

AN EMPIRICALLY INFORMED ETHICAL ANALYSIS OF CONDITIONAL AND DIRECTED
DECEASED ORGAN DONATION

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Abstract

This thesis explores the ethics of conditional and directed deceased organ donation. It uses an empirical bioethics approach that uses empirical data to inform and enhance philosophical analysis.

An initial philosophical analysis of the key ethical considerations was undertaken, and it is argued that the policy prohibiting most conditional and directed donations is wrong. The concept of altruism, in particular, is poorly conceived and applied in transplantation policy.

Qualitative data obtained by interviewing relevant stakeholders are presented. The data suggest that although there are concerns about the consequences of accepting conditional and directed donations, many participants thought these donations should be accepted in some circumstances. The data also provide lines of argument against conditional and directed donations, and these are considered.

Using this data, and making some reasonable assumptions, it is argued that it is better to accept conditional and directed donations than it is to reject them.

The thesis culminates with 8 recommendations for policy regarding conditional and directed donations, and argues that a trial period of accepting these donations should be implemented so that the effects can be accurately observed.

Dedication:

To my parents, Madge and Brian.

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Chapter 1 - Introduction

The aim of this thesis was to produce an empirically informed ethical analysis of conditional and directed deceased donation. A request for conditional donation occurs when a donor, or donor family, is willing to donate only if the organs are not given to a certain type of person. A directed donation occurs when a donor, or donor family, requests that organs are only given to a certain person or certain type of person. Current policy banning conditional deceased donation has been criticised in the academic literature and faced challenges from situations that have occurred in recent years. The empirically informed ethical analysis was therefore intended to assess existing policy and make recommendations for future policy where appropriate.

The empirical bioethics approach combines a philosophical analysis with data gathered from a qualitative study looking at the views of key transplantation stakeholders. Although in theoretical terms these aspects of the thesis could be considered separately, in reality the boundaries between the two are blurred; initial philosophical reflections informed the design of the empirical study, and aspects of the empirical project undoubtedly informed the on-going philosophical analysis. This thesis starts with an explanation and justification of the overarching empirical bioethics approach used, from which the overall structure of the thesis is then outlined and explained.

1.1 Complex nature of the problem

Conditional organ donation is a complex ethical issue which has been discussed in some detail in the philosophical literature. Some people have argued in favour of conditional donations^{1,2}, whereas others have argued against^{3,4}. The fact that there is

¹ Wilkinson TM, 'Ethics and the Acquisition of Organs', (Oxford: Oxford University Press, 2012)

² Radcliffe-Richards J, 'The Ethics of Transplants: Why Careless Thought Costs Lives', (Oxford: Oxford University Press, 2012)

³ Pennings G, 'Directed Organ Donation: Discrimination or Autonomy?', *Journal of Applied Philosophy* 24 (2007) pp41-49

disagreement is not surprising – these sorts of disagreements are common in philosophy – but one reason for this sort of disagreement is that different people consider different things to be important and worthy of extra consideration in moral arguments. Wilkinson, for instance, takes a broadly consequentialist approach and uses this to justify accepting conditional donations in some situations. Pennings, in contrast, takes equality and justice to be of more importance than maximising the number of donated organs and promoting positive consequences. In terms of guiding policy, the purely philosophical arguments appear to have reached an impasse. It is not clear that one approach is better than another, although there could undoubtedly be more philosophical debate about this (which would probably again end in a deadlock, albeit at a more fundamental level of moral theory).

In order to get beyond this stalemate, one might want to look beyond theoretical philosophy and consider the views of those likely to be affected by the issues. A policy based upon purely consequentialist reasoning is unlikely to receive much support if everybody affected by it considers other things to be more important and therefore disagreed **with the policy. In the words of Ives and Draper “an effective policy ... cannot** afford to disregard or alienate a significant proportion of the community **at which it is aimed”**⁵. Producing recommendations so unpopular they are rendered ineffective does not seem worthwhile. Similarly, a recommendation is unlikely to be taken seriously if it is based upon intuitions that are not shared by others, or incorrect assumptions about particular important things.

There are facts about the nature of organ donation and allocation systems in the UK that distinguish them from systems in, for example, the USA. These facts may, in some cases, reveal morally relevant differences. Some of these differences are defined in policy (The United States has different policies from the United Kingdom, for

⁴ Veatch RM, 'Transplantation Ethics', (Washington, D.C.: Georgetown University Press, 2000)

⁵ Ives J and Draper H, 'Appropriate Methodologies for Empirical Bioethics: It's All Relative', *Bioethics* 23 (2009) p251

instance⁶), whereas others can only be discovered by speaking to people who have experience of the intricacies of the transplantation system. A full understanding of how transplantation works *in practice* could be quite different from a full understanding of how transplantation works according to policy, and this practical account is more useful to philosophy that intends to guide future policy and practice.

As well as potentially ignoring context, abstract theoretical philosophy may also lack an awareness of differing perspectives. This may be problematic for something like conditional donation, the perceived acceptability of which may vary according to the perspective from which it is viewed. A potential recipient who urgently needs a transplant in order to live may consider a conditional donation more acceptable than someone who does not need a transplant so urgently. Difference in perspective may **mean that different moral considerations need to be taken into account, and a 'one-size-fits-all' take on the ethical issues may ignore these considerations. A philosopher** may try to imagine what is important to people from each perspective, but actually **having "encounters with experience"**⁷ is likely to provide more credible representations of different perspectives. Empirical data can highlight the considerations taken to be important from various perspectives, and put these forward for philosophical scrutiny. Although in the past there may have been a tendency to undertake philosophy from a detached, impartial, and supposedly objective perspective, there is now recognition that other perspectives have to be taken seriously in order for an ethical problem to be understood. For Leget *et al*, one of the requirements for a good description of an ethical **problem is to know how "relevant actors experience a practice"**⁸. It may be tempting to give these different perspectives some epistemic authority, but there ultimately needs to be a final arbiter to determine which considerations are valid and need to be taken

⁶ For instance in the USA it is relatively commonplace for recipients to advertise for living donors through websites such as MatchingDonors.com. Traditionally UK living donation has either been living-related or altruistic non-directed.

⁷ Ives J, 'Encounters with Experience': Empirical Bioethics and the Future', *Health Care Analysis* 16 (2008) p2

⁸ Leget C, Borry P, and De Vries R, 'Nobody Tosses a Dwarf!' The Relation between the Empirical and the Normative Reexamined', *Bioethics* 23 (2009) p232

most seriously. For instance, different perspectives may consider *directly conflicting* things to be important, or a certain perspective may consider something to be important that is actually completely unjustifiable. Taking these perspectives at face value could result in defending the indefensible, or cause difficulties in resolving conflicts if each perspective is given epistemic authority. An awareness of perspectives is vital, but philosophy is still needed to distinguish between those which are justifiable and those which are not.

These theoretical issues are not unique to this project, and there is increasing recognition within bioethics that a purely philosophical approach is often insufficient at answering complex applied questions.

1.2 The empirical turn

The problems of taking a purely philosophical approach have been articulated in detail by Hedgecoe⁹, but others have raised similar concerns. Lopez, for instance, claims that **bioethics' origins within philosophy have led to a "selectivity towards a formalistic, procedural, disembodied and universalistic way of identifying and resolving bioethical dilemmas"**¹⁰. This criticism may be valid of some philosophical bioethics, but can clearly be side-stepped by those who avoid a universalistic approach. Herrera correctly points out that different bioethicists **"align themselves with radically different perspectives"**¹¹, and this will be true even of bioethicists who practice under the broad and varied banner of applied ethics. Hedgecoe asserts that **"[b]ioethics is constructed in such a way as to ignore the role of social and cultural factors"**¹². Again, this seems true of some bioethics, but need not be true for all. Most philosophers do not exist in a social vacuum, and many of their intuitions and arguments will already be influenced by social and cultural factors. One need only look at different philosophical traditions within

⁹ Hedgecoe AM, 'Critical Bioethics: Beyond the Social Science Critique of Applied Ethics', *Bioethics* 18 (2004) pp120-43

¹⁰ López J, 'How Sociology Can Save Bioethics . . . maybe', *Sociology of Health & Illness* 26 (2004) p878

¹¹ Herrera C, 'Is It Time for Bioethics to Go Empirical?', *Bioethics* 22 (2008) pp137-46

¹² Hedgecoe AM, (2004) *op. cit.* p125

different societies to see that this is the case¹³. **Hedgecoe's criticism is probably** intended to cut deeper than this, however, and suggest that bioethics does not give sufficient weight to cultural and social factors affecting people other than the philosopher. This criticism is more convincing, since a purely theoretical piece of bioethics may attempt to reflect social and cultural factors affecting various people, but **these would ordinarily be based upon the philosopher's assumptions and these** assumptions may be quite different from the empirical reality. As with the earlier criticism, however, philosophy can still provide a way forward, so long as it is in possession of certain empirical data that helps the philosopher overcome her own assumptions, prejudices and limited perspectives.

Hoffmaster states that the applied ethics approach has no way of resolving the conflict that occurs when two or more principles work against each other¹⁴, and this does seem like a limitation of applied ethics. There is scope to appeal to different moral theories to justify a certain weighing of various principles, but then it is not clear why one moral theory should be given weight over another. Moreover, it is difficult to argue conclusively that one course of action is *the* right approach when someone endorsing a different moral theory might contend the same about a completely different course of action. This sort of conflict, although perfectly acceptable moral disagreement, could stand in the way of applied philosophical approaches acting as a useful and practical guide to specific problems, particularly when clear and consistent policy guidance is required.

Theoretical ethics (particularly with a consequentialist leaning) tends to predict the likely consequences of certain courses of action, and this can form part of the justification for normative conclusions – even if one does not adopt a fully consequentialist standpoint. Where theoretical ethics can be criticised is that often the

¹³ For instance, the morality underpinning Chinese bioethics is quite different from that underpinning western bioethics: Nie J-B, 'The Plurality of Chinese and American Medical Moralities: Toward an Interpretive Cross-Cultural Bioethics', *Kennedy Institute of Ethics Journal* 10 (2000) pp239-60

¹⁴ Hoffmaster B, 'Can Ethnography Save the Life of Medical Ethics?', *Social Science and Medicine* 35 (1992) pp1421-31

person predicting the likely consequences does so from a distant non-involved position, and may not actually have an accurate picture of the depth and range of the likely consequences. Although it would require an ambitious empirical study (probably taking both quantitative and qualitative approaches) to confidently predict all likely consequences, speaking to relevant stakeholders will give *a better* understanding of possible consequences than not doing so. The results gained from a qualitative study cannot be used to predict the statistical likelihood of a certain consequence, but they can give an indication of the range of possible consequences that ought to be considered. A creatively-minded philosopher may, in theory, be able to envisage these consequences without an empirical study, but by engaging stakeholders in the process there is less likelihood of things being overlooked.

Given the sometimes valid criticisms of traditional applied ethics, one may think it obvious that using empirical data is a requirement for good bioethics, and that using empirical data can provide all the answers to these criticisms. This is only true, however, if the right sort of empirical data is obtained, and if the data is used in the right way. The role given to empirical data must be given careful consideration, as there are limits to its capacity to inform ethical reasoning. As Callahan points out, when **confronted with an individual's belief about a particular problem, one can, from an ethical perspective, say "so what?"**¹⁵. The same is true if the view is held by many people. Just because one person or many people think that something is right or wrong, this does not mean that the something *is* right or wrong. The beliefs may be based upon invalid reasoning, or factually incorrect premises. This is a simplistic example of the is/ought problem¹⁶, but nevertheless it is a problem that may impose genuine restrictions on the role that empirical data can play in ethical debate.

¹⁵ Callahan D, 'The Social Sciences and the Task of Bioethics', *Daedalus* 128 (1999) p286

¹⁶ **This claims that "no descriptive statements** can entail an evaluative statement without the addition of at **least one evaluative premise"** Searle JR, 'How to Derive "Ought" from "Is"', *The Philosophical Review* 73 (1964) pp43-58

In a paper that is largely critical of applied ethics approaches, Hoffmaster concedes that some philosophers have contributed to the “moral improvement of front-line activities” by producing “highly nuanced, particularized analyses of cases and problems [with] an appreciation of the settings in which these cases and problems arise”¹⁷. If philosophy *can* do this, then one has to consider exactly what additional data is required for this to be achieved, as opposed to simply doing philosophy well.

1.3 Choosing a method for this project

The difficulties in combining empirical data with philosophy have been widely discussed, and several approaches have been suggested. Some of the first people to take the approach of combining empirical data with bioethical theorising were Alderson, Farsides, and Williams¹⁸ and Rogers¹⁹, and the approach to data collection for this project has strong similarities with Alderson *et al* (the merits of this approach are discussed in more detail in Chapter 8). There have been many attempts to explain how empirical data can be combined with theoretical philosophy^{20,21,22}, and various methods and techniques have been suggested for overcoming potential problems that are encountered.

The aim of this project was not to provide a sociological description of how study participants regard and think about conditional organ donation. The aim was instead to produce normative conclusions to guide acceptable practice involving conditional organ donation. The role of the qualitative data was as a resource to inform and improve the philosophy. The influence of the qualitative data was restricted to this role, and this may provide ammunition for claims that this project uses social science as a junior

¹⁷ Hoffmaster B, (1992) *op. cit.* p1422

¹⁸ Alderson P, Farsides B, and Williams C, 'Examining Ethics in Practice: Health Service Professionals' Evaluations of in-Hospital Ethics Seminars', *Nursing Ethics* 9 (2002) pp508-21

¹⁹ Rogers WA, 'Beneficence in General Practice: An Empirical Investigation', *Journal of Medical Ethics* 25 (1999) pp388-93

²⁰ Frith L, 'Symbiotic Empirical Ethics: A Practical Methodology', *Bioethics* 26 (2012) pp198-206

²¹ Leget C, Borry P, and de Vries R, (2009) *op. cit.* pp226-35

²² Molewijk B et al., 'Empirical Data and Moral Theory. A Plea for Integrated Empirical Ethics', *Medicine, Health Care and Philosophy* 7 (2004) pp55-69

partner²³, or places it in a handmaiden role²⁴. The production of good philosophy aimed for by this project, however, does not require cross-disciplinary equality.

Where matters of policy are involved, it is important that discussion focuses on rationality, consistency and robustness²⁵. Stakeholder views should be considered, but ought to be subjected to the same robust scrutiny that a philosophical argument should be. If the views are shown to be grounded in mistaken beliefs, or cannot be justified, then they can have no role in determining what ought to happen.

There is undoubtedly some merit in performing the integrated bioethics approaches described in much of the literature^{26,27} but it seems that many of the criticisms of more theoretical bioethics can be relatively simply overcome by conducting qualitative research to augment and inform a traditional applied ethics approach. The **aim of this project is not to formally 'integrate' philosophy and qualitative data in the manner described in the literature (see Molewijk et al for example²⁸)**. Rather, the aim is to do philosophy, but to do it in a way that is well positioned to provide practical, achievable and realistic guidance to a real-world problem. The qualitative data informs the philosophy, and enhances its fitness for purpose, but ultimately it is philosophy that provides the normative conclusions.

1.3.1 The limits of empirical data – A consistent philosophical approach

The approach taken for this project is quite distinct from those that attempt to seamlessly merge empirical data with theoretical philosophy into an integrated blend of

²³ Hedgecoe AM, (2004) *op. cit.* p133

²⁴ Haimes E, 'What Can the Social Sciences Contribute to the Study of Ethics? Theoretical, Empirical and Substantive Considerations', *Bioethics* 16 (2002) pp89-113

²⁵ Fischer F, Miller GJ, and Sidney MS, 'Handbook of Public Policy Analysis: Theory, Politics, and Methods', (Boca Raton, FL.: Taylor & Francis, 2006) p161

²⁶ Frith L, (2012) *op. cit.* pp198-206

²⁷ Molewijk B et al., (2004) *op. cit.* pp55-69

²⁸ *Ibid.*

the prescriptive and descriptive. Philosophy is the final arbiter for this project. In the rhetorical words of Callahan, **"ethics must, in the end, be ethics, not social science"**²⁹.

The approach used for this project uses empirical data for two primary reasons: to provide the facts, and to provide new lines of potential enquiry. This approach has been criticised^{30,31}. Nelson is concerned that, regardless of approach, empirical enquiry **is shaped by the "schedules of value endorsed by those directing such enquiry"**³². This would raise questions about the objectivity of the facts provided by any empirical study, particularly a study such as the one in this project where the philosophy and empirical study are conducted by the same person. The data has been collected, analysed and viewed with a philosophical mindset, and this will limit its applicability and usefulness in other settings. For the purposes of a largely philosophical project such as this, a philosophical approach to data collection is not inappropriate. It is, however, important to constantly bear in mind the impact on the data that this will have had, and the implications for this in terms of the overall conclusions of the project. This falls under the remit of reflexivity, **which requires "a critical interrogation of the relationship between the researcher, the world she is studying, and her experience and awareness of that world"**³³. **Although this thesis will not make use of the 'confessional tale'** espoused by Ives and Dunn (primarily because this would distract from the main body of the thesis), there is a need for open reflection and transparency when it comes to **starting points of the philosophical arguments, how participants' data has been coded and interpreted and why certain lines of argument have been chosen**. This will be discussed in more detail in Chapter 12, as will the impact that this has on the nature of the conclusions.

²⁹ Callahan D, (1999) *op. cit.* p285

³⁰ Hedgecoe AM, (2004) *op. cit.* pp120-43

³¹ Nelson JL, 'Moral Teachings from Unexpected Quarters: Lessons for Bioethics from the Social Sciences and Managed Care', *The Hastings Center Report* 30 (2000) p13

³² *Ibid.* p13

³³ Ives J and Dunn M, 'Who's Arguing? A Call for Reflexivity in Bioethics', *Bioethics* 24 (2010) pp256-65

1.3.2 The starting point

Conditional donation has been discussed in Government reports³⁴, in academic literature³⁵ and in the media³⁶. These sources have highlighted interesting areas of debate that demand further philosophical scrutiny. The DH report, for instance, suggested that altruism was a significant factor in assessing the acceptability of conditional donation, and this acted as a springboard for a more detailed philosophical analysis of altruism in Chapter 4. Similarly, existing philosophical literature provided subject matter for further examination, as did various media reports. This has formed the primary content of the philosophy chapters (3-7).

This process of undertaking this project began with a review of philosophical and sociological literature, policy documents/reports, and media stories. Immersion in these various types of literature provides a more varied understanding of the problem than merely focussing on one type of literature. This step is no different from what a good applied philosopher would (or should) do. Describing a problem requires researching it, and taking this approach provides a description based upon the perspectives that are already available³⁷. An applied philosopher ought to be aware that a full description of a problem may require viewing the problem from many additional perspectives, and although the ethical issues raised by conditional donation has been covered by ethicists, there is a lack of similar literature from the perspective of those most likely to be affected by it.

³⁴ For example, Department of Health (2000) 'An Investigation into Conditional Organ Donation', Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4035465.pdf, Last Accessed: 31/10/2012

³⁵ For example, Wilkinson TM, 'What's Not Wrong with Conditional Organ Donation?', *Journal of Medical Ethics* 29 (2003) pp163-64

³⁶ For example, BBC News (1999) 'No Health Apartheid', Available at: <http://news.bbc.co.uk/1/hi/health/387817.stm>, Last Accessed: 22/10/2012

³⁷ This description stage is present in most approaches to empirical bioethics. See, for example, Leget C, Borry P, and de Vries R, (2009) *op. cit.* pp226-35, and Frith L, (2012) *op. cit.* pp198-206

1.3.3 Intuitions and 'Encounters with Experience'

Qualitative data can reveal the way that participants reason and debate ethical issues. This may include their background assumptions, as well as the structure and form of their arguments. Taking these arguments and using them uncritically to construct more general ethical arguments relating to conditional donation would fall foul of the is/ought problem. Participants thinking that a certain argument can justify certain conclusions should not be accepted at face value. Instead, the arguments used by participants should be examined and subjected to rigorous philosophical scrutiny. As Callahan says, **it is important to "oppose forthrightly cultural values and moral convictions that do not withstand the scrutiny of fair and careful judgment"**³⁸. By knowing the sorts of arguments that participants are using, one can know what sorts of recommendations are likely to receive support in practice, and also know what types of argument are likely to be met with resistance. Potential resistance to a valid and sound argument does not necessarily speak strongly against that argument, because sometimes necessary reforms are not popular. It does, however, provide guidance about where **one's argumentative energies might need to be directed.**

One criticism of conventional applied ethics is that decisions about what is right or wrong are made on the basis of one individual's reasoning³⁹, and this reasoning may be based upon intuitions that nobody else shares. The role that these moral intuitions can play in the moral reasoning process has been described by van Delden and van Thiel⁴⁰ in their reflective equilibrium account of normative empirical ethics. Under traditional reflective equilibrium⁴¹, moral intuitions (or more strictly speaking, considered moral judgements) are given the same weight as moral principles, and the **'to-ing and fro-ing' between the two can result in modifications to them both.** The method described by van Delden and van Thiel incorporates the moral intuitions of

³⁸ Callahan D, (1999) *op. cit.* p277

³⁹ Hedgecoe AM, (2004) *op. cit.* p125

⁴⁰ Van Thiel G and Van Delden J, 'Reflective Equilibrium as a Normative Empirical Model', *Ethical Perspectives* 17 (2010) pp183-202

⁴¹ Rawls J, 'A Theory of Justice', (Cambridge, Mass: Belknap Press of Harvard University Press, 1971)

participants into the equilibrium, alongside the intuitions of **'the thinker' and moral principles**. None of these is afforded a pre-determined privileged position, and each is **open to revision**. One problem with this account is that it asks a lot of **'the thinker'** by requiring them to consider their intuitions on a similar footing to the intuitions of others. It would take a particularly humble (and honest) philosopher to undertake a truly transparent and impartial equilibrium of this kind⁴². This is not a knock-down argument against a true reflective equilibrium approach, but it presents a practical barrier to achieving its goal⁴³.

The moral intuitions and reasoning from participants in this study have been used to identify lines of argument that may otherwise have been overlooked, and to provide a springboard for philosophical discussion. They have not been included in a clearly-structured reflective equilibrium, as such, because the distinction between the **thinker's intuitions and participants' intuitions is not as clear-cut** as van Delden and van Thiel suggest. Philosophy does not take place in a social vacuum, and is rarely written in an instant. Discussions with colleagues, encounters in everyday life, and media stories may also influence one's views and beliefs, so the idea that applied ethics is conducted according to one person's isolated **'ivory tower' intuitions** is mistaken. A result of this is that the **'thinker' is already subject to the various pushes and pulls of their environment and the context of the research**. As Elliott has noted, exposure to **different perspectives can change one's moral intuitions**⁴⁴. By conducting interviews, **one's intuitions** come into critical contact with the moral intuitions of participants, and this process would be almost impossible to avoid with single-researcher projects. It could, in theory be documented over the course of a project, but knowing exactly when and **why one's intuitions or considered moral judgements have changed would be**

⁴² This may give a justification for projects like this being undertaken by interdisciplinary teams, but as a PhD this was a single-researcher project.

⁴³ A similar point about the demandingness of Reflective Equilibrium approaches is made by Arras in: Steinbock B, 'The Oxford Handbook of Bioethics', (Oxford: Oxford University Press, USA, 2007)

⁴⁴ Elliott C, 'Where Ethics Comes from and What to Do About It', *The Hastings Center Report* 22 (1992) pp28-35

impossible in practice. A formal reflective equilibrium approach of combining the philosophical and the empirical was not undertaken within the discussion chapter, but it is probable that some form of reflective equilibrium has already taken place over the course of the project.

In this project the boundary between researcher intuitions and participant intuitions was blurred further by the nature of the interviews. The interview process was deliberately critical, so the moral intuitions and judgments of participants were challenged throughout the data collection process. A previous study had success using **this critical approach and ensuring “that principles and values were at the centre of the discussions [in order to] examine the logic and structures underlying common arguments”⁴⁵, and this was also used as the model for Ives’** doctorate on Paternal Responsibilities⁴⁶. Although the embedded study in this project involved interviews rather than focus groups, the approach was largely similar. A philosophically-minded researcher conducted the interviews, and the topic guide for the interview was designed to focus on certain ethical aspects of conditional donations (although the semi-structured nature of the interviews allowed other areas to be discussed if participants wished). Participants were presented with modified counterfactual scenarios in order to encourage them to consider the justifications for their views, and were asked probing questions to try to get to the root of their reasoning.

1.3.4 Consequences and making acceptable recommendations

As discussed, philosophy can encounter problems when principles come into conflict, and the weight afforded to principles in these situations is open to debate. Different philosophers will afford different weight to different principles, as will members of the public. It seems obvious to state that a policy will be most acceptable to the public if it aligns best with what the public thinks the policy should be. If one wants to make

⁴⁵ Alderson P, Farsides B, and Williams C, (2002) *op. cit.* p509

⁴⁶ Ives J 'Becoming a Father/Refusing Fatherhood: How Paternal Responsibilities and Rights Are Generated', (PhD, University of Birmingham), (2007)

acceptable recommendations for policy, then one needs to know **what** the public thinks and **how** the public thinks⁴⁷.

In this project, in matters where there was more than one valid solution (where validity has been determined by a philosophical analysis of an argument), the option that aligned best with the views of participants has been endorsed. This was not to **deem one philosophical approach 'better' than another, but was instead merely a** practical concession to ensure that the recommendations, where possible, are based upon the sorts of reasoning and arguments that stakeholders would find acceptable. **This did not give participants' views an overwhelming power** – philosophy was the tool used to determine whether a particular line of argument is a suitable candidate for a policy recommendation – **but participants' views helped to select a recommendation** that was likely to be acceptable to stakeholders. Sometimes consistency and acceptability clash: the most acceptable policy for one thing may have a justification that is not consistent with the most acceptable policy for another thing. If this situation occurred, a recommendation that was thought to be as acceptable as possible whilst maintaining consistency was sought. Although acceptability of each recommendation is important, it is possible that people may find inconsistency unacceptable.

In many instances this process has, at first, worked backwards by taking the views of stakeholders and attempting to formulate consistent and coherent philosophical arguments out of them by seeing how they link to arguments discussed in the philosophy chapters and the wider literature. The vast majority of this takes place in Chapter 10. In this way, stakeholder views have provided a springboard for philosophical discussion. In some specific instances, the stakeholder views failed to provide suitably consistent and robust lines of argument, and here philosophical lines of argument have been used that best fit with the general lines of argument used

⁴⁷ This is an oversimplification, of course. One could consider many different publics, and even within each of these it seems unlikely that views would be homogeneous.

throughout. It should be noted that this method is markedly different to that discussed by Hoffmaster⁴⁸, **as this is not the 'ground up' approach that he espouses. There was no attempt to understand morality contextually⁴⁹**, as this runs the risk of relativism. Instead this was an attempt to apply moral reasoning to a specific context in a way that is acceptable to people within that context.

One might argue that by trying to make recommendations based upon what is acceptable to participants, there may be a tendency to maintain the status quo. This, however, would be much more likely in cases where participants generally believed that the status quo represented the right approach, which many of the participants in the embedded study did not. Moreover, one might argue that recommendations ought not be concerned with acceptability to stakeholders. Stakeholders may potentially have views that are completely at odds with ethical theory, and it would seem wrong to give decisive weight to the recommendation likely to prove most popular. For the approach detailed here however, this is of limited concern. A recommendation was not judged on its acceptability to stakeholders unless it was first shown to be independently ethically justifiable.

1.4 Thesis Structure

The next few chapters (3-7) take an in-depth look at the philosophy behind organ donation in general, and more specifically conditional and directed donations. They assess the acceptability of these donations within the context of an altruistic organ donation system and suggest that the understanding of altruism apparently used by transplantation policy-makers is inconsistent and unrealistic. Several philosophical arguments in favour of conditional and directed donations are then outlined. In order to abide by convention, the empirical study has separate methods and results chapters (Chapters 8 and 9 respectively). **A detailed summary of participants' views is presented**

⁴⁸ Hoffmaster B, (1992) *op. cit.* pp1421-31

⁴⁹ *Ibid.* p1425

in the results chapter. These results are then compared with those of other empirical studies and discussed alongside, and in conjunction with, philosophical arguments in the discussion chapter (Chapter 10). Finally, based on several (realistic) assumptions about the outcomes of permitting conditional and directed donations, in Chapter 12 proposals are made for a framework for handling requests to make conditional and directed donations.

The philosophy chapters, empirical study and subsequent discussions each have their own sub-aims that form part of the larger empirical bioethics methodology. These are outlined at the start of each of chapters.

The next chapter explains the background to conditional and directed donation within the United Kingdom (UK). This will set the scene for further and more detailed philosophical discussion in subsequent chapters.

Chapter 2 - Background

This chapter introduces the background to conditional and directed organ donation. It starts by describing the transplantation system in the UK, and then details a brief history of conditional donation and policy development. Finally, background literature is introduced and discussed to bring the ethical issues to attention.

2.1 How organ donation in the UK works

2.1.1 Transplant authorities and organisations in the United Kingdom

Transplantation in the UK takes place under the governance, control and advice of the following three key organisations:

The HTA was established in 2005 under the HTAct, and is the statutory authority charged with the giving of **"guidance on the Act's consent requirements for deceased donation of organs"**⁵⁰. It provides Codes of Practice, and is responsible for ensuring that human tissue is used ethically and with proper consent, in accordance with the law. It is also responsible for approving living solid organ donations.

NHS Blood and Transplant (NHSBT) is a Special Health Authority in the UK charged with optimising the supply of organs, blood and tissue. Part of its remit involves encouraging people to donate organs and helping to improve the quality, effectiveness and clinical outcomes of transplantation within the UK.

The Department of Health (DH) is responsible for legislation and overall direction of policy, and acts as a link between the HTA, NHSBT, and Ministers. The DH, HTA and NHSBT are agreed that they all **"have a locus in determining the rules for directed deceased donation"**⁵¹.

⁵⁰ Human Tissue Authority (2008) 'Minutes of Thirtieth Meeting of the Human Tissue Authority', Available at: http://hta.gov.uk/_db/_documents/July_08_Authority_papers_for_the_website.doc, Last Accessed: 31/10/2012

⁵¹ *Ibid.*

2.1.2 Parallel donation systems

There are two general sources of donated organs within the UK; living donors and deceased donors. Both systems share the goal of obtaining organs for transplantation in order to save or improve the lives of people who require transplants, but the principles that underpin each system, and thereby define acceptable donation, are very different.

2.1.3 Deceased donation

Deceased donation refers to donation after death has been declared (using either brain stem⁵² or circulatory criteria⁵³). The UK operates an opt-in deceased organ donation system; those who wish to become organ donors when they die register on the national Organ Donor Register (ODR). Due to the nature of the injuries that commonly result in someone being a potential organ donor⁵⁴, it is not normally possible to speak to the potential donor to establish her wishes around **the time of death. Where a person's** wishes regarding organ donation have not been recorded, the next-of-kin⁵⁵ are consulted. In cases where a person is on the ODR but their next-of-kin do not want to proceed with a donation, the **next-of-kin's wishes will** be respected, even though the HTAct is explicit in requiring only **the dying/dead person's consent**⁵⁶. Although there are

⁵² Brain stem death occurs when the brain stem has been damaged to the extent that its functions are irreversibly destroyed. Circulation and respiration can be artificially maintained, but the patient is considered dead nonetheless. Organ donation following brain stem death is sometimes referred to as 'heart beating donation' but more commonly as donation after brainstem death (DBD). The DH's Code of Practice provides more detail:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4035462.pdf (last accessed 29/06/2012)

⁵³ Circulatory death occurs when there is an irreversible cessation of neurological, cardiac and respiratory activity. Organ donation after circulatory death is sometimes referred to as 'non-heart beating donation', but more commonly as donation after circulatory death (DCD). Further information is provided in the Academy of Medical Royal Colleges' Code of Practice, available at: <http://www.aomrc.org.uk/item/a-code-of-practice-for-the-diagnosis-and-confirmation-of-death.html> (last accessed 29/06/2012)

⁵⁴ Often traumatic head injuries, which render the patient unable to consent for him/herself

⁵⁵ The HTA operates a hierarchy of qualifying relationships for next-of-kin, which is as follows: spouse or partner, parent or child, brother or sister, grandparent or grandchild, niece or nephew, stepmother or stepfather, half brother or half sister, friend of long-standing. Human Tissue Authority (2006) 'Code of Practice - Consent', Available at: http://www.hta.gov.uk/_db/_documents/2006-07-04_Approved_by_Parliament_-_Code_of_Practice_1_-_Consent.pdf, Last Accessed: 31/10/2012

⁵⁶ Human Tissue Authority 'Code of Practice 2 – Deceased Organ Donation', Available at: http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm?FaAreal=customwidgets.content_view_1&cit_id=674&cit_parent_cit_id=669, Last Accessed: 31/10/2012

arguments that the organs of dead people *should* be donated (i.e. without consent)⁵⁷, organ donation is not compulsory and the wishes of individuals and next-of-kin are respected.

Donors or donor families can choose which organs they would like to donate and whether they want these organs to be donated for transplantation or research or both. There is no obligation to donate all potentially transplantable organs; it is possible, for example, for someone to donate their liver and kidneys, but not their heart and lungs.

Deceased organ donation within the UK has traditionally been described as 'altruistic'. As will be discussed in Chapter 5 there is a lack of clarity about what this actually means, specifically within transplant policy, but it is often cited as a reason to prohibit payment for organs⁵⁸. Indeed, for many years organ donation has been regarded as 'The Gift of Life'⁵⁹, with 'gift' suggesting that deceased donors should receive no tangible reward in return for their donation.

Control over what happens to deceased organs is a controversial issue, since some people regard them as the property of individuals or families⁶⁰, whilst other people view them as a public resource⁶¹. If donated organs truly are a 'gift of life', this is at odds with them being a public resource, since they would not need to be given in order to be used⁶². Cronin and Price state that the law is "uncertain and unclear"⁶³; there is provision for individuals to control the way their bodies are used after death, but equally it is accepted that there is no property in a corpse⁶⁴. In order for organ donation to be 'a gift', the person doing the giving must have some disposal rights over

⁵⁷ Howard RJ, 'We Have an Obligation to Provide Organs for Transplantation after We Die', *American Journal of Transplantation* 6 (2006) pp1786-89

⁵⁸ Jasper JD et al., 'Altruism, Incentives, and Organ Donation: Attitudes of the Transplant Community', *Medical Care* 42 (2004) pp378-86

⁵⁹ NHSBT (2007) 'My Life, My Gift', Available at: https://www.organdonation.nhs.uk/ukt/campaigns/other_campaigns/detail.asp?id=6, Last Accessed: 22/10/2012

⁶⁰ Giordano S, 'Is the Body a Republic?', *Journal of Medical Ethics* 31 (2005) pp470-75

⁶¹ Truog RD, 'Are Organs Personal Property or a Societal Resource?', *The American Journal of Bioethics* 5 (2005) pp14-16

⁶² Cronin AJ and Price D, 'Directed Organ Donation: Is the Donor the Owner?', *Clinical Ethics* 3 (2008) p129

⁶³ *Ibid.* p129

⁶⁴ *Ibid.* p129

whatever is being disposed of, which would appear to point towards individual ownership. As Cronin and Price state, "[o]ne cannot give what one does not have"⁶⁵.

Although the situation regarding ownership is unclear, the policy regarding what happens after organs are donated is clear: specific organs can be offered for transplantation and whilst individuals can determine which organs are donated they have no control over who they are allocated to. Organs obtained from deceased donors are allocated according to a number of variables, including greatest medical need⁶⁶, best match, age, and (for some organs) waiting time⁶⁷. This is designed to result in a system that is fair and equitable⁶⁸, and free from personal prejudice.

2.1.4 Conditional and Directed Deceased Donation

Although most deceased organ donations are given freely and organs are allocated by medical professionals, some donors or donor families wish to have some say over who receives or does not receive the organs. 'Conditional' donation is also sometimes used to refer to any donation with conditions or directions attached, where the donation proceeding is contingent upon the conditions or directions being granted. Throughout this chapter, this sort of conditionality will be referred to as 'if and only if (iff) conditionality'.

Discussion of conditional and directed donation tends to focus on a narrow range of conditions, despite there being a potentially infinite number of possibilities. The most objectionable sorts of conditions tend to receive most attention, but commonly discussed examples include donations directed towards family members, individuals with certain health conditions, or people who have lived certain kinds of lives.

⁶⁵ *Ibid.* p129

⁶⁶ NHSBT 'Liver Organ Sharing Principles', Available at: http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/liver/liver_organ_sharing_principles/liver_organ_sharing_principles.jsp, Last Accessed: 23/10/2012

⁶⁷ NHSBT 'Deceased Donor Kidney Allocation Scheme', Available at: [http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/kidney_\(renal\)/renal_organ_sharing_principles/kidney_organ_allocation_scheme_2006.jsp](http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/kidney_(renal)/renal_organ_sharing_principles/kidney_organ_allocation_scheme_2006.jsp), Last Accessed: 23/10/2012

⁶⁸ NHSBT 'Organ Allocation', Available at: http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/organ_allocation.asp, Last Accessed: 23/10/2012

2.1.5 Living Donation – normally directed

Kidneys comprise the majority of living donations, and the number of living donors is approximately equal to the number of deceased donors. (1047 living donors in the financial year 2011/2012, compared with 1088 deceased donors⁶⁹). Although lung lobes can now be donated by live donors, none of these donations took place last year⁷⁰. Recent advances in transplantation have allowed livers to be split, which has allowed partial livers to be donated by living donors (although this is the subject of some ethical debate due to the risk that it currently involves⁷¹). Some organs, such as the heart and complete lungs, cannot be removed without causing the donor to die and can therefore only be obtained from dead donors.

Living donation has traditionally taken the form of 'living-related' donation, where the donor is either genetically or emotionally related to the recipient^{72,73}. In the UK, the living donation system is **based upon donor autonomy, consent and individuals' wishes**⁷⁴.

⁶⁹ NHSBT (2012) 'Latest Statistics', Available at: http://www.organdonation.nhs.uk/ukt/statistics/latest_statistics/latest_statistics.jsp, Last Accessed: 31/10/2012

⁷⁰ *Ibid.*

⁷¹ Surman OS, 'The Ethics of Partial-Liver Donation', *New England Journal of Medicine* 346 (2002) p1038

⁷² Human Tissue Authority (2009) 'Code of Practice 2 - Donation of Solid Organs for Transplantation', Available at: <http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm>, Last Accessed: 31/10/2012 p9

⁷³ Sometimes living donation takes more complex forms, such as paired or pooled donations, where directed donations take place across two or more pairs of donor and recipient in a qualifying relationship. This practice enables living donation where a donor is willing and able to donate, but is not a suitable tissue match with their intended recipient. If there is another donor/recipient pair in the same situation, and the donor in each pair is compatible with the recipient in the other pair, donation can go ahead from the donor in each pair to the recipient in the other. This sort of donation is directed (and presumably iff conditional given that the donor only agrees to donate to the intended recipient on condition that another donor will donate to the person with whom the first donor is tissue incompatible). Each donor donates an organ, and each recipient receives an organ, so the donor sacrifice and recipient benefit is the same as living-related, even though the donor-recipient relationship is not living-related.

⁷⁴ Cronin AJ and Douglas JF, 'Directed and Conditional Deceased Donor Organ Donations: Laws and Misconceptions', *Medical Law Review* 18 (2010) p277

2.1.6 Altruistic living donation

Although the vast majority of living organ donation takes the form of living-related (and is therefore directed), since September 2006⁷⁵ the Human Tissue Authority has **permitted 'altruistic living donations' in which a living donor agrees to donate an organ** to be allocated according to the same principles governing deceased donation. Although directing donations towards family members and friends is commonplace in living donation, altruistic donations are required to be completely non-directed – so, for example, it would not be possible to watch an appeal from a specific individual on **television and then request that one's kidney was given to her. The guidelines** are very clear; directed donations are only permissible if there is an appropriate genetic or emotional relationship, otherwise a living donation must be altruistic and non-directed.

2.2 Law, policy and guidance – history and development

2.2.1 1998 – racist conditions

There is little mention in the literature of conditional or directed donation before 1998, although this is not to say that requests for donations of this nature were not received, or indeed that they did not proceed. In 1998 a case of directed donation in the north of England caused controversy and a substantial media attention. In this case, the **relatives of a deceased man specified that the deceased's organs should only be made** available for transplantation if they would be transplanted to white recipients. This decision was made because the family felt it was what the deceased man would have wanted⁷⁶. Unsuccessful attempts were made to persuade the relatives to agree to a donation without any restrictions. Despite the nature of the directions attached to the donation, the organs were accepted, and two kidneys and a liver were transplanted into three white recipients. The remaining organs were unsuitable for transplantation, although the pancreas and lung tissue were retrieved and used for research (with no

⁷⁵ NHSBT 'Living Donors Boost Transplant Numbers', Available at: http://www.organdonation.nhs.uk/ukt/newsroom/news_releases/printTemplate.jsp?releaseId=162, Last Accessed: 23/10/2012

⁷⁶ Department of Health (2000) *op. cit.*

suggestion that this donation for research had any conditions or directions placed upon it)⁷⁷.

Although the directions in this case were racist, the donation would not have proceeded unless the directions were respected. As a result of accepting the donation, three people were given a chance to have their lives saved or improved. The white recipients, however, were at the top of their respective waiting lists anyway so no non-white person was deprived of an organ because of their ethnicity. The person at the top of the liver waiting list would probably have died within 24 hours if they had not received a transplant, **so there was an urgent need to obtain a liver. This 'benefit without harm' position might give a *prima facie* reason to think that even racist donations are acceptable**, but the subsequent Department of Health (DH) report and **reaction from the UK's media illustrate the contentious nature of directed donation**, particularly where the conditions attached are racist.

2.2.2 Backlash, DH report and outcomes

A DH investigation was ordered by the then Health Secretary Frank Dobson, who likened the racist conditions **to Apartheid regimes: "I have not been an opponent of the Apartheid movement for the whole of my adult life to see it introduced into the NHS"**⁷⁸. The then Shadow Health Secretary Liam Fox issued a statement saying that "this is an extremely disturbing case. There must be no question of ethnicity clouding clinical judgement in such matters."⁷⁹ Although these sorts of responses to the case are likely to be a reflex reaction from anybody opposed to racism, they perhaps fail to recognise the complexities of the situation. In this instance, the dilemma was not a case of **'accept the conditions and give the organs to white people, or reject the conditions and give the organs to people in greatest need regardless of ethnicity'**, but was instead **'accept the conditions and give the organs to white people, or reject the conditions and**

⁷⁷ *Ibid.* p16

⁷⁸ BBC News (1999) Available at: <http://news.bbc.co.uk/1/hi/health/387817.stm>, Last Accessed: 22/10/2012

⁷⁹ *Ibid.*

lose the organs'. A spokesperson for the British Medical Association (BMA) captured the situation with more subtlety:

This situation will place doctors in an almost unethical dilemma. They would be instinctively repulsed by the idea of discriminating between black and white patients. But faced with a dying patient and a matching organ they might well feel that their overriding duty was to save the patient's life.⁸⁰

On 8th July 1999, shortly after this case was picked up by the media, Frank Dobson issued a press statement declaring that "organs must not be accepted if conditions about the recipient are attached"⁸¹.

It is apparent that at the time of this case, policy on the acceptance of organs with conditions placed upon them was less clear than it is today, with the DH report stating that "there was no guidance explicitly addressing the point in 1998"⁸². Indeed, as a result of this case, and following requests for guidance on policy, the duty office manager of the UK Transplant Support Services Authority issued a memo on behalf of the organisation's Chief Executive stating that:

[The Chief Executive] has stated that the Duty Office must offer all organs that they are asked to by the transplant community. If that also entails conditions being set then this information must be passed on when offering.⁸³

This memo was later criticised in the DH's report, resulting in the Chief Executive resigning her position.

The report that resulted from the DH investigation concluded that "to attach any condition to a donation is unacceptable, because it offends against the fundamental principle that organs are donated altruistically and should go to patients in the greatest

⁸⁰ *Ibid.*

⁸¹ Department of Health (2000) *op. cit.* p22

⁸² *Ibid.* p23

⁸³ *Ibid.* p20

need.”⁸⁴ The report recommended that earlier statement issued by Frank Dobson should be formalised by the DH, and that this guidance should forbid conditions of any kind being attached to donated organs. Despite looking only at racist conditions in detail, the report endorsed the view that ***all*** conditions should be prohibited. The report also declared that although changes in guidance were required, legal advice is already **clear that “organs should not be allocated on the basis of race”**⁸⁵ (according to the Race Relations Act 1976).

Although the recommendations of the DH report were adopted as policy after their publication, they have not met with universal approval within the academic community. Wilkinson, for instance, argues that the DH panel’s findings are flawed because they fail to distinguish between ***making*** an offer and ***accepting*** an offer⁸⁶. It might well be utterly wrong for someone to place abhorrent racist conditions such as these on their organs, but whether this conditional offer of organs should be accepted is an entirely different question. The DH report purports to answer the question of whether or not conditional offers of donations should be accepted, but it actually focuses on the question of whether it is acceptable to place conditions on organs.

2.2.3 Legal aspects of the report

Prior to 2000, there was no specific legislation or guidance covering conditional and directed donation. The HTAct 1961 did not anticipate conditional donation, although the Race Relations Act 1976 would have made it illegal for racist conditions to be acted upon⁸⁷. The same Act also made it unlawful for somebody to induce or attempt to induce somebody to do anything contrary to the Act, so somebody placing racist conditions on a donation could be regarded as being in breach of the Act⁸⁸. The Panel concluded that no change to legislation was required, but that guidance should clearly

⁸⁴ *Ibid.* p1

⁸⁵ *Ibid.* p25

⁸⁶ Wilkinson TM, (2003) 'What's Not Wrong with Conditional Organ Donation?' *op. cit.* pp163-64

⁸⁷ Department of Health (2000) *op. cit.* p23

⁸⁸ *Ibid.* p23

prohibit any conditions being placed on donations. As Cronin and Douglas suggest, however, the DH Panel made a number of assumptions that were incorrect and lacked support from common law or statute⁸⁹. The over-riding assumption was that the **transplant authority's acceptance policy represented the law, and that if conditional and directed donations were contrary to this policy then they were unlawful**⁹⁰. However, since the 1961 Act did not directly prohibit conditional and directed donations, and not all conditions or directions would be contrary to the Race Relations Act 1976, the **transplant authority's (at the time this was the United Kingdom Transplant Services Support Authority) acceptance policy did not accurately represent the law**. Therefore, whilst it became a matter of policy for conditional and directed donations to be rejected, there was little legal backing for this.

The HTAct 2004, met the call for new legislation to govern the removal, storage and use of human tissue and organs as a result of the retained organs controversy⁹¹. The introduction of the HTAct actually had little impact upon conditional and directed donations, as it mostly focussed upon issues of consent, and NHSBT remains free to reject conditional and directed offers of organs according to its policy⁹².

2.2.4 Challenges to the Report – Specific Cases

The DH report prohibited all types of conditions and directions being placed on organs, despite only looking at racist conditions. Although adopted as policy, the coherence of **the report's recommendations has been challenged by subsequent requests for conditional or directed donation that have received public support**.

⁸⁹ Cronin AJ and Douglas JF, (2010) 'Directed and Conditional Deceased Donor Organ Donations: Laws and Misconceptions' *op. cit.* p292

⁹⁰ *Ibid.* p292

⁹¹ 'Royal Liverpool Children's Inquiry Report', (2001) Available at:

<http://www.rlcinquiry.org.uk/contents.htm>, Last Accessed: 31/10/2012

⁹² Cronin AJ and Douglas JF, (2010) 'Directed and Conditional Deceased Donor Organ Donations: Laws and Misconceptions' *op. cit.* p292

In one case⁹³ a 3 year old girl required a liver transplant, and her parents appealed on television for potential donors. Shortly after the appeal a 14 year old boy suffered a fatal head injury and his parents agreed for his organs to be donated to the general pool, except for his liver which they specifically requested should be given to this 3 year old girl. The parents of the deceased boy were informed that there was no guarantee that the liver would be transplanted to the young girl, but that suitable children are generally given priority over adults to paediatric organs. The parents agreed to the donation on this basis, and were persuaded to remove the condition from the donation.

Using media appeals to solicit directed donations is criticised by Price on the basis that media appeals are not available to everybody and that this **favours “those with access to such avenues of persuasion.”**⁹⁴ It would seem fair to say that media appeals themselves can be a good thing insofar as they may lead to an increase in the number of donated organs or an increase in awareness about donation-related issues, but using media appeals to obtain organs for specific individuals would almost certainly give these individuals an unfair advantage. This sort of unfairness is admittedly rife within wider society, but amongst other principles, the NHS has a duty to promote equality . One might argue that a system of equal access to media appeals could be established, where everyone wishing to launch an appeal was able to do so, but this could still result in unfairness, since some types of people benefit more from media appeals than others⁹⁵.

Another case in 2008 received sympathetic reactions from the academic community and the UK press. In March 2008, Laura Ashworth suffered complications following a severe asthma attack which resulted in her brain being starved of oxygen. **She died after two days in the intensive care unit of a local hospital. Laura’s mother**

⁹³ Neuberger J and Mayer D, 'Conditional Organ Donation-Case Scenarios and Questions', *Transplantation* 85 (2008) p1527

⁹⁴ Price D, 'Conditional Organ Donation-a View of the Ethicist', *Transplantation* 85 (2008) p1540

⁹⁵ Ross LF, 'Media Appeals for Directed Altruistic Living Liver Donations: Lessons from Camilo Sandoval Ewen', *Perspectives in Biology and Medicine* 45 (2002) pp329-37

had been suffering from kidney failure for several years, and Laura had intended to start the **process living kidney donation to her mother**. However, following Laura's death the HTA decided that existing policy dictated that her organs should be donated to the general pool, and that a directed cadaveric kidney donation to her mother was impermissible.

The emotions provoked by this decision are made clear on a memorial webpage for Laura. The friend who constructed **the page states**: "To rub salt in the wound, organ transplant authorities refused to allow Laura's Kidneys and Pancreas go to her sick **mother**"⁹⁶. **Rachel Leake, Laura's mother, said**: "It's an absolutely ridiculous law. Laura's helped three people through this, but Laura would have wanted to help me. To **help her mum**."⁹⁷ This quotation is particularly interesting, because it reveals something about the duties and responsibilities that family members often feel that they have to one another, and how these could over-ride impartial principles such as helping the greatest number of people, or those most in need of help. Rachel Leake is also quoted **as saying** "All I wanted to do was carry out her [Laura's] wishes. She would have been so upset that she was able to help other people and not her own mum."⁹⁸

The HTA issued a statement following this case which outlined what it regarded as the current position in transplantation policy:

The central principle of matching and allocating organs from the deceased is that they are allocated to the person on the UKT[ransplant] waiting list who is most in need and who is the best match with the donor. This is regardless of gender, race, religion or any other factor. The ethics of this position have long been supported by the government and professionals working in the field. In

⁹⁶ 'Laura Ashworth Memorial Webpage', (2008) Available at: <http://laura-ashworth.gonetoosoon.org/>, Last Accessed: 31/10/2012

⁹⁷ BBC News (2008) 'Mother Denied Daughter's Organs', Available at: <http://news.bbc.co.uk/1/hi/england/bradford/7344205.stm>, Last Accessed: 31/10/2012

⁹⁸ The Telegraph (2009) 'Mother Denied Daughter's Kidney Dies', Available at: <http://www.telegraph.co.uk/health/6076752/Mother-denied-daughters-kidney-dies.html>, Last Accessed: 31/10/2012

line with this central principle, a person cannot choose to whom their organ can be given when they die; nor can their family.⁹⁹

This is in line with the report from the DH on the 1998 case. Importantly though, while standing by existing guidance in this instance, the HTA recognised that **there could be “exceptional situations when this rule might be reconsidered”¹⁰⁰** and proposed to consult professionals and organisations representing families in order to consider whether the policy should be changed. UK Transplant (now part of NHSBT) issued a statement similar to that of the HTA, stating that it keenly awaited the results **of the HTA’s own review into directed donation after death.** This represents a turning point, and highlights the demand for further consideration of the outright ban of conditions being placed upon donated organs.

2.2.5 March 2010 – policy revisions

In March 2010, and as a result of NHSBT and HTA being asked on several occasions about the acceptability of directed donations¹⁰¹, the DH issued guidance regarding requested allocation of deceased donor organs. This document provided specific guidance for instances where a request is made for an organ obtained via deceased donation to be directed to a close relative or friend, in a manner akin to living donation. The document states that, in some exceptional circumstances, a request for directed donation can be accepted where the potential recipient is on a transplant waiting list and has an appropriately close relationship with the donor. This changes the previous policy of not accepting **any** conditions or directions on organs from deceased donors. It is worth noting that the document anticipates that directed deceased donations to family members or friends will occur only very infrequently, and **“should not, therefore,**

⁹⁹ Human Tissue Authority (2008) 'HTA Statement on Directed Donation of Organs after Death', Available at: <http://www.hta.gov.uk/media/mediareleases.cfm/411-HTA-statement-on-directed-donation-of-organs-after-death.html>, Last Accessed: 31/10/2012

¹⁰⁰ *Ibid.*

¹⁰¹ Department of Health (2010) 'Requested Allocation of a Deceased Donor Organ', Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114800, Last Accessed: 31/10/2012

have any significant impact on the UK-wide organ allocation scheme now on the individuals on the transplant list waiting for a transplant”¹⁰².

Although the guidance resolves some of the inconsistency between living and deceased donation, it does not attempt to align the two donation systems entirely. Importantly, the document emphasises that any deceased donation (even one featuring directions) must be unconditional, and that absence of conditionality is an underlying principle of **the UK deceased organ donation system. This does not mean ‘conditional’** in the sense of excluding people from receiving the donated organs, but instead refers to donations that will go ahead iff certain requests are complied with. So in order for a request for a directed deceased donation to even be considered, it must first be established that consent for donation is not contingent upon the direction being granted. Since, however, consent for donation can be withdrawn at a later stage it could be withdrawn after it was known that the direction was likely to not be granted, thereby allowing determined relatives to bypass this stipulation. The policy is also inconsistent with cases of directed living donation, where consent for the donation is ordinarily wholly contingent upon the direction being followed.

The second underlying principle mentioned by the document is equitable **treatment. It states that organs must be allocated in a “fair and unbiased way”** and according to agreed criteria. One of the factors used when allocating organs is the likelihood of achieving the best possible match between donor and recipient, and the likelihood of a good match is increased when the donor and recipient are closely related. The principles of equitable treatment and absence of conditionality are, **according to the policy document, key to ensuring that “the integrity of the UK and donation allocation programme is not compromised”**¹⁰³, and must be respected when requests for directed allocation are considered.

¹⁰² *Ibid.* p3

¹⁰³ *Ibid.* p4

Requests for directed allocation of deceased donors can be considered in two general circumstances. First, when a potential live donor dies before the live donation can go ahead, the request can be considered. Second, it may be the case that the **'working up' process for live donation** has not commenced or progressed sufficiently for the deceased's intentions to be clear, in which case the next-of-kin will be consulted to provide information relating to the **deceased's** intentions. Even in cases where consent is given unconditionally and a direction is requested, the policy does not guarantee that the direction will be granted. In circumstances where there is somebody with a **"desperately urgent clinical need"**¹⁰⁴, that person will be given priority.

It is clear that this updated guidance has been implemented in an attempt to recognise the complexities of cases such as Laura Ashworth, whilst still attempting to maintain the existing principles governing deceased donation in the UK. There is, however, inevitably some tension here. Allowing directed donation in some circumstances must compromise the equitable treatment principle, unless it is argued that the relative would have received the organ regardless of the request for direction (due to the strong match between related donor and recipient). But as established by the 1998 case, the fact that organs would have gone to that person regardless of the **directions does not appear to lend any particular weight to the donation's acceptability**. Presumably the 1998 case would still have been deemed unacceptable if the request **had been for an unconditional (in the 'if and only if' sense) directed donation towards white people**. This suggests that some directions/conditions are simply considered more acceptable than others; that racist conditions are unacceptable whilst family/friend directions are acceptable.

2.2.6 Inconsistencies

Cronin and Price draw attention to the inconsistencies that are present within the parallel donation systems:

¹⁰⁴ *Ibid.* p2

Although we are allowed to decide for ourselves whether or not we want to be organ donors upon our death, in the event that we do, we cannot attach a **condition to our 'gift' to society. Instead, somehow or another, our donation** slips straight into the net of public resource and impartial allocation. If, however, we are alive when we donate, we may legitimately direct our donation (our gift) to someone with whom we hold a relationship of some kind or another.¹⁰⁵

This was written prior to the policy revision issued in March 2010. Hilhorst, also before the 2010 policy revision, states:

"In short, although impartiality will probably be the main feature of a cadaveric allocation scheme, we can and should grant directed donation, when applicable, also in this context. Coherent policy-making requires this, and it would be unwise, inadequate and ineffective – if this option was not taken into **account.**"¹⁰⁶

He cites, as an example of something that might be acceptable, a mentally competent adult who is dying but expresses a wish for one of his kidneys to be transplanted to a good friend, whilst the other is donated to the general pool.

2.2.7 Shortage and need

The number of useable organs donated (living and deceased) each year in the UK is insufficient to meet demand. During the financial year 2011-2012, there was a total of 2135 organ donors (excluding cornea only donors), 1088 deceased donors and 1047 living donors¹⁰⁷. These donations resulted in 3960 organ transplants, of which the vast

¹⁰⁵ Cronin AJ and Price D, (2008) 'Directed Organ Donation: Is the Donor the Owner?' *op. cit.* p129

¹⁰⁶ Hilhorst MT, 'Directed Altruistic Living Organ Donation: Partial but Not Unfair', *Ethical Theory and Moral Practice* 8 (2005) p208

¹⁰⁷ NHSBT (2012) 'Latest Statistics', Available at:

http://www.organdonation.nhs.uk/ukt/statistics/latest_statistics/latest_statistics.jsp, Last Accessed: 31/10/2012

majority (2608) were kidney transplants. Even if somebody is willing to donate their organs after death, this is not always possible as other factors can dictate the likelihood of successful donation and transplantation. In order for organs to be successfully donated, the manner of death must result in an acceptable warm ischemic time (the time between cross-clamping - or asystole for brain-stem dead donors - and cold perfusion of the organ¹⁰⁸, and this ordinarily means that the patient must have died in hospital.

Although these figures represent a significant number of lives saved or improved, at the end of the financial year 2011-2012 there remained a total of 7636 people on transplant waiting lists¹⁰⁹. The simple fact that supply does not meet demand has negative consequences for those waiting for **organs: "1000 [people] each year – that's three a day – will die waiting as there are not enough organs available"**¹¹⁰.

2.2.8 Organ Donation and South Asians in the UK

Organ donation and transplantation is a particularly important issue for people of South Asian ethnic origin living in the UK. Despite several campaigns and initiatives designed to increase donation rates from this demographic¹¹¹, donation rates are still relatively low. This situation is exacerbated by the fact that people of South Asian ethnic origin are over-represented on transplant waiting lists (particularly renal transplant waiting lists). South Asian people are 3 times as likely as the general population in the UK to require an organ transplant, yet only 1% of people registered on the ODR are of South Asian ethnicity¹¹² **although South Asians account for approximately 4% of the UK's**

¹⁰⁸ Halazun KJ et al., 'Warm Ischemia in Transplantation: Search for a Consensus Definition', *Transplantation Proceedings* 39 (2007) pp1329-31

¹⁰⁹ NHSBT (2012) 'Latest Statistics', Available at: http://www.organdonation.nhs.uk/ukt/statistics/latest_statistics/latest_statistics.jsp, Last Accessed: 31/10/2012

¹¹⁰ NHSBT 'Homepage', Available at: <http://www.organdonation.nhs.uk/ukt/>, Last Accessed: 23/10/2012

¹¹¹ NHSBT 'Black and Asian Campaigns', Available at: http://www.organdonation.nhs.uk/ukt/campaigns/other_campaigns/black_and_asian/index.jsp, Last Accessed: 23/10/2012

¹¹² NHSBT 'Hindi Leaflet', Available at: http://www.organdonation.nhs.uk:8001/ukt/campaigns/pdf/hindi_leaflet.pdf, Last Accessed: 18/10/2012

population¹¹³. This combination of high demand and low supply, particularly for organs such as kidneys where there is an increased likelihood of a tissue-match if donor and recipient are of the same ethnicity, means that South Asian people tend to wait longer, and are more likely to die waiting, for organs to become available.

Many attempts have been made to explain the low donation rates from these communities, with some people suggesting that there may be religious barriers¹¹⁴, lack of awareness/understanding¹¹⁵ or a general mistrust of organisations like the NHS¹¹⁶.

It is possible that some barriers to donation from these communities may involve how organs are allocated. A small study conducted in the north of England **looking at Muslims of Pakistani origin found that "donation was considered less acceptable beyond the family, even when the deceased had expressed the desire"**¹¹⁷. One of the study participants also suggested **that "if you're giving it to your own family that will encourage others as well to give their organs to somebody in their own family"**¹¹⁸, and although it is not clear whether they were referring to living or deceased donation, it does suggest that if people could see the immediate benefits of organ donation in terms of impact upon family members, they might be more likely to donate.

Randhawa conducted a study looking at the influence of religion on organ donation amongst the Asian population in Luton, and although the study did not address conditional and directed donation specifically, one of the questions participants were asked was who they would feel comfortable receiving an organ from. A quarter of respondents indicated that they had **"a preference for organs from those with whom**

¹¹³ Office for National Statistics 'Ethnicity and Identity', Available at: <http://www.ons.gov.uk/ons/rel/ethnicity/focus-on-ethnicity-and-identity/focus-on-ethnicity-and-identity-summary-report/focus-on---ethnicity-and-identity-summary-report.pdf>, Last Accessed: 23/10/2012 p2

¹¹⁴ Randhawa G, 'An Exploratory Study Examining the Influence of Religion on Attitudes Towards Organ Donation among the Asian Population in Luton, UK', *Nephrology Dialysis Transplantation* 13 (1998) pp1949-54

¹¹⁵ Darr A and Randhawa G, 'Awareness and Attitudes Towards Organ Donation and Transplantation among the Asian Population', *Transplant International* 12 (1999) pp365-71

¹¹⁶ Morgan M et al., 'Attitudes to Kidney Donation and Registering as a Donor among Ethnic Groups in the UK', *Journal of Public Health* 28 (2006) pp226-34

¹¹⁷ Hayward C and Madill A, 'The Meanings of Organ Donation: Muslims of Pakistani Origin and White English Nationals Living in North England', *Social Science and Medicine* 57 (2003) p13

¹¹⁸ *Ibid.* p13

they have a biological or sociocultural bond”¹¹⁹, with some participants suggesting they would want organs from people of the same religion or same community. Even though this question focussed on receiving an organ, it suggests that biological and sociocultural bonds have some importance amongst these ethnic groups, and this might also transfer to donation.

Allowing conditional and directed donations may remove some barriers to donation for South Asian people, and therefore increase donation rates. This thesis has therefore given some focus to the South Asian population (for instance, South Asian potential donors were specifically recruited for the embedded study – see Chapter 8).

2.3 What the literature says

Much has been said about conditional and directed donation in the media, although this **has, as would perhaps be expected, focussed on specific cases and people’s emotional responses** to these. These sorts of donations have also received attention from the academic community. The arguments for and against conditional and directed donations can be categorised into key groups.

2.3.1 Consequentialism

One way of looking at conditional and directed donation is by focussing primarily on the consequences. Wilkinson, in particular, has presented a defence of the 1998 donation and other conditional and directed donations so long as certain conditions are met. He **defends the claim that “conditional allocation¹²⁰ is justified when it would save the life of at least one person without reducing anyone’s access to organs”¹²¹**. The 1998 case **satisfies the criteria of not reducing anyone’s access to organs because the organs** would not have been donated had the directions not been granted. If the organs were

¹¹⁹ Randhawa G, (1998) *op. cit.* p1952

¹²⁰ Wilkinson makes a distinction between conditional donation and conditional allocation. Conditional allocation is the acceptance and acting upon of a conditional donation.

¹²¹ Wilkinson TM, 'Racist Organ Donors and Saving Lives', *Bioethics* 21 (2007) p64

not going to be donated without the racist directions, access to organs for those who fail to meet the racist criteria is not *reduced*. Additionally, in the 1998 case the directions placed on the organs did not affect who the organs went to, since people at the top of the waiting list and best match were white anyway. Although it may have been wrong for the donor/donor family to place the racist directions on the donation, from a purely consequentialist point of view it would appear, at first glance, reasonable to accept the donation complete with directions.

Volk and Ubel argue, contra Wilkinson, that consequentialism cannot justify routinely accepting racist donations¹²². They cite evidence¹²³ to suggest that allowing these types of donations would actually reduce public support for organ donation, and therefore reduce future access to organs. Examination of the evidence cited reveals that they rely on questionable assumptions. The study they cite observed the effect of perceived transparency and fairness on willingness to donate within a sample of the United States population. Setting aside the different healthcare system in the United States, the results do show that willingness to donate is linked to perceived transparency and fairness; the lower perceived transparency and fairness, the less willingness to donate.

Volk and Ubel, in order to substantiate their claim, however, need to show that conditional and directed donations reduce perceived transparency and fairness, and they fail to do this. Indeed, it is not obvious that conditional and directed donations **would have this effect. It is possible that operating a system of 'donor choice' where donors can select recipients could be considered more transparent than the current system where complicated allocation algorithms are used which the lay public may find bewildering.** Similarly, the issue of perceived fairness is a complex issue (some of the perceived unfairness present in the study that Volk and Ubel cite is based upon income-

¹²² Volk ML and Ubel PA, 'A Gift of Life: Ethical and Practical Problems with Conditional and Directed Donation', *Transplantation* 85 (2008) pp1542-4

¹²³ Boulware LE et al., 'Perceived Transparency and Fairness of the Organ Allocation System and Willingness to Donate Organs: A National Study', *American Journal of Transplantation* 7 (2007) pp1778-87

based discrimination in healthcare allocation, which may not apply within the NHS), and it does not seem necessarily true that conditional and directed donations reduce fairness. To the extent that every donor would have the option to conditionally donate, the system could be perceived as fair. Although there is evidence that perceived transparency and fairness has an impact upon willingness to donate, it would be difficult to confidently predict the effect that conditional and directed donations would have on perceptions of transparency and fairness. Volk and Ubel have merely deferred the problem by assuming a causal pathway for which there is no evidence.

Consequentialist arguments about conditional donation must take into account possible impact upon overall donation rates. Wilkinson does not neglect this longer term consideration, and indeed the claim he seeks to defend takes it into account. He **states** "(a) natural worry about a policy of conditional allocation is that it could have bad effects on the patterns or levels of donation, making it harder for some groups to **get access to organs or even reducing the overall number of donations.**"¹²⁴, but he argues that this need not be the case. He suggests that these sorts of concerns are mere speculation, and that without clear empirical evidence, they provide no argument for **or** against conditional and directed donations. Wilkinson suggests that empirical findings are likely to differ from place to place, and this highlights the difficulty in attempting to justify conditional and directed donations on consequentialist grounds; the consequences are difficult to predict accurately, measure and compare¹²⁵. This highlights the problem with ascertaining the soundness of **Volk and Ubel's broader** argument that conditional and directed donations may not be justifiable on consequentialist grounds – the consequences are simply unknown.

¹²⁴ Wilkinson TM, (2007) 'Racist Organ Donors and Saving Lives' *op. cit.* p72

¹²⁵ Hypothetically, allowing conditional donations might supply enough organs for every person who needs one to receive one immediately, and this could be regarded as consequentially positive. Yet allowing these sorts of donations might encourage discrimination in wider society, which might be consequentially bad. It is not clear how these consequences should be weighed against one another.

2.3.2 Special obligations and partiality

Quigley suggests that we already allow directed donations in living donation¹²⁶, which shows that the HTA accepts that direction *per se* is not unethical. She suggests that **this may be because the relationship “between living donor and recipient is... morally significant”**¹²⁷ and the decision to direct a donation is therefore not borne out of prejudicial judgments towards another person or class of person. This is unclear though, since to favour a family member over a stranger *is* to make a prejudicial judgment about that stranger; specifically that their importance to oneself is less than that of a family member. It might not be a viciously motivated judgment, but it is a judgment nonetheless and Quigley does not attempt to explain what makes some judgments more acceptable than others.

Quigley criticises the handling of the Laura Ashworth case, suggesting that **“when regulatory bodies make what are essentially moral decisions they should take care to ensure that common sense thinking triumphs over the algorithmic application of inadequately considered and unjustified policy that parades as ethical principles”**¹²⁸. An appeal to common sense thinking is itself an appeal to common sense thinking, but it is not obvious that common sense thinking can provide all the answers. The medical professionals who accepted the racist organ donation in 1998 may have thought that they were using common sense (saving the very lives that would have been saved if no conditions had been placed on the organs), yet the subsequent report strongly criticised their actions. While this criticism does not mean that the staff who accepted the racist donation used incorrect common sense reasoning, it does suggest that people regard different things as being common sense. If common sense thinking can provide different answers to the same problem, then some means of determining which is the best answer is required. It is not clear that the most commonly held view is necessarily

¹²⁶ Quigley M (2008) 'Directed Deceased Organ Donation: The Problem with Algorithmic Ethics', Available at: <http://www.ccels.cf.ac.uk/archives/issues/2008/quigley.pdf>, Last Accessed: 31/10/2012

¹²⁷ *Ibid.* p4

¹²⁸ *Ibid.* p7

the right one¹²⁹. More importantly though, an appeal to common sense thinking may merely be an appeal to intuition; and intuitions can frequently be wrong.

One way of attempting to defend conditional and directed donation to family and friends is to speak of the special obligations that may exist between certain people.

Many philosophers suggest that one owes things to one's family and friends that one does not owe to strangers, and that this permits or even demands special treatment of one's family and friends^{130,131}. Although the details of different accounts of special obligations vary, the general claim is that one has obligations to certain people by **virtue of one's relationship to them, and these are obligations** that one does not ordinarily have with people with whom one does not have a relationship.

If it can be shown that special obligations exist, then using them as the basis of a defence for conditional and directed donation is straightforward. If one has a special obligation to help a certain person (but not others), then one ought, morally, to help this person. By not permitting conditional and directed donations, the transplant authorities prevent people from fulfilling their special obligations. While it may not be the case that this results in people acting immorally (since arguably one does not act immorally if one fails to fulfil a duty that one is unable to fulfil), it may be the case that fulfilling special obligations promotes valuable goods and that by preventing the fulfilment of these obligations the transplant authorities reduce the possible promotion of these goods. First, however, it would have to be shown that special obligations do exist.

Glannon and Ross¹³² suggest that when one stands in a certain relationship with another person, there may be expectations and obligations that arise from this. They consider two ways of grounding these obligations; voluntariness and intimacy. Starting

¹²⁹ Callahan D, (1999) *op. cit.* pp275-94

¹³⁰ Cottingham J, 'Partiality, Favouritism and Morality', *The Philosophical Quarterly* 36 (1986) pp357-73

¹³¹ Friedman M, 'The Practice of Partiality', *Ethics* 101 (1991) pp818-35

¹³² Glannon W and Ross LF, 'Do Genetic Relationships Create Moral Obligations in Organ Transplantation?', *Cambridge Quarterly of Healthcare Ethics* 11 (2002) pp153-59

with the former, they suggest that if a parent voluntarily conceives a child then the parent voluntarily establishes a relationship (both biological and social) that involves duties to the welfare of the child. This may seem a reasonable basis for this type of obligation¹³³, but it offers an incomplete picture when considering the obligations that one may consider oneself to have. Just as many parents feel an obligation to their children, many children (particularly adult children) feel obligations to their parents (the Laura Ashworth case would be a good example of this), and siblings also feel obligations to one another. Glannon and Ross state that special obligations require a grounding that considers something beyond the origins of a relationship, and suggest that this grounding is intimacy.

According to Glannon and Ross, intimacy is a pre-requisite for special obligations between family members and develops over time through shared needs and interests¹³⁴. Moreover, intimacy *implies* shared needs and interests¹³⁵. The extent of the special obligations increases according to the degree of intimacy. They incorporate **Sharpe's idea that the phenomenology of intimacy requires both benevolence and beneficence and suggest that a morality between intimates requires a "positive conception of promoting the other's well-being"**¹³⁶. If donating an organ meets the needs of someone with whom one is intimate, then the intimacy results in a special obligation to donate that organ for that person.

Glannon and Ross talk about these obligations broadly in the context of living donation (indeed, as does most of the literature), and it is not obvious how significant intimacy is once one of the intimates has died as it may seem misguided to assert that, after death, there is still an intimate relationship in which to ground a special obligation. A distinction between types of death may help here, however. It has been

¹³³ There is a wealth of literature agreeing or disagreeing with this issue. See Archard D, Benatar D, (eds.), *'Procreation and Parenthood'*, (Oxford: Oxford University Press, 2010) for instance.

¹³⁴ It seems that this intimacy need not be restricted to family members, and could extend to close friends.

¹³⁵ Glannon W and Ross LF, (2002) *op. cit.* p149

¹³⁶ *Ibid.* p157

argued that a person suffers two types of death; biological and social¹³⁷. The order of these can vary¹³⁸, but one might argue that there is still a relationship present until the point of social death. If social death occurred after the decision about organ donation was made, then this relationship could be used to ground a special obligation. Even if one does not accept this concept of two deaths, one could consider a directed donation towards a family member/friend as the final act within an intimate relationship, or the final discharge of duty (particularly if the decision to direct the donation is made *by* the intimate before she dies).

Volk and Ubel also suggest that a pre-existing relationship¹³⁹ between donor and recipient can produce a special obligation, although they offer less in support of this idea, claiming only that ethicists and evolutionary biologists have argued for years that it is the case, and that relationships have shaped human behaviour over the course of history¹⁴⁰. **They suggest that an obligation of this sort “outweighs concerns about fairness and waiting times”¹⁴¹.**

They also suggest that other patients on the waiting list might not mind being bypassed in cases where there is a special relationship between donor and recipient. It is true that some people on the waiting list might be particularly selfless and put many other people in front of them, but this does not entail that other people *should* be in front of them, as special relationships may just be one factor amongst many to consider.

¹³⁷Sweeting H and Gilhooly M, 'Dementia and the Phenomenon of Social Death', *Sociology of Health & Illness* 19 (1997) pp93-117

¹³⁸ *Ibid.* pp93-117

¹³⁹ They do not specify the type of relationship, but their mention of “loved ones” suggests close emotional relationships.

¹⁴⁰ Volk ML and Ubel PA, (2008) *op. cit.* p1544

¹⁴¹ Much has been written about the moral status of human relationships, and how they may warrant extra concern or priority over other notions of moral duty. For instance, Williams has argued that there are certain **ground projects that relate to people’s sense of identity**, and these may include certain human relationships. **Although utilitarianism may suggest that that abandoning some of one’s personal projects is obligatory if it promotes overall well-being**, Williams suggests that it cannot demand that one **overlooks one’s ground projects**. Smart JJC and Williams B, 'Utilitarianism: For and Against', (Cambridge: Cambridge University Press, 1973)

Hilhorst discusses related issues, suggesting that family ties or close relationships might motivate people to give permission for their organs to be donated, in a way similar to living donation. He suggests that although impartiality should remain the main feature of deceased allocation, directed donations should be granted in some circumstances. The specific situation to which he refers is a case where a dying patient wishes to direct one kidney to a family member/friend and the other kidney to the general pool. This would align at least partially with the March 2010 policy revision, and according to Hilhorst, would result in a more coherent overall donation system¹⁴². As will be discussed shortly, however, this sort of situation is unlikely to arise frequently, due to the sudden way in which most potential organ donors die.

Ankeny adopts a slightly different strategy, and asserts that donating to relatives or people with whom one has an emotional relationship is intuitively acceptable, and can sometimes be admirable. Unlike the ideas discussed earlier, Ankeny does not suggest that it can be obligatory to favour a friend or relative. Ankeny takes a broadly utilitarian approach to the issue, suggesting that preferences expressed in donating an organ to a relative are strictly personal and because they are generally **regarded as appropriate they do not "unduly corrupt the egalitarian basis of utilitarianism"**¹⁴³. She claims that directing living donation is permitted *because* of the partiality of the donor towards the recipient, since the donor serves her *own* interests by saving the life of a loved one. It is not obviously true that conditional deceased donations ought to be permitted *because they allow the donor's interests to be fulfilled, but if the donor's interests are compatible with the aims of deceased organ donation* then this provides *a* reason to allow them to be fulfilled.

The general idea of special obligations accords with the March 2010 policy revision, and clearly features in living donations. Indeed some defenders of directed

¹⁴² Hilhorst MT, (2005) *op. cit.* p207

¹⁴³ Ankeny RA, 'The Moral Status of Preferences for Directed Donation: Who Should Decide Who Gets Transplantable Organs?', *Cambridge Quarterly of Healthcare Ethics* 10 (2001) p392

donation towards family members have focussed on the idea that the donation *could* have gone ahead as a directed living donation were the donor still alive¹⁴⁴. This would only be true for a small set of potential conditional or directed donations however, so does not provide a more general argument in favour of allowing them.

There is a significant difference between directed living donation and requests for directed deceased donation, because in many cases of deceased donation the dying/dead person is not in a position to direct her own organs; instead it falls to the next-of-kin to make decisions. Interesting cases arise when it is the next-of-kin herself who requires an organ and essentially requesting that an organ is directed to her. While it may be the case that this is what the deceased would have wanted, the fact that the organ is being directed by the next-of-kin to herself raises a question of whether this donation decision reflects the special obligation the donor is thought to have had or whether it is an act of pure self-interest¹⁴⁵. This scenario highlights the difficulty in distinguishing between different types of motivation, but also highlights the difficulty of determining who the donor is (this is discussed in more detail in Chapter 3), since it is hard to see how a dying/dead donor can be considered to be fulfilling an obligation if they lack the agency required to do so¹⁴⁶.

Even if one accepts that obligations do exist between family members or friends, this is not to say that these obligations are the only consideration; the NHS, as a publically funded institution premised on notions of equality of access, may have an obligation to impartially allocate healthcare resources according to strictly medical factors. For this reason, the NHS may have strong justification for choosing not to

¹⁴⁴ Price D, (2008) *op. cit.* p1541

¹⁴⁵ Pure self-interest should be distinguished from self-interest entangled with others' interests. If one agrees to donate an organ to a family member, then there is some entanglement of interests. If one agrees only to **for a deceased relative's organs to be donated to oneself, then this is purely self-interested.**

¹⁴⁶ One concern is that if it is the next-of-kin making the decision to donate the organs, then the next-of-kin is essentially the agent, and there may be an argument that the next-of-kin should be able to direct an organ to her friend/family member even if that person is not a family member or friend of the dead patient.

facilitate the sorts of directed donations that reflect special obligations between family members/friends¹⁴⁷.

The NHS does appear to accept the existence of, and act upon, the special obligations that arise between family members and friends, as evidenced by the living donation programme in the UK and the March 2010 policy revision. It seems, however, that these are regarded only as *prima facie* obligations, and that other concerns can over-ride them. For instance, the 2010 policy revision still gives super-urgent patients priority over family members, so although special obligations appear to garner some consideration, they are only one of a larger set of considerations.

2.3.3 Justice/fairness/equality vs autonomy

The most common arguments against accepting conditional and directed donations hinge upon the related ideas of justice, fairness and equality. Pennings, for instance, recognises that the positive consequence of saving a life carries some weight, but considers directed donations on the basis of non-medical criteria to be violating too many deontological constraints to be acceptable¹⁴⁸. He asserts that society does not want to maximise the number of organs available at any cost, and states that instead it wants to maximise the amount of organs available within a set of normative ethical rules. The balance between maximising the number of available organs and the constraints of the other normative rules is something that Pennings does not specifically justify. He does, however, state that some deontological rules express the character of the donation, and that by removing some deontological constraints (such as altruism or voluntariness) the donation would no longer be a gift.

Pennings states that distributive justice comes to the fore when resources are scarce, and that for a donation system to be fair and egalitarian, only morally relevant

¹⁴⁷ This is not to say that conditional and directed donations should not be permitted however; there would perhaps still be scope for them to be permitted outside the NHS, within the realms of private healthcare which is not generally grounded on the same ideal of equal access.

¹⁴⁸ Pennings G, (2007) *op. cit.* pp41-49

criteria should be used to make allocation decisions¹⁴⁹. Criteria such as race, social class and religion are arguably not morally relevant and would be best described as subjective non-medical criteria¹⁵⁰. The egalitarian position described by Pennings is founded on the claim that every person has an equal right to live, and although some people may argue that this is a false claim, it is a claim that underpins many aspects of public policy.

A statement from the Transplantation Society (an organisation aiming to provide the focus for global leadership in transplantation¹⁵¹) **declares that “the allocation of organs from deceased donors should be based on the principles of justice, equality, and utility”¹⁵²**. Price seems to agree that the transplant system should at least appear to be **just, saying in relation to a case with racist conditions** “it was correct to reject the gift even if the same recipient would have received the organ in any event, as an appearance of injustice would otherwise be generated and would be just as potentially **detrimental to the image of fairness in distribution”¹⁵³**.

Conflicting with broader societal concerns such as fairness and equality is the respect for individual wishes and preferences that forms an important part of what is taken to be autonomy. Pennings states that the principle of autonomy implies that one has the right to make important decisions in **one’s own life, and that this includes the right to “do what he or she thinks is right”¹⁵⁴**. Some respect for autonomy is present in existing law and policy, since consent is sought for organ donation; were autonomy not important, routinely retrieving organs without consent may be less objectionable. During life, people can choose what they donate time, money or effort to and their decisions will often reflect their values and beliefs. Pennings suggests that some people

¹⁴⁹ *Ibid.* p43

¹⁵⁰ Although as will be discussed in Chapter 10, even so-called ‘objective medical criteria’ draw on implicit moral values

¹⁵¹ Transplantation Society ‘Vision Statement’, Available at: http://www.tts.org/index.php?option=com_content&view=article&id=3&Itemid=6, Last Accessed: 31/10/2012

¹⁵² Tibell A and On Behalf of the Ethics Committee of the Transplantation S, ‘The Transplantation Society Statement on Directed and Conditional Donation’, *Transplantation* 85 (2008) pp1538-39

¹⁵³ Price D, (2008) *op. cit.* p1540

¹⁵⁴ Pennings G, (2007) *op. cit.* p45

might consider the right to autonomy to extend to specifying recipients or types of **recipients, and again such decisions could stem from the individual's values and beliefs.** This sort of argument holds some intuitive appeal, especially when one considers what happens generally to possessions and wishes after death. One can choose to whom one leaves possessions via a will, and given this is an acceptable means of disposing of possessions, maybe the same should apply to organs. Decisions about the disposal of possessions can leave a **long-lasting memory and impression of individuals' lives after** their deaths, and arguably people should have some control over how they are remembered. It is, of course, true that organs are not possessions in the sense of being property that is owned, but some control over what they are used for is permitted; an individual can choose whether her organs are donated for transplantation or research, for instance, which is a variant of direction.

Pennings disagrees with this argument, claiming that whilst people are allowed to choose who receives their time or money, they are not allowed to choose who lives **and dies. Pennings' claim seems incorrect, however. By choosing to give money to one** life-saving charity over another, one *can* effectively choose who lives or dies, or more precisely, what type of people live or die. One can choose to donate time or money to a famine relief charity which works in Ethiopia, rather than give time or money to an earthquake aid charity responding to a specific disaster in Japan, for instance. This sort of picking and choosing *is* allowed and moreover it is commonplace¹⁵⁵. It could be argued that giving money is not the same as giving an organ, on the basis that an organ is itself a life-saving resource whereas money simply allows life-saving resources to be obtained. This additional step in the chain does not seem morally relevant, however. Donating a food parcel to a disaster relief charity would be donating a life-

¹⁵⁵ Of course, something is not morally acceptable just because it is commonplace. Lots of wrongdoing is **commonplace. Highlighting some practices as 'commonplace' or 'generally acceptable' here is merely** intended to highlight inconsistencies between attitudes to, and perceptions of, conditional and directed donations and other practices. It may be that the perceptions of conditional donation are incorrect, but equally it may be that the perceptions of other practices are incorrect.

saving resource, yet one could still choose a disaster relief charity working in one country over another charity working in another.

Pennings also fails to make clear the extent to which it *is* permissible to choose who lives or dies, or at least fails to recognise the full implications of his statement. In **one sense, making a decision about whether or not to donate one's organs could be** seen as making choices about who lives or dies; if one chooses to donate a liver but not a heart, then one is choosing to potentially save the lives of people who need liver transplants but not people who need heart transplants. So in order for Pennings to be **consistent, he would have to endorse an 'all or nothing' approach to organ donation,** where donors either donate all of their organs or none of their organs. Yet even choosing to donate or not donate potentially has an effect upon who lives or dies (since choosing to not donate organs increases the likelihood of people who need transplants dying). A further problem that Pennings encounters is that *someone* has to choose who lives or dies; if it is not the donor, it will fall to medical staff, and it is not obvious that their position gives them additional moral authority to decide who should live and die (despite the fact that this is routinely what happens in practice, as discussed in Chapter 10).

Pennings goes on to sum up the problem by saying "[t]he broader philosophical question raised by these considerations is to what extent the society should recognise specific preferences and value judgements of individual citizens and to what extent the society should contribute and support these preferences"¹⁵⁶.

Ankeny describes the situation in a similar way:

A tradition of liberal pluralism grounds respect for individual preferences and affirmation of competing conceptions of the good. But we struggle to maintain (or at times explicitly reject) this tradition in the face of individual preferences

¹⁵⁶ Pennings G, (2007) *op. cit.* p46

that we find distasteful, suspect, or even repugnant, especially where the broader social good or respect for equality is at stake¹⁵⁷.

As Pennings correctly states though, the real issue is about more than just autonomy. Donated organs require a transplantation system in order for them to be utilised, and certainly under the current system this is a socially institutionalised system¹⁵⁸. If the autonomy of donors who wish to conditionally donate their organs is to be fully respected, then the transplantation system must do more than tolerate **people's wishes** – the system must actively facilitate and collaborate with them.

2.3.4 Gifting/altruism

Volk and Ubel draw some distinctions that they consider to be ethically relevant. First, they claim that it is commonplace in our culture to direct gifts towards individuals, whilst directing gifts towards certain groups of people can lead to concerns about exclusion¹⁵⁹. It is certainly true that it is commonplace to direct gifts towards individuals, but it is not also true that directing gifts towards certain groups *necessarily* leads to concerns about exclusion (and indeed they do not claim it does). Someone donating a large sum of money to a specific charity is unlikely to be particularly concerned with exclusion, but it seems inevitable that unless all the basic needs of all **the world's population are being met, there will be an element of exclusion. Moreover,** Volk and Ubel seem to suggest that it is not objectionable for certain groups (such as children) to be favoured so long as this is part of a publically supported allocation policy backed up by ethical theory¹⁶⁰. This suggests that they are perhaps more concerned with the potentially objectionable reasons for wanting to include/exclude certain types of recipients rather than merely the consequences.

¹⁵⁷ Ankeny RA, (2001) *op. cit.* p387

¹⁵⁸ Pennings G, (2007) *op. cit.* p46

¹⁵⁹ Volk ML and Ubel PA, (2008) *op. cit.* pp1542-4

¹⁶⁰ *Ibid.* p1543

Of course, many charities tend to cater for the needs of multiple groups of people and it might seem unusual for a charity to accept a donation on the condition that it was only used to help specific sub-groups defined by the donor. Some charities do have specific campaigns though, and it would not seem wrong (and possibly unlawful) to do otherwise, for money raised for a particular campaign only to be used to benefit those who were the focus of the campaign. One might argue that charities aimed at alleviating famine use images of particular starving children to highlight the bigger issue, and that the particular children featured in the marketing materials may not be the ones receiving benefit. This may be why charities tend to use language like **"your donation will help children like [name]", rather than naming specific individuals** as the recipients of aid. What is also notable is that some charities receive much more media exposure than others (Comic Relief, for instance has a whole night of television devoted to fundraising), yet it would be absurd to suggest that *donations* to these charities were unethical and should be turned down simply because other charities do not have equal access to media coverage. One might argue that some charities receive much more exposure than others, and that *this* is unfair, but this does not make the donations to these charities unethical.

There is a subtle difference between charities and the transplantation system in the UK. Because there are many charities to choose between, one can probably ensure **that one's donation can be targeted only to benefit those types of people one wants to help**. One can be partial, prejudiced and even racist, simply by choosing one charity over another. In the UK there is only one system available for organ donation, which prevents this degree of choice; if there were parallel donation systems aimed at giving organs to specific groups of people, it might be more akin to the charity situation. It would seem too strong a claim to argue that NHSBT has an obligation to offer people a similar level of choice when it comes to donating organs, but the weaker claim that the level of specificity involved in some charitable donations does not render them non-

altruistic or non-gifting is more reasonable. Indeed, giving to charity is generally considered to be altruistic and a good thing even though the charity might arguably be considered the *wrong*¹⁶¹ charity

Volk and Ubel draw a distinction between conditional (in the iff sense) and **unconditional donation, by saying “if organ donation is truly a gift then it should not be contingent on certain conditions”**¹⁶². The claim here is clearly that something can only be considered a gift if it is given without any conditions, yet this need not be the case. Children are often given pets by their parents on the condition that they look after the pet and keep its cage clean. If a child failed to agree to these conditions they would not be allowed a pet.

Volk and Ubel may be alluding to the idea that if a gift is contingent upon certain conditions, the giver of the gift may be considered to be getting something out of the gifting process. Arguably someone who gives someone money to secure a vote should not be considered to be generously gifting; they are giving a bribe¹⁶³. It is also true that some gifts are given on the assumption that the giver will get something out of it; **treating one’s** partner to a romantic weekend for two for her birthday could be a gift, but one would expect to be selected as the second attendee – the gift would probably rapidly be retracted if one were not. Something like this would be considered a gift by many people, yet the giver certainly gets something out of the gifting process. Conditional donation is not *necessarily* like this though, since the donor or donor family may receive no direct benefit themselves, other than knowing that the organ has gone to someone who they want it to go to (which is presumably also the case for **unconditional donations, assuming that the donor wants the organ to go to ‘someone**

¹⁶¹ Which charities are right or wrong is clearly open to debate, but it is arguably better to give to some charities than others. As an example, Giving What We Can recommend that people give money only to certain very efficient human-benefitting charities:

<http://www.givingwhatwecan.org/resources/recommended-charities.php> (last accessed 31/10/2012)

¹⁶² Volk ML and Ubel PA, (2008) *op. cit.* p1544

¹⁶³ So, not all gifts should be considered altruistic. One might make a financial donation to a political party, but this may be motivated by the possibility that doing so would further one’s business interests, for instance.

who needs an organ'). The bribe is also different because it is not just contingent upon a condition being met; it is entirely motivated by something external being introduced into the gifting transaction (a vote in the case of the bribe). Although a conditional donation may be contingent upon a condition being met, it need not be motivated by the condition. For instance, a person may be motivated to donate her organs by a desire to help other people in need, but not want her donation to help people who have caused their own poor health.

Price seems to consider directed donations to be compatible with gifting, as suggested by his comments in relation to a scenario presented by Neuberger and Mayer¹⁶⁴. In the scenario a father has been declared brain-dead, but has a poorly **daughter who requires a liver transplant. The family agree to donate the father's liver** (and only the liver) on the condition that it is split, and one half of the split liver is **transplanted to the daughter. Commenting on this, Price says "(t)here is no self-servingness here and it is indeed a gift which the father could have made as a living donor before death had he been compatible and well enough"**¹⁶⁵. Price has sympathy for a donation such as this because it is well-intentioned, yet he also describes badly-intentioned directed donations as gifts, too. Commenting on another of Neuberger and Mayer's scenarios, this time involving racist directions, he states **"it was correct to reject the gift"**¹⁶⁶. He goes on to say that **"(s)ome forms of conditional donation might indeed be legitimate. It is a gift *from the individual after all*"**¹⁶⁷. This makes an insightful point: in everyday life gifts **do reflect the specific individual giver's** relationships and values. Gifts are given to friends, families, communities, churches and charities – these are all directed, and this direction does not ordinarily detract from the gifting nature. Indeed, there are very few gifts that are given to **'humanity in general'**.

¹⁶⁴ Neuberger J and Mayer D, (2008) *op. cit.* p1529

¹⁶⁵ Price D, (2008) *op. cit.* p1542

¹⁶⁶ *Ibid.* p1541

¹⁶⁷ *Ibid.* p1541

There is clearly disagreement over the nature of gifting and conditional and directed organ donation. Volk and Ubel appear to think that 'if and only if' conditionality renders a donation a non-gift, yet Price disagrees. Volk and Ubel's assessment of gifting raises the questions of why it is the concern of individuals to ensure that their gifts do not exclude groups of people, and why is it important for organs to be gifted in a way that is not exclusive or conditional. In this respect, they appear to be placing constraints on gifting within the organ donation context (where gifting seemingly has to be impartially disinterested) that do not apply to gifting in everyday life (where gifting can involve self-interest and even expectation of reciprocity). It is possible that gifting in organ donation means something slightly different from gifting in everyday life.

The gift relationship has been widely discussed since organ donation first started¹⁶⁸, and at least part of the justification for referring to gifting is to keep organ donation separated from organ trading¹⁶⁹. Indeed, the way that gifting is used seems to suggest that within the context of organ donation, a gift is something that is given freely with no explicit restrictions placed on its use¹⁷⁰. But this cannot be consistently applied, since organs can be donated solely for the purposes of research (which is an explicit restriction on the use of the organs), and this is still considered a gift.

2.3.5 Why is this important?

If conditional and directed donations cause such controversy and disagreement, it may be tempting to suggest that the UK is better off rejecting them. Anything that risks losing public faith in the transplantation system could result in donation rates decreasing, with a subsequent increase in waiting times and deaths on the waiting lists. It is possible, however, that allowing some or all conditional or directed donations

¹⁶⁸ Titmuss RM, 'The Gift Relationship: From Human Blood to Social Policy', (New York: Pantheon Books, 1971)

¹⁶⁹ Delmonico FL et al., 'Ethical Incentives Not Payment for Organ Donation', *New England Journal of Medicine* 346 (2002) pp2002-05

¹⁷⁰ Volk ML and Ubel PA, (2008) *op. cit.* pp1542-4

might have a **positive** impact upon donation rates; after all, rejecting organs because they have conditions attached is effectively wasting a life-saving or life-improving resource. There does appear to be some public support for some conditional and directed donation. An Ipsos-Mori poll funded by University Hospital Birmingham Charities, and written-up by Neuberger and Mayer¹⁷¹, asked the public a number of questions about the acceptability of different kinds of conditional and directed donation. The results showed that although support for some groups of people having priority was fairly widespread (one question found that 59% of participants believed that children should have priority for organs, and another question found that 36% of participants believed it was acceptable for family members to have priority), this did not extend to controversial conditions such as race-based allocation. 79% of total participants felt that it was **unacceptable** for conditions to be placed on the basis of race (but 4% thought it was very acceptable, 9% thought it to be fairly acceptable and the **remaining 8% answered 'it depends' or had no opinion**)¹⁷². Whilst these statistics say nothing about the likely impact upon donation rates, or indeed whether many people would want to place conditions or directions on organs themselves, they do at least **show that there are large numbers of people who do not agree with the DH report's** conclusion that all conditions are unacceptable, and there are even some people who deem race-based conditions to be acceptable.

Some people are removed from the ODR when they are told that they are not allowed to set conditions on their donations. From 1st April – 31st March 2011, a total of 13,900 people removed themselves from the ODR for reasons other than death, and 40 of these people were removed¹⁷³ from the ODR because they set conditions¹⁷⁴.

Although 40 people may seem insignificant when compared with the number of people

¹⁷¹ Neuberger J and Mayer D, 'Conditional Organ Donation-the Views of the UK General Public Findings of an Ipsos-Mori Poll', *Transplantation* 85 (2008) pp1545-47

¹⁷² *Ibid.*

¹⁷³ It is not clear whether these were self-removed or otherwise

¹⁷⁴ Michael Patrick, Statistics and Clinical Audit, NHS Blood and Transplant: Letter to G Moorlock, 25/08/2011 (Appendix 2)

already on the ODR, any loss of potential donors may have an impact on the number of lives saved by transplantation. It is worth noting that these 40 people are those who were removed from the ODR; there may be many more people on the ODR who would want conditions placed on their donations, and there may be people who do not join the ODR *because* they are unable to place conditions on their donation.

The simple truth, as Radcliffe-Richards suggests, is: **"we have no idea how much effect the principle of unconditionality has on supply"**¹⁷⁵. There is a risk that permitting conditional donations would reduce long-term donation rates, but there is equally a risk that continuing to prohibit them may put off some potential donors.

Regardless of the impact upon donation rates, there may be good reasons to permit conditional and directed donations. It is clear from existing policy that maximising donation rates is not the over-riding aim of transplant policy (since donation rates would increase significantly if organs were compulsorily retrieved from dead people), so it may be that other factors such as autonomy are also relevant when considering what is acceptable. As discussed, some people have argued that close relationships form moral obligations between individuals, and it is possible that by prohibiting conditional and directed donations, the state may be preventing individuals from fulfilling the obligations that they have.

Moreover, the Organ Donation Taskforce made a number of specific recommendations relating to organ donation, two of which suggest that further research on conditional and directed donation is necessary. Recommendation 3 states that:

Urgent attention is required to resolve outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and are able to work

¹⁷⁵ Radcliffe-Richards J, (2012) *op. cit.* p178

within a clear and unambiguous framework of good practice.¹⁷⁶

Although attempts have been made to produce a clear and unambiguous framework of good practice, some of these attempts have served to muddy the waters. For instance the 2010 DH Guidance¹⁷⁷ attempted to provide clear guidance on handling requests for directed allocation of organs, but has actually introduced new principles that appear to contradict those of the DH Panel in 2000¹⁷⁸. Inconsistencies still exist between the deceased and living donation systems, and these inconsistencies require either clear justification or resolution.

Recommendation 13 from the Taskforce's report states that:

There is an urgent requirement to identify and implement the most effective **methods through which organ donation and the 'gift of life' can be promoted to** the general public, and specifically to the BME [Black and Ethnic Minority] population. Research should be commissioned through Department of Health research and development funding.¹⁷⁹

If, as some suggest¹⁸⁰, conditional and directed donation might incline minority groups (such as people of South Asian ethnicity) to donate their organs, then allowing these sorts of donations might be an effective method of promoting organ donation to BME populations. Conversely, if the prospect of conditional and directed donations eroded faith in the organ donation system, or created a perception of increased

¹⁷⁶ Department of Health (2008) 'Organs for Transplants: A Report from the Organ Donation Taskforce', Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082122, Last Accessed: 31/10/2012 p9

¹⁷⁷ Department of Health (2010) *op. cit.*

¹⁷⁸ Department of Health (2000) *op. cit.*

¹⁷⁹ Department of Health (2008) *op. cit.* p18

¹⁸⁰ Radcliffe-Richards J, (2012) *op. cit.* p177

unfairness, this could have a particularly negative impact upon BME groups for whom there is already a mistrust of systems such as the NHS¹⁸¹.

In short, a decision has to be made on what the aims of the transplantation system in the UK should be. There is a drive to increase the number of donors in order to save or improve more lives, yet some donations of medically useable organs are turned away in the interests of justice, fairness and impartiality. At the same time, within living donation, ideas such as justice, fairness and impartiality seem to be less important, with more emphasis on individual autonomy and permissible partiality. Deceased donation and living donation have the same aim of obtaining organs for transplantation, yet acceptable allocation of the organs differs according to the circumstances in which the organs are obtained.

Chapters 3-7 will consider some of the philosophical elements of organ donation, and in particular conditional and directed donation. The aim of these chapters is to lay the groundwork for the qualitative study and perform some of the background philosophy necessary for later discussion.

¹⁸¹ Morgan M et al., (2006) *op. cit.* pp226-34

Chapter 3 - Philosophical Introduction and Groundwork

This chapter will start with some philosophical scene-setting, and lay the groundwork for further analysis. This is necessary because the concept of organ donation is clouded by conflicts and contradictions, some of which need to be resolved decisively so that further analysis can be built upon solid foundations.

Chapter 4 will examine the philosophy of altruism and partiality. Two main accounts of altruism **will be examined in detail, and Cottingham's defence of partiality** will also be presented. This will provide some theoretical underpinnings for further discussion in the next chapter, with particular regard to DH policy on conditional and directed donations.

Chapter 5 will explain and analyse current policy on conditional donation, and explore the philosophical reasoning behind the restrictions placed on permissible types of organ donation. It will next consider the demands and restrictions that these place on individuals and whether these can withstand ethical scrutiny. It will then consider whether conditional and directed donation might be compatible with these restrictions, or otherwise ethically permissible. Here it will be argued that the definition of altruism used by the DH combines some features of the strictly rational account proposed by Nagel, whilst also incorporating features of the more emotional account put forward by Blum. This results in the DH appearing to endorse a type of hybrid altruism which is incoherent. This can be reconciled by embracing the view that there are different sorts of altruism, and that an action is not simply either altruistic or non-altruistic. Instead it is suggested that it is possible for one action to be more, or less, altruistic than another.

Chapter 6 will look at conditional and directed donation from the perspective of potential organ recipients and will argue that these people have basic obligations towards one another. It will be argued that conditional and directed donations would

not necessarily conflict with those obligations and that, from the perspective of recipients, accepting conditional donations can be viewed as a positive thing.

Chapter 7 will look in-depth at the responsibilities of the NHS and relevant transplant authorities with a view to establishing the impact that conditional and directed donation could have upon these. It will be argued that conditional donations require more than just *allowing* and that they need to be *actively facilitated*. Some might claim that this implicates the NHS and transplant authorities in unsavoury activities. However, it will be argued that, at worst, the NHS and transplant authorities can be accused of furthering wrongful ends, and that the eventual ends (saving or improving lives) may justify this as a means. It is argued that it might be justifiable to accept donations with even the most objectionable conditions attached, if the consequences are sufficiently good.

3.1 Introduction

By considering the philosophical aspects of organ donation in more detail, it has become apparent that some aspects of the concept of organ donation are potentially misleading. This is probably a result of how donation is marketed to the public; the aims of marketing campaigns are to increase donation rates, and some of the details and technicalities have understandably been sacrificed in order to achieve these aims. A very brief analysis of these details now will provide clarity for later in this analysis.

3.2 The nature of organ transplantation

It is tempting to regard organ donation as a one-off event that occurs following the death of an individual. A person dies, her organs are retrieved, and donation is complete. But in reality, and particularly within the context of the UK NHS, organ transplantation is a longer process with implications before the death of the donor, around the time of death of the donor and after the death of the donor; and these implications reach beyond the donor.

Thinking of organ donation as a single event does not accurately reflect the complexity of the process, and ignores many morally relevant features of deceased organ donation. For instance, a person may make her wishes and decisions about donation known during her lifetime and these may have an impact on her life (she might enjoy a general sense of wellbeing, a certain comfort in knowing that if she dies her organs will go to good use, and she might also enjoy the respect and admiration of her friends and family). Leading up to death, treatment to facilitate organ donation may differ from the standard end-of-life management of non-donors¹⁸². The organ donation process might also impact significantly on family members (possibly providing them with comfort, distress or worry about whether they are doing the right thing). Thinking of organ donation as a process allows these issues to be taken into consideration, whereas effectively reducing organ donation to organ retrieval would lead to these factors being ignored.

Assuming that donation is a process, it starts as soon as an individual expresses a wish to donate her organs, be it via the Organ Donor Register (ODR) or a discussion with family members. If the process does not start here, it seems difficult to think where it could start. One might argue that the process of becoming an organ donor starts with whatever causes a preliminary interest in becoming a donor (for instance, seeing NHSBT publicity material), but until an individual has taken active measures to put their wishes into action (or potential action), it would seem incorrect to think of them as an organ donor. Although the physical retrieval of organs starts after a patient dies, this cannot be regarded at the start of the process if the notion of *donation* is to be meaningful. Although the deceased person is regarded as the person doing the donating, it makes no sense to consider someone performing an action after their own death. Donation must, in order to count as *donation*, require agency on the part of the

¹⁸² This treatment is the subject of controversy. Examples include the use of Heparin: Motta ED, 'The Ethics of Heparin Administration to the Potential Non-Heart-Beating Organ Donor', *Journal of Professional Nursing* 21 (2005) pp97-102, and elective ventilation Browne A, Gillett G, and Tweeddale M, 'Elective Ventilation: Reply to Kluge', *Bioethics* 14 (2000) pp248-53

donor, and since agency is absent after death, the donation process must commence during life.

3.3 Who is the donor?

Consent for organ donation in the UK is generally obtained from the next-of-kin. The next-of-kin will ordinarily be told whether or not their relative is on the ODR, and this is **regarded as an indication of that person's wishes. The next-of-kin** do not have to respect this wish, however, and can veto organ donation if they want to¹⁸³. Despite the fact that it is the next-of-kin who generally make the final donation decision, it is the dead person who is regarded as the donor. There is a point to this beyond semantic pedantry, and that is that if organ donation is supposed to be altruistic, it is important to know who is supposed to be acting altruistically. Also, if organ donation is supposed to be a praiseworthy act, it is important to know who should be praised.

If a person has joined the ODR and had discussions with their next-of-kin making it clear that they would like their organs to be donated if possible, then that person should clearly be regarded as the donor. They have clearly thought about donation, and taken active measures to ensure that it happens after their death. If organ donation is praiseworthy, then this person is deserving of praise.

A seriously ill or dying person will probably not be on the ODR (as only 30% of **the UK's population are currently registered**¹⁸⁴). Some people may have expressed a wish to donate organs to their family but not joined the ODR. In these cases the most promising way of establishing the views of the individual towards organ donation is to speak to relatives. In other cases, a person may not have explicitly discussed organ donation, but they may have generally lived their life wanting to help other people. Their next-of-kin may agree to organ donation on the basis that it is what the person

¹⁸³ The right to family veto is not protected by law, but in practice it is generally respected. There is much debate about whether this is the right or wrong approach. See Wilkinson TM, (2012) *op. cit.*

¹⁸⁴ NHSBT (2012) 'Transplant Activity Report - Organ Donor Register', Available at: http://www.organdonation.nhs.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/nhs_organ_donor_register.pdf, Last Accessed: 26/10/2012

would have wanted, had they been able to make the decision themselves. Even though the dying patient may not make the final decision herself, it seems correct in these instances to regard the patient as the donor, since the decision is based upon her beliefs and values as perceived by her relatives. The deceased person is not the decision-making agent, but if the decision is made on the basis of the values and beliefs of the deceased, there ought to be some recognition of this.

In cases where, in life, a deceased person has never spoken of organ donation and her wishes, value and beliefs are genuinely unknown, it would fall to her next-of-kin to make decisions about donation. In an instance such as this, it is less clear who should count as the donor. In one sense the *body* of the deceased person is the vehicle for donation, but cases such as these are more complex than this, given how people tend to regard organ donation. Donation is marketed as a praiseworthy act and a good thing to do, but it would appear absolutely wrong to praise a deceased person for something that they have had no control over. It cannot be claimed that the deceased person is altruistically motivated, since she is not motivated at all. In these cases, it seems reasonable to regard the next-of-kin as being the donors, since it is the next-of-kin who will ultimately make the decision about whether or not to proceed with donation.

In conclusion, as this last example suggests, the next-of-kin can be regarded as donors in some cases, but it actually makes sense to think of them as donors in all cases if one wants to achieve a coherent view of the donation process. The next-of-kin are able to over-**rule the deceased's wishes and veto donation, or permit donation even** if the deceased was opposed (as long as this fact is not disclosed). Indeed, the next-of-kin generally make the final decision on whether organs are donated, so they ought to be considered as being actively involved in the donation. The organ donation process involves more than just the physical movement of organs, and acknowledging the sacrifices/donation made by the family is important. If organ donation must be

altruistic consideration needs to be given to both the dead person's motivations and their next-of-kin's.

Chapter 4 - Altruism and regarding others

In the 2000 report discussed in the Chapter 2, the DH stated that no organs with **conditions attached should be accepted, since placing conditions on organs “offends against the fundamental principle that organs are donated altruistically and should go to patients in the greatest need”**¹⁸⁵. Although described as a single principle, it actually expressed two; that organs should be donated altruistically and that organs should go to patients in greatest need. It may, therefore, be fruitful first to examine the underlying principle of altruism to determine whether this can justify the **DH’s and HTA’s position on conditional and directed organ donation**, before moving on to consider allocation.

4.1 Altruism in the philosophical literature

Although it is often stated that altruism underpins many deceased organ donation systems, little attention is given to what altruism actually is. Precise definitions of the concept are not offered, although they can be inferred from the way in which the term is employed. These definitions may differ from the more complex definitions found in the philosophical literature. Altruism features in a number of different theories linked to areas as diverse as biology and economics¹⁸⁶. The most relevant theories within the context of organ donation are those that link altruism to morality, and with this in mind the candidates considered in this thesis are going to be philosophical accounts of altruism.

Two characterisations of altruism will be outlined here, and although there is some overlap, these two types will be shown to result in stark differences between what does and does not count as altruistic. These two characterisations have been chosen because they are the most developed and coherent accounts of altruism in the

¹⁸⁵ Department of Health (2000) *op. cit.* p1

¹⁸⁶ Becker GS, 'Altruism, Egoism, and Genetic Fitness: Economics and Sociobiology', *Journal of Economic Literature* 14 (1976) pp817-26

current philosophical literature and because they illustrate how much fundamental disagreement there is about what altruism entails.

4.2 Nagel's pure altruism

Altruism as described by Nagel in *The Possibility of Altruism*¹⁸⁷ can be regarded as 'pure altruism' as it is not 'clouded' by emotion or self-interest. Nagel's account of altruism is particularly demanding and is rather specific; Nagel states that the altruism he describes is "not to be confused with a generalized affection for the human race. It is not a feeling"¹⁸⁸.

Nagel takes as the basis of his argument some ideas about what motivates us to act, and specifically what motivates us to act in the interests of other people. Here he aligns himself against the view that the source of all motivation to act is desire¹⁸⁹. In order to do this, he points out a supposed confusion between motivated and unmotivated desires. An unmotivated desire is one that "simply assails us"¹⁹⁰ and includes appetites and certain emotions. Motivated desires, on the other hand, are desires that are arrived at after rational deliberation. If one has a sudden thirst, this would be an unmotivated desire. If one, on the basis of this thirst discovers that there is nothing to drink in one's house and has a subsequent desire to go to the shops, this can be considered a desire motivated by thirst. Nagel states that in order for the claim that desires underlie every act to be true, one must include both motivated and unmotivated desires but then this does not say anything about the actual motivational force behind an act. When one has a motivation to pursue a certain goal, a desire to pursue that goal is a logical consequence, but this does not express anything about what the motivation actually is. As Montmarquet states, "unless a motivated desire is, in turn, motivated by an unmotivated one, we don't yet know what the motivational

¹⁸⁷Nagel T, 'The Possibility of Altruism', (Oxford: Princeton University Press, 1978)

¹⁸⁸ *Ibid.* p1

¹⁸⁹ *Ibid.* p27

¹⁹⁰ *Ibid.* p29

source of the action is”¹⁹¹. Nagel argues that *reasons* are capable of being this source of motivation.

In order to act altruistically, according to Nagel, the interests of others must provide one with a reason to act in a certain way, and for this to be the case one must consider oneself to be one person amongst many. In his own words: “[i]n any situation in which there is reason for one person to promote some end, we must be able to discover an end which there is reason for anyone to promote, should he be in a position to do so.”¹⁹²

Nagel’s definition of a reason for acting is “a predicate R, such that for all persons p and events A, if R is true of A, then p has prima facie reason to promote A”¹⁹³. He distinguishes between two types of reason; objective and subjective. A subjective reason is one where the predicate R contains “a free occurrence of the variable p”¹⁹⁴. The occurrence of the variable p within predicate R entails that the reason will only provide someone with a motivation to perform an action if she knows her place in the situation. In contrast: “[a] reason is objective if it commits one to valuing certain states of affairs regardless who is involved in them”¹⁹⁵. This is explained clearly by Darwall:

‘A is in one’s interest’, ‘A is what one desires’, or ‘A is good from one’s own point of view’, if they are reasons to act, are subjective reasons... Objective reasons are all reasons which are not subjective; for example ‘A will be in someone’s interest’ or ‘A will benefit Thomas Nagel’.¹⁹⁶

¹⁹¹ Montmarquet J, ‘Nagel on Motivation’, *Australasian Journal of Philosophy* 60 (1982) p21

¹⁹² Nagel T, (1978) *op. cit.* p90

¹⁹³ *Ibid.* p90

¹⁹⁴ *Ibid.* p90

¹⁹⁵ Reba M, ‘A Second Look at Nagel’s Argument for Altruism’, *Philosophical Studies* 25 (1974) p430

¹⁹⁶ Darwall SL, ‘Nagel’s Argument for Altruism’, *Philosophical Studies* 25 (1974) p126

In order to act altruistically according to Nagel, one must act for objective reasons¹⁹⁷. Nagel gives the example of someone who finds himself in the path of an oncoming truck. By removing himself from the path of the truck, this person's life can be prolonged, which would generally be taken to be in that person's interests. That person's reason to get out of the way of the truck can be formulated objectively as 'the act (of getting out of the way) will prolong someone's life'. This provides an objective reason to act, and is therefore a reason that anyone can have to promote that act. Someone acting according to this reason, who helps the person get out of the way of the truck, can be said to be acting altruistically.

4.3 Blum – emotions and altruism

Nagel's account of altruism is unflinchingly focussed on rationality and practical reasoning, and deliberately avoids basing altruism on "intermediate factors such as one's own interests or one's antecedent sentiments of sympathy and benevolence"¹⁹⁸. In this sense it is a strict and pure version of altruism, unwilling to account for the sorts of benevolent emotions that one might experience throughout life. This is not a significant criticism of Nagel's account as this is exactly what he set out to achieve, but there are other forms of altruism that frame other-regarding behaviour and altruistic emotions as valuable.

One such example is Blum's account, in which he argues against the Kantian notion that all emotions are "transitory, changeable and capricious" and that actions motivated in some significant way by emotions are likely to be "inconsistent, unprincipled or even irrational"¹⁹⁹.

¹⁹⁷ The position that Nagel defends shares some similarities with Kant's work. Nagel himself notes these similarities, suggesting that both he and Kant provide accounts of moral motivation that do "not rely on the assumption that a motivational factor is already present among the *conditions* of any moral requirement" (Nagel, p11). A second similarity is that both Nagel's and Kant's work argue that an aspect of the agent's conception of himself plays a role in the operation of moral motives (Nagel T, (1978) *op. cit.* p12).

¹⁹⁸ Nagel T, (1978) *op. cit.* p16

¹⁹⁹ Blum LA, 'Friendship, Altruism, and Morality', (London: Routledge & Kegan Paul, 1980) p2

Blum's argument is guided by the judgment that "it is good to be sympathetic, compassionate, concerned, and caring for other human beings"²⁰⁰ and that these qualities are linked with morality. Sympathy, compassion, concern and care are what Blum terms "altruistic emotions"²⁰¹, and Blum argues that these differ from other emotions in a way that allows this link to morality. He claims that true altruistic emotions involve a motivational aspect, "relating to the promotion of beneficent acts aimed at helping the other person"²⁰². Blum distinguishes between altruistic emotions and moods which may lead to beneficent action. If one found oneself in a particularly cheerful mood, one might feel more inclined to act beneficently towards others. However, this mood is exactly the kind of "transitory, changeable, and capricious"²⁰³ state that Kant was so wary of. It is also perfectly plausible that this cheerful mood might fail to result in beneficent acts, or that one might act altruistically despite being in a much less-than-beneficent mood. Altruistic emotions, in contrast to moods, "involve an appreciation of another person's situation regarding his weal and woe"²⁰⁴, and it is from this appreciation that beneficent acts originate²⁰⁵.

The Kantian view, according to Blum, mischaracterises these altruistic emotions and denies them the moral weight that they deserve. Blum's criticism of Kant here also applies to Nagel. Blum argues that altruistic emotions themselves form a part of the good of beneficent acts. For example, if one sees someone having problems with a computer before a deadline, and one chooses to help them out of sympathy for that person's plight, that person will receive the good of having their computer problem sorted, but in addition would value one's act as "expressive of the human sympathy and compassion it showed"²⁰⁶. If it turned out that one had chosen to help because one

²⁰⁰ *Ibid.* p7

²⁰¹ *Ibid.* p12

²⁰² *Ibid.* p13

²⁰³ *Ibid.* p2

²⁰⁴ *Ibid.* p16

²⁰⁵ For Blum, altruistic emotions lead to beneficent action, but beneficent action alone does not entail the presence of altruistic emotions. A joyful mood could also lead to beneficent action, but this, according to Blum, would not be altruistic because it is not a genuine altruistic emotion.

²⁰⁶ Blum LA, (1980) *op. cit.* p144

was an IT professional and expected payment **for one's services, the lack of an** expressed altruistic emotion would change the nature and extent of the good given.

Blum discusses Kant's famous passage in *Foundations of the Metaphysics of Morals*²⁰⁷, which describes a person whose situation has clouded his mind with personal sorrow to the extent that he can no longer feel sympathy for the plight of others. However, purely out of a sense of duty, this person acts beneficently towards others (and in doing this, according to Kant, does something of genuine moral worth). A case such as this is designed to illustrate the unreliability of emotions as a moral motive. Blum, however, argues that altruistic emotions are not unreliable in this way.

Blum distinguishes between altruistic sentiments, emotions and attitudes, and **argues that some involve a stronger desire for another person's good than others. His example of a 'weak' altruistic sentiment is that of well-wishing, which although** involving a regard **for another person's good, fails to imply a sufficiently strong desire** to act beneficently if doing so would be particularly inconvenient. **Blum's differentiation** between altruistic sentiments and altruistic emotions helps him to justify his claim that altruistic emotions are reliable. Altruistic emotions, may involve desires of various strengths, but according to Blum have a minimum threshold strength of desire²⁰⁸. Anything that falls beneath this threshold cannot be considered an altruistic emotion, and the attitudes and sentiments that fall beneath this threshold would be vulnerable to **criticisms of unreliability. By necessarily entailing a high strength of desire for another's** good, altruistic emotions are reliable moral motives, and the higher the strength of the desire, the more reliable they are.

Blum further defends the reliability of altruistic emotions by arguing that **although "negative moods and states of mind can have an effect on our altruistic** feelings, they do not typically extinguish existing ones or necessarily prevent potential

²⁰⁷ Kant I and Wood AW, 'Groundwork for the Metaphysics of Morals', (New Haven, Conn: Yale University Press, 2002)

²⁰⁸ Blum LA, (1980) *op. cit.* p19

ones”²⁰⁹. According to Blum, altruistic emotions can survive negative moods, and be responsible for us acting contrary to these negative moods. As a response to Kant’s example, Blum states that personal sorrow would be unlikely to remove one’s sympathy for another person for whom one has previously felt sympathy. If one performed an act of beneficence towards this person in these circumstances, it could still be performed out of sympathy. He accepts that the beneficent act *could* be performed out of duty (as claimed by Kant), and that a deep sorrow *could* remove one’s sympathy for another person, but does not see these as *necessarily* true. Blum’s argument is not that negative moods cannot extinguish altruistic emotions, but that they do not necessarily do so. According to Blum, altruistic emotions may be, to some extent, affected by negative moods, but are not controlled by them²¹⁰.

4.4 Altruism, partiality and self-interest

These different accounts of altruism, although sharing some aspect of other-regardingness, differ significantly in the sorts of actions that they consider to be **altruistic**. Nagel’s strictly reason-based approach to altruism is less permissive than Blum’s emotion-based account, which means that the results of their applications are quite different.

4.4.1 Applying Nagel

If, as demanded by Nagel, in order to be altruistic one has to consider oneself just one amongst many and afford no extra weight to one’s own subjective reasons, altruism is clearly going to involve some level of impartiality. Whether absolute impartiality is demanded is, however, unclear. A distinction can be drawn between subjective and objective partiality;

- i) Subjective partiality favours one person over another because of some feature of them that relates to the agent making the decision

²⁰⁹ *Ibid.* p21

²¹⁰ *Ibid.* p22

ii) Objective partiality favours one person over another because of some feature of them that relates to anybody (this is the sort of partiality in action when organs are allocated according to greatest need, for example)

Subjective partiality is the sort of partiality that Nagel does not permit. If confronted with two drowning people, one of whom was one's brother, one could not choose to favour one's brother *because* he was one's brother and still claim for this to be altruistic.

An alternative might be to permit a sort of objective partiality that is not based upon one's relationship with someone, but instead some impersonal feature of that individual. So for instance, if one is presented with two drowning people with whom one has no relationship, but one can see that one is very old and the other is very young, one might choose to favour the very young person because of one's belief that the younger person potentially had more life ahead of him. Partiality of this sort is objective to the extent that the partiality is not based upon any relationship between the rescuer and the rescued. However, this sort of partiality is still, to some extent personal and subjective – since it is based on one's preference for youth, which may not be shared by everyone. Although this partiality is more objective, it may fall short of the strict objectivity required by Nagel.

Nagel discusses some issues relating to partiality in his chapter entitled 'The Consequences'. Nagel's account of altruism outlined thus far provides only *prima facie* reasons for considering others. He describes the difficulty that one faces when one considers the interests and reasons of others, especially where they come into conflict (and indeed the same conflict arises when one's own interests clash with those of another person)²¹¹. In order to make the leap from *prima facie* reasons to what one should actually do, one requires what Nagel refers to as a 'combinatorial principle'²¹².

²¹¹ Nagel T, (1978) *op. cit.* p134

²¹² *Ibid.* p133

The problem that Nagel faces in suggesting a suitable combinatorial principle is that individuals will have subjective reasons for preferring certain combinatorial principles, and this may result in an inability to objectively select a suitable combinatorial principle.

The first type of principles that Nagel rules out are the subjectively appealing ones that favour oneself in the conflict between oneself and another. Nagel observes that a principle of this nature cannot be universalised without contradiction, as the objective version of it would demand that everyone received preferential treatment. Nagel argues that this problem will be the same for any subjective principle that singles out one individual for preferential treatment, so one could instead seek a principle that is already objective and impersonal²¹³. Yet this still would not resolve the issue. Individuals might still have subjective preferences for different objective principles and might be more likely to favour an objective principle that resulted in a better outcome for themselves in any given situation. This suggests that, even given the distinction between subjective and objective partiality above, one may still have subjective reasons to endorse one supposedly objective form of partiality over another. As Nagel says, “[i]f individuals consider the possibilities subjectively, these factors will influence their preference among combinatorial principles according to their assessments of their own chances”²¹⁴.

Nagel concedes this is problematic, and proposes a constraint on the choice of combinatorial principles available, **all of which impose “uniformity on the informational conditions of choice”**²¹⁵. He discusses four possible solutions, although he believes at least two of them are completely inadequate. First, he dismisses the utilitarian approach, which according to Nagel attempts to settle conflict between different people using the same principles that would be used to settle conflicts within a single person.

²¹³ *Ibid.* p135

²¹⁴ *Ibid.* p135

²¹⁵ *Ibid.* p137

This entails that in attempting to settle conflict between different people, one should treat the competing claims as if they were all due to **one's own interests**. According to Nagel, "to sacrifice one individual life for another, or one individual's happiness for another's is very different from sacrificing one gratification for another within a *single life*"²¹⁶, and this combinatorial principle ignores this fact.

The second principle proposed by Nagel aimed at achieving unanimity proposes that each person should choose a weighting system with the assumption that the life that she will live is randomly selected, entailing an equal possibility of living the life of **anyone in the world (and importantly she would have that person's preferences, tastes and experiences)**²¹⁷. The problem with this proposal, according to Nagel, is that people ultimately disadvantaged by the outcomes could argue that their claims and needs have not been afforded the weight that they deserve, because they are regarded as possibilities rather than realities.

The third principle that Nagel discusses borrows from the Rawlsian veil of ignorance²¹⁸, under which individuals have no knowledge of their identities or position within society. Nagel is slightly critical of this approach, suggesting that its emphasis on possibilities rather than actualities (similar to the previous proposal) fails to fully take into account the interests of the real people who lose out as a result of the veil of ignorance. When one considers various lives from behind the veil of ignorance, one views them as being possibilities – but Nagel argues that they are actualities, for these possible lives are lives that people actually have. This appears to be a more general criticism of the veil of ignorance, a full defence and analysis of which is beyond the scope of this chapter.

Although accepting that the Rawlsian approach might be salvageable, Nagel proposes a fourth possible solution. He acknowledges the obvious difficulty of this

²¹⁶ *Ibid.* p138

²¹⁷ *Ibid.* p138

²¹⁸ Rawls J, (1971) *op. cit.*

solution, stating that “I do not know how the method I am about to propose can actually be applied”²¹⁹, but believes that his proposal does offer adequate recognition to the claims of every individual being considered. Nagel’s proposal is that the choice of a weighting principle should be made under the condition that “the chooser expects to lead *all* of the lives in question, not as a single super-life but as a set of distinct individual lives, each of them a complete set of experience and activities”²²⁰. This seems extremely problematic to conceive of, and therefore less helpful than the veil of ignorance. Furthermore, one might conceive of leading all of the lives in question, and think that living some particularly disadvantaged lives is justified if some of the other lives were particularly good. In other words, one might offset the bad in one life against the good in another. This sort of reasoning is inappropriate for a combinatorial principle because, in reality, a person only has one life so cannot offset the good or bad against other lives in the future or past.

Acknowledging the shortcomings of the proposals, including his fourth one, Nagel does not explicitly endorse any of them as providing the ultimate solution. However, he does suggest that his fourth proposal would be likely to bring about very similar conclusions to the veil of ignorance (although, for the reasons just discussed, he may be mistaken). Despite the ultimate lack of certainty over how one ought to balance competing reasons, Nagel has given an account of the conditions necessary for pure altruism which can be used to examine altruism within organ donation in more detail.

4.4.2 Applying Blum

Blum’s account of altruism is much more permissive than Nagel’s in terms of partiality, and potentially allows for the sort of familial and friend-related partiality that often features in everyday life. The traditional Kantian view does not permit this sort of partiality, since “every human being, simply in virtue of being human, is worthy of

²¹⁹ Nagel T, (1978) *op. cit.* p140

²²⁰ *Ibid.* p141

equal consideration, and his good is equally worthy of being promoted"²²¹. The sort of favouring of family members or friends, or people of a certain type that one values, is generally not considered moral by this view, since choosing to further the good of these people can be considered to be acting with regard to one's own interests, preferences or attachments. In short, according to Kant, for something to be moral it must be justifiable from an impartial perspective. Nagel's view that for something to be altruistic it must be motivated by objective reasons is clearly at odds with Blum's account.

Blum does not entirely condemn this impartial perspective, or fully undermine its importance – he merely places limitations on its scope. He argues for the position that "friendship does not typically involve us in situations in which impartiality between the interests of our friends and those of others is a moral requirement: hence in acting beneficently towards our friends we do not typically violate a duty of impartiality"²²².

Although Blum focuses his discussion on friends, a lot of what he says also applies to family members. He states that there are two aspects of friendship that are most relevant to discussion of partiality and altruism.

i) "the personal importance which our friends have to us – the fact that friends are people we like, enjoy being with, trust and rely on, that they are part of what in our lives is valued by us."²²³

ii) "friendship involves a substantial concern for the good of the friend for his own sake, and a disposition to act to foster that good."²²⁴

While the ties between close family members may be different from friends in some respects (it would seem incorrect to regard one's parents as merely one's friends), it seems that the majority of what is said here of friends is also true of close

²²¹ Blum LA, (1980) *op. cit.* p44

²²² *Ibid.* p46

²²³ *Ibid.* p43

²²⁴ *Ibid.* p43

family members. It may not be true of distant family members with whom one only has a genetic rather than personal relationship, but equally one may be less inclined to act partially towards these people.

Blum discusses three types of case in which one is confronted with more than one person in need, one of whom is a friend:

- i) One is required to treat the interests of the relevant parties from a strictly impartial perspective in which personal attachments are overlooked;
- ii) One is required to give some weight to the interests of others, but this need not be weighted impartially, so some weight can be given to personal attachments;
- iii) One is not required to consider the interests of others at all. One is **morally permitted to act solely for the benefit of one's friend, so personal attachments can override other considerations.**²²⁵

Blum argues that the type of impartiality described in i) is only demanded in **what he terms "institutional-role contexts"**²²⁶. An example of this is a judge, who is required by virtue of her institutional role to be impartial. If she presided over cases featuring her friends and family and failed to remain impartial, resulting in unjustified leniency or complete injustice, she would clearly be doing something wrong. Blum also cites teachers, nurses, doctors, and ship captains as occupying institutional roles that demand impartiality.

Blum uses the example of a train crash to illustrate ii). If one found oneself in a train crash but escaped personal injury, one would be in a position to attend to the needs of other injured passengers. If one of these passengers was a close friend, Blum suggests that it **would be justifiable to give one's first attention to one's friend.**

²²⁵ *Ibid.* p150

²²⁶ *Ibid.* p48

Importantly though, he acknowledges that one would also be required to attend to the needs of others – so although strict impartiality is not required, one cannot ignore the needs and interests of others simply because one has appreciated the weal and woe of a friend.

Blum does not illustrate iii) clearly, but the closest he gets is of someone who has duties to various people (a doctor with duties to many patients, for instance) who has fulfilled all of his duties at a particular point in time. In this situation, the doctor could now dedicate extra time to seeing a patient who is also a friend with no concern for the fact that he is spending extra time with one patient.

As well as arguing that acting in the interests of a friend **because she is one's** friend can be entirely appropriate, Blum argues for the more important conclusion, within the context of organ donation, namely that acting in the interests of a friend **because she is one's friend** can be morally good. His argument has two central claims:

i) acts of friendship are morally good insofar as they involve acting from regard for another person for his own sake (although this is qualified)

ii) the deeper and stronger the desire and willingness to act in the interests of a friend, the greater the moral worth

He gives an example of what he considers to be a morally excellent friendship, **in which the levels of altruistic emotions and "willingness to give of oneself to the friend"**²²⁷ go far beyond what is ordinarily expected of people. The important point that Blum is trying to convey is that close friends have a stronger identification with the good of each other than they generally do with non-friends. In addition to this, Blum believes that good friends are willing to give of themselves to each other without regarding this as a significant sacrifice, and that they consider this to be a part of

²²⁷ *Ibid.* p69

caring for each other. For Blum it is this willing self-giving that forms the basis of the moral excellence of the friendship.

Not all friendships will have these features, or at least not to the same extent, so Blum would presumably concede that not all friendships are morally excellent, and that some relationships that might ordinarily be **considered 'friendships' might not have any particular moral value. One can imagine 'friendships' where one friend is much more willing to give of herself and act in the good of her friend than the other, and this would intuitively appear a less morally excellent scenario.** Blum accepts that some people may have no friendships that achieve moral excellence.

Although until now Blum has talked of friendships that have the capacity to be **morally excellent, he is also willing to concede that "genuine devotion to a particular group – family, neighbourhood, ethnic community, ethnic group, club – is in itself morally good, and becomes morally suspect only when it involves a deficient stance towards others"**²²⁸. The moral goodness for this stems from the involvement of "an **admirable degree of sympathy, compassion, and concern for others**"²²⁹.

If one accepts Blum's account of the moral value of friendship, one might still have concerns about the conditional nature of the altruism that is expressed when one acts partially. This is relevant to conditional organ donation, since the altruism displayed should be considered conditional altruism. If one agrees only to donate to a family member, one is willing to do for a family member what one is unwilling to do for any other. So **one's actions are arguably motivated not by recognition of the humanity** of the individuals involved, but instead by the relationship of the individuals to oneself. Blum responds to this concern by arguing that conditional altruism of this type does still

²²⁸ *Ibid.* p80

²²⁹ *Ibid.* p80

feature a concern for another person for her own sake, and this is a claim endorsed by the likes of Cottingham²³⁰ (see section 4.5.2).

Conditional altruism can, of course, take different forms. There is a difference between someone simply favouring a friend or group of friends, and hating or opposing those who fall outside this relationship. Blum uses the example of an Italian who has a particular concern for helping poor Italians, and who has a real concern for the welfare of these people. Blum argues that even though this person might not show the same levels of concern for non-Italians, his attitude towards Italians stems from a concern for them for their own sake, and therefore has moral value. In contrast, an Italian who despises non-Italians and who considers them to be lesser people with interests of lesser value has an attitude which, according to Blum, is bad in itself. Also, a negative attitude towards people outside of a relationship of some sort, might impact upon the motivation for acting in the interests of those within the relationship. If one favours **one's countrymen *because one hates everybody else, one's favouring one's countrymen need not be motivated by any concern for their good but rather by one's hatred of*** those who may benefit from any alternative action.

Importantly, Blum claims that if one's concern for the good of others is genuine, there is nothing intrinsically wrong with conditional altruism; the wrongness in some instances of conditional altruism lies in the chauvinistic attitudes that it can represent, rather than a moral failing of the conditional altruism itself.

4.5 Cottingham's defence of partiality

Blum's limitations on the scope of impartiality raise some questions about exactly what sort of partiality is acceptable. Blum details the sort of partiality that is compatible with altruism, but this does not necessarily mean that this sort of partiality is acceptable on a wider level, or that there is anything wrong with partiality of certain types. Indeed,

²³⁰ Cottingham J, (1986) *op. cit.* pp357-73

Blum states that his view **"allows for the condemning of the despicable attitude towards those outside the special relationship and also accords no moral value to the attitude towards those within it which does not consist in a genuine regard for the weal and woe of the persons in question"**²³¹. So the fact that certain partiality might promote altruism does not entail that partiality itself is always good in a broader sense. When considering appropriate levels of partiality in organ donation, one needs to narrow down the list of all partialities to the list of generally acceptable partialities, and see whether these can be compatible with altruism to establish whether the partiality can apply to organ donation.

A defence of appropriate partiality must justify why some people's interests can be given more weight than others' when making decisions about to whom one can justifiably allocate one's time and resources. Cottingham starts his defence of partiality with an attack on impartiality, noting that there are instances when failing to favour one's own child, for example, is not an admirable or praiseworthy act, but rather the actions of a "moral leper"²³².

Cottingham refers to partiality as partialism, but in the interests of consistency and clarity the term 'partialism' in Cottingham's terminology will be replaced with 'partiality' as this can be done without loss of meaning. Cottingham defines the thesis of partiality as: **"unless one is under a direct or indirect duty to be impartial, it is morally correct to favour one's own"**²³³. The qualification here is necessary to take account of instances where one has a clear duty to remain impartial; for example in relation to what Blum calls institutional-role contexts.

Cottingham explains that there are two possible strategies that could be used to **justify favouring one's own**. The argument from bald preference, which Cottingham argues is not successful at justifying partiality, is summarised by asking: **"assuming an**

²³¹ Blum LA, (1980) *op. cit.* p79

²³² Cottingham J, (1986) *op. cit.* p357

²³³ *Ibid.* p358

agent is under no direct or indirect duty to be impartial, is he not morally entitled to **exercise his preference as he wishes?**"²³⁴. If an autonomous moral agent chooses to give something that is ostensibly hers (such as time, money, property) to another person, there is certainly some intuitive sense in thinking that by virtue of this something belonging to her, she is entitled to make decisions regarding its allocation. But as Cottingham points out, being in this privileged position does not protect the moral agent from criticism. Just because a person is morally entitled to make a choice, this does not entail that all choices that flow from that entitlement are equally good or immune from moral criticism. One cannot defend the morality of a choice simply by pointing to the fact that one had the right to make it.

Cottingham suggests that given the failure of this argument, one should instead consider a second strategy. He starts with the claim that when making an ethical judgment, one must be prepared to **explain how one's judgment contributes to a conception of the good life**²³⁵. His argument attempts to differentiate between acceptable and unacceptable forms of partiality by showing how some forms of partiality can contribute towards a fulfilled life, on the principle that forms of partiality that contribute to a fulfilled life are acceptable and those that detract from a fulfilled life are unacceptable. Cottingham lists various kinds of partiality, ranging from the intuitively acceptable to the seemingly objectionable. Starting with 'Familism', the circle extends to 'clanism', 'patriotism', 'racism', 'sexism', 'planetism' and potentially beyond. Each partiality takes the form of 'S favours X because X is a member of his [group]'²³⁶. Partiality that favours someone simply because they are in some sense 'one's own' is a form of discrimination, and as such requires further justification. One might take racism or sexism to be a bad sort of discrimination, whereas favouring one's family members

²³⁴ *Ibid.* p362

²³⁵ *Ibid.* p363

²³⁶ *Ibid.* p359

is often a desirable form of discrimination. So the challenge for the partialist is to show that some forms of discrimination are acceptable, whereas others are improper.

Cottingham defends three sorts of partiality, of varying degrees of relevance to conditional and directed organ donation. These are agent related partiality, self-directed **partiality and philophilic partiality**. **Cottingham's defence of agent-related partiality** provides the grounding for philophilic partiality, which is emphasised here due to its relevance to altruism. The basis for these defences is the idea of life-plans. A judgment that a particular type of partiality is morally acceptable must be backed up by showing that this form of partiality links to some defensible concept of a worthwhile and flourishing life.

Before considering Cottingham's position further, one might spot a flaw in using life-plans to assess the acceptability of partiality in relation to deceased organ donation. It is reasonable to presume that the importance of life-plans is diminished by death. There are two ways to resolve this issue. First, if life-plans are important, then deciding what happens when one dies (and maybe after one dies) is perhaps the ultimate life-plan. Second, and more convincingly, if one takes organ donation to be a process that starts during life, rather than an event that takes place after death, the problem does **not arise**. **If one makes a decision during one's life about directing one's organs, and** this has consequences for oneself during life, this can legitimately be considered part of **one's life-plans without any apparent objections**. **One might argue that one's life plans** cease to be important as soon as one dies, but there are many instances where respect for the wishes of the dead are respected (wills, burial wishes, even some aspects of organ donation). This respect can be justified on the grounds that respecting the wishes of the dead provides solace to the dying. If the convention of respecting the wishes of the dead was not operated, then life would overall be worse because one would have no confidence that those who remain alive would follow through on one's life work or final wishes.

4.5.1 Agent related partiality

Cottingham gives an example of partiality that many people would be willing to accept: **partiality towards one's own projects. He argues that to afford priority to one's own projects just because they are one's own is an important part of being a person.** In his words: "[t]o be a person – one who has continuing desires, plans, projects – is to have commitments, to be *involved*"²³⁷. If one was determined to maximise overall utility at all times and would embark upon any new project to achieve this with no regard for **one's current projects, one would be falling short of achieving any sense of individuality or personality. Insisting that one sacrifices one's own individuality in order to achieve maximum utility or some other moral goal would result in a sort of moral sainthood, which, Wolf has argued, entails a life dominated by morality to the extent that an identifiable sense of self either cannot exist or is necessarily denied**²³⁸. Cottingham refers to this sort of partiality as Agent Related Partiality, and argues that showing **some preference for one's own projects is an integral part of any reasonable conception of the good life because having commitments is part of being a person with continuing desires, plans and projects**²³⁹ – having life plans requires this sort of partiality.

4.5.2 Philophilic partiality

Cottingham takes the general form of agent-related partiality into more specific territory by exploring philophilic partiality, which is best expressed as follows:

in deciding whether to promote the interests of X or Y, I may legitimately assign a certain moral weight to the fact that X is *my* loved one²⁴⁰

What sets this partiality apart from others that Cottingham discusses (and aligns it in part with partiality that Blum endorses), and also makes it interesting within the context of organ donation is that it allows for partiality to be considered altruistic.

²³⁷ *Ibid.* p365

²³⁸ Wolf S, 'Moral Saints', *The Journal of Philosophy* 79 (1982) p424

²³⁹ Cottingham J, (1986) *op. cit.* p364

²⁴⁰ *Ibid.* p368

According to Cottingham, despite the reference to oneself in the definition of this sort of **partiality, to love someone "is to desire his/her happiness *for its own sake*"**²⁴¹.

Cottingham believes that parental love is an example of this because it frequently includes a desire on the part of the parent that her child should flourish even after her **own death. He doesn't just restrict this to parental love though; any love that involves a desire of someone's happiness for its own sake** would fall into this category of permissible partiality.

Favouring certain people simply because one happens to love them might be regarded as questionable; it suggests a special feature of love that raises it above other failed attempted justifications for partiality such as favouring one's own race.

Cottingham's answer is that giving certain people special consideration is a **pre-requisite for the close relationships that most people regard as a "source of major psychological enrichment"**²⁴². This appears fairly uncontroversial²⁴³; there is something intuitively convincing about the idea that a life devoid of any close relationships would be a sorry existence. It seems equally true that these close relationships require some special consideration of **certain people's interests by virtue of their position in that relationship** (indeed this may form a part of how these relationships are defined).

Where Cottingham's and Blum's views on partiality start to differ is in the sorts of relationships that they consider can allow one to further the good of another for her own sake, or desire the happiness of another for its own sake. Blum suggests that this concern for the interest of another for her own sake can exist within the relationships between family members, members of the same neighbourhood, ethnic community, ethnic group or club. Cottingham, suggests that **"genuine love"**²⁴⁴ is required in order to

²⁴¹ *Ibid.* p368

²⁴² *Ibid.* p369

²⁴³ Relationships do, of course, also sometimes bring negative emotions and distress, but on balance they are still considered part of a flourishing life.

²⁴⁴ Cottingham J, (1986) *op. cit.* p369

desire the happiness of another for her own sake, and philophilic partiality can only occur where there is genuine love.

Cottingham's list of relationships that allow partiality is therefore shorter than Blum's, as it seems unlikely that genuine love exists between members of the same ethnic group (simply by virtue of their shared ethnicity), for instance. So whilst a white person might claim to love all other white people, it seems unlikely that this would be the sort of genuine love that Cottingham endorses, since Cottingham speaks of the special relationship between the loved one and the agent²⁴⁵. Although Cottingham does not define 'special relationship', merely sharing an ethnic identity with someone does not denote a sufficiently close and personal relationship to be morally significant in the required sense.

Blum's view is that genuine devotion to a particular group can bring about the concern to further the good of another for her own sake. Cottingham's view is that genuine love is required to further the good of another for her own sake. It seems that only one of these views can be correct, and it may be that empirical psychological research could shed light on this. In the absence of this, Cottingham's view is more convincing, as Blum appears to conflate concern for a group with concern for an individual. The link between genuine devotion to a particular group and a concern to further the good of another within this group does not seem as likely as Blum makes out; in favouring a member of a group to which one is devoted, one is acting out of concern for the group rather than the individual, and devotion to a particular group does not require devotion to all the individuals who comprise it. Using Blum's own example, someone devoted to the Italian nation might wish to further the good of Italians. But this is not because of a particular concern for the good of specific Italians, rather it is borne of a concern for the general group.

²⁴⁵ *Ibid.* p369

Cottingham's view suggests that while Blum may be right that partiality between many groups is compatible with altruism this does not entail that this sort of favouritism is acceptable on a broader moral level. Cottingham's view that philophilic partiality is acceptable and compatible with altruism is convincing – allowing one to favour those who one genuinely loves, in a way that is compatible with Blum's altruism.

4.6 Other accounts of altruism/beneficent behaviour

Nagel and Blum are not the only philosophers writing about altruism, and they do not necessarily discuss all motivation/action that might ordinarily be considered altruistic. Some definitions of altruism are much more simplistic, although the common feature is other-regardingness to some extent. Wilkinson, for example, defines altruism as being roughly "a non self-interested concern for the interests of others"²⁴⁶. Another common feature of most conceptions of altruism is that it is virtuous, and should be praised and encouraged. Guidelines for ethical practice relating to organ donation in Australia for instance state that "altruism is a universal human virtue that is extolled as part of our Australian culture"²⁴⁷. The meaning of altruism in this case entails that: "[o]rgans and tissues are given by donors and their families without expectation of reward or even acknowledgement by those who benefit"²⁴⁸, which is more simplistic than the philosophical accounts outlined above. De Wispelaere states that altruism is a "motivational disposition, according to which an intention or motivation to furthering other persons' good is both the necessary and sufficient condition for an act to classify as altruistic"²⁴⁹. Daar opts for a bald definition: "behaviour meant to benefit another"²⁵⁰, although he believes that altruism is not necessarily negated by self-interest. Although these definitions of altruism have not been looked at in detail, they

²⁴⁶ Wilkinson TM, (2003) 'What's Not Wrong with Conditional Organ Donation?' *op. cit.* p163

²⁴⁷ Australian Government (2007) 'Organ and Tissue Donation after Death, for Transplantation – Guidelines for Ethical Practice for Health Professionals', Available at: http://www.nhmrc.gov.au/publications/synopses/e70_1_4_5syn.htm, Last Accessed: 31/10/2012 p4

²⁴⁸ *Ibid.*

²⁴⁹ De Wispelaere J, 'Altruism, Impartiality and Moral Demands', *Critical Review of International Social and Political Philosophy* 5 (2002) p11

²⁵⁰ Daar AS, 'Altruism and Reciprocity in Organ Donation: Compatible or Not?', *Transplantation* 70 (2000) p705

are mentioned here to illustrate that the set of behaviours that can be classed as altruistically motivated goes beyond those described by Nagel and Blum.

A recent addition to the altruism debate can be found in the Nuffield Council on Bioethics 2011 report²⁵¹. Here it is argued that altruism is compatible with some forms of payment for organs, whereas in transplantation policy documents it is generally considered to be incompatible with any kind of financial reward. The Nuffield Report also accepts that the intended beneficiaries of altruistically motivated donation need not **be the organ recipients. The Nuffield Council's report argues for altruism-based donation on the grounds that "an altruistic basis for donation helps underpin a communal, and collective, approach to the provision of bodily material for others' needs, where generosity and compassion are valued"**²⁵². They define as altruistic **actions that are "motivated by** concern for the welfare of the recipient of some beneficent behaviour, rather than by concern for the welfare of the person carrying out **the action"**²⁵³. This definition obviously lacks some of the detail **of Nagel's and Blum's** accounts, but does seem to capture what altruism is taken to mean in general parlance as suggested by a dictionary: "disinterested and selfless concern for the well-being of others"²⁵⁴.

The Nuffield Report definition is, however, at odds with the understanding of altruism used by DH, since it permits forms of payment. It also allows for conditional and directed donations to be considered altruistic. Moreover, compatible with altruism in the Nuffield Report **is 'directed altruism' provided this is at least partly motivated by the desire to benefit specific people – which is more in line with Blum's account. The** Report notes that a decision to join the ODR could in part be motivated by a financial

²⁵¹ Nuffield Council on Bioethics, 'Human Bodies: Donation for Medicine and Research', (2011)

²⁵² *Ibid.* p5

²⁵³ *Ibid.* p139

²⁵⁴ Oxford English Dictionary (2012) 'Entry for 'Altruism'', Available at: <http://www.oed.com/view/Entry/5857?redirectedFrom=altruism#eid>, Last Accessed: 31/10/2012

incentive (in this case funeral expenses²⁵⁵) and still be altruistic. The payment of funeral expenses, for example, would not benefit the individual donor, but would benefit her family. This leaves open the possibility that the directed altruism involved in some conditional donations, for example wanting an organ to be transplanted to a **member of one's religion, could be regarded as altruistic. The Report's understanding of** altruism accommodates the likelihood that some donors act from mixed and complex motives, rather than a straightforward and exclusive desire to help others.

4.7 Sliding scale of altruism

A range of actions and motivations can be considered altruistic depending upon the definition used, and there are disagreements over what altruism is. **Both Nagel's and Blum's accounts of altruism have strengths and weaknesses, but both, in different** ways, capture motivations and behaviour that one would want to consider to be altruistic. It may therefore, be helpful to assume that there is a variety of types of altruism, all of which are morally praiseworthy to some extent, rather than a single monolithic definition. The important and basic element, consistent across all definitions of altruism (although it is represented in various ways), is a genuine concern for other people and their interests *for their own sake*. Where definitions differ is the extent to which self-interest and partiality can feature in altruism, but it is, perhaps, reasonable to hold that as self-interest increases in relation to regard for the interests of others, altruism is likely to decrease because **self-interest may counter a regard for others'** interests. In real life, motivating factors for considered actions are likely to be complex and difficult accurately to establish (indeed it is difficult to see how they could be accurately established), and self-interest can never be ruled out in many actions that would ordinarily be considered altruistic (one need only look at some of the debate on egoism²⁵⁶).

²⁵⁵ Nuffield Council on Bioethics, (2011) *op. cit.* p175

²⁵⁶ Van Der Steen WJ, 'Egoism and Altruism in Ethics: Dispensing with Spurious Generality', *The Journal of Value Inquiry* 29 (1995) pp31-44

Nagel's altruism is rigid and demanding, and referred to above as 'pure altruism' because it is devoid of self-interest or emotion²⁵⁷. **Nagel's focus on objective reasoning** removes room for self-interest and personal attachments, resulting in an account of altruism that is arguably difficult to meet. **Blum's version of altruism, though less demanding than Nagel's, reflects the weight and value generally attached to altruistic emotions.** Nagel's focus on rationality and objectivity provides an account of how pure altruism can exist, but one could argue that his account does not reflect the importance of families and personal relationships to individuals. **Blum's account accommodates the moral significance afforded to these relationships.** Blum himself suggests that altruism can take many forms²⁵⁸, and recognises the value of the pure altruism proposed by Nagel.

Beneath Blum's account in the hierarchy of altruism, one can consider situations where actions are beneficent (and possibly still altruistic) but where self-interest plays an increasingly significant role. It seems likely that people's reasons for acting are thoroughly mixed and will involve a combination of self-interest and other-regardingness. The organ donor who wants to be remembered in a positive light might be partly motivated by the idea of helping others, but also by a self-interested concern for how she wants to be remembered. There is an altruistic element to a donation of this nature, because there is a wish to help other people, but there is also a degree of self-interest which counters this somewhat. But this illustrates the complexity of donation decisions, and a strict insistence upon purely altruistic or even emotionally altruistic donations might wrongly rule out a significant number of deceased organ donations. **The Nuffield Report's account of altruism could conceivably** be placed around here on a sliding scale of altruism, with the possibility of mixed and non-altruistic motivations featuring alongside more altruistic ones.

²⁵⁷ This is a descriptive, not evaluative, term.

²⁵⁸ Blum LA, (1980) *op. cit.* p117

4.8 Altruism tracking morality

Two accounts of altruism have been presented here in some detail, but an important limitation of altruism has not yet been mentioned. Due to its Kantian grounding, **Nagel's altruism aligns altruistic actions with morally right actions**²⁵⁹. Other accounts of altruism, including **Blum's are unable to do this to the same extent. De Wispelaere** describes this as a failure of altruism to track moral demands²⁶⁰. The problem is that although an action may be other-regarding and altruistic in a general sense, there may be other factors that prevent it from being morally good. Giving money to charity can generally be considered to be altruistic, but if a person decided on their chosen charity on the grounds that it helped people of a certain race (and this person was a racist bigot with a preference for people of this race), then this does not seem like a morally good action. Under many accounts of altruism (Nagel excepted) something can be altruistic yet still morally questionable. Similarly, something can be non-altruistic and still be **morally permissible (even under Nagel's account)**. **Affording some additional weight to one's own interests in some situations may be entirely permissible (although not necessarily praiseworthy)**. It might be altruistic to dedicate one's spare time to charity work, for instance, but choosing to spend some of one's spare time doing things for oneself does not seem impermissible (even though it is non-altruistic).

4.9 Conclusions

This chapter has presented two contrasting accounts of altruism, and introduced **Cottingham's justification for partiality. It has been argued that altruism ought to be** understood as a spectrum, and that partiality and self-interest can influence where particular altruistic acts fall on this spectrum. The discussion in this chapter will provide some of the theoretical underpinnings for discussion in the next chapter, which will look

²⁵⁹ Although a consequentialist could disagree with this on the grounds that following an altruistic course of action might not bring about the best overall consequences.

²⁶⁰ De Wispelaere J, (2002) *op. cit.* pp9-33

at how the DH has used altruism and other principles in relation to conditional and directed donations.

Chapter 5 - The DH's Position on Conditional and Directed Donations

The previous chapter explored two competing philosophical accounts of altruism, and **explored Cottingham's ideas on agent-relative partiality**. This chapter will look at how the DH has used altruism, greatest need, and equitable treatment to control practice **relating to conditional and directed donations**. The DH's claim that placing conditions on a donation renders it a non-altruistic act warrants scrutiny because this was given as a justification for **banning all conditional donations**. This chapter will argue that the DH's principles are used inconsistently, and therefore cannot provide coherent justifications for prohibiting conditional donations.

5.1 Why the DH does not permit conditional donations

The DH revised policy on directed donation (March 2010) states that there are two "key principles which underpin the UK organ donation programme"²⁶¹; absence of conditionality and equitable treatment. Taken together with the principles stated in its 2000 Report, four key principles for deceased organ donation are supported by the DH:

- i) Organs should be donated unconditionally²⁶²
- ii) Organs should be donated altruistically²⁶³
- iii) Organs should go to patients in the greatest need²⁶⁴/according to agreed criteria²⁶⁵
- iv) Organs should be donated in a way that permits equitable treatment²⁶⁶

Each of these will now be scrutinised to assess their suitability and robustness as principles for deceased organ donation.

²⁶¹ Department of Health (2010) *op. cit.* p4

²⁶² *Ibid.* p4

²⁶³ Department of Health (2000) *op. cit.* p25

²⁶⁴ *Ibid.* p25

²⁶⁵ Department of Health (2010) *op. cit.* p4

²⁶⁶ *Ibid.* p4

5.2 Organs should be donated unconditionally

According to the March 2010 guidance, “[t]he fundamental principle of all deceased donation is that, it must be unconditional”²⁶⁷. This principle is derived from the claim that conditionality “offends against the fundamental principle that organs are donated voluntarily and freely and should go to patients according to the agreed criteria”²⁶⁸. In order for the principle of unconditional donation to be justifiable then, it must be shown that conditionality does indeed offend against the principle of organs being donated voluntarily and freely, and being allocated according to the agreed criteria. Taking each part of the principle in turn, it will be argued that conditionality does not *necessarily* entail offending against any aspect of it.

“Voluntarily” and “freely” are not defined in the DH documents, and are therefore open to interpretation. Although they may normally be considered separate, albeit related, concepts, the DH appears to entangle them. Used together, they underscore the need to ensure the absence of coercion (which could include undue influence created by commercial practice), but this interpretation would not seem to be an issue specific to conditional donations²⁶⁹. “Freely”, in particular, could also be taken to mean ‘without constraint’, but this would be inconsistent with the constraints that are routinely placed on donations. For instance, one may request that one’s organs are only used for transplantation rather than research, or that some organs are donated on the condition that others are not. It therefore cannot be the case that “freely” simply means ‘without constraint’. A charitable interpretation of “freely” that provides consistency *and* links to conditionality, could be that “freely” means ‘without constraints on who the organs can be allocated to’. There would, however, need to be further justification for why it is important that donations do not have constraints like this. One justification could be that placing constraints prevents organs being allocated according

²⁶⁷ *Ibid.* p2

²⁶⁸ *Ibid.* p4

²⁶⁹ Conditional donations need not be any more likely to involve coercion than unconditional donations, and prohibiting conditional donations would be a rather heavy-handed approach to ensuring an absence of coercion.

to the 'agreed criteria', with some further justification of why it is important that the agreed criteria are adhered to. But it is not the case that conditions necessarily prevent organs being allocated according to these criteria. The 1998 case featuring racist conditions is a good example: the conditions did not affect who the organs were given to (white people were at the top of the waiting lists).

It is not the case that conditional donations necessarily result in donations that are neither voluntary nor free. The principle that organs must be donated unconditionally, then, appears to lack justification. It may be *preferable* that organs are donated unconditionally (this will be discussed in the Chapter 7), but this does not provide a reason why organs *must* be donated unconditionally.

5.3 Organs should be donated altruistically

The DH regards altruism to be a fundamental principle for organ donation, and altruism is common to many organ donation systems throughout the world (the World Health Organization, for instance, refers to altruism in its guiding principles of organ donation²⁷⁰). The DH offers no definition of altruism, but a working definition can be gained from how the term is used by the DH to justify refusing certain donations or describing them as impermissible.

5.3.1 2000 report points towards Nagel

The 2000 report states that all conditions offend against the principle that organs are donated altruistically, and uses this as a reason to ban all conditional donations. Conditional donations can be other-regarding, so it cannot simply be a lack of other-regardingness that renders these donations non-altruistic. It also cannot simply be the outcomes of the donation/allocation that are regarded as altruistic. Some conditions

²⁷⁰ World Health Organization (2004) 'WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation', Available at: http://www.esot.org/Files/Elpat/Content_Files/PEUfKWHO%20Guiding%20Principles%20Transplantation%20EB123.pdf, Last Accessed: 25/10/2012 p5

have no impact upon the eventual allocation, so it would be wrong to describe all conditional donations as non-altruistic on these grounds²⁷¹.

If placing conditions on a donation is non-altruistic, it could simply be that having an interest in who the eventual recipients are is considered contrary to altruism. **This understanding would be compatible with the naming and practice of 'altruistic'** living kidney donations where, unlike living-related donation, the donor cannot specify the recipient. If altruism requires that one is disinterested in the identity of eventual recipients, it may be that it is impartiality that is being aimed for here: when a certain recipient or type of recipient is requested by a donor, the donation is no longer **impartial, and therefore not altruistic. If so, the DH's account of altruism accords with Nagel's altruism, which requires impartiality.**

5.3.2 The DH cannot consistently require pure altruism

The DH cannot consistently be using Nagel's account of altruism, however. The reason that Nagel's altruism does not permit partiality is because one's own subjective reasons are motivations, which results in self-interest and prevents pure altruism. The pure altruism described by Nagel requires no self-interest or ulterior motives, but it seems probable that some degree of self-interest or ulterior motive is present in many unconditional donations that are currently accepted. If the DH permits these levels of self-interest, then it is not consistently applying **Nagel's account of altruism. Moreover,** if some self-interest *is* permissible, then it also has to be shown that partiality either introduces too much self-interest or is non-altruistic for other reasons.

Exploring the claim that some self-interest may be present in many organ donations reveals some of the inconsistency. When registering for the ODR, one may be genuinely moved to act by objective reasons and the interests of others. Equally, however, one may be partly motivated by a desire to appear to others as a generous

²⁷¹ In addition, as argued in 4.2, altruism ought to be focussed on motivation rather than outcomes.

and altruistic person. This introduces a self-interested component which is incompatible with Nagel's altruism. Similarly, someone agreeing to donate a loved one's organs in the hope that bringing about something positive from a terrible situation will help them come to terms with the situation is acting with a degree of self-interest. Even agreeing to donate a loved one's organs because one believed it was what they would have wanted should not be considered purely altruistic.

There are other instances where motives that fall short of pure altruism feature in people's decisions to donate organs. Organ donation can have positive impacts upon donors (during their life, and perhaps afterwards if one accepts the existence of posthumous interests²⁷²), and donor families²⁷³. A distinction can be drawn between three types of positive consequence that can emerge from organ donation: unforeseeable positive consequences that cannot and do not feature in the decision making process; foreseeable positive consequences that do not feature significantly in the decision making process; and, foreseeable positive consequences that do feature significantly in the decision making process. These distinctions are relevant when determining the level of self-interest, and thus the level or type of altruism in donation decisions.

If a deceased person's family chooses to donate their relative's organs to the general pool, and by chance the organ is transplanted to a friend who they did not know required a transplant, this could have unforeseen positive consequences for the deceased person's relatives. For instance, whilst the positive feelings resulting from helping a friend might not lessen the impact of grief, they may nonetheless help to make some sense of the loved one's death. The positive consequences here would have no impact upon how altruistic the donation was, since they were not known at the time of donation. In a different situation, the same family might be aware that their friend is

²⁷² Wilkinson TM, (2012) *op. cit.* p85

²⁷³ Batten HL and Prottas JM, 'Kind Strangers: The Families of Organ Donors', *Health Affairs* 6 (1987) pp35-47

on the transplant waiting list, but they would have donated the organs anyway. That their friend might be the recipient had no impact upon their donation decision. In this scenario, although the positive consequences are foreseeable, they do not detract from the altruistic nature of the donation by introducing a new level of self-interest into the donation. However, if the family choose to donate **because** they know their friend stands a chance of receiving the organ (or that someone else might receive an organ and their friend might move up a place on the waiting list), and they are aware that **their interests are also served if he is the recipient (insofar as their friend's interest in staying alive is an interest shared by them)**, and there is a level of self-interest which renders the donation not purely altruistic.

It is not obvious that conditional donation **always** results in more self-interest than unconditional donations. Knowing during life that one's organs are going to go to a particular group of people might have some benefits for oneself; if one planned on placing conditions specifying that one's organs could only be transplanted to members of the local community, one might feel more happily integrated with that community²⁷⁴, happy that one will be performing a positive action that will help one's friends (or friends of friends), and comfortable in the knowledge that when one dies, one's organs will be going to someone who will contribute towards something that one values. It seems plausible that this could also apply to unconditional donation, however. One could feel more integrated with one's community (albeit a community on a larger scale, e.g. national community); one could also be happy that one will be performing a positive action to help others (even if these are strangers), and one could also be happy to know that one's organs will contribute towards something that one values (life itself, perhaps). These could be just as self-interested as explicitly conditional or directed donation. It seems unlikely that a donation of this nature would be refused, even though a strict interpretation of pure altruism suggests it should be.

²⁷⁴ Hilhorst speaks of a sense of belonging: Hilhorst MT, (2005) *op. cit.* p205, for instance

The DH's concern may be that allowing more self-interest to feature in allocation decisions would result in donors being motivated by potential rewards during their lifetime. The sort of rewards that would contravene the HTAct are primarily financial or other material rewards, but these would probably never materialise. Since few people actually die in a way that allows organs to be donated, it would have to be a very wealthy individual, group or community that could afford to reward a sufficient number of potential donors to theoretically assure that a certain recipient would receive a directed organ. It would be possible, in theory, for someone to approach a very recently (or imminently to be) bereaved next-of-kin and offer them rewards for directing an organ to a certain individual, but there would be practical obstacles in the way of this occurring (such as gaining access to intensive care units).

It seems then, that although the DH state that deceased organ donation must be altruistic, they routinely accept donations that may feature a degree of self-interest. These donations cannot be purely altruistic, and therefore the DH cannot be using **Nagel's account of altruism**. The March 2010 policy revision also suggests that this is not the case.

5.3.3 March 2010 recommendation points towards Blum

The March 2010 revision permits partiality to family members and close friends of longstanding in exceptional circumstances, echoing the norm in the majority of living donations, which are directed to specified family members or friends. These exceptional **circumstances are largely confined to cases where the deceased was being 'worked-up'** to become a live donor to the named individual, but died before the donation was completed. This revision allows donations that clearly **conflict with Nagel's pure altruism**, and align much more with Blum's. Both DH documents, however, oppose the **'conditional altruism'** that Blum's position would include as altruistic. The March 2010 revision states, in agreement with the 2000 report, that donation must remain **unconditional**. In cases where there is someone in the **'Super Urgent'** category on the

transplant waiting list organs will be made available to this person instead of the nominated recipient, so it is not possible to agree to donation *if and only if* the organ is allocated to the specified recipient. Blum allows someone acting out of altruistic emotions in the interests of another person *because* of a friendship/relationship with that person to be considered altruistic. One might do for a loved one what one would not be willing to do for a stranger; so if one considered organ donation to be a significant sacrifice, one may not be willing to donate for just anyone, and hence donate iff conditionally. Blum would consider this altruistic, but the DH would not permit it.

5.3.4 Pick and mix altruism and its implications

Table 1- Policy and accounts of altruism

	Nagel	Blum
Impartiality (DH Report)	Yes	No
Unconditionality (DH report and March 2010 guidance)	No (a condition placed for objective reasons could be permitted)	No
Permits directed donation to family/friends	No	Yes

The table above illustrates the conflicting requirements of DH policy and the two accounts of altruism. UK transplant policy seems to **borrow features from Nagel's and Blum's accounts of altruism, without fully endorsing either, and moulds these borrowed features into one hybrid account.** This is not likely to be a conscious decision, but even if it was it would be difficult to defend. **Nagel's and Blum's accounts are not open to a 'pick and mix' approach as each is underpinned by a radically different and incompatible account of morality (the strictly rational and impartial Kantian grounding of Nagel, compared with the partial, emotional basis of Blum).** A sensible way of

resolving this situation is to accept, as proposed in the previous chapter that there are different types of altruism, and that donations with conditions or directions attached can be altruistic to varying degrees.

Conditions might, therefore, communicate something about the level of altruism present in a certain donation – insofar as they may introduce self-interest - but they generally cannot in and of themselves shed light on whether a donation is or is not altruistic. A donation with conditions attached stating that the organs can only be given to a specific friend is not purely altruistic in Nagel's sense, but it is still other-regarding and motivated by a desire to help someone else. If this donation was motivated by **altruistic emotions, such as sympathy or concern for a friend, this falls within Blum's** account of altruism.

Blum's account of altruism has even more significant implications for conditional and directed organ donation, since it permits an extended level of partiality in altruistic motivation and acts. For Blum an act is altruistic if it stems from one's concern for the good of another for its own sake, and this allows the sorts of partiality that the DH has previously forbidden. Blum gives a list of the special attachments that he believes can be the source of stronger sympathy, concern and willingness to help others, which **includes "family member, neighbour (in the non-Christian sense), fellow worker, comrade, fellow member (of various organisations), member of same ethnic group or community, regular frequenter of the same pub, fellow citizen, or countryman"**²⁷⁵.

There are, however, reasons to object to at least some of these on grounds that are independent of altruism. For instance, favouring someone because they are a member of the same organisation could be compatible with altruism, but external factors may still render this morally unacceptable – favouring a member of the Ku Klux Klan and giving additional weight to the interests of them over anybody else would seem dubious if it furthered the racist ends of the Ku Klux Klan. So whilst some partiality might be

²⁷⁵ Blum LA, (1980) *op. cit.* p78

morally good insofar as it facilitates altruistic emotions, it can still result in decisions that are bad for other reasons.

This difficulty is addressed by Cottingham's view that partiality on a personal level should be philophilic and stem from a genuine love for those whom one is favouring. This limits the ways in which one can justifiably restrict one's donation – one is no longer justified in favouring one's countrymen since one cannot claim to have a genuine love for each and every one of one's countrymen. The genuine love required for philophilic partiality cannot exist between strangers; it requires a knowledge and understanding of the other person, complete with some personal relationship. This restricts the types of conditions and directions that one may legitimately **place on one's** organs. The restrictions implied by philophilic partiality would likely be the same as the current DH restrictions on directed allocation, so permissible partiality would be limited to close friends and family. The important thing to note here is, however, that it is not altruism that is acting as the guiding principle so much as the limits of acceptable partiality. Using the proposed sliding scale of altruism without further restrictions as the guiding principle for organ donation may permit some conditional donations that are altruistic, but nonetheless morally wrong.

5.4 Organs should go to patients in the greatest need/according to agreed criteria

The DH Report states that it is a fundamental principle of transplantation that organs are allocated according to greatest need²⁷⁶. Stating that organs should be allocated according to greatest need requires a clear definition of greatest need before it can provide guidance for organ allocation, but the panel does not provide this. When detailing the allocation process for organs, the DH Report does not mention greatest need, and instead refers to factors that seem unrelated, such as tissue matching, organ size and donor age²⁷⁷. Greatest need therefore remains open to interpretation.

²⁷⁶ Department of Health (2000) *op. cit.* p1

²⁷⁷ *Ibid.* p7

To say that someone needs a transplant is to say something quite specific. A person with minor liver damage may theoretically receive **some** benefit from a transplant, but this does not mean that they need one. A person with severe liver damage who requires a transplant to stay alive could be considered to **need** a transplant, but this need is related to something else: staying alive. Need is determined in relation to having some goal. So, for instance, a person with no immediate danger of death but a severely restricted quality of life could **need** a transplant to have a reasonable quality of life; a person who is bed-bound without a transplant may **need** a **transplant in order to attend their sister's wedding; a person may need** a transplant in order to be eligible for the Transplant Games²⁷⁸. Looking at this list one may think that some of these goals are more important than others, so one needs to determine what the appropriate goals for transplantation are. An obvious candidate is to save life or improve poor quality of life.

Taking liver transplantation as an example shows how life-saving is factored in. **Within liver transplantation, there are ways in which medical need is calculated. 'Model for End-Stage Liver Disease' (MELD) - and more specifically within the UK, UKELD -** scores are used to give numerical representations of medical need. Neuberger states that **"need may be considered a surrogate for likelihood of death while awaiting transplantation", and that MELD "has been widely adopted as a surrogate of need"**²⁷⁹. Neuberger describes MELD scores as objective, and to some extent this is true – MELD scores consider the same factors from person to person and provide a consistently reproducible result that is true regardless of perspective. As the right measure of medical need however, MELD may fall short. This is illustrated by the fact that there is disagreement over which factors ought to be included in the calculations²⁸⁰, and that

²⁷⁸ A sporting event where competitors have to be transplant recipients.

²⁷⁹ Neuberger J, 'Transplant Benefit in Liver Transplantation: Right Time or Too Premature?', *Organs, Tissues and Cells* 14 (2011) pp81-85

²⁸⁰ Bernardi M, Gitto S, and Biselli M, 'The MELD Score in Patients Awaiting Liver Transplant: Strengths and Weaknesses', *J Hepatol* 54 (2011) pp1297-306

the UK uses a different calculation from other countries²⁸¹. It is uncertain whether MELD always calculates the correct likelihood of dying on the waiting list²⁸², let alone whether this is a true surrogate for need. The key point here is that although it is stated that organs should be allocated according to greatest need, and the definition of need in transplantation seems to focus around urgency and life-saving, there is room for disagreement over what greatest need is.

Even though MELD/UKELD scores appear to consider a single factor (likelihood of dying on the waiting list), other factors also feature. A person who has become so ill that their post-transplant prognosis has worsened may not even be considered for a transplant. This person may still need a transplant in order to survive, even if the additional lifetime gained would not meet the thresholds outlined in policy. By excluding individuals whose urgency of need results in them having particularly poor predicted transplant outcomes, the concept of greatest need incorporates a qualification relating to prognosis. Stating that organs must be allocated according to greatest need is therefore a slightly misleading over-simplification: organs are allocated according to a very specific definition of greatest need that is disputed.

5.4.1 The impact of conditions and directions

Accepting conditional donations would often result in organs being allocated contrary to greatest need (as currently defined within UK transplantation). There could be instances, however, when due to specific circumstances, the conditions would make no difference to allocation. For instance, if a condition specified that donated organs were only to be allocated to men, and men were at the top of the waiting lists and the best

²⁸¹ Neuberger J, (2011) 'Transplant Benefit in Liver Transplantation: Right Time or Too Premature?' *op. cit.* p82

²⁸² Neuberger J, 'Allocation of Donor Livers — Is MELD Enough?', *Liver Transplantation* 10 (2004) pp908-10

tissue matches²⁸³. It is not true that conditional donations *always* prevent allocation according to greatest need.

It is true, however, that conditional and directed donations are likely to result in situations where those with the greatest need receive lower priority than those with lesser need. Research suggests that, aside from greatest need, factors that may be considered by donors are: age, gender, ethnicity, marital status and educational achievements²⁸⁴. Allocating according to these factors rather than greatest need would probably result in more people dying on the waiting list than if the organs had been donated unconditionally, since those most likely to die would not be given priority. This provides a reason to favour unconditional donation over conditional donation. It does not, however, provide a reason to reject conditional donations if there is no possibility of unconditional donation.

5.4.2 Need and other principles

Allocating organs according to greatest need is important to the DH, but the needs of recipients **are not considered important enough to override respect for the deceased's or next-of-kin's wishes about organ donation**²⁸⁵. This is true by virtue of the system being opt-in²⁸⁶. If a deceased person or their next-of-kin have refused consent for donation, then the needs of recipients carry no weight in this decision. In living-related donation, the needs of recipients other than the intended recipient are not considered at the time of allocation. The March 2010 guidance also permits the allocation of organs contrary to greatest need in some instances: only recipients with urgent clinical need are given precedence over the requested directed recipient. The guidance states that **directed allocation can be considered provided that "that there are not others in**

²⁸³ This was a feature of the 1998 racist donation: the conditions specified white people and white people were at the top of the waiting lists.

²⁸⁴ Neuberger J and Mayer D. (2008) 'Conditional Organ Donation-the Views of the UK General Public Findings of an Ipsos-Mori Poll' *op. cit.* pp1545-47

²⁸⁵ Pattinson SD, 'Directed Donation and Ownership of Human Organs', *Legal Studies* 31 (2011) p394

²⁸⁶ This is currently true for the UK, although Wales is proposing a move to an opt-out system. See: Draft Human Transplantation (Wales) Bill, available at: <http://wales.gov.uk/consultation/dhss/organ2/item:jsessionId=vvpkQ71C9C46B9IXBTwZr1G7fHDNQKCK8pQ71rTqbpv95JfWJP5m!-1203216161?lang=en> (last accessed 13/10/2012)

desperately urgent clinical need of the organ... who may be harmed by a request for the organ to be allocated to a named individual going ahead"²⁸⁷. This suggests that the DH would consider it potentially harmful to allocate an organ contrary to greatest need if it was possible to do otherwise. This does not entail that it would also be harmful to allocate an organ contrary to greatest need if the alternative was to turn the organ away²⁸⁸.

This all suggests that tensions between principles are resolved differently in different situations, but more importantly that there are some instances when allocating contrary to greatest need is considered acceptable.

5.4.3 The shift to 'agreed criteria'

A subtle shift in terminology occurred **between the DH's 2000 Report and 2010** guidance. The 2000 Report refers to greatest need whereas the more recent document **stated that organs** "should go to patients according **to the agreed criteria**"²⁸⁹. This latter, **vaguer statement allows 'best match' to also be a consideration, amongst a** range of other factors (which are not specified in the guidance). It is not clear why the terminology has changed, but one might speculate that it lends an element of medical justification to directed allocation. Justifying directed allocation in terms of a stronger tissue-matching may be an attempt to side-step some of the wider ethical issues.

5.4.4 Why should donors care?

Although it may be important for the NHS to allocate according to greatest need, the question of why donors ought to be concerned about greatest need remains unanswered. In many other areas of life (including living organ donation), individuals do not feel obliged to allocate their efforts and resources according to greatest need, and there are good reasons for thinking that some forms of partiality are desirable or

²⁸⁷ Department of Health (2010) *op. cit.* p2

²⁸⁸ Unless one accepts that all organ allocation is harmful, since it entails some people missing out benefits they could have had if the organs had been allocated differently.

²⁸⁹ Department of Health (2010) *op. cit.* p4

necessary (as discussed in Chapters 2 and 4). Given this, it is unclear why, in the case of deceased organ donation, the principle of greatest need (which is itself an expression of partiality in favour of those with the most acute health problems) should take automatic precedence.

One might instead prefer to give one's organs to those one considers most deserving, or those who will contribute most to society in future, or those with whom one has a personal relationship. From an individual's perspective, a range of different allocation principles may be morally justified, including some recognition of the recipient's merit or worth. Given the option of saving the life of an unemployed bachelor who has no family, friends, or intention of ever *contributing anything significant to society, or* saving the life of a leading scientist who has managed to juggle the responsibilities of her day-job of trying to find a cure for cancer with the responsibilities of bringing up a young family, there would be strong utilitarian reasons for favouring the scientist. Her contribution to society in future is likely to be greater, and she has children who depend on her and would very much benefit from her being alive. The unemployed bachelor on the other hand is less likely to make significant contributions to society, and has no family or friends who would be affected by him not having his life saved. All other things being equal, it would be difficult to criticise a life-saver for choosing the scientist over the bachelor.

The NHS's responsibilities are discussed in greater detail in Chapter 7, but for now it will suffice to say that from a donor's perspective there can be morally justifiable reasons to want one's organs allocated contrary to greatest need.

5.5 Equitable treatment

The DH states that organs should be donated in a way that allows equitable treatment²⁹⁰, and conditional donations have the potential to prevent equitable treatment. Not all conditions necessarily fall foul of this, however, so a coherent

²⁹⁰ *Ibid.* p4

argument against **all** conditions cannot be put forward on this basis. One could imagine a scenario in which an awkward organ donor agreed to donate her organs on the condition that her organs were allocated according to the HTA's organ allocation policies. This would still be a conditional donation, so under a strict interpretation of policy should not be accepted. Yet conditions of this nature would make no difference to whom organs were allocated. This is also true of the 1998 case, where white people were at the top of the relevant waiting lists, so the conditions specifying only white recipients did not affect allocation. It is therefore not possible to justify a blanket ban on **all** conditional and directed donations on the grounds that they prevent organs from being allocated in an equitable way.

A distinction ought to be drawn here, along similar lines to Wilkinson²⁹¹, between offering and accepting organs. Individuals are generally free to offer resources according to the principles that they choose, but it is up to the receiving organisation to determine the principles under which such offers are accepted. It may be that a donor placing certain conditions is morally wrong, but this does not necessarily mean that it is also wrong to accept those conditions. One can see why the NHS may have a duty to generally allocate organs in an equitable way, because it is a publically funded institution bound by equality legislation. In some cases of conditional donation, the aim of treating people equitably will be in tension with another aim of saving lives. In cases of conditional donation, treating people equitably can come at the cost of treating **anybody at all** if the organs are turned away. This tension (and 'levelling down' more generally) will be discussed in greater detail in Chapter 7. It is true to say that not all conditional donations prevent equitable treatment, and that there may be other factors that are more important than maintaining equitable treatment.

²⁹¹ Wilkinson TM, (2003) 'What's Not Wrong with Conditional Organ Donation?' *op. cit.* pp163-64

5.6 Conclusions

As far as the four statements made by the DH are concerned, it is clear that conditional and directed donation do not always or necessarily contravene the principles that the DH sets out as fundamental to ethical donation. Conditional donation does not necessarily offend against the principle that organs should be donated altruistically – it has been argued that some conditions are compatible with the account of altruism used by the DH. As discussed in the previous chapter, altruism is not always a good measure of the moral worth of an action. A racist donation may be altruistic, but this is only one consideration when assessing its moral worth. Given this limitation of altruism, its suitability as an absolute principle of acceptable organ donation is restricted. The concept of altruism certainly does not seem able to do the work that the DH tries to use it for in relation to conditional donation²⁹². The principle that organs should go to patients in the greatest need might be a reasonable general policy for the DH to hold, but the March 2010 revision and living-related donation allow allocation contrary to greatest need, so the principle is not consistently enforced to override other principles. The fourth statement relating to equitable treatment may act as a reason to prohibit some conditions, but it is not the case that all conditional donations prevent equitable treatment (as illustrated by the 1998 case). Accordingly, the principle that organs should be donated unconditionally seems fairly redundant, since there is nothing wrong with conditions *per se* – conditions will not always conflict with the other principles.

One outcome of the discussion in this chapter is that the DH's stated reasons for prohibiting cases like the 1998 racist condition situation look unconvincing. If the principles discussed above can be applied differently to accommodate different situations (in some situations it is considered acceptable to allocate contrary to greatest

²⁹² Although this chapter has criticised the use of altruism as a guiding principle for organ donation, it is important to note that this is different from using the idea of altruism to promote organ donation. Altruism may be the best way to promote organ donation, but it is invalid to conclude that this is therefore the only acceptable motive for donation.

need, for example), then it is unclear why they are being used as a barrier to conditional donations. The 1998 donation could fall under the broad category of altruistically motivated actions, the organs were donated in a way that permitted equitable treatment, and they were allocated to those with the greatest need. The only principle that it falls foul of is that organs must be donated unconditionally, but the justification for this principle relies upon false assumptions (that conditionality means that organs cannot be allocated according to medical need, for instance). By focussing its justifications for prohibiting donations like the 1998 case on altruism and other fundamental principles of organ donation, the DH could be accused of skirting around the glaringly obvious issue. The feature that made the 1998 donation particularly unpleasant was the fact that it was racist (and indeed this is also what made it illegal). The leap from objecting to one racist donation to objecting to all conditional donations goes too far, and the DH's justifications for taking this step are inadequate.

Chapter 6 - Recipient Obligations and Waiting One's Turn

The previous chapters looked at conditional and directed donation from the point of **view of donors and related this to the DH's stance on altruism and partiality**. This chapter will focus on conditional and directed donation from the perspective of recipients. It will be argued that recipients have obligations to one another in light of their shared plight. Three key obligations will be explored:

- i) **Waiting one's turn**
- ii) Avoiding negative loss
- iii) Removing oneself from the list when one has an opportunity to do so

It will then be argued that conditional and directed donations would not necessarily conflict with any of these obligations, and that therefore there is little, if anything, wrong with recipients accepting a conditionally donated or directed organ.

6.1 What recipients owe to one another

Being on a transplant waiting list in the UK means that one has a need for a life-saving or life-enhancing organ transplant. **Organs are a scarce resource, and once 'listed', one** is competing with a number of other potential recipients for each compatible organ that becomes available. The UK allocation policies aim to ensure that organ allocation is consistent, but the allocation principles applied are contested, and may - as will be argued shortly - fall short of maximising the efficiency of the transplantation system.

Potential recipients are competing for scarce resources, yet are in some sense **'all in this together'**. **Although recipients may never meet each other, as soon as they** are listed, they become part of a collective resource allocation system intended to either save, or improve the quality of, their lives. For this reason, it is arguable that actions and behaviour whilst on transplant waiting lists are constrained by mutual responsibilities to each other and the group (of people listed) in general. These

responsibilities reflect what potential recipients owe to each other by virtue of their own conditions, recognition of and moral respect for plight of others, and a shared reliance upon the same system for relief from their respective plights. These responsibilities should guide acceptable behaviour when it comes to choosing to receive organs.

It could be argued that potential recipients are justified in applying an 'every man for himself' principle, and that from a recipient's perspective the right person to receive an organ is always himself, but this level of self-interest is difficult to justify. It is tempting to say that when one's life is in danger, one need not concern oneself with the plight of others and that one's own interest in surviving should over-ride concerns for anything else. But not everyone on the transplant waiting list is in *immediate* danger of death; some can spend months or years waiting without being in immediate danger of dying (or even experiencing anything roughly comparable). Focussing one's attention only on one's own situation would represent a failure to recognise and acknowledge the plight of other potential recipients whose lives *are* in immediate danger²⁹³. Although as someone needing an organ, one might experience degrees of suffering, discomfort and worry, it is likely that at any time there will be people experiencing the same things to a greater or lesser extent.

To recognise that one is just one amongst many is an important part of many systems of morality (see discussion of Nagel in previous section), and the responsibilities between potential recipients need to be acknowledged explicitly. This is not to say that these responsibilities arise from the sort of altruism described by Nagel in the previous section; these responsibilities can instead arise from a form of enlightened self-interest, in which co-operation and agreement with basic principles results in a better system for everybody involved.

²⁹³ For those people whose lives are in immediate danger, their urgent need for organs could justify them working on an 'every man for himself' basis. It might be altruistic, even heroic, for them to consider the welfare of people in similarly bad positions, but this consideration would be too demanding to be obligatory.

6.2 Scarcity

When there is competition for scarce resources, there are a number of ways in which the people competing for these resources might want them to be allocated and organs are no exception. With resources such as precious metals there is a finite amount available. With organs, however, there is a potentially limitless number over the course of time, but there is no assurance that any will be available at a given point or specifically the point at which **one's life is at risk. This is a distinction that Kamm draws** with great clarity, differentiating between three types of scarcity:

- i) True scarcity – If an organ is given to one person rather than another, no organ will ever become available for that other person until it is too late for that person to benefit.
- ii) Temporary scarcity – If the organ is given to one person rather than another, the other person will have to wait for an organ, possibly at cost to herself, but she will receive an organ.
- iii) Uncertainty – In a state of uncertainty, it is not known whether the scarcity is temporary or true²⁹⁴.

At present, the type of scarcity most frequently experienced by people on the transplant waiting lists is uncertainty; there is no guarantee that a suitable organ will **become available before a potential recipient's health deteriorates** to the extent that they are too ill to receive a transplant, or they die. This is the type of scarcity that could potentially have a significant impact upon what potential recipients owe to each other. If true scarcity existed, it would be very demanding to suggest that a potential recipient is obliged to refuse an organ because there is someone in worse health than she is; the fact that whoever does not receive the organ will die seems to be the most relevant feature in true scarcity.

²⁹⁴ Kamm FM, 'Morality, Mortality Volume I: Death and Whom to Save from It', (New York: Oxford University Press, 1998) p233

If temporary scarcity more accurately represents the situation on the waiting list, it would seem more reasonable to think that there is an obligation on recipients to wait their turn, as determined by previous and future costs to themselves and others. The fact that uncertainty is prevalent, though, complicates obligations and responsibilities to other recipients somewhat, albeit not beyond potential resolution. In a state of uncertainty, the obligations that would arise under true scarcity and temporary scarcity are in tension. This being the case one might argue that the less demanding obligations of true scarcity should take priority. The consequences of uncertain scarcity proving to be **true** scarcity would likely be much more severe than uncertain scarcity proving to be temporary scarcity, so this could be viewed as erring on the side of personal caution. However, this is not a particularly compelling argument – without the transplantation system, the type of scarcity would not matter – everybody needing an organ transplant would suffer greatly, die prematurely or both. A maximally effective transplantation system relies on the hope that the uncertain scarcity would prove to be temporary scarcity, and this should be reflected in the obligations that recipients have towards one another. All potential recipients involved in the transplantation system have a rational interest in a maximally effective system. If the transplantation system relies upon the hope that uncertain scarcity proves to be temporary scarcity, recipients should share this hope.

6.3 Queuing

Discussion of organ donation within the UK often mentions the idea of waiting lists, and the problems associated with demand exceeding supply. In other areas of life, waiting lists are relatively simplistic affairs. Those who have been on the waiting list the longest generally move furthest up the list as a result of people in front of them being taken off so that they are eventually next in line for whatever is being allocated. It is easy to conceive of a waiting list as being a queue, with people joining the back of the line when they require whatever good is being queued for. The transplant waiting list does

not operate on a simple 'first come, first served' basis, and other factors impact upon one's position in the queue. Someone who has been on the waiting list for a long time will be behind others who enter the queue nearer the front, or jump forward, due to factors such as medical priority or better tissue match. The term 'queue jumping' will be used in the following discussion to denote re-ordering of a queue, and not just wrongful re-ordering of a queue.

Not all organs are suitable for all people; for instance a heart donated from a child might not be suitable for a fully grown adult and vice versa. Similarly, relative risk has to be considered when allocating organs. It might be reasonable to expect a potential recipient with a particularly urgent need for a liver transplant to accept a lower quality liver than someone who is not in such urgent need of a transplant, because receiving *any* liver is better than the possible alternative of receiving *no* liver.

Queues in organ allocation perhaps have to be conceived of in a fairly dynamic way. In essence, each time an organ becomes available for transplantation, a new queue is formed on the basis of the various criteria that are used to allocate organs. Some patients may not be suitable for a specific donated organ so will not feature in this queue. Other patients may be more or less suitable, so will be ordered accordingly. Some patients may have been waiting much longer than others, and will also be **ordered accordingly. It is this 'queue' for each organ, rather than the waiting list in general, that is of concern.**

Before queuing can be discussed further, the necessity of queuing needs to be justified. Perhaps the strongest justification can be made on consequentialist grounds; queuing, and ensuring that organs are given to appropriately matched recipients (since mismatched organs are unlikely to be transplanted successfully) at the right time (however this is ultimately defined), brings about better overall consequences than alternative options. An alternative non-consequentialist justification could be made on the grounds of fairness; scarce resources should perhaps be distributed and allocated

fairly, and this means that relevant and impartial criteria²⁹⁵ (however defined) should be used to decide the right people to receive them. Without a fair system of organising and ordering potential recipients, people who only have a moderately urgent need for an organ might receive transplants before people who have a very urgent need for a transplant with the result that the latter may die before another suitable organ becomes available. Although there are arguably worse things than dying and death, preventing a severely ill person from dying seems to be a more worthy aim than enhancing the life of a moderately ill person. This is a point supported by MELD/UKELD allocation systems which aim to minimise deaths on the liver waiting list²⁹⁶. A lack of a fair system would also mean that those who have waited the longest to receive an organ would not necessarily be amongst the most likely to receive organs in future, so there would be no attempt to equalise waiting times.

In day-to-day life queue jumping is often considered rude and objectionable, as it results in additional waiting and inconvenience for those behind the queue jumper. In cases where queues are organised on a first-come first-served basis, there is also likely **to be some resentment towards the queue jumper because she will not have 'earned'** her place in the queue. Queue jumping in organ donation is more than just inconvenient though; the stakes are high. Failing to respect the queue can result in resources not being made best use of, and this can result in needless death.

There are some cases, however, where queue-jumping is apparently unobjectionable. There is nothing wrong with queue jumping if the person at the front of the queue is unable to take advantage of the good at the front of the queue. In the context of transplantation this could occur when the person at the front of the queue cannot be contacted, or is too far away from a transplant centre to receive the transplant in time, or too poorly on the day to be transplanted. Even though this person may have earned their place at the front of the queue, rigidly maintaining the order of

²⁹⁵ This can also appeal to consequentialists, if the relevant impartial criteria featured maximal effectiveness.

²⁹⁶ Neuberger J, (2011) 'Transplant Benefit in Liver Transplantation: Right Time or Too Premature?' *op. cit.* pp81-85

the queue and refusing to allocate the organ to anybody else would be unreasonable. Similarly there is nothing wrong with moving to the front of a new queue from any position in an existing queue if one is the person nearest the front of that existing queue able to utilise the good at the front of the new queue. To give an every-day example, supermarket checkouts are prime queuing locations, with many queues consisting of several people, some of whom have trolleys full of shopping whilst others may only **have a few items in a basket. If a new 'Ten items or fewer' checkout is** opened (and this was the only other checkout type available in the store), no-one with a trolley could reasonably resent someone with a basket moving over to this new queue. This would mean that people in the original queue would get to the front of that queue more quickly (presuming that the individuals with ten items or fewer were in front of them). If more than one person had ten items or fewer, the people with few items would expect the order from the old queue to be transferred to the new queue²⁹⁷. This is not wrongful queue-jumping; it is just a flexible approach to queuing to make best use of available resources. This flexible approach to queuing could be utilised in organ allocation to ensure the best use of resources in a situation where conditional and directed donations were permitted.

6.4 Waiting one's turn

If recipients could be assured that the type of scarcity present in transplantation was merely temporary scarcity, and that ultimately everybody would receive an organ, then it would be best for everyone if everybody waited their turn. The neediest people would receive organs before less needy people, and this would work to minimise the time people spent in the most severe of health conditions. If one knew that one was definitely going to receive an organ, one would presumably feel inclined to let the neediest people have first claim on suitable organs. If everyone viewed this as a mutual

²⁹⁷ In practice it is often the person who is most alert or who moves quickest who gets to the front of the new queue – but the resentment one feels when someone does this may suggest it is perceived as being unfair.

responsibility to each other, people could be assured that if they became sufficiently needy, their claim for an organ would have higher priority than those who were less needy, and their time spent in this needy state (where suffering and risk of death is likely to be higher) would be minimised. In this sense, the general principle of waiting **one's turn is better for everybody.**

Due to the uncertain nature of organ scarcity, the idea of waiting one's turn is **potentially more problematic.** Waiting one's turn does not entail, as it would do if the scarcity was temporary, that one is only accepting that one will undergo a degree of **suffering; when one waits one's turn when the type of scarcity is uncertain, one accepts** that there is a risk that the scarcity might prove to be true scarcity and that turning down an organ, or an organ being given to someone more urgent than one is now, **might result in one's death.** The degree of risk of the scarcity proving to be true scarcity is contingent upon a number of factors, including how long one could live without a transplant, the commonness of the type of organ that one requires, and the number and medical characteristics of people ahead of oneself on the waiting list. However, the risk of the uncertain scarcity becoming true scarcity is, for organs such as livers where urgency is a significant factor in list order, likely to be greater for people ahead of oneself on the waiting list (since their health is likely to be worse, so they will be able to live for less time without a transplant). It seems reasonable, then, that one should not ordinarily accept an organ unless one is in a position that has the highest (relative to anyone else eligible for the organ) risk of the uncertain scarcity proving to be true scarcity. This would appear to be the sort of thing that everyone on the transplant waiting list might agree to if they were behind a veil of ignorance.

Generally, the principle of queuing is accepting one should not queue-jump without good reason, but as will be discussed shortly, there can be good reason to not **always wait one's turn.**

6.5 Avoiding negative loss

An important goal of the transplant community should be to minimise negative loss; that is a loss of benefit for somebody without a corresponding increase in benefit for somebody else. Given that organs are a scarce resource that can save or improve lives, and the consequences of not using them effectively are severe (additional people may die), it is important that potential good that organs can provide is not wasted. In simple terms this means that every effort should be made to utilise donated organs. Whether attempts to attain this goal should be unconstrained is questionable though, since there may be other relevant factors that should be taken into account. A more qualified goal **of the transplant community could be 'to minimise negative loss in a way that is ethically acceptable'**.

In simplistic consequentialist terms, avoiding negative loss by any means is **superficially desirable. It is in nobody's immediate interests for a medically useable organ to not be utilised.** Under the current system, if someone wishes to donate an organ with conditions attached that restrict the recipient to a certain type of person, this organ would not be accepted. Rejecting a donation of this sort constitutes a negative loss – a benefit is rejected and lost, without a corresponding increase in benefit for somebody else (this is true at least in terms of simple immediate benefits)²⁹⁸.

One could argue that a recipient rejecting an offer of a conditionally donated organ would have other benefits, such as keeping their hands clean of any wrongdoing reflected by the conditions. One might suggest that this benefit of moral rectitude outweighs the benefit of life-saving. A potential recipient might feel virtuous because she had preserved her integrity and not accepted an organ offered according to unacceptable **partiality, but this integrity may come at the cost of other people's lives.**

²⁹⁸ This chapter is only considering negative loss from recipients' perspectives. It will be looked at in more detail from the NHS's perspective in Chapter 7

Her integrity may be a form of self-interest, which may partly undermine the reason for rejecting a conditional donation.

If the system was changed to permit the acceptance conditional donations that would otherwise be turned away, negative loss could be minimised. This would be at **odds with the general principle of waiting one's turn though, so accepting such an** organ may be contrary to the obligations of potential recipients just outlined. If recipients are obliged by their responsibilities to one another to wait their turn, yet at the same time have a duty to help avoid negative loss, then there is some tension surrounding what they should actually do.

Accepting an organ with conditions attached would not just be of immediate benefit to the eventual recipient: everybody behind the potential recipient on the waiting list also benefits, because there is one person fewer standing between them and the top of the waiting list. The people ahead of the eventual recipient on the waiting list *also* receive some benefit, since there would be one less person competing for the organ. Waiting lists are relatively dynamic, and a person can move up the list quickly if their condition worsens, **so it is in everyone's interests to have fewer people** on the waiting list. Furthermore, it is difficult to see how anybody could be immediately harmed by accepting a donation of this type (and following the conditions), since if the conditions were not granted the organ would not be donated anyway.

Accordingly, where an organ is directed to a specific person or type of person, and the donation is conditional upon the recipient being this person or this type of person, we can conclude that the *recipient* does nothing wrong, on consequentialist grounds, if she accepts this organ. As discussed earlier, this is not queue-jumping in the conventional sense because the item being queued for is not suitable (by virtue of its conditions) for anyone in the queue ahead of the intended, or intended type of, recipient.

This approach clearly focuses on consequences to a large extent, but this does not seem unreasonable. When the stakes are so high (risk of death and certain

continued suffering), it would seem fair for the aim to be to bring about the best consequences from a situation that might otherwise be non-ideal. A person who receives priority for a donated organ because of an objectionable condition could be criticised for tacitly endorsing the condition and furthering the wrongful ends of the donor. This assumes that the recipient would be told about the condition, and this need not be the case (see 6.7 below).

Potential recipients may object to a medically suitable organ becoming available and not being offered to them because of non-medical conditions attached. Given, however, that this organ would never have been made available to them anyway (because it would have had to have been rejected), they would appear to have little cause for complaint. Indeed, continuing to object in these circumstances appears to be a **form of 'if I can't have it, nobody should have it' reasoning, which** is very difficult to justify.

6.6 Getting off the list and staying off the list

Linked very closely to the idea of avoiding negative loss is the idea that potential recipients should do what they can to remove themselves from the list. Each person who is already on or added to the transplant waiting list is an additional person competing for the same scarce resources. Each additional person competing for the same scarce resources increases the likelihood of uncertain scarcity proving to be true scarcity for recipients further down the waiting list. It is therefore in the interests of potential recipients to have as few people competing for these scarce resources as possible, and when potential resources are made available, recipients should utilise them.

This should be qualified however, since there are ways to remove oneself from the list that would seem unreasonable to expect a potential recipient to do. For instance, asking an otherwise healthy young person with a non-life-threatening liver condition to accept a low-quality organ that may fail might remove her from the waiting

list, but would probably not significantly extend her life, might result in her returning to the list relatively quickly (which is fairly self-defeating), and may leave her actually worse off as a re-transplant patient^{299,300}. Although not strictly linked to conditional and directed donation, it is worth mentioning that there may also be an obligation for people who have received organs previously thereby benefitting from the transplantation system, to take reasonable measures to keep themselves from returning to the waiting lists in future.

6.7 Information for recipients – do they need to know about conditions?

The prospect of permitting conditional and directed donation raises the issue of potential recipients being offered organs with conditions attached that conflict with their own values and beliefs, to varying degrees. There are two separate questions that need answering here; should potential recipients be informed of the conditions attached to an organ that they are offered? And, are potential recipients obliged to accept an organ with conditions attached even if these conditions conflict with their own values and beliefs?

The first question links to recent debate about how much information recipients should be told about their donors³⁰¹. Broadly speaking, recipients are told little about their donors, as this would run the risk of compromising the anonymity that forms a key part of the deceased transplantation system in the UK. However, the lack of information required by the importance of anonymity is in tension, in part at least, with the demands of information required for informed consent.

²⁹⁹ European Liver Transplant Registry (2010) 'Mortality and Retransplantation', Available at: <http://www.eltr.org/spip.php?rubrique37>, Last Accessed: 31/10/2012

³⁰⁰ Self-killing would also remove a person from the waiting list (and could even supply additional organs), but would be too onerous to be obligatory.

³⁰¹ NHSBT (2011) 'Guidelines for Consent for Solid Organ Transplantation in Adults', Available at: http://www.nhsbt.nhs.uk/pdf/guidelines_for_consent.pdf, Last Accessed: 31/10/2012

A full discussion of what recipients need to know about their donors and the circumstances surrounding the donation is beyond the scope of this thesis³⁰², but there is at least one good reason for not telling potential recipients about any conditions placed upon an organ that they are offered: it would potentially place a significant burden on someone who would already be very ill. Making someone decide whether they are willing to accept an organ with conditions attached to it that they find objectionable presents them with an awful dilemma: accept an organ offered against their principles, or stay on the waiting list and potentially die or become even more ill before receiving an organ. Equally, potential recipients might feel uncomfortable about **receiving organs 'out of turn', even though this can be ethically justified with reference** to avoiding negative loss. Explaining the idea of negative loss would promote understanding, but this may run the risk of then pressuring recipients to go against their own principles for the good of others. It is clearly not satisfactory to say that **'ignorance is bliss', but it would appear that there are certainly some reasons to not** inform recipients about conditions attached to donations.

6.8 Conclusions

In this section it has been argued that potential organ recipients have some basic **obligations to each other. The general importance of waiting one's turn has been** defended, to draw the conclusion that as a potential recipient one should not normally **'queue-jump'.** It was then argued that the principles of avoiding negative loss and removing oneself from the transplant waiting list could provide justifications for not **waiting one's turn (and that this need not be considered queue-jumping).**

Conditional and directed donations would require recipients to behave in certain ways in order to maximise the utility of these donations, but this is not particularly troubling. It would therefore appear that there is not necessarily anything wrong with

³⁰² Recently this debate has focussed on the use of marginal organs, and whether recipients ought to be told **about donors' lifestyles or causes of death.** – *ibid.*

conditional and directed donation from the perspective of recipients and potential recipients.

Chapter 7 - The NHS, its options and furthering wrongful ends

Conditional and directed donation has thus far been explored from the perspectives of organ donors and organ recipients. It has been argued that, from these perspectives, conditional and directed donation is not necessarily a bad thing. The final perspective to explore is that of the UK transplant authorities and NHS. This chapter will explore the implications of permitting conditional and directed donation from the perspective of these organisations. It will be argued that this perspective provides few reasons to object to such donations, and that permitting and facilitating them can be justified in some circumstances.

7.1 A preliminary note on efficiency

Efficiency is a concept that features in the following discussion, so a clear definition is required. In simple terms, efficiency is the ratio of input to output, but input and output in the context of transplantation require definition. Input could be measured in donated **organs: these are what are 'put in' to the transplantation system via donation. This is** not useful in determining efficiency, however, since output should consider more than just the number of organs successfully transplanted. Moreover, not all organs are of equal quality, and differences in quality result in different transplant outcomes.

Alternatively, organs can be regarded as sources of potential good. Each donated organ has the capability to produce some good, and some organs can produce more good than others. A top quality organ from a young, healthy donor will have the capacity to produce more good than a poor quality organ from donor with a history of chronic ill health. Efficiency, for these purposes, then, refers to the ratio between the maximum potential good achievable by an organ and the good that is actually realised by that organ. **This definition of efficiency leaves open the question of how 'good' ought to be** defined. A full exploration of this complex issue is not possible here, but a suitable and

practical candidate is the Quality Adjusted Life Year³⁰³. A transplantation system working at maximum efficiency would be one that brought about the most possible QALYs from its available donated organs. Although QALYs have been criticised³⁰⁴, they are currently used in cost-benefit analyses produced by the National Institute for Health and Clinical Excellence³⁰⁵ and it would be consistent with other areas of the NHS to use them in relation to organ allocation.

Efficiency is not the only consideration when allocating organs³⁰⁶, but a simple example illustrates its importance. Transplanting a top quality liver into a patient who is going to die within 6 months from other causes would be an inefficient (and therefore poor) use of that organ if there were other potential recipients with a post-transplantation life-expectancy of ten years.

7.2 A defence of unconditional donation

Now that efficiency has been outlined, it is possible to defend an important claim: that, from a neutral perspective, unconditional donation is generally preferable to conditional donation. This starts with the assumption **that the NHS's allocation criteria are, all things considered, the best criteria currently available**. They are undoubtedly not perfect, and ought to be continuously scrutinised and questioned, but they take into account and balance many complex factors and they have been developed over time by people who understand transplantation. Many conditional donations will prevent organs being allocated according to the usual criteria. This is likely to result in compromised transplant efficiency, because tissue matching and other medical factors may not be given appropriate consideration. It may also result in deaths on the waiting list that

³⁰³ Sassi F, 'Calculating Qalys, Comparing QALY and DALY Calculations', *Health Policy and Planning* 21 (2006) pp402-08

³⁰⁴ Harris J, 'Qalyfying the Value of Life', *Journal of Medical Ethics* 13 (1987) pp117-23

³⁰⁵ Nice, 'Measuring Effectiveness and Cost Effectiveness: The QALY', (2010)

³⁰⁶ Fairness operates as a constraint on efficiency for some organs, so someone who has been waiting a long time for a kidney transplant could be allocated an organ ahead of someone who has not been waiting as long but who has more predicted QALYs.

could have been avoided if the organs were donated unconditionally. In these instances, conditional donations are not ideal.

Where attached conditions do not make a difference to organ allocation, this objection fails. In the 1998 case of conditional donation involving racist conditions, the organs were allocated to the people at the top of the waiting list anyway. This suggests that conditional donation per se does not always cause non-ideal allocation. However, at the time of donation, conditions should still be considered non-ideal insofar as they *may* prevent the organs being allocated according to standard criteria. Although some conditional donations may not compromise the final allocation, at the time of donation the final implications of the conditions may not be fully known.

There is also a risk that conditional donations, even if accepted, may result in wastage. If a donor stated that they were only willing for an organ to be transplanted to a specific person, or a particularly specific type of person, it may prove to be impossible to follow this request.

7.3 Conditional donation and the supply of organs

Successful transplants are a good thing because they save, or significantly improve, the lives of the people who receive them, and NHSBT, the DH and HTA are constituted to achieve these goods to the best of their ability and resources, and within the law. There is a consistent drive to increase the number of organ donors in order to meet demand.

The impact on organ supply of permitting conditional donations is unknown. In simple terms it may increase the number of organs, decrease the number of organs, or have negligible effect. In more complex terms, it may lead to more donations overall, but fewer unconditional donations. Conditional donation may encourage some people to donate who otherwise would not, but this may be offset by other people choosing to not donate organs if they perceive the system to be unfair. Even if they do not significantly increase overall donation rates, there is something to be said for accepting

conditional donations, since they will provide an organ that otherwise would not be available, and would remove at least one person from transplant waiting lists. This would potentially benefit many other people on the lists. Allowing conditional and directed donation, however, might compromise some of the key ideals of a publically funded institution such as the NHS. Just as a survival lottery³⁰⁷ might be one way of meeting the demand for organs, objections to it³⁰⁸ suggest that organ donation should not necessarily be maximised by **any** means, and that there are other considerations beyond immediate positive consequences for the recipients that need to be considered.

7.4 The NHS's role

Transplants in the UK rely on the transplantation system that is in place, and this transplantation system seems unlikely to change significantly in the immediate future. Transplants are not simply a product of donor and recipient meeting in a dark alley and organs being passed from one person to another. Skilled surgeons are needed in sterile operating theatres, with appropriate pre and post transplant care packages available to recipients.

This renders the question of whether conditional and directed donations should be **allowed** rather meaningless. **Allowing** is not the issue here since allowing implies, superficially at least, a level of non-interference. Transplants **require** interference by the NHS and transplant authorities, so the NHS allowing conditional and directed donation would have little impact (presuming that a privatised system of transplantation is not **on any UK Government's immediate agenda**³⁰⁹). Instead the important questions are whether the NHS should accept conditional and directed donations and facilitate or perform transplants on the basis of these conditions or directions.

³⁰⁷ Harris J, 'The Survival Lottery', *Philosophy* 50 (1975) pp81-87

³⁰⁸ For instance, people question what life would be like in a world where any innocent person could be killed for their organs at any moment. Others question the acceptability of killing one person to save others.

³⁰⁹ Buggins E (2009) 'Allocation of Organs to Non-UK Eu Residents', Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103515, Last Accessed: 31/10/2012 p7

The NHS and transplant authorities are *involved* in the process of accepting and allocating donations, and performing transplants. Bearing in mind those conditional and directed donations will often reflect objectionable personal preferences (the 1998 case featured racist conditions, for instance³¹⁰), there is an instant temptation to suggest that the necessary level of involvement that the NHS and transplant authorities have in organ donation would dirty the hands of these organisations to an unacceptable extent. There is a legal requirement that organisations such as the NHS should not be racist or indeed unjustly discriminatory on any other grounds³¹¹.

7.5 The NHS's options

If one accepts that unconditional donation is preferable, then one can argue that the NHS ought to promote unconditional donation. This, however, leaves open the question of how the NHS ought to respond to conditional offers of organs if they do occur. There are many reasons why the NHS should not operate a general policy of allocating organs according to desert, responsibility, ethnic origin or similar conditions³¹². There is a difference, however, between having a general policy of allocating organs according to these factors, and having a general policy of allowing donors a say in who the recipients of their organs are, and fulfilling these wishes.

The term 'allocative authority' is used here to refer to control over to whom donated organs are transplanted. Transplant authorities can only work with what they are given, and if they are given organs with conditions attached that constrain their allocative abilities, they can:

- i) Accept the donation but lie to the next-of-kin and ignore the conditions;
- ii) Turn the organs away and provide no benefit to transplant recipients;
- iii) Allocate within these constraints and provide benefit to transplant recipients.

³¹⁰ Department of Health (2000) *op. cit.*

³¹¹ Equality Act (C 15) 2010

³¹² Ho D, 'When Good Organs Go to Bad People', *Bioethics* 22 (2008) pp77-83

Each of these options will now be examined in turn. It will be argued that the first two are worse options to choose than the third.

7.5.1 Lie to the next-of-kin and ignore the conditions completely

One possible way to handle conditional donations would be to accept the donation, allocate the organs according to standard criteria, but lie to the next-of-kin so that they think their conditions have been followed. This would have the advantage of not having to turn away medically useable organs, and would maintain the freedom for the NHS to allocate according to the principles that it considers correct. This option can be rejected on both ethical and legal grounds.

First, one might simply consider it unethical to lie to the next-of-kin. Kantian moral theory would suggest this was the case, but a consequentialist may argue that lying in these circumstances is justifiable if it brought about good consequences. Allocating organs according to medical criteria is, in very simple terms, likely to bring about better transplant outcomes than allocating according to non-medical factors. A consequentialist may also have to consider lying in these circumstances to be wrong, however, since organ donation relies upon public trust and good will. The Organ Retention Scandal³¹³ has shown that being dishonest about what happens to body parts after death can cause great upset, and this sort of upset could harbour mistrust and cause a consequent decline in donated organs. Although in principle it could remain a secret, the risk of it entering public knowledge should be sufficient to rule out such a policy.

More importantly, if consent for organ donation is given on the basis that the organs are only allocated to certain types of people, then accepting the organs and then allocating them contrary to this would undermine the consent. Cronin and Douglas suggest that **"If a donor's consent has been limited to specific situations, it follows that any allocation of organs contrary to such limitations vitiates that consent and amounts**

³¹³ 'Royal Liverpool Children's Inquiry Report', (2001) Available at: <http://www.rlcinquiry.org.uk/contents.htm>, Last Accessed: 31/10/2012

to dealing with the organs *without consent*³¹⁴. The HTA's Code of Practice for consent states that consent *can* be limited to specific situations³¹⁵, and conditional donation would be an example of this³¹⁶. Given that authorised activities (of which donation for transplantation is one) are only lawful if done with appropriate consent³¹⁷, it would be unlawful to accept a conditional donation and then allocate contrary to the conditions.

7.5.2 Turn the organs away and provide no benefit to transplant recipients

The option of turning away organs with conditions attached is the one currently exercised in the UK. As discussed in Chapter 5, the justification given for this is to preserve the fundamental principle of organs being donated altruistically in a way that allows them to be allocated to people in greatest need. It has been argued in Chapter 5 that conditional donations can still be altruistic, so this by itself cannot provide a reason to turn away conditional offers of organs.

Insisting that organs are allocated according to greatest need also cannot provide a reason to turn all away conditional offers³¹⁸. An important distinction made by Wilkinson is the difference between allocating according to an impartial principle and allocating according to an impartially defensible method³¹⁹. Under the current system, adherence to the impartial principle of allocating according to greatest need entails that organs with conditions or directions attached to them are turned away. Taking the **direct method of achieving impartiality (following the impartial principle of 'allocate organs according to greatest need)**, the medical needs of recipients are actually met less well than they otherwise could be. One might argue that accepting and allocating

³¹⁴ Cronin AJ and Douglas JF, (2010) 'Directed and Conditional Deceased Donor Organ Donations: Laws and Misconceptions' *op. cit.* p295

³¹⁵ Human Tissue Authority (2006) 'Code of Practice - Consent', Available at: http://www.hta.gov.uk/_db/_documents/2006-07-04_Approved_by_Parliament_-_Code_of_Practice_1_-_Consent.pdf, Last Accessed: 31/10/2012

³¹⁶ Cronin AJ and Douglas JF, (2010) 'Directed and Conditional Deceased Donor Organ Donations: Laws and Misconceptions' *op. cit.* p294

³¹⁷ Human Tissue Act (C 30) 2004

³¹⁸ For one, not all conditions prevent this anyway.

³¹⁹ Wilkinson TM, (2007) 'Racist Organ Donors and Saving Lives' *op. cit.* pp63-74

according to the conditions on a donation may prevent the very neediest from receiving a transplant, so even accepting the donation does not meet greatest need. This does not, however, provide a reason to turn away a donation, rather than offer it to an eligible person with greatest need. An unconditionally donated organ may not be the right tissue-type for the patient with greatest need, but this does not mean the organ should be rejected and not offered to people with the correct tissue-type but lesser need. Wilkinson argues that accepting conditional and directed donations could allow for need to be *better met* and that ultimately this fulfils the reason for having impartial principles in the first place³²⁰.

Fairness

One possible reason to reject conditional donations is because they are unfair. For this objection to be valid, it must be true that the current allocation system is fair, or at least fairer than accepting conditional donations would be. Wilkinson argues that an appeal to fairness is not a valid objection³²¹. Due to the scarcity of organs, it is a reality that some people receive a benefit that others do not. A fair way to deal with this problem would be to give everyone the same treatment, but due to organs being scarce this could only be achieved by treating nobody. Wilkinson suggests that few people would support banning transplantation on these grounds because saving lives trumps rigid adherence to fair allocation. If this is the case accepting conditional donations also trumps fairness (since accepting conditional donations saves lives), or fairness must be conceived of differently³²².

Wilkinson goes on to discuss the possibility that when organs are scarce, transplantation *per se* ought not be considered fair or unfair, but that if it is going to happen then it ought to be done fairly. Fair allocation systems may include, amongst others, a lottery, or a fair queue. A fair queue would need to be based upon the fixed

³²⁰ *Ibid.*

³²¹ *Ibid.*

³²² *Ibid.* p70

principle of a substantive fairness criteria, such as ensuring equal waiting time³²³. It would then be unfair for an organ to be allocated in a way that did not respect the order of the queue. As Wilkinson points out, however, waiting lists generally (and this is true of the UK) take into account factors other than waiting time, such as transplant benefit, and this can be considered trading off other factors (efficiency, in the case of transplant benefit) against absolute fairness. If this is the case, it is not clear why the additional transplant benefit gained by accepting conditional donations cannot be taken to outweigh a loss of fairness.

Levelling down

If it was possible for the NHS to allocate according to its own relatively fair (see above) allocation policy, and it chose to allocate according to other factors, then this *could* be considered unfair and unacceptable. With conditional donations, however, the NHS is faced with a different situation: allocate the organs according to other possibly unfair factors, or preserve fairness and do not allocate the organs at all.

Turning away organs in order to preserve fairness, in this situation, would be a form of levelling down^{324, 325}, insofar as it makes some people worse off without any subsequent gain for others. This relates very closely to the concept of negative loss discussed in Chapter 6.

Using a common form of thought experiment may show that levelling down is counterintuitive. One can imagine a publically-owned swimming pool, in which a number of children are unfortunately drowning. A passer-by is a strong swimmer and offers to save as many children as he can. Unfortunately he is also a racist, and makes it clear that he is only willing to save the white children. It is uncertain whether any other life-savers will arrive in time to save the children. The pool manager is faced with

³²³ *Ibid.* p71

³²⁴ Parfit D, 'Equality and Priority', *Ratio* 10 (1997) pp202-21

³²⁵ Wilkinson TM, (2012) *op. cit.*

a dilemma: allow some of the children to be saved but accept that they are being selected on the grounds of race, or turn down the offer of life-saving and accept the possibility that additional children may drown. It would take a fairly inflexible egalitarian to suggest that the life-saving offer should be turned down in this case. Although the swimming pool manager could quite rightly be asked to justify why only white children were saved, an explanation of the alternatives would surely vindicate him.

It would seem reasonable to think that sometimes levelling down is appropriate. For instance, if one changes the scenario to a school where a generous donor is offering book-tokens to pupils, but only to white children, then the school would be justified in turning down the book tokens. The difference between this example and the swimming pool is the severity of the consequences. By turning down book-tokens, a few children will miss a relatively insignificant benefit. By turning down organs, people may die or endure additional severe illness. Where the consequences are this severe, and the need so acute, levelling down is the wrong thing to do.

7.5.3 Accept the conditions and allocate accordingly

It has been argued that the first two options available to the NHS would be the wrong course of action to follow. The third option available to the NHS is to accept conditional donations and allocate according to the conditions. This can have benefits for all people waiting to receive organs, but could also cause harm. These potential benefits and risks will now be considered.

Accepting is better for all transplant recipients

Having additional organs available for transplantation is beneficial to people waiting for transplants, and this is true even if the organs are donated conditionally. More organs available for transplantation means more lives can be saved or improved, and this benefits the people who actually receive these additional organs. Everybody on the

waiting lists behind the people who receive the organs will effectively be moved up a place on the waiting list, so these people also benefit.

Conditions attached to these additional donations may mean that the people at the top of the waiting lists according to standard criteria are deemed ineligible for these organs. One could argue then that accepting conditional donations is bad for these people because they are overlooked during the allocation of certain organs. This is wrong, however, because the organ would not have been available for donation were the conditions not accepted. This being the case, it is actually *better* for the people ahead of the eventual recipient if the donation is accepted, because it removes somebody else from the waiting list who could potentially move ahead of them in future. Removing people from the waiting list benefits everybody on the list, as there is less competition for organs. Accepting conditional donations when they occur is, for recipients, better than turning them away.

7.6 Accepting the unobjectionable

As discussed earlier, some conditions that an individual might choose to place on the use of organs can be morally acceptable and compatible with the altruistic principles of deceased donation in the UK. Indeed, in some instances it might be more than permissible that conditions or directions are placed on an organ, it might be required, as we have seen in the discussion above about the mother failing to direct an organ to a needy offspring³²⁶.

The March 2010 revision to guidance³²⁷ regarding deceased donations directed to **family members goes some way towards permitting similar levels of the “partial autonomy-driven rationale” that underpins live donations**³²⁸. It has been argued that

³²⁶ Cottingham J, (1986) *op. cit.* p357

³²⁷ Department of Health (2010) *op. cit.*

³²⁸ Cronin AJ and Douglas JF, (2010) 'Directed and Conditional Deceased Donor Organ Donations: Laws and Misconceptions' *op. cit.* p278

this level of partial autonomy can “create and sustain intimate personal relationships”³²⁹

within the context of live donation, and it seems equally plausible that this can occur with deceased donation. In living donation this power to create and sustain intimate personal relationships generates exceptions to impartial allocation, and it is reasonable to also apply this to deceased donation. The relationship obviously perhaps be between the deceased person and the recipient (although one might argue that *something* positive can still be produced here, such as a positive and meaningful memory), but as discussed earlier it does not always make sense to think of the deceased person as the donor anyway. A father who directs his deceased wife’s organs towards their needy child might sustain the intimate personal relationship between him and his child, and at the same time strengthen the memory that the child has of its mother.

This is not to say that impartial justice is not an important ethical principle; it is just an acknowledgement that it is not appropriate in all situations and that there can be other things that are of greater importance. Given that this is the case for living donation, then it is inconsistent for this to not also be the case for deceased donation.

7.7 Accepting the objectionable

Although some people may wish to place conditions or directions on organs for morally acceptable reasons, it is probable that some people would have less noble reasons for doing so. Some people will want to allocate organs according to race, gender, sexuality or lifestyle and often this might reflect unjustifiable prejudice against groups or individuals. It is possible that someone might choose to allocate organs according to **any of these criteria with good intentions, but it seems implausible that ‘true’ intentions** could ever really be accessed and/or known by the transplant authorities. The most difficult donations to justify accepting are those that appear morally unacceptable – the spiteful homophobe who does not want her organs to be transplanted to a homosexual,

³²⁹ Kluge E-HW, 'Designated Organ Donation: Private Choice in Social Context', *The Hastings Center Report* 19 (1989) p10

or the anti-Islam bigot who deliberately and intentionally wants to deprive Muslims of her organs. These are the sorts of donations where allocative authority is misused, and the values represented are at odds with the norms of a decent and equality-based society.

7.8 Involvement in the wrong

When it comes to accepting organs with morally objectionable conditions attached, the question appears not to rest on any account of immediate harm to potential recipients, but instead on whether it is acceptable for the NHS to be complicit in wrongdoing and to further wrongful ends - which could cause harm, perhaps on a wider scale.

Complicity in wrongdoing has two main components: assistance and shared intentions³³⁰. The wrongdoing in the case of a racist conditional donation is complex, but can be considered on two levels. First, it is wrong to attempt to deliberately disadvantage people on the basis of race. Second, it is wrong for people to actually be disadvantaged on the basis of race. By accepting a donation with racist conditions attached, the NHS would not be deliberately attempting to disadvantage people on the basis of race, but it would be helping to bring about the disadvantaging of people on the basis of race. The NHS can therefore be considered to be assisting, but not sharing intentions.

The extent to which the NHS should be considered complicit varies according to the extent that its actions help to achieve the racist end. The racist end in this case cannot be achieved without the assistance of the NHS, so the NHS must be considered relatively complicit. It could be more complicit, if, for example, it deliberately made it easier for people to place racist conditions, or even promoted the idea. There are also ways in which it could make itself less complicit (see section 7.10). Kluge has argued that "[i]f a first party engages in an unethical act which, as act, becomes materially

³³⁰ Lepora C and Millum J, 'The Tortured Patient', *Hastings Center Report* 41 (2011) p40

possible only through the aid of a second party, then the second party shares in the guilt of the first to the degree that its participation is instrumental in allowing the act to take place³³¹. If one accepts that it is unethical to make a racist conditional offer of organs, one might argue that this act only becomes materially possible through the aid of the NHS. Even if the NHS does not accept the donation, however, the act of conditionally offering organs has still been performed. By implementing a consent-based framework for organ donation, the NHS is instrumental in allowing the act (conditionally offering organs) to take place, yet consent is currently considered fundamental³³² for organ donation. The NHS is therefore in a difficult position: supporting the principle of consent for organ donation is instrumental in allowing people to act unethically (which implicates the NHS in the wrongdoing, according to Kluge), but abandoning a consent-based system would also be considered unethical by many³³³. **If one accepts Kluge's general principle, yet still supports consent for organ donation**, one must accept that although the NHS allows and aids people to act unethically and therefore shares some of the guilt for their unethical actions, other principles (such as consent) are more important than complete non-complicity in wrong-doing.

In terms of shared intention, the situation is simpler. The NHS cannot be considered complicit. There is the possibility of **a** shared intention, insofar as both the donor and the NHS may act because of a wish to save lives, but the relevant bad intention - to deprive certain people of organs on the basis of race - would not be shared by the NHS. The NHS and transplant authorities would merely be making use of available resources to save or improve lives, and this need not reflect anything negative about the views or wishes of these organisations.

³³¹ Kluge E-HW, (1989) *op. cit.* p14

³³² Human Tissue Authority (2006) 'Code of Practice - Consent', Available at: http://www.hta.gov.uk/_db/_documents/2006-07-04_Approved_by_Parliament_-_Code_of_Practice_1_-_Consent.pdf, Last Accessed: 31/10/2012

³³³ Truog RD, 'Consent for Organ Donation — Balancing Conflicting Ethical Obligations', *New England Journal of Medicine* 358 (2008) pp1209-11

If the NHS and transplant authorities did decide to accept donations with objectionable conditions attached, they should still strive to bring about the fairest and most medically-justifiable allocation of organs within the constraints of the conditions. For instance if someone donated a liver with the condition that it was only transplanted to white people, this would still provide scope for the transplant authorities to allocate the organ to the most medically suitable white person. By doing this it would be very clear that the aim was purely to make the best use of available resources.

7.9 Negotiating with terrorists

Allocating according to constraints might be akin to paying a ransom to release a hostage – insofar as the NHS has to concede to the wishes of the donor in order to be able to use the organs - but the alternative situation of the organ going to waste might **render this acceptable. Although one might argue that 'negotiating with terrorists' is** wrong, it need not be framed like this. The NHS may have to pay drugs companies inflated prices for life-saving medication, and this may be undesirable insofar as it uses up finite financial resources. In an ideal world, the NHS would not have to pay such a price for medications, but it is forced to do so in order to obtain the life-saving resources that it needs. Similarly, in an ideal world the NHS might not want to follow **donor's conditions**, but it may have to in order to obtain the life-saving resources that it needs.

7.10 Minimising harm and possibilities for offsetting

If indeed, as is proposed, even objectionable conditional and directed donations are acceptable due to the good consequences that they result in, consideration has to be given to any potential harm that they may cause. Something that has positive consequences in terms of donation rates might have negative consequences more broadly conceived. In a country like the UK where racial tension has historically been a significant issue, and still continues to be, there is the risk that a public organisation such as the NHS facilitating racist donations and furthering the ends of racists might be

viewed as symbolically supporting racism, and this could have farther-reaching implications that impact negatively upon different ethnic groups. The same could be said of conditions that discriminate against other minority groups who may already feel alienated from mainstream society.

It is difficult to predict the precise harms that accepting donations such as these might cause. It does seem likely though that at least some harm would be caused, and although this may be justified in terms of the removing barriers to life-saving or improving organ donations, it would seem sensible for some efforts to be taken to minimise the harm of accepting these donations.

The simplest method of minimising harm would be to release a statement each time a conditional or directed donation was accepted. The statement need only declare **the NHS's position on the conditions placed, and reiterate the preference** for unconditional donations. If an organ was accepted with racist conditions attached, the statement might declare that the NHS and transplant authorities do not support racism, but that organs are such a precious resource that they feel justified in accepting the donation. It might also mention that within the constraints of the conditions, the fairest allocation of organs was sought. If the reasons for accepting these donations were clear and transparent, it would seem difficult for people to consider the NHS and transplant authorities to be racist or otherwise unjustly discriminatory. It could also be emphasised that people of any ethnic group could place conditions or directions on their **organs, although one might rightly be concerned that this might result in 'tit-for-tat'** conditions being placed on donations. Other forms of offsetting or harm minimisation could also be considered. One such option would be to attempt to offset the discriminatory effect of some conditions. For example, if a donor specified that her organs could only be allocated to white people, the NHS could ensure that the next available organ was allocated to a non-white person. This would obviously be

dependent upon tissue-matching, but it does suggest that the negative impacts of conditional donations can be reduced.

7.11 Issues of equality

It has been argued there are justifications for accepting conditional donations. But one might argue that the current donation and transplant system works well, is appropriately principled, and that there is nothing to be gained by changing to a policy that compromises valued **principles and potentially allows people to act 'badly'**.

However, there are problems with the current policy, and one of these is the way in which organs are currently distributed.

Whilst it is correct to say that current organ allocation is fair in some sense, there is another sense in which organ allocation in the UK is unfair. Ethnic minority groups in the UK tend to donate fewer organs than majority groups, so for organs where shared ethnic origin leads to a better tissue match, there are fewer organs available for ethnic minority potential recipients. This situation is exacerbated by high demand for these organs from those very groups. This system has resulted in a situation where people of South Asian ethnic origin stay on kidney transplant waiting lists for three times as long as people of other ethnicities. This does not occur as a result of direct prejudice or discrimination, but when outcomes are as unequal as this, consideration should be given to any alternative that might result in a more even distribution of available organs, or a system that improves the lot of those that tend to fare particularly badly.

One might be tempted to argue that because this situation arises from low donation rates from these communities it is somehow acceptable, but this essentially holds people responsible for the actions (or lack of actions) of other people where the only link is shared ethnic origin. It does not seem right to say that it is acceptable for South Asian people to wait a long time for organ transplants simply because fewer

South Asian people choose to donate organs, because this is like saying 'people like you can wait longer to receive organs because people like you are less likely to donate organs', where the 'like you' refers to a feature that is beyond the control of the individuals concerned. It is not necessarily *unfair* for South Asian people to have to wait longer for transplants, but the inequality in waiting times suggests that action is required to specifically promote organ donation to groups that currently have low donation rates.

One option to resolve the situation could be to permit conditional donation amongst groups with low donation rates, if this was likely to remove a barrier to donation. If, for instance, allowing South Asian donors to direct their organs towards fellow South Asians would result in an increased number of South Asian people donating organs, then this would provide *a* reason for permitting it. If, however, other ethnic groups thought this unfair they may feel less inclined to donate into the same system. Some white people may insist that they will only donate if their organs are given to other white people, which would result in the organs being turned away if white people were not permitted to place conditions³³⁴.

A 'one-size-fits-all' unconditional approach to organ donation may not appeal to all types of people equally. The extent to which conditional and directed donation might result in increased equality of outcome is an empirical matter. But a system that does not maximise the amount of organs available harms those in need of an organ³³⁵, so consideration should be given to ways that donation rates can be maximised.

Permitting people to make these donations might result in donations that would ordinarily be unconditional and purely altruistic becoming conditional and discriminatory. One potential outcome of this could be that certain groups of people (perhaps those already on the fringes of society) experience a much reduced access to

³³⁴ Radcliffe-Richards J, (2012) *op. cit.*

³³⁵ Sade RM, 'Cadaveric Organ Donation: Rethinking Donor Motivation', *Archives of Internal Medicine* 159 (1999)

organs for transplantation, increasing healthcare inequality. This would be undesirable, and it is difficult to see conditional and directed donation being acceptable if this were the case. However, it is challenging to predict how likely this would be and one would hope that there would still be a sufficient supply of unconditional donations to cater for the needs of those excluded by the majority of conditions (if such a pattern emerged).

It is worth noting the earlier discussion that even under the current system some groups are severely disadvantaged, so the notion that conditional and directed donation might result in some groups being disadvantaged is not a knock-down argument against it; this would all depend upon the scale and reach of the disadvantage, and this could only accurately be known by gathering empirical data.

7.12 Conclusions

This section has looked at conditional and directed donation from the perspective of the NHS and attempted to approach the issue with an open mind. It has argued that there are good reasons why the NHS should accept conditional donations. In situations where **the donor's conditions are** morally acceptable and compatible with altruism, it has been argued that these donations should be accepted. The more difficult donations to justify accepting are those that are not necessarily altruistic³³⁶ and represent morally questionable prejudice on the part of the donor or their family. Accepting donations of these sorts, however, does not necessarily reflect badly on the NHS and transplant authorities so long as they are accepted for the right reasons. Furthermore, efforts must be made to allocate the organs as fairly as possible within the constraints of the conditions or directions, and further reasonable efforts must be made to reduce any consequent harm caused by accepting these donations.

³³⁶ Not because altruism is inherently important, but because it is part of existing policy

Chapter 8 - The Embedded Study

Having completed the initial philosophical exploration of the issues, the next step was to conduct an empirical study. The aim of the empirical study was to gather data to inform and enhance further philosophical discussion of conditional and directed donation, as detailed in Chapter 1. As discussed, a purely philosophical approach can potentially suffer from a number of shortcomings that limit practical application, so the empirical study was designed to gather specific data to help overcome these shortcomings.

8.1 Study Aims

This study aimed to gather data on the attitudes of potential organ donors, potential organ recipients and transplant staff towards conditional and directed organ donation.

In order to produce a practically useful philosophical analysis, it was important **to access stakeholder's moral intuitions, considered judgments and to gain an insight** into the sorts of reasons they appeal to when thinking about directed and conditional donation in order to uncover new lines **of argument, and to have 'encounters with experience'**³³⁷ that could enrich the philosophical analysis. Taking a qualitative approach allowed for the gathering of this sort of data and for an in-depth picture of **participants' views to be obtained. It was** important not just to discover **participant's** views on conditional donation, but also to determine how and why these views have been reached, which made a qualitative approach appropriate³³⁸. Undertaking a quantitative survey could have provided data about popular support for certain conditions, for instance, but it would not have provided the depth of information needed to help explore new lines of argument.

³³⁷ Ives J, (2008) "Encounters with Experience': Empirical Bioethics and the Future' *op. cit.*

³³⁸ Green J and Thorogood N, 'Qualitative Methods for Health Research', (London: SAGE Publications, 2004) p5

A review of the literature and the philosophical analysis in Chapters 3-7 revealed several areas of potential interest and uncertainty. Based on these, a series of empirical research questions were generated, the answers to which could be used to inform the ongoing philosophical analysis:

1. How acceptable is directed and conditional donation to potential organ donors, and what ethical considerations inform these views?
2. How acceptable is directed and conditional donation to those practitioners working in transplantation in the UK NHS, and what ethical considerations inform these views?
3. How acceptable is directed and conditional donation to those awaiting a transplant in the UK NHS, and what ethical considerations inform these views?
4. What factors do participants think should be used to allocate organs, and why?
5. How do participants conceive of concepts such as fairness, justice, altruism and medical need?

A qualitative design was appropriate to answer these questions because qualitative research allows for the gathering of detailed and in-depth data that can go beyond simply describing surface views and preferences. It has the potential to obtain data on the reasons **that lie behind peoples' views and preferences**, how strongly the views are held, and to understand them in the context of the unique experiences of each participant. The approach used was tailored to the needs of the project, with the qualitative intervention (in this case interviews – see 8.5) being undertaken in a way that is more akin to a philosophy seminar than a research encounter. This approach was first used by Alderson, Williams and Farsides (albeit in focus groups rather than interviews) in their studies of prenatal screening and testing³³⁹, the ambiguous status

³³⁹ Williams C, Alderson P, and Farsides B, 'Too Many Choices? Hospital and Community Staff Reflect on the Future of Prenatal Screening', *Social Science and Medicine* 55 (2002) pp743-53

of the foetus³⁴⁰, and just and equitable services³⁴¹. A key benefit of this approach, particularly relevant to the aims of this empirical study, is that discussion can be focussed on principles and values³⁴². Similarly, in this project, given that the empirical study aimed to gather data useful for philosophical discussion this more questioning and challenging approach to interviewing is warranted, and facilitates a research encounter that encourages participants to articulate the (sometimes previously unconsidered) reasoning behind the views they hold, and explores how consistently, and vehemently, those reasons are adhered to. This approach to data collection aimed to enable participants to engage with the topic and their own existing beliefs. The nature of the interviews led to some participants changing their minds throughout the interview, and revising earlier statements to avoid inconsistency. There is a possibility that this critically engaged approach led to the co-production of data that did not accurately represent the views or types of reasoning that participants use on a day-to-day basis. Critical engagement with the issues during interviews, however, led participants to reach judgments that were more carefully considered and justified than their initial intuitive responses to scenarios, and is likely to lead to more considered lines of argument that better serve the aims of this project. Participants in the Alderson *et al* studies valued having a facilitator who was non-judgmental and non-partisan³⁴³, so it was important for Moorlock as interviewer to not appear to endorse or reject particular viewpoints.

8.2 Setting

The study took place in the West Midlands. Some participants for the study were recruited from a large inner city hospital in the West Midlands with expertise in solid

³⁴⁰ Williams C, Alderson P, and Farsides B, 'Drawing the Line' in Prenatal Screening and Testing: Health Practitioners' Discussions', *Health, Risk & Society* 4 (2002) pp61-75

³⁴¹ Alderson P, Williams C, and Farsides B, 'Practitioners' Views About Equity within Prenatal Services', *Sociology* 38 (2004) pp61-80

³⁴² Alderson P, Farsides B, and Williams C, (2002) 'Examining Ethics in Practice: Health Service Professionals' Evaluations of in-Hospital Ethics Seminars' *op. cit.* pp508-21

³⁴³ *Ibid.*

organ transplantation. Other participants were recruited from the general Birmingham/West Midlands population via snowballing.

Birmingham has a relatively high proportion of South Asian residents, with 5.8% of the population identifying as 'Asian or Asian British: Indian', 9.7% 'Asian or Asian British: Pakistani' and 2.5% 'Asian or Asian British: Bangladeshi'³⁴⁴. This made it particularly suitable given the various issues surrounding organ donation and BME communities (such as low donation rates and high demand for organs, see Chapter 2).

8.3 Sampling, participants and recruitment

The study sought to obtain the views of people with specific relationships to, and experiences of, the research topic so purposive sampling was used based upon criteria derived from the research questions. Participants were recruited from 3 main groups; potential donors, potential recipients and NHS transplant staff. It was felt that potential donors, potential recipients and transplant staff were likely to be *most* affected (and most *directly* affected) by conditional and directed donations, and that each of the groups was likely to contain individuals with interesting and relevant perspectives and experiences. Transplant staff, for example, would be affected by conditional and directed donations insofar as they could potentially have to facilitate transplants using organs with conditions attached to them; they may also have experienced requests for conditional or directed donations in the past and be able to discuss their reactions to such requests. In addition, they care for patients who never get transplanted. The perspective of potential recipients is of importance because they would be the people receiving (or not receiving, if conditions so specified) the organs. The views of potential donors were sought because it was important to understand the sorts of reasoning that people use when making decisions about donation. The

³⁴⁴ Birmingham City Council (2012) 'Ethnicity in Birmingham', Available at: http://www.birmingham.gov.uk/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobheadernam e1=Content-Disposition&blobkey=id&blobtable=MungoBlobs&blobwhere=1223468028667&ssbinary=true&blobheadervalu e1=attachment%3B+filename%3D61653BDB_2011-02_2009_Ethnic_Groups.pdf, Last Accessed: 31/10/2012

philosophical analysis in Chapters 3-7 suggested several justifications for placing conditions or directions on donations, but by speaking to potential donors one can explore how important these are to the individuals involved. The potential donor group consisted of two sub-groups, divided on the basis of ethnicity. It was particularly important to obtain the views of members of the South Asian population, given that they are over-represented on transplantation waiting lists, under-represented as deceased donors, and that permitting conditional donations may remove a barrier to them choosing to donate organs³⁴⁵.

Participants within each purposive group, where possible, were selected for maximum variation, in order to obtain a wide range of demographic characteristics. For instance, it was desirable to interview a variety of different types of transplant staff, since differing job-roles may have led to different perspectives on the topic. Similarly **there was a need to adequately represent the views of Birmingham's South Asian population within the potential donor category, and to interview people from a variety of South Asian backgrounds.**

Although efforts were made to interview a variety people, no attempt was made to achieve statistically representation – which is typical of this research paradigm³⁴⁶. Qualitative research is nonetheless often criticised for not being strictly generalisable³⁴⁷. **Generalisability is defined as “the extent to which findings from a study apply to a wider population or to different contexts”³⁴⁸,** and the criticism is that one might not be able to **confidently generalise findings from one's data to a broader population because of the generally small and statistically non-representative sample.** Mays and Pope say that **“(t)he nature and extent of the data will ascertain which conclusions can be drawn about what”³⁴⁹.** For this project, the data have been used to provide new lines of

³⁴⁵ Radcliffe-Richards J, (2012) *op. cit.*

³⁴⁶ Green J and Thorogood N, (2004) *op. cit.* p225

³⁴⁷ Mays N and Pope C, 'Qualitative Research: Rigour and Qualitative Research', *BMJ* 311 (1995) pp109-12

³⁴⁸ Green J and Thorogood N, (2004) *op. cit.* p224

³⁴⁹ Malterud K, 'Qualitative Research: Standards, Challenges, and Guidelines', *The Lancet* 358 (2001) p482

inquiry and to act as a springboard for further philosophical discussion. When data are employed for this purpose, the problem of generalisability is less pressing because no claim is being made that people in a broader population share the views elicited. The data have also been used to suggest what sort of things people might find acceptable/unacceptable, and this has played a role in determining the final recommendations. Generalisability *is* more of a problem here, and this is borne in mind when the final recommendations are stated in Chapter 12.

The sampling strategy and size was intended to elicit a range of responses. Undertaking more interviews could enhance transferability, but practical constraints acted as a limiting factor. The timescale of the project and the rate of recruitment ultimately dictated the sample size. Because this was a qualitative study, formal sample size calculations did not apply. Due to time and resource limitations, it was decided that a maximum of 15 interviews would be conducted for each group as this would be likely to result in varied, if not saturated, data.

Sampling for the potential recipient and transplant staff groups was an ongoing process that was driven by the data. If the ongoing analysis of collected data suggested that the views of a certain type of staff member or potential organ recipient might prove particularly interesting, participants of this type were sought. This was conducted according to the model of theoretical sampling outlined by Glaser and Strauss³⁵⁰. This **process occurs when "the analyst jointly collects, codes and analyzes his data and decides what data to collect next and where to find them"**³⁵¹. This was a desirable approach because it permitted the deliberate targeting of specific viewpoints and perspectives in order to either confirm existing hypotheses, or provide new and different views. This was not possible for the potential donor group due in part to the recruitment method, and partly due to difficulty obtaining sufficient numbers of

³⁵⁰ Glaser BG and Strauss AL, 'The Discovery of Grounded Theory: Strategies for Qualitative Research', (New York: Aldine de Gruyter, 1967)

³⁵¹ *Ibid.* p45

participants; potential participants for the potential donor group were initially selected from GPs lists and invited to take part via a mass-mailing, and it would not have been practical to perform subsequent more targeted mailings. Due to the recruitment difficulties, which will be discussed shortly, it was impossible to actively seek out certain types of potential donor.

8.4 Participants

8.4.1 Transplant staff

The inclusion criteria for transplant staff were as follows:

- i) Staff at a large inner city hospital in the West Midlands with expertise in solid organ transplantation who are involved in the transplantation process, or the care of donors/recipients involved in the transplantation process.

Members of staff were only excluded if it proved impossible to arrange a mutually convenient interview.

8.4.2 Potential donors

The group of potential organ donors was split into two sub-groups, with the aim of recruiting fifteen participants to each. One sub-group consisted of people of South Asian ethnicity (Indian, Pakistani, Bangladeshi, Sri Lankan), and the other was people of any other ethnicity. Since anybody can *potentially* be an organ donor, the inclusion criteria for this category were broad.

- i) Eligible members of the general adult population registered with a GP at selected practices within the Birmingham area, who could potentially choose to donate their organs when they die.

To recruit these selected practices, a presentation on the study was given to a Host Nurse meeting. Host Nurses are nurses embedded in research-active GP practices with the aim of facilitating research activities. Following this presentation, 3 practices agreed to assist with the selection of potential participants.

There were several exclusion criteria:

- i) Individuals with underlying health conditions relating to major transplantable organs. It was important to maintain distinct boundaries between the groups of people to be interviewed. Individuals with health conditions relating to major transplantable organs may require a transplant in future, and therefore might occupy the boundary between potential donor and potential recipient (to a greater extent than most). It was important, as far as possible, to avoid the risk of participants who were taking part as donors answering questions from the perspective of becoming a potential recipient in the near future.
- ii) Individuals with family members on transplant waiting lists because they were likely to be influenced by their family **member's condition rather than having the views and perspective of 'standard' potential donors.**
- iii) Individuals in poor health because the intention was to recruit members of the generally healthy population, since these are people who are most likely to be able to donate their organs after death. As a potential donor category, people who are unlikely to be able to donate organs were excluded. Poor health for these purposes was defined as attendance at a GP practice within the last 12 months (except for Family Planning).
- iv) Individuals known to their GP as being potentially volatile or aggressive in order to mitigate the risks to the researcher.

- v) Individuals under the age of 16 or adults without the capacity to consent.

Special considerations apply to the donation of organs from deceased minors and adults without capacity to consent during their lifetime³⁵² which were beyond the scope of this study.

Non-English Speaking South Asian Potential Donors

Birmingham's Asian population includes a number of non-English speakers. Although data specific to Birmingham or the West Midlands was not available, national data suggests that speaking English is commonplace for younger Asian males, but rarer for Asian females, particularly older ones. A study that looked at English speaking ability and literacy³⁵³ found that 93% of men of Indian ethnic origin aged 30-49 in the UK speak English, whereas only 80% of women of Indian ethnic origin aged 30-49 speak English. This disparity increases with age, with only 47% of women of Indian ethnic origin aged 50-74 speaking English, compared to 86% of men. These figures are echoed amongst other Pakistanis and Bangladeshis, with the latter having particularly low rates of English speaking. Only 21% of women of Bangladeshi origin aged 30-49 speak English, and this figure declines to 10% for women aged 50-74. English literacy followed a similar pattern for these groups, which would have restricted non-English **speakers' ability to read and understand the study materials (information sheets, consent forms, invitation letters)**

Because there was a possibility that non-English speaking South Asian **participants may be less 'culturally integrated' than English speaking South Asians, and** therefore of value to the study, efforts were made to accommodate non-English

³⁵² Human Tissue Authority 'Code of Practice 2 – Deceased Organ Donation', Available at: http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm?FaA_rea1=customwidgets.content_view_1&cit_id=674&cit_parent_cit_id=669, Last Accessed: 31/10/2012

³⁵³ Szczepura A et al. (2005) 'An Overview of the Research Evidence on Ethnicity and Communication in Healthcare', Available at: <http://www2.warwick.ac.uk/fac/med/research/csri/ethnicityhealth/research/communicationsreview.pdf>, Last Accessed: 31/10/2012

speakers. South Asian potential donors were asked to pass on information to non-English speakers, and communication between interested non-English speakers and Moorlock would be facilitated by either an English-speaking family member or an interpreter. Anecdotal advice suggested that most people who do not speak English will have a family member who is able to translate for them, but an interpreter was offered as an additional measure. Although measures were in place to accommodate non-English speakers, and attempts were made to recruit them, no non-English speakers expressed an interest in taking part in the study. Interpreters were also available to facilitate the recruitment and interviewing of non-English speaking potential recipients, but again, no non-English speakers expressed an interest in participating.

8.4.3 Potential Recipients

Potential recipients were identified as being patients who were currently on, or might soon be on, the transplant waiting lists for livers or kidneys. Although conditional and directed donations would also likely affect people waiting for other major organs, the decision was made to focus on livers and kidneys for two reasons. First, potential liver and kidney recipients were easier to access, and many patients suitable for interviewing in the chosen setting were expected. Second, because there are other potential factors **that influence people's thinking relating to other organs (hearts in particular are sometimes thought to be have particular symbolic meaning³⁵⁴)**, these factors might serve to muddy the waters in terms of thinking about conditional and directed donation specifically.

Inclusion criteria were:

- i) Competent adult patients from an inner city hospital in the West Midlands undergoing transplant assessments, or dialysis, and who were either on the

³⁵⁴ Mai FM, 'Graft and Donor Denial in Heart Transplant Recipients', *American Journal of Psychiatry* 143 (1986) pp1159-61

organ transplant waiting list or expected to be placed on the waiting list in the near future.

Recruitment of potential recipients started in the Liver Unit of an inner city hospital in the West Midlands. Initially it had been planned to recruit people undergoing inpatient liver transplant assessments and outpatient renal dialysis, but it soon became apparent that this would yield insufficient participants. The reason for this was just prior to study commencement there had been a change to the way patients were classified as inpatient/outpatient, resulting in fewer inpatients being available for recruitment. The initial protocol stated that only inpatients would be recruited, so a substantial amendment was obtained from the Research Ethics Committee to allow the recruitment of transplant assessment outpatients.

Exclusion criteria were as follows:

- i) Patients currently in poor health as determined by the Transplant Recipient Coordinators. Patients undergoing transplant assessments, particularly for liver transplantation, are often very unwell, and participating in an interview would be unduly burdensome. Transplant Recipient Coordinators acted as **gatekeepers to very ill patients, because they had knowledge of patients' conditions.**
- ii) Anyone thought likely to become particularly distressed by the interview and its content was excluded. Transplant assessments involve intensive medical tests, consultations and education sessions, and naturally this can make them a stressful experience. Discussing transplantation with people undergoing assessments potentially makes them consider their own mortality and poor health, and this could have been distressing for some people. Transplant Coordinators were therefore asked to highlight anybody

who had been finding the assessment experience particularly difficult, and these people were not approached for involvement in the study.

8.5 Interviews

According to Kvale, “(q)ualitative research starts from the idea that methods and theories should be **appropriate to what is studied**”³⁵⁵. Semi-structured interviews were chosen as the method for data collection because semi-structured interviews provide a balance between consistency across multiple interviews and scope for additional probing and unscripted questions. Qualitative interviewing is seen as being “**particularly useful as a research method for accessing individual’s attitudes and values**”³⁵⁶ and this makes it appropriate for answering the research questions for this study. Interviews have been described as “**a conversation that has a structure and a purpose determined by the one party – the interviewer**”³⁵⁷. Semi-structured interviews, however, allow for the direction of the interview to be decided to some extent by the interviewee, since the interviewer will **react and respond to the interviewee’s answers, and the subsequent shape of the interview is dictated by those answers.**

A feasible alternative to interviews would have been focus groups. One advantage of focus groups compared to interviews is that although some interviewees **may be more inclined to ‘open up’ in interviews, others may be intimidated, and** therefore more reserved, in a one to one encounter. Focus groups bring together a group of people with shared experiences, which can make participants feel more comfortable about disclosing personal information^{358,359}. Focus groups would have been inappropriate for this research, however, for several reasons. First, there was little reason to think that groups of, for example, potential recipients, would be sufficiently similar, by virtue of that shared experience, to create a comfortable environment to

³⁵⁵ Kvale S and Flick U, 'Doing Interviews', (London: Sage, 2007) pxi

³⁵⁶ Seale C, 'Researching Society and Culture', (London: SAGE, 2004) p182

³⁵⁷ Kvale S and Flick U, (2007) *op. cit.* p7

³⁵⁸ Kitzinger J, 'Qualitative Research: Introducing Focus Groups', *British Medical Journal* 311 (1995) pp299-302

³⁵⁹ Kvale S and Flick U, (2007) *op. cit.*

disclose personal information. The same could be expected of groups of potential donors, and transplant staff. Second, focus groups seem particularly unsuitable for use with transplant staff, because individual staff may be reticent to voice honest and perhaps controversial opinions if there were other (perhaps more senior) members of transplant staff present. Third, it would have been very difficult to organise focus groups for participants who potentially require organ transplants in future. These are people who are generally in poor or fluctuating health, and using interviews allowed more flexibility in terms of scheduling (and rescheduling), and allowed for data to be obtained in a way that minimised the burden for participants (where possible, patients were interviewed whilst they were already attending hospital for other reasons).

The flexibility offered by semi-structured interviews (as opposed to rigidly structured interviews or questionnaires) allows potentially sensitive or controversial **topics to be broached in a way that “opens up a dialogue” and produces “fuller accounts”**³⁶⁰. This is particularly important for a topic such as conditional donation, because questions are likely to touch on potentially controversial areas of prejudice. The topic is also, by its nature, potentially sensitive because it involves thinking about death and dying, and the measures one is willing to take to avoid death. This flexibility also allows for other sensitive issues to be dealt with appropriately; for instance, asking someone who needs a transplant a set of rigid questions about transplantation may cause distress. Although these sorts of topics and questions do have to be covered even in semi-structured interviews, the option to pursue lines of questioning further or to phrase questions differently if they appear to be causing distress allows for sensitive topics to be covered in a way that does not isolate, offend or needlessly distress the interviewee. Structured interviews also run the risk of appearing to the interviewee as **an interrogation, who might feel bombarded by questions that aren’t appropriately** reactive to answers already provided.

³⁶⁰ *Ibid.*

A concern throughout the interview process was that the interviewer might, on occasion, be regarded as an expert or authority on the issues surrounding conditional donation. Although Moorlock did not disclose information regarding his academic training during interviews, some of the staff participants were aware of his background, and had attended talks and presentations by him in the past (albeit not on the specific research topic). A careful line needed treading between appearing sufficiently knowledgeable to discuss the issues in sufficient depth and detail, without ever claiming a degree of expertise over what is right or wrong. There are many arguments about the **rightness or wrongness of claiming 'moral expertise'**^{361,362,363} but the concern for the purposes of these interviews went beyond this. First, the use of counterfactuals and counterexamples, though a conventional and widely used technique in philosophy, could potentially lead participants to think that the interviewer was actually disagreeing with them and telling them that their views were wrong, rather than simply exploring their views in more detail. Indeed, adopting a typical philosophical technique might even appear abrupt and confrontational. However it has been suggested that thought experiments and counterfactuals are an important part of the research process³⁶⁴, so incorporating them into the interview was desirable, and their use is neither novel nor controversial^{365,366}. **Where inconsistencies in someone's responses were present,** suitable questions and prompts were devised to make these inconsistencies apparent to the participant rather than merely have the interviewer telling the participant that their views were inconsistent. Although the process was one of critical engagement, it was undertaken with tact and sensitivity in order to help participants explore *their own* beliefs. Second, there was a risk that participants might be inclined to express what

³⁶¹ Crosthwaite J, 'Moral Expertise: A Problem in the Professional Ethics of Professional Ethicists', *Bioethics* 9 (1995) pp361-79

³⁶² Archard D, 'Why Moral Philosophers Are Not and Should Not Be Moral Experts', *Bioethics* 25 (2011) pp119-27

³⁶³ Singer P, 'Moral Experts', *Analysis* 32 (1972) pp115-17

³⁶⁴ Brady HE and Collier D, 'Rethinking Social Inquiry: Diverse Tools, Shared Standards', (Oxford: Rowman & Littlefield, 2004) p163

³⁶⁵ Alderson P, Farsides B, and Williams C, (2002) 'Examining Ethics in Practice: Health Service Professionals' Evaluations of in-Hospital Ethics Seminars' *op. cit.* pp508-21

³⁶⁶ Ives J 'Becoming a Father/Refusing Fatherhood: How Paternal Responsibilities and Rights Are Generated', (PhD, University of Birmingham), (2007)

they thought was **the 'correct' answer to questions, rather than an answer that** reflected their own personal views, values and experiences. Care was therefore taken to avoid appearing to endorse specific views or opinions in order to minimise the risk of imposing personal values upon the interviewee.

8.6 Topic guide and scenarios - development

A topic guide was devised, based upon three hypothetical scenarios involving conditional and directed donations. These scenarios (see Table 2) were intended to provide a basis for discussion, and the topic guide detailed a number of questions to be asked. Although by no means exhaustive, the scenarios were intended to illustrate the different types of conditions that people might want to place on organs, as well as the different motivations behind these conditions. The first scenario featured conditions based upon deservingness and responsibility, the second scenario featured conditions based upon religious preference, and the final scenario featured conditions based upon immigration status. The same scenarios were used for all participants, in line with the semi-structured format.

The decision to use scenarios was made because of the nature of these sorts of donations. Looking at the issues from an abstract and theoretical perspective serves some purpose, but it was felt that participants may find it easier to talk about ethical issues when related to a concrete example rather than an abstract discussion of moral theory. These scenarios were designed to put donation decisions into a context, and to some extent, to humanise the issues. The scenarios provided specific context, but it was then the task of Moorlock, as interviewer, to ensure that discussion covered more abstract principles and values in a way that participants could engage with and feel confident talking about.

Although the scenarios were designed to put these sorts of donations into context, care was taken to avoid personalising them too much or making them too

specific. A lot of discussion of conditional and directed donation tends to focus on conditions relating to either alcoholism or race, but basing scenarios on these sorts of specific conditions would run the risk of causing offense to some interview participants. Many people who need liver transplants, for instance, will require these as a result of alcoholic liver disease, and it would have been unfair to present these potential recipients with scenarios suggesting, however implicitly, that they might be less deserving of treatment. The scenarios were therefore designed to illustrate more generic conditions that might be placed on organs, and it was decided that some of the more potentially sensitive topics would only be discussed in interview only if raised by the interviewee. The scenario focusing on religious conditions was originally designed to include a reference to a specific religion (in this case Islam), but it was felt by the Research Ethics Committee that the scenario should be made more generic. The scenario was therefore modified so that it did not refer to any specific religion. Another scenario was originally intended to include racist conditions, but this was modified to instead refer to immigrants in order to make it less specific. Although in some ways it may have been interesting to use specific examples as these may have provoked stronger or more emotional responses, this had to be balanced against the risk of offending or upsetting participants.

Specific questions were devised for the three categories of participants, with a number of more general questions that would be asked to all participants (see Appendix 3). Some questions could only be asked to certain types of people (for instance a question about how the participant would feel if they received an organ with conditions attached would really only be relevant to potential recipients). Because of the semi-structured nature of the interviews, not all of the questions were necessarily asked, and additional questions were often asked in order to probe or clarify **interviewees' responses.**

8.7 Recruitment

8.7.1 Staff

Transplant staff were invited to participate in the study by an email sent by a Consultant with an interest in the project who had access to staff email addresses by virtue of working for the same organisation. The participant information sheet was attached to the email, and people interested in participating were asked to contact Moorlock directly. The Consultant was asked to send an initial invitation email to the following categories of staff:

Specialist Nurses – Organ Donation (SNODs)

Renal and Liver Recipient coordinators

Renal and Liver transplant surgeons

Psychiatric Nurse attached to the unit

The doctors involved with transplant recipients both pre & post surgery

Anybody associated with the listing of potential recipients

The email was sent to 35 members of staff, and the Consultant requested that 2 selected members of staff forwarded the email to members of their teams. 7 members of transplant staff responded to the initial invitation email, expressing a willingness to take part in the study. A further 2 individuals expressed an interest in participating once their colleagues had participated; presumably as a result of discussions with these colleagues. A further email was sent out at a later date in an attempt to recruit further participants, and this resulted in 2 additional participants.

8.7.2 Potential donors

Initially, Practice Managers and Host Nurses performed a database search of patients registered at their practice and selected potential participants using the inclusion and exclusion criteria. These potential participants were then sent invitation letters and a Participant Information Sheet, along with a covering letter from their GP introducing,

but not endorsing, the study. People interested in participating were asked to complete and return a brief form using a stamped addressed envelope to Moorlock, confirming their initial interest in participating, and providing contact details and details of convenient times to contact them to arrange interviews. Alternatively, people wishing to participate could also telephone, text or email Moorlock. A mutually convenient time **and location for interview would then be arranged, and confirmed via the participant's** preferred method (post, email, text message, and telephone). A reminder was to be sent out to each participant approximately one week before the interview was due to take place.

In addition to this, snowballing was to be used to recruit South Asian speakers of languages other than English. Letters sent to potential participants of South Asian **ethnicity recruited via GP's lists included a request that the invitation and information** was relayed to non-English speaking members of the South Asian community who were known to the recipient (anticipated to be close friends or family members). Interested individuals were asked to contact Moorlock by telephone (using the assistance of a family member if necessary), at which point filter questions would be asked to establish suitability (based upon the inclusion/exclusion criteria). Once suitability was ascertained, a convenient time would be arranged for an interpreter to telephone the potential participant to organise an interview and talk the potential participant through the Participant Information Sheet in their own language. Any English speaking South Asian person responding to the letters as a potential participant would be asked if s/he had any non-English speaking friends or relatives who may be interested in the study, **and to pass Moorlock's contact details onto these people.**

A second letter was sent to the potential participants two weeks after the initial letter, to remind potential participants to respond if they were interested in taking part. This letter was sent to all of the recipients of the original letter (including those who had already responded), since for data protection reasons it was not possible to

compare a list of people who had already responded (only available to Moorlock) with the list of all people invited (only available to GP practices).

It was intended that 200 people would be selected and contacted in this way, with the aim of recruiting a total of 30 people. After an initial mailing from one GP Practice to 100 people (50 South Asian, 50 non-South Asian) yielded no responses, it was decided that an alternative recruitment method might prove more fruitful. An application for ethical approval was submitted to the University of Birmingham (see 8.12 and Appendix 1) in order to gain permission for more direct recruitment methods.

The first alternative method involved Moorlock approaching people in specified public locations in Birmingham and speaking to them about the study. Although many people were approached, only 12 people took information packs containing information sheets and contact details, and this yielded no participants. Accordingly, it was decided that snowballing would be used instead. Moorlock provided friends and colleagues with information packs and requested that they pass these on to their own friends. This was immediately successful and ultimately provided 10 participants for the non-South Asian potential donor category, and 3 for the South Asian potential donor category.

Due to the low recruitment for the South Asian potential donor category, an advert was placed in the University of Birmingham College of Medical and Dental Sciences weekly email newsletter, seeking interested participants, particularly of South Asian ethnicity. The advert also encouraged anyone who knew of anyone else who might be interested in taking part **to pass on Moorlock's contact details. This yielded an** additional 7 participants for the South Asian potential donor category. This method was not ideal because it predictably resulted in a relatively unvaried sample (the limitations of this are discussed in more detail in Chapter 11), but it was necessary in order to obtain sufficient numbers of participants. Attempting earlier recruitment methods had taken a substantial amount of project time, and the deadline for the completion of data collection meant that a compromise had to be made.

8.7.3 Recipients

Once identified by transplant co-ordinators as suitable for recruitment, potential participants were approached by Moorlock on the transplant assessment ward and given a brief oral overview of the research, an invitation letter and participant information sheet. Potential participants were then given at least 24 hours to decide whether or not to participate. Generally potential participants were initially approached on Tuesdays (since this provided sufficient time for Transplant Co-ordinators to determine whether patients were suitable for the study), and then interested participants were approached again on Wednesday to see if they wanted to take part in an interview the following day. Because these potential participants were in hospital to undergo a number of tests and procedures, it was not always possible to meet with them again on the Wednesday. On these occasions, efforts were made to speak to potential participants early on Thursday morning to see if they would be willing to participate in an interview later that day. A restrictive factor was that due to the number of tests and procedures that these patients have to undergo, time available for **interview was limited to a 'window of opportunity' on a Thursday** afternoon. This problem was exacerbated by patients often wanting to leave hospital quickly once their tests had been completed, so some people who earlier in the week had agreed to take part in interviews had changed their mind by Thursday. These factors combined to make recruitment much slower than hoped, so alternative methods were developed (for which ethical approval was obtained).

The alternative method used was the same as above, but recruitment took place at transplant clinics. If a potential participant was interested in participating, Moorlock obtained their contact details and contacted them a few days after the initial conversation to see if they were still interested in participating, and if so, to arrange an interview. These interviews were arranged to coincide with a future transplant clinic appointment, or at a convenient time in their own home. This recruitment method

proved to be much more successful and resulted in an additional 7 participants, compared with just 2 by using the original approach.

8.8 Location of interviews

The location of interviews varied. Transplant staff were interviewed in their offices where possible, otherwise an available private meeting room was used. Potential recipients were offered interviews in private rooms, although 2 preferred to conduct the interview sitting on their hospital bed³⁶⁷. Potential recipients recruited via transplant clinics often chose to have the interview conducted in their own homes. Potential donors were offered interviews in their own homes. If anyone from the 3 groups preferred an alternative location for their interview, this was arranged on an *ad hoc* basis³⁶⁸.

8.9 Recording

Interviews were audio recorded. If particularly important or telling non-verbal cues were exhibited by the participant at any time, a note was made so that they could be reflected in the interview transcript.

8.10 Consent

All potential participants were provided with a participant information sheet when they were invited to participate in the research or expressed an interest in participation, and were given sufficient time (more than 24 hours) to consider participating and opportunities to ask any questions. Signed consent was obtained from participants prior to interviews taking place, using a consent form.

It was important that this study attempted include speakers of languages other than English, so appropriate measures had to be in place to take consent from non-English

³⁶⁷ Conducting interviews at the bedside presented some challenges to privacy, due to the open nature of the ward and close proximity to other patients. The ward was busy, the screen was drawn around the patient's bed, and there was constant background noise/conversation. Participants were, however, made aware of the limitations to their privacy and were offered a more private setting. It was not obvious that privacy limitations had any effect on the participants' answers, but it should be acknowledged as a possibility.

³⁶⁸ Two potential donor participants requested that their interview took place in coffee shops.

speakers. A separate consent form was devised, which an interpreter would sign to confirm that verbal consent had been obtained from the participant. The interpreter would also sign to confirm that the participant had understood the information given to them (as explained by the interpreter) and had been given the opportunity to ask any questions they might have had.

8.11 Method of analysis

Transcripts were analysed using NVivo software. Analysis started by adopting a relatively open-ended approach to coding, described by Saldana as Initial Coding³⁶⁹. This involved going through the interview transcripts, and breaking them down into smaller sections, often only a single sentence, according to the subject of that section. This is a common and accepted starting point for qualitative analysis, and it serves to organise ideas emerging from the data³⁷⁰. This process started before all data had been collected, which facilitated a degree of theoretical sampling. Although coding was largely led by the data in order to permit the emergence of original ideas³⁷¹, the codes used tended to relate closely to accepted philosophical concepts. For instance, codes **such as 'fairness' and 'consequentialist reasoning' emerged quickly. This was because of** the underlying aim of the qualitative study, which was to provide data to enhance further philosophical analysis. Coding the data along the lines of philosophical concepts helped manage the data to facilitate an analysis of the way in which arguments were made and concepts used. It was, however important to not restrict coding to philosophical concepts, in order to allow subtleties to emerge from the data³⁷². The codes used were not pre-determined, and tended to evolve and develop as coding progressed. For instance, if it became apparent that a code was becoming too broad and incorporating things with subtle but significant differences, then the code could be broken into two or more separate codes in order to better reflect these variations.

³⁶⁹ Saldana J, 'The Coding Manual for Qualitative Researchers', (London: SAGE Publications, 2009) p81

³⁷⁰ Strauss AL, 'Qualitative Analysis for Social Scientists', (Cambridge: Cambridge University Press, 1987)

³⁷¹ Charmaz K, 'Constructing Grounded Theory: A Practical Guide through Qualitative Analysis', (London: SAGE Publications, 2006)

³⁷² Silverman D, 'Interpreting Qualitative Data', (London: SAGE Publications, 2011)

Conversely, if it became apparent that there were multiple codes relating to the same concept, then these codes would be merged together.

Some sections of text were attributed multiple codes if they referred to more than one concept. In contrast, some sections of text were not linked to any codes if it was felt that they were entirely irrelevant to the focus of the study. Additional codes were introduced as necessary during this process, which resulted in some codes being used in later transcripts that were not used in earlier ones. Early transcripts were therefore re-coded as part of an iterative approach once a more complete framework of codes had been developed³⁷³. As more codes were introduced, it became possible to organise related codes into themes³⁷⁴. These themes were again fairly dynamic, and were sometimes merged with one another or separated if there was significant overlap or differences appearing.

Small samples of transcripts were coded by Ives and Draper in order to ensure that the impact of researcher bias was minimised, and this has been suggested as a way to improve rigour³⁷⁵. Although there was minor variation in the exact codes used, the general themes emerging from the data were the same. It is unlikely that Ives or Draper approached the topic with the exact same background views and perspective as Moorlock, so it is likely that Moorlock's choice of codes and themes were not chosen as a result of his own personal biases (for more detail on this, see Chapter 12).

8.12 Ethical approval and NHS permissions

Favourable opinion was granted by the West Midlands Research Ethics Committee on 25/05/2010 – ref: 10/H1208/34 (Appendix 1). The West Midlands Research Ethics Committee gave a favourable opinion to the substantial amendment on 31/01/2011 –

³⁷³ Weitzman EA, 'Analyzing Qualitative Data with Computer Software', *Health Services Research* 34 (1999) pp1241-63

³⁷⁴ Ritchie J and Spencer L, 'Qualitative Data Analysis for Applied Policy Research', in *The Qualitative Researcher's Companion*, ed. M.B. Miles and M. Huberman (London: SAGE Publications, 2002)

³⁷⁵ Barbour RS, 'Checklists for Improving Rigour in Qualitative Research: A Case of the Tail Wagging the Dog?', *BMJ* 322 (2001) pp1115-17

ref: AM01 (Appendix 1). A **'Letter of NHS Agreement for Participant Identification Centres'** was issued on 19/08/2010 (Appendix 1). The University of Birmingham's Science, Technology, Engineering and Mathematics Ethical Review Committee gave a favourable ethical opinion on 19/09/2011 – ref: ERN_10-0900 (Appendix 1).

Table 2 - Interview scenarios

Scenario 1

Two young men are killed in a car accident. The driver was driving recklessly and above the speed limit, which caused him to lose control of his car and crash, killing both himself and his passenger. The parents of the passenger are very distressed that their son was killed by someone acting so recklessly and are angry and upset that two lives have, in their eyes, been wasted.

The parents of the passenger are very keen that their son's organs should be donated, but they have concerns about the sort of person that his organs might be transplanted to. They would like their son's organs to be transplanted to people who will look after them and live responsibly, and they consider young people to be risk-takers who are less likely to act responsibly than slightly older people with families. They therefore request that their son's organs are only transplanted to people who are over the age of 25 and have children. In the parents' opinion, these are likely to be responsible people who will look after themselves and deserve the improvements to quality of life that an organ transplant can bring.

Staff at the hospital tell the parents that they are not allowed to say who their son's organs will go to, and that decisions like this are made by medical staff on the basis of medical considerations. If the organ donation is to go ahead, the organs must be donated without any restrictions being placed on who the organs can be transplanted to.

The parents decide that because of the chance that their son's organs will go to people who they consider don't deserve them, they won't give permission for their son's organs to be donated.

Scenario 2

A young woman dies following an accident. All of her organs are suitable for **transplantation. This woman's faith and religious beliefs shaped how she chose to lead** her life, and she placed great value in being what she considered a good member of her religion. Her parents know that her religious beliefs were very important to her, and are confident that, given a choice, she would have preferred for her organs to go to another **member of her religion. Her parents therefore give consent for their daughter's organs to be donated, but request that priority is given to members of their daughter's** religion. This request is not motivated by any dislike for a particular group of people; it is made simply because the parents believe that their daughter would prefer for her organs to go to people with similar beliefs and values to her own.

The hospital staff explain that these sorts of requests cannot be complied with under existing policy, which states that organs will be given to the people who are in greatest need and who are the best match.

Scenario 3

A man has died in an accident. All of his organs are suitable for donation, and his family are very keen that his organs should be donated. Prior to his death, the man had expressed concerns about the number of immigrants that had moved to his area. He believed that a lot of the immigrants were taking jobs, benefits and resources that would otherwise be given to local people. He believed that people like himself who have lived in the area all of their lives should have everything that they need before things are given away to people who have arrived from other countries.

The man had made clear, prior to his death, that if he died he wanted to donate his **organs, but that he didn't want his organs to be transplanted to immigrants. Knowing** that their relative held these views, the next-of-kin agree to donation only if the organs

do not go to immigrants.

Staff at the hospital tell the next-of-kin that they are not allowed to say who the organs should or should not go to, and that if the organs are going to be donated they have to be donated to the general pool. The family insist that they will not agree to donate the **man's organs if there** is a risk of them going to immigrants, as the deceased man would have been opposed to this.

Chapter 9 - Results

9.1 Participants

40 participants were interviewed for the embedded study as detailed in Table 3. To preserve anonymity, each participant has been allocated a unique identifier consisting of an acronym denoting the category to which they belong and a number.

Table 3 – Outline demographics

	Acronym	Number	Gender	Other Information
Transplant Staff	TS	11		2 x Consultant Anaesthetists/Intensivists 3 x Specialist Nurses – Organ Donation 2 x Liver Recipient Transplant Co-ordinators 2 x Liver Transplant Surgeons 1 x Liver Consultant Physician 1 x Clinical Nurse Specialist in Addiction Psychiatry
South Asian Potential Donors	SAPD	10	9 female, 1 male	
Non-South Asian Potential Donors	PD	10	4 female, 6 male	
Potential Recipients	PR	9	4 female, 5 male	4 x liver, 5 x kidney

The genders of staff participants have not been reported due to the risk of identifying individual participants. This risk does not apply to non-staff groups.

9.2 Overview

The mind map (Figure 1) gives an overview of the themes and how they are related to each other. The key argument against conditional and directed donation used by participants is that it would prevent organs being allocated according to medical criteria. There was some disagreement **over exactly what 'medical criteria' entails, with** some participants thinking that transplant outcomes are most important and others thinking that organs should be allocated to those in greatest need or the most urgent. These ideas were closely tied to themes of objectivity and impartiality, which many people thought were necessary for a fair transplant system.

The main theme in favour of conditional and directed donation was not so much outright acceptance, but rather a willingness to at least consider accepting organs offered with conditions/directions. Many participants thought that conditional or directed donations were not ideal and thought that organs should be donated without restrictions, but in cases where the organs will **only** be donated if the restrictions are in place, transplant staff should at least look at the waiting list and see what the effect of accepting them would be. These views were justified with reference to avoiding waste; **if organs are offered, and there's generally a significant** shortage of donated organs, it is a waste to turn away these potentially life-saving organs.

Specifying the number of respondents who held views under each of the sub-themes reported has generally been avoided. Numbers alone can present a potentially **misleading image of respondents' views: it does not, for example, indicate *strength*** of view or how important something was to a particular participant. Maxwell discusses some of the problems of including these figures, suggesting that they can lead to

invalid inferences about improved generalisability (by reader or researcher), and a tendency towards the variance-style thinking employed in quantitative research³⁷⁶. Additionally, the results presented in this chapter are intended to provide a range of views, so conflicting views will be presented that may only have been held by one or two participants if they were felt to be particularly important. In this context, whether not a particular view was prevalent is not an indication of importance, and providing numbers adds nothing to the analysis³⁷⁷.

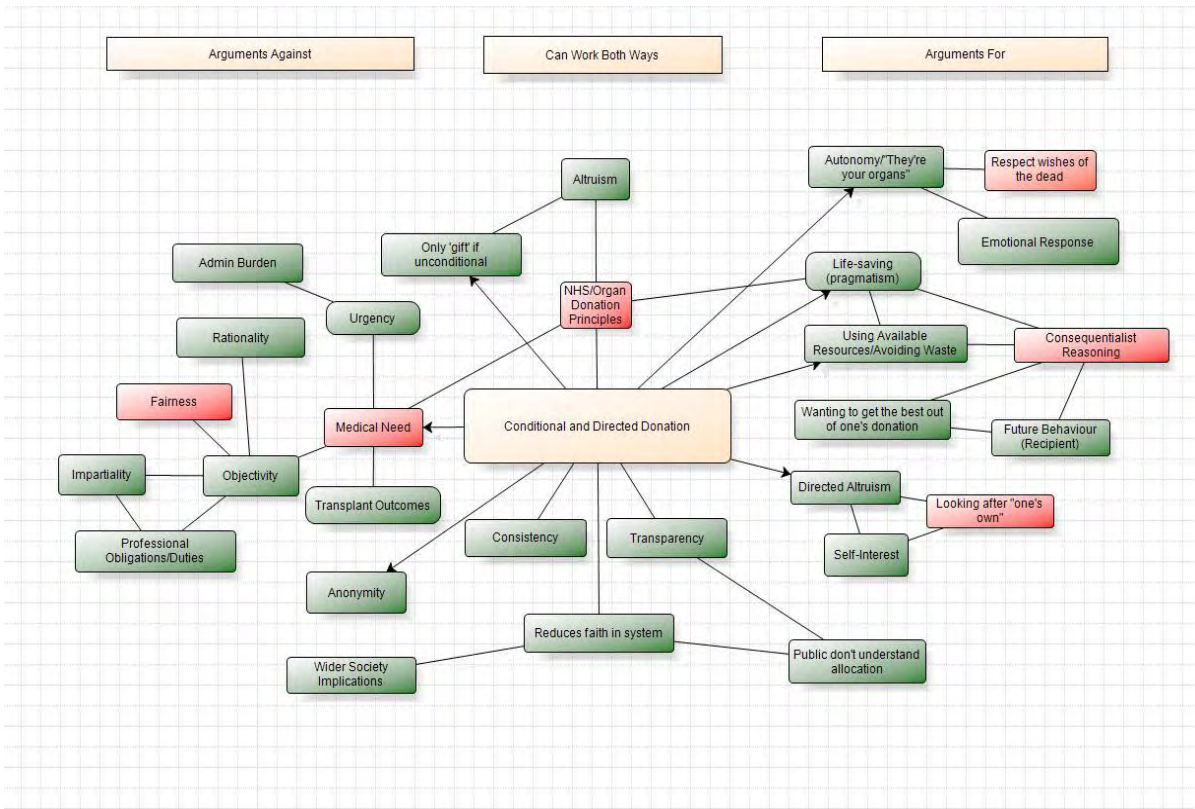
In order to aid clarity, quotations have had non-meaningful utterances such as 'er' and 'um' removed. Where it has been necessary to remove other extraneous words or short phrases, this will be indicated with '...' ³⁷⁸.

³⁷⁶ Maxwell JA, 'Using Numbers in Qualitative Research', *Qualitative Inquiry* 16 (2010) pp475-82

³⁷⁷ *Ibid.* p480

³⁷⁸ Sainsbury ACR, (2006) 'Using Verbatim Quotations in Reporting Qualitative Social Research: Researchers' Views', 2006 p18

Figure 1 - Mind Map



9.3 Medical decisions and allocation – keeping the medical ‘medical’

There was a general feeling that organ allocation decisions are best made by medical staff using medical criteria:

"They should leave that type of judgment for scientists who have the data to back up those kinds of claims...they should be guided by numbers and science...and not opinion. People [the public] can't be trusted to make good decisions, I think we all know that" – PD6

Many participants across all groups thought that medical criteria are likely to bring about the best transplant outcomes, and that medical staff are in the best position to use and understand these criteria. This view was particularly prevalent in the staff group; participants here were generally unwilling to allow non-medical criteria to feature in allocation decisions. But this was a view also held by the majority of participants in other groups (see Table 3).

Table 3 - Unwillingness for non-medical criteria to feature in allocation decision

It should just be done on greatest need... and I think it's the job obviously of the team behind transplantation to say how the organs should be allocated – TS1

I think people in the medical profession are just best placed to decide, you know what I mean, people with the right training will be able to look at it, decide who's got the most chance of coming out of it better – PD1

Many of the non-staff participants, particularly within the potential donor groups, and some in the potential recipient group, trusted medical staff to make the right decisions despite not having an in-depth knowledge of allocation procedures (see Table 4).

Table 4 - Faith in medical staff

<p><i>I put a lot of faith in science and scientists and people who should know better, although there are blips in the system and things do go wrong, I do think that a medic should have an overall...there should be someone in the whole chain that can sit there and look at the details and go well actually no this needs to go here for whatever reasons. – PD1</i></p>
<p><i>If that's how they feel, they're worried about who the organs go to and whether the organs will be used well, they should leave that type of judgment for scientists who have the data to back up those kind of claims. – PD6</i></p>
<p><i>I think it's up to the medical staff to actually decide who gets that organ.... Because I think they have a better idea of who's out there and which class of people actually need a liver transplant - SAPD4</i></p>
<p><i>You've got to rely on, not necessarily the law, you've got to rely on the surgeons and the national list – PR4</i></p>

Although non-staff participants had faith in medical staff's ability to make the right decisions, transplant staff appeared to put their faith in *medical criteria* producing the right decisions. Some medical staff suggested that medical decisions are objective and absolute (see Table 5).

Table 5 - Staff's faith in medical criteria

<p><i>as long as the principles on which you do the allocation is transparent, and it's objective, so that you can justify why you give it to A or B or why C doesn't get a chance at getting the organ, I think that's the best you can do – TS4</i></p>

It's impossible for us to open that gate even a little bit, that chink even a little bit, to allow directed sort of donation because that would allow unfairness to be built into the process from the beginning and what we desperately try to do is be fair, and that's why we use all these calculation scores etc and we try and make it objective – TS5

Most participants could sympathise with the donor families featured in the interview scenarios, and could understand that there might be emotional reasons for wanting to place restrictions on donations. This sympathy and understanding was present in all groups, and participants thought that stressful and traumatic situations might give rise to decisions or requests that, with hindsight, might be considered irrational (see Table 6).

Table 6 - Emotional factors

Yeah, because the problem here is that...their reasoning for wanting to donate the organs to a specific demographic are, their reasoning is kind of biased, it may not be logical, they're going to be in shock, so that might impair their judgement - SAPD1

There are obviously a lot of emotional factors involved but generally the medical principles are that organs go to people in greatest need - PR1

Many participants believed that decisions about organ allocation should ideally be objective, made by transplant staff, and devoid of emotional involvement. This view was particularly prevalent amongst transplant staff, but was present in all groups (see Table 7).

Table 7 - No emotion in allocation decisions

<p><i>Yes I do, I really do...you've gotta take emotion out of the argument and I think that's the only way to do it, is try and get someone who hopefully has a more objective view than the family of the deceased. – PD2</i></p>
<p><i>I'm hoping the medical community will make them without bias and on medical needs, somebody who needs an organ in order to survive or a better quality of life, rather than somebody's more deserving... I think that it should be allocated on medical needs. It shouldn't be, you shouldn't have incentives, you shouldn't say I'm only going to give it to x people or y people, you're then setting conditions, what if the right person isn't available, then the organ's being wasted anyway so how is that a donation – SAPD8</i></p>
<p><i>...we're all human at the end of the day, and ... if you've got very strongly held beliefs about a situation, I'm sure it can be difficult to be totally impartial, which is why it's good it's a team decision as to who we transplant and who we don't because that way hopefully everything will be fair and as impartial as it can be. – TS6</i></p>

This notion of objectivity links with a view shared by participants across all groups that the NHS should, in principle, treat people equally and not let non-medical factors influence treatment. By using what the participants regarded as objective measures, factors that were generally considered to be irrelevant are excluded, which participants thought would reduce prejudice and provide more equality within the NHS (see Table 8).

Table 8 - Ignore irrelevant factors

<p><i>if you had two people and one was white and one was black, I'd like to believe that I would...or most medics would ignore the fact that one is black. PD1</i></p>

[treat] everybody as if they're the same and ... other factors should just be completely ignored, all they're really there to do is to make people healthy regardless of any of their history – PD4

There shouldn't be any restriction of these people. Everybody should get a chance. – PR5

One staff participant was concerned that using non-medical criteria may result in legal action against the NHS (possibly on the grounds of unjust discrimination), and that using purely medical criteria acts as a safeguard against this as it can be considered justifiable discrimination. This is further evidence that participants thought that medical decisions are objectively justifiable and cannot be argued with.

Then maybe I could foresee a scenario that parents of the 16 year old then sue maybe the Trust and say when my daughter was on the super urgent list, why didn't she receive it? You know, there's all sorts of dreadful scenarios, and without any underlying law it's difficult to position yourself isn't it? So for us the easiest position is first rule should be that just purely just to do it on the base on medical need. – TS10

9.3.1 What are 'Medical Criteria'?

There was much support amongst participants for using medical criteria to allocate organs, but there was disagreement about exactly which criteria should be used and how 'greatest need' should be defined.

9.3.1.1 Transplant Outcomes

Some participants thought that transplant outcomes were an important factor in allocating organs, and felt that allocating according to non-medical criteria may

compromise transplant outcomes (see Table 9). These views were particularly prevalent within the staff group.

Table 9 - Support for transplant outcomes

if you take any random organ and then put it into another person the body's not going to accept it, there's a very big chance it's going to be rejected straightaway so you have to go on that method and that criteria will fit and it's the best way to do it. It's also the best way to, best way to ensure the survival of the patient as well– SAPD5

what's their chances of survival, what's the chances of the graft surviving, as long as you know a reasonable length of time and they're then allocated onto the list in that way, on that basis – if however their chances of survival are so small or less then you wouldn't transplant, if we all put our hand on our heart and said we just don't think this patient's going to make it and have a meaningful life after yet another transplant then we'd say no I don't think it's appropriate and we've done that before – TS5

I still think that the decision should be made medically on perhaps who is less likely to reject it and who is more... likely to come out of it successfully. – PD1

9.3.1.2 Greatest Need

Most participants within all groups agreed that recipients in greatest need should be prioritised. Conceptions of greatest need were fairly consistent, and urgency tended to be the main feature (See Table 10). Urgency was associated with saving lives of those likely to die soonest, rather than the urgency of improving the poor quality of a life.

Table 10 - Greatest need as urgency

In the sense of fair play, probably the case you give to the most urgent case first. – PR3

I guess at the end of the day it's got to be, it can't be that important, it's got to be done on merit hasn't it and need and the urgency and suitability I suppose, as far as size and things go. – PR4

I ... guess it's a return to a normal life... return to a, reasonably healthy state. And the nearer you are to losing that I guess they've got to be fastest. – PR2

at the end of the day I think it must regardless of who that individual is and what they might have done, it has to be based on medical, medical need. – SAPD3

There was a general feeling across all groups that urgency, defined in terms of closeness of death without a transplant, plays a significant role in determining medical need:

there may be somebody who's who hasn't got very long to live, who's a super-urgent person on the waiting list, and needs the organ more than that person – TS6

Nevertheless, one potential recipient had an alternative conception of need, which regarded saving an immediately threatened life as much less important. This view did not require increased urgency to result in higher priority for transplantation, and appeared to be grounded in the idea that urgency can change very rapidly.

you can be in the situation where one day you can be fine, and the following day you could be in that urgent medical need, so I don't think that again should come into it really, that's wrong, if you're in the condition that you need a transplant, you're as much in need of that as somebody else. You know, I mean, whether you're you know it's imperative that you get it within months or whether you get it within 12 months, you know, it's not, to me you're both in a similar situation. – PR4

A member of transplant staff also had alternative views on medical need, and suggested that medical need is actually a subjective thing with competing definitions. This participant did not express support for a particular definition, but instead supported the idea that people may reasonably have different conceptions of greatest need:

Should it go to greatest need? Greatest need by whose definition, that's my problem. Who's defined the greatest need, you know, what because they're hooked onto a hundred million life support machines, you know what about the greatest need of someone's gonna be left without a husband, so you know, once again it's been by definition. What we all interpret as greatest need is different for us all. – TS6

9.3.2 Fairness

Most participants felt it was important that organ allocation was a fair process with fair outcomes.

I think it's important that it's done in a fair basis, how you decide fair is another question but I think if it was done on medical need basis. – SAPD4

But conceptions of fairness varied. Most participants thought that the fairest way to allocate organs was according to broadly medical criteria, and this seemed to tie in to the belief that medical criteria are the most objectively justifiable. It was felt that if organs are allocated according to objective criteria, then this must be a fair process.

Ok, to me fair would be based on like I say if you have your waiting list, you have an organ come in, I think it should all be based on effectively percentage chance of...of survival's the wrong word but being able to lead a reasonable life afterwards... so that would be the definition, you know, with some more medical and correct terms for that. – PD9

One individual thought that a fair process should consider the reasons why somebody needs an organ in the first place.

Fair is I don't know what I've already mentioned, like based on how the person and why the person requires the organ in the first place, based on how they're willing to live their life and yeah I can't think of anything more for that. - PD

Another participant thought that a fair way of allocating organs would be to allow all donors to specify who they would the recipients to be:

I suppose the only fair way of doing it would be for the person actually donating their organ to specify where they would like it to go – PD2

9.3.3 Who am I to judge?

Some participants within all categories were willing to give examples (“Alcoholics” – PD2, “drug abusers” – PD9) of types of potential recipients who they considered less deserving, but were also aware that other people may have different beliefs about this. This was often viewed as problematic, and left many participants suggesting that since there is likely to be disagreement over who is a deserving recipient, donors ought not to judge (see Table 11). This reasoning is interesting given that there is also room for disagreement about how medical criteria should be applied, yet the similarities here were not generally acknowledged.

Table 11 – Donors are not in a position to judge

I don't think as individuals we should then have that right to say well somebody deserves it more than somebody else, so from that point of view I kind of thought well maybe no it's not such a good idea. – SAPD3

I think sometimes actually when you meet individuals who are desperately looking for it and you can see that they're very ill and unfortunately possibly lived a very good life actually and you think to yourself in actual fact yes they do, but on the whole who's to say in actual fact how people will turn out actually, eventually so you know, I don't think it's for us to make that decision actually to a certain extent actually. – TS7

I think donation should be on medical need rather than somebody's more deserving. Who are you to judge somebody being deserving or somebody having children or not having children, somebody may be infertile, so does that make them irresponsible. – SAPD8

9.3.4 Such serious decisions should not be left to individuals

As well as concerns about the prospects of disagreement and the difficulties of individuals making value judgments, some participants just thought that it is wrong or distasteful for donors or donor families to make these kinds of decisions (see table 12). When asked what was special about organ donation, and why donors ought to be concerned with ideas such as greatest need, many participants appealed to the idea that organ donation is a matter of life and death and that choosing recipients or types of recipients is akin to playing god.

Table 12 - Donors should not choose who lives or dies

That gets into some dangerous territory doesn't it, because you've got life and death panel then haven't you? – PR3

I think it's mainly because of it's that life and death thing isn't it? As opposed to just cash or whatever. Just giving stuff away... you could give it to anybody couldn't you? Him on the street if you wanted. But when it comes to a matter of life and death it's a

different issue. – PR2

Probably from a religious side I think there's only one God that can judge whether a person is good or bad... we're not in a position to judge – SAPD2

9.4 Factors beyond the medical

9.4.1 Family partiality is acceptable

Most participants thought that favouring family members is acceptable (see Table 13). Participants often struggled to articulate justifications for this, but suggested that you often do things for family members that you would not do for strangers, and that you should naturally want to 'look after your own'.

Table 13 - Support for family partiality

I think that extends in to every... aspect of your life, you know lots of things you do for family and loved ones that you would never ever do for random people and I don't think that's a bad thing on the whole. – PD1

I think naturally for anyone, first of all it would be your family kind of you know blood's kind of thicker than water and you would naturally reach out to those who mean something to you but you know a life's a life and if you can save anybody's... Because they mean something to me obviously and they are kind of nearest, dearest or your kind of closest to you so naturally someone was needing something in the family then you would probably do that whilst you were alive let alone when you consider something later. – SAPD6

Some participants, particularly potential recipients who have a basic understanding of tissue matching, justified priority for family members in more clinical terms, citing an increased likelihood of tissue match.

I think it's probably a good, a good thing that they could because I mean you've got more chance of it being a match as well because of being like a family member, you can obviously, I presume your blood groups going to closer match than and so on, so it's less chance of rejection and so on. – PR4

9.4.2 Responsibility for condition

Many people felt that those who are responsible for their ill-health are less deserving, but this did not always translate into favouring conditional donation. Sometimes this was grounded in the idea that people who have brought about their own illness may find it difficult to change their behaviour and will therefore have increased risk of recidivism:

I suppose the risk is that if someone's an alcoholic they have messed up their liver, they get a new liver, if they're just going to carry on abusing that one, is that fair? – PD2

When asked whether they thought any types of people were less deserving of receiving transplants, several people singled out alcoholics. Partly, this was grounded in a belief that alcoholics may find it hard to change their lifestyles and will therefore have an increased risk of needing further transplants (and this is related to the idea of waste mentioned shortly).

More often, however, there was a sense that someone who has made certain choices in life that are known to be carry health risks ought not to be as high a priority as someone who is just unfortunate (see Table 14).

Table 14 - Support for lower priority for those responsible for illness

<p><i>I think it does, I think if someone has had the choice and has you know actively put themselves [sic] in a position where they damage their body and they've chosen to do that then I think they should be further down the list in comparison to someone who was actively you know not done that and mistreated their body. – PD5</i></p>
<p><i>if there's one who is sort of a life-time alcoholic, drug abuser perhaps and then the other one is a 20 something up and coming athlete, do you know what I mean then you can perhaps go well yeah he's going to make more use of it but I think that's quite a unique situation that.- PD1</i></p>
<p><i>And if people are just gonna say oh knocked down again, oh waste time of getting up, I find that quite difficult to cope with. If there's a deficiency in genes and it's a proved illness then perhaps I'd be more able to accept it. – PR8</i></p>

9.4.3 Priority for Children

Some participants felt that children should have priority for organs (see Table 15). For some participants this was based upon the idea that children have lived less life and could have more life ahead of them.

Table 15 - Support for priority for children

<p><i>if the child's received a potential organ and it helps them kind of lead a you know healthy life, they've got kind of a long lifespan ahead, I would think, you know, that maybe a child's more deserving than perhaps a senior member – SAPD5</i></p>
<p><i>Just because a child has I don't know, they've arguably probably got more of their life to lead, they have had less of a life because they're younger than you know someone older and I don't know I guess they'd be seen as being more vulnerable, weaker, which</i></p>

is not necessarily true, but they've just got more of their life to live, haven't they? –

PD5

Some participants failed to provide justification for giving children priority, yet still held firm beliefs.

Just is. That's, that's the way I think, children should always come first. – PR6

Other participants were more interested in helping other parents avoid the pain of bereavement that would be caused by a child dying before receiving a transplant, and seemed to think that being able to direct their child's organs to another child it might help to bring about something good from a negative experience for donor-parents.

But potentially I'd want my child's organs to go to another child and I'd probably feel quite strongly about that because you wouldn't want another parent to go through what you'd gone through and if you can save a child's life at the expense, albeit at the expense of your own, you'd probably want that to happen – PD2

Some transplant staff also thought that it might be acceptable for requests for priority to be given to children, so long as the donation was not contingent upon the request being granted, a caveat that reflects the March 2010 policy revision³⁷⁹. Given that organs are matched for size, and children already have priority for transplants, staff may have been aware that a request like this would probably not make a difference to how the organ was allocated.

So that's one direction that I'd probably feel comfortable, a lot of these directions would be that you know, I'd like it to go to a child you know, first, if it can't go to a child then that's fine – TS6

³⁷⁹ Department of Health (2010) *op. cit.*

9.4.4 Future Behaviour/Willingness to Change

Many participants, particularly amongst the non-staff groups focussed on future recipient behaviour and willingness to change as being related to deservingness (see Table 16). Many participants thought that there is no point in giving an organ to someone who will not look after it. Participants within the staff group were not explicitly concerned with future behaviour, perhaps because they are aware of the safeguards that are already in place when deciding which potential recipients are placed on transplant waiting lists.

Table 16 - Support for future behaviour being important consideration

I: I think there should be a predefined set of restrictions they can put on it, not allow people to freewheel it so to speak.

G: So what sort of restrictions do you think may be included in that?

I: also you know willingness to change I suppose, people who are who are completely selfish and not willing to do anything about their problem or people that are actively trying to solve that problem – PD7

Yeah, the only one I can think of really is if, but then you can't do it 'cause you wouldn't know. Is ... ensuring someone is going to respect the additional years they've been given as opposed to abusing them. – PR2

I think somebody who's blatantly in actual fact not taking on board actually advice that's been given actually and you know obviously not looking after their health and possibly would not look after a new liver in actual fact so yes in that case, yes." – TS7

9.5 Inaccurate Conditions

While transplant staff tended to oppose conditional donations because they would interfere with the usual medical allocation of organs, non-staff participants objected to the conditions presented in the scenarios because they deemed them to be inaccurate or incorrect (see Table 17). This was not a moral criticism of the condition, and is instead a claim about the factual premise for the condition (e.g. a condition may state that organs are not to be given to young people, on the grounds that they are irresponsible, even though young people can be as responsible as older people). There may be a moral component to this objection, insofar as excluding people from receiving transplants on the basis of something that is factually incorrect could be unfair, but non-staff participants did not tend to focus on this aspect.

Table 17 - Concerns about factual accuracy of conditions

Yeah I think it should be objective because just because someone's slightly older and got kids doesn't actually, you know, doesn't necessarily mean they're a nice person – they might hit their kids – PD2

It may be that younger people are risk takers, but it may also be that someone over the 25 who's got children might you know, use coke, at the weekend and may damage the heart anyway – SAPD7

It seems very arbitrary and I don't know, the person over 25 could be more reckless than the person at the top of the list so I think the only fair way to do it is to look at who needs it the most. - SAPD4

These participants were concerned that some conditions, such as the ones in Scenario 1 (Table 2) where the family request that organs are only allocated to people over the age of 25, cannot be applied without unfairly excluding other potential recipients. So while participants did not necessarily object to the idea of more responsible people

being favoured by a condition, they were concerned that a condition like this may also accidentally exclude responsible people under the age of 25.

9.6 Life-Saving and Waste

9.6.1 Life-Saving is paramount

Participants who favoured a more flexible approach appeared to do so because of the life-saving consequences. Although these participants generally thought that other principles such as fairness and equality were important, saving lives was more important to them (see Table 18). This view was most prevalent within the potential recipient category, with the most participants within this group holding it.

Table 18 - Support for life-saving being important

<i>at the end of the day it's better to save some than to throw a chance away that, you know I mean, people could last another 10, 20 years with the treatment and what you have, a heart transplant could carry somebody's life on for another 20 years, a kidney transplant again could carry on somebody's life for another 20 years, so it's giving 5 to 6 people a chance to live that little bit longer in life and probably enjoy their lives – PR4</i>
<i>Well the people who were you know judging this basically thought well you know, we'd rather that it went to the people than we just flat out refused, so I think they were probably in the right there. – PD7 (this was in the context of discussing the 1998 case of conditional donation)</i>

For some participants, saving life is of sufficient importance that it may justify the NHS lying to donor families. These participants thought that the NHS should accept conditional donations, tell the donor family that they would act according to the conditions, and then allocate the organs in the usual manner, ignoring the restrictions.

It seems like they should accept them, but secretly, so not; because, or maybe they should just say to the family, okay, we'll do that but then actually not necessarily give them to the people that they want them to be given to because...otherwise it's just a waste – SAPD1

This was not a view that featured at all in the staff interviews. The staff were conscious of the need to maintain public goodwill towards transplantation (in relation to taking organs without consent: *"there would be a backlash and negative publicity, which would do organ donation a great deal of harm"* – TS1) and would presumably regard this strategy as potentially damaging to that good will.

A number of participants in all groups felt that one way to handle conditional donations would be to allow them as and when they do occur, but not to promote or encourage conditional donation more generally (see Table 19). This is linked to the idea of these donations being non-ideal, and a reluctance to promote something that brings about sub-optimal transplant outcomes.

Table 19 - Support for accepting conditional donations as a last resort

I think again it has to be a last resort kind of situation, I don't think in general we should say put any restriction you want on because that way more people will donate, I think we should try our very hardest to get unrestricted donations – SAPD4

so you wouldn't be given a choice in the donation conversation but if a family came forward with those restrictions then I think they should be respected. But unless they come forward I don't think it should be given as a choice –TS2

9.6.2 Wastage

Support for more flexibility regarding conditional and directed donations was also based on the idea of avoiding waste, which was closely linked to saving lives.

The idea of wasting organs was used in two ways; first, turning away medically useable organs was considered to be a waste. Second, allocating organs to people who will not look after them was considered to be a waste – there are some similarities here with 9.6.1.

Some people considered the first form of wastage to be wrong on the part of the donor/donor family (due to the potential loss of life associated with wasting organs), and others considered it wrong for the NHS to waste organs in this way. Others, particularly transplant staff, viewed this wastage as being an unfortunate necessity in order to maintain other principles (see Table 20).

Table 20 - Views on waste

<i>our society at the moment is prepared to pay the price of losing the occasional organ in this situation because of the, you know, the greater good and the overriding principle really – TS3</i>
<i>In this instance they're not giving them at all [as a result of not being permitted to place conditions], so they're being wasted really. It could have brought someone a better or prolonged life, its just being totally wasted – PD3</i>
<i>At the end of the day it's better to save some than to throw a chance away – PR8</i>

Despite the view that wasting medically useable organs is a bad thing, and that some principles could be compromised in order to avoid waste, participants, when asked, were unanimously in favour of respecting donor/donor family wishes and not removing organs without consent, for instance. So the idea of avoiding waste in this sense

appears only to apply to organs that have actually been offered for donation, and cannot be generalised to changing to an opt-out system or routinely taking organs without consent.

The second way in which 'waste' was used was primarily a forward-looking concept, concerning the future behaviour of recipients rather than their past behaviour (see Table 21). This conception of waste did not arise in the transplant staff group, possibly because they are aware that policies are already in place to ensure that organs are only given to people who are likely to abstain from potentially damaging lifestyles.

Table 21- Waste and future behaviour

<i>I can understand if you like the feelings of the parents about not wanting their son's organs to be wasted and feeling that they want someone who really deserves them to get them - PD2</i>
<i>I don't care whether they're gays, fags, Pakis, I don't care what they are, there's got to be a fair system but like, but their life chance survival has got to be; if he's just going out and drinking again, what is the point, it's just wasting a good kidney and all our time, do you know what I mean, there must be some sort of, I'm not saying an ethical committee but there must be some sort of...just a committee, but I don't really want to set up a jury. - PR3</i>

9.6.3 Donor Wishes and Flexibility

Some participants within each group thought that donor wishes or donor-family wishes should be given some consideration, but generally not over-riding consideration (see Table 22). It was not always clear to what extent participants thought donor wishes could or should be respected, particularly when the wishes conflict with usual medical allocation procedures.

Table 22 - Respecting donor wishes

*They should have authority to, you know, give a donation to who they like, you know?
They should have a freedom.- PR2*

*I think that well I think that people have a right to, to some extent to be able to say
where their organs are going and how they would be used – PD2*

Several participants suggested that if someone places a condition on a donation, transplant staff should check the waiting lists to see whether that condition can be complied with without depriving anybody of an organ who urgently needs one (see Table 23). This approach offers a compromise between allowing donor wishes to be listened to and using usual medical allocation procedures.

Table 23 - Support for considering the implications of specific donations

Yeah, yeah I do think yeah, they should be given a say in the matter but again in the heat of the moment, you know, you do make some irrational decisions when you're in that situation, I know first hand, so you know, things that you sit back later and think that probably wasn't the right thing to do but ... if the family views are taken on board to be rational decisions, not just something absolutely ridiculous then yeah I think they should be should be listened to and looked up. – PD3

you would think that doctors could look at the list of very needy people and chose the person nearest the top who fulfils their requirements so that...so the organs would go to somebody who definitely was desperate and needed them and would fulfil the requirements of the family who's been bereaved. – PD8

Although most participants were opposed to the idea of more widespread conditional and directed donations, some participants (particularly within the non-staff groups)

thought that the general ban on these sorts of donations might be too rigid. Some participants (including two members of transplant staff) thought that although conditional and directed donations deviate from the ideal, they may be acceptable if they encourage people to donate organs who otherwise would not (see Table 24).

Table 24 - Conditional donations more acceptable if they increase donation rates

in an ideal world, yes I think people should say I donate or no I don't, you know it should be black and white, yes I am willing to donate but if you believe everything you read in the papers about there not being enough organs and the quality of people's lives being absolutely terrible, then you have to say to yourself well is there any way you can encourage more people to donate and if it is by having a stipulation like that, then fine – PD8

Well I think if directed donation helps to improve the number of donors we've got then that's why I feel it should be something that should be considered, ... to try and increase the number of potential donors. - TS8

Some participants believed that the NHS should be more flexible about conditional donations, and consider each case on its own merits (see Table 25). This view was particularly popular within the potential recipient group and potential donor groups. The potential recipients may be particularly aware of the consequences of a rigid policy that involves turning away offered donations, and the potential good that can be achieved by transplants. Several participants thought that accepting conditional donations should be viewed as a last resort, but can be justified if the alternative is turning away a donation.

Table 25 - Accept conditional donations if the alternative is turning donations away

<p><i>I think it's a good overall generalised policy and I think they should try their very hardest to implement it and I think if someone tries to put restrictions on they should go to the policy and say they've got a policy but I think maybe there comes a stage where if you really can't get through to someone just take the organ. – SAPD4</i></p>
<p><i>it's quite ludicrous that you bin ... a useable organ and let somebody die because some over-zealous adherence to legal niceties – it's like saying sorry the patient died but I didn't want to stop at the red light to take the patient to hospital – it's just ludicrous – TS3</i></p>
<p><i>I think for the sake of a recommendation, I think that your default position should be on medical needs and only if they are risking to lose organs, then maybe as a kind of sub parameter, perhaps a back door, we should allow the donor actually to voice conditions or direct the donation. – TS10</i></p>
<p><i>they should say alright, thanks for your input, thanks for your advice, we'll see what we can do, but we can't guarantee that, we can't guarantee that it'll go to Joe Bloggs character type, I mean there's a small chance it might go to a young person, a person with a child, and in theory you're not lying to them, there is a small chance that would happen, and you can say yeah we'll take into consideration, but just do what you want with it. – PD10</i></p>
<p><i>By throwing them away... or discarding them, you're stopping somebody aren't you, with the potential to have a good life. And maybe it goes against everything I've said... No, I think the NHS should take them. – PR8</i></p>

9.7 Other Considerations

9.7.1 Reasons behind donation

The motivation for donating organs was often regarded as being important, but reasons other than pure altruism were considered to be acceptable.

Transplant staff appeared to be more in favour of altruism as a motivation than members of the public, which is perhaps because they are more embedded in the culture of organ donation where altruism is a central principle of policy. Even amongst this group, however, there was suggestion that the focus on altruism may be unnecessary or misplaced (see Table 26).

Table 26 - Staff views on altruism

Well I've already said that I think that people should have, you know... some say if they really feel they want it, but I think I think it's very important that organ donation is altruistic. – TS8

I do empathise with families who are in that position, but I still I still don't believe it has anything to do with altruism – altruism I don't believe is the right word. I think it's all about you know providing the families feel better for it, but whatever itch it scratches or whatever hole it fills, it's not an altruistic thing – TS5

I think actually it's a bit more theoretical actually, because people don't know that donation's supposed to be altruistic, they're doing it for the reasons they want to do it for, so I think I'm not sure that it would actually affect it that much because people don't know, they don't think in that way when they're donating – TS11

For some participants, motivation was important, but not as important as obtaining organs per se.

I think the most important thing is that they're donated but I think underneath that I would prefer that there was good reasons but I think if you're going to get them you're going to get them. – SAPD4

The 1998 case of conditional organ donation was criticised for being non-altruistic, but some participants thought that the staff did the right thing by accepting the donation anyway because of the greater good that resulted in terms of saving lives (see Table 27). Everybody expressed some degree of disgust with the donor family's wishes in this case, and participants were quick to condemn the apparently racist motivation behind it.

Table 27 - Views on 1998 case

I think they did the right thing in the fact that they save people's lives again, but again it's down to well basically racial politics isn't it - PR4

ultimately again from a sort of clinical point of view, they were completely right to do it because they took that sort of emotional side out of it and said you know your reaction is this is probably wrong, this is wrong, but look at the good we could ultimately do. - PD4

Yeah I remember that happening erm, I, it was quite disgusting really, I find it pretty disgusting and...it's not a bad thing that the organs went to help other people - SAPD1

9.7.2 More Information

Some participants from all groups, but particularly the staff, thought that wanting to place conditions on organs stemmed from a lack of knowledge or understanding about organ donation and the organ allocation process (see Table 28). When prompted, most participants thought that if a family made a conditional offer of organs, it would be quite reasonable to speak to the family about organ allocation procedures and request that they reconsider their conditions.

Table 28 - More information might prevent conditions

<i>But I think maybe with a little bit more counselling or something they might actually come round to the idea that, you know, they can't go into that much detail – PR2</i>
<i>I would hope that there would be a bit more effort put into trying to explain why maybe someone under the age of 25 who doesn't have children would be equally as deserving. – SAPD4</i>
<i>maybe if somebody spoke to them and saying that there are lots of young people who are very responsible, I'm sorry, not all young people despite all the media are irresponsible... – SAPD8</i>
<i>I think people do it they say, from a point of view of ignorance really about the whole donation process and where the organs go, and most people, once you explain... how patients are assessed and they go to the most suitable patient and with hopefully the best outcomes... - TS11</i>

9.7.3 The Slippery Slope/Setting a Precedent

Almost every participant was concerned about the potential slippery slope from allowing conditions that may be regarded widely as acceptable to allowing other much more objectionable conditions (see Table 29).

Table 29 - Concerns about slippery slopes

but the thing is when you start on, you're setting a precedent, you accept these on this condition, what happens if another, say I don't want to give it to anybody over 50... or why you wanna give it to this, aren't you therefore wasting the time in sort of making sure the organ goes straight away to somebody who needs it rather than, cos where do you stop – I see that as a slippery slope. – SAPD8

do you take that, you know, and how many caveats can you put in, you know, one minute it's sort of ok you've gotta be over 25, well then you start asking people who are earning a certain amount of money and things like that, I just don't think it's a good idea – PD1

One staff participant actually thought it important, in terms of consistency, that if you allow some conditions, you allow them all.

I think if you allow conditions, then they should be allowed unconditionally...so I think if you open Pandora's box and say conditions are allowed, then conditions should be allowed. – TS11

Although there was widespread support for favouring family members, some staff participants were even concerned about the precedent that this set in terms of compromising the principle of unconditional donation and starting a slippery slope.

But I think so far as sticking to things objectively I would say that even that is the thin end of the wedge and is... a danger really that the principle will be lost because once you start to breach this question of unconditional altruistic donation then it's very difficult to know where to stop really. – TS3

9.7.4 Reduced access to organs

Many participants, particularly within the potential donor categories, were concerned that allowing people to place conditions might encourage some people who would otherwise have donated unconditionally to donate with conditions attached. These participants were concerned that general acceptance of conditional donations might reduce access to organs for those likely to be consistently on the wrong side of individuals' direction decisions (see Table 30).

Table 30 - Concerns about access to organs

<i>although next thing you know everyone has signed this register and everyone's put in some caveat and then you end up with this kind of marginal sub-section of society</i> <i>- PD1</i>
<i>No, I think if you start doing that then you're going to have a load of people that will be on that list, that will have higher priority than everybody else just because they've got kids or they've got such and such going on in their life and then you'll find there'll be a handful of people that will just be waiting around, waiting around and waiting around-</i> SAPD 5

9.7.5 Recipients' views on receiving conditional donations

Recipients' views on receiving a conditional donation were mixed, ranging from strong opposition to not being concerned at all. Recipients views have been singled out here for separate discussion because if recipients were completely opposed to receiving conditionally donated organs, then there would be little reason to accept them anyway.

The following comment was from a participant who had already received one liver transplant but required a subsequent re-transplant, and had a good understanding of the transplant system and how organs are allocated. Despite the severity of her

condition, this participant thought it absolutely essential that the allocation process was fair. This desire for a generally fair system was common amongst recipients.

...actually I would have felt pretty terrible. I've never ever thought about that before but yeah I would have done, I would have thought that it [receiving an organ because of a condition other than medical need] was most unfair. – PR9

A theme that emerged from potential recipients was that many would be willing to accept a conditional donation. What varied amongst potential recipients was the extent to which they considered this to be potentially selfish. Some justified accepting an organ on the basis that it would be better for everyone, while others seemed to think that the severity of the situation can justify some selfishness. The quotation below illustrates some of the tensions that a potential recipient could experience. On the one hand there is the desire to survive (coupled with his wife's desire for him to survive), but he would also have the issue of deservingness in his mind. This person also appreciated the bigger picture, where potentially everyone would benefit if more organs were donated as a result of permitting conditional or directed donations.

Being selfish you'd take it, got well again. But I guess it, it would be tinged with a feeling of 'Am I deserving' wouldn't it? ...It would have happened eventually, it would come along eventually I suppose. So there's that feeling. It's all a bit, yeah, tricky one isn't it? Because I know what my wife would say. She'd say 'Grab it while you can'... You get all these relations would say that wouldn't they? And I think probably the ethics have to take over. If the law was different and people were able to do that, and it did increase the number of organs donated significantly, I guess everybody would benefit wouldn't they? – PR2

Another participant was undergoing a liver transplant assessment, and had not yet been told whether s/he would be placed on the waiting list. The views of this participant

suggest that the severity of a condition can eventually outweigh concerns one might otherwise have (for justice or fairness, for instance).

I suppose if you were told, see that's another thing to deal with and you really could do without that cos you have a lot to deal with anyway. But how would I feel? I dunno, 'tall depends on what physical state and emotional state I was ...because I wouldn't give a monkey's cos... it's a dog eat dog world out there, it's very competitive and it'll only ever get worse but you know when things get critical, you know, you'll do what you have to do. – PR1

Another participant, who was on the kidney transplant waiting list, had more straightforward views and was more interested in just getting a transplant than worrying about the origins of the organ or its allocation:

I wouldn't care...It's just an organ isn't it, you can look into the politics at its deepest part but really, at the end of the day, it's just an organ isn't it, and it's got no views of its own has it? - PR3

9.7.6 Role-based differences

Staff participants' views varied according to their professional role. For instance, one transplant recipient coordinator was in favour of some conditional donation as long as it did not compromise overall fairness (and it increased the amount of organs available for recipients).

I'm a cog in the machine and there are other people in the machine who've got more responsibility for donor families and less responsibility for recipients, but my own particular responsibility I think I have more responsibility for recipients than donors – TS7

In contrast, a (SNOD) felt that she had more of an obligation towards the donor family, saying:

I would have to be professional but I in my professional capacity of someone that's cared for people that are bereaved I would have to be on their side to some degree. I'm their advocate, I believe that, I'm not advocating for the recipients – TS5

The same participant still seemed to value the importance of the impartial perspective overall (even though her own perspective, as an advocate for donor families might not be impartial), but felt that it would be difficult to obtain from someone involved in the transplantation process:

Yeah, as long as it's not a transplant surgeon on them, because they'd never be able to make sort of, they'd never be able to view it from, that's the problem isn't it – when you say experts, I agree they need to be experts that can look at that completely outside the box, you know, whereas I'm stuck in front of a family that are grieving I can probably see their point of view, transplant surgeon can see the point of view of the recipient waiting, it's getting a group of people that can view it as it is. – TS5

9.7.7 Professional obligations

Although the non-staff groups have faith in transplant staff to allocate organs, many staff participants acknowledged that they had personal views about some people being more deserving of organ transplants than others; the justification for these generally centred on responsibility for condition and likelihood of treating the transplanted organ well. Even those staff who did feel that some people are more deserving than others felt that allocation decisions should be based purely on medical criteria, so there may be some tension between their personal views and the responsibilities and public expectations of their job roles (see Table 31). This reflects the ideas of Cottingham and Blum, who both suggest that there can be contexts where one's institutional role demands impartiality^{380,381}.

³⁸⁰ Blum LA, (1980) *op. cit.*

Table 31 - Staff's professional obligations

<p><i>Probably as an individual I do, I mean cuz we all have our prejudices and people we you know we don't like either ...you talk about alcohol or they're smokers or they're obese ...so individuals will have prejudices against a number of other individuals but I think that we have to put that aside really and we have to objective about it – TS6</i></p>
<p><i>you can't voice that because you have to be impartial, but there are people who I've thought, I wouldn't give you my liver – TS1</i></p>

9.8 Conclusions

These results suggest that although there is support for an allocation system broadly based on medical criteria, there could be some support for conditional and directed donations in some circumstances. There was particular support for the avoidance of waste, where waste is something that occurs when an organ could be used to save or improve lives but is not. One would expect both the staff and recipient groups to be generally pro-transplantation and in favour of increasing the amount of organs available. Although the potential donor categories may not share the perspectives of these two other groups, without exception everyone was pro-transplantation (although some had not decided whether to join the ODR themselves). This may have had an impact on the views expressed, and will be discussed further as a potential limitation in Chapter 11. There were very few people who thought that a generalised policy of allowing conditional and directed donations was a desirable situation.

The results presented in this chapter detail what a relatively small number of people think about conditional and directed donation. In Chapter 10, these results will be discussed in conjunction with the philosophical analysis presented in Chapters 3-7 and the existing literature.

³⁸¹ Cottingham J, (1986) *op. cit.*

Chapter 10 - Discussion

The philosophy chapters of this thesis looked at several aspects of conditional and **directed donation**. It was argued in Chapters 4 and 5 that the DH's reasons for prohibiting conditional donations are unconvincing, and **that the DH's reliance on** altruism to prohibit conditional donations has resulted in confusing inconsistencies, particularly in relation to conditional donation. It was then argued in Chapter 6 that accepting conditional donations would be compatible with the obligations of recipients to each other. Accepting a conditional donation rather than turning it down is better, in some way, for **everyone** on the waiting list. Recipients ought not to feel like they are queue-jumping by accepting an organ with conditions attached, as this can simply be considered making the most of available resources. It was then argued in Chapter 7 that there are good reasons for accepting conditional donations in some circumstances. This was justified on the grounds of avoiding levelling down/negative loss. While some (but not all) conditional donations reflect moral failings in the donor or next-of-kin, it was also argued that the NHS is not responsible for the placing of conditions and would only be bringing about the best outcomes from a non-ideal situation.

The empirical study collected a large amount of data relating to these and to other aspects of conditional donation. This chapter will consider these data in conjunction with the philosophical conclusions drawn in Chapters 3-7 and existing literature in accordance with the method described in Chapter 1. The aim is to use the data gathered by the embedded study alongside further philosophical discussion to produce practical recommendations that can guide ethical practice in relation to conditional and directed deceased organ donation. The first section will look at what the participants said about the specific conditions they focussed on. This has raised lines of argument that were not considered in the philosophy chapters. These lines of argument were charitably constructed and then subjected to rigorous philosophical scrutiny. Where the arguments were shown to be robust they were worked into the final

recommendations. If the arguments could not withstand scrutiny, they have no place in recommendations for policy. The second section will build a defence of accepting any conditional donation, regardless of the content of the condition, supported by the **participants' ideas of avoiding waste and the earlier philosophical discussion** in Chapter 7. The third section will use results from the embedded study to formulate potential criticisms of and opposition to this position, ultimately concluding that although these concerns need taking into account, they do not provide compelling reasons to prohibit conditional donations.

Throughout this chapter, 'conditional donation' will refer to donations that are contingent upon a request being followed. Donations that include an expressed preference for a certain kind of recipient, but will go ahead even if the request is not/cannot be followed need different attention and will be discussed in the final section **of this chapter, under the heading 'Preferences'.**

'Condition content' is used throughout to refer to the specifics of the restriction imposed by the condition, as opposed to making conditions per se. For instance the condition content of a condition restricting a donation to children would be the restriction to children. It will be argued that few conditional donations can be justified on the basis of their condition content.

10.1 Ideas Arising from the Data

As discussed in 1.3.1, one reason to collect qualitative data from stakeholders was to consider new lines of argument that were not considered in the philosophy chapters or other literature. This ensures that arguments beyond those considered relevant by Moorlock are given due consideration, and results in a more complete philosophical analysis. The philosophy chapters did discuss some specific conditions (such as those that involve racism, or directed donation to family members), but three additional lines of argument emerged from the interviews, relating to specific conditions:

- i) Priority for children;
- ii) Lower priority for people responsible for their own illness;
- iii) Priority for family members

In line with the empirical bioethics methodology described in Chapter 1, each of these will now be explained and assessed in turn below. Consistent with the argument provided in Chapter 7 that it is preferable for donations to be unconditional, for the content of any of these conditions to be acceptable it must provide good reason to over-rule the general policy of unconditional donation.

10.1.1 Priority for Children

Some participants thought that it was acceptable for children to receive priority for transplants, and donors to specify this preference. Some participants had the interests of paediatric recipients in mind, on the grounds that children have lived less life, and potentially have a lot of life ahead of them. Other participants thought that allowing these sorts of conditions/directions could help bereaved families during difficult **circumstances; a bereaved parent could at least take comfort that their child's** death was helping other parents avoid a similar bereavement.

Neuberger and Mayer reported that 59% of their respondents thought that it was very or fairly acceptable for donors to request that priority is given to children³⁸². A similar study conducted in Australia found that 65.5% of participants thought that, all other things being equal, a younger person should receive priority for transplantation over an older person (0.8% thought an older person should receive priority, and 33.6% thought it should make no difference)³⁸³. This suggests widespread public support for favouring children.

³⁸² Neuberger J and Mayer D, (2008) 'Conditional Organ Donation-the Views of the UK General Public Findings of an Ipsos-Mori Poll' *op. cit.* pp1545-47

³⁸³ Browning CJ and Thomas SA, 'Community Values and Preferences in Transplantation Organ Allocation Decisions', *Social Science and Medicine* 52 (2001) pp853-61

Children do tend to receive priority for transplantation of some organs, although **the grounds for this can be broadly construed as 'medical'.** Where the size of organs is important, organs donated from children will generally be allocated to children, for example. This is partly because there are so few paediatric donors (there were 43 in the financial year 2011-2012³⁸⁴). Splitting livers so that both a paediatric recipient and an adult recipient can benefit could also be construed as putting the interests of children ahead of adults because doing so has a negative effect on the transplant outcomes for the adult recipient when compared with the outcomes had they received a whole liver³⁸⁵. Other medical reasons can also justify prioritising children. Children with renal failure, for example, can experience neurodevelopmental and growth delays which can potentially affect them for their lifetime³⁸⁶. This provides a reason based on maximal effectiveness to give children priority over adults for kidney transplants. A study conducted in Canada found that giving priority to children dramatically reduced paediatric waiting times, yet because children only represent a small proportion of people on the waiting list, had negligible impact on adult waiting times³⁸⁷.

Other arguments supporting the prioritisation of children will now be examined.

10.1.1.1 Fair Innings

The claim that children have lived less life and have their whole lives ahead of them can be broken into two separate arguments. First, it is trivially true that a child has lived less life than an adult. In order for this to be developed into a claim about priority for organs it must be supported by the premise that those who have had less life should be given more life ahead of those who have either reached an acceptable baseline or who **have just had more life.** Tong's systematic review found that some participants used a

³⁸⁴ NHSBT (2012) 'Latest Statistics', Available at: http://www.organdonation.nhs.uk/ukt/statistics/latest_statistics/latest_statistics.jsp, Last Accessed: 31/10/2012

³⁸⁵ Merion RM et al., 'Predicted Lifetimes for Adult and Pediatric Split Liver Versus Adult Whole Liver Transplant Recipients', *American Journal of Transplantation* 4 (2004)

³⁸⁶ Crafter SR, Bell L, and Foster BJ, 'Balancing Organ Quality, HLA-Matching, and Waiting Times: Impact of a Pediatric Priority Allocation Policy for Deceased Donor Kidneys in Quebec', *Transplantation* 83 (2007) pp1411-15

³⁸⁷ *Ibid.*

'fair innings'-style argument, claiming that people are entitled to a reasonable/normal life span³⁸⁸. This view was not explicitly referred to by the participants in this study, but it is worth considering as it may provide justification for prioritising children.

The fair innings argument, in its basic form, asserts that there is some amount of life that is considered reasonable to have, and that those who have not had this amount should be given priority for resources over those who have. This approach may appear to systematically discriminate against older people and result in unfairness, but this is mistaken if years already lived is a concern of fairness³⁸⁹. The fair innings argument has, however, received support specifically in relation to kidney allocation, with Reese and Caplan arguing that this approach actually enhances fairness³⁹⁰. They claim that **"everyone old on the waiting list had a chance to be young, but the young patients on the waiting list deserve every chance to become old"**³⁹¹. If, however, the fair innings threshold is set at 70 years, then two individuals aged 40 and 50 would both have not reached the threshold, but would be entitled to an equal chance of reaching it. This simplistic interpretation of the fair innings argument would not support the prioritisation of children per se, but would instead support priority for all people under the age of 70 ahead of those over 70.

Veatch presents a variation of the fair innings argument, which he calls the **"justice-over-a-lifetime argument"**³⁹². This argument separates two conceptions of worst off: the 'slice-of-time' perspective and the 'over-a-lifetime' perspective. The slice-of-time perspective considers who is worst off at a given point in time, roughly akin to current allocation based upon greatest need. Veatch gives the example of a forty year old and a seventy year old who are both dying of heart failure. From a slice-of-time

³⁸⁸ Tong A et al., 'Community Preferences for the Allocation of Solid Organs for Transplantation: A Systematic Review', *Transplantation* 89 (2010) pp796-805

³⁸⁹ If x amount of life years is a fair amount to have, then a person who already has x years but wants x + y years is not obviously treated unfairly if the resources that it would take for her to gain y years are allocated to help someone else achieve x years.

³⁹⁰ Reese PP and Caplan AL, 'Better Off Living—the Ethics of the New UNOS Proposal for Allocating Kidneys for Transplantation', *Clinical Journal of the American Society of Nephrology* 6 (2011) p2311

³⁹¹ *Ibid.* p2311

³⁹² Veatch RM, (2000) *op. cit.* p340

perspective they are equally badly off, but from the over-a-lifetime perspective the patient who has reached seventy years of age is better off than the person who has reached forty. According to Veatch, justice therefore demands that “we target organs for these younger people who are so poorly off that they will not make it to old age without being given special priority”³⁹³. This also entails that the younger a person is the stronger their claim to preferential allocation.

A problem with this fair innings argument is the apparently necessary inclusion of an ‘all other things being equal’ clause³⁹⁴. Veatch does not specify this, but without it, his version of the fair innings argument could be too simplistic. A forty year old who has, up until that point, had an exceptional quality of life, should arguably not be considered badly off when compared with a seventy year old who has endured the previous forty years with a miserable quality of life. While having a longer life is better than having a shorter life, all other things being equal, it seems that other factors will prevent cases from being equal. The introduction of an ‘all other things being equal’ clause reduces the clarity of the fair innings argument and makes it more difficult to apply. The fair innings argument may function sufficiently as a tie-breaker when all other things *are* equal, but as Rivlin argues, there are so many other factors to consider that it unlikely that tie-breaking situations will be required³⁹⁵. Veatch suggests that his fair innings argument should be just one of the factors used to allocate organs, and that although age should be taken into account, it should not dominate³⁹⁶. A conditional donation giving priority to children would act as a dominating factor, so would be difficult to justify using a fair innings argument.

If the fair innings argument is given a decisive role in allocating organs via conditional donations, there is a chance that it could impact negatively upon efficiency. A child could be given priority over an adult for a particular organ even if their

³⁹³ *Ibid.* p341

³⁹⁴ Rivlin M, 'Why the Fair Innings Argument Is Not Persuasive', *BMC Medical Ethics* 1 (2000) p4

³⁹⁵ *Ibid.* p341

³⁹⁶ Veatch RM, (2000) *op. cit.* p343

predicted post-transplant outcomes with that organ were not particularly good. If that transplant then failed, the child would then require a further transplant, which, as a re-transplant, **would have less likelihood of being successful. A child's aims of achieving** old age could be better served by ensuring that the organ best-matched to her according to medical criteria is allocated to her, so it is not clear that giving children priority over adults for all organs would necessarily be the best way of achieving a fair innings.

The participants in this study appeared to favour priority for children, rather than those of a younger age relative to other contenders for a specific graft. They would not necessarily think, then, that a 35 year old should receive priority over a 40 year old nor that younger children have priority over older children. The claim that children have their whole lives ahead of them and should therefore receive priority could perhaps be justified on the grounds of prognosis and transplant efficiency. The situation could potentially get very complicated, however; a liver transplant could give a 40% chance of an increased quantity of life (n) to a ten year old, or an 80% chance of an increased quantity of life equal to $n/2$ for a 50 year old. The child may have the most life to gain, but their chances of doing so could be equal to or less than an older adult – if the argument for giving a child priority is on the basis of prognosis and transplant efficiency, it is not obvious in a case like this that the child should have priority. There are, of course, potential answers to these kinds of problems in terms of QALYs, but it is unlikely that QALYs would support over-riding priority for children in all cases.

10.1.1.2 Vulnerability and Sympathy

Some participants suggested that children are vulnerable, and felt increased sympathy or even obligation towards them. A special obligation to provide support to the most vulnerable could perhaps be defended in other contexts, but the vulnerability here must be carefully considered. Children may be **generally** more vulnerable than most adults,

but vulnerability in other areas does not necessarily justify special obligations in organ allocation³⁹⁷. The relevant vulnerability here would be a vulnerability to death (or appalling quality of life/future life) as a result of needing an organ transplant, and in this respect adult potential recipients may be just as vulnerable. Vulnerability to death or appalling quality of life already plays a role in how waiting lists are organised, and those likely to die soonest or who are experiencing the worst quality of life tend to be prioritised. Giving additional priority for children on the basis of vulnerability in this sense, therefore, is unjustified because their relevant vulnerability is no greater than **adults'**. One might suggest that another meaning of vulnerability could be intended, but it is difficult to think of one that should make a difference to organ allocation³⁹⁸.

A further concern with allowing organs to be directed according to conditions derived from sympathy for certain types of people is that there is a strong possibility that the same types of people will tend to benefit from or suffer the consequences. One of the common objections to solicited directed donation via media appeals is that they benefit certain types of people more than others³⁹⁹, and that this can be related to the appeal of the potential recipient. This means that cute children are likely to receive priority over middle-aged adults, not on the basis of medical or morally relevant criteria, but instead on their appeal to donor families. Many participants in the embedded study thought that emotions should play no role in organ allocation, and the argument from vulnerability or sympathy fails to provide a rational justification to favour children.

³⁹⁷ A child may be more vulnerable to becoming corrupted by playing violent computer games, and one may have an obligation to protect the child from exposure to these games, but this does not mean they should receive priority for medical treatment.

³⁹⁸ For completeness it should also be noted that some adults can be considered generally vulnerable in the way that children are (such as those with severe learning difficulties), and there was no suggestion from participants that vulnerable adults should receive priority.

³⁹⁹ Ross LF, (2002) *op. cit.* pp329-37

10.1.1.3 Helping bereaved families

Some participants suggested that being able to donate specifically to children could provide comfort to donor families because they would know that they were helping other families to avoid a similar sort of bereavement. It may provide comfort to donor families, but this does not itself provide a convincing reason for allowing it. Allocating organs according to racist wishes could provide comfort to a donor family if they felt that their dead relative would have wanted this to happen, but this can still fail to provide justification for doing so if there are other relevant countervailing factors. The argument also seems to imply that it is more important to prevent some kinds of bereavement than others. Prioritising a child may mean that some other parents do not suffer the loss of their child, but it could result in another child suffering the loss of their parent (if that parent was the patient at the top of the waiting list who was overlooked for transplantation due to a condition). It would be difficult to suggest that one bereavement here was obviously worse than the other.

The arguments discussed suggest that conditions giving children priority are questionable. Although it may sometimes be clinically appropriate⁴⁰⁰ to give children priority, an idea reflected by allocation policy, conditional donation is not an appropriate way to achieve this. Although it is important to consider the emotions and wishes of the bereaved, this does not entail that their requests should be granted *just* because it makes them feel better⁴⁰¹.

10.1.2 Responsibility for condition

Many participants, when asked whether they thought some people were less deserving of receiving transplants, replied that people who were responsible for causing their own

⁴⁰⁰ The size of organs from adult donors can make them unsuitable for paediatric recipients, but some smaller organs from paediatric donors can be suitable for adult recipients. Children have a smaller pool of available organs available to them than adults, so it is reasonable to give children priority for organs that are suitable for children. Because organs suitable for paediatric recipients are relatively rare, waiting for the next organ to become available is more likely to result in death than it would do for an adult. This argument does not just apply to children, however, and also works for any person who requires an organ with a relatively rare property.

⁴⁰¹ There may, however, be other good reasons to accept a condition if the donation would otherwise be rejected. This will be discussed in section 10.2.4

ill health could be so regarded. Those included in this broad group were alcoholics, drug users and people with risky lifestyles (people who take part in extreme sports, for example). This would tend to support findings in other studies, where participants' views on allocation have been influenced by whether recipients are thought to be responsible for their own condition^{402,403}. Alcoholics were frequently singled out by the participants, possibly because of well publicised cases like that of George Best⁴⁰⁴. A previous study by Neuberger and Meyer⁴⁰⁵ found that 38% of participants considered it acceptable for donor families to place conditions on donations which prevented alcoholics from receiving the donated organs.

The reasoning behind these views in the embedded study appeared to be based on both past and future behaviour. There was a concern that post-transplant behaviour would revert back to that which caused or contributed to the original organ failure, and also a belief that if one knowingly indulges in risky behaviour one should not expect to be bailed out when the adverse risks are manifested. The first of these arguments can be considered to be an argument based on effectiveness, whereas the second is more of a moral claim (although there is inevitably moral content in the first argument).

To highlight some of the difficulties encountered when allocating resources according to responsibility, the following discussion will focus on alcoholism. This was also the condition most frequently discussed by participants. Much of what is said can, however, be applied to other risky lifestyles. In the interests of precision, a distinction should be drawn between alcoholics and reformed alcoholics. The term 'alcoholic' is used here to describe someone who currently suffers from alcohol addiction. A

⁴⁰² Ubel PA, Baron J, and Asch DA, 'Social Acceptability, Personal Responsibility, and Prognosis in Public Judgments and Transplant Allocation', *Bioethics* 13 (1999) pp57-68

⁴⁰³ Ubel PA et al., 'Allocation of Transplantable Organs: Do People Want to Punish Patients for Causing Their Illness?', *Liver Transplantation* 7 (2001) pp600-07

⁴⁰⁴ BBC News (2005) 'Best: Decline of the Golden Boy', Available at: <http://news.bbc.co.uk/1/hi/uk/4090840.stm>, Last Accessed: 31/10/2012

⁴⁰⁵ Neuberger J and Mayer D, (2008) 'Conditional Organ Donation-the Views of the UK General Public Findings of an Ipsos-Mori Poll' *op. cit.* pp1545-47

'reformed alcoholic' refers to someone who has successfully overcome an alcohol addiction⁴⁰⁶.

A preliminary assumption for the following discussion is that the behaviour in question is voluntary, and that the consequences are foreseeable. There is debate over the nature of alcoholism and similar addictive illnesses, but the strongest argument in favour of allocating according to responsibility for illness must be formulated on the assumption of voluntariness⁴⁰⁷. Even given this strong starting position, it will be argued that organs should not be allocated according to responsibility.

One participant (a potential recipient) summed up the general line of argument when she claimed that it was unfair that she had lived her whole life responsibly without drinking or taking drugs, yet people who have indulged in these things and damaged their own bodies are just as entitled to a transplant as she is.

Much has been written about allocating healthcare resources according to past behaviour^{408,409,410}. Glannon, writing specifically about the allocation of organs, argues that people who are responsible for their own condition are less deserving of receiving treatment⁴¹¹. **He bases his argument on the claim that the more control over one's health one has, the more responsible one is for negative health consequences that result from one's choices. Veatch outlines a deontological justification for giving lower priority to people who are responsible for their own condition. He claims that deontologists are concerned about "equality of opportunity of well being"**⁴¹². A logical implication of equality of opportunity is that when two people have a health problem

⁴⁰⁶ One might argue that once someone is an alcoholic, they are always an alcoholic even if they have succeeded in abstaining for many years. While this may be true, it seems reasonable to treat someone who has successfully given up alcohol the same way as someone who is not an alcoholic. Just as a reformed alcoholic may revert to drinking, a non-alcoholic could become an alcoholic in future.

⁴⁰⁷ Setting aside the deeper philosophical issues of free will and determinism, it is not unreasonable to claim that, generally, for someone to be considered responsible for something, they must have engaged in it voluntarily.

⁴⁰⁸ Smart B, 'Fault and the Allocation of Spare Organs', *Journal of Medical Ethics* 20 (1994) pp26-30

⁴⁰⁹ Glannon W, 'Responsibility, Alcoholism, and Liver Transplantation', *Journal of Medicine and Philosophy* 23 (1998) pp31-49

⁴¹⁰ Veatch RM, (2000) *op. cit.*

⁴¹¹ Glannon W, (1998) 'Responsibility, Alcoholism, and Liver Transplantation' *op. cit.* pp31-49

⁴¹² Veatch RM, (2000) *op. cit.* p313

and are deemed to be equally needy, if one of those people had an opportunity to avoid the health problem then they have a weaker claim to well-being⁴¹³. Veatch makes it clear that his argument is not about judging the morality of actions and then punishing wrongdoers, but is instead about holding people responsible for the consequences of their actions when it impacts upon a health care system⁴¹⁴.

Brudney offers a general summary of **Veatch's and Glannon's** positions with the following principle:

An agent is responsible for knowingly, voluntarily, and repeatedly engaging in easily avoidable conduct that might significantly contribute to that **agent's** needing a scarce, lifesaving resource. An agent who is responsible for such conduct may legitimately be given a weaker claim on scarce, lifesaving resources if her need for such resources is due to such conduct.⁴¹⁵

This idea of responsibility aligns well with the NHS constitution, which states that **"You should recognise that you can make a significant contribution to your own, and your family's, good health and well-being, and take some personal responsibility for it"**⁴¹⁶. Taking responsibility does not, however, necessarily entail suffering all of the consequences of it if they can be avoided⁴¹⁷, which is presumably why healthcare under the NHS is not generally allocated according to personal responsibility.

Walker has presented a more detailed and precise argument for treating people differently according to responsibility for illness when resources are scarce⁴¹⁸. He

⁴¹³ *Ibid.* p313

⁴¹⁴ *Ibid.* p313

⁴¹⁵ Brudney D, 'Are Alcoholics Less Deserving of Liver Transplants?', *The Hastings Center Report* 37 (2007) p42

⁴¹⁶ NHS (2012) 'NHS Constitution', Available at: <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/nhs-constitution-interactive-version-march-2012.pdf>, Last Accessed: 31/10/2012 p10

⁴¹⁷ A cyclist might be responsible for getting knocked off their bike, but this does not entail that they should be left in the road to be run over.

⁴¹⁸ Walker T, 'Who Do We Treat First When Resources Are Scarce?', *Journal of Applied Philosophy* 27 (2010) pp200-11

outlines a principle for justifying treating Person A over Person B in cases where they have similar needs, but the following conditions are true of A and not B:

- i) A is ill as a result of a competent, voluntary choice;
- ii) A would not be ill if she had not made this choice;
- iii) A has not adequately attempted to ensure that her becoming ill would not diminish supply of resources (organs in this context) needed to help others;
- iv) Treating A first would decrease the amount of organs available for others;
- v) A could reasonably have known that making this choice could lead to her becoming ill;
- vi) There were realistic alternatives available to Person A at the time she made the choice and these carried less risk;
- vii) Person A could have been expected to know about these alternatives and to know they carried less risk.

Walker argues that, if **all** seven of these conditions are met, it is reasonable to treat person B over person A. This is justified on the basis that if A and B were given **equal priority, then A's taking part in risky behaviour would indirectly put the lives of others at risk** (because taking part in the risky behaviour has a fair chance of using scarce life-saving resources). It seems wrong to think that by choosing to take part in **risky behaviour A is permitted to put other people's lives at risk. Walker's way of resolving this is to give A lower priority than people who have not taken part in the risky behaviour, so that A's actions are not able to deprive these people of a scarce life-saving resource.**

Assuming Walker's argument is theoretically valid, applying it is not straight- forward. First, it is not clear where the causal chain of choices starts. Someone having

their first drink as a teenager may be starting a causal chain leading ultimately towards alcoholism, but it is not reasonable to expect the average teenager to know that this first drink could lead them to become ill in later life. Of the many people who drink alcohol, only 9% of men, and 4% of women in England show signs of alcohol dependence⁴¹⁹. This suggests that drinking alcohol only leads to alcoholism for a minority of people, and the proportion of these people who then require transplants will be smaller still. Consumption of alcohol in moderate quantities is even *recommended* by some studies for its health benefits⁴²⁰, so it is not obvious that drinking alcohol should always be considered risky behaviour. Expecting someone considering their first drink to therefore foresee and consider the possibility of a subsequent need for a transplant seems particularly demanding. If the causal chain is considered to start later, it is not obvious where this should be. It seems unlikely that there is a single point at which one changes from being a non-alcoholic to an alcoholic, or a single drink that pushes a person over the line between not having Alcoholic Liver Disease (ALD) and having ALD. There could, however, be a point at which a person is advised by a health professional to stop drinking because of impending negative health effects. If a person, having been given this advice and knowing the likely health effects, freely chose to continue drinking, then it would seem reasonable to think that this person was responsible for future drinking-related illness.

Although Walker's argument is difficult to apply in some cases, Veatch's and Glannon's arguments, as summarised by Brudney's principle, are easier to apply. It does seem true that many alcoholics have knowingly and repeatedly engaged in easily avoidable behaviour that has led to them requiring a transplant. If the behaviour is also voluntary, then **Veatch's and Glannon's** arguments would entail that alcoholics have a weaker claim to lifesaving resources. There is, however, evidence that genes influence

⁴¹⁹ The NHS Information Centre (2011) 'Statistics on Alcohol: England, 2011', Available at: http://www.ic.nhs.uk/webfiles/publications/003_Health_Lifestyles/Alcohol_2011/NHSIC_Statistics_on_Alcohol_England_2011.pdf, Last Accessed: 31/10/2012

⁴²⁰ Thakker KD, 'An Overview of Health Risks and Benefits of Alcohol Consumption', *Alcoholism: Clinical and Experimental Research* 22 (1998) pp285-98

alcoholism and evidence that alcoholism may result from behaviour learned from role models at a young age⁴²¹, suggesting that this behaviour is not entirely voluntary. Nonetheless, it could be argued that even individuals predisposed towards alcoholism have **some** opportunity to change their lifestyles for the better. Sufficient scope for voluntary decision-making could render individuals responsible for their alcoholism even where there is a genetic or learned component. The question is whether there is sufficient scope at the point that continuing drinking is identified as posing a risk to **one's health, as one may already be in the grasp of addiction and therefore not acting** completely voluntarily. This is open to debate, but there are other good reasons to not permit conditions based upon responsibility for illness.

An objection to these arguments can be formulated based on the proportionality of the consequences. One may concede that people responsible for their condition, all other things being equal, should receive lower priority than people who are not responsible for their condition. There is, however, a need to consider how this should be weighed against other factors when all other **things are not equal**. **Walker's argument specifically refers to two patients with 'similar needs', and it is only** simplistically true that people on transplant waiting lists have similar needs. They all need a transplant, but the degree of need varies from patient to patient. For example, if patient A (a recovering alcoholic) requires a transplant within 24 hours, and patient B (someone with genetically-caused liver failure) can wait without immediate risk to his life for several months for a transplant, they have quite different levels of need. Patient A could be considered to need **that** organ, whereas patient B can wait for another to become available. It would be wrong to give patient B priority over A in this instance simply because A is responsible for his illness; if responsibility is to be taken into account, it is just one consideration amongst many. Similarly, if patient A **has** been on the waiting list for twice as long as patient B, and A still has much better expected

⁴²¹ Veatch RM, (2000) *op. cit.* p317

transplant outcomes than patient B, it would not seem obvious that B ought to get priority over A. If B did get priority over A, efficiency would be compromised, as would the fairness criterion of waiting time. Placing a condition to exclude alcoholics from receiving a particular organ would make responsibility an exclusion criterion, and this goes beyond the tie-breaking factor in 'all other things being equal' situations that the above arguments support. Such a condition introduces an irrelevant criterion into allocation, but it would be giving a relevant criterion too much weight, which could be considered to be just as bad, because it means that the other relevant criteria are denied the weight that they ought to be given.

For some participants there was a related concern that introducing moral judgments into medical decisions is not right when the stakes are so high. While medical decisions do contain moral content, it could be argued that introducing backward-looking considerations into allocation is wrong. There appeared to be a concern that it is somewhat cruel to say to someone who needs a transplant that because they have caused their own condition they will receive lower priority than people who may need a transplant less urgently⁴²². Some participants in the study were sympathetic towards alcoholics, and suggested that people should not be punished for something that ultimately may have come about through only one or two bad decisions in the past. These participants thought that people deserve a second chance in life, and that a liver transplant could be just what is needed for an alcoholic to turn her life around. **This finding corresponds roughly with Tong's systematic review, which found** that some participants thought that no matter what the cause of the illness, everyone deserves a chance⁴²³. This perception of transplantation as a second chance perhaps expresses an attitude that transplantation allocation exists to best satisfy need rather

⁴²² One may argue that it is also cruel to remove very seriously ill people from transplant waiting lists, or to exclude some cancer patients from transplantation, but this could be considered in the best interests of those patients insofar as transplantation would no longer be deemed a suitable treatment for them. Transplanting someone with little chance of post-transplant survival could be considered to be putting a patient through an inappropriate treatment. Similarly, transplanting cancer patients introduces additional complications for that patient because of the need for immunosuppressant medication.

⁴²³ Tong A et al., (2010) *op. cit.* pp796-805

than to judge people's reasons for that need. Glannon, Veatch and Walker could all deny that their arguments entail judging the moral status of the actions that caused the need for a transplant, but refusing to help someone in need because of some bad decisions they have made does deny them the opportunity to learn from their mistakes.

According to Johri and Ubel, some research suggesting that members of the public think "people with controversial behaviours are simply less deserving of scarce transplantable organs"⁴²⁴ reflects prejudice rather than morally defensible argument. They go on to state that public attitudes that are a result of prejudice deserve no place in transplantation policy, as they do not express considered moral judgments⁴²⁵. Participants in the embedded study did not overtly appear to be seeking to punish people for controversial behaviour, and seemed keen to hold people responsible for their behaviour only when it was absolutely certain that they were responsible. There was a tendency to single out alcoholics and drug users, and whilst this may superficially suggest a desire to punish behaviours that society deems less acceptable it might equally be because these are obvious examples that are known to have long-term health implications. Elsewhere it has been suggested that attitudes vary according to the nature of the behaviour. Risky behaviour that is generally approved of is treated differently from risky behaviour that is not approved of⁴²⁶. For instance, choosing to become pregnant carries risks, yet it seems unlikely that people would favour lower priority for people with complications arising from pregnancy. Someone who showed some symptoms of illness but who was scared of visiting their GP could also be considered responsible for their condition if their condition significantly worsened as a result of them delaying treatment. This shows that sometimes there are other factors that lead one (still voluntarily) towards risky behaviour, and that these may make it unreasonable to hold someone responsible for their behaviour. The fact that

⁴²⁴ Johri M and Ubel PA, 'Setting Organ Allocation Priorities: Should We Care What the Public Cares About?', *Liver Transplantation* 9 (2003) p879

⁴²⁵ *Ibid.* p879

⁴²⁶ Wikler D, 'Personal and Social Responsibility for Health', *Ethics & International Affairs* 16 (2002) p52

participants in the embedded study chose to focus on certain obvious risky behaviours suggests that there is a chance that certain behaviours could be singled out, while other risky behaviours are overlooked. If responsibility is viewed as a valid allocation criterion, it ought to be consistently applied⁴²⁷. Relying on conditional donations to enforce allocation according to responsibility would likely result in the principle being inconsistently applied, which could result in arbitrary unfairness.

Argument from effectiveness

The effectiveness argument, in contrast to the moral one, is somewhat simpler. It is, at this stage, important to acknowledge that some form of filtering happens before organs are allocated. Potential recipients who require a transplant due to behaviours such as excessive drinking or intravenous drug use will only be accepted onto, and continue on, transplant waiting lists if they abstain from drinking/drug-use, and are regularly tested for compliance. Some participants, however, appeared to be unaware of this and viewed conditional donation as a means of preventing those who may damage or destroy their transplanted organ from receiving one. Current listing practice, however, renders such conditions redundant, because they have already been applied. This is perhaps a situation where donors and their next-of-kin *ought* to defer to the expertise of medical staff in determining which potential recipients are suitable, and where transplant staff ought to inform the next-of-kin that organs are not allocated to alcoholics who cannot commit to abstinence. The fact that certain people are excluded from receiving transplants suggests, however, that the desire to exclude alcoholics who are still drinking is not morally *objectionable*⁴²⁸ just unnecessary.

Most participants' views were suggestive of concurrence with the argument from effectiveness. In contrast, although many participants thought that, in principle, people

⁴²⁷ The NHS could potentially have a consistent policy that judged some risks to be acceptable or non-acceptable, but there would obviously be some disagreement over what activities would fall into which category.

⁴²⁸ Or if it is, so too are current listing practices.

who are responsible for their own condition are less deserving of transplants, very few were in favour of this being factored into allocation policy.

The arguments in favour of allocating organs according to responsibility, although theoretically valid, are difficult to apply in practice, and leave open the question of how much weight responsibility ought to carry in allocation decisions. They suggest that responsibility should carry some weight, but not ultimate weight. The important question is whether there are good reasons to allow conditions based upon responsibility. On the basis of other research⁴²⁹, it does seem likely that only certain types of illness would be the focus of conditions like this. A condition specifying a preference that those responsible for their illness should receive lower priority would not necessarily be objectionable, but a condition specifying that only alcoholics or drug users should receive lower priority could be arbitrarily targeting certain behaviours. Moreover, it may be difficult to establish causal responsibility and voluntariness in many cases, which could again mean that certain behaviours where responsibility was more clear cut would be unfairly targeted.

10.1.3 Family Partiality

Many participants in this study, like those who objected to the decisions made in the Laura Ashworth case⁴³⁰, believed that it was acceptable to direct an organ towards a family member or a close friend. The reasons for this were:

- i) blood is thicker than water;
- ii) you have to look after your own first;
- iii) you do things for your family or friends that you would not do for others.

Neuberger and Mayer reported that 36% of their respondents thought it was very/fairly acceptable to request that a liver is only given to a family member and not

⁴²⁹ Ubel PA et al., (2001) 'Allocation of Transplantable Organs: Do People Want to Punish Patients for Causing Their Illness?' *op. cit.* pp600-07

⁴³⁰ BBC News (2008) 'Mother Denied Daughter's Organs', Available at: <http://news.bbc.co.uk/1/hi/england/bradford/7344205.stm>, Last Accessed: 31/10/2012

to anybody else on the waiting list (even though the family member may not be top of the list); 24% thought that it was not very acceptable, and 26% thought it was not at all acceptable⁴³¹. In the Neuberger and Mayer study, the donation would only go ahead **if the direction was granted, so was 'iff conditional', which may explain why only a minority of participants in that study thought that it was acceptable.**

The three reasons outlined above tend to support slightly different arguments relating to directed/conditional donation to family members.

10.1.3.1 Blood is thicker than water

The claim that **'blood is thicker than water', although largely rhetorical**, suggests that ties between family members are more important (or literally, one supposes, stronger) than the ties between strangers. This could be interpreted as a lay appeal to familial partiality, and although it does not itself possess any real justificatory power, it suggests that participants consider there to be **something** special about family members that does not apply to strangers. This, then, leads to two more detailed arguments.

10.1.3.2 Looking after your own first

The idea of **'looking after your own first', could be used to formulate an argument in favour of a request for directed allocation, roughly akin to policy since March 2010. One might express a preference that one's relative is given priority for a transplant, but if the organ is not compatible then other people are given an opportunity to receive it⁴³². Slightly more tenuously, this type of reasoning could be linked to someone agreeing to donate the rest of their organs unconditionally if one of the organs is transplanted to their relative; a donation such as this may effectively communicate 'once my loved one has been looked after, you can give the other organs to whoever you like'. The idea of**

⁴³¹ Neuberger J and Mayer D, (2008) 'Conditional Organ Donation-the Views of the UK General Public Findings of an Ipsos-Mori Poll' *op. cit.* pp1545-47

⁴³² This may seem an obvious position for someone to take, but there was a case where the next-of-kin was initially adamant that the organ could **only** be donated if it was transplanted to him: Neuberger J and Mayer D, (2008) 'Conditional Organ Donation-Case Scenarios and Questions' *op. cit.* pp1527-29

prioritising your own loved one's interests can be justified on the grounds of Cottingham's philophilic partiality⁴³³.

Hilhorst writes specifically about the parallel living and deceased Dutch donation systems, but due to largely similar systems his comments will also apply to the UK. He suggests that **"it is hard for many people to understand why they are allowed to donate to a relative before they die but not afterwards"**⁴³⁴, something which many participants in this study also thought. Hilhorst suggests that turning down requests for directed allocation of organs to family members (offers that he considers to be morally decent) **harms "partial values"**⁴³⁵ because it calls into question the meanings of personal loyalty and relationships. Interestingly he also suggests that prohibiting these donations may **harm impartial donations as well, if doing so reduces people's willingness to donate** organs after death. To establish the validity of this concern would require empirical evidence, but it is at least plausible.

Ankeny suggests that directed donation to a family member can be considered admirable even after death⁴³⁶. According to Ankeny, a directed donation towards a **family member would reflect a personal preference that would not "corrupt the egalitarian basis of utilitarianism"**⁴³⁷ because these sorts of preferences are *generally* **deemed to be appropriate. Moreover, given that it is morally correct to favour one's** own in some circumstances, then any policy prohibiting conditional/directed donation to family or close friends could be standing in the way of people doing the right thing with their organs. The question remains, however, of whether organ donation *is* one of the **circumstances in which it is permissible to favour one's own loved ones, and if so, how** much weight one can give to this. Ankeny states that it is such a situation, and makes

⁴³³ Cottingham J, (1986) *op. cit.* pp357-73

⁴³⁴ Hilhorst MT, "Living Apart Together": Moral Frictions between Two Coexisting Organ Transplantation Schemes', *Journal of Medical Ethics* 34 (2008) pp484-88

⁴³⁵ *Ibid.* p485

⁴³⁶ Ankeny RA, (2001) *op. cit.* p392

⁴³⁷ *Ibid.* p392

this basis on the claim of accepted practice in living donation⁴³⁸. It would certainly take a staunch impartialist to assert that one ought, if faced with the prospect of saving a family member or a stranger, to not give additional weight to the family member.

Cottingham's claim for partiality is that "unless one is under a direct or indirect duty to be impartial, it is morally correct to favour one's own"⁴³⁹, and it is difficult to see why **one would be under a duty to donate one's organs impartially** after death.

10.1.3.3 Doing for family what one would not do for others

At present, policy only permits deceased directed allocation towards family members or close friends, and does not permit truly conditional donations featuring these requests: request can be ignored if there is someone who urgently requires a transplant. Using the **line of argument that one does things for one's family that** one would not do for others, one could make an argument for changing the March 2010 guidance to also accept iff conditional donations. If organ donation is considered by an individual or their next-of-kin to be particularly burdensome (for whatever reason) then they may only be prepared to accept this burden to benefit specific people. The conditionality on which living donation is often based is not considered offensive, so it is inconsistent that it is considered problematic within deceased donations. One possible justification of the **March 2010 guidance's refusal to allow truly conditional donations to family members** is that the DH wanted to incorporate family partiality into deceased donation without setting a precedent for permitting conditional donations more generally. As established in Chapter 5, there is nothing inherently non-altruistic or ethically unacceptable about conditionality, especially not when conditions represent philophilic partiality. If it is acceptable for donors to request that their organs are directed towards a family member over other needier people (i.e. to circumvent standard medical allocation of organs), the added aspect of conditionality does not make the situation any less acceptable.

⁴³⁸ *Ibid.* p392

⁴³⁹ Cottingham J, (1986) *op. cit.* p358

These arguments have suggested that conditional donations to family members should be accepted, and it would be reasonable to extend this to friends with whom one has particularly close relationships. In a departure from current policy, it has been argued that there is nothing inherently objectionable about a iff conditional donation to a family member or close friend.

10.1.4 Section conclusions

The arguments for allowing donors to place conditions giving children priority are not convincing. Although children are already given priority in some situations, there are good medical reasons for this, and these are quite distinct from the arguments put forward by participants. Conditions relating to priority for children, then, cannot be justified on the basis of the condition content.

Allowing donors to specify conditions based on responsibility for illness is also problematic. As well as a practical difficulty in establishing whether the specified behaviour cited in the condition is truly causally linked to a need for a transplant, the arguments provide limited guidance over how things should be weighted when all other considerations are not equal. The arguments may be applicable in tie-breaking situations, but this does not entail that conditions based upon responsibility are acceptable.

In contrast, there are very good reasons to permit directed donations towards family members. In a departure from current policy, however, there seems little reason to not also permit iff conditional donations towards family members. The principle of unconditional donation lacks justification once the greatest need principle is relaxed. It therefore fails to provide a reason to prohibit truly conditional donations to family members.

This section has examined new lines of argument that were put forward by participants. It has been argued that most of these arguments cannot withstand

scrutiny. Although this means that these arguments have not directly impacted upon the final recommendations, they have been given the fair consideration described in Chapter 1.

10.2 Life-Saving and Avoiding Waste

The previous section has looked at specific conditions and whether there are good reasons for accepting these donations on the basis of the condition content. This section will build upon the philosophical discussion in Chapter 7, where it was argued that there are good reasons to accept conditional or directed donations regardless of their content. The following discussion will draw on data from the embedded study that supports the arguments in Chapter 7. It will be argued that the arguments in favour of accepting conditional donation in Chapter 7 are supported by the views and reasoning of participants, and this provides a strong and practically applicable argument in favour of accepting conditional donations.

10.2.1 Avoiding Waste

The concept of negative loss was introduced in Chapter 6, where it was defined as a loss of benefit for somebody without a corresponding increase in benefit for somebody else. Participants in this study, rather than referring to negative loss, tended to talk about wasting organs. The idea of waste is closely linked to negative loss, and was used to make two points:

- i) allocating organs to people who will not look after them is a relative waste
- ii) turning away organs that could be used is an absolute waste

These will now both be examined in detail.

Allocating organs to people who will not look after them is a relative waste

The first way that organs could be wasted is by allocating them to recipients who will not look after them. There is an assumption here that the recipient is likely to damage the organ, and not make the most of the potential benefit that it could provide. This would not be an absolute waste, as some benefit may still be gained from the transplant, but the benefit would not be as great as if the organ had been allocated to someone who lived in such a way as to maximise the life of their graft. Safeguards

already exist to exclude from listing anyone who is engaging in behaviour likely to damage their future graft, so there is some protection against relative waste factored into policy.

Relative waste could be defined as the difference between the good that an organ could provide if it was allocated in order to maximise its use, and the good that the organ provides when it is allocated according to current criteria. Wastage, defined like this, may be deemed necessary in order to promote fairness. Generally, organs are allocated to the sickest recipients first, as this is a way to minimise the number of people who die on the waiting list. This may result in sub-maximal transplant outcomes, but it means that fewer people die while waiting, which seems desirable⁴⁴⁰. Many participants thought that the most important aim of transplantation should be saving lives. There was support for the idea that saving lives is a consideration that can trump others. If relative waste is construed as a failure to maximise potential transplant benefit, and it is generally desirable to avoid this, then a good reason is necessary to not allocate solely according to transplant benefit. Saving lives can provide this reason⁴⁴¹. Tying this conception of waste into conditional donation reveals two different lines of argument. In principle, someone could place a condition specifying that their organs should only be allocated according to best predicted transplant outcomes. Here conditional donation would be contributing to the avoidance of relative waste by achieving maximum transplant benefit. Conversely, however, they can also generate relative wastage. A condition specifying that recipients must only be white could result in people with better predicted transplant outcomes being excluded from receiving those organs. Bearing in mind that safeguards are already in place to ensure that organs are not allocated to people whose behaviour is are likely result in relative

⁴⁴⁰ Veatch RM, (2000) *op. cit.*

⁴⁴¹ Indeed it could be argued that using a life-saving resource to improve the life of someone who is not in immediate danger of death is a waste of a life-saving resource.

waste, it seems likely that allowing conditional donations would cause more of *relative* wastage than it would prevent.

Just as allocating an organ to somebody may be a relative waste, there may be some threshold at which it should be deemed an *absolute* waste to allocate an organ to somebody. Currently liver transplantation is only generally considered as a treatment option where there is at least a 50% chance of survival beyond 5 years post-transplant⁴⁴², which suggests that the medical profession thinks that allocating an organ to anybody with less than a 50% chance of 5 year survival is a poor use of organs. It seems probable that organs are donated by people in the expectation that they will be used effectively, and allocating an organ to someone with a predicted a low QALYs score could be considered a relative waste of that organ. The threshold at which an allocation is considered to be an absolute waste is obviously open to debate, however, and could vary from organ to organ and situation to situation⁴⁴³.

10.2.2 Turning away organs is a form of absolute waste

Many participants thought that turning away medically useable organs when they could be used to save or improve lives was an absolute waste of a valuable resource – the failure to use the organs *at all* to save life. By itself, the view that refusing organs constitutes waste does not provide an argument for accepting conditional donations. As discussed, *relative* waste may be a necessary by-product of maintaining other principles. Nonetheless, in the non-staff groups particularly, participants felt it desirable to avoid absolute waste and thought this could be achieved by accepting the conditional donation.

⁴⁴² NHSBT (2007) 'UK Liver Transplant Group Recommendations for Liver Transplant Assessment in the Context of Illicit Drug Use', Available at: http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/pdf/uk_liver_transplant_group_recommendations_for_liver_transplant_assessment_illicit_drug_use-2007.pdf, Last Accessed: 31/10/2012

⁴⁴³ A poor quality organ could potentially be used to 'tide over' a recipient until a better quality organ became available. Although the QALYs gained from that particular organ could be low, it is not obviously a waste.

Turning away organs with conditions attached is a clear example of negative loss. Somebody loses the benefit (primarily the person(s) who would have received the organ(s) according to the conditions, but also everybody else on the waiting list), and there is no directly corresponding gain for anybody else⁴⁴⁴. The non-staff participants in this study were generally keen to avoid this negative loss, and this was particularly true amongst the potential recipient group.

10.2.3 Flexibility avoids absolute waste

To prevent absolute waste, some participants suggested that the NHS should take a more flexible approach to conditional and directed donations. In particular, some participants suggested that transplant staff could look at the transplant waiting lists and see what the impact of accepting the donation would be – for instance, to establish whether following the condition would deprive someone at the top of the waiting list of **an organ. This solution would be contrary to the DH Panel’s 2000 report, which stated** that conditional donations are unacceptable regardless of the implications in terms of allocation.

The willingness of the participants to endorse this suggests that although many conditional donations can be considered bad, wasting the organs would be even worse. **Few people thought that saying ‘I will only donate if...’ was** completely unacceptable, possibly because it is still an offer of a life-saving resource. Conditional donations may (but do not always, as in the 1998 case) offend against the principle that organs are allocated according to medical need, but many of the participants felt it better that organs were allocated contrary to this principle than refused and absolutely wasted.

If the impact of the conditions is taken to be important, then some consequences must be considered acceptable and others not. An obvious candidate for

⁴⁴⁴ One might argue that the system gains benefit from remaining fair and keeping its hands clean, but this would not be a corresponding gain in benefit. This would merely be the avoidance of a *loss* of benefit (and it was argued in Chapter 7 that the loss of fairness is outweighed by the gain in organs): the transplant system would be no fairer than before the conditional donation was offered.

an acceptable consequence would be if the conditions made no difference to organ allocation (as in the 1998 racist case). Unacceptable consequences may include the most urgent candidates being excluded from receiving those organs and dying as a result (although these patients would also die if the donation was refused), and loss of fairness in allocation as a result of this. Excluding the most urgent candidates and introducing unfairness into allocation are certainly *prima facie* undesirable consequences, but further consideration will show them to be the best available consequences in some circumstances. A donation that has to be allocated according to non-medical constraints and excludes the most urgent potential recipients is not ideal. If the NHS is offered a conditional donation, it is faced with a choice: accept the donation and help some people (even though this may be unfair), or turn down the donation and help nobody. Turning down the donation may preserve fairness, but it would be an instance of levelling down.

10.2.4 Accept any donation – regardless of condition

By looking at waiting lists and assessing the likely consequences of accepting specific donations with conditions attached, the positives and negatives of accepting the donation in a particular situation can be best assessed. There is, however, a sense in which the positives and negatives are relatively fixed. One obvious positive is that if the donation is accepted, some people will receive transplants and lives can be saved or improved. One obvious negative is that the organs may be allocated in a way that is unfair, unjust or otherwise undesirable. If this positive can, on the basis of reasonable background assumptions, be taken to outweigh this negative in all cases, then this provides a reason to accept any conditional donation. The negatives of accepting conditional donations will be discussed in the final section of this chapter, but it will be argued that they are unlikely to outweigh the positives.

Levelling down was discussed in Chapter 7, where it was argued that levelling down is, in some situations, the wrong thing to do. In particular, it was argued by

analogy with drowning children in a swimming pool that refusing life-saving offers is wrong, even if the offer is only to save **some** lives (even if the motivation behind the choice of lives saved is morally wrong). Applying this to conditional organ donation is straight-forward. To turn away a conditional donation is to turn away a life-saving resource. Even if it is the case that the organ can only help some people, it is better to help these people than nobody. This argument should be convincing by itself, but there is an added argument in favour of accepting conditional donations. **Everybody** on the waiting list receives some benefit, so even though the primary benefit may be distributed unfairly, even those who are treated unfairly are better off than they would have been if the organ was turned away. The person who receives the organ is better off because they have received an organ, and the people behind that person on the waiting list all move up a place so are also better off. Even the people above the actual recipient on the waiting list are better off, since it is better to have fewer people competing for available resources.

10.2.5 Avoiding waste may cause waste

As discussed, waste can be thought of in two ways – relative and absolute. A consequence of accepting conditional donations is that donated organs could be allocated contrary to standard medical criteria, and this may result in sub-optimal transplant outcomes which can be construed as relative waste. Avoiding absolute waste by accepting conditional donations and allocating according to the conditions may therefore cause some relative waste. This relative waste, however, in each individual case, is less than the absolute waste involved in turning a donation down (since it is a loss of **some** benefit rather than **all** benefit). If only a minority of donations were conditional, then accepting them would prevent more waste than it caused.

10.2.6 Section Conclusions

This section has built on the discussion in Chapters 6 and 7, where the ideas of negative loss and levelling down were introduced. Accepting conditional donations in

the interests of avoiding waste, negative loss and levelling down was supported by many participants. Although accepting conditional donations and allocating according to the conditions forces a deviation from the usual principles of allocation, and is not an ideal situation, the alternative is to refuse to accept the organ, meaning no allocation is made to anyone. Saving or improving lives was more important to most participants than maintaining a rigid allocation system based on current principles. A similar argument was proposed in Chapter 7, which suggested that when the consequences of levelling down are that people die, saving lives provides a good reason to avoid levelling down. It is therefore argued that, in the light of some **participants' views**, regardless of the actual content of the condition, all conditional donations should be accepted. Other views of participants have raised some concerns about this proposal, however, and these will be discussed in the next section.

10.3 Concerns and Barriers

It has been argued in Chapter 7 that avoiding levelling down and negative loss can justify accepting any conditional donation, even if the content of the condition is morally objectionable. The previous section in this chapter discussed this in light of **participants' views on waste, and made the same proposal: conditional donations ought to be accepted regardless of the specific condition.** This is a bold claim, and contrary to existing policy and practice. The acceptability of this argument to stakeholders has to be carefully considered. Participants in the embedded study raised a number of concerns about conditional donations that need to now be considered in light of the proposal to accept all conditional donations. Each concern will be considered as a potential barrier to permitting conditional donations, and will be assessed to establish whether it is insurmountable. It will be argued that although some of the concerns suggest measures need to be taken to minimise the potential negative implications of conditional donations, they do not provide compelling reasons to prohibit conditional donations.

10.3.1 Recipient views: avoiding negative loss and queue jumping

An initial potential concern is the views of potential organ recipients. These are ultimately the people who would be offered conditional donations, so it is important to establish how they would view them. It was argued in Chapter 6 that avoiding negative loss can be in the interests of recipients, since it can be said to improve efficiency. Prioritising the avoidance of negative loss would entail a form of queue-jumping, and some potential recipients may object to this. Although avoiding negative loss may appear desirable to a neutral bystander, there may be other concerns for people who **are waiting for organs. The results of this study suggest that recipients' views regarding conditional donations were mixed.** When asked how they would feel if they were offered **an organ that had been conditionally donated recipients' views varied from a feeling that it would be unfair (PR9), to a feeling that one would have to accept it but**

potentially feel selfish and less deserving (PR1), to simply not caring (PR3). Most potential recipients were keen to avoid absolute waste, but this was not universal.

The fact that there was not universal support amongst participants does not necessarily act as a barrier to conditional donations, but does suggest that some recipients personally think that fairness is still an important consideration, possibly more important than avoiding negative loss. This may seem like a barrier to permitting conditional donations, but could be handled as a matter of personal choice. Potential organ recipients are currently permitted to exclude themselves from receiving certain organs⁴⁴⁵, and could add organs which have been offered conditionally or organs with specific conditions attached that they find objectionable to this list. They would need to be free to reconsider their position periodically, as their state of health may change and have an impact upon their willingness to accept some organs. There is, of course, a question about whether recipients would need to be told about conditions placed upon organs that they received. One participant (PR1) thought that it would just be another thing for recipients to worry about and that additional worry was something that they could do without. Most other potential recipient participants seemed to assume that they would have to be told about any conditions. Assuming donor anonymity could be preserved, there would seem to be little harm⁴⁴⁶ in giving potential recipients the choice about whether they were willing to receive organs with specific conditions attached.

10.3.2 Slippery Slope

Nearly all the participants were concerned that accepting some conditions or directions would be a slippery slope towards accepting *all* conditional or directed organs. Some

⁴⁴⁵ Some organs retrieved from marginal donors carry an increased risk of complications or failure post-transplant. Patients are able to request that they are not offered organs according to certain risk factors. NHSBT (2011) 'Guidelines for Consent for Solid Organ Transplantation in Adults'. Available at: http://www.nhsbt.nhs.uk/pdf/guidelines_for_consent.pdf, Last Accessed: 31/10/2012

⁴⁴⁶ **Aside from an additional psychological burden of having to choose whether or not to accept a 'morally dubious' donation.**

participants were worried that even allowing the seemingly morally acceptable directed donations as specified in the March 2010 policy revision would be the start of the slippery slope leading to less acceptable donations.

There are two ways of viewing this. First there is the logical slippery slope⁴⁴⁷, that accepting **some** seemingly acceptable conditional/directed donations logically implies accepting **any** (however objectionable) conditions. As chapters 3-7 have argued, however, not all conditions are equal. For instance, the partiality displayed between family members is justifiable and acceptable in some instances of organ donation, whereas the partiality displayed between members of the same race is not. The differences between these donations mean that it is logically consistent to permit donations that display familial partiality and to prohibit donations that display racist partiality.

The second way of looking at the slippery slope, called the empirical slippery slope⁴⁴⁸, uses an empirical claim that permitting some seemingly acceptable conditions or directions does not **necessarily** lead to more objectionable conditional donations being accepted, but that it **probably** would. For instance, permitting directed donation to family members may result in directed donation to friends being considered acceptable and then to friends of friends, and so on. In due course, directed donation to strangers of the same race could potentially be permitted, as the concept of conditional donation becomes more familiar and routine. The validity of the empirical claim is difficult to ascertain without actually trialling conditional and directed donations, but recent developments in living donation suggest that there is some basis for thinking it may be correct. Over the last few years the HTA has gone from only permitting living related (or friend of longstanding) donations, to also allowing altruistic donations to strangers. Recently it has been considering the implications of allowing more remote or

⁴⁴⁷ Van Der Burg W, 'The Slippery Slope Argument', *Ethics* 102 (1991) p44

⁴⁴⁸ *Ibid.* p51

less substantial relationships to count as qualifying relationships, and this has included friends of friends, or Facebook friends who have never met outside of the virtual world⁴⁴⁹. While this could be the result of reasoned thought, and is not *necessarily* a slippery slope, it does suggest that the boundaries of what is considered acceptable can have a tendency to expand.

While participants in the study were concerned about slippery slopes, their concerns were based on the premise that some conditions are more acceptable than others, and that allowing some conditions may lead to less morally acceptable ones also being permitted. It has been argued in this chapter, however, that there are good reasons to allow *any* condition so long as it results in organs being donated that otherwise would not be. In effect, what some people considered the peril at the end of the slippery slope (accepting objectionable conditions) must now be considered at the top of another slippery slope. This therefore raises the question of what the perilous consequences of accepting *any* condition could be. An undesirable scenario that could occur if all conditional donations were permitted is that the majority of those who would otherwise have donated unconditionally now donate conditionally making most or all donations conditional. This could reduce access to organs for certain types of people, cause a loss of faith in the transplantation system and result in fewer organs being donated. Although it is not clear that this would happen, it is certainly something that requires consideration - accepting conditional donations has the potential to have negative consequences as well as positive ones, so careful data monitoring would be required to detect changing patterns of donation at the earliest stage. If conditional donation looked likely to result in largely reduced transplant efficiency, then the reason to permit it would be undermined.

⁴⁴⁹ Human Tissue Authority (2011) 'Review of the Year', Available at: <http://www.hta.gov.uk/newsandevents/htaevents.cfm/993-Public-Authority-meeting-and-review-of-the-year-2011.html>, Last Accessed: 31/10/2012

In summary: the logical slippery slope argument against conditional and directed donation does not provide a sound argument against permitting at least some forms of conditional and directed donations. A potential slide to the overwhelmingly frequent conditional donation is at least plausible, but a lack of empirical evidence makes it difficult to assess this risk. The potential threat does, however, provide a reason to carefully monitor the impact that conditional donations have if it is thought that they may result in widespread undesirable patterns of allocation.

10.3.3 Conditions arise from lack of understanding

Many participants, particularly transplant staff, thought that conditional donations generally arise due to a lack of understanding about organ donation and allocation. When asked how transplant staff should handle conditional offers of donation, it was often suggested, by all types of participant, that transplant coordinators should counsel the family and explain how organ allocation works, and why it is important that organs are donated unconditionally. Many staff participants thought that doing this would help donor families to see why conditional donations are undesirable (see Chapter 7) and would help them to change their mind and donate unconditionally. This would be a way to avoid both absolute and relative waste without compromising other principles, which on the face of it would be preferable to accepting conditional donations.

Some staff felt that nobody in possession of full knowledge about organ allocation would want to donate their organs conditionally. Whether this is true is not known. Certainly, lack of knowledge and understanding of organ donation, allocation and transplantation has often been suggested as a key factor in people choosing to not donate their organs⁴⁵⁰. Campaigns aimed at segments of society with relatively low donation rates have traditionally focussed on raising awareness and providing information. Clearly *some* conditions may reflect a lack of understanding about organ

⁴⁵⁰ Morgan S and Miller J, 'Communicating About Gifts of Life: The Effect of Knowledge, Attitudes, and Altruism on Behavior and Behavioral Intentions Regarding Organ Donation', *Journal of Applied Communication Research* 30 (2002) pp163-78

allocation, for instance individuals excluding alcoholics on the basis that alcoholics would waste the organs may not be aware that unreformed alcoholics are already excluded from the transplant list. In this case, explaining the listing process may persuade the donor/donor family to donate unconditionally, which would be the ideal situation.

Not all conditions, however, necessarily stem from a misunderstanding of the process, and the specific examples mentioned at the start of this chapter illustrate this. Wanting to prioritise people who are not responsible for their illness, for example, need not arise from a misunderstanding of organ allocation, and may instead represent an **individual donor's views on responsibility**. Explaining organ allocation processes in this instance may have no impact on their wishes. Similarly, deeply-held racist beliefs are unlikely to be challenged by more information or education about organ donation and there may be little that could be done to convince them to donate unconditionally. Convincing racists of the wrongs of their fundamental belief, which may be what it takes to change their views, is not the responsibility of transplant staff⁴⁵¹.

The extent to which transplant staff ought to try to convince donor families to change their mind about donating conditionally raises its own difficulties, as there is a fine line between persuasion and coercion⁴⁵². Elsewhere it has been stated that "persuasion aims to enlist the patient's reason by providing information and coercion aims to manipulate the patient's decision by influences which undermine independent reasoning"⁴⁵³. If handled sensitively and with compassion, it would seem reasonable for transplant staff to at least explain the reasons why unconditional donation is generally desirable and to correct any obvious misunderstandings about organ allocation.

⁴⁵¹ Indeed it could be contrary to the NHS constitution: "We value each person as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits. We take what others have to say seriously" NHS (2012) Available at: <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/nhs-constitution-interactive-version-march-2012.pdf>, Last Accessed: 31/10/2012

⁴⁵² It also raises questions about the role of SNODs and whether their overriding concern/loyalty should be to the donor and donor family or to transplantation more generally.

⁴⁵³ Gillett GR, 'Informed Consent and Moral Integrity', *Journal of Medical Ethics* 15 (1989) p118

Although unconditional donations may be desirable, this outcome has to be balanced against the potential for causing additional distress to individuals who are already in emotionally taxing circumstances. If the next-of-kin are, having been given additional information, unwilling to donate unconditionally, then the conditional donation ought to be accepted.

10.3.4 Furthering Wrongful Ends

Chapter 7 explored whether in accepting condition and directed donation, the NHS may be furthering wrongful ends. Participants did not explicitly mention wrongful ends, but some participants were concerned that the NHS could be *perceived to be 'getting its hands dirty'* if it became involved in conditional donations.

If the NHS accepts a conditional donation and facilitates the discriminatory wishes of a racist, for instance, it would be furthering a wrongful end, insofar as it is **active in manifesting a racist outcome**. One could argue that in order to 'keep its hands clean' the NHS ought to reject such a donation but it should be borne in mind that in doing so the racist donor's wishes are still partially fulfilled: turning down the donation also means that members of the undesirable-to-the-donor race do not receive those organs. The racist donor has deprived a certain race of a transplant, and the NHS has ensured that **every** race has been deprived of a transplant. In effect, as soon as a conditional donation has been offered, the NHS is placed in a position where it has to act. Not accepting a donation *is* still acting – it is not merely an omission – so the NHS must consider the consequences of doing so. One might argue that if a conditional donation is accepted, the NHS has to then do more to further the wrongful ends – the wrong is not specifically in the acceptance, but instead lies in allocating organs according to the conditions (assuming that the conditions are morally wrong). However, if the condition was formulated in a negative sense (the donation will go ahead on the condition that people of type x are not allocated the organs), turning away the donation ensures that the condition is still met. This unwanted effect may provide an additional

reason to further the wrongful end by accepting the donation. If a wrongful end is going to be furthered regardless of whether the donation is accepted or not, then it is reasonable to choose the course of action that also brings about the most good.

Permitting conditional and directed donations could introduce unfairness into the allocation process, but it would not be NHSBT introducing it – rather it would be the individuals placing the conditions or directions. One participant commented that **‘decisions are made on the basis of what your options are’ (PD6), and although it is** obvious, it also makes a useful point. If the NHS was to accept a donation with some objectionable conditions attached to it – racist conditions, for instance – and then allocated the organs according to the conditions, should the NHS be considered to be **racist? Certainly the donor’s wishes** may be, but as far as the NHS is concerned, this could just be considered a narrowing of options. Sometimes organs are only medically suitable for certain recipients. If an organ is donated that, by virtue of tissue-matching, is only suitable for people of a certain race, the NHS would not be acting partially or unfairly if it allocated the organ to somebody of that race. The allocation to a certain race would be because of the nature of the organ. Similarly, conditions attached to a donation could be considered to change the nature of the organs. There is agency involved in the placing of racist conditions, whereas there is not in tissue-matching, but **the agency is the donor’s or next-of-kin’s** – the NHS is would merely be allocating according to the options available to it with that specific organ.

If the NHS allocates according to the options available, it is bringing about the best outcomes from a non-ideal situation. There is, quite clearly, the possibility that the **NHS’s actions could be wrongly interpreted by the public. If its reasons for accepting** conditional donations are clear, it distances itself from the objectionable aspects of the donation, and it has made reasonable attempts to obtain an unconditional donation, it would be unfair to accuse the NHS of acting in a racist or otherwise discriminatory way.

Although the NHS can legitimately claim to have 'clean hands', it is likely to have to take active measures to make this clear to the public.

10.3.5 Staff views on waste

Staff participants' viewed waste and life-saving slightly differently from non-staff participants. Although they still generally thought that it was a shame that medically useable but conditional donations might be refused and absolutely wasted, many viewed this as being necessary in order to preserve the integrity of the system. One participant said:

our society at the moment is prepared to pay the price of losing the occasional organ in this situation because of the, you know, the greater good and the overriding principle [greatest need] – TS3

Whether occasionally turning away donated organs serves the greater good is open to speculation; it seems *prima facie* mistaken to think that turning away a rare and potentially life-saving resource can be good at all, but the broader impact of accepting conditional donations is unknown⁴⁵⁴. The medical needs of those who require transplants may be better met, in some circumstances, by accepting donations that **would otherwise be turned away. Despite this participant's assertion that society is** prepared to pay the price of losing occasional organs, many other participants considered this to be waste and not a price worth paying to preserve the principle of greatest need and fair allocation.

One reason for the difference between staff and non-staff views here may be that staff are more concerned about the need to maintain public faith in the donation/allocation systems, and fear that public perceptions of unfairness may lead to decreased donation rates. Trust is often cited as being of paramount importance to the

⁴⁵⁴ Radcliffe-Richards J, (2012) *op. cit.*

success of the organ donation system, and staff were understandably concerned about the implications of something they felt could reduce public trust.

For staff, the best way to avoid the absolute waste of turning away conditional donations was to convince the next-of-kin to donate unconditionally. Failing this, staff generally viewed the resulting negative loss as a necessary evil to preserve public faith in the system. This view certainly needs taking seriously, as it is possible that accepting conditional donations would reduce faith in the transplant system; this rests, however, upon an empirical claim, the accuracy of which is unknown. Although the accuracy of the empirical claim is unknown, one can still weigh up the risks involved. This links closely to the ideas of transparency and perceived fairness, which will now be discussed.

10.3.6 Transparency and perceived fairness

Participants generally considered it important that organ allocation is a transparent process, and there appeared to be an implied link between transparency and fairness – specifically that a transparent system is more likely to be a fair system.

Research conducted in the USA has suggested that transparency and perceived **fairness is linked to willingness to donate organs; the greater an individual's** understanding of the transplant system and greater their perception of fairness, the more likely they are to be willing to donate their organs⁴⁵⁵. The healthcare system in the USA is clearly very different to that in the UK, and there are some different issues in play (like unequal access to healthcare) but it would seem reasonable to think that the same links between transparency, perceived fairness and willingness to donate could be drawn in the UK.

If a perception of fairness affects donation rates, then one needs to consider how transparency may affect perception of fairness. It is useful to draw a distinction

⁴⁵⁵ Boulware LE et al., (2007) *op. cit.* pp1778-87

between transparency and understandability. A transparent process could be completely incomprehensible to lay members of the public due to its complexities. If the process was assessed, monitored and regulated by trustworthy, independent and appropriate people/organisations who did understand the process, then this could still be regarded as transparent and perceived as fair if the appropriate people declared that it was. It seems likely that a desire for transparency is partly to ensure that nothing **underhand can go on 'behind closed doors'**. **Transparency on this level does not require** the public to understand the process, but does require a willingness to defer to expertise. Transparency could be further enhanced if processes are more readily understandable, as this would remove the need for deference to expertise, and more people would be able to assess the fairness of processes themselves if they wished to. Persad et al state that in order for an allocation system to be perceived as legitimate, it **ought to be "publicly understandable, accessible, and subject to public discussion and revision"**⁴⁵⁶.

Organ allocation in the UK is transparent insofar as allocation policies are publically available on the NHSBT website⁴⁵⁷, and these are devised in an open way. Organ allocation, however, is a complex process which is often articulated using **technical language. Allocation can be explained in simplified terms such as 'best match' and 'greatest need', but this can result in simplification that obscures relevant details (such as what 'greatest need' means).** Allocation in the UK is, then, transparent but unlikely to be fully understood by many. If transparency and understandability are important, one has to consider the impact of permitting conditional donations. Conditional donations need not have a negative impact upon transparency **or** understandability, if handled correctly. If the NHS was found, in several years time, to have been secretly allocating organs according to clearly non-medical criteria based

⁴⁵⁶ Persad G, Wertheimer A, and Emanuel EJ, 'Principles for Allocation of Scarce Medical Interventions', *The Lancet* 373 (2009) p429

⁴⁵⁷ NHSBT 'Organ Allocation', Available at: http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/organ_allocation.asp, Last Accessed: 23/10/2012

upon race, sexuality or responsibility for condition, one might expect there to be a backlash and reduced trust in the system. But this would be because the NHS had failed to be open and transparent about its allocation policies. If, in contrast, the NHS anonymously published details of all conditions placed on donations every month and how these affected allocation, this would be open and transparent.

Permitting conditional donations would not appear to make organ allocation any less understandable either. It might even make it more understandable if the public knew that a recipient had been given higher priority due to meeting a simple condition as opposed to a complex combination of tissue matching, waiting time and prognosis.

A transparent system is not necessarily a fair system, and a fair system need not be transparent or readily understandable – but perhaps having a transparent system is *likely* to lead to a fair system since the people who set allocation principles are aware that their policies can be scrutinised. Introducing conditional donations could result in people perceiving the system as unfair, if as a result of its willingness to accept conditional donations, they thought that the NHS was engaging in discriminatory practices. This is a significant concern. If perceived fairness affects the motivation to donation, then it is obviously important to avoid things that reduce perceived fairness. It has been argued in 7.8 that the NHS need not be considered to be acting wrongly by accepting conditional donations, but there is still a risk that even after a full explanation of why conditional donations are accepted, the public could *perceive* the NHS as acting wrongly and unfairly. It has been argued that this perception would be mistaken, but it still has to be taken seriously, as it is perceived unfairness rather than actual unfairness that will affect donation rates.

If handled correctly, permitting conditional and directed donations need not pose a threat to transparency or understandability, so this does not provide reasons to prohibit them. There is, however, a possibility that accepting conditional donations may

create a perception of unfairness surrounding organ allocation, and this could have subsequent effects upon donation rates. Careful monitoring of public attitudes towards donation, and any fluctuations in donation rates, would therefore be necessary to ensure that the justification for accepting conditional donations (that they increase the number of organs available for transplantation) still held true.

10.3.7 Introducing non-medical factors

Most participants, though aware of other factors that could be used to allocate organs, were reluctant to endorse a system based upon anything other than medical criteria. Many participants viewed medical criteria as providing objectivity, and there was a concern that allowing donors to specify the types of people who could receive their organs would *introduce* non-medical factors into allocation decisions. There was a desire to keep non-medical factors out of medical practices.

A systematic review by Tong *et al* included 15 studies examining community preferences for the allocation of organs for transplantation⁴⁵⁸. The reviewers identified seven themes underlying community preferences: maximum benefit, social value, moral deservingness, prejudice, fair innings, first come – first served and medical urgency. These findings contrast with the views of participants in the embedded study, who generally wanted to keep factors such as moral deservingness and social value out of allocation decisions.

Non-medical factors do, however, already play a significant role in organ allocation. As Veatch points out, allocation of resources such as organs is unavoidably a moral issue⁴⁵⁹. A superficially objective measure upon which to base allocation could be transplant benefit, so that people likely to accrue the most transplant benefit will receive priority for transplants. The problem is that transplant benefit is not something that can be determined purely from medical data:

⁴⁵⁸ Tong A et al., (2010) *op. cit.* pp796-805

⁴⁵⁹ Veatch RM, (2000) *op. cit.* p279

[o]ne patient may have the greatest chance of survival of acute illness, another may have the greatest predicted years of survival; still another may receive the greatest relief from suffering or morbidity; and another get the most satisfaction. Medical facts alone cannot tell us which of these patients will benefit the most from transplant.⁴⁶⁰

While it may be possible to argue that one of these patients will experience the greatest transplant benefit, this argument will rely on the balancing of several non-medical claims such as whether avoiding pain is more or less important than having the longest possible life. Given this, the claim that medical data alone can provide a carefully considered allocation system seems much weaker. Like Veatch, Parsad *et al* point out that allocation cannot be based upon purely clinical facts, and that although these **can provide information about current condition and prognosis “responding to these facts requires ethical, value-based judgments”**⁴⁶¹.

There was a lack of awareness amongst the participants in the embedded study about the role that non-medical criteria already play in allocation based upon medical criteria, and this was present across all groups including transplant staff. This belief in the objectivity of allocation appeared to be a key reason why most participants were reluctant to see an allocation system that routinely deviated from medical allocation.

Given that non-medical factors already feature in allocation decisions, **participants’ concerns here do not provide a convincing objection to conditional donations.** Conditional donations may give certain non-medical factors additional weight, which could result in allocation contrary to usual allocation policy, but this could be justified on the grounds of avoiding absolute waste/negative loss. It is better to allocate contrary to usual allocation policy in exceptional circumstances than it would be to not allocate the offered organs at all.

⁴⁶⁰ *Ibid.* p279

⁴⁶¹ Parsad G, Wertheimer A, and Emanuel EJ, (2009) *op. cit.* p423

10.3.8 No room for emotion

Closely linked to the reluctance for non-medical factors to influence allocation was that allocation decisions should be based on rationality rather than emotions. Participants generally displayed sympathy for the individuals in the interview scenarios, and could understand their reasons for wanting to place conditions. Most participants thought, however, that conditions were likely to be irrational emotional responses to the traumatic situations that they found themselves in, and that these should have no bearing on organ allocation.

One explanation for rejecting supposedly irrational and emotional responses could be they introduce irrelevant considerations into allocation and that this would bias the system making it unfair. Ordinarily it is possible to draw a distinction between organ donation and organ allocation: a decision to donate organs may not be entirely rational, but so long as the donation is unconditional, the organs can still be allocated according to rational criteria. Conditional donation blurs the boundaries between the donation and allocation decisions. It is not obvious that all donation decisions are completely rational, since they occur at a time of (normally sudden) bereavement and emotional turmoil. They are unlikely to be completely irrational, but it is likely that emotion will be high in many donation situations.

As a barrier to conditional donation, objection to emotion affecting allocation decisions is not impossible to overcome. In an ideal situation, organs would be donated unconditionally and emotional factors would be kept out of the allocation of organs⁴⁶². If, in some situations, a donation can only go ahead if emotional or irrational factors are taken into account, then, as discussed, the donation can be accepted and allocated according to the conditions in the interests of avoiding waste/negative loss.

⁴⁶² Emotion could, of course, play a significant role in choosing to donate unconditionally. One could, for emotional reasons, want emotions to not influence which recipient is chosen.

10.3.9 Who am I to Judge?

Although many participants from all groups were willing to specify types of people who, in principle, they considered less deserving of transplants, very few participants actually thought that organs should be allocated according to their own views on **desert: they felt they were not in a position to cast judgment. The 'who am I to judge' view was used in two ways. The first way reflected an acknowledgement that different people have different beliefs, and that using one's personal beliefs to decide who is worthy of receiving a transplant would be wrong. The second way was simply that a lack of information about specific circumstances would render accurate judgment impossible.**

Who am I to judge - Playing God

Some participants likened making judgments about who ought to receive **transplants to 'playing God', or having a 'life and death panel'. There appeared to be a concern that these decisions ought not to be based on the views of individuals, or even groups of individuals. Pennings makes a similar claim, stating that:**

We allow people to decide what to do with their time and money but we do not allow people to decide who will live and who will die. That decision is, like decisions regarding the spending of health care resources, a choice that has to be negotiated within society.⁴⁶³

Someone has to choose who lives and dies: the important questions are whether placing conditions on a donation amounts to choosing who lives or dies, and if so, whether it is right for individuals to make these decisions. First, it may be helpful to consider living donations, where directed donation to family members is the norm. In **living donation, one can choose to donate one's kidney to one's sibling, even if it means**

⁴⁶³ Pennings G, (2007) *op. cit.* p46

that the most urgent patient on the transplant waiting list is overlooked. There are not any calls to prohibit directed living donation on the grounds that donors can choose whose life to save. This may, however, only show that it is acceptable to choose a relative over a stranger, rather than one stranger over another. In deceased donation, one can choose to donate some organs but not others – this could be construed as choosing what sort of people to save or not save (insofar as one might choose to save people who need a heart transplant, but not those who need a liver transplant). Again, however, this is not an example of an individual choosing one stranger over another for a particular resource. Pennings appears to suggest that it is because the stakes are so high that these decisions should not be made by individuals – this is presumably why he differentiates between time/money and saving lives. If allocating an organ to one person over another, or many others, on the basis of individual preferences is objectionable, then perhaps it should be considered objectionable for individuals to have any say over whether their organs are donated at all. If choosing one person over another is construed as choosing that the other potential recipients will die, then choosing to not donate at all should be construed as choosing that all potential **recipients of one's various viable organs will die. By the same token, choosing to not accept** conditional donation would be choosing for all potential recipients of that organ to die.

It is also worth noting that although there are policies that fairly rigidly determine how organs are allocated, and to some extent these could be considered to **'automate' the process, it is wrong to think that individuals are therefore not choosing** who lives and dies. The policies are created by people, and people agree to be bound by them. This still, however, involves judgement, and someone ultimately has to act as judge. Whether a transplant will go ahead for a particular patient depends upon the transplant **surgeon. Participants' reluctance to be the judge might** reflect a moral stand against such judgement having to be made (which would seem unreasonable since the

only way to avoid such a judgement when the demand for an indivisible resource is greater than supply is to not give the resource to anyone). Alternatively it might reflect an unwillingness to make those kinds of decisions, and a desire to have someone else do it so that they do not feel personally responsible. Indeed, there is a sense in which **this latter explanation might form a central part of participants' general desire to rely** on an objective system of medical allocation criteria. Whether intentional or not, the use of, and reliance on, an external and objective set of decision-making tools serves to distance the individual from the decision and moral responsibility for the allocation.

Who am I to judge - Factual Accuracy

The second way in which 'who am I to judge' was used has significant overlap with another concern – factual accuracy. The most common objection to the donations featured in the interview scenarios was that the conditions may be based on factually incorrect beliefs. For example, many participants suggested that not all people under 25 are irresponsible and not everyone over 25 are responsible. This is perhaps the most obvious objection to the restrictions placed in the scenarios, but it links with ideas about fairness and wrongly excluding potential recipients. The objection is not about the placing of conditions, but more about outcomes. If a person under 25 who happens to be responsible was excluded from receiving a transplant because a donor had specified that they only wanted responsible people (in this case the donor believed that only people over the age of 25 are responsible), then that potential recipient would be excluded on the basis of something factually incorrect.

This finding is interesting because objections to conditional donation in the ethical literature tend to focus on the use of morally irrelevant considerations being used to allocate scarce resources, rather than the practical application of the irrelevant consideration. The main objection from participants in this study was not that a condition may be irrelevant, but that it may be incorrect. This concern led some participants to claim that conditions they thought **were** morally relevant (such as

responsibility for illness) should never be acted upon because of the risk of applying them incorrectly. Some participants were concerned that it is difficult to ascertain causal responsibility for illness, and that this may therefore result in people being held wrongly responsible.

This does again provide a consideration that has to be taken seriously in cases of conditional donation. One can imagine a situation where a patient becomes aware that they are being wrongly excluded from receiving an organ on the basis of something factually incorrect. Not only would this be unfair (with the consequent potential for negative media stories), but there could also be legal implications. Individuals might consider legal action against the NHS if they felt that they had been incorrectly excluded. There are two ways in which this sort of error could be made. First, if the donor had placed a condition based upon factually incorrect assumptions. Second, given the relatively short window of opportunity in which organs can be allocated and transplanted, the NHS may be unable to ensure that some recipients **do or do not meet the donor's criteria**. This does not provide a reason to not allow conditional donations, however. Patients willing to accept organs that had been conditionally donated could perhaps have to agree in advance that they accepted that conditions could be based upon factually incorrect assumptions, and that there was a possibility in mistakes being made at the time of allocation.

Although participants may feel uneasy about the idea of 'life and death panels' or individuals making decisions about who lives and dies, this is already the unfortunate reality of organ allocation and determining who is placed on or removed from transplant waiting lists. If these decisions were made on the basis of conditions attached to donations, it is true that factors other than those ordinarily used may be considered. The importance of avoiding negative loss and absolute waste, however, would suggest that although it is not ideal for irrelevant factors to be considered, it is better than turning down the offered organs.

The potential for factual inaccuracy is almost unavoidable when conditions are placed on donations that consider things like past behaviour and responsibility for illness. Because terms like this are vague, there is room for generous interpretation, which could allow flexibility during allocation. This might allow organs to be allocated closer to the standard principles, but would also introduce a risk of the next-of-kin perceiving their conditions to have been ignored. A condition specifying that people under 25 should not receive the organs is, in practice, more concrete than a condition stating that those responsible for their own illness should not receive the organs. Although this raises concerns, they are not insurmountable. Next-of-kin could be disgruntled if they felt their wishes were not followed accurately, but it could be explained to them that there is a risk that this could happen. Potential recipients may also justifiably be disgruntled by individual injustices, but hopefully they would see that the gains of accepting conditional donations outweigh the negatives.

10.3.10 Impartiality

The partiality in living donation allocation decisions was supported by many participants, yet impartiality was generally felt to be desirable in deceased donation. This presents a potential barrier to conditional donation, since conditional donations tend to reflect partiality. Sometimes this partiality is morally acceptable, but other times (racist preferences being a prime example), it clearly is not.

This barrier may be overcome by considering *who* is expected to be impartial. It would be wrong for transplant staff to allocate organs according to their own partial preferences: some people have a duty as part of their institutional role to remain impartial⁴⁶⁴, this ought to apply to medical staff employed by a publically-funded state institution to serve a diverse public. There is a potential tension between impartiality and conditional donation; the conditions imposed could require transplant staff to behave in a way that suggests partiality in contradiction to their obligation to be

⁴⁶⁴ Cottingham J, (1986) *op. cit.* pp357-73

impartial. The partiality in question would probably not be the agent-relative partiality of the transplant staff; instead it would be the partiality of the donor or her next-of-kin.

It is not always considered wrong for transplant staff to act in accordance with the partiality of donors. Wilkinson suggests that one of the reasons organ donation/allocation is associated with impartiality is the involvement of the state (and NHS in the UK), but he also states that this link cannot be consistently applied due to the partiality considered acceptable in living donation⁴⁶⁵. If it is acceptable for transplant staff to facilitate partiality in living donation, staff are not consistently required to act impartially.

Cronin and Price state that once an organ is donated after death it “slips into the net of public resource and impartial allocation”⁴⁶⁶, and the view that deceased organ allocation is impartial is relatively commonplace. Often partiality in organ donation is discussed as a contrast between the partiality generally present in living donation and the impartiality present in deceased donation. Impartiality is also sometimes required in living donation in cases of altruistic donation, and partiality is sometimes permitted in deceased donation. This is evidenced in the March 2010 policy revision permitting requested directed allocation of organs, which permits staff to facilitate directed donation that reflect partiality for family and friends. That impartiality and partiality are both sometimes required in living and deceased donation suggests that there is nothing special about a donor being alive that requires partiality in all cases, and nothing special about a donor being dead that requires impartiality in all cases.

A distinction drawn in Chapter 7 was between impartial principles and impartially justified allocations. This is an idea discussed by Wilkinson⁴⁶⁷. An impartial principle might be to allocate organs according to greatest need, with the person in greatest need being defined as the person in most imminent danger of death. Yet rigidly using

⁴⁶⁵ Wilkinson TM, (2012) *op. cit.* p152

⁴⁶⁶ Cronin AJ and Price D, (2008) 'Directed Organ Donation: Is the Donor the Owner?' *op. cit.* p129

⁴⁶⁷ Wilkinson TM, (2012) *op. cit.*

this principle, and rejecting any organs that cannot be allocated according to it, may result in need not being met as well as if the conditional donations had been accepted. If it is impartially important to meet need, and accepting conditional donation meets need better than rejecting them, then one ought to accept the conditional donations.

As discussed in section 2.3.2 and 4.5, some forms of partiality expressed by conditional donation are morally legitimate and can, according to Wilkinson, be considered impartially defensible (and were considered acceptable by many participants). Although impartiality in organ allocation may generally be desirable (for the same reasons that it is desirable to have unconditional donations – see 7.2), allowing partiality in some circumstances can help to achieve an end that it is impartially desirable. In the case of conditional organ donation, that end is saving or improving more lives.

10.3.11 Fairness and Justice

Participants seemed to consider fairness in three ways: overall fairness of distribution, **fairness of each allocation, and fairness from the donor family's perspective.** The concerns relating to overall fairness of distribution were not based on equality as such, but were more about organs being **allocated using the right factors (and 'right' was** mostly construed as the medical factors that currently guide allocation). The general view seemed to be that so long as these factors were used, nobody could reasonably complain about organ allocation being unfair.

As an argument against conditional donation, fairness may appear superficially convincing. Although there is debate within philosophy over what fairness entails, it would seem reasonable to think that conditional donations risk compromising it. Carr gives a non-exhaustive list of conceptions of fairness containing ideas such as not disadvantaging others, being unbiased and impartial, adhering to rules and treating

equal cases equally⁴⁶⁸. In comparison to unconditional donations, conditional donations are likely to disadvantage others⁴⁶⁹, be biased and partial, promote inconsistent allocation rules and treat equal cases differently on the basis of irrelevant considerations. If fairness is particularly important, conditional donations may be unacceptable.

Given that organs are a scarce and, split livers aside, indivisible resource, a strictly fair way to treat people (insofar as it treats everybody exactly equally) would be to not give organs to anybody. This would require a demanding account of fairness and would be levelling down to the extreme. This would be an undesirable situation though, as it would rank absolute fairness above all other considerations, which would benefit nobody.

Wilkinson discusses the idea of fairness with some clarity, suggesting that one fair way to handle allocation would be to have a queue based upon substantive fairness criteria, such as ensuring that recipients wait the same amount of time for transplants⁴⁷⁰. As Wilkinson points out, the waiting list systems in most countries, including the UK, take other factors into account, such as urgency and transplant benefit. The presence of these other factors may be contrary to strict fairness, but they promote life-saving as a consideration. If this can be the case for these factors, a concern for fairness should arguably not stand in the way of the potential for the additional lifesaving that could be gained by accepting conditional donations rather than refusing them. Just as abandoning transplantation altogether would be levelling down, so would turning away a conditional donation that could not be allocated fairly. If an organ is made available in such a way that it can be donated fairly, then it ought to be. But if the available options are to allocate the organ unfairly or not allocate the organ

⁴⁶⁸ Carr CL, 'On Fairness', (Aldershot: Ashgate, 2000) p2

⁴⁶⁹ Although accepting conditional donations benefits everybody on transplant waiting lists, one might argue that because the wrong factors may be used to allocate organs, the wrong people receive the most benefits.

⁴⁷⁰ Wilkinson TM, (2007) 'Racist Organ Donors and Saving Lives' *op. cit.* p71

at all, it seems reasonable to accept some compromise in fairness in order to promote life-saving.

Some participants' conception of fairness took into account non-medical factors, such as how recipients have lived their life, and their likely future behaviour. This was both backwards and forwards looking, but was more to do with individual deservingness than overall fairness. On this account of fairness, if a patient does not deserve an organ, then it is unfair if they receive one. There is room for disagreement about what deserving an organ entails; for some participants, simply needing an organ was enough, whereas a minority of participants brought in factors such as past and future behaviour, which itself raises issues of fairness. This idea of fairness can work for or against conditional donation. On the one hand, if one thinks that deserving an organ is related to past and future behaviour, then conditions relating to this could serve to enhance fairness. Equally, however, if one construes deserving a transplant as simply needing a transplant, then bringing in other factors may make allocation less fair.

One participant viewed fairness quite differently from others, saying:

I suppose the only fair way of doing it would be for the person actually donating their organ erm to specify where they would like it to go – PD2

This participant was discussing this in the context of giving everyone equal opportunity to place conditions on donation. This appears to view fairness as being a concern for donors rather than the outcomes of organ allocation. It seems more **concerned with treating donors equally and giving them 'fair' control over their organs.** Although allowing people to specify the recipients of their organs may introduce unfairness into the distribution of organs, it could be considered fair insofar as **all**

donors/donor families would be given the same opportunity to allocate their organs in this way.

Fairness certainly needs to be taken seriously, given the link between perceived fairness and the motivation for donation. If conditional donations remained the exception, rather than the rule, overall fairness of allocation would not be significantly compromised, and any loss of fairness could be justified by an increase in life-saving or life-improving transplants. The two alternative views of fairness put forward by participants are not convincing. The first of these, which takes into account non-medical factors, is vulnerable to the same criticism as overall fairness; a compromise in fairness (however conceived) for one donation may promote other desirable outcomes. The final conception of fairness was as an issue for the donor family. Allowing conditional donation would be fair insofar as anyone *could* have the opportunity to place conditions, but this does not really speak for or against allowing conditional donations.

10.3.12 Urgency and loss of life

Allocating organs according to the conditions placed by donors or their next-of-kin would mean that organs might not be available for those with most urgent need. The interference of conditional donation on allocation according to urgency emerged as a theme from the interviews. The urgency discussed by participants was related to loss of life, rather than any other sort of urgency (participants did not mention within this context, for instance, the urgent need for somebody with terrible quality of life to receive treatment to make their life bearable).

Under the March 2010 policy that permits requests for directed allocation to family members⁴⁷¹, urgency is given a pre-emptory role. If there is someone on a **transplant waiting list who is classified as 'super urgent'**⁴⁷², then that person will be

⁴⁷¹ Department of Health (2010) *op. cit.*

⁴⁷² This is the highest priority category, and generally refers to people who will die unless they receive a transplant promptly.

given priority over the specified directed recipient. A donor is allowed to direct their donation provided doing so is unlikely to cause another potential recipient to die as a result of missing out on that organ. These donations are not, however, strictly conditional, so the donation goes ahead on the understanding that the request for direction may or may not be followed. This allows urgency to have a trumping status over family partiality, which is in contrast to living related donation where urgency plays no role and the organ is given to the individual identified by the donor, regardless of their place on the waiting list, and regardless of whether someone else could have benefitted more (by having their life saved).

Organs being generally allocated according to urgency is desirable, because it minimises the number of people who die while waiting for a transplant. Since the introduction of MELD/UKELD rankings (a measure of urgency) for liver allocation, for instance, mortality on transplant waiting lists has generally reduced⁴⁷³. Although the **DH's policy for requested directed allocation of organs is clever because it allows** urgency to be a trumping factor (so to some extent allows partiality to family members and the impartial, greatest need principles that drive deceased organ donation to coexist), it offers little assistance when an offer of organs is truly conditional. Indeed, according to this policy, truly conditional donations must still be rejected.

This, again, amounts to levelling down. If one assumes that fairness dictates that those with the most urgent need for a transplant are given priority, then it is obviously desirable that the most urgent patients receive transplants first so that they can avoid death. If no organs at all are donated in time, it is unfortunate but not unfair. If no organs suitable for these patients are donated in time, it is again unfortunate, but not unfair. If organs are donated that **are** suitable for these patients, but cannot be allocated to them due to conditions attached, this is again unfortunate. There is

⁴⁷³ Neuberger J, (2011) 'Transplant Benefit in Liver Transplantation: Right Time or Too Premature?' *op. cit.* p82

perhaps an argument to suggest that this is also unfair, since there is nothing inherent to the physical nature of the organs that makes them unsuitable for the most urgent patients. As far as the NHS is concerned, however, it is unable to allocate the organs to the most urgent patients; it is not as if it has the option but is choosing not to. It is certainly unfortunate that organs with conditions attached cannot always be allocated to the most urgent patients, but this does not provide a reason to not accept the donation and allocate according to the conditions.

10.3.13 Donor Motivation - Altruism

Although deceased donation is (according to the DH) *supposed* to be altruistic, there was some disagreement and confusion amongst participants about what altruism is. Most participants were unable or unwilling to engage with the concept on a technical level, so the collected data cannot add much to a technical discussion of altruism. This may not be surprising, given the complex and nebulous nature of the concept. Transplant staff (more so than other groups) generally felt it was important that organ donation was altruistic, but their conception of altruism seemed to be specific to transplantation, **featuring phrases such as 'freely given' that do not occur in** philosophical definitions but are a feature of DH policy documents⁴⁷⁴.

One staff participant suggested that donors/donor families do not know that deceased donation is supposed to be altruistic:

people don't know that donation's supposed to be altruistic, they're doing it for the reasons they want to do it for, so I think I'm not sure that it would actually affect it that much because people don't know, they don't think in that way when they're donating – TS11

Some participants thought the motivation behind a donation is important, and that altruistic motivations are preferable, but also believed that the most important thing is

⁴⁷⁴ Department of Health (2010) *op. cit.*

that the organs are actually donated, regardless of the motivation. Although participants were specifically asked about altruism, few suggested that a lack of it was a reason to not allow conditional donations, and many seemed to regard it as being of little relevance or interest.

One reason that conditional and directed donations have been prohibited is because they are considered non-altruistic⁴⁷⁵. It was argued in Chapter 5, however, that it is not necessarily the case. Actions are rarely either altruistic or non-altruistic, but there is instead is a sliding scale of altruism, such that many conditional and directed donations could contain an element of altruism. The fact that some staff **referred to aspects of altruism that are implied by DH policy documents (such as 'freely given')** suggests that staff are aware that altruism is supposed to be a principle of organ donation. That there is a lack of clarity about the concept, evidenced by disagreement and confusion about what altruism means, even among transplant staff, may point to its unsuitability as a guiding principle for organ donation, however.

It may be desirable for organ donation to primarily be altruistic, and good reasons for this have recently been put forward by a Nuffield Council on Bioethics panel⁴⁷⁶. For instance, it seems generally preferable to live in a society where people are motivated by the health needs of other people, rather than self-interest or financial gain. Altruism need not be the only acceptable motivation for donations, however. Perhaps the most important thing to come out of the collected data, in relation to altruism, is that many participants do not even think of organ donation in terms of altruism. Some staff participants also suggested that some donor families do not think in terms of altruism when they choose to donate organs, and these participants did not suggest that this made those donations unacceptable. Concepts such as reciprocity and

⁴⁷⁵ Department of Health (2000) *op. cit.* p1

⁴⁷⁶ Nuffield Council on Bioethics, (2011) *op. cit.*

solidarity have received support in the ethical literature⁴⁷⁷, so these could be other acceptable reasons to donate organs. For the reasons discussed in chapters 4 and 5, altruism is not a convincing guiding principle for organ donation, particularly in relation to conditional donations. It is not true that all conditional donations are non-altruistic, and it is also not true that all altruistically motivated donations are ethically acceptable.

10.3.14 Preferences

Until now, discussion has focussed on donations that are truly conditional. That is, unless the conditions or directions are granted, the donation will not go ahead. One outcome of the preceding discussion has been that accepting these donations can be justified on the grounds that they avoid waste. Some conditional or directed donations do not take the iff form, and instead merely express preferences. Someone may request that people of type x are given priority for the donated organs, but that if this is not possible the organs should be allocated to other people.

Some participants found these sorts of requests more acceptable than iff conditional donations, and the March 2010 DH policy update also permits requests that organs are allocated to family members ahead of strangers. The primary reason for accepting iff conditional donations is to avoid absolute waste, but in cases where the request is merely for priority, the organs will be donated even if the request is not followed. The justification of avoiding absolute waste therefore does not apply, which means there is less reason to act upon the request than the truly conditional donations. In cases where a request for priority is made, there is no good reason to turn down the **donation, but equally there appears limited reason to follow the donor's or** next-of-kin's wishes.

This presents an interesting problem. Despite some participants considering preferences *more* ethically acceptable than iff conditions, there is actually *less* of a

⁴⁷⁷ Saunders B, 'Altruism or Solidarity? The Motives for Organ Donation and Two Proposals', *Bioethics* 26 (2012) pp376-81

reason to follow the preference. But, if the NHS refuses to follow the preference, the **donor family could 'convert' the preference into an iff condition and have their wishes followed.** A pragmatic solution is therefore required.

If allocating according to the preference would mean that someone with the best match and super-urgent clinical need would not receive an organ and would probably die, then allocating according to the preference would be undesirable. This could be explained to the next-of-kin, in the hope that they would agree for the organ to be donated unconditionally. But if allocating according to the preference would not deprive anyone with a particularly urgent need of a transplant and was therefore relatively harmless, then it seems reasonable to allocate according to this preference, given that refusing to do so might **'force the donor family's hand' and result in an iff conditional donation/no donation at all.** With a preference rather than an iff condition, the donor family may be more amenable to counselling which could result in an unconditional donation, and this would seem like the appropriate first course of action to be attempted.

There may also be circumstances where following the request for priority is entirely or relatively harmless. This may be the case if doing so deprives nobody who urgently needs an organ, or if the request follows acceptable partiality. In these cases, although efforts should be made to encourage the donor family to donate unconditionally, it would be reasonable to allocate according to these preferences. Where the request for priority has more negative effects, however, it would seem undesirable to allocate according to the request if doing so is avoidable. In this situation it should be explained that there are particularly needy patients who require transplants urgently, and that the organs will be allocated to these people contrary to the preferences. The donor family *may* then convert their donation into an iff conditional, but in terms of practical consequences this would result in nothing worse than following the preferences to begin with.

10.3.15 A note about South Asian potential donors

South Asian potential donors were included as a distinct category for the empirical study due to particular problems with low donation rates from this community⁴⁷⁸. The Organ Donation Taskforce report states that **more work is needed to “establish how best to encourage engagement with the option of organ donation after death”**⁴⁷⁹ for BME groups, and some people have suggested that allowing conditional donation may be one way to do this⁴⁸⁰. This was not something reflected in the views of the South Asian participants in this study. The views of the South Asian participants were not generally different from the views of non-South Asian participants. There certainly did not appear to be a desire to choose deserving recipients, and many South Asian participants shared the view that donors ought not to judge the deservingness of recipients. Elsewhere, others have speculated that the concept of solidarity may prompt conditional donations restricted to ethnic groups⁴⁸¹ but this view did not emerge in this study.

It should be noted that due to recruitment difficulties (discussed in Chapters 8 and 11), the sample of South Asian potential donors for the embedded study was not typical of the larger South Asian population. Most participants were fairly westernised, educated, and there were no first generation immigrants. There were also no non-English speakers. This study makes no claims to have obtained an in-depth understanding of the concerns and perspectives of the South Asian community. This is a clear limitation of the study, and is discussed in Chapter 11.

10.3.16 Section Conclusions

A number of potential barriers to permitting conditional donations have been presented. It has been argued that none of them provide good reasons to prohibit conditional

⁴⁷⁸ NHSBT 'South Asian Organ Donation Campaign', Available at: http://www.organdonation.nhs.uk/ukt/campaigns/other_campaigns/detail.asp?id=3, Last Accessed: 31/10/2012

⁴⁷⁹ Department of Health (2008) *op. cit.*

⁴⁸⁰ Radcliffe-Richards J, (2012) *op. cit.* p117

⁴⁸¹ Saunders B, (2012) *op. cit.* pp376-81

donations, but some of them need to be taken into account when making policy recommendations. For instance, it is important that potential recipients have a choice about receiving conditionally donated organs, so that they are not forced to accept donations with conditions attached that they find objectionable.

It is also important that the potential negative aspects of conditional donation raised by perceived fairness and slippery slopes are given due consideration. Although it has been argued that the positives of accepting conditional donations can outweigh the negatives, this has the potential to change. If the public started to distrust the transplantation system as a result of conditional donations, fewer people may donate organs. For this reason it is essential that the negative effects of conditional donations are monitored and minimised. These concerns need to be taken into account when making recommendations for policy.

In chapter 12, a series of recommendations will be put forward, summarising what has been discussed and concluded in this chapter. First, the limitations and positive aspects of the project will be discussed in the next chapter.

Chapter 11 - Limitations, transferability and positives

11.1 Limitations

Although the embedded study met the aim of gaining the views of a variety of key stakeholders, its limitations must be acknowledged, as these will have had an impact upon the results.

Most of the limitations arose from difficulties with recruiting participants, which was a longer process than anticipated. Recruitment for the potential donor categories proved problematic, and ultimately this led to a less varied sample than was desired.

The original recruitment method of sending letters to people registered at specific GP practices failed to recruit any participants. One possible explanation for this could be that the study was likely to appeal most to those who were pro-donation. A relatively small proportion of people register to donate organs (under 30% of the UK population⁴⁸², and many fewer from the South Asian population). It is not clear whether there was any correlation between unwillingness to register and unwillingness to participate. It is also possible that people who had not visited their GP in the last 12 months did not feel engaged with the medical research community. Another study found that response rates are relatively high (even in hard to reach groups) if telephone contact can be established as well as mailed invitation being sent⁴⁸³. This would have proved difficult for this study because Moorlock did not have access to the telephone numbers of potential participants, for reasons of data protection, but it could be an effective method in other studies.

11.1.1 South Asian Potential Donors

It proved particularly difficult to recruit South Asian potential donors, and the final sample was not gender balanced. Of the 10 people interested in participating, 9 were

⁴⁸² NHSBT 'Homepage', Available at: <http://www.organdonation.nhs.uk/ukt/>, Last Accessed: 23/10/2012

⁴⁸³ Kiezebrink K et al., 'Strategies for Achieving a High Response Rate in a Home Interview Survey', *BMC Medical Research Methodology* 9 (2009) p46

female. A more balanced sample would have been desirable, as it is possible that men view things differently to women. Similarly, the final method of recruiting South Asian potential donors (advertising in a University of Birmingham weekly email newsletter, and snowballing from these participants) meant that several of the participants in the South Asian potential donor category were well-educated, with links to the University.

Participants' levels of education were not recorded so it is not possible to give precise details. This data could have proved useful in ensuring that a more varied sample of participants was obtained, so it was a mistake to not record it. This recruitment method also meant that the South Asian participants were generally fairly integrated with British culture, so the data gathered in my study will only represent a small proportion of views of the varied South Asian population in the West Midlands. It would have been preferable to obtain a wider variety of views, but the study still captured some relevant and useful perspectives.

Arrangements were in place to include non-English speakers in the study, to include those who may be less culturally integrated and therefore have different views from English-speaking South Asians, and also to reflect the composition of the waiting list in terms of race and age. As discussed in Chapter 8, literacy rates and English speaking rates for this South Asians in the UK were investigated, and it was clear that excluding non-English speakers could exclude large proportions of potential participants, particularly older people and females. Unfortunately, no non-English speaking people expressed an interest in taking part in the study, so none of these views were represented. South Asian participants were requested at the time of interview to speak to friends and family about the study, and particularly people who **didn't speak English. Although all participants agreed to do this, it did not yield any** non-English speaking participants.

Mixed advice was given about trying to engage with the South Asian community; one academic researcher with experience of working with the South Asian

community advised that it would be difficult unless there was an Asian person on the research team, due to a supposed mistrust of white academics. This was not something that could be addressed within this study, as this was a single-researcher project and there was no scope to recruit and employ a South Asian researcher to conduct interviews with South Asian participants. Very late in the study, two South Asian participants of different faiths suggested that a good way to recruit participants would be to visit places of worship. They did not foresee it being difficult to access places of worship or to gain the trust of the South Asian community (contrary to the advice from the academic researcher mentioned earlier). Regrettably, by this stage it was too late in the project to do any further data collection, but this approach could have yielded a more varied sample of South Asian participants, and perhaps given increased access to non-English speakers.

As a result of recruitment difficulties, the sample that comprised the South Asian potential donor group is, therefore, probably too homogeneous to be considered transferable in any way to the South Asian population of the West Midlands, as it has almost certainly missed out on capturing the variety of views that this larger population holds. This is particularly disappointing as one of the aims of the project was to have some focus on this population an attempt to establish whether conditional donation may be a potentially effective ways of increasing donation in this group.

11.1.2 Potential Recipients

The sample for the potential recipient group only included potential liver or kidney recipients, and the views expressed by these individuals may differ from people who need heart or lung transplants. The proportion of liver to kidney recipients was 4:5, which does not reflect the proportions of the waiting lists (the kidney waiting list has twelve times more patients than the liver list). Within this very small sample there did not appear to be a noticeable difference between the views of kidney and liver recipients, but this may not be the case amongst these patients more generally. A

relevant difference could be that people can be kept alive for some time after kidney failure using dialysis⁴⁸⁴, whereas there is no similar treatment for liver failure. A further difference is that living donation provides an additional relatively low-risk supply of kidneys, whereas living liver donation is a riskier and rarer event⁴⁸⁵. One might speculate that these factors may have an impact upon how these recipients regard need and urgency, for instance.

The reasons for focussing on liver and kidney potential recipients were practical; there are more of these potential recipients, so a larger pool of potential participants. A further reason for focussing on these recipients was that staff from these departments were forthcoming with assistance, and provided access to patients during clinics. Also, the number of donated livers and kidneys each year suitable for transplantation is much greater than for other organs⁴⁸⁶(a person can generally donate two kidneys once dead, and livers can also be, though are not always, split in two). Since the majority of transplants from deceased donors in the UK are liver or kidney, focussing the study on these meant that views from individuals belonging to majority of those on the waiting list were obtained.

A further limitation of the sample for the potential recipient group was that seriously ill potential recipients were excluded because of the risk that interviews would prove particularly burdensome. Participants then, although ill enough to be potential candidates for transplantation, were not in urgent need of a transplant. It is possible that the views of people who urgently require transplants could differ from those whose need for a transplant is less urgent. This necessary consideration for the potential

⁴⁸⁴ Kusiak A, Dixon B, and Shah S, 'Predicting Survival Time for Kidney Dialysis Patients: A Data Mining Approach', *Computers in Biology and Medicine* 35 (2005) pp311-27

⁴⁸⁵ Simpson MA and Pomfret EA, 'Checking the Harness: Safety for Living Liver Donors', *Liver Transplantation* 18 (2012) pp15-19

⁴⁸⁶ NHSBT (2012) 'Latest Statistics', Available at: http://www.organdonation.nhs.uk/ukt/statistics/latest_statistics/latest_statistics.jsp, Last Accessed: 31/10/2012

burden of participation may have prevented access to a potentially different set of views.

11.1.3 General

Due to the difficulties in recruiting sufficient numbers of participants across all categories except staff, it was not easy to actively seek out participants who had specific characteristics; ultimately it was necessary to settle for those who were willing to participate.

The study *may* have been improved by using more controversial scenarios during interviews. Alternative scenarios could have been presented, featuring more explicitly the sorts of conditional donations that people might be expected to find objectionable, controversial, or feel strongest about. However, a balance had to be struck between provoking strong reactions and concerns for welfare of the participants. Having a scenario based upon alcoholism for example could, however, be upsetting to participants who have experience of alcoholism, particularly potential recipients. The scenarios were therefore designed to be less specific, and talked about responsible lifestyles, for example, instead. Similarly, one of the scenarios originally referred to a specific religion, but the Research Ethics Committee requested that this be changed to something more generic to avoid potential offense to participants. Although avoiding offending participants is obviously important, part of the problem of conditional donations is that they *can* be offensive. By altering the scenarios to be more generic some of the strongest reactions to specific conditions may have been missed by the study because the participants were not prompted to comment on them, and may not have thought to do so. On the other hand, this more open approach did have an advantage; it allowed participants to explore their own ideas of offensive conditions, which **reduced the risk of the researcher's pre-conceived ideas** influencing the findings.

11.2 Transferability of conclusions

As discussed, in section 8.3 qualitative research is often criticised for not being generalisable. This is a particularly difficult criticism to avoid when the sample size is small, not representative, and therefore unlikely to elicit the full range of views held by the population from which the sample was drawn. It is not, however, the purpose of qualitative research that its results are generalisable.

Using qualitative methods was appropriate for this project, given the aim of producing good quality philosophy that can provide practical recommendations for policy. To expect the findings and conclusions to be generalisable in the way that the conclusions of a quantitative study may be is to misunderstand the research paradigm. Rather than comparing the research and conclusions to quantitative research, the success and limitations of using qualitative data are best established by comparing the project to a traditional applied philosophy approach.

When compared with conventional applied philosophy, the project seems to build on the strengths of this approach, yet avoid some of the weaknesses. The qualitative data were given a relatively restricted role, and were mostly used to provide and challenge potential lines of argument. Arguments were first assessed according to their rational justifications rather than widespread support amongst participants, and it is rational justification that provides generalisability in philosophy. By providing additional lines of argument the data lead to a more complete philosophical analysis than would otherwise have been achieved. For instance, some participants thought that it was acceptable to give priority to children, and this was something not originally considered in the philosophy chapters. Although this argument was ultimately rejected, it was given fair consideration. This meant that arguments beyond those originally conceived by Moorlock were considered. This is not to say that every conceivable line of argument has been pursued or considered. Indeed it seems likely that, in virtue of the difficulties with the South Asian sample, that some particularly interesting lines of

argument may have been overlooked. This could be an interesting area for future research, particularly given the need to engage the South Asian population with organ donation.

Qualitative data were also used to gain some insight into the acceptability of certain lines of argument. For example, the argument in Chapter 7 for avoiding levelling down and negative loss was very similar to an argument put forward by participants for avoiding waste. This suggests that this line of argument may receive support from some stakeholders, which played a role in deciding the final recommendations.

Nonetheless, caution is required when making claims about the transferability of the empirical conclusions. Although it would seem reasonable to think that they could apply to transplantation on a broader level within the UK, this is not *necessarily* the case.

11.3 Positives

Despite its limitations this project also has some strong positive features. First, taking a philosophical approach to interviews was generally successful in engaging the participants with the underlying principles. This resulted in data that was generally very suited to the purpose of being used alongside philosophy, and also made for some interesting discussions during interviews. Not all participants were able or willing to engage to the same level, but many participants appeared to enjoy debating the issues, **and several participants commented afterwards that it had 'really made them think'**⁴⁸⁷. The semi-structured interviews lent themselves well to this philosophical approach, because it made it possible to pitch interviews at the appropriate level. Some **participants were capable of very sophisticated ethical thought, whereas others'** responses seemed much more driven by gut reaction and intuition. Engaging with participants on an appropriate level was necessary to elicit the most useful data from

⁴⁸⁷ Transplant staff, in particular, seemed to appreciate the opportunity to discuss ethical issues, and Moorlock has since been invited to facilitate ethical discussion and present at Reflective Practice Days for transplant coordinators.

them. Occasionally during interviews, questions were pitched at the wrong level, which resulted in blank expressions or confusion from the participant, so it was necessary to have the option of rephrasing questions to make them more understandable.

A further positive feature of the study is the variety of transplant staff that participated. Nursing staff from donation and recipient perspectives were represented, as were surgeons, physicians and intensivists. This meant that a fairly wide range of perspectives was obtained from this category, and this led to some variation in views, as mentioned in Chapter 9.

Despite its limitations, the project has resulted in the development of 8 key recommendations, which are presented in the next chapter.

Chapter 12 - Framework and Conclusions

The discussion in this thesis has resulted in 8 key recommendations, which are now presented (see also Table 32) and explained. The conclusions to the thesis overall are presented at the end of this chapter.

Recommendation 1

Altruism should no longer be regarded as the only acceptable motivating factor for deceased organ donation. Not all altruistically motivated donations are ethically acceptable, and not all non-altruistically motivated donations are unacceptable.

Chapters 4 and 5 concluded that altruism alone cannot consistently be used to determine whether organ donations are ethical or not. There are competing philosophical accounts of altruism and disagreements over what it means for something to be altruistically motivated. It is clear, however, that an altruistic act is one motivated, to some extent, by a genuine concern for the interests of other people. The **DH's policies on conditional and directed donations seem to reflect** the view that altruism can take different forms, and the recent Nuffield report also endorsed this view. The set of behaviours that could be classed as altruistically motivated is large. To say that all altruistically motivated acts are ethically acceptable is too simplistic. For **instance, donating one's time to a charity may be altruistically motivated, but it would not necessarily be ethically acceptable if it meant that one neglected one's children.**

Under a broader definition of altruism that the DH would have to use in order to remain consistent, altruism cannot by itself determine the ethical acceptability of something. It was argued in Chapter 5 that the DH ought to accept that altruism can be rationally or emotionally motivated, and that there can be a sliding scale of altruistic motivations ranging from pure altruism to more self-interested but still other-regarding reasons. **The Nuffield Council's report defines altruistic behaviour as being "motivated by concern for the welfare of the recipient of some beneficent behaviour, rather than by**

concern for the welfare of the person carrying out the action”⁴⁸⁸, and this would be a suitable account of altruism for the DH to adopt. Crucially, however, it only considers whether an action is altruistically motivated or not – other principles may be required to justify why things such as payment are not considered acceptable. This may make the principle of altruism inappropriate for single-handedly defining which donations are acceptable, but this simply reflects the limited scope of the concept.

It is also misguided to regard altruism as the only ethically acceptable motivator for organ donation. The primary aim of the organ donation system is not to promote altruism, but to obtain organs. Living in a society where all organ donation was altruistically motivated would be desirable, but so would living in a society where there were more organs available for transplantation. Motivators such as solidarity, reciprocity or even a degree of self-interest would not necessarily reduce the amount of altruism in society, but may increase the number of donated organs. It seems contrary to the primary aim of the organ donation system, then, to insist that only altruistic donations are acceptable. As altruism is ingrained in transplantation practice a bold and sudden change of policy in favour of accepting other motives may meet resistance. However, this alone is not an argument for failing to embrace change. Recent marketing campaigns by NHSBT have appealed to other motivations⁴⁸⁹ and this can be seen as both reflecting and shaping changing attitudes.

Recommendation 2

Accept conditional donations where the alternative is turning away medically useable organs (subject to the conditions set in Recommendations 7 and 8).

⁴⁸⁸ Nuffield Council on Bioethics, (2011) *op. cit.* p139

⁴⁸⁹ Recent marketing on organ donation has explicitly appealed to reciprocity. This is stated in: NHSBT (2009) 'National Organ Donor Campaign Board Paper', Available at: http://www.nhsbt.nhs.uk/downloads/board_papers/sept09/NATIONAL_ORGAN_DONATION_CAMPAIGN_BOARD_PAPER_Sept09.pdf, Last Accessed: 24/10/2012, and evidenced by NHSBT (2009) 'NHSBT Prove It Campaign Leaflet', Available at: <https://www3.access-24.co.uk/Downloads/OLC209P-1.PDF>, Last Accessed: 24/10/2012

When a donation is 'iff' conditional, transplant staff are faced with a choice of either accepting the donation (and therefore the conditions) or turning the donation down. It has been argued in Chapters 7 and 10 that rejecting the organ is levelling down and benefits nobody. Accepting a conditional donation that otherwise would not be donated benefits everybody on the waiting list in some way, and other potential negative effects may be minimised (see Recommendations 3 and 5).

Some conditions do not affect the final allocation of donated organs: a condition specifying that only children should be given the organs would not alter allocation if the organs were only medically suitable for children. Accepting such donations is at odds with existing policy, but not the actions of the doctors involved in the 1998 case. In the 1998 case, although the donation went ahead on the condition that the organs were only allocated to white people, the patients at the top of the waiting lists were all white anyway. In a situation like this, it is not true that the organs are being donated in a way that prevents them being allocated according to greatest need⁴⁹⁰. This means that fairness in terms of outcomes to those waiting for organs is no less than if the same donation was made unconditionally. Recommendation 1 proposed that altruism should not be considered the only ethical motivation for organ donation. Conditional donations *can* be altruistic, but alternatively may be motivated by solidarity, reciprocity or self-interest. Even non-altruistically motivated conditional donations should be accepted if they do not affect allocation, because doing so provides life-saving or improving benefit without introducing additional unfairness.

Some conditional donations do affect allocation, and do introduce unfairness. The claim that these donations should also be accepted is bolder, but may be justified with reference to the primary aim of the transplantation system, which is to save and improve lives. If accepting conditional donations results in additional donations that

⁴⁹⁰ Although, quite wrongly in this specific case, this was one of the DH Panel's objections to conditional donations.

would otherwise not occur, then the medical needs of all people who require transplants are better met. Deviation from impartial principles may therefore be justified on the same grounds as the impartial principles themselves. If allowing some partiality is the best way to meet the aims of an otherwise impartial system, then allowing partiality in some instances can be impartially justified. Many participants in the embedded stakeholder study supported this line of reasoning, but it is important to remain aware **that organ donation/transplantation is just one of the NHS's activities, and** compromises that benefit transplantation (such as accepting conditional donation), may have wider undesirable implications. Although there is a rational argument for occasionally deviating from a strictly impartial system, it is important that the public at large also understand and support this justification for what might otherwise appear to be an endorsement of unacceptable attitudes.

Recommendation 3

Some participants were concerned that by accepting the conditions placed on organ donations the NHS as an institution might be endorsing those conditions. This concern is, however, misplaced and should not be used as a reason for objecting to conditional and directed donation. The NHS should, however, be aware of public **perceptions** of its role in conditional donations, and should publish details (type of condition, and frequency) of all conditional donations periodically, in the interests of transparency.

Contrary to a concern raised by some participants that by accepting objectionable conditions the NHS would be dirtying its own hands, it was argued in chapters 7 and 11 that the NHS should not be considered to be endorsing, tacitly or otherwise, the conditions placed on donations. Some (but not all) conditional donations will reflect regrettable or even immoral motivations such as racial hatred, and whilst the NHS as an institution should never appear to endorse these motivations, it is not obvious that accepting conditional donations is perceived in this way correctly. It is the person placing the objectionable conditions who acts wrongly, not the NHS. Unfortunately, **whether or not the NHS accepts organs with these conditions, the donor's wishes are**

granted, insofar as whoever s/he is trying to exclude will still not receive the organs. By accepting the donation and the conditions, the NHS can legitimately claim to be bringing about the best outcome from a non-ideal situation. Since conditional donation benefits everybody on transplant waiting lists, the NHS distributes some benefit to all potential recipients, even the ones who the donor may have wanted to disadvantage.

Despite it being argued that the NHS would not be endorsing the conditions placed on donations, there is still a risk that the public may perceive the NHS to be doing so. Some may therefore argue that the NHS ought not involve itself *in any way* with morally objectionable conditional donations, and must therefore reject these donations. It has been argued that the benefits of saving additional lives may outweigh the possible damage to public perceptions, but further research would be useful to establish the extent and consequences of possible damage to public perceptions, the best ways to minimise any damage, and how the public would want to balance these concerns.

In order to avoid a perception of underhandedness that could lead people to believe that the NHS is trying to cover up discriminatory practices, the NHS could accept conditional organ donations openly and transparently. If the NHS attempted to keep conditional donations and subsequent conditional allocation secret, one can imagine the potential media stories if it was ever discovered. The most transparent way to handle conditional donations would be for the NHS to publish suitably anonymised details of each conditional donation. This would only need to give a general impression of the conditions placed (e.g. type of condition and number of times it occurred). At the same time, the NHS ought to distance itself from objectionable conditions and explain that the reasons for accepting them are merely a result of the organ shortage. Although placing details of conditional donations in the public domain might be a constant reminder of discriminatory donations and may therefore dissuade some people from donating, there is also the possibility that anyone opposed to the discrimination behind

conditional donations might combat this simply by donating unconditionally. This, again, is an area where further evidence on the likely consequences would be useful.

Recommendation 4

Unconditional donation should remain the default type of donation. This allows organs to be allocated according to current policy, a policy which provides a balance between efficiency and fairness constraints.

Conditional donations normally prevent allocation according to the criteria that are thought to reflect all relevant considerations. A condition could result in organs being allocated to patients who are not in immediate urgent need, at the cost to patients who are. Similarly a condition could result in an organ being allocated to someone with whom there is not an optimal tissue-match, which may increase the likelihood of post-transplant complications to the extent that the transplant surgeon decides not to proceed. A condition could therefore result in organs being wasted if nobody on the waiting list met both the criteria of the conditions and the medical criteria for appropriate transplant risk. For these reasons it is preferable for organs to be donated unconditionally, and for the conditional donation not to be used to promote organ donation. It is desirable that if conditional donations are accepted, that they remain the exception rather than the rule.

Conditional donations should not be accepted without question. Transplant staff and the donation team should explain to those making conditions that there are advantages to organs being donated unconditionally. Misunderstandings about allocation policy should be corrected if this is likely to result in unconditional donation⁴⁹¹.

⁴⁹¹ There could also be an argument for misunderstandings of allocation policy being corrected in all cases, regardless of the impact on conditionality.

Recommendation 5

Offsetting the potential harms of conditional donation should be considered

Accepting certain conditions may potentially cause unfairness, and the NHS could be perceived to be supporting the conditions. Although it has been argued that accepting a racist condition does not entail that the NHS is racist, any resulting unfairness may cause some people to consider the acceptance to symbolically support racism⁴⁹². Forms of offsetting any unfairness may help to further distance the NHS from such conditions. Furthermore, offsetting may provide a disincentive for people wishing to place conditions on their donation. For instance, someone wanting to disadvantage a particular group may feel less inclined to place conditions if she was aware that the action would be taken to counter this disadvantage⁴⁹³.

Offsetting could take various forms, and the appropriate form would depend upon what was needed to be offset. If it became apparent that people, for instance, thought that the NHS was supporting racism by accepting a racist donation, the NHS could simply make a statement condemning the racist motivation behind the donation. If more offsetting was required, the NHS could make a donation to an anti-racism charity⁴⁹⁴. An alternative form of offsetting might involve allocating the next available organ to somebody of a different race, if this was possible without significantly undermining existing allocation policy, to offset the previous allocation. The exact forms of offsetting required can only be established once the implications of allowing conditional donations are known (see Recommendation 8). As discussed under

⁴⁹² Wilkinson TM, (2007) 'Racist Organ Donors and Saving Lives' *op. cit.* pp63-74

⁴⁹³ Though it is equally possible that a person might feel that placing conditions is more acceptable given the measures in place to combat unfairness; we can only speculate at this stage and introduce careful monitoring to determine trends in either direction.

⁴⁹⁴ Although some might argue that this is not a good use of public resources, one could counter this claim with evidence that transplantation is a cost-effective treatment and that the cost of 'offsetting' might be outweighed by the savings created by having additional organs available. Kidney transplantation, for instance, is much cheaper than keeping a patient on dialysis: NHSBT 'Cost-Effectiveness of Transplantation', Available at: http://www.organdonation.nhs.uk/newsroom/fact_sheets/Organ_Donation_Registry_Fact_Sheet_7_21337.pdf, Last Accessed: 08/03/2013

Recommendation 3, there is the potential for harm to the perceived integrity of the NHS, and this harm may be difficult to offset or repair. It would therefore also be prudent to conduct wide scale research on the potential public reaction to conditional donations, and the possible effects this may have on perceived integrity of, and public trust in, the NHS.

Recommendation 6

Conditions that favour family and friends are acceptable. These conditions ought to be factored into allocation policy.

There are good reasons for permitting directed donation to family members and close friends on the basis of philophilic partiality. This is largely compatible with current policy following the 2010 guidance. Current policy only permits requests for directed allocation, rather than a truly conditional donation. The policy is very clear that the next-of-kin must agree to donate even if the organ is not suitable for the requested recipient. There is, however, nothing inherently objectionable about conditionality per se, and where the condition reflects appropriate partiality it seems entirely reasonable to permit this donation. People regularly do things for their loved ones that they would not do for other people. Accepting a conditional donation of this nature can be justified by the acceptable nature of the condition content, rather than the appeal to avoiding waste needed to justify accepting other types of condition.

Directed allocation is only considered if it is specifically requested by the donor before death, or the next-of-kin. At present, SNODs are not permitted to raise the possibility of directed allocation with the next-of-kin – it can only be considered if the next-of-kin request it themselves. Directed allocation to close friends or family members ought to be factored into allocation policy. It should, therefore, become routine, at the time of donation, for next-of-kin to be asked if the deceased has a close friend or family member who they would have wanted their organs to be allocated to.

There should also be an additional question on the ODR to specify that one would like priority for family and close friends to be considered.

It should be noted that a situation where someone who dies has a relative or close friend on a transplant waiting list is rare. The HTA estimates that it may arise once every two and a half years, so this is not something that will have a significant impact on overall organ allocation.

Recommendation 7

Preferences expressed by donors may be followed but the implications for super urgent allocations should be assessed before deciding whether or not to do so.

Not all conditional donations are 'iff' conditional. Some donors could potentially express a preference that a certain type of recipient is given priority, but that if this is not possible, the organ should be allocated according to the standard criteria. When a donation has a preference like this attached to it, as opposed to a true condition, the primary reason for accepting and allocating according to the preference – that an organ is obtained that otherwise would not be – is lost. There is therefore, at first glance, less reason to allocate according to preferences than there is a true iff condition. What has to be considered, however, is that the next-of-kin **are able to 'convert' a preference into** a true condition if they are informed that the preference will be ignored.

It therefore seems reasonable to consider the consequences of accepting the preference before making a decision on whether to follow it. If the preference is likely to deprive someone who urgently needs a transplant, then this ought to be explained to the next-of-kin in the hope that they will choose to donate unconditionally. If, following this discussion, the next-of-kin agree to donate unconditionally then the donation can be allocated according to standard principles. If, in contrast, they choose to make the donation iff conditional, then Recommendation 2 should be followed.

If the preference was unlikely to deprive anyone of an urgent transplant, then, bearing in mind that the next-of-kin can potentially make the donation iff conditional anyway, the preference ought to be followed and the organs allocated accordingly. Even preferences like this should not be accepted without objection. The SNOD should discuss with the next-of-kin why it is generally preferable to have unconditional donations and to allocate according to the standard principles.

Recommendation 8

A trial period to assess the impact of conditional donation should be implemented.

Data monitoring should continue after the formal trial period, and the effects of conditional donation should be continually evaluated.

Many of the arguments about conditional and directed donation incorporate empirical claims. Allowing these donations may increase donation rates, decrease donation rates, or have no impact upon donation rates. Although some arguments make claims about likely outcomes⁴⁹⁵, outcomes are actually difficult to predict. There is evidence to suggest that perceived transparency and fairness can affect willingness to donate⁴⁹⁶, but no evidence to suggest how conditional donation would affect perceived transparency and fairness. In the absence of empirical evidence, valid arguments that incorporate a concern for likely consequences lack the factual premises required to make them sound.

It is therefore proposed that the recommendations above are implemented during a trial period. Careful data monitoring would ensure that the impact of allowing these donations could be measured, and this could then help to determine whether arguments in favour of permitting or prohibiting these donations are sound.

⁴⁹⁵ Radcliffe-Richards J, (2012) *op. cit.*

⁴⁹⁶ Boulware LE et al., (2007) *op. cit.* pp1778-87

The trial period could take two forms, which could be implemented in stages. First, donor co-ordinators and transplant staff could accept conditional organ donations if and when they occur. To do so would be consistent with '**removing barriers**' to organ donation. The present policy of refusing to accept conditional donations results in medically useable organs being wasted that could otherwise be used to save and improve lives, albeit not necessarily the same lives as if they were given unconditionally.

Second, conditional and directed donations *could* be actively employed as a means of promoting organ donation and the resulting conditions/directions recorded on the Organ Donor Register (ODR). At present, some next-of-kin may refuse consent for organ donation *because* they are aware that they are not allowed to specify the recipient. Similarly, some people may not join the ODR because they are concerned about the types of people who may receive their organs. Informing the public that they are now able to have some say on who receives their organs could encourage the reluctant to donate. One could imagine various marketing campaigns that could focus on helping people who are currently disadvantaged in organ allocation.

The barrier removing approach would be lower impact than the second approach, and would involve less risk. If it could be shown that the first approach had no negative impact upon overall donation rates, then the second approach could be considered for subsequent trialling⁴⁹⁷ if conditional donation was thought likely to increase donation rates without resulting in massively unfair patterns of allocation.

As was discussed in Chapter 3, the arguments in this thesis started with the assumption that it is good to save and improve lives, and that increasing the number of organs available for transplantation can increase the number of lives that can be saved or improved. If a change in policy demonstrably increases the number of organs

⁴⁹⁷ This would, however, require careful implementation. If people joined the ODR during the trial period and specified conditions when doing so, their registration would require reconsideration if it was subsequently decided that conditional donations would not be permitted after the trial period.

available for transplantation then, unless there is a good reason to prohibit it, it ought to be permitted. The results of the trial would provide key information for this argument.

A trial of conditional organ donation would have to collect data on several factors. The first stage of the trial would have to record the number of people choosing to place conditions, the types of conditions that were placed, and any impact that this had on the overall number of donations. It would also be necessary to have an awareness of media and public reactions to any incidents that occurred, to gauge possible wider consequences.

The second stage of the trial would have to gather more complex data, but again the key concerns would be whether allowing conditional donations would encourage people to donate organs who otherwise would not do so, and whether this had a positive or negative overall impact on organ donation rates. If this trial was likely to result in a significant increase in the amount of conditional donations, it would be important to monitor any emerging patterns of conditions. Emerging patterns of conditions could potentially provide arguments against conditional donation (if it transpired that certain types of people stood no chance of receiving an organ), but they could also provide an insight into the most effective ways to market conditional donation and organ donation more generally.

The precise details of the trial would require careful consideration of scope, timeframes and numbers. It would also need to be decided whether the trial would initially be implemented nationwide, or on a regional basis in order to allow for comparison with control regions. If conducted appropriately a trial period could provide reliable empirical data that many of the arguments surrounding conditional donation are currently lacking.

If the trial did suggest that conditional donations were acceptable to the public, and that they would lead to organs being donated that previously would not have been, then it may be tempting to simply regard conditional donation as a good thing and therefore permit it. However, the changing patterns of donation discussed in the previous recommendation may not become visible over the course of a trial period, or other factors in society may contribute to further changes in donation patterns after the trial period has finished. Because conditional donation has the potential to result in discrimination, unfairness and disadvantage, it is crucial to continually monitor its effects. If it transpired that conditional donations were resulting in widespread unfairness, decreased transplant efficiency and/or increased waste, then policy would need to be reconsidered.

Table 32 - Summary Recommendations

<p><u>Recommendation 1</u></p> <p>Altruism should no longer be regarded as the only acceptable motivating factor for deceased organ donation. Not all altruistically motivated donations are ethically acceptable, and not all non-altruistically motivated donations are unacceptable.</p>
<p><u>Recommendation 2</u></p> <p>Accept conditional donations where the alternative is turning away medically useable organs (subject to the conditions set in Recommendations 7 and 8).</p>
<p><u>Recommendation 3</u></p> <p>Some participants were concerned that by accepting the conditions placed on organ donations the NHS as an institution might be endorsing those conditions. This concern is, however, misplaced and should not be used as a reason for objecting to conditional and directed donation. The NHS should, however, be aware of public <i>perceptions</i> of its role in conditional donations, and should publish details (type of condition, and frequency) of all conditional donations periodically, in the interests of transparency.</p>
<p><u>Recommendation 4</u></p> <p>Unconditional donation should remain the default type of donation. This allows organs to be allocated according to current policy, a policy which provides a balance between efficiency and fairness constraints.</p>
<p><u>Recommendation 5</u></p> <p>Offsetting the potential harms of conditional donation should be considered</p>
<p><u>Recommendation 6</u></p> <p>Conditions that favour family and friends are acceptable. These conditions ought to be factored into allocation policy.</p>
<p><u>Recommendation 7</u></p> <p>Preferences expressed by donors may be followed but the implications for super urgent allocations should be assessed before deciding whether or not to do so.</p>
<p><u>Recommendation 8</u></p> <p>A trial period to assess the impact of conditional donation should be implemented.</p> <p>Data monitoring should continue after the formal trial period, and the effects of conditional donation should be continually evaluated.</p>

12.1 Thesis Conclusions

The aim of this thesis was to conduct an empirically informed ethical analysis of conditional and directed deceased organ donation. This required using qualitative data from relevant stakeholders to create a philosophically-focussed discussion that took seriously the views of those likely to be affected by the issues raised. To this extent, the aims of the project have been achieved.

The aims were met by first conducting an initial philosophical analysis of the key issues. This covered the lines of argument thought most important and relevant by Moorlock. The empirical study was then used to gather data to provide additional lines of argument that Moorlock had not considered or given due weight to, and to provide facts about the sorts of arguments and reasoning acceptable to key stakeholders. Finally, these data were used alongside the earlier philosophical analysis in order to aid and enhance further philosophical discussion. One of the difficulties for this project was deciding upon a suitable method to combine the philosophy and the qualitative data, but the final method, although philosophically-driven, gave the qualitative data opportunity to play a significant role. Ultimately, many of the lines of argument suggested by the data could not withstand philosophical scrutiny.

The approach taken was specifically chosen to overcome some of the shortcomings of theoretical philosophy when it comes to addressing applied and practical ethical problems. The qualitative data met this aim, insofar as it has helped the philosophical discussion to produce a number of recommendations that could form part of a practical policy on conditional and directed donations.

The final recommendations reached are not necessarily unique. Wilkinson has argued for similar conclusions⁴⁹⁸, and Radcliffe-Richards has also discussed the issue in detail. **Wilkinson's conclusion is that there is a good reason (on the basis of avoiding**

⁴⁹⁸Wilkinson TM, (2012) *op. cit.*

levelling down) to accept conditional donations if they result in organs being donated that otherwise would not be. Wilkinson fails, however, to provide guidance on how to handle preferences as opposed to iff conditions, and also does not discuss in detail directed allocation to family members and close friends. Radcliffe-Richards argues that the traditional reasons to not accept conditional and directed donations are not convincing. She, however, stops short of making clear recommendations for handling conditional donations when they do arise⁴⁹⁹. Both Radcliffe-Richards and Wilkinson used purely theoretical arguments, however, without the inclusion of any stakeholder views. The combination of stakeholder views with the theoretical philosophy in this project has resulted in findings and the consideration of arguments that neither Wilkinson nor Richards consider, such as the misunderstanding of the roles that medical data and moral judgements play in allocation policy. Taking wider considerations such as this into account has hopefully resulted in a richer discussion than would otherwise have been achieved. Using stakeholder views has also ensured that the recommendations are not merely the personal opinions of a sole researcher.

One original contribution that this thesis has made is a detailed assessment of altruism in the context of organ donation policy, particularly in relation to conditional donation. The theoretical underpinnings of organ donation policy have been examined and criticised, and ultimately it has been argued that altruism should not be used in the way that it currently is. This is a bold recommendation, and calls into question one of the traditionally accepted principles of organ donation (at least in the UK). Altruism is, however, an ingrained and embedded principle and may be hard to dislodge from its central role – but a frank assessment of the principle has shown it to be incoherent and unnecessary.

⁴⁹⁹ She goes on to discuss a further debate, which she suggests may render any further discussion of conditional donation redundant. This does not, however, mean that the discussion of conditional donation in this thesis is redundant, as her argument is for a system involving reciprocity. Given that the current system is not based upon reciprocity, consideration of conditional donation remains important and worthwhile.

The project has resulted in eight key recommendations for policy relating to conditional donations. Many of the recommendations would require a change to current policy. The justifications and explanations provided demonstrate that the recommendations are well-reasoned and well-intentioned, and not merely an acceptance or **endorsement of the public's** various prejudices. The recommendations have taken seriously the views of stakeholders, and provide guidance that can be applied to transplantation in the UK.

12.2 Reflexivity

As discussed in Chapter 1, it is important to consider the impact that the researcher has on the research, and vice versa. The entire research process will have been affected by my own values and perspective, and being open and transparent about these allows me to reflect on my impact on the research, and allows others to also gain an insight into my impact.

I do not think I approached data analysis with a particular conclusion in mind, but my own views will have shaped the analysis to some extent. I am a white, middle-class male with no prior personal experience of transplantation. I do, however, hold strong views on organ donation, and consider donating organs to be the right and obvious thing to do if one dies in a way that permits it. Furthermore, I believe that transplantation ought to use an opt out system based upon reciprocity, where people who choose to opt out of organ donation also opt out of receiving transplants. For the purposes of this study, I tried to set these views aside and assume nothing in particular about the right organ donation system. This was necessary because it would have led immediately to the conclusion that anyone trying to withhold their organs for donation for any reason was acting wrongly. Although this could have been the starting point for this thesis, it was more useful to focus the discussion within the confines of the donation system in existence today.

I did not speak with participants about my own views on organ donation before or during interviews, and tried to take the same approach of providing counter arguments and playing devil's advocate whether the participants' views were the same as mine or not.

Before commencing data collection I undertook a placement at the participating Transplant Centre which allowed me to increase my understanding of the issues faced by people involved in transplantation. The placement also allowed me to acclimatise myself and learn how to engage with and talk to transplant staff. During this placement, and during various talks and facilitated discussions⁵⁰⁰ at the Transplant Centre, I was cautious to not express my own personal views on organ donation, as I viewed all staff members as potential participants.

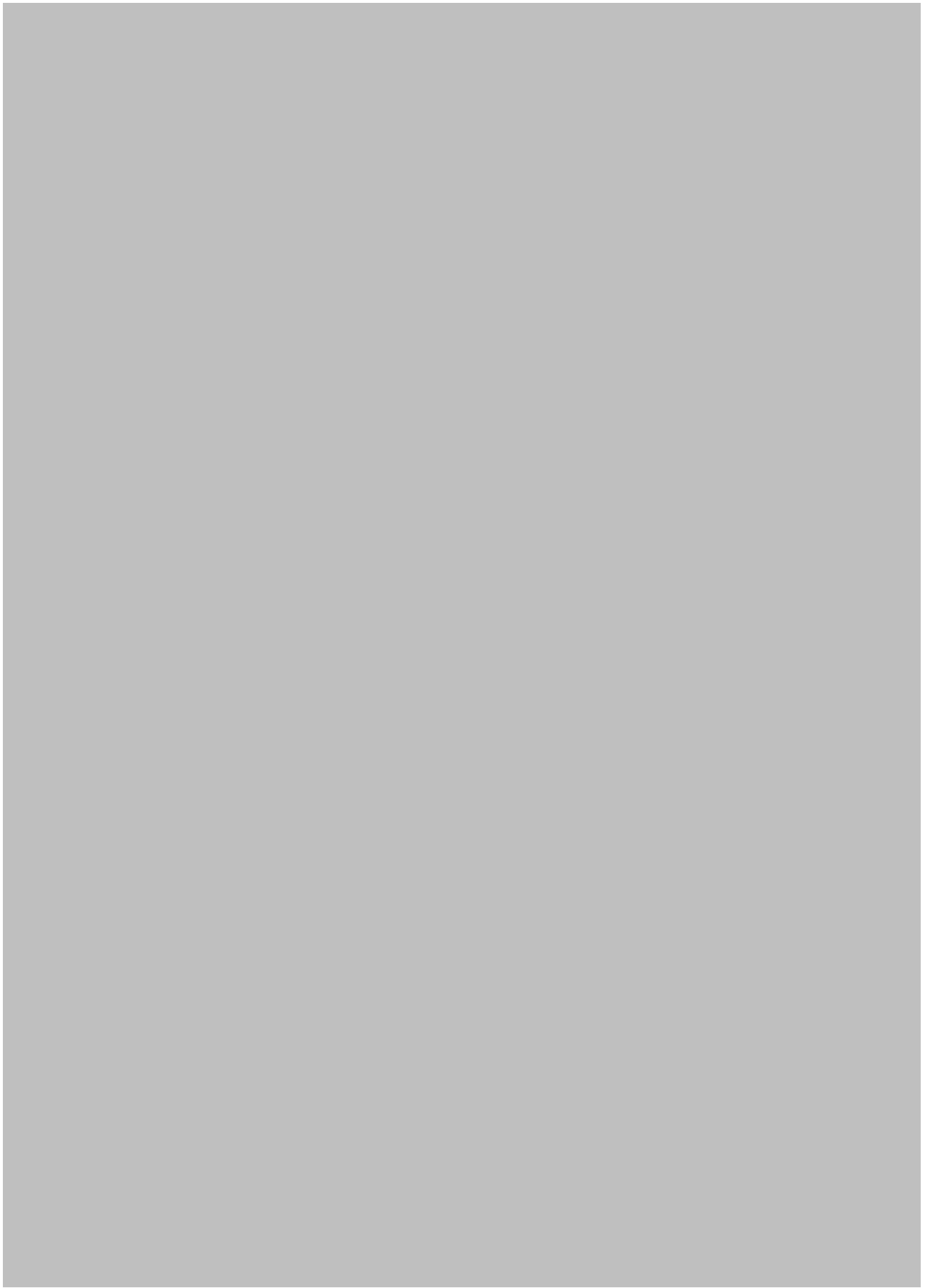
Before this, my exposure to hospitals had been fairly limited; I have enjoyed good health, and I did not know anyone who had needed a transplant. This may have led to a tendency to look at the ethical issues in an abstract way, without really considering the fact that for some people these are very real and immediate life and death issues. Visiting the hospital wards and seeing the people affected by waiting for transplants, and people who have received the benefits of transplants, certainly made me question my previous attitudes towards the issues and gave new perspectives. I initially approached the problem of conditional donation from a principled perspective, valuing things like equality, fairness and due process as being the most important factors for organ allocation. After seeing patients on the transplant ward my views changed to favour maximising the number of available organs, but then changed again as I spent more time away from the wards.

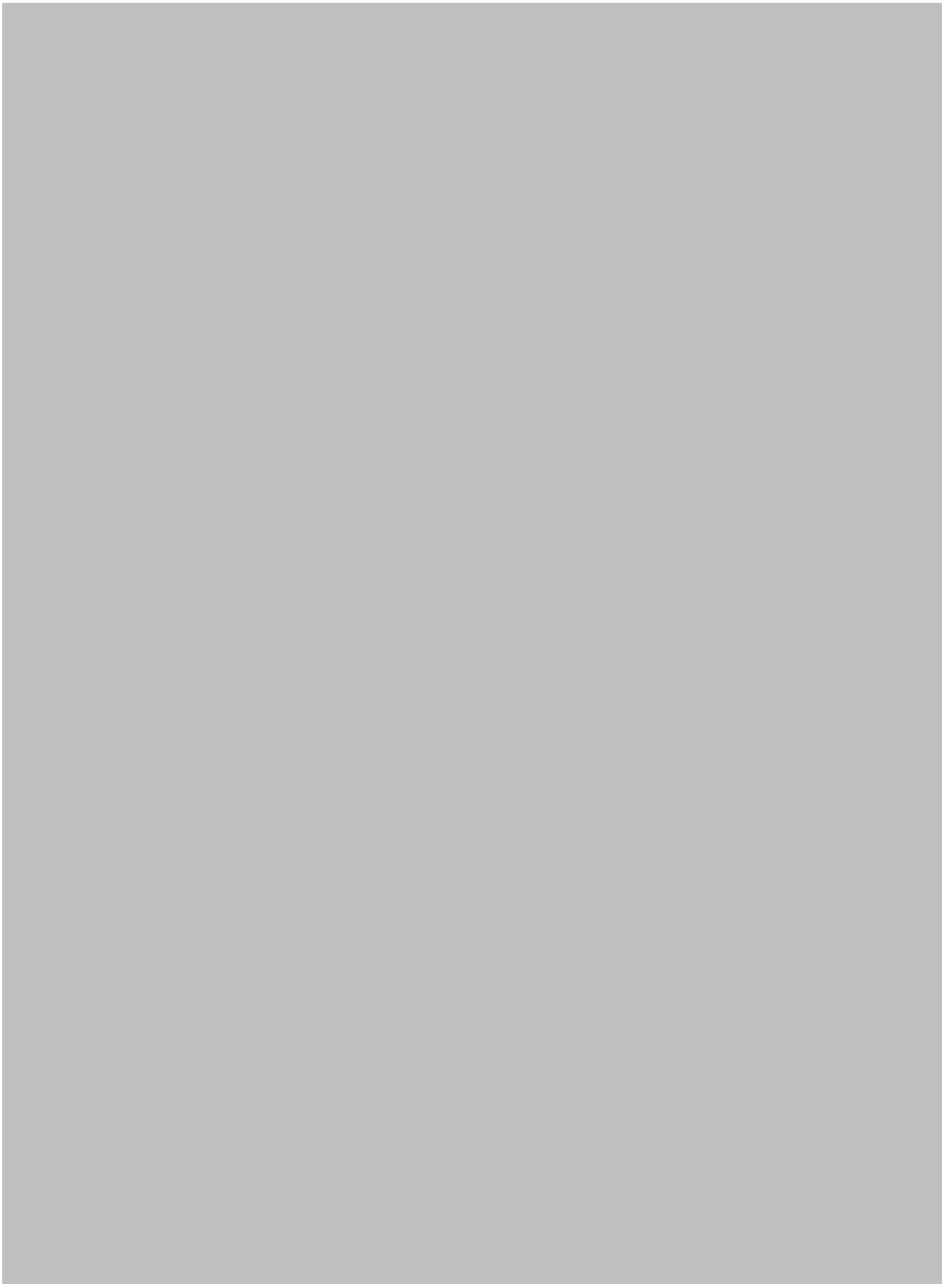
⁵⁰⁰ This PhD was partly funded by the AHRC under the Collaborative Doctoral Awards scheme. This means that it was also partly funded by Queen Elizabeth Hospital Birmingham Charities. The aim of this scheme is to "encourage and develop collaborations between Higher Education Institutions and non-academic organisations". Accordingly, the project was designed with Queen Elizabeth Hospital Birmingham Charities to be useful for the organisation and was co-supervised by Simon Bramhall. As part of 'placement' in the non-HEI, an ethics forum was established at the transplant centre by me, with the encouragement and support of my supervisors, for the discussion of ethical issues arising in transplantation. Several meetings were held, including two to respond public consultations, but the topics were carefully picked to avoid discussion of issues related to this thesis to avoid biasing the interviews.

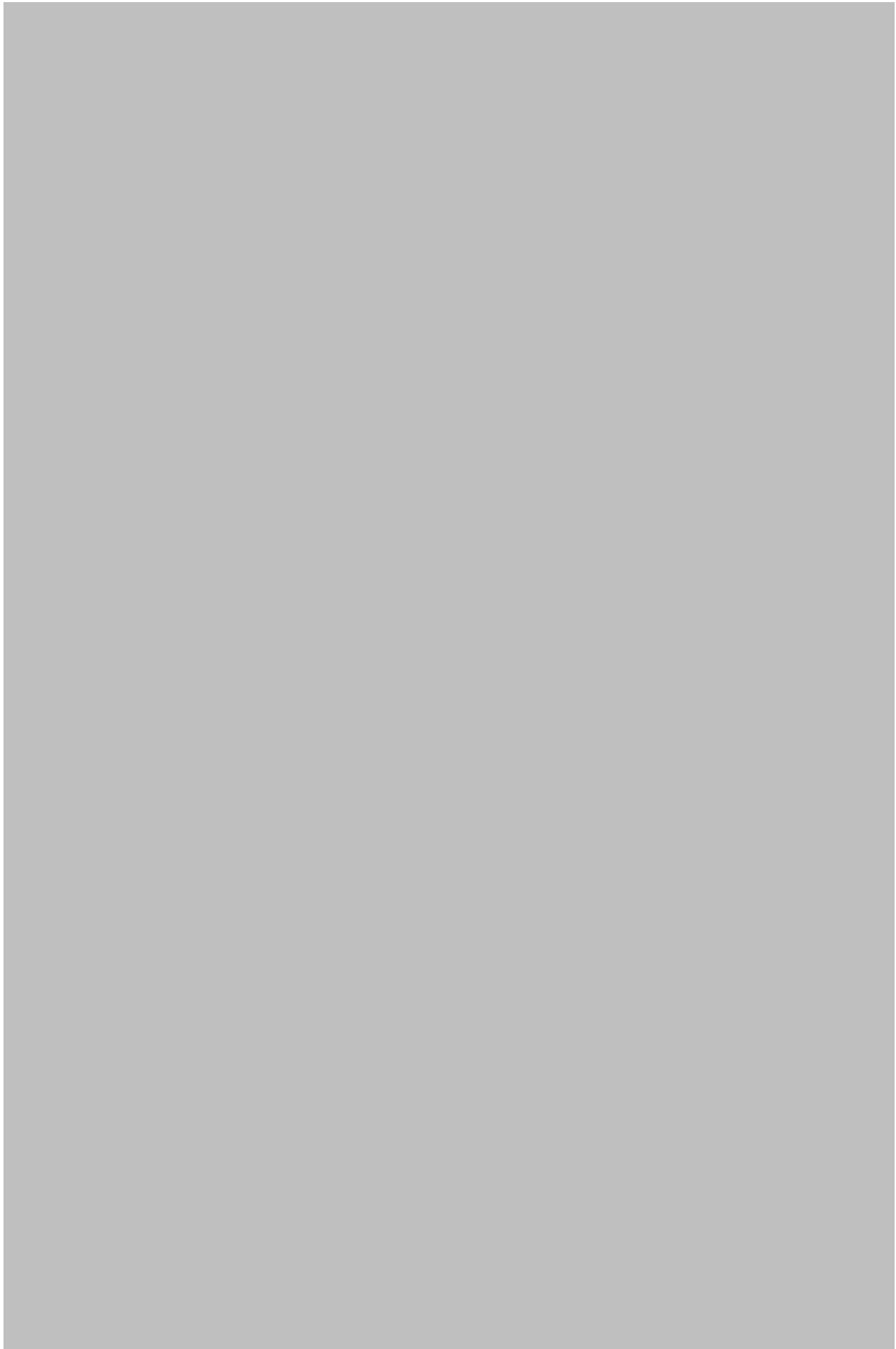
An outcome of taking the empirical bioethics approach is that I have ultimately argued for conclusions that I do not think I would have done if I had taken a purely theoretical approach. This may show that the approach has been partly successful, but it has also resulted in me proposing recommendations that I would previously have considered unacceptable. I have provided arguments in favour of accepting even those conditions that are badly motivated, such as racist conditions. This does not sit easy, but ultimately concedes principle to desperate need to increase the number of deceased organ donations. When people are dying due to a shortage of a life-saving resource, ordinarily unacceptable ways of obtaining that resource seem more reasonable and, ultimately, justified.

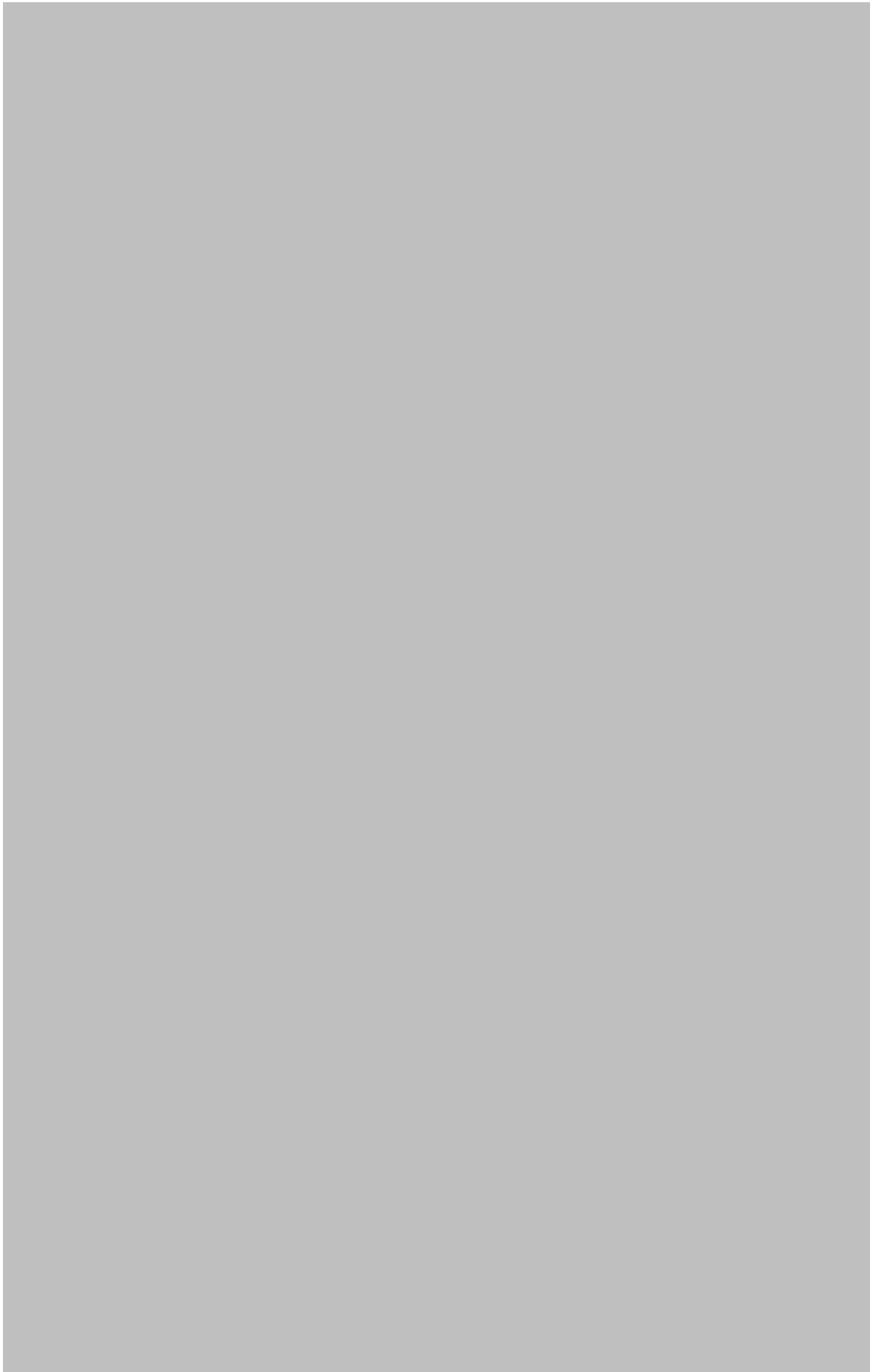
This thesis has looked at conditional donation as a particular issue that arises within the existing organ donation system, but it has not considered whether this existing, opt-in organ system should itself be changed. Accepting conditional donations may result in a small increase in the number of donated organs, but it would be unlikely to fully satisfy demand for transplants. Accepting conditional donations is only a partial solution to the organ shortage; bigger gains may be achieved by focussing on more fundamental changes to the organ donation system. Moving to an opt-out system (possibly incorporating elements of reciprocity) - whilst generating different complex ethical issues to be addressed - may provide the foundations for the greatly improved donation rates that are needed to prevent people dying while waiting for transplants⁵⁰¹.

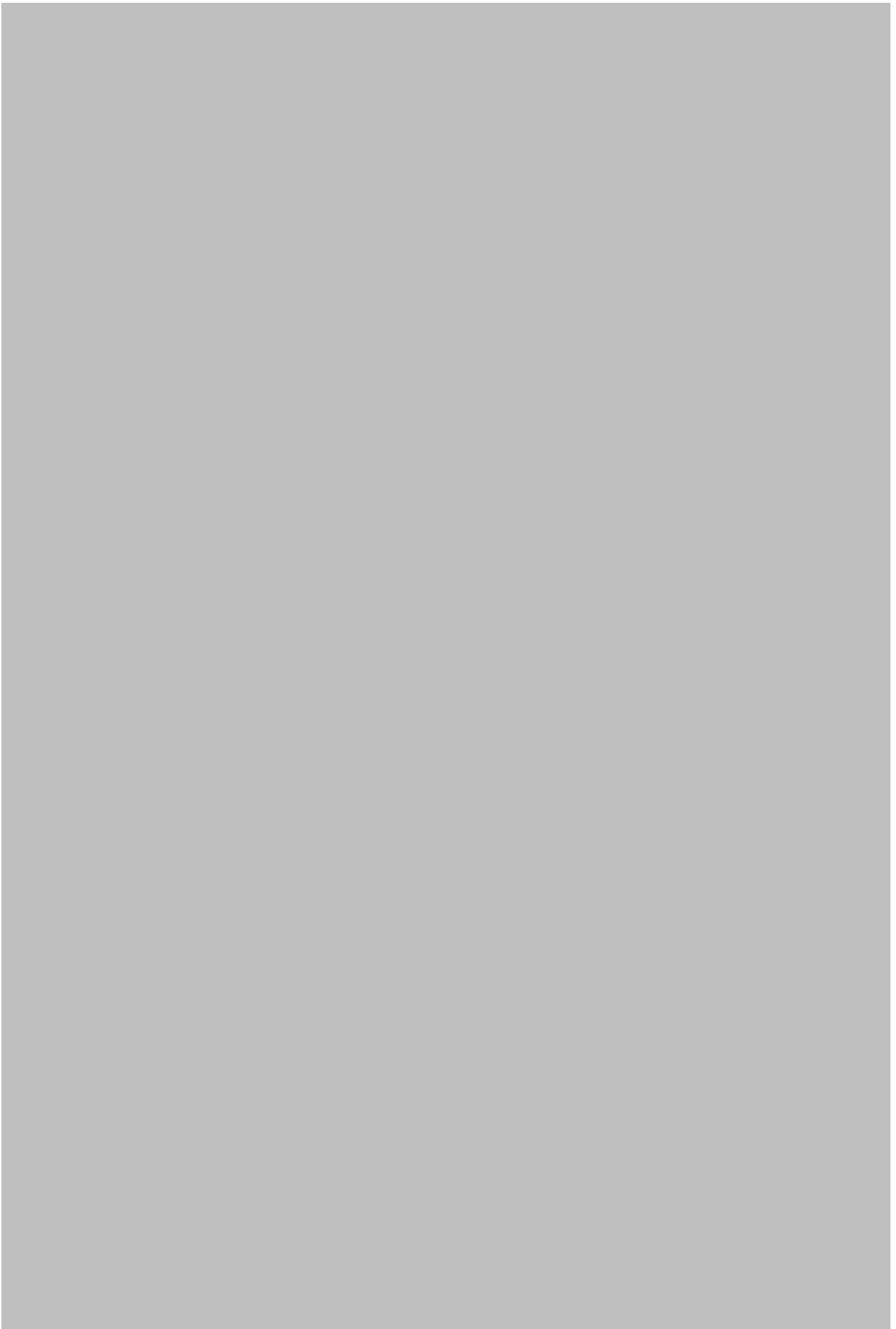
⁵⁰¹ It emerged during the viva that whilst this thesis does reflect my own views on conditional donations, as well as my research efforts, my overarching view is that a more fundamental change to the organ donation system is justifiable and likely to have a bigger impact than any changes relating to conditional donations. My preferred donation system would be an opt-out system based upon reciprocity where those who do opt-out have a reduced likelihood of receiving a transplant. The examiners suggested that this was recorded in the conclusion.

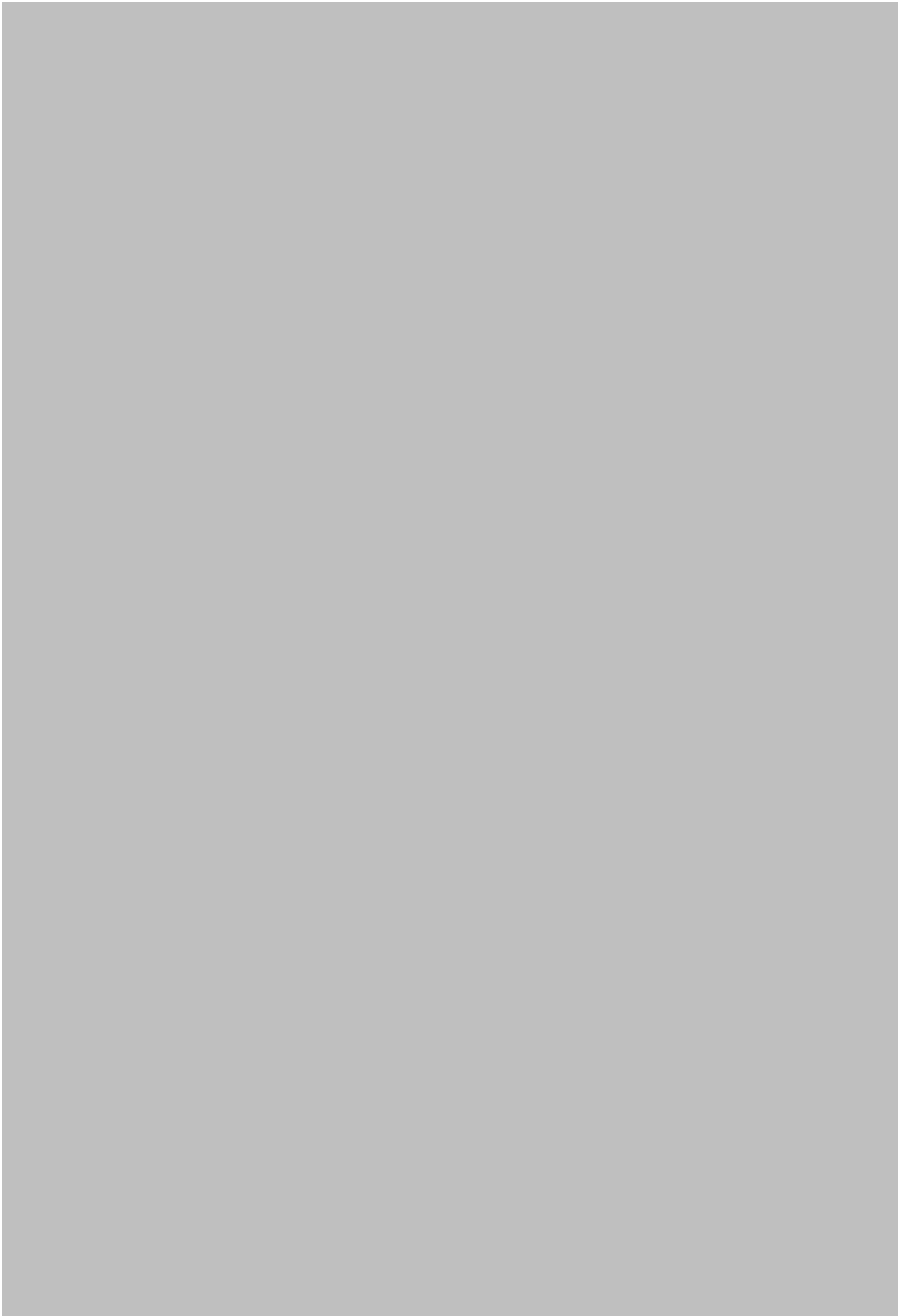


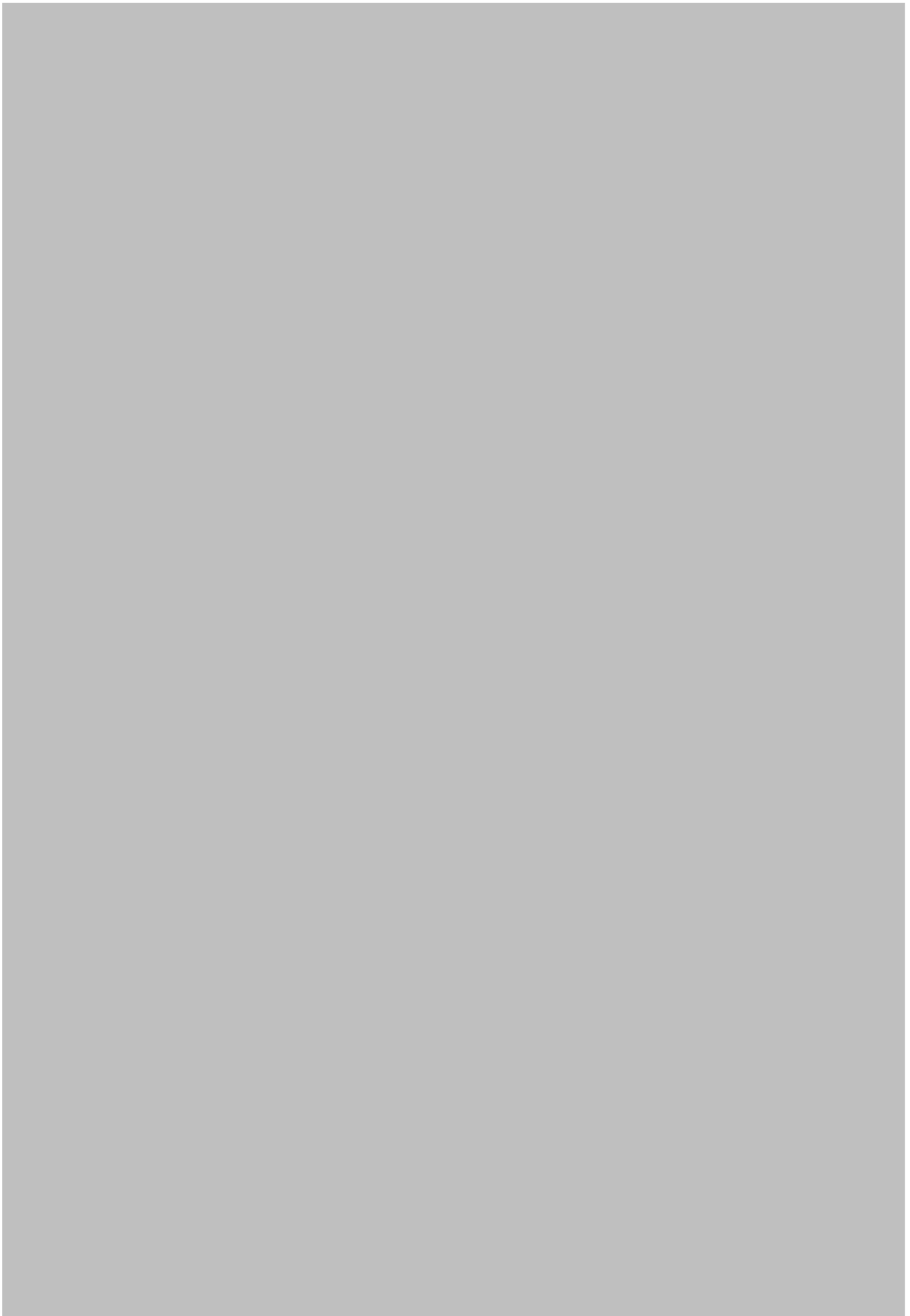


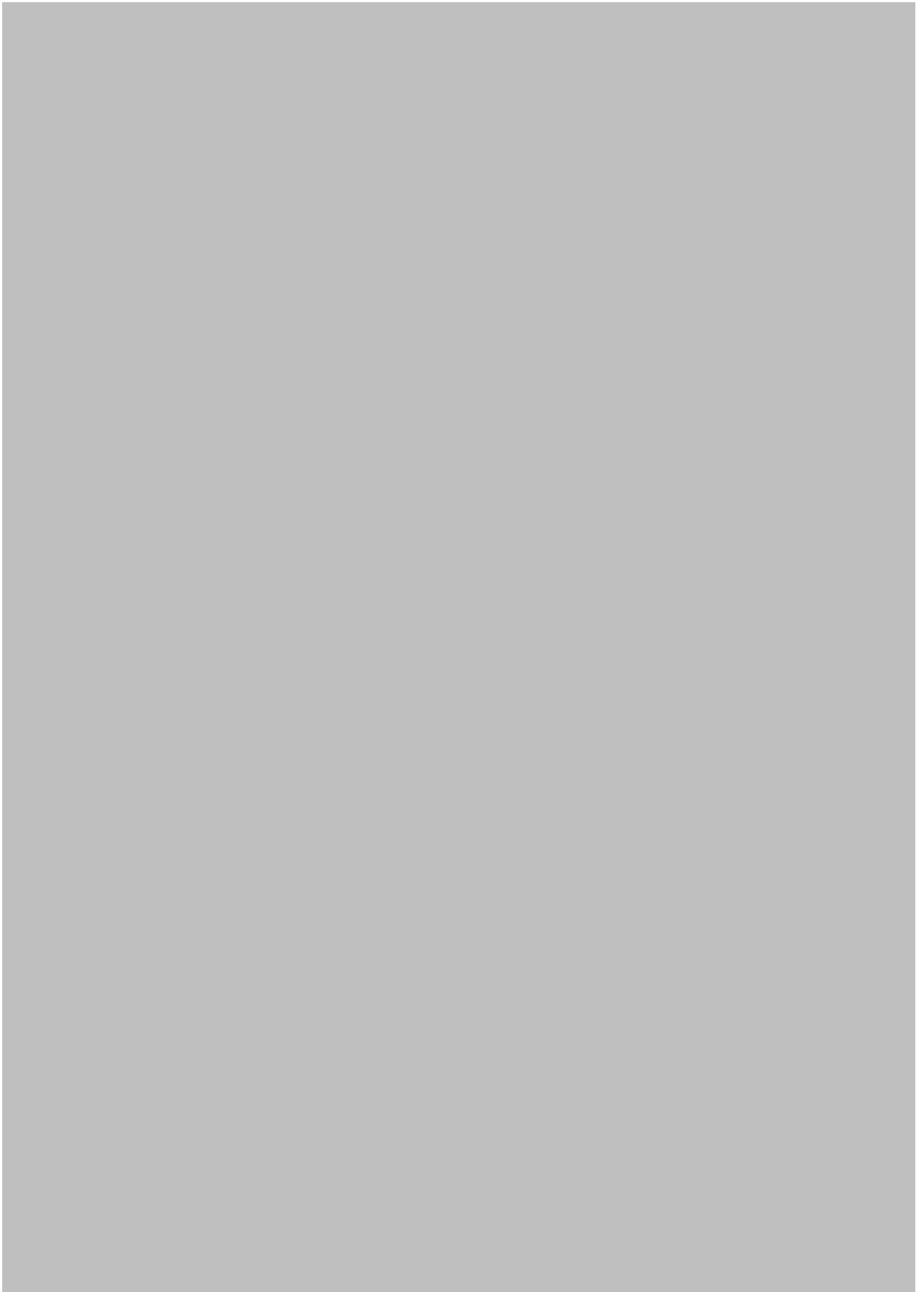


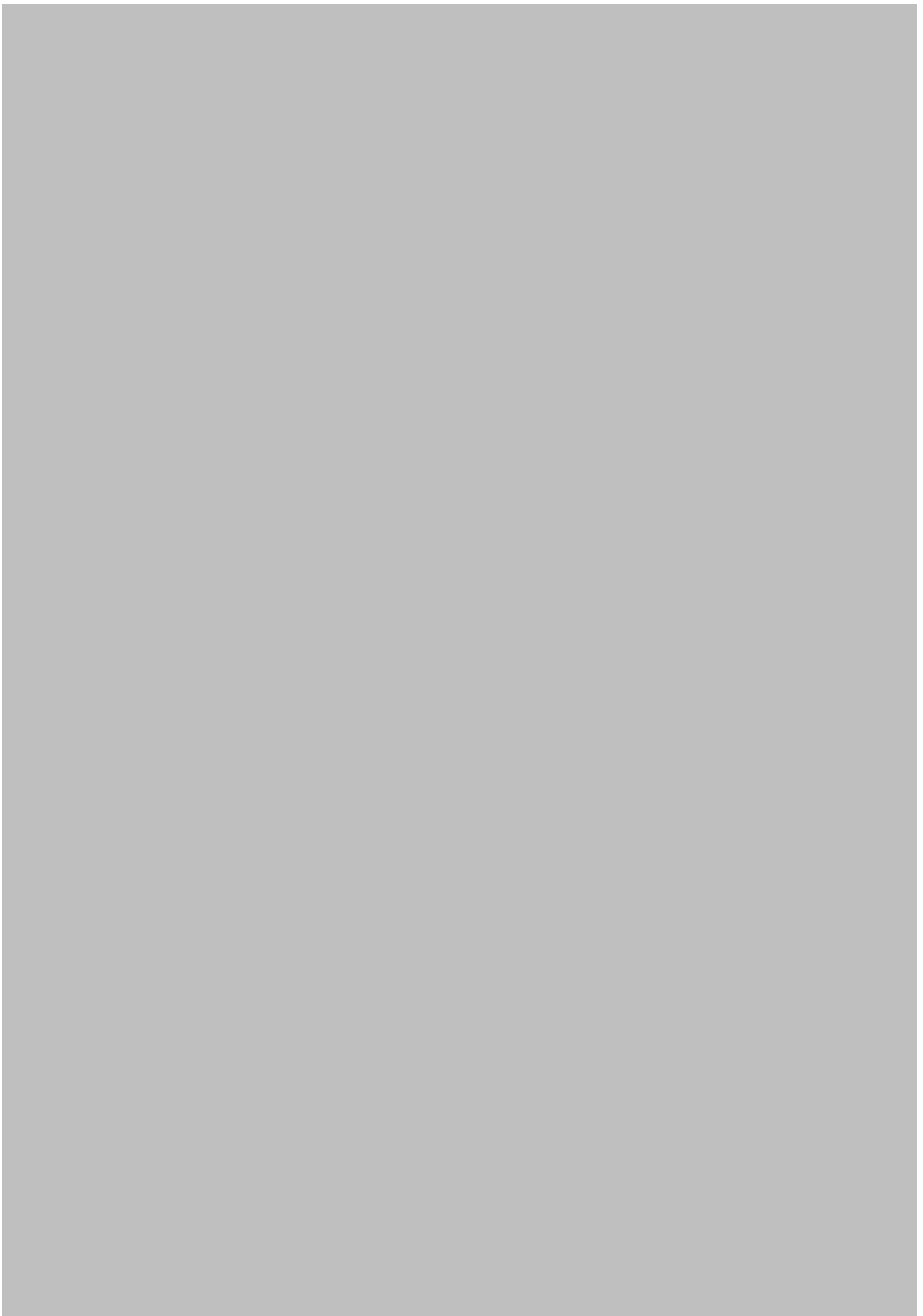




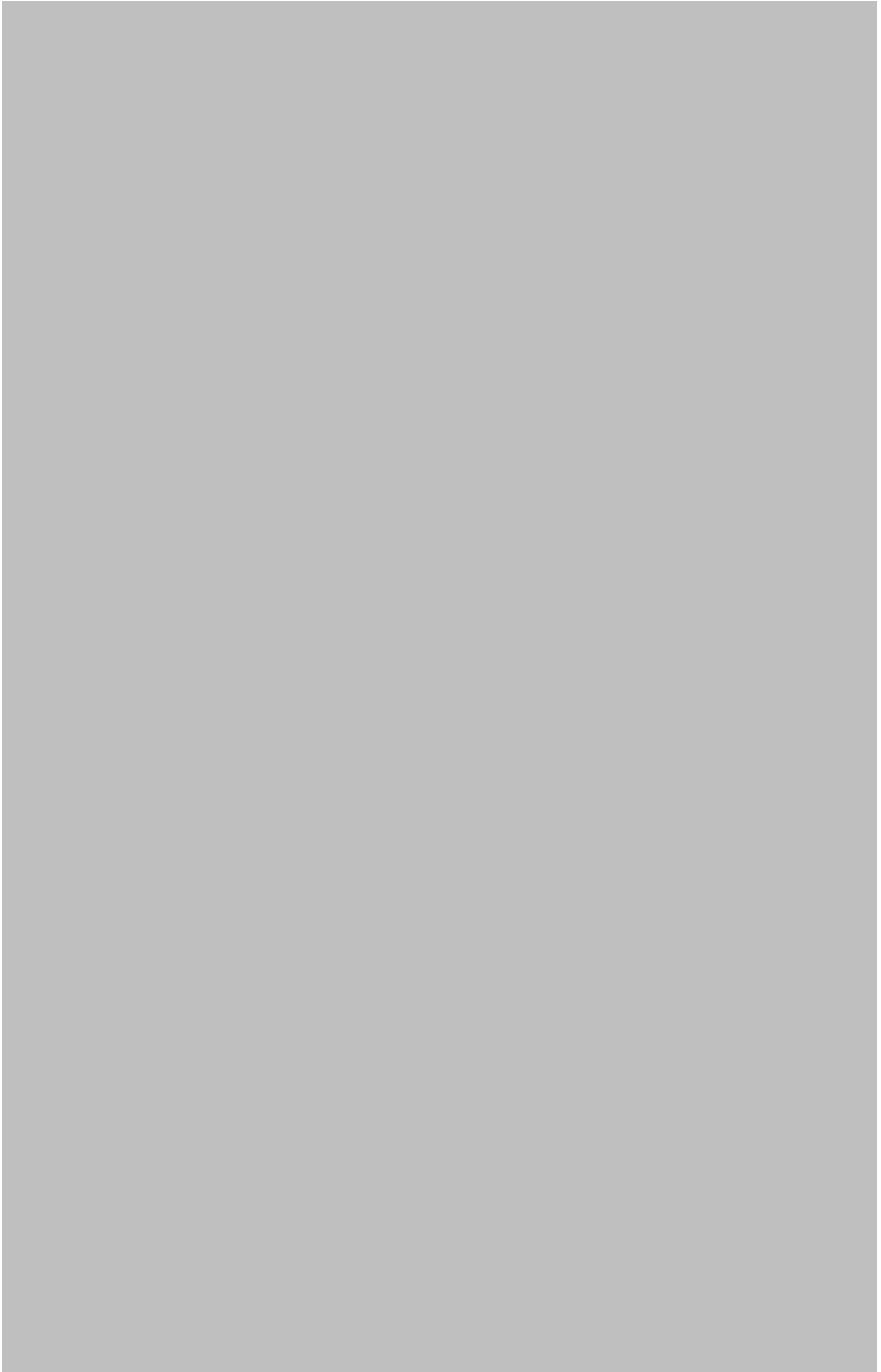






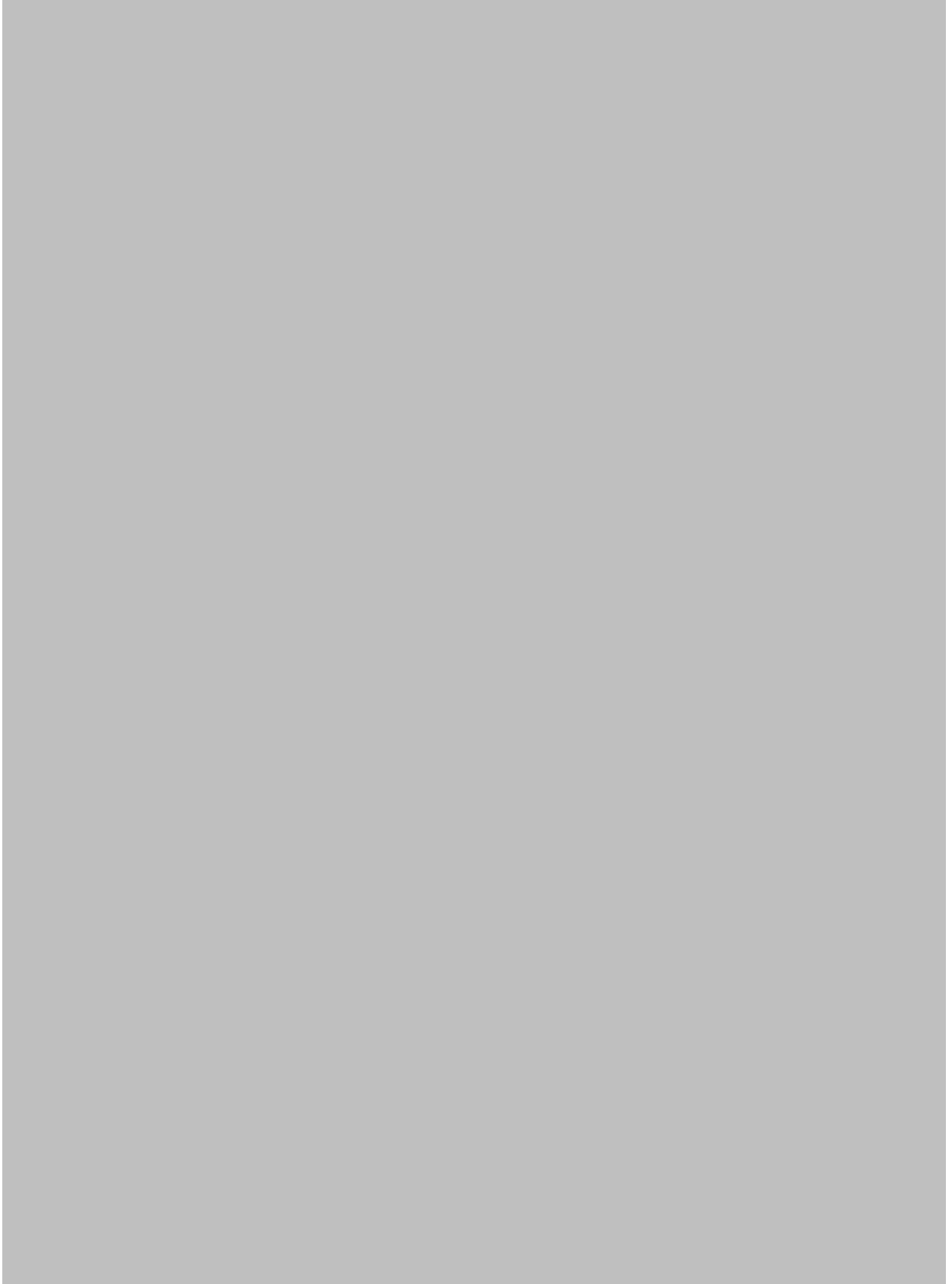








Appendix 2 – Letter from NHSBT re: removal from ODR



Appendix 3 – Interview Topic Guide

Introduction:

Thank interviewee for taking part

Introduce self

Remind interviewee that they are free to stop at any point without having to give a reason.

Generic Scenario Number 1 (Responsibility and Desert)

Two young men are killed in a car accident. The driver was driving recklessly and above the speed limit, which caused him to lose control of his car and crash, killing both himself and his passenger. The parents of the passenger are very distressed that their son was killed by someone acting so recklessly and are angry and upset that two lives have, in their eyes, been wasted.

The parents of the passenger are very keen that their son's organs should be donated, but they have concerns about the sort of person that his organs might be transplanted to. They would like their son's organs to be transplanted to people who will look after them and live responsibly, and they consider young people to be risk-takers who are less likely to act responsibly than slightly older people with families. They therefore request that their son's organs are only transplanted to people who are over the age of 25 and have children. In the parents' opinion, these are likely to be responsible people who will look after themselves and deserve the improvements to quality of life that an organ transplant can bring.

Staff at the hospital tell the parents that they are not allowed to say who their son's organs will go to, and that decisions like this are made by medical staff on the basis of medical considerations. If the organ donation is to go ahead, the organs must be donated without any restrictions being placed on who the organs can be transplanted to.

The parents decide that because of the chance that their son's organs will go to people who they consider don't deserve them, they won't give permission for their son's organs to be donated.

Questions for All

1) This is an example of directed donation. What do you think about putting these kinds of directions on donation? [Prompt responder to give reasons for what they think]

1a) Can you tell me what you think about the parents' request? Do you think that the parents' request is reasonable? Why?

2) What do you think about transplant staff not being allowed to accept organs in examples like this?

2a) How do you think that transplant staff should react to conditional offers of organs such as this?

[prompt] If the organs are rejected, medically useable organs might go to waste?

3) What do you think about people who want to donate their organs also being able to say that only certain types of people should receive them?

3a) Do you think there are any types or groups of people that are more deserving of transplants than others?

3b) If so, how important do you think this should be when deciding who should get organs?

4) How important do you think it is that donated organs go to the people in greatest need?

[prompt] Can you explain a little about what you take 'the greatest need' to mean?

Additional Questions for Potential Donors

- 1) If you have ever thought about organ donation, have you thought about the type of person who might receive your organs?
- 2) How do you think your views about organ donation would change if donors were allowed to say who gets their donated organs?

Additional Questions for Potential Recipients

- 1) How would you feel if you benefitted from a conditional organ donation (e.g. if the person above you on the waiting list was excluded because of a condition placed on a donation, and you got the organ instead)?
- 2) If you were given an organ with conditions attached to it, how important would it be for you to know about the conditions before or after the transplant?

Additional Questions for Transplant Staff

- 1) How would you feel about being involved in the transplantation process if directions such as those in this scenario were placed on the organs?
 - 1a) How would you feel about being involved in the transplantation process if either you, or another member of staff, strongly objected to the conditions/directions placed on the organs?

Generic Scenario Number 2 (Religion)

A young woman dies following an accident. All of her organs are suitable for transplantation. This woman's faith and religious beliefs shaped how she chose to lead her life, and she placed great value in being what she considered a good member of her religion. Her parents know that her religious beliefs were very important to her, and are confident that, given a choice, she would have preferred for her organs to go to another member of her religion. Her parents therefore give consent for their daughter's organs to be donated, but request that priority is given to members of their daughter's religion. This request is not motivated by any dislike for a particular group of people; it is made simply because the parents believe that their daughter would prefer for her organs to go to people with similar beliefs and values to her own.

The hospital staff explain that these sorts of requests cannot be complied with under existing policy, which states that organs will be given to the people who are in greatest need and who are the best match.

Questions to All

- 1) This is an example of directed donation. What do you think about putting these kinds of directions on donation? [Prompt responder to give reasons for what they think]
- 2) The request in this scenario favours one group of people over others, but does not do so with bad or malicious intentions. How important do you think intentions and the reasons behind the request are?
- 3) In this scenario, the request is for priority to be given to members of the same religion as the donor. How would you feel about a request for priority to be given to a family member or friend?

Additional Questions for Potential Recipients

- 1) How would you feel about receiving an organ with conditions such as the ones in this scenario attached to it? E.g. How would you feel if you received an organ just because you were of a certain [ethnic origin], [gender] or [religion]?

Generic Scenario Number 3 (conditional donation)

A man has died in an accident. All of his organs are suitable for donation, and his family are very keen that his organs should be donated. Prior to his death, the man had expressed concerns about the number of immigrants that had moved to his area. He believed that a lot of the immigrants were taking jobs, benefits

and resources that would otherwise be given to local people. He believed that people like himself who have lived in the area all of their lives should have everything that they need before things are given away to people who have arrived from other countries.

The man had made clear, prior to his death, that if he died he wanted to donate his organs, but that he didn't want his organs to be transplanted to immigrants. Knowing that their relative held these views, the next-of-kin agree to donation only if the organs do not go to immigrants.

Staff at the hospital tell the next-of-kin that they are not allowed to say who the organs should or should not go to, and that if the organs are going to be donated they have to be donated to the general pool. The family insist that they will not agree to donate the man's organs if there is a risk of them going to immigrants, as the deceased man would have been opposed to this.

Questions for All

1) This is an example of conditional donation. What do you think about putting these kinds of conditions on donation? [Prompt responder to give reasons for what they think]

2) How do you think the transplant staff should respond to this offer to donate organs?

[Prompt] If they turn down the offer, they risk medically useable (and potentially life-saving) organs going to waste.

3) Do you think it would make any difference if the people at the top of the waiting list happen to be British anyway? If this were the case, the organs would go to the same people whether the conditions were followed or not, but the doctors can pretend they are accepting the conditions.

4) The conditions in this case discriminate against a group of people and the organs would not currently be **accepted. In other areas of life people's personal beliefs and decisions about who or what to donate time or money to are respected though, even if some people might disagree with them.** How do you feel about this, and what do you think about the same ideas being applied to organ donation?

5) **Bearing in mind that there currently aren't enough organs to meet demand, do you think that allowing donations with directions such as these attached could ever be an acceptable way of increasing donation rates?**

6) **How would you feel if usable organs were not transplanted because they've got conditions attached to them?**

General Questions to All about Conditional and Directed Donation:

1) The three scenarios have shown that there are different sorts of conditions or directions that a donor might wish to place on their organs. Are there any other sorts of conditions that you can think of that you, or somebody else, might want to place on organs?

2) Are there any conditions that you think are more acceptable than others?

[Prompt] what makes these more acceptable?

3) How important do you think the wishes or preferences of the donor are when it comes to deciding who gets organs?

4) Do you think that the current policy of only accepting organs donated unconditionally should be changed if the change resulted in more organs being donated?

5) One potential policy change could be to leave decisions about accepting conditional or directed donations up to local health authorities. How important do you think it is that any policy on conditional or directed donation is consistent throughout the UK?

6) Do you think that the preferences of the public should play any role in who organs go to? Why/why not?

Appendix 4 – Consent Form

An empirically informed ethical analysis of directed and conditional deceased organ donation

REC reference number: 10/H1208/34

University of Birmingham reference number: RG-10-094

Name of Researcher: Greg Moorlock, PhD Student, University of Birmingham

Please
initial
box

I confirm that I have read and understood the information sheet (Version 1.3, 12/04/2010) given to me, and I have had the opportunity to consider this information, ask questions, and these questions have been answered to my satisfaction.

☐

I understand that taking part is completely up to me, and I am free to stop the interview at any time without giving a reason and that this will not affect my healthcare in any way. I also understand that I am free to withdraw from the study up to three days after the interview has been taken place and that if I choose to do this my data will not be included in the research.

☐

I understand that my interview will be audio recorded, and that this recording will be stored securely.

☐

I understand that a written record of the interview I take part in will be made from the audio recording, and that my real name will not be used in this written version.

☐

I understand that the researchers might use my words in their research and publications, and I understand that my real name will not be used.

☐

a) I would like to be sent a summary of the results of this research

☐

6. b) I would like to receive this summary by:

Email

☐

Post

☐

I agree to take part in the above study.

☐

Participant name:.....

Signature:.....

Date:.....

Name of person taking consent:.....

Signature:.....

Date:.....

Introduction

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what you are being asked to do. Please take the time to read the information on this sheet, and please ask questions if there is anything that you are unsure about or would like to know more about.

What is the purpose of the study?

If a person who has died wanted to be an organ donor, their organs are given to the person who is the best tissue match and in most urgent need. This study is looking at whether or not people who would like to donate organs after their death should be allowed to say who they want to have their organs, even if this person or type of person is not at the **top of the list**. This isn't normally allowed in the UK. ***Directed donation*** is when a person, or a person's family, asks that the donated organs should be given to a particular person, or type of person. ***Conditional donation*** is when a donor or their family makes a request that donated organs should not be given to a particular type of person. Sometimes ***Conditional donation*** is the term used for organ donation when any special requests are made.

We would like to know whether giving people this kind of choice will mean that they are more or less likely to think about being a donor in the future. Allowing people to have a choice about who gets their organs after their death might cause people who are not registered donors to think about becoming a donor. Or it might cause people to lose faith in the organ donation system and become less likely to donate. We would also like to know whether or not people think that it is right to have this kind of choice

Why have I been chosen?

We want to know what healthy members of the public think about directed and conditional organ donation. You have been randomly selected by your GP because you have not been to see your GP in the last 12 months, so we think that you must be fairly fit and well. We are sorry if this is not the case. **We will not be asking you to agree to**

donate your organs after your death. We are only interested in hearing your views on organ donation.

What would you like me to do if I decide to take part?

We would like you to talk to us about your views about donation. We will ask questions about what you think about organ donation in general, your views about whether people should be allowed to decide who gets their organs, and whether allowing conditional and directed donation in the UK might affect your decision about whether or not to be a donor in the future. To make the interview convenient for you, we would like to interview you in your own home but we can arrange to interview you at University Hospital Birmingham if you would prefer. We expect that the interview would take less than one hour, but it might take longer if you would prefer to be interviewed in a language other than English using an interpreter.

Do I have to take part?

No. Taking part is completely up to you. If you decide to take part and **then change your mind that's OK. You do not need to give a reason**, just tell us that you have changed your mind. If you decide not to take part, or decide to withdraw, this will not affect your healthcare in any way.

What are the benefits of taking part?

There are no direct benefits to taking part, although you may value the opportunity to discuss these issues. If you choose to be interviewed at the hospital, your travel expenses will be reimbursed (you will need to provide receipts or mileage). We will also provide you with a hot or cold drink and a small snack if you are being interviewed there.

What are the risks of taking part?

There are no big risks to taking part. Some people might find it difficult or distressing to think and talk about what will happen to their bodies after their death. If this does happen to you, you are free to stop the interview.

What will happen to the information that I give?

Your interview will be audio recorded, and typed up word for word. This written interview will be analysed, and we will write or talk about results so that other people know what we found out. When we do this we may

use some of your exact words from the interview, but we will not use your name. **Any information that might identify you will be removed before any of the results are talked or written about.**

If an interpreter is used during the interview, another interpreter will listen to the recorded interview to make sure it has been translated accurately.

Your personal information will be stored securely at the University of Birmingham, and no one outside of the research team will be allowed to see it. Members of the research team need to know when, where and with whom interviews are taking place, so your name, address and contact details will be available to the people supervising this research. Your personal information will be destroyed when the study is finished, but your consent form and typed up-interview will be stored for 10 years before being destroyed.

Who is organising and funding the study?

The research is being organised by Greg Moorlock, a PhD student at the University of Birmingham. The research is being supervised by Dr Heather Draper and Dr Jonathan Ives from the Centre for Biomedical Ethics at the University of Birmingham, and Mr Simon Bramhall from the Liver Unit at University Hospital Birmingham. Funding is provided by the *Arts and Humanities Research Council* and *University Hospital Birmingham Charities*.

A research ethics committee has approved this research project.

Contacts for further information or to take part in the research

If you have any questions about this research or anything mentioned in this document, or if you are interested in taking part, please complete and return the reply slip or contact Greg Moorlock:

████████████████████ █ ████████████████████

If you have any complaints during any stage of your involvement with this research, please contact Dr Heather Draper:

████████████████████
██

[REDACTED]

[REDACTED]

[REDACTED]

Introduction

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what you are being asked to do. Please take time to read the information on this sheet, and please ask questions if there is anything that you are unsure about or would like to know more about.

What is the purpose of the study?

If a person who has died wanted to be an organ donor, their organs are given to the person who is the best tissue match and in most urgent need. This study is looking at whether or not people who would like to donate organs after their death should be allowed to say who they want to have their organs, even if this person or type of person is not at the **top of the list**. This isn't normally allowed in the UK. ***Directed donation*** is when a person, or a person's family, asks that the donated organs should be given to a particular person, or type of person. ***Conditional donation*** is when a donor or their family makes a request that donated organs should not be given to a particular type of person. Sometimes ***Conditional donation*** is the term used for organ donation when any special requests are made.

We would like to know whether giving people this kind of choice will mean that they are more or less likely to think about being a donor in the future. Allowing people to have a choice about who gets their organs after their death might cause people who are not registered donors to think about becoming a donor. Or it might cause people to lose faith in the organ donation system and become less likely to donate. We would also like to know whether or not people think that it is right to have this kind of choice.

Why have I been chosen?

You are being invited to take part because we are interested to know what people who might require organ transplants in the future think. We are interested in your views whether or not you are already on a transplant waiting list.

What do you want me to do if I decide to take part?

We would like you to talk to us about your views about organ donation. We will ask questions about what you think about organ donation in general, your views about whether people should be allowed to decide who gets their organs, and how you might feel about being given an organ just because you are a particular type of person. To make the interview convenient for you, we would like to interview you whilst you are already attending University Hospital Birmingham, but we can interview you at another time or location if you prefer. We expect that the interview would take less than one hour, but it might take longer if you would prefer to be interviewed in a language other than English using an interpreter.

Do I have to take part?

No. Taking part is completely up to you. If you decide to take part and **then change your mind that's OK. You** do not need to give a reason, just tell us that you have changed your mind. If you decide not to take part, or decide to withdraw, this will not affect your healthcare in any **way nor whether or not you receive an organ in the future.**

What are the benefits of taking part?

There are no direct benefits to taking part, although you may value the opportunity to discuss these issues. If taking part in the interview requires you to make any special travel arrangements, you will be reimbursed the cost of these (you will need to provide receipts or mileage).

What are the risks of taking part?

There are no big risks to taking part. Some people who may need an organ transplant might find it difficult or distressing to think or talk about the donor. If this happens to you, you can stop the interview.

What will happen to the information that I give?

Your interview will be audio recorded, and typed up word for word. This written interview will be analysed, and we will write or talk about the results so that other people know what we found out. When we do this we may use some of your exact words from the interview, but we will not use your name. **Any information that might identify you will be**

removed before any of the results are reported and nothing you say will affect your healthcare in any way, nor affect whether you get an organ in the future.

If an interpreter is used during the interview, another interpreter will listen to the recorded interview to make sure it has been translated accurately.

Your personal information will be stored securely at the University of Birmingham, and no one outside of the research team will be allowed to see it. Your personal information will be destroyed when the study is finished, but your consent form and typed-up interview will be stored for 10 years before being destroyed.

Who is organising and funding the study?

The research is being organised by Greg Moorlock, a PhD student at the University of Birmingham. The research is being supervised by Dr Heather Draper and Dr Jonathan Ives from the Centre for Biomedical Ethics at the University of Birmingham, and Mr Simon Bramhall from the Liver Unit at University Hospital Birmingham. Funding is provided by the *Arts and Humanities Research Council* and *University Hospital Birmingham Charities*.

A research ethics committee has approved this research project.

Contacts for further information or to take part in the research

If you have any questions about this research or anything mentioned in this document, or would like to take part in the research please contact

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

If you are affected by any of the issues discussed in this information sheet, or during the research in general, please contact the NHS Patient Advice and Liaison Service (PALS) at the hospital:



Introduction

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what you are being asked to do. Please take time to read the information on this sheet, and please ask questions if there is anything that you are unsure about or would like to know more about.

What is the purpose of the study?

If a person who has died wanted to be an organ donor, their organs are given to the person who is the best tissue match and in most urgent need. This study is looking at whether or not people who would like to donate organs after their death should be allowed to say who they want to have their organs, even if this person or type of person is not at the top of the list. **This isn't normally** allowed in the UK. ***Directed donation*** is when a person, or a person's family, asks that the donated organs should be given to a particular person, or type of person. ***Conditional donation*** is when a donor or their family makes a request the donated organs should not be given to a particular type of person. Sometimes ***Conditional donation*** is the term used for organ donation when any special requests are made.

We would like to know whether giving people this kind of choice will mean that they are more or less likely to think about being a donor in the future. Allowing people to have a choice about who gets their organs after their death might cause people who are not registered donors to think about becoming a donor. Or it might cause people to lose faith in the organ donation system and become less likely to donate. We would also like to know whether or not people think that it is right to have this kind of choice.

Why have I been chosen?

You are being invited to take part because you are involved in the care of organ donors and/or recipients, and we want to know what you think about these issues. Your views on this topic are important because if conditional and directed donation were allowed, you and your colleagues would be the people implementing the policy. So we are interested in

whether or not you agree with conditional and directed donation, and why.

What would you like me to do if I decide to take part?

We would like you to talk to us about your views about organ donation. We will ask questions about what you think about organ donation in general, your views about whether people should be allowed to decide who gets their organs, and how you might feel about being involved in a system that allowed conditional and directed donation. To make the interview convenient for you, we would like to interview you at University Hospital Birmingham, but we could arrange an alternative location if you would prefer. We expect that the interview would take less than one hour.

Do I have to take part?

No. Taking part is completely up to you. If you decide to take part and **then change your mind that's OK. You do not need to give a reason**, just tell us that you have changed your mind. If you decide not to take part, or decide to withdraw, this will not affect your employment in any way as no one at the Trust will be told who has participated.

What are the benefits of taking part?

There are no direct benefits to taking part, although you may value the opportunity to discuss these issues. We will provide you with a hot or cold drink and a small snack during the interview. If taking part in the interview requires you to make any special travel arrangements, you will be reimbursed for the cost of this.

What are the risks of taking part?

There are no substantial risks to taking part. It is, however, possible that you might be asked difficult questions, or that topics may be raised that you find distressing. If this does happen, you are free to stop the interview.

What will happen to the information that I give?

Your interview will be audio recorded, and typed up word for word. This written interview will be analysed, and we will write or talk about the results so that other people know what we found out. When we do this we may use some of your exact words from the interview, but we will

not use your name. **Any information that might identify you will be removed before any of the results are talked or written about.**

Your personal information will be stored securely at the University of Birmingham, and will be kept confidential (it will not be available to anyone outside of the research team or Simon Bramhall). Your personal information will be destroyed when the study is finished, but your consent form and typed-up interview will be stored for 10 years before being destroyed.

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A research ethics committee has approved this research project.

Contacts for further information or to take part in the research

If you have any questions about this research or anything mentioned in this document, or would like to take part in this research, please contact

Response	Percentage
Yes, the current government is responsible	100%
No, the current government is not responsible	0%

326

326

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