

An opt-out policy with a combined registry would provide a far more failsafe mechanism than the current system affords to protect the interests of these individuals as well as those who wish to object to organ procurement. Those who make their decision explicit must have their wishes respected, as this represents a deliberate decision and therefore should not be allowed to be overruled by another whose opinion towards procurement is less favourable. A system which enables relatives to offer proof of the deceased's objection, where no formal objection or consent has been registered, such as that which is legislated for in Belgium and Wales could be adopted in England. The current model practised under the HTA 2004 enables a relative who stood in a qualifying relationship to the deceased immediately before death occurred to provide consent for organs to be retrieved. This wording around a relative standing in a qualifying relationship could be adopted in a soft opt-out policy, so as to allow for such a relative to present evidence of an objection. This would provide a system which individuals and relatives could have confidence in by facilitating the opportunity for advocacy to occur where no decision has been made. Having one spokesperson approaching HCPs may also serve to prevent unnecessary involvement of the HCP in potential disagreement amongst family members. Such situations can force difficult discussions around weighting evidence of the desire to donate or withhold one's organs.

An issue raised and discussed at length in chapter 4 relates to the concern expressed as to whether a soft opt-out policy alone would ultimately undermine the opportunity to behave altruistically if it is all but forced upon society, even where there is the option to opt-out (ODT 2008). An organ procurement policy which does not feature this could result in members of the public actively disengaging from the process. This may in part be as a result of not being able to fulfil a strong desire to act altruistically. However, it is difficult to know just how many individuals feel this strongly, especially when looking at the statistics, which have been referred to throughout this thesis, demonstrating a tendency towards apathy rather than active altruism. That said, this could result in a small but significant number dissenting, whose organs would then potentially be lost. A system such as the one introduced in Belgium does allow for this level of

altruism to be included, by way of facilitating the opportunity to opt in. Such a system has resulted in a high donor rate; moreover, as Roels and Michielsen (1991) point out, the objections¹¹¹ centring on a system such as the one in Belgium, including the idea that catering to society's need for organs "would inhibit altruism and would violate individual choice dignity and autonomy" (p.2515) have been unfounded. Opposition expressed in these terms is therefore less cogent or persuasive.

A more serious problem which may lead to a greater level of objection would be as a result of the public feeling that their voices and concern had been heard and then ignored. A feeling of betrayal of trust in policymakers and those working at the coalface, in terms of this dismissal of opinion, could lead to an increased level of opposition. The most powerful way of expressing opposition to this policy would then be to opt out. This could seriously jeopardise the success of the policy in respect of increasing the number of organs retrieved. Chapter 5 provided a focussed discussion around the importance of public trust. This is because trust often leads to cooperation. One of the most effective ways to increase trust is to collaborate with those whose trust is sought. In this case, this can be achieved by engaging with members of the public and providing information to help educate and clarify points around this area of healthcare. From this, concerns can be raised and discussed at a local level and then incorporated into the planning phase of the policy. Public opinion needs to be effectively listened to, not simply heard. Public trust is essential for this system to work; without it failure is a very real possibility. Working with the public to deliver this policy is instrumental to its outcome in terms of success or failure.

There may be an air of scepticism on the public's part towards politicians' ability or desire to understand the needs of society and govern accordingly. In addition to this, recent events, such as those concerning organ retention, and failures by healthcare workers to provide decent care and compassion to patients and their families, have resulted in public confidence in the NHS

¹¹¹ The ODT's criticisms can be included in this.

waning. However, this should not deter policymakers from providing a policy which is beneficial to such a large number of people. These events should behave them to act openly and honestly with the public, addressing concerns as they arise and facilitating the opportunity for those who remain opposed to organ procurement to register this and have their wish respected.

Commenting on the advice provided by the Ethics Working Group (ODT 2008, Annex D) on introducing an opt-out system, the ODT stressed that “the ethical goal in terms of organ donation is to acquire the maximum number of organs via a system that is seen to be morally acceptable and consistent with a society’s values” (ODT 2008, p. 15). In accordance with this, what was needed was a system that would improve the number of organs provided for transplant. When considering the role of the public in succeeding in this, the Taskforce stated that within the constraints of morally acceptability, “Society has an opportunity to do something morally significant by improving donation rates, as it is an opportunity to remove suffering and bring about substantial benefits for many people” (ODT 2008, p. 15). The points which the ODT make here reflect the struggle between liberty and authority that can make policy decisions challenging, especially in a pluralist society with individuals expressing different values and priorities, all competing for recognition and support. Those charged with responsibility for devising a system for organ procurement need to consider these varying principles and individual values, and then factor these into a policy, the principal objective of which is to benefit the majority.

For an organ procurement policy to be successful in terms of increasing the number of organs retrieved for transplant the default position should be one which maximises utility for the living. Therefore, the interests of those in ESOF must take priority over the interests of deceased. Imperative to achieving this primary end is retaining public support; in view of this, freedom of choice -something which public opinion suggests is important- should remain protected under the policy, allowing individuals to determine what should happen to their organs posthumously. Relying on altruism of individuals alone is resulting in harm for a growing number of people, so

this should not be the main driver for the policy- saving lives should be. However, these need not be competing objectives; producing a policy which is ethically acceptable will require some practical considerations. In order to maximise the supply of organs, cooperating with the public is required.

Taking all of these issues into consideration, I would argue that a soft opt-out system with a combined registry appears to be the most effective of all three potential strategies- opt-in, soft opt-out and soft opt-out with a combined registry- in place for the procurement of organs which have been looked at in this thesis. Rather than enforcing procurement upon society, it gives individuals the opportunity to behave altruistically if they so choose, whilst at the same time defaulting to collective beneficence, reflecting the public's support for organ procurement. This system prioritises the needs of the living without riding roughshod over privacy interests, as it enables one's choices to be respected by preventing others from vetoing the deceased's personal directive. This will help to alleviate the suffering of more of those in need of a transplant than the present system is able to. It is therefore, I believe, a system which would most effectively acquire organs for transplant and remain consistent with a society's values.

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