



Title Renal Transplantation Among South Asians in
 the UK

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**RENAL TRANSPLANTATION
AMONG SOUTH ASIANS IN THE UK**

GURCH RANDHAWA

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Contents

| | |
|---|-----------|
| Abstract | 1 |
| Introduction | 2 |
| Theme 1 – Mapping and highlighting the inequalities in health experienced by minority ethnic groups in relation to renal transplantation | 4 |
| Theme 2 – Examining national and international organ procurement programmes and their relevance to minority ethnic groups | 16 |
| Theme 3 - Examining the empirical research that explores the reasons for low organ donation rates among minority ethnic groups | 31 |
| Conclusion | 37 |
| Bibliography | 40 |

Appendix 1: Key publications to be considered for PhD by Publication. Where these are cited in the text and the bibliography, they appear in bold)

Appendix 2: From key publications, those that make an original contribution to Theme 1 – Mapping and highlighting the inequalities in health experienced by minority ethnic groups in relation to renal transplantation

Appendix 3: From key publications, those that make an original contribution to Theme 2 – Examining national and international organ procurement programmes and their relevance to minority ethnic groups

Appendix 4: From key publications, those that make an original contribution to Theme 3 - Examining the empirical research that explores the reasons for low organ donation rates among minority ethnic groups

Appendix 5: Supplementary publications to support PhD by publication

Appendix 6: Curriculum Vitae

Renal Transplantation among South Asians in the UK

Gurch Randhawa

Abstract

This work represents a significant contribution to the body of knowledge in the area of renal transplantation as it brings together the research related to policy analysis, empirical research, and cultural and religious issues related to organ donation and transplantation among South Asians in the UK. The candidate's work in this area is the first in the UK to systematically document and map a *national* picture of kidney transplant waiting lists and to identify and examine the complex reasons underlying how and why patient ethnicity impacts upon the likelihood of receiving a kidney transplant. The candidate has also developed a new evidence-base exploring the adequacies of the existing procurement arrangements and the implications of introducing any alternative policies within the context of a multi-ethnic and multi-faith UK. Finally, the candidate's work has focused on developing an evidence-base of the public perceptions, attitudes, and religious viewpoints towards organ donation and transplantation among a cross-section of the South Asian population.

The candidate's published works have been the foundation blocks for stimulating and informing the debate on the provision of renal transplant services for minority ethnic groups through the generation of an empirical evidence-base in a subject area which has traditionally relied upon anecdotal evidence. The evidence-base illuminates a very complex issue which has multi-faceted solutions that need to be addressed in different settings.

Key words: South Asian, organ donation, renal transplantation, inequalities, kidney

Renal Transplantation among South Asians in the UK

Introduction

The Government's seminal Transplant Framework, *Saving Lives, Valuing donors* (DoH, 2003a) points out that not only do inequalities still exist on transplant waiting lists in the UK but also that minority ethnic groups in particular are likely to suffer as a consequence.

"At present black people and those from a South Asian background may wait longer for a matching kidney. Because the best-matched organs are likely to come from people with the same ethnic background, it is important to ensure that all groups in society have the willingness and opportunity to donate organs." (DoH, 2003a).

This statement reflects a shift in focus of renal transplant policy during the last twenty years in which there has been a growing interest in the health of minority ethnic populations in the UK. Throughout this period, the provision of renal transplant services for minority ethnic groups has become a particularly important area of debate. This is due to the observation of growing rates of end stage renal failure (as a result of diabetic nephropathy) among South Asians (those originating from the Indian subcontinent) in the UK and the disproportionately higher numbers of South Asians represented on transplant waiting lists.

The candidate's published works have been the foundation blocks for stimulating and informing the debate on the provision of renal transplant services for minority ethnic groups through the generation of an empirical evidence-base in a subject area which has traditionally relied upon anecdotal evidence. The evidence-base illuminates a

very complex issue which has multi-faceted solutions that need to be addressed in different settings – such as preventative renal disease policy formulation, curriculum development for Transplant Co-ordinators and Intensive Care Unit (ICU) staff, and Organ Donor Register campaign planning.

The published works presented here can be divided into 3 main themes:

- (1) Mapping and highlighting the inequalities in health experienced by minority ethnic groups in relation to renal transplantation;
- (2) Examining national and international organ procurement programmes and their relevance to minority ethnic groups;
- (3) Examining the empirical research that explores the reasons for low organ donation rates among minority ethnic groups.

In creating this body of work the candidate has used different methodologies – choosing those which were fit for purpose – including statistical analysis of national transplant datasets, policy analysis of organ procurement programmes, analysis of religious literature, and grounded theory methodology in researching a sensitive subject area.

The candidate's work is unique and the candidate is recognised as the leading expert in the UK on the study of ethnicity and organ donation and transplantation. The candidate is regularly invited as a keynote speaker to national and international conferences and is an Advisory member to the National Kidney Research Fund and a Non-Executive Director at UK Transplant. The candidate also is a member of a number of the Department of Health's Renal Services NSF Working Groups.

Theme 1 – Mapping and highlighting the inequalities in health experienced by minority ethnic groups in relation to renal transplantation

During the early 1990s anecdotal evidence from certain parts of the UK suggested discrepancies in waiting lists and waiting times for South Asian patients awaiting renal transplantation (Hooker, 1994). At the same time, a number of researchers were documenting the increased rate of renal failure secondary to diabetes among minority ethnic groups (Raleigh, 1997). However, the impact of this latter phenomenon on kidney transplant services had not been explored. The candidate's work in this area was the first in the UK to systematically document and map a ***national*** picture of kidney transplant waiting lists and explore its relevance for South Asian communities (Randhawa, 1998a, 2001a, 2004a, 2004b).

Government initiatives, such as those outlined in the Transplant Framework, *Saving Lives, Valuing donors* (DoH, 2003a), have sought to reduce the inequalities in health that minority ethnic populations frequently experience by engaging Transplant Units to consider the specific needs of such populations. More recently, the Renal Services National Service Framework (NSF) has provided a renewed focus upon Renal Services and Transplant Units, with the Government indicating the prospect of greater resources to expand service provision and to even out inequalities in access (DoH, 2003b). There is a recognition that the history of uneven commitment to renal care service provision - thereby Transplant Units - by local Health Authorities has evolved outside of a framework of strategic national planning. This has created a situation where access to such services has become something of a geographical lottery. A particular concern is that there appears to be reduced access to, or take up of, diabetic

and renal services within deprived areas and within parts of the country where there are substantial minority ethnic populations (Clark et al, 1993; Roderick et al, 1994; Jeffrey et al, 2002). This has subsequently resulted in major inequalities in transplant waiting times for minority ethnic groups.

At the same time as these policy initiatives, the field of transplant services has itself been changing in ways that have stimulated practitioners to think more carefully about meeting the needs of different segments of the population. First and foremost has been the recognition that effective data collection is required on the ethnicity of transplant patients (**Randhawa 1998a**). Only since 1st January 2000 has ethnic background reporting become of a substantive level for reporting on a UK wide basis.

Concomitant to the progress in the introduction of Government policy in reducing inequalities and the advances in data collection within transplant services, there has been increased media and public interest in kidney transplant opportunities for minority ethnic groups. This has been stimulated largely by the recent General Medical Council (GMC) investigations of GPs trading in kidneys to assist South Asian patients requiring a kidney transplant (**Randhawa, 2004b**).

Kidney transplantation is the preferred mode of Renal Replacement Therapy (RRT) for patients with end-stage renal failure. At the end of April 2005, there were over 5,500 people on the transplant waiting list in the UK – the majority waiting for kidney transplants, but substantial numbers also waiting for heart, lung, and liver transplants. However, a closer examination of the national waiting list reveals that some minority ethnic groups are represented in greater numbers than others (**Randhawa, 1998a**,

2001a, 2004a, 2004b). The candidate's work in the subject area has been the first to identify and examine the complex reasons underlying how and why patient ethnicity impacts upon the likelihood of receiving a kidney transplant.

The allocation of kidneys for transplant is based primarily on blood group and tissue type (HLA) matching between donor and recipient to ensure the best possible outcome. Since HLA tissue type and blood group distributions differ across ethnic groups, the differences between the ethnicity of organ donors and patients on the waiting list may affect the waiting times of patients. In particular, there are concerns that minority ethnic patients may wait longer for kidney transplants than Caucasian patients. The candidate has examined these apparent inequalities by reviewing UK data on ethnicity and blood group of cadaveric kidney donors, transplant recipients and patients on the kidney transplant waiting list. These analyses have become more comprehensive over the years as data collection regarding ethnic monitoring has improved (Randhawa, 1998a, 2001a, 2004a, 2004b).

Transplant Units have been asked to collect data on the ethnicity of patients since the mid 1990's. The National Transplant Database (NTxD), held by UK Transplant, contains information on the ethnicity of donors and recipients in the UK. Until recently, reporting levels have been far from complete and only a preliminary analysis of the data has been attempted by the candidate in order to stimulate and inform the debate concerning kidney transplant waiting lists and the implications for South Asians communities (Randhawa, 1998a). However, adequate donor and recipient ethnicity data are now available for cadaveric kidney transplants performed since 1 January 2000. Consequently, the candidate's work in this area has evolved,

culminating in the most up-to-date and comprehensive analyses of transplant data (Randhawa, 2004b).

Data analysed most recently relates to 2262 transplants performed in the UK between 1 January 2000 and 27 August 2001 and to 4933 patients who were on the active waiting list on 27 August 2001. During the time period considered there were 1226 cadaveric kidney donors. One or both kidneys were not used from 112 of these donors. Ethnicity was not recorded for 28 (2%) donors, 132 (6%) recipients and 178 (4%) waiting list patients, all of whom were excluded from the analyses. A further eight (< 1%) patients were excluded due to unknown HLA tissue type match grade (Randhawa, 2004b).

Ethnicity of donors, recipients, and waiting list patients

Table 1 compares ethnic origin distributions among donors, transplant recipients and patients on the active waiting list.

| Ethnic origin | Donors | | Recipients | | Waiting list patients | |
|-------------------|-------------|------------|-------------|------------|-----------------------|------------|
| | No. | % | No. | % | No. | % |
| | Caucasian | 1169 | 98 | 1863 | 88 | 3727 |
| South Asian | 18 | 1 | 170 | 8 | 652 | 14 |
| African-Caribbean | 7 | < 1 | 68 | 3 | 299 | 6 |
| Other | 4 | < 1 | 30 | 1 | 77 | 2 |
| Total | 1198 | 100 | 2131 | 100 | 4755 | 100 |

(Randhawa, 2004b)

Ethnic origin has been reported for 97% of those patients awaiting a kidney transplant on 27 August 2001. Of those patients on the waiting list whose ethnic origin is known, 78% were Caucasian, 14% were South Asian and 6% were African-Caribbean. The remaining 2% of patients have their ethnic origin recorded as Oriental, Mixed or Other.

One can see that at UK level, large discrepancies exist between the make-up of the general population and that of the kidney transplant waiting list population. Whereas, South Asians make up only 4% of the UK population they represent 14% of the waiting list population. African-Caribbeans form 2% of the UK population yet represent 6% of the waiting list population (**Randhawa, 2004b**). It is evident therefore, that further work is required to prevent the onset of renal disease among minority ethnic groups.

The proportion of minority ethnic patients in the transplant recipient pool was significantly lower than the proportion of minority ethnic patients on the waiting list ($p < 0.0001$), although greater than the proportion of donors reported. Conversely, the proportion of Caucasian patients was greater among transplant recipients than among waiting list patients (**Randhawa, 2004b**).

Ethnicity and blood group of donors, recipients, and waiting list patients

Table 2 compares blood group distributions among donors, transplant recipients and waiting list patients.

| Blood group | Donors | | Recipients | | Waiting list patients | |
|--------------|-------------|------------|-------------|------------|-----------------------|------------|
| | No. | % | No. | % | No. | % |
| O | 615 | 50 | 1061 | 47 | 2411 | 49 |
| A | 474 | 39 | 868 | 38 | 1575 | 32 |
| B | 91 | 7 | 225 | 10 | 818 | 16 |
| AB | 46 | 4 | 108 | 5 | 129 | 3 |
| <u>Total</u> | 1226 | 100 | 2262 | 100 | 4933 | 100 |

(Randhawa, 2004b)

The proportion of blood group B patients on the waiting list was significantly greater than that among transplant recipients ($p < 0.0001$) (Randhawa, 2004b). This is likely to be an increasing problem as the proportion of blood group B donors is also significantly lower than that of blood group B patients both in the transplant recipient pool as well as on the waiting list.

The frequency of the different blood groups varies according to ethnicity, causing a mismatch for South Asians and African-Caribbeans. Only 7% of kidney donors are blood group B, whilst on the waiting list, 39% of patients with a South Asian origin and 22% of those with an African-Caribbean background are blood group B (compared to 12% of those of European origin) (UK Transplant, 2003). Thus fewer kidneys of the appropriate blood group are available for people of South Asian or African-Caribbean origin.

Table 3 displays the ethnic origin distribution of kidney donors and their recipients.

| Donor ethnic origin | | Recipient ethnic origin | | | | Total |
|---------------------|-----|-------------------------|-------------|-------------------|-----------|-------------|
| | | Caucasian | South Asian | African-Caribbean | Other | |
| <u>Caucasian</u> | No. | 1791 | 156 | 63 | 26 | 2036 |
| | % | 88 | 8 | 3 | 1 | 100 |
| South Asian | No. | 17 | 8 | 3 | 2 | 30 |
| | % | 56 | 27 | 10 | 7 | 100 |
| African-Caribbean | No. | 10 | 3 | 0 | 1 | 14 |
| | % | 71 | 22 | 0 | 7 | 100 |
| Other | No. | 3 | 1 | 1 | 0 | 5 |
| | % | 60 | 20 | 20 | 0 | 100 |
| Total | No. | 1821 | 168 | 67 | 29 | 2085 |
| | % | 87 | 8 | 3 | 2 | |

(Randhawa, 2004b)

Approximately, 61% (30 out of 49) of kidneys donated by minority ethnic cadaveric donors were received by Caucasian recipients, while 93% of the minority ethnic transplant recipients received kidneys from Caucasian donors. None of the 19 kidneys retrieved from African-Caribbean and 'Other' donors were received by a patient of the same ethnic origin. Thus the majority of kidneys donated by minority ethnic donors are not being received by patients of the same ethnic origin **(Randhawa, 2004b)**.

Figures 1 and 2 display recipient and donor blood group distributions respectively, in the different ethnic groups. **Figure 1** highlights the difference in blood group distributions among the ethnic groups, with South Asians having more blood group B than blood group A transplant recipients in contrast to the other ethnic groups. **Figure 2** demonstrates the lack of donors from minority ethnic groups **(Randhawa, 2004b)**.

Figure 1 (Randhawa 2004b)

Recipient blood group distribution for cadaveric kidney transplants in the UK
1 January 2000 - 27 August 2001

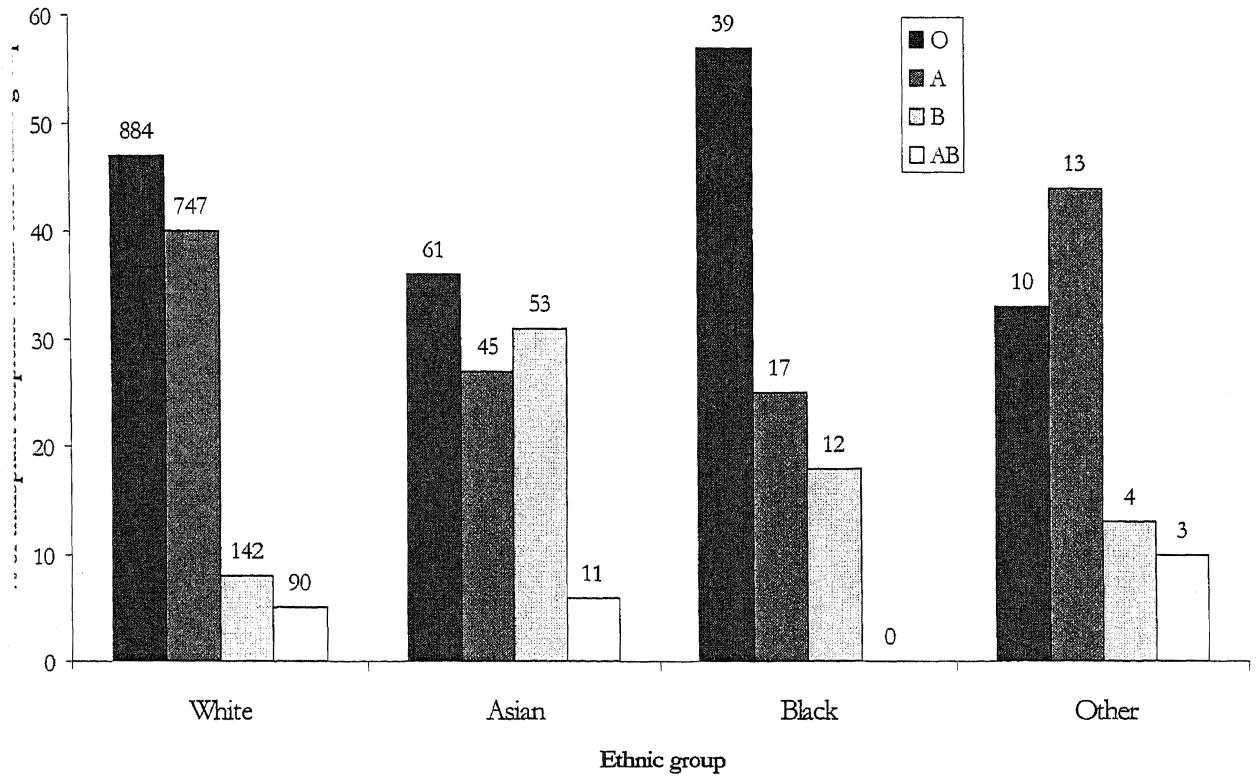
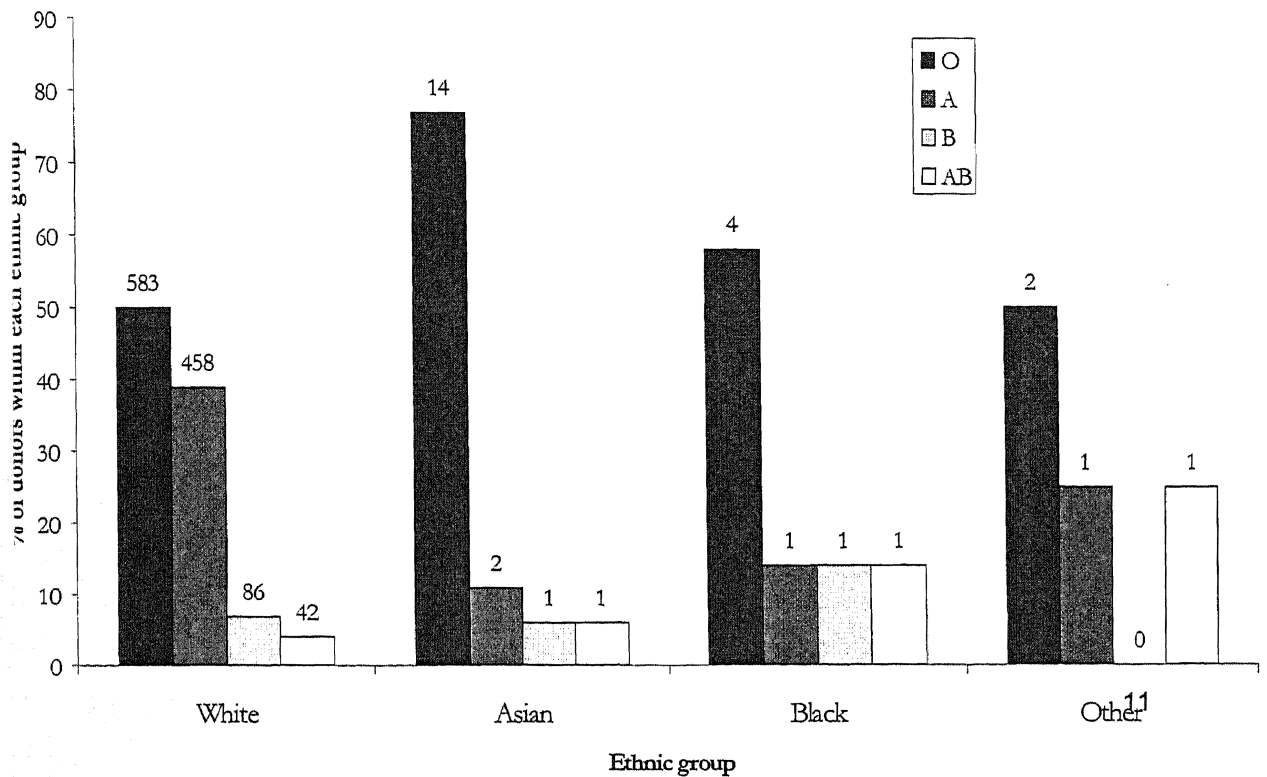


Figure 2 (Randhawa 2004b)

Donor blood group distribution for cadaveric kidney transplants in the UK
1 January 2000 - 27 August 2001



The imbalance in the ethnic origin distribution between donors and waiting list patients is clear. People with a South Asian origin make up 14% of the UK waiting list, but only 1% of the donors; African-Caribbeans comprise 6% of the waiting list and <1% of the donors. Although the majority of minority ethnic patients can and do receive kidneys from Caucasian donors, there is still an excess of these patients on the waiting list. This excess is partly explained by the lack of blood group B donors (7% of all donors) compared with the excess of blood group B patients on the waiting list (16%). The frequency of the different blood groups varies according to ethnicity, causing a mismatch for South Asians and African-Caribbeans. Thus fewer kidneys of the appropriate blood group are available for people with these minority ethnic backgrounds (**Randhawa, 2004b**).

In addition, people with a non-Caucasian origin have different genetic backgrounds to those of Caucasian origin, and as a result often have different tissue types, making organ (HLA) matching more difficult. This situation is compounded further by the lack of organ donors from minority ethnic groups.

Drawing some conclusions

On the basis of the above analyses, the candidate's work has sought to develop practical policy and research recommendations (**Randhawa, 1998a, 2000, 2001a, 2003, 2004a, 2004b**). End-Stage Renal Failure (ESRF) is much more prevalent among the UK's South Asian population. Currently, the demand for kidneys for transplant among South Asian patients far outstrips the supply of suitable organs. This situation is likely to worsen in the future due to the relationship between age and ESRF as the population grows older. As a result, the number of South Asian patients,

in particular, requiring a kidney transplant will increase further and consequently so will the need for histocompatible donors.

The situation is clear: there is an urgent need to address the number of South Asian patients requiring a kidney transplant, otherwise the human and economic costs will be very severe. In the short term there needs to be a greater number of donors coming forward from these communities to increase the pool of suitable organs (**Randhawa, 1998a**). There is also a need to explore the recently emerging evidence base for greater flexibility of blood group matching (Haji et al., 2004). In the long term, there needs to be greater attention on preventive strategies to reduce the number of South Asians requiring RRT. The latter can only be achieved if we begin to address the problem of poor access to services for minority ethnic groups (**Randhawa, 2003**).

Improving access to renal services

Importantly, the South Asian population in the UK is relatively young compared to the Caucasian population. Since the prevalence of ESRF increases with age, this has major implications for the future need for RRT and highlights the urgent need for preventive measures (**Randhawa, 1998a**). The incidence of ESRF has significant consequences for both local and national NHS resources. The National Renal Review estimated an increase over the next decade of 80% in the 20,000 or so patients receiving RRT and a doubling of the current cost, to about £600m a year of providing renal services (Raleigh, 1997).

The Diabetes National Service Framework highlights the importance of access to services, in particular to meet the needs of minority ethnic groups (DoH, 2002). The

Renal Services NSF also focuses on 'renal disease complicating diabetes' and emphasises the inequalities experienced by minority ethnic groups and the need to target resources and interventions to this issue (DoH, 2003b). However, there is evidence that knowledge of diabetes and its complications is poor among South Asians (Nazroo, 1997; Johnson et al, 2000). Preliminary evidence also suggests that the quality of health care for South Asians is inadequate and compliance with treatment is poor (Johnson et al, 2000; Raleigh, 1997). There is also a low-uptake of hospital-based diabetes services, with growing evidence that South Asians are subsequently referred later for renal care, and are more likely to be lost to follow-up (Jeffrey et al, 2002). Late referral may reduce opportunities to implement measures to slow progression of renal failure, or to prepare adequately for RRT thus adding to morbidity and mortality. It is clear that minority ethnic groups are disproportionately affected by renal health problems both in terms of access to appropriate services and the higher prevalence of renal complications.

As a result of the candidate's analyses in this area of study, he has established specific research foci for further exploration. A major imperative, for researchers and clinicians in the UK is to explore *access* to and the *progression through* the diabetes and 'renal disease complicating diabetes' care pathways, and to identify health beliefs and experiences associated with diabetes and diabetic renal complications among South Asian groups. A systematic exploration of these would provide a valuable resource for health professionals working with these groups and allow for the development of a culturally competent diabetic and renal service, which is sensitive to the needs of minority ethnic groups (Randhawa, 2000, 2003, 2004a).

Specifically, the identified gaps in knowledge are:

- Identification of cultural beliefs and practices relevant to diabetes and diabetic renal disease self-management, including attitudes to medication and attendance to - GPs, diabetic services and nephrology services - for routine monitoring;
- Examination of referral patterns to hospital-based diabetic services, and subsequent attendance;
- Exploration of referral patterns to nephrology services;
- Exploration of the relevance of current renal complications education programmes for minority ethnic groups (**Randhawa, 2000, 2003, 2004a**).

These issues will be further explored in a UK wide research project which has recently been commissioned through a grant from the Big Lottery Fund (Ref: ABLE CF1/2002 £248,671) for which the candidate is the lead applicant of a multi-disciplinary team also including Imperial College, the University of Leicester, and the University of Southampton.

Theme 2 – Examining national and international organ procurement programmes and their relevance to minority ethnic groups

Cognisant of the transplant inequalities affecting South Asians in the UK, the candidate has also developed a new evidence-base examining the transplant policy framework in which organ donation and transplantation takes place. The shift away from socialised forms of welfare over the past twenty years has changed the symbolic basis on which bodily parts are exchanged. Titmuss viewed the newly-formed National Health Service in the United Kingdom as a vehicle for institutionalising altruistic practices, notably the voluntary 'gift' of blood to strangers represented by the transfusion service (Titmuss, 1973). More recent advances in medical technology have made new forms of bodily tissue donation possible, including the transplantation of whole organs. Yet the excess of demand over supply is forcing a change from the principle of voluntarism on which 'opting-in' procurement arrangements have hitherto rested to one of presumed consent and the system of 'opting-out' adopted in other countries. The implications of this transition within the context of multi-cultural Britain have been examined by the candidate in a series of published works (Randhawa, 1995a, 1995b, 1996, 1997a, 1998b, 1998c, 2001b, 2004a).

Organs are procured in the UK on a voluntary basis based upon the principle of altruism. Titmuss (1973) advocated such a 'gift' system in the area of blood donation. Unfortunately, the demand for transplant organs far exceeds the supply, and the situation is getting worse. Several other organ procurement systems as alternatives to opting-in such as routine enquiry, required request, and presumed consent (also known as opting-out) have been implemented in other countries. This shift in policy represents a change in attitude concerning the control of body organs after death. Whereas on the one hand, opting-in relies upon voluntarism and the notion of a 'gift',

presumed consent depends on affirmative action to prevent organs being used for transplantation.

More recently, a proposal has been made for the use of animal organs for transplant, xenotransplantation, which is under review by the Department of Health. This would eliminate the issues surrounding the transition from voluntarism to presumed consent but introduces new debates. These developments in the organ procurement arena are continuing under the media spotlight and are open to increasing scrutiny as public interest in the bounds of medical science grows with stories of animal cloning and, ultimately, the possibility of cloning humans.

The candidate has explored the adequacies of the existing procurement arrangements and the implications of introducing any alternative policies in the context of a multi-ethnic and multi-faith UK. The published works have drawn upon international policy analysis and empirical research of European organ donation rates in relation to a country's organ procurement arrangements (**Randhawa, 1995a, 1995b, 1996, 1997a, 1998b, 1998c, 2001b, 2004a**). **Table 4** highlights some of the key advantages and disadvantages of the various organ procurement programmes in existence.

Table 4: The advantages and disadvantages of the various procurement policies

| |
|--|
| <p>Opting-in</p> <p><i>Advantages:</i> Relies upon altruistic motives; gives people freedom of choice</p> <p><i>Disadvantages:</i> Wishes of the donor card holder may be frustrated because no one looked for the card, or the family concealed the fact that one was held</p> |
| <p>Presumed consent</p> <p><i>Advantages:</i> Marked reduction in transplant waiting lists; utilises all potential donors</p> <p><i>Disadvantages:</i> Only the educated and more advantaged groups of society would be able to exercise autonomy in their presumption of donation, and the situation may occur where the poor and uneducated would not have the same autonomy.</p> |
| <p>Routine enquiry</p> <p><i>Advantages:</i> Seeks to overcome the reluctance of those health professionals who themselves may not advocate donation</p> <p><i>Disadvantages:</i> Requires adequately trained and qualified personnel</p> |
| <p>Required request</p> <p><i>Advantages:</i> Ascertains the donor status of all admitted hospital patients</p> <p><i>Disadvantages:</i> Requires institutional commitment from all hospitals</p> |
| <p>Commercialisation</p> <p><i>Advantages:</i> Increases the supply of kidneys for transplantation</p> <p><i>Disadvantages:</i> Divides society, where the donors are always poor, and the recipients always rich</p> |
| <p>Xenotransplantation</p> <p><i>Advantages:</i> Reduces the need for human organs which are in short supply</p> <p><i>Disadvantages:</i> Risk of a variety of diseases spreading into humans and there are a number of ethical and moral concerns to overcome</p> |

(Randhawa, 2001b)

Voluntarism/Opting in

Donor cards/Organ donor registers

The opting-in system is in use in many countries and is facilitated by people carrying a donor card or signing on a organ donor register. For this system to have a direct impact on procurement rates either a donor card must be found on the body of the deceased at or shortly after the time of death or the deceased person's name should be on the donor register. Even so, in the UK and in some other European countries, it is usual to obtain the consent of the next-of-kin in addition, if this can be done in time for the organs to be viable **(Randhawa, 1995a, 1995b, 1996)**.

As an indirect way of raising public awareness the impact of the card and register cannot be overestimated. In several countries, national publicity campaigns have been used to increase the uptake of donor cards and ultimately increase donation rates. One example of their potential influence can be seen in the 42% increase in the number of kidney donations in Britain in 1984 which coincided with a 6 month campaign conducted by the Department of Health and Social Security using television and newspaper advertising to describe the donor card system. Such publicity can affect card carrying directly and can also have indirect effects on donation by initiating debate and increasing awareness **(Randhawa, 1995a, 1995b, 1996)**.

Efforts such as these are highly commendable but have done little to address the underlying problem which is to achieve card carrying or signing on the donor register amongst those members of the public whose families would otherwise have refused consent. This can only be tackled through concerted education campaigns, using various forms of media to highlight the benefits of transplantation and appeal to the public's sense of altruism **(Randhawa, 1995a, 1995b, 1996)**.

Routine Enquiry

The procedure of routine enquiry is well established in the United States. It seeks to overcome the reluctance of those health professionals who may not themselves advocate donation. It requires the professionals involved to ascertain from family members the donor status of those who have met, or are about to meet, the definition of brain death.

Eighteen states have legislated for routine enquiry. Indeed, the US Congress has made the implementation of routine enquiry arrangements a condition of payment under their health insurance schemes (Medicare and Medicaid), and they are required as a condition of certification by the Joint Commission on the Accreditation of Healthcare Organisations (**Randhawa, 1995b, 2001b**).

Required Request

Required request is also common practice in the USA and involves staff ascertaining the donor status of all patients admitted to hospital. The development of these arrangements by hospitals was encouraged by the Omnibus (Budget) Reconciliation Act 1986. As is the case for routine enquiry, this Act provides that failure on the part of hospitals to adopt required request policies will lead to the denial of Medicare and Medicaid reimbursements from the Health Care Finance Authority (New et al, 1994). Twenty six US states have adopted this type of policy.

Estimates in the USA suggest that whilst 200,000 persons are declared brain dead each year, organs are only harvested from 2,000. The combined need for hearts, lungs, and kidneys, is estimated at over 50,000 (Schwartz, 1985). Would required request procedures provide a solution to the disparity between supply of and demand for organs in the UK? In an audit undertaken in 1991, it was estimated that brain-stem criteria could be applied in an approximate 2,300 cases (Gore et al, 1992). If this pattern were to continue in future years required request procedure may provide a

part-solution in alleviating some of the pressure from the waiting transplant lists. In the UK required request was considered in the 1980s by the Department of Health and Social Security, but rejected in favour of a policy of better disseminated information concerning donation and an extension of the donor card system (**Randhawa, 1995b, 2001b**).

Although there was an initial increase over time in the number of procured organs, evaluation of routine enquiry and required request programmes has shown little, if any, increase in organ procurement rates in the USA (New et al, 1994). One reason for this, it is suggested, is the lack of institutional commitment to ensuring that the required request procedures are followed (McDonald, 1990). The United States experience illustrates that simply to enact required request legislation is not enough. It is vital to have adequately motivated, trained and qualified personnel (**Randhawa, 1995b, 1997, 2001b**).

Live donation

Live donation legislation has been introduced throughout Europe and implemented with varying degrees of success. The principal source of live donations is from those who are both genetically similar and related to the recipient but sometimes donors are those who are not genetically similar but are related (spouses) and, in special circumstances, donors who are genetically similar but unrelated to the recipient. Strict regulations have been implemented to control the latter type of donation to reduce the possibility of non-voluntary donors.

It is evident from the analysis on European transplant activity that Norway has pursued a live donation policy more actively than its counterparts in Europe (**Randhawa, 1998b**). The main reason for this is its low population density, there are organizational implications for transplantation activity attached to a small population living in a large country. Norway is constrained by the fact that it has only one

ransplant centre in Oslo. This has had a major influence on the low rate of cadaveric ransplant activity due to the large distances between the donor hospitals and the ransplant centre. Thus, the live donor alternative is a much more appealing proposition and is pro-actively pursued as a procurement option (**Randhawa, 1995b, 1998b, 2001b**).

The Norwegian programme involves exploring the possibility of live donation as soon as the decision for transplant is taken. Family members are assessed for suitability and the possibility of live donation is discussed where transplantation is feasible. The act of donation must be demonstrably voluntary and, if there appears to be any signs of coercion or feelings of obligation, the physician will declare the potential donor medically ineligible for donation thus relieving the family member of any responsibility for making such a decision. This also serves to dispel any doubts or suspicion on the part of other family members of the donor's willingness to take part (**Randhawa, 1995b, 1998b, 2001b**).

For those patients waiting for a kidney transplant, the time and financial and emotional costs of travelling to and from the dialysis centre two or three times a week are extremely heavy. This is true for all patients regardless of their country of residence. Taking a pro-active approach to live donation has been shown to be an important determinant in increasing procurement rates since the number of live transplants performed in Finland, another country with a low population density but a less-organized approach to live donation, is far fewer (**Randhawa, 1995b, 1998b, 2001b**).

As is the case with all other forms of transplant policy, live donation raises a number of ethical concerns. Firstly, there is the issue that live donation is a procedure that may not be in the medical interests of the donor. As such, it is a practice that runs counter to the medical profession's code of ethics. However, what needs to be

balanced are, on the one hand, the medical benefits to the recipient and the emotional benefit to the donor, who is in most cases the recipient's close relative and, on the other, the minimal but nevertheless real risk to the donor of invasive surgery (**Randhawa, 1995b, 1998b, 2001b**).

A final concern is that there may be financial inducements offered to persuade people to donate organs. This relates more specifically to unrelated donors. Measures have been taken to outlaw this procedure in Europe and throughout the rest of the world by introducing statutes prohibiting trading in human organs such as the Human Organ Transplants Act (1989) in the UK. However, this practice is very difficult to monitor, particularly in the case of intrafamily exploitation (**Randhawa, 1995b, 1998b, 2001b**).

Alternatives to voluntarism

Presumed consent/opting-out

A presumed consent law presumes that an individual has consented to organ donation at the time of death unless there is contrary documentary evidence or, in some countries, objections by the family. Assuming that the commitment of society were strong towards donation and that the public trusted the concept and application of brain death, this system should theoretically reduce the donor shortage drastically. The positive impact on transplantation rates is visible in **Table 5**, but there are moral issues to consider in implementing such a policy (**Randhawa, 1998b**).

**TABLE 5 – CADAVERIC KIDNEY TRANSPLANTATION RATES (PMP)
IN EUROPE’S LEADING TRANSPLANT COUNTRIES, 1994**

| | PMP | OPTING-OUT LEGISLATION |
|-----------------------|------|---------------------------|
| AUSTRIA | 42.2 | YES |
| SPAIN | 42.0 | YES |
| BELGIUM | 37.4 | YES |
| FINLAND | 35.0 | YES |
| PORTUGAL ^a | 43.9 | YES |
| SWITZERLAND | 30.2 | |
| UNITED KINGDOM | 28.8 | |
| SWEDEN | 27.5 | |
| NORWAY | 26.8 | YES |
| DENMARK | 25.8 | |
| THE NETHERLANDS | 25.8 | |
| FRANCE | 24.7 | YES |
| GERMANY | 23.7 | |
| HUNGARY | 23.4 | |
| ITALY | 14.8 | |
| LUXEMBOURG | 10.0 | |
| GREECE | 4.6 | |

a: Opting-out legislation in Portugal was introduced in 1994

(Randhawa, 1998b)

Presumed consent schemes have been introduced into many European countries (Austria, Belgium, Finland, France, Italy, Norway, Spain, and Sweden). The arguments in favour of presumed consent are based on the presumption that there will be a marked reduction in transplant waiting lists. It is argued that such a statute could be introduced whilst giving people the opportunity to opt-out on religious or moral grounds. This is the case in Singapore where a presumed consent system is in

operation but excludes all Muslim citizens, as they prefer to exercise the right of opting-in (**Randhawa, 1995b, 1998b, 2001b**).

The arguments against presumed consent are that only the educated and more advantaged groups in society are able to exercise informed choice and act autonomously in such a scheme and the situation can arise where the poor and uneducated would not have the same autonomy due to lack of knowledge. We could also reach the stage where patients close to death would be looked upon solely as a source of organs (**Randhawa, 1995b, 1998b, 2001b**).

Commercialisation

Trading in organs has been reported around the world and is widespread in certain countries. In India, for instance, where the cadaveric organ procurement programme has only been recently established, the practice of buying and selling of organs has been rife for many years. Over 70,000 patients are diagnosed each year as requiring a kidney transplant. This is more than 10 times the entire kidney transplant waiting list in the UK. In 1989, nearly all of the 2,000 kidney transplants carried out in India, involved living donors. However, in 1994, The Transplantation of Human Organs Bill was introduced which prohibits commercial use of organs (**Randhawa, 1995b, 1998b, 2001b**). In other Asian countries such as Hong Kong, there have been reports of sales of kidneys which have been extracted from executed prisoners from China (**Randhawa, 1995b, 1998b, 2001b**).

Western countries have not been immune from this practice. There have been reports of people paying large sums of money far exceeding normal costs in order to move to the top of transplant waiting lists in the United States. In the UK, there was mass condemnation of organ selling when reports surfaced of four Turkish peasants being brought to the country to act as live kidney donors in return for payment. As a result

of this, the Government introduced legislation banning the buying and selling of organs. However, as mentioned at the outset of this document, there have been some very recent cases of GPs trading in kidneys to assist South Asian patients requiring a kidney transplant (**Randhawa, 2004b**).

It has been argued that the sale of organs is justifiable as it would increase the supply. There is also the case that individuals should have ownership of their body and do with it what they wish. However, laws restricting the use of the body prevail even in countries that profess to promote free choice. These include prostitution, limits on abortion, limits on boxers who fail to meet health standards, health and safety regulations at work and participation in dangerous experiments.

The arguments opposing organ trading are much stronger. In the free market where profit is the first objective, normal standards of medical screening may well not be exerted. There have been reports of post-operative deaths from HIV transmission at the time of transplantation. Most importantly, for surgeons, operations should be performed for therapeutic reasons. A financial reward does not represent a therapeutic indication for surgery. Allowing markets in organs may predispose to the 'slippery slope', down which the market may slide, to the ultimate sacrifice whereby a person may sell all their transplantable organs, and therefore their life, in return for their family's financial well-being. Commercialisation of organs divides society, where the donors are always poor, and the recipients always rich (**Randhawa, 1995b, 1998b, 2001b**).

Xenotransplantation

Recent advances in technology have made the possibility of xenotransplantation - the use of animal organs for transplant - becoming a routine procedure a distinct reality in the next couple of years. The early 1960s saw the first breakthrough in xenotransplantation when a patient survived nine months with a kidney from a

chimpanzee. Five other patients who underwent the same procedure died within days. Liver transplantation was also attempted from chimpanzee to human but was unsuccessful. In the early 1980s a baboon heart was transplanted into a baby girl known as "Baby Fae", this unfortunately also failed after 20 days (**Randhawa, 1996, 1998c, 2001b**).

The most recent development to this has been the use of a pig as a donor. Research is being carried out in Cambridge, where it is hoped the strong human immunological response to foreign tissue can be overcome with genetically altered pigs. The idea is to trick the human immunological response into thinking the pig's heart is its own. This seeks to overcome the medical concerns with the problems of hyperacute rejection and the spread of new diseases in humans. The research into transfer of diseases from one species to another is well documented. Common examples include influenza viruses which have their origins in pigs, ducks, and chickens which act as reservoirs for the diseases. Most worrying of all is research in Central Africa which suggests that AIDS was transmitted from the monkey virus into humans (**Randhawa, 1996, 1998c, 2001b**).

Clearly, xenotransplantation is controversial and involves a number of ethical debates. Importantly, are the ethical issues involved in breeding of animals for food and those involved in the breeding of animals for organs the same? The candidate would argue that the issues involved are separate and should be considered on their own merits. The acceptability of one practice does not necessarily legitimise the other. The debate about breeding animals for food is a hotly contested area in Britain today and arouses strong emotions. Animal rights activists would claim that neither practice is necessary for human health and survival as alternative options are available (**Randhawa, 1996, 1998c, 2001b**).

For people awaiting heart and liver transplants there are no alternatives to transplantation. Thus, it could be argued that those people who protest to using animal organs for transplant should provide a stronger case than those who are against using animals for food. Alternative food sources are available yet it is generally believed to be morally accepted to kill animals for food (**Randhawa, 1996, 1998c, 2001b**).

The religious stance on the use of animal organs for transplant must also be considered. Certain animals are considered sacred for some religions, thus organs from these animals would be unacceptable. For example, in Hinduism the cow is sacred, whereas for Jews and Muslims the pig is considered unclean (**Randhawa, 1996, 1998c, 2001b**).

Drawing some conclusions

At present, public policy in the UK relies upon voluntarism and the need for consent with any attempts to shift from this being rejected in previous years. Titmuss (1973) saw the welfare state in general, and the system of blood donation in particular, as removing the exchange of bodily parts from the market place and restoring the gift relationship. This has occurred to some extent in the case of organ donation in that commercial markets for human organs are banned in Western countries with such legislation being implemented slowly worldwide. However, what we are now seeing in many countries is the positive right to give as advocated by Titmuss (1973) being replaced by the case for a negative right which may be waived. The future nature of organ procurement systems remains uncertain with the on-going scientific advances, which on the one hand enable us 'unnaturally' to prolong human life and on the other, 'unnaturally' to exploit the organs of non-human creatures, likely to have a great influence (**Randhawa, 2001b**).

In the shorter term, an increase in the supply of organs is urgently required particularly from the South Asian population to alleviate the burden on current waiting lists and for those patients on dialysis. The candidate has argued that this process can only begin if the South Asian public are in an informed position to consider and debate the issues surrounding organ donation and transplantation. Central to attaining this goal are increased levels of health education and awareness of the specific problems concerning renal disease within the South Asian communities (**Randhawa 1996, 1997a, 1998c, 2001b, 2004a**).

As well as focusing on national organ procurement policies, there is also a need to examine the number of South Asian patients who are eligible to become organ donors in the Intensive Care Unit (ICU). The limited research conducted so far suggests that low rates of organ donation for South Asian people may be related to factors pertaining to the low rates of admission to ICUs rather than to other issues relating to the donation of organs (Exley et al, 1996a).

On a related point, anecdotal evidence also suggests that the proportion of brain-stem deaths may be lower among minority ethnic groups. An audit of potential organ donors, identifying ethnic background, is currently being undertaken by UK Transplant. Within the ICU also, there is a need for clear guidelines on how to approach patients for making a request for their loved one's organs with specific training and counselling in a multicultural and multi-faith environment. The candidate's series of publications in developing culturally competent training for medical staff have formed the basis of commissioning guidelines for UK Transplant's national training programme for Transplant Co-ordinators (**Randhawa, 1997b, 1998d, 1998e, 1999, 2003**).

Alongside these initiatives, efforts to promote living related kidney donation among South Asian families need to be implemented, especially in the light of low admission rates to ICUs and the subsequent low cadaveric donation rates. Most importantly, the above initiatives in collating a sound evidence-base from which to meet the needs of minority ethnic groups has to *recognise* and *reflect* the heterogeneity of the UK's South Asian population (**Randhawa 2004a**).

The above analyses and subsequent recommendations have been used as a basis to develop the direction of policy for the Department of Health and UK Transplant in increasing the number of organ donors from the South Asian communities.

Theme 3 - Examining the empirical research that explores the reasons for low organ donation rates among minority ethnic groups

Unfortunately, the transplant option may be medically and economically favourable but in reality it is not available due to constraints relating to the severe lack of donors from the South Asian population. This has been attributed to two main reasons – a lack of awareness concerning organ donation and transplantation, and low referral rates to the Intensive Care Unit (New et al, 1994). It must be stressed that these factors are not unique to the South Asian population and have relevance to other members of the UK's population. Furthermore, it is extremely important to recognise that the South Asian communities in the UK are heterogenous and thus it is important to familiarise oneself with the demographics of the local population (**Randhawa, 2005**). The candidate's work has focused on developing an evidence-base of the public perceptions, attitudes, and religious viewpoints towards organ donation and transplantation among a cross-section of the South Asian population (**Randhawa, 1998f**), and more recently, exploring these issues among a cross-section of the African-Caribbean population (Davis & Randhawa, 2004).

Increasing awareness of the need for organ donors among the South Asian communities

Unfortunately, very little research has been devoted to this area. Only four empirical studies have been undertaken in the UK to explore the views of South Asian communities towards organ donation and transplantation. Exley et al. (1996b) focused upon the Sikh community in Coventry, Hayward et al. (2003) focused upon the Muslim community in West Yorkshire, Alkhawari (2004) focused upon the Muslim community in West London, and the candidate's work which focused upon

the South Asian population in Luton (**Randhawa 1998f, 2000**). The latter study was, and still is, unique in that it was the first and only study to include the broad cross-section of the South Asian population reflecting the different faith and cultural groups. This project was supported with a grant from the King's Fund. The candidate was Principal Investigator for the study and there was a funded Research Assistant, A Darr. The study sample involved eight single-sex focus groups, with a total of 64 participants, and a further 64 individual interviews. The sample was selected on the basis of language spoken and religion and to reflect the demographic profile of the Asian population in Luton. These comprise:

- Gujarati speaking Hindu women originating from India (Indian Gujarati);
- Punjabi speaking Sikh women originating from the Indian Punjab (Indian Punjabi);
- Punjabi speaking Muslim women originating from Pakistan (Pakistani Punjabi);
- Sylheti speaking Muslim women originating from Bangladesh (Bangladeshi Sylheti);
- and four, otherwise culturally similar, groups of men.

The study explored the following key areas:

- Knowledge and awareness of transplantation;
- Views of and attitudes towards organ donation;
- Perceived position of religion towards organ donation;
- Most appropriate way of informing people about organ donation.

Grounded theory methodology was adopted for the study. It has been argued that the grounded theory method is ideally suited to investigation of those topics about which there is little prior knowledge which requires an approach to data collection without a preconceived framework (Flick, 1998). In grounded theory, reality is socially and

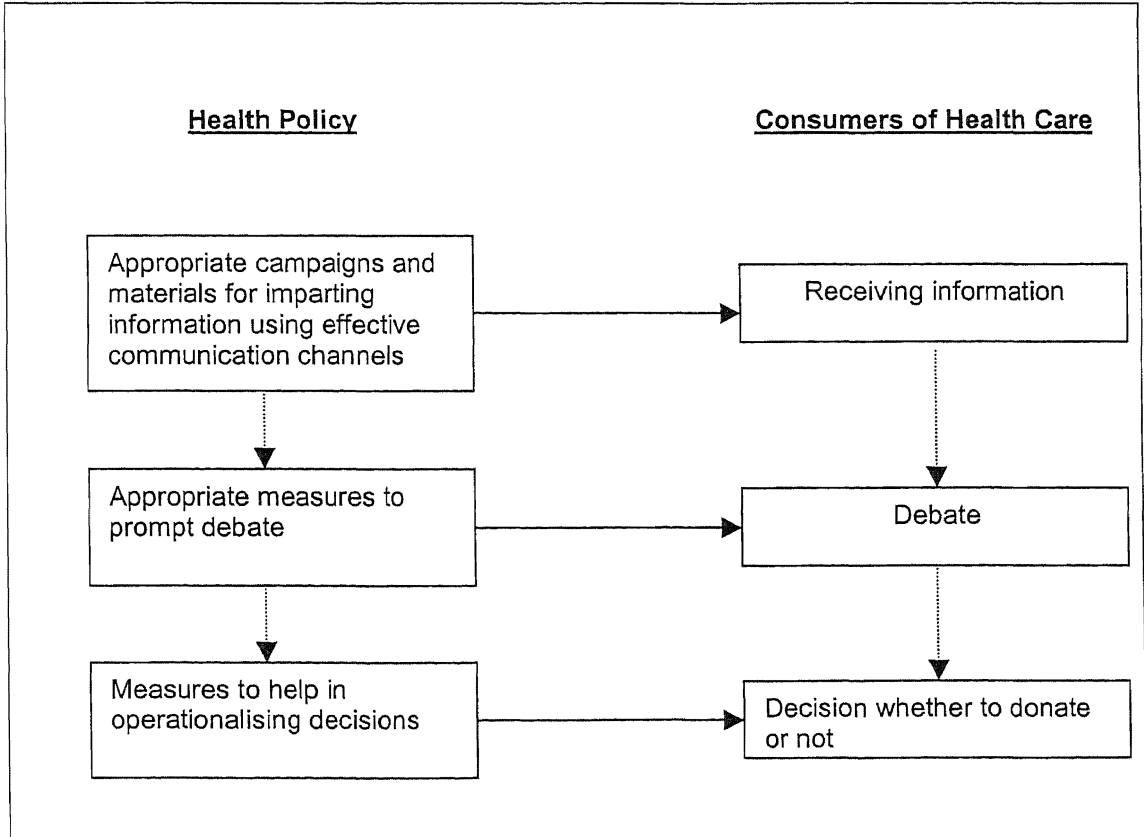
culturally based and the aim of using the grounded theory approach is to understand the nature of human behaviour by generating theories about social phenomena (Chenitz & Swanson, 1986). This approach was deemed to lend itself well to the exploration of the phenomena of low organ donation rates among the South Asian community in the UK and the potential reasons why.

This empirical work has made an important contribution by developing methodological approaches to researching sensitive issues across different groups of the UK's South Asian population (Randhawa & Darr, 2001). This has thus enabled particular 'sensitive' areas of enquiry to be explored with what might traditionally be described as 'difficult to reach' populations (Qureshi et al, 2000, Randhawa & Owens, 2004). The study showed, consistently with the other three studies in the subject area, that South Asians are supportive of organ donation and transplantation, but are not aware of the specific needs for organs from their community (Randhawa, 1998f). There was a clear need to review the dissemination of information to the South Asian communities (Exley et al, 1996b, Randhawa, 1998f, Alkhawari et al, 2005).

At the time of the study (1994/5), the Department of Health had produced a range of educational material (including leaflets, posters, and videos) in the main South Asian languages to increase awareness of transplant related issues. However, the study findings suggested that further consideration was required about the dissemination of this literature among South Asian populations (Randhawa, 1998f). Specifically, care needs to be taken in specifying the target population, selecting the persons who will communicate the campaign appeal, designating the methodology of appeal delivery,

and deciding upon the content of the appeal. There were indications from the work in the UK and research overseas involving minority ethnic groups, that appeals for South Asian donors may be more effectively communicated by employing a grassroots, community networking approach (Exley et al., 1996b; **Randhawa, 1998f**). **Figure 4** sets out how this community-based approach may be operationalised (**Randhawa, 2004a**). This approach differs from traditional health information campaigns by introducing measures to prompt debate, employing culturally appropriate staff who can network within the community creating a 'safe' environment for the public to discuss health issues. It is hoped that the period of debate enables the public to come to a more informed decision rather than rely solely upon reading the information provided in leaflets and posters.

Figure 4: Stages for consideration in the development of a comprehensive approach to organ procurement



(**Randhawa, 2004a**)

The candidate has also been cognisant of the growing amount of literature from overseas that has shown that the role of religion has been known to play an important part in the decision to donate organs (Callender, 1989; Kyriakides, 1993; Spina et al., 1993). However, such work had not been undertaken in the UK until the candidate began to examine the issue. The religious beliefs of the major faiths of the UK's African-Caribbeans and South Asians, namely Islam, Hinduism, Sikhism, Buddhism, and Christianity, have been scrutinised in the literature (**Randhawa 1995a, 1999, 2001b**). None of the religions object to organ donation in principle, although in some there are varying schools of thought. Furthermore, the candidate has examined religious literature in relation to death rituals for the South Asian population (**Randhawa, 1999**). These analyses have informed the development and production of educational leaflets for the public and transplant staff.

Drawing some conclusions

Unfortunately, the examination of religious issues have not been prominent in empirical research carried out in the UK but the findings of the candidate's study to examine the attitudes towards organ donation and transplantation among a cross-section of the UK's South Asian population shed some light on these matters for the first time among a *cross-section* of the South populations' faiths (**Randhawa, 1998f**). It was found that, far from being a barrier to organ donation, the respondents were more supportive of donation and transplantation, in general, when they were aware of the position of their religion with regards to these issues. This highlights the importance of education and raising awareness among the South Asian public.

Due to the uniqueness of the study, it has formed the basis for Department of Health, and subsequently, UK Transplant funded organ donation awareness campaigns among the UK's South Asian population. The campaigns now employ a localised approach to targeting South Asian communities and also utilize material setting out the different religious perspectives towards organ donation and transplantation.

Conclusion

In summary, the candidate's series of publications has led to Government and academic recognition that inequalities do exist in renal transplantation for the UK's South Asian population. The candidate's work has made an original contribution in the following ways:

- The candidate's work in this area was the first in the UK to systematically document and map a *national* picture of kidney transplant waiting lists and explore its relevance for South Asian communities.
- The candidate's subsequent work in the subject area has been the first to identify and examine the complex reasons underlying how and why patient ethnicity impacts upon the likelihood of receiving a kidney transplant. On the basis of the above analyses, the candidate's work has sought to develop practical policy and research recommendations.
- The candidate has also developed a new evidence-base exploring the adequacies of the existing procurement arrangements and the implications of introducing any alternative policies within the context of a multi-ethnic and multi-faith UK. The candidate's analyses and subsequent recommendations have been used as a basis to develop the direction of policy for the Department of Health and UK Transplant in increasing the number of organ donors from the South Asian communities. For example, an audit of potential organ donors and an audit of the source of Organ Donor Registration, identifying ethnicity, are currently being undertaken by UK Transplant.
- The candidate's series of publications in developing culturally competent training for medical staff have formed the basis of commissioning guidelines for UK Transplant's national training programme for Transplant Co-ordinators.

- The candidate's work has focused on developing an evidence-base of the public perceptions, attitudes, and religious viewpoints towards organ donation and transplantation among a cross-section of the South Asian population. The candidate's empirical study was, and still is, unique in that it was the first and only study in the UK to include the broad cross-section of the South Asian population reflecting the different faith and cultural groups. Due to the uniqueness of the study, it has formed the basis for Department of Health, and subsequently, UK Transplant funded organ donation awareness campaigns among the UK's South Asian population.
- The candidate has also undertaken a detailed analysis of the religious literature in relation to organ donation and transplantation. Furthermore, the candidate has examined religious literature in relation to death rituals for the South Asian population. These analyses have informed the development and production of educational leaflets for the public and transplant staff. Consequently, UK Transplant campaigns now employ a localised approach to targeting South Asian communities and also utilize material setting out the different religious perspectives towards organ donation and transplantation.

Consequently, there has been increased recognition, at national policy level, to address the specific needs of minority ethnic groups in relation to renal transplantation. This has been demonstrated within the Diabetes NSF (DoH, 2002) which recommends the need to provide more appropriate preventative and care management services for minority ethnic groups in order to reduce the number of patients with diabetes complications such as renal failure. The Renal NSF (DoH, 2003b) has outlined specific recommendations for managing renal disease among

minority ethnic groups. The candidate's recent Grant Award from the Big Lottery Fund for a UK-wide study, 'To explore *access* to and the *progression through* the diabetes and 'renal disease complicating diabetes' care pathways, and to identify health beliefs and experiences associated with diabetes and diabetic renal complications among South Asian groups,' will be integral to developing implementation guidance for the NSFs.

The Transplant Framework (2003a) has also set out the urgent need to increase the number of organ donors from minority ethnic groups. The candidate is cognisant that the published works to date have focussed on the ethnicity of transplant waiting list patients, donors, and recipients. However, as the transplant datasets become richer, a future focus of work in this area will be to explore the relationship between ethnicity and socio-economic status in relation to transplantation.

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Appendix 1: Key publications to be considered for PhD by Publication. Where these are cited in the text and the bibliography, they appear in bold)

1. Randhawa G. (forthcoming September 2005) Promoting organ donation and transplantation among South Asians in the UK - can utilizing South Asian community social networks provide the answer?. *Progress in Transplantation*.
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17. Randhawa G. (1996) The prospect of xenotransplantation in India. *Indian Journal of Asian Affairs*. 9, 114-120.
18. Randhawa G. (1995a) Organ donation: social and cultural issues. *Nursing Standard*. 9, 41, 25-27.
19. Randhawa G. (1995b) Improving the supply of donors in the UK - A review of public policies. *Health Education Journal*. 54, 241-250.

Appendix 2: From key publications, those that make an original contribution to Theme 1 – Mapping and highlighting the inequalities in health experienced by minority ethnic groups in relation to renal transplantation

1. Randhawa G. (2004a) Issues in Nephrology, Dialysis and Transplantation for minority ethnic groups. In: Thomas N (Ed), *Advanced Renal Nursing*, Blackwell Publishing.
2. Randhawa G. (2004b) The challenge of kidney transplantation among minority ethnic groups in the UK. *EDTNA, Journal of the European Dialysis and Transplant Nurses Association*. 30, 182-187.
3. Randhawa G. (2003) Developing culturally competent renal services In the United Kingdom: Tackling Inequalities In Health. *Transplantation Proceedings*. 35, 21-23.
4. Randhawa G. (2001a) The UK's Asian population: Solving the transplant crisis. *EDTNA, Journal of the European Dialysis and Transplant Nurses Association*. 27, 97-100.
5. Randhawa G. (2000) Increasing the donor supply from the UK's Asian population: The need for further research. *Transplantation Proceedings*. 32, 1561-1562.
6. Randhawa G. (1998a) The impending kidney transplant crisis for the Asian population in the UK. *Public Health*. 112, 265-68.

Appendix 3: From key publications, those that make an original contribution to Theme 2 – Examining national and international organ procurement programmes and their relevance to minority ethnic groups

1. Randhawa G. (2004a) Issues in Nephrology, Dialysis and Transplantation for minority ethnic groups. In: Thomas N (Ed), *Advanced Renal Nursing*, Blackwell Publishing.
2. Randhawa G. (2004b) The challenge of kidney transplantation among minority ethnic groups in the UK. *EDTNA, Journal of the European Dialysis and Transplant Nurses Association*. 30, 182-187.
3. Randhawa G. (2003) Developing culturally competent renal services In the United Kingdom: Tackling Inequalities In Health. *Transplantation Proceedings*. 35, 21-23.
4. Randhawa G. (2001b) The changing nature of organ procurement policies and the implications for the UK. *Journal of Health and Social Policy*. 12, 53-74.
5. Randhawa G. (1999) Organ donation from an Asian perspective. *Bereavement Care*. 18, 9-10.
6. Randhawa G. (1998b) Public policies for procuring organs for transplantation: a European perspective. *European Journal of Public Health*. 8, 299-304.
7. Randhawa G. (1998c) Xenotransplantation: Is there an alternative ?. *Animal Issues*. 2, 51-62.
8. Randhawa G. (1998d) Specialist nurse training programme: Dealing with asking for organ donation. *Journal of Advanced Nursing*. 28 (2), 405-408.
9. Randhawa G. (1998e) Coping with grieving relatives and making a request for organs: Principles for staff training. *Medical Teacher*. 20, 247-249.

10. Randhawa G. (1997a) Fighting the organ transplant crisis: What can schools do ? *Education and Health*. 15, 14-15.
11. Randhawa G. (1997b) Enhancing the health professional's role in requesting transplant organs. *British Journal of Nursing*. 6, 429-434.
12. Randhawa G. (1996) The prospect of xenotransplantation in India. *Indian Journal of Asian Affairs*. 9, 114-120.
13. Randhawa G. (1995a) Organ donation: social and cultural issues. *Nursing Standard*. 9, 41, 25-27.
14. Randhawa G. (1995b) Improving the supply of donors in the UK - A review of public policies. *Health Education Journal*. 54, 241-250.

Appendix 4: From key publications, those that make an original contribution to Theme 3 - Examining the empirical research that explores the reasons for low organ donation rates among minority ethnic groups

1. Randhawa G. (forthcoming September 2005) Promoting organ donation and transplantation among South Asians in the UK - can utilizing South Asian community social networks provide the answer?. *Progress in Transplantation*.
2. Randhawa G. (2004a) Issues in Nephrology, Dialysis and Transplantation for minority ethnic groups. In: Thomas N (Ed), *Advanced Renal Nursing*, Blackwell Publishing.
3. Randhawa G. (2001b) The changing nature of organ procurement policies and the implications for the UK. *Journal of Health and Social Policy*. 12, 53-74.
4. Randhawa G. (2000) Increasing the donor supply from the UK's Asian population: The need for further research. *Transplantation Proceedings*. 32, 1561-1562.
5. Randhawa G. (1999) Organ donation from an Asian perspective. *Bereavement Care*. 18, 9-10.
6. Randhawa G. (1998f) An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology Dialysis Transplantation*. 13, 1949-54.
7. Randhawa G. (1995a) Organ donation: social and cultural issues. *Nursing Standard*. 9, 41, 25-27.

Appendix 5: Supplementary publications to support PhD by publication

1. Baluch B. & **Randhawa G.** (1998) Attitude measures, personality characteristics and the role of persuasion in organ donation. *TransplantationsMedizin*. **10**, 102-106.
2. Baluch B, **Randhawa G**, Holmes S. (2001) Signing the organ donor card: The relationship between expressed attitude, the actual behaviour and personality traits. *Journal of Social Psychology*. **141**, 124-6.
3. Darr A. & **Randhawa G.** (1999) Public opinion and perceptions of organ donation and transplantation among Asian communities - An exploratory study in Luton, UK. *International Journal of Health Promotion and Education*. **37**, 65-71.
4. Davis C. & **Randhawa G.** (forthcoming 2005) The Influence of religion on organ donation and transplantation among the Black Caribbean and Black African population - A pilot study In the UK. *Transplant International*.
5. Davis C. & **Randhawa G.** (2004) "Don't know enough about it!" - Awareness and attitudes towards organ donation and transplantation among the black Caribbean and black African population in Lambeth, Southwark, and Lewisham, UK. *Transplantation*; **78**, 420-425.
6. Khan Z. & **Randhawa G.** (1999) Informing the UK's South Asian communities on organ donation and transplantation. *EDTNA, Journal of the European Dialysis and Transplant Nurses Association*. **25**, 12-14.
7. **Randhawa G.** (1999) The Gift of Body Organs. In: Ellis K & Dean H (Eds), *Social Policy and the Body: Transitions in corporeal discourse*. Macmillan.
8. **Randhawa G.** (1999) Identifying religious beliefs towards organ donation among the UK's Asian population. *Trends and Topics in Transplantation*. **10**,

17-19.

9. **Randhawa G.** (1998) Alternatives to xenotransplantation: A UK perspective. *Journal of Applied Animal Welfare Science.* 1 (4), 369-71.
10. **Randhawa G.** (1998) Targeting the UK's young potential donors: Placing organ donation on the school agenda, *TransplantationsMedizin.* 10, 38-40.
11. **Randhawa G. & Darr A.** (2001) Conducting focus groups for health research among Asian communities: Insights and experiences. *Ethnicity and Disease.* 11, 438-445.
12. **Randhawa G, Darr A.** (1997) The introduction of the NHS Organ Donor Register and its impact in the UK. *TransplantationsMedizin.* 9, 10-16.