THE CULTURAL ANATOMY OF DECISION MAKING: ORGAN DONATION AND THE 'PROBLEM' OF ETHNICITY

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy

Jessie Claire Cooper

February 2012

Contents

List of Figures:

Abstract

The Cultural Anatomy of Decision Making: Organ Donation and the 'Problem' of Ethnicity

Organ transplantation is considered the optimal treatment for those in kidney failure, yet there is a growing gap between the global demand for transplantable organs and their supply. Transplant medicine has largely concentrated upon solving this problem by securing the willingness of the public to donate their organs after death. In the UK context, attention has been trained upon black and minority ethnic ('BME') groups, who make up 28% of the kidney transplant waiting list, yet just 4% of organ donors. Since transplant medicine has traditionally favoured sharing organs between similar ethnic groups, 'BME' patients have a greatly reduced chance of receiving a transplant, despite their higher levels of need. Searching for ways to solve this problem, policy and research responses have focused upon understanding the 'cultural' barriers which 'BME' 'communities' present for organ donation, with subsequent interventions aimed at promoting organ donation to these groups. In so doing, minority ethnic groups have been positioned as the cause of transplant inequalities, and handed responsibility for solving an issue originally created within the practices of transplant medicine itself.

This study aims to resituate this 'problem' by focusing upon the institutional organ donation encounter: where potential donors are decided upon and families are requested to donate their relative's organs. A multi-sited ethnographic approach was taken to examine the work involved in organ donation in two acute hospital Trusts in the North of England, and wider 'community' domains, such as religious temples. Narrative and observational methods were used to understand the experiences of Intensive Care staff and donation nurses involved in requesting donation from minority ethnic families, and those connected to the 'problem', such as religious leaders and minority ethnic transplant recipients. Findings reveal ('BME') organ donation to be an embedded, negotiated practice, which goes far beyond the willingness, or reluctance, of an individual to donate their organs after death. Instead, this study demonstrates that donation is dependent upon the practices of health professionals, who make decisions on the suitability of dead and dying patients for donation. Moreover, it shows how donation decisions are *produced* in the negotiations between families and health professionals over the medical diagnosis of death; in the discussions of the immediate and extended family of the potential donor; and by the ability of donation nurse to secure a family's consent for donation. This study therefore illustrates how the 'problem' of ethnicity in organ donation is far from an isolated matter, created as a result of the 'culture' of 'BME' populations. Instead, it argues that the categories of the 'BME organ donor' and the 'BME donor family' – as problematic for donation – are maintained and reproduced within the very processes which make organ donation possible.

Declaration

This thesis is the result of my own work. The material contained in this thesis has not been presented, nor is currently being presented, either in part or wholly for any other degree qualification.

I was solely responsible for all data collection and analysis.

Acknowledgements

Writing up this thesis has proven to be the hardest thing I have ever done. It has involved many tears, late nights in an empty office, and protestations of my inability to keep going. I did though, and I could not have reached this stage without the support and kindness of numerous people.

First and foremost I want to thank my supervisor, Ciara Kierans. She has been unwavering throughout with her enthusiasm, support, and intellectual guidance. This thesis would not have come together in the way it has without her continued nudging of my capabilities, despite my many protests. I also want to thank my supervisor, Paula Byrne, for her continual help, and especially for introducing me to the wonderful world of science and technology studies. Many have had to put up with my tempers and tears on a personal basis during the course of this PhD. I am especially grateful to my friend and colleague Lois Orton, for her patient proof reading and personal support throughout, alongside many other colleagues, including Jackie Crowther, Marija Kovandzic, and Elisa Puzzolo for their kind words and help along the way. I also want to thank my best friend, Helen Wilson, for always proffering tea and sympathy, and I am especially grateful to my family for their unending support. To my Mum, Helen, for her listening ear, my Dad, Kurt, for his wonderful proof reading and enthusiasm for my writing, and my sister, Ruth, for keeping me on my toes.

Special thanks go to my wonderful boyfriend, Dan. We have gone through the hell of doing a PhD at the same time, and he has kept me sane throughout with his love, support, intellectual stimulation, and his later ban on talking about our respective studies at home!

And last, but not least, I want to extend my gratitude to everyone who gave their time and energy to share their intimate experiences of organ donation with me, without which this project would not have been possible. Particular thanks needs to go to 'Emily', for her extended help with access, insight into the donation process, and her honesty about her experiences as a donation nurse.

Dedication

This thesis is dedicated to the memory of my grandmothers, Patricia Cooper (nana Bristol), and Kathleen Bibby (nana Blackpool).

List of Abbreviations

A&E   Accident and Emergency

AMRC   Academy of Medical Royal Colleges

BME   Black and minority ethnic

BSD   Brain stem death

BTS   British Transplant Society

DBD   Donation after brain death

DCD   Donation after cardiac death

DH   Department of Health

ESRD   End Stage Renal Disease

GMC   General Medical Council

HLA   Human Leukocyte Antigen

HTA   Human Tissue Authority/Human Tissue Act

ICS   Intensive Care Society

ICU   Intensive Care Unit

NHS   National Health Service

NHSBT   National Health Service Blood and Transplant

NICE   National Institute for Clinical Excellence

NKAS   National Kidney Allocation Scheme

NSF   National Service Framework for Renal Services

ODT   Organ Donor Taskforce

PICU   Paediatric Intensive Care Unit

UKT   UK Transplant

Introduction

Organ transplantation is commonly held up as an "icon" of medical progress (Sharp, 2006: 1). This status has been sustained by the fact that, today, people with kidney, heart, liver and lung failure, among others, are able to survive for longer with the transplantation of an organ from the one person (dead or living) into the body of another. Alongside its iconic status, developments in surgical techniques and the ability of immunosuppressant medication to suspend the body's attack on the presence of a 'foreign' organ, mean that transplantation has also evolved as the optimal form of treatment for conditions such as chronic kidney disease (CKD) in the West. However, despite its now routine practice, transplantation remains the subject of intense debate in public, medical, and academic domains over the host of ethical conundrums it engenders. In addition, transplantation's ability to function is dependent upon the publics' participation in, and acceptance of, organ donation. This relationship has opened up a vast gap between the demand for transplantable organs and their available supply. It is in this gap that inequities of access and availability of transplantation for different populations in diverse socio-political contexts has arisen. One such disparity can be seen in the UK: with the problem of the lack of available donor organs for black and minority ethnic ('BME') populations waiting for transplant. It is in looking at *how* this inequality has been produced in transplant medicine and discursively presented in policy, health campaigns, and research as a *problem of* organ donation amongst 'BME' groups, with which this thesis begins. However, before doing so, it is important to trace how we got to this stage, by mapping a brief history of the mutually related development of transplantation and deceased organ donation.

Organ transplantation: the development of a medical technology

It was during World War II that the problem of renal failure began to receive public attention in Europe; when soldiers who had survived severe injuries later died from related renal failure. This attention led to the development in the Netherlands of the artificial kidney machine in 1944 by Willem Kloff. This early form of dialysis – a technology which mechanically filters harmful waste (urea and creatinine) and excess water out of the blood of those without adequate kidney function – allowed those with damaged kidneys to be kept alive. The ability of dialysis to maintain life was key for early experimenters of transplant medicine, leading to hope that kidney transplantation could become a reality in the future.

However, there was also the problem of the immune system and its rejection of outside matter, which had resulted in the failure of previous transplant attempts. In 1954 the first successful kidney transplant was carried out in the United States by Joseph Murray, using live donation between genetically identical twins. This was to confirm the importance of the immunological reaction for transplantation. When the body receives an organ which it deems to be "foreign", i.e. from another body, its response is to attack and destroy the invader. This has been theoretically referred to as a battle between "self" and "nonself" (Martin, 1994; Joralemon 1995: 337) – which leads to inevitable graft failure. Nineteen fifty four was thus a turning point for transplant medicine. It subsequently began to focus upon the importance of blood and tissue matching to reduce the effect of immune system attack, and ways of manipulating the immune system to allow for the transplantation of organs from non-identical related donors (Saeb-Parsy and Watson, 2011).

The gradual development of immunosuppressant drugs and their combination with steroid treatment in the 1960s and 70s led to the dream of transplantation – for kidney and other

forms of organ failure – becoming a reality. In the 1980s the introduction of Cyclosporine, a drug able to sufficiently suppress the recipient's immune reaction to foreign organs, without the need for dangerously high combinations of steroids, led to dramatic improvement in graft, and thus patient survival from transplantation. With this, the number of transplant operations, and demand for the treatment – understood to be the best option for kidney failure, both in biological and economic terms – dramatically increased (Jorelamon, 1995; Saeb-Parsy and Watson, 2011).

However, along with the problem of rejection, another major stumbling block in transplant medicine's development has been its reliance upon the public to donate their organs after death, and thus their acceptance of this new medical technology. This focus has led to the public definition of organ donation as the "gift of life". This concept is understood as both ethically troubling[1], yet necessary to promote the "altruistic" act of donating organs to a "known or unknown other" (Fox and Swayzey, 2001: ix).   Despite the first successful transplant resulting from a living kidney donation (with the body's ability to function with a single kidney), transplantation has traditionally relied upon the donation of organs from the bodies of the dead. However, that this is a very specific form of death is understood to add further to the ethical dilemmas of transplant medicine, as I detail below.

The problem of donation: brain death and inequality of access

Supplies of transplantable organs traditionally originate from brain dead donors. These are individuals who have been pronounced brain dead, yet are still breathing – and thus their

---

[1] The construction of the gift discourse around organ donation has been well debated in the literature (see e.g. Titmuss, 1997 [1970]; Healey, 2004; Davies 2006; Svendsen, 2007; Parry, 2008; Shaw, 2010). The general argument is that, in promoting donation as an altruistic act, the very process of gift exchange – originally laid out by Mauss (1954), as a reciprocal act of giving and receiving which constructs and reinforces social relationships – is cut short. By disavowing the expectation of return for donor families, and limiting the possibility for recipients to reciprocate, it is argued that suffering is amplified on both sides (see e.g. Kierans, 2005; Sque, Payne, and Macleod Clark, 2006).

organs functioning – with the assistance of a mechanical ventilator. The re-formulation of death as occurring in the brain, rather than its traditional locus in the respiratory system (heart and lungs), was catalysed by the development of Intensive Care medicine – specifically with the ability of the artificial ventilator to keep the 'dead' 'alive', and with the use of deceased organ donors in transplantation[2]. Following the initial formalisation, in 1968, of medical criteria for diagnosing whole brain death in the United States (US), by the Harvard Ad Hoc committee, the British Conference of Medical Royal Colleges laid out clinical criteria in 1978 for brain death in the UK context. This differed in one main respect from the Harvard Criteria, in that brain-death is verifiable with the diagnosis of *brain-stem death* (the lower part of the brain), rather than whole brain death. The brain stem is understood as the part of the brain which controls our heartbeat, our ability to be conscious, and our ability to breathe. In other words it is taken as "the body's control centre" (Academy of Medical Royal Colleges 2008: 34), which allows us to function as sentient persons. This new form of death, despite its now commonplace practice in many countries, continues to cause debate in terms of what death actually *means* and thus when, exactly, it can be pronounced (Lock, 2002).

The introduction of brain death was the first in a proliferation of measures to increase the supply of donor organs for transplant medicine (Fox and Swayzey, 2001). Such measures, all of which have their own practical and ethical debates, include increasing the prevalence of donation after cardiac death – where organs are procured after cardiac arrest; increasing the use of living organ donors[3]; relaxing the criteria for what constitutes viable donor organs – including the increasing use of marginal donors, considered previously too risky for

---

[2] Until developments in Intensive Care medicine and the subsequent recognition of brain death as a legitimate form of death, transplantation traditionally utilised organs procured from donors who had died after cardiac arrest, known as donation after cardiac death.

[3] In the UK, kidneys, liver, and lung lobes can now be donated for transplantation from patient's friends, colleagues, and even strangers.

recipients (e.g. over 80 years of age; diabetic; and donors deemed at high risk of HIV) (Fox and Swayzey, 2001; Sharp, 2006); the introduction of presumed consent (opt-out) for organ donation in countries such as Spain and Sweden – where organs can be legally procured after death unless the donor or their family has specifically objected; the implementation, in certain countries like Spain and the US, of measures to provide compensation for donor families in the form of funeral expenses; the ever growing market for organ-selling and trafficking – despite the consensus of condemnation surrounding these practices – in countries such as India and Pakistan (e.g. see Scheper-Hughes, 2001; 2002; Lundin, 2010, and Yea, 2010 for recent ethnographic accounts); and research into xenotransplantation (using animal organs) as a workable alternative to the reliance on human organs for transplant.

What is clear then is that this icon of medicine remains mired in ethical, practical, and theoretical debates around its future. Despite the hosts of measures described above, organ scarcity persists on a global context. This has engendered questions about equality of access to transplantation for different patient population groups, both within and across national boundaries (Fox and Swayzey, 2001). In the US, for example, with its private healthcare system, problems persist for those on low incomes without healthcare insurance; and, in conjunction, for 'Black' patients who are less likely to be placed on a transplant waiting list, and have less chance of receiving a transplant once on the waiting list (Hall *et al*., 2011).

In the UK context, despite the presence of the National Health Service – free for all at the point of service – similar disparities exist for patients from minority ethnic backgrounds. In general terms, the UK has a poor record of deceased donation levels compared with some of its European equivalents: 16.3 deceased donors per million population (pmp) (NHSBT, 2011), compared to levels in Italy of 21 pmp, and Spain of 35.1 pmp (Commission of The European Communities, 2007). Despite the fact that between 2010 and 2011 transplant waiting lists

decreased (2% overall and by 4% for kidney waiting lists) for the first time in ten years, there are still 7800 patients actively waiting for an organ transplant, of which, 6871 are waiting for a kidney (NHSBT, 2011). This represents 111 patients pmp (NHSBT, 2011), which is starkly contrasted to the figure of 16.3 deceased donors pmp in the UK each year. This disparity has been singled out as particularly affecting individuals from what are routinely referred to as black and minority ethnic ('BME') 'communities'.

The shortage of organs for 'BME' groups has been understood through a number of related issues, namely that 'BME' populations are 3-5 times more likely to develop End Stage Renal Disease (ESRD) than the majority population. As a result, these groups[4] make up 28% of the kidney transplant waiting list, yet just 8% of the UK population, and 4% of organ donors (NHSBT, 2011). High rates of ESRD and low rates of deceased organ donors from 'BME' groups, in the context of the UK's opt-in donation system, have had material effects upon those waiting for transplant. The UK currently favours good tissue matching in kidney transplantation, to maximise survival time and decrease the potential of graft rejection (Saeb-Parsy and Watson, 2011). This translates into a preference for sharing organs between individuals from similar ethnic backgrounds (largely understood as mapping on to similar blood groups and tissue types). In the context of low rates of organ donors from 'BME' populations and a majority white donor pool, waiting times for 'BME' patients on the kidney transplant list are almost double those of the white population. As a result of these factors, individuals from 'BME' groups have a vastly reduced chance of receiving an organ transplant than their white counterparts, despite their higher level of need (Wright, 2000).

---

[4] National Health Blood and Transplant (NHSBT) currently categorises minority ethnic patients under the categories: 'Asian', 'black', 'Chinese', and 'other' (NHSBT, 2011). In the context of the 'BME' transplant problem, this refers to patients from African, Caribbean, and South Asian (Indian, Pakistani, Bangladeshi and Sri-Lankan) backgrounds.

In public, policy, and research domains these inequities have been understood as a specific problem of ethnicity. This is shown by the way in which problems of access to transplantation have been largely discussed in terms of 'BME' communities' failure to donate their organs after death. This failure is attributed to the 'cultural' – such as religious beliefs – barriers which 'BME' groups present for attempts to increase organ donation rates. In turn, interventions to solve the inequality have come in the form of targeted campaigns to promote organ donation to 'black' and 'South Asian' 'communities'. In this way, lack of access to transplantation *for* 'BME' populations has been discursively constructed as a 'problem' *of* low rates of deceased organ donation *from* these groups (Kierans and Cooper, 2011).

In a recent BBC Radio 4 documentary, *Blood for Blood* (2010), the programme looked at the disparity between the need for blood and organ donors in the UK's 'black' and 'Asian' populations by beginning with the question: "What lies behind the reluctance of black and Asian people in Britain to act as blood and organ donors?" It is the way in which questions such as these set up the 'problem' as a *problem of* minority ethnic populations with which this thesis begins. Rather than retain the focus upon transplant inequalities as directly caused by the supposed "reluctance" of 'BME' groups to donate their organs, this study examines the way in which such a focus has come about, and how this 'problem' can be traced to institutional domains. It therefore aims to understand the 'problem' by looking at the contextual experiences and practices around the organ donation encounter[5] – where

---

[5] I define practices as the assembly and (re)production of knowledge and social orders by means of the "situated accomplishments" (Lynch, 2001: 141) and "arrays of activities" (Schatzki, 2001: 11) of different actors. According to Schatzki (1996; 2001), practices assemble, arise from, and make sense of existing knowledge (which is tacitly performed); available resources; objects; bodily (embodied) activity; emotions; and skills. In this thesis, the term practice therefore refers to both what is *done* – the actions of different actors in the organ donation encounter – and how this 'doing' interacts with and transforms wider contexts and institutional norms (Casper and Berg, 1995) in organ donation – such as end of life care pathways and the Human Tissue Act's (2004) legislation on consent.

patients are referred as potential donors and families are requested to donate their relative's organs. This it does by taking a phenomenological ethnographic approach, to examine the institutional processes of, and decision-making around organ donation within two hospital Trusts in the North of England. In aiming its focus towards institutions, rather than 'communities', this study differently asks: just what happens when ('BME') families are approached after the death of their relative and asked to donate their organs?

In writing a critical study about the relationship between organ donation and ethnicity it is important to outline, from the outset, my own understanding of the term 'ethnicity' (Bhopal, 2007). In this study I understand 'ethnicity' to refer to malleable, rather than static identities, constituted at both personal and structural levels (Smaje, 1996). 'Ethnicity' therefore encompasses both commonly defined characteristics including language, religion and country of origin etc (Bhopal, 1997), alongside how an individual's self-image interacts with wider factors, such as the impact of racism (Karlsen and Nazroo, 2002). Throughout this thesis I deliberately draw on commonly deployed categories such as 'South Asian', 'black', 'BME', 'community', and 'culture', to bring attention to their problematic construction within the literature and in the research field. It is for this reason that these terms are presented within inverted commas throughout.

Overview of the thesis

This thesis is presented in 7 chapters, beginning with a review of the literature connected to the phenomenon of organ donation and ethnicity, and moving through to the study methodology and its subsequent findings. In chapter 1, I outline and critique the literature relating to the 'problem'[6] of organ donation and ethnicity. This begins with an examination

---

[6] I place the notion of the 'problem' in inverted commas throughout this thesis, in recognition of my understanding of ethnicity in organ donation as a constructed, rather than innate, 'problem'.

of how the focus upon the 'problem' has developed: from the discovery of high rates of renal failure among 'BME' groups, and the subsequent disparities in access to transplantation, to the way in which policy, health promotion, and research responses have attributed these inequities to low rates of organ donation from 'BME' groups. Broadening the perspective, I then consider wider research into minority ethnic health inequalities and the practices of donation and transplant medicine, to justify the study's institutional focus, and highlight the myopia of current research approaches.

In chapter 2, the methodology, I describe and rationalise the study's phenomenological ethnographic approach. This I used to alternatively examine the 'problem' of ethnicity and organ donation from the perspective of the organ donation encounter. I provide an overview of the phenomenological epistemology which underpinned the research, and the ethnographic methodology I employed. I then describe the research settings and participants; the subsequent development of the study's focus; and the methods which were used to *do* the study and analyse the data, before finally exploring the ethical issues involved in undertaking such research. Chapters 3 through to 6 present the study findings. In chapter 3, I provide a procedural overview of *how* deceased organ donation actually happens and *who* and *what* it involves, according to policy guidelines. This gives initial insight into the complexity of the donation process, and illustrates the variety of different actors involved in making decisions around donation, beyond 'BME' individuals and their families.

Chapter 4 moves to explore the work which gets done within local hospital settings to increase organ donor rates. It takes recent policy recommendations for the re-organisation of donation services, and looks at how these are made to happen in practice by the key figure of the donation nurse. Here I highlight the way in which organ donors, and thus donor organs are *made possible* as a result of the situated practices and decisions of health

professionals. In chapter 5, I focus upon the issue of consent in organ donation. Here, I evidence the ways in which standard procedures for, and representations of *what* consent for donation entails, break down in practice with 'BME' families – represented by health professionals as problematic groups for donation. I show that consent for donation begins with the agreement of a family to the medical diagnosis of the death of their relative; and how, rather than necessarily being the product of the donor's wishes, donation is an outcome of the negotiations of a variety of family and 'community' members. In so doing, I demonstrate how the 'BME' family are *produced* as a problem for donation by virtue of the fact that they fail to conform to the procedural norms which underpin donation.

The final results chapter, 6, scrutinises the practices and procedures involved in securing legal consent from a patient's family for donation. I reveal consent to be a precarious and interactional process, with families' formal decisions on donation dependent upon the interpretative work of the donation nurse. I also show these practices to be problematic, however, when they turn upon preconceived notions of a family's ethnicity; illustrating the way in which health professionals reflect and reconstruct the 'problem' of ethnicity in their practice. The insights from these chapters lead me to ultimately conclude, in chapter 7, that the 'problem' of ethnicity in organ donation is not something which can be simply attributed to the 'culture' of 'BME' 'communities'. Instead, as this thesis shows, it is a phenomenon which can be traced to institutional domains, and to the procedures, practices, and practitioners who, whilst responsible for increasing donor rates, simultaneously reproduce the 'problem' itself.

Chapter 1. Literature Review: The Problem of Understanding Transplant Inequalities in 'Ethnic' Terms

Introduction and search strategy

This study aims to move beyond current research, policy, and public understandings which relate inequalities of access to organ transplantation for 'BME' populations to a problem of low rates of organ donation from 'BME' groups. To do this, I begin by examining the literature related to this 'problem'. Rather than presenting a systematic review, this chapter offers a comprehensive examination and critique of the literature which deals explicitly with the study topic, along with wider research relating to this complex area. For example, alongside reviewing research and policy directly relating to organ donation and ethnicity, I also look at studies linked to ethnicity and transplantation, the experiences of donor and non-donor families, and the institutional practices of transplant medicine – all of which have direct bearing upon the ability to fully understand the study 'problem'.

The literature was searched by scouring electronic databases, including JSTOR, MEDLINE, CINAHL, Cochrane library, and Web of Knowledge, at regular intervals throughout the study, until September 2011. Different search terms were combined in advanced search options, and included: "organ donation"; "organ transplantation"; "minority ethnic"; "black"; "Asian"; "African"; "ethnicity"; "donor family"; "health professional"; and "request", among others (see Appendix 1). Sources were retrieved and critiqued according to their relevance to the topic; the methodological approach and methods employed; whether analytical and classificatory terms pertinent to the study topic, such as 'BME', were explained and the researchers' perspective made clear; and whether the conclusions drawn were justified (see Mays and Pope, 2000; Greenhalgh, 2001). Reference lists were scanned from retrieved

articles and further papers and book sources were subsequently generated. Recommendations from my supervisors, colleagues, and the health professionals who participated in my study were also taken up. In addition, I retrieved policy documents, medical guidelines, promotional material, and recent statistics for organ donation and transplantation from Google searches and the Department of Health (DH) and NHS Blood and Transplant (NHSBT) websites. The internet sites of charitable organisations, such as Kidney Research UK and the Donor Family Network were also searched for unpublished reports and grey literature. As this topic has featured widely in the media in recent years, various media websites, such as the BBC, and the Guardian, were additionally searched for relevant news articles and coverage. This accumulated evidence is presented in this chapter in four parts, which I outline below.

In part 1 of the literature review I show how evidence of high rates of renal failure amongst the UK's 'BME' groups has developed into a focus upon the problem of ethnicity for transplant medicine, specifically around requirements for organ matching from donor to recipient. I discuss how such focus has led to an understanding of ethnicity as a 'problem' for organ donation, and the concurrent responsibility given to 'BME' 'communities' to solve disparities of access to transplantation by donating more organs. In part 2, I demonstrate how this responsibility has been fixed in place by transplant policy, public campaigns, and research responses to the 'issue'. These position low rates of organ donation in terms of the 'culture' of minority ethnic groups – conceptualised through notions of religious beliefs, traditions, and practices. This literature I critique by utilising wider social science work to argue that such understandings result from the conflation of the concepts of biology, ethnicity, and 'culture', and by the misuse of the culture concept.

In part 3 I show how wider research, which examines families' experiences of being asked to donate their relative's organs, highlights the importance of looking at institutional practices

to understand donation decision-making. This research provides an opening for an alternative understanding of the 'problem' of ethnicity in organ donation: that low donation rates cannot be simply attributed to 'BME' 'communities' and, instead, need to be seen in the context of the interactional nature of decision-making. This leads to the focus upon the socially-constructed practices of transplant medicine in part 4 of the literature review. Here, I highlight how anthropological and sociological research into brain death in organ donation, and the organisation of death in medicine, illustrate donation decisions to be contingent upon the ability of medicine to render death acceptable to families. In addition, I highlight research on the work of donation and transplant professionals, which shows how donation is made possible by the locally-constituted practices around dead and dying patients. In this way, I argue that the 'problem' of organ donation and ethnicity can only be fully grasped by examining the way in which ethnicity is experienced, practiced, and produced within institutional donation domains.

Part 1. Situating the 'problem': transplantation and ethnicity

In 2009 National Health Service Blood and Transplant (NHSBT), the organisation responsible for managing transplant and donation services in the UK, brought out a new campaign to promote organ donation to the general public. The *Prove It* (fig. 1) campaign sets out to urge the public to "prove" their belief in organ donation by joining the organ donor register. This it does by directly appealing for individuals to identify with the potential for needing a transplant in the future: with the image of a healthy individual juxtaposed alongside their sick doppelganger. In this way, the campaign secures a moral imperative for the public to donate their organs by appealing to a possibility. Rather than something which happens to other people, organ failure is pictured as something that can happen to anybody, even to *you*.

Figure 1. One of NHSBT's *Prove It* poster campaigns (2009)

A further arm of the campaign specifically targets its message at 'black' and 'South Asian' 'communities' (see figs. 2 and 4). Here, rather than individuals, the campaign is re-formulated around a notion of 'communities'. 'Black' or 'South Asian' people are asked to prove their belief in organ donation for *their community*. This is done by the marrying of statistics: revealing the stark fact of high need for transplant amongst 'black' or 'South

Asian' people, alongside the 1% figure of people from these 'communities' on the organ donor register.

Figure 2. NHSBT's (2009) 'South Asian' *Prove It* campaign poster

It is in drawing these co-dependent boundaries of responsibility and belonging in relation to organ donation from minority ethnic groups, with which this literature review begins. It will chart how we have arrived at this stage; where the problem of transplant inequalities within

minority population groups has come to be represented as a problem of deceased organ donation within these same groups. As I will show, however, this 'problem' has emerged within the organisation of transplant services, and in the drawing of boundaries of difference through a "complex interweaving of biology/genetics and ethnicity/race [...] that both modifies and reinforces ideas of culture and responsibility" (Kierans and Cooper, 2011: 21).

Representing transplant inequalities by ethnicity

In the last fifteen years, inequalities of access to organ, particularly kidney, transplantation have been increasingly discussed in terms of the difference in waiting times to transplant between 'white', 'black', and 'South Asian' patients with End Stage Renal Disease (ESRD). This difference, however, has been understood in a way which implicates the disparity with low rates of deceased organ donation from black and minority ethnic ('BME') groups. The 'problem' is commonly represented by the interwoven statistics below:

- 'BME' (denoting 'black African', 'Black Caribbean' and 'South Asian' here) groups have been found to have a higher prevalence of chronic illness, like diabetes and hypertension, which means they are 3-5 times more likely to develop ESRD than the majority ('white') population (ODT, 2008; Randhawa, 2010).

- At present, 'BME' groups represent around 8% of the UK population, yet make up 28% of the kidney transplant waiting list, and just 4% of organ donors (NHSBT, 2011). In addition, reported refusal rates for deceased donation stand at 75% for the 'BME' population, compared with 40% for the 'white' British population (ODT, 2008).

- As current UK transplantation practice favours tissue and exact blood group matching, to decrease the potential of graft rejection (Saeb-Parsy and Watson,

2011), this translates into a preference for sharing organs between individuals with similar ethnic backgrounds (meaning similar blood group and tissue type).

- The result is that, in relation to kidney transplantation, for those of minority ethnic background who do receive an organ, the waiting times are almost double those of the white population who have an average wait of 719 days, compared to 1,368 days for 'South Asian' patients and 1,419 days for 'black' patients (ODT, 2008). This means that individuals from 'BME' groups have a vastly reduced chance of receiving an organ transplant than their white counterparts, despite their higher level of need (Wright, 2000).

As we see then, the problem of inequalities of access to transplantation for patients from 'BME' populations has been discursively tied to the 'problem' of low organ donation rates, from these same populations. Underpinning the transplant-donation domains is the requirement for Human Leukocyte Antigen (HLA [tissue]) matching in UK kidney transplant practice. Here, the relationship *between* the identities of those in need of transplantation, and those (potential donors) able to ease this need, has been concretised by classificatory boundaries drawn around notions of biological relatedness (genetic, HLA). This, in turn, is linked to ethnic and 'cultural' group membership. As I show below, however, the conventional understanding of the 'BME' organ transplant/donor 'problem' has been created within the practices of transplant medicine itself.

The development of UK transplant policy and the 'problem' of biology as ethnicity

We can map the genealogy (Foucault, 1977) of the BME transplant/donation 'problem' to the recognition, nearly 2 decades ago, of growing rates of renal failure amongst minority ethnic populations. In the 1990s, UK researchers began to report on the high numbers of

'BME', specifically 'black' and 'Asian'[7] patients with ESRD. One of the earliest studies was by Clark *et al.* (1993) who found a larger proportion of 'black' and 'Asian' patients with ESRF, compared to 'white' patients. The researchers put this down to the fact that there was higher prevalence of hypertension and vascular disease, as a cause of ESRF, in these patients. Such findings, the authors argue, had important ramifications for provision of renal services. In similar studies, Roderick *et al.* (1994; 1996) found greater rates of Renal Replacement Therapies (RRT) among 'black' and 'South Asian' groups, compared to the 'white' population. They warn of this need only increasing as 'BME' populations' age, recommending interventions to prevent renal failure, and pointing out the limited possibility of the most cost effective form of treatment for ESRD – transplantation – being used. This, they argue, is due to low donor rates generally, and specifically because of difficulties with tissue (HLA) matching for 'BME' groups (Roderick *et al.*, 1994; 1996; Raleigh, 1997).

What stands out from these early studies is the absence of transplantation as a suggested intervention. Here, access to suitable organs for the UK's BME populations was constrained by an explicit orientation towards cadaveric organ donation, alongside an 'opt-in' system for organ donation[8]. However, this began to shift with the introduction of the organ donor register in 1994, in attempts to improve overall rates of organ donation, and with growing recognition of transplantation as the optimal treatment for kidney failure in both clinical and economic[9] terms.

---

[7] Commonly understood to represent individuals of Caribbean origin, or Indian, Pakistani or Bangladeshi background, respectively.

[8] This means that organs can only be procured with the explicit consent of either the donor (i.e. by being on the organ donor register) or their relatives after their death.

[9] This is laid out by the National Service Framework for Renal Services (2004) where, compared with the daily regimes of dialysis, a kidney transplant is understood to allow patients to lead a near normal life (DH, 2004: 13). In economic terms, compared with the enormous costs of keeping a patient on haemodialysis, a kidney transplant saves the NHS around £241,000 over a ten year period for each patient (NHSBT, 2009).

In 1997 Higgins *et al.* reported on Coventry's kidney transplant programme, which distributed locally-donated kidneys in line with HLA matching policy at the time. Their records showed only a tiny proportion (2%) of their transplants were done with HLA mismatches, with a higher proportion of "Indo-Asian" patients, compared with white patients, waiting for transplant after two years (33% and 19% respectively). They also discovered significantly lower organ donation rates amongst 'Indo-Asians' than 'white' groups. Despite this discrepancy, the authors assert: "We believe that Indo-Asian patients should not be denied access to renal transplantation because there is a low rate of organ donation from their ethnic group" (Higgins *et* al., 1997: 1355). In attempts to improve these inequalities, the hospital subsequently changed its allocation policy to ensure that HLA matching was relaxed for patients waiting more than two years for transplant. This shows how, for those categorised as a 'BME' patient, constraints on access to transplantation have been tied to the reliance upon strict HLA and (as I will show) blood group matching between donor and recipient. In this way, the problem of inequality of transplant access becomes not simply one related to organ donation, but also one which has been fixed in place by the allocation policies of transplant medicine.

In 1998 Gurch Randhawa warned of the future economic and human "crisis" which would happen if the discrepancy between the number of 'Asians' on the kidney transplant waiting list, and the number of kidney transplants performed, was not resolved (Randhawa, 1998a: 265). In a reflection of these growing inequities, the UK National Kidney Allocation Scheme (NKAS) has twice shifted its criteria to widen transplant access. In 1998 a new scheme was introduced which, whilst still favouring HLA matching, brought in a second-tier points system. This meant that if no recipient could be found with a zero HLA mismatch (the optimal type of match between donor and recipient) the organ would be allocated on the basis of time waited, amongst other factors. In other words, patients who had a lower

likelihood of receiving a match received a larger score and therefore higher priority. Such patients included those from 'BME' backgrounds – less likely to receive a HLA matched organ (Fuggle *et al.* 2004).

Despite these changes, the scheme left inequalities of transplant access little changed. Writing in 2007 Rudge *et al.* found that under the 1998 criteria, 'Asian' and 'black' patients waited nearly twice as long for a transplant compared to their 'white' counterparts. They assert that such discrepancies were down to low rates of deceased donation from 'BME' groups, as well as the fact that the:

> [...] allocation system [is] based on white blood group distribution and HLA phenotypes. This system accurately represents the donor population but not the recipient waiting list, largely as a result of the biological diversity of different ethnic groups. (Rudge *et al.,* 2007: 1171-1172).

Crucially, Rudge *et al*. (2007) point out that even if donor consent rates from these populations were improved, the problem would remain because of higher rates of ESRF in the UK's 'Asian' and 'black' populations. In other words, they saw the allocation system, rather than low rates of donation from minority ethnic groups, as the main factor in transplant inequalities.

I want to look at these points about blood group and HLA matching in transplantation more closely here. Beginning with blood group distribution, kidneys have been traditionally allocated on the basis of strict matching by ABO blood type[10]. In theoretical terms, individuals with A, B, or AB blood types are able to donate to and receive blood (and thus

---

[10] This is because of the presence of different antigens in the blood. 'Foreign' antigens set off the production of antibodies in the body to get rid of the invader. This means that if blood or organs were received from a donor with an incompatible blood group (e.g. a blood group A organ went to a blood group B recipient), the recipient's immune system would produce antibodies to fight against the foreign antigen, resulting in graft failure.

organs) from different groups. For example, those with blood group B can donate blood to an individual with blood type B or AB, and can receive blood from an individual with type B or type O blood. In contrast, someone with blood group O can only receive blood and organs from those with the same blood type, yet they can donate to *any other* blood group. Despite this, until relatively recently, blood group O donor organs were restricted to blood group O recipients. As blood group O is the most common blood type in the UK, therefore constituting the majority of the organ donor pool, this had material ramifications for patients waiting for transplant from different blood groups. This was especially so for 'Asian' patients, who make up the majority of the UK's blood group B population: with 38% of 'Asian' people having blood type B, compared with 24% of 'black' people, and just 10% of 'white' people (Davies, 2006; Rudge *et al.*, 2007). As such, 'Asian' patients waiting for transplant were disadvantaged due to the strict criteria for exact blood type matching in organ allocation (Davies, 2006). It was not until 2002 that blood group O organs were allowed to be donated to blood group B recipients, in reflection of the inequalities the previous policy had brought about (Rudge *et al.*, 2007).

The role of tissue matching in UK organ allocation policies has also had similar effects. Tissue matching refers to the use of HLA -A, -B, and -DR matching in transplantation to improve the chances of graft success. Human Leukocyte Antigens are proteins on the surface of the body's white blood cells and other tissues. They are vital for the workings of the immune system as they present "foreign" substances in the body to the "killer" T- and B-cells, which produce antibodies to "destroy" these invaders (Joralemon, 1995: 337; Tinckam and Chandraker, 2006); of which transplanted organs are included. As such, the better a HLA match between organ donor and recipient, the less of a chance that the organ will be rejected. The distribution of HLAs in humans is hugely diverse and have been traced to the geographic origins of populations, along with migration (and thus conversion of HLAs into

different types), and disease history (Marsh *et al*., 2000). Despite the reported diversity of HLA types *within* population groups, HLA matching in transplantation has generally been mapped to an understanding of biological difference, by stratifying HLA type to racial/ethnic groups (Gordon, 2002; Duster, 2003; 2005). In this way, 'black' and 'Asian' people have been differentiated from 'white' people by HLA type.

In the UK context, minority ethnic patients have been ascribed through "rare" HLA types, which are compared with more "common" (white) HLA types in the donor population (see Fuggle *et al.,* 2003; Johnson *et al.,* 2010: 388). As such, HLA types are differentiated by (BME) recipient and (white) donor, generating a focus upon the shortfall in HLA aligned donor kidneys at the same time. With the UK's focus upon close HLA matching this has also had material effects upon BME transplant waiting times.

Although evidenced that poor HLA matching in kidney transplantation may lead to increased risk of graft failure, developments in immunosuppressant therapy and the importance of other factors, such as recipient age, have led to acknowledgments of the "diminishing significance" of HLA compatibility in kidney transplantation (Held *et al.*, 1994; Su *et al.,* 2004: 1501; Cecka, 2007). In the US this – alongside the fact that HLA matching was adversely impacting 'African American' renal patients – was recognised with the alteration of the kidney allocation scheme to remove priority points for HLA-A and HLA-B matching in 1990 and 2003, respectively (Cecka, 2007; Hall *et al.,* 2011; Malek, *et al.,* 2011). This has seen a significant decrease in waiting inequities between 'white' and 'African American' patients (Hall *et al.,* 2011). However, it was not until 2006 that the UK altered its kidney allocation policy, in recognition of such developments. Here, the scheme attempted to balance "equality" of access with "utility" of transplant outcome (Johnson *et al.,* 2010: 393). One way this was done was by "defaulting" rarer HLA types, less common in the donor population, to more prevalent forms. For example, HLA-A36 occurs in 0.2 per cent of

patients on the transplant list, yet is present in only 0.05 per cent of donors. In contrast, its more "common" form, HLA-A1 occurs in 18 per cent of the donor population. In this way, by re-categorising HLA-A36 as HLA-A1, patients with the former have a greater likelihood of receiving a matched organ (Johnson *et al*., 2010: 393). Initial analyses of the scheme suggest that whilst waiting times for "difficult to match [BME] patients" (Johnson *et al*., 2010: 392), have *not* decreased, the disparity in waiting times *between* 'white' and 'BME' patients has significantly lowered (Johnson, 2011 – personal correspondence).

Despite the fact that the 2006 allocation changes effectively shifted biological boundaries – and thus the gap between 'white' and 'BME' transplant waiting times – by the re-labelling of HLA types, the fact remains that boundaries of ethnic identity have been drawn around these notions of "rare" and "common" HLA types. This, in turn, means that the focus on minority ethnic transplantation remains tied to notions of genetic sameness or genetic difference. Writing about the construction of the UK's 'BME' transplant problem, Kierans and Cooper (2011) argue that:

> the criteria that are used to determine who may be matched with whom treat membership of social and cultural groups (understood in terms of 'race' and 'ethnicity') as proxies for genetic makeup. In its attempts to accommodate 'rare' HLA types, transplant medicine has fallen back on the same classificatory schemas that were implicated in the creation of the inequalities that recent policy shifts were intended to address – schemas that are based, primarily, on the assumption of a 'natural' basis for cultural differences. (P.13)

This biological inscription of 'cultural' difference – in which the categories of race and ethnicity have been mapped as the biosocial basis (e.g. Rabinow, 1996) for HLA types, and thus the main reason for transplant inequalities – has been taken up by the anthropologist

Elisa Gordon. Gordon (2002) describes a similar process in the US in relation to 'African American' transplant inequalities. She contends that the focus on, and assumptions of, HLA difference between population groups obscures alternative understandings about transplant inequalities. These assumptions she relates to the way in which 'races' are represented as genetically differentiated groups. This fails to account for the high level of HLA diversity *within* ethnic groups, rather than simply *across* them; and how HLA types in 'white' people are used as the scientific default, meaning that 'BME' groups get positioned as the "nonstandard" in transplant medicine (Gordon, 2002: 136). As Gordon argues, this has the effect of essentialising racial/ethnic difference.

Troy Duster has also taken up a parallel analysis of scientific accounts of minority ethnic health inequalities in the US. Similar to how the UK 'BME' transplant issue has been constructed, Duster (2003; 2005) argues that race and ethnicity become the primary organising factor by which minority ethnic health disparities are understood. This leads to "complex interactive feedback loops between biology and culture and social stratification" (Duster, 2003: 258), where the categories deployed by science to understand inequalities come to have very real effects upon the health outcomes of individuals (see also Bowker and Star, 1999). Duster (2003) describes the feedback loop involved in the mapping of blood group types to ethnic groups, in the context of blood transfusions in the US.

This feedback begins with the "biological fact" (Duster, 2003: 258) of the greater prevalence of antigens in blood from Americans with European heritage, compared to those with African or Asian ancestry. As such, 'blacks' and 'Asians' have more risk of having a serious reaction to a blood transfusion from a white person, and vice versa. In turn, the "social fact" that white people constitute the majority general and blood donor population has biological effects on 'black' and 'Asian' transfusion recipients (Duster, 2003: 258). This relates to how

the majority of blood banks only test for the most common blood group antigens in the general population. This practice, Duster argues, effectively leads to a greater risk of transfusion reaction for people from minority ethnic groups. Despite this fact, the problem has been largely discussed and acted on by relating it to the need to increase blood donation from minority populations. This effectively veils the production of inequality within medical practice; positioning it, instead, at the door of ethnic (biological) difference. In a similar way, Avera (2009) utilises Duster's feedback concept to understand the drive in South Africa to increase 'black' and 'coloured' bone marrow donors: where 'black' and 'coloured' potential donor identities are produced by their conflation with HLA type.

These feedback processes which Duster and Avera describe provide us with a way of seeing how the 'problem' of transplant access for 'BME' groups in the UK has been understood. In this case, the feedback relates to how, what began as an inequality around renal failure and disparities in access to transplantation, has been later related to the biology (HLA and blood type) of population groups. These ascribed biological identities have been used to stratify these groups, which we see in the classification of 'BME' transplant patients by 'rare' HLA type. This has the effect of furthering the original social inequality, with transplant allocation policies which utilise understandings of racial difference in the context of the 'social fact' of a majority 'white' donor pool. In turn, with the growing focus upon 'black' and 'Asian' populations' reluctance to donate their organs after death, differences in access to transplantation – as a problem described as originating *within* bodies – have subsequently been fixed in place as a problem *between* the bodies (Strathern, 2009) of ethnic/'cultural' groups.

These shifts have determined the specific character of kidney disease in this context, giving us insight into how the categories of the 'BME' transplant patient and organ donor have been conceived in response to a specifically defined health inequality. That minority ethnic

people donate less than their 'white' equivalents is thus a *conditional* problem: understood as the product of transplant medicine's development. Around the time of the first change in organ allocation policy, research also began to emerge which attempted to explain the minority ethnic transplant 'problem' through the lens of low donor rates from these populations. However, before moving to this literature, I want to expand on policy which specifically discusses the 'issue' of, and interventions for, increasing organ donation from the UK's 'BME' groups. This will then be followed by an analysis of the academic research which addresses transplant inequalities.

Part 2. Policy, promotion, and research responses: the responsibility of organ donation

In this section, I show how UK policy and research responses to 'BME' transplant inequalities are symptomatic of the way in which the problem has been practically and discursively constructed around notions of biological difference. Drawing on Duster's feedback loop (2003; 2005), we went from the social inequality of transplant access, into the biology of transplant matching. This, in turn, has been used to stratify population groups, resulting in material effects on the potential for 'BME' patients to receive a transplant, in the context of a majority 'white' donor pool. As I demonstrate in the following section, this moves back to society in the responses to solving the issue: namely in how 'BME' groups are further rendered by the construction of their collective responsibility to donate organs.

Policy responses to transplant inequalities

Organised policy responses to recognised donor organ deficits began to crystallise with the introduction of the NHS organ donor register in 1994; the Department of Health's (DH) transplant strategy (2003); and the related National Service Framework for Renal Services (NSF) (2004). These represented the first comprehensive policy responses in recognition of

the growing 'problem' of a gap between the supply of, and demand for organs for transplant. Despite the general drive to increase the number of organs for transplant across the board, UK policy addressing the organ shortage has tended to isolate minority ethnic populations as a specific and difficult-to-tackle group.

In positioning transplantation as the optimum form of treatment for ESRF, the NSF (2004) pointed to the critical need to increase organ donation, specifically from 'BME' groups, to ensure equity of transplant access. This was reflected in the *Saving Lives, Valuing Donors* strategy (DH, 2003). Here, the challenge for a new transplant framework revolved around 4 aspects, including prevention of disease (thus limiting the need for transplantation), and increasing the number of donor organs. In discussing the 'problem' of higher need for renal transplants amongst 'South Asian' and 'African Caribbean' 'communities', the strategy points out that: "because the best-matched organs are likely to come from people with the same ethnic background, it is important to ensure that all groups have the willingness and opportunity to donate organs" (DH, 2003: 9). It later charges UK Transplant with increasing the "profile" of organ donation within 'South Asian' and 'African Caribbean' groups through targeted promotions. In 2007 the organ donor taskforce established a specific 'Cultural' Working Group, which had the explicit remit of looking at prevailing 'cultural' attitudes to, and their implications for organ donation. The strategy of awareness-raising around donation is also discussed in the Organ Donor Taskforce's (ODT) more recent *Organs for Transplant* (2008) policy report.

This report laid out drastic plans for an overhaul of donor-transplant services within the NHS, in order to increase deceased donation rates by 50% over five years. Using evidence from Spain and the US, where high organ procurement rates are linked to institutional donation practices, recommended changes included increasing the workforce of donor-

transplant coordinators[11]; hospital-wide recording and monitoring of potential and actual donors; required referral of all potential organ donors to a donor-transplant coordinator; and the introduction of collaborative approaches to donation requests between donor-transplant coordinators and hospital staff. While the main changes to increase donation are concerned with altering the organisational structure of donation processes, the report also recommends attention towards public promotion and recognition of donation.

The report points out how, with family consent for donation averaging 60%, there are a large number of potential organs not obtained. This, it asserts, means that "the public as well as the NHS has a major role to play" (ODT, 2008: 26). In addition, it singles out the issue of higher rates of kidney disease amongst 'Asian' and 'African-Caribbean' populations, and the corresponding 'problem' of low rates of organ donation from these 'communities'. It details the importance of understanding the "barriers" (p.49) to donation within 'BME' communities, and finding ways to tackle these. In comparing the UK's donation refusal rates to Spain's record (just 20%), the report touches on the importance of institutional practice in gaining consent for donation. However, when it comes to recommending how to tackle low donor consent rates, this institutional connection disappears. It states:

> 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 population. (ODT, 2008: 48)

In this way, by simply placing targeted promotion as the only way of talking about the 'BME' donor 'problem', the report fails to link together its focus on institutional practice with low 'BME' donor consent rates.

---

[11] Donor Transplant Coordinators have since been re-named as Specialist Nurses in Organ Donation (SN-OD). These are clinical nurse specialists whose job it is to manage all aspects of the donation process; from requesting donation from families, to organising theatre teams for organ retrievals, as well as providing education to hospital staff around donation.

With this recommendation, the production of transplant inequalities resulting not just from the historical outcome of transplant allocation schemes, but also the structural organisation of donation services, recedes from view. The classification of 'BME' groups within transplant allocation policies therefore feeds back into how these groups have come to be defined as the main solution to this problem in the public/policy domain. As Ian Hacking (2006: 23) has argued, individuals get "made up" by their transformation into objects for scientific inquiry. In this way, the classification of 'BME' transplant recipients and 'BME' potential donors have been constructed around the high need for transplant and the fact of low donation rates. They are then further categorised and overlapped as groups-in-need (of transplant) and groups-as-solution (donors) to those in need. In "making up" population groups in this way, the "engines" of transplantation and donation policies involved in their formation are rendered invisible (Hacking, 2006: 24). This process is continued in public interventions which have been taken up to tackle the transplant problem and the related donor shortage within 'BME' groups, which I turn to next.

'Black' and 'Asian' donor campaigns: making a moral imperative

Reflecting the gradual shift from the focus upon preventing kidney failure through to organ donation, the first significant public response to 'BME' renal health and transplant inequalities came with Kidney Research UK's ABLE campaign (A better life through education and empowerment) in 2001. On Kidney Research UK's website, the project's aims are outlined as such:

> [...] to help these at risk communities by raising awareness into kidney disease, highlighting the importance of healthy living and finding research into the causes, prevention and treatment of kidney disease among the South Asian and African Caribbean communities.

The ABLE project picked out these "at risk" 'communities' by focusing upon urban areas with high 'BME' populations, such as West London and Leicester. The Leicester project, for example, involved research with the 'South Asian' 'community' and primary healthcare professionals to look at knowledge around kidney disease. Findings led to the production of educational materials and training of peer educators to promote prevention of risk factors for ESRF (Farooqui, Jain, and Freehally, 2008). Whilst not wanting to undermine the importance of such projects, the fact remains that the focus has been squarely placed upon these "at risk" 'communities', who become the target of interventions to reduce kidney health inequalities.

In a similar way, organ donation promotions aimed at 'BME' 'communities' have become the public face of minority ethnic transplant inequalities. In being tasked with increasing the profile of organ donation within 'BME' groups, UK Transplant bought out its first 'black' and 'South Asian' targeted nation-wide donation campaign in 2007. The *Can We Count on You?* leaflet and poster campaign (fig. 3) featured well-known 'black' and 'Asian' comedians delivering the 'facts' of the 'gift' of organ donation to *their community*. In a direct appeal the leaflets state: "you may not have thought organ donation is something that affects you. But as Asian [/black] people, we're at least three times more likely to need a kidney transplant than the rest of the population". In laying out these stark facts for 'Asian' people it then asks them to help "their community" by joining the organ donor register. In this way, the audience is asked to give the gift of an organ through the binding of individual identities to notions of 'community' (ethnic) responsibility. This moral appeal to save lives is reflected in NHSBT's most recent (2009) 'black' and 'South Asian' arm of their general *Prove It* campaign, discussed previously (see figs. 2 and 4).
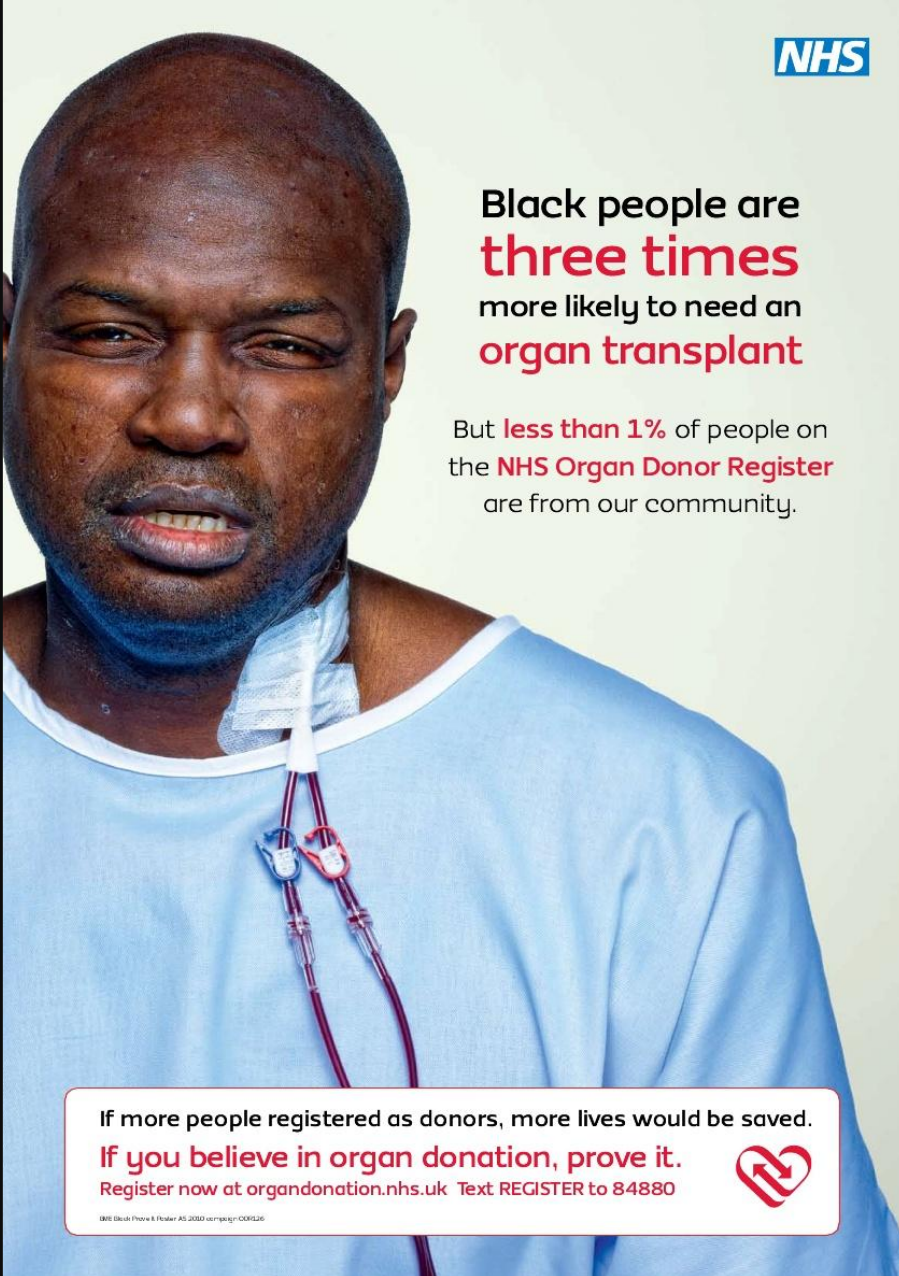
Alongside urging 'black' and 'Asian' people to "prove" their belief in organ donation through the re-formulation of individuals as 'communities', these groups were also singled out in

street plays and faith road shows in cities with high minority ethnic populations, such as Birmingham and London. The message is therefore a moral one: as 'black' and 'South Asian' people, *you* have a collective responsibility to help *your* community by donating *your* organs.

Figure. 3 UK Transplant's (2007) *Can We Count On You?* 'Black' and 'Asian' leaflet campaign.

Figure. 4 NHSBT's (2009) 'black' *Prove It* campaign poster.

NHS

Black people are
three times
more likely to need an
organ transplant

But **less than 1%** of people on
the **NHS Organ Donor Register**
are from our community.

If more people registered as donors, more lives would be saved.
If you believe in organ donation, prove it.
Register now at organdonation.nhs.uk Text REGISTER to 84880

BME Black Prove It Poster A5 2010 campaign CORL26

The moral imperative for 'black' and 'South Asian' individuals to register as an organ donor
has therefore been firmly entrenched by these campaigns. These follow from policy
responses which have taken the binding of genetically distinguished groups to transplant
inequalities through to the domain of organ donation – as the key site to tackling these
disparities. In this way, the campaigns move one further, asking their 'black' and 'Asian'
audiences to make a personal, moral connection to the constructed sense of (ethnically
distinct) 'community'. Organ donations' publics then, in the context of transplant

inequalities, have been specifically worked-up to denote distinct and distinguishable population groups.

The work of Cori Hayden (2007) helps us articulate this idea more clearly. In her examination of debates over calls for a new ethical principle of participant benefit sharing in clinical research, Hayden argues for a consideration of *who* the publics' benefitting actually *are*. In describing a research project which gathered plant artefacts in Latin America for US drug development, Hayden shows how the benefitting Latin American 'communities' – who would receive royalties from any subsequent drug production – were *made* by enrolling chosen groups, such as traditional healers, as future benefit-sharers. Through such processes, Hayden argues, the notion of 'community' becomes a "site and mode of conversion" (2007: 737). In this way she shows how 'communities', such as 'BME' potential donors and transplant recipients, are not necessarily the precondition for, but rather are the *result of*, research (and, in our case, transplant medicine's) efforts.

However, it is not simply policy and its public manifestations which have taken up the problem of transplant inequalities as a 'problem' of organ donation. Over the past decade, researchers have been searching for ways to understand why donor rates from 'BME' communities are so low, and how to subsequently increase consent rates for deceased donation. Existing research on this subject is therefore largely driven by, and constructed around policy frameworks. The literature appears to be looking for ways to solve the 'problem' as it is presented, without necessarily fully exploring the issue itself, as I demonstrate below.

Research responses: fixing 'culture' as the solution

At present, UK research has reflected the concerns of policy which links the origin of minority ethnic transplant inequalities to the lack of 'BME' organ donors. The research thus addresses this disparity by firstly examining the potential for donation within 'BME' 'communities', and secondly, assessing how this potential is constrained by 'cultural' factors. The intention is to use this knowledge to formulate educational interventions to increase 'BME' organ donation in the long-term. This small body of research has largely focused upon minority ethnic/minority religious groups in localised geographic areas, such as 'Muslims' in Birmingham (e.g. Razaq and Sajad, 2007), and 'black African' and 'black Caribbean' people in London (Davis and Randhawa, 2004). It consists of mainly qualitative focus-group and interview work, where participants are asked about their general opinions on donation; with some quantitative studies also assessing people's overall willingness to donate organs.

Findings from the research can be broadly grouped into 4 thematic sets. These cover: mistrust of the medical system; knowledge and understanding about organ donation; beliefs about the body after death; and religious and wider 'community' factors. These are positioned as barriers to, and thus openings for, interventions to increase donation rates. In this way, as I will later argue, 'culture' has been positioned as a barrier to organ donation and therefore operates as shorthand for a range of complex issues related to organ donation and minority ethnic groups. These assumptions feed into one other, with the effect that 'BME' groups have become racialised and "culturalised" in relation to organ donation (Kierans and Cooper, 2011: 11). In addition to UK work, I also draw upon a sample of mainly survey-based studies from the US, where there is similar focus upon transplant inequalities among 'African Americans' and 'Asian Americans'. I firstly report on the 4 main findings from this research, before drawing out my critique of this work.

Mistrust of the medical establishment

The UK research consistently reports that 'BME' groups' mistrust of the medical establishment holds weight in their opinions about donation. This includes a general lack of confidence in the health care system; the fear that doctors might not do as much to save your life if you are registered as a donor; or would even remove your organs before death (Exley *et* al., 1996; Davis and Randhawa, 2004; Alkhawari *et al.,* 2005). For example, Alkhawari *et al's*. (2005) qualitative study with 'Muslim Indo-Asians' in West London found a high level of alienation from the UK's healthcare system, which they partly linked to wider racial discrimination. In another study, Davis and Randhawa (2004) researched attitudes towards organ donation amongst the 'Black African' and 'Black Caribbean' population in the Lewisham and Lambeth areas of London. Findings from focus groups included negative perceptions of donation due to mistrust and fear of the medical establishment, with some participants expressing the belief that health professionals would not try as hard to save their life if they carried a donor card. They conclude by highlighting the importance of effective distribution of information about organ donation to the 'black' community. Here, the 'problem' of donation is attributed to the 'culture' of fear around the medical donation procedure. The understanding is that education may reduce this 'cultural' barrier to donation. In this way, 'culture' is explicitly placed outside of medical institutions and their practices, with the notion that such fear inhibits medicine's potential to procure organs from the 'black' 'community'.

In the US, reflecting the privatised organisation of the healthcare system, and the lower socio-economic status of 'African Americans' (Siminoff *et al*., 2006), this mistrust of medicine as a factor in negative donation attitudes has been attributed to wariness of the fairness of organ allocation systems. This includes perceptions that donated organs are more likely to be given to 'white' well-off people, or the 'rich or famous' (Cheung *et al.*, 1998; Sing, 2000;

Boulware *et al.,* 2002; Siminoff *et al.,* 2003; Sander and Kopp Miller*,* 2005, Siminoff *et al*., 2006).

Knowledge and understanding of donation

Another major 'issue' highlighted by the research is the lack of understanding and awareness about organ donation within minority ethnic 'communities'. This is taken to include whether people know how to register as an organ donor; whether someone has thought about donation before; and if they are aware of the conditions for becoming an organ donor (Exley *et al.,* 1996; Perez *et al.,* 1988; Randhawa, 1998b; Ahmed *et al.,* 1999; Darr and Randhawa, 1999, Davis and Randhawa, 2004; Molzahn *et al.,* 2005). Knowledge has also been linked to peoples' awareness of their religion's stance on organ donation. In Razaq and Sajad's (2007) questionnaire study among 'Muslims' in Birmingham, religion was understood as the primary organising factor in peoples' attitudes towards, and thus decisions on whether to become an organ donor. The authors argue that, with the majority of respondents believing that donation was not permitted in Islam, "it is the awareness, or the lack of, which is the first hurdle in combating low donor rates" (Razaq and Sajad, 2007: 1529).

In the US, lower levels of knowledge about organ donation among 'African Americans' has been used to predict the (decreased) likelihood of consent for organ donation (Morgan and Cannon, 2003). Research which suggests possible interventions thus focuses upon the potential for individual behaviour change through increased public knowledge about donation – delivered via an appropriate means, such as religious leaders, community networks (Baines *et al.*, 2002; Randhawa, 2005), and targeted promotion (e.g. Baines *et al.,* 2002; Davis and Randhawa, 2004). As pointed out above, this therefore produces 'communities' as the primary target for intervention.

Bodily Integrity after death

Another way in which minority ethnic groups are problematised in relation to organ donation is in reported concerns over donation as a form of bodily mutilation after death. Despite the fact that such worries about donation have been expressed within the general population (e.g. Haddow, 2005), BME groups have been focused upon in terms of their religious concerns about preserving bodily integrity after death, and the worry that funeral customs, such as preparing the body for burial, would not be possible with donation (Exley *et al.,* 1996; Hayward and Madhill, 2003; Davis and Randhawa, 2004; Alkhawari *et al.,* 2005; Molzahn, *et al.,* 2005; Morgan *et al.,* 2008). Similar findings were reported in Albright *et al's.* (2005) US study on attitudes of Filipino 'Asian Americans' towards organ donation and Cheung *et al*'s (1998) comparison survey of 'Asian-Americans' and 'caucasians'. In the UK specifically, Alkhawari *et al*. (2005: 1328) reported on the "culture specific issue" of body sacredness in Islam with 'Muslim Indo-Asians'. Participants reported Islam's prohibition of interference with the body after death, and the belief that organs are not ones' personal property to give away after death. In another example, Hayward and Madhill (2003) looked at the meanings of organ donation amongst 'Muslims' of Pakistani origin, and 'white' English nationals in the North of England. They found that both groups conceptualised donation in terms of personal costs. For example, some respondents in the 'Muslim' women's group expressed their worries over donation in terms of Islam's stance on bodily integrity after death. In comparison, 'white' participants felt that the 'costs' were related to their mistrust of the medical establishment. By juxtaposing attitudes in this way, 'Muslim' participants' (religious) views on the body become problematised as a 'culture' specific issue for targeting 'Muslim' populations for donation education.

Religious beliefs and the involvement of 'community'

Similar to the way in which religion has been specifically linked to bodily concerns around organ donation, UK and US studies problematise minority groups' uncertainty about their religion's stance on donation, and other religious concerns in general (Randhawa, 1998b; Boulware *et* al., 2002; Hayward and Madhill, 2003; Razaq and Sajad, 2007). Religion has also been linked to participants' worries about community responses to, and the need for extended family involvement in donation decisions (Exley *et al.,* 1996; Randhawa, 1998b; Albright *et al*., 2005). For example, Randhawa's (1998b) study of the 'Asian' population in Luton reported that 'Muslim' respondents "relied particularly heavily on the religious prescriptive in their faith to direct their beliefs and behaviour towards organ donation" (p.1951). This was also related to participants' expressions of how donation decisions, rather than being an individual choice, would be a product of different family members. In response to religious concerns, a few studies have pointed to the permitted status of organ donation within the UK's major religions: Christianity, Islam, Hinduism and Sikhism (Exley *et al.,* 1996; Randhawa *et al.*, 2010). However, it has been found that even with recognition of the legitimacy of donation, e.g. through Islamic Fatwas, the gap between official views of religious leaders and the everyday practices and concerns of individuals (Randhawa, 1998b; Alkhawari *et al.,* 2005; Arriola *et* al., 2007; Razaq and Sajad, 2007), means that no simple conclusions can be drawn between the position of religion and donation beliefs (Sheik and Dhami, 2000; Randhawa *et al.*, 2010).

Critiquing the donation research

Not wishing to undermine the insights this work provides around people's everyday concerns over organ donation, the fact remains that in defining 'BME' 'communities' and asking them about their attitudes towards organ donation, the research has rooted itself in a pre-defined schema. This schema fixes transplant inequalities to constructed notions of

'BME' 'communities' and 'culture', therefore failing to adequately explore any further aspects to the 'problem'. Below, I provide the main points of critique around these studies, which I will address by utilising wider social science literature around ethnicity, 'culture', and health:

Firstly, in taking 'BME' 'communities' and their 'culture' as the point of departure for understanding transplant inequalities, the research continues with the perceived link between biology (HLA and blood type), race, and ethnicity, which I described in part 1. This has the effect of conflating and assuming a direct association between the categories of biology, race, ethnicity, culture, and the 'fact' of low donation rates.

The conflation of categories such as 'race' and 'ethnicity' has been evidenced as a common phenomenon in scientific research (Pfeffer, 1998; Ahmad and Bradby, 2007, Bhopal, 2007; Fujimura *et al.,* 2010). Social science researchers have shown that, despite the continued utilisation of categories such as 'race' and 'ethnicity' in research, there is a lack of understanding over what these terms actually *mean*. For example, Lee (2009) looked at researchers' use of race and ethnicity in journal articles of biomedical cancer studies. She found that despite researchers giving weight to the concepts, they did not sufficiently use or define them. Similarly, Smart *et al*. (2008) found there was little consensus on the utilisation and understanding of these classifications in their research with UK biobank scientists. Amongst interviewees, understandings of ethnicity ranged from genetic ascriptions, to ones of 'culture' and lifestyle, right through to acknowledgement of their socially constructed nature. As Lee argues, such problematic and interchangeable usage of 'race' and 'ethnicity' "reifies" racial and ethnic categories as biologically significant, thereby restricting wider interpretations of ethnic health inequalities (Lee, 2009: 1186).

In the research on ethnicity and organ donation, the category of ethnicity has been specifically conflated with the concept of 'culture'. Such conflation has a distorting effect

where, as Ahmad and Bradby (2007: 798) point out, "the disadvantage [i.e. lack of access to transplant] of minority ethnic groups is seen as caused by their diseased genetic and dysfunctional cultural inheritance" (see also Ahmad, 1993; Taylor, 2007). In a similar vein, Bhopal (1997) argues that epidemiology has become racialised through its common practice of relating health inequalities to notions of the innate characteristics (including notions of 'culture') of 'BME' groups (Nazroo, 1998). Such racialisation of health inequalities has been linked to medicine's long history of pathologising minority ethnic groups (Ahmad, 1993)[12]. This has the effect of veiling wider, structural issues of inequality, such as how racism and religious prejudice have been linked to pervasive patterns of deprivation, along with persistent health inequalities among non-white groups (Nazroo, 1998; 2003; Karlsen and Nazroo, 2002; 2010; Harris *et al.*, 2006a; Ahmad and Bradby, 2007; Krieger, 2010; Priest *et al.*, 2011).

As we see therefore, the alignment of biological difference with groups of people constructs knowledge categories in a complex and seemingly unavoidable way in medicine (Duster, 2003; Epstein, 2007)**.** In merging ideas about the (biological) origins of transplant inequalities with notions of ethnicity and 'culture', the research has continued with the understanding which classifies minority ethnic groups as an innate factor in transplant inequalities. Disparities in access to kidney transplantation have therefore been positioned as a 'problem' of ethnicity; a category which is operationalised through notions of 'culture'. By taking 'culture' as the end point of the complex issues around transplant matching, the 'problem' of transplant inequities has been boiled down to the concept of 'culture'. In addition, 'culture' has been problematically related to the innate practices and beliefs of

---

12 One example is the case of 'Asian' rickets in the UK in the 1970s. A disease which had previously been seen as one of poverty later became understood by specific reference to 'Asian' lifestyle habits and 'Asian' peoples' genetic inability to absorb vitamin D (Ahmad, 1993).

population groups. It is this misuse of the 'culture' concept which I offer as my second point of critique.

As demonstrated, research which attempts to find out reasons for low 'BME' donor rates has largely represented 'culture' as a causal factor. 'Culture' therefore becomes a variable, which is not only aligned with ethnic group membership, but has also been understood as a static set of rules relating to religion, traditions, and beliefs etc which merely exist within different communities (Ahmad and Bradbury, 2007). For example, we saw how expressions of bodily sacredness after death in Islam was understood by Alkhawari *et al*. (2005) as a "culture specific issue". This has the effect of placing culture as a stable and closed system which belongs to mutually exclusive groups of people (Barth, 1969; Rosaldo, 1993; Agar, 2006). In this way, ethnicity and culture become mutually derived (Ali *et al*., 2006), with 'culture' transformed into the object of inquiry in relation to transplant inequalities.

As anthropologists have noted, 'culture' is a highly contested and complex concept (Rosaldo, 1993; Agar, 2006; Baker, 2010), with a troubling history relating to colonial projects (Baker, 2010). Rather than being able to describe '*a* culture' or behaviour as 'cultural', as the research on donation and ethnicity does, anthropologists have come to increasingly refer to 'culture' as process, which takes change, time, and different perspectives, rather than overarching beliefs or practices, as the focus (Abu-Lughod, 1991; Rosaldo, 1993; Taylor, 2007). For example, Agar (2006) advocates the notion of 'translation', in reflection of the intersubjective nature of 'culture'. Rather than a descriptive label, he tells us, 'culture' only comes about in the recognition of difference in the interaction between different people. Through such understandings, Islamic sacredness around the body (Alkhawari *et al*. 2005) is named as a 'cultural issue' only in the context of research on organ donation, and its recognition as a potential 'barrier' to donation consent.

The sole focus in the research upon 'BME' populations has also led to 'culture' becoming the framework by which to distinguish the minority from the majority group (Barth, 1969) in relation to organ donation. In this way, 'culture' is seen as the main variable for intervention, with the assumption that knowledge (about donation) will lead to direct behaviour change (in donation consent). In examining research into HIV/AIDS prevention in Africa, Taylor (2007) similarly argues that 'culture' has been utilised as a catch-all term to describe behaviour and beliefs which lead to the transmission of HIV and act as barrier to its prevention. 'Culture' is therefore understood as a 'problem' for medicine to overcome by effecting interventions to promote behaviour change around donation. In this way, as I thirdly argue below, in positioning 'culture' as the sole preserve of 'BME' groups it gets placed outside of medicine's domain of practice, which renders invisible the part that medicine has played in making and maintaining transplant inequalities.

As we saw in part 1, with the effect that transplant allocation policies have had on transplant inequities, the organisation of healthcare has an important part to play in 'BME' health outcomes. Yet, despite this, research has continued to ignore medical practice in the debate on organ donation and ethnicity. Wider research into healthcare organisation, however, reinforces the importance of bringing medicine into the picture. For example, social research has consistently called attention to disparities in access to healthcare for minority ethnic groups, which may contribute to health inequalities (Commander *et al*., 1997; Modell *et al*., 1997; Szczepura, 2005; Taylor and Marandi, 2008; Kovandzic *et al*., 2011). In addition, a body of qualitative research has shown how minority ethnic health inequalities can also be traced to the everyday interactions between health professionals and minority ethnic patients. For example, Cass *et al*'s. (2002) study on Yolngu-speaking, Aboriginal patients and their doctors in an Australian dialysis department found general incidents of miscommunication, which went largely unrecognised by healthcare providers. These miscommunications related to

vital factors in the care trajectory (diagnosis, treatment, prevention), which had the potential to jeopardise quality of patient care. Taking a provider viewpoint, Kai *et al*. (2007) found that UK health professionals felt discomfort and uncertainty when encountering patients perceived as culturally different from themselves. As a result, health professionals felt their ability to adapt their practice to patients' needs was inhibited, affecting quality of care. Divergent understandings of health and notions of identity between health professionals and minority ethnic patients therefore has the potential to negatively affect quality of care and health outcomes. Other studies have highlighted the detrimental effects upon the treatment offered, and how information is communicated to minority ethnic patients when provider care revolves around stereotyped notions of ethnicity (Bowler, 1993; Atkin *et al*., 1998).

These examples differently illustrate the importance of 'culture' in minority ethnic health inequalities. They show how, far from standing outside of medicine and being drawn around 'communities', 'culture' is understood in the context of the organisation of healthcare institutions and in the work of practitioners with minority ethnic patients. By ignoring such intersubjective understandings of culture, and thus limiting insight on organ donation to the 'cultural' beliefs of 'BME' 'communities', researchers have failed to draw medicine into the debate. Part 3 of the literature review takes up this point to highlight findings from key – yet isolated – research on institutional donation practices and the experiences of donor families. This research points to the importance of the encounter between 'BME' groups, health institutions, and their practitioners in donation outcomes. In so doing, we move away from the specific focus upon 'BME' groups as the sole problem in transplant inequalities, and towards an understanding of the production of these disparities within the context of medicine.

Part 3. Understanding organ donation: the role of medical institutions

In this part of the literature review I provide evidence from a small body of research on organ donation which illustrates the importance of bringing institutional practices around donation into an understanding of low 'BME' donor rates. I Firstly describe the largely survey-based research from the US and Europe, which highlights disparities between how 'white' and 'black' families are approached about organ donation, as well as how donation decisions can be seen as the outcome of a number of factors; of which healthcare practices are an important part. Secondly, I utilise research which has been conducted with donor and non-donor families across different national contexts, to highlight how these families draw on their institutional experiences to make sense of their decision to donate their relative's organs or not. Taken together, this work points towards the importance of taking a better look at medical institutions and their practices in understanding donation disparities.

'Race' and 'ethnicity' in donation practice

A number of studies have come out of North America which provide an entry point for beginning to think differently about the relationship between ethnicity and organ donation. These mainly survey-based studies explore the organ donation request encounter, along with the pre-encounter (where brain-dead patients are transferred to the status of potential donors), to look at what goes on between health professionals and families when a patient has died with potential for organ donation.

Perez *et al's.* early study (1988) found refusal rates for organ donation in three US cities were higher for 'black' and 'Latino' patients (45% and 43% respectively) compared with 'white' patients (17%). Along with speculating on the importance of 'cultural' factors, such as religious beliefs, in understanding these disparities, the researchers also indicate that the possibility of organ donation was not followed through as much by staff with non-white

families. Here, the suggestion is that despite refusal rates being higher from non-white families, there is a factor of non-referral which needs to be brought into the equation. In a similar vein, research by Guadagnoli *et al.* (1999) showed that families of 'white' patients who met the criteria for brain death were almost twice as likely to be approached about donation as the family of an 'African American' patient. Hartwig *et al.* (1993) also found 'African American' families were less likely to be approached about donation by a health care professional than any other ethnic group. With this, we begin to see how inequalities in organ donation, and thus transplantation, are very much embedded within institutional (medical) practices – which seem to further entrench these disparities.

These insights are supported by Siminoff *et al's.* (2003) study of 451 'black' and 'white' families' experiences of organ donation requests. They report how 'black' respondents perceived that they were put under pressure to make a decision on donation and were given less chance to discuss their decision with a health professional. Crucially, the authors point out that simple measures to increase awareness about the need for more 'black' organ donors in the US will not, therefore, solve the shortage if 'black' families are not given equal treatment in the donation encounter to their 'white' counterparts.

Other, more general research in the US, UK, and Sweden strengthens the argument that medical institutions need to be brought into understandings of donation disparities. In their earlier study with potential donor families and health professionals, Siminoff *et al.* (2001) found 4 factors relating directly to donation decisions. These included the pattern of consent: who the request was made by, and who discussed donation with families; and that families were found to be five times more likely to donate if they were involved in more discussions about donation with staff. If we then compare this with Siminoff *et al's.* 2003 findings that 'black' families had less chance to discuss donation, we gain a stark insight into

how organ donation inequalities may be *produced* by institutional donation practices, specifically when these differ between 'white' and 'black' families.

Further to such insight, Sanner's (2007) research, comparing the donation experiences of potential donor families with Intensive Care doctors in Sweden, found that only half of the 25 doctors interviewed were comfortable with requesting donation from bereaved families. Importantly, when families were unaware of their relative's wishes around donation, only doctors with a "pro-donation" (p. 296) approach in their requests gained consent for organ donation. In this way, Lesoeurs *et al's.* (2009) findings of how French Donor-Transplant Coordinators viewed migrant potential donor families' situations as more 'difficult' than other families are important, if it were to affect their subsequent approach to families. And in their systematic review of factors influencing families' decisions on organ donation, Simpkin *et al's*. (2009) findings mainly related to institutional practices. Reduced rates of refusal for donation were linked to the separation of the request for organs from the discussion of brain death; the delivery of adequate information about the donation process; and the skill and training of the person making the request, among others.

Bringing these insights together, I argue that it is therefore far from simply about whether someone has a positive attitude/belief about organ donation that is the issue in low donor rates, as the research on 'BME' 'communities' would have us believe. Here, the notion of 'community' and 'culture' in organ donation widens out to one which involves *both* families and health professionals. This insight is further expanded with research which looks at the general experiences of donor and non-donor families across different national settings.

Family experiences of donation requests

Studies which have looked at families' experiences of being asked to donate their deceased relative's organs also attest to the importance of examining medical practices in donation

decision-making. Research in the UK, Greece, the US, and Taiwan with donor (those who consented to donate) and non-donor (those who refused to donate) families, has identified overlapping factors influencing families' decisions over donation. Specifically of importance are those which show how families struggle with accepting organ donation not simply because of personal beliefs/'culture', but as a result of the care they receive, and the information provided by health professionals.

One major issue brought up by families as affecting their decision to donate their relative's organs was around their struggles to come to terms with the concept of brain death (Foulton *et al.,* 1987; Sque and Payne, 1996; Franz *et al.*, 1997; DeJong *et al.*, 1998; Sque *et al.*, 2005; Bellali and Papadatou, 2007; Sque *et al.*, 2007). This has been theorised around whether the deceased's body and its parts are viewed mechanistically, or whether families perceive their relative as still embodied after death (Sanner, 2001; Haddow, 2005). Taken on their own, these understandings would fit with a 'culturalist' view of organ donation, where families' pre-conceived ideas about what happens to an individual after death dictates their donation decisions. However, families who eventually donated were found to demonstrate a greater understanding of brain death than those who declined donation (Franz *et al.*, 1997; DeJong *et al.*, 1998; Haddow, 2005). This understanding has been linked to the way in which health professionals convey this form of death to families (Haddow, 2005). This illustrates the importance of how views on death may be *produced* in the context of how death is explained by health professionals, rather than something which can be predicted by peoples' de-contextualised attitudes towards death.

Families' experiences with Intensive Care staff and donation professionals were also emphasised as important factors in donation decisions. Donor and non-donor families gave weight to the perceived quality of care provided; how appropriately information was tailored to their needs; and how the request for organs was done – with donation nurses

pointed to as key in this (Sque and Payne, 1996; DeJong *et al.*, 1998; Martinez *et al.*, 2001; Shih *et al.*, 2001; Haddow, 2004; Bellali and Papadatou, 2007; Sque *et al.*, 2007). This attests to the importance of looking at donation procedures, and the practices of health professionals around these, in understanding how family decisions are reached. Bellali and Papadatou's (2007) qualitative interview study of Greek parents asked to donate their child's organs provides a good example of this. They found that most families who consented to donate experienced a two-fold request process, where the formal request was precluded by an informal suggestion of donation. Parents reported the benefit of having a double request: it gave them time to think about the possibility of donation before they were formally approached by the treating doctor. In contrast, *none* of the families who refused donation experienced this informal pattern of request.

In addition to the influence of *how* and *when* donation requests are made, donor and non-donor relatives also expressed the importance of having a trusting relationship with healthcare staff. This encompasses the perception that staff had done all they could to save their relative's life, and feeling like they were treated with care and compassion (DeJong *et al.*, 1998; Shih *et* al., 2001; Haddow, 2004; Bellali and Papadatou, 2007). In contrast, non-donor families reported the lack of such a relationship as a factor in their decision to refuse donation (DeJong *et al.*, 1998; Sque *et al.,* 2005; Bellali and Papadatou, 2007). In this way, the development of rapport between staff and families is a vital factor in the decision making process.

These findings link into the insights by Siminoff *et al*. (2001; 2003) and Simpkin *et al*. (2009) of the importance of institutional practice in organ donation outcomes. They help us move beyond the methodological and theoretical blinkers witnessed in policy, health promotion campaigns, and research which ties 'BME' transplant inequalities to 'BME' organ donor rates and 'BME' 'culture'. As I argued in part 1, these inequalities have been *produced* within the

practices and policies of transplant medicine. Yet this is veiled in the discourse and practices surrounding the issue, which potently tie transplant inequalities to a specifically formulated notion of 'BME' 'culture'.

In contrast, these studies show the importance of viewing donation decisions as a contextual process *between* families and health professionals in institutional contexts; the outcome of which does not simply converge with isolated attitudes towards organ donation (Sque *et al.*, 2007). However, much like how the Organ Donor Taskforce's report (2008) failed to make the link between 'BME' transplant inequalities and institutional donation practices explicit, this body of research seems to have been ignored in public and academic domains discussing the 'issue'. In addition, these studies provide only a glimpse into the practices which are set up as vital in donation decisions. We are given little insight into the context or detail of, for example, how brain death is explained, or how families are actually asked about donation. This brings us to the fourth and final part of the literature review. Here I take ethnographic research into the institutional practices of organ donation and transplantation to illustrate the importance of understanding transplant inequalities *through* the institutional contexts in which these are initially produced. In this way, I widen the boundaries of the 'community/'publics' in ('BME') organ donation to also encompass medicine's domains.

Part 4. Institutional assemblages of organ donation

In this section I focus upon a body of ethnographic research which demonstrates the importance of paying attention to national, institutional, and practice contexts in order to understand the phenomena of transplantation and donation. To recap on previous arguments, I have shown how research, health promotion, and policy responses to inequities of transplant access for minority ethnic groups in the UK have fixed ethnicity and 'culture' as both the source of, and solution to, these disparities. In this way, inequalities in

transplant access have been largely tackled by the focus upon getting the ('BME') public to donate more organs. This has the effect of not only veiling the part transplant medicine has played in the production of these inequalities, but also renders opaque any further part medicine may have to play in the donation decisions of 'BME' families. By shifting the focus from 'BME' 'culture' to the institutional contexts of organ donation in the previous section, I argued for a different approach to studying ethnicity in relation to organ donation, which would take these contexts into account. Such an approach has been taken up by anthropologists and sociologists in studies of the practices and wider institutional, political, social, and economic contexts which make organ transplantation and donation *possible*. It is to such work that I now turn to provide detailed insight into the importance of bringing institutions and their practices into alternative understandings of the 'problem' of ethnicity in organ donation.

The biosocial domains of transplantation

In contrast to research outlined previously, there is a large body of ethnographic, social science research which takes up the phenomena of organ donation and transplantation as 'biosocial' (Rabinow, 1996) or 'sociomedical' processes (Sharp, 2006: 4). Rather than polarising medical with public domains, this work, drawing on the approach of science and technology studies (STS), shows how transplant medicine is constituted by diverse actors, such as health professionals, brain dead donors, medical technologies, transplant recipients, and donor families, among others. This is an area which is thus acknowledged as enormously complex, with a variety of debates taken up to explain the phenomenon of transplantation.

These debates encompass: the impact of receiving another person's organ on a transplant recipient's sense of self, and the un-repayable burden of debt in receiving a donor organ (Fox and Swayzey, 2001; Crowley Matoka, 2005; Kierans, 2005; Shimanzono, 2008; Poole *et al,*

2011); the everyday experience of caring for a brain dead cadaver, requesting donation from bereaved families, and living with the experience of having donated a relative's organs (Sharp, 2006; Jensen, 2010); and the practices of organ trafficking and selling in non-Western nations, understood as symbolic of global economic inequalities (Scheper-Hughes, 2001; 2002; Sanal, 2004; Tober, 2007; Lundin, 2010; Yea, 2010). This work has also theoretically tracked the polarised discourses which characterise transplant medicine in terms of bodily objectification, commodification, and the reciprocal act of gift giving – creating social obligations between recipient and donor (Mauss, 1954; Appaduri, 1986; Sharp, 2001; 2006; Lock, 2002; Ben-David, 2006); alongside the shortfalls of using such concepts to understand the complexity of donation and recipient experience (Parry, 2008; Kierans, 2011).

To focus such a large body of work for the purpose of this review, I take up in more detail research which pays attention to the institutional practices of deceased organ donation and transplantation. I will show how this research provides insight into the co-constructed relationship (Jasanoff, 2004) between organ donors, the institutions, and their practitioners who make donation possible (Healy, 2004). This work I have grouped into two sections, summarised below:

I firstly draw on ethnographic work by the anthropologists Margaret Lock (1996; 2002) and Lesley Sharp (2001; 2006; 2007), to show how brain death is a complex, phenomenological, concern for *all* involved constituents. Linking to the 'BME' issue, I argue that this work demonstrates how organ donation is not simply the product of pre-conceived 'attitudes', but also a result of the ability of health professionals' to render death, and thus donation, acceptable to families. These insights will be contextualised by (anthropological and STS) research on death and dying within medical domains.

Secondly, I utilise work by Linda Hogle (1995; 1996), Sharp (2006), and Megan Crowley-Matoka (2005) on the *work* of donation and transplant professionals, who actively produce organ donors for transplant, and frame transplantation as a desirable form of treatment. This I use to argue for the importance of contextualising 'BME' transplant inequalities by understanding the networks of relations involved in making donation possible. These examples will be grounded with a further discussion of research which examines the work of scientists and health professionals: providing justification for my research focus upon institutional donation practices.

The problem of brain death

The figure of the brain dead cadaver[13] – from which the majority of donor organs are procured in the UK – has been variously conceived as a hybrid of nature/culture, human/machine, person/non-person, and alive/dead (Gaylin, 1974; Lock, 2002; Staiano-Ross, 2005). As Margaret Lock (2002) argues, it is the hybridity of the brain-dead that brings about anxiety, precisely because we cannot place them into any "morally absolute" categories (p.41).

As a result, brain death has been commonly held up as a problem for gaining consent in organ donation by virtue of the way in which families struggle to accept the death of their still-breathing relative (see e.g. Franz *et al.*, 1997; DeJong *et al.*, 1998; Haddow, 2005; Sque *et al.*, 2005, outlined in part 3). In medicine, debates have formally clustered around standardising criteria for brain death, to provide medical practitioners certainty in the legitimacy of their diagnosis (Lock, 2002). Much like how the 'cultural' beliefs of 'BME' 'communities' have been framed as inhibiting the potential to reduce transplant inequities, brain death has largely been understood as a problem of families, or the public – unable to

---

[13] See thesis introduction and chapter 3 for an overview and explanation of brain death in organ donation.

understand the finality of this form of death. However, as Lesley Sharp (2001; 2006) argues, organ donation is only possible by virtue of *all* involved parties (clinical staff, donor nurses, potential donor families etc) accepting brain death. Sharp and Lock's ethnographic research therefore provides an alternative perspective on the problem of brain death for organ donation. It shows how it as much as an issue for health professionals as it is for families and the public, as I describe below.

Lock's (1996; 2002) work on brain death in America and Japan contrasts the apparent ease in America with which brain death was accepted by both medicine and the public with the situation in Japan, where brain death was only legally recognised in 1997. However, when scratching beneath the surface, Lock reveals the ambiguities which exist between brain death as a notion in principle, and how this is interpreted by professionals caring for brain dead donors. This includes the ambivalence of Intensive Care doctors in conceiving of brain dead patients as truly *dead*. All of the 32 Intensivists Lock interviewed discussed the belief that brain dead donors were *not* biologically dead when sent for organ retrieval. Many of these doctors understood brain death as "not quite dead but neither alive"; with one expressing his belief that "real" death only occurs with the cessation of the heartbeat (2002: 248). Similar uncertainties over brain death were found in Youngner *et al*'s. (1989) survey research into US health professionals' understanding of brain death. When presented with hypothetical scenarios of brain dead patients, some respondents explained the patient's 'dead' status by their unacceptable quality of life and their "hopelessly dying" situation (p.2207). Importantly, Youngner *et al.* (1989) argue that, although the criteria for recognition of whole brain death has been accepted in the US, there are discrepancies in its application in practice. They suggest that if staff are confused, this may impact negatively upon their ability to deal with brain dead patients and their relatives, with the implication

that the potential for securing donation is dependent upon the knowledge of health professionals around brain death.

From this, I suggest that for healthcare staff involved in donation there may be discomfort in the process of asking for, and removing organs from the still-breathing dead. If we link this to the research in part 3, which indicates the importance of how the donation request is done by health professionals in families' donation decisions, we begin to see how low organ donor rates (and transplant inequalities) can only be understood in the encounter between these two (artificially polarised) sides. Lesley Sharp (2006) has also shown how ambivalences over brain death are evidenced in the peculiar practice of anaesthetising brain-dead donors prior to procurement surgery. Rarely discussed in medical literature, the practice is justified as a way of relaxing the donor's muscles, to ensure donation surgery is not jeopardised by residual spinal reflexes. However, in her interviews with anaesthetists, Sharp found another explanation: that it is used for the emotional comfort of operating staff, to quell distress if a 'dead' patient starts thrashing about in theatre. This example also indicates the way in which death is put to work in healthcare domains: how the dead are made acceptable for both families and health professionals, so as to make donation possible.

This leads us to briefly contextualise such arguments with wider research into the organisation and practices around death and dying in medical domains. This literature I draw on in light of the above insights into death as an important concern in organ donation.

Medical practice organises death

As indicated above, death in organ donation is not simply an issue for families/the public, and nor can it be reduced to a simple matter of the technical criteria for determining death. Rather, death can be understood as an ongoing process, where the relationship between

the dead and the living are contingent upon the contexts in which these are played out (Kellehear, 2008: 1540). As Kaufman and Morgan (2005) have argued, the practices and technological developments of medicine have come to organise the Western dying experience.

One of the first ethnographic studies into hospital dying was conducted in the US by Glaser and Strauss (1965; 1974). They found that dying had a specific trajectory; the most important stage they classified as "nothing more to do" (1965: 177). This is when a person's death is certain, with medical practice moving from recovery to comfort and preparing the family for death. Glaser and Strauss therefore showed how dying is not only organised by medical practice, but is also *brought about* for families in practices which indicate the dying status of their relative. Similarly, Sudnow's (1967) ethnography of US hospital staff involved in care of the dying shows how death and dying are "*constituted by the practices of hospital personnel* as they engage in their daily routinised interactions within an organisational milieu*" (p.8, italics in original). For example, Sudnow argues that a distinction can be made between clinical, biological, and social death, with social death enacted in activities around the patient in preparation for their 'final' death. This was evidenced by a nurse trying to close the eyes of a dying woman, which she justified by the comparative ease of closing the eyes *before* death occurs, when the muscles have not yet become rigid (Sudnow, 1967: 74). Death is thus inscribed on the dying by the practices of health professionals, which indicate the shift from dying to dead. Here we might argue that, for the still-breathing brain dead, the symbolic status of death, and thus its acceptance, is much harder to achieve.

More recent research has attested to the enduring relevance of these early studies. For example, Kaufman's (2005: 56) observations of dying in American Hospitals evidences how death is routinised or "moved along" in the context of private, economically driven healthcare systems. And Seymour's (2000; 2001) ethnography of death and dying in UK

Intensive Care Units (ICU) shows how decisions to withdraw treatment on a patient are made when understandings of technical and bodily dying converge. In this way, death is rendered as 'natural' and thus legitimate for families. Such practices, Timmermans refers to as "death brokering": where deaths are made "culturally meaningful" for families (2005: 993) and health professionals alike. This he evidences (2005; 1998) in the common practice of cardio-pulmonary resuscitation (CPR) on patients whose situations are deemed hopeless, so as to provide a dying stage for families. In a similar way, Johnson *et al*. (2000) show how families are equipped for the death of their relative by health professionals' construction of a narrative-trajectory of dying, which gradually indicates the hopelessness of a patient's condition to the family. Equally, when these communications are done badly, families may feel unprepared for their relative's death (Russ and Kaufman, 2005). Medical practices around the dying are not always done for the sake of families, however, as we saw with Sharp's example. Hadders (2007, 2009a) shows how medical technologies and practices *construct* the dead for both families and health professionals. For example, he illustrates how ICU nurses' post mortem care of the dead, such as shrouding the body, allows for an "ontological switch" in their re-conception of a patient as a corpse (2007: 215).

These studies attest to the fact that death and dying are constituted and organised within medical spaces and their practices. With this, and the work of Lock, Sharp, and Youngner, we see how acceptance of brain death is not just about the personal understandings or misunderstandings of families. Rather, they are the product of how dying is organised and communicated to families, and how death itself is practiced by health professionals. Here, death, and subsequent decisions on organ donation requests are seen as the product of an agreement between professionals, patients, and families; made through the practices which give meaning to death. The following section of this review picks up on the importance of medical practices around donation, to show how the locally-situated work of health

professionals makes organ donation possible. This evidence culminates in the justification for the orientation of my study into ethnicity and organ donation, which takes the study of healthcare institutions and their practitioners as the site for understanding the 'BME' organ donor 'problem'.

Producing organ donors and transplant recipients

A small body of ethnographic work has looked at the practices by which donor organs are obtained, and kidney patients are rendered as potential transplant recipients. This research highlights the complex networks of constituents, procedures, practices, and national and institutional settings involved in producing organ donors and transplanting donor organs. In detailing this work I aim to provide a further perspective to the BME donor 'issue': this being one which sees medical domains as vital in making organ donation happen; and thus as a key site for tackling 'BME' transplant inequalities.

In her ethnography on procurement professionals in the US, Linda Hogle (1995) illustrates how the standardised criteria for establishing the clinical viability of potential donors is negotiated by staff in their everyday work. Such procedures were brought about in the context of increasing need for donor organs: to optimise donor outcomes and make the procurement process more efficient. These standards were put in place with the donor tracking tool: a form designed to gather information about the donor from, for example, clinical testing for the presence of transmissible diseases, to enable judgement on donor suitability. Hogle observed how this tool conversely contributed to pluralistic local practices in its negotiation by procurement professionals to meet local organ demands, and in their personal judgements of patients as "good" or "bad" potential donors (1995: 491). In one example, Hogle observed a four-month old baby being assessed for donation. Despite testing positive for Hepatitis C, the procurement coordinators decided the baby was a suitable donor by judging that the test was likely to be a false-positive. This they justified by

their knowledge of the family history, deciding that because the Mother (and not the baby) was a drug user, the virus "was not really there" (Hogle, 1995: 490). Hogle discusses how the "facts" (p. 490) in this case, and thus the standardised donor criteria, were adapted to legitimise donor suitability in the context of a high demand for baby organs and the relative rarity of such donors.

Hogle's work suggests that deceased organ donors therefore get *made* as a result of health professionals' decisions around suitability, and in their manipulation of practice standards. This is done in the context of local and national demands where, in the US, procurement practices are highly competitive and economically driven. Similarly, Sharp (2006) has shown how family counsellors making requests to families for donation readily draw upon a large pool of metaphors to talk about brain death. This is done with the understanding that imparting *too much* information may ultimately deter a family from donating their relative's organs. Brain death thus gets interpreted to families in ways which frame it favourably for organ donation. Lock (2002) also highlights how, despite the standardised criteria for diagnosing brain death in the US, there is little use of formal frameworks for doing this at local levels, with the practice differing between institutions and professionals. I argue therefore that the practices which get done by health professionals around potential donors and their families, prior to any requests for donation, make organ donation *happen*.

Other research has highlighted how the demand for organs is not only negotiated at local levels, but is also embedded within wider national contexts. Crowley-Matoka and Lock (2006) have argued for the importance of considering national, socio-economic, and historical contexts to understand donation and transplant practices, and the disparities between available donor organs and transplant demand. For example, Hogle (1996), in her research on the practices around donor organs in Germany, discusses the "contested practice" (p. 676) of acquiring organs from brain dead bodies in the context of Germany's

71

history of Nazi atrocities. In contrast to the US, where she found widespread use of pharmaceuticals to optimise the 'quality' of donated organs, in Germany, donation professionals practised minimal intervention on donors. For Hogle, these national differences reflect the increased sensitivity of medical intervention in Germany, in light of its historical past.

Another example is provided by Megan Crowley-Matoka (2005) in her study of pre- and post-kidney transplant patients in Mexico. She showed how the desire for a transplant is actively "cultivated" (p. 823) by healthcare staff, by projecting a 'normal' future for patients in a country with scarce haemodialysis resources. In one hospital, regular meetings were held for kidney patients and their families[14] to promote the benefits of transplantation in attempts to "mobilise motivation for transplant" (p.825). However, in the context of Mexico's largely fragmented and multi-tiered healthcare system – where those who cannot pay into social security rely on public, charity-run hospitals which do not provide immunosuppressant medication post transplant – Crowley-Matoka (2005) details the troubling outcomes of this cultivation for patients not able to hold down or get a job post-transplant, and thus maintain their new kidney. This provides insight into how national contexts shape both transplant practices and patient outcomes. This is important in grounding an understanding of how transplant inequalities, such as the 'BME' 'problem' in the UK, are specific to different settings.

Organ donation procedures and their practices are therefore understood within national, local, and institutional contexts[15]. These affect how donation is *done*, and the way in which

---

[14] In Mexico, transplantation is largely done with live donor organs, with family members usually acting as the donor.

[15] In this way, we may also trace the UK's low rates of organ donors to the organ retention scandals in the 1990s. Here, the media storm around the use of organs in research, procured after post-mortem without adequate consent from the families of the dead, negatively affected donation rates and deterred hospital staff

dead or dying individuals come to be potential donors. In public understandings of the 'BME' donor 'issue' these contingencies have been written out of the picture. This study is therefore concerned with bringing these processes and experiences back into view, in order to alternatively understand the 'problem' of ethnicity in organ donation. Before moving into detail of how I did this though, I finally demonstrate how wider research into the work of scientists and health professionals provides further evidence for the importance of such an approach.

The work of medicine

Beginning in the 1970s, a body of ethnographic research has documented the institutional processes and practices of medical professionals and scientists (Pickering, 1992). This work has contributed to an understanding of how things, such as scientific facts – and in our case, organ donors – are produced within practice contexts and in the formal and informal networks created between practitioners (e.g. Woolgar and Latour, 1986; Latour, 1987; Pickering, 1992; Rabinow, 1996; Knorr Cetina, 1999; Rapp, 1999; Timmermans and Berg, 2003). Such work, commonly referred to as science and technology studies (STS), is largely associated with the approach of actor network theory (ANT). Here, things – such as organ donors and donor organs – are made real by the effects of relations between diverse human and non-human actors (Law, 1999; Latour, 2005), such as health professionals, brain dead patients, potential donor families, mechanical ventilators, and donation consent forms and protocols, among others.

As Woolgar and Latour, in their seminal *Laboratory Life* (1986) study demonstrated, the production of scientific knowledge depends upon: diverse possibilities, institutional contexts, competing interests, funding sources, resources, standards, and "microprocesses"

---

from asking families for donation (Seale *et al.*, 2005; Bird and Harris, 2010). I outline this in more detail in chapters 3 and 6.

of practice, among others (1986: 41). In addition, as Mol's (2002) work on atherosclerosis demonstrates, medical objects are constituted by the *enactments* – the 'doing' upon and around them – of differently involved actors. For example, bringing a donor organ into being may involve various actors and practices including: donation procedures and policy, dead and dying patients, intensive care staff and wards, brain stem death testing, mechanical ventilators, potential donor families, and taking consent, among others.

In addition, work on standardisation has highlighted how medical objects are formally produced through protocols, classificatory devices, and standardised forms, such as the donor tracking tool which Hogle described (1995). Such standards – designed to organise and co-ordinate the activities of practitioners, to achieve optimal results – are made to work in local contexts, according to the diverse preferences of patients and practitioners, and in their formal and informal interactions (e.g. Berg, 1998; Timmermans and Berg, 1997; 2003; Castel, 2009; Mol, 2009). For example, Struhkamp *et al*. (2009) show how the standard measure used in physical rehabilitation in the US to assess functional independence is negotiated by physical therapists in the treatment clinic. This is done by a process of "doctoring" (p. 55), where knowledge of patients' situations are utilised to reach everyday solutions for improving their daily independence. Similarly, Singleton's work on public health policy (2005) illustrates how standardised systems for involving the public in locally-responsive public health interventions can be made to work through their tinkering at local, practice, levels.

The objects of medicine can therefore be traced to the actors and processes which cohere around them, and the practices which are done upon them – underpinned by standards designed to regulate medical outcomes. In this way, *how* we conceive of the presented lack of 'BME' organ donors can only be understood by examining the network of associations – beyond that of just 'BME' 'communities' – which bring organ donors into being.

Conclusion

In this literature review I have gradually demonstrated the importance of removing the black box which has been placed around the 'issue' of 'BME' transplant inequalities and organ donation rates in the UK. The black box refers to how, in research, policy, and donation promotions, we only see the inputs and outputs which have been linked to the 'problem' (Latour, 1987). These being 'BME' potential donors and 'BME' patients in need of transplant. This means that all other processes and actors involved in the 'issue', such as brain death diagnoses, negotiations between potential donor families and health professionals, and transplant allocation policies, among others, are rendered invisible. To reach this view I firstly showed how the reported 'problem' of low 'BME' donor rates has come about within the organ allocation policies of transplant medicine itself. These historically privileged 'white' patients and disadvantaged 'BME' patients, as a result of blood and tissue matching requirements. Despite recent changes to these policies to rectify this disparity, there is a complex feedback loop (Duster, 2003) at play between the social inequality of transplant access and the way in which this 'issue' has been linked to the biology ('rare' blood and tissue types) of 'BME' groups, as the source of the problem.

The linking of transplant inequalities to notions of biology continues in policy, public interventions, and research responses to the 'issue', which fix 'BME' 'communities' as the solution to the 'problem'. As a result, the practices and policies of transplant medicine have been made invisible in understandings of the 'issue'; 'culture' is configured as something which exists outside of medicine; and peoples' attitudes towards donation are assumed to indicate the likelihood of them donating their organs after death. However, insights into the experiences of donor families highlight the key part that health professionals have to play in families' donation decisions. Moreover, donation is understood as something which must be made available to families by the act of request, which was evidenced as occurring less for

'black', compared to 'white' families (e.g. Siminoff *et al.*, 2003). Additional ethnographic insights into brain death, the medical organisation of death, and the work of transplant professionals and medical practitioners also highlights the fact that organ donors are *produced* as a result of the locally negotiated work of health professionals, and in the interactions between families and health professionals within institutional contexts.

With these insights I argue that we cannot understand transplant inequalities and low donor rates by solely looking at 'BME' 'communities'. To fully grasp the 'problem' we need to also examine the settings within which organ donation actually occurs; the practices which make donation happen; and the people who experience these processes, such as Intensive Care staff, donation nurses, and individuals from 'BME' backgrounds with direct experience of transplantation and donation. In this way, my study into ethnicity and organ donation takes experiences of, and practices around the institutional *organ donation encounter* – where patients are identified as potential donors and families are requested to donate their relative's organs – as its starting point. It is to this approach that I now turn, to outline the study's methodological underpinnings, and how I went about doing such a piece of research.

Chapter 2. Epistemological and Methodological Considerations

Introduction

This chapter outlines the phenomenological ethnographic approach I adopted for this study on the 'problem' of organ donation and ethnicity. By examining the literature around donation and ethnicity in the previous chapter, I concluded that a broader perspective needs to be taken up in understandings of low 'BME' donor rates. Such a perspective would not limit its gaze to looking at 'BME' 'communities' and their ('cultural') attitudes towards donation, as previous research, policy, and health promotion interventions have done. Instead, to understand the 'problem' of organ donation and ethnicity we need follow the various people, institutional procedures and their practices, things, and settings which can be traced to the phenomenon. This was to be done by initially focusing upon the organ donation encounter, which I describe below.

Outline of the research objectives

The aim of this research is to therefore examine the 'problem' of organ donation and ethnicity by looking at the *organ donation encounter* with 'BME' families, and the people, practices, and meanings attached to donation from this initial point of contact.

The principal objective of the study is:

> *To understand the 'problem' of organ donation and ethnicity by generating a richly detailed understanding of the organ donation encounter, linking it to the social, 'cultural', and institutional contexts with which it outwardly connects.*

The organ donation encounter encompasses the immediate site where potential donors are decided upon and families are requested to provide consent for donation, alongside the settings and actors which make up and background this encounter. This may include not just people, such as Intensive Care staff and 'BME' potential donor families, but also procedures, practices and medical technologies, like the mechanical ventilator. To research the encounter therefore involves, among others, examining the experiences of health professionals involved in organ donation; the practices which get done around organ donors in the setting of the Intensive Care Unit (ICU); and the communications which take place between health professionals and potential donor families. It would also mean looking at how decisions are made to refer potential donors; how consent for organ donation is achieved; and the negotiations which take place prior to donation discussions, such as around medical decisions of death.

In order to investigate this area a series of **sub-objectives** were used to focus the research angle. These were:

1. To understand under what conditions the donation encounter occurs (and in some cases does not occur).

2. Explore how decisions are made to approach potential donors, what training medical staff receive, and the practices they enact around donation.

3. Map out the experience of the donation encounter, and how this is structured.

4. Map out how decisions are made by potential donor families, and who is involved in making these decisions.

5. Explore how people reflect on this encounter, and how their actions and decisions feature in collective donation experiences, understandings of 'ethnicity', and personal histories.

Starting with the encounter, as opposed to preconceived notions of 'cultural' factors involved in low 'BME' donation rates, provides greater theoretical and methodological flexibility for the research. It enables the 'problem' of donation and ethnicity to be understood as a question of meaning and practice; and 'culture' as that which comes into play in the interaction *between* different people and things (Agar, 2006), rather than a set of static 'rules', existing outside of medicine (Good, 1994; Crowley-Matoka and Lock, 2006).

This way of researching fits with a phenomenological epistemological approach, which enables rich insight into the sense-making practices of those involved with the donation and ethnicity 'problem' on an everyday basis. A phenomenological approach therefore opens up an alternative path of inquiry for the 'problem' than has been previously presented. Beginning with the encounter also assumes an ethnographic methodology. This is concerned with documenting the routine ways in which people make sense of their everyday world by using in-depth, qualitative methods, such as interviews and observations (Hammersley and Atkinson, 2007). Such a methodology is different from the current research into organ donation and ethnicity, which examines 'BME' 'communities'' attitudes towards donation, thereby representing the phenomenon as if it were isolated from the medical contexts and practices of organ donation.

In part 1 of this chapter I outline the phenomenological epistemology which underpins my research approach (Crotty, 2003), including my reflexive positioning as the researcher. I then show how this can be put into practice using an ethnographic methodology, in part 2. From this I describe, in part 3, how the research was done (the methods), by outlining the process of gaining access to donation settings, and interviewing and observing health professionals and 'community' members. I finally detail the process of analysis which led to the study findings, and the ethical considerations involved in researching the topic.

Part 1. Approaching the 'world' of organ donation: phenomenological positions

Phenomenology is the study of the social world or, rather, the 'lifeworld' as it is encountered by individuals. The lifeworld can be understood as the world that is common to an individual or group, and is constituted by familiar systems of meanings and language (Moran and Mooney, 2002). Taking a phenomenological approach in research involves looking at peoples' lived experience: how they make sense of the world around them, what they *do* within this world, and how they understand what they do (Benner, 1994). Phenomenology is not concerned with trying to discover the facts of a phenomenon, but seeks to describe the quality of an experience in all its fullness, as it is told to us (Van Manen, 1997). Adopting a phenomenological perspective for this study therefore allows us to focus upon how different people make sense of their donation experiences, the practices they enact around this process, and how ethnicity is made sense of and constructed within donation contexts.

In its historical context, phenomenology is focused upon the philosophical *nature* of experience, as a pre-reflective entity. One of the founders of this approach, Edmund Husserl, believed phenomenology to be the study of the lifeworld "as it is in itself" (Husserl, 1981: 12). Husserl developed his philosophy as a way of demonstrating a crisis in the positivist tradition of the European objective sciences, which tried to see the world as if it were a totality, therefore leaving out the specificity of experience. For Husserl, objects in the world are given "purely in consciousness" (Moran and Mooney, 2002: 62), and can be distinguished by focusing upon what we access in our pure reflection. In this sense, the phenomenologist is tasked with "bracketing" her/himself from her/his pre-existing experience to go "back to things themselves" (Husserl cited in Moran, 2000: 9). The body is therefore understood to mediate between object (the world) and consciousness (ideas

about the world), undermining the Cartesian mind/body dualism (Laverty, 2003). Later work by Merleau-Ponty (1962) was to take this idea further and emphasise the corporeal nature of experience, referring to the way in which the world (and experience of the world) is always embodied within the perceiver (Moran, 2000).

Husserl's phenomenology was subsequently taken up by the philosopher Martin Heidegger (1967), who developed a theory of hermeneutic phenomenology. This differed from Husserl's approach, in that it takes experience and its interpretation as the point of departure. For Heidegger, in contrast to Husserl, it is impossible to separate our lived experience of the world from the (historical) context in which we encounter it (Laverty, 2003). This he conceptualised as *being-in-the-world* (dasein): where experience and things are mediated by, and thus are a *product of* one's specific position, or background (Koch, 1995). The world is therefore interpreted by individuals, rather than pre-reflexively experienced. Influenced by Heidegger, Hans-Georg Gadamer later emphasised an ongoing process of interpretation as the key to understanding the world. For Gadamer (2004), there are two 'senses' of interpretation. In its original form, interpretation is about highlighting what is already there, but which may be concealed in its everyday appearance. The second level involves interpreting the meaning that we have revealed (Van Manen, 1997). In this sense, all description is ultimately interpretation, since in describing the world and its objects we have already mediated between it and ourselves.

To phenomenologically research organ donation and ethnicity then means to *aim* my gaze towards experiences of the donation encounter, and draw attention to the *meaning* of these experiences and the practices around them (Van Manen, 1997). At the same time – taking a hermeneutic phenomenological perspective – it also involves taking into account the settings in which organ donation occurs and the historically situated backgrounds of my participants. The basis to such lines of inquiry can be traced in the application of the

philosophy of hermeneutic phenomenology to a social science methodology, which more recent thinkers have taken up, as I describe below.

The researcher as professional stranger

In his seminal essay, *The Stranger* (1944), Alfred Schutz was the first to make an explicit link between phenomenology and its potential use in the context of a social science methodology. For a researcher to understand how people operate, Schutz argues that it is important for them to firstly forego their own familiar frameworks of reference. This is to avoid interpreting phenomena along the lines of "thinking as usual" (Schutz, 1944: 502): where one understands the research topic in the context of their own, rather than others' understanding of the world. Schutz describes this process using the metaphor of the immigrant, whereby the "recipes" (1944: 501) – such as appropriate behaviour and modes of communication – for conducting oneself in a strange environment are not yet known. As such, the immigrant must go about learning, adopting, and integrating the "new cultural pattern" (Schutz, 1944: 504), so that they may actively take part in their new 'community'.

However, this recognition of the new "cultural pattern" takes a different form for the sociologist compared to the immigrant. According to Schutz (1944), the sociologist must act as a disinterested observer, with the intention of obtaining knowledge about peoples' taken-for-granted behaviour, rather than necessarily integrating themselves within their 'world'. Here, Schutz aligns the process of knowledge construction with an objective, scientific, approach, in his view that the researcher should objectively classify and analyse, in order to interpret peoples' commonsense 'recipes'. However, different from the natural sciences, Schutz (1967) also posed the notion of first and second order constructs in research on "self-reflecting humans" (Flyvberg, 2001: 32). First-order constructs refer to the common-sense thinking of research participants: how they make sense of the world around them. Social scientists' interpretations of this are thus second-order constructs (Blaikie,

2007). This means the researcher essentially "construct the constructs" (Schutz, 1967: 59) as a result of their own way of thinking about the world and in their orientation to their object of study. In interpreting the phenomenon of organ donation and ethnicity then, it is only *through* these first order constructs – entering the 'world' of those involved in organ donation – that would allow me to fully interpret the research problem (Aspers, 2009).

It is through the experience of examining and interpreting such 'worlds' that the researcher must also acknowledge their own position and its influence on the study, in a reflexive research process, which I describe below.

Reflexively researching organ donation and ethnicity

Social research can never operate in a vacuum, and as researchers it is our position in the world which lends us our research stance (Moss and Dyck, 2002). In the context of a phenomenological approach, Emmanuel Levinas (1969) explicitly linked the philosophy to an ethics of being. This he articulated in terms of our relationship with the 'other' (Moran, 2000). In research, the 'other' encompasses the research participants and settings, and the process involved in acknowledging somebody's world on an individual level, rather than simply placing them into categories (Wild, 1969: 13-14) – as past research into organ donation and ethnicity has done by its focus upon 'BME' 'communities'. It also includes being aware of how meaning is constructed between researcher and researched (Finlay, 2006). In so doing, the researcher is able to achieve a type of objectivity, different to that of the disinterested observer (Schutz, 1944), in the research process.

A form of objectivity can be gained in phenomenological research by recognising our place in the world. Donna Haraway (1991: 183) advocated such a research, which recognises the importance of "partial perspectives". She argued that a form of embodied objectivity can be achieved if we are open about our position in the world. Similarly, for Max Van Manen, to

do phenomenological research it is vital to have a "strong orientation" (1997: 20) towards one's topic. This effectively means that we live the research question by interrogating it within the context of our own existence (Van Manen, 1997: 43), and acknowledging how our own identity may impact upon the research process and its findings (Grewal and Ritchie, 2006). This I map out below, by scrutinising how my personal position on organ donation, and my own ethnic identity had bearing upon the study.

Prior to entering the research 'world' of organ donation and ethnicity, my own experience of donation and transplantation was limited to carrying a donor card, which I had done since I was a child; and knowing that a friend of my mother's had died after two failed kidney transplants and years on dialysis. Upon beginning the study I was firmly prodonation: I saw no reason *not* to give my organs away after my death, since I had no specific belief in an afterlife. I had never given thought to the moral responsibility which backgrounded appeals for the public to donate their organs, which I described in chapter 1; or questioned the outcomes of transplant medicine for organ recipients as anything other than positive (despite the fact that transplantation had been far from successful for my mother's friend). This stance meant that there was the potential for me to examine the research topic and analyse my data with the aim of 'solving' the shortage of 'BME' donor organs, thereby reproducing the blame discourse of current research and policy on the issue.

However, upon beginning the study I became immersed in research literature which went beyond scrutinising the donation attitudes of minority ethnic groups, and into ethnographic accounts of the medical practices of donation and transplantation, and the experiences of donor families and transplant recipients. I began to learn that, far from being a 'miracle' cure, transplant patients continued – in many ways – to be sick: with daily medication regimes and the constant risk of graft failure (e.g. Crowley Matoka, 2005; Kierans, 2005). In addition, I learnt that, for donor families, the experience of donating a loved one's organs

went far beyond their agreement to donate, and into the subsequent suffering engendered by the medical rules of anonymity, which largely kept donor families and recipients from forming relationships (Sharp, 2001; 2006). Whilst I remained convinced of my own desire to donate my organs after death, my views on transplant medicine began to shift as the study progressed, to eventually be characterised as one of ambivalence. I became acutely aware of the messiness involved in people's decisions to donate, and how these cannot be reduced to questions of individual responsibility to donate organs for the sake of a wider 'public' good (see chapter 1). This stance is reflected in how I approached my analysis and presented the study findings, which draw attention to the ways in which donation decision-making is the product of heterogeneous actors and practices, rather than a simple matter of an individual's/community's 'cultural' beliefs about organ donation.

As my fieldwork progressed I experienced a similar process of awareness, in terms of how my relationship with the research topic and its subjects gradually developed. Initially adopting a hermeneutic phenomenological approach in my research involved me entering the ('medical') 'world' of organ donation, and the people who had experience of this 'world'. Like Schutz's immigrant, this world was initially strange to me: I was hearing stories about death and dying on a near daily basis, and visiting what was, at first, the daunting setting of the ICU – where organ donation usually occurs, and professionals involved in donation work. Often waiting on these wards for a member of staff, I could not help but feel overwhelmed at the seemingly monstrous machinery which looked to be engulfing patients. I also found myself wondering that if I, as a researcher *of* this world felt intimidated by this environment, then how must families who experience the death of their relative here, feel?

This world, however, gradually became more familiar. Over time I was able to understand the once foreign-sounding medical terms such as 'coning' and 'perfusion', and my shock at tales of death dissipated. In addition, at the time of my research, UK donation services were

undergoing huge organisational changes. One such change included the move of the donation nurses[16] – who facilitate and manage the organ donation process – from their previous office bases into Intensive Care Units (ICU). Therefore, at the same time as I was learning the recipe knowledge used in the course of work around donation, donation nurses were also involved in their own process of learning the 'thinking as usual' of Intensive Care wards and their staff, to make workable new procedures around donation. In this way, the donation nurses were well placed as informants of these worlds (which I detail in part 3), since they were able to make explicit the 'recipes' they themselves were navigating.

As my interviews developed with members of Intensive Care staff and donation nurses however, I found myself becoming increasingly involved in this 'world' of death and potential life. To some extent, the later lack of strangeness of the stories I was hearing and the practices I was observing indicated that I had begun to take the donation process and the workings of health professionals – specifically the donation nurses, whom gave me access to the research world, and to whom I was therefore largely reliant upon for progressing my insights – for granted. In the words of Schutz (1944), I was in danger of beginning to 'think as usual' about my research phenomena. Rather than maintaining my distance, I was at risk of becoming too sympathetic towards the donation nurses, which had the potential to jeapordise my ability to critically analyse my data.

Kaufman (2005: 14) documents a similar existential process in her research on death and dying in American hospitals, recounting how she gradually came to view death and its organisation as "routine". In the middle of my fieldwork, however, I was suddenly shaken out of my blasé attitude towards this 'world' with an exposure to the process of a potential donor referral in 'real'-time. This happened when I overheard a phone call discussing the referral of a young man, whilst waiting to interview one of the donation nurses in her

---

[16] I explain their role and these changes in detail in the next chapter.

regional office. Asking about the case, I was told that a man had been brought in after a motor vehicle accident, and that the Intensive Care staff were about to carry out brain stem death tests before speaking to his family. Upon hearing this I felt sick. I realised the actuality of a donor process was being played out in real time and *I knew* about a young man's death before his family. Speaking about this to the donation nurse, she expressed her understanding, telling me how some cases "hit home" and make you realise the "strange" outlook on life which working in organ donation brings. Thus, I later came to understand my position in relation to my research subjects by gradually understanding their relation to this 'strange' world of donation, and my own imperative to maintain the strangeness of this world in my analysis, rather than take it too much for granted[17].

In addition to outlining my stance on organ donation, it is also important to document how my own ethnic identity had bearing upon the research process. In initially approaching the topic of organ donation and ethnicity, in a reflection of the way in which the 'problem' has been commonly constructed, I felt uncomfortable with the idea that I would be doing research into minority ethnic 'communities'. Looking back, I now realise that this was linked to my own mixed ethnic background. Positioning my identity in relation to this research is complex, since I see myself as a hybrid of backgrounds. On census forms I have always categorised myself as 'Mixed: White and Asian'. My mother ticks 'White British' – her relatives being traceable to the North of England; my father, 'Other'; and my sister 'White British' – her reasoning being that she looks 'white'.

My father arrived in Bristol in 1954, aged 2, on a ship from Rangoon in Burma, accompanied by his mother and five siblings (this number would later multiply to seven). My grandfather had arrived in the UK some time before to find work, after he and my grandmother decided

---

[17] I further reflect on how I considered my relationship to the donation nurses when analysing my data in the epilogue.

to remain British citizens and leave Burma after the dissolution of British rule in 1948. The reason for this, I am told, being that my grandfather, unlike my grandmother[18], was not considered 'Burmese', being of Greek and German background. With the institution of a fledgling Burmese Government it became virtually impossible for him to find the work he was used to, as a ship's captain. During childhood visits to my grandparents, I was always aware of a difference. This I later came to understand through my interpretation of the process of fitting-in which the family encountered as immigrants to the UK. This included them anglicising their family name; raising eight children in a three-bed council house; and my grandparents refusing to speak Burmese to their children once in England, for fear they would not otherwise integrate. My father was the only child who ended up at university, working his way through night school and day-release from a laboratory to eventually complete a PhD in Biochemistry and becoming a teacher. In contrast, my own upbringing in a suburban, largely 'white', town in an affluent area was what might be described as very middle class: with a teacher father and nurse (later lecturer) mother, a grammar school education, and straight into university to take up a Cultural Studies degree. As a result of my upbringing I have never felt part of a minority group as such, but my memories and sense of self will always be infused with my grandmother's tales of Burma and my understanding of my father's immigrant background.

My familial straddling of the 'white' British and immigrant worlds means that my position in this research study is far from 'objective' and value free. It provides me with a particular vantage point on the world, which I need to be aware of, by documenting how this impacted the research process. For example, my sensitivity towards the impact of being categorised as somehow different (such as in how 'BME' transplant patients and potential donors have been) has obviously influenced how I approached the research topic: as a

---

[18] My Burmese grandmother was herself a hybrid: a product of British imperialism. Her grandfather was an English Lord who illegitimately fathered a child with her Burmese grandmother.

constructed, rather than a taken for granted 'problem'. It also will have had consequences for the questions I asked of the topic (Gunaratnam, 2003), such as around how ethnicity is experienced and practiced in the donation process by health professionals, rather than solely focusing upon what people from 'BME' backgrounds think about organ donation. Moreover, my understanding of the complexity of ethnic identities – beyond the simple classifications of 'white' 'black' and 'South Asian' which get made in relation to donation and ethnicity – means that I came to largely label my research participants by using their own identity descriptions[19]. This ranged from the singular label of 'Muslim'; to the more complex identity claims of Chris: a kidney transplant recipient with Ghanaian parents, whose father told him he was "made in England", and how he questions his lack of ties to the 'black' 'community', having mainly 'white' friends and a 'white' wife. In addition, my position on the topic will have also influenced how I interpreted the research data and presented the final findings, which argue that ethnicity is produced within the institutional contexts of organ donation, rather than necessarily that which offers an implicit problem for the donation process.

In making these positions clear, I could be accused of bias towards the topic. However, as Howard Becker has argued (1967), all researchers inevitably choose their subject matter and take sides according to what values they believe in. Becker believes that accusations of bias can be diffused by making clear which side the research is on, to allow transparency in its critique. Thus, my approach to the 'problem' of donation and ethnicity could be seen as less of a pragmatic one and more of a political project. Rather than trying to 'solve' the issue as previous research has done, I have attempted to highlight the way in which this 'problem' has been produced in the first place, and how we might see it differently by looking outside of constructed notions of the 'BME' public.

---

[19] With a few exceptions, I would rarely ask participants to describe their ethnic identity. This is something I later regretted: wishing I had explicitly asked for a personal description of how they might classify themselves.

In addition to my identity affecting how I did the research, it may also have impacted upon how participants responded to me, the stories they told about their experiences, and the way in which these were told (Grewal and Ritchie, 2006). In relation to medical staff, my non-medical status (as a social scientist) instantly established my outsider position (Mullins, 1999) to the world of organ donation, in that I was not versed in its clinical procedures. This status I saw as both a help and hindrance. Whilst some participants took care and time to explain the practices and medical terms of donation, others, I perceived, saw my lack of knowledge as evidence of my inability to do such a piece of research. In addition, queries about my own ethnic background rarely came up with health professionals. On the only occasion it did, with a donation nurse, I was told that she had "assumed" I was 'white'. This may explain the sometimes borderline racist ways in which some health professionals (not just 'white') talked about minority ethnic families in front of me. With 'community' participants, I came to see my hybrid background as an advantage, even sometimes exploiting it to allow for a point of commonality. Many such participants were also at pains to convey their positivity towards organ donation, and their belief that more minority ethnic people needed to donate their organs. Power issues were implicit here (Gunaratnam, 2003), since these responses might have resulted from the assumption that my status as a university researcher meant I was somehow trying to solve the 'issue' of low 'BME' donor rates, even though I would always tell participants that this was not my aim.

My identity in relation to the world I was researching therefore meant I was able to adopt and adapt to different assigned and embodied identities. This not only allowed me to draw out my participants' responses, but also meant I researched from a position of empathy; conscious to the feelings and positions of those who inhabited this – as one donation nurse put it – "strange world" of organ donation (Finlay, 2006). My involvement in this 'world', spanning Intensive Care wards, hospital offices, 'community' centres, homes and temples,

came about through the adoption of a multi-sited ethnographic methodology. This reflected the concerns of phenomenology, in that it allowed me to develop the research focus around what I was finding in the field, rather than remain faithful to a set way of approaching the phenomena. In the next section, I will briefly outline the principles and theory of using an ethnographic methodology, and how this is appropriate for the research problem.

Part 2. Methodological approach: (multi-sited) ethnography

The phenomenologist Max Van Manen (1997) points out that there are definite ways of doing a research project which lends itself to a phenomenological approach. He argues that what methodological choice is made, and thus what methods are employed, need to reflect the concerns of phenomenology, which "tries to ward off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research project" (Van Manen, 1997: 37). Adopting an ethnographic methodology can reflect the phenomenological need for openness towards its research topic, in that it permits contingency in the research process. Rather than being able to say exactly what will be done at each stage, an ethnographic methodology responds to the research findings as they unfold (Hammersley and Atkinson, 2007). It also offers a way of researching which allows for insight into how the 'problem' of donation and ethnicity has been produced, by following the various social actors, such as ICU staff and donation nurses, involved in the 'problem' on a daily basis.

In general terms, ethnography can be conceptualised as an *approach* to its subject. It is a way of looking at the world, with 'culture' and context operating as its key concerns. The origins of ethnography came out of the practices of anthropology, where the term was originally used in reference to a descriptive text about a 'community', usually outside of the

Western world (Hammersley and Atkinson, 2007). In practice, ethnography usually involves employing a variety of (generally) qualitative methods to study people's actions in their everyday worlds (the field). The use of triangulation, or 'complementary' methods (Barbour, 2001), is typical of ethnography, which, according to Hammersley and Atkinson (2007), usually obtains data from as wide a range of sources as possible. The most common method – and one which ethnography is most recognised for – is in the use of participant observation (Fox, 2004). This involves the researcher spending time with, and adopting an everyday role within the research 'community', and detailing these interactions in fieldnotes (a form of research diary). Ethnography also commonly involves the use of formal and informal interviews, and may include the use of quantitative approaches, such as questionnaires.

Traditionally, ethnography was based upon a naturalistic research process. This involved the idea that the social world should be studied in its 'natural' state, left undisturbed by the researcher. This usually translated into the anthropologist entering a small 'community' and spending an extended period of time there, in order to answer some sort of 'problem' regarding that 'community' (e.g. see Evans-Pritchard, 1937; Mead, 1943). One of the characteristics of such an approach, however, was the tendency to objectify these 'communities' in the description of their 'culture', as portrayed by the 'objective' ethnographer whose own values were rendered absent (Hammersley and Atkinson, 2007). This objective gaze of classical anthropology has been accused of complicity with imperialism, whereby reported 'facts' about non-Western 'primitive' societies – as seen through the eyes of the (usually) 'white', Western anthropologist – were taken as justification for the colonialist project (Said, 1989; Faubion, 2007). In this way, anthropology and its subjects were borne out of a reliance on, and subsequent representation of difference (Said, 1989). Parallels can be drawn between these traditions and the seemingly

objective stance which has been taken in the UK research on organ donation and ethnicity. By directing the focus upon community 'culture' as a barrier to donation, members of 'BME' populations are effectively 'other-d', with wider medical contexts left unquestioned.

Today, such un-reflexive practice has been widely criticised in anthropology, and labelled as the "crisis of representation" (Marcus, 1998: 15). More recent forms of ethnography, as first proposed by Scholte (1969) in his call for a critical ethnography, have opened themselves out by adopting a more phenomenological orientation (e.g. Steedly, 1993; Tsing, 1994). This is done by blurring the boundaries between 'self' and 'other' – researcher and researched – in the writing of "positioned truths" (Abu Lughod, 1991: 142). Such an approach means showing that the ethnographer's interpretations are the outcome of the research process: which produces the 'world' it describes, rather than taking this 'world' for granted (Hammersley and Atkinson, 2007). A phenomenological ethnography also interprets its phenomena by following the practices, settings, and sense making processes of those involved with the phenomena (e.g. Rosaldo, 1993). In my study, this therefore includes not just individuals from 'BME' backgrounds involved in donation, but also the health professionals who make the process happen.

In a similar vein, George Marcus (1998) has called for a re-thinking of anthropology's traditionally holistic approach. He argues that the usual tactic of situating oneself within a bound 'community', which could be a village, or even a hospital ward, creates a "fiction" of a whole and "fully-probed micro-world", rather than that which is constructed by the purposes of inquiry (much like the category of 'BME') (Marcus, 1998: 33). In pointing out the shortfalls of locally-focused ethnography, Marcus proposed a re-creation of the approach in the form of a multi-locale (or multi-sited) ethnography. This involves the ethnographer widening her lens across different places, people, and systems, so that neither side – such as transplant medicine (the macro) and 'BME' groups (the micro) – is polarised with the other.

Employing a phenomenological, multi-sited ethnographic methodology therefore involves looking at different places and parties to represent the multiplicity of phenomena. In relation to organ donation and ethnicity these places and parties encompass, among others: donation and transplant professionals, Intensive Care staff and Intensive Care wards, 'BME' transplant recipients and organ donors, potential donor families and religious leaders, and organ donation guidelines and consent forms. In Emily Martin's (1994) ethnography on the role of immunity in American culture, the multiplicity of immunity was represented by conceptualising the immune system as a field, rather than a 'community'. For Martin, the immune system could only be understood by looking at it from numerous angles, through differently related actors and settings. These included analysing public representations of the immune system in advertisements, volunteering as a 'buddy' at a centre for HIV sufferers, and conducting observation in an immunology research lab.

In this study I have adopted a multi-sited ethnographic methodology to open up the phenomena of organ donation and ethnicity in a way that a qualitative interview study, or quantitative (questionnaire) approach (both of which have been used in previous research on the issue) would not allow. It broadens out an examination of the 'problem' from the perspective of different constituents, such as 'BME' families who have been requested to donate their relative's organs, and the health professionals who navigate this ethically problematic field. As outlined in the research objective, the original focus for the study was to work outwards from the organ donation encounter. The meanings and practices of donation in relation to ethnicity were to be elucidated by starting with the donation encounter and allowing this to shape who I talked to, and where I went around this. In the next part, the methods, I detail the multi-sited field of organ donation and ethnicity, how I went about accessing this field, and the methods I drew on to do the research.

Part 3. Methods: accessing specialist domains and doing the research

In this section I describe the process of how I went about actually researching the 'problem' of organ donation and ethnicity. I firstly detail the issues involved in accessing the specialist field of organ donation, the people I talked to, and the range of methods I used in the research. Secondly, I describe the process of analysing my data and producing the research findings, along with the ethical issues involved in doing the research.

As highlighted in the previous section, an ethnographic approach uses different methods within numerous sites to build up a multi-faceted understanding of a study problem. My research therefore encompassed a variety of settings spanning: Intensive Care units (ICU), family interview rooms, seminar rooms, ICU offices, hospital chaplaincies, regional donor nurse team offices, hospital canteens, religious temples, 'community' centres, and participants' homes; and different people including: ICU nurses and doctors, donation nurses, transplant recipients, 'live' organ donors, donor families, and religious leaders such as Imams. Below, I outline the process of gaining access to and researching these settings and people, in an account which aims to show the gradual shift in focus as my fieldwork progressed.

Access: research sites, gatekeeping, and tricky recruitment

Organ donation usually occurs within the specialised domain of the Intensive Care Unit[20], and in the offices of regional donation nurse teams. These teams are responsible for facilitating and managing the donation process, and are contacted by Intensive Care staff with potential donor referrals. For the purposes of this study, I needed access to these settings to speak with health professionals involved in donation, as well as the minority

---

[20] The process also takes place less commonly in the Accident and Emergency Department, with the actual organ procurement occuring in operating theatres.

ethnic families these professionals encountered. Hospital ethnographies have evidenced the struggles experienced by researchers in accessing medical realms, and the bureaucratic ethical process this entails. This work has also highlighted the importance of developing relationships with key gatekeepers to facilitate access to these tricky research sites (e.g. Seymour, 2001; Wind, 2008). As a way in to my research 'field', a kidney transplant surgeon working in the North of England, with an interest in ethnicity, agreed to act as an informal supervisor to the study. Meeting with him facilitated a spontaneous introduction to the Specialist Nurses in Organ Donation (SN-OD) – whom I refer to throughout the study as donation nurses – working across the hall from his office. A subsequent meeting was arranged, and they, along with their allied regional team, agreed to be involved in the study. Their collaboration was vital not only in helping to recruit donor families and acting as participants to the study themselves, but also in acting as gatekeepers into the Intensive Care Units.

Once initial agreement had been reached with the donation nurses, I began the tangled process of applying for NHS ethical approval from the Local Research Ethics Committee (LREC) in January 2009. This process of gaining approval took six months. It involved completing a mountain of forms to submit to both the LREC and each of the three Research and Development (R&D) departments within the hospital Trusts[21] I had initially selected for the study, only one of which (I call 'Lakeland') I ended up researching[22]. The initial Trusts applied to were those in which the donation nurses were originally based. However, as a result of the organisational changes taking place at the time, following the Organ Donor Taskforce's (ODT) recommendations (see chapters 1 and 3), soon after I gained approvals

---

[21] NHS hospital Trusts, which may be housed within one or a number of local hospitals, provide acute or secondary health care to a designated geographic area.

[22] This was because, after further discussions with ICU staff in these Trusts, I realised that these sites did not provide enough opportunity for the research, due to their generally low numbers of organ donors and their lack of experience with requesting donation from 'BME' families.

the two donation nurse teams merged to become employees of NHS Blood and Transplant (NHSBT), and were re-located to a centralised office base (I refer to this merged team as team 1). This meant that I was also required to seek approval from NHSBT to 'use' their donation nurses in the research. This was gained alongside negotiating the participation of a further regional donation nurse team (which I refer to as team 2) in the North of England, who operated in an area with a large 'BME' population, thus offering further opportunities for me to find donor/non-donor families. This team also suggested that I apply for further R&D approval to access a large teaching hospital, 'Hillview', in which one of their donation nurses worked. Hillview was presented as an "interesting" opportunity for my research, since it hardly ever referred potential donors to the donation nurse team and had a large 'South Asian' patient population.

The main research sites therefore spanned the two hospital Trusts of Lakeland and Hillview, specifically their Intensive Care Units, and the regional offices of the two donation nurse teams. These teams were each made up of around 20[23] members, including team leaders, donation nurses, and administrative staff. As a result of the ODT's recommendations, whilst these teams were based within a centralised NHSBT office[24] (usually also housing other departments, such as blood donation, and marketing staff), their work took place largely within the hospitals they had been newly assigned to as 'embedded' donation nurses. The term 'embedded' is used to refer to donation nurses physically based within one or two hospital Trusts on a day-to-day level. Their embedded 'office' was usually in an Intensive Care Unit and was either shared with other ICU staff, making it difficult for the donation nurses to carry out confidential work, or was a tiny, cupboard-like room, with little space for

---

[23] This number was much lower at the beginning of my research. As the ODT's recommendations (2008) began to take effect, more donation nurses were employed, to be based within regional hospitals.

[24] These offices were worked out of on an everyday basis by the donation nurse team leaders and the administrators. The embedded donation nurses only occasionally worked from these centres to catch up on paperwork and attend team meetings.

much beyond a computer and a few files. The 'field' for researching these teams therefore spanned their centralised base, along with their ICU offices, and the seminar rooms in which they carried out donation training for hospital staff.

The embedded donation nurses at 'Hillview' and 'Lakeland' also acted as vital gatekeepers in helping me access ICU staff to interview at these sites. Emily, Hillview's embedded donation nurse, along with being my gatekeeper to the hospital's Clinical Organ Donor Champion[25], also became my main informant. Emily had many years of experience in the donation nurse role, and was therefore able to offer me an historical perspective on the role, and how the ODT's changes had affected her work as a result. Her experience also meant that she was well connected to a large network of other donation professionals. She therefore played a vital part in the study, not least because of her willingness to help, and the insight she offered into her experience at Hillview, but also because of the people she was able to put me in touch with, to help widen the scope of the study.

At Lakeland – a University hospital serving a city with large 'South Asian' and 'African Caribbean' populations – there were two embedded donation nurses, Jennie and Rachel. They covered donation within the large Trust, which spanned two hospitals and an adult and paediatric Intensive Care Unit (PICU). Different to my experience with Emily, their initially enthusiastic response to the study soon waned as – I interpreted – their workload widened. Nonetheless, they provided me with vital initial access to staff, organ donation committee meetings at the Trust, donation training days, and the Trust's Clinical Donor Champion, Sarah. Following my numerous hampered attempts to gain access to Lakeland's

---

[25] These posts are a new role generated by the ODT's 2008 recommendations. They are generally Intensive Care consultants who give around 4-12 hours a week to work on organ donation. This may take the form of training staff, checking referrals, and working with the donation nurses in their general task of promoting donation to the Trust. At Hillview, the clinical lead, John, was a 'white', middle-aged male consultant Intensivist in the adult ICU.

adult ICU, Sarah, a Paediatric Intensive Care consultant, facilitated my eventual focus upon the PICU at Lakeland by helping me access the Unit's staff.

Once granted all necessary approvals for accessing these sites I began asking the donation nurses from both teams to send out recruitment packs[26] to donor and non-donor families from 'BME' backgrounds. The inclusion criteria were based upon the aims of the study (deliberate sampling), rather than trying to gain a representative sample as such (as is more fitting to quantitative research (Barbour, 2001)). This was based upon prospective participants having been approached about donating their relative's organs, and that they identified themselves (or had been identified) as being from a minority ethnic background.

This stage of attempting to recruit donor and non-donor families was slow, frustrating, and, ultimately futile. At the start I had envisaged that the donation nurse teams would be able to quickly send out recruitment packs from lists of families. This reflected my naiveté about the way in which the teams worked – each nurse had their own caseload, rather than there being a centralised system – and the fact that the number of families who fitted the research criteria was extremely low. This meant I had to approach individual donation nurses about each potential family I heard about as a result of presenting my work and from subsequent pleading emails to the two teams. As I had initially planned to recruit ICU staff and donation nurses who had been involved with participating donor and non-donor families, staff recruitment was to be done after I had 'found' such families. After three months of trying to recruit families via donation nurses and outside promotion of the research[27], I had no replies. I began to worry that the research would fail if I did not start

---

[26] These packs, see Appendix 3, included a letter of invitation to the family/individual, signed by myself and the appropriate donation nurse; an information sheet giving further details about the study and what would be involved in taking part; and a reply slip.

[27] This included attending community meetings, Hindu and Sikh Temples, and Mosques to tell their members about the research, in the hope of spreading word and finding families who had experienced being asked for

some form of data collection. As such, I decided to widen my focus and begin recruiting hospital staff and donation nurses for interviews about their general experiences of donation with 'BME' families, whilst I continued to search for families[28].

This search carried on fruitlessly throughout, and beyond, the period of fieldwork (September 2009 - February 2011). Eventually, in contacting 'community' organisations, such as donation charities, who might help with my search, I stumbled across Arjun. After mentioning my research, he told me that his brother had recently died and they had been asked to donate his organs. He initially agreed to be interviewed for the study, but, after two broken dates I only managed a brief phone interview with him; during which it became obvious that he did not wish to discuss the experience at length, so I did not ask for further contact. As a compromise for this shortfall, I widened my focus to people of minority ethnic backgrounds who were connected to organ donation in some way. These included the 'Sikh' transplant recipient and his daughter (who donated her kidney to her father) whom I met whilst spending time in a Sikh temple. Overall 8 such participants who were connected with organ donation in some way were formally recruited to the study to be interviewed. These ranged from transplant recipients and their friends, to hospital Imams and the 'British Asian' founders of a donation campaign charity.

My 'failure' to speak to 'BME' donor/non-donor families I understand as such: firstly, there were a limited number of minority ethnic donor families in the areas I was researching. This not only limited my chance of recruitment, but also offers interesting insight into the fact that so few 'BME' families had been approached about organ donation in the first place. Secondly, I had limited resources to pay for outside advertising for recruitment, and limited

---

organ donation. I also placed a number of adverts for the study in community newsletters, newspapers and on the walls of community centres across various locations (see appendix 2).

[28] I gained a substantial ethics amendment for this shift in November 2009 (see Appendix 5).

support structures to help me access 'community' gatekeepers, (which have been evidenced as vital in research with minority ethnic groups (Sheik *et al*., 2009)). Thirdly, whilst health professional could be readily accessed within hospital domains, the idea of accessing people from minority ethnic groups with the uncommon experience of organ donation is problematic in itself. Researchers have pointed out difficulties with recruiting minority ethnic groups to research generally, arguing that research *on* 'BME' communities in the UK has often resulted from negative attention, such as in the aftermath of the 1980's 'riots'. As such, research may be perceived as stigmatising or unwelcome by minority ethnic groups (Johnson, 2006). In light of media coverage and advertising campaigns on the 'BME' donor issue (see chapter 1), my research may have therefore been perceived as an unwanted invitation to be further labelled and differentiated. Shriya, a 'British Muslim' woman working for a donation charity, summed it up in her description of being subjected to tick box exercises by policy makers, whom she understood as having little interest in properly representing 'Muslim communities'.

Beginning my recruitment with ICU staff and donation nurses meant that instead of asking them about specific cases, I would be focusing upon their general experiences of requesting organ donation from 'BME' families. Recruitment of health professionals snowballed from initial presentations about my research, given to PICU and ICU staff at Lakeland and Hillview, and the donation nurse teams. This was largely done using convenience sampling, in terms of *who* was willing to give me their time in the first place. These initial recruits also acted as gatekeepers to further members of staff. I soon realised however, in line with the statistics on low 'BME' donation rates, that staff experience of requesting from non-'white' families was few and far between. As such, I widened my criteria to also include staff who wished to talk about their experiences of donation generally. In line with the developing focus of an ethnographic study (Hammersley and Atkinson, 2007), this came after the topic of struggles

over withdrawal of care with 'BME' families was brought up during my first few interviews. As such, even if staff had no experience of donation with 'BME' families, all of them were able to discuss their experience of negotiations around death with minority ethnic families.

The majority of health professionals interviewed for the study were white[29]. With the donation nurse teams, this was unavoidable, since – by their own admission – they were all of 'white' background. At Hillview, all the main consultants on the ICU were white and male, and only one (white) nurse on the unit came forward to participate, limiting my sample. I did eventually interview a 'British Muslim' liver consultant, who had been helping Emily with her local donation initiatives. In Lakeland, the staff were visibly more diverse. However, despite my attempts to recruit staff from different ethnic backgrounds, all but one who came forward were 'white'. The only non-white participant, a 'British Hindu' consultant was collared into participating by his colleague, who asked whether I needed any 'ethnic' doctors for the study! In total, within hospital settings, I conducted 13 interviews with 10 specialist nurses in organ donation (5 from each of the 2 teams), 6 interviews with 5 paediatric and adult Intensive Care consultants, 2 interviews with a transplant surgeon and liver consultant, and 5 interviews with PICU/ICU nurses (22 participants/26 interviews).

Doing **ethnography in the field: observation and narrative interviews**

In accordance with the traditions of ethnography (Fox, 2004), observation was used where appropriate in this study. In the context of the hospital settings, where roles are clearly defined (Wind, 2008), and with my lack of a healthcare background, I used non-participant observation for the study. Initially defining *what* to observe, however, was far from straightforward. Because of the nature of the topic, and the openness of a multi-sited

---

[29] Or, rather, I mostly assumed they were white. By 'eyeballing' (Ahmad, 1993) participants for their whiteness, rather than asking them to describe their ethnic identity, I was guilty of being a hypocrite of my own critiques about the homogenising effects of categorisation.

approach, I would have ideally positioned myself in the Intensive Care Units to observe the workings of donation on a daily basis, as Linda Hogle did in her research into the work around organ donors in the US and Germany (1995; 1996). However, I saw this approach as unrealistic. This was mainly because I was aware of the relative infrequency of organ donation at these sites, but also due to the ethical difficulties I foresaw with gaining permission for such observations, which would involve gaining the consent of immediately bereaved families. Observations were therefore done in settings and situations which allowed me insight into the daily 'work' of organ donation, without having to rely on direct observations of donation as it happened. These observations included: donation nurses' training of hospital staff around organ donation, informal meetings with staff about my study, ICU staff and donation nurse team meetings, and organ donor committee meetings at Lakeland. As documented with my struggle to recruit 'BME' donor and non-donor families, observations with 'community' members eventually encompassed: spending time in a Sikh Gurdwara (Temple), where one of its members had had a kidney transplant, visits to Mosques, 'community' centres, and Hindu temples, and during interviews and informal discussions with interview participants.

As most observations took place in public settings, permission to observe was gained from whoever was in charge, with anyone I spoke to also made aware of my role. For example, at Lakeland's donation committee meeting, oral consent was given by the chair of the meeting. I also informed all attendees of my role, and made it clear that I would be taking observational notes at the start of each meeting. At the beginning of my fieldwork I would write extensive field notes[30] about anything and everything that struck me as important. As is usual to the ethnographer, however, I was able to hone my observations more readily as

---

[30] Sometimes field notes were taken at the time, when I felt it appropriate. This included at donation committee meetings, and organ donor training sessions, where I could excuse my scribbling with the need to get 'information' down.

they progressed (Fox, 2004; Hammersley and Atkinson, 2007) and as my findings about the 'problem' of donation and ethnicity became more focused. Thus, in later stages my field notes acted as initial analyses for the study, and provided a continual reflective diary of my feelings about what I was finding.

Alongside my observations, interviews – which eventually formed the bulk of my data – were conducted with participants about their donation experiences. As an interview methodology I adopted a narrative approach. This was in keeping with the phenomenological concern to explore people's sense making processes and practices around organ donation and ethnicity (Van Manen, 1997). Narrative interviews use stories as a vehicle to explore how people construct meaning and make sense of their experiences. This provides a way of accessing individual experience, with reference to the wider world around them. Bruner (1986; 1990: 51) calls this the "dual landscape" aspect of narratives: where stories have both a moral and epistemic function. By engaging with peoples' stories, the researcher is concerned with interpreting accounts by examining *how* events are *made* meaningful through their telling (Reissman, 1993). In this way, stories are not seen as unproblematic representations of a reality which we can directly access, but are viewed as a tool for exploring how people make sense of events, such as organ donation (Riessman, 1993; Mishler, 1995; Spector-Mersel, 2010).

In gathering participants' stories, alongside observations of donation training sessions and committee meetings, I was able to not only trace the meanings of organ donation in relation to ethnicity, but also analyse how these relations were made sense of, performed, and subsequently (re)produced by the practices of health professionals[31]. Since narrative

---

[31] See footnote 5 in the introduction for a definition of 'practices. In this study practices included: the medical maintenance of potential organ donors by health professionals, so that their organs can be suitable for donation; the processes of filling out donor consent forms and performing brain stem death tests; communications between health professionals on courses of action around potential organ donors;

interviews emphasise the importance of participants' accounts about the events in which they were involved (rather than simply gathering opinion on the ethnic donor 'problem'), they can also function as a form of "extended ethnographic observation" (Mol, 2008: 11)[32], thereby opening out insight into the relationship between meaning-making and practice in the context of the research 'problem'.

Working on the basis of a *"tell me about..."* approach, narrative interviews avoid asking sensitive questions by not pre-determining the direction of discussion. In this way respondents can talk about what is meaningful to *them*, in contrast to traditional question-answer interview formats, which can suppress participants' accounts (Mishler, 1986a). This approach is thus appropriate for the sensitive topic of organ donation, in which people are being asked to talk about their experiences of death and dying.

In the traditions of doing a narrative interview (see e.g. Wengraf, 2001), interviews with participants were highly unstructured, with just one question asked to open out the discussion[33]. For example the health professionals' question asked:

> *Can you tell me the 'story' of your experiences of being involved in requesting organ donation from families of a minority ethnic background, as well as any other experiences you have of organ donation that you may wish to talk about.*

---

discussions of death and donation with patients' families; and the process of withdrawing treatment on brain dead and dying patients, among others.

[32] In her work on the logic of care Mol (2008) points out that, as her interviews with participants asked about the activities and events they were involved in, their accounts offered insight into situations that as researchers they had "no time or licence to go" (p.11). Whilst not specifically naming her interviews as narrative, her focus upon events is similar to the narrative concentration in my interviews upon obtaining stories of donation experiences.

[33] See appendix 7 for interview schedules of the different questions asked of different participants.

For participants with no direct experience of the donation encounter, such as religious representatives and transplant recipients, the interviews would often ask a few 'tell me about...' questions. For example, with the two hospital Imams I interviewed, I asked them firstly for any general experiences related to organ donation, and specifically about their experiences of mediating between health professionals and families around decisions over withdrawal of care. For health professional interviewees, the initial question would sometimes lead to lengthy narrative, with little further prompting required. Many of the donation nurses, who spend a large chunk of their working time speaking to potential donor families, talked in great detail about their experiences. Interviews with Intensive Care staff, however, were slightly more stilted, with less 'narrative' and more opinion being put forward. In these situations, my initial inexperience with the narrative format meant I found myself interjecting with further questions, unable to stand the expectant look of staff, and their silence.

My desire to fulfil the narrative requirement for stories led to me constantly asking "return to narrative questions" like: *can you think of a case in which this occurred?* (Wengraf, 2001: 127). Further prompting questions such as: *how do you ask families for donation?/what is it like to ask families?*, were also sometimes used for participants who found it difficult to talk within the open narrative format. Towards the end of my fieldwork, I also began to ask more specific questions of my interviewees about themes which had been highlighted in previous interviews, such as withdrawal of care struggles.

Different to a conventional narrative approach, which usually conducts multiple interviews with a small number of participants (Wengraf, 2001), I largely conducted just one interview with each participant. This was since I aimed to interview a wide range of constituents – in keeping with the multi-sited ethnographic approach (Marcus, 1998). In addition, I perceived that many interviewees, especially ICU staff who gave up their shift time to be interviewed,

might have felt burdened by a second interview. Some participants (n=4), however, did undergo a second interview upon my request. These were carried out with those whom had detailed a case which I wanted to find out more about, or when I felt that there were important aspects from the first interview which needed further probing. For the second interviews, after initial analyses of their transcript, participants' words from their first interview were used as the basis for further questions. These would generally ask for more details about an event which they described (Wengraf, 2001). Overall I conducted 34 interviews with 30 participants (26 interviews with 22 health professionals, and 8 interviews with 8 'community' participants).

At the start of every initial interview I went through the study information sheet with each participant, ensuring they understood the key points of anonymity and confidentiality. Written consent was taken once any questions had been answered, and talk was collected using a digital recorder. As soon as possible after an interview I wrote down my reflections in field notes, covering, among others: a description of where it took place, what point I thought the interviewee was making (Mishler, 1986b), their demeanour throughout, and my feelings about the interaction. I transcribed each interview verbatim, simultaneously anonymising the accounts as I went along. This process of transcription cannot be readily separated from the analytical process (Reissman, 1993). As such, transcription acted as an analytical *way in* to begin to interrogate what the accounts were telling me about the 'issue' of organ donation and ethnicity. This process of analysis I describe below.

Analysis: understanding my data

In ethnography the process of data collection and interpretation is iterative and ongoing. The ethnographic process means that analysis begins unsystematically and is gradually "funnelled" over time (Hammersley and Atkinson, 2007: 206). Analysis was thus not a

wholly isolated period but was grounded within the research contexts (Bamberg, 1997; Hammersley and Atkinson, 2007). The production of field notes was crucial to this process. By setting my interviews in context and documenting my research observations, field notes were used to plot emergent themes and continually re-assess the focus of my inquiry. The complementary material of my observations and narrative interviews adds to the eventual quality of interpretation (and, if we were being positivistic, the validity of the findings) – where one is contextualised by the other and vice versa (Atkinson and Delamont, 2006).

Once the bulk of my fieldwork had come to an end I begin a period of focused, intense analysis. The initial problem I encountered during this period was how to do justice to both types of data (observations and interviews), without becoming overwhelmed with the sheer amount of material[34] I had. In keeping with the study's phenomenological approach I decided to employ a largely narrative analytical approach, which "privileges the subject's ways of representing experience" (Reissman, 1991: 66). With this, I took the formal narrative interviews as the starting point for my analysis.

Narrative analysis pays particular attention to structure, coherence, and temporality to highlight *how* events are given meaning by their teller (Mishler, 1986b; 1995 Reissman, 2008). However, despite this common grounding there are a huge diversity of approaches around narrative analysis, which are often dependent upon the aims and philosophical approach of the study (Mishler, 1995). Elliot Mishler (1995) has distinguished three models of narrative interpretation. These he outlines as: 1. representation and temporality; 2. structure and coherence; and 3. the cultural, social and psychological contexts of narrative.

The first model has its basis in the work of the socio-linguist Labov (1972), who approached narrative analysis by isolating clauses within accounts, as if they corresponded with the

---

[34] This included over 30 hours worth of transcribed talk, and four notebooks of field notes.

"sequence of real events" (Mishler, 1995: 90). Labov asserted that a "fully formed story" consisted of 6 isolatable elements, these being:

1. Abstract (the summary/point to the story);

2. Orientation (time, place, who involved etc);

3. Complicating action (the 'plot' – moving the story forward);

4. Evaluation (where the teller comments on the meaning of events);

5. Resolution (outcome of the experience);

6. Coda (rounding off the story and bringing it back to the present context) (From Reissman, 2008: 84).

Although a practical model for doing analysis, critique of Labov's approach has centred upon its positivistic stance, where stories are seen as a representation of external reality, rather than concentrating upon the meaning they convey (Mishler, 1995).

The second form of analysis: coherence and structure, focuses upon "narrative strategies" (Mishler, 1995: 90). This approach looks at how language constructs the meaning of a narrative (e.g. Ricoeur, 1984). Accounts are therefore analysed for the way in which stories are used to create a sense of coherence and discursively frame events. The final model Mishler outlines concentrates upon the work and effect of stories: how they construct individual and collective identities and a moral evaluation of events. This form, Mishler argues, does not just relate to stories told by research participants, but also to stories produced in ethnographic accounts.

As Mishler (1995) and Reissman (2008) have argued however, such analytical modes, and ways of actually *doing* analysis – which can include thematic and more structural

approaches, like Labov's – are far from discrete. Instead, Mishler(1995) calls for recognition of the overlapping strategies of analysis, which amalgamate different perspectives and aims. In approaching my analysis from a phenomenological ethnographic perspective, I was concerned with looking at *how* narratives of donation experiences conveyed meanings about events, alongside how meaning was created in relation to the people and practices described. In this way, I would be able to move in and out of a focus upon particular experiences, and the wider processes and constituents involved in the donation and ethnicity 'problem' (see Saris, 1995; Menard-Warick, 2007; and Jacobs *et* al., 2011 for examples of narrative research which incorporate individual stories into understandings of wider socio-political contexts). For example, specific accounts about struggles around withdrawal of care between BME families and health professionals were eventually mapped to wider understandings of medical practices around death, and the way in which 'BME' families were described as problematic in relation to these practices.

To allow for both insight into individual stories and the creation of a general account of the 'problem' around donation and ethnicity, I therefore took an adapted narrative and thematic approach to interpreting my data. Reissman (2008) has advocated using thematic interpretation (what is said) alongside a structural, narrative analysis (how stories are constructed and meaning conveyed) for narrative material. This enables an overview of the data, whilst using select accounts to add a deeper layer to the findings. I decided to therefore begin my analysis by using a structural, narrative analysis on a sample of interviews. This would allow for working insights focused initially upon the stories around donation and its related processes. These insights would then be used to focus my thematic analysis.

I subsequently picked 8 interviews from 6 participants[35], or just under 25% of my total interviews, for the narrative analysis. These were chosen because they featured the richest, most detailed narratives. This is what Ochs and Capps (2001) conceptualise as a story's *tellability*, in that they convey the importance of occurrences for the speaker within the telling context. The detailed stories within these interviews thus offered rich insight into events and practices around donation, alongside how participants' constructed their personal identity/moral message (Mishler, 1995) within these. To analyse this sample I adapted the structural approach of Labov (1972), to scrutinise how the teller conveys meaning through the organisation of their story (Reissman, 2008). However, not wishing to take such a positivistic stance as Labov, rather than separating each narrative into 6 categories, I used just 2:

- *complicating actions* (CA): how the story is produced by detailing the actions/events which took place over time;

- *evaluation* (EV) of these actions: where the narrator imposes their moral judgements upon the events and their protagonists.

This process involved taking an interview, and, after repeated reading to get a feel for its stories and what was being said (Mishler, 1986b; Reissman, 1993), isolating the main narratives (the most in-depth stories within the account) within each interview. These were subsequently separated into the 2 categories above, and placed within an Excel table. This meant the narrative could be read across the table: from complicating action to the interpretation of those actions (evaluation), and down (to the next point of action). I then mapped the remaining parts of the interview on to the sections of narrative that it seemed to be pointing to, under the category *further interpretations*. For example, this included

---

[35] Two participants from this sample had undergone 2 interviews.

smaller stories and opinions which seemed to make similar moral points to a main narrative, or section of that narrative. I then looked at each row, constituted by CA, EV, and further interpretation, and added a further column for *my interpretation* of these sections (see appendix 8). This involved thinking about how the narrative was arranged, and how each sequence of actions was given meaning in relation to the overall point of the story (Reissman, 2008). Later on, it also involved thinking about what these stories told me about the wider assemblages around, and institutional landscape (Foucault, 1980; Saris, 1995) of, organ donation and ethnicity.

The analysis of this sample eventually led to the construction of preliminary working categories (or themes), such as *consent complexities* and *conceptualising ethnicity*, which best described what was going on in the stories. It also provided me with questions, relating to the initial findings, which I could ask of the rest of my data (see appendix 9). These categories and questions were then used as an analytical framework to interrogate my remaining interviews and fieldnotes, which I thematically analysed. For the thematic analysis, rather than taking a grounded-theory, line-by-line coding method (Glaser and Strauss, 1968), I used a broader story-by-story approach (or point-by-point, if there were few stories), which would allow me to develop general themes (Reissman, 2008). This also meant I could explore individual stories within the context of each interview; how the stories related to one another; and how themes intersected within the stories themselves.

The process of developing my findings therefore involved an iterative to-ing and fro-ing between narrative and thematic analysis, with the narrative approach often informally employed to interrogate stories within the thematically-analysed interviews. Findings were also developed in lengthy discussions with my supervisors, from informal discussions with Emily, my main informant, and in presenting my data at PhD analysis sessions in my

department. These meetings acted as a key space by which to re-position myself in relation to the findings, as a result of others' opinion about the data.

It was during the initial period of analysis that I began to look at the work of science and technology studies (STS) (see part 4 of chapter 1), and subsequently actor-network theory (ANT), to help me understand my emerging insights. This came about by the fact that I began to notice how things – such as donation protocols, consent forms, and mechanical ventilators – featured prominently in many of my participant's narratives, and in my observations of organ donor training and committee meetings. These things seemed to be intimately tied to, and wholly inseperable from, the practices around the organ donation encounter. As Casper and Berg (1995) have argued, paying attention to practice involves examining both the 'social' interactions and the materials which are involved in, and have relational effects upon practice. For example, donation protocols were often referred to in stories where they broke down in practice, such as when a coroner could not be contacted to ask permission for donation; and were embedded in the donation nurses' delivery of donation training, such as in their demonstrations of how they worked through donation consent and patient assessment forms with families. In searching for a language which would help me open out my analysis to incorporate these materials, I came across science and technology accounts of how medical standards – such as policies and protocols – are put into practice (e.g. Timmermans and Berg, 2003; Singleton, 2005; Struhkamp *et al.,* 2009), and subsequently, the Actor Network approach (ANT) in research.

In an ANT approach, phenomena (reality/categories/objects/subjects) – such as the category of ethnicity in organ donation – are understood as the effect of relations between diverse human and non-human entities (Latour, 2000; 2005; Law, 2008). In this way, materials feature as a way of thinking through phenomena as much as the experiences, interactions, and concerns of humans (Law, 2008). According to Bruno Latour (2005: 71-2),

these 'things', or 'non-human actors' – including consent and patient assessment forms, protocols, mechanical ventilators, laboratory testing technologies etc – function as "actors or more precisely participants" which "back-drop", "authorise", "suggest", "influence" and "permit" human action. In this sense, they form an integral part of the relations which make up the phenomena of organ donation and ethnicity. So, for example, my analysis in chapter 6 draws attention to the way in which donation consent forms mediate the encounter between donation nurses and potential donor families, and play an integral role in the interpretation of 'BME' families as problematic populations for organ donation.

Whilst not at first an obvious (or necessarily comfortable) 'fit' with a phenomenological approach[36], an ANT sensibility came about by following the sense-making processes of my participants, as advocated by a phenomenological and narrative approach, and as is fitting to an ethnographic methodology. Thus, by analysing what the research subjects were telling me, and by contemplating the way in which materials featured in their meaning-making, my phenomenological approach overlapped with the importance of 'following the actor' in ANT (Latour, 2005) – tracing the relations between different actors which/whom make up the 'problem' of organ donation and ethnicity. Far from being imposed upon the data then, my later use of ANT and the incorporation of materials into my analysis[37] developed from the constructions of those being researched.

In keeping with the study's ethnographic approach, analysis did not end with the resultant write-up, but was furthered *through* the process of writing, as an "analytical tool" (Hammersley and Atkinson, 2007: 163), and by the integration of related empirical and

---

[36] This is because, whilst phenomenology is focused upon how humans inhabit, experience, and make meaning of the world around them, with this world – to some extent – taken for granted, ANT is interested in how this world is formed, or made real; how it is done (performed); and how things occur as an effect of the relations between heterogenous (human and non-human) actors (Law, 2008).

[37] Materials take a more explicit position in some of the results chapters than others. This I further discuss in the epilogue.

theoretical literature, such as research into the work of health professionals, and Foucault's ideas around power and biopolitics. The data employed to present the results, in the main, come from the institutional research contexts. Since these are the settings which have been largely ignored by current literature into ethnicity and organ donation, I decided to focus upon the institutional material to tell the 'story' of my results. Fieldnotes and interview data from my time spent with 'community' participants were, however, drawn on throughout to inform my thinking. My results thus emplot the institutional landscape (Foucault, 1980; Saris, 1995) of organ donation and ethnicity. This I do by using individual cases/stories to illustrate the meaning of everyday experiences around the phenomenon, and how these experiences interact with wider issues, including medical authority, standardisation, the family, and the classification of individuals.

In the final part of this chapter, I detail the ethical considerations involved in doing this study, and in writing and disseminating its potentially sensitive findings; which focus upon institutions and their practices, rather than solely 'BME' 'communities'.

Ethical considerations

The domain of organ donation, as highlighted in the anthropological literature (Lock, 2002; Sharp, 2006, Scheper-Hughes, 2002) is a highly ethicised area, with its proliferation of debates about the body, inequalities, and the meaning of death, among others. My academic entry into this domain meant that the study's particular focus, and my conduct within it, has always been entwined within the broader context of such concerns. This was not, however, what the NHS ethics committee I applied to, seemed interested in. The process of gaining NHS ethical approval to access hospital sites seemed more of a painful, bureaucratic form-filling exercise with a tick-box ethics, than one done for the good of participants. Whilst obviously important, ethical review processes have been criticised for their "formulaic" approach (Hammersley and Atkinson, 2007: 227). I experienced this with

the NHS ethics forms for non-experimental studies (including qualitative research), which asked for details of the "total number of interventions" for each participant and how long each of these will likely last. Questions such as these left little room for an ethnographic study such as mine, which could not specify exactly what would happen or who would be talked to prior to the research beginning (Christians, 2005).

Outside of such formalised criterion, ethics, for me, is embodied within the research process. As ethnography moulds its research focus around what is unfolding in the field, the ethics of such research can be linked to Levinas's (1969) notion of the 'other', detailed previously. In my encounter as a researcher with 'others' (participants), my "moral obligations" to both the topic and those I came into contact with, was formed (Christians, 2005: 150). In this way, ethics is not something which can simply be dropped on to a study from above – as the NHS review process seemed to require. Instead it is tied to the moral development of the researcher, in *doing* the work and critically engaging with participants.

Despite the frustrations of the ethics process, it also gave me the time to formally consider the (ethical) implications of this study. Hammersley (1990) lists four considerations for ethical ethnographic research, these being: deception, privacy, damaging consequences for others (or harm), and consequences for future research. The notion of deception can also be placed under the umbrella of informed consent: where the researcher has a moral obligation to provide open information about the study to participants, and ensure their involvement is voluntary. All participants undertaking interviews in my research underwent a process of consent, involving the provision of information about the study, and the completion of a consent form (see appendix 3 and 4). This asked for, among others, their understanding of the study, and their permission to be directly quoted under an anonymous guise; covering their right to privacy and protection. Due to the sensitivity of accounts describing death and donation, participants were also offered a copy of their transcribed

interview to check they were happy with their talk being used. Of those (about half) who took this up, a few asked for further anonymisation, or even whole sections of their interview – which they felt were too sensitive – to be deleted.

The notion of harm is complex in ethnography and can refer to the consequences for participants during the research and its aftermath (Hammersley and Atkinson, 2007). Whilst I had little chance to ask families about their direct experiences of organ donation, many health professionals disclosed highly personal, sometimes overtly emotional accounts. In addition, I interviewed transplant recipients and one live kidney donor about their experiences, which had the potential to cause distress. The use of narrative interview was thus seen to be appropriate, since participants decided on the course and general focus of their interview. Building rapport is also a key part of an ethical ethnographic research, with the researcher's ability to develop trust between themselves and their participants (Fox, 2004). A number of participants, such as Emily, the embedded donation nurse at Hillview, acted as key gatekeepers and informants for my study. With her interest in the study and ready willingness to help me throughout and beyond my fieldwork, I strove to develop this relationship and involve her in the progress of the research and development of findings through regular email contact.

Harm can also include the consequences of research findings becoming public, and the possibility that individuals may be recognised by a wider audience, or, indeed recognise themselves and others within the research account (Hammersley, 1990; Christians, 2005; Hammersley and Atkinson, 2007). This would have devastating ramifications in a study such as mine, with the possibility for deceased donors to be identified, and in the context of the sensitivity of certain findings, such as the implicit ethnic stereotyping employed by some health professionals. To mitigate these effects pseudonyms are always used, and I have removed or altered identifying features relating to participants (e.g. ages, appearance,

accents, and particular job titles), research settings, and the people described in interview accounts. For example, particular details about donor's deaths have been changed, to avoid them being traced back.

In a similar way, harm (or offence) caused as the result of my research could have negative implications for future research. Since ethnography relies upon the help of gatekeepers and key informants, if offence is taken at the reported research findings, this can jeopardise the potential for further research (Hammersley, 1990). In presenting findings, one therefore has to tread a fine line between being representative and taking into account the feelings of those involved. 'Community' members involved will be fed back a written account of the findings. However, as pointed out above, the topic and eventual (institutional) focus of the research has the potential to cause controversy, especially for the health professionals who took part. For Becker though, a hostile reaction to research is reflective of a 'good' study which represents "the irreconcilable conflict between the interests of science and the interests of those studied" (1964: 276). I will eventually present my findings to the health professionals who took part. *How* I actually present these, and in what language will thus need be adapted for the various audiences.

Conclusion and overview of the results chapters

In the following chapters I present my findings, which resulted from following the various people (ICU staff professionals, donation nurses, transplant recipients, religious leaders etc), procedures (donation guidelines, standards, recommendations, and legislation), things (mechanical ventilators, monitoring machines, hospital beds etc), and settings (ICU wards, operating theatres, transplant centres, homes, hospital offices etc) connected to the organ donation and ethnicity 'problem'. In so doing, rather than portraying a de-contextualised account of how the 'cultural' attitudes of 'communities' inhibit donation rates (and

therefore the ability to transplant 'BME' patients), I illustrate how the 'problem' can be traced to, among others: how organisational changes around organ donation are put to work in hospitals with high 'BME' patient populations; how struggles between ICU staff and 'BME' families over decisions around death muddy the waters of what consent for organ donation actually *means*; and how donation nurses' consent practices get done through their assumptions about 'BME' families. In this way, I demonstrate how the 'BME' donor 'issue' is both constituted by, and reproduced within, institutional donation domains, and is not, therefore, something which can be reduced to persuading 'communities' to sign up to the organ donor register.

To give life to the findings, I have mapped them on to the organ donation pathway, beginning, in chapter 3, with an overview of how this trajectory should look, according to donation policy and guidelines. This chapter aims to show the complexity of the organ donation process, and how reaching the stage of requesting organs from a donor family is dependent upon the practices and decisions of various actors, such as coroners, ICU consultants, and donation nurses. In so doing, I highlight how decisions around donation are not limited to the 'yes' or 'no' answer to donation requests by 'BME' families. This chapter therefore offers a way in to the main research findings, which demonstrate how donation procedures are experienced, done, and made problematic in practice. In chapter 4, I examine the work done around organ donation, by looking at how the ODT's (2008) recommendations for changes to donation services are put into practice by donation nurses, within local hospital settings. I demonstrate the problems encountered in attempts to increase ('BME') donation rates, and how donation nurses act as crucial agents for the production of practice norms around donation in Intensive Care Units. In this way, I argue that organ donors are ultimately produced as an outcome of practice, and not, necessarily the willingness of 'BME' individuals to donate their organs after death.

In chapter 5, I focus upon the issue of consent in organ donation with 'BME' families. Specifically, I problematise standardised constructions of donation consent in policy and donation promotions, which represent consent as the singular choice of an individual. In contrast, I show how these standardised presentations break down in practice: where consent to donate is predicated upon a family's acceptance of the death of their relative; and how the final decision to donate is made by the potential donor's family and *not* the potential donor. I highlight how these stages of consent are considered more complex with 'BME' families, who are represented as problematic populations for donation by virtue of their failure to conform to the norms of practice around donation. In the final results chapter, 6, I look at the practice of obtaining formal consent for organ donation. Here, I demonstrate that achieving consent from families to donate their relative's organs is contingent upon the interpretative, interactional work of the donation nurse, who adapts consent procedures according to their assessment of a family's needs. It is these practices, however, which also construct and reify the 'BME' donor family as a problem for donation. In this way, I highlight how ethnicity is reproduced as a 'problem' within donation domains by health professionals, who act as agents for dealing with this 'problem' in practice.

Chapter 3. Donation Pathways: Standard (and Idealised) Processes

Introduction

The aim of this chapter is to outline the UK organ donation pathway as it is presented in procedural guidelines and standards, such as the Intensive Care Society's (ICS) *guidelines for Organ and Tissue Donation* (2005) and the Human Tissue Authority's *Code of Practice: Donation of Solid Organs for Transplant* (2009a). In so doing, it will highlight the complex process of organ donation: from how decisions get made to transfer a patient to the status of potential donor; to ensuring the requirements of consent and donor risk assessment are fulfilled; to gaining coroner consent for organ donation to take place; and facilitating theatre teams to remove the organs.

The chapter is organised in two parts. I firstly contextualise these procedures by providing an historical insight into the development of donation guidelines in the UK. Secondly, I present the procedural stages involved in an organ donation process, and the different social actors responsible for making these stages happen – so that organs can be procured for transplant. In so doing, I show how decision-making and acts of formal and informal consent around donation are practiced across the *entire* process by differently involved actors. This is in contrast to how donation decisions have been presented in promotional campaigns and research on organ donation and ethnicity (see chapter 1) as a simple matter of a ('BME') family or individual saying 'yes' or 'no' to the question of donation.

As I will demonstrate in this chapter, the organ donation process is a complicated trajectory, spanning different domains, actors, and forms of consent along the way. What became clear when researching this pathway, from both my fieldwork and the literature, was how

disparate the national information is regarding this process. Apart from the Human Tissue

Act's (2004) legislation around consent, there were no national standards for organ

donation in place during my fieldwork[38]. Instead, there was a variety of procedural

guidelines and legislation that practitioners drew on. Despite advice in 2008 by the Organ

Donor Taskforce (ODT) for local donation policies - constructed around their

recommendations - to be implemented within each hospital Trust, piecing together the full

pathway involved searching not only across the ODTs report, but also (among others) the

Academy of Medical Royal Colleges (AMRC) *Code of Practice for the Diagnosis and*

Confirmation of Death (2008), the ICS's *Guidelines for Adult Organ and Tissue Donation*

(2005), UK Transplant's (UKT) *Hospital Policy for Organ and Tissue Donation* (2003), the

Human Tissue Authority's (HTA) Codes of Practice for the *Donation of Solid Organs for*

Transplant; and *Consent* (2009a; 2009b), as well as local Trust policies gathered from my

fieldwork and open internet access. Further information on the recommended pathway was

gathered from my observations of A&E and ICU nurses' training in organ donation, delivered

by the donation nurses.

Figure 5 – which is adapted from, and integrates the ICS's (2005) guideline diagram for the

donation process with the ODT's (2008) new recommendations for practice – illustrates the

procedural donation process, in green. Alongside these procedures, I have highlighted the

points of decision-making (not obvious in the standard pathway) which get made across this

trajectory, in red.

---

[38] NICE guidelines for organ donation came out in December 2011. See footnote 40.

Figure 5. Donation pathways for donation after brain death (DBD) and donation after cardiac death (DCD), indicating key consent and decision-making points

■ (green)	= donation procedure
■ (red)	= decision-making / consent

Patient admitted to Accident and Emergency (A&E)/referred to Intensive Care(ICU)/already in Intensive Care

Clinical decision to carry out Brain Stem Death (BSD) tests

Clinical decision: further life-sustaining treatment is futile.

Clinician rules out contra-indications for donation

Decision to refer

Clinician rules out contra-indications for donation

Patient referred as potential donor to donation nurse (required/automatic referral)

Organ donor register checked

Initial suitability decision

Patient initially assessed

Informal consent – family accept death

Family informed of futility (DCD) or prediction of BSD (DBD)

Informal consent – family accept death

DBD potential donor

DCD potential donor

BSD tests carried out. Diagnosis confirmed

Formal consent

Coroner may be contacted along with police

Formal consent

```
                    ┌──────────────────────────────────────────┐
                    │ Decision: who is next of kin for consent   │
                    └──────────────────────────────────────────┘

┌────────────────────┐   ┌──────────────────────────┐   ┌────────────────────┐
│ Family: initial     │   │ Potential donor family    │   │ Family: initial     │
│ decision on         │   │ approached by donation    │   │ decision on         │
│ donation            │   │ nurse and/or              │   │ donation            │
│                     │   │ clinician/nurse about     │   │                     │
└────────────────────┘   │ donation                  │   └────────────────────┘
                         └──────────────────────────┘

                              ┌──────────────────────────────┐
                              │ Patient transferred to ICU if DCD │
                              └──────────────────────────────┘

┌────────────────────┐   ┌──────────────────────────────┐   ┌────────────────────┐
│ Formal consent –    │   │ Consent for donation taken.   │   │ Formal consent –    │
│ Next of kin         │   │ Completion of patient          │   │ Next of kin         │
└────────────────────┘   │ assessment questionnaire      │   └────────────────────┘
┌────────────────────┐   └──────────────────────────────┘   ┌────────────────────┐
│ Decision on donor   │                                       │ Decision on donor   │
│ 'risk'              │                                       │ 'risk'              │
└────────────────────┘                                       └────────────────────┘

┌────────────────────┐   ┌──────────────────────────────┐   ┌────────────────────┐
│ Formal consent:     │   │ Coroner may be contacted at   │   │ Formal consent:     │
│ donation to         │   │ this point (if not before)    │   │ donation to         │
│ proceed             │   └──────────────────────────────┘   │ proceed             │
└────────────────────┘                                       └────────────────────┘

                              ┌──────────────────────────┐
                              │      Donation Nurse        │
                              └──────────────────────────┘
```

Decision: donor 'risk' & matching — Blood & tissue tests taken and assessed — Arrange theatre time & contact retrieval team — Organs offered — Decision: suitability for recipients

DBD — DCD

Withdrawal of care (dies within 2 hours)

Last chance to withdraw consent — Last chance to withdraw consent

Taken to theatre for organ procurement

Last acts of care in ICU

124

Part 1. The development of organ donation guidelines in the UK

The large variety of guidelines drawn on during the organ donation trajectory, as listed above, can be traced to shifts in the organisation of donation services in the UK over the past decade. As Griffith's *et al.* (2009: 1459) tell us, before 2000 the UK, different to other European countries like Spain, had no national "unified" approach to improving organ donation rates. There was little in the way of donation guidelines and formalised education around donation for health professionals. In addition, there was a lack of formal management and reporting structures for donation nurses[39], who, today, are responsible for managing and facilitating all aspects of the donation process, including obtaining legal consent for donation.

Prior to 2000, donation nurses were employed by local hospital Trusts and worked within small teams, only attending other hospitals with a potential donor referral. Historically, Intensive Care Units (ICU) were responsible for identifying, referring and approaching families about organ donation. As such, the donation nurse usually only arrived on the scene once a family had agreed to donate. They therefore had little influence over donation practice at hospital level. In addition, most donation nurses – who largely came to the role from ICU and Accident and Emergency (A&E) backgrounds – had never received any formal training in consent and communicating to families about donation. This informal model of practice is understood to be one reason why the UK's deceased organ donor rates remained below their potential, prior to changes implemented after 2000 (Griffiths *et al.*, 2009). For example, the introduction of the Potential Donor Audit (PDA) in 2003 found that between 2003 and 2004, 33% of potential brain stem dead patients were never formally tested for brain death (Griffiths *et al.*, 2009), meaning their potential for donation was lost.

---

[39] Prior to 2010, donation nurses were referred to as 'donor-transplant coordinators', or DTCs. Their title then changed to 'specialist nurse in organ donation' (SN-OD).

The creation of UK Transplant (UKT) in 2000 was the start of a drastic change, which saw the previously informal approach to organ donation transformed into one underpinned by a vast range of procedures, guidelines, and legislation. Alongside operating as the professional body which managed donation nurses, UKT was also tasked with generally improving deceased organ donation rates. This it did firstly with the implementation of the PDA, to assess the potential for improving deceased donation rates and to function as a measure of its progress over time. In addition, in 2004, it introduced a new strategy which focused upon maximising donation rates by providing formal training for donation nurses (and some ICU consultants) around collaboratively communicating donation to families with ICU staff, and obtaining consent (Griffiths *et al.*, 2009). This resulted in guidelines such as the *Donor Family Care Policy* (UKT, 2004a) and the ICS's organ donation guidelines (2005). The increasing focus upon standardised procedures for organ donation have also been mirrored by updates of related guidelines and legislation around end of life decision making (GMC, 2010), diagnosing and confirming death (AMRC, 2008), and the Human Tissue Act (2004).

Changes introduced by UKT were formalised in 2008 with the implementation of the ODT's recommendations for organisational changes to donation services (outlined in chapter 1), and the superseding of UKT by the NHS Blood and Transplant (NHSBT) service. The ODT's recommendations were an attempt to make organ donation a "usual not unusual" event (ODT, 2008: 9) in end of life care, so as to dramatically improve donation rates. They included: appointing a clinical lead for organ donation within every acute hospital Trust, introducing minimum notification criteria for all potential organ donors to be referred to a donation nurse, and the creation of specialist surgical organ retrieval teams.

The role of the organ donation nurse also changed with these recommendations. Small teams were merged to create large, regional teams covering wide geographical areas, and the donation nurse workforce dramatically increased. Instead of working out of a

centralised hospital base, donation nurses were newly embedded within one, or a few hospital Trusts, with responsibility to implement donation procedures, policy, and ultimately increase donation rates within 'their' hospital/s. The development of the donation nurses' role has formalised their place in the donation trajectory. It can also be seen as symptomatic of the increasingly standardised nature of organ donation in the UK, which has culminated in recently (2011) introduced guidelines for organ donation from the National Institute for Clinical Excellence (NICE) [40]. It is to this standardised pathway that I now turn, with two aims. These are to firstly outline the idealised, procedural stages of the organ donation process. This forms the background for the following chapter, which demonstrates how these procedures are put to work by ICU staff and donation nurses within local institutions. Secondly, I aim to highlight the fact that organ donation is premised upon different stages of decision-making and consent which occur *all along* the donation trajectory. This enables an initial problematisation of the policy and research focus on 'BME' populations, which represents them as the sole decision-makers in the task to increase organ donor rates from these groups.

Part 2. The organ donation pathway

There are currently two pathways to becoming an organ donor after death in the UK. The first, and most common, is donation after brain death (DBD), where death is diagnosed by neurological criteria (AMRC, 2008) and the patient remains breathing with the aid of a ventilator. This means that the heart and lungs[41] can be used for transplant, since the

---

[40] These guidelines were implemented in December, 2011, after my fieldwork had ended. NICE is a government funded organisation responsible for setting national guidance and quality standards to improve health and prevent and treat diseases. NICE guidelines are taken as the UK's 'gold standard' for achieving optimum outcomes from medical practice (Timmermans and Berg, 2003).

[41] Other organs, such as the pancreas, which are not usually used in donation after cardiac death – the other form of donation – can also be used for transplant from brain death donors.

donor's heart continues to beat (giving oxygen to the lungs) right up until its removal in the operating theatre. The decision to refer a patient for DBD is usually taken after a patient has suffered an unsurvivable head injury and where brain stem death (BSD) testing is deemed appropriate. This usually follows some kind of trauma to a person's brain, which may result from internal 'events', such as a Subarachnoid Haemorrhage (bleeding over the surface of the brain) as the result of a stroke, or from external trauma, which can occur after a violent accident, like a car crash, or after a person has suffered from prolonged deprivation of oxygen, from drowning, for example (AMRC, 2008). Upon their arrival to hospital, the patient will be assessed in the A&E department, where they are usually admitted as an emergency trauma. Once in A&E, if a patient is suspected of being, or becoming, brain stem dead, they will usually be taken to the ICU to be managed and to facilitate brain stem death (BSD) testing. In the case of long-standing conditions or a neurological injury which has deteriorated over time, the patient may have been in ICU for a number of days or even weeks before suffering brain stem death.

The second, and less common form of donation is known as donation after cardiac death (DCD)[42]. The conditions for referring a patient for DCD are similar to those of DBD, in that they are commonly referred after suffering a "catastrophic" brain injury (ICS/BTS, 2010). However, the difference comes with the fact that the patient is not suitable for brain stem death testing. This may be because they still have some brain stem function, or because they have too high a level of sedative or other drugs in their system to enable testing (which I cover later in the chapter). A patient is referred for DCD once a decision is made by the treating consultants to withdraw medical care – usually in the form of breathing support – on the grounds that the patient is going to die, and that further treatment would be futile[43].

---

[42] Between 2010/11 there were 637 DBD donors, compared with 373 DCD donors (NHSBT, 2011).

[43] This notion of futility is linked to a wide-ranging body of ethics literature, which tackles the contested understanding of what is considered to be in a patient's 'best interest'. For the purposes of my discussion on

This diagnosis is negotiated with the patient's relatives, with donation requests occurring after the diagnosis has been accepted by the family (ICS, 2005). The decision to withdraw treatment may be made in A&E. However, because of the time and resources needed for donation, withdrawal of treatment usually occurs in the ICU. In this instance, the family generally has to agree to donation before the patient is moved, since this transfer is made to facilitate donation, rather than 'treat' the patient as such. Organ donation can then only take place if the patient dies (has an absence of a heartbeat and any electrical activity by the heart) within two hours of treatment being stopped, to maximise the potential for organs being suitable for transplant (ICS, 2005). Since a cardiac death donor's heart stops beating prior to donation surgery, only kidneys and liver are usually suitable for transplant, since the heart, lungs, and other organs, like the pancreas, need to have a continual blood flow to survive.

Despite making up about 35% of the UK's deceased organ donations, DCD has yet to be implemented in around one-third of UK Intensive Care departments. In addition, in Trusts which do carry out the practice, referral and donation rates remain low, at 50% and 15%, respectively (ICS/BTS, 2010). In recent years, with the rates of DBD in continuous decline (a fall of 9% between 2001/02), DCD offers huge potential for increasing organ donor rates. The reasons for its uncommon practice are various, but are largely pointed to the tricky ethical and legal questions it raises. These include: the potential "conflicts of interest" between families and medical staff, with DCD only possible if the family consent to donation *prior to* the patient's death, and the "lawfulness of interventions" involved, such as admitting a dying patient to ICU to facilitate donation and increasing medical therapies to stabilise organs for donation, prior to donation consent being provided (ICS/BTS, 2010: 12).

---

the donation pathway, I have not gone into such debates. For an understanding of such issues see Mohammed and Peter, 2009 and part 1 of chapter 5.

These introductory explanations of the different donation pathways highlight the various decisions which need to be made by health professionals in order for donation to actually occur. The first of these comes with the decision by the treating ICU or A&E consultant (or registrar) to refer a patient as a potential donor. According to the ODT (2008) this transfer of status is only made once a decision over diagnosis of death or withdrawal of treatment has been reached:

> A patient only becomes a potential organ donor when death is confirmed following clearly defined tests of the brain stem, in which case DBD may be possible; or when a decision has been taken – in the best interests of the patient – that further active treatment is no longer appropriate and should be withdrawn, in which case DCD may be possible. (ODT, 2008: 7-8)

However, the separation of decisions around donation from decisions around death are contradicted within the same report by the ODT's recommendation for a 'minimum notification criteria'. Minimum notification criteria, sometimes referred to as 'required' or 'automatic referral', means that ICU staff are supposed to notify a donation nurse "at the earliest opportunity" about the patient if there is a plan to diagnose death by neurological criteria (brain stem testing) and as soon as sedation and/or pain relief is stopped; or when the decision has been made to withdraw treatment on a patient deemed suitable for donation (Bleakley, 2010: 186). This is reflected in the ICS guidelines (2005), where the pathway diagram points to donation referral occuring prior to brain stem death testing. With both forms of donation, the decisions to diagnose death or withdraw care are asserted as being entirely separate from the decision to refer the patient as a potential donor (ODT, 2008; AMRC, 2008). Yet, for an ICU or A&E doctor, the implementation of minimum

notification criteria suggests that their end-of-life diagnoses are intimately tied to decisions to refer a patient as a potential donor.

In the following sections I describe each of the stages and the decisions involved in the 2 organ donation pathways, from transferring a patient to the status of 'potential donor', to ultimately reaching the stage of organ procurement, so that organs may be used for transplant.

The shift from 'patient' to 'potential donor'

What is clear from the above, is that the decision-making process around donation *begins* at the point of diagnosis of an individual deemed to be near (or at) the end of life. The decision to place a patient into the category of 'potential donor' is formalised with the gatekeeping act of potential donor referral by ICU or A&E staff to the donation nurse.

Referral at this point is recommended by the ODT under the concept of 'minimum notification criteria' (see above). The OTD asserts that:

> This notification should take place even if the attending clinical staff believe that donation might be contra-indicated or inappropriate. These proposals [....] should be implemented in all acute Trusts." (ODT, 2008: 11)

With this responsibility for clinical staff to refer potential donors, even when falling against their personal judgement, the decision over *who* is an initially suitable potential donor (prior to any clinical tests being carried out) becomes the responsibility of the donation nurse. The recommendation for a compulsory donor referral policy in hospitals has been seen to dramatically increase donation referral rates in Trusts where it has been implemented (Bleakley, 2010).

Once called about a possible donor, it is the donation nurse's responsibility to initiate the process of assessing a patient's suitability for donation[44], usually before any conversations are had with their family (HTA, 2009a). This is done through a preliminary assessment of the patient's medical notes (UKT, 2004a), in conversations with potential transplant centres, alongside checking whether the patient is on the organ donor register. If the patient is deemed initially suitable[45], the on-call or embedded donation nurse, often accompanied by a colleague[46], will go to the ICU or A&E department to discuss the family approach with the treating consultant. This is known as 'collaborative requesting': where breaking news of death to a family and the organ donation request are the outcome of a planned approach between the donation nurse and consultant. This is underpinned by the understanding that consent rates for donation are higher when there is involvement of a donation nurse, rather than solely the treating clinician (Griffiths *et al.*, 2009; Bleakley, 2010).

Breaking news of death: reaching consensus on medical decisions

At this point the family will be informed by one of the ICU/A&E clinicians, sometimes accompanied by a donation nurse and/or a nurse caring for the patient, of the hopelessness of their relative's situation. The family will be told that doctors either suspect brain stem death (DBD) and wish to carry out tests (and withdraw treatment if they are positive), or that they believe their relative's situation to be hopeless and wish to remove active treatment so that they can die (DCD). This conversation has the function of breaking news

---

[44] This may be done on site, if the embedded donation nurse is already present, or at the regional offices of the donation nurse team.

[45] Absolute contraindications for organ donation include known HIV infection, Creutzfeldt-Jacob disease (CJD), or other neurodegenerative diseases linked to infection. Patients are also unlikely to be suitable donors if they are over 90 years of age and if they have had active cancer within 3 years prior to their death.

[46] The ODT (2008) recommended that up to three donation nurses may need to be involved in each donation process, each dealing with different aspects. This includes one nurse to communicate with and support the family, the other to obtain and keep a record of clinical information and liaise with transplant centres, and another to be present during the organ retrieval procedure and fulfil the last offices of the deceased.

of the medical prognosis of death, alongside reaching consensus with the patient's family as to their acceptance and understanding of the situation. This stage is vital in the the organ donation trajectory, since the family have to be deemed to have understood the death/accepted the justification for withdrawal of treatment for the donation request to take place (ICS, 2005).

The AMRC guidelines for diagnosing and confirming death impart the imperative of involving relatives and carers in discussions of death as decisions are made. The guidelines state that relatives "should be given appropriate explanation of the investigations being undertaken and of their interpretations throughout the process of the determination of death in a sympathetic, timely and appropriate fashion." (AMRC, 2008: 9). Equally, recently published guidelines by the General Medical Council (GMC) on end of life care stipulate the importance of taking into account the "role and responsibilities of people close to the patient" (GMC, 2010: 20) in discussing care decisions. However, in the case of adults, the guidelines impress the authority of the *clinical* decision:

> Some members of the healthcare team, or people who are close to the patient, may find it more difficult to contemplate withdrawing a life-prolonging treatment than to decide not to start the treatment in the first place. This may be because of the emotional distress that can accompany a decision to withdraw treatment, or because they would feel responsible for the patient's death. However, you should not allow these anxieties to override your clinical judgement and lead you [...] to continue treatment that is of no overall benefit.
> (GMC, 2010: 25)

When it comes to children though (classified below the age of 16), the decision-making process is posed in terms of a partnered negotiation between the clinical team and the parents/legal guardians when "identifying options that are clinically appropriate and likely

to be in the child's best interests" (GMC, 2010: 46). However, in the case of both adults and children, disagreements over the diagnosis/prognosis of death may lead to mediation by others, second opinions, or even obtaining the views of a court to reach a resolution. Such medical decisions about death, particularly concerning the withdrawal of treatment are justified in medical case law. One ruling drawn on by the GMC is linked to the medical imperative to act in the patient's best interest, which is "interpreted as meaning that a patient should not be subjected to more treatment than is necessary to allow them to die peacefully and with dignity." (GMC, 2010: 81).

Breaking the news of death or impending death to a family thus also acts as a decision-making process and key point of consent, whereby the family must accept this diagnosis for organ donation to be a possibility. In drawing on the guidelines, this process is understood as one which takes into account the family's views (especially in the case of a child), but is ultimately configured as one where clinicians have authority: with the imperative to discontinue treatment if a patient's situation is deemed futile.

Confirming brain death

In cases where brain stem death is suspected, once the family has been informed of this likelihood (and initially accepted this), two doctors – one of whom must be a consultant – will perform brain stem death tests to confirm their diagnosis. These tests are carried out at the patient's bedside in the ICU, sometimes with the family present – especially where it is felt that they need further clarification to understand brain stem death as a final form of death.

The AMRC (2008) reports that although there is still no statutory definition of death in the UK, the criteria for brain death has been incorporated into law in Northern Ireland and England. According to the guidelines, there are two conditions necessary for diagnosing

death. These being: "the irreversible loss of the capacity for consciousness", coupled with the "irreversible loss of the capacity to breathe" (AMRC, 2008: 11). In the case of brain stem death, death is diagnosed while the patient is still breathing, with tests indicating the loss of ability to breathe with the removal of ventilator support.

Before testing, the clinician must exclude any other possibilities causing the patient's coma, such as large amounts of depressants – like narcotic drugs, tranquillisers or sedative drugs in the system; as well as hypothermia, all of which may induce coma-like symptoms which mimic brain stem death. To test for the absence of consciousness, doctors perform a number of seemingly simple tests to check for different reflexes, including the patient's response to pain and changing light intensities. These tests include injecting ice-cold water over 60 seconds into each ear, and checking for eye movements (ICS, 2005); inserting a spatula towards the back of the throat to check for a gag reflex; and applying pressure to the forehead to test for pain response. The apnoea test is the final check carried out and this looks for the absence of the patient's ability to breathe on their own. This involves disconnecting the patient from the ventilator, usually by removing the tube, and observing them over a five minute period, to see whether they make any attempt to breathe unaided (ICS, 2005; AMRC, 2008).

Once the first set of tests has been done, another set is carried out, often straight after, to eliminate error and re-assure the family (ICS, 2005) of the certainty of death. Although death is confirmed once the second set of tests have been done, the legal time of death is taken after the first tests are completed (AMRC, 2008).

Requesting donation and taking consent for organs

Once death has been confirmed or predicted, and seen to have been understood by the family, the request for organ donation can finally take place. If a best-practice, collaborative

approach has been taken the specialist nurse in organ donation will usually make the request, sometimes accompanied by the treating doctor and/or nurse. The request is expected to take place face-to-face in a private, quiet space (UKT, 2004b). This most often occurs in a separate room, away from the ward: often a 'family interview room', designed for sensitive conversations between families and treating health professionals. Requests occasionally also take place at the patient's bedside, if deemed private enough.

The approaching health professional also has to decide which individuals qualify as relevant next of kin (UKT, 2004b), and will sometimes speak to all family members wishing to be present, or may ask to only talk with immediate family. *Who* is able to legally provide consent for donation is configured in the UK's Human Tissue Act's (HTA) legislation of 2004. This was brought into force in 2006, replacing the 1961 Human Tissue Act, and outlines the legal framework relating to the process of consent for organ and tissue donation. The Act was brought about largely as a result of the public mistrust which arose from the organ retention scandal at Alder Hey Children's Hospital and the Bristol Royal Infirmary during the 1990s. A public inquiry into these events found that tissue and organs were often being taken, stored, and used without adequate consent after the post-mortems of deceased patients[47] (Sheach Leath, 2007). The product of this public judgement resulted in a ruling that the existing laws around organ and tissue retention were insufficient and opaque, hence new legislation was brought about in 2004 (DH, 2004*)*.

In a bid to re-frame donation as a transparent act, the HTA outlines the process of consent at the heart of the principle "underpinning the lawful retention and use of body parts, organs and tissues from the living or the deceased" (DH, 2004: 3). In the context of the UK's

---

[47] Consent is not actually required for a coroner's post-mortem, but the retention of organs is only legal if it is for the specific purpose of finding out the cause of death. There are also hospital post-mortems, which clinicians or relatives can request after the death of an individual in hospital. Under the 1961 Human Tissue Act, hospital post-mortems only required a "lack of objection" from relatives for this process, rather than specific consent (Sheach Leath, 2007).

current opt-in organ donation system, the HTA's code of practice on *Donation of Solid Organs for Transplant* (2009a) defines 'valid' consent for donation as that which is firstly sought from evidence of the deceased's consent before death, such as their name on the donor register. If this is not available then a nominated representative or a 'qualifying relative' – usually a family member – can provide consent.

In theory the Act makes it legal to remove someone's organs simply on the basis that the individual has given their prior consent to donate. However, realising the ethical implications of such practice, the Act recognises the standard practice of asking for, and taking consent from family members, even if their relative's wishes are already known (HTA, 2009a; 2009b). Donation nurses, in collaboration with the treating ICU or A&E clinician, are responsible for approaching and taking donation consent from a potential donor family (NHSBT, 2010). In line with the ODT's (2008) recommendations, all donation nurses now undergo specialist training in how to talk to families about organ donation, and how to structure the consent conversation. This involves taking the family through a step-by-step process: from the request, to explaining the donation process, to obtaining written consent and a medical and social history of the potential donor, right through to initiating any specific requests by the family for care of their relative after donation (UKT, 2004a; 2004b). Much of the donation nurses' training is provided by an American company called *Verble, Worth & Verble*, who facilitate 'master classes' in consent and interviewing families about organ donation.

This Verble and Worth training promotes the practice of requesting donation and taking informed consent through what is known as the 'ladder of information of consent'. This firstly involves the donation nurse asking the family about their understanding of events around their relative's diagnosis. After ensuring the family have understood and accepted

137

the clinician's decision on death[48], the donation nurse will continue the request process by introducing the family to their 'options' after death. These include those that are legally required, such as the registration of death, and potential coroner involvement, alongside asking the family whether they have considered the possibility of organ donation for their relative. If the patient is on the organ donor register this information may also be shared with the family, as a way of introducing the possibility of donation. At this point, the family will usually have a chance to ask any questions and/or may be left with some information and given time to think through the request (HTA, 2009b).

If the family refuse donation, the donation nurse may discuss it further with them, to check their decision is final. If this is the case, treatment will be withdrawn from their relative (in both brain stem dead patients and those whose situation has been assessed as futile – potential DCD donors). If, however, the family express an interest in going ahead with donation, the donation nurse must then guide them through the formal process of consent. This is done by the completion of a standardised consent form, within which the designated family member must give general consent for donation, along with consent for each organ and any tissues they wish to be donated, i.e. kidneys, heart, corneas etc.

As part of the process of informed consent, the donation nurse will also provide the family with certain details of: any likely coroner involvement, what the surgical procedure will involve and who carries it out, details of what exactly will be removed[49], how the organs will be allocated, how long the process will take, the appearance of their relative's body after the retrieval, and the possibility that some or all of the organs might be unsuitable for

---

[48] If the family are still judged as not understanding the situation, i.e. are refusing to accept that withdrawal of care is the right decision for their relative, then the donation conversation will usually not go ahead, or may be postponed so that the family can be given further explanation (by the consultant or donation nurse) about the death, to aid their understanding.

[49] E.g. in the case of heart valve donation, the whole heart is removed.

transplantation after their removal (UKT, 2004a). The family are also made aware that they can withdraw their consent at any time; right until the first incision is made in the operating theatre (HTA, 2009a). Consent for donation is therefore only final once the donation operation has started. In the case of DCD, the family are informed that donation can only go ahead if their relative's heart stops within a certain time (usually two hours) once treatment has been withdrawn, and that once they have been declared dead they will only have around five minutes to spend with their relative before they are taken to the operating theatre[50] (ICS, 2005).

The donation nurse also explains to the family that blood and tissue samples will need to be taken from their relative to test for certain diseases, like HIV and Hepatitis, to ensure that their organs are suitable to transplant. Along with the consent forms, the donation nurse must also complete a patient assessment form with the family, to obtain details of the donor's social and medical history. This form is essentially used to find out the patient's illness history and lifestyle, to assess the safety of the organs to be used for transplant[51]. It includes questions about the potential donor's sexual history and their drug, alcohol, and tobacco use, alongside queries about their general health, such as whether they have ever been treated for cancer. Recognising the delicate nature of this part of the consent process, interview guidelines in UKT's *Donor Family Care Policy* (2004a) advocate the importance of imparting the procedural nature of this process, stating that the donation nurse should explain "that some questions are of an intimate nature", that they are required for *all* potential donors and that they "are not meant to cause offence" (UKT, 2004a: 10).

---

[50] This is to ensure that there is a limited amount of time that the organs are without oxygen, in order to maximise the chance of them being useable.

[51] This would include assessing whether there is any chance that the donor could have recently contracted HIV – by asking about their sexual and substance use history - as the virus is usually only detected in blood tests two to six months after exposure.

Once these forms are complete, the donation nurse assesses whether the family has any special requests for the after care of their relative after donation. This includes asking about religious/ spiritual needs; whether they want any locks of hair, hand, and/or foot prints, photographs, and a body viewing. It also includes asking whether they would like follow up support after the donation, including information about the donation outcome and anonymised details of recipients. This makes it clear to the family that the donation nurses's involvement does not simply end with the act of donation.

Coroner consent

Due to the sudden and unexpected nature of most donor deaths, the coroner is often involved in donation cases. Once a patient has died/treatment is to be withdrawn, the healthcare team are obliged to notify the local coroner if the cause of death is unknown, violent, considered 'unnatural', or if death occurs less than twenty-four hours after hospital admittance; in which case the coroner is legally bound to investigate. In the case of coroner involvement, donation can only go ahead with a coroner's agreement, "who must be satisfied that such donation will not interfere with his/her duty to investigate the death" (DH, 2010). Coroner consent is therefore vital, since, even when a family have agreed for their relative's organs to be donated, if the coroner feels the donation may disrupt their investigation, it cannot take place. Other forms of authoritative consent may also be needed from the police and pathologist (if a post-mortem is required). Here, the coroner must discuss the case with the senior police Investigating Officer and the pathologist responsible for the post-mortem if a potential donor's death is implicated in criminal proceedings (DH, 2010). Consent from the coroner is therefore mediated via these authorities.

Coroner consent is sometimes sought by the treating clinician, prior to, or in parallel with the family approach This involves contacting the on-call coroner with details of the circumstances surrounding the death, any police involvement, the type of donation being

proposed and organs likely to be suitable for retrieval, along with whether the patient was on the organ donor register (ICS, 2005). Sometimes the coroner will be called by the donation nurse, which may be done before or after the family consent process. This form of approval is a key stage in the donation pathway, with the coroner understood to act as a key gatekeeper in the process.

Backroom activities: testing, managing, and allocating organs

Once both family and coroner consent have been secured, the donation nurse (who may be the same as the one approaching the family, or may be a colleague designated responsibility to deal with the largely administrative side of the process) will begin the testing process and continue to facilitate the management of the potential donor. Managing the donor involves monitoring their heart rate, blood pressure, blood sugar and fluid levels, and their respiratory rate. This is to ensure that any physical instability (like high blood sugar levels) in the donor is corrected, often with the administration of medication such as insulin (ICS, 2005), to optimise the chances of successful donation. In the case of DCD, the notion of managing a patient – sustaining their organs in order to facilitate donation – has recently been clarified by the Department of Health, around a shift in understanding of what is considered the patient's best interests:

> Maintenance of life-sustaining treatment may be considered to be in the best interests of someone who wanted to be a donor if it facilitates donation and does not cause them harm, or place them at significant risk of experiencing harm or distress. (DH, 2009: 10)

In parallel, the donation nurse will also take blood from the potential donor and send these to the local hospital lab for virology, tissue, and blood group testing. The latter are used in decisions over how to allocate the organs; with virology testing done to rule out any chance

of HIV and hepatitis B or C transmission between donor and recipient. Other tests include liver function, along with x-rays if the heart or lungs are being removed. These results may take up to four hours to return, during which time the donation nurse will register the potential donor with UK Transplant and begin the organ offering process – usually done via the National Electronic Offering System.

The allocation procedure can be lengthy, and involves offering organs according to organ-specific allocation policies. For example, kidneys from DBD donors are electronically allocated by the placement of patients waiting for transplant on to a tiered hierarchy. This prioritises HLA matches (between donor and recipient) and distinguishes recipient need according to a points-based system, incorporating time waited for a transplant and age, amongst others, with paediatric patients given priority in all cases (Johnson *et al*., 2010). In contrast, with DCD donors, because of the decreased time in which kidneys can be outside of the body, they tend to be offered to transplant centres in order of location closest to the donor hospital. Here, transplant surgeons within each centre are given 45 minutes to accept or reject an organ, before the next centre is contacted.

Alongside this, the donation nurse will also negotiate an operating theatre location and time, usually with the on-call anaesthetist and theatre co-ordinator. Due to scheduled surgery times, this will often be during the evening or night. The donation nurse will also contact the regional organ retrieval teams - specialist surgical teams employed by NHSBT to carry out organ procurements - to arrange for their arrival and details of the donation.

The organ retrieval

Once all virology tests have been returned (presuming they are negative), the organ allocation organised, the retrieval teams arrived, scrubbed and ready in theatre, and the family given chance to spend time with their relative and say goodbye, the procurement

process can begin. In the case of a DBD donor, this is a matter of transferring the donor to theatre, still attached to the ventilator, with an anaesthetist present to administer general anaesthetic[52], before the initial surgical incision is made. With DCD however, this stage is more complex and involves withdrawing treatment on the donor according to usual protocol within the local ICU, waiting for the patient's heart to stop beating, and declaring death prior to taking the patient to theatre.

Withdrawal of treatment usually involves stopping ventilation and airway support to the patient, and administering sedatives (if not already done so) to elicit a pain-free death (ICS, 2005). The family are then left with the patient, who will be observed by the donation nurse so that they can act immediately once the patient goes into asystole (meaning there is no cardiac output: the heart stops beating). If this happens within two hours[53], a clinician will certify death after five minutes of the patient being in cardio-respiratory arrest (ICS, 2005). Although there is no standard criteria for diagnosing this form of death, it usually involves a doctor confirming the patient is no longer breathing (respiratory) and is without a pulse (cardiac), along with checking for the absence of brain activity by assessing pupil (shining a light into the eyes) and corneal reflexes (AMRC, 2008). Once death is confirmed, the donor will then be quickly taken to the operating theatre for the organ retrieval.

Final (and continuing) acts of care

Once the organs have been removed, the donor will be stitched and transferred back to the ICU for the performance of final acts of care. Depending on local policy, these may be carried out by both ICU nurses and the donation nurse, sometimes in conjunction with the

---

[52] This practice was explained in chapter 1.

[53] Usually, if the patient has not died within two hours of withdrawal of treatment, then the donation cannot go ahead, and the family will be informed of this by the donation nurse.

family. This includes removing any remaining tubes and catheters[54], washing and dressing the donor, and taking mementoes such as locks of hair and handprints for the family (ICS, 2005; UKT, 2004a). If the family wish to spend further time with their relative, the donor will be transferred to the chapel of rest, and finally on to the mortuary.

If the family have agreed to follow-up, the donation nurse will send them a letter, usually within a few weeks of the donation, thanking them and outlining the outcome of the retrieval, along with providing anonymised details of the organ recipients. The letter may also offer the family a follow-up visit by the donation nurse (UKT, 2004a), which is used to facilitate further support, such as bereavement counselling. It also provides information about contacting the transplant recipients, for which the donation nurse would act as mediator. The donation nurse also usually sends a card to each donor family on the anniversary of the donation. Contact with a donor family can therefore continue for years after the donation event.

Conclusion

The purpose of outlining the standardised donation pathway in this chapter has been to show what this process entails, alongside highlighting the complexity of procedures involved in facilitating a donation; the multiple stages of consent (such as decisions to refer, family acceptance of death, and coroner consent); and the huge variety of different actors (including families, ICU staff, donation nurses, coroners, mechanical ventilators, laboratory equipment, tools for conducting brain stem death tests, consent forms etc) involved in the process. In so doing, it becomes clear that the 'issue' of low 'BME' donation rates goes beyond questions about why certain population groups do or do not believe in organ donation, and into queries about whether patients are referred in the first place for

---

[54] These may be left in if a post mortem is required after the organ retrieval (ICS, 2005).

donation, and how death and donation requests are communicated to a family by health professionals.

In addition, despite recommendations by the ODT (2008) to make donation a usual process in hospitals, and for staff to refer potential donors as a routine part of end of life care, these recommendations were to be implemented in locally-produced (within each Trust) donation guidelines and policy. This has implications for how recommendations to increase ('BME') organ donor rates are made to work at local, institutional levels, and indicates that we are not, therefore, dealing with uniform procedures (as outlined in this chapter) in everyday donation practice. In this way, donation decisions, and thus donation rates among certain population groups, can be understood by viewing organ donation as a multi-faceted process, contingent upon certain requirements being met along this pathway. It is important, therefore, to look at how this process is done and experienced in practice. This will provide us with a point of departure for understanding how 'BME' organ donors and their families are constituted as a result.

In the following chapters I therefore take up different stages of the organ donation trajectory in everyday practice, to show how the 'problem' of organ donation and ethnicity can be traced in the organ donation encounter. Findings, in chapter 4, include the interaction of the ODT's recommendations, such as required referral, with the practices of ICU staff – who may continue to make decisions on the suitability of a potential donor and approach a family about donation, despite this no longer being their responsibility. In chapter 5, I show what happens when an 'Asian' family do not agree with the diagnosis of death of their relative – inhibiting the pathway towards donation request – and how they, and other 'Asian' families are constructed as a 'problem' for donation as a result. In addition, in chapter 6, I demonstrate how securing organs for donation is dependent upon the interpretative work of the donation nurse, and their ability to balance a family's needs

with the requirements for legal consent. Moreover, I show how 'BME' families get reproduced as a 'problem' through the assumptions made by practitioners during these consent encounters. The following chapters therefore aim to provide insight into the various practices and experiences in everyday donation domains – and beyond – as a way of illustrating the complex 'issue' of organ donation and ethnicity.

Chapter 4. From Patient to Potential Donor:

Standardised Recommendations, Localised Practices

Introduction

This chapter focuses upon the work of organ donation. Specifically, it will look at how the Organ Donor Taskforce's (ODT) 2008 recommendations for organisational changes to donation processes get *made to work* at local (Trust) levels by the figure of the donation nurse. Drawing on work around standardisation and its enactments – how things, like policy, get done and conceived "on the ground" (e.g. Timmermans and Berg, 2003; Miller and Bowker, 2009: 152) – my *way in* to understanding donation and ethnicity takes experiences of implementing the ODT's recommendations as its point of departure. In making the work involved in organ donation visible, I highlight the tension between guidelines and how these actually work in practice. With this, the question of low ('BME') donor rates becomes not just one relating to familial consent, but also gets embedded in an understanding of how the stage of requesting organs from families is actually reached in the first place.

One of the hospital Trusts I researched, Hillview, and its embedded donation nurse, Emily, will be focused on in the first two sections of this chapter, as an exemplar to highlight general findings about how recommendations to increase donor rates are put into practice. The final, third, section contextualises these findings by looking at the emotional work involved in the donation process for health professionals. Emily, a donation nurse with many years experience, became my main informant in the study. I followed her progress during her first year at Hillview through interviews, observations of her training staff, informal meetings and regular communication through emails and phone calls. The first section of this chapter therefore examines how the ODT's recommendations were put to

work by Emily in her implementation of a donation after cardiac death (DCD) programme at Hillview. With a responsibility to optimise donation rates within local Trusts, I show how donation nurses must carefully respond to the requirements of national recommendations according to the heterogeneous needs of local practice settings and their staff. In so doing, I illustrate the contingencies involved in making the ODT's recommendations work in practice, and thus increasing organ donor rates.

The second part of this chapter will look at decision-making around potential donor referral. As Latour (1987; 1988) has shown, things, such as the ODT's recommendations, only become 'real' through the actors – human and non-human – who perform this reality. In this way, I show how, even when successful in implementing changes to donation procedure within Intensive Care Units (ICU), there is no guarantee for the donation nurse that staff will necessarily adhere to such changes. To get around such difficulties, donation nurses develop informal tactics to *work through* the contingencies involved in professional relationships around donation. In so doing, they are shown to be acutely aware of balancing the responsibility of increasing donor rates, with the needs of ICU staff.

The final section backgrounds the above issues by demonstrating the overlap of public and medical sensitivity around organ donation, and how the work of donation nurses must encompass such concerns. I show how public worries around donation are also expressed by Intensive Care professionals, who worry about the implications of the ODT's push to increase organ donors for their everyday work. At the same time, organ donation is experienced as an emotionally difficult experience for all staff involved in the process. In this way, the donation nurses' job is far from a simple matter of implementing donation procedures in clinical contexts. To affect donation rates they must also work at making organ donation acceptable for medical practitioners and the 'public' alike. By showing how organ donation is made to work, practiced, and experienced at institutional levels, this

chapter makes visible wider difficulties around increasing donation rates, which have been largely ignored in conceptualisations of the 'BME' donor 'problem'.

Part 1. Making donation work in local settings

> I don't know if I should say this or not but donation's very much like a postcode lottery. You know, you go to a certain hospital you get cancer treatment, you go to another one you wouldn't. Donation, and offering donation in *my* opinion is the same because, yes required referral is in a lot of places but I've talked about organ donation...organisational culture. If you end up in one hospital you're less likely to get asked [to donate] than if you end up in another one. (Stephanie, donation nurse with team 1)

Encountering Hillview

On my way up the steep hills towards Hillview hospital for the first time, I was struck by the ethnic diversity of the city. Most of the shops I passed could be characterised as 'Asian': from Indian and Islamic clothes shops, to Islamic superstores, Indian takeaways, sweet shops and delicatessens, to the travel agents specialising in 'Hajj' packages. Upon arriving at Hillview, I was taken by the grand quality of the building. In contrast to the rabbit-warren corridors of many other hospitals I had visited, Hillview was filled with light. This gave a sense of space and calm, rather than the confusion I often felt upon entering other hospitals for the first time. Walking through the ICU, I realised how different it was to the Paediatric Intensive Care Unit (PICU) at Lakeland; where I had already spent some time. In sharp contrast to the modernity of Lakeland's PICU – all shiny new machines and state-of-the-art equipment, with large gaps between each bed – Hillview's ICU looked archaic. Beds were closely spaced along each wall, and everything seemed bunched together. The unit was full and claustrophobically warm. Faded green curtains were drawn around a few beds and

there was one central cubicle, where an elderly man of 'Asian' appearance was half-sitting, half lying in an easy chair. What sounded like Islamic chanting was playing out of his hi-fi, as he stared, glazed-eyed, into space. Most of the patients looked elderly: shrivelled, frail, and overwhelmed in their large beds with sheets draped over them, wires and tubes connected at all ends. In the middle of the ward was the nurses' station-come-reception. Files were piled higgledy piggledy, and staff stood chattering about anything from having a fish and chip lunch to the need for more fire safety-belts. This Intensive Care ward was less daunting to me than Lakeland's. Partly because the mess and out-of-date decor made it seem somehow more human, despite the mass of machinery. On the other hand, the closeness of the beds, the clutter and the generally cramped space made it feel chaotic and claustrophobic. The lack of privacy was reflected in the staff coffee room, which seemed to be the only place specifically for staff to go, unless they had the luxury of their own office, like John, Hillview's Clinical Donor Champion and consultant Intensivist.

DCD at Hillview: translating national recommendations in local contexts

The ODT's recommendations aimed to increase the UK's deceased organ donation rates by 50% by 2013 by making organ donation a "usual not unusual" (2008: 9) event in hospitals. To reach this target, these recommendations were to be implemented in hospital Trusts by embedded donation nurses and a Clinical Donor Champion: tasked with making these changes at local levels, with an eye on working "to a UK wide perspective" (ODT, 2008: 6). One way that this was to be achieved at Hillview was by introducing a donation after cardiac death (DCD) policy. As outlined in the previous chapter, DCD has yet to become commonplace in all UK hospitals, mainly because of the ethical and legal questions which persist around its practice. These include the fact that a patient may need to be given medications to preserve their organs for donation *before* their family have provided their consent for donation to take place (ICS/BTS, 2010).

Emily, the newly embedded donation nurse at Hillview had the initial job of implementing a DCD programme within the Trust, to begin the process of increasing its donor rates. The hospital not only had a reputation for rarely referring potential donors to the donation nurse team[55], but also serves a large 'South Asian' (mainly of 'Pakistani-Muslim' heritage) patient population. It was thus pointed out as a key site for tackling the 'issue' of low 'BME' organ donation within the area the donation nurse team 2 covered; which encompassed a number of towns and cities with high minority ethnic populations. In implementing DCD at Hillview, Emily was also working towards ensuring that the ODT's recommendations around making donation "a usual not unusual event" with "discussions about donation [...] part of all end of life care" (ODT, 2008: 36), *happened*, within the context of a Trust with poor rates of donation after brain death (DBD)[56].

Emily's job to increase Hillview's donation rates was variously difficult. This was not only because of the general ethical issues around DCD (described in the previous chapter), but also due to the presence of a large 'Asian' patient population – with her knowledge of their historically high refusal rates – and the 'culture' of donation on the ICU, which she acknowledged as being initially difficult to engage with. With the help of John, an ICU consultant and the Trust's Clinical Donor Champion – responsible for collaborating with Emily to increase Hillview's donor rates – Emily began work on creating a DCD programme at Hillview. This was seen as a way of tackling the hospital's general donation problem, and specifically offering an opportunity to increase their even poorer rate of 'Asian' organ

---

[55] Prior to Emily's arrival, Hillview had had only one organ donor in eighteen months.

[56] One factor pointed to for the poor rate of DBD referrals at the Trust was that many patients with brain injuries, i.e. suspected to become brain stem dead, were often referred to the large neurological centre in a nearby city. This meant that the potential for DBD at Hillview was restricted, because the ICU had limited admittances of potentially brain dead patients.

donation[57]. In addition, kidneys from DCD donors are often locally allocated, since organs have a decreased time limit for being outside the body compared with those from a brain dead donor (NHSBT, 2010). Since a large percentage of Hillview's kidney transplant list was made up of patients from 'South Asian' backgrounds, the DCD programme therefore also offered the potential to decrease its own transplant waiting lists.

Emily was thus tasked with implementing an ethically challenging practice in the context of an ICU initially perceived as less than friendly towards donation, as she explained:

> Historically, the unit had always had, I think it's fair to say, a very poor donation rate. And the fact that there'd been one donor...since 2008 I think speaks for itself. So a number of problems here: no DCD programme, a large percentage of the local population are from South Asian community, and er fairly high refusal rate from this community. It had been the last six years we'd been trying to get a DCD programme in here. Hit a brick wall all the time. Not me personally, sort of like with the team. Different individuals have tried and every time: brick wall, brick wall. Consultants were all concerned about the legal and ethical things around it [DCD]. They seemed to believe that if they made a decision about withdrawing treatment then went forward with organ donation they would have a criminal prosecution against them. So it's been a long drawn-out thing, but as from a few months ago, we have finally got the DCD programme up and running.
> (Emily, donation nurse at Hillview)

Emily's work therefore involved balancing the general need to increase donor rates with producing a DCD policy that not only addressed national and ethical issues around DCD practice, but also the specific contingencies at Hillview. These consisted of: an ICU team

---

[57] Everyone I spoke to at Hillview was unable to recall ever having had an 'Asian' organ donor. I did not have access to records to confirm this.

152

little used to donation in the context of its previously poor donation rates; the understanding that donation was more difficult at 'Hillview' because of its large 'Asian' patient population; and the past experience of her colleagues failing to implement the policy because of the consultants' fears over litigation. In this way, a crucial part of making this practice happen would be in the development of a DCD protocol, to provide practical certainty (Hogle, 2009) – what is to be done at each stage of DCD and by whom – to this somewhat controversial practice. Here, I understand protocols or procedures as: "a set of instructions (...) informing the user what to do in a specified situation" (Berg, 1998: 227). In other words, the DCD protocol would designate each task, and who is responsible for carrying these out, at each stage in the donation trajectory.

In bringing about DCD, Emily was required to negotiate the requirements of different actors at different levels. I use the term 'negotiate' in this chapter to describe the process of making something work in practice, such as the DCD policy, by adjusting it around the needs of differently involved actors – such as ICU consultants and nurses, and the hospital itself (Hogle, 1995). As a local institution, Hillview stands in for both the concerns expressed around DCD at a macro-level (existing standards surrounding organ donation and the documented legal and ethical difficulties), and for the everyday, micro-level, concerns (Vaughan, 1999) around donation in practice, such as the fear that a decision to withdraw care and then refer a patient for organ donation may result in prosecution. In this way, to fulfil her role and effect any sort of change, Emily had to balance wider national, legal, and ethical concerns with an understanding of Hillview's historic 'culture' around donation, and the fears of its staff. Drawing from Star and Lampland (2009: 14), implementing and locally standardising a DCD process can thus be conceived as a *historical* process, entwined to existing structures and events at Hillview.

With the collaboration of John – who spent much time persuading Hillview's main ICU consultants to agree to the initial development of a DCD policy – Emily finally managed to launch the DCD programme in 2010, one year after being assigned to the hospital. Reaching this stage involved Emily and John facilitating lengthy discussions with ICU and A&E staff, hospital management, and operating theatre staff, to ensure that everyone was on board with the legal, ethical, and practical implications of implementing such a programme. As John explained, the ODTs recommendations came as the push to finally put DCD in place at the Trust:

> The DCD programme was [...] challenging in terms of the ethical and legal issues associated with it, and we've been reluctant here to embark upon this kind of programme, mainly for those sorts of reasons. So, since the new sort of taskforce recommendations had started to make the muddy waters a little bit clearer, people were more...cooperative in signing up to the programme. So initially it took right until the beginning of this year to convince the 6 main Intensive Care consultants to agree to set up this programme, and the feeling was we couldn't really set it up without everybody's agreement. So having got the agreement of the 6 main Intensivists, we then had to seek support from the rest of the team: all the nursing staff, both here and theatres, and the Emergency department, and the consultants in the Emergency department. And we've talked to an awful lot of people in the last six months, and we got to the point where we'd got a fairly good pathway defined and we're having a debriefing about the first DCD patient later on this week and I guess well, part of that is to re-examine that pathway and make sure that we're all happy in how its set out. (John, consultant intensivist and Clinical Donor Champion at Hillview)

The work to implement a DCD programme at Hillview and increase its almost non-existent organ donor rates, was therefore a drawn-out process. This began with the authority of the organ donor taskforce's recommendations and was made 'real' by Emily and John bringing together the interests of diverse people (donation nurse teams, consultants, nurses, Hillview's patient population); processes (withdrawal of care, diagnosing death etc); and 'worlds' (management, surgery, intensive and emergency medicine), necessary to get the policy into place (Hogle, 2009; Miller and Bowker, 2009: 151). This process – drawing on the actor network approach[58] (e.g. Latour, 1987; 2005: 108; Callon, 1986) – I interpret as one of *translation*. This refers to the alignment of people, places, processes, and things – brought together to make DCD happen. In this sense, the ODT's recommendations are transformed at local levels by defining and entwining the roles of those, such as ICU nurses and consultants, who were to be involved in making new donation practices happen.

Over one year after Emily started at Hillview, the DCD programme had begun; with a localised Trust policy document – detailing the stages of the DCD pathway – acting as a locally-specific procedure for the process. Emily was tasked with training the ICU and A&E nurses in DCD, with John taking the mantle for teaching the consultants. Training the ICU nurses involved Emily taking them through the donation procedures and highlighting their role along the way. The training sessions, one of which I observed, took place in Emily's office, which doubled up as the ICU's seminar room. At the session a few chairs were clustered around the table, with nurses dropping in, one-by-one, eventually making up a group of seven. Most are quiet, slumped in their chairs, as Emily takes them through the various stages of DCD and their involvement:

> Emily presents Hillview's new DCD protocol on PowerPoint slides. She goes
>
> through the background as to why the new practice is important – in the context

---

[58] See chapter 1 and 2 for an explanation of this approach in research.

of decreasing rates of brain dead donors and the UK's need to increase its overall donor numbers – before discussing each stage of the DCD procedure and who would be involved. Emily emphasises the ownership of Hillview's new policy for her audience, discussing how decisions would be made as events unfolded. She asks the nurses whether they thought a dying patient should be maintained with therapy if a relative was taking too long to arrive at the hospital[59]. One nurse replies, 'I wouldn't', to which Emily replies 'You can only decide on the day'. She then brings up a slide with bold italic writing stating: ***Consent can be revoked at any time***. She further explains: 'that is until they go through the theatre door' – referring to the fact that families can withdraw their consent for donation right up until the first incision has been made in the operating theatre. The nurses regularly interject with their concerns about what might happen in practice, with one piping up that she had images of family members chasing their relative down the hospital corridor as they were taken into theatre. In response, Emily reassures them: 'I know what you're thinking. That's what I thought before I did it for the first time, but it's not like that at all.' A strange discussion then ensues about the logistics of getting someone who *looks* dead – who *is* dead – out of ICU and into the operating theatre without attracting too much attention from members of the public. Emily discusses the likely tactics: 'We'll have someone waiting by the lift and to clear the corridors. We may even cover their face with an oxygen mask for sanity reasons, so that you don't get people stopping you and asking what you're doing with *that* patient.'

(Fieldnotes, October 2010)

---

[59] This relates to the fact that, to be suitable for DCD, a potential donor may need to be 'treated' with certain medical therapies in a certain time, to preserve the quality of their organs. This may be done before a family have consented to donate – leading to questions about the legal and ethical implications of such practice, as discussed in chapter 3.

This example shows the tensions for Emily in putting new donation processes into practice; unfamiliar to staff with little experience of donation generally. From a unit who previously had just one donor in eighteen months, to six in one year after Emily's arrival, we see how the dramatic shift in donation rates through the "culture change" (Griffiths *et al.*, 2009: 1459) in practice, is difficult for staff to initially engage with. We witness Emily working through the possible contingencies of DCD with the nursing staff, whose personal worries about the practice overlap with wider ethical, legal, medical, and public concerns. These include how decisions about patients, and whether to clinically manage them as donors, will need to be made as events occur, such as when a family might not always be present to give timely consent for donation. They also encompass the constant potential of a family withdrawing consent, with the nurses relating this to their own ideas about the trauma for a family in their relative being taken to theatre so quickly after death (which usually happens within 10 minutes). Emily dissipates these worries by conveying her own practical experience of the process: "it's not like that at all", grounding the nurses projected concerns in the context of practice, where such fears have not been upheld. She also manages perceptions of what *she* imagines of the public reaction to a dead body being taken into theatre. Here she mediates between public perceptions and professional concerns by proposing practicalities for resolving these, such as making a dead body appear alive by employing the symbolism of an oxygen mask (Hadders, 2007). In so doing, she pre-empts and neutralises any future problems, such as a member of the public delaying the donor transfer.

By working through the possible problems which might arise in the practice of DCD, Emily not only manages staff (and imagined public) concerns over the process but also offers nurses the tools to be able to work through these contingencies in practice, so that they can take ownership of the process. Emily thus uses this training session to transform, align, and

neutralise any tensions in the DCD policy by giving life to procedure: placing it in the context of the nurses' everyday, practical concerns (Miller and Bowker, 2009). In so doing she creates a space of possibility (Singleton, 2005), where the procedures are hypothesised as working with, rather than being constrained by, everyday contingencies. In working through the various practices of DCD, Emily also normalises them. She makes them *acceptable* for medical practitioners, families, and the public, to fulfil her task of "realising every opportunity for donation" (ODT, 2008: 14). In this way, we see how the donation nurse acts as a vital agent for mobilising the interests of the ODT in practice. This they do by mediating between, and translating and aligning the ODT's interests with the concerns of local institutions, their staff, and the public.

When examined at institutional levels then, we see how the task to achieve more 'BME' organ donors is a hugely complex process. It goes far beyond promoting the message of donation to 'BME' 'communities' – a notion which underpins current research (e.g. Davis and Randhawa, 2004; Morgan *et al.*, 2008). Insights into how the ODT's recommendations to increase donor rates get interpreted at local, institutional levels cannot be seen as separate from the 'BME' organ donor 'problem', with the knowledge that a family's *access* to organ donation in the first place depends upon the ability of the donation nurse (with the collaboration of the Clinical Donor Champions) to bring about change. The ODT's recommendations for change thus shape practice, while always being embedded in the context of local peculiarities, organisational compositions, collective processes of negotiations between diversely involved constituents, and the political and historical environment surrounding organ donation (Timmermans and Berg, 1997, 2003; Hogle, 2009; Star and Lampland, 2009; Miller and Bowker, 2009). These complexities subsequently impact upon the success or otherwise of the changes, and thus the ability of 'BME' 'communities' to donate more organs.

Part 2. Navigating professional relationships: making donation happen

Even when new donation policies, like DCD, are formally implemented, there is no guarantee for the donation nurse that ICU staff will adhere to these procedures. As Miller and Bowker (2009) remind us – in their research on the construction of a standard computer package to enable data sharing between ecological scientists – standards "assume specific configurations, actors, tools and data" (2009: 152). In other words, they are constructed around assumptions of stable occurrences: people and technology coming together to produce a desirable outcome (Berg, 1998; Timmermans and Berg, 2003). When put into practice, however, the contingencies of complex donation situations means that experiences may look very different from their ideal. This ideal is encapsulated in the ODT's recommendations and in procedural pathways, which intend to make donation practice, and thus donation outcomes, certain. Drawing from Latour (1987; 1988), "technical objects" such as guidelines, procedures etc, can only be seen as 'real' through the actors (human and non-human) who align themselves with its purpose (cited in Miller and Bowker, 2009: 151). Organ donation procedures are thus only as good as the staff who enact this material practice trajectory in moving from the potential for organ donation to the act of organ procurement itself. In the examples below this point will be highlighted by looking at Emily's, and other donation nurses', difficulties with getting staff to practice new procedures around donation.

Donation practices and clinical hierarchies

In the case of Hillview's new DCD policy, one configuration upon which the whole process hinges is in the act of a potential donor being referred, by a member of the ICU staff[60], to the on-call donation nurse once the decision has been made to withdraw treatment. The

---

[60] The policy does not specify *who* can refer. I came to learn that doctors and nurses were each as likely as the other to implement a potential donor referral.

DCD policy outlines the best practice process of referring *all* potential donors to the donation team. However, it also includes a clause which states that the ultimate decision on the appropriateness of referral lies with the treating ICU or A&E consultant. As detailed in the previous chapter, required referral, or minimum notification criteria, whilst not specifically named in Hillview's DCD policy, was outlined by the OTD as one of the key recommendations to increasing donor rates. Where this policy has been formally brought into place in local Trusts, dramatic increases have been seen in both potential donor referrals and donation rates themselves (e.g. Bleakley, 2010). For Emily, the DCD policy at Hillview incorporated the requirements for the automatic referral of potential donors. Whilst no specific policy for DBD was yet in place, her ongoing donation training for the ICU staff addressed this need, in order to optimise both types of organ donors at the Trust.

For Hillview's ICU, Emily's everyday presence on the ward represented a significant change for the conventional infrastructure of the department. In the past, ICU teams would generally only encounter donation nurses after inviting them into the department with a potential donor referral. With the recent move to their embedded roles, donation nurses can now be present from the time a patient arrives on the ward; with staff expected to make timely referrals of potential donors, and collaborate with the donation nurse in planning the donation request to the family. Whilst having noticeable impact on donor rates, this change also means that donation nurses have to carefully manage their relations with hospital staff, whose collaboration is vital in making these changes work.

Over time, Emily made much progress in gaining the trust of Hillview's ICU staff. Upon her initial entry into this seemingly unfriendly donation environment she had played the part of Schutz's stranger (1944, see chapter 2): gradually learning and integrating to Hillview's local ('cultural') ways of working – thus making these ways available for my analysis. Later on, she expressed her adaptation to this setting and the people within it, feeling embraced as an

'insider'. Crucially, in their collaboration around the DCD policy, Emily and John had developed a good working relationship[61] and had begun to take this outside of the immediate setting of the ICU, by working together on localised donation promotions: writing press releases, and appearing in local newspapers and on the regional television news. However, despite this progress, I also heard Emily's concerns about the changes she was bringing about and how this affected her relationship with staff. She had worked hard at training staff in the re-organised donation procedures through formal training sessions (both for DCD and DBD) and in her informal interactions with them. This was to ensure the unit alerted her or her colleagues to any potential donors, and that the practice of collaborative requesting (see chapter 3) – whereby donation requests are planned in advance with clinical staff – became a usual way of working.

Despite her insistence that most of the staff were on board with the new procedures, Emily recounted a frustrating experience with one of the consultants, forcing her to reflect on the relational implications of newly imposed donation practices. Arriving on the unit one morning, whilst walking through the ward to fetch her morning cup of coffee, Emily was made aware of a potentially brain dead patient by a staff nurse she was familiar with. To her surprise, however, the nurse prevents her from accessing the potential donor, conveying this through the message of the treating consultant, Peter:

> He [nurse] was like standing by the bed and he said: 'Don't you come near here.' And, it was this gentleman who they were going to test that day [for brain stem death], and he said that Peter [the consultant] had said 'I don't want anybody talking to Emily about this patient until I've done the (amused voice) test'. And it was like *really* weird. (Emily, Hillview's donation nurse)

---

[61] The ODT argues that the "collaboration between DTC's [donation nurses] and Trust donation champions is key to the success" of its recommendations (2008: 45).

Emily expresses her surprise at the consultant's actions, as he is both a regular doctor on the unit and someone she knows well. The staff nurse, unable to give her an explanation for the consultant's blockade, later approaches her with an update, informing her that Peter had gone ahead with the donation request on his own:

> He [nurse] came up to me and said: 'He's [Peter] just made a pig's ear of that interview [with the family about donation], and you nearly lost the whole thing.' He said 'I turned it round.' Peter wouldn't let me talk to them about donation, he brought it up himself, and I say, didn't do it particularly well and admitted to me afterwards that he hadn't done it particularly well as well. So it was the staff nurse who said: 'hang on, I think we've got somebody here who can give you more information, who can sit down and talk you through it.' And the staff nurse was brilliant 'cause I had to come in. (Emily, donation nurse at Hillview)

Emily perceives her ability to influence the consultant's actions here as frustratingly limited: her only ally in this situation being the staff nurse, who, despite relaying the consultant's authority, manages to claw back his supposedly disastrous donation request to allow Emily eventual access to the family. This contradicts what she had previously been discussing in her interview about feeling accepted on the unit. With this story she tells a different tale: relating the perception that she had her authority undermined by the consultant's ability to navigate – find his own way through – the now-usual procedure of collaboratively working with a donation nurse once a patient is predicted to be brain stem dead.

This example illustrates, to employ Star and Lampland's term, the "slippage" between the ODT's recommendations and their "realization in action" (2009: 15). In other words, by the consultant refusing to allow Emily's involvement in a potential donor case, the procedure for collaborative working breaks down in practice. The *work* of organ donation, specifically

here the task of donor referral from consultant to donation nurse[62], is thus a process of navigation – of constructing an individual course in the space of everyday ICU processes (Struhkamp *et al.,* 2009). On the one hand, we can understand Emily's experience of the consultant's flouting of the 'rules' as his attempt to make the procedures of donation referral and request work for him, his patient, and their family (Timmermans and Berg, 2003). On the other side, we can pose the question of *who* has the authority to navigate donation procedures, and how this relates to wider issues of power relations in medical domains.

In its recommendations, the ODT (2008: 42) conveys that there should be a "close and defined collaboration between DTC's [donation nurses], clinical staff and Trust donor champions". However, in practice, the donation nurses sometimes struggled to effect collaboration with ICU staff, especially consultants. In Emily's example, we see how her attempts to bring about a way of working, which would see her being involved with a potential donor early on, are obstructed by the consultant, who, in Emily's view, chooses to conduct the procedure in his own way. Here, the consultant's actions also inhibit Emily's ability to do her job properly. Her narrative conveys the tension involved in trying to enforce the very procedures she has helped to implement, with the consultant's ability to act as authoritative gatekeeper to a potential donor.

Megan Hall, one of the newer donation nurses in Emily's regional donation nurse team, conveyed a related experience in her training of ICU consultants in potential donor referral. For Megan, a key point of her training is in the emphasis that decisions of potential donor suitability, especially in the case of donation after cardiac death, are *not* for the doctors to make:

---

[62] This process can also be understood as the act of staff handing over ownership of a patient to a donation nurse; shifting their ontological status from patient to potential donor as they do so (e.g. see Hadders, 2007 for a similar understanding of the switch from dead patient to corpse through post-mortem practices).

When I maybe do some sessions with consultants and give examples of patients that they haven't asked for retrieval, we try and highlight that they are missing potential donors from the cardiac death. Because they [consultants] don't miss them from the brain death really, it's from the cardiac death. And we say to the consultants that we don't want them to assess a patient's suitability for donation, that should be the transplant surgeon's decision. And some struggle to give that up to the transplant surgeons. But what we try and do is highlight to them, you know, in May for example, you didn't refer Mrs Smith. And say: 'You can't absolutely say whether they definitely would have been a donor or not, but you can say it was likely that she would have been'. And the consultants will maybe respond with: 'Well I didn't because of kidney failure.' And you say 'that doesn't absolutely exclude them'. And I've had a consultant say to me: 'I'll refer people like that over my dead body.' So what can you say to that?! [laughs] 'I'll refer patients like that over my dead body.' [...] Who *he* thinks wouldn't be medically suitable. Erm...[little laugh] and the only way you can change that is by making it a policy that is a required element of their job to refer. And that will come, but it just takes time to get that in. (Megan, donation nurse with team 2)

In this example, Megan gives examples from practice – relating to missed donation opportunities by virtue of the non-referral of potential DCD donors by consultants – to show how consultants' decisions have the potential to affect organ donor rates. She negotiates their concerns around handing over responsibility for decisions on donor suitability to the transplant surgeon by highlighting real-life incidents, where their decisions to *not* refer a patient were clinically incorrect. In so doing, she attempts to bring their practice into line with recommended procedure around donation referral.

I draw upon Foucault's (2003) conception of biopolitics to understand Megan's interaction with the consultants here. Biopolitics refers to how governments have power (which Foucault refers to as 'biopower') to intervene in people's lives at the level of populations. This is done through "rational" management using, for example the "instruments" of demography (Macey, 2009: 189) and public health to control birth rates, disease processes, and thus mortality rates in the general population. In this way, I argue that the ODT's intervention to increase organ donor rates is a biopolitical one, in that the recommendations operate with the intention of affecting transplant rates, and thus the lives (and mortality rates) of patients waiting for transplant. As discussed above, for this biopolitical intervention to take effect, the donation nurses (with the help of Clinical Donor Champions) are responsible for implementing new donation procedures to ensure "that appropriate policies [are] in place, that any local obstacles [are] identified and resolved and that all necessary steps [are] in place to realise every opportunity for donation" (ODT, 2008: 14). To do this, donation nurses mobilise these policies into action. As we saw with Megan, this was done by imparting the importance of procedure to consultants, by showing how their decisions have the potential to affect donor rates and thus the bodies of potential donors and transplant recipients. In this way, the donation nurses act as regulators of staff actions, and the agents of (biopolitical) governance around donation. In highlighting the importance of donation practices, such as required referral, to the consultants, and the implications of *not* carrying them out, Megan makes them accountable for their own actions. In so doing, she also creates the possibility for staff to self-regulate their practices around the new norms of procedure; which she, herself, produces (Foucault, 1977).

In this example, however, Megan also conveys how her attempts to change consultants' practice around DCD referral are undermined with the rebuttal of one consultant – "I'll refer people like that over my dead body" – to her assertion that certain conditions, such as

kidney disease, do not necessarily rule out donation. Megan expresses how her only options for enforcing such procedures, in light of the consultant's remark, is to bring in a referral policy. This she could utilise as a "strategic resource" (Castel, 2009): giving formalised authority to her training, and weight to her status as the main actor responsible for delivering the ODT's recommendations. Here then, as with Emily, we also see how the governing role of the donation nurse gets undermined in practice, with hospital staff refusing to fulfil their newly designated responsibilities around donation.

Donation nurses' frustrations with the ability of ICU staff, particularly consultants, to get round the new organisation of donation practice were not limited to potential donor referral. Their stories consistently drew upon the problem of staff not fulfilling their responsibilities properly. These included refusals to call the coroner, asking families at the "wrong time", or not asking them at all, and making decisions about the unsuitability of a patient for organ donation without first consulting a donation nurse. Donation nurses therefore remain limited in being able to enforce the very standards they have worked at implementing, especially since the ODT's recommendations were not brought in as uniform, national guidelines.

As Timmermans and Berg (1997) argue, although allowing for legitimacy in the actions of professionals, protocols – or, in our case, recommendations for practice – do not fundamentally change the world they act on because they "feed off existing infrastructures and power relationships" (1997: 295). In donation contexts, this means that despite the donation nurses having responsibility to effect change, in practice they do not always have the authority to make this happen. This was evidenced by the way in which the Clinical Donor Champions for organ donation, usually ICU/A&E consultants, were seen as key figures for bringing authority to the ODT's recommendations. As discussed above, at Hillview, John was the one who had brought about the possibility of DCD by his ability to get the necessary

hospital authorities – managers and ICU consultants – to agree to the policy. However, it was the donation nurses who often did most of the work to bring these changes into being. For example, during the donation committee meetings at Lakeland it became increasingly obvious that nearly all of the tasks – such as implementing a required referral policy and creating staff manuals for the organ donation pathway – for changing donation practice at the Trust were delegated to the two embedded donation nurses, Rachel and Jennie. Despite other committee members, including Sarah, Lakeland's Clinical Donor Champion, acknowledging the enormity of their task, Jennie and Rachel were offered little practical support, beyond administrative help, to achieve the Trust's goals.

Drawing from Timmermans and Berg's argument above, I approach these disparities between the responsibility designated to donation nurses and their struggle to implement change in practice, with insights into how power is understood to work. Power is a tricky concept, which, in the context of clinical decision-making, is traditionally posed as top-down: conventionally discussed around the assumption that doctors wield formal power while nurses posses little (Laschinger and Havens, 1997; Coombs, 2007). This is manifested in conceptualisations of nursing as 'invisible work' and 'women's work' (Timmermans *et al.*, 1998; Bolton, 2005): a set-up which essentialises and reifies notions of gender, and the patriarchal organisation of society (Turner, 1995; Wall, 2010). Such understandings, however, simplify the concept of power – as something which exists within an immoveable hierarchy (Di Palma, 2004), rather than that which can be traced in everyday interactions.

For Foucault, power should be analysed at micro-levels, tracing its macro forms to institutions[63], relations, and their strategic operations and effects (1980). Rather than simply conceive of the traditionally gendered boundaries between doctors and nurses, and the

---

[63] Foucault understands 'institutions' as "applied to every kind of more or less constrained, learned behaviour" (1980: 187).

imposed domination of the former – which is one way in which we could read Emily and Megan's narratives – Foucault offers a conception of power as that which offers potential. Instead of just inhibiting action, constraint also conversely creates opportunity (Foucault, 1978; 1980; De Certeau, 1984). Therefore, for the consultant in Emily's story, the newly taught relations around donation referral provoke the possibility of other forms of practice, evidenced in his subversion of these relations by refusing Emily access to a potential donor.

In this way, the donation nurses' localised construction of donation policy and guidelines, whilst "strategically organising" "a set of relations" (Law, 1991: 172) around donation, have differential power effects in practice. Despite the "legitimising function" (Shore and Wright, 2005: 9) of the ODT's recommendations, everyday interactions around their implementation evidence the fact that policies function as contested sites of negotiation (Shore and Wright, 2005: 15). Here, hierarchies in the organisation of medical work, whilst not taken for granted, obviously background Emily and Megan's frustration with their inability to affect the actions of ICU consultants, and, ultimately affect organ donation rates. For the consultants, their power lies in the potential for them to make decisions about the fate of a dead or dying patient, with their responsibility to refer potential donors to the donation nurse team. This, as we see, can be given or withheld (Law, 1991: 178) in their position as a patient's gatekeeper. Moreover, this has bearing upon the ability of the donation nurse to fulfil the task laid down by the ODT. In this way, Law (1991) argues that Foucault's conception of power fails to conceive of its differential distribution and consequences for diverse constituents. Thus, the institution of organisational changes to affect donor rates has different effects for ICU doctors, and donation nurses, along with ('BME') 'potential donors' and their families – whose status as such is dependent upon the negotiated work of the donation nurse, and the gatekeeping practices of ICU staff.

However, this remains a still limited view of the relations of power in organ donation. As Emily's story above tells us, and grapples back power as it does so, the consultant who restricted her access to a potential donor, did not do the donation request "particularly well", and it was the staff nurse who was left to clean up the mess[64]. Coombs' (2007) study on decision-making in Intensive Care evidences how, because of the difficulties for nurses in influencing clinical decision-making, they develop subversive strategies to affect decisions and develop their own professional agenda, with one participant stating:

> You need to play games with the managers and the doctors [...]. You don't do anything different, just differently. You need to be more proactive and think how to respond to the different personalities. (Coombs 2007: 132)

This ability to "play games" became essential for the donation nurses in their attempts to influence donation practice, and ultimately increase donation rates, as I go on to show below.

Re-appropriating power in donation practice

Returning to Emily's story of the consultant, Peter, who blocked her way to a potential donor, Emily subsequently reflected on his actions as symptomatic of his general concerns over the workability of collaborative practice:

> You've probably heard some of my colleagues talk about Verble and Worth[65]. They're these two American women who talk about this long contact model for donation, which involves us getting involved with families before their relative has died. And like Peter, he's been on a Verble and Worth workshop, and he has

---

[64] This I metaphorically relate to the notion of nursing as 'dirty work': nurses mop up the detritus of medicine both metaphorically and in practice (Bolton, 2005).

[65] See chapter 3. Verble and Worth are the American company who train all donation nurses in the practice of gaining consent for organ donation, and how to collaboratively work with hospital staff to achieve this.

some concerns I think about this long contact. And he's not the only person cause I, personally, have concerns as well about it, in the fact that long contact starts, you know, a good 48, 72 hours before somebody becomes brain stem dead. And then you're making the family [said in disbelieving tone] tea and all this lot and like sitting and talking to them, and he [Peter] said: 'And at what point do you reveal who you really are?' So I said, 'Well yeah, there is that.' And I, you know, I am uncomfortable with it, Jessie. People say it does work, but Peter's not convinced that collaborative requesting works. And he said: 'John's always telling us that we need to get you lot [donation nurses] involved, but the research doesn't back up that collaborative requesting makes any difference'. So I said: 'Fair comment', I said, 'but what [it] does show is that if you have a planned approach with you and me, and we sit down and say what we're going to say and how we're going to say it [to the family], then that does work'. But I think unfortunately there's been a couple of cases recently where our team have been called too early, and I think that's where Peter has sort of like had his fingers burned a little bit, so he was very much: right, you know, I want this very black and white. I want brain stem death, there, done. Then you can go and talk to the family. (Emily, donation nurse at Hillview)

Emily here refers back to the story of how Peter prevented her initial involvement in a potential donor case, relating his actions to his general concerns with collaborative requesting/long contact. This approach – not part of the ODT's recommendations, yet which has been brought into practice as a result of the donation nurses' Verble and Worth training – involves the donation nurse being introduced to a family prior to brain stem death testing, or upon the decision of withdrawal of care, with the family not necessarily aware of their role until the donation request. In reflecting on Peter's unease with this approach, Emily

170

also takes the opportunity to divulge her own concerns about it. In so doing, she qualifies the consultant's right to his actions, which blocked her initial involvement in a donor case.

Emily relates how she managed this situation by conveying the collaborative approach to Peter in everyday terms: sitting down and having a conversation about how to approach a family at the time. In this way, she attempts to involve Peter as an active, influential, participant in the donation process by creating a relationship between his work, the training around collaborative requesting, and her role (Callon, 1986). Emily's attempt to work through the situation in this way also highlights her sensitivity to the implications of changes around donation practice on the autonomy of ICU practitioners. The experience demonstrates, for Emily, the limitations of new donation procedures in the context of specific people and situations. She adapts to the situation with Peter by drawing on her existing knowledge, experience, and resources (Dodier, 1998; Struhkamp *et al.,* 2009) to manage the traditionally-tricky relationship between ICU staff and donation nurses. Here, underlying clashes of interest, such as shifting from the imperative to treat to the imperative to manage a body for donation, have the potential to bubble over (Sharp, 2006).

In developing their new role as integrated within – rather than outside of – a healthcare team, donation nurses were acutely aware of the implications of such changes and the discomfort this caused for ICU staff. As Emily emphasises, integration is a slow process which requires careful navigation to accommodate new ways of working into existing ones:

> I've said to the new guys that have started doing the job at the other hospitals: 'you've got to give a period of time for a certain amount of trust to develop as well'. And I think, I said to my boss, 'I could have come in here [Hillview] like a bull in a china shop and said: *Right*, well we're gonna do this and we're gonna do that, and you *are* gonna have this DCD programme whether you like it or *not*.' But I knew that we wouldn't get anywhere with that because people would, you

know, some of my previous colleagues had tried to do that and got nowhere. So it's tiny tiny little steps, and just do things really slowly. (Emily, donation nurse at Hillview)

In order to negotiate the shift in conventions (Star, 1991; Star and Lampland, 2009) around donation, donation nurses required an awareness of the importance of subtly implementing change. In practice, this sometimes involved defying existing authorities, such as hospital managers and ICU consultants, to fulfil the requirements of their role. In the case of attaining donor referrals, donation nurses adopted a range of subversive tactics (De Certeau, 1984) to implement formalised or informal required referral practice within ICUs. This included: by-passing consultants (as gatekeepers to potential donors) altogether, by befriending others with access to patient information, such as ward clerks; ensuring clinicians were accountable for their decisions to *not* refer a potential donor by bringing in required referral forms to be completed for *all* deaths in ICU; and conveying to ICU and A&E nurses during donation training sessions that they are able to refer a potential donor, even when the treating consultant has refused to do so.

Ellie Harris, an outspoken donation nurse with a number of years experience, described how she countered the difficulties of implementing donation changes in her embedded Trust, by – as she goes on to describe – her "slightly devious" strategy for getting a minimum notification criteria (required referral) policy in place:

 I've sat with a consultant in one of the hospitals I used to deal with, and...it's a case possibly of being...erm, slightly devious [laughs] in that you're letting them have their say. Some people will just say 'I am *not* having the policy called that.' So simply: 'That's fine'. What you have to do is make sure what *we* [my emphasis] call minimum notification criteria is in that policy. After that they [consultants] can call it whatever they want. They can call it Mickey mouse, I

don't care. Some of them don't like it called required referral, some of them will call it automatic referral, some of them it's just the organ donation policy. I don't really care. So if you let them think that they've won, god love them, then you're more likely to [get the policy in]. If you try and sort of enforce that you'll just never get anywhere. [....] The two Trusts that went 'No, no, no. We're not having it', I sat down and wrote the policy with them. [...] I just sort of had to say [...] 'If you speak to us early at this point then I can give you an idea about suitability, and if you ring me at this point there's less delays for you and it's better for you to have this information before you talk to them'. 'Oh yeah, so it is'. In it goes! (Ellie, donation nurse for team 1)

In this example, Ellie understands the hospitals' turn-around to the idea of required referral through her practice of ensuring that managers and consultants see the policy as a direct result of their own decision making. This she does by agreeing with their disagreement with the policy in its standardised form (from the ODT's recommendations); making suggestions to rectify the situation; ensuring they play an active role in the localised policy construction; and impressing the benefits for staff if they were to adopt the new procedure. In this way she formulates the process of decision-making around a new policy as *belonging to* the hospital. Using a process of tactical consensus building, which positions the policy around the interests of the necessary Trust constituents, Ellie re-creates their interests to mirror her own (Latour, 1987). For Ellie, the knowledge that the eventual message is essentially the same as the official recommendation for required referral provides a sense of satisfaction. She has been able to implement policy without visibly undermining existing power structures. Here she employs 'face-work' (Goffman, 1955; 1967) to maintain an impression of cooperation and conformity to "patterns of action and representation" (Star, 1991: 28).

This enables her to overcome seemingly impenetrable hierarchies of decision-making in medical institutions.

In their work on medical protocols and the use of standards in local practice, Timmermans and Berg (1997) use examples of nurses negotiating authority, such as one hinting to a junior doctor about the treatment he might want to give an arresting drug-addict, to show that nurses' influence only largely extends to what they label as "repairwork" (p. 295). This continues, rather than deviates from, the hierarchical picture. For the donation nurses, however, their knowledge of hierarchies and the importance of maintaining these to get their job done are actively drawn on and exploited through subtle negotiations. Reflecting this, Hughes' early ethnography (1988) on nurse-doctor interactions in a casualty department showed how casualty nurses regularly led patient information gathering, with their assessments on pre-diagnosis paving the way for the doctors' treatment decisions. Despite this, many nurses distanced themselves from personal culpability for their assessments. This left medical dominance intact, whilst the nurses were able to skilfully influence and aid the doctors to make the 'right' decision and to get things done.

Conversely then, the conventions and constraints of medical hierarchies simultaneously provide openings for donation nurses to influence practice (Foucault, 1980). Despite being caught up in power relations, the donation nurses were able to manipulate clinical hierarchies to effect new norms around donation practice, whilst not directly effacing the authority of gatekeepers, like ICU consultants. This I also relate to Foucault's (1980) conception of how the relations of power – such as the existing hierarchies between doctors and (donation) nurses – are internalised, in the donation nurses' use of face-work to get round the tricky process of implementing change. In so doing, donation nurses employ self governance which keeps intact the "systems of relations" (Foucault, 1980: 194) traditionally established between nurses, doctors, ICU wards etc, as discussed above. Their ability to

174

make change without disrupting existing relations shows that they are acutely aware of the importance of these relations for their ultimate aim of increasing donor rates.

In looking at how new donation policies are brought into practice, the micro-politics of clinical life are made visible in relation to the biopolitics (macro-politics) of organ procurement. Medicine is seen here as a mass or multiple of parts (e.g. Mol, 2002), rather than simply unified around the cause of increasing ('BME') organ donation. Rather than the new roles and responsibilities around donation being something which naturally happen as an outcome of policy designations, these must be actively negotiated within local settings. In other words, policy both determines and is an outcome of practice (Timmermans and Berg, 2003). However, despite being invested with the responsibility to improve local (and thus national) donation rates, donation nurses did not necessarily have the immediate authority to do so. As such, they employed tactical work, which manipulated and even exploited existing roles and hierarchies, to achieve the biopolitical aims of the ODT. Increasing the chances of reaching the stage of donation consent is therefore dependent upon these negotiations – within which ('BME') potential donors, their families, and potential transplant recipients are thus also caught up.

In addition to their manipulations, donation nurses also illustrated times when they blatantly effaced authority. This was often recounted around cases which they were made aware of, yet were explicitly advised by ICU staff to *not* request donation from the patient's family. This was usually when the family were perceived as too upset or angry about the death of their relative, with the assumption that a donation request would exacerbate the situation. Rachel, the embedded donation nurse at Lakeland, recounted a time when ICU staff told her not to approach the family of a potential donor, which they justified by the family's anger at their relative's treatment being withdrawn. Despite this order Rachel went ahead and asked the family, eventually obtaining consent for donation from them. She

justified her actions by the fact that the patient was on the donor register, and that, in her words, the family "calmed down" once she had requested donation from them.

For the donation nurses, their belief in the benefit of donation for a family, coupled with the fact that, as one put it: it is their *job* to approach every potential donor family, means that they sometimes went directly against the concerns of healthcare staff. Stories such as Rachel's were often constructed as tales conveying the moral imperative of asking families for organ donation. This imperative, which I discussed in chapter 1, is publically presented in NHSBT's (2009) 'black' and 'South Asian' *Prove It* donation campaigns, with the plea for 'black' and 'South Asian' people to register as a donor for the sake of the 'community' with which they are supposed to identify. Here, I argue that this imperative for the public to donate can also be traced to the imperative for health professionals to *ask* for donation, as underpinned by the ODT's assertion of making donation a "usual" practice in end of life care (ODT, 2008: 9). As I demonstrated above, it is the donation nurses who are tasked with monitoring and enforcing this imperative. As I show in part 3, however, this has implications for the everyday work of Intensive Care staff, in how they balance this imperative with their own emotional struggles with the donation process.

Part 3. Donation and its discontents: medical and public concerns

Moving our lens wider, it is important to view the problems encountered by the donation nurse in implementing new donation procedures by looking at the discomfort caused by the upheaval in donation services, alongside the personal struggles of ICU staff with donation. The focus of the ODTs recommendations to optimise donation rates has led to concern for those involved in treating patients, since this aim is underpinned by the presumption that donation requests will become a norm at the end of a patient's life, as I show below.

The personal becomes public: donation concerns

The very nature of the donation nurses' work means they occupy a marginalised position in medicine. Solely working with dead or dying patients and their families means they are neither a member of the healthcare team; actively treating patients, nor an outsider to the medical institutions in which they are based. This marginality can also be understood as a product of the precarious place organ donation occupies in the public, and how these concerns get carried through to the medical domain. These sensitivities encompass not simply bio-ethical concerns around donation practice, as in the case of DCD, but also public fears that donation equates with a lack of treatment, as found in the research with 'BME' groups, outlined in chapter 1 (Davis and Randhawa, 2004; Alkhawari *et al.,* 2005; Morgan *et al.*, 2008). I was made aware of the existence of such concerns when helping out on the organ donation stall at Hillview's Open Day. One question asked repeatedly by members of the public concerned their desire to become an organ donor after their death, but their fear that signing up to the donor register meant that doctors would do less to save their life. These myths, however, do have a basis in historical experience: from Victorian grave-robbers (Richardson, 2000; 2006), to the UK organ retention scandal in the 1990s, and the 'Body Snatchers of New York' case, where tissue and bone was removed from the bodies of the dead in funeral homes, without the knowledge of relatives, by a bio-bank company in the US (Scheper-Hughes, 2006). Concerns over donation also perfused the narratives of ICU staff. This reflects research which acknowledges the process of requesting donation from recently bereaved families to be an enormously burdensome experience (Stoeckle, 1990; Featherstone, 1994).

With the increasing push to maximise donation rates, some ICU staff expressed their concern over how this would affect their everyday work, and their discomfort with the perceived pressure this might place on families. The struggles of the donation nurse to

enforce new donation procedures needs to seen from this wider perspective, which concerns the ethically sensitive and emotional dimension of organ donation. As John, Hillview's Clinical Donor Champion, explained when questioned about his role: "... [w]ell obviously I believe passionately in what we're doing is right...but at the same time [I'm] wary of being too keen and creating the wrong impression". I relayed my understanding of this to him as meaning he must balance the imperative of care with organ donation. His reply revealed his sensitivity to the ethical issues associated with donation:

> You don't want to be construed as body snatchers, and I guess that's the potential problems historically that's sort of been associated with initiatives in the past. So there's a complete separation between the clinical care and the organ donation side of things, in that the conflict of interest has been one of the priorities to solve and to reassure people that what we're doing is entirely appropriate. (John, ICU consultant and clinical donor champion at Hillview)

John here expresses his awareness of potential (mis)understandings around his involvement in organ donation. Rather than being viewed as working towards saving a life, he could be seen as taking a life away, for his own interests. Since these positions could be construed as conflicting, this leads him to carefully demonstrate the separation between them. In expressing his concerns with "creating the wrong impression", he also reveals his ambivalence about his position as both ICU consultant and Donor Champion. He takes responsibility for being both a doctor who both saves lives and champions the practice of organ donation by viewing this position from the perspectives of others, such as families and the public. In acknowledging this tension, John also suggests its management in practice (Goffman, 1969): he must do enough to affect donor rates on his unit, yet not go so far as to undermine his position as a doctor who treats acutely ill patients.

During my observation of Emily's training of Hillview's ICU nurses around the new DCD pathway, an incident occurred, which further highlights such tensions, and how these are managed by the donation nurse:

> As the training draws to a close, with Emily asking for questions and feedback, one nurse becomes quite opinionated, expressing her worries about the implications of a family member giving consent for donation if they are not aware of their relative's wishes. Emily reassures her, saying firmly that she wouldn't allow it, and would advise against a family member going ahead if they weren't comfortable with the idea. The same nurse, now sitting straight-backed, with a fairly aggressive stance, asserts that she 'just doesn't agree with it' [DCD]: 'It sounds like you're pushing it on a family. I've got a donor card but you get some families who are so distressed and everything and then to have a team approaching them. I just think it's wrong.' Emily, in response, tries to play, as she puts it, devil's advocate: 'well what about if that family also had a relative waiting for an organ?' The nurse thinks, but her body language remains unconvinced. Emily, smiling and maintaining her cool, tells her that everybody is entitled to their opinions, which is why it is important to talk about issues like this. (Fieldnotes, October 2010)

In this example, the nurse expresses her concerns about the ethics of asking a family to donate organs when they are unaware of their relative's position on donation. The nurse is worried that a family may feel put under pressure to say yes, as a result of being asked about donation in the first place. In response, Emily poses the scenario that the family might themselves have a relative waiting for transplant. This subtly implies that if they were *not* asked to donate by staff, then the potential for saving a life may be inhibited. Rather than

179

addressing the valid concern of the nurse, Emily re-imposes the moral order, by framing the importance of asking in terms of the (biopolitical) imperative to save more lives.

As we also see in this example, the concerned nurse initially positions her opinions as if they were distanced from her own identity around donation. She uses the disclaimer of her possession of a donor card to displace her concerns; aligning them with the interests of families, rather than her own. That ICU staff struggled with their own feelings about aspects of the donation process, yet often presented these feelings as if in the interests of families and the public, is telling. In light of the moral discourse around the imperative to donate organs after death, the worries of staff about organ donation must be carefully managed – presented as public – so that they are not seen to inhibit attempts to increase organ donation, and thus save lives. In this way, adopting a public face to express their worries about donation might be one of the few resources they have at their disposal to voice their concerns, whilst ensuring they are not accused of blocking the potential for increasing access to transplantation.

The emotional work of organ donation

These ambivalences also came out in the narratives of ICU staff and donation nurses, who conveyed the deeply emotional effect of being involved in donation. In the same way that staff managed the presentation of their concerns, even when claiming to be able to professionally distance themselves from the emotive practice of donation, stories recounted often revealed a different picture.

This was especially the case with David, a consultant on the Paediatric Intensive Care Unit (PICU) at Lakeland, where it was still common practice for staff to make the donation request. Throughout most of his interview, David conveyed a certain blasé breeziness about his donation experiences. Whilst acknowledging that some of his colleagues tend to

become, as he put it, "emotionally taxed by the whole issue", he told me that he did not find approaching families about donation "too taxing". However, when I asked him whether there were any donation experiences which stuck in his mind, the story he told impressed a very different image of the professional distancing he initially conveyed:

> D: I remember once being accused by a family of keeping their child alive *just* for organ donation. Which, erm...was quite an unpleasant experience. Erm, because it's not what we do.
>
> J: Can you tell me about that?
>
> D: So that would be, I think a child who had a catastrophic head injury and was admitted late one evening from another hospital. [coughs] And was assessed by the neurosurgeons and had scans which showed a catastrophic head injury that was non-survivable. And by this time it was around midnight or so. I was on call and my plan was to keep the child steady until the morning to do some brain-stem tests. Which we did, and the child was brain-stem dead, and I said that [to the family], you know, things were futile. We should stop [treatment] and consider organ donation if that was something that they wished. Erm, and they [family] said, 'well, why weren't we having this discussion last night?' And as I said, basically they accused me of keeping their child alive just so that we could take the organs off them, which wasn't really the case. (David, PICU consultant at Lakeland)

David's story here conveys his deep unease with how his medical decisions were challenged by the patient's family[66], with their implication that by delaying certain processes overnight

---

[66] In the background to this is also the constant threat for doctors of being legally challenged for malpractice by families, especially in cases where patients have died (see GMC, 2010).

he had acted in his own, rather than their child's, best interests. In his initial disclaimer of the unpleasantness of the experience, David conveys the lasting impact of the situation. His story reveals the facade behind his comments of not finding donation requests "too taxing", and highlights the distressing nature that donation work can pose for those involved. However, that he told this story *after* positioning himself as distanced from such emotions also illustrates the self-surveillance of practitioners involved in intensive care medicine and organ donation. Here, one's own emotional concerns must be deferred to the responsibility to care for patients/donors and their families (Hochschild, 1983; Gray, 2009)[67].

Dealing with child and adolescent donors was also highlighted as one of the more difficult aspects of the job, especially for those who had children themselves. One nurse, Elizabeth, who had worked for many years on Lakeland's PICU was alarmingly honest about her own struggles to stop herself from becoming emotionally distressed in front of grieving families. She recounted her embodied – here referring to how the world of donation is experienced and expressed *through* the body – tactic of how she digs her nails into the palm of her hand to preventing herself from crying in front of families. One story, however, illustrated her struggle with always being able to separate her private feelings from her work:

> I do find it quite hard because I think once you've had your own children and you work *here* [PICU] it does very subtly just shift your perspective on things. And you *do*, rather selfishly I suppose, you do compare what happens *here* with: Oh my God that could be my child. What would I do? You can't help it. And especially when I see little boys and girls the same age as my kids. There was a lad not long ago went for donation who had the same name as my son, he was the same age and lying there in the bed with the same colour hair, and I was just

---

[67] This point references the notion of 'emotional labour', developed by Hochschild (1983). This refers to the process of withholding one's personal feelings; so as to continue with an external impression to ensure that others remain (feeling) cared for.

like: No [Little laugh]. No. I *can't* do this one. [...] I couldn't. I mean it was nearly the end of my shift and we'd done all the sort of acute interventions to see what we could salvage, to see if we could make anything any better. And it became quite apparent that we couldn't [save his life]. So the family went off with the consultant for 'The talk' [to be told about the diagnosis] and I was handing over to the staff on the next shift and then I just said: 'That's it now, I have to walk away before this family come back after that discussion.' And so I said 'I want the day staff to handle it because they're gonna be here for the next 12 hours and I'm not.' So I sort of...handed everything over, wrote everything up, and didn't, didn't get involved with him. [Be]cause that was too hard. (Elizabeth, PICU nurse at Lakeland)

Elizabeth's story tells of the distress at the failure to save this little boy with the team's medical interventions (e.g. Delvecchio Good *et al.*, 2004), and her subsequent realisation that the case was too close to home for her to continue with. Reflecting on her awareness of her own emotional limits, she recounts consciously pulling away from the situation by deliberately leaving before the family came back from being told of their son's death. Since Elizabeth struggled to distance herself from the pain of bereaved families, she had developed tactics to self-manage and mask her emotions in the public domains of the PICU bedside and family interview room (Goffman, 1969). This involved suppressing her own feelings for the sake of families, pushing to the fore her professional membership as a nurse (Star, 1991).

The fact that organ donation requires dead patients, and necessarily involves families recently traumatised by the news of their relative's death makes it far from an easy practice. As one donation nurse speculated, for Intensive Care staff, whose usual role is to treat acutely ill patients, the presence of an organ donor implies a failure in their practice: they

183

have been unable to save a life. For the donation nurses, as demonstrated in Emily's training, they manage these emotions by re-asserting the importance (moral imperative) of asking families, in terms which impart the ultimate aim of organ donation: to save lives. In so doing, they make problematic the everyday concerns which staff have about donation and the recent organisational changes, ensuring, simultaneously, that the biopolitical project of increasing donor rates remains on course.

Moreover, as I showed in chapter 1, the 'BME' organ donor shortage is generally presented as a problem of families' and 'communities'' failure to accept donation as a 'culturally' acceptable act. In contrast, the stories here attest to the fact that donation is not only difficult for families (the 'public') but also for staff who facilitate the donation process. In tracing the personal struggles of health professionals involved in donation we see the precariousness of its practice, especially in light of evidence which demonstrates the importance of health professional conduct in families' donation decisions (Siminoff *et al*., 2001; Simpkin *et al*., 2009). In this way, if donation is experienced as a difficult practical and conceptual process for staff who regularly encounter death and dying, we must ask the question of *why* it is that minority ethnic communities have become, and continue to be, maligned for their perceived failure to participate in this process.

Conclusion

In this chapter I have highlighted the complexities involved in increasing 'BME' donor rates, by examining the institutional work involved in implementing the ODT's national recommendations to optimise deceased donation. As I have shown, increasing 'BME' organ donation goes beyond the issue of solely securing a 'yes' or 'no' from a 'BME' family for donation and into the fact that 'BME' 'communities' only get to donate by virtue of the medical practices around donation.

As demonstrated, the figure of the donation nurse is pivotal to the success of the ODT's project. They bridge the diverse practical, ethical, and legal issues around donation, created at the interface of medicine and its publics. This they do by negotiating the contingencies of the hospital Trusts in which they are embedded; and transforming de-contextualised recommendations into everyday forms. It is within these contexts that we also see the donation nurse as an agent of governance: mobilising the interests of differently involved actors, such as ICU consultants and nurses, hospital managers, and theatre staff, to bring about change and produce new norms of practice around donation. Moreover, increasing donation also involves the donation nurse neutralising the concerns of staff about new procedures, by imparting the moral imperative of requesting donation from a family.

The process of making these new procedures happen in practice is therefore conditional upon the adjustment of roles and relationships within local settings – often involving a challenge to the structure of clinical hierarchies of decision-making. Here we see how a patient's transformation to the status of 'potential donor' is dependent upon the negotiated interactions of ICU staff and donation nurses – who attempt to impose self-governance and the norms of *when*, *where*, and *who* does the asking for organ donation. In addition, since donation nurses are specially trained in the process of donation request, that they were not always able to access families and be the ones to ask has implications for how ('BME') families are asked about donation, and whether donation is consented for, or refused, as a result.

In making visible the work involved in organ donation, prior to reaching the stage of donation request, I have demonstrated the difficulties involved in generating more organs for transplant. Since organ donation is only *possible* as an outcome of the negotiated practices of health professionals, decisions about organ donation come to be understood as not just the concern of 'BME' potential donor families and 'communities', but can be traced

to the uncertainties involved in satisfying the requirements for reaching the stage of donation request. These include: what gets practiced or not practiced in different hospital Trusts; the decisions of ICU staff to refer or not refer a patient for donation; and the ability of the donation nurses to re-align practice with its procedural forms, thereby increasing the chances of gaining consent for organ donation. In the next chapter, I focus upon experiences with 'BME' families at particular stages of the organ donation pathway, to question the notion of what consent for donation actually means in practice, and thus further an understanding of ethnicity in organ donation.

Chapter 5. Consent Complexities: Death and the 'BME' Family

Introduction

In the previous chapter I showed how the implementation of the ODT's recommendations for changes to donation practice illustrated the complexity involved in increasing organ donor rates at local levels. In facilitating these changes, donation nurses worked at increasing the likelihood of patients being referred as potential donors. With the responsibility of health professionals to refer dead or dying patients for organ donation to the donation nurse, consent for organ donation therefore encompasses not just the decisions of families in response to the donation request, but also the decisions of health professionals, in their referral, or non-referral, of a patient for donation. In this chapter I take up this issue of consent for donation, to illustrate the protracted nature of this process for families.

In the three parts to this chapter I will show how standardised constructions of consent for organ donation – manifested in NHSBT's *Can We Count on You?* (2007) and *Prove It* (2009) donation campaigns, and formalised in the 2004 Human Tissue Act – become problematic in the donation encounter with 'BME' families. In its standardised form, consent is configured as an outcome of a singular choice: to donate or not to donate, and as a product of individual decision-making – either by a person placing their name on the organ donor register, or by an appropriate "representative" (HTA, 2009a; 2009b) providing agreement to donate a person's organs after their death. In contrast, I argue that consent in everyday donation encounters is far more complex. Rather than the individual donor providing consent, in practice, the decision to donate falls to the donor's family. In addition, consent

from the family begins prior to them being asked about donation, and involves their acceptance of the diagnosis of the death of their relative. Consent is therefore a hugely protracted and complex process, which, as I demonstrate, is experienced as particularly so in the case of minority ethnic families.

In the first section, I show how refusals for organ donation from minority ethnic families were often understood by health professionals in terms of 'BME' families' refusals to accept the diagnosis of the death of their relative. This led ICU staff to "broker" their decisions around death with families (Timmermans, 2005: 993), through a process of negotiation to legitimate their medical diagnoses. This work of legitimation, I argue, also acts as a process of smoothing the pathway towards donation request, by getting families to informally agree (consent) to the death of their relative.

In the second part, I illustrate how the 'BME' family get specifically problematised in relation to formalised notions of donation consent. This I relate to the Human Tissue Authority's (HTA) guidelines for consent (2009b), which lay out a hierarchy for who can make donation decisions: from the donor themselves to a person considered the highest qualifying relation to the donor. In practice however, with minority ethnic families, this hierarchy did not work, since decisions around donation were seen as a product of negotiation between a number of differently involved actors. Negotiating donation decisions with 'BME' families was therefore perceived as a complex process, and, as a consequence, health professionals sometimes called into question the legitimacy of families' decisions around donation.

Finally, in the third section, I show how 'BME' families are *produced* as a problematic category for organ donation by virtue of the way in which they were perceived as difficult to manage in relation to the norms of Intensive Care medicine. In this way, I argue that medical standards and bureaucracies *create* normative notions of what a family *is*, and what behaviour is appropriate within ICU domains. In turn, 'BME' families are constructed as a

problem for donation in the context of the standards upon which donation is premised, such as family acceptance of medical decisions around death. It is to this issue of death in donation which I now turn, in the first section below.

Part 1. Donation refusal and death discussions

> You've got to get a family to accept the death first absolutely, and then the lack of hope. And if you go in there with those [donation] conversations *before* they accept death and they accept that there's no hope, they'll be upset and angry. (Joanne Hill, PICU consultant at Lakeland)

As detailed in chapter 3, once a decision has been made by the treating Intensive Care doctors that a patient is not going to survive, the next stage in the donation pathway is to break the news of potential brain death, or the hopelessness of a patient's condition – meaning their death is inevitable – to the family. The decision on death is usually made by the clinical team once initial brain stem death tests have been carried out on a patient, or when all suitable medical interventions have failed in the attempt to save a patient's life. The patient's family will then be called into a meeting – which one nurse referred to as "*the talk*" – with the treating doctor/s and nurses, to discuss their findings with the family. Here, the doctor will, as one put it, "summarise where we are up to with that patient", before conveying to the family what happens next. Sometimes families may be encouraged to watch brain stem death tests as part of this discussion, to help them understand the finality of the diagnosis. The doctor will then convey to the family their decision to stop – what is medically termed 'withdraw' – life prolonging medical treatment (GMC, 2010) on the

patient, so that they can die[68]. This action is considered to be in the patient's best interests, with the understanding that further, often aggressive, treatment will cause more harm than good, since the patient's death is inevitable (GMC, 2010).This stage of discussing death with a family is understood as vital in progressing towards organ donation since, according to guidelines, only when a family are seen to have accepted that their relative's condition is irreversible should the donation request take place (UKT, 2004a; ICS, 2005).

The task of breaking and negotiating the news of a patient's death to relatives usually takes place in designated private rooms, set away from the treatment ward. These are used for discussions of death, meetings between staff and families on a patient's progress, or even as a space for family members to have privacy, away from the public setting of the ward. I conducted a number of my interviews with staff in the "family interview rooms" – as they were labelled on the door – of Lakeland's PICU. These consisted of three, tiny, box-like rooms, positioned alongside each other in the main corridor, directly outside of the treatment ward. Inside these rooms the walls were painted white and the lighting was harsh. Two good-sized peach coloured couches were squeezed into the space. A coffee table was placed in the middle of the room, with a box of tissues stood on top: seemingly waiting for the outpouring of emotions involved in bad news discussions with families. There were no windows in these rooms, which, along with their small size, gave them an oppressive, claustrophobic atmosphere. The rooms felt like small, private cells: where families live out both good and terrible news about their relative.

Conflicting decisions on death

The process of breaking news of death to families was emphasised by the donation nurses – as well as is imparted by guidelines (ICS, 2005; AMRC, 2008) – as that which should remain

---

[68] In the case of brain stem dead patients, who are already legally certified as dead, it means that they will stop breathing.

separate from the request for organ donation. This means that families should be given news of death, and have shown their understanding and acceptance of this diagnosis, prior to any discussions about organ donation beginning. This was largely due to the fear that families might interpret the decision to withdraw care from their relative as being in the interests of donation, rather than of the patient. Such practice was seen as especially important in the case of DCD, where, because death has not yet happened – yet is diagnosed as inevitable – potential conflicts of interest were highlighted (ICS/BTS, 2010. See previous chapter). Despite this theoretical separation between death and donation[69], many ICU staff gave prominent position to the stage of discussing death with a family in their donation stories. In other words, this separation did not happen in practice, since the stage of imparting the diagnosis of death to a family was described as integral to the donation process. This was especially the case when conflicts arose between families and staff over these decisions. Such struggles happened with families of *all* ethnicities, yet were described as an especially common occurrence with minority ethnic, particularly 'Muslim', families.

These conflicts ranged from families refusing to accept the diagnosis of death and asking staff to continue with treatment on their relative – in the belief that not enough had been done to save their life; to families being unable to understand that their still-breathing (brain dead) relative could really be dead. As I show therefore, differences of opinion between families and health professionals around death were understood to be pre-emptive of donation refusals. In other words, families' lack of acceptance of death was linked to their lack of acceptance – refusal – of organ donation.

---

[69] This separation is formalised by the AMRC's (2008) *Code of Practice for the Diagnosis and Confirmation of Death*, where it states: "The Working Party decided that it was important to separate completely the diagnosis and confirmation of death from anything to do with the issues surrounding organ donation and transplantation" (p. 9). Within this document, issues of organ donation in relation to death diagnoses are referred to the ICS's (2005) donation guidelines and the HTA's (2009b) code of practice for consent.

Sophie, a highly experienced donation nurse, recalled a case from when she was still working as an Intensive Care nurse of, as she described, a "lady" from an "Indian island" who died of a brain haemorrhage during child birth, whilst the baby survived. Despite this woman being flagged up as a potential donor, Sophie narrated the negative donation outcome as ultimately down to the disjuncture between the medical diagnosis of death and the family's interpretation of the situation:

I looked after her for four days. And my enduring memory about her was actually...organ donation could *never* have come into it because [the] family, wouldn't accept brain stem death as a definition of death. A lot of her religion seemed to be a fusion of Hinduism and Christianity and she had Christian and Hindu symbols on the pillow all the time. We had to make sure [they] were placed in a certain order. And even though the doctors had done the brain-stem death tests and said she is brain-stem dead, and we did briefly discuss donation, they [family] just put an end to that, they said: 'we don't accept that she won't get better.' And, 'you're not going to take her off the ventilator.' So you can't facilitate organ donation from someone like that and in the end the hospital lawyers had to, because erm...to take her off, you know, when they say you're not taking her off the ventilator, if they'd [doctors] have done that [taken her off the ventilator] they could have been open to, you know, perhaps [legal action by the family], even though she was legally certified dead. So she stayed on the unit another two days and I cared for her for another two days. And her husband...he'd come in and spend 5 minutes, and he wouldn't engage. We tried to engage in conversation; he wouldn't engage [....] When you're brain-stem dead, the rest of your organs try to follow. So no matter how much you support this patient, every brain-stem dead patient that's been ventilated, their heart

has stopped within 2 to 4 days. Then about 2 days later she just [cardiac] arrested. So, donation wasn't an option with her in the sense that they [family] wouldn't *never ever* gonna even accept that she could be taken off the ventilator; that there wasn't hope for her to survive. (Sophie, donation nurse with team 2)

This example illustrates how discussions of death with the family are linked to, rather than separated from, the donation request. In this case, the family are asked about donation despite the fact that they do not agree with their relative's diagnosis of death. Sophie describes their refusal for organ donation as an *outcome* of their refusal to accept the brain death diagnosis, and thus the decision of staff to withdraw treatment from their relative. Moreover, she juxtaposes her description of the family's lack of acceptance of the death of their relative with insight into their religious status, by detailing the religious artefacts placed around the patient. Here, she conveys subtle markers of difference between her own view of death and the family's (religious) understanding of the situation. The implication being that the family's conflicting views of death, and their subsequent lack of engagement with the donation request are an outcome of their religious beliefs around death.

Sophie describes how the conflict played out in this situation: the family continue to demand that their relative can be saved and insist that she not be taken off the ventilator, whilst Sophie and the medical team have diagnosed her as already (brain) dead. This decision is eventually vindicated when the woman dies two days later, despite being allowed to remain on the ventilator. With Sophie's evaluation: "you can't facilitate organ donation from someone like that" – drawn from her experiences as both an ICU and donation nurse, we gain insight into the contingent arrangements around donation. These being that donation consent, and thus refusal, are understood to be predicated upon a family's agreement, or lack of agreement, with medical decisions around death. However, as

we also see here, and as I later develop in parts 2 and 3, understandings of donation refusal from minority ethnic families are linked to specific constructions of the difficulties these families present for healthcare staff. This includes perceptions of religious needs around death, and how these clash with the medical practice of withdrawing care.

Positive donation outcomes are therefore understood as dependent upon the capacity of all involved constituents – family, ICU doctors and nurses – to come to a shared, or co-constructed, definition of the situation around death (Thomas, 1931). Discussions of death between health professionals and 'BME' families thus organise donation outcomes, and in turn, highlight how death is a socially determined process, integral to decisions around donation. A family's acceptance of death thereby acts as an informal stage of consent in the organ donation process. Without this acceptance, stories often described an outcome of donation refusal, or the donation request not happening. This is in contrast to the HTA's *code of practice on consent* (2009b), which makes no reference to discussions of death with a family in its outline of the process and stages of gaining consent for donation.

David Sudnow's (1967) study on dying in American hospitals highlights the importance of situating families' understandings of death within the context of how death is organised in hospitals. Sudnow was the first to "locate 'death' and 'dying' as an organisationally relevant event" (1967: 3), by looking at the practices done around death by health professionals. He made a distinction between biological death (when the body has ceased to function), clinical death ("the appearance of death signs upon physical examination") and social death, where the patient is treated as essentially dead by staff and family alike, since they have ceased to have any "socially relevant attributes" (1967: 74). In relation to this, stories like Sophie's highlight how, even when a patient is declared clinically dead, families may not always accept this, since they perceive their relative to be still *socially alive* (Sudnow, 1967; Seymour, 2000). In other words, they still see them as a person, rather than a dead body.

This indicates that there is a gap between the medical definition of death and families' understanding of death. This was especially so in the case of brain death: where the dead are still breathing – appear alive – with the aid of a ventilator. In Sophie's example, since the potential donor's clinical and biological death status was not entirely obvious, the family argued for her to be kept on the ventilator in their understanding that she would get better.

In these struggles the ontology of the dead or dying patient is thus brought into question (Hadders, 2007; 2009a; 2009b) by families. As discussed in chapter 1, studies with donor and non-donor families found that many families struggled to come to terms with the concept of their relative being brain dead. In turn, families who donated demonstrated a greater understanding of the finality involved in brain death than those who refused donation (e.g. Sque and Payne, 1996; Franz *et al*., 1997; De Jong *et al*., 1998; Bellali and Papadatou, 2007; Sque *et al*., 2007). Margaret Lock (2002) highlights similar ambivalences over brain death in Japan, where the brain dead person is only legally recognised when a patient has previously given written consent for donation, *and* their families agree to this upon their death. In this way, similar to Sudnow, brain death is understood as a "socially determined" form of death (Lock, 2002: 183), brought about by the negotiation of different constituents. Without this consensus, potential donors may enter, what Kaufman (2005: 152) refers to as the "zone of indistinction". This occurs when a patient is neither responding to treatment, nor are they "dying quickly enough" (Kaufman, 2005: 152). They enter a sort of no-place: neither (biologically) dead nor (socially) alive. In Sophie's story, the brain dead patient remaining on the ventilator therefore – from Turner (1974) – occupies a position of liminality for the family: pausing in the passage between the socially stable identities of life and death, thereby reducing the chance of them becoming an organ donor.

Decisions around death therefore frame the outcome of family decisions on organ donation. In NHSBT's recent general and 'BME' targeted *Prove It* campaign (2009. See figs. 1, 2 and 4

in chapter 1), which encourages the public to donate their organs after death, individuals are asked to "prove" their belief in donation by putting their name on the organ donor register. Specifically the 'black' and 'South Asian' campaigns state: "if more people registered as donors, more lives would be saved". Here, the act of organ donation – and reduction in inequality of access to transplantation for 'BME' populations – is equated with a singular decision by a member of the public to register as an organ donor[70]. In contrast, stories describing the struggles between health professionals and 'BME' families around decisions on death reveal the simplicity of constructing donation decision-making in this way. I therefore add a further dimension to understandings of low 'BME' donor rates, beyond the assumptions that donation refusals are an outcome of the 'cultural' reluctance of 'BME' groups to donate organs. Here, 'BME' donation refusal is seen as an outcome of the break-down of discussions around death, and not simply the result of a refusal to the direct request for organs.

Negotiating death diagnoses

There is a further dimension to the view that conflicts over death inhibit the likelihood of gaining donation consent, which we glimpsed in Sophie's brief description of the involvement of hospital solicitors in the case above. This being that discussions around death also involve the active negotiation of death diagnoses with families, in attempts to gain their acceptance of the situation. As I will argue, this also acts as a process of smoothing the path towards donation request and consent. Health professionals described the various ways in which this was done, including: demonstrating brain death tests in front of a family; attempting to impart the biological hopelessness of their relative's condition by

---

[70] See Singleton, 2005, for a similar argument relating to public participation in CPR. Singleton argues that leaflets about a 'community' CPR training initiative construct the act of an individual's financial contribution to the scheme as a way of directly helping to save lives (2005: 778).

listing the clinical reasons for the death; and drawing on other authorities, such as solicitors and religious leaders, to mediate their decisions with families.

At Hillview, John, an ICU consultant and the hospital's Clinical Donor Champion, told of the difficulty of one particular case where a 'South Asian' family refused to recognise the dying status of their relative and agree to the usual process of withdrawal of care. Legal action from the hospital was only averted after the medical team managed to reach a compromise with the family:

> There was one family, and I guess they were erm...part of the South Asian community in the city, and it was all a very difficult experience even before we got to the topic of organ donation. And it was very difficult to... persuade [the family] that continuing treatment wasn't in their mother's best interests; who was a woman who developed multiple organ failure and was failing to respond to all the supportive treatments. And we took several days to convince the family to limit the care that we were giving. They completely refused to have the care withdrawn, and I guess rather than go through the courts we negotiated a limitation of treatment. And in her particular case she did become brain stem dead...but...[sighs] we had a very difficult time convincing them that that meant she was dead in terms of medical and legal authorities. So subsequent discussions after the brain stem death testing were pretty short and eventually she actually died on the ventilator, which I guess we went along with in the end. But clearly we had reservations about whether we were acting in that lady's best interests. It was a very large family, very articulate family, and...[I] guess we tried to come to what we thought was a win-win for both sides. But it's the writing was on the wall at the beginning that she was unlikely to go on and donate any organs. (John, ICU consultant and Clinical Donor Champion at Hillview)

John's experience conveys the struggle to legitimate the unit's medical decision on the woman's dying status with her family. In contrast to the view of staff, John describes how the family perceived further treatment to be the best option for their relative. He justifies the medical diagnosis by listing the hopelessness of the patient's situation: multiple organ failure, unresponsive to treatment, and her subsequent deterioration into brain stem death. John therefore legitimates his decision through the narration of biomedical markers indicating the imminence of the patient's death (Johnson *et* al., 2000; Aldridge and Barton, 2007; Hadders, 2011). The family's refusal to allow withdrawal of treatment meant he was forced to negotiate a compromise of limited – rather than halted – care. He describes how it took a period of days to persuade them that the continuation of care was not in the best interests of their mother. This means that, rather than having a positive effect, such as saving or making the patient more comfortable, treatment is viewed as causing more harm – pain or distress – to a patient who will inevitably die. This persuasion involved imparting the medical and legal reasons for the patient's death to the family, and thus the (legal) justification for removing active treatment.

Here we see how conflicts between families and medical staff over decisions around death are negotiated by staff, in attempts to reach a consensus on the situation. This is reflected in John's statement: "we tried to come to what we thought was a win-win for both sides". It is only in reaching an agreement that organ donation is understood as possible. As such, the work to aid this agreement, I argue, is also done so as to make donation a possibility.

Timmermans (2005) has coined the notion of "death brokering" to describe such processes of negotiation, where medical professionals "render individual deaths culturally meaningful" (2005: 993) to families. Following from Foucault (1976), an individual's death, originally kept at bay by medical attempts to save a life, is subsequently conveyed to families as a natural outcome of illness. As John describes above, this brokering took the form of relaying the

198

hopelessness of continuing treatment, and later persuading the family of their relative's legal death status. Studies into medical communication with families around death and dying have highlighted how such negotiations have a vital function in the process of moving patients from the phase of dying into death (Curtis and Patrick, 2001; Kaufman, 2005). As Johnson *et al.* (2000), in their study with American doctors found, this often involves the gradual incorporation of the possibility of death in discussions with families. This eventually ensures that any hope of the patient's recovery is dispelled, and they are understood to be (socially) dying (see also, Sudnow, 1967: 93-96). Similarly, Aldridge and Barton (2007) found that where doctors were consistent in their summaries of the hopelessness of a patient's condition, families would more readily agree to the decision to withdraw care, than in cases where doctors had referenced a chance of survival. In this way, when these strategies for breaking bad news are compromised, as in the case of sudden death – of which many organ donors make up – families may struggle to engage with medical diagnoses of death (Russ and Kaufman, 2005: 117).

John describes the various attempts to legitimate the death to the family: spending time "convincing them", so as to align their understanding of the situation with that of the medical team (Hadders, 2011). In so doing, attempts are made to re-stabilise the disrupted donation trajectory; where a family's consent for death allows for a successful donation request. However, in John's case, consensus on withdrawal of care never came about. Instead, an agreement was made – between staff and the family – to a limitation, rather than complete withdrawal of care. This meant that any chance of organ donation was impossible[71].

---

[71] This is due to the fact that a potential donor must be actively managed and their organs quickly procured once brain death has occurred/death is understood imminent (in the case of DCD) to ensure their viability for transplant. In the case of brain dead or dying patients remaining on a ventilator, their condition is likely to become unstable, meaning their organs become increasingly damaged and therefore unsuitable for donation.

Even when attempts to legitimate medical decisions of death to a family resulted in the family subsequently accepting the diagnosis, this did not necessarily result in donation consent. Sandra, an ICU nurse at Hillview narrated a case involving a 'Muslim' family, where their initial scepticism over the diagnosis of brain stem death of their father – "they weren't believing what we were telling them about the death" – was turned around after they witnessed the brain stem death tests. Once the family had demonstrated their understanding of death they were asked about organ donation. However, Sandra described how this request resulted in an angry response, and was interpreted as the reason for their father's diagnosis. In other words, the family saw the decision of the death of their father as being made for the purposes of organ donation, rather than his death being inevitable.

In this case, the process of successful death brokering with the family meant that organ donation was seen as a possibility. However, as both John and Sandra's examples demonstrate, even with such negotiations, consensus on death and donation are not always reached. That these conflicts were described as particularly prevalent with 'BME', especially 'Muslim', families calls into question *how* discussions of death are actually *done* by health professional with minority ethnic families. In this way, I argue that refusal to donate organs is not simply about the failure of families to accept – what Foucault (1976) describes as – medical authority on death, but may also be about the failure of health professionals to successfully communicate their decisions on death to families (e.g. Russ and Kaufman, 2005). In addition, as I will take up in part 3, it leads us to ponder the way in which 'BME' families are potentially constructed by health professionals as a 'problem' for organ donation, through particular interpretations of the difficulties they present around death.

Mediating death

Health professionals' stories also described how, in some cases, conflicts over death between families and ICU practitioners were further mediated by figures outside of the

treating medical team. Sometimes the donation nurses themselves acted as mediators between families and ICU teams. They described how one of their first actions when speaking to a family – prior to any mention of donation being made – is to ask for their understanding of the situation. If the family indicate a lack of acceptance of their relative's death the donation nurse will then guide them through a further explanation of the diagnosis. In other cases, not always linked to potential donors, hospital solicitors were consulted to provide legal advice for staff who wanted to withdraw treatment, yet did not have the consent of families to do so. At other times, religious figures, such as hospital chaplains, were called on – sometimes by a family, sometimes the ICU staff – to act as a mediator in the situation.

At Hillview, where there were regular disputes between 'Muslim' families and staff over death diagnoses, the hospital's resident Imam, Aatif, was regularly called on to arbitrate between the two sides. Whilst he had never been involved in a potential donor case, his commonplace involvement in death discussions tells us much about the difficulty ICU staff had with neutralising such situations with 'Muslim' families. A "typical scenario", as Aatif described, usually involved a 'Muslim' patient who had been attached to a ventilator in Intensive Care for a number of days. With continual deterioration and lack of improvement in their condition after treatment, a decision is made by the treating team that any further intervention is futile. The family are then told about this decision in terms which frame it around the interests of the patient: treatment should be withdrawn so as not to prolong their relative's suffering (Johnson *et al.*, 2000). Aatif described the common disputes that subsequently arise at this point – when a family disagree with the situation being presented to them – and his ensuing involvement as mediator between the interests of a family and the interests of the medical team, with the dying patient at the centre:

The family turn round and say: 'no, he's still breathing.' Okay [doctors respond with] 'he's still breathing, but it's not him that's breathing, he's been assisted by this aid. He is unable to do that himself.' The family will then come back with: 'oh no, but he might improve' and that kind of thing. So, somebody needs to...come and bridge the gap between...*their* [family] expectations and *their* [staff] expectations. So who comes along? Call the chaplain: I come in fully armoured! (Aatif, Hillview's Imam Chaplain)

Aatif explained how, upon his arrival at such scenes, his first actions are to ask questions of the medical team about the patient's situation: what treatment they have and haven't explored, and what the patient's prognosis is – so as to give him a medical understanding of the situation. He then approaches the family, who, in his words: "will throw it on to your shoulders and say 'Imam, whatever *you* think. We are happy with the outcome of whatever God has to say.'" As Aatif goes on to describe, his position as intermediary is therefore far from easy:

And it's like: am I being asked here to make a decision on behalf of your loved one? And that is where this thing is very very difficult for me. Because in the hereafter I would not like to be questioned by God that a decision was in your hands, and *you* took somebody's life away when they could have lived for another six months, a year, whatever it is. So *Islamically* I seek a second opinion from another Islamic Scholar, just like your medical clinical staff would. [....] There are times when I haven't agreed with our staff, and I didn't even need a second opinion. Where I've actually gone up to the consultants, asked leading questions and thought: no wait a minute, there's still some mileage in this. And I have actually turned around and said 'No, I don't think you can be supported on this [decision to withdraw care].' [Be]cause first thing is medical staff winning

202

your approval. Then it's about medical staff saying 'Okay, now that you're with us, go and sort them lot [family] out.' (laughs) When all fails, they know that I can pull it together for 'em. And as I say, in one particular incident, I *wasn't* convinced. So I said to the consultant: 'I don't think so. I'm not convinced [with the decision to withdraw care].' Er and basically, he [consultant] said 'Okay.' I said 'I think if you give us another weekend or so and let's see what happens'. I think it was Thursday or Friday then, and this patient was sat up on Monday morning. (Aatif, Hillview's Imam Chaplain)

Widening the scope of his official role to provide religious guidance for patients around their health needs, Aatif's place at Hillview, as both hospital employee and, as he described, "one of them" ('Muslim'), also involves "bridging the gap" between the largely white ICU consultant body and 'Muslim' families. Aatif positions himself as a vital resource for medical staff struggling to convince families of the dying or dead status of their relative. He is therefore both a key ally for staff and someone with authority, over that of families, to challenge medical decision-making – as we saw in the example of the patient who survived after his intervention. With this he highlights a different perspective to medical decisions of death (Luce and White, 2007) and the multiple moments of diagnosis in medical practice (Byrne and Stengel, 2010). In Aatif's regular role as mediator a form of parliament of death (Latour, 1993) is played out. Here, medical decisions on death are verified or refuted via his position of religious authority, and in his use of similar techniques to medicine by calling on a further (religious) expert.

In his description of his role as decision-maker between the two sides, Aatif also conveys the responsibility involved: he is mediator not only between families and health professionals, but also between life and death, and God and medicine. I draw on Haraway's (1997) transmuted interpretation of Schaper and Schaffin's notion of the modest witness to think

about his positioning here. Haraway draws out the modest witness from its original inception as an impartial (white, male) figure, able to objectively mediate between the domains of science and the public, to her reconfiguration of a partial, self-aware, and accountable figure. For Haraway, the modest witness, like Aatif, is one who makes science transparent: bringing it into question in terms of "possible liveable worlds" (1997: 39). In questioning his role as mediator, Aatif acknowledges the burden of such responsibility, calling attention to his partiality in the process: "this thing is very very difficult for me".

My time spent with Aatif helped me understand a further layer to the work done by ICU staff to legitimate their decisions around death (and ultimately move the donation process forward) – by calling on mediating figures such as Aatif. These legitimating processes are not simply confined to the function of facilitating donation, however. Instead, they need to also be understood in the wider context of the moral and emotional struggles of ICU staff with continuing treatment on dying patients, as I show below.

Continuing treatment on dying patients: moral struggles

In the examples above we witness how tensions around decisions of death lead to difficulties in gaining consent for donation. In addition, we also glimpse how the interests of families and health professionals may differ in relation to bioethical notions of futility. Futility refers to the use of "inappropriate treatments that will not improve disease prognosis, alleviate physiological symptoms, or prolong survival" (Mohammed and Peter, 2009: 292). Stopping intensive treatment on a patient whose situation is deemed beyond hope, or where death has already occurred (in the case of brain stem death), is linked to the bioethical imperatives of beneficence and non-malfeasance (Luce and White, 2007). This means that medical practice should do no harm to a patient, and should only be carried out in consideration of the patient's 'best interest'. In this way, when ICU staff are impelled by a family to continue to ventilate and treat a dead or dying patient, this is understood to

compromise the best interests of a patient. This is because such care is considered superfluous and the cause of further pain or distress in a patient (Luce and White, 2007; Mohammed and Peter, 2009). However, as Mohammed and Peter (2009) argue, and as we saw in John and Sophie's examples, negotiations with families resulting in the continuation – rather than withdrawal – of a patient's ventilation can be understood as "moral practices" which benefit the family (p.292); in that they allow them a dying stage, to come to terms with their relative's death (Timmermans, 2005).

Such practice is contrasted with the General Medical Council's (GMC) recommendation that family "anxieties" over withdrawing care should not "override [...] clinical judgement and lead you [...] to continue treatment that is of no overall benefit" (GMC, 2010: 25). The guidance to have "clinical" decisions take precedent over the feelings of a family are enacted very differently in the cases Sophie and John described. Their experience of such situations (and fear of legal action by families) contrasts with the GMC'S recommendation to follow through with 'medical' decisions. Some nurses and consultants I interviewed, especially those working in Lakeland's Paediatric Intensive Care Unit (PICU), confessed to their moral and emotional wrestling with continuing treatment on dying patients at the behest of families, and their personal feelings about the situation.

For Ketu, a PICU consultant at Lakeland, the ability of medical technologies to keep a dying child alive presented him with routine quandaries between his own, moral concerns, and the pressure he feels from families, colleagues, and society to keep a patient alive:

> The *difficulty* is, and there's one example already on the unit, where the family
> are not where you are despite lots of you as Intensivists, and other specialities
> saying the same thing [that the patient is dying]. And those are the really
> difficult ones. What do you do in those circumstances? Some of those you can
> actually get the family eventually to come on board, but it takes them a lot

longer. [....] And a case on the unit at the moment, I've actually said to Dad, this is far higher pressure than I would use on you, and your child is only twelve months old. So to put it into context, into something they could understand, so that, with time you actually end up making the family understand that continuing treatment is a futile exercise. [....] Erm [coughs] and I always think, is it right what I'm doing? Is it in the best interests of the child? And I always ask myself that question. But it's still difficult. [....] A lot of the decisions we make now I think are driven by pressures beyond that of my own working environment. Society's expectations, families' expectations, fellow physicians' expectations, nursing expectations. All of these drive you to...to treatment options that you don't necessarily believe in. But it's coming to a compromise between what sits comfortably with your conscience and what you can do or *have* to do as a physician. (Ketu, PICU consultant at Lakeland)

Negotiations around end of life decisions, and their impact upon donation decision-making, thus extend into the general emotional and moral difficulty for staff in continuing, as one nurse described, "aggressive" treatment on patients deemed beyond saving. Ketu's example reveals the everyday struggles of Intensive Care professionals who navigate moral uncertainties in the care of dying patients. In the case he describes, the increase in treatment on a young baby to a level beyond that usually used on adults is conveyed to the family in these terms, to emphasise how it is at the limit of what the medical team can feasibly do. Ketu conveys how such actions are done alongside attempts to persuade the family of the legitimacy of the medical decision to remove care, allowing them time to come to terms with the fact that their child will die (Mohammed and Peter, 2009).

Here, decisions to treat, or not, have ramifications for the production of a 'good' (equated as natural), or 'bad' (linked to aggressive treatment) death (Delvecchio Good *et al*., 2004;

Mohammed and Peter, 2009). Ketu describes the process of struggling with his own conscience in the context of the needs and interests not only of families, but also his colleagues, and society; referencing the continual expectations on medicine to stave off death (Kaufman, 2005; Chapple, 2010). With Ketu's narrative we glean insight into the difficult emotional process for health professionals in imparting and acting out their decisions on death to families. In practice, this encompasses a moral responsibility towards the welfare of families, which, in turn, leads to health professionals struggling with their decisions to treat (for the sake of families) or not treat (for the sake of patients). Far from the authority of medical decisions taking precedent – manifested in the GMC's (2010) recommendations – dying, and thus the pathway towards donation, is witnessed here as "a nuanced social process that involves a negotiation of moral responsibilities, identities, positions, and viewpoints" (Mohammed and Peter, 2009: 301).

In the examples presented in this section I have shown how discussions around death with potential ('BME') donor families act as a vital stage in the organ donation trajectory. When medical decisions of death are not accepted by a family this is understood to jeopardise, and even lead to the failure of, subsequent requests for donation. In this way, I firstly argued that for families to agree to organ donation, they are required to provide their informal consent for the death of their relative to occur. Secondly, when such disagreement happens, Intensive Care staff actively attempt to legitimate their diagnoses to families by a process of negotiating the death to render it acceptable. In the case of potential donors, this process also prepares the family for donation request. In addition, other figures, such as hospital Imams and solicitors, are sometimes called on to further mediate general disputes between families desperate for their relative to survive, and health professionals who do not wish to continue with futile care on a dying patient. Lastly, similar to how donation was described as an emotional process for health professionals in chapter 4, in the wider

background to such struggles we also witness the emotional work involved for staff in continuing aggressive treatment on patients they deem beyond hope.

In this way, I argue that to understand the problem of consent for organ donation from 'BME' families we need to conceive of the stage in which death is discussed with families as a form of, and integral to, donation consent. That these communications were described as especially difficult with 'BME' families indicates that this is not simply about families' lack of acceptance of death, but also the ability of health professionals to communicate death and make it understandable – and thus acceptable – for a family. The next section will continue with the problem of consent along the donation pathway: showing how the Human Tissue Authority's guidelines around consent fail to capture experiences of working with non-'white' families, when it comes to assessing a potential donor's next of kin.

Part 2. Multiple consent constituents: the ''BME' family'

As highlighted above, consent for organ donation has been publically constructed by donation campaigns as a discrete act of rejection or acceptance, in the act of an individual registering their willingness to become an organ donor. In addition, as I argued in chapter 1, NHSBT's targeted 'black' and 'South Asian' *Prove It* (2009) and *Can we Count on You?* (2007) campaigns utilise the polarised statistics of the increased likelihood of 'black' and 'South Asian' people needing a transplant and the small (1%) percentage of 'black' and 'South Asian' people on the organ donor register. In this way, the private act of organ donation is re-constituted around the responsibility to act on behalf of a collective ('black' or 'South Asian') to which individuals have been ascribed (Hacking, 2006; Hayden, 2007; Kierans and Cooper, 2011). However, despite the linking of individuals to notions of 'community', NHSBT's *Prove It* campaign slogan states on all its posters: "if you believe in organ donation,

prove it". With this, the individual is represented as ultimately responsible for the decision to donate, and thus save lives.

In contrast, the 2004 Human Tissue Act (HTA) configures one of the main stages in consent as involving an understanding of *who* is able to provide permission for organ donation. The main Act (2004) describes how 'appropriate consent'[72] can be provided by the donor if they have left evidence of their wishes prior to death, such as by joining the organ donor register. The Human Tissue Act therefore enshrines the legal ability to carry out organ donation if the deceased's wishes are known. However, in practice, rather than donation happening as a result of an individual's decision to join the donor register, it is their family who usually give the say so for donation to go ahead (May, Auliso and Devita, 2000). The HTA takes this into account in its *Code of Practice for Consent* (HTA, 2009b), where it acknowledges the usual process of gaining agreement for donation from a "qualifying" relation (para. 29). *Who* can be included within this notion of a 'qualifying relationship' to the deceased, and thus who can provide consent for donation, is provided by the HTA's hierarchy for consent (2009b). This hierarchy places spouse or partner at the top, moving through to parent or child, then brother or sister, aunt or uncle, through to friend of longstanding at the bottom. This means that the relative of the donor who is highest up the hierarchy should theoretically be the one to make the decision on donation, and provide their consent for it to go ahead. In configuring consent in this way, the HTA also constructs a normative notion of the family, in terms of who is most closely related to whom, which I take up later in this section.

Despite the HTA's acknowledgement of family involvement in donation consent, the formal act of consent falls to just one, 'qualifying' relation. Similar to the donation campaign

---

[72] In bioethical terms, consent has traditionally been legislated around the notion of the individual's right to voluntary participation in, for example, organ donation or medical trials. This was originally enshrined in the Neuremberg Code of 1947, and was later developed in the World Medical Association's Helsinki Declaration (1964), which broadened out consent to also encompass "proxy" consent by relatives, to "supplement" consent in the case of children or those with learning disabilities (Hoeyer, 2009: 273).

209

discourse of an individual giver, the HTA positions responsibility for decision-making upon just one individual. This is reflected in the donation consent forms, which provide a single space for a relative to formally register their consent. On the first page of the consent form (see fig. 6), underneath a section for the "patient's details", the box titled: "consent for organs and tissue" has a space for the patient's name, and below this, just one box for the name of the relation giving consent for donation, alongside details of the nature of their relationship to the patient. This is presented as such: "I, (name) the (e.g. mother, husband) of (patient's name) give consent to the donation of the following organs/tissue for transplantation". Here, the decision-maker for the donation of a dead patient's organs is configured as a singular relation.

In this section, I argue that such standardised notions of consent – as an outcome of an individual, hierarchical process of decision-making – fails to account for the complexity of how donation decisions are made by 'BME' families, and, in turn, also serves to make these decisions problematic.

Donation decision-making: the complexity of family

When first approaching a family about organ donation, donation nurses must decide on who can act as the "qualifying" relative – or, as the donation nurses usually referred to, next of kin – to provide consent for organ donation. Some donation nurses emphasised the difficult nature of this stage of the consent process with minority ethnic families. They described large numbers of family members – sometimes up to 15 or 20 – present during the donation request, and their struggle to ensure that the appropriate family member/s make/s the final decision on donation; along with trying to sufficiently explain the process to others present. In this way, 'BME' families were understood to pose a problem for negotiations around donation, since their decisions were viewed as the outcome of a complex process of deliberation between various individuals. These included immediate and extended family -

Figure 6. The first page of NHSBT's consent form for organ donation.

FORM ▮▮▮▮▮▮
Approved: 12/08/09

NHS
Blood and Transplant

Consent   ODT Donor number ☐☐☐☐☐☐

PATIENT DETAILS	Section 1

Name _____   NHS number ☐☐☐☐☐☐☐☐☐☐

Address _____   Hospital number ☐☐☐☐☐☐☐☐☐☐☐☐

_____   Date of birth ☐☐ ☐☐ ☐☐☐☐

_____   Age *(If under 3 years record years and months)* ☐☐ years ☐☐ months

Postcode ☐☐☐☐☐☐☐

CONSENT FOR ORGANS AND TISSUE	Section 2

Complete Box A, if not applicable continue to Box B

A Name of patient _____

requested the donation of the following organs/tissue for transplantation via the Organ Donor Register/donor card/expressed wish/Will* *(*Delete as appropriate)*

B I _____ the _____ of _____

(Name)   *(Relationship to the patient)*   *(Patient's name)*

give consent to the donation of the following organs/tissue* for transplantation.
*(*Delete as appropriate)*

Organ   **Please tick appropriate box**

Organ	Yes	Mode	No	Outside age criteria	Clinical contraindication	No Coroner's permission
Kidneys	☐	☐	☐		End-stage renal failure ☐	☐
Liver	☐	☐	☐			☐
Liver hepatocytes (including storage)	☐	☐	☐	☐		☐
Heart	☐	☐	☐	☐		☐
Lungs	☐	☐	☐	☐		☐
Pancreas	☐	☐	☐	☐	History of diabetes ☐	☐
Pancreas for Islet cells (including storage)	☐	☐	☐	☐	History of diabetes ☐	☐
Bowel	☐	☐	☐	☐		☐
Eyes	☐	☐	☐	☐	History of diabetes ☐	☐
Other (eg stomach where appropriate)	☐	☐				

Mode of consent
1 - ODR
2 - Donor Card
3 - Will
4 - Expressed wish (written or verbal)
5 - Nominated Representative
6 - Consent from Family

If YES | Please specify explicitly _____

Cross-reference in primary document: ▮▮▮▮▮▮   Page 1 of 5

aunts, uncles, cousins etc, 'community' members, and religious figures, such as Imams. This was in contrast to the commonly described small 'white' family units: parents and siblings, or partner and children.

In this way, standardised notions of the family, and *who* should be involved in donation decision-making, sometimes broke down in encounters with 'BME' families. One ICU Consultant at Hillview, Matthew, had even developed tactics for getting past this 'difficulty' by only allowing 3 people in the room during donation requests and in discussions with families about the death of their relative. As he put it, when discussing his withdrawal of care conversations with 'Asian' families: "if they ['Asian' families] had their way there would be about thirty of them in the room, and the person you really want to speak to is the wife". Disparaging comments such as these also illustrated the way in which 'BME' families were perceived to be an issue for donation negotiations, by virtue of how they were implicitly contrasted with standardised notions of the ('white') family. Rather than 30 people in the room, 3 people are considered to be an appropriate, more manageable number by Matthew here. In conceptualising 'Asian' families in this way, Matthew also *produces* them as a homogenous category. 'Asian families' are automatically classified as an unruly and difficult to manage group for the consultant's routine work of communicating death and donation to families. This problematic construction of the 'BME' family in relation to norms of donation practice I further deal with in section 3.

One story highlighting the complexity of 'family' in donation consent came from Emily's experience of requesting donation from a 'Muslim' family at Hillview. Emily's narrative began with an ideal donation scenario: a woman had suffered a spontaneous subarachnoid haemorrhage and was transferred to Intensive Care. Emily described it as:

> *Absolutely* text book stuff regarding, you know, identification of brain stem
> death, the [brain stem] testing had all been done by John [the Clinical Donor

Champion] and one of the other consultants. I was on call, and came along after

the patient was referred. [It was a] planned approach: the consultant did the

brain stem death talk [with the family] and I then spoke to them about donation.

(Emily, donation nurse at Hillview)

Emily reflects on the initial stages of this encounter as exactly in line with donation procedure (covered in chapter 3): she is called early and adopts a collaborative approach, which involves her being present from the time the consultant delivers the news of death to the potential donor family. As her story opens out, however, this ideal scenario becomes more complex, when, after agreeing to speak with her about donation, the family do not fit the usual notion of next of kin. She describes how, rather than the husband of the potential donor including his children in the donation conversation, he requests that his nephew and niece accompany him. As Emily recounts, this was seen as "odd" by other members of staff. However, in recognition of her long experience as a donation nurse, Emily describes how she responded with: "Well if that's what he [husband] wants, you know, we'll just do what he wants."

Emily then asks the family whether they would consider organ donation, describing how she fully expected them to say 'no' to the request. This reveals her entrenched presumptions about 'Asian' families in donation situations: that donation requests to such families will automatically result in donation refusal. However, her expectations are confounded when the husband expresses an interest in donating his wife's organs. This he pivots around the chance of his sick nephew, who was on the transplant list, receiving part of her liver. Emily describes her excitement at the possibility of Hillview having its first 'Asian' donation that she can recall. However, as her story unfolds, this chance of consent never materialises:

We went through the whole spiel of, you know, all the options available [to the

family], one of them being organ donation. And I'd carried on talking and was

213

waiting for him [husband] to say 'No'. But, you know, he continued to listen. I stopped and asked whether he had any questions': [husband:] 'No, this is something I want to think about.' The family then started talking in Punjabi and I could hear 'liver', 'heart', 'kidneys'. And I'm thinking they are *actually* going to go ahead with this [donation]. Then the husband asked his niece to explain to me another part of it, which was the fact that the nephew who was sitting in front of me was waiting for a liver transplant. So obviously the question was then: can he receive the liver? So I said, you know, 'We'll see.' So made the enquiries and all the enquiries we came out that yes: it looked like the transplant centre would let this lady's liver be used for her nephew. So I went back to the family and the husband asked if he could just have five minutes by himself. And when I came back again the next thing that he [husband] said, was that he'd spoken to his Mullah[73], and he was extremely sorry, but the Mullah had said that he couldn't consent to donation. He said that he could not consent for his wife because it was Allah's way that his wife had died. It was Allah's decision. And he [husband] said you know, 'donation is not allowed within our religion.' So I said 'Well actually that's not correct. It is all about interpretation of the Quran, and did you tell your Mullah that your nephew was waiting for a liver transplant as well?'; 'Yes I did.' And I said: 'your Mullah still said no?'; 'Yes.' And that's when he [husband] said that 'My Mullah had said that if we had discussed donation during her lifetime, or she had been on the [donor] register then she would have been allowed to donate.' (Emily, donation nurse at Hillview)

Emily's example here illustrates the complexity of the process involved in the husband's eventual refusal to donate his wife's organs. His decision is understood as an outcome of

---

[73] A Mullah is a Muslim man educated in Islamic theology and law, and often refers to any type of Muslim clergy.

negotiations between differently involved individuals. To begin with, the husband's initial interest in donation is described through his hope that his nephew might directly benefit from the donation. In this way, Emily implicitly conveys the husband's personal responsibility to donate his wife's organs for the sake of his nephew, who constitutes a vital part of the decision. Emily describes her process of negotiation with the transplant team, to confirm that the nephew could take part of the liver. She constructs this part of the process as manageable and positive: the motivation to donate can be met and the key relative – the husband – seems keen. However, upon her returning to the group, a further decision-maker has been brought into the picture: the Mullah, and, with this, the rule of Allah (God). Religion and its representative thus become active participants in the husband's final decision to refuse donation, with his explanation that, without knowledge of his wife's wishes, he is unable to provide consent on her behalf.

This drawn-out process of decision-making, involving immediate and wider family, along with a religious authority, highlights the perceived difficulty of negotiating donation decisions with 'BME' families. Moreover, with the involvement of the potential donor's nephew and niece, rather than her children, the standardised notion – laid out in the HTA's consent guidelines (2009a) – of *who* constitutes a qualifying relative is shown to break down in practice. Here, rather than simply the highest qualifying relative – the husband – being the one who decides, the decision is meted out to various individuals, including nephews and nieces, the mullah and God, alongside the potential donor herself – who never registered her wishes around donation. For Emily, this decision is initially difficult to understand. This is shown in her challenge to the husband over his choice, using her understanding of Islam's official positive stance on donation. This frustration Emily also links to the fact that not only did the nephew lose out on a liver transplant, but she also later

discovered that a young baby of compatible blood group to the potential donor was on the super-urgent waiting list for a liver[74].

The disgruntlement over the husband's decision was not confined to Emily. She recounts how it caused continued consternation amongst Hillview's Intensive Care staff:

> But, so [louder] since then that has caused, as I say...discussion: a lot of discussion amongst the staff and not necessarily, you know, nice discussion should we say. Because you can imagine sort of like what people are saying.
> (Emily, donation nurse at Hillview)

The negative discussion over the outcome of this case can be mapped to the way in which 'BME' groups have been handed responsibility by policy, research, and public campaigns to solve 'BME' transplant inequalities by donating more organs, as described in chapter 1. In this example, staff frustration at the 'Asian' family's eventual refusal to donate is traced to their obligation to donate for the sake of various parties. These include not only the donor's nephew and the baby in need of an urgent liver transplant, but also the potential for Hillview to generate more 'Asian' organ donors – which we witness with Emily's excitement at the husband's interest in donation. In contrast, the husband's perceived responsibility towards Islam, and his bringing of the Mullah into the process, seemingly undermines these constructed responsibilities.

This frustration over the husband's eventual decision I also understand through the HTA's standardised package (Fujimura, 1992) of *who* makes up a qualifying relation in organ donation, described earlier. The often described extended family involvement in 'BME' donation decisions contrasts with the neat notion of family, delineated in the HTA's consent hierarchy. The way in which 'BME' families were constructed by health professionals as a

---

[74] The super-urgent list is made up of patients who will die within a few days without a transplant.

difficult group for donation negotiations can therefore be connected to normative notions of what constitutes a family – and thus a donation decision-maker.

In the traditional Anglo-European context the family takes the form of biological, bilateral relations (Strathern, 1992; Featherstone *et al.,* 2006; Gibbon, 2011). Here the notion of family is constituted by blood relations on both the mother's and father's side, with relatedness assigned by degree from this central point, i.e. sibling, aunt etc. That 'BME' families' decision-making around donation involved various individuals – not necessarily understood to be family members (in the traditional sense) of the deceased – problematises the standardised notion of what makes up a family, and thus who can act as key donation decision-makers. In a similar way, Shih *et* al's. (2001) study of donor families in Taiwan showed how the collective process of donation decision-making by Taiwanese extended families was not represented by consent procedures and forms; which only recognised the legal next of kin – the spouse – as the sole consent provider, and thus decision-maker, for donation.

In stories of the complex negotiations by differently involved decision-makers in 'BME' donation scenarios, we see the problem of viewing consent as a product of individual decision-making. Firstly, the notion of family is understood as fundamental to the donation process, in that donation nurses and other health professionals must involve various family members in their negotiations around donation. However, secondly, this concept of the family was often made problematic in encounters with 'BME' families. These families were often described as differing from the normative family unit: in their drawing on different resources – beyond family and into 'community' and religion – to make donation decisions. This was thirdly perceived to have an impact upon health professionals' ability to facilitate decision-making.

As Bowker and Star remind us in their work on classification and its consequences, categories, such as the ''BME' family' act as boundary objects. These "are able to both travel across borders and maintain some kind of constant identity" (1999:15-16). In organ donation, the notion of family gets differently constituted in the interaction of variously involved individuals (family in practice) with the classificatory norms of the HTA (family in theory). In this way, the ''BME' family' was differentiated from the normative notion of what a family *should* be in organ donation. This differentiation meant that they were perceived to present particular problems for donation request, and were seen as an innate barrier for successful donation negotiations and thus in need of careful management. In addition, as I go on to describe below, a small number of stories conveyed how standardised notions of the family may lead to queries over the legitimacy of 'BME' families' responses to donation requests.

Questioning the legitimacy of donation decisions

I was directed to interview Megan, one of the more inexperienced donation nurses with team 2, after her team leader told me that she had an interesting case for my study. During her interview, Megan recounted how she was called to an Intensive Care ward to request the donation of a young 'African-Caribbean'[75] man who had experienced, as she explained, a "lifetime of illness". The man's family had been informed of his death and checks revealed he had registered as a donor, as part of his driving licence application, a few years earlier. The family had been told Megan would be coming to talk to them about donation, however, upon her arrival she was informed that they were not yet ready to speak with her. Megan

---

[75] Going through this man's case notes after our interview, Megan later realised that this man was actually from Africa. She had categorised him as 'African-Caribbean' without knowing his heritage, showing the contingencies of how individuals get assigned to ethnic identity categories by health professionals (Ahmad, 1993).

then waited a number of hours to talk with the potential donor family, during which time she started her own investigations of the situation:

> The sister in charge of the unit that day, she approached *me* and said that there was a letter for me that she was quite confused about. Erm...now the nurse at the bedside, [who] had been involved with the family, she had said that when the patient's wife was on her own at his bedside, that they'd talked quite freely about a lot of things: about her husband and his illness. But whenever the rest of the family were there she didn't seem to have a voice, she was very quiet. As I say, this letter was presented to me from just the family in general, and it said that they understood their relative was on the organ donor register. However, they felt that it [donation] was against their cultural beliefs, and that he should remain whole and shouldn't donate any organs. (Megan, donation nurse for team 2)

Megan here questions the position of the potential donor's wife by her understanding that she – deduced from the description given by the patient's nurse – occupies a passive position within the family. She then describes the letter, written by the family and handed to her by the Sister on the unit. In this, the family outline their, as she describes "cultural" reasons for refusing donation: wanting their relative to remain intact, alongside their, as she later describes, understanding that their relative had changed his mind about being on the donor register. For Megan, this was a tricky position to be put in, since, according to her records, the patient had registered his wish to donate. Megan goes on to describe this case as a problem to be solved: did the potential donor really change his mind on donation? And did the family have the right to refuse donation on his behalf? Her questioning of the validity of the family's decision continues with her description – gathered again from the

treating nurse – of how the patient's wife was unaware that her husband was even on the donor register:

> And she [wife to the nurse] actually said 'we've never talked about organ donation.' And yet in the letter it said that the conversations they'd had had been with her. So...being someone of relatively new experience I'd never encountered anything like that before. But [...] I didn't feel like I just wanted to walk away. Because I did feel that his wishes were that he wanted to donate his organs. (Megan, donation nurse for team 2)

This conviction that the patient would have wanted to donate his organs, Megan goes on to reference around her belief that his ongoing illness and routine hospital admissions meant he would have known what he was doing when he joined the donor register. She explains: "he knew about hospitals, he knew what illness was about". With this understanding, along with the knowledge that the wife was not even aware of his being on the register, she finds herself disbelieving of the family's claim that the patient had since changed his mind on donation. Megan here makes a value judgement on this family, implicitly categorising their decision, and, in turn, the family themselves, as troublesome for her practice. Determined to try and find out more about the situation, Megan asks the treating nurse to tell the family that she wanted to speak with them. As she then describes, her encounter with the potential donor's brother and wife leaves her further convinced that the family's decision did not fully represent the wishes of the donor:

> So I was approached by the brother and the patient's wife. And the brother immediately said, 'I don't know why you want to talk to us. We've already said we don't want to do this.' So I just said to him 'I understand, I've read your letter. Thank you for thinking about it.' And I just said that 'I *have* to also make sure that you understand that from my point of view that was his last recorded

wishes [to donate], and that we have to try and fulfil that. But if you know of otherwise.' Then he [brother] said to the patient's wife: 'He spoke to you and said he didn't want to do it didn't he?' And she nodded. But she had already told the nurse at the bedside that they'd never spoke about organ donation. So, I couldn't say any more. If I said any more it would have looked like I was harassing them. (Megan, donation nurse for team 2)

In this case we see how the formalised (HTA) hierarchies concerning *who* can legally provide consent for donation have weight, when a family seemingly makes a decision which does not conform to these standards. Megan explains how she described her responsibility to fulfil the last recorded wishes of the patient to his family. Since the patient was on the donor register, Megan had the legal right to proceed with donation. However, she goes through the usual practice of seeking agreement from the family. This agreement, according to the HTA hierarchy, would usually fall to the donor's wife. However, the letter, describing the family's collective decision and Megan's puzzlement over the wife's position complicates her ability to ascertain who has made the decision to refuse. She conveys the brother's confrontational introduction: "I don't know why you want to talk to us" to imply that it was the brother, rather than the wife, who was directing the donation refusal. This she emphasises by contrasting the wife's agreement to the brother's assertion that the patient had changed his mind on donation, with her knowledge of the wife's ignorance of her husband's donor registration. With this, Megan calls into question the negative outcome of this case.

Megan's narrative here demonstrates the questions which get asked in practice about *who* is qualified to make a decision on donation. Similar to the way in which 'BME' families are constructed as a problem for donation negotiations, when their decision-making processes fail to conform to standardised notions of consent, the legitimacy of their donation

decisions are called into question. In addition, Megan conveys how she did all she could to facilitate a decision from the wife – the most appropriate relation to provide consent, according to the HTA. This illustrates how donation practice is also responsive to the norms and standardised definitions of 'family' (Crowley Matoka, 2005), as laid out in the HTA's consent hierarchy. With the above example, we also see, from Featherstone *et al.* (2006) how *the* family – as decision-makers in organ donation – is far from a "naturally given entity" (p. 25) which can be neatly mapped to formal (legal) and biological (scientific) notions of relatedness. Instead, relations, and thus the practice of decision-making are produced "through the everyday practical work of mutual recognition and interaction" (Featherstone *et al*., 2006: 54; see also Franklin, 2001). For Megan therefore, her ideas about *how* and by *whom* a donation decision should be made are thrown into relief in the encounter with a family who do not conform to these norms (Agar, 2006).

In this way, the standardised *idea* of family interacts with health professionals' understanding of donation outcomes, and, in turn, their donation practices around 'BME' families. This also leads to the implicit categorisation of the ''BME' family' as a problem for donation negotiations, as demonstrated by the example of the consultant who limited the number of family members in his discussions. As such, and as I draw out below, I argue that the 'BME' family do not simply present a problem for health professionals in organ donation because they *are* a problem, but that they become *constructed* as a problem by the bureaucratic norms upon which the donation process, and routine ways of working in Intensive Care, are premised.

Part 3. The 'BME' family as outsiders

The previous two sections have demonstrated how standardised notions of consent for organ donation break down in practice with 'BME' families. This occurred firstly during discussions about a patient's diagnosis of death between ICU staff and families, with 'BME' families' refusal to accept medical decisions on death; and secondly during donation negotiations with 'BME' families – conceived as problematic for consent by virtue of their extended family set up and the diversity of actors involved in their donation decisions. In this way, 'BME' families came to be perceived as a particularly problematic group for the everyday processes which function as vital stages towards securing donation. The understanding that 'BME' families presented particular difficulties during the donation trajectory was not limited, however, to donation practice. In this section, I argue that conceptualisations of the ''BME' family' as a problematic group in donation can be traced to wider portrayals of the disruption such families present for the routine work of Intensive Care medicine; upon which the procedures of donation are premised.

Intensive care staff often discussed their interactions with 'BME' families in wider terms to the donation encounter. In my questions to ICU staff about their experiences of withdrawal of care with 'BME' families, I contextualised their struggles around donation with their depictions of the specific problems which 'BME', particularly 'Muslim' families posed for their routine medical work. Here, staff perceptions of large families with demands for information about their relative's condition and certain needs around death – such as 'Muslim' families' requirements for the quick burial of their relative – were often contrasted with the behaviour of 'white' families in similar situations. In turn, the needs of 'BME' families were conveyed as inhibiting the ability of staff to carry out their usual responsibilities, such as facilitating legal requirements at the end of life. Such requirements

include the involvement of coroners after patient deaths in Intensive Care[76] and the need for a post mortem on a patient, if a coroner cannot satisfactorily establish the cause of death. Coroner involvement also acts as a vital stage for organ donation, since in cases with coroner involvement, donation can only proceed with their permission. In situations where ICU staff called for a coroner and/or post mortem investigation on dead 'Muslim' patients, the families of the dead were described in terms which referenced their specific difficulties with these practices. These 'difficulties', however, were often based on staff presumptions about the specific needs of 'Muslim' families after death: needs made problematic by their comparison with the perceived needs of 'white' families.

One consultant at Hillview, Matthew, described a case where a 'Muslim' family became distressed when their relative died on a Friday, meaning he struggled to get hold of the coroner until after the weekend[77]. This delayed his ability to issue a death certificate, and therefore release the body to the family. Matthew described the family's distress, however, in terms of their specific need for a quick funeral, remarking: "Asian families tend to want everything done before sunset don't they?" This disparaging remark has the effect of firstly stereotyping 'Asian' families through homogenising notions of their 'culture' around death, and secondly, reducing their distress to a technicality of their relative's body being released. By conceptualising the behaviour of 'Asian' (specifically 'Muslim') families in this way, they became constructed as a uniform, problematic group for Intensive Care practitioners, as the example below further demonstrates.

Ketu, a PICU consultant at Lakeland, described his general experience of dealing with 'Muslim' families in his routine care of patients and the requirements involved after death:

---

[76] See chapter 3 for an explanation of the circumstances under which a coroner must investigate a death.

[77] Weekends were described as particularly slow times for releasing a body, since even coroners have weekends!

It [in the case of 'Muslim' families] does potentially cause a problem for us in simple things like who actually comes in and visits the patient, as opposed to having twenty people on the corridor of the Intensive Care Unit, or everybody wanting to come and everybody wailing when a child's care is being withdrawn. To also the fact that they're [Muslim families] very keen on having access to the child far more so than other families. I mean I'll give you an example, there was a child post-operative surgical patient [who] had lots of problems, Caucasian parents, and the child died over the weekend on a Saturday or Sunday. And wasn't amenable to organ donation, but I remember specifically saying to Mum and Dad, 'obviously I'm going to have to speak to the coroner before I can issue a death certificate and release the body. And I'll try very hard to get hold of the coroner on Saturday. I can't promise you anything, it might be Monday'. And Mum turned round to me and said, 'It doesn't really matter 'cause she's gone now.' Whereas Muslim families, my own personal perception, and I'm sure most of my colleagues will agree. [....] so one Muslim family I was involved with, similar sort of age child, they kept on ringing me *every* hour on the Unit. The nurses were very good at shielding me because I couldn't do anything until I'd spoken to the coroner, and I couldn't get hold of the coroner. And the family were ringing *every* hour to ask 'has Ketu spoken to the coroner? Has the body been released?' And that puts a huge amount of pressure on us I think as well. (Ketu, PICU consultant at Lakeland)

Here, 'Muslim' families are framed as a problem in the specific context of Ketu's routine, pressured work as a PICU doctor. He positions their needs as overly-demanding, demonstrated by his descriptions of their disruptive presence on the ward: large numbers of people making a lot of noise, and their requirement for greater access to their relative than

225

he considers usual. In describing his contrasting experience with families after the death of a 'white' patient, compared to that of a 'Muslim' one, he affirms his point of the specific difficulty 'Muslim' families present for his job. He describes the 'Caucasian' family's lack of upset when he tells them that their child's body will not likely be released until after the weekend. This he then compares with an example of a 'Muslim' family in similar circumstances. In contrast to the 'Caucasian' family, the 'Muslim' family are perceived as difficult because of their demands for the body to be released as soon as possible. He describes being called every hour, and being "shielded" from the family by nurses, conveying the pressure he felt such actions put him under, and his powerlessness to do anything further until speaking with the coroner.

In Ketu's detailing of two family scenarios, we see how 'Muslim' families get specifically derived *through* their comparison with 'Caucasian' families; positioned as the unproblematic norm. Whilst 'white' families allow for routine bureaucracies around death, which, as one nurse described, were tied to the usual practice of having a funeral one week after death, the needs of 'Muslim' families were described as placing specific demands upon health professionals at the time of death. Moreover, by referring to 'Muslim' families as "they", Ketu, like Matthew, composes them as an aggregate, with certain – assumed – 'cultural' characteristics, which throw up problems for his everyday work. Medical literature on death and dying practices of minority ethnic groups similarly tends to present descriptions of their requirements around death according to religious and 'cultural' traditions. For example, Gatrad (1994) describes 'Muslims' in terms of their requirement for a burial before sundown, and their preference to die in their own homes; and Gupta (2011: 254) talks about the 'Hindu' requirement for "a basil leaf, ghee and piece of gold" to be placed in the mouth to fulfil the need for wealth and food in the afterlife. In this way, I argue that 'BME' families are *produced* as a specific problem in their differentiation from the norms of

practice and behaviour around death in the UK context. This not only has the effect of homogenising the individual status of minority ethnic families (Bowler, 1993; Atkin *et* al., 1998), but also produces them as *outsiders* to, and deviant from, medical norms, and thus as problematic populations (Becker, 1963).

For Howard Becker (1963), the notion of the outsider – such as the ''BME' family' in organ donation – comes about when people or groups break with understood norms of behaviour. Such rules include those which are "formally enacted into law" (Becker, 1963: 2), which, in our case, includes coroner involvement at death. These rules define the standards of behaviour in certain contexts, like the agreement to allow a deceased relative to be subject to post-mortem, and compliance with the rules of an Intensive Care ward, such as the restriction on the number of visitors to a patient. People are therefore defined as deviant when their actions are viewed as breaking with normative rules. Since certain – 'Muslim' – families were experienced as difficult in relation to the norms of Intensive Care medicine, they became conceptualised as problematic. According to Becker, this outsider status is a process by which people are labelled as different, rather than an inherent "quality of the act the person commits" (1963: 9). The status of 'BME' families as a problem for organ donation practice specifically, and Intensive Care medicine generally, can therefore be understood as not so much of a given (they are not innately a problem), but as a result of the difference created in the interactions between 'BME' families and the norms and infrastructures of Intensive Care medicine (Becker, 1963; Agar, 2006; Star and Lampland, 2009).

In Ketu's story we glimpse the production of this difference in his description of the difficulties with getting hold of a coroner in the case of both the 'white' and 'Muslim' family, and his expectation that families will wait for this process to happen. With this we see the assumptions which guide the work of ICU practitioners: that legal authorities, and hence the Intensive Care ward, has the right, over a family, to retain a body for further investigation.

This throws into relief the expectations about how things *should* work around death, highlighting the artificial construction of the category of the ''BME' family' as a problematic group.

Elizabeth Moran, an experienced PICU nurse at Lakeland, was the only participant who actively made these assumptions visible, in her insider critique of the clinical 'culture' of ICU medicine. For Elizabeth, rather than characterising 'Muslim' families as inherently problematic for her work as a nurse, she described the bureaucracies required by medicine and the law – death certificates, post mortem, and coroner examinations – as inhibiting the needs of families:

> The difficulty is if a [Muslim] child's going for a PM [post-mortem]...that they're [family] not going to be able to bury that child in 24 hours. They can't get the child out and it's like we're saying to them: we completely respect your religious beliefs and what you want to do, but you can't have your child back because we're going to do a PM and that's a legal requirement. So the law doesn't actually respect that. [....] [and] when it becomes a coroner's case, which seems to happen more and more often now [...] and it seems a lot more complicated and a lot more time consuming now, there's a lot more times recently that we haven't been able to get children home or to the mosque before sundown. There was one family with a newborn baby who'd been sent over from another hospital. He [baby] was going to die with an incurable condition. So we withdrew treatment and then the coroner agreed that because of the diagnosis, which *was* confirmed, the family could go. But then trying to sort out the red tape to get this poor baby back to their town was just a nightmare, because they had to register the death over here. Of course they've not even registered the birth yet, so we had to get dad in a taxi to the registrars, then we helped mum to do

228

everything she wanted to do with the baby and then we had to get the funeral

directors over from their town and it was...it just seemed to take so long. It's just

dead frustrating really. (Elizabeth, PICU nurse at Lakeland)

In Elizabeth's highly reflexive account she is less focused on the difficulty of 'Muslim' death practices (i.e. that their needs inhibit her ability to do her job properly), and more on how medical and legal bureaucracies prevent families' needs being met. She goes so far as to say that such processes do not "respect" the needs of certain population groups. In addition, revealing her own position in such situations, Elizabeth conveys her own frustration with these normative procedures around death. This disquiet is produced in the tension between trying to care for recently bereaved families and having to meet the legal requirements to release a body. She therefore highlights the assumptions behind standard practices, such as coroner involvement after death, which presume a family's acceptance of the bureaucratic processes which legally construct a dead body for burial.

Here we are given an alternative understanding to the commonly described 'problem' of 'BME' families in organ donation. This being that the norms and bureaucracies of Intensive Care medicine produce the problematic status of the ''BME' family'. Importantly, these standardised practices, like coroner involvement after death, and the limitation of visitor numbers to a patient's bedside, also background the procedures of organ donation. That the standards of Intensive Care medicine form the rules upon which organ donation is predicated also has implications for the production of power relations in donation encounters (Becker, 1963). According to Foucault, the "systems of relations that are established between" elements such as laws, institutions (hospitals etc), and people are "always inscribed in a play of power" (1980: 196), since they simultaneously construct the norms of discourse, relating to, for example 'the family'. In this way, the systems in place around death and donation in medical institutions not only impact upon the individual

229

experiences of families (Star, 1991; Star and Lampland, 2009), but also construct a normalising benchmark upon which families are interpreted and differentiated (Foucault, 1977: 184; Martin, 2005).

Conclusion

In this chapter I have called into question public and policy representations of *what* consent for organ donation entails, and shown how these break down in encounters with 'BME' families. As demonstrated, donation refusals can be traced beyond the assumptions made, in research and policy, about the unwillingness of 'BME' populations to donate their organs. Alternatively, donation refusal – and thus consent – can be linked to the struggles between health professionals and 'BME' families to come to a shared understanding of the death of a patient. Donation success is thus premised upon families accepting the medical diagnosis of the death or dying status of their relative; an acceptance fostered by the negotiations of medical staff to legitimate their decisions to families. In addition, this process illuminates wider issues around the moral status assigned to the practice of withdrawing care on dying patients, and the place of religion in death: in the challenge by religious figures to the authority of medical decisions on death.

Moreover, 'BME' families were not just viewed as problematic in death diagnoses, but were also *produced* as a problematic category in relation to the standardised understanding of *who* has the right to act as a decision-maker and consent-giver in donation. This relies upon the delineation of *what* the normative family *is* – a small and thus manageable unit – which backgrounds the HTA's hierarchy of consent. Norms such as these therefore underpin firstly, the troublesome status ascribed to 'BME' families in donation negotiations; and secondly, the way in which their donation decisions – described as an outcome of various actors encompassing immediate and extended family, and religious figures – were called into

question. In this way, we see how donation practice is responsive to the norms and standards of donation procedures. In turn, this contributes to the way in which certain populations, such as 'Muslim' families, are viewed as disruptive to, and in need of careful management during donation negotiations.

When families did not conform to the definitions upon which they are supposed to act within donation contexts, they became viewed as problematic groups. The ''BME' family' are thereby constructed as an issue for donation consent when they fall outside of classificatory norms relating to *the* 'family', and fail to conform to the routine practices around death in Intensive Care medicine – which buttress the procedures of organ donation. In the next chapter, I develop the theme of consent by examining the work done to obtain formal consent for organ donation from families. As I will show, this is a stage which, whilst vital for making donation happen, also worryingly reproduces the 'problem' of ethnicity in organ donation.

Chapter 6. Consent Practices and the (Re)production of Ethnicity in Organ Donation

Introduction

In the preceding results chapters I have demonstrated how the 'problem' of low donor rates in minority ethnic populations goes beyond the presumed 'cultural' barriers which 'BME' 'communities' present for organ donation. Instead, I have traced the 'problem' into the organ donation encounter, and the procedures, practices, and decisions of health professionals who make donation possible. I also evidenced the way in which 'BME' donation refusals are related to the difficulties involved in negotiating death diagnoses and donation requests with 'BME' families. Getting through these stages are vital if a family is to provide their formal consent for organ donation. It is this process of gaining 'valid' consent from a family with which this chapter takes up, in 2 parts.

In the first part of this chapter I focus upon the procedures and practices involved in taking formal consent for donation from potential donor families. This involves the donation nurse taking the family of the deceased through a series of forms, conveying information about *what*, exactly, they are consenting for, and gathering a medical and social history of the potential donor, to assess the suitability of their organs for transplant. Using examples of this process, I show that the ability to secure consent from a family is contingent upon the work of the donation nurse: in their adaptation of formal forms and procedures around the perceived needs of recently bereaved families. As such, I argue that consent for donation can be considered a precarious process; dependent upon the interpretative practices of the donation nurse and their ability to balance families' needs with the legal requirements for consent.

However, in part 2, I also highlight the problematic nature of this interpretative process. This occurs when the practices of the donation nurse turn upon preconceived notions of the characteristics of 'BME' potential donors and their families. Here, I argue that the work which gets done around consent by the donation nurse – and other health professionals – actively constructs ethnicity as a problem, thereby reproducing the assumptions originally created in transplant policy, research, and health promotion responses to the 'BME' donor 'problem'. This leads me to finally argue that the 'problem' of ethnicity in organ donation is as much about the assumptions which get made around ethnicity and their interaction with donation practice, as they are about families simply refusing the request to donate their relative's organs.

Part 1. Formal requests, informal practices: producing donation consent

During my participation in an organ donation "simulation day" for Intensive Care and Accident and Emergency (A&E) nurses – the purpose of which was to train the nurses in the procedures of donation – I observed a role play, which demonstrated how donation consent is done with families:

> The day is taken by a group of donation nurses from team 2, who guide their audience through each and every part of the donation trajectory, using an interactively-designed training package. In the afternoon there is a session on a*pproaching a family for consent*. The donation nurse taking this session begins by outlining the consent process for her audience by relaying the standard *Verble and Worth*[78] training they now all receive in requesting donation and obtaining formal consent from a family. She conveys to her audience how this

---

[78] See chapter 3 for a further explanation of the donation nurses' Verble and Worth training.

training instructs them to look out for non-verbal cues from a family that would indicate any discomfort, and how they, in turn, are told to adopt a relaxed posture to put a family at ease during the process. Demonstrating this posture, the nurse asserts: 'we're taught to sit forwards, legs slightly apart, palms up.' There is much laughter from the group as she performs an exaggerated form of this pose; looking like some type of sexual offering is taking place. 'Can you imagine?!' she exclaims, making fun of the standardised version of what a relaxed posture should look like.

Furthering this parody of their training, the donation nurse then describes to her audience how they are told not to touch family members during their interaction. She goes on to relate her position on this rule, stating: 'I'm quite touchy feely. I won't give them a snog or anything, but if they want to give me a hug I'm not going to say no'. She then, more seriously, explains their acute awareness of everything they do during the consent process, since, as she puts it: 'we have it drummed down our throats'. Another donation nurse pipes up, expressing her opinion on the importance of being able to negotiate their formal training to ensure each case is dealt with according to the situation. 'You've gotta use it as you feel appropriate' she explains. (Fieldnotes, February 2011)

This part of chapter 6 is about the practice of taking formal consent for organ donation, and how consent guidelines get adapted by donation nurses in their everyday work. In the above example we see that the training which donation nurses receive in taking consent, and the standards this imparts – such as exactly *how* they should act around a family during the process – are not necessarily adhered to in practice. Here, the donation nurse takes her audience of ICU and A&E nurses through the consent procedure by initially parodying her own consent training. For example, she uses comedic effect to demonstrate the absurdity of

not being able to touch a distressed family who have just lost their relative. Instead, she and her colleague convey how, rather than simply fulfilling standardised consent procedures – such as not obliging the request for a hug from a family because it goes against what they are taught is appropriate – they use their knowledge of procedure to adapt their practice to different situations.

Taking formal informed consent for organ donation from a family is a complex process for the donation nurse. They are tasked with ensuring that the needs of the recently bereaved are met, whilst balancing these alongside the requirements of legal consent. To *do* consent the donation nurse must draw upon a vast range of: resources, skills, recognised standards and procedures, training, information, and experiential, embodied – by which I mean tacit – knowledge and caring practices (e.g. Berg, 1996; Timmermans and Berg, 2003; Singleton, 2010). As I go on to demonstrate, consent is an interactional process, involving the donation nurse's adaptation of procedure around their interpretation of a family's characteristics, behaviour, and thus needs. By moulding consent to each situation, donation nurses also ensure that it gets done, and the act of procuring organs from a donor can thus take place.

The way in which consent is *done* for deceased organ donation was formalised with the introduction of the Human Tissue Act (HTA) in 2004, and its later Codes of Practice for the *Donation of Solid Organs for Transplant* (2009a) and *Consent* (2009b). These lay out "how the law should be applied to consent for the removal of tissue, including organs, from the deceased" (2009a: para. 94). To take consent, donation nurses must draw on these codes in addition to further standards, encompassing UK Transplant's (2004a) *Donor Family Care Policy*[79] and the *Verble and Worth* consent training, described above.

---

[79] This includes a step-by-step table which outlines the stages for the 'family interview', including the initial request for donation through to the forms of information which must be provided to the family, and the process for doing a social and medical assessment of the donor.

The Human Tissue Act was brought into force in 2006 after the UK organ retention scandal, which came to public attention in 1999. As discussed in chapter 3, this found that tissues and organs were being procured and used in research without proper consent, after the post mortems of deceased patients at Alder Hey Children's Hospital and the Bristol Royal Infirmary. During the inquiry it emerged that the ambiguous framing of consent as "lack of objection" in the previous (1961) Act, along with the "evasive and paternalistic attitudes towards bereaved parents" had contributed towards the "violations" of medical authority (Buchner and Vinci, 2001: 309; Hunter, 2001). The focus of the new HTA is therefore upon ensuring that donation consent is *informed* and *valid*. This is manifested in its conception of consent as a *process*, with the onus on transparency. This means that information needs to be provided to a family throughout the donation trajectory, rather than just during the procedure to obtain their signature on the consent form (DH, 2005). The implication here is that the accumulated provision of knowledge about donation leads up to an informed decision by a family to consent to, or refuse, the donation request. Informed consent is therefore positioned as a linear, stable process. As we will see, however, it is far from straightforward in practice.

In everyday donation encounters, formal consent is a lengthy process, with the donation nurse at the centre of proceedings. The donation nurse is responsible for ensuring that *all* aspects of consent are covered, and that the needs of differently involved constituents are met. This includes, for example, ensuring the coroner, if involved, is provided with all necessary detail about a potential donor to make a decision on whether donation can take place; and keeping the potential donor family informed about such activities along the way. Obtaining consent from a family for organ donation usually takes place face-to-face in a private space (UKT, 2004a). This most often occurs in the Intensive Care 'family interview room'; designed for sensitive conversations between families and treating health

professionals (these rooms I described chapter 5). These formal spaces of request are reflected in the consent procedure, where, once a family have initially agreed to donation[80], the donation nurse will guide them through the process of formal, written consent[81]. This involves what is known in the *Verble and Worth* training, as the 'ladder of information of consent'. Here, the family are involved in the completion of a standard five-page consent form (see fig. 6 for an example page of this form), where each organ/any tissues to be donated need to be consented for.

With the onus on *informed* consent the donation nurse must also explain what is involved in the donation of each organ/tissues. This includes what implications the operation will have for the appearance of the donor's body[82]; details of exactly what will be removed; the length of the donation process; along with the chance that the organs may be deemed not healthy enough for transplantation once they are removed (UKT 2004a). In addition, a patient assessment form (see fig. 7) is used to assess the donor's social and medical history, to help rule out risk of HIV and Hepatitis transmission to transplant recipients. Questions on this form cover the potential donor's illness history, along with more sensitive queries such as: "has [your relative] ever been given payment for sex with money or drugs?"

---

[80] This may be a quick decision, or may take hours, with the family being given time to discuss the "option" of donation – as described by the donation nurses – and ask questions of the donation nurse about the process.

[81] Written consent is not actually a legal requirement for organ donation. For donation to be "valid", the consent-giver must "understand what the activity involves and, where appropriate, what the risks are" (HTA, 2009b: para. 32). The HTA outlines how written consent "serves as evidence of consent, but a signature on a form will not itself make the consent valid" (HTA, 2009b: para. 57). In practice, however, consent forms seemed to serve as the framework for taking a family through the process of gaining "valid" consent.

[82] For example, if just the kidneys are donated, the wound on the donor's body will be restricted to the abdomen. If the heart and lungs are consented for, the wound will be much larger and extend to the thorax.

Figure 7. Example pages from NHSBT's Patient Assessment Form

NHS
Blood and Transplant

ODT Donor number ☐ ☐ ☐ ☐ ☐

PATIENT ASSESSMENT *(Information obtained from relative/significant other)*

Patient's name	Please print
Donor hospital	

Hospital number ☐☐☐☐☐☐☐☐☐☐   Cause of death: _____

Patient date of birth *(dd/mm/yyyy)* ☐☐☐☐☐☐☐☐

In order to proceed with organ and tissue donation it is necessary for us to ask you some questions - which should be answered to the best of your knowledge - about your relative's medical and behavioural history. All information will be treated with the strictest confidence.

For paediatric patients under the age of 18 months or those who have been breast-fed in the past twelve months the mother is required to answer these questions with regard to both her own and her child's health.

For children: has your child been breast-fed in the last twelve months?   Yes ☐   No ☐   Not applicable ☐

NOTE: For all donors under the age of 18 months (irrespective of breastfeeding): a blood sample is required from the mother of the donor

GENERAL HEALTH INFORMATION

1. Has your relative visited his/her general practitioner in the last two years? Was he/she currently seeing or waiting to see their general practitioner or any other healthcare professional?   Yes ☐   No ☐   Unknown ☐

   If YES, give details

2. Did your relative have diabetes?   Yes ☐   No ☐   Unknown ☐

   If yes, were they on insulin?   Yes ☐   No ☐   Unknown ☐

   Is there a family history of diabetes?   Yes ☐   No ☐   Unknown ☐

   If yes, is it insulin dependent diabetes?   Yes ☐   No ☐   Unknown ☐

3. Did your relative take regular medication?   Yes ☐   No ☐   Unknown ☐

   If YES, give details

4. Did your relative ever undergo any investigations for cancer or have they ever been diagnosed with cancer?   Yes ☐   No ☐   Unknown ☐

   If YES, give details

5. Did your relative recently suffer from any significant weight loss?   Yes ☐   No ☐   Unknown ☐

   If YES, give details

6. Did your relative have any signs of recent infection, eg colds, flu, fever, night sweats, swollen glands, diarrhoea, vomiting or skin rash?   Yes ☐   No ☐   Unknown ☐

   If YES, please specify

7. Did your relative come into contact with any infectious disease recently or have any immunisations within the last eight weeks?   Yes ☐   No ☐   Unknown ☐

   If YES, give details

8. Did your relative ever have hepatitis, jaundice or liver disease?   Yes ☐   No ☐   Unknown ☐

   If YES, give age and any diagnosis

Form PA1 Version 03 (12/08/09)   Page 1

Patient Assessment Form

ODT Donor number [ ] [ ] [ ] [ ]

GENERAL HEALTH INFORMATION continued

21 In the last twelve months has your relative been in close contact with a bat anywhere in the world or been bitten by an animal whilst abroad?   Yes [ ]   No [ ]   Unknown [ ]

If YES, give details of animal and place of treatment

22 Did your relative ever have a sexually transmitted infection e.g. syphilis, gonorrhoea, genital herpes, genital warts?   Yes [ ]   No [ ]   Unknown [ ]

If YES, give details of diseases, dates and treatment

TRAVEL RISK ASSESSMENT

23 Did your relative ever travel outside the UK?
*(If NO or UNKNOWN, proceed to **26b** then continue with Behavioural Risk Assessment. If YES, continue with questions below)*   Yes [ ]   No [ ]   Unknown [ ]

24 Has your relative travelled outside the UK in the last 12 months?   Yes [ ]   No [ ]   Unknown [ ]

If yes, give details of date of visit/return and destination.

25 Ever had a fever or received treatment for a illness whilst abroad or within six months of leaving an area where there is malaria?   Yes [ ]   No [ ]   Unknown [ ]

If YES, give date of fever/illness and places visited

26 (a) Ever live or work in an area of rural subsistence farming in Central or South America for a continuous period of four weeks or more?   Yes [ ]   No [ ]   Unknown [ ]

If YES, specify place and date of last visit, and details of living conditions

26 (b) Was your relative or their mother born in Central or South America?   Yes [ ]   No [ ]   Unknown [ ]

(c) Was your relative ever given a blood transfusion in that country?   Yes [ ]   No [ ]   Unknown [ ]

27 (a) Ever spend a continuous period of six months or longer in an area where there is malaria at any time during his/her life?   Yes [ ]   No [ ]   Unknown [ ]

(b) If YES, have they travelled to a malaria area since then?   Yes [ ]   No [ ]   Unknown [ ]

If YES, give details of where

BEHAVIOURAL RISK ASSESSMENT

28 Did your relative:

(a) consume alcohol?   Yes [ ]   No [ ]   Unknown [ ]

If YES, approximately how many units per week

(b) smoke tobacco or any other substance?   Yes [ ]   No [ ]   Unknown [ ]

If YES, give details

29 Is it possible that any of the following apply to your relative?

(a) is, or may be infected with HTLV, HIV or hepatitis B or C?   Yes [ ]   No [ ]   Unknown [ ]

(b) has ever injected or been injected with non-prescriptive drugs, including body building drugs, even if it was a long time ago or only once?   Yes [ ]   No [ ]   Unknown [ ]

(c) has ever been given payment for sex with money or drugs?   Yes [ ]   No [ ]   Unknown [ ]

(d) *(for male patients only)* ever had oral or anal sex with another man with or without a condom?   Yes [ ]   No [ ]   Unknown [ ]

Many donation nurses acknowledged the difficulty of completing these forms and fulfilling the requirements of informed consent in the context of distressed, shocked, and even angry families; recently told their relative was dead, or was to have their care withdrawn. One PICU nurse at Lakeland, Maria, who had previously worked as a donation nurse, went so far as to say that going through the consent forms with a family felt "barbaric". For Maria, having to mechanically go through a long list of each and *every* organ with a family jeopardised not only consent itself, but also her relationship with families:

> Then you'd have to say, 'a heart, would you donate his heart?' and then you'd have to give reasons why somebody might want a heart transplant. And then you'd have to [...] move on to lungs and then it'd be liver, kidneys and you'd, it just seemed like a whole *list* and once you'd gone through the solid organs then you'd have to start on the tissues. [...] So you used to feel quite...as if you were just greedy really [...] and sometimes you'd think, *Gosh they're* [family] *going to turn round and say 'No! Go away, there'll be nothing left.'* And so that was quite...hard, sort of asking them, but trying to do it in a sensitive way so it didn't seem as if you were asking for everything that they'd ever had. (Maria, PICU nurse at Lakeland)

Often, I learnt, families would express their wish to *not* know any details of the donation procedure. This placed the donation nurse in the tricky position of balancing their care for the family with the legal responsibilities of consent. In addition, the process of completing the patient assessment form, where the intimate nature of asking about drug, alcohol and sexual history was understood as difficult for families, was seen as especially problematic. To make consent *work* then donation nurses developed their own strategies for getting through the forms and the informational requirements of consent, which I describe below.

240

Obtaining consent: adaptation and adjustment

One of the ways in which consent with families was managed was by adapting, or tinkering with formal consent procedure (Timmermans and Berg, 1997; 2003; Sharp, 2006; Struhkamp *et* al., 2009; Singleton, 2010). This was to, as one donation nurse expressed, transform the "cold" process of form filling into a more "humanised" version; sensitive to the needs of potential donor families. Ellie, an experienced donation nurse, describes her own negotiation of the patient assessment forms:

> We have the same conversation with *every single family,* we have to. And they look very *cold* the forms. They're black and white NHS written forms, [little laugh] you know. It's very difficult to have a conversation with this sort of paperwork but what I try and do *personally* is put forms to one side and just try and have a chat, and you find that people will volunteer information much more easily than if you go to a tick box exercise. So I ask them [family] things like: 'Did they [donor] go on holiday last year?'[83] And, 'where did they go?' Because the instant you ask that, you know, that rules out the: 'have you been to Africa?' questions and, 'were they alright when they came back? Did they have a bit of, you know, a funny tummy or?'; [family:] 'Oh yeah they did. She wasn't well when she came back.' The family rumble you straight away. They know exactly what you're doing. [....] And, you know, there's a way of, way of doing it. If, for example, there's a section about the sexual health and risk factor questions and they're *horrible* questions: have you had sex with another man?"
>
> J: Like really intimate?

---

[83] One of the questions on the patient assessment forms asks whether the donor has travelled outside the UK in the last 12 months. This is to assess their potential for exposure to HIV and hepatitis infections if they had visited countries, such as South Africa, with high rates of these diseases.

E: Yeah. *Really* intimate questions. [....] So what I'll sort of do is just say 'there's a little section here at the bottom. I'd like you to just read that, and go through it. If there's anything you'd like to speak to me about afterwards then just come and grab me'. And you know we found out from one person that [....] [we] had a young girl who *absolutely* idolised her Dad. Wouldn't hear a bad thing about him. And his brother actually grabbed my colleague and he [donor] had indulged in some quite high-risk behaviour, and his brother didn't feel it was appropriate to discuss it because he knew the relationship the girl had [with her father]. (Ellie, donation nurse for team 1)

Ellie here begins by describing the *standardised* nature of consent: "we have the same conversation with *every single family*". However, this she contradicts with her explanation of her informal ways of working around the process. She does this to bring the coldness of the "black and white" forms into a more everyday format, receptive to the perceived needs of a bereaved family. By asking a family questions such as "did they [donor] go on holiday last year?", rather than using the standard question on the patient assessment form, which asks: "Has your relative travelled outside the UK in the last 12 months?" Ellie removes the bureaucratic appearance of the consent and donor information gathering process. Instead, she provides formal information to, and gains formal information about the donor from the family, in an informal way. By incorporating the procedure into conversational form, Ellie *transforms* the standardised forms and thereby the process of consent itself, to make it *work* in practice. (Hogle, 1995; Timmermans and Berg, 1997; 2003; Struhkamp *et* al., 2009).

In addition, Ellie conveys how this process has the potential to negatively interact with a family's memory of their dead relative, with the story of the donor whose brother divulged his 'risky' lifestyle, out of earshot of his adoring daughter. Ellie's *lack* of questions around the "behavioural risk" section of the assessment form leads paradoxically to the answers

242

she needs to assess the donor's suitability. Here, her strategies are sufficiently developed from experience to get through the tricky, mundane, and potentially distressing consent forms, so as to progress towards procurement. The ability of the donation nurse to complete the reams of paperwork and information gathering needed for donation, whilst maintaining sensitivity towards the family, also attests to their tacit knowledge (Latimer *et al.,* 2006; Singleton, 2010) of the consent process.

Donation nurses therefore drew on diverse "communicative scripts" to adjust practice standards around their understanding of a family's characteristics and needs (Rapp, 1999: 63; Lutfey and Freese, 2007). In the same way that Singleton (1998) describes how workers in a cervical screening laboratory incorporated their diagnostic decisions with information about sample-givers' identities, donation nurses integrate their understanding of potential donor families into their consent work. This involves assessing the amount of information a family may want or need – with one donation nurse describing a case with an 'African Caribbean' family, where the donor's mother specifically asked not to be given a "list of things you're taking" [referring to her daughter's organs]. It also involves interpreting a family's level of education; the relationship individual family members had with the donor – as we saw in Ellie's description above; or reading their body language and taking regular breaks during the process, if a family seem tired or distressed.

The Human Tissue Authority's code of practice for consent (2009b) recognises the importance of such nuanced practice, stating the imperative for health professionals to:

> [...] tailor the information they provide to each specific situation, as some people may insist on in-depth detail, whereas others would prefer to consent having only had the basics of the procedure explained to them (HTA, 2009b: para.98).

Here, policy is in recognition, rather than in tension (as chapter 5 describes) with practice. The "authoritative centre" (Singleton, 2005: 775) of the HTA lays out the boundaries for manoeuvre, according to the situated judgement of practitioners during the consent procedure.

Obtaining formal consent for organ donation therefore involves far more than getting an individual to place their signature on a form. It is a complex process, which depends upon the interpretative work of the donation nurse and their ability to transform formalised procedures within practice contexts. In his research on the work of doctors around medical records, Berg argues that the "organisational rules inscribed in [...] forms are constantly reinterpreted or overridden" (1996: 514) to deal with the contingencies of practice. Similarly Struhkamp *et al.* (2009: 57) name "doctoring" as the mode of performing and knowing in clinical contexts – where patient, and in our case, family situations, are far from clear cut. And Linda Hogle's (1995) insights into how procurement professionals construct the viability of potential donors – by adapting standardised criteria for donor suitability according to their personal interpretations of a patient's social history – also illustrates this process.

For the donation nurses, consent guidelines operate as the framework for their practice, with their own interpretations brought to the fore in everyday interactions with families. As Fujimura tells us, "standardised packages are used as a dynamic interface to translate interests between social worlds" (1992: 168). In this way, donation nurses straddle the interface between the (legal) interests of medical consent and the needs of bereaved families through their interaction with consent procedures. As a result, a family's initial decision on donation is fashioned into a formalised form, and is thus made *stable* (e.g. Callon, 1986) – by which I mean firm – enabling progression towards the actual organ procurement.

In Ellie's example, we also see how her informal strategies for consent incorporate her own identity into the procedure. She describes how her everyday questions about potential donors are "rumbled" straight away by families, who realise they are not simply innocent queries but serve a specific purpose for the situation. This tells us that the informal strategies around consent are not simply done to meet the needs of families and secure their consent, but also to make the formal process of form-filling – described as "barbaric" by Maria – bearable for the donation nurses. As John, an experienced donation nurse for team 2 described:

> Even though we have like a Verble and Worth [way], we have a *standard* way and we have a *spine* of how we do things. We'll all do stuff slightly differently because [of] how individually we might work and how we're comfortable in doing it. (John, donation nurse for team 2)

With John's description of the different ways in which donation nurses work around consent, he imparts that this is also done for their own comfort. Similarly, Ellie and other donation nurses asserted the importance of not becoming too "robotic" during the consent process. This shows that their strategies ensure they also retain their *own* humanity during consent, allowing them, in turn, to make the best of the process for a family. However, as I show below, consent sometimes gets done by actively drawing on standard procedure, which, at the same time, highlights its problematic and precarious nature.

The precarious process of consent: interpreting families

In addition to their ability to informally work through consent with families, some donation nurses described how they actively drew on formal consent procedures to move the process forwards with families. This was especially so when it came to conveying certain aspects of the donation to families, and asking the more intimate questions on the patient assessment

form. Having to provide intricate details about donation and collect detailed personal information about a potential donor from grieving families is never easy, especially when family members express their desire to receive as little information as possible. To work through such difficulties, donation nurses sometimes actively imparted the standardised nature of the process to families. This was to rationalise their provision of information to families, and justify their requirement for intimate details about the donor's lifestyle. However, as the example below illustrates, the use of procedure also reveals potential anxieties around consent and, at the same time, shows how consent practice is underpinned by certain assumptions which get made about donor families.

Stephanie Welsh was less than one year into her role as a donation nurse when she was called to facilitate the donation of a young 'Asian' woman, who became brain stem dead after being admitted to Intensive Care. Narrating this case, Stephanie conveyed her initial nervousness at approaching the potential donor's family because of their medical background – they were all doctors – and because they were 'Asian'. Stephanie described her anguish upon realising, some way into taking consent with the family, that the information she had provided them had seemingly distressed the donor's mother:

> I had gone through the standard information you need to tell the family for legal reasons and everything, and it was all going quite smoothly until we came to the discussion of appearances: funeral arrangements and that sort of thing. I said: 'I need to say so much information for legal reasons, but how much detail do you want me to go into?' She [mum] said 'Well keep going until I tell you to, to stop.' The conversation came to explaining the appearance of their daughter following bone donation, as the family wanted this to happen but I wasn't convinced they knew exactly what they were giving consent for. I went into explaining how bone would be taken from the leg, and then mum got *very very* upset and...started

246

saying 'I don't want to know about that. It sounds like you're *mutilating* her [donor]'. [So] I said, 'I'm sorry, we'll stop that train of thought for now.' And in the end they did give consent and to the best of *my* ability they were informed about what they were giving consent to. But later on the mum approached me and said she wasn't happy with the fact that I'd mentioned the appearance of their daughter after donation. However, that's something that we have to say, but, in as much detail as the family are willing to hear really. But erm...saying that, maybe they didn't need to know that much information. But at that point I didn't know whether or not the family wanted a burial, whether or not it affected their chance to view. All these things matter. [....] Now, from experience...*now* dealing with more families, I ask them what their plans would be. Whether or not they planned for a cremation, did they plan for a burial of sorts; would you like a viewing because I can give you some more information about what to expect if you were to go and see them [donor]. That's from *experience*. But this was my *first* time and I was shaking because of the fact that it was an Asian family – I'd never come into much contact with people from an ethnic minority background; the fact that I'd never done consent before in my life; and the fact that they were all medical background. (Stephanie, donation nurse for team 1)

Stephanie's account here relays her understanding that the mother of the potential donor had become distressed *as a result of* the information she provided to the family about bone donation. After asserting her legal responsibilities around consent – pre-empting any difficulties the family may have with the information she is about to provide them – Stephanie recalls checking how much detail the family might want to hear. With the mother's apparent go ahead, she relays information about the procedure, including details

of bone donation. This she justifies by her understanding that the family might not have been totally aware of what they were consenting for. The reason for this being that bone donation results in a visible alteration of the appearance of the donor, since it involves the removal of bone from below the knees up to the hip joints, leaving stitching down the sides of the legs (UKT, 2004a). The mother's upset at the detail of this procedure stops Stephanie in her tracks however. It leads her to reflect upon how she would have done the process differently today, in light of her further experience.

At one level, Stephanie's story illustrates the fine line donation nurses must walk between ensuring the legal conditions of consent for donation are met, whilst being acutely aware of *how* to appropriately meet these conditions in their interactions with individual families. With Stephanie's desire to impart detailed information to the family – with her judgement that they might not have known what they were consenting for – this line is dismantled. Stephanie puts this down to her relative inexperience at the time. She explains how, as a result of this case, she has subsequently shifted her practice to ask certain questions of a family, like whether they would want to view the body after donation, prior to providing them with information. Here the formal process of consent is revealed as a precarious one, which has the potential to both *make* and *unmake* a family's initial decision on donation. In the same way that donation decisions may be stabilised by the work of the donation nurse, they may also be destabilised during this process. Consent is therefore predicated upon the successful interaction of the donation nurse with families, and the capacity for a shared understanding around consent to be produced in the process (as I also argued is the case in communications around death, in chapter 5). Tell a family too little and the donation nurse risks failing the legal requirements of consent; leaving themselves open to accusations of malpractice. On the other side, giving too much information, or conveying it in the 'wrong' way, risks distressing a family further and jeopardising the donation.

248

As we learn from Timmermans and Berg (2003), the enactment of [consent] standards link donation nurses to wider public and legal concerns [around organ donation]. This is especially pertinent in the context of the legacy of the UK's organ retention scandal. In Stephanie's account we witness the collision between the legal forms of consent, her attempts to meet the needs of this family, and her personal anxiety over covering the requirements of consent. This anxiety, I speculate, may be linked to her knowledge of the public outcry over the organ retention scandal. Here, the bioethical imperatives of informed consent – acutely highlighted since the organ scandal and with the implementation of the 2004 Human Tissue Act (Sheich Leith, 2007) – are revealed as potentially damaging in practice. The imperative to *inform* a family about all aspects of the donation is witnessed in Stephanie's example as abstracted from everyday consent relations, such as relatives' concerns over bodily wholeness (Sheich Leith, 2007). In addition, it has the potential to *disrupt* the relations between those giving and those taking consent (Corrigan, 2003), and therefore the consent process itself.

At another level, Stephanie's account also shows how the consent practices of donation nurses are sometimes driven by assumptions about potential donor families, in their attempts to make the process fit with a family's anticipated needs. As she later went on to explain, Stephanie perceived that the family's medical background meant they were knowledgeable about the details she was giving them about donation. She described how the family would: "say something that made me understand that they knew what I was talking about from a medical point of view, in more detail than a lay person would have done". Here, I argue that her understanding of the family's medical knowledge partly underpinned her anxiety to impart such detail about the donation; with the implication that their medical status equated to a requirement for in-depth information. In addition, Stephanie explains how her nervousness during this case also stemmed from the family's

'Asian' status, since, as she put it, she had "never come into much contact with people from an ethnic minority background". She describes how she was unaware of their needs after death: whether they wanted to view their relative and have a burial after the donation, leading to her provision of the details about bone donation. At the same time, her *lack* of questions to the family about their needs also highlights her discomfort in taking consent from an 'Asian' family. This simultaneously reveals – as I go on to develop in part 2 – how preconceived ideas about ethnicity interact with the consent practices of health professionals.

Part 2. Ethnicity and expectation: (re)producing the 'BME' donor

The complex practice of securing donation consent from families was described as sometimes more difficult in the case of minority ethnic families, as the account of Ruth, a relatively new donation nurse, illustrates.

Ruth was on call one evening when she was referred to a potential donor from a large hospital that, in her words, "does everything the right way round"[84]. The potential donor's family, who Ruth describes as being "Hindu"[85], were initially approached about donation by Intensive Care staff, after being given time to "absorb" the diagnosis that their daughter, whilst on a University night out, had sustained a "catastrophic brain injury".

However, what began as a well-laid out starting point for Ruth – with the patient also identified on the donor register – soon involves various problems, which end up delaying

---

[84] She is referring to the way that the hospital adheres to donation procedure, such as referring potential donors to the donation nurse team at the earliest opportunity.

[85] I regrettably never asked Ruth how she knew the family were 'Hindu'. She describes how the parents of the donor were originally from India and had lived in the UK for a number of years, yet I never found out whether their 'Hindu' status was from their own identification, or one she had assumed.

the eventual donation. Among the issues which crop up along the way, including a delay in being able to contact the coroner, Ruth also organises her account of this, as she describes, "difficult" donation experience, by placing the "very large" family of the potential donor at the centre of her narrative. This begins with her description of the family's disbelief that their daughter was on the donor register. Ruth explains how she had to request a faxed copy of the woman's registration from NHSBT before the family accepted this information; eventually indicating their willingness to donate.

With the family's initial agreement to donate, Ruth begins to take them through the process of formal consent. She discusses their specific difficulty with aspects of the patient assessment forms, which she evaluates by drawing on assumptions about the family's 'Hindu' faith. In contrast, Ruth interprets their decision to donate as a *product* of their faith:

> And the family wanted some time to discuss this [the donation], and then came back after half an hour to say, well yes, she was a giving person in life, it's very fitting that she should be a giving person in death. And I think from reading the religious information about Hinduism, not that I'm any great expert, that basically this is their kind of take on donation. It's about giving in life and giving in death, and that's how their religion supports it. So they wanted to talk more about donation, so I said that I would go back in and bring the consent papers with me to go through with them. Which I did. It was a very very very long conversation, and the family had a lot of difficulties with a lot of the questions that were being asked. We do need in the patient assessment to ask about things such as erm habits really. Not just smoking: drinking, drug taking, sexual habits. Which obviously, I mean I think mum and dad thought that she was a girl who was living very much by the Hindu faith: didn't drink, no sex before marriage etcetera. Erm, however, it seemed that she was leading quite a

251

westernised life really from some of the information that we did come across [Ruth later describes how one of the cousins told her the donor liked an "occasional drink", and how her GP records revealed she had been prescribed the morning after pill]. Certainly the longest and most in-depth consent process I have ever done. Coupled with the family saying [puts on slightly irritated voice] 'I can't believe you need to ask all these questions. I can't believe that you need to put us through all this [...]. Can we not just say yes or no?' And explained about informed consent and why I need all this information. (Ruth, donation nurse for team 1)

In her account, Ruth initially contemplates the family's agreement to donate through their justification of their daughter's generous character. This character she relates to her perception of the Hindu religion. Here, Ruth's knowledge about Hinduism leads her to imply that the family's decision to donate is a *result* of their Hindu faith. However, her understanding of their faith as a factor which initially *aids* her task of securing donation is in tension with her later description of the struggle the family had with the consent process. She describes the "very very very long conversation" (she estimated it lasted around 5 hours) this involved, and emphasises the difficulty the family presented by questioning the relevance of the queries she was making about the donor. She imparts how the family became distressed with her queries from the patient assessment form about their relative's sexual and substance use history. However, their upset she relates to the discrepancy she sees between the 'Hindu' status of the donor's parents and the questions relating to their daughter's lifestyle "habits", like drinking alcohol – activities which she perceives as going against their 'Hinduism'. She subsequently deals with their discomfort by relying on the standardised nature of the questions: utilising consent procedures as a "strategic resource" (Castel, 2009:743) to get through the "difficult" process.

The questions on the patient assessment form which ask about "habits" such as drinking and sexual activity, Ruth also implicitly relates to a "western" lifestyle. We see this with her explanation of her discovery of the donor's "western life": her drinking of alcohol and her medical records indicating she had taken the morning after pill. As Ruth later went on to explain, this, for her, meant the donor was not "leading a Hindu kind of lifestyle". Ruth therefore assigns the family's difficulty with the consent process, and thus the difficult consent process itself, to their ethnic ('Hindu') status. She projects her interpretations about the 'Hindu' faith on to the family, which, at the same time, turns them into an issue to be dealt with. This effaces any alternative understandings of the family's upset during the process, such as the fact that being asked about your daughter's sex life is not something many parents would wish to discuss, no matter what their ethnicity or faith! In so doing, Ruth also links the family's religious identity to norms and rules (see chapter 5 also), rather than identities which are "negotiable and contingent" (Atkin *et al.*, 2008: 77) upon broader contexts and everyday experiences, as recent work on the medical decision-making of families' from faith backgrounds tells us (Atkin *et al.,* 2008; Shaw, 2009). We therefore see how, as Stephanie's story also illustrated, the interpretative process of consent also involves working from certain assumptions about the ethnicity of a potential donor family.

Ruth then continued to describe further difficulties in this case, which ended up delaying the donation operation until the following morning. After finally completing consent with the family late in the evening, Ruth discovers that the consultants on the previous shift had been unable to get in touch with the coroner to gain permission for the donation to go ahead[86]. To Ruth's chagrin, the ICU consultant in charge of the evening shift then refuses to contact the coroner, telling her that the approval – and thus the donation – would have to

---

[86] See chapter 3 for a more detailed explanation of coroner involvement in organ donation.

wait until the morning[87]. Ruth describes the family's distress at finding out about the prospect of the operation being postponed, and subsequently tasks herself with gaining the necessary approvals. This involves her waking the coroner up at home and sending a police car round to the senior police officer's house[88] in the middle of the night, before she finally gains all the necessary, legal approvals for the donation. Here, as demonstrated in part 1, we witness consent for donation as a precarious and knotty process. As this case additionally shows, however, formal consent also involves other actors, beyond that of the potential donor family and the donation nurse. Even when a family's legal consent has been documented, this far from secures a donation. As we see here, the donation nurse must ensure a family's consent, and thus the donation itself, is made a reality by gaining the further consent of authority figures, such as the coroner. Consent is thus contingent not only upon the interactional process of form filling with families, but also on wider practicalities, such as being able to contact authority figures in time; a family's preparedness to wait for further approvals; and, as I describe below, the clinical suitability of the deceased.

Ruth describes it being the early hours of the morning when she discovers yet another complexity, which further interrupts the donation. With the return of the donor's blood and urine test results[89], Ruth discovers she has tested positive for pregnancy on a urine test[90].

---

[87] See chapter 4 for my analysis of how clinical hierarchies affect the ability of the donation nurse to do their job properly.

[88] The accidental circumstances of the donor's death meant police permission was also necessary for the donation. In such circumstances, the police will only agree to donation if it is not seen to interfere with their investigations.

[89] These are routine clinical tests which are used as one way of assessing the donor's clinical suitability for donation, by ruling out the presence of transmittable diseases, such as HIV.

[90] In the case of a potential donor being pregnant, this has implications for their clinical management and the donation itself. If the pregnancy is far enough advanced, attempts will be made to clinically manage the donor for a number of weeks or even months, to enable the baby to be delivered. Donation may be possible after this has occurred, or in the case of intrauterine foetus death (Esmaeilzadeh *et al.,* 2010).

Horrified at the thought of breaking this news to the donor's parents, and sure of her knowledge that brain stem death can lead to a surge of hormones which may indicate false pregnancy, Ruth sends for an emergency blood test to rule out the pregnancy:

> Basically we did this pregnancy test and it was...positive. [I was] like, Oh my God. And then I suddenly said to my colleague that was with me, 'I'm sure, for some reason [...] that when you're brain stem dead the surge of different hormones and things can give you a false positive pregnancy test.'. Erm..so I said [...] 'I'm sure we need to do a blood test.' So we organised an urgent blood test through the lab, and one of the student nurses on the unit like ran it down there. By this time the embedded donation nurses had arrived [to relieve Ruth, as she had been working through the night on this case] and the [organ] retrieval had been delayed because there was someone in the operating theatre. The surgical teams had all arrived [to carry out the retrieval] but someone was in theatre, which was kind of thankful because we had a reason to tell the family about the delay, [since] I didn't want to tell them about this pregnancy thing *until* we got to the bottom of what was happening. (Ruth, donation nurse for team 1)

Here, Ruth describes her relief at how a backlog of procedures in the operating theatre provided her with an alternative explanation for the family about their further wait for the donation to go ahead. However, when the GP records arrive, detailing the donor's morning after pill prescription, the treating consultants decide they should tell the family about the pregnancy test *before* the blood tests return. This went against Ruth's explicit request for them to wait for the test results. Ruth describes her frustration at this turn of events, which she could do little about with her shift coming to an end:

> Another donation nurse arrived with the policy, which basically says, although we've contested this, that you *should* say to a family: is there any chance that

255

your relative could be pregnant, because we'll need to do a pregnancy test [if so]. But if the family say no they couldn't be pregnant then you don't do a pregnancy test. Now in this situation, if the donor had been pregnant her family would have said no, she couldn't be pregnant anyway. [...] And then the blood tests came back negative, so the team had to tell the family [that] actually the pregnancy was a false positive. So the family were then fairly annoyed: it had been a smear on her [daughter's] name really, and they were saying: 'she wouldn't have done that kind of thing, and you've said she's pregnant and she's not actually pregnant at all.' (Ruth, donation nurse for team 1)

In addition to witnessing Ruth's powerlessness to assert her authority over the decisions of the consultants here[91], we also see how her actions reproduce the problematic status which she has already assigned to this 'Hindu' family. Ruth impresses that she did everything she could to prevent the family from being told about their daughter's possible pregnancy. This included: rushing through a blood test to the lab, asking the consultants to wait for the test results to return before speaking with the family, and contesting the hospital's donation policy. According to Ruth, the policy of assessing the need for a pregnancy test, by asking a family about the likelihood of their relative being pregnant, would not have worked with the 'Hindu' family in this case. In her view, they would have denied any possibility of their daughter being pregnant since, as Ruth saw it, they believed their daughter to be following a 'Hindu' lifestyle.

Ruth here gives the impression that her actions to prevent the family from discovering the potential pregnancy were linked to her understanding of their 'Hindu' identity. As I described earlier, this identity, for Ruth, turns upon ideas of a certain lifestyle, involving chastity before marriage and abstinence from alcohol. These characteristics Ruth constructs

---

[91] I discuss the lack of authority of the donation nurses as a general issue for donation in chapter 4.

as *barriers* in her attempts to secure donation consent – assigning the family's struggle with the process to their 'Hindu' identity. With her attempts to delay their discovery of the pregnancy test results, we also see how her assumptions about the family's ethnicity interact with her practice. As a result, I argue that Ruth simultaneously *constructs* and *reproduces* the problematic 'ethnic' status of the family through her consent and subsequent donation practices.

With Ruth's example we see the way in which reductive understandings of a family's minority ethnic status become embodied – by which I refer to the concrete form given in practice – and enacted in the everyday consent work of the donation nurse. These reductions, however, did not just relate to the donation nurses' practice. I was told time and again by the donation nurses that minority ethnic families were not as readily approached by ICU staff about donation as white families. This, they explained, was due to staff expectation that 'BME' families would say *no* to donation. In turn, these assumptions were conveyed in the narratives of ICU staff, who, like Ruth, drew on particular inferences about 'BME' groups to reflect on their donation interactions with minority ethnic families.

A few health professionals went so far as to explain their failings to secure organ donation from 'BME', particularly 'Muslim', families by explicitly framing them as a barrier for donation. One consultant at Lakeland described the "brick wall" that 'Muslim' families presented for donation requests. Another ICU nurse at Hillview puzzled over 'Muslim' family refusals, suggesting that – with racist undertones – they might see donation requests as an "insult" akin to "showing the soles of your feet to them". Moreover, ICU staff and donation nurses often described 'BME' families who *did* consent to donate their relative's organs as a "westernised" minority. Here, 'western' was implicitly related not just to the privileged default of whiteness, as the unexamined, unproblematic category (Dyer, 1997; Byrne, 2006; Garner 2010) for donation (see chapter 5), but also to families who were judged to be

educated and of 'professional' status, such as doctors and solicitors. It was also linked to the lack of any apparent religious appearance, such as the wearing of a hijab, which indicated 'Muslim' identity; to a small family set-up (as discussed in chapter 5); and families' existing knowledge of donation. In this way, minority ethnic families were distinguished from each other as a barrier, or lack of, for donation by perceptions about the obviousness of their 'ethnic' status, and whether or not they fulfilled their (ethnic) responsibility to donate (Gilroy, 1987; 2004; Rose and Novas, 2005).

Some ICU staff and donation nurses – as we saw with Stephanie's example – also admitted their personal discomfort with requesting donation from minority ethnic families. This was especially the case at Hillview, where the hospital's poor track-record for securing *any* donations from 'Asian' families became part of usual expectation. Matthew, one of Hillview's ICU consultants, spelled out this feeling:

> [Be]cause I myself am happier asking a Caucasian family for donation than I am an Asian family, and honestly my heart sort of sinks a little bit. I know I've gotta have the conversation...but I know it's going to be a lot harder [with an 'Asian' family] and then, if [there is] any sort of excuse to shy away from it, I think [I] do. And ultimately [the] majority of ['Asian'] people say no, in my experience. I mean, unfortunately these things happen at the moment on such a rare basis that I can't think of any specific examples, but I know that if it happened today and there's an Asian family and we were sort of thinking of DCD donation, I know I would go and have the conversation with a weight on my shoulders, because I know it will be an uphill struggle trying to convince. (Matthew, ICU consultant at Hillview)

Here, Matthew describes how his expectations of refusal prior to approaching an 'Asian' family get embodied in his dread at the approach. He communicates the heart sinking

feeling he experiences if he knows the potential donor family are 'Asian', admitting that he would try and get out of doing the request if he could. His assumption of the "uphill struggle" that a donation request to an 'Asian' family would entail is therefore carried through in to his donation approach with 'Asian' families.

In documenting the various ways in which ethnicity gets acted out in donation practice – as Ruth and Matthew highlight – we see how ethnicity is both a script which gets drawn on in the course of health professionals' work, and a construction which is produced as a result. In other words, understandings of the categories of the *'BME' organ donor* and the *'BME' donor family* – as an automatically assumed problem for organ donation – overlap with the decisions and actions of health professionals (e.g. Jeffery, 1979; Bowler, 1993; Atkin *et al.*, 1998; Atkin, 2003). Since we know that the *way* in which donation is introduced, and discussions are *done* with families has influence over their donation decisions (Siminoff *et al.*, 2001; Bellali and Papadatou, 2007; Simpkin *et al.,* 2009), I argue that the structuring of donation practice around reductive perceptions of ethnicity, may have very real consequences for attempts to increase 'BME' organ donation rates.

The practices of health professionals around minority ethnic families therefore problematically *reflects* and *reproduces* the 'problem' of ethnicity in organ donation, as originally assigned by transplant policy, donation campaigns, and research. As drawn out in chapter 1, these frame certain population groups as both the *source of*, and *solution to*, transplant inequalities. These we saw in donation promotion campaigns which assigned responsibility for 'BME' individuals to help *their* 'community' by becoming an organ donor (see figs. 2, 3 and 4); and research which positions religious beliefs as a barrier to donation (e.g. Exley *et al.,* 1996; Alkhawari *et al.*, 2005; Morgan *et al.*, 2008). The outcome of these approaches has resulted in the construction, and thus naturalisation, of ethnicity as a 'problem' for organ donation – which carries through into the work of health professionals.

As Bowker and Star, drawing upon the work of Thomas and Thomas explain, in their work on classification and its consequences:

> We know that things *perceived* as real are real in their consequences [...]. So even when people take classifications to be purely mental, or purely formal they *also* mould their behaviour to fit those conceptions. When formal characteristics are built into wide-scale bureaucracies [...] then the compelling power of those beliefs is strengthened considerably. They often come to be considered as natural". (Bowker and Star, 1999: 53)

In this way, the category of ethnicity in organ donation is maintained and reproduced by practitioners, who construct reductive notions of the *'BME' potential donor* and the *'BME' potential donor family* in their donation request and consent practices with minority ethnic families. As such, I argue that donation nurses and ICU staff also make up the very parts of the machinery which have transformed 'ethnicity' into a problem to be solved for transplant medicine.

Conclusion

In this chapter I have demonstrated the tangled and difficult nature of the stage of obtaining formal consent for organ donation. As evidenced, securing consent involves far more than simply acquiring material evidence of a family's agreement by obtaining a signature on a form. Instead, it is dependent upon, and is actively *generated* by the ability of the donation nurse to balance the needs of recently bereaved families with the legal requirements for donation. Consent is thus a situated, interpretative process, involving the adaptation of standardised procedures and forms, to ensure a family's decision on donation is formalised. In other words, the donation nurse makes consent *happen* in practice; thereby making the prospect of organ donation a reality.

However, as I also showed, just as donation nurses have the ability to secure a family's consent, there is also the potential for unmaking a family's decision during the procedure. This was seen when donation nurses let their preconceived assumptions about the ('BME') donor and their family drive their consent practice. Whilst the consent process was described by donation nurses as more difficult with minority ethnic families, they also demonstrated reductive expectations about what a family's ethnicity *meant* for their routine consent practice. Here, ethnicity was drawn on as a script to understand families' behaviour during consent, and their donation decisions as a result.

In this way, we saw how the micro practices of consent between donation nurses and potential donor families link in to macro constructions of ethnicity in organ donation – as ascribed by transplant policy, research and health promotion campaigns. Whilst donation nurses occupy the vital role of agent for fulfilling the ODT's biopolitical aims to increase donation rates (see chapter 4), they also demonstrate problematic treatments of ethnicity in their practice. Moreover, assumptions about ethnicity were also traced to the work of ICU staff. 'Ethnicity', as an issue for donation, is thus *constructed* and *reproduced* by those responsible for making the possibility of organ donation a reality. In other words, donation nurses and ICU staff form part of the 'problem' itself. They make up parts of the very machinery which has transformed diverse groups of people into the category of 'BME', and framed them as an 'issue' for donation and transplantation. In turn, I argue that this has implications for how individuals are treated in practice, and the donation decisions they may make as a result.

Chapter 7. Conclusion: Re-Thinking Ethnicity and Organ Donation

Introduction

Despite the iconic status of transplantation as a life-saving measure (Sharp, 2006) for organ failure, it remains enmeshed in complex bioethical tensions and debates. The most prominent of which, and the conundrum which underpinned the focus of this study, is in *how* to meet the ever increasing demand for organs. Since transplant medicine relies upon the public to provide its materials for functioning, it has concentrated upon securing the public's willingness to donate their organs after death. This has resulted in the representation of organ donation as a moral imperative: an act vital for the wider public good. As this study has demonstrated, however, expectations on the public to donate their organs are not always evenly distributed.

This research has focused upon the donation imperative with which the UK's 'BME' population has been drawn upon as a particular concern. With waiting times to transplant almost twice as long for 'BME', compared with 'white' patients, and low organ donor rates from 'BME' groups, policy and health promotion campaigns have conveyed the urgent need for more people from minority ethnic backgrounds to donate their organs, for the sake of *their* 'community'. In the same way that 'BME' patients are subject to inequalities of transplant access, individuals assigned to the categories of 'black' and 'South Asian' have been handed unequal responsibility to solve a problem, which – as I argued in chapter 1 – originated within the practices of transplant medicine itself. Policy, health promotion, and research responses to this 'problem' have therefore focused less on transplant medicine,

and more on understanding the 'cultural' 'barriers' which 'BME' groups present for organ donation.

In this study I have offered a recalibration of this 'problem'. Instead of scrutinising 'BME' 'communities', I steered my line of vision towards ethnographically examining the organ donation encounter: where potential donors are decided on, and families' decisions on whether or not to donate their relative's organs are made. Consequently, I have illustrated that the phenomenon of organ donation and ethnicity is less of an innate 'problem'; solely produced as a result of the 'culture' – such as religious beliefs and traditions – of 'BME' populations. Rather, it is an 'issue' which can be alternatively understood from within the institutional settings of transplant medicine itself. Here, organ donation is evidenced as a negotiated and embedded process, contingent upon assemblages of diverse procedures, practices, people, and things (Kierans, 2011). These include government policy; donation guidelines; ICU staff; donation nurses; coroners; potential donor families; religious representatives; negotiated practices underpinned by professional hierarchies; understandings of death and the ontological status of the brain dead; legislation; mechanical ventilators; and consent and patient assessment forms. Together these make 'BME' decisions on donation, and donation itself, *possible*.

However, at the same time as these assemblages construct organ donation and organ donors, they also problematically *(re)produce* the status of the minority ethnic donor, thereby maintaining ethnicity as a 'problem' for donation. This work has therefore provided an important methodological, conceptual, and moral re-interpretation of a 'problem', which has thus far isolated understandings of inequalities around minority ethnic groups. Below, I draw out these insights, to firstly highlight the processes and practices which construct organ donation. Secondly, I explain how these processes lead to production of the ethnic

donor, before arguing for the wider contribution this research has made to the contentious area of organ transplantation.

Making donation possible: negotiated practices and the production of decision-making

This thesis has demonstrated the way in which organ donation is structured within institutional settings, by the negotiated practices of health professionals. These are actors who work at making donation *happen* against a backdrop of government policies and procedural guidelines. Within these settings, the donation nurse acts as the key agent of governance – in their work at implementing recommendations to increase donor rates within local practice settings. Here, the biopolitical project to secure more deceased organ donors – and thus more 'BME' donors – involves instilling new norms of practice around dead and dying patients and their families. These are responsive to, among others: the 'cultural' workings of an Intensive Care Unit and its existing patient population; prevailing clinical hierarchies; everyday practice contingencies; staff anxiety at handing over decisions on dead or dying patients to donation teams; and wider emotional and bioethical concerns with donation. Organ donation is not, therefore, something which solely happens as an outcome of an individual's willingness to donate. Instead, it is structured, and *made possible* by the negotiated practices of ICU consultants, ICU nurses, and donation nurses, and through the integration of policy imperatives into everyday decision-making processes around dead and dying patients – who only become organ donors by virtue of these interactions.

My work has thus established the contentious and contingent conditions under which 'BME' individuals become organ donors in the first place, and is corroborated by ethnographic

insights into the production of organ donors in institutional domains (e.g. Hogle, 1995; 1996; Lock, 2002; Sharp, 2006). In turn, I have revealed the paucity behind existing approaches to solving the donation and ethnicity 'problem', which concentrate upon selling the message of donation to the 'BME' public. Far from the 'culture' of 'BME' populations having foremost bearing upon donation rates, I have established that the decisions and practices of health professionals are what initially structure the inclination or reluctance to donate (Healey, 2004) – and thus the fate of the bodies of 'BME' potential organ donors and transplant recipients.

Moreover, just as decisions on donation begin long before the request is made to a family to donate their relative's organs, I have evidenced consent for organ donation as a *multiply constituted, interactional* process. Instead of a simple matter of an individual placing their name on the donor register, or gaining the signature of a family member on a form, donation consent involves the negotiations of different individuals, including the immediate and extended family of potential donors; religious figures; ICU staff; donation nurses; and coroners. As demonstrated, consent starts with the decisions of clinical staff over a patient's dead or dying status, and in their discussions about their diagnosis of death with a patient's family. For donation to become a possibility, a shared understanding of death must therefore be reached between families and health professionals.

Since death is the *precondition* for deceased organ donation, a family's acceptance of the clinical diagnosis of death thus acts as an informal form of consent in the donation pathway. It also allows for the "ontological switch" (Hadders, 2007: 218) of a patient's status from 'living' to 'dead' (Sudnow, 1967), and thus a potential donor. Gaining a ('BME') family's agreement to the dead or dying status their relative, however, often involves health professionals working to legitimate their medical decisions with a family, as sociological and anthropological research into medical communication with families at the end of life, has

also attested (e.g. Johnson *et al*., 2000; Kaufman, 2005; Russ and Kaufman, 2005; Timmermans, 2005; Aldridge and Barton, 2007). My results have illustrated the way in which these negotiations also served a specific purpose for organ donation, in that they smoothed the pathway towards donation consent. Decisions on donation are therefore actively fashioned in the early stages of the donation pathway: in clinicians' management of families' understandings, and thus acceptance of death.

The interactional process of consent also continues into the stage of acquiring formal consent for donation, where consent is additionally witnessed as an *interpretative* procedure. Here, families' decisions on donation are actively fostered and *generated* by the donation nurse, in their work at securing donation consent. Donation decisions are thus formalised by practice strategies which transform formal procedures into an accessible form (Berg, 1996; Timmermans and Berg, 1997; 2003); responsive to the needs of recently bereaved families. This develops findings from research with donor families, which links family consent for donation to the appropriate tailoring, by health professionals, of information to their needs (Sque and Payne, 1996; DeJong *et al*., 1998; Shih *et al*., 2001; Haddow, 2004; Bellali and Papadatou, 2007; Sque *et al*., 2007). However, my research has gone beyond simply looking at families' *reasons* for donation. It shows how donation decisions hang upon, and thus are *actively constructed by* the multiple processes, interactions, negotiations, and practices which characterise consent.

Consent for organ donation cannot, therefore, be predicted by assessing the attitudes of 'BME' groups towards donation, as past research has done (e.g. Hayward and Madhill, 2003; Davis and Randhawa, 2004; Morgan *et al*., 2008). It needs to be alternatively understood as a process in which family's decisions are actively managed, and thus produced. Moreover, in the same way that donation consent is made in practice, I also showed how donation refusals can be linked to these processes. Like consent, donation refusal is an interactive

process – contingent upon different actors and situations along the donation pathway. This includes how 'BME' families' disagreements with ICU staff over the diagnosis of their relative's death leads to them being unable to contemplate the possibility of donation. Refusal also travels into the decisions of coroners and police, who have the authority to prevent a donation going ahead. In addition, refusal does not necessarily relate to the negative answer to a donation request. In this research, negative donation outcomes were back-grounded by the subjective decisions of ICU staff about the unsuitability of a patient for donation; and the evidenced power struggles between donation nurses and ICU consultants.

These findings undermine the assumptions underpinning existing research, which tries to understand low 'BME' donor rates and high levels of donation refusals from 'BME' families by focusing upon the 'cultural' barriers these populations present for organ donation (e.g. Exley *et al.,* 1996; Alkhawari *et al*., 2005; Morgan *et al*., 2008). In contrast, my research has illustrated that 'culture', and thus donation refusal or consent, is created in the interaction between different groups of people – such as ICU staff and families – settings, and things – such as the mechanical ventilator which keeps brain dead patients breathing (Rosaldo, 1993; Agar, 2006). For example, medical understandings of death are made visible when they clash with ('BME') families' conceptualisations of their relative as still socially alive (Sudnow, 1967). 'Culture' may therefore be linked to donation refusals in terms of the disjuncture between family and clinical understandings of death, but it is *not* a concept which should be used as a pre-defined marker of population groups by which to predict donation outcomes.

My findings here do, however, build on wider research, which has linked low donor rates from minority ethnic populations to donation practice. Specifically, US survey research has evidenced the lack of referral of 'black' patients as potential donors, and inequities in the

quality of discussions about donation with 'white' and 'black' families as potential factors in donation disparities (Guadagnoli *et al.*, 1999; Siminoff *et al.*, 2003). In addition, interview research with donor and non-donor families has related donation decisions to the *way* in which information about brain death and donation was delivered to families; and to the relationship between families and the professionals delivering the request (e.g. Sque and Payne, 1996; Haddow, 2004; Bellali and Papadatou, 2007; Sque *et al.*, 2007). Different to this research, however, which gives little insight into the background of these interactions, my study has provided a rich view of the practices of donation professionals, and the procedural standards and environments which structure this work.

By providing insights into the micro-practices around the donation encounter, this research has therefore offered a perspective on the conceptual character of organ donation – as a negotiated, embedded process, contingent upon a variety of procedures, practices, and interactions. In so doing, it evidences how donation decisions, and thus donation refusals, are actively produced in practice. Importantly though, by highlighting the institutional constitution of organ donation, we also witnessed the way in which these processes feed back into the biopolitical project of transplantation, and thus the phenomenon of ethnicity and organ donation itself, as I explain below.

The production of the 'BME' donor and the 'BME' donor family

Within the procedures which make organ donation possible, we additionally saw how the category of ethnicity was explicitly constructed by health professionals, who defined 'BME' potential donors and their families as problematic populations for organ donation. Rather than taking this status for granted – as existing research and policy has done – this study traced the classification of ethnicity into the standards which background the work of

donation. These include the Human Tissue Act's (2004) consent hierarchy, which defines *who* has the right to make a decision about donation on behalf of the deceased.

When 'BME' families did not conform to these standards – as we saw with the involvement of extended family members and religious leaders in donation decisions – they were understood by health professionals as outsider populations (Becker, 1963), in need of careful management during donation procedures. 'BME' families are thus *constructed* as a problem for organ donation, not because they necessarily *are* a problem, but because they fell outside of the frameworks by which 'good' and 'bad' donors and their families are defined. The differentiation of 'BME' families in organ donation is therefore constituted in the collision between the norms and routines which underpin institutional processes with the actions of individual families (Foucault, 1980). In turn, health professionals' preconceptions about *what* a family's ethnicity *meant* for their work – i.e. assumptions about the automatic difficulties ethnicity presented – *interacted* with their everyday donation practice, such as in gaining formal consent for donation.

In this way, the classification of ethnicity as a negative variable for donation – mobilised within transplant medicine (Hacking, 2006), and taken up by policy, health promotion and research – is reproduced by practitioners, who work from the basis of ethnicity as a preconceived 'problem'. This builds on work which has looked at the ways in which the categorisation of individuals – such as 'BME' – feeds back into medical policies, practice, and thus health outcomes (Duster, 2003; 2005; Hacking, 2006; Smart *et* al., 2008; Avera, 2009). The institutional infrastructures and micro-processes of health professionals around 'BME' families thus reflects and reifies the focus of the transplant project, which categorises 'BME' organs as resources for solving inequalities. In other words, those responsible (ICU staff and donation nurses etc) for solving the 'issue' of low donor rates, paradoxically maintain it at the same time.

This study not only therefore speaks to the immediate issue of ethnicity and organ donation, but also provides an important contribution to ethnographic work on the growing, yet contentious domain of transplant medicine. My research has characterised transplant medicine as a technology which, in its quest to save lives, also simultaneously produces the very inequities it sets out to tackle. Wider ethnographic work has testified to the way in which these inequalities are formed by the promotion of transplantation as a desirable form of treatment; as a result of procurement and allocation practices; and in the differential distribution of organs within diverse socio-economic and political settings (e.g. Gordon, 2002; Lock, 2002; Crowley-Matoka, 2005; Parry, 2008; Yea, 2010; Kierans, 2011; Kierans and Cooper 2011). These insights are furthered by this thesis, which argues that ethnicity comes to be classified, produced, and thus knotted to unequal outcomes in transplantation by the structures, practices, and policies of transplant medicine itself.

My work has also drawn attention to the social actors – like the donation nurse – who, in their work towards optimising donor rates also *produce* the very disparities they are charged with reducing. This draws together different spheres of ethnographic influence by depicting the ways in which the micro practices of donation are underpinned by the macro concerns of governance. Here, existing work on the ways in which practitioners negotiate standards to bring about donor organs (Hogle, 1995; 1996; Sharp, 2006) is brought together with wider research in science and technology studies, which reveals how standards are made to work in specific practice communities, and the policy imperatives which underpin these (e.g. Mol, 2002; 2008; 2009 Timmermans and Berg, 2003; Struhkamp *et al.*, 2009; Singleton, 2005; 2010). Much like how organ donors are *produced* in the work done around dead and dying patients, the category of the 'BME organ donor' is thus constructed within practices which are buttressed by a multiplicity of policy concerns – which pre-define ethnicity as a 'problem'.

In conclusion then, this research has evidenced the fact that we cannot any longer conceive of 'BME' populations as the precondition for transplant inequalities. When surveyed with an ethnographic gaze, and from an alternative angle to the focus of the past, we have seen that the category of ethnicity – as a seemingly stable factor in low donation rates – collapses (Bowker and Star, 1999; Hacking, 2006). Instead, medicine is revealed as an integral actor in the production of the very inequalities it sets out to solve. From this perspective, I also offer an additional, moral call for researchers, policy makers, and practitioners to interrogate the ways in which minority ethnic health inequalities are interpreted, and the processes by which certain groups of people come to be reified as the source of these disparities. In taking a more nuanced approach towards understanding health inequities, we might prevent the continued reduction of diverse groups of people to the status of a label, like 'BME', and the suffering which is engendered as a result.

Epilogue: Reflections on the Research Process

Every piece of research is done within a certain amount of constraint, and a PhD study like mine is no exception. In the final part of this thesis I want to offer some reflections on the research process, the implications of the study's results for policy and practice, and ideas by which the research could be enhanced in further study.

As the sole researcher approaching the complex phenomenon of organ donation and ethnicity, I encountered numerous issues in gaining access to the domains, settings, and people which were connected to this problem. Whilst providing insight into the experiences of practitioners involved in donation, limited resources, and the bounded duration of the field work meant I did not get the chance to speak with donor and non-donor families from minority ethnic backgrounds[92]. Whilst my work would have been enormously enhanced if I had spent the same amount of time with families as I did with health professionals, it might also have led to a subsequent anaemia of insight into the different experiences. As Hannerz (2003) has pointed out, the difficulty of *doing* a multi-sited ethnography is in following the *ideal* of the multi-sited method into to the field, without spreading yourself, or the depth of findings too thin.

In addition, in relation to the presentation of my findings, I initially highlighted in chapter 2 how I came to adopt an ANT approach during the analytical stages of my research. In this theoretical approach materials, such as mechanical ventilators and consent forms, are central to an understanding of the 'problem' of organ donation and ethnicity and the categorisation of 'BME' groups as problematic populations for transplant medicine. In arriving late to ANT, whilst I did, subsequently, incorporate materials into my analytical process and theoretical discussion of my findings, materials do not feature as prominently

---

[92] see chapter 2 for my reasons for not being able to find these families.

as they may have done had I utilised ANT throughout the study. For example, whilst I emphasise the centrality of consent and patient assessment forms in the production of 'BME' families as troublesome groups for donation (chapter 6), I did not explicitly draw out the relationship between the mechanical ventilator and conflicts over decisions on death between families and ICU staff. In an ANT approach the mechanical ventilator would occupy a crucial role in the performance of different realities of death (Latour, 2005; Law, 2008) for health professionals and families. This analytical and theoretical utilisation of materials could be developed to greater effect in subsequent publications; and would add further depth to the recognition of the diversity of actors involved – beyond 'BME' 'communities' – in donation decision-making.

I am also acutely aware of the fact that I privileged my institutional data – observations and interviews with health professionals – to report my findings, over the interviews I conducted with 'community' participants. Whilst not explicitly presented in the results, these were, however, drawn on during my analyses to inform the findings. This I did firstly because my institutional data presented the opportunity to fully explore the organ donation encounter. And, secondly, in structuring my findings around the encounter, any attempts I made to incorporate the 'community' material turned into a shoe-horning exercise, which would have done the data an injustice. By concentrating upon health professionals, I was able to gather rich detail about the institutional production of ethnicity, thus providing novel findings about the phenomenon. In addition, by *studying up* (Nader, 1969) – focusing upon institutions instead of 'communities' – I have avoided the reifying gaze which has so far been used to characterise 'BME' communities, thereby opening the 'problem' out to different interpretation.

However, my focus upon the institutional aspects of organ donation also meant there was the potential for me to adopt too sympathetic a stance towards my research subjects; in

particular towards the donation nurses, who were key actors for helping me gain insight into the 'world' of organ donation. As discussed in chapter 2, my eventual familiarity with the processes involved in organ donation and the practices of the donation nurses may have influenced my analysis and subsequent findings, such as by representing the donation nurses in an uncritical way, and taking their work for granted. In addition, this relationship also presented conflicts *within* my own research objectives. In other words, whilst I set out to critically examine how the 'problem' of organ donation and ethnicity occurs within the donation encounter, my close relationship with some donation nurses had the obvious potential for my analytical gaze to become subsumed under their agenda to increase 'BME' consent rates.

Jessica Mesman (2007) highlights such concerns in reflecting on her ethnographic work on patient safety in a neonatology ward. She articulates how the collaborative nature of her study held the possibility for her research agenda to be integrated into the interests of her participants. These included the hospital 'risk managers', who initially saw her as a potential ally in their project to strengthen patient safety by elimitating practice errors (whereas Mesman was interested in the *strengths* of safety practices). However, Mesman documents how her fears failed to manifest in practice: she was able to find common ground with the managers and develop a relationship of mutual respect. She subsequently argues that the roles and responsibilities of the researcher are always fluid in research, with the unavoidable entanglement in "multiple engagements, conflicting feelings of loyalty, and a multitude of positions" (p.293). In this way, I could alternatively reflect on my relationship with the donation nurses as both a constraint and as a way by which my analysis was opened out with the realisation of my – and my research subjects' – multiple positions in relation to the topic. For example, the donation nurses' stories about the difficulties placed upon their work by ICU staff meant I drew attention to how their ability to obtain donation

consent was constrained by institutional relations, alongside pointing out their role as agents of biopolitical governance in implementing organisational changes around donation. As Mesman argues, research constraints thus also hold the possibility for transforming into "corridors for collaborative work" (2007: 282 and 293).

One of these 'corridors' is the realisation of my responsibility to not only widely disseminate my results, but additionally highlight how my research can impact upon the practices and policies of organ donation. In making recommendations my work becomes of obvious 'use' to donation professionals and organisations, such as NHSBT, whose agenda is to secure more 'BME' donors. Whilst this is not something I set out to do, my findings mean that I *do* have a responsibility to intervene in the 'issue' in some way. Such intervention will only be possible with my ability to disseminate the findings to a diversity of audiences. These include policy-makers, practitioners, and social scientists (working with similar concerns such as categorisation, medical practice, and organ donation). This dissemination will (and has) include(ed) the production of publications for both social science and medical journals and conference presentations, alongside distributing my findings in clinical training days for donation nurses and ICU staff; in presentations to the ICU and donation nurse teams I worked with; and in the production of formal research summaries, as required by the NHS ethics committee and NHSBT.

The policy and practice implications of this research work on three levels. Firstly, in evidencing donation consent as a multiply constituted, interpretative process, there is a need to widen current policy presentations of *what* consent for organ donation entails. Whilst emphasising consent as a process, the Human Tissue Act's (2004) legislation on consent largely concentrates upon *who* qualifies to give valid consent for donation. This fails to encompass the fact that consent occurs *all along* the donation trajectory (such as in relation to decisions on death); and is a product of the decisions and interactions of multiple

actors (families, health professionals, coroners, and the materials – mechanical ventilators, local donation policies, consent and patient assessment forms – which mediate these decisions). Broadening out policy explanations of consent would also act as a step towards changing the debate on organ donation and ethnicity (which I discuss in the third implication).

Secondly, the research illustrates the importance of bringing the organisation of donation services and the practices of health professionals into policy discussions of, and interventions towards 'solving' low 'BME' donation rates[93]. As this thesis has demonstrated, separating the donation decisions of 'BME' individuals from the decisions, practices, and policies of procurement services is an impossible task, since donation decision-making is situated and actively produced within institutional contexts. Incorporating institutional practice into the 'problem' might involve the development of training packages for donation nurses and ICU staff, which would focus upon specific cases of organ donation with minority ethnic families (this could include the narratives told in this research). These cases could be used to convey the complexity of the 'problem' to health professionals, and resituate the focus of practice away from a concentration upon the family as sole decision-makers, to an explicit recognition of the diverse constituents and processes involved in obtaining donation consent.

Finally, and most importantly, it is imperative to advocate a shift in how the debate on organ donation and ethnicity has been framed[94] by research, policy, and health promotion.

---

[93] As discussed in chapter 1, this is something which the ODT's (2008) recommendations failed to do, since the recommendations isolated the 'BME' issue from discussions about the reorganisation of donation services.

[94] This argument is influenced by the work of Mol (2008), who argues for a resituation of the logic of choice in healthcare to one of a logic of care. For Mol, the logic of care – which acknowledges how care, and thus illness, are negotiated within the practices of patients, providers, and medical technologies – offers a more appropriate way of thinking about good care than the logic of choice, which frames care in terms of the patient as 'good' consumer and responsible citizen.

By disseminating the study's findings I aim to resituate the debate on the 'problem'. This would move from one which concentrates its reifying gaze upon communities, towards one which acknowledges the nuanced, negotiated process of organ donation. In turn, the policy focus upon donation *rates* and securing consent might shift to a focus upon donation *decision-making*, where the 'problem' becomes understood as a dynamic and multiply constituted process, rather than a question of a 'yes' or 'no' answer to the donation request.

Reflecting on the potential constraints and policy implications of this research also offers openings for thinking about how its findings could be enhanced by future work. Whilst this study portrayed the practices of donation as vital to understanding the construction of ethnicity, my phenomenological approach mean I largely concentrated upon how these practices were made sense of in participants' narratives. In this way, I did not directly see these practices as they played out since I was not present during doctors' communications of death to families, and nor did I witness the interactions between donation nurses and donor families during the consent process. Additional research might, therefore, focus upon the daily actions within ICU and A&E wards to observe the encounters between 'BME' potential donor families and health professionals.

Such an approach would also enable access to the minority ethnic families I was unable to speak to in my research. However, this would require the jumping of numerous ethical hurdles, like how to gain informed consent to observe families who are in the midst of finding out that their relative is dead or dying. To ensure the likelihood of accessing 'BME' families, it would also mean being situated in a hospital with both a neurological centre (where patients who eventually become brain stem dead are often sent) and a high minority ethnic patient population. Doing such a piece of research would further open up opportunities to observe the donation scenarios of 'white' families. This would enable

comparison of how potential donor families are communicated and interacted with – which would build on the US survey research, described previously (e.g. Siminoff *et al*., 2003).

Owing to the insights I made in chapter 1, about how organ allocation policies have traditionally disadvantaged 'BME' patients waiting for kidney transplants, another research avenue might include examining *how* organs are allocated in practice. This would be pertinent in light of changes to the kidney allocation policy in 2006, which aimed to reduce disparities of access for 'BME' patients (Johnson *et al*., 2010). It could investigate how these changes have had an effect in practice, and how these processes affect the lives of 'BME' patients on the transplant waiting list. Such research might involve observing the work of laboratory staff who carry out tissue matching tests; speaking with policy makers responsible for the allocation criteria; and spending time with kidney patients from minority ethnic backgrounds.

Research like this would also further one of the original reasons for doing my study. This was to undermine the blame discourse which has been placed upon minority ethnic groups for transplant disparities by integrating medical knowledge and practice into understandings of the 'problem'. This I believe I have achieved with my research. By casting the net further – beyond catching the obvious sources of inequalities, like 'BME' groups themselves – I have started the process of removing the 'problem' of ethnicity in organ donation from its black box; one with which I fully intend to continue.

References

Abu Lughod, L. (1991) 'Writing against culture'. In: R.G. Fox (Ed.) *Recapturing Anthropology: Working in the Present*. Santa Fe, New Mexico: School of American Research Press: 137-162.

Academy of Medical Royal Colleges (2008) *A Code of Practice for the Diagnosis and Confirmation of Death*. Available from: http://www.aomrc.org.uk/publications/reports-guidance.html. [Accessed January, 2009].

Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Death (1968) 'A definition of irreversible coma'. *JAMA*, 205 (6): 85-88.

Agar, M. (2006) 'Culture: can you take it anywhere?' *International Journal of Qualitative Methods*, 5 (2): 1-12.

Ahmad, W.I.U. (1993) 'Making black people sick: 'race', ideology and health research'. In: W.I.U Ahmad (Ed.) *Race and Health in Contemporary Britain*. Buckingham: Open University Press: 11-33.

Ahmad, W.I.U, and Bradby, H. (2007) 'Locating ethnicity and health: exploring concepts and contexts'. *Sociology of Health and Illness*, 29: 795-810.

Ahmed, W., Harris, S., and Brown, E. (1999) 'Attitudes to organ donation among South Asians in an English high street'. *Journal of the Royal Society of Medicine*, 92: 626-627.

Albright, C.L., Glanz, K., Wong, L., Dela Cruz, M.R., Abe, L., and Sagayadoro, T.L. (2005) 'Knowledge and attitudes about deceased organ donation in Filipinos: a qualitative assessment.' *Transplantation Proceedings,* 37: 4153-4158.

Aldridge, M., and Barton, E. (2007) 'Establishing terminal status in end-of-life discussions'. *Qualitative Health Research*, 17 (7): 908-918.

Ali, N., Atkin, K., and Neal, R. (2006) 'The role of culture in the general practice consultation process'. *Ethnicity & Health*, 11 (4): 389-408.

Alkhawari, F.S., Stimson, G.V., and Warrens, A.N. (2005) 'Attitudes towards transplantation in U.K. Muslim Indo-Asians in West London.' *American Journal of Transplantation*, 5: 1326-1331.

Appadurai, A. (Ed.) (1986) *The Social Life of Things: Commodities in Cultural Perspective*. Cambridge: Cambridge University Press.

Arriola, K.R.J., Perryman, J.P., Doldren, M.A., Warren, C.M., and Robinson, D.H.Z. (2007) 'Understanding the role of clergy in African American organ and tissue donation decision-making'. *Ethnicity & Health*, 12 (5): 465-482.

Aspers, P. (2009) 'Empirical phenomenology: a qualitative research approach'. *Indo-Pacific Journal of Phenomenology*, 9 (2): 1-12.

Atkin, K. (2003) 'Ethnicity and the politics of new genetics: principles and engagement'. *Ethnicity & Health*, 8 (2): 91-109.

Atkin, K., Ahmad, W.I.U., and Anionwu, E.N. (1998) 'Screening and Counselling for Sickle Cell Disorders and Thalassaemia: the experiences of parents and health professionals'. *Social Science & Medicine*, 47 (11): 1639-1651.

Atkin, K., Ahmed, S., Hewison, J., and Green, J. (2008) 'Decision-making and ante-natal screening for sickle cell and thalassaemia disorders: to what extent do faith and religious identity mediate choice?' *Current Sociology*, 56: 77-98.

Atkinson, P., and Delamont, S. (2006) 'Rescuing narrative from qualitative research'. *Narrative Inquiry*, 16 (1): 164-172.

Avera, E. (2009) 'Rationalisation and racialisation in the rainbow nation: inequalities and identity in the South African bone marrow transplant network'. *Anthropology and Medicine*, 16 (2): 179-193.

Baines, L.S., Jospeh, J.T., and Jindal, R.M. (2002) 'A public forum to promote organ donation among Asians: the Scottish Initiative.' *Transplant International*, 15: 124-131.

Baker, L.D. (2010) *Anthropology and the Racial Politics of Culture*. London: Duke University Press.

Bamberg, M.G.W. (1997) 'Positioning between structure and performance'. *Journal of Narrative and Life History*, 7 (1-4): 335-342.

Barbour, R. (2001) 'Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?' *BMJ*, 322: 1115-1117.

Barth, F. (1969) 'Introduction'. In: F. Barth (Ed.) *Ethnic Groups and Boundaries. The Social Organization of Cultural Difference*. London: George Allen & Unwin: 9-38.

BBC Radio 4 (2010) *Blood for Blood*. Thursday 25th February.

Becker, H.S. (1963) *Outsiders. Studies in the Sociology of Deviance*. New York: Free Press.

Becker, H.S. (1964) 'Problems in the publication of field studies'. In: A. Vidich, J. Bensman, and M. Stein (Eds.) *Reflections on Community Studies*. New York: Wiley.

Becker, H.S. (1967) 'Whose side are we on?' *Social Problems*, 14 (3): 239-247.

Bellali , T. and Papadatou, D. (2007) 'The decision-making process of parents regarding organ donation of their brain dead child: a Greek study'. *Social Science & Medicine*, 64: 439-450.

Ben-David, O.B. (2006) 'Ranking deaths in Israeli society: premature deaths and organ donation'. *Mortality*, 11 (1): 79-96.

Benner, P. (1994) 'The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices.' In: P. Benner (Ed.) *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness.* London: Sage: 99-127.

Berg, M. (1996) 'Practices of reading and writing: the constitutive role of the patient record in medical work'. *Sociology of Health and Illness*, 18 (4): 499-524.

Berg, M. (1998) 'Order(s) and disorders: of protocols and medical practices'. In: M. Berg, and A. Mol (Eds.) *Differences in Medicine. Unravelling Practices, Techniques and Bodies*. Durham and London: Duke University Press: 226-246.

Bhopal, R. (1997) 'Is research into ethnicity and health racist, unsound, or important science?' *BMJ*, 314: 1751.

Bhopal, R. (2007) *Ethnicity, Race, and Health in Multicultural Societies: Foundations for a Better Epidemiology, Public Health, and Health Care.* Oxford: Oxford University Press.

Bird, S., and Harris, J. (2010) Rapid response. ''Opting out': a response to our critics'. *BMJ*, 340.

Blaikie, N. (2007) *Approaches to Social Enquiry: Advancing Knowledge*. Cambridge: Polity Press.

Bleakley, G. (2010) 'Implementing minimum notification criteria for organ donation in an acute hospital's critical care units'. *Nursing in Critical Care*, 15 (4): 185-191.

Blok, G.E. (2006) 'Approaching donor families: culture, religion and ethnicity.' *Current Opinion in Organ Transplantation*, 11: 123-129.

Bolton, S.C. (2005) 'Women's work, dirty work: the gynaecology nurse as 'other''. *Gender, Work and Organization*, 12 (2): 169-186.

Boulware, E.L., Ratner, L.E., Cooper, L.A., Sosa, J.A., Laveist, T.A., and Powe, N.R. (2002) 'Understanding disparities in donor behaviour: race and gender differences in willingness to donate blood and cadaveric organs'. *Medical Care*, 40 (2): 85-95.

Bowker, G.C., and Star, S.L. (1999) *Sorting Things Out. Classification and its Consequences*. London: MIT Press.

Bowler, I. (1993) ''They're not the same as us': midwives' stereotypes of South Asian descent maternity patients'. *Sociology of Health and Illness*, 15 (2): 157-178.

Bowler, I. (1995) 'Further notes on record taking and making in maternity care: the case of South Asian descent women'. *Sociological Review*, 43: 36-51.

Bradby, H. (2003) 'Describing ethnicity in health research'. *Ethnicity and Health*, 8: 5-13.

Bruner, J. (1986) *Actual Minds, Possible Worlds*. Cambridge (Mass.) and London: Harvard University Press.

Bruner, J. (1990) *Acts of Meaning*. Cambridge (Mass.) and London: Harvard University Press.

Buchner, H., and Vinci, R. (2001) 'What have we learnt from the Alder Hey affair?' *BMJ*, 322: 309-310.

Byrne, B. (2006) *White Lives: The Interplay of 'Race', Class and Gender in Everyday Life*. London: Routledge.

Byrne, P., and Stengel, K. (2010) 'Heartfelt and heartseen: making a diagnosis through coronary angiogram'. In: M. Buscher, D. Goodwin, and J. Mesman (Eds.) *Ethnographies of Diagnostic Work. Dimensions of Transformative Practice*. Basingstoke: Palgrave Macmillan: 133-148.

Callon, M. (1986) 'Some elements of a sociology of translation: domestication of the scallops and the fisherman of St Brieuc Bay'. In: J. Law (Ed.) *Power, Action and Belief: A New Sociology of Knowledge?* London: Routledge: 196-223.

Casper, M.J., and Berg, M. (1995) 'Constructivist perspectives on medical work: medical practices and science and technology studies'. *Science, Technology & Human Values,* 20 (4): 395-407.

Cass, A., Lowell, A., Christie, M., Snelling, P.L., Flack, M., Marrnganyin, B., and Brown, I. (2002) 'Sharing true stories: improving communication between Aboriginal patients and healthcare workers'. *MJA*, 176: 466-470.

Castel, P. (2009) 'What's behind a guideline? Authority, competition and collaboration in the French oncology sector'. *Social Studies of Science*, 39: 743-764.

Cecka, M.J. (2007) 'Significance of histocompatability in organ transplantation'. *Current Opinion in Organ Transplantation*, 12 (4): 402-408.

Chapple, S. (2010) *No Place for Dying: Hospitals and the Ideology of Rescue*. Walnut Creek (CA): Left Coast Press.

Cheung, A.H.S., Alden, D.L., and Wheeler, M.S. (1998) 'Cultural attitudes of Asian-Americans toward death adversely impact organ donation'. *Transplantation Proceedings*, 30: 3609-3610.

Christians, C.G. (2005) 'Ethics and politics in qualitative research'. In N.K. Denzin, and Y.S. Lincoln (Eds.) *The Sage Handbook of Qualitative Research*. *Third Edition*. London: Sage: 139-164.

Clark, T.J, Richards, N.T., Adu, D., and Michael, J. (1993) 'Increased prevalence of dialysis-dependent renal failure in ethnic minorities in the West Midlands.' *Nephrology, Dialysis, Transplantation*, 8: 146-148.

Commander, M.J., Dharan, S.P., Odell, S.M., Surtees, P.G. (1997) 'Access to mental health care in an inner-city health district. II: association with demographic factors'. *The British Journal of Psychiatry*, vol. 170: 317-320.

Commission of the European Communities (2007) *Organ Donation and Transplantation: Policy Actions at EU Level*. Available from: http://ec.europa.eu/health/ph_threats/human_substance/documents/organs_impact_en.pdf. [Accessed 20th October, 2008].

Coombs, M. (2007) 'Power and conflict in intensive care clinical decision making'. *Intensive and Critical Care Nursing*, 19: 125-135.

Corrigan, O. (2003) 'Empty ethics: the problem with informed consent'. *Sociology of Health and Illness*, 25 (3): 768-792.

Crotty, M. (1998) *The Foundations of Social Research: Meaning and Perspective in the Research Process*. London: Sage.

Crowley Matoka, M. (2005) 'Desperately seeking "normal": the promise and perils of living with kidney transplantation'. *Social Science & Medicine,* 61: 821-831.

Crowley-Matoka, M., and Lock, M. (2006) 'Organ transplantation in a globalised world'. *Mortality*, 11: 167-181.

Curtis, J.R., and Patrick, D. (2001) 'How to discuss dying and death in the ICU'. In: J.R. Curtis, and G. Rubenfeld (Eds.) *Managing Death in the ICU*. New York: Oxford University Press: 85-102.

Darr, A., and Randhawa, G. (1999) 'Awareness and attitudes towards organ donation and transplantation among the Asian population'. *Transplant International*, 12: 365-371.

Davis, C., and Randhawa, G. (2004) '"Don't know enough about it!" Awareness towards organ donation and transplantation among the Black African and Black Caribbean population in Lambeth, Southwark, and Lewisham, United Kingdom.' *Transplantation*. 78 (3): 420-425.

Davies, G. (2006) 'Patterning the geographies of organ transplantation: corporeality, generosity and justice'. *Transactions of the Institute of British Geographers*, 31: 257-271.

De Certeau, M. (1984) *The Practice of Everyday Life*. London: University of California Press.

DeJong, W., Franz, H.G., Wolfe, S.M., Nathan, H., Payne, D., Reitsma, W., and Beasley, C. (1998) 'Requesting organ donation: an interview study of donor and nondonor families.' *American Journal of Critical Care*, 7 (1): 13-23.

Delvecchio Good, M.J., Gadmer, N.M., Ruopp, P., Lakoma, M., Sullivan, A.M., Redinbaugh, E., Arnold, R.M., and Block, S.D. (2004) 'Narrative nuances on good and bad deaths: internist's tales from high-technology work places'. *Social Science & Medicine*, 58: 939-953.

Department of Health (2003) *Saving Lives, Valuing Donors: A Transplant Framework for England*. London: HMSO.

Department of Health (2004) *National Service Framework for Renal Services: Part One – Dialysis and Transplantation*. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4070359. [Accessed January, 2011].

Department of Health (2005) *The Human Tissue Act 2004: New Legislation on Human Organs and Tissue*. Available from:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_4109578. [Accessed June, 2010].

Department of Health (2009) *Legal Issues Relevant to Non-heartbeating Donation*. Available from: http://www.ics.ac.uk/intensive_care_professional/legal_issues. [Accessed April, 2011].

Department of Health (2010) *Guidance for Donor Coordinators working with Coroners*. Available from:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114801.pdf. [Accessed February, 2011].

Di Palma, C. (2004) 'Power at work: navigating hierarchies, teamwork and webs'. *Medical Humanities*, 25 (4): 291-308.

Dodier, N. (1998) 'Clinical practice and procedures in occupational medicine: a study of the framing of individual'. In: M. Berg, and A. Mol (Eds.) *Differences in Medicine. Unravelling Practices, Techniques and Bodies*. Durham and London: Duke University Press: 53-85.

Duster, T. (2003) 'Buried alive: the concept of race in science'. In: A. Goodman, D. Heath, and M.S. Lindee (Eds.) *Genetic Nature/Culture: Anthropology Beyond the Two-Culture Divide*. Berkley: University of California Press: 258-277.

Duster, T. (2005) 'Race and reification in science'. *Science*, 307: 1050-1051.

Dyer, R. (1997) *White*. London: Routledge.

Epstein, S. (2007) *Inclusion: The Politics of Difference in Medical Research*. Chicago and London: The University of Chicago Press.

Epstein, S. (2008) 'Culture and science/technology: rethinking knowledge, power, materiality and nature'. *The Annals of the American Academy of Political Science*, 619: 165-182.

Esmaeilzadeh, M., Dictus, C., Kayvanpour, E., Sedaghat-Hamedani, F., Eichbaum, M., Hofer, S., Engleman, G., Fonouni, H., Golriz, M., Schmidt, J., Unterberg, A., Mehrabi, A., and Ahman, R. (2010) 'One life ends, another begins: management of a brain dead pregnant mother – a systematic review'. *BMC Medicine*, 8 (74): Epub.

Evans-Pritchard, E.E. (1937) *Witchcraft, Oracles and Magic among the Azande*. Oxford: Clarendon Press.

Exley, C., Sim, J., Reid, N., Jackson, S., and West, N. (1996) 'Attitudes and beliefs within the Sikh community regarding organ donation: a pilot study.' *Social Science and Medicine*, 43: 23-28.

Farooqi A., Jain, N., and Feehally, J. (2008) *A Better Life through Education and Empowerment: the Leicester ABLE Project to raise awareness of renal disease in the South Asian community.* Kidney Research UK. Available from: http://www.kidneyresearchuk.org/assets/asset500.pdf. [Accessed 10th January, 2011].

Faubion, J.D. (2007) 'Currents of cultural fieldwork'. In: P. Atkinson, P., A. Coffey, s. Delamont, J. Loftland, and L. Loftland (Eds.) *Handbook of Ethnography*. London: Sage: 39-55.

Featherstone, K. (1994) 'Nurses' knowledge and attitudes towards organ and tissue donation in a community hospital'. *Journal of Trauma Nursing*, 1: 57-63.

Featherstone, K., Bharadwaj, A., and Clarke, A. (2006) *Risky Relations: Family Kinship and the New Genetics.* Oxford: Berg Publishers.

Finlay, L. (2006) 'Dancing between embodied empathy and phenomenological reflection'. *The Indo-Pacific Journal of Phenomenology*, 6. Available from: http://www.ipjp.org/index.php?option=com_jdownloads&Itemid=25&task=finish&cid=58&catid=15&m=0. [Accessed 14th June 2010].

Flyvberg, B. (2001) *Making Social Science Matter: Why Social Inquiry Fails and How it Can Succeed Again*. Cambridge: Cambridge University Press.

Foucault, M. (1976) The *Birth of the Clinic: An Archaeology of Medical Perception*. London: Routledge.

Foucault, M. (1977) *Discipline and Punish: The Birth of the Prison*. London: Lane.

Foucault, M. (1979) *The History of Sexuality. Volume I.* London: Lane.

Foucault, M. (1980) *Power/Knowledge. Selected Interviews and other Writings 1972-1977.* (Ed. Gordon, C.) Brighton: Harvester.

Foucault, M. (1984) 'The order of discourse'. In: Shapiro, M. (ed.) *Language and Politics*. New York: New York Press: 108-138.

Foucault (2003) *Society Must be Defended: Lectures at the College de France 1975-1976*. London: Allen Lane.

Foulton, J., Foulton, R., and Simmons, R. (1987) 'The cadaver donor and the gift of life'. In: R.G. Simmons, S.K. Marine, and R.L. Simmons (Eds.) *Gift of Life. The Effect of Organ Transplantation on Individual, Family and Societal Dynamics*. New Brunswick: Transaction Books: 60-82.

Fox, R.C., and Swazey, J.P. (2001) *The Courage to Fail. A Social View of Organ Transplants and Dialysis*. *New edition*. London: Transaction Publishers.

Fox, R.C. (2004) 'observations and reflections of a perpetual fieldworker.' *Annals of the American Academy of Political and Social Science*, 59: 309-326.

Franklin, S. (2001) 'Biologization revisited: kinship theory in the context of new biologies'. In: S. Franklin, and S. McKinnon (Eds.) *Relative Values: Reconfiguring Kinship Studies*. Durham: Duke University Press: 302-322.

Franz, H.G., DeJong, W., Wolfe, S.W., Nathan, H., Payne, D., Reitsma, W., Beasley, C. (1997) 'Explaining brain death: a critical feature of the donation process'. *Journal of Transplant Coordination*, 7 (1): 14-21.

Fuggle, S.V., Johnson, R.J., Rudge, C.J., Forsythe, J.L.R. (2004) 'Human Leukocyte Antigen and the allocation of kidneys from cadaver donors in the United Kingdom'. *Transplantation*, 77 (4): 618-620.

Fujimura, J.H. (1992) 'Crafting science: standardised packages, boundary objects, and 'translation'. In: A. Pickering (Ed.) *Science as Practice and Culture*. London: University of Chicago Press: 168-213.

Fujimura, J.H., Rajagopalan, R., Ossorio, P.N., and Doksum, K.A. (2010) 'Race and ancestry: operationalizing populations in human genetic variation studies'. In: I. Whitmarsh, and D.S. Jones (Eds.) *Whats the Use of Race?* Cambridge (Mass) and London: MIT Press: 169-186.

Gadamer, H.G. (2004 [1989]) *Truth and Method*. *Second Revised Edition.* London: Continuum.

Garner, S. (2010) *Racisms: An Introduction*. London: Sage.

Gatrad, A.R. (1994) 'Muslim customs surrounding death, bereavement, post-mortem examinations, and organ transplants'. *BMJ*, 309: 521-523.Gaylin, W. (1974) 'Harvesting the dead'. *Harpers*, 52: 23-30.

General Medical Council (2010) *Treatment and Care towards the End of Life: Good Practice in Decision Making*. Available from: http://www.gmc-uk.org/guidance/ethical_guidance/6869.asp. [Accessed April, 2011].

Ghoneim, M.A., and Refaie, A.F. (2009) 'Is matching for human leukocyte antigen-DR beneficial in pediatric kidney transplantation?' *Nature Clinical Practice Nephrology*, 5: 70-71.

Gibbon, S. (2011) 'Family medicine, 'La Herencia' and breast cancer: understanding the (dis)continuities of predictive genetics'. *Social Science & Medicine,* 72: 1784-1792.

Gilroy, P. (1987) *There Ain't no Black in the Union Jack*. London: Routledge.

Gilroy, P. (2004) *Between Camps. Nations, Cultures and the Allure of Race*. London: Routledge.

Glaser, B.G., and Strauss, A.L. (1965) *Awareness of Dying*. London: Weidenfeld and Nicolson.

Glaser, B.G., and Strauss, A.L. (1968) *The Discovery of Grounded Theory; Strategies for Qualitative Research*. London: Weidenfeld & Nicolson.

Glaser, B.G., and Strauss, A.L. (1974) *Time for Dying*. Chicago: Aldine.

Goffman, E. (1955) 'On face-work: an analysis of ritual elements in social interaction'. *Journal for the Study of Interpersonal Processes*, 18: 213-231.

Goffman, E. (1967) *Interaction Ritual*. London: Penguin.

Goffman, E. (1969) *The Presentation of Self in Everyday Life*. London: Lane.

Good, B.J. (1994) *Medicine, Rationality and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.

Gordon, E.J. (2002) 'What "race" cannot tell us about access to kidney transplantation'. *Cambridge Quarterly of Healthcare Ethics*, 11: 134-141.

Gordon, A.K., Herzhog, A., and Lichtenfeld., D. (1995) 'Surveying donor families. A comparison of two organ procurement organisations'. *Clinical Transplantation, Part 1,* 9: 141-145.

Gray, B. (2009) 'The emotional labour of nursing 1: exploring the concept'. *Nursing Times*, 105 (8): 26-29.

Greenhalgh, T. (2001) *How to Read a Paper. The Basics of Evidence Based Medicine*, 2nd Edition. London: British Medical Journal Publishing Group.

Grewal, I., and Ritchie, J. (2006) 'Ethnic and language matching of the researcher and the research group during design, fieldwork and analysis'. In: J.Y. Nazroo (Ed.) *Health and Social Research in Multiethnic Societies*. London: Routledge: 65-81.

Griffiths, J., Verble, M., Falvey, S., Bell, S., Logan, L., Morgan, K., and Wellington, F. (2009) 'Culture change initiatives in the procurement of organs in the United Kingdom.' *Transplantation Proceedings*, 41: 1459-1462.

Guadagnoli, E., McNamara, P., Evanisko, M., Beasley, C., Callender, C.O., and Poretsky, A. (1999) 'The influence of race on approaching families for organ donation and their decision to donate'. *American Journal of Public Health*, 89: 244-247.

Gunaratnam, Y. (2003) *Researching 'Race' and Ethnicity: Methods, Knowledge and Power*. London: Sage.

Gupta, J.A., and Richters, A. (2008) 'Embodied subjects and fragmented objects: women's bodies, assisted reproduction technologies and the right to self-determination'. *Bioethical Inquiry*, 5: 239-249.

Gupta, R. (2011) 'Death beliefs and practices from an Asian Indian American Hindu perspective'. *Death Studies*, 35: 244-266.

Gupta, S., de Belder, A., and O'Hughes, L. (1995) 'Avoiding premature deaths in Asians in Britain: spend now on prevention or pay later for treatment'. *BMJ*, 311: 1035-6.

Hacking, I. (2000) *The Social Construction of What?* London: Harvard University Press.

Hacking, I. (2006) 'Making Up People'. *The London Review of Books*, 28 (16): 23-26.

Hadders, H. (2007) 'Dealing with the dead patient at the Intensive Care Unit'. *Mortality*, 12 (3): 207-222.

Hadders, H. (2009a) 'Enacting death in the Intensive Care Unit: medical technology and the multiple ontologies of death'. *Health*, 13 (6): 571-587.

Hadders, H. (2009b) 'Medical practice, procedure manuals and the standardisation of hospital death'. *Nursing Inquiry*, 16 (1): 22-32.

Hadders, H. (2011) 'Negotiating leave-taking events in the palliative medical unit'. *Qualitative Health Research*, 21 (2): 223-232.

Haddow, G. (2004) 'Donor and nondonor families' accounts of communication and relations with healthcare professionals'. *Progress in Transplantation*, 14: 41-48.

Haddow, G. (2005) 'The phenomenology of death, embodiment and organ transplantation'. *Sociology of Health and Illness*, 27: 92-113.

Hall, E.C., Massie, A.B., James, N.T., Garonzic Wang, J.M., Montgomery, R.A., Berger, J.C., and Segev, D.L., (2011) 'Effect of eliminating priority points for HLA-B matching on racial disparities in kidney transplantation rates'. *American Journal of Kidney Diseases*, 58 (5): 813-816.

Hammersley, M. (1990) *Reading Ethnographic Research*. London: Longman.

Hammersley, M., and Atkinson, P. (2007) *Ethnography: Principles in Practice. Third Edition*. London and New York: Routledge.

Hannerz, U. (2003) 'Being there...and there...and there! Reflections on multi-site ethnography.' *Ethnography*, 4: 210-216.

Haraway, D. (1991) *Simians, Cyborgs, and Women. The Reinvention of Nature*. London: Free Association Books.

Haraway, D. (1997) *Modest_Witness@Second-Millenium.FemaleMan-Meets-OncoMouse: Feminism and Technoscience*. New York; London: Routledge.

Harris, R., Tobias, M., Jeffreys, M., Waldegrave, K., Karlsen, S., Nazroo, J. (2006a) 'Racism and health: the relationship between experience of racial discrimination and health in New Zealand'. *Social Science & Medicine*, 63: 1428-1441.

Harris, R., Tobias, M., Jeffreys, M., Waldegrave, K., Karlsen, S., and Nazroo, J. (2006b) 'Effects of self-reported racial discrimination and deprivation on Maori health and inequalities in New Zealand: cross-sectional study'. *The Lancet*, 367 (9527): 2005-2009.

Hartwig, M. S., Hall, G., Hathaway, D., and Gaber, A.O. (1993) 'Effect of organ donor race on health team procurement efforts.' *Archives of Surgery*, 128: 1331-1335.

Hayden, C. (2007) 'Taking as giving: bioscience, exchange and the politics of benefit-sharing'. *Social Studies of Science*, 37 (5): 729-758.

Hayward, C., and Madill, A. (2003) 'The meanings of organ donation: Muslims of Pakistani origin and White English nationals living in North England'. *Social Science & Medicine*, 57: 389-401.

Healey, K. (2004) 'Altruism as an organizational problem: the case of organ procurement'. *American Sociological Review*, 69: 387-404.

Heidegger, M. (1967) *Being and Time*. Oxford: Blackwell.

Held, P.J., Kahan, B.D., Hunsicker, L.G., Liska, D., Wolfe, R.A., Port, F.K., Gaylin, D.S., Garcia, J.R., Agoda, L., and Krakauer, H. (1994) 'The impact of HLA mismatches on the survival of first cadaveric kidney transplants'. *New England Journal of Medicine*, 331: 765-770.

Higgins, R.M., West, N., Edmunds, M.E., Dukes, C.D., Kashi, H., Jurewicz, A., and Lam, F.T. (1997) 'Effect of strict HLA matching policy on distribution of cadaveric kidney transplants to Indo-Asian and white European recipients: regional study'. *BMJ*, 315: 1354-1355.

Hochschild, A.R. (1983) *The Managed Heart. Commercialization of Human Feeling*. Berkley (CA) and London: University of California Press.

Hoeyer, K. (2009) 'Informed consent: the making of an ubiquitous role in medical practice'. *Organization*, 16 (2): 267-288.

Hogle, L.F. (1995) 'Standardisation across non-standard domains: the case of organ procurement.' *Science, Technology, & Human Values*, 20 (4): 482-500.

Hogle, L.F. (1996) 'Transforming 'body parts' into therapeutic tools: a report from Germany'. *Medical Anthropology Quarterly*, 10 (4): 675-682.

Hogle, L.F. (2009) 'Pragmatic objectivity and the standardisation of engineered tissues'. *Social Studies of Science*, 39: 717-742.

House of Lords European Union Committee (2008) *Increasing the Supply of Donor Organs within the European Union. Volume I: Report.* London: The Stationary Office Limited.

Hughes, D. (1988) 'When nurse knows best: some aspects of nurse/doctor interaction in a casualty department'. *Sociology of Health and Illness*, 10 (1): 1-22.

Human Tissue Act 2004. Available from:

http://www.legislation.gov.uk/ukpga/2004/30/contents. [Accessed December 2010].

Human Tissue Authority (2009a) *Code of Practice 2: Donation of Solid Organs for Transplant*. Available from:

http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cfm. [Accessed February, 2011].

Human Tissue Authority (2009b) *Code of Practice 1: Consent*. Available from:

http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code1consent.cfm. [Accessed February, 2011].

Hunter, M. (2001) 'Alder Hey condemns doctors, management, and coroner'. *BMJ*, 322: 255.

Husserl, E. (1981) 'Pure Phenomenology, its Method, and its Field of Investigation.' In: Husserl, E. *Shorter Works*. Brighton: Harvester Press: 10-17.

Intensive Care Society (2005) *Guidelines for Adult Organ and Tissue Donation*. Available from:

http://www.ics.ac.uk/intensive_care_professional/standards_and_guidelines/organ_and_tissue_donation_2005. [Accessed January, 2011]

Intensive Care Society/British Transplantation Society (2010) *Donation after Circulatory Death.* Available from:

http://www.ics.ac.uk/intensive_care_professional/standards_and_guidelines/dcd. [Accessed April, 2011].

Jackson, M. (2002) 'Familiar and foreign bodies: a phenomenological exploration of the human-technology interface. *Journal of the Royal Anthropological Institute*, vol. 8: 333-346.

Jacobs, L., Lawler, M., and Mattingly, C. (2011) 'I/we narratives among African American families raising children with special needs'. *Culture, Medicine and Psychiatry*, vol. 35: 3-25.

Jasanoff, S. (2004) 'The idiom of co-production'. In: S. Jasanoff (Ed.) *States of Knowledge: The Co-Production of Science and the Social Order*. London: Routledge: 1-12.

Jeffrey, R. (1979) 'Normal rubbish: deviant patients in casualty departments'. *Sociology of Health and Illness,* 1 (1): 90-107.

Jensen, A.M.B. (2010) 'A sense of absence: the staging of heroic deaths and ongoing lives among American donor families'. In: M. Bille, F. Hastrup, and T.F. Sorensen (Eds.) *An Anthropology of Absence. Materializations of transcendence and loss.* New York: Springer: 63-80.

Johnson, M.D. (2009) 'Engaging communities and users: health and social care research with ethnic minority communities'. In: J.Y. Nazroo (Ed.) *Health and Social Research in Multiethnic Societies*. London: Routledge: 48-66.

Johnson, N., Cook, D., Giacomini, M., and Willms, D. (2000) 'Towards a "good" death: end-of- life narratives constructed in an Intensive Care Unit'. *Culture, Medicine & Psychiatry*, 24: 275-295.

Johnson, R.J., Fuggle, S.V., Mumford, L., Bradley, J.A., Forsythe, J.L.R., Rudge, C. (2010) 'A new UK 2006 National kidney allocation scheme for deceased heart-beating donor kidneys'. *Transplantation*, 89 (4): 387-394.

Joralemon, D. (1995) 'Organ wars: the battle for body parts'. *Medical Anthropology Quarterly*, 9 (3): 335-356.

Kai, J., Beavan, J., Faull, C., Dodson, L., Gill, P., and Beighton, A. (2007) 'Professional uncertainty and disempowerment responding to ethnic diversity in health care: a Qualitative study'. *PLoS Medicine*, 4 (11): 1766-1775.

Karlsen, S., and Nazroo, J.Y. (2002) 'Agency and structure: the impact of ethnic identity and racism on the health of ethnic minority people'. *Sociology of Health and Illness*, 24: 1-20.

Karlsen, S., and Nazroo, J.Y. (2006) 'Defining and Measuring ethnicity and 'race': theoretical and conceptual issues for health and social care research'. In: J.Y. Nazroo (Ed.) *Health and Social Research in Multiethnic Societies*. London: Routledge: 20-38.

Karlsen, S., and Nazroo, J.Y. (2010) 'Religious and ethnic differences in health: evidence from the health surveys for England 1999 and 2004'. *Ethnicity and Health*, 15 (6): 549-568.

Kaufman, S.R. (2005) 'And a Time to Die. How American Hospitals Shape the End of Life'. New York and London: Lisa Drew/Scribner.

Kaufman, S.R., and Morgan, L.M. (2005) 'The anthropology of the beginnings and ends of life'. *The Annual Review of Anthropology*, 34: 317-341.

Kellehear, A. (2008) 'Dying as a social relationship: a sociological review of debates on the determination of death'. *Social Science & Medicine*, 66: 1533-1544.

Kierans, C. (2005) 'Narrating kidney disease: the significance of sensation and time in the emplotment of patient experience'. *Culture, Medicine & Psychiatry,* 29: 341-359.

Kierans, C. (2011) 'Anthropology, organ transplantation and the immune system: resituating commodity and gift exchange'. *Social Science & Medicine*, 73: 1469-1476.

Kierans, C., and Cooper, J. (2011) 'Organ donation, genetics, race and culture: the making of a medical problem'. *Anthropology Today*, 26 (6): 11-14.

Knorr Cetina, K. (1992) 'The couch, the cathedral, and the laboratory: on the relationship between experiment and laboratory in science'. In: A. Pickering (Ed.) *Science as Practice and Culture*. London: University of Chicago Press: 113-138.

Knorr Cetina, K. (1999) *Epistemic Cultures. How the Sciences Make Knowledge*. London: Harvard University Press.

Koch, T. (1995) 'Interpretive approaches in nursing research: the influence of Husserl and Heidegger'. *Journal of Advanced Nursing*, 24: 174-184.

Kovandzic, M., Chew-Graham, C., Reeve, J., Edwards, S., Peters, S., Edge, D., Aseem, S., Gask, L., and Dowrick, C. (2011) 'Access to primary mental health care for hard-to-reach groups: from 'silent suffering' to 'making it work''. *Social Science & Medicine*, 72 (5): 763-772.

Krieger, N. (2010) 'The science and epidemiology of racism and health: racial/ethnic categories, biological expression of racism, and the embodiment of inequality – an ecosocial perspective'. In: I. Whitmarsh, and D.S. Jones (Eds.) *What's the Use of Race?* Cambridge (Mass) and London: MIT Press: 225-258.

Labov, W. (1972) 'The transformation of experience in narrative syntax'. In: W. Labov (Ed.) Language in the Inner City: Studies in Black English Vernacular. Philadelphia: University of Philadelphia Press: 354-396.

Laschinger, H.K.S., and Havens, D.S. (1997) 'The effect of workplace empowerment on staff nurses' occupational mental health and work effectiveness'. *Journal of Nursing Administration*, 27 (6): 42-50.

Latimer, J., Featherstone, K., Atkinson, P., Clarke, A., Pilz, D.T., and Shaw, A. (2006) 'Rebirthing the clinic. The interaction of clinical judgement and genetic technology in the production medical science'. *Science, Technology and Human Values*, 31 (5): 599-630.

Latour, B. (1987) *Science in Action. How to Follow Scientists and Engineers through Society*. Milton Keynes: Open University Press.

Latour, B. (1988) *The Pasteurization of France*. Cambridge (Mass.): Harvard University Press.

Latour, B. (1993) *We Have Never Been Modern.* Harlow: Longman.

Latour, B. (2000) 'When things strike back: a possible contribution of 'science studies' to the social sciences'. *British Journal of Sociology*, 51 (1): 107-123.

Latour, B. (2005) *Reassembling the Social. An Introduction to Actor-Network Theory*. Oxford: Oxford University Press.

Laverty, S.M. (2003) 'Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations'. *International Journal of Qualitative Methods*, 2 (3): 21-35.

Law, J. (1991) 'Power, discretion and strategy'. In: J. Law (Ed.) *A Sociology of Monsters. Essays on Power, Technology and Domination*: London and New York: Routledge*: 165-191.

Law, J. (1999) 'After ANT: complexity, naming and topology'. In: J. Law, and J. Hassard (Eds.) *Actor Network Theory and After*. Oxford: Blackwell/The Sociological Review: 1-14.

Law, J. (2008) 'On sociology and STS'. *The Sociological Review*, 56 (4): 623-649.

Law, J., and Mol, A. (Eds.) (2006) *Complexities: Social Studies of Knowledge Practices*. Durham (NC): Duke University Press.

Lee, C. (2009) '"Race" and "ethnicity" in biomedical research: how do scientists construct and explain differences in health?' *Social Science & Medicine*, 68: 1183-1190.

Lesoeurs, G., Cossart, J., Olivier, C., Ferradji, T. (2009) 'Transplant coordinators and communication with potential organ donor migrant families in France: an exploratory qualitative study'. *Transplantation Proceedings,* 41: 631-633.

Levinas, E (1969) *Totality and Infinity*. Pittsburg: Duquesne University Press.

Liaschenko, J., and Peter, E. (2004) 'Nursing ethics and conceptualisations of nursing: profession, practice and work'. *Journal of Advanced Nursing*, 46 (5): 488-495.

Lock, M. (1996) 'Death in technological time: locating the end of meaningful life'. *Medical Anthropology Quarterly*, 10 (4): 575-600.

Lock, M. (2002) *Twice Dead: Organ Transplants and the Reinvention of Death*. London: University of California Press.

Lock, M., and Crowley-Matoka, M. (2008) 'Situating the practice of organ donation in familial, cultural and political context'. *Transplantation Reviews*, 22: 154-157.

Lowry, D.J, Lamb, P., Watson, R.D., Ellis, K.E., Singh, S.P., and Littler, W.A. (1991) 'Influence of racial origin on admission prevalences of patients with suspected myocardial infarction in Birmingham.' *British Heart Journal*, 66: 29-35.

Luce, J.M., and White, D.B. (2007) 'The pressure to withhold or withdraw life-sustaining therapy from critically ill patients in the United States'. *American Journal of Respiratory and Critical Care Medicine*, 175: 1104-1108.

Lutfey, K.E., and Freese, J. (2007) 'Ambiguities of chronic illness management and challenges to the medical error paradigm'. *Social Science & Medicine*, 64: 314-325.

Lundin, S.M. (2010). 'Organ economy: organ trafficking in Moldova and Israel'. *Public Understanding of Science,* 1: 1-16.

Lynch, M. (2001) 'Ethnomethodology and the logic of practice'. In: T.R. Schatzki, K. Knorr Cetina, and E. Von Savigny (Eds.), *The Practice Turn in Contemporary Theory*. London and New York: Routledge: 140-157.

Lyons, C. (1970) *Organ Transplants. The Moral Issues.* London: SCM Press.

Macey, D. (2009) 'Rethinking biopolitics, race and power in the wake of Foucault'. *Theory, Culture & Society*, 26 (6): 186-205.

Malek, S.K., Keys, B.J., Kumar, S., Milford, E., and Tullius, S.G. (2011) 'Racial and ethnic disparities in kidney transplantation'. *Transplant International*, 24: 419-424.

Marcus, G. E., and Clifford, J. (1986) *Writing Culture: The Politics and Poetics of Ethnography*. Berkley: University of California Press.

Marcus, G. E. (1998) *Ethnography through Thick and Thin.* Princeton (NJ): Princeton University Press.

Marsh, S.G.E., Parham, P., and Barber, L.D. (2000) *The HLA Factsbook*. San Diego: Academic Press.

Martin, E. (1994) *Flexible Bodies: tracking immunity in American culture – from the days of Polio to the age of AIDS*. Boston: Beacon Press.

Martin, E. (2005) 'Managing Americans. Policy and changes in the meanings of work and the self'. In: C. Shore, and S. Wright (Eds.), *The Anthropology of Policy: Critical Perspectives on Governance and Power.* London and New York: Routledge: 183-197.

Martinez, J.M., Lopez, J.S., Martin, A., Martin, M., Scandroglio, B. And Martin, J. (2001) 'Organ donation and family decision-making within the Spanish donation system'. *Social Science & Medicine*, 53: 405-421.

Mauss, M. (1954) *The Gift. Forms and Functions of Exchange in Archaic societies*. London: Cohen & West.

May, T., Auliso, M.P., and Devita, M.A. (2000) 'Patients, families, and organ donation: who should decide?' *The Millbank Quarterly*, 78 (2): 323-336.

Mays, N., and Pope, C. (2000) 'Quality in Qualitative Research'. *BMJ*, 320: 50-52.

McGibbon, E., and Peter, E. (2008) 'An ethnography of everyday caring for the living, the dying, and the dead: toward a biomedical technography'. *Qualitative Inquiry*, 14 (7): 1134-1156.

McKenzie, P.J. (2006) 'Mapping textually mediated information practice in clinical midwifery care'. In: A. Spink, and C. Cole (Eds.) *New Directions in Human Information Behaviour*. Dordrecht: Springer: 73-92.

Mead, M. (1943) *Coming of Age in Samoa: a study of adolescence and sex in primitive societies*. Harmondsworth: Penguin.

Menard-Warick, J. (2007) '"My little sister had a disaster, she had a baby". Gendered performance, relational identities, and dialogic voicing'. *Narrative Inquiry*, 17 (2): 279-297.

Merleau-Ponty, M. (1962) *Phenomenology of Perception*. London: Routledge and Keegan Paul.

Mesman, J. (2007) 'Disturbing observations as a basis for collaborative research'. *Science as Culture*, 16 (3): 281-295.

Miller, F., and Bowker, G. (2009) 'Metadata standards. Trajectories and enactment in the life of an ontology'. In: M. Lampland, and S.L. Star (Eds.) *Standards and their Stories. How*

Quantifying, Classifying, and Formalizing Practices Shape Everyday Life. Ithaca and London: Cornell University Press: 149-165.

Mishler, E. G. (1986a) *Research Interviewing: Context and Narrative.* Cambridge, Mass: Harvard University Press.

Mishler, E. (1986b) 'The analysis of interview-narratives'. In: T.R. Sarbin (Ed.) *Narrative Psychology. The Storied Nature of Human Conduct*. New York: Praeger: 233-255.

Mishler, E. (1995) 'Models of narrative analysis: a typology'. *Journal of Narrative and Life History*, 5: 87-123.

Modell, B., Petrou, M., Layton, M., Varnavides, L., Slater, C., Ward, R.H., Rodeck, C., Nicolaides, K., Gibbons, S., Fitches, A., and Old, J. (1997) 'Audit of prenatal diagnosis for haemoglobin disorders in the United Kingdom: the first 20 years'. *BMJ*, 315: 779-785.

Mohammed, S., and Peter, E. (2009) 'Rituals, death and the moral practice of medical futility'. *Nursing Ethics*, 16 (3): 292-302.

Mol, A. (2002) *The Body Multiple: Ontology in Medical Practice.* Durham and London: Duke University Press.

Mol, A. (2008) *The Logic of Care. Health and the Problem of Patient Choice*. Oxon: Routledge.

Mol, A. (2009) 'The art of medicine. Living with diabetes: care beyond choice and control'. *The Lancet*, 727: 1756-1757.

Molzahn, A.E., Starzomski, R., McDonald, M., O'Loughlin, C. (2005) 'Chinese Canadian beliefs towards organ donation'. *Qualitative Health Research*, 15: 82-98.

Moran, D. (2000) *Introduction to Phenomenology*. London: Routledge.

Moran, D., and Mooney, T. (2002) 'Edmund Husserl (1859-1938). Introduction.' In: D. Moran, and T. Mooney (Eds.) *The Phenomenology Reader*. London: Routledge: 59-64.

Morgan, M., Mayblin, M., and Jones, R. (2008) 'Ethnicity and registration as a kidney donor. The significance of identity and belonging'. *Social Science & Medicine*, 66: 147-158.

Morgan, M., Adams, P., Seed, P.T., and Jones, R. (2010) 'Ethnicity and attitudes to deceased kidney donation: a survey in Barbados and comparison with Black Caribbean people in the United Kingdom'. *BMC Public Health*, 10: 266.

Morgan, S.E., and Cannon, T. (2003) 'African Americans' knowledge about organ donation: closing the gap with more effective persuasive message strategies'. *Journal of the National Medical Association*, 95 (11): 1066-1071.

Moss, P. and Dyck, I. (2002) *Women, Body, Illness: Space and Identity in the Everyday Lives of Women with Chronic Illness*. Lanham, MD: Rowman and Littlefield.

Mullins, B. (1999) 'Insider or outsider, both or neither: some dilemmas of interviewing in a cross-cultural setting'. *Geoforum*, 30: 337-350.

Nader, L. (1969) Up the anthropologist – perspectives gained from studying up'. In: D. Hymes (Ed.), *Reinventing Anthropology*. New York: Pantheon: 284-311.

Nazroo, J.Y. (1998) 'Genetic, cultural or socio-economic vulnerability? Explaining ethnic inequalities in health.' *Sociology of health and Illness*, 20 (5): 710-730.

Nazroo, J.Y. (2003) 'The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism'. *Public Health Matters*, 93 (2): 277-284.

NHSBT (2006) *Deceased Donor Kidney Allocation Scheme*. Available from:

http://www.uktransplant.org.uk/ukt/about_transplants/organ_allocation/kidney_(renal)/re

nal_organ_sharing_principles/kidney_organ_allocation_scheme_2006.jsp. [Accessed January, 2011]

NHSBT (2009) *Statistics*. Available from: http://www.organdonation.nhs.uk/ukt/statistics/statistics.jsp. [Accessed 19th June, 2010].

NHSBT (2010) *National Standards for Organ Retrieval from Deceased Donors*. Available from: http://www.nhsbt.nhs.uk/downloads/board_papers/mar10/standards_deceased_donors.pdf. [Accessed April 2011].

NHSBT (2011) *Transplant Activity in the UK. Activity Report 2010-2011.* Available from: http://www.uktransplant.org.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2010_11.pdf. [Accessed June, 2011]

NICE (2011) *Organ Donation for Transplantation: Improving Donor Identification and Consent Rates for Deceased Organ Donation. NICE Clinical Guidleine 135.* Available from: http://www.nice.org.uk/nicemedia/live/13628/57502/57502.pdf. [Accessed December, 2011]

Ochs, E., and Capps, L. (2001) *Living Narrative: Creating Lives in Everyday Storytelling*. Cambridge (MA): Harvard University Press.

Ohnuki-Tierney, E. (1994) 'Brain death and organ transplantation. Cultural bases of medical technology'. *Current Anthropology*, 35 (3): 233-254.

Organ Donation Taskforce (2008) *Organs for Transplant*. London: HMSO.

Parry, B. (2008) 'Entangled exchange: reconceptualising the characterisation and practice of bodily commodification'. *Geoform*, 39: 1133-1144.

Perez, L.M., Schulman, B., Davis, F., Olson, L., Tellis, V.A., and Matas, A.J. (1988) 'Organ donation in three major American cities with large Latino and Black populations.' *Transplantation*, 46: 553-557.

Pfeffer, N. (1998) 'Theories of race, ethnicity, and culture'. *BMJ*, 317: 1381-1384.

Pickering, A. (1992) 'From science as knowledge to science as practice'. In: A. Pickering (Ed.) *Science as Practice and Culture*. London: University of Chicago Press: 113-138.

Poole, J.M., Shildrick, M., De Luca, E., Abbey, S.T., Mauthner, O.E., McKeever, P.D., and Ross, J.H. (2011) 'The obligation to say 'thank you': heart transplant recipients' experience of writing to the donor family'. *American Journal of Transplantation*, 11 (3): 619-622.

Priest, N., Paradies, Y., Stewart, P., and Luke, J. (2011) 'Racism and health among urban Aboriginal young people'. *BMC Public Health*, 11: 568.

Rabinow, P. (1996) *Essays on the Anthropology of Reason.* Princeton (NJ): Princeton University Press.

Raleigh, V.S. (1997) 'Diabetes and hypertension in Britain's ethnic minorities: implications for the future of renal services'. *BMJ*, 314 (7075): 209-214.

Randhawa G. (1998a) 'The impending kidney transplant crisis for the Asian population in the UK'. *Public Health,* 112: 265-268.

Randhawa, G. (1998b) 'An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology Dialysis Transplantation*, 13: 1949-1954.

Randhawa, G. (2005) 'Promoting organ donation and transplantation among South Asians in the United Kingdom: the role of social networks in the South Asian community'. *Progress in Transplantation*, 15 (3): 286-290.

Randhawa, G. (2010) 'Renal health disparities in the United Kingdom: a focus on ethnicity'. *Seminars in Nephrology*, 30 (1): 8-11.

Randhawa, G., Brocklehurst, A., Pateman, R., Kinsella, S., and Parry, V. (2010) 'Religion and organ donation: the views of UK faith leaders'. *Journal of Religion and Health* [Epub ahead of print].

Rapp, R. (1999) *Testing Women, Testing the Fetus. The Social Impact of Amniocentesis in America*. New York and London: Routledge.

Razaq, S., and Sajad, M. (2007) 'A cross-sectional study to investigate reasons for low organ donor rates amongst Muslims in Birmingham'. *The Internet Journal of Law, Healthcare and Ethics*, 4 (2).

Reissman, C.K. (1991) 'Beyond reductionism: narrative genres in divorce accounts'. *Journal of Narrative and Life History*, 1 (1): 41-68.

Reissman, C. K. (1993) *Narrative Analysis.* London: Sage.

Reissman, C.K. (2008) *Narrative Methods for the Human Sciences*. London: Sage.

Richardson, R. (2000) *Death Dissection and the Destitute. Second Edition*. Chicago: Chicago University Press.

Richardson, R. (2006) 'Human dissection and organ donation: a historical and social background. *Mortality*, 11 (2): 151-165.

Ricoeur, P. (1984) *Time and Narrative. Volume 1*. London: University of Chicago Press.

Roderick, P.J., Jones, I., Raleigh, V.S., McGeown, M., and Makkick, N. (1994) 'Population need for renal replacement therapy in Thames regions: ethnic dimension'. *BMJ*, 309 (6962): 1111.

Roderick, P.J, Raleigh, V.S., Hallam, L., and Mallick, N.P. (1996) 'The need and demand for renal replacement therapy in ethnic minorities in England'. *Journal of Epidemiology and Community Health*, 50: 334-339.

Rosaldo, R. (1993) *Culture and Truth: The Remaking of Social Analysis*. London: Routledge.

Rose, N., and Novas, C. (2005) 'Biological citizenship'. In: A. Ong, and S.J. Collier (Eds.) *Global Assemblages. Technology, Politics, and Ethics as Anthropological Problems*. Malden (MA) and Oxford: Blackwell: 439-463.

Rudge, C., Johnson, J., Fuggle, S.V., Forsythe, J.L.R. (2007) 'Renal transplantation in the United Kingdom for patients from ethnic minorities'. *Transplantation*, 83 (9): 1169-1173.

Russ, A.J., and Kaufman, S.R. (2005) 'Family perceptions of prognosis, silence and the 'suddenness' of death'. *Culture, Medicine & Psychiatry*, 29: 103-123.

Saeb-Parsy, K., and Watson, C.J.E. (2011) 'Kidney transplantation: surgical aspects'. *Medicine*, 39 (8): 443-447.

Said, E. (1989) 'Representing the colonized: anthropology's interlocutors'. *Critical Inquiry*, 15 (2): 205-225.

Sanal, A. (2004) '"Robin hood" of techno-turkey or organ trafficking in the state of ethical beings'. *Culture, Medicine and Psychiatry*, 28: 281-309.

Sander, S. L. And Kopp Miller, B. (2005) 'Public knowledge and attitudes regarding organ and tissue donation: an analysis of the northwest Ohio community'. *Patient Education and Counselling*, 58: 154 – 163.

Sanner, M. A. (2001) 'Exchanging spare parts or becoming a new person? People's attitudes toward receiving and donating organs'. *Social Science & Medicine*, 52: 1491-1499.

Sanner, M.A. (2007) 'Two perspectives on organ donation: experiences of potential donor families and intensive care physicians of the same event'. *Journal of Critical Care*, 22: 296-304.

Saris, A.J. (1995) 'Telling stories: life histories, illness narratives, and institutional landscapes'. *Culture, Medicine & Psychiatry*, 19: 39-72.

Schatzki, T. (1996) *Social Practices: A Wittgensteinian Approach to Human Activity and the Social.* Cambridge: Cambridge University Press.

Schatzki, T. (2001) 'Intorduction: practice theory'. In: T.R. Schatzki, K. Knorr Cetina, and E. Von Savigny (Eds.), *The Practice Turn in Contemporary Theory*. London and New York: Routledge: 10-23.

Scheper-Hughes, N. (2001) 'Commodity fetishism in organs trafficking'. *Body & Society*, 7 (2-3): 31-62.

Scheper-Hughes, N. (2002). 'Bodies for sale: whole or parts'. In: N. Scheper-Hughes, and L. Wacquant (Eds.), *Commodifying Bodies*. London: Sage: 1-8.

Scheper-Hughes, N. (2006) 'Alistair Cooke's bones'. *Anthropology Today*, 22 (6): 10-15.

Scholte, B. (1969) 'Toward a reflexive and critical anthropology'. In: D. Hymes (Ed.), *Reinventing Anthropology*. New York: Pantheon: 430-457.

Schutz, A. (1944) 'The stranger: An essay in social psychology.' *The American Journal of Sociology*, 49 (6): 499-507.

Schutz, A. (1967) *The Phenomenology of the Social World*. Evanston (ILL): Northwestern University Press.

Seale, C., Kirk, D., Tobin, M., Burton, P., Grundy, R., Pritchard-Jones, K., and Dixon-Woods, M. (2005) 'Effect of media portrayals of removal of children's tissue on UK tumour bank'. *BMJ,* 331: 401-403.

Seymour, J. (2000) 'Negotiating natural death in Intensive Care'. *Social Science & Medicine*, 51 (8): 1241-1252.

Seymour, J. (2001) *Critical Moments: Death and Dying in Intensive Care*. Buckingham: Open University Press.

Sharp, L. (1995) 'Organ transplantation as transformative experience: anthropological insights into the restructuring of the self.' *Medical Anthropology Quarterly*, 9 (3): 357-389.

Sharp, L. (2000) 'The Commodification of the body and its parts'. *Annual Review of Anthropology*, 29: 287-328.

Sharp, L. (2001) 'Commodified kin: death, mourning and competing claims on the bodies of organ donors in the United States'. *American Anthropologist*, 103 (1): 112-133.

Sharp, L. (2006) *Strange Harvest: Organ Transplants, Denatured Bodies, and the Transformed Self.* London: University of California Press.

Sharp, L. (2007) *Bodies, Commodities and Biotechnologies*. New York: Columbia University Press.

Shaw, A. (2009) *Negotiating Risk: British Pakistani Experiences of Genetics*. Oxford: Berghahn Books.

Shaw, R. (2010) 'Perceptions of the gift relationship in organ and tissue donation: views of intensivists and donor and recipient coordinators'. *Social Science & Medicine*, 70: 609-615.

Sheach Leith, V.M. (2007) 'Consent and nothing but consent? The organ retention scandal'. *Sociology of Health and Illness*, 29 (7): 1023-42.

Sheik, A., and Dhami, S. (2000) 'Attitudes to organ donation among South Asians in the UK'. Letters to the Editor, *Journal of the Royal Society of Medicine*, 93: 161.

Sheik, A., Halani, L., Bhopal, R., Netuveli, G., Partridge, M., Car, J., Griffiths, C., and Levy, M. (2009) 'Facilitating the recruitment of minority ethnic people into research: qualitative case study of South Asians and asthma'. *PLoS Medicine*, 6 (10): 1-11.

Shih, F.J., Lai, M., Lin, M., Tsao, C., Duh, B., and Chu, S. (2001) 'The dilemma of "*to-be of not-to-be*": needs and expectations of the Taiwanese Cadaveric organ donor families during the pre-donation transition. *Social Science & Medicine*, 53: 693-706.

Shimazono, Y. (2008) 'Repaying and cherishing the gift of life: gift exchange and living related kidney transplantation in the Philippines'. *Anthropology in Action*, 15 (3): 34-46.

Shore, C., and Wright, S. (2005) 'Policy. A new field of anthropology'. In: C. Shore, and S. Wright (Eds.) *Anthropology of Policy. Critical Perspectives on Governance and Power.* London and New York: Routledge: 3-30.

Siminoff, L.A., Gordon, N., and Hewlett, J. (2001) 'Factors influencing families consent for donation of solid organs for transplantation'. *JAMA,* 286 (1): 71-77.

Siminoff, L.A., Lawrence, R.H., and Arnold, R.M. (2003) 'Comparison of black and white families' experiences and perceptions regarding organ donation requests.' *Critical Care Medicine*, 31, (1): 146-151.

Siminoff, L.A., Burant, C.J., and Ibrahim, S.A. (2006) 'Racial disparities in preferences and perceptions regarding organ donation'. *Journal of General Internal Medicine*, 21 (9): 995-1000.

Simpkin, A.L., Robertson, L.C., Barber, V.S., Young, D.J. (2009) 'Modifiable factors influencing relatives' decision to offer organ donation: systematic review'. *BMJ*, 338: 3162.

Sing, A. (2000) 'Correlates of willingness to donate organs among African Americans in North Carolina'. *Guru Nanak Journal of Sociology*, 21 (1-2): 53-65.

Singleton, V. (1998) 'Stabilising instabilities: the role of the laboratory in the United Kingdom cervical screening programme'. In: M. Berg, and A. Mol (Eds.) *Differences in Medicine. Unravelling Practices, Techniques and Bodies*. Durham and London: Duke University Press: 86-104.

Singleton, V. (2005) 'The promise of public health: vulnerable policy and lazy citizens'. *Environment and Planning*: *Society and Space*, 23 (5): 771-786

Singleton, V. (2010) 'Good farming. Control or Care?' In: A. Mol, I. Moser, and J. Pols (Eds.) *Care in Practice. On Tinkering in Clinics, Homes and Farms.* Bielefeld: Transcript Verlag/Transaction: 235-256.

Smaje, C. (1996) 'The ethnic patterning of health: new directions for theory and research'. *Sociology of Health and Illness*, 18 (2): 139-171.

Smart, A., Tutton, R., Martin, P., Ellison, G.T.H., and Ashcroft, R. (2008) 'The standardisation of race and ethnicity in biomedical science editorials and UK biobanks'. *Social Studies of Science,* 38 (3): 407-423.

Spector-Mersel (2010) 'Narrative research. Time for a paradigm'. *Narrative Inquiry*, 20 (1): 204-224.

Sque, M., and Payne, S. (1996) 'Dissonant loss: the experiences of donor relatives'. *Social Science & Medicine*, 43: 1359-1370.

Sque, M., Long, T., and Payne, S. (2005) 'Organ Donation: key factors influencing families' decision-making'. *Transplantation Proceedings*, 37: 543-546.

Sque, M., Long, T., Payne, S., and Allardyce, D. (2006) *Exploring the End of Life Decision-Making and Hospital Experiences of Families who did not Donate Organs or Tissues for Transplant Operations*. *Final Report for UK Transplant*. University of Southampton.

Sque, M., Payne, S., and Macleod Clark, J. (2006) 'Organ donation: gift of life or sacrifice?' *Mortality*, 11 (2): 117-132.

Sque, M., Long, T., Payne, S., and Allardyce, D. (2007) 'Why relatives do not donate organs for transplant: 'sacrifice' or 'gift of life'?' *Journal of Advanced Nursing*, 61 (2): 134-144.

Staiano-Ross, K. (2005) 'Losing myself: body as icon/body as object(s)'. *Semiotica*, 154-1/4: 57-94.

Star, S.L. (1991) 'Power, technology and the phenomenology of conventions: on being allergic to onions'. In: J. Law (Ed.) *A Sociology of Monsters. Essays on Power, Technology and Domination*. London: Routledge: 26-56.

Star, S.L., and Lampland, M. (2009) 'Reckoning with standards'. In: M. Lampland, and S.L. Star (Eds.) *Standards and their Stories. How Quantifying, Classifying, and Formalizing Practices Shape Everyday Life*. Ithaca and London: Cornell University Press: 3-24.

Steedly, M.M. (1993) *Hanging Without a Rope: Narrative Experience in Colonial and Post-Colonial Karoland*. Princeton (NJ): Princeton University Press.

Stoeckle, M. (1990) 'Attitudes of critical care nurses towards organ donation'. *Dimensions of Critical Care Nursing*, 9: 354-361.

Strathern, M. (1992) *After Nature: English Kinship in the Late Twentieth Century*. Cambridge: Cambridge University Press.

Strathern, M. (2009) 'Afterword'. *Body & Society*, 15 (2): 217-222.

Struhkamp, R., Mol, A., and Swierstra, T. (2009) 'Dealing with In/dependence. Doctoring in physical rehabilitation practice'. *Science, Technology & Human Values*, 34 (1): 55-76.

Su, X., Zenios, S.A., Chakkera, H., Milford, E.L., and Chertow, G.M. (2004) 'Diminishing significance of HLA matching in kidney transplantation'. *American Journal of Transplantation*, 4 (9): 1501-1508.

Sudnow, D. (1967) *Passing On: The Social Organisation of Dying*. Englewood-Cliffs (NJ): Prentice-Hall.

Svendsen, M.N. (2007) 'Between reproductive and regenerative medicine: practising embryo donation and civil responsibility in Denmark'. *Body & Society*, 13 (4): 21-45.

Szczepura, A. (2005) 'Access to health care for ethnic minority populations'. *Postgraduate Medical Journal*, 81: 141-147.

Taylor, J. J. (2007) 'Assisting or compromising intervention? The concept of 'culture' in biomedical and social research on HIV/AIDS'. *Social Science & Medicine*, 64: 965-975.

Taylor, S., and Marandi, A. (2008) 'Social determinants of health and the design of health programmes for the poor'. *BMJ*, 337: bmj.a290.

Thomas, W.I. (1931) *The Unadjusted Girl*. Boston: Little Brown.

Tilney, N.L. (2003) *Transplant:* f*rom Myth to Reality*. London: Yale University Press.

Timmermans, S. (1998) 'Resuscitation technology in the emergency department: towards a dignified death'. *Sociology of Health and Illness*, 20 (2): 144-167.

Timmermans, S. (2005) 'Death brokering: constructing culturally appropriate deaths'. *Sociology of Health and Illness*, 27: 993-1013.

Timmermans, S., and Berg, M. (1997) 'Standardization in action: achieving local universality through medical protocols'. *Social Studies of Science*, 27: 273-305.

Timmermans, S., and Berg, M. (2003) *The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care.* Philadelphia: Temple University Press.

Timmermans, S., Bowker, G.C., and Star, S.L. (1998) 'The architecture of difference: visibility, control, and comparability in building a nursing interventions classification'. In: M. Berg, and A. Mol (Eds.) *Differences in Medicine. Unravelling Practices, Techniques and Bodies*. Durham and London: Duke University Press: 202-225.

Timmermans, S., and Epstein, S. (2010) 'A world of standards but not a standard world: toward a sociology of standards and standardisation. *Annual Review of Sociology*, 36: 69-89.

Tinckam, K.J. and Chandraker, A. (2006) 'Mechanisms and role of HLA and non-HLA alloantibodies'. *Clinical Journal of the American Society of Nephrology*, (3): 404-414.

Titmuss, R.M. (1997 [1970]) *The Gift Relationship: From Human Blood to Social Policy*. New York: New Press.

Tober, D.M. (2007) 'Kidneys and controversies in the Islamic Republic of Iran: the case of organ sale'. *Body & Society*, 13 (3): 151-170.

Tsing, A.L. (1994) *In the Realm of the Diamond Queen: Marginality in an out of the way Place*. Princeton (NJ): Princeton University Press.

Turner, B. (1995) *Medical Power and Social Knowledge*. Thousand Oaks (CA): Sage.

Turner, B. (1996) *The Body and Society*: *Exploration in Social Theory*. *Second Edition*. London: Sage.

Turner, V.W. (1974) *Dramas, Fields, and Metaphors: Symbolic Action in Human Society*. Ithaca: Cornell University Press.

Tutton, R. (2002) 'Gift relationships in genetics research'. *Science as Culture*, 11 (4): 523-542.

UK Transplant (2003) *United Kingdom Hospital Policy for Organ and Tissue Donation*. Available from:

http://www.uktransplant.org.uk/ukt/about_transplants/donor_care/donor_care.jsp. [Accessed April, 2010].

UK Transplant (2004a) *Donor Family Care Policy.* Available from:

http://www.uktransplant.org.uk/ukt/about_transplants/donor_care/donor_care.jsp. [Accessed April, 2010].

UK Transplant (2004b) *Standards of Practice for Donor Transplant Co-ordinators*. Available from:

http://www.organdonation.nhs.uk/ukt/about_transplants/donor_care/donor_care.jsp. [Accessed April, 2010].

Van Manen, M. (1997) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. *Second Edition.* London, Ontario: Althouse Press.

Vaughan, D. (1999) 'The role of organisation in the production of techno-scientific knowledge'. *Social Studies of Science*, 29: 913-943.

Wall, S. (2010) 'Critical perspectives in the study of nursing work'. *Journal of Health Organization and Management*, 24 (2): 145-166.

Wengraf, T. (2001) *Qualitative Research Interviewing*. London: Sage.

Wild, J. (1969) 'Introduction'. In: Levinas, E. *Totality and Infinity*. Pittsburg: Duquesne University Press.

Wind, G. (2008) 'Negotiated interactive observation: doing fieldwork in hospital settings.' *Anthropology and Medicine*, 15 (2): 79-89.

Woolgar, S., and Latour, B. (1986) *Laboratory Life: the Construction of Scientific Facts*. Ewing, NJ: Princeton University Press.

Wright K. (2000) *Organ Donation and Transplantation: the multi-faith perspective*. Conference report, Bradford.

Yea, S. (2010) 'Trafficking in part(s): the commercial kidney market in a Manila slum, Philippines'. *Global Social Policy,* 10 (3): 358-376.

Youngner, S. J., Landefeld, S., Coulton, C. J., Juknialis, B. W., and Leary, M. (1989) 'Brain death and organ retrieval: a cross-sectional survey of knowledge and concepts among health professionals' *JAMA*, 261 (15): 2205-2210.

Appendices

Appendix 1. Example Literature Search Strategy

JSTOR database (using advanced search option)

Search	Terms used	Results (number of hits)
1	Organ donate£ **OR** organ transplant*	6670
2	1 **AND** Asian	692
3	1 **AND** African	1223
3	1 **AND** black	2253
4	1 **AND** minority ethnic	440
5	1 **AND** 'BME' OR ethnic*	87382
6	Organ donor family **OR** organ donor relative	3779
7	6 **AND** Asian **OR** black **OR** African	913903
8	1 **AND** health professional **OR** doctor **OR** nurse	180228
9	8 **AND** request **OR** communicate	142500

Appendix 2. Advertisement for Recruiting 'Community' Members

Liverpool study wants to find out about the experiences of South Asian and African-Caribbean families who were asked to donate their relative's organs after their death

If you were asked about organ donation after your relative's death, and if you are from a South Asian/Asian British (Indian, Pakistani, Bangladeshi, or Sri Lankan heritage) or African-Caribbean/Black British (Caribbean heritage) ethnic background, living in the North-West of England or Yorkshire, would you be willing to discuss your experiences with us?

➢ **We are looking for people who decided not to donate their relative's organs, as well as people who consented to donation. The experiences of both donor and non-donor families and individuals are equally important to us.**

➢ **All participation would be fully confidential and anonymous.**

➢ **The interviews will be participant directed, meaning that there are no set questions: you talk to the researcher about your experiences in your own words.**

➢ **We would also like to talk to any members of the community who are interested in discussing this subject.**

If you are interested in taking part in the study, or are generally interested in discussing the research, you can find out more by calling Jessie Cooper on: 0151 794 5272 or 07516067657 or emailing her at jessie21@liv.ac.uk. Any help would be hugely appreciated.

Appendix 3. Participant Covering Letters, Information Sheets and Reply Slip

Covering Letter – BME donor and non-donor families

UNIVERSITY OF LIVERPOOL

An exploration of organ donation among Black and Minority Ethnic communities and involved health professionals

Dear

A research study is being carried out at The University of Liverpool by Jessie Cooper, who is a PhD student in the Division of Public Health.

The study wants to explore the experiences of individuals/families from Black and Minority Ethnic (BME) backgrounds who have been asked to donate their relative's organs after their death. It will also be finding out about the experiences of health professionals who are involved in asking for organ donation.

As you were involved in being asked to donate your relative's organs after their death and have identified yourself as being from a BME background, we would like to invite you to take part in this study. Please find enclosed an information sheet which explains what the study is about in more detail, and what your role in the research will be if you choose to take part. Please read through this carefully.

If you would like to participate we would be grateful if you could send the completed reply slip and contact details form back to Jessie (an SAE is enclosed), so that she can get in touch with you; or contact her directly, using the details given on the information sheet. If you do not wish to participate we would be grateful if you could send the reply slip back to Jessie declining this invitation.

Thank you for taking the time to read this letter. If you have any questions Jessie will be happy to chat with you before you make up your mind about the study (her contact details are provided on the information sheet).

Kind Regards,

Donor-Transplant Coordinator   Jessie Cooper (PhD Student)

Participant Information Sheet – BME donor and non-donor families

An exploration of organ donation among Black and Minority Ethnic communities and involved health professionals

<u>Participant Information Sheet</u>

You are being invited to take part in a research study. Before you decide whether you want to be involved, we would like to explain the research study to you

Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand.

Feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Who is doing the research?

Jessie Cooper: who is a PhD student in the Division of Public Health at the University of Liverpool.

Dr. Ciara Kierans: who is a lecturer at Liverpool University and will be supervising the research.

What is the purpose of the study?

The purpose of this study is to understand the experiences of families and individuals who have been asked to donate their relative's organs; as well as the experiences of health professionals who are involved in asking for organ donation.

We are doing this because there has been a large amount of publicity and research on attitudes towards organ donation within Black and Minority Ethnic (BME) communities in the UK. However, there are no studies on the experiences of donor and non-donor families (those who said 'no' to donation) from these backgrounds. Because of this, we feel that it is important to gain an understanding of how people experience this process.

If possible, we will also be asking the health professionals who were involved in requesting the donation of your relative's organs to take part in the study. This study will run until October 2011.

Why have I been invited to take part?

You have been asked to take part in this study because you were involved in being asked to donate your relative's organs after their death, and also because you have identified yourself as being from a BME background. Your experiences are therefore very important to us.

Do I have to take part?

It is completely up to you. You only take part if you decide you want to. If you do decide you would like to take part in the study you will be asked to sign a consent form to say that you agree to take part when you first meet the researcher.

If you decide later on that you no longer wish to take part then you can leave the study at any time and do not have to give a reason.

What will happen if I take part?

This research study will be asking you to be involved in a few ways, depending upon what you feel comfortable with:

In-depth interviews: You will be asked to take part in two interviews. You can choose to be interviewed on your own, or with your family/a friend present.

The interviews will involve you talking to the researcher about your experiences of being asked to donate your relative's organs. These interviews will last for as long as you would like to talk about your experiences. With your permission, these interviews will be audio-recorded.

fieldwork and informal interviews: If you agree to it, the researcher may also spend some time with you to chat informally about your experiences and your life in general. From this she will take field notes, which is like a research diary.

Where will the research take place?

The research will be carried out at a time and place of your choice. You may like this to be your home, a public setting (e.g. a cafe), or even at Liverpool University. It is up to you to decide.

Are there any disadvantages or risks in taking part?

We do not expect there to be any risks associated with participating in this research study. However, we realise that the topic is very sensitive, so if you feel uncomfortable or distressed at any time then you can stop the interview. You can also leave the study without having to give a reason.

Are there any benefits in taking part?

You will be helping with a new area of research. Your experiences will help us to better understand how families from Minority Ethnic backgrounds experience the process of being asked for organ donation.

What if I am unhappy with the research or there is a problem?

If you are unhappy or there is a problem, please feel free to let us know by contacting the researcher, Jessie Cooper on 0151 794 5272 or by email: jessie21@liv.ac.uk, who will try to help. If you are still unhappy or have a complaint which you feel you cannot come to us with, then you should contact the Research Governance Officer, Sarah Fletcher, at Liverpool University on 0151 794 8290 (ethics@liv.ac.uk).

Will my participation be kept confidential?

All the information that you give us will be kept strictly confidential. The procedures for handling, processing, storing and destroying the data will comply with the Data Protection Act of 1998.

This means that only the researcher will see what you have said. All the information which you provide us with during the study will be stored in locked filing cabinets or password protected computers. Anything about you, including any quotes which are used in the write-up of the study, will have your name removed and a different one put in place, so that you will remain anonymous. At the end of the study the research data (consent forms, anonymised interview transcripts, field notes, and your contact details) will be kept in locked filing cabinets and/or password protected university computers. The data will be kept for ten years.

Please note that if you did tell us something that meant you were in danger or could come to any harm, the researcher would have a duty to tell her supervisor about this.

What will happen with the results of the study?

After the study has finished, the results will be put together as part of the researcher's PhD. The research will be stored at The University of Liverpool. The research will also be published in academic journals and presented at conferences.

During the study we will ask you about your opinions on its findings, to get your ideas, and criticisms of what the research has found. You will also be provided with a summary of the findings at the end of the study and you can have a copy of the final research report if you would like it.

What will happen if I want to stop taking part?

If you decide at any point that you no longer wish to be part of the study, then you can stop and do not have to give a reason for this. You can also ask for your data to be destroyed if you decide to stop being in the study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a research ethics committee to protect your safety, rights and dignity. This study has been viewed and given approval by Liverpool NHS Research Ethics Committee. It is also being sponsored by The University of Liverpool.

How can I find out more?

Just get in touch with the researcher, Jessie Cooper (PhD student):

Tel: 0151 794 5272

Email: jessie21@liv.ac.uk

Participant Information Sheet – 'community' members

UNIVERSITY OF
LIVERPOOL

An exploration of organ donation among Black and Minority Ethnic (BME) communities and involved health professionals

Participant Information Sheet

You are being invited to take part in a research study. Before you decide whether you want to be involved, we would like to explain the research study to you

Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand.

Feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Who is doing the research?

Jessie Cooper: who is a PhD student in the Division of Public Health at the University of Liverpool.

Dr. Ciara Kierans: who is a lecturer at Liverpool University and will be supervising the research.

What is the purpose of the study?

The purpose of this study is to understand the experiences of families and individuals who have been asked to donate their relative's organs, as well as the health professionals who were involved in asking for these organs. It is also interested in talking to members of BME communities who are willing to discuss the issue of organ donation/have been involved in organ donation or transplantation in some way.

We are doing this because there has been a large amount of publicity and research on attitudes towards organ donation within BME communities in the UK. However, there are no studies on the experiences of donor and non-donor families (those who said 'no' to donation) from these communities. Because of this, we feel that it is important to gain an understanding of how people experience this process.

This study will run until October 2011.

Why have I been invited to take part?

You have been asked to take part in this study because you have expressed a willingness to talk about your views on/any experiences you have of organ donation and/or transplantation as a member of a BME community. Your thoughts and experiences are very important to us.

Do I have to take part?

It is completely up to you. You only take part if you decide you want to. If you decide you would like to take part in the study the researcher will ask you to sign a consent form to say that you agree to take part.

If you decide later on that you no longer wish to take part then you can leave the study at any time and do not have to give a reason.

What will happen if I take part?

You will be asked to take part in an informal interview as part of the researchers' fieldwork. You can choose to be interviewed on your own, or with your family or a friend present. The researcher may also spend some time with you to chat informally about your experiences and your life in general. From this she will take field notes, which is like a research diary.

The interviews will involve you talking to the researcher about your thoughts on organ donation and any experiences you have had relating to organ donation. These interviews will last for as long as you would like to talk about your experiences. With your permission, these interviews will be audio-recorded.

Where will the research take place?

The research will be carried out at a time and place of your choice. You may like this to be your home, a public setting (e.g. a cafe), or even at Liverpool University. It is up to you to decide

Are there any disadvantages or risks in taking part?

We do not expect there to be any risks associated with participating in this research study. However, we realise that the topic is very sensitive, so if you feel uncomfortable at any time then you can stop the interview. You can also leave the study without having to give a reason.

Are there any benefits in taking part?

You will be helping with a new area of research. Your experiences and opinions will help us to better understand organ donation in relation to Minority Ethnic Communities in the North of England.

What if I am unhappy with the research or there is a problem?

If you are unhappy or there is a problem, please feel free to let us know by contacting the researcher, Jessie Cooper on 0151 794 5272 or by email: jessie21@liv.ac.uk, who will try to help. If you are still unhappy or have a complaint which you feel you cannot come to us with, then you should contact the Research Governance Officer, Sarah Fletcher, at Liverpool University on 0151 794 8290 (ethics@liv.ac.uk).

Will my participation be kept confidential?

All the information that you give us will be kept strictly confidential. The procedures for handling, processing, storing and destroying the data will comply with the Data Protection Act of 1998.

This means that only the researcher will see what you have said. All the information which you provide us with during the study will be stored in locked filing cabinets or password protected computers. Anything about you, including any quotes which are used in the write-up of the study, will have your name removed and a different one put in place, so that you will remain anonymous. At the end of the study the research data (consent forms, anonymised interview transcripts, field notes, and your contact details) will be kept in locked filing cabinets and/or password protected university computers. The data will be kept for ten years.

Please note that if you did tell us something that meant you were in danger or could come to any harm, the researcher would have a duty to tell her supervisor about this.

What will happen with the results of the study?

After the study has finished, the results will be put together as part of the researcher's PhD. The research will be stored at The University of Liverpool. The research will also be published in academic journals and presented at conferences.

You will also be provided with a summary of the findings at the end of the study and you can have a copy of the final research report if you would like it.

What will happen if I want to stop taking part?

If you decide at any point that you no longer wish to be part of the study, then you can stop and do not have to give a reason for this. You can also ask for your data to be destroyed if you decide to stop being in the study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a research ethics committee to protect your safety, rights and dignity. This study has been viewed and given approval by Liverpool NHS Research Ethics Committee. It is also being sponsored by The University of Liverpool.

How can I find out more?

Just get in touch with the researcher, Jessie Cooper (PhD student):

Tel: 0151 794 5272

Email: jessie21@liv.ac.uk

Thank you for reading this

This information sheet is for you to keep

Participant Information Sheet – health professionals

An exploration of organ donation among Black and Minority Ethnic (BME) communities and involved health professionals.

Taking Part in Research:

Information for Health Professionals

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Feel free to discuss this with your friends, relatives and colleagues if you wish.

Who is doing the research?

Jessie Cooper: who is a PhD student in the Division of Public Health at the University of Liverpool.

Dr. Ciara Kierans: who is a lecturer at Liverpool University and will be supervising the research.

What is the purpose of the study?

The purpose of the study is to explore the relationship between ethnicity and organ donation by finding out about, and understanding the experiences of families and health professionals who are involved in the process of organ donation. It will do this by talking to BME donor/non-donor families (those who said 'no' to donation); health professionals who are involved in

requesting organs from these families; as well as speaking with a range of health professionals generally involved in organ donation/transplantation. It is doing this is response to the lack of in-depth research in this area. This study will be running until October 2011.

Why have I been invited to take part?

You have been asked to take part in this study because you have expressed a willingness to be interviewed about your experiences of being involved in asking for organ donation from families of a BME background; **and/or** about your experiences of being professionally involved in organ donation (or transplantation) generally. Your experiences are very important to us.

Do I have to take part?

You only take part if you decide you want to. If you do decide you would like to take part in the study you will be asked to sign a consent form to say that you have agreed to take part when you meet the researcher. If you decide later on that you no longer wish to take part then you can leave the study at any time without giving a reason.

What will happen if I take part?

This research study will be asking you to be involved in a few ways, depending upon what you feel comfortable with.

*Narrative interviews: You will be asked to take part in at least one narrative interview (preferably two if possible). The interview/s will involve you talking to the researcher about your experiences of the organ donation process, as well as any experiences you have of being involved in asking BME families to donate their relative's organs (if applicable). These interviews will last for as long as you would like to talk about your experiences for. With your permission, these interviews will be audio-recorded.

During her time spent with you the researcher will also take field notes from her observations, which acts as a research diary.

During these interviews, the researcher may also ask you about your thoughts on promotional and media material about organ donation.

*Fieldwork and informal interviews: If you agree to it, the researcher may also spend some time with you in your place of work to chat informally about your experiences of organ donation and explore your role as a health professional. From this she will take field notes, which is like a research diary

Where will the research take place?

The research will be carried out in a place of your choosing. This will be negotiated with you at your discretion.

Are there any disadvantages or risks in taking part?

We do not expect there to be any risks associated with participating in this research study. However, if you feel uncomfortable at any time, then you can stop and/or leave the study without having to give a reason.

Are there any benefits in taking part?

You will be helping with a new area of research. Your experiences and opinions will help us to better understand organ donation in relation to BME families, from the perspective and experiences of a health professional. It is aimed for the research to be used to inform health policy on the issue.

What if I am unhappy with the research or there is a problem?

If you are unhappy or there is a problem, please feel free to let us know by contacting the researcher, Jessie Cooper on 0151 794 5272 or by email: jessie21@liv.ac.uk, who will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with, then you should contact the Research Governance Officer, Sarah Fletcher, at Liverpool University on 0151 794 8290 (ethics@liv.ac.uk).

Will my participation be kept confidential?

All the information that you give us will remain confidential. The procedures for handling, processing, storing and destroying the data will comply with the Data Protection Act of 1998.

What this means is that only the researcher will see what you have said. All the information which you provide us with during the study will be stored in locked filing cabinets or password protected computers. Anything about you, including any quotes which are used in the write-up of the study, will have your name removed and a different one put in place, so that you will remain anonymous. The hospital in which you work will also remain anonymous. At the end of the study the research data (consent forms, anonymised interview transcripts, field notes, and your contact details) will be kept securely in locked filing cabinets and/or password protected University computers. This will be kept for ten years.

Please note that if you did tell us something that meant you were in danger or could come to any harm, the researcher would have a duty to tell her supervisor about this.

What will happen with the results of the study?

After the study has finished, the results will be put together as part of the researcher's PhD. This will be marked by two examiners. The research will also be published in academic journals and presented at conferences.

If you want, you will be consulted throughout the study about the findings to get your ideas, opinions and criticisms of what the research has found. At the end of the study you will be provided with a summary of the findings, and you can request the final report if you would like it.

What will happen if I want to stop taking part?

If you decide at any point that you no longer wish to be part of the study, then you can stop and do not have to give a reason for this.

Who has reviewed the study?

This study has been viewed and given approval by Liverpool NHS Research Ethics Committee. It is also being sponsored by The University of Liverpool.

How can I find out more?

Just get in touch with the researcher, Jessie Cooper (PhD student):

Tel: 0151 794 5272   Email: jessie21@liv.ac.uk

Thank you for reading this!

This information sheet is for you to keep

Reply Slip (donor and non-donor families)

Jessie Cooper, PhD Student
Division of Public Health
School of Population, Community and Behavioural Sciences
2nd Floor, Block B , Waterhouse Building
1-5 Brownlow Street
Liverpool
L69 3GL.
Tel: 0151 794 5272

Reply Slip

An exploration of organ donation among Black and Minority Ethnic communities and involved health professionals

I would be grateful if you could complete this form (along with the contact details form, if you are interested in taking part) and send it in the stamped addressed envelope provided.

Name: _____

Please tick the box which applies:

I am interested in taking part in the study and would like to be contacted about it.

I do not wish to take part in the study

Signature: _____

Thank you.

Appendix 4. Consent Form

UNIVERSITY OF
LIVERPOOL

Centre number:

Participant identification number for this study:

Consent Form

An exploration of organ donation among black and minority ethnic communities and involved health professionals

Name of researcher: Jessie Cooper

Please initial box

1. I confirm that I have read and understand the information sheet dated_____for the above study. I have had the opportunity to consider the Information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

3. I understand that quotes from what I say during the study may be used where necessary, on the condition that my identity will remain anonymous.

4. I agree to being audio-recorded during the study interviews.

5. I understand that, under the Data Protection Act, I can at any

339

time ask for access to the information I provide and I can also
request the destruction of that information if I wish.

6. I agree to the research data being stored. I understand that
    the anonymised data (interview transcripts and notes) may be
    shared with other researchers in the future.

7. I agree to the researcher taking my contact details (name,
    telephone number etc) and contacting me during
    the study to arrange interview times.

8. I agree to take part in the above study.

_____   _____   _____

Name of participant   Date   Signature

The contact details of the researcher are:

Jessie Cooper:

Email: jessie21@liverpool.ac.uk   **Tel:** 0151 794 5272

Appendix 5. Letters of Ethical Approval from the NHS

NHS

National Research Ethics Service

Liverpool (Adult) Research Ethics Committee

Bishop Goss Complex
Victoria Building
Rose Place
Liverpool
L3 3AN

Telephone: 0151 330 2071
Facsimile: 0151 330 2075

19 June 2009

Ms Jessie Cooper
PhD researcher
Rm 1.07, Division of Public Health,
The Muspratt Building,
The University of Liverpool,
L69 3GB

Dear Ms Cooper

Study Title:	**The Cultural Anatomy of Decision Making: understanding the practices of organ donation among Black and Minority ethnic (BME) communities and involved health professionals.**
REC reference number:	**09/H1005/36**
Protocol number:	**1**

Thank you for your letter of 15 June 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
C.V. for Supervisor		08 April 2009
Participant Consent Form	1	08 April 2009 ·
Participant Information Sheet	1	08 April 2009
Letter of invitation to participant	1	08 April 2009
Advertisement	1	08 April 2009
Interview Schedules/Topic Guides	1	08 April 2009
Letter from Sponsor		07 April 2009
Protocol	1	08 April 2009
Investigator CV		08 April 2009
Application	2.0	08 April 2009
Covering Letter		07 April 2009
Response to Request for Further Information		15 June 2009
Participant Consent Form	2	01 May 2009
Participant Information Sheet: Health Professionals	2	01 May 2009
Participant Information Sheet: Participant	2	01 May 2009
Covering Letter		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
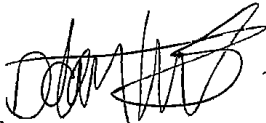
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H1005/36	Please quote this number on all correspondence

Yours sincerely

– Adam Lewis

Pp Professor Sobhan Vinjamuri
Chair

Email: adam.lewis@liverpoolpct.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Miss Sarah Fletcher*
Faculty of Medicine Support
University of Liverpool

North West 2 Research Ethics Committee - Liverpool Central

National Research Ethics Service

Room 181
Gateway House
Piccadilly South
Manchester
M60 7LP

Tel: 0161 237 2336
Fax: 0161 237 2383

16 November 2009

Ms Jessie Cooper
PhD researcher
Rm 1.07, Division of Public Health,
The Muspratt Building,
The University of Liverpool,
L69 3GB

Dear Ms Cooper

Study title:	**The Cultural Anatomy of Decision Making: understanding the practices of organ donation among Black and Minority ethnic (BME) communities and involved health professionals.**
REC reference:	**09/H1005/36**
Amendment number:	**2.0**
Amendment date:	**11 November 2009**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	2.0	11 November 2009
Participant Information Sheet: Health professionals	1	01 November 2009
Participant Information Sheet: PIS	1	01 November 2009
Protocol	2	01 November 2009
CI original signature	1	11 November 2009

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

This Research Ethics Committee is an advisory committee to North West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.
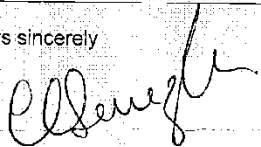
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/H1005/36:	Please quote this number on all correspondence

Yours sincerely

Mrs Carol Ebenezer
Committee Co-ordinator

E-mail: carol.ebenezer@northwest.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Miss Sarah Fletcher*

Appendix 6. Letters of Research and Development Approval

 Teaching Hospitals **NHS**

NHS Foundation Trust

Enquiries on this matter should be made to:
The Research Support & Governance Office
Email:

Governance Manager
Email:
Tel: (

Telephone:

29th March 2010

Dr
Intensive Care Consultant (Anaesthesia) and Clinical Lead for Organ Donation
Hospitals Foundation Trust

Dear

R&D Management Approval - Hospitals NHS Foundation Trust

Re: The Cultural Anatomy of Decision Making: understanding the practices of organ donation among Black and Minority ethnic (BME) communities and involved health professionals.
Sponsor: University of Liverpool
REC Ref No: 1148

On behalf of Hospitals NHS Foundation Trust, I authorize on the terms of this letter the Trust's involvement in this study as Employer/Care Organisation/Research Site as set out in your SSI form dated 16/12/2009 and supporting documentation. A record has been created on the Trust's research database. The effective date of R&D Management Approval is 26/03/2010 and this is the earliest commencement date for trial activities at this site.

Documents Reviewed

- **SSI form** 14113/93939/6/510/45855/164877
- **NHS R&D form Parts A-D** 14113/34166/14/790
- **the study protocol** V2 November 2009
- **the patient information sheet** (Families V2 – May09, Community Members V1 – Nov 09, Health Care Professionals (Donation) – Nov 09 and Health Professionals V2 – May09)
- **the consent form** V2
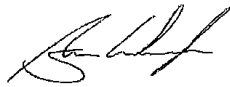- **the CTA/written agreement**

The terms referred to are:

- Ongoing R&D Approval is subject to you adhering to the Trust's standard conditions of R&D Management Approval (attached).

- You do not commence recruitment at the Trust unless there continues to be Research Ethics Committee approval in place.

Version 6: 10 09 2009
INVESTOR IN PEOPLE

- You comply with all reporting requirements within the reporting timeframes to the sponsor and any other authority with a legitimate interest.

- You complete and return to the Research Support & Governance Office the PI Annual Progress Report available to download from the Downloads section of our website at ▮▮▮▮▮▮▮▮▮▮▮▮ due every year for the life of the study on the anniversary of the date of this letter.

- You notify the Research Support & Governance Office immediately should concerns arise about the safety and welfare of participants in this study at the Trust.

- You inform the Research Support & Governance Office immediately when the study has reached its end date together with final accrual figures for this site.

Please help us to improve our service by completing the feedback form and returning it to the Research Support & Governance Office.

Yours sincerely

Director of Research/▮▮▮▮▮

Encs

CC Jessie Cooper

Research & Development
1ˢᵗ Floor Post Graduate Centre

08 July 2009

Ms Jessie Cooper
PhD Researcher
Rm 1.07
Division of Public Health
The Muspratt Building
The University of Liverpool
L69 3GB

Ref: R00688-Ltr 2-Cooper

Dear Ms Cooper

PIN: R00688 (Please quote this number in all future correspondence)
Research Study: The Cultural Anatomy of Decision Making: understanding the practices of organ donation among Black and Minority Ethnic (BME) communities and involved health professionals

Thank you for submitting the above study for approval.

We acknowledge that the University of Liverpool has accepted the role of Research Governance Sponsor for this study.

We understand that this study is not eligible for adoption by the UKCRN Portfolio.

I am pleased to confirm that the Research Office has now received all necessary documentation, and the Trust Director of Research & Innovation has given approval for the project to be undertaken. This approval is in relation to the documentation supplied to us below.
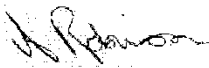
Your R & D Approval is subject to you being issued with a signed Research Passport and Honorary Research Contract by this Trust.

Your R&D Approval is also subject to the Research Team attending (or providing evidence of having attended in the last 2 years), training covering aspects of Good Clinical Practice and Research Governance. CMMC provides monthly ½ day GCP training covering essential elements of GCP and Research Governance (see http://www.cmft.nhs.uk/trust/training.aspx). Please attend within 2 months (or provide a Certificate of Attendance if you attended a course facilitated by another organisation). Continuation of your Approval is dependent upon attendance or receipt of this evidence. We will check our GCP attendance records in the next 2 months to confirm that you have met this requirement, otherwise we will contact you for evidence from an external Provider if not already provided.

Approval is given subject to the attached conditions – please ensure you and all members of the research team are familiar with these before commencing your research.

I would like to take this opportunity to wish you well with your research.
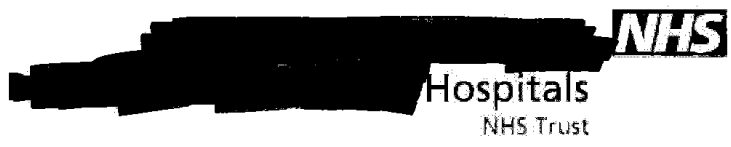
Yours sincerely

Research Operations Manager

Encs

cc

Documents Acknowledged/Approved

	Version Number / Reference	Date
NRES approval	09/H1005/36	19 June 2009
Participant Consent Form	1	08 April 2009
Participant Information Sheet	1	08 April 2009
Letter of Invitation to Participant	1	08 April 2009
Advertisement	1	08 April 2009
Interview Schedules/Topic Guides	1	08 April 2009
Letter from Sponsor		07 April 2009
Protocol	1	08 April 2009
Participant Consent Form	2	01 May 2009
Participant Information Sheet – Health Professionals	2	01 May 2009
Participant Information Sheet – Participant	2	01 May 2009

Hospitals
NHS Trust

Dr Ciara Kierans
Division of Public Health
School of Community, Population and Behavioural Science
University of Liverpool
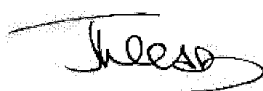Daulby St
L69 3GB
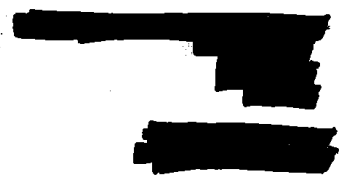
15ᵗʰ July 2009

Dear Dr Kierans

Re: The cultural anatomy of decision making: Understanding the practices of organ donation among Black and Minority Ethnic (BME) communities and involved health professionals
R&D number 3813

I am pleased to confirm that the pre-trial documentation for this study is now complete. The study has received approval form the appropriate Ethics Committee and the financial arrangements meet with NHS executive requirements.

I can confirm, therefore, that the Trust is happy for you to conduct this work on its premises provided that the study is conducted in compliance with the Research Governance Framework 2005.

If this department can be of any further help please do not hesitate to contact us.

Yours Sincerely

Deputy Director of R&D

Cc Jessie Cooper

NHS

Blood and Transplant

Oak House
Reeds Crescent
Watford
Hertfordshire
WD24 4QN

Tel: 01923 486800
Fax: 01923 486801
www.nhsbt.nhs.uk

Jessie Cooper
C/O University of Liverpool

Ref AJC/JC

14th December 2009

Dear Jessie,

Re: The Cultural Anatomy of Decision Making: an exploration of organ donation among Black and Minority ethnic (BME) communities and involved health professionals.

Thank you for your recent communications regarding the above study. I note that in order to facilitate your study you are currently liaising with the ███████ ████████████████████ Organ Donation Team and wish to extend this liaison to the ████████ eam and have requested permission to do so. Your request has been considered by members of the Organ Donation and Transplantation Senior Management Team who have no objection. I understand that you have had initial discussions with ██████████ the Team Leader for this team and I advise that you liaise directly with ██████ to take this forward.

████ is contactable at ████████████████████████████

I wish you well with the study and look forward to considering the findings.

Yours Sincerely

Anthony J. Clarkson
Assistant Director – Organ Donation

CC ████████████████████████

351

Appendix 7. Narrative Interview Guides

Interview guide for initial interview with health professionals

The Interview

Brief the participant as of some of the reasons for wanting to talk to them. Ensure they have read and understood the information sheet and ask if they have any questions. Get them to sign the consent form.

Explain that I will be doing a narrative interview – basically just one question which aims to find out about their own experiences of working as a coordinator/health professional involved in organ donation. The interview is in their control and I will only intervene, or ask additional questions if necessary. I may occasionally ask for more detail about an event, or an example of what they describe to clarify something that you have told me, but, apart from that, it is up to them to talk about what they want and in any order they want.

Question focused upon experiences with asking BME families – for Health Professionals

Can you tell me the 'story' of your experiences of being involved in requesting organ donation from families of a Minority Ethnic background, as well as any other experiences you have of organ donation that you wish to talk about. By this I mean any events and experiences related to this which are important to you.

Begin wherever you like

General Question for health professionals (for those who have had no experience of asking BME families)

Can you tell me the 'story' of your experiences of being involved in the process of requesting organ donation in your role as a health professional? By which I mean any

events and experiences you have had of this process which were, and are important to you.

Begin wherever you like

If I need more detail, or am only getting opinion rather than stories of events/situations use narrative-return questions such as:

- Could you give me an example of that?

- Can you remember an event in which this occurred?

- Have you ever had an experience which is completely unlike that?

- Can you tell me in more detail how that happened?

- Are there any other things you remember happening?

- Do you remember/recall anything else about that?

If they want **more guidance** on what they are talking about I can resort to prompts such as:

- Experiences of deciding to approach families;

- What it is like to ask families for organs?/how do you ask families?

- What is it like to be closely involved with treating a patient and then, after their death, involved in the process of organ donation?

- Are there any particular things going on now that you see as important to your role?

- Who is involved in the process?

- How they reflect on the decisions made by themselves, fellow health professionals and the families?

Interview guide for initial interview with families/ 'community' members

Donor/non-donor families

Can you tell me the 'story' of your experience of being asked to donate your relative's organs after their death? By this I mean any events, or anything else related to the experience which are important to you.

You can begin wherever you like.

If they need **prompting**:

- What happened leading up to them being asked to donate?

- Their experiences of being asked to consent to donate

- Who was involved in the process?

- How they made their decision and who was involved in this

- How they reflect on these decisions in their lives now

'Community' members

Questions aimed at their general experience of transplantation/donation, or, later on, in the case of religious leaders, their experiences of being involved over discussions over withdrawal of care between families and health professionals. For example, questions included:

Can you tell me the 'story' of your experiences of being a transplant recipient/live donor/Imam (e.g.)/donor activist? By this I mean any events, or anything else related to the experience which are important to you.

Appendix 8. Example Section of a Narrative Analysis Table

Excerpt from Ruth's narrative, donation nurse for team 1 (main story can be read across the first 2 columns)

Complicating Actions	Evaluations	Further Interpretations	My Interpretations
(line numbers) 1.126:And er, it was decided that I was going to go in and speak to the family. Erm, which basically I did do erm, but when I mentioned the organ donor register they were a bit dubious as to whether she was actually on the organ donor register: 'How can you prove that to me?'		**F.1.419** J: Yeah, yeah. And then you had all the, then you had this drawn out consent process and then you had all the, the kind of, you know, the trouble with the coroner. R: Coroner issues. J: And how did you, so, it sounds like, cause I know you had your colleague, it sounds like you were having to do a lot of this. R: Yeah, but my colleague was kind of concentrating on doing, we have a lot of erm computer data to input for..er, you know, like offering database. Erm, he was doing a lot of that and erm, doing a few conversations with erm retrieval teams and referral centres and things like that. Erm, we do tend to have two of us at, erm, someone who's donation after cardiac death to try and speed things up a bit. In that situation you just needed one person with the family.	*Describing the actualities of the donation set up here - There are two coordinators on the scene; Ruth and her colleague. Ruth is able to tell the story from her perspective of being the one that was front of house - she spoke to the family, dealt with all the other authority figures necessary for the donation to go ahead. In the background you have her colleague, doing all the administrative tasks necessary for actually allocating the girl's organs. Ruth is the one that takes centre stage in this story though, being the one who actively talks about taking responsibility for the family (she mentions this later on with asking to be the one to follow them up). However, at the start, the decision as to who talks to the family, she puts in passive terms, as if the original set-up was not wholly her choice (something which she later rectifies through stories of her taking charge of the situation.)*
2.129: So basically I had to get a faxed copy from erm NHSBT to show she was on the organ donor register to show them.	**2.130:** Very large family...erm, Mum, Dad looked quite a bit older, er, Dad spoke English but Mum didn't really speak very much English at all. A lot of erm brother's stroke cousins, I think it turned out they were cousins, er it did turn out they were cousins but at one stage I think one person said he was a brother. Erm, however you know, soon realised that a cousin was, was good enough: we will speak to you all, it doesn't matter if you're a brother, cousin, you know, you're all next of kin, it's fine. Erm, and basically erm communicated with all the family that, you know, this is the information that shows she's on the organ donor register.	**F.2.454** J: (laughs) And you said as well, you said this was like a big family as well, and you wanted to kind of talk to, you know, the cousins and the immediate family, and the brothers. R: Yeah, yeah everybody was in the room really, yeah. J: How did you like, so how did you, can you tell me a bit more about that like how you kind of.. managed to get everybody involved. R: Yeah, yeah, I think..there were in the end certain people who you ended up focusing on: the aunty because she kept interjecting with questions and comments. And I kept looking at Dad quite a lot of the time, although I wasn't positioned ideally for Dad	*Ruth here names the complicating action of having to prove to the family that their daughter was on the ODR. She follows this up by describing and evaluating the set up of the (large) family, as if to show what she was up against in her attempts to take consent. Here then, consent does not just relate to one person, but to many: Mum dad, aunties, cousins etc, and then the University friends in the background. And it is this group of up to 15 people that Ruth is having to communicate with and mediate consent. The family she conceptualises as a large mass of people, who, at first she struggles to work out who is actually direct family - what they refer to as brothers, she understands as cousins (different perspectives on what constitutes family for each side). She names two people as being those who she most focused upon: the aunty, because*

355

	There were a couple of vocal males sort of representing the family. One was one of the cousins and the other was erm...a friend who was in the medical profession, and he was, as he said, feeling very guilty because he was supposed to be looking after her; looking out for her while she was up at University here. However, she was living with friends so obviously what could he do? Erm, and the friends, some of the friends were actually there, the University friends, and erm they spoke to parents, the parents and the family and said 'Well yes, she did join the organ donor register at fresher's week. And she spoke to us about it and said 'Well this is why I'm doing it. I really do think I should be on the organ donor register.''	because I went into the room and then Mum went to bring Dad in and he kind of chose to sit round here towards me [indicates the position by her side], so I was a bit like this [indicates having to look both ways] with the aunty over here. And then I just kept scanning the room really (I laugh). You just do the best you can don't you to be honest with you. They obviously felt a lot of support from being all together and wanted everybody in there. It was their choice who they wanted in there. It was a big enough room to accommodate it, it wasn't like a little tiny sitting room, it was a proper big private sitting area, so, you know we could accommodate it. J: How many people are we talking? R: Erm, God, it would have been ten, fifteen.	*she was very vocal, and the Dad, who Ruth seems to focus upon rather than the Mum (we later learn of this decision due to Ruth interpreting the Mum as willing to do whatever Dad wanted), and whom Ruth describes as actively trying to engage with. The large family are seen by her as providing support to each other, which she doesn't see as an issue: she perceives it as their (Mum and Dad's) choice to have everyone in the room.*
3.145: And the family wanted some time to discuss this, and then came back after half an hour to say, well yes, she was a giving person in life. It's very fitting that she should be a giving person in death	**E.148** And I think from reading the religious..information erm, about Hinduism, not that I'm any great expert, that basically this is their kind of, kind of their take on donation. it's about giving in life and giving in death, and that's how their religion supports it.	**F.3.720** However, they are missing some, such as the IV drug user and erm...the ethnic minority family who couldn't possibly understand if we explained brain stem death. J: That was actually in some notes that said? R: Yeah, yeah. Yeah, it was erm an Asian doctor who said that, so whether he'd like assessed this family and just felt that they wouldn't. I do know that..in my experience there've been quite a lot of Asian families, I'd say more than..families with like Caucasian background, it might be a sweeping generalisation cause obviously I've not done a study on it and collated figures, but a lot of..especially from working in London, there were a lot of Muslim groups round there, a lot of resistance to withdrawal of treatment, you know where they just want it in the hands of God: you can't turn the ventilator off, they will die when they're ready. So maybe he picked up on this from the family. **F.748** R: Yeah well I'd just started here erm, basically there was a lady who, I think was Afro-Caribbean. She'd been in the country I a good few years and it	*Here Ruth talks of the family's decision and their justification of their decision through believing their daughter to be a generous person. Ruth then goes on to make a large leap, interpreting this as meaning that it was linked to the daughter's and their status as Hindu. In other words the decision is reduced to and conceptualised in terms of their traditionalism - they decide to donate because it fits in with Ruth's reading of Hinduism's "take on donation". Here, Ruth has unwittingly made assumptions about Hinduism (what it means) as well as the family (in terms of them being traditional and making decisions based on their religion, rather than anything else in their lives). This is interestingly contrasted with Ruth's descriptions about Consultants missing potential donors, or not asking families about donations because of the assumptions they have made about that family, or about a patient's suitability to be a potential donor (IV drug user: assumption that they are too risky because of potential for HIV or hepatitis transmission). However, she then almost contradicts her discussion about assumptions by again leaping to conclusions about a large different population groups/families - Maybe the Dr. didn't ask a Muslim family because Ruth knows that they struggle with accepting*

		was quite a sad story, she'd lost a lot of members of her family, er through some kind of civil unrest, and she had some kind of cardiac condition..that had caused her to collapse and become hypoxic, er, and we approached, well I didn't, the Consultants approached the family about organ donation. [....] 768 Erm, but the family did come back and say no and it very much seemed and I can't remember exactly why, but, it very much seemed that the reason was that they didn't understand what organ donation was. I think it was pretty much, they didn't have organ donation in their country. What is organ donation?; What do you mean?	*withdrawal of treatment because of their religious beliefs; She had not been approached to talk to an African Caribbean family about donation because of their lack of understanding about organ donation (she contradicts herself with this story, because she argues that they had not had the opportunity to speak with someone knowledgeable about donation, like herself.*
4.150: Errm, so they wanted to talk more about donation, so I said that I would go back in and bring the consent papers with me to go through with them, if they did want to consent to donation I would give them more information. Erm, which I did.	**E.153** It was a very very very long conversation, erm, they had a lot of difficulties with a lot of the questions that were being asked. We do need in the patient assessment to ask about things such as erm, as erm habits really. Not just smoking, drinking, drug taking, sexual habits. J: Is that the one that has very intimate questions? R: Yeah. Erm, which obviously erm, I mean I think Mum and Dad thought that she was a, a girl who was living very much by the Hindu faith: didn't drink, didn't, no sex before marriage etcetera etcetera. Erm, however erm, it seemed that she was leading quite a Westernised life really from some of the information that we did come across.	**F.4.405** R: No, I mean when we do the assessment erm we ask the family is there anybody else that would be able to give us more information. Now it wouldn't have felt appropriate to have gone to her friends behind her families' back, er, and the, the cousins were there and present when we were asking questions. And did kind of make..a comment that [quietly] 'I think she does enjoy a little bit of a drink of alcohol sometimes', you know, a little bit more awareness. Erm...and, you know, we were gonna get the GP fax...about, yeah, and I think the friends had gone by now anyway, so, you know, it just didn't feel appropriate to try and source other people to give us information for the purpose of the assessment. And we just documented that..the family, a lot of the family members feel that she's been living a Hindu lifestyle, please refer to GP fax also. And just kind of left it that way really.	*Ruth begins to describe and interpret some of the many complexities involved in this particular case: The family had trouble with being asked the more intimate questions on the consent form, about lifestyle. We learn a number of things from this: the questions can be perceived as being sensitive, because they involve asking about taboo subjects like sex and drug habits; the consent form is far from a simple matter of yes and no: the family are actively involved in creating a picture of the individual so that the DTC can assess their likely risk to a potential recipient (links to Hogle 1995 here); the DTC is responsible for deciding who might be the best source of information about lifestyle, with the knowledge that families aren't always aware of their relative's private lives, and how to 'ask' the families the questions. IS IT ACTUALLY RUTH THAT IS UNCOMFORTABLE WITH THE QUESTIONS? We also learn that Ruth makes the assumption that the family were uncomfortable with the questions because of their Hinduism. She polarises the Mother and Father as traditional, with her assessment of their daughter as 'Western' by the fact that she drunk and had had sex before marriage; information which came from her cousins and from the GP information about her taking the morning after pill. She talks about the cousins as having "a little bit more awareness" from their comments about the donor's drinking, which links back to her assessment of the Mum and Dad's lack of awareness of the life their daughter was actually leading. Sees Hinduism and Westernised as diametrically opposed: they mean very specific things for Ruth, one implying living by a code of traditions and rules, the other in terms of freedom and living an individual life.*

Appendix 9. Initial Categories and Analytical Questions from the Narrative Analysis

Categories:

1. **Procedural accounts/practical negotiations: donation contingencies** *(including the procedures of other authorities, which may inhibit the progression of a case).*

2. **Conceptualising ethnicity and anticipating families** – *How ethnicity is worked through in stories: families' decisions and behaviour come to be understood through notions of ethnicity; how these understandings feed into donation practice.*

3. **Caring and role responsibility: meeting the needs of families** – *qualify their caring and fulfilment of their roles in terms of discursively constructing the donation as offering something positive for the families – and that it was what they wanted. Through this understanding of the donation as a need, the DTCs do all they can to ensure that their wishes are fulfilled.*

4. **Consent complexities** – *Large families of BME potential donors, coroner difficulties, withdrawal of care struggles discussed in terms of inhibiting the potential for donation.*

Negative outcomes of donation requests in relation to BME families often come to be attributed to a family's ethnicity, rather than the actions of health professionals themselves. When there is a story of the donation going ahead, the focus tends to shift from the family to the difficulties of negotiating donation in the context of other professionals.

Analytical Questions used to interrogate remaining data, and develop initial categories and final findings:

1. **What does the process of donation look like?**

   a. How is it characterised in the different stories/settings?

   b. What are its complexities and how do the actors experience the process?

   c. How and what decisions are made during the process?

   d. How can I tell the story of donation?

2. **How is ethnicity worked through by people?**

   a. What does it mean to them (how/ is this manifested in their practice)?

   b. How do they experience interacting with people of different/same backgrounds to themselves?

   c. How is difference defined?

3. **What can we learn and understand about the role of the coordinator** from donation stories/observations, in the context of their role as mediator between each side (family/health professionals; public/medicine – as institution)?

   a. How do coordinators mediate the needs of different parties in the donation process/their role generally?

   b. What are the relational and practical issues they encounter in their role?