

Increasing organ donation in the North West South Asian community through targeted education

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Abbreviations

BAME	Black Asian and Minority Ethnic
BMA	British Medical Association
CKD	Chronic Kidney Disease
DBD	Donor after Brain Death
DCD	Donor after Cardiac Death
ECD	Extended Criteria Donor
ESRD	End Stage Renal Disease
ESRF	End Stage Renal Failure
GFR	Glomerular Filtration Rate
HD	Haemodialysis
HLA	Human Lucas Antigen
HTA	Human Tissue Act
IDB	International Data Base
LURD	Living Unrelated Renal Donation
NHBD	Non-heart beating donor
NHSBT	National Health Service Blood and Transplant
NICE	National Institute for Clinical Excellence
NKF	National Kidney Federation
NSF	National Service Framework
ODR	Organ Donor Register
ODT	Organ Donation and Transplantation
ODTF	Organ Donation Task Force
ODTR	Organ Donation Teaching Resource
ONS	Office for National Statistics
PCT	Primary Care Trust
PD	Peritoneal Dialysis
PMP	Per Million Population
RA	Renal Association
RRT	Renal Replacement Therapy
SNOD	Specialist Nurses for Organ Donation
TDC	Transplant Donor Coordinator
THO	Transplantation of Human Organ
TOT 2020	Taking Organ Transplant to 2020
TPM	Transplant Procurements Manager
TRC	Transplant Recipient Coordinator
UKT	United Kingdom Transplant

Glossary of Terms

Actual Organ Donor	Deceased or living person from whom at least one solid organ or part of it has been recovered for the purpose of transplantation
Anti-rejection drugs	Medicines to suppress the response of a transplant recipients immune system, which recognises the transplanted organ as a foreign tissue and attempts to reject it
Arterio Venous fistula (AVF)	Created by joining a vein to an artery, usually in the forearm, to increase blood flow directly into a vein, causing vein enlargement to allow a needle can be inserted to access the blood stream
Brain Death	Irreversible cessation of cerebral and brain stem function; characterized by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses. A brain dead person is dead, although his or her cardiopulmonary functioning may be artificially maintained for some time
Cardiac Death	Death resulting from the irreversible cessation of circulatory and respiratory function; an individual who is declared dead by circulatory and respiratory criteria may donate tissues and organs for transplantation
Cardiovascular disease	Disease relating to the heart and blood vessels
Catheter	A hollow tube used to transport fluids into and out of the body (such as in peritoneal dialysis)
Chronic Kidney Disease	An abnormality of the structure and function of both kidneys, lasting more than three months often progressive
Co-morbidity	The coexistence of more than one illness or disease, such as chronic kidney disease and diabetes
Compatibility testing	Testing for the presence or absence of recipient antibodies to HLA antigens and to blood group antigens present on the transplant cells, tissues or organs
Deceased Donor	A human being declared, by established medical criteria, to be dead and from whom cells, tissues or organs were recovered for the purpose of transplantation. The possible medical criteria are: <ul style="list-style-type: none"> • Deceased Heart Beating Donor (Donor after Brain Death): a

	<p>donor who was declared dead and diagnosed by means of neurological criteria.</p> <ul style="list-style-type: none"> Deceased Non-Heart Beating Donor (Donor after Cardiac Death) or Non-heart beating donor (NHBD): a donor who was declared dead and diagnosed by means of cardio-pulmonary criteria
Diabetes	A group of disorders in which normal insulin mechanism fails so that glucose in food cannot be metabolised, and builds up in the blood. Over time raised blood glucose causes damage to blood vessels, causing cardiovascular disease and loss of kidney function
Dialysis	A blood purifying treatment in which waste products and excess water are filtered out of a patient's blood artificially. It is used when the patient's kidneys no longer function sufficiently to maintain life (see haemodialysis and peritoneal dialysis)
Donor	A human being, living or deceased, who is a source of cells, tissues or organs for the purpose of transplantation
Established Renal Failure	Also called End Stage Renal Failure (ESRF) and End Stage Renal Disease (ESRD) and is chronic kidney disease (CKD) which has progressed so far that the patient's kidneys no longer function sufficiently to maintain life
Glomerular Filtration Rate	The rate at which the glomeruli in the kidneys excrete waste products and excess fluid. It reflects the percentage of normal filtration functioning remaining. Formulae for calculating estimated <i>eGFR</i> take into account factors such as the patients age, body mass, ethnic origin
Haemodialysis	A blood purifying treatment in which the patient's blood is circulated through a machine drawing out waste products by diffusion and excess water through a filter. Normally performed for four hours, three times a week, usually at a hospital or satellite unit
Hypertension	Persistently high blood pressure
Incidence	The number of people in a population who develop a given condition
Kidney Transplantation	A donated kidney is inserted into the recipient's lower abdomen, and the blood vessels and ureter connected to the recipient's blood vessels and bladder. Anti-rejection medicines prevent organ rejection
Living Donor	A living human being from whom cells, tissues or organs have been removed for the purpose of transplantation

Morbidity	The state of being ill or diseased
Organ	Differentiated and vital part of the human body, formed by different tissues, that maintains its structure, vascularisation and capacity to develop physiological functions with an important level of autonomy
Peritoneal Dialysis	A form of dialysis in which the dialysis fluid is introduced into the peritoneal cavity in the patients abdomen, waste products and excess water drawn out of the blood using the peritoneal membrane as a filter. Fluid exchanged four/five times a day, or a machine used to carry out several fluid exchanges, usually overnight
Potential Deceased Donor	Deceased person without absolute medical contraindications with brain death or cardiac death diagnosis initiated or completed
Presumed consent	Legally valid presumption of permission for removal of cells, tissues and organs for transplantation, in the absence of individual pre-stated refusal of permission. Otherwise known as “opting out”.
Prevalence	The number of people in a population who have a given condition, for treatment the number of new and existing cases
Procurement	The process that includes donor identification, evaluation, obtaining consent, donor maintenance retrieval of cells, tissues or organs
Recipient	The human being into whom allergenic human cells, tissues or organs are transplanted
Renal Replacement Therapy	Treatment to augment or replace the function of failing kidneys, by dialysis or transplantation
Trafficking (Cells, tissues or organs)	The recruitment, transport, transfer, harbouring or receipt of living or deceased persons or their cells, tissues or organs, by means of the threat or use of force or other forms of coercion.
Transplant Tourism	Travel for transplantation when it involves organ trafficking and/or transplant commercialism
Transplantation	The transfer (engraftment) of human cells, tissues or organs from a donor to a recipient with the aim of restoring function(s) in the body
Waiting List	The list of candidates registered to receive a human cell, tissue and organ transplant

(Adapted from DH 2004a and WHO-Global Glossary of Terms and Definitions on Donation and Transplantation, 2009)

Abstract

Organ donation continues to be low among ethnic minorities especially within the South Asian community, with a disproportionate number of South Asian people waiting for transplants because suitable matches are often found between people of same ethnic group. This thesis seeks to explore, identify and overcome the barriers to increase the number of South Asian organ donor registrants (ODR's) and actual donors in the North West of England using and measuring the impact of different education approaches.

A two phased, sequential explanatory mixed-methods approach was underpinned by health belief model theory. *Phase 1:* Questionnaire survey (n=907) and in-depth interviews (n=10) to understand South Asian beliefs, barriers and awareness of organ donation. Chi-squared tests and thematic analysis explored the existence of associations between outcomes, demographics and attitudes. *Phase 2:* Implementation of education approaches: (1) Education and training of Specialist Nurse for Organ Donation (SNOD) to develop skills/confidence to approach South Asian families for cadaver organ donation, measured by 12-month before/after audit of cadaver organs. (2) Education from the General Practitioner's (GP's). (3) Peer education at South Asian community events, impact measured by number of new organ ODR's. Out of 907 South Asian people sampled, 55% did not know about organ donation, they lacked knowledge, mistrusted health professionals, and were misinformed regarding religious objections, despite 88% having higher education. Over 24 months, 2874 South Asian new ODR's were successfully recruited through peer education at 289 community events by a passionate, committed South Asian health professional. Recruitment of ODR within primary care was poor, GPs reluctant and lacking confidence to discuss organ donation, due to lack of time and uncertainty of religious issues. Targeted SNOD's cultural education increased slightly the number of cadaver donors, as their confidence in approaching South Asian families increased. Formal training of SNODs and health professionals (GPs) with respect to culture and religious organ donation was scant and required a national cohesive approach. The research provides a deeper understanding of the reasons for the scarcity of South Asian organ donors gathered from what is currently the largest UK data set of South Asian perspectives. Peer education of the South Asian and collaboration with religious leaders is crucial to overcoming the shortage of organ donors in the future. However, the important and pivotal role played by a South Asian co-ordinator/networker to engage and sustain relationships with key ethnic community leaders cannot be overstated.

1

THE TOPIC AND THE THESIS

1.1 Introduction

The promise of human organ transplant was empirically evidenced when Dr Joseph Murray's first kidney transplant recipient lived for eight years. However, the promise, that donor organs can greatly extend life is not without challenge predominantly because of the critical shortage of those life extending donor organs.

One of the great technological advances in medicine was the discovery that lives could be saved by using the blood or organs of one person to replace that of another. From this perspective, organ transplantation is literally a lifesaving hope for many people; indeed an established therapeutic option for most types of end-stage organ failure (Filho et al. 1995), but unfortunately due to the scarcity of organ donors, many of these patients are dying waiting for an organ to be allocated. However, there is an inequality inherent in our health service. For example, in 2011 and 2012 the number of patients who died whilst on the United Kingdom (UK) transplant list was 508 and a further 819 were removed as their health deteriorated and they often died shortly afterwards (National Health Service Blood and Transplant (NHSBT) report 2012).

Globally, over one million people have received organ transplants, having become routine practice and part of the health care system of virtually all countries in the world. Around 100,000 solid organ transplantations are performed per year worldwide: 68,250 kidneys, 19,850 livers, 5,179 hearts, 3,245 lungs, and 2,797 pancreases (Matesanz et al. 2009: p. 2297), with the kidney being the most frequently transplanted organ. Despite this, the demand for donated kidneys is higher than any other organ and transplantations are limited by the shortage of donated organs (Alashek et al. 2009). This is particularly true of Asian patients due to the shortage of ethnic minority donated organs to match demand (Randhawa et al. 2009).

The phenomenon of globalization dominated the end of the 20th century and the start of the 21st century, with the economies and social structures of many diverse geographical and cultural entities becoming inseparably linked (Hudson and Johnson 2004). Modern medicine faces interesting challenges as individuals from different hereditary pools, having

different susceptibilities to diseases, and probabilities of belonging to specific blood and tissue type groups migrate to different countries (Hudson and Johnson 2004). Migration causes pressure on the health system worldwide, and every health organization is trying hard to ensure equity and justice in the delivery of services to all members of society irrespective of their religion, culture, ethnic, or geographic origins (Whitehead 2000).

This thesis presents focused research on the topic of organ donation within the South Asian community, to develop increased understanding of the community perceptions and barriers to organ donation and identify and test ways to increase the number of organ donor registrants and deceased organ donors. The issues of organ transplantation and organ donation specific to this ethnic group are explored; perceived health beliefs and religious barriers to organ donation challenged; and the education approaches, identified by the ethnic minority group, are piloted to examine the impact on regional organ donor rates. The study generates new knowledge with respect to ethnic minority donation, from the largest data set of South Asian community perceptions and opinions captured to date in the UK, and offers solutions within the current UK model of organ donation that will increase organ donation. The thesis examines other models of organ donation to generate greater understanding of the best approach to inform and influence future organ donation policy.

1.2 Background of the Study

1.2.1 South Asians more at risk of CKD

Studies from the 1980's indicate that the South Asian community living in the UK has a diverse and distinctive culture and has a pattern of mortality and morbidity that is different from that of the white communities they live with (Marmot et al.1984; Balarajan and Bulusu 1984). In addition to lifestyle factors associated with cultural practices such as diet, racial disadvantage resulting in high levels of unemployment, poor housing and low education achievement may also contribute to differential rates of ill health (Daniel 1968; Smith 1977; Brown 1984; Nazroo 1987). All these factors contribute to the increased demand for more organ donors from the South Asian community as the number of patients with organ failure from South Asian community is rising. Minority ethnic communities are at greater risk of developing organ failure for a number of reasons; ranging from genetic predisposition, increased prevalence of underlying conditions, and poorer access to and uptake of services (Randhawa 2011).

The South Asian (Indian, Pakistani, and Bangladeshi) community is the largest ethnic minority group in several urban locations in the UK (Mather and Keen 1985; Khunti et al. 2009). The prevalence of type 2 diabetes, a major cause of renal failure is up to six times greater among South Asians than in the White population (Forouhi et al. 2006). Around 20-25% of Indo-Asian adults in the UK (over the age of 50 years) have type 2 diabetes and diabetes tends to develop 10 years earlier in this ethnic group than it does in Europeans (Wijenaik 2007). It is estimated that 20% of South Asians aged 40–49 have type 2 diabetes and by the age of 65 the proportion rises to one-third (Forouhi et al. 2006). South Asians with diabetes are four times greater relative risk of chronic kidney disease (CKD) caused by diabetic nephropathy and it is the single most important cause of CKD than their white counterparts (Burden et al.1992; Roderick et al. 1996; Raleigh 1997; Whaley-Connell et al. 2012). It has long been known that South Asians with diabetes are 13 times more at risk of developing CKD compared to White Caucasians (Burden et al. 1992).

A study by Trehan et al. (2001) over a decade ago highlighted a higher incidence of CKD in British Indo-Asians than in the White population. Indeed a greater proportion of Indo-Asian patients come to the attention of renal services with advanced renal disease, when Renal Replacement Therapy (RRT) is almost inevitable (Feest 1990). This means the opportunity to halt or slow the progression and avoiding RRT, has been lost which leads to higher mortality and morbidity (Trehan et al. 2001).The median age of patients starting RRT in general is 64.9 years, but the median age of non-White patients is considerably lower at 58.4 years (UK Renal Registry Report 2011), indicating health problems affect people earlier within ethnic minority populations compared to the White population. The implications of higher rates of CKD patients caused by increased rates of diabetes and hypertension amongst British South Asian groups creates a higher need for transplant organs (Randhawa 1998a).

1.2.2 The waiting game

One in eight people who died waiting for a transplant in 2006 were of African-Caribbean or South Asian origin (Farrell et al. 2011). Longer waiting times of between 2-8 years on dialysis have been noted in Asian transplant candidates, and as a result of this long waiting period these patients are more likely to die waiting for a renal transplant (Davis and Randhawa 2004) (Table 1).

The UK Organ Donation and Transplantation (ODT) Activity Report published by NHSBT (2013) reveals that three out of ten (30%) patients on the UK active kidney transplant waiting list at the end of March 2013 were from Black, Asian and Minority Ethnic (BAME) communities.

Table 1 Median waiting time to kidney transplant in the UK

Ethnicity	Registered Patients	Median Waiting Time
White	6904	1092 days
Asian	1276	1413 days

(Patients registered 1/4/06 – 31/3/10) (UKODT Activity Report 2013:p29)

Although only 23% of patients who received a kidney transplant during this period were from these communities. Although South Asian patients gained access to the transplant waiting list at a similar rate to the non South Asian white majority, due to the difficulties with Human Leukocyte Antigen (HLA) matching they were unable to find appropriate donors (Jeffrey et al. 2002). It is clear that the health service system is unable to help South Asian individuals with organ failure to provide the equal transplant opportunity if their community members decline to be organ donors. The lower kidney organ donation rates among ethnic minorities, especially within the South Asian community, results in a disproportionate number of Asian patients waiting longer for transplants (Randhawa et al. 2009).

1.2.3 Tissue typing and blood group compatibility

A further reason for the discrepancy in need and availability of organs is that organs are matched by blood group and tissue type increasing the chance of a successful outcome, (Roderick et al. 1996; Morgan et al. 2006; Bolton and Bradley 2011). This match rests on a person's genetic make-up so; the chances are that a donor is more likely to match a recipient if they are from a similar racial or ethnic background (Roderick et al. 1996; Morgan et al. 2006). Thus the shortage of deceased organ donation among the South Asian group not only adds to the problem of organ shortages, but leads to longer waiting times for a South Asian patients on the transplant list and misleading statements of inequality in organ allocation.

Tissue matching/typing is the process by which likely compatibility between an organ donor and the potential recipient can be predicted on the basis of typing tissues from each individual (Bolton and Bradley 2011). Tissue typing test is also known as Human Leukocyte Antigen (HLA) typing, which identifies antigens on the white blood cells (WBCs) that determine tissue compatibility for organ transplantation. HLA matching is a well described factor that contributes to racial and ethnic disparities in kidney transplantation and the distribution of HLA differs among races (Wolfe and Toomey 2004). There are six loci on chromosome 6, where the genes that produce HLA are inherited (Beutler 2001), which play a vital role in organ transplantation (Cunliffe and Trowsdale 1987), as it contains the major histocompatibility complex and over 100 genes related to the immune response.

The distribution of HLA differs amongst different ethnic groups, and given that most organs are retrieved from the majority white population, the closer a HLA match is sought through organ allocation protocols, the less likely the kidney will be allocated to a person from an ethnic minority (Churak 2005). Due to this HLA factor, Asian patients are significantly disadvantaged in receiving a transplant once listed as it is important for a good tissue match between suitable donors and recipients, in order to ensure good transplant graft function (Locke et al. 2007) and successful prolonged outcome.

The organ availability for South Asian patients is further complicated with blood group, the fact that blood type B is most common in South Asians (Table 2). Therefore the more common blood type O which predominates in Caucasians makes it more difficult to make effective matches between Caucasian donors and Asian recipients (Alden and Cheung 2000; Rudge et al. 2004).

Table 2 Deceased kidney donors, recipients and waiting list - blood group report

Blood Group	Donors (%)	Transplant recipients (%)	Active Transplant List Patients (%)
O Universal Donor	510 (44%)	812 (42%) A, B, AB, O	3314 (52%)
A	467 (41%)	771 (40%) A, AB	1916 (30%)
B	125 (11%)	248 (13%) B, AB	972 (15%)
AB	46 (4%)	99 (5%) AB Universal Recipient	146 (2%)

(1/4/2012 – 31/3/2013) (UK ODT Activity Report, NHSBT-2013: p39)

With the differences in tissue type alongside predominant blood type B being common in Asians, the task of establishing effective matches between donors and Asian recipients becomes more difficult (Alden and Cheung 2000), resulting in few donated kidneys being suitable for transplantation to Asian recipients (Rudge et al. 2004). Indeed over the last 3 years (2010-2013) there has been a severe disparity between the Asian organ donors and the increased number of recipients and Asian patients registered on the transplant waiting list (NHSBT 2013) (Table-3). The best match will be available if the donor and recipient from same ethnicity, so this disparity in Asian donor and recipient data explain the importance of concentrating on increasing organ donors from Asian community.

Table 3 Demographic characteristics: donors, recipients and waiting list patients

Ethnic Group	Donors			Active Transplant List Patients			Transplant Recipients		
	2010-11	2011-12	2012-13	2010-11	2011-12	2012-13	2010-11	2011-12	2012-13
Asian	12	15	19	1099	1114	1074	230	215	260
White	917	988	1097	4954	4673	4386	1305	1425	1473

(1 April 2010 - 31 March 2013) (NHSBT statistics department, August, 2013)

Scarcity of Asian organ donors in the UK has been recognised by the NHS since the late 19th century (Trivedi 1990; Randhawa 1995; Roderick et al. 1996). Indeed the first national campaign by the Department of Health (DoH) was launched in 1999 to raise awareness of the importance of organ donation within the South Asian community. Unfortunately, 15 years following the initial launch, there is still a severe scarcity of South Asian organ donors on the organ donor register (ODR). According to ODT Activity Report (NHSBT 2013) during 2012/13 there were total 1,212 deceased donors in the UK, of those only 21 were Asians. It is not surprising that delays are experienced in finding a suitably matched organ for people from BAME communities, with only a small percentage of deceased donors from BAME communities.

1.3 Current and Increasing Demand for South Asian Organs and Organ Donors

Transplantation faces new challenges despite its progress, such as record numbers of patients' on the waiting list, scarcity of donor organs, and inequity in access to transplantation and organ commercialisation (Oniscu et al. 2003). Unfortunately, continuous growth in the number of patients with kidney failure has not been matched by an increase in the availability of kidneys for transplantation (Symvoulakis et al. 2010). The inadequate supply of donor organs results in many patients, who could receive a renal transplant, being forced to remain unhappily on some form of expensive, regular dialysis and often die waiting for a kidney transplant.

Indeed some people with rare tissue types may only be able to accept an organ from someone of the same ethnic origin, so it is important that people from all ethnic backgrounds donate organs (Organ Donation Teaching Resource Pack (ODTRP) 2010). A further complication is that the ethnic matching of donors and recipients tends to improve success rates (Devlin 1993) which means that suitable donors can be even harder to locate. This has generated a growing debate amongst healthcare professionals, social scientists, voluntary organisations and the minority ethnic press in the UK about the possible reasons for the shortage of donors from minority ethnic groups and the most effective strategy to raise the profile of donation in these communities. The situation amongst donors from minority ethnic communities is particularly acute, with demand far outstripping supply for some groups, especially those originating in the Indian subcontinent, and some regions of the UK having disproportionate numbers on waiting lists (Roderick et al. 1994; Randhawa 1998).

At the end of March 2013, there were total 10,332 patients on the organ waiting list, within which 7,332 patients were in the active category with a further 3,030 temporarily suspended due to personal reasons and deterioration in their general health (NHSBT 2013). A total of 4212 transplants were performed during 2012-13, which was 6% increase in the number of transplants compared to 2011/12, however despite the increases in the number of people benefiting from transplantation, about three people die each day across the UK due to a shortage of organs and we lost 263 kidney failed patients lives during 2013/2014 on the kidney transplant waiting list waiting for kidney (NHSBT 2014). Also it reports that a general rise in organ donation during 2012/2013 and NHS achieved a 50% increase in the number of deceased organ donors compared with 2007/2008. There were 8-10% (Table4) South Asian transplant recipients in total during 2006-2011, although they represent only 5.2% of the total UK population (ONS 2011). Unfortunately Asian donation remains low at only 2% while individuals of South Asian heritage living in the UK are three to four times as likely to need a kidney transplant compared to the White population (Roderick et al. 1996). More worryingly it is reported that, the number of patients on the waiting list will be rising by 8% each year (NHSBT 2008).

Table 4 Ethnicity of patients who received a transplant (2006–2011)

Year	White %	South Asian %	African Caribbean %	Other %	Unknown %
2006	75.5	8.2	6.4	2.0	7.9
2007	75.6	7.9	5.9	2.0	8.7
2008	72.7	8.6	6.2	1.8	10.8
2009	71.4	10.1	6.7	2.3	9.5
2010	72.3	10.0	6.1	2.4	9.2
2011	72.6	9.3	6.6	2.1	9.5

(UK Renal Registry report 2011:p71)

1.4 Scarcity of Asian Donors - International, UK and Manchester

Discrepancy between the need of transplant and the availability of the donor organ is a challenge faced by local, national and international health providers. Probably more than in any other field of medicine, cultural influences are very prominent in transplantation due to the complexity of the process and the ethical issues surrounding every step from

donation, access to transplantation and to outcome (Oniscu and Forsythe 2009). The Global Knowledge Report (2009), based on data from the Transplantation WHO report, states that 100,800 solid organ transplants are performed every year worldwide, and this only covers 10% of the global need.

Data from the UK demonstrated a reduced access to transplantation for patients from Asian and Black minorities (Rudge et al. 2007). Similar results have been noted amongst the African American, Hispanic, Asian, and Pacific Islander communities in the US (Hall et al. 2005); among the Aboriginal people in Australia (Tonelli et al. 2004); the Asian and Eastern Asian communities in Canada (Tonelli et al. 2007); the non-Caucasian communities in New Zealand (Faire and Dittmer 2008); and the ethnic minorities in France or the patients living in the French overseas territories (Cantrelle et al. 2008).

Ansari (2007) indicated that, in South-East Asia and Pakistan, almost all organ donations come from living donors. In Canada, lower donation rates have been reported amongst immigrant ethnic minorities who tend to uphold their traditional spiritual and cultural beliefs and may be less knowledgeable about donation (Bowman et al. 2004; Molzahn et al. 2005). These differences are also reflected in the multicultural environment of the UK and US societies, with lower donation rates among the native Asian, Black and Chinese minorities in the UK (Boulware et al. 2002; Fahrenwald 2005; Morgan et al. 2006). Japan has the highest prevalence of dialysis patients in the world, however less than 5%, of the quarter of a million on maintenance dialysis, have chosen to be registered with Japan's Kidney Transplant Network (Lim and Lim 2004). This situation is paralleled in the US, with a shortage of donors from minority ethnic communities (Yuen et al. 1998; Lam and McCullough 2000). This chronic shortage of human organs for transplantation is one of the most pressing health policy issues in many developed countries, including the United States and UK (Abadie 2006).

The kidney is the most transplanted organ worldwide and currently there are 15.7% of Asians in the UK, waiting for kidney transplant while representing only 5.2% of the total population (Table 5). It is clear that multicultural societies are confronted with a similar dilemma of increased need but reduced access to transplantation for some ethnic minority groups, indeed due to a shortfall of donated organs, the number of patients who need an organ far exceeds the number of patients who receive an organ (Abouna 2008).

Table 5 Ethnicity of transplant waiting list patients (UK)

Transplant listed	Ethnicity						
	White	Asian	Black	Chinese	Other	Unknown	<i>Total</i>
Kidney	5972	1519	844	124	153	145	8757
Pancreas	92	5	1	0	2	1	101
Pancreas islets	52	0	0	0	0	1	52
Kidney & pancreas	280	14	12	1	7	4	318
<i>Total</i>	6396	1538	857	125	162	151	9229

(NHSBT statistics obtained on 15/10/2013 from statisticians)

Local data, however, from Manchester (North West, UK), the researcher's own centre, suggested a larger representation of Asians on the waiting list (24/07/13), 19.2% of those people waiting for a kidney transplant were of Asian ethnicity. Moreover between 2005 and 2010, 15.1% of people who received a kidney transplant on the waiting list were from an Asian background, but there were only 1.7% of Asian donors (Bowman et al. 2011) (Table 6).

Table 6 Ethnicity of transplant waiting list patients (Manchester)

Transplant listed	Ethnicity						
	White	Asian	Black	Chinese	Other	Unknown	<i>Total</i>
Kidney	614	167	44	7	8	28	868
Pancreas	10	0	0	0	0	0	10
Pancreas islets	14	0	0	0	0	0	14
Kidney & pancreas	71	2	1	1	0	0	75
<i>Total</i>	709	169	45	8	8	28	967

(Manchester Transplant Centre, Data Manager 24/07/2013)

1.5 Personal and Professional Passion for the Research Topic

Having started my nursing career as dialysis nurse at Manipal Hospital (one of the leading dialysis and transplant centres) Bangalore, India in 1999, my initial understanding of transplantation was very different. At that time the only available transplant opportunity

was a living donation from a relative, so I knew little about deceased transplantation until I came to work in the UK. I joined the renal unit at Manchester Royal Infirmary (one of the leading hospitals in the UK) in 2001, to start my nursing career in the UK. From the outset I felt the patients had more opportunities and their lifestyle was different compared to dialysis patients in India, not least because they did not have the financial burden of paying for their treatment.

In 2007, I joined the transplant team, as sister on the ward and witnessed the deceased organ donation and transplantation, an eye-opening experience. I was really keen to learn more about the process, so read and listened to patient stories, realising with increasing importance the need to register as an organ donor. I commenced my current role as a Transplant Recipient Coordinator (TRC), in 2010. I am responsible for assessing patient's suitability to go on the transplant waiting list, annual patient review, organising transplant operations, and follow-up consultations for donated patients, acting as a contact point for people on the list.

It was from this role that my passion to address and increase the number of South Asian organ donors grew. Reinforced by the fact that I had been verbally challenged on numerous occasions by South Asian kidney patients who felt the allocation of organs to be inequitable, openly asking why they weren't receiving a transplant as quickly as their white counterparts. Though UK organ allocation is fair and the ethnicity of donors and recipients are of no direct significance in established forms of solid organ transplantation (Davies 2006b), there were deep and worrisome feelings within the South Asian public that organ allocation was not equitable and somehow influenced by ethnicity.

Through a small pilot study, I identified barriers within a small group of South Asian people that suggested as lack of awareness, lack of understanding, and religious uncertainty about whether or not organs should be donated (Pradeep 2010), despite the Muslim Council's Fatwa permitting organ donation and transplantation (Carlisle 1995). I found that culturally directed health education (provided by a South Asian educator) increased the number of registered donors over a short time period (Pradeep 2010). Peer-education within ethnic minority groups has been shown to be effective, particularly concerning disease prevention (Jain et al. 2008), but there is limited evidence reported as to how this has been implemented and sustained within South Asian communities. Within

my study South Asian people suggested introducing strategies like recruitment to the organ donor register by their GP (whom they trust), and actively approaching families when in intensive care to donate their relatives organs. As a transplant co-ordinator I have a biased view, I believe in organ donation and that organ transplantation is an area that has seen amazing medical achievements but has not yet reached its full life-saving and life-transforming potential. It is difficult, when we know that lives are being lost unnecessarily because of lack of awareness among the general public and people who are willing to donate organs after their death simply never getting around to making their views known, or relatives refusing consent to donate. There is limited understanding about the reasons why South Asian individuals do not come forward and register as organ donors (Morgan et al. 2006). The Manchester Hospital is one of the biggest in the UK which serves a very diverse community, with 19.2% Asian representation on our transplant waiting list higher than the national data of 17.5%. This being the case I felt I needed to do something to help. A critical ingredient in developing a good research question is personal interest and begins with a topic which the researcher has a passionate interest in or curiosity (Polit and Beck 2004), I have such a passion. I believe that educating the South Asian community, embedding knowledge into the South Asian culture through increased engagement of religious, business leaders and celebrities (advocated by my pilot study findings) will begin to increase the number of South Asian organ donors registered. From this evidence base a larger targeted educational approach study was conceived to form this PhD Thesis.

1.6 Increasing Organ Donation a National Priority

Since commencing the study the NHSBT released an organ transplantation strategy ‘Taking Organ Transplantation to 2020 – (TOT-2020) a UK Strategy’ (NHSBT, 2013).

The aim of the strategic plan is to:

- Improve consent/authorisation rates to organ donation to above 80% (currently 57%)
- Bring the UK deceased donor rate up to 26 per million population (pmp), currently at 19pmp
- Transplant 5% more of the organs offered from consented, actual donors, currently 92% of actual donors result in at least one organ transplant
- Increase the number of patients receiving a transplant to 74 pmp, currently 49 pmp

In order to achieve these aims by 2020 it is important to tackle the issues such as the scarcity of BAME organ donors and consent refusal from the family. Also in 2013 NHSBT published a Faith Action Plan to work with faith leaders to improve consent rates and increase the number of BAME patients receiving a life-saving transplant. If these strategy could be realised the lives of approximately 1,500 more could be saved by deceased donor transplants per year. This thesis gathers together one of the largest data sets in the UK of South Asian community opinions and perceptions towards organ donation. It highlights the barriers and provides current evidence of issues that continue to prevent BAME people registering as organ donors. More importantly it generates evidence as to the impact of different educational approaches to increase and improve organ donation, which directly informs future sustained implementation of national strategy.

1.7 Structure of the Thesis

The thesis is formed into ten chapters. The first five chapters present an overview of the background, current evidence, practice and policy for organ donor registration, organ retrieval and transplantation, both internationally and within the UK. This begins with Chapter Two which focuses on transplantation as the gold standard treatment for CKD patients and the ethical issues associated with organ donation. Chapter Three draws the reader's attention to the South Asian community, and the people from different countries represented within this group such as; India, Pakistan and Bangladesh. UK Government transplant policies are reviewed alongside different models/approaches of organ donation implemented within different countries. Ways in which the supply of organs could be increased to meet demand, both now and in the future, are discussed generating a rationale for the proposed research.

Chapter Four shifts the focus to identifying through an in-depth review of current research the barriers and reasons behind the scarcity of organ donation from migrant South Asians in Western countries. Chapter Five discusses further the religious aspects that could influence the donation of organs within this multi-faith community, and explores the theory of health beliefs. Finally, Chapter Six outlines the study aims and objectives the chosen methodology, research plan and methods of data collection and analysis.

The second part of the thesis presents the findings of the study. Chapter Seven presents the integrated mixed methods (survey and interview) findings from Phase One that exposed

the current barriers of South Asian people and their perceptions of organ donation. More importantly the findings highlight the difference of opinions across different religious and ethnic groups. To inform national strategies for the future the community's perceptions of living related donation and the policy of 'opt out' are highlighted. Chapter Eight draws together the impact evidence for the educational approaches implemented within the study. The impact is directly measured by the number of organ donors recruited and audit of deceased organ donation throughout the study period. Evidence is also presented from field notes, researcher reflection and community expert opinion to provide a deeper understanding of how to build and sustain successful networks and relationships within this community, in particular the role of the network co-ordinator.

Chapter Nine synthesises and discusses the study findings alongside existing evidence, identifying and discussing the contribution of the new knowledge and impact gained from the focused research study. Educational approaches are examined, alongside the influence of religious leaders in advocating and promoting appropriate education to the community. Health professional roles as educators and promoter's of organ donation are reviewed and the implications for practice discussed, indeed the need for focused cultural training is exposed. The strengths and weaknesses of the study are acknowledged. Finally Chapter Ten draws the thesis to a close and provides recommendations for further study, and the application of the new knowledge generated from the study findings to inform national guidelines.

1.8 Summary

This introductory Chapter has presented an overview of organ donation, highlighted the national shortage of organs, the excessive waiting list for kidney transplants, and the imperative need to increase and recruit BAME, in particular South Asian organ donors. The researcher, also part of the South Asian community, and a transplant co-ordinator is passionate and committed to taking action address problem. This research will add to and extend the current evidence base to inform and take forward national strategies.

The structure of the thesis is presented and next chapter provides a more detailed background of transplantation arguing that kidney transplant is the gold standard of treatment option for the majority of CKD patients. The chapter raises and critically discusses the ethical issues surrounding organ donation and transplantation.

CKD, TRANSPLANTATION AND ETHICS

2.1 Introduction

Due to the growing need of people suffering with CKD it is important to understand the details of the disease and the available treatment options for CKD, and to clarify the need of the study to look at the scarcity of South Asian organ donors. This chapter offers background information of CKD, the different renal replacement therapy (RRT), advances in care and the demand for, and cost of, such treatment. The issues faced by the NHS due to the increasing incidence of CKD combined with a lack of renal transplants due to a shortage of donors, resulting in an increasing dialysis population, of 8% each year (NIHR 2014) are reiterated. Transplantation is presented and described as the gold standard for the treatment for the kidney failure patients. Key ethical issues and challenges faced by the transplant world with respect to organ donation, such as: family consent, diagnosis of death and allocation of deceased organs, organ trafficking, and living related donation, are discussed to better comprehend why there is a shortage of organ donors.

2.2 Chronic kidney disease and renal replacement therapies

Kidney function is essential to life so when a patient's kidney function is impaired, depending upon the severity, it is potentially life threatening (DoH 2004b). CKD is the reduced ability of the kidney to filter waste products from the blood. In addition to removing waste products, the kidney is also responsible for the control of the body's acidity, salt balance, and production of haemoglobin, regulation of blood pressure, and bone formation. Added to this list for adult patients are sexual and reproductive problems such as impotence and a reduced likelihood of conception and successful pregnancy (DoH 2004b). The physical, psychological and socio-economic problems experienced by patients with long term conditions can reduce their quality of life and sometimes lead to social isolation (DoH 2001; Griva et al. 2009). CKD is one of the most serious and growing public health problems, affecting one in 10 of the population, with increasing incidence of CKD in developed and developing countries which has led to a universal epidemic (Dos Reis Santos et al. 2013; NIHR 2014). There is no cure for CKD, but different forms of treatment can slow or halt the progression of the disease and can prevent the development of other serious conditions. The total life expectancy of an individual with CKD is only

one-fourth to one-fifth that of the general population, as they are more prone to developing cardiovascular and infectious complications (USRDS 2009).

The estimated glomerular filtration rate (eGFR) is a test used by clinicians to diagnose the severity of the kidney failure, measuring the volume of blood that is filtered by the glomeruli, the tiny filters in the kidneys, over a given period of time (National Institute for health and Clinical Excellence (NICE 2008). Patients will be diagnosed with CKD stage 1-5 (Table 7), with a patient with severely reduced kidney function diagnosed with CKD stage 5, at which point a form of RRT is essential for survival.

Table 7 Stages of CKD (NICE, 2008)

Stage	GFR*	Description	Treatment Stage
1	90+	Normal kidney function, but urine findings or structural abnormalities or genetic trait point to kidney disease	Observation, control of blood pressure.
2	60 - 89	Mildly reduced kidney function, and other findings(as for stage1) point of kidney disease	Observation, control of blood pressure and risk factors.
3A 3B	45 – 59 30 - 44	Moderately reduced kidney function	Observation, control of blood pressure and risk factors.
4	15 - 29	Severely reduced kidney function	Planning for end stage renal failure
5	<15 or on Dialysis	Very severe or end stage kidney failure	Treatment choice.

According to the UK Renal Registry Report (2013) the number of adult patients starting RRT in the UK during 2012 was 6,891 equating to an incidence rate of 108 pmp which is an increase of approximately 6% in new patients for England between 2007 and 2012. Also it is noted that UK prevalence of RRT was increased to 842 pmp, compared to 523 pmp in 2000. It was noted that prevalence rates of CKD in patients aged >85 nearly doubled between 2006 and 2011, from 524 pmp to 952 pmp (Shaw et al. 2013). The number of patients needing RRT is rapidly growing, and the ageing population living longer, but more importantly the number of ethnic minority patients on RRT in the UK has doubled in the last five years, to 20.7% (Shaw et al. 2013).

2.3 Renal Replacement Therapies

The modalities for RRT are haemodialysis (HD), peritoneal dialysis (PD), conservative management, and kidney transplant. The number of people on dialysis is increasing by 3% each year, and so in turn is the demand for transplantation (NHSBT 2013). In 2012, 53151 people were recorded receiving RRT in the UK (Table 8).

Table 8 Number of patients on different RRT (on 31/12/2012)

Modality	Number
HD	23,034
PD	3,752
Transplant	26,365
All RRT	53,151

(UK Renal Registry Report, 2013:p 49)

2.3.1 Haemodialysis (HD)

HD removes waste products from the blood by passing it out of the body, through a filtering system (dialyser) and returning it, cleaned, to the body. In the UK there were 54,824 adult patients receiving RRT at the end of 2012, in that 48% are on HD (UK Renal Registry Report 2013). HD Patients are, required to adhere to specific schedules; strict diet and fluid control, and may also have to go to a dialysis centre 3 times a week, often for 3 hours or more per visit (Morduchowicz et al. 1993; Lindberg and Wikström 2010). Complications of HD include low BP, light-headedness, shortness of breath, cramps, nausea, vomiting and a high risk of infection (Schreiber 2001; Javed et al. 2012). Since HD requires access to the circulatory system, these patients are more prone to expose their circulatory system to micro organisms, which can lead to sepsis, endocarditis (infection affecting heart valves) or osteomyelitis (an infection affecting the bones) (Weinreich et al. 2006). The adherence to long hours of dialysis has major social implications and leads to financial burden due to lost earnings and reduced income which will possibly affect the whole family and often lead to individual and family lifestyle changes (Finnegan-John and Thomas 2012).

2.3.2 Peritoneal Dialysis (PD)

In PD a soft tube, called a catheter is placed in the patient's abdomen by a minor surgery. This catheter is used to fill the abdomen with a cleansing liquid called dialysis solution. The peritoneal membrane (lining of patients belly) acts as a natural filter and it allows the wastes and extra fluid in the blood pass through into the cleansing fluid. The cleansing liquid or dextrose solution which contains sugar will help to pull the wastes and extra fluid into the abdominal cavity (Teitelbaum and Burkart 2003). At the same time, the lining of the patient's abdomen holds back the important things the body needs, like red blood cells and nutrients. PD has been used throughout the world for more than 25 years (Grassmann et al. 2006). Patients can administer this therapy at home which allows some independence (NICE 2011). Complications of PD can arise as the PD catheter is a potential site for the entry of bacteria into the body and hence peritonitis can occur which if severe can lead to technique failure (Unsal et al. 2013). Long term PD can cause the peritoneal membrane to become thickened and fibrotic over time and unable to function, which leads to encapsulating peritoneal sclerosis and carries high mortality rate of 20%-80% (Tannoury and Abboud 2012). These patients also have a high risk of hernias, changes to body image and weight gain due to glucose absorption from dialysis fluid (Wong et al. 2013).

2.3.3 Conservative Management

Conservative management is also called Supportive Care. Patients have the choice, after consultation with their kidney team, not to have dialysis as it may not improve their survival to any great extent. The aim of conservative management is to maintain a good quality of life by medically prolonging kidney function and controlling symptoms to support patients, families, and carers (Van de Luijtgarden et al. 2013).

2.3.4 Kidney Transplant

A kidney transplant is when a healthy kidney from one person is placed in the body of another person with kidney disease. Kidney transplantation has developed rapidly over the last 20 years and the improvements in surgical procedure, immunosuppressive drugs, and sophisticated post transplant care to achieve long-term success of transplanted organs have made it one of the most effective ways to treat people with CKD (Hourmat and Garandeanu 2011). This treatment is hailed as the gold standard for CKD management, as it replaces native renal function completely and avoids all the unpleasant side effects of dialysis (Joshi et al. 2012). Renal transplantation is established as the optimum treatment for

irreversible kidney failure in terms of results, rehabilitation, and costs; it avoids the increased morbidity and mortality associated with dialysis, the creation of surgical dialysis access and its complications (Halloran 2004). There is no age limit for transplantation and it can be used to treat young children and those aged over 75 years of age (Cameron and Forsythe 2001). Although kidney transplantation involves a major surgical procedure that is not without risk and requires medication for life (Akbar et al. 2005). Deceased donor kidney transplant option is ideal because it improves health status and quality of life for the recipient without interfering with the well-being of a living donor (ODTF report 2008; Symvoulakis et al. 2010). The only limitation on the number of transplants performed is the ongoing shortage of donors (Forsythe 2001; NHSBT 2012).

However, Bendorf et al. (2012) highlighted that in the UK 48% of CKD patients aged below 65 are listed on the transplant waiting list while in France 49%, US 33% and Australia 18%. Even though when comparing with other countries access to transplant in the UK appears to be satisfactory, it is clear that less than 50% of CKD patients only are fortunate to have the access to transplant waiting list in the UK. One of the reasons for this may be that pre-transplant assessment undertaken to assess suitability for transplant which can be time and health care resource consuming (Stevens et al. 2011). The issue of delay in the transplant listing process itself is a subject which requires further attention but not within the focus of this thesis.

2.4 Transplantation: The Gold Standard

Continuing improvements in surgery and anti-rejection drugs has completely developed kidney transplantation from a pioneering experiment into a now common medical procedure that enables the extension of human life through the transplantation of donated organs to others (Siminoff et al. 2001). Transplantation provides the best chance for CKD patients to resume a better quality of life, improves long term health and reduces the risk of dying from kidney disease (Hariharan et al. 2000; Butler 2004; Maglakelidze et al. 2011; Dobbels and Duerinck 2013), and is more cost-effective than standard dialysis treatment.

2.4.1 Improved Clinical Outcomes and Increased Survival Rate

Transplantation increases survival rates because it significantly reduces the risk of myocardial infarction, stroke, heart failure and the incidence of ischemic heart disease (Port et al. 1993; Schnuelle et al. 1998; Stevens et al. 2011). For many years, kidney

transplantation has been associated with substantial reductions in the risk of mortality and cardiovascular events, as well as clinically relevant improvements in quality of life (Tonelli et al. 2012). Recipients of a kidney transplant (aged 20–39 years) are projected to live almost 17 years longer than patients remaining on the waiting list (Wolfe et al. 1999). With modern techniques of organ preservation and advances in immunosuppression a significant percentage of transplant patients reach long-term survival (well over 25 years) with high quality of life(Gill and Lowes 2008; Tonelli et al. 2012) (Table 9).

Table 9 Post kidney transplant patient survival rate

Number of years post transplant	% chance of survival
At 1 year	96 %
At 5 years	88 %

(UK Renal Registry Report, 2013 pp 65)

The mean survival rate for patients on RRT is 5.6 yrs, compared with 10.3 yrs expected survival for transplanted patients but only 3.3yrs for those receiving HD, and 1.8yrs for PD patients(UK Renal Registry Report 2011). However, despite advanced technology, equipment and medicine the expected survival for dialysis patients has not improved since 2007 (Table 10).

Table 10 Survival rates on RRT 2007 and 2011

Modality	Median time treated (yrs) 2007	Median time treated (yrs)2011
HD	2.8	3.3
PD	2.0	1.8
Transplant	10.2	10.3
All RRT	5.1	5.6

(Ansell et al. 2007; UK Renal Registry Report 2011: p47)

2.4.2 Better Quality of Life

Transplant recipients have notably improved quality of life, in comparison with dialysis dependent patients ((Port et al. 1993; Dobbels and Duerinck 2013). Transplantation has a positive impact in CKD patient's lives which enable them to change their perception of quality of life (Tonelli et al. 2011; Rebollo et al. 2000; Karakan et al. 2011).The treatment of CKD often has social and financial implications for the patients and their families with an adjustment in the standard of living. Indeed the physical, psychological and socio-economic problems, experienced by patients with long-term conditions can reduce their quality of life and sometimes lead to social exclusion (DoH 2001). However transplantation results in a greater ability of patients to participate productively in the community (White et al. 2008).

2.4.3 Cost Effective Treatment

A commissioning team in the UK West Midlands identified that the transplant programme delivered a cost saving to the NHS of £316 million per annum (or about £40,000 per transplant)and that savings had the potential to increase further as the number of transplant procedures rise(West Midlands Specialised Commissioning Team 2010). Indeed kidney transplantation is by far more cost-effective long term compared to other RRT (Howard et al. 2009) (Table 11).

Table 11 Cost of RRT (NHSBT; 2009)

RRT	Cost per patient (£s)	Number of patients in UK
Hospital HD	£35,000	15,960
PD	£17,500	5,040
Transplant	£17,000 (1st year including surgery) £5,000 (subsequent years)	16,800

(http://www.organdonation.nhs.uk/newsroom/fact_sheets/cost_effectiveness_of_transplantation.asp)

The average cost to maintain one patient on dialysis is estimated as consuming 3% of the total NHS budget. The cost benefit of kidney transplantation compared to dialysis over a period of ten years (the median transplant survival time) is £241,000 or £24,100 per year

for each year that the patient has a functioning transplanted kidney. However, the increasing number of CKD patients is leading to long waiting lists, higher treatment costs, and negative patient health outcomes (Wolfe et al. 1999; Winkelmayr et al. 2002; Riaño-Galán et al. 2009), placing increased pressure on renal units, health care resources, and the stretched NHS economy.

The shortage of available organs will continue to limit the effectiveness of the gold standard treatment and potential for kidney transplantation until the challenges of increasing organ donors is overcome (Symvoulakis et al. 2010).

2.5 Ethical Issues Surrounding Organ Donation

The scarcity of deceased organ donors has raised many ethical, moral and social issues regarding supply (Abouna 2003; Steigleder 2008). Many, if not most, people agree that taking organs from any source is a justifiable practice within certain ethical boundaries, but, unfortunately, controversies result from an inability to define exactly where those boundaries lie (Childress 2001). In an attempt to eradicate poor ethical practice within different organ donation programmes worldwide, the WHO (2010) introduced a revised ‘Guiding Principles on Human Cell, Tissue and Organ Transplantation’ a framework focusing on advocating ethical living and deceased donation. The guiding principles are applicable internationally among the organ donation and transplantation world and intended to provide an orderly, ethical and acceptable framework for the acquisition and transplantation of human cells, tissues and organs for therapeutic purposes.

Even with these guidelines in place the transplant and organ donation world faces ethical challenges, the primary ethical dilemma being the shortage of organs and how best to tackle this situation (Childress 2001). Even though transplant medicine is a great success for the health of the patients with organ failure, its ethical limits are challenging compared to other medical disciplines (O'Neill 2003). The biggest challenge is that organ donation not only involves a physician and a patient but also a third party, the donor and the organ itself (Jonsen 2012). As such organ transplantation depends on a social contract along with social trust and it requires national and international law to protect both the rights of both organ donor and organ recipient (Delmonico et al. 2002). Legislation in organ donation requires adequate resources to cover many important ethical concerns, including: criteria for brainstem death, consent, donor registration, ethical regulation of institutions and

health professionals, and prevention of commercial transplantation (Gabr 1998). As such it is essential for health professionals involved in organ donation and transplantation to understand the legal guideline and ethical issues for clinical application to their day to day practice (Rahman et al. 2009).

The key ethical issues that have been most debated, such as organ trafficking, altruistic organ donation, extended criteria and marginal donors, diagnosing death, living donation, family consent for donation and allocation of deceased organs will be discussed in further detail.

2.5.1 Commercial organ trafficking

The chronic shortage of deceased donor organs has led to a more general acceptance of living donor transplants (Karam et al. 2009). However, one of the serious ethical concerns around deceased and living organ donation is 'transplant tourism' and 'organ trafficking', accounting for 5-10% of all kidney transplantations world-wide (Steigleder 2008). Organs are sold for financial gain in some parts of the world, such as Pakistan through exploitation of the poor, for the benefit of the wealthy (Abouna 2003). The shortage of deceased donors has contributed to commercial organ trafficking creating more and more ethical and moral dilemmas for transplant medicine. Up to 10% of the kidney transplants that occur annually throughout the world involve donors from developing countries who are unrelated to the recipients (Garwood 2007). Within human society the essential truths of life and autonomy are values that should not have a financial benefit and these morals are compromised when a person feels compelled to risk death for the sole purpose of obtaining monetary payment for a body part (Delmonico et al. 2002). It is important therefore that each health professionals involved in organ donation and transplantation directly or indirectly to be responsible to prevent future ethical and moral problems with live donation (Trey et al. 2013).

The need to prevent the commercialisation of transplantation was identified in late 19th century, the solution suggested was to provide adequate resources to implement effective legislation (Gabr 1998). This legislation approach was implemented in all the countries including South Asian countries by late 19th and early 20th century. Since this time different organ donation and transplant Acts have been introduced to control the organ trafficking and sale of organ, for example:

- Transplantation of Human Organs Act - India 1994
- Human Organ Transplantation Act- Bangladesh 1999
- Transplantation of Human Organs and Tissues Bill – Pakistan 2007

Despite these rules in place and some only recently vulnerable populations in resource-poor and underdeveloped countries are reported to have become a major source of organs for so-called ‘transplant tourists’ who can afford to travel and purchase organs (Naqvi et al. 2007). Thousands of people from Europe, Middle East, United States, and Australia come to India, Pakistan, China, Egypt, Philippines, and other countries in search of poor donors who are willing to give one of their kidneys for financial compensation (Humayun 2007). Pakistan alone hosts up to 1500 transplant tourists every year (Garwood 2007; Heneghan 2007). In 2004, the World Health Assembly (WHA) adopted a resolution that urged member states to take precautions to protect the poorest and vulnerable groups from transplant tourism and the sale of tissues and organs (WHA 2004), but still this activity continues. This issue of organ trafficking is equally as concerning when examining organ procurement practices in China, where a national law in 1984 allowed removing organs from executed prisoners for the purpose of transplantation. Around 90% of the transplant organs from deceased donors in China are from executed prisoners (Beholz and Kipke 2007).

Making organs as a product erodes social, moral, and ethical values and cannot be considered as an alternative way forward to overcome the problem of organ shortage in a civilized society (Shroff 2009). Indeed the Caucasian donor pool will favour Caucasian recipients in the European countries due to better blood group and HLA match, which automatically places ethnic minorities living in the European countries at a disadvantage (Ahmed et al. 1999). This increases the possibility of non transplanted migrant Asians from developed countries to be drawn to organ trafficking schemes due to prolonged waiting times secondary to a lack of non-white deceased donors in their respective countries (Starzl et al. 2009). This reinforces the need to increase the ethnic minority deceased donor pool from within the communities themselves to ensure equitable access to suitable matched organs and ultimately reduce the need for an organ trafficking ethical dilemma.

2.5.2 Altruism in organ donation

Altruism in organ donation is a continuing and debatable topic. An altruistic donor is someone who donates their organ to an unrelated person either whilst they are alive or after their death. In the case of living organ donation, the recipient depends on the voluntary, altruistic donation of a suitable organ by the donor, who puts their own life at risk through their generosity. A deceased donation would be as a result in the donor having already lost their life, before actually donating. In the altruistic decision to donate one's organs is based on free, voluntary, and informed consent (Trey et al. 2013). However, the financial inducements and other incentives to donate are beginning to erode the noble concept of altruism (Woodcock and Wheeler 2010). Therefore it is important that donors are assessed as to the underpinning reasons for donation to ensure they are acting ethically. In the UK this is the role of the Independent Transplant Assessor, employed and regulated by the Human Tissue Authority. Ideally the best organ donor is a person who cannot be harmed by the donation, so the priority should be deceased donors rather than living (Woodcock and Wheeler 2010).

2.5.3 Extended Criteria and Marginal donors

Increased demand for organs from deceased donors has led to the accepting of organs from persons with clinical risk factors (such as hypertension and advanced age) known as Extended Criteria Donor (ECD) organs (Ojo 2005). The term ECD was introduced by Kauffman (1997) to describe transplantable organs that did not meet the criteria for standard donor organs. According to Gopalakrishnan and Gourabathini (2007) marginal deceased kidney donors are all donors older than 60 years and donors older than 50 years with any of the following criteria: hypertension, cerebro-vascular cause of brain death or pre-retrieval serum creatinine (SCr) level > 1.5 mg/dl, with a degree of glomerulosclerosis >15% and prolonged cold ischemia. The true clinical meaning of marginal donor's criteria and ECD is unknown because none of them have been rigorously validated and opinions differ over their individual value (Gopalakrishnan and Gourabathin 2007). A trend is also emerging in which organs from deceased donors with high behavioural or circumstantial risk factors for disease transmission are added to the supply chain (Gustin 2006). Transmission of Human Immunodeficiency Virus (HIV), which has a window period before detection and hard-to-detect viruses to recipients through such sources have been reported (Grady 2007).

Transplanted organs from ECD donors are associated with poorer clinical outcomes compared with those procured from donors who meet standard criteria (Wolfe et al. 1999; Schnitzler et al. 2003; Metzger et al. 2003; Gopalakrishnan and Gourabathin 2007). Poor long-term outcome may be the consequence of an imbalance between the number of viable nephrons supplied by the donor kidney and the metabolic demand of the recipient (Gopalakrishnan and Gourabathin 2007). Although ECD transplanted kidney recipient's survival rates are better in general compared with dialysis dependent patients (Chavalitdhamrong et al. 2008), some ECD patients have shown no improvements, especially patients with a waiting time of less than 1350 days, African Americans, or Asians (Crippin 2004).

Questions about the age limit of potential donors, is another challenge faced by the nephrologists and transplant surgeons. The increased need for organs for renal transplantation has encouraged the use of grafts from increasingly older donors. And it is suggested by the United Network for Organ Sharing (UNOS 2010), that clinicians should not consider advanced age as contraindication for organ donation, and should refer appropriate elderly patients. Study by Galeano et al. (2010) evaluating results using donors >70 years old, showed that patient survival rates (86%) at five years were similar among recipients from donors aged 50-70 and >70 years, but 10% higher (96%) for those who received an organ from a donor <50 years. The ethical issue around transplanting sub-standard, older or potentially infected organs is not going to be resolved whilst the transplant waiting list increases and a scarcity of deceased organ donors persist.

2.5.4 Diagnosis of Death/ Definition of Brain Death

In current practice, most organs for transplant are procured from individuals who are diagnosed as 'brain dead' (Testa and Klintmalm 2000). These people are not dead in the circulation and respiration sense even though their brains are dead (Evans 2000) but are individuals with irreversible loss of all brain functions; which raises the question of whether and how the well-defined condition of irreversible brain death can be equated with the death of an individual (Bosshard et al. 2008). Some opinions suggest that 'brain dead' individuals are not dead and that brain death criteria were developed to allow vital organ donation, rather than being based on a firm scientific or philosophical basis (Hill 2000; Potts and Evans 2005). Thus, the distribution of organs from brain dead donors for transplantation raises additional ethical questions and concerns; whether a brain death

qualifies as confirmation of death and verification towards end of life proclaiming no chance to return to living, for which there is no consensus and ethical debate continues.

A further ethical question that remains unanswered, is how long after the cessation of cardiac activity can death be diagnosed, known as 'cardiac death' (Woodcock and Wheeler 2010). The NHS and Medical Research Council introduced strict procedural checks to alleviate these challenges and safeguard the probity of the organ recovery process (NHMRC 2007). The Academy of Medical Royal College (AMRC), Code of Practice is designed to address the diagnosis and confirmation of death in all situations and to make practical recommendations, acceptable to the relatives of the deceased, society in general and also to the medical, nursing and other professional staff involved (AMRC 2008). All these individual's views in diagnosis and confirmation of death can be different at the point of making the decision, which makes the diagnosis of death more complicated and difficult, thus contributing to the scarcity of organ donors.

2.5.5 Living donation

The shortage of deceased donors has resulted in an increased interest in living donation with taking the risk of a living kidney donor carrying death rate of 1 in 3,000, whilst living liver donation (adult to adult) carries a risk of death to the donor of up to 1 in 100 (ODTF 2008). The critical shortage of deceased donors puts pressure on patients, clinicians and commissioners to accept such risks to the life of a fit, healthy person as in the case of living donors. Living donation remains the single source of transplantation in many parts of the world including developing and developed countries (discussed in subsequent chapters). However, several controversial areas of practice are found in the utilization of living donors, but until the deceased donor programme steadily increases to meet demand, the abuse of human rights will continue to be difficult to police and eliminate. Living donor rates vary widely internationally Netherlands, Turkey, Norway, and the USA now carry out over 20 pmp living donor kidney transplants per year; in the UK the figure is 15.9 pmp, whereas in Spain and France, the rate is less than 5 pmp (Rudge et al. 2012).

Living donation carries a number of advantages including a better match between donors and recipients and psychological benefits for both parties as most of the donors are genetically related to the recipient (Vastag 2001). Living donation transplantation is elective and can be scheduled to the time the patient needs the transplant (Rudge et al.

2012), considered a relatively small burden compared to the enormous benefit achieved by the recipients (Kuczewski 2002). Some critics argue that living donation is inappropriate under any circumstances, and puts the live donor at risk (Ratner and Sandovala 2010), advocating live donation programmes should not only be discouraged but abandoned altogether because of the risk and dangers associated with donating organs (Spital 2002). Critics from the US argue that by doing living donation and extending the recipient's life through costly and physically taxing medical procedures is not the purpose of health and healthcare (Kuczewski 2002). Medical ethics traditionally instructs clinicians not to harm people but in living donation taking organs from healthy person does cause some direct harm, and as such it is contrary act to traditional medical ethics (Wilkinson 2011). Although the 'do no harm' rule is a historical aim of the medical profession's paternalism, if people want to donate their organs and know what they are doing, health professionals should not stop them (Veatch 2000). The ethical concerns surrounding live donation will continue but this approach may provide a potential solution for people from ethnic minority communities, to donate within their own community and begin to overcome the shortage of South Asian organs.

2.5.6 Family's consent for donation

In organ donation one of the most debated ethical issues is the family's role in making the donation decision for the potential donor; those who are already on the organ donor register and those who are not. Some argue that the needs of potential recipients who suffer with organ failure and their families' struggle to cope are much greater than the needs of the deceased or their families (Kamm 1993; Harris 2002; Harris 2003). Indeed the distress of the patient's family who die waiting for an organ will override the distress that donor families would suffer (Brazier 2002). However transplant professionals have a practical reason not to override the family, as they fear bad publicity (Wilkinson 2011). Siminoff (2001) identified that some members of the general public are of the opinion that the doctor may not do as much to save their loved one's life if they knew they were willing to donate their organs. This dilemma of mistrust in the health professional causes more pressure on brain death diagnosis and consent from relatives for organ donation. During 2013-2014 sadly 119 families overruled their loved one's known wish to be an organ donor by declining their consent (NHSBT 2014).

When declaring death it is necessary to ensure the wellbeing of the family and next of kin (Rubenstein et al. 2006), to prevent grief turning into distress, and make sense and meaning of their relatives death by giving the consent for donation decision needs and ethical justification (Voo et al. 2009). How to balance the distress of consenting family with the obligation to those awaiting transplants is a dilemma. Indeed who 'owns' deceased donor organs and who makes the decision regarding allocation are both issues which need clarification (Andrews 1986; Kreis 2005; Spital and Taylor 2009). There is a general presumption that the Government holds the responsibility for allocation or disposal of donated organs, which is then delegated to the appropriate transplant team (Dosssetor 1994). If we consider the body as property in hopes of increasing organ supply, we will be devaluing the very human life and human bodies that we seek to save (Cohen 2003). Within transplantation it is essential for public are reassured, that they can trust the medical staff and respecting and seeking family consent for organ donation is a way of ensuring a positive image continues.

2.5.7 Allocation of deceased donor organs

The shortage of organs for transplantation raises the questions of equal access and maximum benefit, the concept of distributive justice, how to fairly divide resources arises when there are not enough organs available for everyone who needs one. Organ transplantation is vital and a valuable medical procedure for those who need it, as such there should be equal access to it (Benjamin 1988; Ethics of Organ Transplantation 2004). However implementing and ensuring equality in transplant opportunity is a concern internationally. To encourage equality in organ transplantation, the equal access theory encourages a distribution process for transplantable organs that is free of biases based on race, sex, income level and geographic distance from the organ (Douglas 2003).

The government is against any kind of conditions being attached to organ donation and support the view that '*donated organs are a national resource, and are available to people regardless of race, religion, age or other circumstances*' (Boseley 2000: p5). However, despite many rules being in place in allocating organs fairly according to the blood group, tissue type match, age and waiting time there are still concerns about allocation process. Whilst these rules are useful, when organs being donated are predominantly Caucasian then the allocation becomes inequitable for people from ethnic minority groups or with rare tissue typing.

A study among the general population by ethicists suggested that organ distribution preference should be influenced by the recipient's behavioural life style choices (Ubel et al. 2001). Suggesting that people, who lead poor lifestyle choices and behave irresponsibly, are responsible for their illness, so patients who have no control over their illness should be given priority during organ allocation (Neuberger 2003). In addition age and maximizing life years have been suggested as criteria for distributing organs, but by doing so the remaining life of an older person awaiting a transplant is devalued (Small 2002). Both these types of allocation would bring further ethical dilemmas as to who decides whether people have behaved irresponsibly, or are too old to enjoy life, and don't deserve an organ transplant, a very difficult decision and not one a health professional would want to be responsible for.

An alternative perspective for organ allocation is one of achieving maximum benefit. Transplants are performed in those people where maximum outcome success is predicted so as to avoid the wasting of organs because they are very small in number, although predicting success in different individuals is difficult (Neuberger 2003). The argument against maximum benefit is that distributing organs in this way could leave the door open for bias, lying, favouritism and other unfair practices due to the subjective nature of the criteria (Childress 2001). One example was found when physicians in a German transplant departments manipulated patient data to achieve a higher organ recipient priority for their patients, causing the organ donation rate to drop by 12.8% in 2012 (Trey et al. 2013). Unethical organ allocation such as this needs to be eradicated before the general public lose trust and the motivation to donate their organs.

2.6 Summary

This chapter provides an overview of different forms of RRT and makes the case that the best choice and gold standard treatment option for RRT for the majority of patients is a kidney transplant. The ethical dilemmas and challenges surrounding organ donation and transplantation have been presented, with different international organ donation and transplant programmes being examined further in the next chapter.

What is clear from this synopsis is that organ donation and transplantation is a highly complicated issue from an ethical perspective and cannot be reduced to one single ethical value. The noble desire to help patients who are in need of organ transplantation by

making more donated organs available does not justify, overlooking ethical issues associated with organ trafficking, altruism, live donation, diagnosis of death, allocation of organs, and the requirement of consent. Disregarding ethical values and beliefs can be counterproductive in the long term as potential donors and their families may lose trust in organ donation. There is clearly, work to be done to increase trust in the medical practice of transplantation and cadaver organ donation to increase donation rates.

Chapter Three examines the South Asian community, looking briefly into the culture and organ donation practises in the selected three Asian countries (India, Pakistan and Bangladesh). Alongside the UK and successful models/approaches of organ donation programmes implemented in different countries are critiqued.

SOUTH ASIAN AND INTERNATIONAL ORGAN DONATION

3.1 Introduction

Within the UK and this thesis the terminology of South Asians is used to address individuals from India, Pakistan, and Bangladesh. They are a heterogeneous group with diverse religions, languages, and cultural upbringings, along with varying diets, culture and lifestyle habits which cause some complexity in understanding their concerns about organ donation (Karim et al. 2013). To better understand this complexity and indeed the thinking of South Asian migrants to the UK it is useful to explore the culture and practices of organ donation in their native country.

This chapter considers the ethical issues highlighted in the previous chapter and examines the culture of organ donation in the three Asian countries (India, Pakistan and Bangladesh). The UK Government's transplant policies are reviewed and successful models/approaches of organ donation programmes adopted in different countries explored, to gain a wider international understanding of organ donation.

3.2 South Asian People in the UK

South Asians (people who share a common ancestry of the Asian subcontinent), represent the largest ethnic minority in the UK (Office for National Statistics (ONS) 2011). Indeed the UK hosts a multi-ethnic society of round 4.6 million ethnic migrants from various parts of the world (ONS 2011).

The term 'South Asian' is used with different interpretations but all interpretation includes citizens from India, Pakistan and Bangladesh (Pye 1985; Schott and Henley 1996; Bose and Jalal 2004; Juergensmeyer 2006; Bhopal 2007). In the early 19th century Pakistan, India and Bangladesh were one country. After the independence, India was divided into three major countries; India, Pakistan and Bangladesh, which may explain some similarities but today there are distinct differences in their culture, political system, religion, beliefs and practices. Indian, Pakistani and Bangladeshi people are the focus of this study so the use of the term South Asian is appropriate. However, the researcher acknowledges that the 'South Asian' term has been criticised for failing to capture this

diversity among the ethnic groups (Bradby 2003), and is a weak term used to represent a wider group, which contains many different cultures, religions, languages and ethnicities (Feder et al. 2002).

Some regions of the World have been ambivalent in receiving migrant populations and resistant to newcomers to the point of racism, while others have supported and welcomed diversity (Castles and Miller 2003). Negative media and political representations of asylum seekers and particular ethnic groups as deceptive queue-jumpers and amoral terrorist sympathizers (Silove 2003; Grove and Zwi 2006) has increased such distorted perceptions being inextricably linked with ethnic minority. The negative impact often results in immigrants being stereotyped as unscrupulous, fraudulent and manipulative (Silove 2003).

This ongoing construction of immigrants as different or invisible disadvantaged or irrelevant carries paramount risk of the nation to respond equitably and effectively to their health needs. Middle-class immigrants may be subjected to prejudice and racism, and require access to culturally appropriate health literacy, information and healthcare (Klinken and Noble 2000). A lack of culturally appropriate information could be a contributing factor to low donation rates from South Asian community living in the UK.

South Asian immigrants are distinctly different from the UK population in terms of language, host language proficiency, customs, physical appearance, dress, socio-economic status, religion, politics and legal status (Castles and Miller 2003). Thus, it is crucial to be aware of different communities, and their desires, needs, and goals (Mark and Kitayama 1991) this is vital in organ donation due to the sensitivity and the cultural impact of the topic. Marginalised ethnically mixed communities are often characterized by social disadvantage and high unemployment (Morgan et al. 2006). Despite strong levels of 'bonding' social capital in terms of the dense network of ties that hold families and ethnic groups together, one explanation for people's unwillingness to donate their organs is because it may involve gifting outside one's immediate community (Putnam 2000). Again misinformation can result in reduced organ donation, without fully understanding that a successful match is often found between the donor and recipient of the same ethnicity. South Asian people make up the multi-cultural UK community and it is important when campaigning and informing people from different communities to understand one

approach may not suit all, and culturally sensitive material is needed to better inform ethnic minority groups living in the UK regarding organ donation.

The lack of available South Asian organs for transplantation is not limited to the UK but is an international phenomenon. Indeed, the situation in Asia is particularly serious, with deceased donor donation rates being less than 5 donor's pmp (Sung-Gyu 2006) compare to 35.1 donor's pmp in Spain. Historically, Asians living in Asia as well as in Western countries have one of the lowest rates of organ donation in the world (Manninen and Evans 1985; Pham and Spigner 2004). Despite this fact being recognised now for nearly 30 years, little has changed to overcome or address the low organ donation rate from the South Asian community.

3.3 Overview of Organ Donation in India, Bangladesh and Pakistan

3.3.1 India – live donation

India is the second most populous country in the world, with over 1.21 billion people (Census of India 2011), more than a sixth of the world's population. Indeed already containing 17.5% of the world's population, India is projected to be the world's most populous country by 2025 (International Data Base (IDB) 2011). India has more than two thousand cultural groups, and further complexity as a result of the great variation across this population on social parameters such as income and education (Background Note 2012). Every major religion is represented in India, Hindu 80.5%, Muslim 13.4%, Christian 2.3%, Sikh 1.9%, Buddhists 0.8%, Jains 0.4%, others 0.6%, and those unspecified 0.1% (Census of India 2011). The most commonly spoken languages include Hindi, Urdu, Punjabi, Gujarati, Bengali and English, but there are over 1,652 languages and dialects spoken within India (Language in India 2011).

The term British Indian refers to citizens of the UK whose ancestral roots lie in India. This includes people born in the UK who are of Indian descent, and Indian-born people who have migrated to the UK. Indians comprise about 1.4 million people in the UK, making them the single largest visible ethnic minority population in the country (ONS 2011). British Indians have the lowest poverty rates among all ethnic groups in Britain, second only to White British (Platt 2011).

The legislation called the Transplantation of Human Organ (THO) Act was passed in India in 1994 to streamline organ donation and transplantation activities. Broadly, the Act accepted brain death tests as confirmation of death and introduced a law that the sale of organs became a punishable offence (Shroff et al, 2003). Two decades since the implementation THO act, the number of organ donors in India remains low just 0.16 pmp (Kurup 2013). However, the incidence of CKD is rising, with the age-adjusted incidence of CKD in India is estimated at 229 pmp, and >100,000 new patients enter RRT annually (Singh et al. 2013). Reasons for this rise in CKD include environmental pollution, pesticides and other chemicals, analgesic abuse, herbal medicines, and unregulated food additives have been attributed as causes of CKD (Shaheen and Al-Khader 2005).

Less than 10% of Indian CKD patients receive RRT, while up to 70% of those starting dialysis die or stop treatment due to financial burden within the first three months (Sakhuja and Sud 2003; Parameswaran et al. 2011). Living related donor transplants are most common, as deceased organs account for less than 4% of the 21,000 kidney transplants performed to date (Indian Society of Organ Transplantation 2013). The reality in India is that, every year there is a need of approximately 175,000 kidneys for transplantation, even though there is 180 transplant centres sadly only 5,000 kidney transplant are performed annually (Aulakh 2013) and due to the shortage of organs one person dies of kidney failure, every 4-5 minutes. Shroff (2009) reinforced the need for India to seriously explore the deceased donation option as a way to address the problem of organ shortage and to minimise organ trafficking. The death rate is increasing in India due to the high number of fatal road traffic accidents, but a lack of infrastructure to retrieve organs from deceased donors hinders opportunities for transplantation (Mithra et al. 2013). Newspaper reports suggest that approximately 90,000 road accidents occur each year, estimating 245 Indians die on roads every day, 40% of which are left brain dead indicating a potential untapped resource to facilitate a successful cadaver transplantation programme (The Indian Express newspaper 2013). The cost of developing such an infrastructure to retrieve and allocate deceased organs for transplantation is a great barriers for India (Mithra et al. 2013), as the cost of deceased transplantation is more expensive than that from living transplants (Shahbazian et al. 2006). The costs include medical and surgical infrastructure, access to Intensive Care Unit (ICU) and equipped laboratories for tissue typing necessary to support a deceased organ donation programme (De Villa et. al 1997).

3.3.2 Pakistan – unrelated paid live donation

Pakistan's estimated population in 2011 was over 183 million making it the world's sixth most populated country and its population growth rate is estimated at 1.6% (CIA 2010). Pakistan is an Islamic state, which means nearly all, 96% of Pakistanis are Muslim, and the remaining 6% is Christian, Hindu and others (Census of Pakistan 2011) approximately 65% of the country's population live in rural areas, the main language spoken is Urdu, and the income per capita \$408 per year (Haqqani 2005). The Pakistan government pays 40-50% of the costs for RRT to alleviate the finance burden on the patient and their family, but still kidney failure remains as one of the leading causes of death (Rizvi and Naqvi 2000). It is estimated that 50,000 people in Pakistan die of organ failure every year, of which 20,000 die of kidney failure, (Rizvi 2013).

British Pakistanis are British citizens whose ancestral roots lie in Pakistan. This includes people who were born in the UK and are of Pakistani descent, and Pakistani-born people who have migrated to the country. British Pakistanis make up the second largest subgroup of British Asians and are the second largest ethnic minority population in the UK, with over 1,125,000 Pakistani residents in England and Wales (ONS 2011).

In Pakistan transplantation relies mainly on donations from unrelated live donors (Ansari 2007), a contrast to developed countries where living related donation or deceased donation remains the main sources of transplants. In the absence of state law (until 2007) supervising the transplant practices in Pakistan, people from across the world benefited from the organ wholesale market, commonly known as Gurda Piri (Nosheen 2007). A report from Sind Institute of Urology and Transplantation in Karachi revealed that 75% of renal transplantation in 1991 was living related in contrast to 80% unrelated renal transplants in 2003, the majority of which were performed for foreigners (Moazam 2006). The dominant practice of transplanting foreigners over Pakistani people was confirmed when figures in 2005 indicated 2000 transplants performed, two thirds (1500) of which were provided to transplant tourists (Naqvi et al. 2007). Indeed Pakistan became the hub of transplant tourism in the mid-2000s, with recipients from Australia, the Middle East, European Union, and the US constituting the bulk of the beneficiaries paying up to 40,000 dollars for a kidney, but only 1,000 to 2,000 dollars were actually reaching the live donor (Naqvi et al. 2007). It was estimated that in Pakistan transplant packages ranged from

\$13,000 to \$25,000 but the actual figures came close to \$15 million per year annually for transplant physicians and their hospitals (Ilyas et al. 2009).

The organ trade was normal practice it created an inflow of transplant tourists to obtain organs from paid donors often from a poor socioeconomic backgrounds. This approach had serious implications for the recipients of the donated organs where *'patients from overseas, including the UK, are operated on quickly and whisked back to their own country without proper advice or postoperative treatment, so they often succumb to serious complication'* (Noorani 2008: p1378). In 2006/07 Supreme Court of Pakistan called on the federal and provincial authorities to curb the organ trade (Efrat 2013), fearing the countries reputation and thus introduced the Transplantation of Human Organs and Tissues Billing 2007. However, the influential owners and physicians of the private hospitals, involved in the organ trafficking, continue to use their financial power to weaken and obstruct the enforcement of the transplant legislation and facilitate organ trafficking (Moazam 2011; Mustafa 2012), the Pakistan government have not been strong enough to enforce the law (Efrat 2013). No evidence could be located to suggest a deceased organ donor transplant programme exists in Pakistan.

3.3.3 Bangladesh – unclear organ donation

Bangladesh is only two thirds the size of the UK, but has twice the population, one of the most densely populated countries in the world (CIA 2011). The total population in 2011 was 152,518,015 which ranked Bangladesh as the 8th populated in the world (Bangladesh Bureau of Statistics (BBS) 2011). According to figures in 2001 the religious profile of the population was: predominantly Islamic: Islam 89.7%, Hinduism 9.2%, Buddhism 0.7%, Christianity 0.3% and others 0.1% (BANBEIS 2001).

The renal transplant rate in Bangladesh was 0.16 pmp in 2004 with no recent data available for comparison (Vathsala 2004). Even though the Bangladesh Parliament passed the Organ Transplant Act, in 1999 (Bangladesh Gazette 1999) imposing a ban on trading body parts and publishing any related classified advertisements; the organ trade is growing in Bangladesh (Moniruzzaman 2012). The law in Bangladesh states that, organs are only removed if the deceased person carried an organ donor card or if family members give permission, suggesting some form of opt in organ donor programme but evidence is limited (Moniruzzaman 2012). However, systems in Bangladesh do not appear to follow

any set definition of brain death or have any standard legal framework for deceased organ donation (Moosa et al. 2001). A report published in a local newspaper (Hossain 2012) suggested that deceased transplantation was yet to start in Bangladesh.

A British Bangladeshi is a person of Bangladeshi origin who resides in the UK by having immigrated to the UK and attained citizenship through naturalisation or via their parents. British Bangladeshis have the highest overall relative poverty rate of any ethnic group in Britain with 70% of Bangladeshis living in low income households (Palmer and Kenway 2007). In 2001, Bangladesh people in the UK had the highest rate of people with disabilities and illness; men were three times as likely to visit their doctor as men in the general population (ONS 2001). In 2011, there has been no change with persistent inequalities seen in the health of Bangladeshi women, their illness rates 10% higher than White women in 1991, 2001 and 2011 (Bécares 2013). Also 65% of Bangladeshi men aged 65 or older reported a limiting long-term illness compared to 50% in general UK population (Bécares 2013).

3.4 UK Government Practice and Policy: Organ Donation Initiatives

In the UK there are over 7,000 people on the national transplant waiting list, and each year 1,300 people die whilst on the waiting list or become too sick to receive a transplant, highlighting the importance of a well maintained system of organ allocation and donation (NHSBT 2013).

3.4.1 Current UK donation Consent System

UK Parliament passed the Human Tissue Act (HTA 1961) following world's first successful transplant in 1954, which paved the way for the successful transplant programme in the UK (Merrill et al. 1956; Kennedy 1979). However this Act was revised due to the issues uncovered of unethical organ retention at Bristol Royal Infirmary and Royal Liverpool Children's Hospital. Parliament passed a revised HTA in 2004 which came into effect in September 2006 (Office of Public Sector Information 2011). This emphasised the importance of consent, only allowing the lawful preservation of the body once consent has been obtained to harvest the organ(s). Other than these reforms, the legalities relating to deceased organ donation remain unchanged since 1961, with prior consent being the most fundamental obligation. The UK operates an 'opt-in' system

through which informed consent must be obtained and people must opt in to donate their organs (Abadie and Gay 2006).

3.4.2 Organ allocation in the UK

The number of people on the transplant waiting list needing organ transplants in the UK is much greater than the number of available donated organs (NHSBT 2012). So it is vital to ensure that all patients are treated equally and donated organs are allocated in a fair and unbiased way. The UK has such a fair and open organ allocation system, and the process of allocation is equitable and clear where organs are distributed to the most suitable and best match recipients, irrespective of age, gender, ethnicity or religion (Table 12).

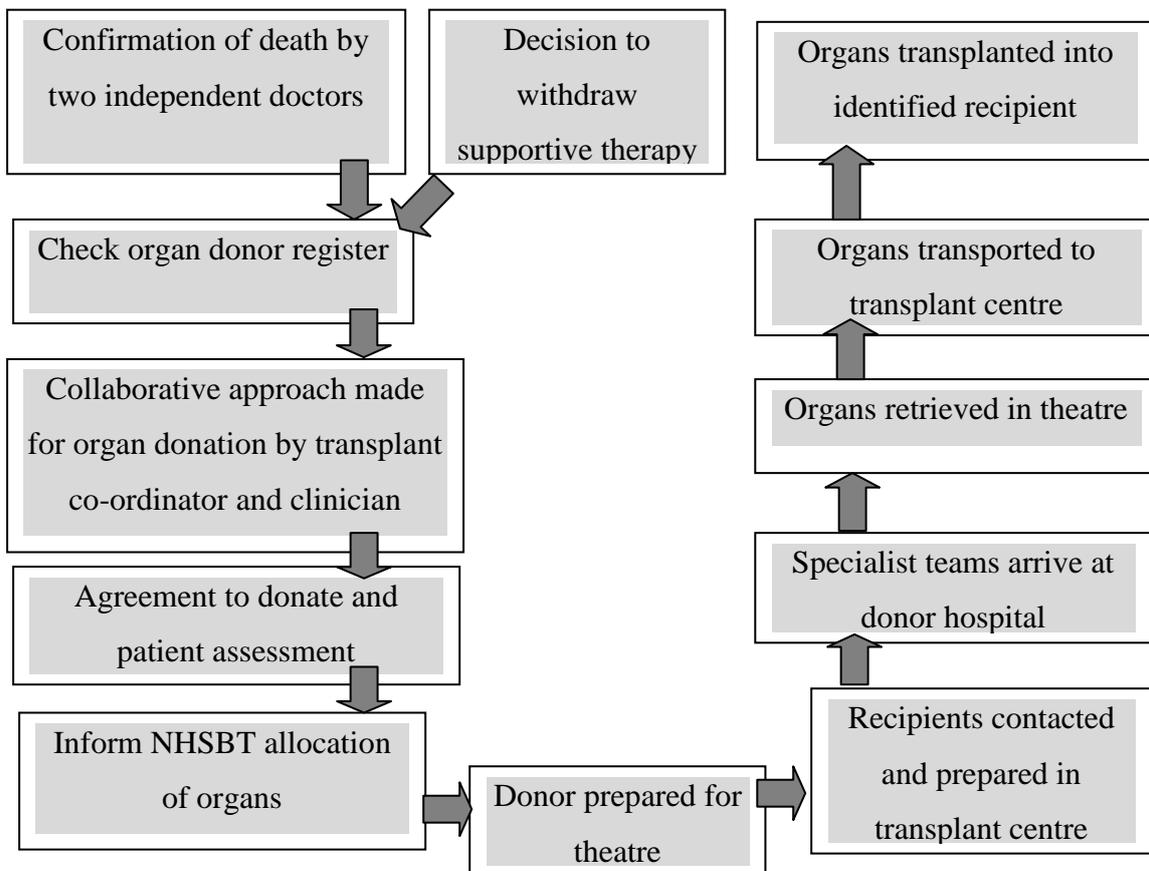
Table 12 Organ allocation system in the UK

- All patients waiting for a transplant are registered on the NHSBT National Transplant Database
- Computer programme used to identify the best match between donor and recipient, and the transplant unit to which the organ is to be offered across UK
- System of allocation different according to the type of organ (heart, lung, kidney, liver or cornea) but common guiding principles
- When an organ becomes available anywhere in the country, the duty office at NHSBT is immediately notified
- The national database is searched to find whether there are any ‘super urgent’ (candidates in whom survival without transplantation is impossible) cases, with blood group or age compatibility, in any of the centres.
- Patients waiting for a heart or liver, classified as ‘super urgent’ given priority, as their life expectancy, without a transplant, can be measured in days or hours
- If there no super urgent patients on the waiting list the organ is offered to patients on the transplant list who are nearest in age, blood group and size to the donor. The location of donor and recipient is also considered, to minimise the delay between retrieving and transplanting organs
- Children are given priority for kidneys because they tend not to thrive on dialysis and may suffer growth impairment. Organs donated from children generally go to paediatric patients to ensure the best match in size, when no suitable paediatric recipient identified then organs from young given to adults
- When there are no suitable patients in the UK a reciprocal arrangement with the European Union (EU) enables donor organs to be offered to other EU countries

(ODTR Pack, 2010:p38-39)

In the UK organ allocation is performed by a computer program monitored by the NHSBT, which identify the best matched patient, or alternatively, the transplant unit to which the organ is to be offered. Organ Donation and Transplantation Directorate within NHSBT monitors the organ allocation procedure and any cases where the rules have not been followed are reported to the director of the transplant unit concerned, the chairman of the appropriate advisory group and the director of Organ Donation and Transplantation (NHSBT 2013). Also, Specialist Nurses for Organ Donation (SNOD) play a vital role in identifying potential donors within the Hospital / Trust and liaising with NHSBT. SNOD's are responsible for identification of potential organ and tissue donors in collaboration with the clinical teams in critical care environments and working with clinical teams to ensure the relevant pathways are established to support timely identification and referral of potential organ and tissue donors (NHSBT 2013). An outline of the UK process of transplantation, from organ donation, allocation and transplantation to the waiting donor is presented and identified in Figure 1.

Figure 1 Process of Transplantation



(ODTR, 2003: <http://www.scotland.gov.uk/Publications/2003/11/18095/25892>)

Even though this fair organ allocation system is in place, how this system operates is not always clearly communicated, as demonstrated in Chapter One where some South Asian people certainly were of the opinion that the system favoured the Caucasians. Despite a fair system, if the organs being donated are only from Caucasian people then it is understandable that they would ultimately be better matched to Caucasian recipients of similar tissue typing, increasing the perception of an inequitable allocation.

3.4.3 Initiatives to Promote BAME Donors

Although there is in principle what would appear a fair allocation system, South Asian people are significantly disadvantaged in receiving a transplant once listed because of their specific histocompatibility and ABO blood group matching (Gaston et al. 1993; Ahmed et al. 1999). There is irrefutable evidence that despite best efforts there is persistent inequality in the access to the transplant waiting list and having a transplant in most transplant programmes (Oniscu et al. 2003). There is a need to increase the number of Asian organ donors to meet demand, but predominantly reasons why organ donation rates vary widely amongst ethnic groups is that, donation of organ from one human being to another is a complex act, involving medical, social, cultural, ethical and legal issues (New et al. 1994).

In the late 19th century, the UK health service system began to explore, discuss and confront the social and cultural barriers surrounding around organ donation for the BAME community. This began with the establishment of UK Transplant (UKT) in 2000, which was given specific responsibilities and funding for this area, since taken over by NHSBT in 2005. Since 2000 successful improvements, such as increasing the number of live donors and donors after cardiac death (DCD donors), have been made by the UKT as well as identifying potential barriers to donation. In the light of changes in Government policy and legal developments, the DoH published the Transplant Framework in 2003. This was followed by the HTA 2004 and the HTA (Scotland) 2006. To tackle additional issues such as public awareness about organ donation, concentrating on minority groups and education of health professionals the Government introduced the Organ Donation Task Force (ODTF) in 2006 to identify and set out targets to improve organ donation in the UK.

To enhance the equity of the UK organ allocation the criteria for listing has undergone numerous revisions to keep up with the changing ethical and cultural values of each

individual society (Oniscu and Forsythe 2009). The main changes, agreed by representatives of patients and professional groups, take more account of waiting time and less of tissue type matching but represent a fairer deal for all patients (Geddes et al. 2006). The scheme continues to take into account many factors relating to the donated kidney and potential recipients using complex computerised simulations designed to balance equity of access and utility of transplanted kidneys. Despite the best efforts of the UK health system to uphold equality for all their patients, regardless of race or creed, patients from ethnic minorities continue to be disadvantaged, partly because of the increased prevalence of rare blood groups and tissue types (Rudge et al. 2006). Following the implementation of the organ allocation system in 2006, there has been little impact on waiting times for BAME; but White patients' transplant waiting time has increased by 328 days and unfortunately the waiting time for BAME patients has decreased only by 38 days (Table 13) as a result of the increased number of patients listed. It remains a continual uphill battle because of the failure of the migrant community to acknowledge and understand the depth and breadth of the need of organ donors.

Table 13 Median waiting time for kidney transplant in UK (2006 and 2013)

Ethnicity	Median waiting time (days)	
	2006	2013
White	719	1047
Asian	1368	1330
Black	1419	1363

(Rudge et al. 2007: p1170; NHSBT, 2013: p34)

The high prevalence of kidney failure and prolonged waiting time for transplant is apparent even in the paediatric kidney waiting list. Asian children represent 21% of those on the list and wait on average twice as long as White children for transplant (Table 14).

Table 14 Child median waiting for kidney transplant in UK (2012-2013)

Ethnicity	Number of children	Median waiting time
White	239	258
Asian	72	563
Black	21	566

(ODT Activity Report 2012/2013: p29)

The ODTF recognised an urgent need to identify and implement the most effective methods to promote organ donation and registration both in the general public, and more specifically ethnic minority populations (ODTF 2008).

The Government initiative to increase BAME donors has been acknowledged by the leading health professionals in the UK. Indeed the Better Health Briefing (Randhawa 2011) discussed the importance of concentrating on the BAME and presented a timeline of initiatives to increase donation rates amongst minority ethnic groups, many led by NHSBT (Figure 2). Whilst these initiatives have been recognised to be at the forefront of culturally competent organ donation educational materials, the lack of a focused approach has led to limited success (Randhawa 2011) suggesting a more consistent, repetitive and sustained approach may now be needed. Despite mass media campaigns and some community engagement activities, the proportion of the population on the ODR has only increased from 15.1pmp in 2008 to 20.2 in 2014 generally (NHSBT 2014), while the actual number of minority ethnic registrants remains small (Deedat et al. 2013).

Figure 2 BAME organ donation initiatives (adapted from Randhawa, 2011: p5)

2000 ↓	<ul style="list-style-type: none"> • A multi-faith symposium organised by donor and transplant professionals targeting eight major faiths in the UK, supported by DoH (Lord Hunt) and senior religious leaders <i>Bradford: 250 delegates from all major faiths.</i>
2001 ↓	<ul style="list-style-type: none"> • Debate arranged for Muftis and Imams in the Muslim school. Unable to go forward with this project for political reasons.
2002 ↓	<ul style="list-style-type: none"> • Appointment of project worker by UKT, to look at organ donation and ethnicity. Leaflets and booklet produced and another seminar held <i>Birmingham: 200 delegates.</i>

2003 ↓	<ul style="list-style-type: none"> • UK Transplant takes over running of all black and Asian donor campaigns developed by DH. Black and Asian celebrities used to highlight the importance of organ donation and transplantation.
2005 ↓	<ul style="list-style-type: none"> • Training developed for DTC and clinicians (Hospital development, Breaking bad news) with a significant component of the training applied to cultural differences.
2006 ↓	<ul style="list-style-type: none"> • Research into attitudes of ethnic minority groups to organ donation, run and commissioned by NHSBT • Cultural guide developed for health professionals, an aid to use when interviewing/speaking to families from different and diverse cultural backgrounds.
2007 ↓	<ul style="list-style-type: none"> • NHSBT launch the ‘<i>Can we count on you?</i>’ an organ donation campaign targeted at minority ethnic groups.
2008 ↓	<ul style="list-style-type: none"> • ODTF report mentioned about engaging with BAME community
2009 ↓	<ul style="list-style-type: none"> • Two-year research study commissioned to explore how to make the gifting of organs relevant and meaningful to the UK’s multi-ethnic and multi-faith population. • DoH commissions a two year program of faith-based engagement on organ donation
2010 ↓	<ul style="list-style-type: none"> • NHSBT launch the ‘<i>If you believe in organ donation, prove it</i>’ campaign
2011 ↓	<ul style="list-style-type: none"> • NHSBT appeal for more minority ethnic organ donors on World Kidney Day
2013	<p><i>Initiative implemented during the study progress</i></p> <ul style="list-style-type: none"> • NHSBT Faith Engagement and Organ Donation Action Plan(Dec)

A report by a BAME campaign ODTF (2008: p5) suggested ‘*there have been many reviews of organ donation in the past, all of them have failed to resolve the problems that result from the lack of a structured and systematic approach to organ donation, and to a lesser extent organ transplantation.*’ Issues with the BAME organ donor rates remain an unresolved problem, despite there being a 50% increase in organ donation up to 2013 from the UK population (Table 15).

Table 15 Summary impact of BAME initiatives

<ul style="list-style-type: none">• Little change in the number of BAME deceased donors• Number of kidney transplant recipients from BAME background increased by almost 50% to 367 in 2011-12.• Number of patients from BAME background on the kidney transplant waiting list has increased by 15% to 1926• BAME registrants (of those with ethnicity reported): 2.8% in March 2008 increased to 3.5% in March 2012 from the current BAME population of 10.8%• Pakistani, Bangladeshi, Black Caribbean and African ethnicities are most poorly represented on the ODR
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(NBTA Report, 2012 p 3)

Despite considerable combined efforts of the Government, NHSBT and ODTF in promoting BAME organ donation in the last 15 years, success has been minimal. There has been some engagement with the BAME community but a deeper understanding and knowledge regarding cultural and religious views on organ donation is lacking, highlighting the need for further research.

3.5 International Organ Donation Policy and Practice

CKD, more than a decade ago, was identified as an important global chronic disease due to the rapid increase of diabetes and hypertension incidence worldwide (Ruggenti et al. 2001; Wild et al. 2004). Different measures have been implemented internationally to tackle this growing problem, with an emphasis on CKD reduction as well as increasing organ donation rates to offer the chance of gold standard, transplant treatment option. The cause of the variation in organ donation rates internationally is poorly understood (Cameron and Forsythe 2001). One reason could be the varied organ donation programmes practised in individual countries, based on the different socioeconomics, cultural values, religious beliefs, legislative barriers, and lack of the infrastructure within countries, which prevents standardised approaches (Mahdavi-Mazdeh 2012). There is however, a strong movement encouraging all countries and regions of the world to work towards autonomy in organ donation practice and to implement standardised international guidelines (Rudge et al. 2012).

There are predominantly two main types of deceased organ donation programme in practice; Opt in and Opt out. Often it is seen that mainly Catholic countries of Central and Southern Europe, with a legal system strongly based in Roman law, practice opting out or presumed consent systems, emphasising the citizen's duties to the state. Compared to countries such as the US, UK, Australia and mainly protestant countries of Northern Europe which rely more on common law, and place importance on individual rights of determination, practicing the opt in system (Cohen and Wight 1999).

3.5.1 Opt in - Informed Consent

Opt in or registration via an ODR demonstrates a willingness of an individual, when they are alive, to donate organs in the event of their death (Mercer 2013). In the UK we follow an Opt in system, and normal practice is to obtain the consent from next of kin even if the person is on the ODR. If a person dies, and did not carry a donor card or had not added their name to the NHS ODR, their nearest relative is asked to provide consent for their organ to be donated. The HTA (2004) and equivalent HTA (2006) introduced changes aimed at increasing the donor pool, reinforcing the validity of an individual's wish to donate following their death, to prevent their wish being overturned by a relative's own preference. Within the Act, it makes clear that a declared wish to donate organs (for example, joining the NHS-ODR) should be regarded as authorisation for organ removal following death, and this should supersede any objections offered by the surviving family. Even though this law is in place family's consent remains a vital factor in proceeding with organ donation in NHS, an aspect of organ donation which requires further examination but is not within the confines of this thesis.

Only 20.2% of the UK population are registered on the ODR, which means that the majority of actual deceased organ donors are often not registered when they die; thus donation requires the consent from their next of kin (NHSBT 2014). The rationale for requesting the consent from the next of kin is to explore if the person was supportive of donation but had not got round to joining the ODR. It is important, not to assume that a person does not wish to donate just because they are not on ODR, since it is possible like the majority of the population, they were supportive of donation but had missed or overlooked the opportunities to register this wish formally (NHSBT 2012). It is also possible that an individual had recorded their wishes in a different way maybe through a

conversation with family and friends. There will also be circumstances when wishes of the potential deceased ‘brain death’ (DBD) donor cannot be determined. In these circumstances the law allows for an individual’s next of kin to decide on their behalf.

The HTA (2004) describe this action of a relation as giving their ‘consent’ and the HTA Scotland (2006) describes it as ‘authorisation’ and both provide a hierarchical list of qualifying relatives who might assist with such decision making. A next of kin can give consent but no conditions can be made by the donor or their family on organ allocation, which is stated under section 49 of the HTA (2006). The Welsh Government has taken the initial step to tackle the family consent refusal rate by planning to implement the Opt out scheme from 2015 (NHSBT 2013). Within the UK, the proposal of a system of presumed consent (Opt out) continues to be debated but there remains a lack of consensus as to whether such a system should be introduced, maybe if the system demonstrates success in Wales the rest of the UK will follow. Whether an Opt out system would be acceptable to the South Asian community or overcome the barriers to donation is unclear.

3.5.2 Opt Out -Presumed Consent

As suggested above to address the shortage of organ donation and increase the number of people offering to donate following their death, a system of presumed consent or Opt out has been developed (Li et al. 2013). Presumed consent allows the removal of organs unless the individual has registered opposition to this during their life time through an opting out or presumed consent system (Kennedy et al. 1998; Goh et al. 2013). In 2008, the ODTF specifically asked the DoH to consider whether it would recommend an Opt out system in the UK, but at that time the request was rejected. The DoH stated reasons for such a decision which included: such a system would potentially undermine the idea of donation as a gift, erode faith in NHS professionals and the Government, and potentially negatively impact on organ donation numbers (DoH 2008), setting a plan to review the situation in 2013. Now in 2014, the situation has not significantly improved, the rest of the UK is still only discussing changing the system rather than planning and implementing, like Wales an Opt out scheme.

Currently there are 14 European nations operating under Opt out or presumed consent systems, introduced in the last 30 years (ODRT Pack 2010) (Table 16). The introduction of

opting out legislation in the European countries resulted in increased rates of deceased donors of more than 30 pmp kidney donor's per annum (Kälble et al. 2009).

Table 16 Donation consent in different countries

Presumed Consent - Opt Out	Informed Consent - Opt In
Finland , Portugal, Austria, Sweden, Czech Republic, Slovak Republic, Hungary, Poland, Belgium, France, Greece, Italy, Spain, Chile, Luxembourg, Argentina	USA, Latin America, UK, Ireland Denmark, Netherlands, Germany Australia

The subject of Opt out or presumed consent has been at the centre of much debate for many years, yet a recent survey by the British Medical Association (BMA) revealed that 74% of participants in Scotland support the introduction of a system of presumed consent (BMA 2007). The ODTF (2008) undertook the most thorough investigation in the UK of the potential impact of moving to an Opt out system and concluded also that such a system will deliver real benefits but warned that it also carried a significant risk of making the current situation worse. In practice, regardless of the type of legislation and of whether a deceased individual is registered as a donor (or as a non-donor), in most countries families are allowed to have the last word (a soft opt out system) on whether organs will be donated.

3.6 Different International Organ Donation Models

Organ donation and transplant rates differ widely across the globe, but one problem remains, an almost universal shortage of deceased donors. The unmet need for transplants internationally has resulted in different systematic approaches being introduced to increase donor rates by individual countries, with varying degrees of success. International bodies, the WHO and the Transplantation Society, have focused their efforts on the development of a series of legal and ethical frameworks, to encourage all countries to eradicate unacceptable practice and introducing programmes that strive to accomplish national or regional self-sufficiency to meet the need for organ transplants (Rudge et al. 2012).

Among the 50 most active countries in terms of transplantation, the majority of practice includes both forms of donation live and deceased, but often counties prioritise one

approach more than another. For example Japan has relied almost entirely on living donors compared to Spain who rely on deceased donors (Rudge et al. 2012). There are some high achieving transplant program models around the world concentrating on the live donor programme along with deceased donors. In Norway, a very active live donor kidney transplant program makes it possible for nearly 90% of patients younger than 65 on dialysis to access the deceased donor transplant waiting list, and almost all of these receive a transplant within 4 years of starting dialysis (Stel et al. 2012).

Four models are examined in more detail, to better understand what mechanisms or systems reduce both the need and wait for an organ through increased organ donor registrants or the number of living donor organs available for transplantation. The models being compared include very different successful European and Arabic countries (Iran and Israel) along with the US approach. The approaches include; organised teams for deceased organ donation, regulated paid unrelated living donation, prioritising organs for donors and their families, presumed and incentivised donation. The rationale for exploring the US organ donation model (presumed and incentivised programme) is not because it is particularly successful, but because the US hosts the largest number of international migrants (45.8 million) (UN Global Migration Statistics Report 2013) living outside of their home region, this includes the highest South Asian migrant population. Exploring whether such a model works and for who is therefore important.

3.6.1 Spanish Model–Deceased donors and organized organ donor teams

Spain has the highest donation rate in Europe and has been leading over the last two decades with current 35.3 donor's pmp and has impressed the international transplant community (Spooner 2003; Rodríguez-Arias et al. 2010; Rada 2013). The WHO (2010) strategy supports the implementation of the successful Spanish Model across the globe to achieve the action plan targets of increased organ donation and transplantation. Spain has almost three times donation rate compared to: UK 13 pmp, France 20 pmp, Germany 12.2pmp, and Canada 15 pmp (Rodríguez-Arias et al. 2010). The first Spanish transplant coordinator team was established in 1985 at Clinic Hospital in Barcelona (Manyalich 1999). This model was gradually extended to other centres, areas and the whole country; consequently, an independent Transplant Coordinator Department was established in each hospital. This department consists of transplant procurement manager (TPM), transplant

donor coordinators (TDC) and other staff, who play an important role in increasing organ donation and transplant activities. Medical care, training, research, management and the quality control are the main functions that are managed under the supervision of TPM, but TDCs influencing the donation rates with their skilful and very well trained approach to grieving families (Matesanz and Miranda 2001; Manyalich 1999).

Even though, the Opt out system for consent to donation was introduced in 1979 the presumed consent policy has never been strictly applied in practice; relatives are always approached and always have the final say and has had no impact for the 10 years that followed the endorsement of the Transplantation Law (Matesanz and Miranda 2001). The Spanish Model success is attributable to the efforts of many to overcome obstacles such as untrained or under trained staff, unidentified donors, and the reluctance to approach grieving family members (Matesanz and Miranda 2001). Success factors of the Spanish Model include its legal approach and a comprehensive programme of education for healthcare professionals particularly the TDC's and TPM's who have a role in donation or transplantation. They are offered training on maximisation of donation through donor detection, brain-death diagnosis, donor management, family approach, communication of bad news, grief, management of refusals, cultural issues, organ allocation, approach to the media, and legal issue communication (Matesanz 2003). In Spain, there are over 50 pmp patients whose death is confirmed by neurological criteria, compared to the UK where the rate is only 19 pmp (Dominguez-Gil et al. 2011). Since the Spanish National Transplant Organization was established in 1989, there has been a national network of in-hospital, specifically trained, part-time, dedicated, and strongly motivated physicians in charge of organ procurement (Matesanz et al. 1994).

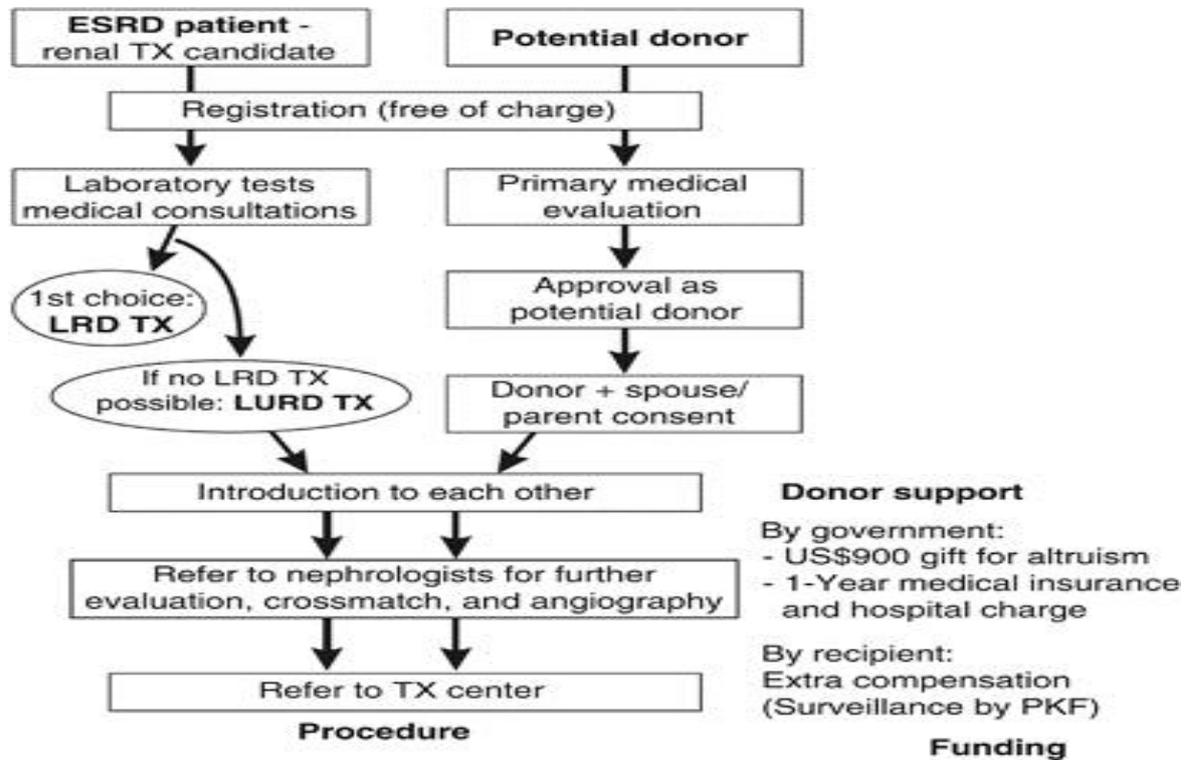
Spain also has better resourced intensive care units and has increased the number of staff responsible for donation (TDC's) and introduced compulsory education programmes, such as European Donor Hospital Education Programme (Kälble et al. 2009). This has increased and maintained the awareness of intensive care physicians for the need for deceased donation and supported them in approaching donor families to discuss donation. Indeed Spain TDC directly report to the medical director of the hospital and have a major role in promoting organ donation among all healthcare and non-healthcare professionals. This activity helps to create and sustain a positive attitude of the entire hospital towards donation influencing the success of donation at every step in the process (Rudge et al.

2012). Most importantly, Spain donation teams use very detailed protocols to identify causes of family refusals and reverse them through adequately trained health professionals resulting in one of the lowest rates of family refusal of organ donation in the world (Domínguez-Gil et al. 2010). It is unclear, given such a successful programme and development of dedicated teams, with appropriate education and expertise, why the Spanish model, identified as successful over a decade ago, has not been implemented worldwide.

3.6.2 Iranian Model - paid and regulated living unrelated donation

Iran has achieved remarkable transplant success through live donor transplantation with a government initiative regulating and financially supporting a programme of living unrelated renal donation (LURD) (Mahdavi-Mazdeh 2012). The Iranian model was introduced 25 years ago (in 1989), managed and conducted by the Iranian Network for Organ Procurement, under the guidance of Management Centre for Transplantation and Special Diseases, affiliated to Ministry of Health and Medical Education programme (Kazemeyni et al. 2004). Also Iranian Patients' Kidney Foundation (PKF) plays a vital role in the LURD programme. If a patient chooses or has to rely on unrelated kidney transplantation they are referred to PKF which has branches all over the country. One of the reasons for the success of this programme could be the PKF members input as this is mainly run by volunteering patients who suffer from CKD (Mahdavi-Mazdeh 2012). Transplant experts expressed their concern on providing financial incentives to organ sources as an alternative to altruistic organ donation. However, the compensated and regulated living unrelated donor program in Iran eliminated the transplant waiting list within 10 years (by 1999) and more than 50% of patients with CKD in the country are living with a functioning graft (Ghods and Savaj 2006). The Iranian government provides the expenses for medical services and the incentive to the donor, which is usually negotiable, is covered by the recipient; although the government remains the mediator between the donor and recipient (Shaheen et al. 2001; Shaheen and Al-Khader 2005). The system (Figure 3) appears to overcome several serious ethical problems of unrelated kidney transplantation observed in other countries; there is no broker, no transplant tourism looking for commercial organ transplantation, no financial benefit for transplantation teams, a law regulating the same citizenship between recipient/donor, and informed consent not only from recipients but also their next of kin (Simforoosh 2007; Mahdavi-Mazdeh et al. 2008).

Figure 3 Iranian LURD model process



(Mahdavi-Mazdeh, 2012:p 629)

The Iran model highlights that tight governmental control can successfully monitor and govern the sale of organs, with material benefit to donors, highlighting that other governments (such as Pakistan, Bangladesh) could potentially solve the problem of organ trafficking with improved government control. A further element that influences Iran's successful transplant rate and better survival rate of CKD patients is the government's role in actively looking after their CKD patients (Aghighi et al. 2008). All patients who need RRT, including renal transplantation, are classified as 'patients with special diseases' and are provided governmental medical insurance to cover all the treatment cost irrespective of the patient's age, sex, and financial situation. The government imports and subsidizes essential immunosuppressive drugs and insurance agencies cover the remaining cost of immunosuppressive drugs to maintain high quality post transplant care (Aghighi et al. 2008). Although such an approach is not without controversy and may not be applicable to a multinational population, a secondary positive outcome has been to develop skills in a generation of surgeons and enabling the setting up of a very promising deceased donor scheme (Mahdavi-Mazdeh 2012).

3.6.3 Israel Approach – Priority organs for donors and their families

Israel has one of the most successful deceased organ donation and transplant programmes by prioritising their patients: the criteria being if the patient and their families are already on the register or have been actual donors. Israel's National Transplant Centre (Adi) is responsible for transplants for all Israeli citizens regardless of religion. Signature on an Adi donor card testifies to the willingness of the holder to donate his/her organs after death for saving the lives of patients waiting for transplant. The bank of the Adi donor cards signatories is computerized and confidential; it is managed by the National Transplant Centre, affiliated to the Ministry of Health. Israel's Organ Transplant Law (2008) includes an article: the first and the only one of its kind in the world that grants priority on the transplant waiting list to the signatories of the donor card (Adi card) and to their close relatives, should they need a transplant in the future (Guttman 2011). *“In this Israeli Organ Transplant Law assigns three levels of priorities in organ allocation to candidates for transplantation based upon their previous attitudes toward organ donation. Top priority is granted to candidates whose first-degree relatives donated organs after death or to candidates who have been themselves live kidney or liver-lobe donors. Second priority is granted to candidates who have registered as organ donors at least 3 years prior of being listed. Finally, the law grants a third and lowest priority to candidates who have not signed the donor card themselves but whose first-degree relatives have registered as organ donors at least 3 years prior of their listing”* (Lavee et al. 2010: p1131). Implementation of this practice has shown tremendous success in taking Israel from the bottom i.e. from 7.8 in 2006 to 11.4 donors' pmp in 2011 and to one of the top ranked western countries in organ donation (Gill 2012; Lavee et al. 2013).

3.6.4 United States (US) – presumed consent, priority, incentivised donation, organ exchange

In US, the rate of deceased donation increased from 20.9 in 1999 to 26.3 donors pmp (25.8%) in 2009 (Halldorson and Roberts 2013) but still on average, 21 people die each day while waiting for a transplant in the US due to the shortage of donors (UNOS 2014). The shortage of human organs for transplantation in the US has prompted numerous strategies in an attempt to alleviate the problem. In addition to presumed consent legislation, many proposals include financial incentives for donors (Kaserman and Barnett 2002; Becker and Elias 2007), xenotransplantation (transplantation of organs from a

different species, usually pigs), and preferential assignment of organs to registered donors (Oz et al. 2003) are suggested but unfortunately none of the proposal was successfully implemented however detailed reasons for the failures of successful implementation for the above proposals are not documented in the literatures. One of the successful initiatives in the US is Kidney Paired Donation (KPD) or organ exchange mechanisms for living donors with incompatible recipients (Connolly et al. 2011). KPD is a transplant option for candidates who have a living donor who is medically able, but cannot donate a kidney to their intended candidate because they are incompatible (i.e., poorly matched) (UNOS 2014). Currently, about 90% of actual deceased organ donors in the US are donors who are declared brain dead and 10% are donors declared dead after permanent cessation of cardiopulmonary function (Rudge et al. 2012).

Despite introducing key strategies which have been successful in other countries it has not increased the donor rate in the US or reduced the demand for organs. This maybe suggests that mixing aspects of models is also not an appropriate way forward, as the US is still facing the issue on scarcity of organ donors and a growing transplant waiting list.

3.7 Summary

The term ‘South Asian’ is used loosely to encompass people originating predominantly from (India, Pakistan and Bangladesh). For the purpose of this study is it used to collectively describe the target population but it is acknowledged that this is a heterogeneous group of people from varied cultural and religious backgrounds.

To gain a deeper understanding of South Asian migrant beliefs and experiences of organ donation practices in their originating countries were reviewed, demonstrating a lack of deceased organ donation programmes and as such an ignorance and lack of knowledge of such organ donation practice. Indeed in many of the Asian countries living donation was usually the primary organ donation option, but this usually operated within an unfair and often corrupt system of organ trafficking, creating mistrust in the transplant medical profession. To originate from such a background reinforces the need to re-educate migrants and their families, even those who may have been established in the UK for generations, to and ensure people from within the South Asian community are aware of the fair and equitable organ donation service within the UK. Although it is important to recognise that the UK system despite an equitable allocation process becomes inequitable

due to the shortage of South Asian donors to meet ethnic demand. Initiatives within the UK to increase BAME organ donation to date have had limited success and evidence supports the notion that further research is needed to explore this issue.

The review of different organ donation models and approaches worldwide identified some key successful strategies and practices (Table 17) that could be adopted across countries with poor donation rates. These models, particularly the Spanish (deceased donor) and Iranian (living donor) demonstrate sustained success having operated for a number of years as such it is difficult to understand why evidence based practice has not transferred across transplantation communities. Although a somewhat reduced hybrid model, implementing some of the key strategies, is maybe not the answer as Opt out, incentivized and priority donation combined have not been a successful approach in the US.

Drawing on the information gleaned from different practices and approaches to organ donation and transplantation Chapter Four presents the findings from a focused literature review to gain a deeper understanding of the scarcity organ donation from the current evidence based drawn from the experiences of migrant South Asians in Western countries. The main focus on the literature is to identify the barriers, attitudes and perceptions to organ donation and transplantation amongst people from the South Asian community.

Table 17 Key strategies to increase the supply of transplantable kidneys

Increase the supply and use of living donors:

- Live related donor transplantation within families
- Unrelated donor transplantation between concerned but unrelated individuals like friends and well wishers
- Non-directed living donor transplantation between an altruistic donor and a recipient unknown to the donor without any monetary benefit.
- Non-directed living donor transplantation between a donor and a recipient unknown to each other with monetary benefit. Donors paid cash to donate kidneys to a central organisation, which will then be matched with a suitable donor.
- Organ exchange mechanisms for living donors with incompatible recipients and sharing scheme (Paired/pooled living donor service)

Increase the supply and use of cadaver donors:

- Population to carry donor cards and register on the national computer donor register opting in to express the individuals wish to donate their organs.

- Or introduce Opt out approach - allow the removal of organs unless the individual has registered opposition
- Priority organ allocation for registered or actual donors and their families
- Dedicated, educated, trained and organised expert organ donor teams in every centre.
- Re-organise medical services to give greater prominence, increase staff, financial support and education (Regional organ retrieval team and nurses for organ donations employed by the NHSBT instead of individual centres ie; SNOD's and National organ retrieval service team)
- Use of multi-organ, non heart-beating cadaver donor supply, with use of perfusion machines to improve the quality of donor kidney
- Extended the criteria for donor suitability: donors above 70 years, inclusion of Hepatitis and HIV positive donors to waiting list recipients with same positive status.
- Ventilate patients solely for purposes of transplantation with the availability of sufficient, adequately staffed ICU beds.

BARRIERS TO ORGAN DONATION – FOCUSED REVIEW

4.1 Introduction

Over the past decade there has been a steady rise in the number of individuals in the UK who have signed on to ODR, from 10.2 million in 2002 to 18.7 million registrants by 2012 (NHSBT 2012). However, despite numerous initiatives to increase the numbers of BAME donors and donor registrants, the Asian community continue to represent only less than 2% of the ODR (NHSBT 2012). Asians are underrepresented within deceased and living kidney donors (Perera and Mamode 2011), but overrepresented (17.5%) on the kidney transplant waiting list. The scarcity of deceased organs from ethnic minorities is a longstanding and disturbing issue internationally (Manninen and Evans 1985; Pham and Spigner 2004; Van Thiel and Kramer 2009).

Mays et al. (2003) suggest that cultural factors, which include a person's racial identity, religious influences, family practices and world view, affect the rate of deceased organ donation and transplantation. The basics for the success of a transplantation program include awareness, positive attitude of the public toward organ donation and consent by relatives for organ donation in the event of brain death (Shroff et al. 2003). Indeed it has been suggested that changing negative attitudes to registration as a donor involves much more than overcoming one barrier or need for information (Bowman and Richard 2004). To gain a deeper understanding of the barriers that prevent or influence organ donation, within the South Asian community, a focused review of the current research evidence was undertaken.

The aim of the literature review was to identify the barriers, attitudes and perceptions to organ donation and transplantation of South Asian community both generally, and with specific focus on the South Asian community residing in the UK. The search strategy employed is described along with the critical appraisal methods adopted to determine the quality and relevance of included studies. This chapter presents the findings of the review and highlights the reasons behind the scarcity of organ donors or the barriers to organ donation among South Asian community.

4.2 Search Strategy

The literature review included online searches of periodical articles, books and reviews, and manual searching of various relevant journals and text book collections. Online electronic searches were accessed through Salford University Library and Central Manchester Foundation Trust Library. The review exposed what is known regarding the study topic and provided a foundation of current evidence from which to build and strengthen theoretical and methodological new knowledge (Boote and Beile 2005; Parahoo 2006).

4.2.1 Methods

The review was completed in October 2013. The search process consecutively combined all the possible terms with respect to three topic areas: organ donation; Asian; South Asian and transplantation. The search was limited by date (2003- Oct 2013), origin of the research, and language.

Key words and Subjects were the first methods used (Stokes 2006): Key words used were Asians, South Asians, transplant, deceased, organ donation, ethnic group, barriers and Medical Subject Headings (MeSH) terms together, for example; Asian's deceased organ donation, South Asians in UK, organ donation Asian, South Asian and barriers. MeSH terms provide a consistent way to retrieve information that may use different terminology for the same concepts.

- Truncation (Harvard 2007): dono* to include donation, donating, donor.
- Wildcards (Harvard 2007): cadav?ric to include cadavaric and deceased.
- Boolean (Stokes 2006): Boolean Strategy was used to combine the search. Asians in UK OR south Asians in UK OR migrant south Asians in UK. South Asian migrants in UK NOT Asian migrants in UK.

Abstracts of identified articles were retrieved manually to select original studies and reviews which mainly focused on the topics of interest. The topics of interest in the field of organ donation among Asian community were, identifying the barriers and attitudes. Studies which had information or findings about Asian views and suggestions were selected. In addition, a number of articles were excluded if they mainly focused on the general non-Asian population and having minimal participants from the Asian community.

When the abstracts were not clear enough to decide whether articles met the inclusion criteria, full articles were read to make the decision. A search to identify studies from the UK, Asian countries and US was undertaken. Although the study was to concentrate on the UK and South Asian group the US was also included as they host the largest group of international migrants living outside of their home region (45.8 million) (UN Global Migration Statistics Report 2013). To manage the volume of papers the search inclusion criterion was limited to research undertaken between 2003 and 2013. However, two studies (Exley et al. 1996; Ahmed et al. 1999) were included identified from hand searching key journals which were considered relevant to the study. The rationale for including these two studies was that the research was located in the UK and they were the only studies that focused more on the Sikh community.

4.2.2 Systematic search: sources and inclusion criteria

This study used five databases to search the literature: OVID MEDLINE, Psycho Info, CINAHL, British Nursing Index (BNI) and Applied Social Sciences Index and Abstracts (ASSIA) (Appendix 1). Further searches for academic and grey literature (for example full reports often not available for research commissioned from private research contractors) were made using search engines and by hand checking relevant publications as well as direct contact with experts in the field. The inclusion and exclusion criteria were broad (Table 18).

Table 18 Search inclusion and exclusion criteria

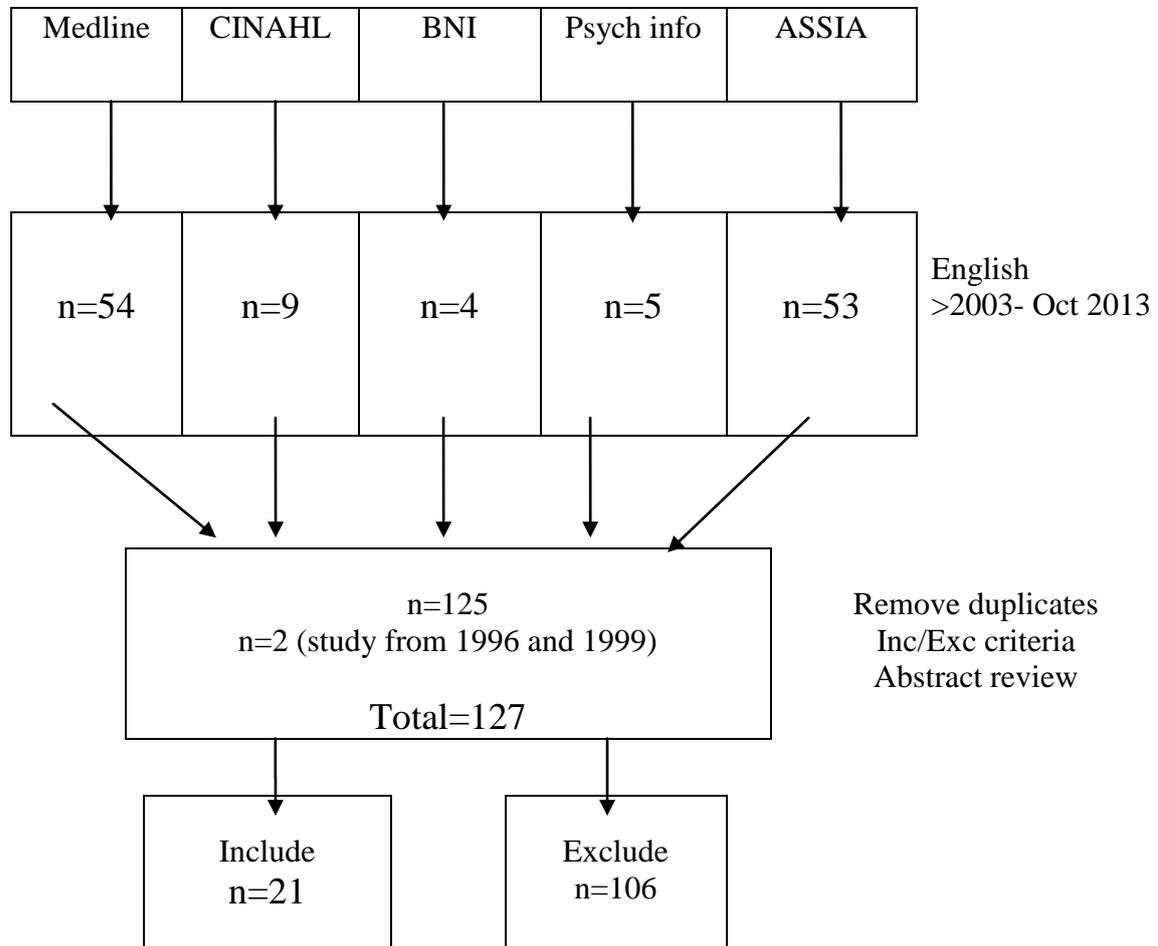
<i>Inclusion</i>	<i>Exclusion</i>
<ul style="list-style-type: none"> • Asian Countries, US and the UK • Ethnic minority participants or health professionals • Organ donation, barriers/facilitators, attitudes, knowledge, family, religious and health beliefs • Research between 2003-2013 	<ul style="list-style-type: none"> • Insufficient numbers of ethnic minority participants to make findings pertinent to specific group

Three main websites were used to provide statistical data and an outline for the study: the UK transplant website and NHSBT, Department of Health website National Service Framework (NSF) for renal patient's, and Google.

4.3 Search Outcome

A total of 125 studies satisfying the search criteria were identified from five databases. Twenty one papers were included of which 19 articles were published between 2003 and 2013 and two further papers were included from the hand search study specifically because they involved the Sikh community in the UK during the late 1990's (Figure 4).

Figure 4 Search Outcome



4.3.1 Updated Search

The original literature search was performed in October 2013. It was necessary, however, to update the search to ensure the wider literature review discussion presented in this

chapter was based on current evidence. So the combined search strategy was rerun from October 2013 – June 2014, no new research papers were identified as relevant.

4.4 Overview of Papers

Nineteen research papers were identified for review, eleven used quantitative and eight qualitative researches. The quantitative studies involved a mix of community surveys and surveys of employees, medical or high school students or attendees at a primary care facility (Karim et al. 2013; Tumin et al. 2012; Abidin et al. 2012; Bapat et al. 2010; Park et al. 2009; Saleem et al. 2009; Razaq and Sajad 2007; Edwards et al. 2007; Morgan et al. 2006; Bennett and Savani 2004; Spigner et al. 2002). The qualitative studies consisted of focus group studies, semi-structured interviews and questionnaires and mainly involved the general public recruited via posters, personal invitations, health care centres, or snowballing (Gaughner et al. 2013; Sims et al. 2012; Clarke-Swaby 2010; Wong 2010; Alkhawari et al. 2005; Hayward and Madill 2003; Ahmed et al. 1999; Exley et al. 1996). Also included two review papers, Morgan et al. 2013; and Perera and Mamode 2011, both reviews included papers from UK. Study by Alkhawari et al. (2005) used three approaches: face-to-face interviews, followed by focus group and participant observation. Since the participants in all three approaches were South Asians, the findings from all three approaches were included. But study by (Clarke-Swaby 2010) used focus group and questionnaire surveys and reported the results separately. The focus group findings did not have any Asian participants and were therefore excluded, and only the questionnaire part of the study was considered which had representation from South Asians.

Quantitative studies were exploratory and cross sectional, qualitative studies mainly used grounded theory. Of the two papers that were not research studies, one was a literature review from the UK and North American Ethnic community (Morgan et al. 2013) and the other is a UK based review of the current available evidence along with recent data from UK Transplant (Perera and Mamode 2011), both papers originated from the UK. Out of nineteen studies, eleven studies were carried out among the different South Asian religious and ethnic communities in different parts of the UK. Three studies in the US were of involving South Asian participants who are high school students, medical students and employees from industries. Further, there were three from Malaysia, two studies of which were among the general public and one with health professionals. The remaining two studies included one from India among medical students and one from Pakistan among the

general public. Time taken to perform the study varied from three months (Morgan et al. 2006; Clarke-Swaby 2010) to 30 months (Karim et al. 2013).

4.4.1 Study Aims

Studies combined various aims to investigate a particular research question. Across the 19 studies and two review papers, aims were similar and five central themes could be discerned, explaining the barriers of organ donation among South Asian community, but the majority were overseeing organ donation from various dimensions. These studies focused on examining the different levels of knowledge, attitudes, barriers, meaning and beliefs related to organ donation and to donor registration among South Asians; within the general public, employees, health professionals, students from medical school and high school. South Asian community opinions of organ donation were explored among different religious and cultural groups and the factors that influence whether people willingly agree to donate their own or their next of kin's organs.

4.4.2 Sample and Sampling Method

The number of participants recruited in the quantitative studies varied from 97 (Razaq and Sajad 2007) to 2896 (Park et al. 2009) and qualitative studies from 22 (Exley et al. 1996) to 105 participants (Wong 2010). Most studies chose to recruit participants from more than one centre or study site. Reporting of sample selection and recruitment was mixed across the 19 research studies, random and convenience sampling were the most common method, although one study used judgmental sampling (Exley et al. 1996) and another one used a theoretical purposeful approach (Alkhawari et al. 2005).

Ethical Approval

Of the 19 studies, eight reported having obtained ethical approval from a recognised authority (School, University, Local Research Ethics Committee, Head of Department, Organiser, Community officer or Institution authority). In the other eleven studies, it was unclear whether ethical approval was obtained or not. Four qualitative studies (Gauher et al. 2013; Clarke-Swaby 2010; Saleem et al. 2009; Hayward and Madill 2003) and one quantitative study (Morgan et al. 2006) reported obtaining informed consent from participants prior to the study but in four, even though it is mentioned about ethical approval and consent from participants it was not identified or reported about how, when

and by whom the consent was obtained. In research using questionnaires, consent was often presumed on return of posted questionnaires.

4.4.3 Data Collection

All quantitative studies used questionnaires, completion of questionnaires were either with the help of an interviewer or self completing and one study used combined online and hard copy questionnaires (Karim et al. 2013) to collect the data. For qualitative studies, different methods such as in-depth interview, focus group, questionnaire and participant observation were used. The most popular approach being face-to-face interview, then focus groups, only one study used participant observation (Alkhawari et al.2005) and one study used questionnaire (Clarke-Swaby 2010). All interviews used a semi-structured approach to guide the interview discussion.

The interviews were conducted predominantly by the researcher with the exception of two studies. Study by Exley et al. (1996), used an experienced field worker, a social scientist as interviewer and study by Bennett and Savani (2004) used paid interviewers who were fully briefed about the study by the researcher during a two hour session. In two quantitative studies the questionnaire survey was administered by paid field workers (Bennett and Savani 2004, Morgan et al. 2006). Unfortunately for two surveys which recruited the high number of participants it was unclear how it was administered (Spigner et al. 2002; Tumin et al. 2012). Local champions within each workplace were used by Park et al. (2009), to obtain the large sample (2896) of completed questionnaires from employees. The methods used within studies are explored further within Chapter six.

4.4.4 Analysis

Eleven (two qualitative, nine quantitative) of the 19 research studies provided an adequate or comprehensive description of the approach used for data analysis. For the remaining eight studies the descriptions were limited. Of the 11 quantitative studies only two studies (Razaq and Sajad 2007; Tumin et al. 2012) did not clearly identify the analysis approach. Five quantitative studies used different versions of SPSS, Karim et al. (2013) version 20; Abidin et al. (2012), version 17; Saleem et al. (2009), version 15; Bapat et al. (2009), version 10; Bennett and Savani (2004) used SPSS Conjoint 11.5. One study used AVOVA, Park et al. (2009) and three used 'STATA' statistical software, Edwards et al. (2007); Morgan et al. (2006); Spigner et al. (2002). From the eight qualitative studies only two

mentioned an analytical approach or tool conceptual micro models based on grounded theory (Hayward and Madill 2003) and thematic coding (Alkhawari et al. 2005).

4.4.5 Theoretical framework

Only one of the 19 studies offered discussion regarding a theoretical framework, Park et al. (2009) who described using the Theory of planned behaviour (explored in Chapter five).

4.4.6 Quality review of the evidence

Papers were initially assessed using three criteria applicable to both qualitative and quantitative research that aims to identify those papers adapted from an existing appraisal tool (HCPRDU 2001) and using a quality coding framework (NICE 2007) (Appendix 2 and 3). All studies were subjected to the same critical appraisal to determine the quality and rigor of the reported findings. Issues for subsequent discussion regarding quality focussed on the three key questions:

- (1) Are the aims and objectives of the research clearly stated?
- (2) Is the research design clearly specified and appropriate for the aims and objectives of the research?
- (3) Is there a clear account of the process by which they selected the sample and outcome?

Out of 125 selected articles, 107 did not meet one or more of these criteria and were excluded leaving 19 studies and two comparative papers taken forward for full critical appraisal; of which twelve were rated as *Good*, and nine *Average*. The findings of these studies are compared and contrasted.

4.5 Findings – Barriers to Organ Donation

There is growing evidence that patients from migrant ethnic minorities are more likely to develop CKD but less likely to receive a renal transplant (Feehally 2010; NHSBT 2012) due to the scarcity of available matched ethnic deceased organs (Roderick et al. 1996; Morgan et al. 2006). Lower donation rates have been reported amongst immigrant ethnic minorities living in a multicultural environment such as Malaysia, Canada, Australia, UK and US, which suggest people are upholding their traditional spiritual and cultural beliefs, and that they may also be less knowledgeable about organ donation (Morgan et al. 2006; Rudge et al. 2006; Wong 2010). From the review of the literature, within the larger scheme

of the problem of organ shortages, particular themes emerged which report barriers and issues that influence organ donation from South Asians, these include:

- Lack of Community Awareness
- Religious Uncertainty
- Medical Mistrust
- Next of kin refusal rate
- Health Professional Training
- Education Strategies

The evidence underpinning each theme will be appraised and synthesised to examine what we currently know regarding what are the barriers to organ donation within the South Asian community. The primary aim of the studies reviewed was to identify barriers not to implement and measure the impact of an intervention to overcome a barrier; that said appropriate strategies were proposed by researchers and members of the South Asian community, discussed in the final theme.

4.5.1 Lack of Community Awareness and Knowledge

Probably the most significant finding from the review, reinforced within the majority of studies, was the complete lack of awareness regarding the importance of deceased organ donation and transplantation within the South Asian community (Extley et al. 1996; Ahmed et al. 1999; Morgan et al. 2006; Razaq and Sajad 2007; Edwards et al. 2007; Wong, 2010; Bapat et al. 2009; Saleem et al. 2009; Tumin et al. 2012; Clarke-Swaby 2010; Perera and Mamode 2011; Abidin et al. 2012; Morgan et al. 2013; Karim et al. 2013). This isn't something new, since 1996 it has been repeatedly identified throughout South Asian communities that people lack knowledge and understanding regarding organ donation and continues to be a significant barrier today. This lack of awareness manifests itself through increased refusal rates for organ donation among Asian families compared to white families in hospitals (Barber et al. 2006; Perera and Mamode 2011). It has been reported that there exists negative attitudes to registration as a cadaver organ donor among ethnic minorities (Morgan et al. 2006). However, it is unclear from the existing evidence whether or how far these attitudes are influenced by ambivalence on the topic, although knowledge of organ donation has been found to be lower among ethnic minorities

compared with the white population adjusting for age and education (Morgan et al. 2006). Other studies indicated that while African-Caribbean and South Asians were supportive of organ donation and transplantation but they remain ignorant and unaware of the specific needs of their community for organs (Exley et al. 1996; Hayward and Madill 2003; Alkhawari et al. 2005; Morgan et al. 2006).

Ahmed et al. (1999) gathered the perceptions of 100 South Asian adults through a questionnaire on the main street of Southall, Middlesex, in the UK. The findings identified that 90 of those questioned were aware of organ transplantation and 69 had heard about donor cards. However, the number of people who carried an actual donor card was only 16%, considerably lower than the general population of 28%. The same results can be found in recent studies too; Karim et al. (2013) explored the views of 556 South Asians in the UK, 68.4% of respondents agreed with organ donation, but only 13.3% were registered organ donors, and 70.5% felt that organ donation was poorly promoted and advertised. Indeed, Exley et al. (1996) identified that among Sikhs living in the UK barriers to organ transplantation were related more to knowledge and understanding than to religious or cultural factors. Respect for cultural diversity and a better understanding of cultural influences is seen as a means for building stronger support for transplantation and ensuring the success of organ donation (Wong 2010).

There was overwhelming support for organ donation across all racial groups; however racial differences were found in awareness and attitudes not only towards organ donation, but also in the signing of organ donation cards (Wong 2010). Results from analysing 26 studies among ethnic groups by Morgan et al. (2013) suggested that making it easier to obtain organ donor cards could increase consent rates to donate organs. Studies in the general population show that those with higher levels of education were more supportive of deceased organ donation because of their greater knowledge and awareness of the importance of organ donation (Conesa et al. 2004; Haustein and Sellers. 2004; Bracellos et al. 2005). However, increased knowledge did not necessarily translate into changes in attitudes or behaviours, with attitudinal responses being significantly more negative among ethnic minorities (Morgan et al. 2006).

A study by Pham and Spigner (2004) among Vietnamese, including migrant Asians, on knowledge and opinions about organ donation and transplantation found that cultural

barriers to having access to appropriate health education information is an issue. They suggest that in order to increase the rate of organ donation, health professionals, and especially organ procurement organizations, would need to take a much more proactive role and provide culture and family oriented education (Pham and Spigner 2004). NHSBT, the organisation that monitors the transplant activity and leads organ donation across the UK, believes a change in public attitudes around donation is needed (NHSBT 2013). The research evidence indicates a clear barrier, among Asians, that still exists today is the lack of awareness and understanding regarding the actual donation process (Hayward and Madill 2003).

4.5.2 Religious Uncertainty

Research over the last decade suggests that religious beliefs and interpretation plays an important role in the decision to donate organs (Spigner et al. 2002; Hayward and Madill, 2003; Alkhawari et al. 2005; Morgan et al. 2006; Saleem et al. 2009; Wong 2010; Clarke-Swaby 2010; Morgan et al. 2013). However, when examining the foundations of the Asian religions it is evident that none actually object to organ donation in principle, although there are various interpretations (Randhawa 1998; Alkhawari et al. 2005). Despite this religion is cited by many people as informing their decision as to whether to donate or not (Ahmed et al. 1999; Razaq and Sajad 2007; Hayward and Madill 2003; Wong 2010).

Saleem et al. (2009) identified that 408 Pakistani people agreed that religion had an immense influence on their opinion towards organ donation. Moreover, a study comparing UK ethnic minority groups (Black Caribbean, Black African and South Asian) to the white British population reported that ethnic minorities were significantly more likely to regard organ donation as unacceptable to their religious beliefs (Morgan et al. 2006). One study identified differences among people of Muslim faith in the UK, reporting that Muslims in the South of England were more knowledgeable and more likely to consider organ donation compared with Muslims in the North of England (Poonia 2006). There was evidence that explored whether Indian Muslims had the same beliefs as Pakistani (Gauher et al. 2013) but no evidence to compare Bangladeshi Muslim's. An international survey by Sharif et al. (2009) of 812 Muslim participants' attitudes to organ donation showed that even though 68.5% agreed with organ donation, only 10.6% were registered as organ donors. Only 2.2% of Muslims would categorically refuse an organ transplant if it was required, and 24.5% would donate only to a fellow Muslim. In this study, the two biggest

reasons cited by Muslims for their reluctance to donate organs was interpretation of religious scripture (78.8%) and advice from their local mosque (70.8%).

Uncertainty prevails regarding whether their faith prefers the body to remain intact following death, and issue raised by Islamic and other ethnic and faith groups (Hayward and Madill 2003; Gauher et al. 2013). There was an uncertainty as to whether Islam permitted organ donation and indeed could offer a single standpoint on the issue (Hayward and Madill 2003; Wong 2010). Hindus, Muslims, and Chinese in Malaysia wanted assurances that the handling of the body of a Muslim would follow the rules and regulations of the Islamic faith, and whether the body would be treated with respect and care (Wong 2010). Sikhism, on the other hand, has an altruistic tradition that is appropriate for organ donation, although some particularly the older people in the community, were unclear whether removal of organs would affect reincarnation (Exley et al. 1996). Studies identified that the older generation views were often a dominant influence within the Sikh family, and they were found to be less likely to support organ donation as it was not part of their traditions, although the younger generation often held more westernised views (Molzahn et al. 2005). However, the younger generation tended to respect the wishes of their elders, particularly during bereavement (Exley et al. 1996).

Opinions are formed on an understanding that deceased organ donation and transplantation violates religious principles (Randhawa et al. 1995; 1998). Despite a declaration issued by religious leaders, from all the major faith groups in the UK, that no religious prohibitions against organ donation exist (Rudge et al. 2007). Indeed most religious scriptures were written hundreds, if not thousands of years ago, before organ transplantation existed (Randhawa 2012) and modern techniques of biology did not exist at the time of the advent of Islam (Ilyas et al. 2009). Religious objections to deceased donation appear to be a myth and a community misconception based on ignorance, potentially reinforced by religious leaders and family elders, over many years. South Asian people have been shown to be more supportive of donation and transplantation when made fully aware of the position of their religion (Poonia 2006). Thus it is important to interpret the religious scriptures correctly, when raising awareness about organ donation among the South Asian community (Exley et al. 1996; Hayward and Madill 2003; Razaq and Sajad 2007). A lack of organ donor knowledge within the community needs to be reinforced with the provision of accurate religious information, but for this to be credible support from religious groups,

leaders and family elders is an important factor to consider when overcoming the donation barrier among ethnic communities (Wong 2010).

4.5.3 Medical Mistrust

Negative comments within studies were indicative of barriers to organ donation, suggesting distrust of the medical community and for some a feeling of being marginalised economic disadvantage and/or through the experience of racism (Park et al. 2009). Study by Loch et al. (2010) among Malaysian Islam, Buddhists and Hindus identified that 90.6% would accept organs, 43.6% would donate, but still only 4.0% carried donor cards. The reasons for reluctance to donate included: fear of organs being used for research (18.8%), desire to be buried whole (18.0%), fear of less active treatment if the patient is known to be a donor (12.8%). Similarly review study findings reinforce the feeling that medical teams would not try as hard to save a donor's life, or that their organs may be used for other purposes such as medical research (Hayward and Madill 2003; Morgan et al. 2006; Wong 2010; Clarke-Swaby 2010; Morgan et al. 2013). There is very limited research available to suggest low rates of organ donation by South Asian people may be related to factors pertaining to the low admission of Asians to intensive care units rather than related to the donation of organs (Exley et al. 1996). This reinforces the need for further research in this area, indeed attention given to the number of South Asian patients who are eligible to become organ donors in the intensive care units.

Widespread concerns among all ethnic groups include that less would be done to save their life if they were known to be an organ donor (Exley et al. 1996; Spigner et al. 2002; Hayward and Madill 2003; Morgan et al. 2008; Morgan et al. 2013). Mistrust in the medical profession when donating organs or tissue samples is inextricably linked to past abuses of minority ethnic patients by the White medical establishment (Dawson 2000). Mass media is perceived as one of the main sources of information regarding organ donation (Bapat et al. 2010) and healthcare providers as one of the least informative (Conesa et al. 2004; Ali et al. 2013). The notion of unethical recovery of organs by medical professionals reflects an apparent lack of awareness of the strict procedural checks and balances that have been instituted to safeguard the probity of the organ recovery process (NHMRC 2007). Obtaining the trust of the South Asian community is an important challenge faced by health professionals in the organ donation and transplant community.

4.5.4 Next of kin refusal rate

Recent evidences suggest that there is an increase in consent among BAME families i.e. 33% of families approached about donation consented in 2012/2013, compared to a 24% in 2011/2012 (NKF 2013). Family refusal rate generally in the UK is a major issue (Barber et al. 2006, NHSBT 2013), but it is more worryingly reported that South Asians show a higher rate than the 40% of UK average rate (DoH 2008b). According to a review report in the USA, next of kin withhold consent for organ donation in 47% of eligible cases (Sheehy et al. 2003), and similar rates of refusal have been reported in both Australia (Opdam and Silvester 2006) and the UK (Barber et al. 2006). This is higher among South Asian families; Sharif et al. (2009) found that 35% of the white population refuses consent for donation compared to 70% of refusal among BAME community. Twenty years ago it was reported by New et al. (1994) that although 70% of the population willing to donate only 27-32% actually carried an organ donor card, ethnic minorities when there are no specific reasons for them not to donate organs.

The dilemma for families and the barrier to organ donation is their own uncertainty about what the deceased would have wanted to do (Sque et al. 2005), with only 31% of families in England willing for donation to go ahead if they are unaware of their loved one's decision to donate. In the UK up to 90% of people support organ donation i.e. more than 15 million people, but only 25% have joined the ODR, and six out of ten families approached about organ donation will give their agreement or authorisation for donation if the potential donor is a registered organ donor (NHSBT 2012). Researches shown that, among the general population next of kin are more likely to grant permission for organ recovery if the deceased had indicated during their lifetime a willingness to become an organ donor (DeJong et al. 1998; Siminoff et al. 2001) but unable to comment whether this will be the same case among South Asian community as there is no clear evident in literatures on the same. But it is clear from literatures that only less Asians discuss organ donation topic with their family members compared to other communities (Spigner et al. 2002; Exley et al. 1996) also there is a fear of family disapproval among the younger Asians (Razaq and Sajad 2007; Bapat et al. 2009; Gauher et al. 2013). It is important to note that Asian women have expressed their own concern of their relatives overriding their decision even to be a live donor for their child (Hayward and Madill 2003).

With the current Opt-in system in the UK evidence suggests education is needed not only for the next of kin but for people registered on the ODR, to ensure their family are aware of and respect their wishes to donate when they die, to prevent consent being refused (NHSBT 2013). But unfortunately, even though Asian community are sympathetic and supportive of organ donation they are reluctant to discuss their wish with the older members of the family or to provide their next of kin consent, as they feel it may cause distress among the family members and may feel going against the wishes of their elders (Razaq and Sajad 2007; Bapat et al. 2009; Gauher et al. 2013; Exley et al. 1996).

4.5.5 Health Professional Training

Promoting donation and organ transplantation in a multicultural environment represents one of the major challenges facing the transplant community. A lack of discussion by health professionals with families of the potential donor is a direct barrier to organ donation and a reason for lower donation rates among black families in the UK (Griffin and Bratton 1995). Trompeta (2008) suggest that in order to promote and facilitate organ donation rates in Asian populations, a body of knowledge that describes Asian attitudes and knowledge towards organ donation and transplantation is essential so that the approach to requesting organ donation is performed in a culturally sensitive manner. From the researchers own experience health professionals are not well trained, indeed no formal course exists that informs for medical staff or SNOD's about culturally sensitive donation practice, in the UK. According to White et al. (2008) establishing organ donor and transplant programmes require first addressing and recognising the cultural and organization challenges to such programmes. Improving transplantation advocacy and confidence in the largest group of health care professionals is an essential step in promoting best practices in transplantation (Hoy et al. 2011).

Study by Bapat et al. (2009); Abidin et al. (2012); Edwards et al. (2007) among Asian medical students and health professionals clearly explained the lack of knowledge and understanding about organ donation topic and the importance of including deceased organ donation topic in the curriculum. A potential barrier, therefore, to preventing donation may be the attitudes and knowledge of health professionals, who do not always support donation or create the right social climate to encourage participation (Zambudio et al. 2009). However, evidence suggests health professionals are the preferred educators with regard to answering questions about organ donation (Gallup 2005).

A study by Aghayan et al. (2009) among nurses identified that educational programs can enhance nurses' knowledge and commitment to the organ donation process and, ultimately, increase the donation rate. Evanisko and colleagues (Evanisko et al. 1998) also indicated that training on organ donation, particularly on making requests for donation, improves the ability and readiness of critical care staff in handling potential donors. A large Spanish multicentre trial showed that an initial negative response can be changed into consent if the approach is right and the relative's reservations about brain death, the integrity of the corpse, or religious concerns are dealt with proficiently (Gomez and Santiago 1995). Appropriate education and training of health professionals approaching donor families is essential, particularly a cultural awareness of different religious and personal beliefs.

Health professionals are not confident to approach relatives about potential organ donation (Abidin et al. 2012; Schaeffner et al. 2004). Also within the ICU, there needs to be clear guidelines on how to approach families in making a request for their loved one's organs, with specific training and counselling being conducted in a multicultural environment (Morgan et al. 2012), which will give more confidence for the ICU team to approach the potential donor family. Formal training should be mandatory for all such staff to give them the confidence to approach the relatives in the first place and to give them the best chance of obtaining a positive response.

In the wider world, organ donation is one of the mandatory components of critical care training in Australia (ODTF report 2008). Brazil, increased the number of deceased donor kidney transplants through a combination of interventions, one being education of transplant and organ donation teams (Ghods 2003). The best practice model for successful cadaver organ donation in Spain, described earlier, operates with appropriately experienced and culturally trained organ donor teams. Whatever the approach, an essential component is the involvement of a team of health professionals who are sensitive to the values and the traditions of each individual group in addition to a coordinated effort to clear any misconceptions of organ donation, improve public education and awareness, and promote communication (Van Embden et al. 2008).

4.5.6 Education Strategies

A theme running throughout the barriers uncovered within this review is the need for education, whether this is for health professionals, South Asian people, young and old, the

religious leaders, and/or community leaders. A lack of knowledge within the community needs to be reinforced with the provision of accurate religious information, but for this to be credible support from religious groups and leaders is an important factor to consider when overcoming the donation barrier among ethnic communities (Baines et al. 2002; Wong 2010; Sharif et al. 2009; Clarke-Swaby, 2010; Alkhwari et al. 2005; Ahmed et al. 1999; Razaq and Sajad 2007; Karim et al 2013; Saleem et al 2009).

Since mainstream campaigns may not be perceived as relevant by some minority communities, it is suggested that targeting information through the South Asian media and minority ethnic press is a potentially effective way to get information to people (Ahmed et al. 1999; Connect 2001; Clarke-Swaby 2010). Public education could act as an important vehicle to correct the misconceptions that people, within this group, have regarding donation (Clarke-Swaby 2010). For deceased donor transplant programmes to develop, the education of health professionals and the public is needed to generate support for organ donation and increase the pool of potential donors (Alkhawari et al. 2005; White et al. 2007; Bapat et al. 2009; Saleem et al. 2009; Morgan et al. 2013). A study by Spigner et al. (2002) among Asian American adolescents identified the need for accurate, up to date culturally sensitive youth-oriented health education. This was reinforced by Trompeta (2008) who suggest that the incorporation of organ donation education in high schools is necessary to reinforce and maintain high knowledge and awareness, and in turn young people may influence and raise organ donation awareness in their parents and families.

To achieve equality in organ donation and transplantation in the UK, the DoH and NHSBT have produced a range of educational materials that set out the position of each religion regarding organ donation. Evidence suggests and the fact that education and awareness in communities has not improved after many different campaigns, that more innovative and meaningful ways are required to appropriately disseminate such literature within South Asian communities (Morgan et al. 2006; Perera and Mamode 2010). Recommendations from the ODTF suggest that efforts should focus on ensuring that organ donation is relevant to all of the UK's multi-ethnic and multi-faith population (DoH 2008b). To achieve this there are plans and suggestions to work with religious stakeholders to develop practical solutions at the local level to remove cultural and religious barriers to donation; the outcomes from these plans are not available (ODTF 2011: Sup p31).

4.6 Summary

There is clear evidence from this focused review that the South Asian community lacks knowledge and awareness of organ donation (Hayward and Madill 2003; Alkhawari et al. 2005; Morgan et al. 2006). Collective findings from studies, identified key religious uncertainties or reasons for the reluctance to donate organs, which included: whether the religion permitted organ donation and how this was interpreted from the scriptures, whether a body should remain intact following death, whether it would affect reincarnation, if the handling of the body would follow the rules and regulations of the specific faith, and following advice from their local Mosque or family elders (Exley et al. 1996; Hayward and Madill 2003; Molzahn et al, 2005; Poonia 2006; Razaq and Sajad 2007; Sharif et al. 2009; Wong 2010; Clarke-Swaby 2010). There was no doubt from the studies that education was the key and needed to be targeted at health professionals as well as people in the community. Studies demonstrated that while South Asians maybe supportive of organ donation and transplantation, they are not aware of the specific needs of their community for organs (Exley et al. 1996; Darr and Randhawa 1999; Hayward and Madill 2003; Alkhawari et al. 2005; Davis and Randhawa 2006; Morgan et al. 2006). The majority of the UK research was focused on communities in the South of England and given that different attitudes were reported between Muslims in the North and South, focusing this research study in the North would appear pertinent (Poonia 2006).

Despite a long list of initiatives introduced over the last 15 years to increase BAME organ donation, described in the previous Chapter (Figure 2), although the number of ODR from the South Asian community has increased, there is still insufficient numbers to meet demand. There was no research evidence exposed with the review to inform whether certain approaches such as campaigns, leaflets, religious leader engagement are more successful than others or not. So research is needed to expand this knowledge base.

Chapter Five explores further the South Asian religious concepts surrounding organ donation and attempts to gain a deeper understanding of the people by examining health belief theory and different theoretical approaches to studying the topic.

SOUTH ASIAN RELIGIOUS, HEALTH AND CULTURAL BELIEFS

5.1 Introduction

For many years it has been identified that the South Asian community living in the UK have a diverse and distinctive culture and a pattern of mortality and morbidity that is different from that of the white communities they live among (Marmot et al. 1984; Balarajan and Bulusu 1990). Some of the reasons for this include lifestyle factors associated with cultural practices, such as diet, racial disadvantage leading to high levels of unemployment, poor housing and low education achievement (Daniel 1968; Smith 1977; Brown 1984) which leads to differential rates of ill health (Nazroo 1987). Inequalities in health through discrimination and racism ‘*contribute to both the health and health concepts of people from ethnic minority groups*’ (Rawaf 2003: p6). Indeed, ethnic minority members may be unwilling to contribute to the general good of the society, because they feel marginalised from the mainstream society through economic disadvantage and/or through the experience of racism (Morgan and Cannon 2003, Park et al. 2009).

Religion is often of major importance in the lives of people who seek medical care. Issues of religious faith and practice can assume prominence in discussion concerning treatment options, the nature of social services provided and day to day interactions of patients with physicians and health professionals. For people within the South Asian community, the literature review highlighted religious uncertainty, myths and misconceptions as a direct barrier to organ donation (Hayward and Madill 2003; Molzahn 2005; Alkhawari et al. 2005; Poonia 2006; Davis and Randhawa 2006; Wong 2009). South Asians living in the UK have diverse religions, languages, and cultural upbringings that cause some complexity in understanding their concerns about organ donation (Karim et al. 2013). Therefore, it was considered important to examine the underpinning philosophy of the religions in the UK and how religion may influence an individual’s health beliefs towards organ donation.

5.2 Religions in the UK and Organ Donation

Christianity is the largest religion (in England and Wales) selected by 59.3% of the population (33.2 million people), although there has been a decrease over the last 10 years

in people who identify as Christian from 71.7% to 59.3% (ONS, 2011). However there is an increase in other main religious group categories particularly those religions pertinent to the South Asian community. People identifying with the Muslim religion has increased from 3.0% to 4.8% of the population (2.7 million), Hindu 1.5% (817,000), Sikh 0.8% (423,000), also Buddhist 0.4% (248,000) and Jain with 20,000 people (ONS, 2011: p3). Across the main South Asian religions namely Hinduism, Sikhism, Buddhism and Islam, the idea of gifting (such as donating an organ) to assist society is a highly valued virtue known as; ‘*Sewa*’, ‘*Sewa*’, ‘*Daana*’ and ‘*Zakat*’ respectively. Each religion is examined to better understand different interpretations, perceptions and beliefs towards organ donation, but primarily organ donation is clearly supported by four out the six religions, with potential religious uncertainty in the Islamic and Buddhism faith (Table 19).

Table 19 Support for organ donation across different religions in the UK

Religion	Views on Organ Donation
Christian	Supports and encourages organ donation
Islam	Lack of Consensus – opposing perceptions using Qur’an to support different interpretations
Hindu	Supports and encourages organ donation
Sikh	Supports and encourages about organ donation
Buddhism	No evidence in favour of or against organ donation
Jain	Supports and encourages organ donation

The summary examination of the scriptures that follows was reflected and checked with relevant religious leaders (in and outside the steering group) to ensure an accurate summary is represented.

5.2.1 Christianity

The Christian faith encourages organ donation and transplantation (Owen 2010), based upon the revelation of God in the life of Jesus Christ, and to love one another as Jesus proved his love for the world upon the cross. According to the Christian Holy book, The Bible, healing and saving life is a great gift and Jesus sent his twelve disciples out with the imperative to heal disease and illness. Some of the organ donations supporting quotes from Bible are; ‘*Heal the sick...freely you have received, freely give*’ (Matthew 10:8); ‘*In*

eternity we will neither have nor need our earthly bodies: former things will pass away, all things will be made new' (Revelation 21:4-5). The Apostle Paul makes it very clear that *'the mortal bodies we now have cannot inherit the kingdom of God'* (1 Corinthians 15:35-58; 2 Corinthians 5:1-10). The Bible also makes it clear that *'to be absent from this body is to be at home with the Lord'* (2 Corinthians, 5:6-10). These phrases provide supporting evidence that could be interpreted to reinforce and confirm that organ donation is supported by Christianity; that the mortal body is not needed for the life after death, and Christians are encouraged to give freely to heal the sick.

5.2.2 Islam

The UK has been witnessing rich discussions for more than three decades on the Islamic perspectives with relevance to organ donation (Darsh 1981). One of the basic aims of the Muslim faith is the saving of life this is a fundamental aim of the Shariah (Muslim Law), and Muslims believe that Allah greatly rewards those who save others from death. In 1996 the UK Muslim Law Council issued a Fatwa (a religious opinion) on organ donation, and this Fatwa remains, till now, the most well known Fatwa on this topic in the UK (Golmakani et al. 2005). The Fatwa is based on the Islamic principle of *al-darurat tubih al-mahzurat* (necessities overrule prohibition) and saving lives, indicating that *'Whosoever saves the life of one person it would be as if he saved the life of all mankind'* (Qur'an, 5:32). The UK Fatwa agreed with organ donation stating that: *'After a thorough consideration regarding medical opinion and several edicts issued by different religious bodies, the Council arrived at the following conclusion'* (Badawi 1995: p13).

However, the Fatwa, made no reference to any of the earlier Fatwa's issued in the Muslim world and well known to Indo-Pakistani religious scholars, these did not permit organ donation, therefore the wider Muslim scholar community in the UK had concerns (Shafi and Muhammad 1995; Badawi 2000). These concerns are still present today as some UK Muslim's do not accept the fatwa issued in 1996, which explains why some Imam's advise their communities against organ donation and why there continues to be religious uncertainty. Even though this Ijtihad (religious ruling) has been in place since 1996, different studies have demonstrated a complete lack of awareness of the fatwa by Muslims in the communities. For example, out of 32 Muslims interviewed in Luton regarding their opinions towards organ donation, only 2 were aware of any Islamic Fatwas regarding organ donation (Randhawa 1998). Similarly, Sheikh and Dhami (2000) interviewed 25

Muslims in the UK and revealed only 2 were of the opinion that Islam regarded organ donation favourably, and 12 were unwilling or unsure and suggested the Muslim Law Council's fatwa should be disseminated wider. In other studies it has been shown that whilst two thirds of Western Muslims agree with organ donation, only one third believe it to be compatible with their faith (Raleigh 1997).

Today whilst most international Islamic scholars accept organ donation, there are still a significant number of Muslim scholars who believe that organ donation is not permissible and hold the view that this does not fall under the criteria of the Islamic principle due to other overriding Islamic principles (Oliver et al. 2011). Within Europe there is religious and ethical discourse on organ donation among Muslims (Ghaly 2012). A report published by the European Union Committee (EUC 2008) explains that the tendency for opposition to organ donation among Muslims is often based on individuals own interpretation of what some Muslim scholars say about the human body. According to these scholars, the teaching that *'the human body is a trust (amanah) that has been given to us by God as such'* means that *"there is no permissibility whatsoever for the transplantation or donation of organs'* (EUC 2008: p270–271). So not only organ donation but transplantation also considered as against the Muslim Faith, however from the researchers professional experience transplantation prohibition is not taken as a religious barrier to proceed among the Muslim community, but organ donation often is. This one sided view needs more support and explanation from Muslim Scholars in the UK and around the World.

The reason for the strong view on organ donation is that some religious leaders do not accept brain death as a criterion and consider cessation of all signs of life including heart beat as a precondition for declaring death (Al-Mousawi et al. 1997; Khan, 1986; Moazam, 2006). The main issue for religion regarding deceased donor transplants is that it violates the sanctity of the human body (Cort 2008). However, Islamic jurisprudence is flexible when society's welfare is at stake, having the view that when it comes to organ donation, the rights of the living supersede those of the dead, because the benefit accrued in the outcome is greater than the harm of bodily disrespect for the deceased donor (El-Shahat, 1993; Ebrahim 1995). The Council of the Islamic Fiqh Academy of the Muslim World League (Makkah, Saudi Arabia) in 1985, and the Council of the Islamic Fiqh Academy of the Organization of Islamic Conference (Jeddah, Saudi Arabia) in 1988 have concluded that it is permissible within Islamic law to remove organs from the deceased (El-Shahat

1993; Ebrahim 1995). Opposing viewpoints take their evidence from the Qur'an and the Ahaadith, therefore individual Muslims are advised to make a decision according to their understanding and interpretation of the Shariah or seek advice from their local Imam or scholar (Hollins 2006). To influence a positive decision towards organ donation education alone is not sufficient to overcome concerns, but local Muslim religious leaders and Imams need to be convinced to change their opinions which influence the community.

5.2.3 Hinduism

Hinduism supports organ donation (Veatch 2000), '*Daan*' is the original word in Sanskrit for donation meaning selfless giving. In the list of the ten Niyamas (virtuous acts) in Hinduism, Daan comes third (Prabhupādā 1996). Life after death is a strong belief of Hindus and is an ongoing process of rebirth. There are references that support the concept of organ donation in Hindu scriptures. '*Bhagavad Gita*' the Holy book of Hindus, describes the mortal body and the immortal soul in a simple way like the relationship of clothes to a body: '*As a person puts on new garments giving up the old ones the soul similarly accepts new material bodies giving up the old and useless ones*' (Bhagavad Gita 2:22). Both Hindus and Buddhists believe in transmigration of the soul and reincarnation however the physical integrity of the dead body is not seen as crucial to reincarnation of the soul (Oliver et al. 2011). For people of the Hindu faith there should not be any religious opposition or uncertainty with regards to organ donation.

5.2.4 Buddhism

There are no instructions in Buddhism, in favour of or against organ donation (Keown 2010). The death process of an individual is viewed as a very important time that should be treated with the greatest care and respect. Buddhists believe that organ and tissue donation is a matter of individual conscience, and they place high value on acts of compassion (Keown 2010). Central to Buddhism is a wish to relieve suffering and there may be circumstances where organ donation may be seen as an act of generosity. According to the Buddhists holy book, when Buddha discovered a monk sick uncared for, He said to the other monks, '*Whoever would care for me, let him care for those who are sick*' (Mahavagga VIII 26:1-8). Helping others is central to Buddhism along with the belief that charity forms an integral part of a spiritual way of life. There are examples in Buddhist scripture of the compassion shown by Buddha in giving his life and body to help others. *The Sutra of Golden Light*, chapter 18, explains how Buddha gave his body to save a

starving tigress and her cubs, later reborn as his disciples. For many Buddhists the most important consideration regarding death is the state of mind as this will influence the rebirth. However, Buddhists believe that the dying process take several hours so taking out an organ as soon as the declaration of death is challenging (Sugunasiri 1990). For people following Buddhism the uncertainty in donation lies in being sure that when an organ is removed from a body determined as ‘brain dead’, has the spirit left at that time and can this be guaranteed. This is the biggest influence on people’s individual decisions to donate and the uncertainty often the reason for donation being refused.

5.2.5 Sikhism

Sikh’s consider organ donation as a highly appropriate means of exhibiting the altruistic tradition of their faith (Exley et al. 1996). Sikh philosophy and teachings place great emphasis on the importance of giving and putting others before oneself it also stresses the importance of performing noble deeds (Oliver et al. 2011). Sikhs believe life after death is a continuous cycle of rebirth but the physical body is not needed in this cycle – a person’s soul is their real essence and the soul of a person is eternal, but the body is simply flesh and perishable. ‘Guru Granth Sahib’ the holy book of Sikh community, explain that ‘*Where self exists, there is no God, Where God exists, there is no self*’ and ‘*The true servants of God are those who serve Him through helping others*’ also ‘*The dead sustain their bond with the living through virtuous deed*’ (Guru Nanak, Guru Granth Sahib: p143). The British Sikh Consultative Forum (BSCF) agreed that the low level of organ donation among the Sikh community is largely due to the lack of awareness and not due to the religious perspective.

5.2.6 Jainism

Jainism is an ancient religion which originated in India and their major virtues considered as compassion and charity, liking closely with Buddhism and Hinduism. Historically, for the Jain people, there have been restrictions on foreign travel, a reason why Jainism is not widespread internationally, like other religions (Porecha 2013). Central to the Jainism philosophy is the idea that all living things, including non-animate objects such as stones, metal and earth, are alive and feeling (Sharda 2013). Organ donation has been widely supported by the Jainism religious leaders and monks (Shroff 2011; Porecha 2013). There are no religious reasons why people of the Jainism faith would oppose organ donation.

5.3 The role of local religious leaders

It was clear from the overview of the religious scriptures that *'all major world religions either actively or passively support organ donation or are neutral'* (ODTP 2010: p54) and UK religions in particular are not against the principles of organ donation and transplantation. However, within each religion there are different schools of thought, which mean that views may differ (Roff 2007). The different interpretations of the Qur'an within the Islam Muslim faith increases uncertainty, and for Buddhists the lack of clarity as to when the spirit/soul leaves a dead body remains a challenge. With this in mind the role of the religious leader is crucial as many advise the final decision for organ donation as an individual choice (Daar and Khitamy 2001; Markwell and Brown 2001; Sotiropoulos and Brokalaki 2004). The international Islamic Fiqh Academy (Majma' al-Fiqh al-Islami), a group of major scholars from around the globe stated after extensive research, that: it was the role of the Muslim leader to uphold a dead person's wish:

'It is permitted to transplant an organ from a dead person to a living person when his life depends on receiving that organ, or when vital functions of his body are otherwise impaired, on the condition that permission is given either by the person before his death or by his heirs, or by the leader of the Muslims in cases where the dead person's identity is unknown or he has no heirs' (International Islamic Fiqh Academy. 1988: Q-2117).

The influential role of the religious leader was recognised within the European Union Committee Report (EUC 2008), published by the House of Lords states that:

"...there is a clear and urgent need for local leaders to use their considerable influence to promote support for organ donation in their communities, particularly given that opinion at grassroots does not always reflect the official view of the faith. When people know what their religion's position is on organ donation, they are far more likely to use that information to make a positive decision. It is not that the religion is blocking them; it is the fact that they do not know what their religion's position is" (EUC 2008: p26).

The information available in the UK, on the major transplant and organ donor websites understandably presents a view promoting organ donation, but also acknowledges the importance of religious leaders in influencing the organ donation decision and their

member's beliefs. For example in the UK Transplant website, under its frequently asked question (UK Transplant.org, FAQ 24), it asks:

Question: *'Are there religious objections to organ and tissue donation?'*

Answer: *'No, none of the major religions in the UK object to organ and tissue donation and transplantation. If you have any doubts you should discuss them with your spiritual or religious adviser'*

The religious leaders have a role to ensure that the position of the specific religion is presented and communicated to their community of followers, supported with credible evidence and where different opinions exist discuss both, and avoid presenting a biased or individual perspective. As well as religious beliefs, health beliefs and theories pertinent to organ donation are worth exploring to provide a context, interpretation and explanation for poor organ donation rates and a theoretical framework to explain subsequent study findings.

5.4 Theories Related to Organ Donation

Health education and health behaviour change strategies achieve greater success if implemented based on a theory or framework especially for social and community initiation to influence attitudes or change behaviour (Glanz et al. 2008). This study explores attitudes of the South Asian community towards organ donation then implements an educational approach to influence society attitudes and behaviour. Three, so exploring theories that guide such an approach is appropriate.

- The Gift of Life
- Theory of Planned Behaviour/ Theory of Reasoned Action
- Health Belief Model

Combined these theories offer different ways of looking at and explaining current and the research presented within this Thesis to better understand individual's perceptions and beliefs towards organ donation.

5.5 The Gift of Life

The theory of 'Gift Exchange' was developed in the 1920s by Marcel Mauss who proposed that gifting was a form of contract governed by three major concepts: the obligation to give, receive and repay (Mauss 1990). This underpinning theory resonates closely with both the prominent South Asian, Hindu and Sikh religious beliefs and altruistic perspective of Islam. Indeed, 'the gift of life' metaphor has traditionally permeated organ transplantation campaigns, primarily because the apparently selfless act of donation by one individual can transform and even save the life of more than one person who is seriously ill. When the focus is on the donated organ itself, the intended sense of gift is much easier to identify with, as the organ is given to someone in a similar way in which a present is given (Gerrand 1994). Also it is mentioned that Gift Exchange could be a useful framework to explore this phenomenon as donating and receiving of organs may be equated with gift-giving, as there is no barter of commodities involved (Sque and Payne 1994). There are many similarities between deceased transplantation and gifting but there are also some fundamental differences, such as the lack of freedom associated with giving and receiving, as the person cannot choose who to give an organ to and the health professional role determining who can and cannot donate (Vernale and Packard 1990; Conrad and Murray 1999). In addition, for a gift to truly be a gift, it has to be the givers to give but in deceased donation process in the UK opt in system it is the donors' family who consent to giving and not the donor.

Within the current procurement regulations to ensure anonymity of the donor prevent a recipient to be able to personally express gratitude to the donors, or even to their families (Gill and Lowes 2008). Titmuss (1971) explored blood donation systems across the UK compared with a market system in the US and described the unique motives behind donating blood may differ from other forms of giving because of the anonymity of receiver as the receiver is not obligated to repay the donor. UK based campaigns promote deceased organ donation as "Gift of Life" message so it is considered as an altruistic gift, so altruism and gift views in deceased organ donation faces challenges arise in the incentives and reciprocity debate (Sharp and Randhawa 2014). Also unlike gift exchange, deceased donation is not connected to an existing relationship between two parties, as it only takes place because the donor has died (Gerrand 1994). Living related donation provides a closer alignment to the gifting exchange theory as the process also involves individual giving, receiving and reciprocating (Fox and Swazey 2002). However, the act of deceased

donation, respecting an organ donors' wish of gifting after death, or indeed those of the next of kin would still fit such a theory to underpin and provide a rationale as to why people may consider registering as an organ donor.

From the review in the previous chapter a number of studies identified attitudes and intentions of South Asian people to donate related to saving the life of another person or gifting their organ after death (Fox and Swazey 2002; Landry 2006; Park et al. 2009). But also it is explained that impact of providing incentives for organ donation as per the gift exchange theory can be revealed only through a trial (Matas et al. 2012; Bryce et al. 2005).

5.6 Theory of Planned Behaviour

A common theory used to explain and underpin many health studies is the Theory of Reasoned Action/Theory of Planned Behaviour (TRA/TPB) (Godin and Kok 1996; Smith and McSweeney 2007; Bresnahan et al. 2007; Hyde and White 2009). TRA/TBP was developed to better understand relationships between attitudes, intentions and behaviours (Fishbein 1967). Although, studies which have explored relationships, found relatively low correspondence between attitudes and behaviour, with some theorists proposing that attitude as a factor underpinning behaviour should be eliminated (Vicker 1969; Abelson 1972; Fishbein 1993).

A review of studies applying the TPB in behavioural change interventions suggested that it could make a valuable contribution, particularly amongst those whose motivation to act cannot be taken for granted (Hardeman et al. 2002). TPB is a theory of behaviour that results from rational planning, (Glanz et al. 2008) although some important health behaviours like organ donation may not be explained by its principles. TPB emerged from research to understand why attitudes did not always prompt behaviour also it focused on rationally decided behaviour but explicitly excludes behaviours that were automatic (such as behavioural responses when suddenly being approached to donate a next of kin organ). Indeed different behaviours highlighted in the previous chapter as barriers to organ donation decisions could potentially be explained using this theory, and translated across different religious, cultural and health beliefs and attitudes (Table 20).

Table 20 Rationale examples for theory of planned organ donation behaviour

Belief/attitude	Rationale /reason	Behaviour
Not opposed to organ donation	Advised by Imam not compatible with Islam so against religion	Not donate
Believe in gift of life, altruism and organ donation	Considered scriptures and own individual interpretation	Donate
Personally in favour of donation	Approached for donation for next of kin and uncertain as to their wishes	Not donate/ Donate
No opinion of organ donation	Lack of knowledge that organs can be donated, unaware of need for organs amongst South Asians	Not donate
No opinion of organ donation	Medical mistrust, may not try hard to save my life, Uncertainty as to	Not donate
Believe in gift of life, altruism and organ donation	Lack of clarification as to the determination of death and when the spirit leaves the body	Not donate

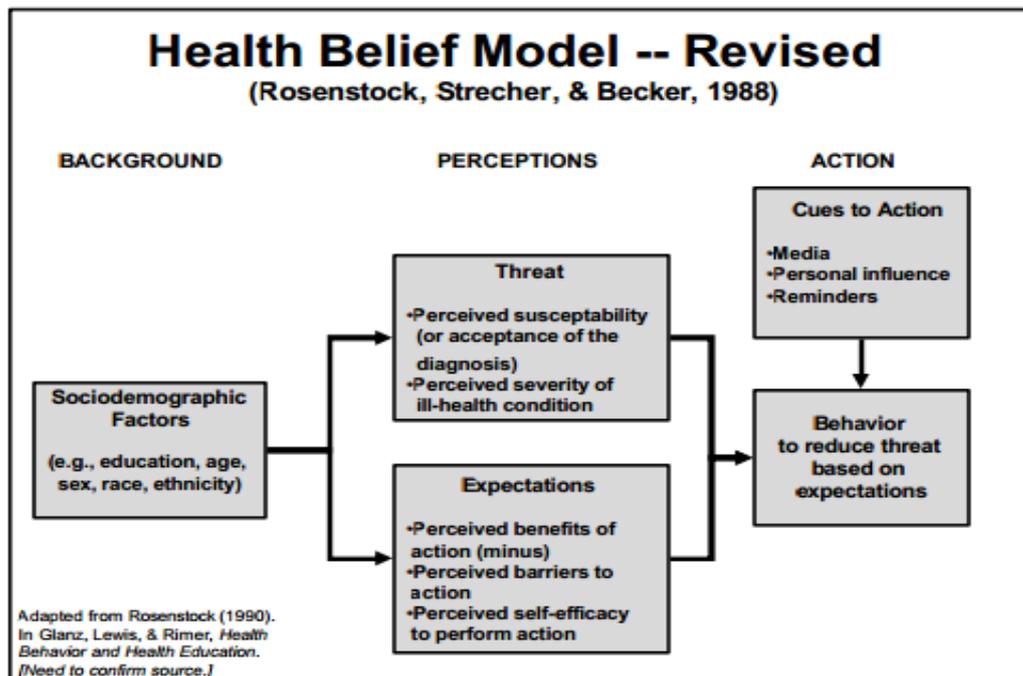
What is clear from this theory is that understanding and exposing a person's rationale behind a behaviour helps inform the education and intervention needed to influence and change such behaviour. From the literature review in the previous chapter, Park et al. (2009) was the only paper that described using a theory to inform the research, this was TRA/TPB. It was identified that campaigners need to target two behaviours in promoting organ donation among ethnic community. First is enrolling in an organ donor register along with engaging in family discussion, secondly concentrating on ethnic similarities and differences in cognitive, affective and behavioural of these two behaviours. The relationship between attitudes and behaviour (such as registering on the organ donor register) was stronger among Asian Americans. Thus a positive attitude to organ donation promoted and encouraged the behaviour of registering as an organ donor (Park et al. 2009; Davis et al. 2004). TPB may be useful to this research to explore the rationale why people do or do not donate their organs, but it is also important to explore beliefs including health beliefs in more detail to understand reasons that influence organ donation behaviour.

5.7 Health Belief Model

Similar to the TPB model the Health Belief Model (HBM) is a psychological model to explain and predict health behaviours by focusing on the attitudes and beliefs of individuals (Rosenstock 1966). The difference between the theories is that HBM provides a more detailed framework with which to consider the rationale that led to a specific behaviour, in this case being organ donation. The HBM is one of the first and certainly the most long-term of theories that helps to explain health behaviour change by means of social cognition. HBM developed initially in 1950's looking into why medical screening programme in the US is not successful in screening tuberculosis (Hochbaum 1958). Later it was expanded by others to predict more general health behaviour by adding self efficacy to original four beliefs (Rosenstock et al. 1988). Explaining that individuals do not do something new, unless they think they can do it focusing on the attitudes and beliefs of individuals as modifying factors through cues of action (Rosenstock et al. 1988). With the HBM, the focus is on the costs and benefits, which the individual perceives to be inherent in the specified health behaviour. Consideration is given to their susceptibility to the health problems and the benefits of performing the advised behaviour and the barriers stopping them, and any internal or external cues to take action (Ogden 2003).

The underpinning theory suggests that a person's belief in a personal threat combined with their belief in the effectiveness of the proposed behaviour will predict the likelihood of that behaviour (Rosenstock et al. 1988). Health beliefs are affected by various factors; when applied to the topic organ donation (evidence from the previous chapter) this could include, knowledge, attitudes, religion, ethnicity, community influences, misconceptions, mistrust and misinterpretation. Unlike the TPB the HBM is particularly well suited to framing interventions for infrequent behaviours, like organ donation (Quick et al. 2010). The HBM assumes that people are largely rational in their thoughts and actions, and will take the best health supporting action if they feel that it is possible to address a negative health issue, believing in taking the proposed action to expect a positive result (Glanz and Rimer 1997). Six key concepts (Figure 5) serve as the foundation for the HBM: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Rosenstock et al. 1988). These will be discussed in turn with specific reference to community collective perceptions and individual behaviour; being an organ donor, consenting to organ donation, or potentially needing an organ.

Figure 5 Health Belief Model (Rosenstock et al. (1988))



Adapted from Rosenstock (1990)

5.8 Perceived Susceptibility

Perceived susceptibility is defined as the person's assessment of the likelihood of an individual (or the collective community) to develop a specific condition. South Asian people living in the UK are three to four times as likely to need a kidney transplant compared with the white population, reflecting their higher rates of diabetes and hypertension, both of which are major causes of CKD (Roderick et al. 1996). Identified in earlier chapters there is a higher number of Asians on the kidney transplant list and transplant waiting list and the most successful transplant match is from a donor of the same ethnic community (Roderick et al.1996; Morgan et al.2006; Rudge et al. 2004). However, the current lack of knowledge and awareness (Razaq and Sajad 2007; Saleem et al. 2009; Clarke-Swaby 2011; Perera and Mamode 2010; Abidin et al. 2012; Morgan et al.2013; Karim et al. 2013) of the needs of the South Asian community and the scarcity of organs reduces both an individual and the overall level of community perceived susceptibility.

With this in mind the perceived susceptibility of an individual and the collective community could be increased to influence and increase the number of people registering as organ donors, if people believed that they or a member of their family in the wider

South Asian community could be susceptible to CKD and require a kidney transplant at some point in the future. Indeed the donation of an organ knowing it will more than likely be allocated to someone of the same ethnicity makes the ‘*gift of life*’ or altruism of being an organ donor, and consenting to your families organs to be donated somewhat easier under the premise of it being for the good of the South Asian community especially with their strong community bonding as mentioned in the previous chapter.

5.8.1 *Perceived Severity*

Perceived severity is defined as how severely a person (or collective community) may be affected if they were to suffer the condition. Like susceptibility the severity of the condition and the impact on South Asian people is evident in the lack of organs being donated impacting on the increased time South Asian people wait for a kidney transplant (Locke et al. 2008). The severity is increased through the difficulties in blood groups and tissue type matching to offer the best possible kidney match (Roderick et al.1996), indeed the treatment option of transplantation is significantly reduced due to the lack of donors from same ethnicity group (Churak 2005).

For an individual with CKD within the South Asian community their perceived severity will be extremely high and so will the severity perceived by their family members watching them wait to received a kidney. For those people in the community unaffected by CKD their perceived severity will be low. It is therefore important to raise awareness through the stories and experiences of those people with high perceived severity to influence wider the perceptions and opinions of the South Asian community towards organ donation. Increasing an individual or collective understanding that they may need a transplant at sometime in their lives could, in turn, encourage an increase in ODR.

5.8.2 *Perceived Benefit*

Perceived benefit is the belief in how effective the action taken will be in mitigating the problems of the condition, the severity or reducing risk will impact directly on an individual’s decision to donate their organ or consent for their next of kin organ to be donated. In this case the perceived benefit of organ donation being; the increase in available ethnic minority appropriate organs, reduced time on the waiting list, more Asians receiving the optimum treatment option of transplantation reducing the number on dialysis and increasing those within the community who can work and contribute.

In addition, an individual or collective community guided by their religious leader could perceive positive benefit through religious beliefs, benefit gained from a selfless act or the 'gift of life' in the afterlife (Buddhism, Sikh, Hindu and Islam). Parisi and Katz's (1986) work suggests that individuals often join an ODR because they want to be a hero by saving or improving the lives of others (Parisi and Katz 1986; Quick et al.2010).Thus, explaining and promoting the notion that by donating deceased organs up to nine people could benefit following their death may influence the decision to donate.

5.8.3 Perceived Barriers

Perceived barriers are the individual's perceptions of the difficulties they would encounter in taking the proposed actions, including both physical and psychological barriers. Highlighted in the previous chapter barriers for the shortage of Asian organ donors joining the ODR include: medical mistrust, religious beliefs, mistrust in the health care system, lack of awareness, misinterpretation of faith, and lack of discussion by the health professionals (Extley et al. 1996; Ahmed et al. 1999; Razaq and Sajad 2007; Edwards et al. 2007; Wong 2010; Bapat et al. 2009; Saleem et al. 2009; Tumin et al. 2010; Clarke-Swabey 2010; Morgan et al. 2013). Also identified is a lack of motivation, being unsure about the donation decision, a lack of knowledge about the process of organ donation, and a simple lack of knowledge about how and where to register (Singh et al. 2002; Morgan et al. 2003; 2004; 2008; Hyde and White 2007).

A religious barrier to organ donation, certainly in the case of Islam, is the lack of consensus and different interpretations of the Qur'an as to whether organ donation is permitted, despite the Muslim Council's Fatwah permitting organ donation and transplantation (Carlisle 1995). There are varying schools of thought (Alkhawari et al. 2005), but what is clear from the evidence is that many Muslims in the UK believe that their religion prohibits organ donation despite efforts of outreach groups to dispel this myth (Randhawa 1988). The opinion of local religious leaders, depending on their school of thought, could provide an additional barrier. It was indicated earlier that many UK Muslims are simply not aware of the Fatwa (Sheikh and Dhama 2000); it has not been well publicised, therefore South Asian community opinion may be influenced and potentially this barrier reduced through appropriate education. More general cultural beliefs, such as regarding death as a taboo subject and/or having an anxiety that registering as a potential

donor might 'tempt fate', may contribute more strongly to ethnic differences in attitudes than formal religion itself (Hayward and Madill 2003).

A further barrier to consenting to the next of kin organ donation is the health professional's cultural understanding and sensitive approach which has been criticised (White et al. 2007; Trompeta 2008). As mentioned by Griffin and Bratton (1995) lack of discussion by health professionals with minority families of the potential donor and not providing a social climate to encourage participation (Zambudio et al. 2009) are some of the reason for lower donation rate in the UK. And it is suggested that improving transplantation advocacy and confidence in the health care professionals is an essential step in promoting transplantation (Hoy et al. 2011).

5.8.4 Cues to Action

Cues to action are the strategies or prompts that allow a person to feel that they are ready to take the prescribed action. Research shows that various media such as newspaper (Feeley and Vincent 2007), television dramas (Morgan et al. 2007) and television news (Quick et al. 2009) can serve as prompt for individuals and strategies to activate willingness to donate. There are strong cues to action that could and should motivate the South Asian community which to date have not been widely disseminated. Cues such as the shortage of organs, need for ethnic minority match for improved success of a transplant, people dying within the community because of the time waiting for an organ. The Asian community needs to be informed of the transplant crisis it faces and its responsibility to provide donated organs, indeed a motivator is '*the majority of donated Indo-Asian kidneys would be used for Indo-Asian recipients*' (Ready 1988: p2493).

Increasing public awareness of the National ODR as a means to record preferences on this issue is clearly a worthwhile goal (Geddes et al. 2006). The implementation of educational programmes by primary health care professionals about organ donation and transplantation could favourably and rapidly influence the attitudes and knowledge of potential donors. Results from a US prospective randomized study, support the belief that family physicians (General Practitioners) can increase the commitment of their patients to organ donation (Bidigare and Ellis 2000). This view was reinforced by a local research study where South Asian people suggested the trust of their GP asking them to donate would positively influence their decision (Pradeep, 2010).

Targeting minority ethnic press and media has been highlighted as a potentially effective way to get information to people (Connect Report 2001); media shapes not only what people think about but also how they think about it (McCombs and Shaw 1972). Particularly as a lack of awareness of cultural and religious factors could have a negative impact on the treatment for Asian people (Netto et al. 2001). Indeed culturally directed health education (by South Asian educator) increased the number of registered donors over a short time period (Pradeep 2010). Similarly peer education within ethnic minority groups has been shown to be effective, particularly concerning disease prevention (Jain et al. 2008), but sustained impact evidence or what and how education works is limited.

The UK has one of the highest rates of family refusal in the Western world, 43% of families refuse to allow donation to proceed and this is particularly relevant for people from BAME community, sometimes even overturning the recorded wishes of their loved one (DoH 2008b; NHSBT 2013). A lack of discussion by health care professionals with families of the potential donor has been suggested as a reason for lower donation rates among black families in the UK (Bratton 1995). Whereas a family information and educational campaign about organ donation and transplantation has been shown to increase the numbers of new donors (Symvoulakis et al. 2009). Organ donation consent by the family member depends on the skill of transplant coordinators in influencing relative's decisions to offer organ donation (Simpkin et al. 2009). Van Embden et al. (2008) advocate that whatever the approach, prompt or cue for action, an essential component is the involvement of the whole team of healthcare workers, sensitive to the values and the traditions of ethnic communities. For this to be achieved health professionals require appropriate training so that there is a coordinated effort to clear any misconceptions about organ donation through improved public education and awareness (Van Embden et al. 2008).

5.8.5 Self-Efficacy

Self-efficacy is described as confidence in one's ability to take action and this can be increased through information, knowledge, encouragement, and support. Recent research by Anker and colleagues (2010) suggested that self-efficacy mediates the attitude-behaviour relationship within the context of organ donation, potentially being a key factor influencing factor then to the TPB. This self-confidence could influence an individual believing in the 'gift of life', but receiving negative advice from their religious leader, and

still deciding to register on the ODR. Alternatively a lack of self-confidence could create completely the opposite outcome. The level of self-efficacy and confidence of a family member consenting to organ donation of their relative will influence their decision. Whether someone responds to a cue for action for organ donation will be influenced by their level of self-efficacy and the influence of the wider community.

The HBM, in particular the six theoretical concepts offer a way of explaining why people behave in a certain way and provides a framework to guide the relationship between individual beliefs, knowledge, attitudes, and behaviours as determinants of willingness to become an organ donor (Table 21). The review of the literature revealed limited evidence with respect to developing a strong theoretical understanding to explain the religious, health and cultural influence on the perceptions, attitudes and behaviours of UK South Asians and organ donation. Therefore an embedded aim of this study will be to generate and explore the application of theory to the topic of organ donation to better understand new knowledge generated and taken forward within this thesis.

5.9 Summary

The donation of an organ for ethnic minority members from one human being to another is a complex act, involving organisational, ethical, medical, legal, cultural, social and emotional factors (BMA 2000). For this reason, it is important that both health professionals and the South Asian community approach organ donation and transplant subject positively and objectively to identify and influence the ethical, religious, cultural and social attitudes and overcome barriers (Robson 2010). The three theories presented (Gift, TPB and HBM) relate well to organ donation in different ways and provide alternative ways of viewing the relationships between the attitudes and behaviours of people; what could motivate, be a barrier, or influences a decision whether to donate an individual organ or give consent for their next of kin.

Table 21 Overview of key HBM concepts and organ donation

	Organ donation	Possible Cues for Action
Perceived susceptibility	<ul style="list-style-type: none"> • Increase awareness of: <ul style="list-style-type: none"> - CKD prevalence - scarcity of ethnic organs - time on waiting list - blood and tissue typing - overall plight of South Asian community 	<ul style="list-style-type: none"> • Provide accurate information to increase knowledge • Information on how to register on ODR • Personal stories and experiences from real people to raise awareness
Perceived severity	<ul style="list-style-type: none"> • Identify level of risks to self, family and wider community • Concerns over deceased organ donation, less active treatment by medical staff to save own life 	<ul style="list-style-type: none"> • Use of South Asian Media/TV • Reassurance of best possible treatment by healthcare professionals when dying • GP recruitment or provision of information for ODR
Perceived benefits	<ul style="list-style-type: none"> • Increased number of available ethnic minority organs incase needed by individual, family or member of wider community • Reduced time on the transplant waiting list for South Asians • Increased number of South Asians receiving the optimum treatment option of transplantedation reducing the number on dialysis • ‘Gift of life’ selfless act to help others fulfilling religious and cultural practices – feeling of being a hero 	<ul style="list-style-type: none"> • Reinforce message that donation will directly benefit ethnic minority community • Share and disseminate Fatwa advice to wider community – clarify religious stance for different groups • Engage local religious leaders to spread positive message, encourage wider religious debate • Cultural reassurance as to how a dead body is managed when donating an organ
Perceived barriers	<ul style="list-style-type: none"> • Lack of knowledge and awareness of need and how to become ODR • Religious misinterpretation • Religious leaders and family elders • Poorly trained health professionals not culturally sensitive • Mistrust in health system to sustain life of ill person • Inappropriate cultural management of deceased donor 	<ul style="list-style-type: none"> • Educate families and in particular elders • Peer education or education by a person who understands and belongs to the South Asian community • Sustained education programs (maybe earlier in schools and universities) • Training/education of whole team of health professionals on South Asian culture and religion to ensure effective communication and trust
Self-efficacy	Encourage individual confidence in own decision making, confidence to make appropriate decisions for next of kin, and wider community	

The perceived susceptibility, severity, barriers and benefits of organ donation need to be communicated effectively and the awareness of the community increased to be able to

develop a positive rationale for their planned behaviour to be on the ODR and want to and feel the need to give the ‘gift of life.’

It is disappointing, with all the evidence from the previous chapter translated here alongside theory, that a sustained education campaign has not been deployed, funded and supported by the community itself over a number of years. There still remains limited evidence through research studies on what campaigns or interventions work within South Asian communities, why and how. Religious leaders have been continually identified as the key and are still today (NHSBT, 2013), but the evidence to understand why strategies to engage religious leader, used previously have not worked or simply have not been sustained is lacking. Using theory may help to identify success factors in the future.

Certainly to achieve the national vision for 2020, to increase the numbers of ethnic minority donors in the UK to 19.1- 26 pmp deceased donors (NHSBT, 2013), more research and research funding is needed, at a local, national and international level. The next chapter presents the methodology for a proposed North West based research study to better understand the barriers to organ donation and introduce different educational approaches to overcome and increase the number of registered South Asian organ donors.

6

METHODOLOGY

6.1 Introduction

All the chapters so far in the Thesis have been building the context, presenting the background and current research evidence of BAME organ donation. The need for further research to ensure the barriers to organ donation in the UK are overcome, is apparent (Hayward and Madill, 2003; Morgan et al. 2006). However, the shortage of Asian donors is an international problem (Tonelli et al. 2004; Hall et al. 2005; Rudge et al. 2007; Faire and Dittmer, 2008; Cantrelle et al. 2008). There is no doubt that successful evidence based strategies are required to increase the number of donated organs within the South Asian community, to meet the high demand due to the increased prevalence of CKD, increased waiting time for transplantation, and the scarcity of ethnic minority donors (Oniscu et al. 2003; Abouna, 2008; Shaw et al. 2013).

This chapter provides an overview of the planned research, the underpinning philosophy of the researcher, methods, and analytical approach. The methods drawn from the papers in the review are critiqued to generate evidence to identify an appropriate methodology. The engagement and recruitment of South Asian people as participants and experts, leaders within the community to disseminate and educate peers is described. Ethical issues associated with researching ethnic minority groups such as language barriers, more general confidentiality and anonymity issues are considered. First, the study aims and objectives are presented to add clarity as to exactly what is the focus of this study and what is not.

6.2 Study Aims and Objectives

The research study has ambitious aims and multiple objectives. The overarching aim of this study is to increase organ donation within the South Asian community in the North West of England through targeted education. This will be achieved through five key objectives:

1. To understand, examine and explore reasons why organ donation within the South Asian community in the North West of UK is much lower than that of other ethnic groups.

2. To identify South Asian community perceptions of presumed consent and the cultural/religious influences that may challenge or support such a donor recruitment strategy.
3. Develop, implement and measure the impact of pilot educational approaches to increase the number of South Asian registered and deceased organ donors.
4. To better understand the South Asian community, cultural and religious influences, networking and impact of influential leaders to develop best practice engagement strategies for future.
5. To provide theoretical evidence to support, influence and inform national strategy to increase both South Asian organ donor registrants and cadaver organ retrieval within this ethnic group.

6.3 Philosophical Perspective and Choice of Methodology

The underpinning philosophical paradigm, thoughts and perspective of the researcher form a critical component and inform any decision and choice of methodology. The study idea originated from the passion of the researcher, a member of the South Asian community, a transplant co-ordinator, witnessing the plight of South Asian people waiting for many years and dying before having the opportunity to have a successful matched kidney transplant. From this perspective the researcher advocates organ donation but at the same time respects that some people will have alternative preferences and informed perspectives. The drive behind the research being to make a difference, to increase the number of South Asian people willing to donate their organs, recognising the inherent difficulty to influence the views of the total population. Through the study the researcher hoped to gain a deeper understanding and a current evidence base of the barriers to organ donation and identify and implement the best education approach to increase the South Asian organ donors. Indeed, fundamental to the study was developing and embedding an education approach '*with*' the South Asian people, not doing research '*on*' the community, drawing on and engaging community expertise, leaders, to develop capacity, knowledge within the South Asian population, as well as direct and guide the study.

The research, like the clinical based researcher, was always intending to be pragmatic and realistic in its approach (Fisher, 2004), designed to answer a health service related research question in the real world, using the best possible approach or combination of approaches. However, the design and conduct of cross-cultural research studies in diverse social

settings can be faced with a range of methodological and ethical challenges; such as migrant status, English fluency, educational qualifications, and access to money and resources (Vickers et al. 2012), all of which can sometimes be difficult to separate (Johnson, 2007). Indeed, the lack of knowledge of the researcher about how, who, and where to contact certain groups or individuals can be a barrier to developing such research (Brown and Scullion, 2010). Using an expert from the country or culture where the study will be conducted; and experts in the language, dialect or patois for data collection is a recommended solution to such challenges (Hoffmeyer-Zlotnik and Harkness, 2005). The methods and approaches from the studies in the literature review are examined to draw out the best and most practical approach to address the research question.

From the studies reviewed in the previous chapter a quantitative approach was the method of choice for many to measure the knowledge and understanding of organ donation among different BAME communities, predominantly using questionnaires and targeting large samples. The questionnaire styles used were piloted and structured with simple scale responses (e.g. agree, disagree, yes, no etc) and kept brief to encourage completion. Questions were often closed-ended, self administered and covering topics related to knowledge, attitudes and perceptions on deceased and live donation, personal experience on organ donation and transplantation, willingness to be an organ donor and to have family discussion, along with baseline demography of the participants.

Whilst the premise of using a quantitative approach was often to achieve large samples, the UK questionnaire studies have failed to engage South Asian people with response rates being considerably low, until a recent study by Karim et al. (2013) (Table 22). Obviously studies undertaken in Asian countries have experienced higher response rates, but similar to the UK low engagement in US studies can be observed.

Table 22 Examples of response rates of Asian questionnaire studies

Authors	Origin of study	Total number Asian participants	Total Number participants
Bennet and Savani (2004)	UK	118 Asians	336
Morgan et al. (2006)	UK	33 Asians	1536
Razaq and Sajad (2007)	UK	97 Asian Muslims	97
Karim et al. (2013)	UK	556 Asians(238 Indians, 318 Pakistanis & Bangladeshi)	556
Edwards et al. (2007)	US	57 Asians	500
Spigner et al. (2007)	US	94 Asians	247
Park et al. (2009)	US	45 Asian	2896
Bapat et al. (2009)	India	123 Asians	123
Saleem et al. (2009)	Pakistan	408 Asians	408
Tumin et al. (2012)	Malaysia	1311 Asians	1311
Abidin et al. (2012)	Malaysia	462 Asians	462

The results from the quantitative studies from UK and US reflect on migrant Asians attitudes and identify some of the perceptions of people from the Asian community and the potential barriers towards the scarcity of Asian organ donors. Although only the recent study (Karim et al. 2013) with a larger sample could be potentially generalised to the wider population, but still the findings offered limited understanding as to the reasons for the perceptions people held. Despite this, quantitative approach would certainly be useful to examine the perceptions of the wider community towards organ donation and identify what barriers exist. However, over two decades ago Horton and Horton (1990) warned researchers that it was important to acknowledge other variables in organ donation instead of relying on a '*simple assessment of awareness, attitudes, and behaviours*' (p791). What a single quantitative approach won't identify is why people have the attitudes and behaviours they do towards not becoming organ donors, therefore qualitative studies to explore the why and how should also be considered.

Qualitative approaches have been used well to gain a deeper understanding of the reasons behind the low number of organ donors. Studies using in-depth interviews have enabled researchers to identify the need to provide the health information in a culturally sensitive

way, exposed suggestions on how to improve the current organ donation campaigns, and a lack of awareness of the religious ruling in Asian community (Gaugher et al. 2013; Alkhwari et al. 2005; Hayward and Madill, 2003; Ahmed et al. 1999). Exley et al. (1996) used interviews within the Sikh community to identify a lack of awareness and clear evidence that DoH campaigns were not reaching the BAME community. Group interviews have also proved to be effective to draw out and discuss the role of religious and community leaders perceptions of organ donation and transplantation (Hayward and Madill, 2003; Wong et al. 2010; Clarke-Swaby, 2010; Sims et al. 2012). However, whilst focus groups stimulated discussion the individual perspectives were more difficult to expose. In addition, the small sample sizes associated with qualitative research methods alone make it a limited method (Murphy et al. 1998) of both individual and group interviews, i.e. Gaugher et al. (2013) with more than 100 participants; Clarke-Swaby, (2010) among 49; Wong (2010) amongst 105; Alkhwari et al. (2005) with 141; Hayward and Madill (2003) among 27; Ahmed et al. (1999) with 100 and Exley et al. (1996) with 22 participants.

Mixed methods research which successfully combines both quantitative (positivist) and qualitative (interpretative) approaches can overcome challenges as each method generates a different but complementary type of knowledge and allow for more complete analysis (Tashakkori and Teddlie, 1998; Lin, 1998). Indeed using both approaches can address complex and multidimensional questions frequently associated with cultural issues that single research methods cannot achieve (Georgiou, 2007). Both confirmatory (deductive) questions through quantitative methods and exploratory (inductive) questions through qualitative methods (Creswell and Plano Clark, 2007) can potentially be answered. Such comprehensiveness potentially improves the credibility of a study, especially if a greater range of divergent views, perspectives and findings are presented than in a single-method study (Tashakkori and Teddlie, 2010). In this instance, the researcher aims to concentrate on the South Asian population which comprises of mostly Indians, Pakistanis and Bangladeshi's people, so expects to encounter divergent feelings influenced by different cultural and religious beliefs. Mixed methods were considered the most appropriate methodology to combine the strengths of the two approaches to seek the depth of knowledge required to better understand the topic.

Consistent evidence across all studies identify that similar barriers exist today as twenty years ago (Exley et al. 1996; Morgan et al. 2006; Karim et al. 2103). Whilst initiatives taken by the DoH and NHSBT since 1996 (Figure 2) have increased donors, there appears limited impact on changing the wider Asian community's knowledge and understanding of organ donation. What seems to be required alongside and embedded within a combined research approach is additional evidence based and understanding of what works and what doesn't work when engaging with South Asian people on this topic.

6.4 Role of the Steering Group

To engage and develop networks throughout the North West South Asian community one of the first initiatives introduced before the study commenced was to gain the participation and passion of key influential individuals in the community, who could guide and would drive the information campaign deep into their community networks. The purpose behind such an approach was to work '*with*' the community and be guided by it not impose the education approaches on it, to maximise success. The researcher coordinated a steering group with 15 members (including the researcher) who were either passionate or experts on the topic, or both, drawn primarily from the South Asian community. The steering group members represented people from different South Asian ethnicities and their experience with organ donation was varied. Member's included CKD patients on dialysis and kidney transplant recipients, experienced transplant professionals, intensive care consultants, GP, politicians, and religious leaders. Non-Asian members included the academic supervisor and Manager from the NHSBT-ODR department with an in-depth knowledge of the ODR and work of the leading national organisation. This wide range of experience and the support of the steering group members helped plan and guide the study in the right direction, generated interesting and insightful discussion, at times created tensions between different communities and religions but remained committed throughout the 2 years of the research.

The steering group had a formal agenda and recorded minutes and the group met initially every 6 months, then more frequently (3-4 monthly) during the education phase to provide sustained support, with funding used to pay members travel expenses (Figure 7). Indeed one of the biggest roles of the Steering Group was supporting the researcher to identify gate keepers within the community, introduce and recommend the researcher to their own

trusted networks, and open doors that would not be opened ordinarily to a researcher cold calling on the telephone.

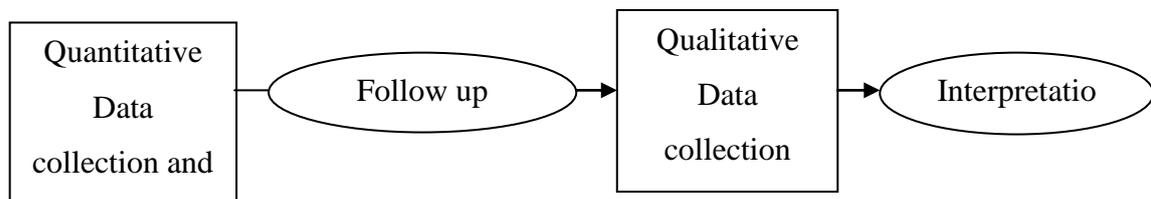
6.5 Mixed Method Study

To realise the aims and objectives a mixed methods study was developed in two progressive phases:

- Phase one: to explore the perceptions, attitudes and opinions of South Asian people with respect to organ donation and identify educational deficits (objectives 1-3)
- Phase two: to implement and measure impact of different educational approaches to increase organ donation amongst South Asian people (objectives 3-5)

Phase one used one of the most popular mixed methods designs in educational research: sequential explanatory mixed methods design, consisting of two components (Creswell, 2002; Creswell et al. 2003), where the quantitative component precedes the qualitative element (Figure 6).

Figure 6 Phase one -sequential explanatory design



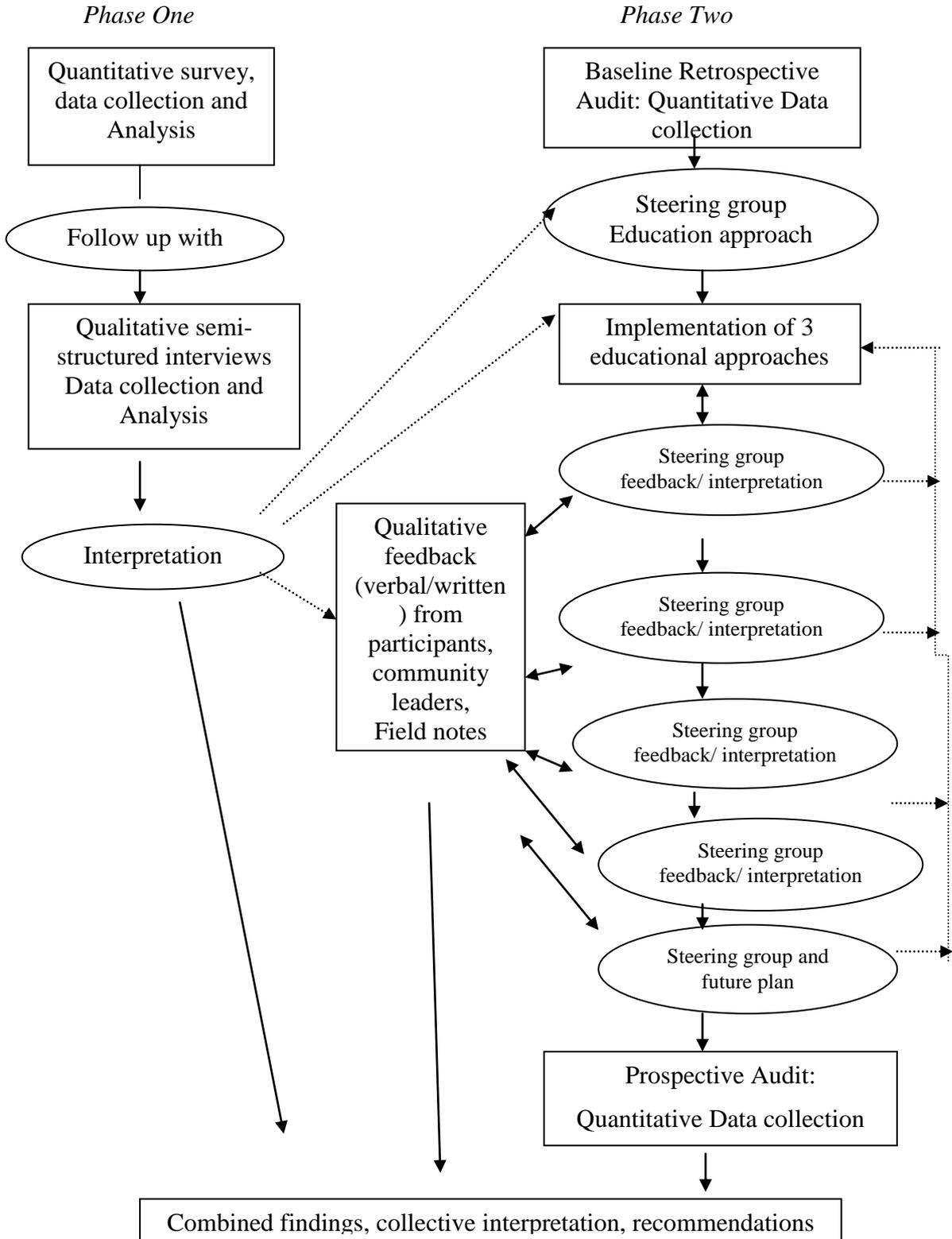
(Creswell and Plano Clark, 2011: p69)

The sequential explanatory design begins with the collection and analysis of quantitative data, which has the priority in this case for addressing more of the ‘*What do South Asian people think about organ donation?*’ study questions, followed by the subsequent collection and analysis of qualitative data, to gain a deeper understanding of ‘*Why do people have this view?*’ This explanatory design was used to identify the reasons behind the scarcity of organ donors from Asian community and to learn an in-depth knowledge on decision of not to donate, using the qualitative results to help explain the initial quantitative results (Morse and Niehaus, 2009).

Whereas phase two used the results of phase one to inform the three educational approaches introduced, then adopted more an iterative approach of implementation,

feedback and adaptation to meet the cultural, religious and health beliefs of the different communities encountered within the wider South Asian population (Figure 7).

Figure 7 Complete two-phased study design



The second approach built on the principles of action research, such as feedback mechanisms, appropriate action discussed by a collective (steering group) and then action taken, and informally evaluated (McNiff and Whitehead, 2005; Hughes, 2008), but did not formally adopt such an approach so as not to be restricted from the outset by the methodology.

The study focused on the South Asian Community of the North West of England, targeting Indian, Pakistani, Bangladeshi, Sikh and Hindu community groups. As the campaign and peer education evolved requests to be involved in peer education sessions outside the area were hard to refuse. The study took place, in total over 2 years and 6 months, throughout the PhD studentship, with Phase one - 12 months, Phase two - 18 months.

6.6 Phase One: Survey

6.6.1 Survey Instrument

Quantitative questionnaires are often the instrument of choice, as suggested earlier a clear advantage of using questionnaire survey methods is the ability to obtain breadth to the research and target a large sample (Parahoo, 2006). Often questionnaires seek written or verbal responses from people to a written set of questions or statement (Cormack, 1996). Usually a questionnaire is predetermined, standardized and structured, and potentially the quickest, cheapest and a relatively confidential and frequently anonymous method of collecting large amounts of information from people scattered over wide geographical area (Parahoo, 2006). For a study hoping to engage ethnic communities across a wide geographical area (the North West of England), a questionnaire was most definitely appropriate. Indeed an anonymous questionnaire can minimise bias in answering questions, particularly on an emotive religious and culturally sensitive topic such as organ donation.

To facilitate comparative analysis with previous studies it was considered appropriate to use an existing validated tool than reinvent and test a new instrument. After reviewing different instruments, the questionnaire developed by Morgan et al. (2006) was identified as the most appropriate to use (with agreed consent). It concentrated on general attitudes and knowledge of organ donation among ethnic groups in the UK and was not limited to just religious reasoning (Razaq and Sajad 2007; Karim et al. 2013). This English questionnaire, was translated into three key languages (Urdu, Hindi and Bengali),

originally by a translation service then the quality and reliability checked by members of the steering committee. Key experts from the different language groups identified independently poor translation and inaccuracies which were checked and changed, with more appropriate phrases inserted. The questionnaire had 25 items divided into three sections to capture knowledge, perceptions and attitudes towards organ donation and demographic details (Appendix 4).

1. *Knowledge*: seven questions, asking about their knowledge of organ failure and willingness to join the ODR; how they felt about the introduction of the Opt out or presumed consent system in the UK. Questions related to willingness to register as a kidney donor, had answers with simple scale responses ranging from ‘*Yes, Definitely*’ to ‘*No Never*’.

2. *Perceptions/Attitudes*: 12 questions reflecting what people think and feel about deceased and live organ donation, along with examining their attitudes towards organ donation and transplantation and the reasons behind those specific attitudes which might affect their decision for being a deceased or live donor. Reassurance was provided to the participants that there are no right or wrong answers. Questions about the participants’ views about deceased organ donation and assessing their willingness to be organ donors after death provided a choice of four options ranging from ‘*Strongly Agree*’ to ‘*Strongly Disagree*’.

3. *Demographic Details*: six demographic questions: age, gender, ethnicity, religion, education level and occupation. The questionnaire was designed to elicit information in the following areas; demographic, social, religious, educational and ethnic characteristics of the population and the known barriers to organ donations.

The time needed to fill out the questionnaire form was not supposed to exceed four to five minutes based on the pilot test with a number of steering group members, family and friends.

6.6.2 Survey Sampling Method and Size

The survey sampling methods employed non probability convenience sample the advantage of which lies in its convenience and economy (Polit and Beck, 2004). Often sampling is a compromise between theoretical requirements and practical issues such as

time and cost (Webb, 2003). It is generally believed that the larger the sample size, the better the estimation of population parameters. Before selecting subjects, quantitative researchers need to know what characteristics participants should possess and to whom study results can be generalised (Polit and Beck, 2004) and the findings can be applicable from the sample back to the population (Parahoo, 2006).

This study was sampling the perceptions of South Asian people which predominantly will include Indian, Pakistani and Bangladeshi residents from in the North West of England. As indicated earlier these people are at high risk of developing type 2 diabetes a major cause of CKD (Khunti et al. 2009). In several urban locations in the UK people of Indian, Pakistani and Bangladeshi descent form the largest ethnic minority group (ONS, 2009). In the North West the target population there are 293,700 South Asian people (ONS, 2009), but to gain the views of so many would be impossible in the time frame. A clear inclusion exclusion criterion was developed to ensure South Asian people were recruited and the sample reflected appropriate community and ethnic groups, but people unable to give informed consent (Table 23).

Table 23 Sample Inclusion/Exclusion criteria

<p><i>Inclusion:</i></p> <ul style="list-style-type: none">• People aged 18 years and above• Attending their religious or social gathering in the North West of UK• From South Asian background (Bangladesh, India, or Pakistan) may or may not have been born in the UK, and at least one parent of South Asian origin <p><i>Exclusion:</i></p> <ul style="list-style-type: none">• Individuals with incapacitating mental health illness• Individuals with a significant audio-visual deficits and verbal expression problems• Individuals too sick or too elderly to participate

This aim of the survey was to explore perceptions/attitudes towards organ donation, recruiting sufficient people for analysis across the three South Asian groups rather than providing a representative sample of the target population. It was anticipated that a convenience sample of more than 500 people would be feasible to recruit given the time frame of the study, similar to Karim et al. (2013). Morgan et al. (2006) powered to test

differences in organ donation barriers between Black Caribbean's and others ethnic groups, but only actually recruited 33 Asians out of 1536 participants. This study is concerned only with South Asian perceptions to inform education strategies. In a smaller Master's level study exploring barriers to organ donation the researcher had experience of recruiting 100 people across two community events (Pradeep, 2010), so 500 responses was considered a realistic target.

In this study the advantage of targeting a larger number of participants was to provide an opportunity to identify the needs for distinct groups within the sample, to understand and explore how demographic characteristics such as: age, gender, employment, education level, religion and ethnicity. There are limits, however, to the benefits which can be gained from selecting a very large sample to improve the accuracy of one's results. Since increasing the sample size often comes at a certain cost to the researcher in time and resources, a trade off is usually necessary to restrict the sample size to an achievable amount (Hicks, 2004).

6.6.3 Survey Recruitment and Data Collection

At community gatherings a hard copy questionnaire was provided along with an invitation letter and information sheet (Appendix 5 and 6). The information sheet explained the need for the study and provided some clear statistics of Asian people waiting for transplant. It explained that most of the frequent questions asked by the participants during a research study; these questions were obtained from the literature review. Answers were written in simple English for the lay person's understanding; and copies translated into Urdu, Hindi and Bengali languages. The invitation letter explained about the researcher and the reason for conducting this study and also provided the contact details of the researcher and the supervisor. A reply slip was available with each questionnaire to enter their contact details if they were not willing to join the register and would like to take part in the interview (discussed later).

Previous methods such as distributing questionnaires through GP practices were not particularly successful in this ethnic group (Morgan et al. 2006), recruiting only 2.1% (33) Asian participants. Whereas distributing questionnaires at community events, through the researcher's own prior experience, was an effective and appropriate method, although time consuming explaining the study face-to-face, it was effective in gaining completed

questionnaires and gaining responses. Naturally occurring South Asian community gatherings including community centres, religious places, social event platforms, in the area where large numbers of people from the local population could easily be contacted, were accessed opportunistically. To gain access to these events study information was made available to religious and community leaders, and their verbal agreement to allow engagement with the community in this way obtained prior to attending any event.

As a result the questionnaire survey was conducted at different times on different days. The researcher had a stand at the meeting with information about organ donation and people who approached the stand were invited to take part in the questionnaire, with a verbal explanation by the researcher as to the purpose of the research study. Care was taken to encourage a range of ages, different ethnic and religious backgrounds to maximise a varied representation of perceptions. Participants were informed that they could complete the questionnaire at home and send it back and were offered a reply paid envelope. There was no monetary incentive for the voluntary participation or completion of this survey, and no names were attached to the questionnaire so anonymity was maintained.

A website (www.southsianorgandonor.org.uk) was constructed at the outset of the study with the intention that overtime it would develop into a platform for the dissemination of organ donation education. It was used to gather people's views to organ donation with an electronic based questionnaire, translated information sheets, invitation letter requesting participation if they lived in the North West of the UK and the link to join the organ donor register. This method of completing the questionnaire was advertised at the different community gathering allowing participants the option to complete survey online at their leisure and in private if preferred, assuring data confidentiality and anonymity. Awareness of the study website was promoted using a specially created Face book group, and linked to Asian media, Trust, University, and British Renal Society.

6.6.4 Reliability and Validity of the Tool

Using an existing tool increases the reliability and validity of the instrument having been previously used, tested and validated (Morgan et al. 2006). Prior to translation of the English questionnaire into three languages (Urdu, Hindi and Bengali languages) the content and face validity was discussed with the steering group. Members were asked to assess whether questions were/whether socially and culturally valid, the wording

appropriate, and if other questions needed to be asked. One concern expressed was the justification of including the question regarding ‘*Do you agree with presumed consent?*’, because many people may not understand what this actually meant.

The researcher presented the current evidence for the committee explaining the importance of capturing the South Asian people’s view on this topic. The arguments of the Welsh Government planning to implement the Opt out (presumed consent) system from 2015; the opposition in the UK in the early 20th century by almost all the professional groups involved in implementing such legislation (Koffman, 2000); the faith leaders disagreement (Coppinet al. 2010); and only 57% of general public in favour (Cameron and Forsythe, 2001) were discussed. The researcher drew attention to the ODTF report (2007) published by cultural working group explaining that an Opt out system could be probably easier to motivate people than to Opt in, but would need a lot of work prior implementation to ensure that everyone knew about the system, and how to Opt out. More recently calls for to identify people’s opinion about presumed consent were stressed (Randhawa et al. 2009) and in particular the perceptions of different communities. The value of such information to the transplant community in future policy and practice was identified. Steering Group members agreed to adopt the same questionnaire without any modifications or changes.

The quality of the translation of the questionnaire was checked by key language experts within the steering group, and fortunately errors from poor translation corrected prior to administration. In addition the comprehensibility, reliability, feasibility, acceptability and completeness of the questionnaire content were independently checked by two senior research managers in the Trust and the University.

6.6.5 Survey Data Analysis

The empirical portion of quantitative studies involves collecting research data and preparing those data for analysis (Polit and Beck, 2004). The initial questionnaire survey data was entered into an electronic survey system (BRISTOL) either directly by the respondent using the online questionnaire or by the researcher from the hard copy questionnaires. A professional statistician assisted with analysis using SPSS (version 20). Initially Chi-squared tests were used to test the existence of associations between outcomes and demographic characteristics and between attitudes, knowledge and demographic characteristics. The perspectives of the target community; Indian Hindu,

Indian Christian, Indian Muslim, Pakistani Muslim, Bangladeshi Muslim and others including Sikh, were examined and characteristics explored according to age, gender, and level of education. A significance level of $p < 0.05$ was used throughout. Descriptive statistics and logistic regression were used to explore differences across community as appropriate.

6.7 Phase One: Semi-Structured Interviews

6.7.1 *Semi-Structured Interview*

The primary advantage of using qualitative methods such as interviews within the context of exploring the reasons behind an attitude, is not just that participant perceptions can be identified but also the opportunity to develop an greater understanding of why such issues arise, the purpose and meaning to an individual in the context of their lives, values and personal perspectives (Julien and Michels, 2004).

The study aims to identify, from South Asian community, why barriers on organ donation arise, the semi structured interview helps to explore a range of different views about the sensitive research topic from the individual perspective (Krueger and Casey, 2009). Recorded individual interviews are a useful tool to examine knowledge, values, beliefs, and attitudes (Whittakar and Williamson, 2011) and transcripts based on recordings provide a highly detailed, publicly accessible representation of social interaction and contextual understanding (Silverman,1998).

Semi-structured face to face audio recorded interviews were used to obtain the in-depth knowledge about the reasons behind why someone would not want to register as an organ donor, used successfully in previous studies (Exley et al. 1996; Alkhawari et al. 2005). The semi-structured interview guide was informed by the phase one questionnaire responses, and the key barriers that emerged explored through probing questioning to elicit a deeper understanding as to what prevented individual's becoming ODR, their beliefs and preferences. Eight core questions examined barriers, knowledge, decisions and preferences for deceased organ donation, needs of a family member's and views on the Opt out system (Table 24) across all interviews.

Table 24 Interview guide

1. You chose not to be recruited onto the organ donor register – can I ask your reasons for this? Had you heard about organ donation? (*prompts to discuss*)
 - *Religious and cultural beliefs- (Meddling with nature/God's creation)*
 - *Understanding of organ donation – discuss*
 - *Personal view*
 - *Family issues/concerns*
 - *Distrust of the medical system, Issues of fairness in donation system*
 - *Myths - Personality change, Reification of body parts*
2. Do you know there is scarcity of organ donation from Asian people, there are more Asian people waiting for transplant?
3. If you had a family member in intensive care who was to pass away, would you consider if appropriate donating their organs to those people who need them? If not why not?
4. What do you think we could do to overcome this problem of organ donor shortage?
5. Do you know anybody who is suffering with kidney failure?
6. Would you or your family member accept a donated organ if you were in need?
7. What do you understand by presumed consent, what is your opinion on this?
8. What do you think we could do to overcome this problem of organ donor shortage?

Within questions different probes explored contextual factors such as religion, culture, social norms and values, politics, economics and technology that may influence an individual's willingness to join the ODR (Morgan et al. 2006; Randhawa 2006; Park et al. 2009; Tumin et al. 2010; Gaugher et al. 2013). In addition when exploring knowledge questions included the impact of different media, the internet, and the nature of the information to which an individual was (Morgan et al. 2006; Feeley and Vincent 2007; Quick et al. 2009). Finally participants were asked directly what strategies could be introduced to overcome any barriers to organ donation and if appropriate influence their own or the decisions of the wider community to actively donate.

6.7.2 Interview Sampling Frame and Sample Size

In this study the interviews were being used to target people who did not agree with organ donation, respondents who answered 'No' to joining the ODR within the questionnaire were identified and those willing to be invited to take part in an interview provided their contact details, on the returned questionnaire. The sample was self-selected including only those people from the outset willing to discuss their views.

From the reply slips received a stratified purposive sampling frame was used, where possible, to select a sample of different people of varied ages, across different ethnic and religious groups, with an equal number of male and female participants. Demographic variables such as age, gender, religion, social and economic status, level of education, ethnicity, have been shown to influence the level of knowledge and both positive and negative views on organ donation (Morgan et al. 2006; Gaugher et al. 2013). Ten interviews were considered manageable in the time available. The sample size is comparable to similar studies that explored this topic using individual interviewing (Exley et al. 1996; Hayward and Madill 2003).

6.7.3 Interview Data Collection

The purpose of the interview was not to convince or educate participants to join the ODR but to obtain a deeper knowledge of the reasons why people decline to be an organ donor. Indeed due to the sensitivity of the topic a non-judgemental approach in relation to the content of the interview and a confirmative, interested and respectful approach to the interviewee as a person were important (Taylor and Bogdan, 1984). The study used an open-ended question format to obtain reactions, beliefs, and motives of individuals with negative attitudes towards organ donation and transplantation from varying backgrounds.

The researcher contacted each person to be included in the sample, to answer questions regarding the purpose of the interview, and arrange an appropriate time and preferred venue at which the interview would take place. Care was taken to approach only those individuals who voluntarily consented to take part in the study, and no vulnerable adults were included, following the study inclusion/exclusion criteria (Table 24). Parahoo (2006) emphasizes that caution needs to be taken in exploring the psychological harm that can arise from participating in the interview. Whilst the researcher believed the study topic

would not cause physical or psychological harm to the participant they were mindful of the cultural and religious sensitivity of the subject. Participants were given the name and contact details of the researcher and the academic supervisor overseeing this research to express any concerns, gain reassurance or ask a question. Indeed participants were encouraged to seek clarification and ask questions regarding the study or the research process before signing the consent form, after reading the information sheet (Appendix 6). Informed consent (Appendix 7) was obtained on a voluntary basis from the participants before the interview following the initial introduction of the study, which gave an opportunity for the participants to withdraw from the study at any point without discrimination and prejudice (Pope and Mays 2006).

Each participant was offered the use of an interpreter to speak in their mother tongue/native language. It was perceived that interviews would last no more than 90 minutes. Within this study all conversations interviews were recorded with the participants consent, it allowed the full conversation to be captured and enabled the preservation of meaning during data analysis (Polit and Beck 2004; Finlay and Ballinger 2006; Whittakar and Williamson 2011). Moreover it allowed the researcher to focus their attention on their participant, without being engaged in writing or listening.

6.7.4 South Asian Female Interviewer

Previous research has suggested that certain Asian women find the prospect of a young, non-Asian male interviewing as a negative experience, intimidating or inappropriate (Brice 2008). Such a barrier did not exist in this research as the interviewer/researcher being female from the same Asian background, indeed ethnic and gender matching for the interview facilitated from female participant engagement and overcome any potential problem (Hillier and Rahman 1996; Phillipson et al. 2003). Research demonstrates that how interviewees respond to an interviewer depends on who they are in their lives, as well as the social categories to which they belong suggesting difficulties can arise when people study groups with whom they do not share membership (Silverman 2000). Certainly a social, religious and cultural distance, and the sensitivity of the organ donation topic, could result in a researcher not asking the right questions at the right time, mistrust in the interview and a misunderstanding of both the question and the response. Collins (1990) suggests that *'in order to make legitimate knowledge claims, researchers should have lived or experienced their material in some fashion'* (p 232). As the researcher/interviewer was

from the same cultural background, she felt more confident in asking the questions and making that personal/professional connection to develop a closer and important rapport with each participant.

6.7.5 Interview Analysis

Participant interviews were transcribed verbatim and analysed using thematic analysis to generate a deeper understanding of the barriers to organ donation within the South Asian community. Verbatim transcription of data collection has become a frequent method of managing data in qualitative research and is considered as a fundamental to the analysis and interpretation of verbal data generation (Halcomb and Davidson 2006). Simultaneous reflection was often used throughout the interview process to clarify and verify aspects of the discussion back to participants (Julien and Michels 2004; McCaughan and McKenna 2006). As masses of data can be gathered over the course of a study, Silverman (2010) advocates an early start to the analysis process to avoid the situation where the researcher is always in catch up mode. In this study, the researcher commenced data analysis concurrently with data collection, which provided the researcher with the opportunity to follow up on themes and seek confirmation of similar patterns or differences between the views (Kreuger and Casey 2009). This approach enabled the researcher to understand the emotions and feelings of the participants.

This study employed systematic method of thematic analysis to explore the data by following three stages, which included, descriptive coding, interpretive coding and overarching themes (King and Horrocks 2010). Participant interviews were coded with an identification number that indicated gender, and religion. Transcripts were thematically coded (according to the research questions and themes that emerged in discussions). The interview transcripts were indexed and mapped on the basis of recurring themes, known as descriptive coding.

The second stage of analysis included clustering the descriptive codes together with other codes that seem to share common meaning to create an interpretative code that captured that meaning. Re-reading the transcript carefully, highlighted content that was potentially relevant to the topic and rechecking with the corresponding audiotape provided credibility to the researcher's interpretation. The researcher redefined and reapplied the interpretative codes from one interview to the next. At the end of data analysis from each interview, the

researcher reviewed and interpreted the meaning of the clusters, in relation to the research question and aim, and calculated the number of persons who had given one or more statements belonging to a category, indicative to show how common the different categories were across the participants.

The final step identified the overarching themes that characterised key concepts about organ donation from the analysis. The researcher interpreted the reason for the participant's decision for not joining the organ donor register as themes to explain to the wider community. The different inductive techniques were used to analyse interview transcripts and identify emerging themes (King and Horrocks 2010). This helped to describe each of the overarching themes and referring to examples from the data and using direct quotes to help characterise the theme for readers. Moving beyond such steps as coding and thematic analysis, researchers need to determine how best to interpret the data they are examining, and adopt an approach which suits the phenomenon under investigation, the paradigm in which they are operating, their own personal styles as researchers, and the data with which they are working (Sitlington et al. 2007).

6.8 Phase Two: Education Approaches

Phase Two of the study involved action with the aim to increase organ donation amongst South Asian people through different approaches and primarily education and the provision of accurate information. The three education approaches selected included:

1. Recruitment of potential donors by and through GP services.
2. Education and training of SNOD'S to increase confidence in approaching South Asian families to donate a deceased relative's organ.
3. Peer-led education, information and awareness campaign within the local South Asian community in partnership with community and religious leaders, using appropriate media.

The evidence underpinning the rationale for these approaches and how and what was implemented is described. The three approaches were not selected because they were considered the most effective methods because there was limited evidence to demonstrate this, but primarily they were selected in response to evidence from South Asian people

suggesting they may be useful to influence opinion. The focus of phase two then was to pilot the three approaches to education and gather more robust evidence as to what works for whom, why and how.

6.9 GP Education and Recruitment of South Asian people to the ODR

6.9.1 Rationale for the GP approach

There is evidence available from late 19th century that GP involvement in health-related education is an influencing factor to raise awareness (Weinehallet al. 1998). Promoting best practice in transplantation includes improving health care professional advocacy and confidence, such as general practitioner's (Hoy et al. 2011). The advantage of targeting primary care doctors (GPs) includes; the fairly high level of contact they have with all groups in the population, people generally perceive their own doctor to be a credible and trusted source of expertise, despite them often holding more negative views than other doctors in the wider health system (Calnan and Sandford, 2004; Pradeep, 2010). The potentially promising role a GP could take with respect to organ donation has not really been explored. A study of 200 GPs working in Ireland revealed that only a minority provided donor cards (38%) or displayed information regarding organ donation (28.2%) (Ward et al. 2012). The study also identified a lack of discussion and unfamiliarity among the primary healthcare practitioners regarding organ donation, when they were supposed to be in a vital position to convey the organ donation message (Ward et al. 2012).

Results from a prospective randomized study among family physicians (GP's) in the US highlighted that GP's can increase the commitment of their patients to be an organ donor registrant (Bidigare and Ellis, 2000). The UK Government advised GP surgeries in 2001 to display posters, advertising organ donation and present donor cards as part of their public health promotion role. Cameron and Forsythe (2001) called for a survey to determine why the message has not been displayed, and suggested that the practices not doing so be held responsible. Unfortunately, till today the non compliance issue persists and feedback from Steering Group member's confirmed that the majority had not seen posters in the different GP surgeries attended. The aim of this small pilot project was to test out such an approach and the willingness of GP's to promote organ donation for people from the South Asian community.

6.9.2 The Planned and Modified GP Approach

The planned approach with GPs included a two-pronged approach to education, that of educating the GPs and the GP in turn educating the South Asian patients within their practice. Initially a joint education session was planned for 50 GPs (from five-ten practices) to discuss their perceptions of organ donation, provide religious and cultural clarification, and information packs regarding organ donation, the scarcity of organs in the South Asian population and the long waiting times for South Asian patients. There was a poor response to attend this so each individual GP surgery recruited was visited separately by the researcher, the study was explained and the education materials distributed. Education materials to display in the practice centre and consultation room included:

- Patient organ donor recruitment packages (with coded ODR forms)
- Organ donation advertisement posters
- NHSBT translated organ donation leaflets and information flyers

The approach included the GP practice displaying posters advertising and informing patients coming to the practice about the opportunity to be a registered organ donor and the plight of the South Asian community. The education focused on beliefs regarding perceived susceptibility and perceived severity for an individual and the wider South Asian community with information summarised on a vibrant poster (Appendix 9). The NHSBT literature translated included information to overcome barriers of religious misconceptions and myths of organ donation. In addition the whole approach was built on the premise that information provided by a figure of trust was seen to be far more important and relevant to the Asian population than information provided by a stranger (Baines et al. 2002; Morgan et al. 2006).

The ideal approach was that GPs would ask patients from the South Asian community after a consultation, where appropriate, about their perception of organ donation and briefly discuss the need for South Asian people to help their own community. If interested the GPs would provide information for their patients to take home, or forms if applicable, to recruit them as ODR's. The posters displayed in the waiting rooms allowed people to be thinking about the issue prior to entering the GP consultation. This information could also be distributed by the reception to all the South Asian people entering the surgery. This approach was recommended and supported by the South Asian GP representative on the

study Steering Group, patients and community experts, and considered simple enough to implement within a general practice.

However, the approach when implemented needed to be modified as from the outset GPs refused to initiate an organ donation discussion with patients unless they enquired about the topic first. GP feedback suggested consensus that posters displayed in the waiting room and consultation areas and literature made available would be sufficient for a person to come forward to discuss, if interested in being an ODR. Reluctantly, despite the researcher trying to encourage a more proactive approach this was the modified approach that was taken forward for a 12-month observation period.

6.9.3 Identifying and Recruiting GP Centres

It was important to recruit GP centres to the study that served a high population of South Asian people to maximise the number of people being targeted. Areas in the North West high in South Asian population (>70% of the population recorded) were searched, and through small area census statistics and the collaboration of Lancashire and South Cumbria Agency (LaSCA), primary care trusts, with high number of South Asian patients could be identified. It was anticipated that five GP study practices (medium to large with 6-10 GPs) would be approached and recruited. National Research Ethics approval was obtained to recruit NHS primary care trusts and GP practices within the research study.

6.9.4 Measuring Impact of GP Recruitment to ODR

The number of people recruited by GPs as ODR through specially coded registration forms were monitored by NHSBT, as a direct outcome measure as to the impact of the GP education approach. Activity of new registrants on the donor register was observed for a 12-month period. The statistics of ODR were collated by NHSBT and an update provided every three months. Throughout the observation period the ODR activity for each GP site was fed back to the GP practice every three months, to act as both a motivator and reminder to sustain activity.

6.10 Education of ITU and SNOD's

6.10.1 Rationale for ITU/ SNOD Education Approach

One of the barriers identified in earlier chapters preventing or hindering donation may be the attitude of health care professionals who are not always in favour and therefore do not create the right social climate to encourage participation (Guadagnoli 1999; Zambudio et al. 2009). Randhawa (1997) identified over 17 years ago the need within the hospitals, for clear guidelines on how to approach individuals with requests for the donation of their loved one's organs. The family approach should be coupled with specific training and counselling relating to working with families from a range of ethnic and faith backgrounds as this will influence consent rates (Sque et al. 2005). Whatever the approach, an essential component is the involvement of the healthcare team, workers sensitive to the values and the traditions of each individual group, to generate a coordinated effort to clear misconceptions about organ donation through improved public education and awareness (Van Embden et al. 2008).

Studies amongst nurses highlighted that education can enhance their knowledge and commitment to organ donation and directly increase donation rates (Aghayan et al. 2009). Conversely a lack of education and training reduces the number of medical staff who feel sufficiently confident to approach relatives about potential organ donation (Schaeffner 2004). Many years ago there was evidence in Spain that an initial negative response can be changed into consent if the approach is right and the relative's reservations about brain death, the integrity of the corpse, or religious concerns are dealt with proficiently (Gomez and Santiago 1995). Moreover whole team education in Spain of organ donation teams has had a significant impact on deceased organ donation rates (Rada 2013). In addition, training to critical care staff on organ donation, improves their ability and readiness to make requests and the handling of potential donors and their families (Evanisko et al. 1998). However, Shafer (2009) identified no structured training programme for donor transplant coordinators, and this is still the case today, and advocated that structure was needed to make organ retrieval and donation more effective.

6.10.2 The Planned and Modified ITU/SNOD Education Approach

The health professional education approach was informed and took forward the recommendations from Randhawa (2012) to provide training on religious and cultural

views relating to death, burial and cremation practice so anyone caring for a family and the dying patient, who has the potential to become an organ donor, would be able to recognize and meet their spiritual and cultural needs.

Initially it was planned to engage 10 ITU sites serving areas of high South Asian populations and provide education workshop to teams of intensive care staff including the SNOD in an attempt to assure a coordinated approach to cadaver organ donation. Ethical approval was obtained to engage NHS staff and recruit the ITU sites for the education training, and measure the impact on cadaver organ donation rates. However, when the researcher met with the North West SNOD's team manager to discuss the study further, they recommended a more focused education approach through the SNOD's, not the whole ITU team. The rationale for such an approach was that whilst potential donors were identified by the nursing and medical team, current practice and policy was that they informed the SNOD who was the only person responsible for approaching the family and discussing organ donation. NHSBT guidance that SNOD's are involved in every donor family approach, suggesting that when a family is approached by a SNOD the consent rate is more promising than approached by another health professional (NHSBT 2013). NICE (2011) recommendation that as a standard of care, SNODs should be involved as early as a possible when approaching the families of potential organ donors. In addition due to on-call and holidays a SNOD attached to a particular Trust may not always be available and could be replaced at times by a different SNOD from a nearby Trust, so educating just within one Trust would not generate a coordinated approach and consistent training.

The suggestion and full rationale was communicated and discussed at the next steering group meeting and with the researcher's Trust ITU Lead Consultant, and a unanimous decision was made to follow recommendation the SNOD's team manager. The modified education approach then was to concentrate on training the North West SNOD's instead of trying to educate individual teams of ITU staff.

Education was planned accessing the scheduled North West SNOD meetings. The aim of cultural and religious awareness training specifically orientated to the South Asian people is to improve staff confidence, communication skills and knowledge base to better ensure a more family-centred approach to organ requesting and to be in a far more informed position to support a family dealing with death, grief, and potential organ donation

(Randhawa 2012). In addition the purpose was to explore peoples' fears, experiences and misconceptions, as well as identify with SNODs a 'best practice' approach for potential South Asian donor families. Education was delivered by the researcher with the assistance of key community experts who formed the Steering Group membership, a Transplant Surgeon and Muslim Scholar.

Access to the SNOD team was gained with the ethical approval of NHSBT and with the permission of the North West SNOD Team Manager. The education training took place during a planned meeting date for the SNOD team members, across the North West SNOD's. Verbal agreement to take part in the education session was gained from SNODs prior to the training.

6.10.3 Audit of ITU Cadaver Organ Donation Rates

Cadaver organ donations were observed across the North West for a 24 month period; 12 months before the education was introduced and 12 months after, forming a retrospective and prospective audit on deceased donor data. The NHSBT statistics team agreed to provide the anonymous audit data informing the donor activity on proceeded South Asian donors, potential donors and refusal reasons, which overcame the issue of needing to gain access to ITU sites to retrieve the data manually.

6.11 Peer-Education and Recruitment to ODR

6.11.1 Rationale for Peer-led Education Approach

From the literature review (Exley et al. 1996; Davis and Randhawa 2004) and confirmed by the phase one findings of the study; a lack of information, awareness and knowledge was a serious obstacle among the South Asian community to promote organ donation. Therefore an iterative and responsive approach was developed to overcome this lack of awareness and to ensure the community were informed and equipped with accurate, culturally sensitive, pertinent and relevant information. Similar to the GP approach the education focused on addressing beliefs regarding perceived susceptibility, perceived severity, but also overcoming perceived barriers and actively promoting the perceived benefits of organ donation.

Education among the South Asian community is important to raise the awareness and to change the negative attitudes of people towards organ donation from a dead person

(Shahbazian et al. 2006). But it is also explained that health education alone is not enough in health promotion but need a pro active, supporting and culturally competent initiatives, to educate among the BAME community (Cochran and Conn 2008; Jain 2014). To provide this pro active education sessions among the BAME community Jain (2014) suggest peer educators as they have natural empathy with the target groups in terms of culture, religion and language, as these are important factors which impact on health decisions and behaviours. But there is limited robust evidence on the success of this approach.

Evidence suggests beliefs from migrants, who originated from South East Asian countries, may well view organ donation as a Western concept and not accept it (Cheng 1992). Indeed they may have witnessed unjustified organ allocation from deceased organ donors and organ trafficking from their home country, so misconceptions could be transferred to the UK. Such misconceptions and a lack of awareness can be influenced if the South Asians are in an informed position, through community education by South Asian people who are positive about organ donation, advocates of organ donation for future generations, and the key to closing the ethnic gap between a willingness to donate and the act of donation (Smith et al. 2008).

6.11.2 Peer Education Approach

A peer-education team were recruited from the steering group members; including CKD transplanted patients, Transplant Surgeons, religious leaders, community leaders (as well at times family and friends) to work alongside the researcher to deliver a minimum of four outreach peer-led education sessions each to encourage organ donation within the local South Asian community. Relevant community groups were identified to build and on establish networks (from Phase One), and accessed with the permission and support of religious and community leaders. Information resources for BAME groups were supplied by NHSBT. In addition, a media and social network campaigns combined the following strategies to distribute culturally appropriate information and increase awareness:

- Attend annual Religious gatherings in the North West (>10,000 people)
- Attend religious/community group gatherings at Temples, Mosques, and Churches and community centres (older people, mothers, different male/female groups)
- South Asian specific radio, TV, advertisements/talk shows
- Website – information portal, access to register, stream sound bites

In addition, the researcher developed different video, audio clips and South Asian publications press releases/articles in different languages with participation from religious/community leaders, patients on the transplant waiting list and transplant recipients to develop promotional materials to encourage organ donation. Featuring stories of potential organ recipients and family members of deceased organ donors and patients who are on dialysis waiting for a transplant has been shown to be an effective way of raising awareness (Wong 2010). With participants consent these were streamed through the website and shown at educational events. This task was assisted by the media students from the University of Salford, who filmed and edited as part of their course project; and the Central Manchester University Hospital Communication Officers advice and guidance on the rules and ethics of filming, and promoting the study wider in the Trust.

6.11.3 Empowering the Community (partnerships with key influential figures)

Evidence has highlighted that religious and social leaders have a role to play in spreading the organ donation message, when they are in favour then the community is more likely to donate (Morgan and Cannon 2003). Muslim people prefer their religious leaders to be involved in organ donation awareness and education as this adds confirmation that it is acceptable, indeed support from religious groups is an important factor in overcoming barriers to organ donation (Lam and McCullough 2000; Wong 2010). To build on this knowledge the researcher from the outset and throughout the study embedded a continuous strategy of developing relationships with different religious groups, networking with key community influential leaders, and community groups, initially within the North West but soon extended to involve key national and international figures. Some of these influential people were invited to be members of the study Steering Group.

6.11.4 Measuring Impact of Peer -education on ODR

Activity on the donor register was observed for a 12-24 month period from the introduction and attendance to deliver the first peer education community event until the very latest event attended just prior to submitting the thesis. The activity was monitored with the help of NHSBT statistician. ODR forms with specific codes tacked to peer education events, different to the GP codes, were used to monitor the direct impact of recruiting and registering new South Asian organ donors. More as a long term measure,

new registrants were monitored throughout the study, using the unique study identifier by the NHSBT to identify if any actually donated their organs if and when they died.

Secondary informal data was captured during the peer education events, trying to extrapolate what works and what doesn't work and why and how, to increase the South Asian organ donor registrants from the North West, and adapting and changing the approach depending on the community being addressed. This was achieved by gathering naturally occurring data, experiences and reflecting on observations through:

- Qualitative observations and reflective field notes
- Feedback from event organisers and media editorial boards
- Steering group discussion
- Email communication from community partners

6.12 Ethical Considerations

Due to the sensitivity and complexity of the subject, the ethical approval process was both a challenge and time consuming. The study needed ethical approval from different organizations; the National Research Ethics Committee (to involve initially ITU sites and GP practices), Central Manchester University Hospital (CMUH) Ethical Committee (employer of the researcher), University of Salford Research Ethics Committee (where the researcher was a PhD student) and NHSBT (to access the statistics of the ODR) and the individual Primary Care Trusts and ITU Research and Development committees. In total, 19 different ethical and governance committees were accessed in order to obtain full approval and commence the planned study. Each ethical committee had different guidelines and questions to answer and their review reports varied. These steps provided more opportunities to review and fine-tune the study. The researcher successfully managed to satisfy individual ethical committees' concern and obtained their approval. This positive outcome provided the researcher and the team a lot more confidence and reassurance to proceed with study.

Particular ethical issues which required consideration included informed consent, involving non-English speaking participants, confidentiality, justification of sample and safe storage of data. All these documents were approved by the ethical approval committee and were translated in three key South Asian languages i.e., Hindi, Urdu and Bengali.

6.12.1 Informed Consent

A comprehensive information leaflet (Appendix 6) was developed in order to inform the potential participants of the background, purpose and methods of the study in writing and asserting that they understood and agreed on how they may participate in the questionnaire survey if they so wished. Time was provided to read the leaflet and to decide whether or not to take part. Participants were expected to complete the questionnaire without any further interaction with the researcher in order to avoid bias (Long and Johnson 2007). Questionnaire participants were informed that participation is voluntary in order to obtain informed consent (Green and Thorogood 2004). So informed consent was presumed on return of a completed paper or on-line questionnaire.

Interview participants were required to sign a consent form (Appendix 7) prior to the interview, giving permission to use their anonymous quotes in media, journals and social websites. Participants were asked to sign two copies of the consent form, a copy for themselves the other kept by the researcher in order to provide both parties with a record that consent had been given (Bell, 2005). Additional separate written consent (Appendix 8) was obtained from participants, religious leaders, transplanted patients, or celebrities to use film and media footage on the advertisements and giving permission to upload onto the study website platform and social medias.

Recruitment of South Asian people onto the ODR was at all points throughout every peer-education session voluntary. Information was given about; if after being recruited a person changed their minds they could remove themselves immediately from the register by contacting NHSBT. Permission from religious/community leaders was gained prior to accessing community groups. Participation in the study and the different education approaches by SNODs, clinicians, GPs, and selected ITU sites was voluntary.

6.12.2 Non-English Speaking Participants

It was crucial to the aims of the study to attract people from the South Asian community who maybe could not speak English or for whom English was their second language. To overcome such language barriers all the study information (questionnaire survey, invitation letter and information sheets) were translated into three key south Asian languages (Hindi, Urdu and Bengali). The quality and reliability of the translations were checked for by

independent language experts across the different communities and phrases amended where appropriate. An interpreter was available if required at the interview so conversations could take place fluently in their native tongue if preferred. However, Steering group members who were bi-lingual also offered to assist where necessary to overcome any communication barriers and peer-educators who were all multilingual, and also NHS employees, assisted with the interview interpretation. This approach was considered comprehensive to overcome language barriers, for non-English speaking people to feel included, and indeed foster participation.

6.12.3 Confidentiality

All questionnaires were anonymous and coded so when stored there were no identifying labels, just non-identifiable demographic information. Participants retained a copy of the information sheet and invitation letter, for future contacts and clarifications. Any information pertaining to the participant's demographic data was treated as confidential and access was granted only to the researcher, academic supervisor and NHS statistician.

Participants were given the right to anonymity, with neither their names nor potentially identifying data appearing in the final report or this thesis; Interview participant anonymity was maintained, identified by a number codes, their gender and the first letter of their religion (for example 3FM, participant number 3, Female Muslim). It was reinforced to participants that could chose or refuse to answer any questions they found inappropriate or upsetting and/or withdraw from the interview at anytime. The information sheet also contained contact details of the researcher so if participants wished to withdraw their consent at a later stage they could contact her direct (Bell 2005), although none did. All the recorded interviews were stored with initials to maintain the confidentiality, with a master list of personal contact details stored separately on a password protected computer, known only to the researcher.

All the interpreters to be involved in the study were NHS employees (Consultant Transplant Surgeon, Specialist Registrar and Senior Charge Nurse). Therefore it was not necessary to have them sign a confidentiality agreement as they are bound by their code of professional ethics such as; Ethical Principles for Medical Research Involving Human Subjects (The Declaration of Helsinki 2008). The researcher followed "Code of Good

Practice” throughout the study to ensure participant information gathered as part of research studies remain confidential and personal participant data protection.

6.12.4 Data Handling and Storage

Data will be stored for three months following the submission of the project in a locked filing cabinet and any personal details was kept separated from the data. This was in accordance with the term of Data Protection Act (1998). All databases at the Trust were password protected and participants’ responses were numbered to maintain the anonymity. The main database, which contained the names and addresses of participants and their subsequent research code, was stored in the clinical area on a password-protected computer. Access to this was restricted to the researcher and the academic supervisor. All paper based copies of completed questionnaires and field notes were research coded and stored in a locked filing cabinet and in a locked office, the key accessible only to a member of the research team. All data will be stored for a period of 10 years (recommended by the University and CMUH) after publication of the results to enable verification of data if challenged. These data are anonymous and stored securely until a time when it can be shredded and disposed of appropriately.

The information from the reply slips were held in a research coded master list on a password protected computer held by the lead researcher. The research code on a reply slip corresponds to a questionnaire code and enabled the identification of those people who provided negative responses to organ donation and did not want to be registered as an organ donor.

Audio recorded interviews were digitally uploaded to a password protected computer which can be accessed only by the primary researcher, who will be responsible for the complete transcribing of the data. Any data that are shared with the main research team will be transferred using encrypted email or an encrypted Universal Serial Bus (USB). No agency outside the research team will be used to transcribe the interviews.

The researcher will provide a copy of the final research report to the South Asian religious and community leaders who helped the research process by permitting the conduct the questionnaire survey (Bernard 2002). This report is intended to act as fair remuneration for

the efforts by the wider community. Providing the feedback of findings to the studied group is useful in health studies, as it will help to provide more effective education approaches to increase South Asian organ donors.

6.12.5 Ensuring Trustworthy and Reliable Data

Parahoo (2006) identifies three key concepts to facilitate credible, reliable and trustworthy data: fidelity, justice, veracity and truthfulness. Research must be built on fidelity and trust between the participants and the researcher and offer transparency throughout the process (Parahoo 2006). Participants in this study were self selected opting to take the questionnaire survey, having been provided with comprehensive information explaining the purpose of the study, benefits and risks. All participants had sufficient time to decide if they wanted to participate, either taking their questionnaire home from a peer education event, completing it on-line at their leisure or not completing it at all (Pope and Mays 2006). Participants were made aware that although direct quotes from the interviews would be incorporated into this research, identifiable references would be removed to maintain anonymity. The researcher made every effort to safeguard all the participants and their information at all times, and as part of the relationship, a duty of care was maintained throughout this study.

Fairness and justice in this research study was maintained with all the interviews conducted at a participants preferred date, time and venue. All were offered a drink or snack before commencing the interview to make sure that they were comfortable, more importantly interpreters were available if needed. The researcher ensured each participant was of equal importance and their welfare placed at all times before the objectives of the study, and power relations were not tilted unfairly at anytime in the researcher's favour (Parahoo 2006).

In order to maintain trust and establish trustworthy data the researcher had to remain truthful throughout the study, even if it may cause the participant not to participate or withdraw during the study. It was stipulated from the outset prior to an interview that the purpose was not to make them change their mind or convince them to join the ODR, but to gain more understanding of their reasons for not wanting to be a donor. This in turn helped establish a respectful appreciation for their valuable contribution.

It was important to note that the three concepts exposed by Parahoo (2006) formed an important role throughout the study. Not just when applied to the research process but in establishing, developing and sustaining relationships with the different communities, religious leaders and key community figures, partnership and networks crucial to the success of the research and education approaches.

6.13 Summary

The methodology and methods (interviews and questionnaires) for the proposed study, including the three educational approaches have been presented and designed to achieve the aim of the study and increase South Asian organ donation in the North West. A mixed method, two phased approach which first identifies the current barriers and problems with organ donation; then implements an appropriate educational response using theoretical belief and behaviour models to better understand the education being delivered; finally measuring the overall impact on the ODR and deceased organ donation rates. The purpose of the study, highlighted at the outset, is to make a difference and take action, with a passionate South Asian researcher, raising awareness and the importance of increasing available organs for people within their own community. The new knowledge generated from the study, the confirmation or identification of new or persistent barriers, changing or new perceptions and attitudes within the South Asian migrant population in the UK, and the intelligence of what education approach may work for who, why and how will contribute significantly to moving this topic forward.

Chapter 7 and 8 present the findings of the two study phases separately. Chapter 7 combines the integrated findings of the interview and questionnaires to synthesise the barriers, perceptions and attitudes of the South Asian people. Chapter 8 draws together data generated from the different education approaches and explores the critical factors of success. Chapter 9 draws together the findings and discusses them in the context of the current evidence base synthesised and presented in earlier chapters. Chapter 10 draws the thesis to a close and makes recommendations for the study and future research.

SOUTH ASIAN ATTITUDES TOWARDS ORGAN DONATION

7.1 Introduction

One of the key aims of the study was to identify and understand the reasons why organ donation within the South Asian community in the North West is much lower than that of other ethnic groups. For this purpose it was essential to gather information as much as possible from the community. The wider views and perceptions of people from the South Asian community regarding organ donation were gathered using a questionnaire survey and explored further using semi-structured interviews to gain a deeper understanding, from those who did not wish to donate their organs.

This chapter combines the findings from Phase One, both the qualitative and quantitative data through ten key themes which emerged from the data; focusing on respondent willingness to donate their organs, lack of awareness, religious and personal beliefs, alongside perceptions of opt-out and living related donation. Themes were interrogated according to religion, age and gender where appropriate to highlight differences and similarities of opinion and misinformation within ethnic groups.

The findings from Phase One were used to inform the content of the targeted education approach used adopted within Phase Two. The key aspects that were taken forward are summarized at the end of the chapter.

7.2 Survey Response Rate and Analysis

This study used the questionnaire from Morgan et al. (2006) exploring knowledge, perceptions and attitudes towards organ donation. The third section captured the demographic details of the respondent, six questions asked for confirmation about ethnicity, religion, gender, age, occupation and education; as occupation was so poorly completed it was not a demographic included in the final analysis.

Chi-squared tests were used to test the existence of associations between outcomes and demographic characteristics, between attitudes and demographic characteristics, and between outcomes and attitudes, with p values set at <0.05 considered statistically

significant. However, the sample obtained was self-selected and convenient, so it was difficult to identify how representative the respondents were of the communities they come from. The distribution of data across ethnicity, religion, community, age and education groups was considerably different. A large number of tests were carried out to identify the likely barriers on organ donation and to understand the attitudes and devise an intervention, so correcting for multiple testing was not feasible. Therefore p-values reported are raw results from the tests keeping in mind that, due to multiple testing, there are some chance significances. The distributions among different subgroups were unbalanced and some subgroups were small. Therefore tests had limited power to detect differences.

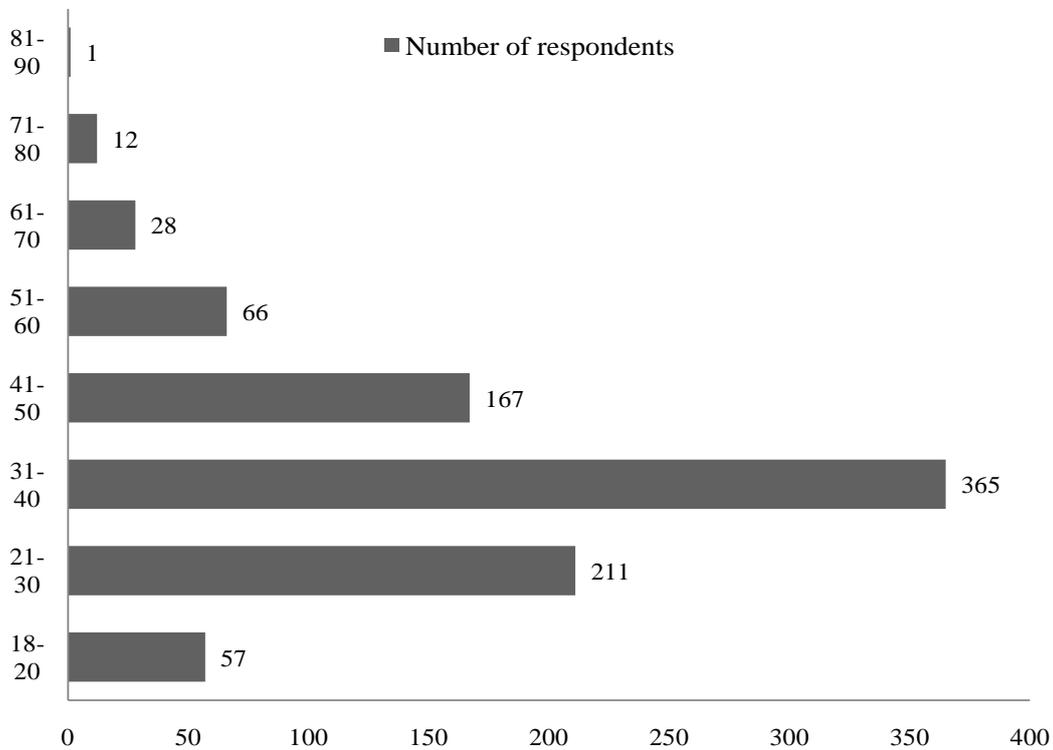
Initial analysis indicated significant associations with religion and ethnicity, particularly differences within the same religious groups from different ethnicities. Further analysis was carried out to compare the six major existing communities; Indian Christian, Indian Hindu, Indian Muslim, Bangladeshi Muslim, Pakistani Muslim and Sikh. Previous studies have demonstrated significant differences in results using religion as a grouping alongside a person's ethnic identity (Nazroo 1997; Bradby 2003). Indeed, religious practice and health have been shown to be entwined in intricate balance for South Asians (Labun and Emblen 2007) so it was important to look at the ethnicity in relation to religion.

A total of 1000 questionnaires were distributed in the North West region at 17 social and religious events. In cases where not all questionnaire items were fully or clearly completed, they were reported as missing data. There were 554 completed questionnaires returned with another 353 questionnaires completed online, making total sample of 907. This forms the largest data set of its kind in the UK exploring the opinions and perspectives of South Asian people towards organ donation, nearly double Karim et al. (2013) who recruited 556 Asian people.

7.3 Quantitative Survey Sample Characteristics

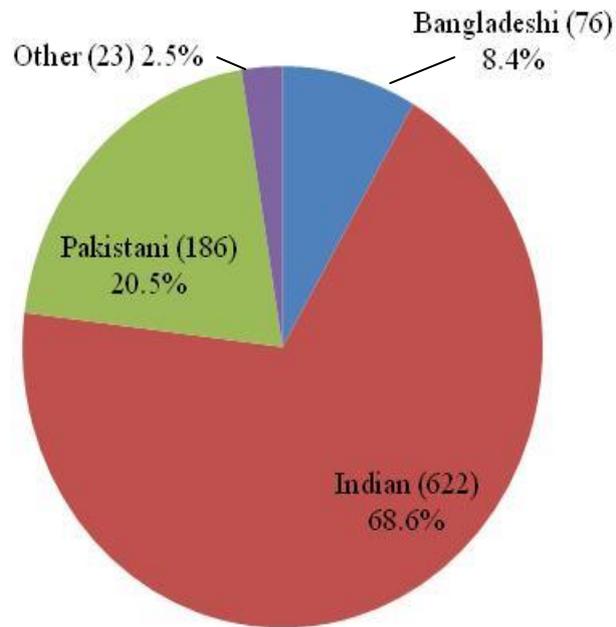
The youngest respondent was 18 years and the oldest was 81 years, with the majority of respondents between 30-40 yrs (Figure 8). Both male and females were equally represented, 47.2% females and 52.8% male.

Figure 8 Number of respondents per Age range (in yrs)



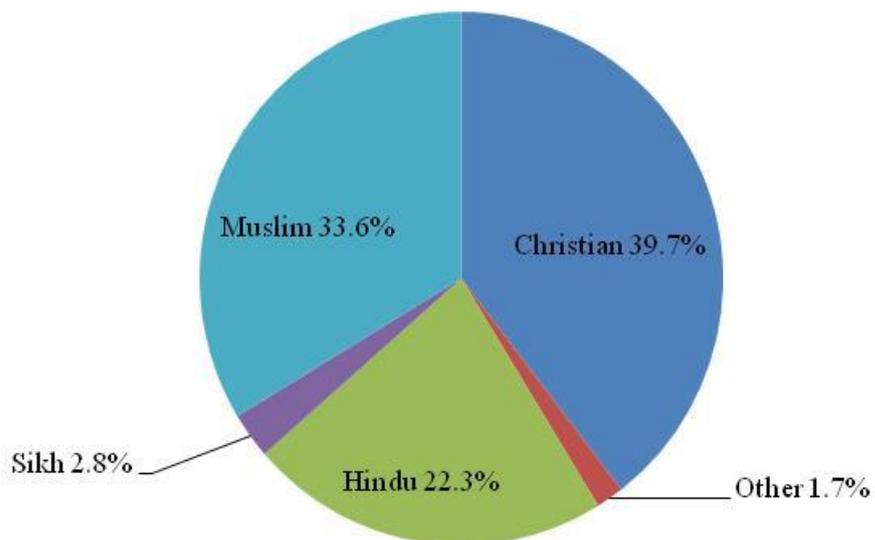
Indians formed the largest group of respondents 68.6%, and Bangladeshi only 8.4%, a harder to reach community (Figure 9). Despite repeated attempts to obtain a more equivalent ethnic group sample, by approaching different Bangladeshi community and religious leaders, there appeared little interest in the topic and a lack of enthusiasm to convey the message of the study to the community to encourage recruitment. Bangladeshi leaders indicated that they were too busy, forgot or just not interested as reasons for not informing the researcher of forthcoming opportunities and meetings events occurring in the Bangladeshi community. This lack of engagement by the Bangladeshi leaders and community continued throughout all phases of the study.

Figure 9 Ethnicity of respondents



Three major religious groups were represented, 39.7% (360) were classified as Christians, 22.3% (202) as Hindus, 33.6% (305) as Muslims, 2.8% (25) as Sikh and 1.7% (15) Figure 10). It was hoped that a comparable number of people from the Sikh community would also engage with the study but only a small number responded (2.8%) from this group.

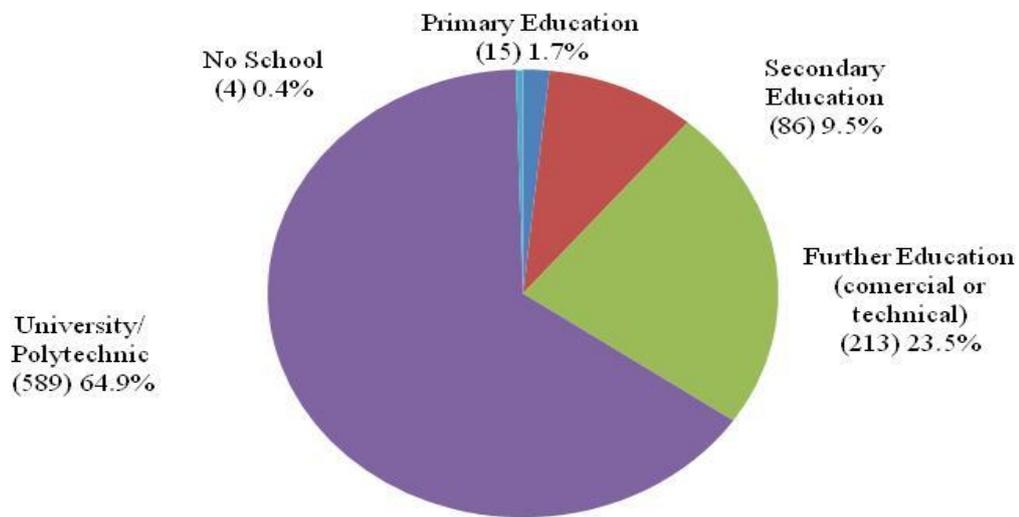
Figure 10 Religious representation



Initially when the Sikh religious leaders were approached they were very positive to accept the study and willing to participate but unfortunately they failed to provide information regarding upcoming events to enable administration of the questionnaire direct to the community. However sustained networking with the Sikh leaders facilitated access to the community and successful meetings during Phase Two, presented later in the thesis.

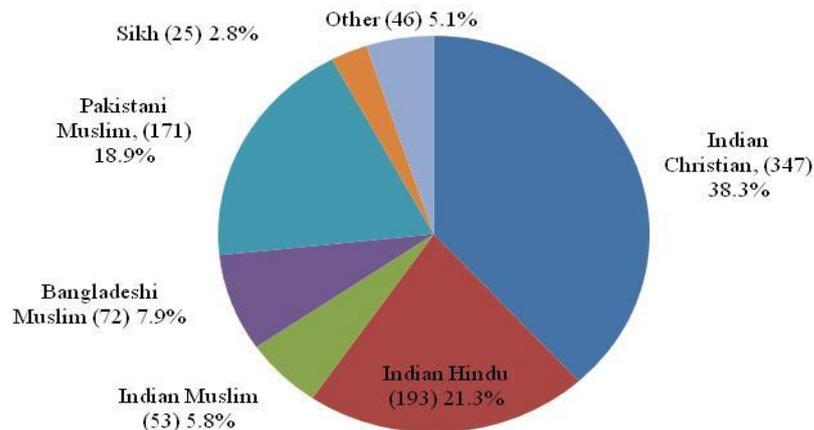
The majority of respondents (64.9%) had university or higher education qualification and 33% had secondary school or above education (Figure 11). Even though translated questionnaires were readily available they were only requested by six individuals.

Figure 11 Education status



Indian Christians 347 (38.3%) was highly represented and Sikh community was the least represented with only 25 (2.8%) participants (Figure 12)

Figure 12 Community



The demographic details of respondents from each religious/ethnic community are presented in Table 25, highlighting a higher educated and younger/middle aged cohort.

Table 25 Survey sample demographic characteristics

Religion/ Ethnicity	Gender		Education		Age (yrs)		
	M	F	School	Post school	18-25	25-45	45-81
Indian Christian (n=347)	178 (51.3%)	169 (48.7%)	45 (13.0%)	302 (87.0%)	44 (12.7%)	24 (71.2%)	56 (16.1%)
Indian Hindu (n=193)	118 (61.1%)	75 (38.9%)	18 (9.3 %)	175 (90.7 %)	20 (10.4%)	115 (59.6 %)	58 (30.1%)
Indian Muslim (n=53)	26 (49.1%)	27 (50.9%)	6 (11.3 %)	47 (88.7%)	11 (20.8 %)	35 (66.0 %)	7 (13.2 %)
Bangladesh Muslim (n=72)	44 (61.1 %)	28 (38.9%)	7 (9.7 %)	65 (90.3 %)	21 (29.2 %)	37 (51.4 %)	14 (19.4 %)
Pakistani Muslim (n=171)	83 (48.5 %)	88 (51.5 %)	23 (13.5%)	148 (86.5%)	38 (22.2 %)	108 (63.2 %)	25 (14.6%)
Sikh (n=25)	7 (28.0 %)	18 (72.0%)	3 (12.0%)	22 (88.0%)	9 (36.0%)	13 (52%)	3 (12%)
Other (n=46)	23 (50.0 %)	23 (50.0%)	3 (6.50%)	43 (93.5%)	4 (8.7%)	28 (60.9%)	14 (30.4%)
Total	479 (52.8%)	428 (47.2%)	105 (11.6%)	802 (88.4%)	147 (16.2%)	583 (64.3%)	177 (19.5%)

7.4 Qualitative Interview Analysis and Sample Characteristics

The face-to-face interview was effective in understanding an individual's rationale behind not joining the ODR. Ten interviews were considered manageable in the time available therefore ten people were selected from the purposive stratified sampling frame drawing out participants across different age groups (20-50years), and different religious/ethnic communities (Indian Hindu, Indian Christian, Indian Muslim, Pakistani Muslim and

Bangladeshi Muslim) (Table 26). An increased number of Bangladeshi Muslim's were selected (n=4) to explore further their lack of knowledge highlighted from the questionnaire findings, with 50% indicating they were not sure about registering as organ donor. This diversity gave richness to the data, a valued aspect of the interpretive research paradigm. From the Sikh community not one respondent agreed to take part in an interview resulting in no Sikh community representation.

Table 26 Interview sample demographic characteristics

Research code	Religion	Ethnicity	Age (yrs)	Gender	Education
1FH	Hindu	Indian	30-40	F	University
2FC	Christian	Indian	40-50	F	College
3MM	Muslim	Pakistani	30-40	M	University
4FM	Muslim	Bangladeshi	30-40	F	College
5FM	Muslim	Bangladeshi	30-40	F	College
6MM	Muslim	Indian	30-40	M	University
7MM	Muslim	Pakistani	20-30	M	University
8FM	Muslim	Indian	20-30	F	University
9FM	Muslim	Bangladeshi	20-30	F	College
10FM	Muslim	Bangladeshi	40-50	F	College

Interviews took place over a two month period (Nov-Dec 2012), were tape (audio) recorded after obtaining written consent from each participant, and lasted between 20-80 minutes. Field notes were taken to enhance the memory of discussion for rich and accurate transcription and (Krueger and Casey 2009). The interviews were held in varied locations determined by the participants: such as Mosques (2), community centres/cafe (3), individual's homes (2) place of work (3). Participants were given the choice of being interviewed in their native language, but all preferred to use English for the interview. The use of open ended questions allowed the researcher some degree of control within the interview in relation to exploring the topic but enabled interviewees to express their concern or understanding for different aspects facilitating rich data collection without restriction (Krueger and Casey 2009). The participants appreciated the opportunity to express their feelings on the difficult and sensitive topic, and following the survey some of

them had a raised awareness having read more about the issue. However, at times the participant's knowledge of terms like opt out and live donation was vague, requiring the researcher to offer a detailed explanation.

Data was analysed using a simple thematic analysis immediately after each interview, themes were compared and contrasted between interviews and issues taken forward and explored within the subsequent interviews. Using comparative analysis no new themes emerged after the sixth interview, at which point data could be considered saturated even from such a small number of participants (Strauss and Corbin 1998; Holloway and Wheeler 2002; King and Horrocks 2010), but the researcher chose to continue interviewing to add depth and confirm existing themes. The credibility and trustworthiness of emerging themes was increased by data analysis being performed by more than one person and/or participant verification of theme accuracy (Leydon et al. 2000; McCaughan and McKenna 2006). In this study individual participant verification was not used to check the credibility of the findings, although when findings were disseminated back to a multi-faith steering group they confirmed, understood, and were not surprised by the variations across the South Asian ethnic communities. In addition five interview transcripts were selected at random, read and coded independently by the researcher's supervisor, to test the accuracy of both the coding framework and the researcher's coding decisions. No new themes were identified so the analytical framework remained unchanged and consensus was achieved as the supervisor codes mirrored those allocated by the researcher, where differences occurred, discussion facilitated agreement. A summary of all the themes and interview data can be found in Appendix 10.

Again not one person interviewed took up the offer to use an interpreter or speak in a different language, all interviewees chose to converse in English. The extra cost of translating study information, questionnaires and making available translators, when only six people used this service was not an effective use of resources. Having implemented all these measures to encourage participation from non-English speaking South Asians the lack of uptake was disappointing; this topic alone requires further research.

7.5 South Asian perceptions of Organ Donation – Findings

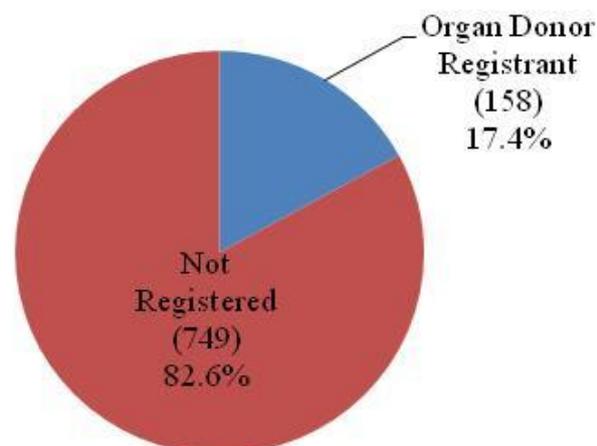
The combined findings from the questionnaire and interviews generated eight core themes and numerous sub-themes. Each theme will be presented in turn to explore and highlight the key findings of the study:

- Registered or Not...
- Attitudes and Beliefs Influencing Organ Donation
 - *Chance of life– Gift of Life*
 - *Reincarnation, Tempting Fate and Intact Body*
 - *Religious Uncertainty and Lack of Consensus*
 - *Mistrust in the Medical Team*
- Highly Educated Lacking Awareness
- Media Influence on Organ Donation
- Consent For or From Next of Kin
- Support for Live Donation
- Perceptions of an Opt Out System
- Receive But Not Give...

7.6 Registered or Not...

The most notable finding from this study was that out of 907 South Asian respondents only 17.4% were actually registered as potential organ donors (Figure 13).

Figure 13 Number of ODR registrants



Indeed the sample characteristics of those people registered and those who were not were explored further, which identified no significant difference in answers between males and females, or education level as majority of the sample were highly educated (Table 27).

Table 27 Demographic relationship and ODR registration

Are you registered		NO	YES	p Value
Total Sample		749 (82.6%)	158 (17.4%)	
Gender	Female	347 (81.1%)	81 (18.9%)	p=0.29
	Male	402 (83.9%)	77 (16.1%)	
Ethnicity	Bangladeshi	67 (88.2 %)	9 (11.8 %)	p=0.046
	Indian	502 (80.4 %)	123 (19.6 %)	
	Pakistani	164 (88.2 %)	22 (11.8 %)	
	Other	16 (78.9 %)	4 (21.1 %)	
Religion	Christian	295 (81.9 %)	65 (18.1 %)	p<0.0001
	Hindu	154 (76.2 %)	48 (23.8 %)	
	Muslim	271 (88.9 %)	34 (11.1 %)	
	Sikh	22 (88 %)	3 (12 %)	
	Other	7 (46.7 %)	8 (53.3 %)	
Education	University	473 (80%)	116 (19.7%)	p=0.11
	Further	183 (85.9%)	30 (14.1%)	
	Secondary	77 (89.5%)	9 (10.5%)	
	Primary	12 (80%)	3 (20%)	
	No school	4 (100%)	0	
Age (yrs)	18-25	126 (85.7%)	21 (14.3%)	p=0.49
	26-45	474 (81.3%)	109 (18.7%)	
	46-65	129 (83.2%)	26 (16.8%)	
	66-81	20 (90.9%)	2 (9.1%)	
Community	Indian Christian	288 (83%)	59 (17%)	p=0.0053
	Indian Hindu	146 (75.6%)	47 (24.4%)	
	Indian Muslim	49 (92.5%)	4 (7.5%)	
	Bangladeshi Muslim	64 (88.9%)	8 (11.1%)	
	Pakistani Muslim	151 (88.3%)	20 (11.7%)	
	Sikh	22 (88%)	3 (12%)	

Respondents from Muslim and Sikh religions were less likely to be registered on the ODR. Although ‘being registered’ was not significantly different between ethnicities ($p=0.046$) it was highly significant across different religions ($p<0.0001$) (Figure 14) and different communities ($p=0.005$) (Figure 15).

Figure 14 ODR and religion

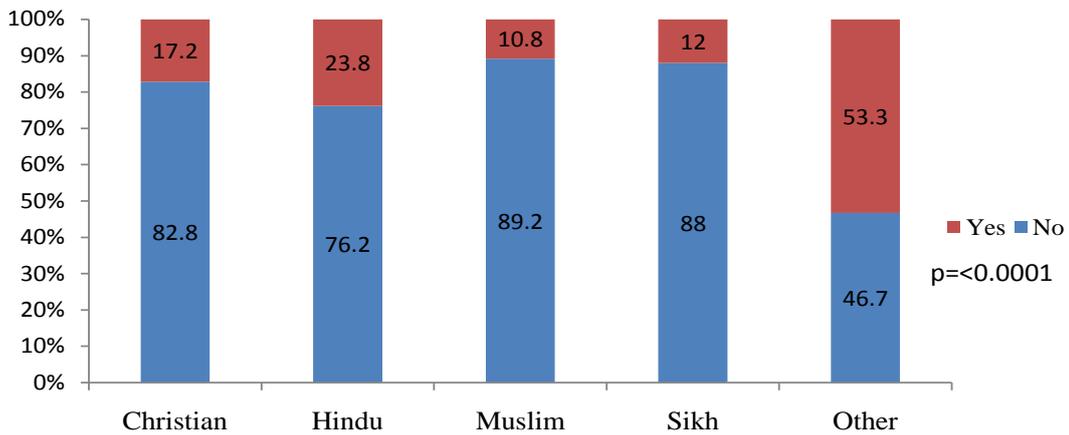
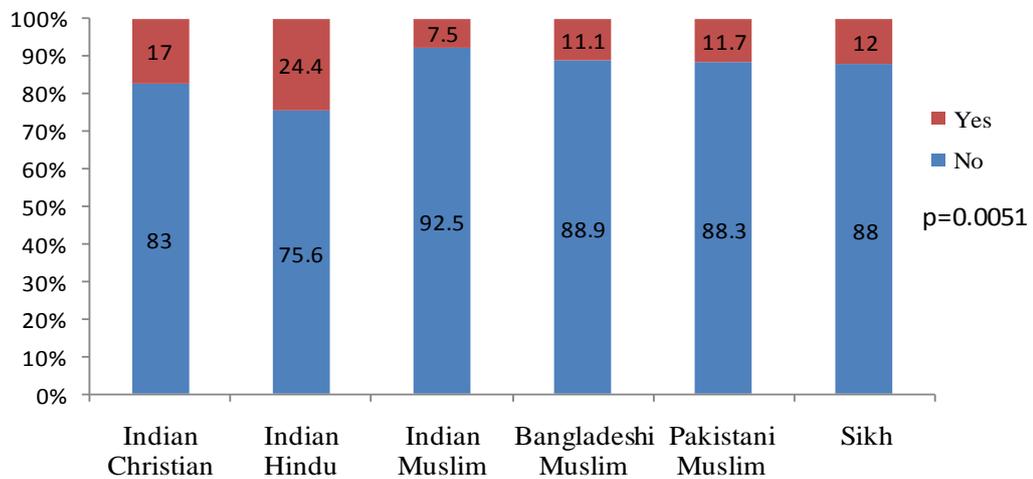
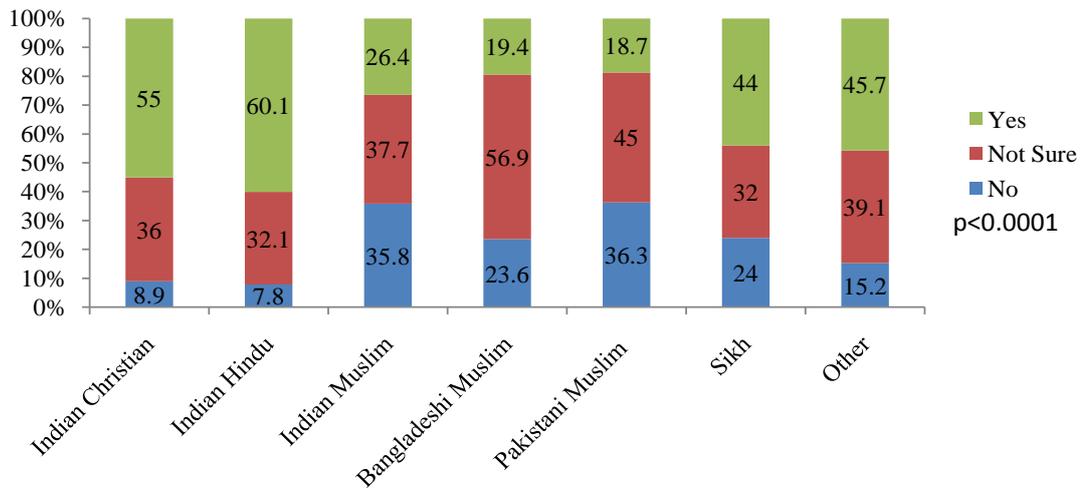


Figure 15 ODR religion and community



Interestingly 44% of the sample who were not on the ODR expressed that, they were willing to join, 38.7% said they were *Not Sure* instead of *No*. This is a very positive finding as it suggests a large number of people within the community who could be potential donors. This was explored further within religion and communities (Figure 16).

Figure 16 Willingness to join the register



The Indian Hindu community showed more willingness to join the ODR (60.1%) compared to all other communities, but it is important to note that they had greater awareness (94.3%) about organ donation, which reinforces the need for an education approach to increase awareness and potential donors, examined within the next theme.

7.7 Attitudes and Beliefs Influencing Donation

A series of eight questions comprised statements about previously identified cultural, religious and personal barriers to registration, with responses on a 5-point scale (strongly agree, agree (combined as agree), disagree, strongly disagree (combined as disagree) and don't know). The responses to these statements are explored examining the significant differences in perceptions which on closer examination appeared to exist across between different ethnic community groups, rather than sensitive to a particular religion. There were no significant difference noted across different demographics, except ethnic community which is presented throughout where applicable and age with respect to medical mistrust.

The results to the questions are summarised in Table 28, exploring attitudes towards willingness to register against the different statements being explored; and Table 29, summarises attitudes of those not registered compared by community group. The findings and interpretation of the whole data set indicate that willingness to register was significantly associated with attitude.

Responses highlighted concerns shared across groups that exposed the need for health professionals to establish a more trusting relationship with the South Asian people to alleviate the strongest and widespread attitude and misconception of mistrust, associated with the medical staff and the retrieval of organs, within the UK.

The use of odds ratios as summaries became difficult to interpret with three optional responses (No, Yes, Not sure) for *willingness to register* so the percentages for each response are presented (Table 28 and 29).

Table 28 Summary of attitudes towards willingness to register

Statement	Agree/ Disagree	No	Not Sure	Yes	Test of Association
I don't mind who will receive my organ	Agree	89(11.3 %)	317(40.2 %)	382(48.5 %)	P<0.0001
	Disagree	68 (57.1 %)	34 (28.6 %)	17 (14.3 %)	
It is important to give chance of life.	Agree	101 (12.4%)	320(39.4 %)	391(48.2 %)	P<0.0001
	Disagree	56 (58.9 %)	31 (32.6 %)	8 (8.4 %)	
I worry medical team won't try as hard to save me	Agree	73 (18.3 %)	173(43.5 %)	152(38.2 %)	
	Disagree	84(16.5 %)	178(35 %)	247(48.5 %)	
I worry they use my organs without consent for other purposes	Agree	80 (22 %)	157(43.1 %)	127(34.9 %)	
	Disagree	77 (14.2 %)	194(35.7 %)	272(50.1 %)	
It is important to have intact body hereafter	Agree	80 (24.5 %)	142(43.6 %)	104(31.9 %)	P<0.0001
	Disagree	77 (13.3 %)	209(36 %)	295(50.8 %)	
I feel uneasy of the thought my body being cut up.	Agree	101 (25.1%)	176(43.7 %)	126(31.3 %)	
	Disagree	56 (11.1%)	175(34.7 %)	273(54.2 %)	
Registering is tempting my own death	Agree	47 (24.2 %)	79 (40.7 %)	68 (35.1 %)	P=0.0033
	Disagree	110 (15.4%)	272(38.1 %)	331(46.4 %)	
Donating is a way of serving God.	Agree	35 (6.2 %)	26 (40.4 %)	299(53.4 %)	P<0.0001
	Disagree	122(35.2%)	125(36 %)	100(28.8 %)	

Table 29 Summary attitudes of those Not registered compared by ethnic community

Attitudes	Indian Christian (288)	Indian Hindu (146)	Indian Muslim (49)	Banglade shiMslim (64)	Pakistani Muslim (151)	Sikh (22)
An intact body is needed hereafter	96 (33.3%)	50 (34.2%)	22 (44.9%)	27 (42.2%)	83 (55.0%)	11 (50.0%)
Registering is tempting my own death	72 (25.0%)	25 (17.1%)	9 (18.4%)	15 (23.4%)	38 (25.2%)	6 (27.3%)
I worry medical team will not try to save me	140 (48.6%)	62 (42.5%)	17 (34.7%)	25 (39.1%)	77 (51.0%)	16 (72.7%)
I worry my organ will be used for other purposes without my consent	101 (35.1%)	56 (38.4%)	19 (38.8%)	23 (35.9%)	89 (58.9%)	14 (63.6%)
I feel uneasy of the thought of my body being cut	122 (42.4%)	52 (35.6%)	24 (49%)	31 (48.4%)	99 (65.6%)	8 (36.4%)
It is not important to give a chance of life to somebody after my death	23 (8.0%)	14 (9.6%)	6 (12.2%)	10 (15.6%)	32 (21.2%)	6 (27.3%)
I do mind who will receive my organs	23 (8.0%)	10 (6.8%)	8 (16.3%)	18 (28.1%)	44 (29.1%)	6 (27.3%)
Donation is not a way of serving God	65 (22.6%)	58 (39.7%)	28 (57.1%)	31 (48.4%)	84 (55.6%)	14 (63.6%)

The findings within Tables 28 and 29 will be discussed within a number of sub-themes which emerged and included: chance of life, reincarnation and keeping the body intact, religious uncertainty and misinformation, myths of donor disfigurement, and mistrust in the medical profession.

7.7.1 *Chance of life– Gift of Life*

Those who believed that '*It is important to give a chance of life*', were more likely to be registered than those who didn't agree (Odds ratio=10.71, 95% Confidence interval (CI) (2.61, 43.94), $P < 0.0001$), suggesting this attitude of helping others to live or the 'Gift of life' theory may be a useful way to encourage people to register as organ donors. Apart from the Indian Muslim community, willingness to register was significantly different between those who thought '*It is important to give a chance of life to somebody else*', and those who did not; $p = 0.039$ for Bangladeshis and $p < 0.0005$ for all other communities (Table 29).

In all communities except for the Indian Hindu community ($p = 0.1410$), willingness to register was significantly different between those who '*Do not mind who receives the organ*' and those who do mind; $p = 0.028$ for Bangladeshi, $p = 0.031$ for Indian Muslims, $p = 0.02$ for others, and $p < 0.0002$ for all other communities (Table 29).

A comment from a female Muslim participant in an interview indicated a clear preference to donate only to another Muslim. This comment reinforced the need to maximise education within the community on the scarcity of organs and the need to match ethnic minority organs to the same ethnic group. By increasing awareness that a donated organ would more than likely match to another South Asian person may well increase the potential of someone to donate, although whether it would be a Muslim could not be guaranteed.

'Personally I would only donate my organ to a family member and they have to be Muslim.' (8FM)

Although the person went on to explain that if people were to die waiting for organs it was possibly God's will and not really their problem, indicating that emphasising the scarcity, demand and need for organs may not have any impact on some people. Such a perception provides a rationale and a planned behaviour (TPB) not to donate using the possibility of it being God's will and potentially not working as an excuse not to try. However a further male interviewee reinforced the view that if God allowed the scarcity of organs, then that is what is to be, feeling powerless to help overcome the problem. Here building a person's self-efficacy that they have a choice to make a difference could increase confidence and provide a cue to take action.

'If it's an outsider, the way I see it is if it's God's intention, then that's what it is, people can survive without them. This may sound really bad at this moment in time, it's just that with my organ what is the guarantee that they are going to have a life, it could reject and I have seen the rejection.' (8FM)

'Scarcity of donors-I mean it's in the hands of the creator at the end of the day, so I don't have any problem. What's going to happen it will happen and it's to be it is to be? If people die due to the organ failure it will be Gods purpose.' (6MM)

7.7.2 Reincarnation, Tempting Fate and Intact Body

People who believed *'An intact body is needed after death'*, were less likely to be registered than those who did not believe (Odds ratio= 0.41; 95% CI= (0.27, 0.62), P<0.0001) (Table 28). In particular the Pakistani Muslim community, willingness to register was significantly different between those who held the belief *'needing an intact body after death'* and those who did not (p<0.0001), compared to the majority of other communities where no significant difference were noted (Table 29).

Within the interviews there were concerns expressed among two Muslim and one Hindu participant regarding the ownership of the body and reincarnation. From the Hindu perspective it was described as their religious faith, needing a body to be intact to move on to the next life. Donating an organ to someone could risk some of their spirit having to stay and not allowing movement to the next life.

'We believe the body has to be intact as it came. You don't want to risk part of the body, It's important for Hindus we get move on to the next life. Even though we believe that body is shalom and the spirit goes as soon as it dies, it's almost like you don't want leave your part of the body lying around with if the spirit cling on that part and the body can't move on to the next life.' (1FH).

Similar preferences were expressed by two Muslim participants but more from the perspective that God gave them the body and wants in back in one piece, it should be the same and nothing left behind after death, these were personal preferences rather than religious instructions.

'I was given birth with this (points to body) and I want to go with everything. Allah has given this body to me, and personally I do not think that my burial is complete

without all my body part. I understand that when you die your soul goes up and the rest of the body is in the ground still. This body does not belongs to me, this belongs to him up there, He has given to me, He trusted me to look after it and to go back with it. That's the way I see it.' (8FM)

'Allah created us in the perfect form. So why do anyone change it for. That will affect even after my death, after I die I do not believe in leaving behind, that's my personal perspective.' (6MM)

Losing an unhealthy organ however was acceptable, but where possible nothing should be removed.

'...my belief is that we are born with this organ and when we leave this world we have to go with this as well unless it has to be removed for health purpose, nothing should be taken away from you.' (6MM)

Other Muslim opinions believed that *'God does not want it back'* (3MM), referring to their organs when dead so donation would be appropriate.

Moreover those who felt *'uneasy of the thought of their body being cut'*, were less likely to be registered than the others (O= 0.52, 95% CI= (0.36, 0.75), P=0.0005) (Table 28). Again interview participants who refused to be registered organ donors expressed both positive and negative attitudes towards being *'cut open'* after death, one preferring not to be cut another ambivalent.

'Ideas of having you cut open things like that, I wanted to preserve myself. I have seen a post-mortem and things like that I have seen the way they do it, which put me off completely so I did not want to donate.' (2FC)

'Why should I take to underground when I am dead, nobody is going to use, anyway.' (3MM)

Some interview participants held perceptions that the body would be disfigured if they donated, particularly sensitive to their eyes, which prevented them from saying yes to being an organ donor. The highlighted the need to explore what someone perceives before providing education to understand what to discuss first you need to know what fears people have and myths they believe.

'Yes, there are still myths around. That can be sorted out by education. I would say nothing on my face only because we have open coffin, when my son see my body basically. If I have an eye missing I think he will struggle with it, I don't mind anything else missing as it is all covered.' (1FH)

'Also mentally, I don't know it may play a part on, you know once you pass away for the family you are living behind, they may say he was a donor, so organs are here, they may not come into terms with it not some of it kept in hospital and where you keep it and some of it's gone to grave, so they are not getting full closure. Especially if its heart or eyes, they may say he has got my husbands, wife's.....heart or eyes, something in their back of their mind, someone out there with my partners or husbands heart.' (6MM)

Another person believed completely the opposite:

'Believe me after my death I am not worried about anything, if you want to bury me or keep in the museum I don't care. The whole issue is about the souls if you believe in God, if there is some sort of life after death, it will be about the soul, so I am not bothered about the disfigurement.' (3MM)

Similarly people who thought '*Registering is tempting own death*', were less likely to be registered (O= 0.58, 95% CI= (0.36, 0.92), P=0.02) (Table 28). In particular in the Indian Hindu community willingness to register was significantly different based on the idea of '*registering is like tempting their own death*' (p =0.0002), compared to other communities where no significant difference was noted (Table 29). A comment from a female Hindu participant reinforced the perception that even carrying a donor card was considered '*tempting fate*'.

'Carrying a donor card in Hindu faith believe that if you carry things or do certain things it's like tempting my own death, tempting fate.' (1FH)

7.7.3 Religious Uncertainty and Lack of Consensus

In all communities the belief that '*Donation is a way of serving God*' made a significant difference to their willingness to register; p=0.0142 for Indian Muslims, p=0.038 for Sikhs, and p<0.0032 for all other communities. Indeed those who thought this '*Donation is a way*

of serving God', were more likely to be registered than those who didn't agree (Odds ratio=1.51, 95% CI (1.05, 2.2), P<0.036) (Table 28).

Apart from one Christian participant all the remaining interviewees identified a religious reason or uncertainty as to why they were unable to join the ODR or carry a donor card. More importantly all four Bangladeshi Muslim participants interviewed identified that they had heard from their religious leaders that organ donation was not permissible, but the majority were uncertain as to whether or not it was allowed.

'I do not know whether the religion allows or not allows. That is the reason I am not registered. Yes definitely religion plays a role in making the decision.' (9FM)

'As I am from Muslim culture, obviously there is a belief that you cannot be a kidney donor, so that's all it is really, and we all believe that you can't be a donor and that's what everybody believes. It is not personal or individual reluctance, it is because of the religion.' (5FM)

'Religious understanding I have been told that you are not allowed to accept or give any organs. But in this stain age we need to move forward and I agree with organ donation.' (10FM)

'I am not sure, I think I may have heard or read somewhere that it is not possible for us from the religious perspective... If it's permissible through religion, I will consider it. It is the religious angle I want to clear about it.' (6MM)

'I don't agree with it. I find it very difficult accepts. At this moment in time my belief is that, I wouldn't go onto the transplant waiting list, I may act differently if I was in that situation. But as it stands, well, if God wills me to be here, I will be here without kidneys...the way I see it whichever way God wills it. Yes, my religion has got bit an influence on this (my decision). Again with as every religion you have the choice.' (8FM)

'It is hard for Muslims to donate. We especially in Muslim religion we have to listen, whatever say in Qur'an it's always right. We will listen...(to our religious leaders), all Muslims will donate, but I am not sure about it. If the clarification comes from religious leaders I will donate.' (4FM).

It was clear from these responses that religion was influential in their decision making and education that continued to clarify the religious stance would be really useful, and at the same time involving religious leaders, and educating leader's who are reinforcing their own interpretation of the Qur'an to discourage donation.

7.7.4 Mistrust in the Medical Team

The results highlighted a real concern that 40.1% of the total sample (the majority of which were higher educated) (Figures 17-18) expressed a feeling of mistrust in the medical team mentioning concern about the misuse of organs or not providing the appropriate medical care.

Figure 17 Worry my organs will be used without my consent

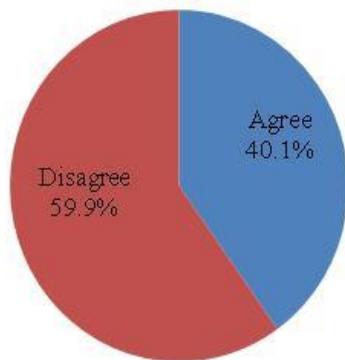
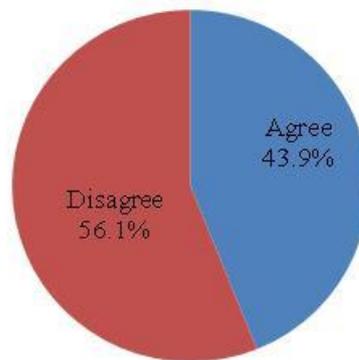


Figure 18 Worry the medical team will not try to save me



It was evident that those who worried that ‘*Medical team will not try hard to save*’, were less likely to be registered than those who don’t agree (Odds ratio= 0.57; 95% CI= (0.4,0.82), P=0.002). There was no statistical significant difference in being registered between people who worried ‘*organs will be used without their consent*’ and those who didn’t so (Odds ratio= 0.79; 95% CI=(0.55,1.12), P=0.24) (Table 28).

In the Indian Hindus willingness to register was significantly different between those who worried ‘*The organ will be used for other purposes without their consent*’ and those who didn’t (p=0.036), compared to other communities where no significant difference was noted. Willing to register was significantly different when they were asked if they worried ‘*medical teams will not try hard to save the person in order to use the organ*’, in Indian Christians (p=0.028) and others (p=0.006) compared to other communities where there was no significant difference was noted (Table 29).

Differences were identified between age groups with regard to the responses to the statement indicating mistrust in the medical team, these were explored further and

relationships between age and community group responses compared (Figures 18-23). Older people were more likely to disagree with ‘Worry organs will be used without consent’ particularly those from the Sikh community. The most significant difference were in Indian Christian community in which the 18-25yrs group were less likely to disagree compared to the >25-45yr (Odds ratio=0.28, P=0.0002) and in the Pakistani community the odds of disagreement in >45-81yr group was greater compared to that in >25-45yr group (Odds ratio=3.02, P=0.02). The same trend was seen in the responses to ‘Worry medical team will not try to save’, except in the Indian Hindu community in which odds of agreement in >45-81yr group was greater compared to that in >25-45yr group (Odds ratio=4.68, P=0.22). In Indian Christian, Indian Hindu and Pakistani communities age 18-25yr groups were significantly more likely to agree (Odds ratio= 3.019, 4.24 and 2.23, P= 0.002,0.005 and 0.041 respectively) (Table 29, Figures 19-24).

Figures 19-24: Worry organs will be used without your consent: Community relationship across different age groups

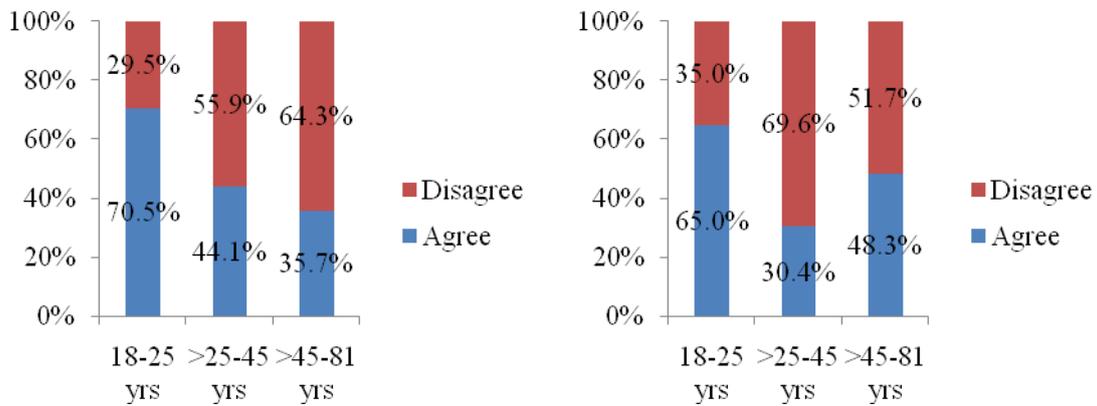


Figure 19 Indian Christian community

Figure 20 Indian Hindu community

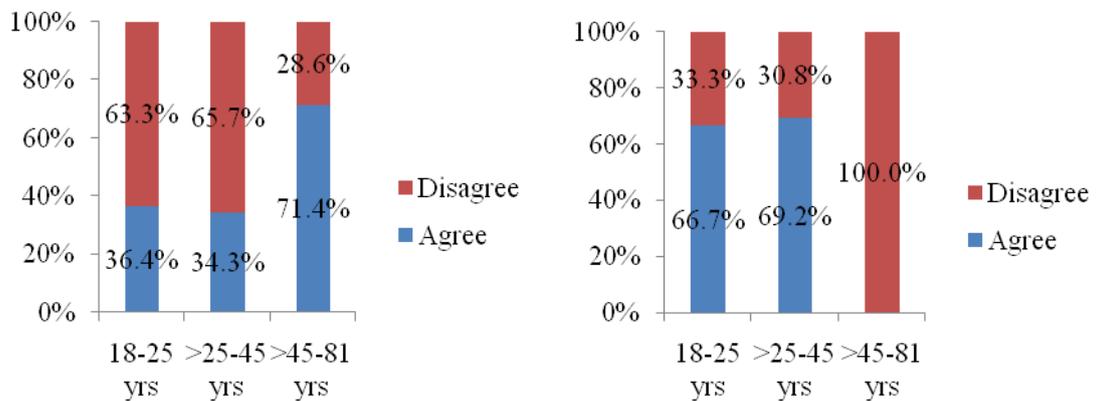


Figure 21 Indian Muslim community

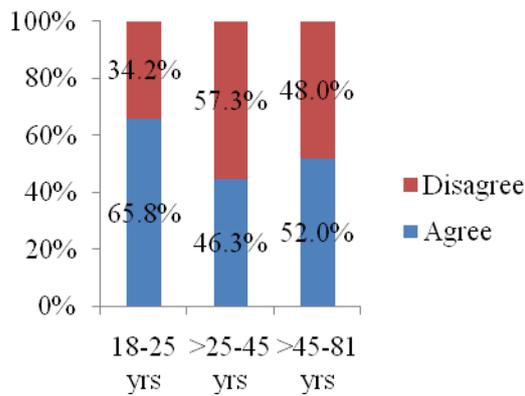


Figure 22 Sikh community

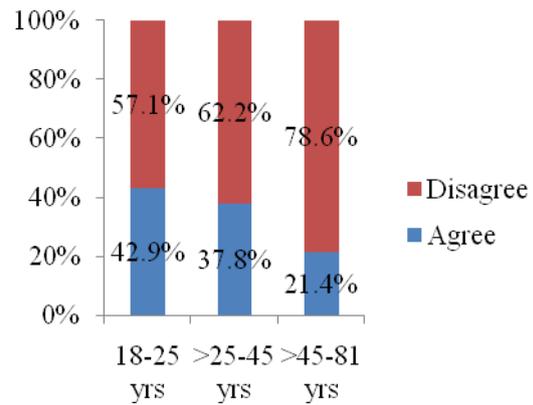


Figure 23 Pakistani community

Figure 24 Bangladeshi community

It is important to notice that mistrust in the medical team is present in every community, compared to other attitude questions the concern among the participants on this particular aspect represent the highest percentage with more than 35% in every community. Worryingly the Sikh community had more than 63% who expressed their concern about the medical care and misuse of the organs (Figure 22, Table 29).

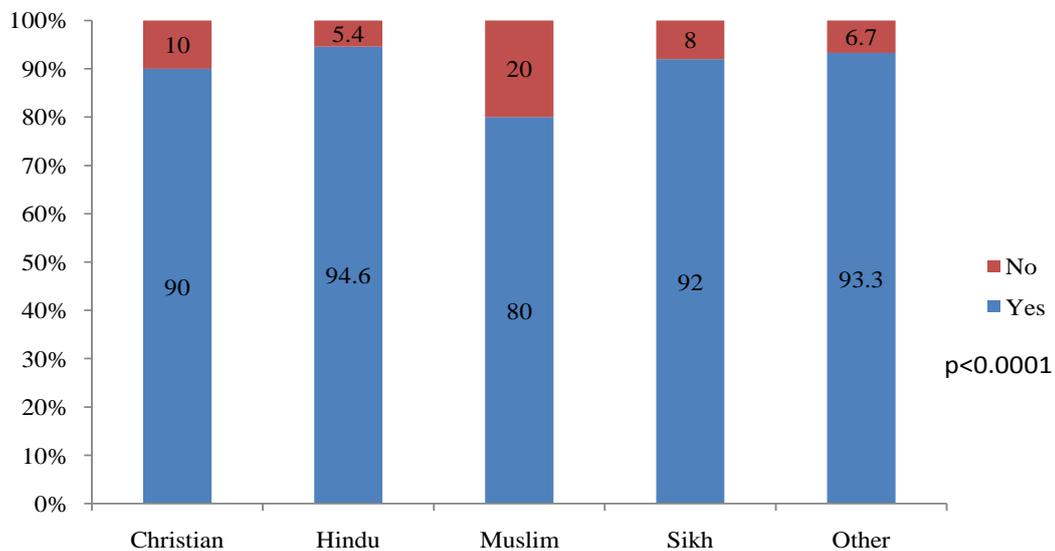
Despite such a strong view regarding medical mistrust within the questionnaire this theme was not expressed as a concern for the majority of interview participants. Only one woman commented on medical trust and provided an example of a news item reporting organs taken without consent but also her own personal experience suggested she felt that her Mother was kept alive only for the purpose of organ donation. Indeed the finding highlighted that the sensitivity and timing of asking about organ donation needs to be considered carefully by health professionals.

'I think there is also people don't trust medical authorities as well as they should do like there was that baby organ donation scandal happened few years before and where organs been kept and all.I did think to myself that they kept my Mom alive with the help of machines to get her organs, because one of the first thing they did when they said we are going to turn the machine off was ask about organ donation.'
(1FH)

7.8 Highly Educated Lacking Awareness

Knowledge about registering for organ donation was significantly different between ethnicities, religions and between communities ($p < 0.0001$ in all cases). Over 54% of the participants did not feel well informed about registering as a kidney donor. Respondents from Muslim religions were less likely to be registered on the ODR and they were less likely to be aware that it was possible to leave your kidneys for transplant and how to register.

Figure 25 Aware you can donate your organs?



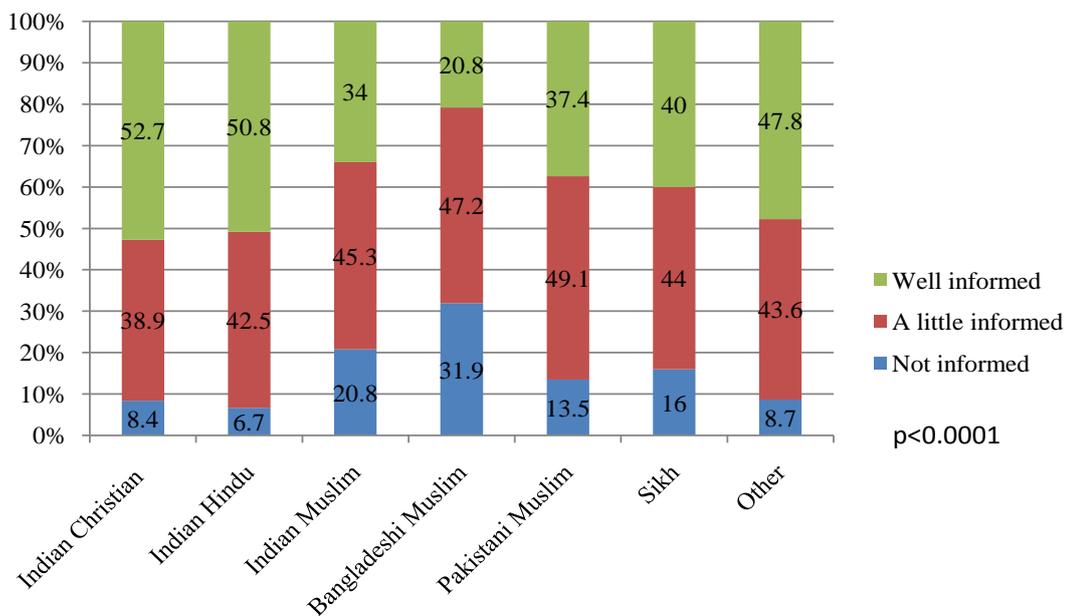
Even though more than 90% Indian Hindu community knew that it is possible to leave their kidneys for transplant after the death when considering about how to register and how to become an organ donor it was identified that all the religious groups felt poorly informed about registering on ODR (Figure 25).

Among the communities Bangladeshi Muslim's (31.9% unaware) were the least informed group about organ donation (Table 30). Knowledge about donation was significantly different between ethnicities, religions and between communities ($p < 0.0001$ in all cases) (Figure 26).

Table 30 Informed or not about organ donation

Community	Not informed	Little informed	Well informed	Test Association
Indian Christian	29 (8.4%)	135 (38.9%)	183 (52.7%)	p<0.0001
Indian Hindu	13 (6.7%)	82 (42.5%)	98 (50.8%)	
Indian Muslim	11 (20.8%)	24 (45.3%)	18 (34%)	
Bangladeshi Muslim	23 (31.9%)	34 (47.2%)	15 (20.8%)	
Pakistani Muslim	23 (13.5%)	84 (49.1%)	64 (37.4%)	
Sikh	4 (16%)	11 (44%)	10 (40%)	

Figure 26 Community levels of awareness of organ donation



From the interviews all ten participants indicated that they had little or no knowledge about organ donation, which directly influenced their decision not to donate. Two participants had grown up in India and Bangladesh and both highlighted that this topic was never mentioned in their home country, reinforcing the need to provide different education for South Asian migrants.

‘When I filled the questionnaire, I wrote no, because the idea of organ donation I had very less knowledge about especially about donating the organs after death I

have not heard much about. Back at home, I am from India we have seen relatives donating to relatives (live donation). But back at home people are not those aware of deceased donation' (2FC)

'Back home in Bangladesh also we have not heard much about it'(5FM)

None of the participants had received information during their school or college education and many were educated throughout different parts of the UK, although one person had seen campaigns on their university campus they did not feel the campaign was targeted at them. Schools seem to be a missed opportunity for educating young South Asians regarding the importance of organ donation for the people in their own community.

'Not really to be frank and honestly during my school, college and university I have not heard about organ donation.' (7MM)

'I never heard during my schooling about organ donation, so the education need is there.' (6MM)

'No I did not hear about organ donation during my schooling.'(10FM)

'Never in my schooling I heard this, in university I have seen odd campaigns here and there. Nothing ever been specifically delivered to us.'(8FM)

Even among South Asian people working in health care organ donation was not a common subject; *'...in fact, I never heard working in care home in last 17yrs, so I don't think any of Asians heard about it (organ donation)'* (6MM).

The evidence indicated that information and awareness of organ donation was certainly lacking across the communities despite national organ donor ethnic minority campaigns the message was not filtering through to the South Asian people. One participant described how a lack of knowledge results in people not donating their organs, but a depth of understanding could change their minds, supporting the need for continued education.

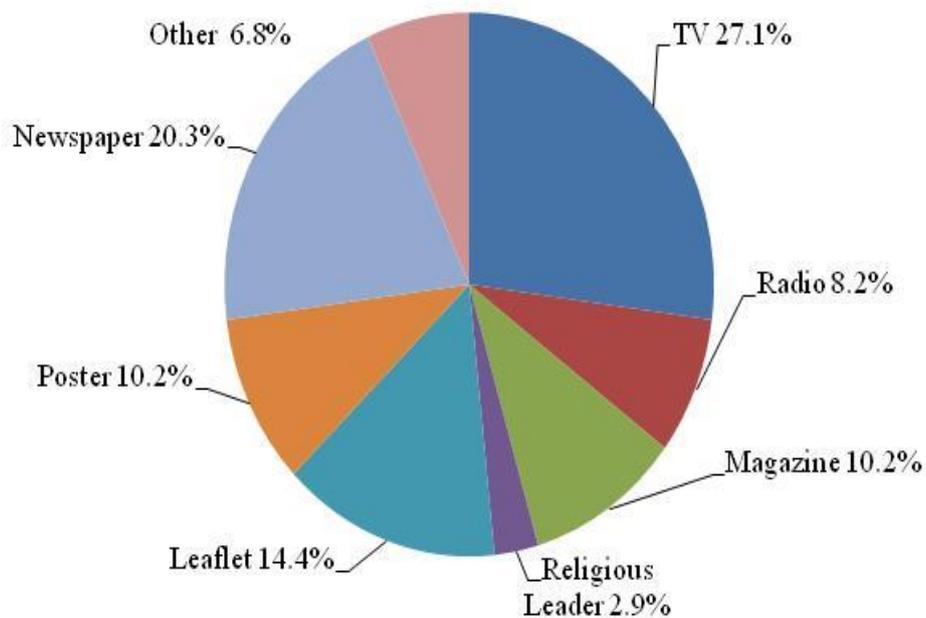
'When people are not aware of things they can go negative on it. When a depth understanding and awareness is given, people can change their mind. Organ donation is not something that is spoken about like diabetes, blood pressure or something like that.' (5FM)

7.9 Media Influence on Organ Donation

Having identified in the previous section that South Asian people were misinformed, lacked an understanding and basic knowledge as to what organ donation entailed questions probed if what was the best media to use to provide information about this topic to their community (Figure 27).

From a total of 769 respondents who knew about organ donation, Television (TV) was suggested as the most popular media for of information provision (27.1%), in particular Asian TV channels. The religious leader was not necessary the person identified as the provider of information on this topic (2.9%).

Figure 27 Sources of information about organ donation



This result was similar among the different religions and ethnic communities (Table 31). Again it was important to note from the responses the role of the religious leader to provide information on this topic within each community was minimal, between 3.3-8.7% only.

Table 31 Sources of information about organ donation

n=769 Sources	Indian Christian	Indian Hindu	Indian Muslim	Banglades hi Muslim	Pakistani Muslim	Sikh
TV	145(46.3%)	88(48.4%)	20(45.5%)	20(39.2%)	72(50.3%)	10(43.5%)
Radio	32(10.2%)	29(15.9%)	8(18.2%)	6(11.8%)	23(16.1%)	4(17.4%)
Religious Leader	18(5.8%)	6(3.3%)	2(4.5%)	2(3.9%)	9(6.3%)	2(8.7%)
Newspaper	115(36.7%)	68(37.4%)	13(29.5%)	12(23.5%)	49(34.3%)	7(30.4%)
Magazine	67(21.4%)	33(18.1%)	5(11.4%)	4(7.8%)	19(13.3%)	3(13%)
Leaflet	72(23%)	43(23.6%)	9(20.5%)	19(37.3%)	37(25.9%)	9(39.1%)
Poster	62(19.8%)	27(14.8%)	4(9.1%)	9(17.6%)	27(18.9%)	2(8.7%)

The role of media was recognised by all participants as a valuable way to engage and push out messages about organ donation, but equally participants within the interviews who were against organ donation could recount negative stories that had or could influence decisions to donate within their community. For example Bollywood films and documentaries were considered a medium that tell silly stories that the community believe and such an approach could be useful in the future.

‘I think sometimes we hear this horror story like George Best, celebrity he got liver and what did he do drink drink...Media does and always will I think, but some time some Trusts (Hospitals) are not accountable.’ (1FH)

‘It’s to do with media, its shame because many of our early generation are into Bollywood, and they have common stories (dramas and documentaries) coming up, you know if you give someone’s eye and he/she got my husbands/wife’s.... eyes, so much of silliness, the media plays and they get so much drawn into it and they will think it’s happening for real, because Bollywood does play a vital role in many Asians life.’ (6MM)

More importantly a lack of information and discussion within the wider South Asian press was a concern and potentially an untapped resource and a recommended strategy to educate the community, taking care to address the topic with sensitivity, a balanced approach.

'I don't think there is much discussion about this in media especially targeting Asian community. You get lot of this, Islam channels, Asian channels, so many of them I don't think any of this channels I have seen saying anything about organ donation. That is the main sort of information they get. Even radios, newspaper never mentioned about organ donation. Majority doesn't know what's happening out there. I think if we can concentrate on Asian Medias, that's the only way to get them. That's what I think anyway.' (6MM)

'It is a sensitive topic so I will be very careful about the media itself, we have to be very careful about the wording, we can't be too bold or too lineate we have to find a balance in our approach. We can use community hubs ad mosques on health education. When we start educating health we can actually educate on organ donation. Obviously not encouraging because we got this tense issue, but we can educate on why we need organ donation the side effect. If it's a correct education approach and we have to watch the sensitivity of the topic... so you are not putting anybody off either.' (7MM)

7.10 Consent For or From Next of Kin

The interviews provided valuable information regarding the thoughts of people as to whether they would consent for their next of kin to donate. Difficulties arose when people considered consenting for their child, even if a child next to them needed an organ to stay alive. Again the reasons for not donating rest on the perceived and actual interference of a dead body, not something people find easy to accept.

'If my son dies I do not think I could donate his organ even if there is a baby next to him and his mom saying that he is waiting for an organ, because I think it's more about my son's body being interfered with.' (IFH).

Different and opposing opinions within the family raises the importance of family education with respect to organ donation to ensure family members know the preferences of the dying person and respect their decision, particularly if it is to be a donor. Generational differences in beliefs were posed as potential barrier to consenting for next of kin organ donation.

'There could be restrictions from family donating organs there could be negative points from my family, because of awareness, if we can make them understand and tell them the reason and the scarcity and how people are suffering and if they are

also aware of it I think they would agree. But I think what I would be and what I decide is/should what happens to me.'(2FC)

'Within my family with my wife it may be easy but for my parents maybe it will be difficult. In the old generation there is actually, they always still live in same well, they have not come out of it. So awareness may be a lacking factor. Actually the new generation, when the old generation vanishes from the world it may change.' (3MM)

One participant mentioned that even if his family member was on ODR and expressed a wish in the past to donate he would still decline to consent if the decision was his to make. Although, in the interview there was a moment of indecision that suggested the objection against donation was not rigid, but could maybe be influenced and changed in the future.

'I would object that person's consent, I am acting that persons best interest, I know that person made that wish but now he is not here so he can't make that decision so I am making it for his best intention on his behalf. Unless...if my view and thinking was different, if I am completely with idea of organ donation then I will say yes. All depends on what my thinking at that time. All depends on the individual left behind.'(6MM)

What was interesting to note was an indication why national campaigns attempting to increase organ donation may not be effective because many of the ideas and ways of thinking are passed down through the family and community comes, not influenced by the wider world, as though it is viewed as a separate entity, an *'outside world'*. However each generation is slowly changing and becoming wider educated so eventually perceptions will change.

'Especially coming from Asian background, bit oblivious on what's going on outside the world. Like you learn from your Mom, my Mom didn't get to teach me about all this organ donation so it's very new to me, but I speak to my children about organ donation other aspects of life aspects ...which I did not have from my Mom. So it's the different generation.'(10FM)

7.11 Support for Live Donation

Within the questionnaire respondents were informed that it is had now become possible becoming possible to donate one of your kidneys while you are still alive, to a close

relative or friend. They were then asked ‘If a close relative or friend of yours needed a kidney transplant would you be willing to consider becoming a live donor?’

Compared to all other questions, the live donor option received the most positive replies, but also indicated a substantial proportion of the community (33%) remain unsure about this approach (Figure 28). When comparing Bangladeshi and Pakistani Muslims (Figure 27, Table 34) live donation was more accepted by Pakistani Muslim community (50.3%) and deceased donation was favoured more than live donation by Bangladeshi Muslim community (19.4%).

Figure 28 Would you be willing to consider becoming a live donor?

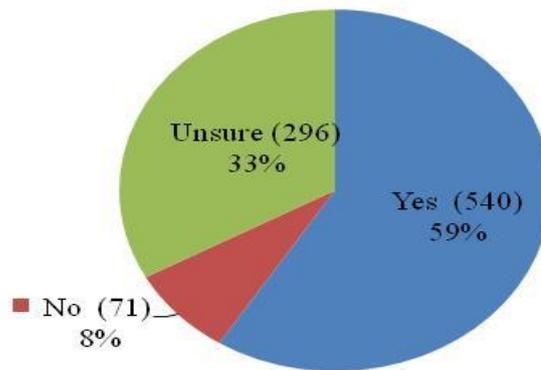
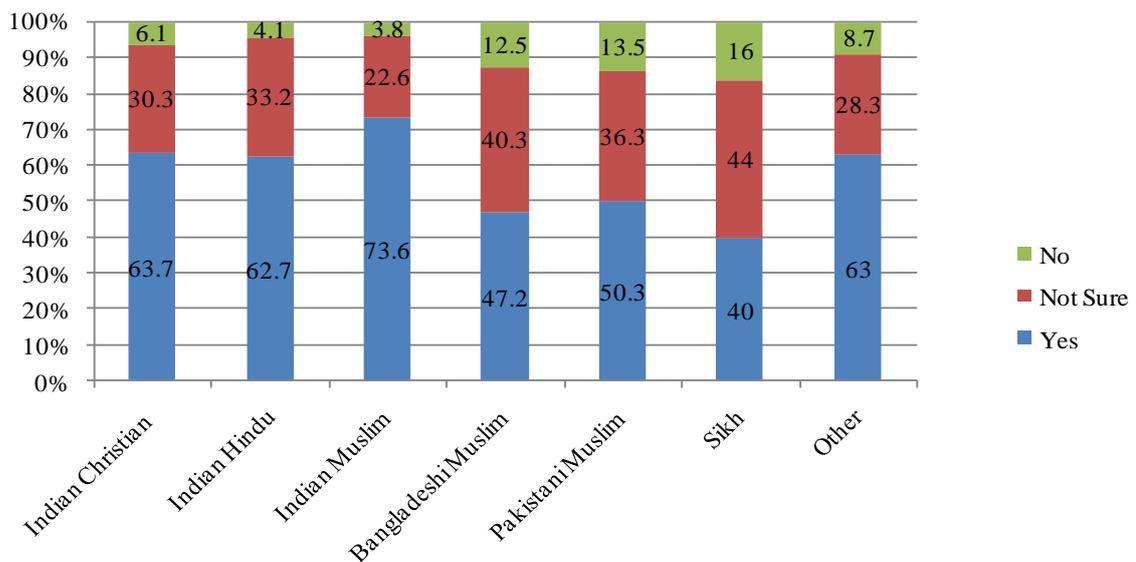


Figure 29 Willingness to be a live donor and ethnic community perception



One person interviewed commented that they had:

'...been told that you are not allowed to accept or give any organs. But in this age we need to move forward and I agree with organ donation. If it's your family you would give up your life wouldn't you?' (10FM)

The Sikh community (16%) were more unwilling to consider live donation compared to the other communities and among the Muslim community, Pakistani Muslims (13.6%) would not consider live donation (Figure 29). Whereas all interview participants were supportive of live donation, although the sample failed to recruit anyone from the Sikh community to be interviewed. The participants indicated they would consider giving to their loved one only if they were in that desperate need, but may be put off if it was painful, or were concerned about risks and rejection, but more importantly needed more information about this potential alternative option.

'I would have second thoughts about it because of the pain after that.' (2FC)

'I think it's something that it's very new to me, if it was my immediate family I would donate my organs as live donor. It's still very new to me; there is a lot that I would need to understand risks and everything. I think I would do especially if it was an immediate family even as extended family I would come forward as a live donor.' (10FM)

'I have seen son donating to father and the kidneys got rejected so both of them lost their kidneys so all that in your mind. Only when time comes you would decide on something like that. If it's something that I have to do I will do it.' (2FC)

7.12 Perceptions of an Opt Out System

To ensure responses to the questions were reliable and the participants understood the meaning of the questions, clarification was offered in the questionnaire. Respondents were informed that; *'In some countries it is lawful to take kidneys from any adult who has just died, unless that person had specifically forbidden it while they were alive'*, then they were asked whether they would oppose such an Opt out system in the UK to organ donation. Only 18.1% opposed such an idea and 57.3% were in favour of the Opt out and a further 24.6% not sure or not bothered (Figure 30).

Figure 30 Do you support an Opt Out system in the UK?

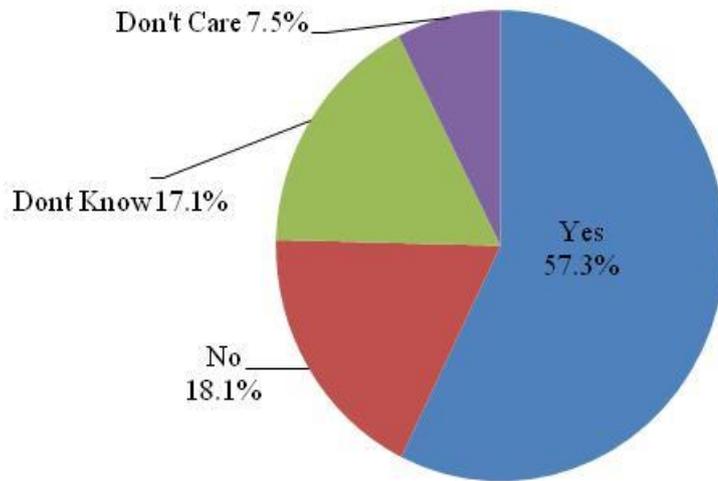
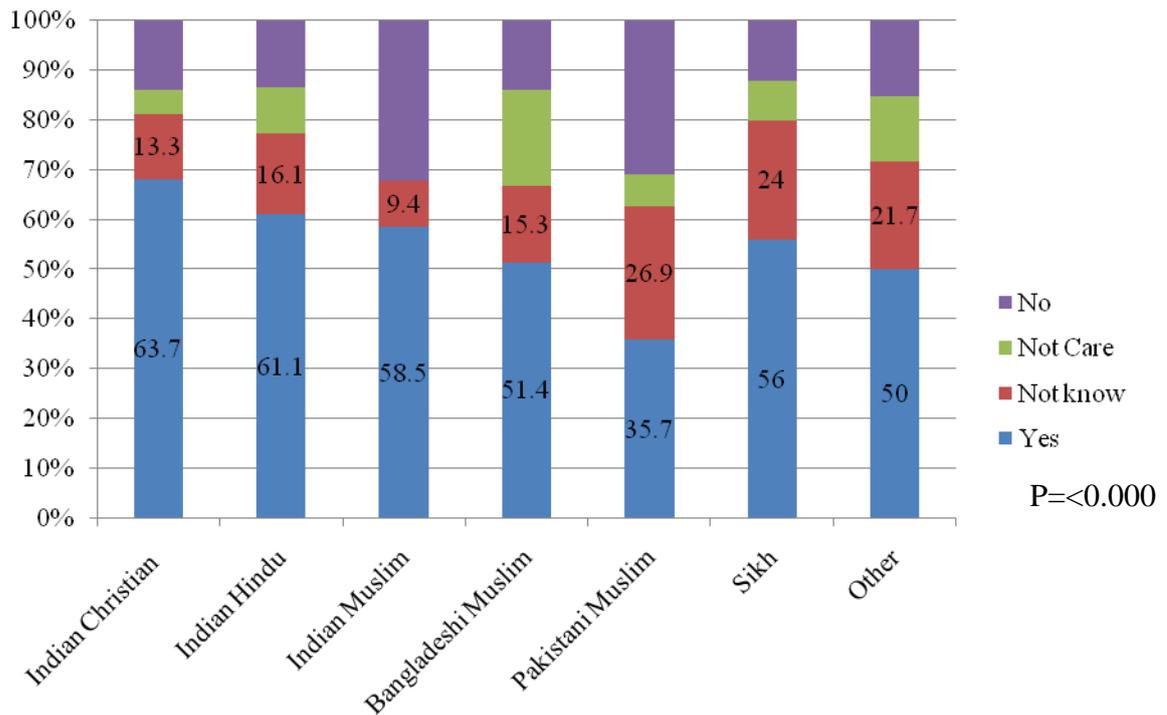


Figure 31 Community perceptions



Do you support the Opt out system in the UK?

The Muslim ethnic communities appeared less in favour of such an approach compared with other groups (Figure 31), particular the Pakistani Muslim community. Analysis of the different ethnic communities rather than simple religious groups identifies differences that create barriers for some cultural groups and not others of the same religion, important when providing pertinent education.

From the ten interview participants only eight discussed about the Opt out, five who responded were unreceptive and opposed to the idea. Their main concern was worry about the knowledge among the public and unaware about how they would Opt out if they did not want to donate. All five participants who opposed the idea agreed that if the whole community was educated on this topic, then the Opt out idea could possibly be implemented successfully. Although concerns about government control were voiced, the need to educate and increase individual self-efficacy and control over the Opt out decision, worries that people would just not be informed and it would be wrong to take organs in that way.

'I heard about it, it's kind of like part of being on the register, still it bit serious commitment given that I am not still not sure about how I feel about. I would straight away opt out for two reasons. (1). For my beliefs (2). Another reason that's too much control that the Government is having on my body and life to opt me in. To make that point I will straight away opt out. And if in case I change my mind I may opt in later. In that way I will have greater control over, I think that would help me to feel ease spiritually.' (1FH)

'I heard about it. It's not fair; automatically you are getting organ donation system. Especially with the Asians they are very laid back and let it happen until the last minute and they will say I don't want this anymore.' (6MM)

'I do not agree with it, because everybody not knows about it, due to the cultural and linguistic barriers not everybody knows that. Like my 70yr old grandma who has not many of her family members here, they are not aware so when she goes back, as she automatically opted in, she has been opened, no I do not agree with it. I do not think you will ever be able to raise the enough awareness for everybody to know that they have been opted in and they have to be opted out.' (8FM)

'I am not very happy to hear about this, I did not know about this. I am not very happy to hear about it. There must be lot of people who have not heard about it. They might have not It is something you are forced into it. I wouldn't agree with it.' (10FM)

Some were receptive but needed more information before they would make a decision.

'I don't know really. Well, I am 50:50. So for example, I don't know how the system works out. If I am not sign up will they be able to take my organs, so if I opt out of it

they may not. So I don't know, I never thought about. I might not object. Before, it was different, but now people believe in that.'(5FM)

'I wouldn't say it's bad thing, from my own personal point, after the education and awareness people will have sufficient amount knowledge to decide whether they want to stay in Opt out or to remain inside the system for transplant. Otherwise if it's no education and awareness then that person is already in the system and that person will start argument and then it will become extremely ugly.'(7MM)

Others agreed with it and after the interview and the opportunity to discuss their fears and perceptions their attitude towards organ donation became more positive, but this was not the purpose of the interview, to change views to explore why and what those views were.

'I agree with it, it depends people have different views. Even if it becomes a national law some people may be happy and some still not be happy. People may say why should we this is my own body I can do whatever I want. It shouldn't be national thing; everyone should have their rights.'(9FM)

'Only time will tell. I don't think earlier on I would have opted out, but now with being aware of need and what you can do to a person after you dead and gone and if you can help somebody that's what God want in this world . You are here to be a blessing if I am blessing even after my death yes I will go for it and agree with opt out.'(2FC)

7.13 Receive But Not Give...

It was important to note that a few participants passed comments on the overall negative attitude of people within their own community, many adopting an 'receive but not to give' attitude and the reinforced the need to address this selfish behaviour through education.

'We need to educate our Asian community, because we like to take but they don't like to give. God forbid if it happens to me if I was in need of an organ, why they are like this, why they are not giving to me. I am sure everyone will be same. But when it is time to give, it's not for me they will move it back. It's just the way our mentality is, to change that we need to put lot of effort, if it's permissible from Islam.'(6MM)

'Yes, I am very aware about the Asian community, that they are very reluctant to give, but when it come other way around sadly they are very quick to take, that's when I paused to them asking if you are so very strong against organ donation but

when you are in need of transplant you are quick to run to NHS and put yourself on the organ waiting list, random persons from somewhere will have perfect organ and that organ is inside you and then you don't question. I think we have to work in harmony together has to be a good human being and to help others and to progress in our life if we can help someone else to have a good life I think that's become our duty as well.'(7MM)

Despite this negative trait observed in the South Asian people, the willingness to join the ODR, potentially positive feeling to introducing the Opt out or presumed consent system with sufficient education, and the extremely positive perception to being a live donor, was both encouraging and reassuring for the education campaign. Comments recommended moving forward and working for both sides of the community those who can give, give to those who are in need.

'But in this age we need to move forward and I agree with organ donation.'(10FM)
'... it should not be working one side it should be working both ways.'(7MM)

7.14 Summary

This mixed method approach in identifying the reasons behind the scarcity of organ donors highlights that seemingly intractable factors, such as religion and culture, are often tied in with more complex issues such as a distrust of the medical system, misunderstandings about religious stances/grey area, lack of awareness, media misinterpretation, myths and knowledge from their home country. Potential education approaches must include culturally appropriate strategies to engage minority groups, especially through religious or cultural leaders, and make more widely available information about the donation process and its positive outcomes. It was interesting to note that gender or education status did not affect the view of the individuals but their lack of awareness of the organ donation topic directly influenced the individual's decision to join the ODR.

Table 32 Summary of Phase One Key Findings and Strategies to move forward

<p>Key Barriers</p> <ul style="list-style-type: none"> • Lack of knowledge and awareness • Misinterpretation/guidance of religion/not clear, grey area/ worry about tempting fate
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- Lack of knowledge from home country
- Mistrust in the medical system/ Worry about misuse of organs including organs giving to patients who are non compliant with post transplant care e.g. alcoholic
- Negative influence of media

Key Findings

- Provides an evidence base as one of the largest data sets of South Asian perspectives with respect to organ donation in the UK
- Higher education level does not provide increased knowledge on organ donation topic
- Lack of knowledge and awareness of organ donation whilst growing up in school and organ donation topic is not reflected as important in health education like No smoking, Cancer awareness campaigns etc
- It is important to concentrate on communities rather than religion and ethnicity as there is difference in their beliefs and attitudes. From the literature review it was evident that this is the first study which looked in different community perceptions in details with sample size of 907 in the UK.
- Need to concentrate on younger generation to clarify their mistrust in medical team/misuse of organ, may be secondary to effect from social and digital media input.
- Lack of knowledge among elders reflecting negative on youngsters decision making

Strategies suggested by South Asians:

- Gain religious leaders support
- Concentrate on South Asian media to raise awareness on organ donation
- Develop education programs in Schools and Universities
- Culturally sensitive approach by the SNOD's and availability of the religious leader when the family is approached by SNOD's in ICU.
- Preference to discuss with GP's.

Policy considerations:

- Presumed consent (opt –out) possible future option
- Living related donation favorable option
- Education in the community crucial to move forward and facilitate organ donation from South Asian people.

The next Chapter presents the findings of Phase Two of the study, the implementation and measurement of the impact of the different education approaches within the South Asian community.

8

INCREASING ORGAN DONATION THROUGH EDUCATION: RESULTS

8.1 Introduction

The findings from the implementation, development and impact of the three different education approaches form this second results chapter. The inherent and widespread lack of awareness and knowledge of organ donation reinforced the need for the second phase of the study. It was interesting to note from the first phase that even people from a higher education had little or no understanding of organ donation. The key barriers and findings from phase one informed the content of the education delivered to the South Asian community. Education was designed to provide information to answer key questions with respect to:

- Perceived barriers: uncertainty of religious stance, personal and religious beliefs surrounding death and dying, medical mistrust, lack of awareness and knowledge, clarified through presenting the perspectives of different religious leaders, information leaflets workshops, training health professionals to be culturally sensitive.
- Perceived susceptibility and severity: the scarcity of organs, the increasing problems of CKD within the community, the time sat waiting for an organ, real life experiences of people on the waiting list with CKD, waiting list reinforced.
- Perceived benefits: captured through telling stories, real life experiences of experienced people within the South Asian community, those receiving successful transplanted organs – given a chance to live, gift of life, views of families and friends.

Three approaches were introduced to target education in different ways and increase the number of South Asian organ donors within the North West:

- Increase awareness and recruitment to the ODR by the GP in primary care.
- Education and training of the SNODs to facilitate a culturally sensitive approach to potential deceased organ donor South Asian family.

- Peer education increasing knowledge and awareness direct to the community from experienced South Asian organ donor experts and the use of a media campaign.

The impact of each approach was directly measured by either an increase in the number of ODRs or an increase in the number of consented cadaver organ donations, reported and monitored by the NHSBT audit department and statistician. Each approach is discussed in turn the challenges, results, success and limitations discussed and presented. Gathering additional qualitative data within the education approaches was ‘*messy*’, often opportunistic, reactive and informal, with the researcher using field notes and a diary to capture unplanned conversations, observations, and discussions as well as her own thought’s, experience and reflection. Where possible people were asked to write their experiences down on email to try and draw out what was good, did it work, why and how with respect to the networking and education approaches that naturally developed. Verbal consent to use the email communications as evidence within the thesis was gained from all involved, and clarification to do so was confirmed by the R&D ethics committee. The credibility of such a disordered process can be criticized but not knowing what for example a peer education event may look like, who may be in the audience, when it may take place made planning at times difficult.

8.2 Recruitment to the ODR by the GP

8.2.1 Challenges in identifying and engaging GP’s

Gaining ethical approval to engage GP practices was a lengthy process. Even after obtaining the site specific R&D approval from the Primary Care Trusts engaging GPs in the study was a challenge. However, the GP with the highest number of South Asian patients in the North West declined to take part in the study, feedback from the practice manager indicated that the ‘*practice is really busy and do not think this is a priority.*’ As a result the next largest practice was contacted and so on until five practices agreed to be involved with each having: 94.66%, 93.67%, 92.19%, 90.96% and 74% of their registered patients were of South Asian ethnicity.

As planned GP practices were visited by the researcher in February 2013 and met the practice manager and/or the leading GP (who was not always available). During the meeting both information and education was provided about the study and organ donation to ensure increased of the organ donation systems in the UK, how a patient is registered,

the information a donor requires, the need for South Asian donor recruitment due to scarcity of organs for transplantation. Each GP had access to patient organ donor recruitment packages to discuss with their patients. Also, provided study related posters to assist in donor recruitment, raise awareness, and stimulate discussion. All information materials on organ donation, in different languages from NHSBT, were displayed in the practice waiting area and consultation room. The GPs had specially coded ODR forms that when sent to NHSBT to register a person would be tagged to the study, so success from each site could be measured. It was agreed that GPs, if asked, would encourage patients to consider organ donation, provide additional information and answer questions where appropriate. For their participation irrespective of how many people were recruited GP practices were offered a nominal fee of £200 for their extra involvement.

A South Asian GP within the steering group advised on the approach. Three GP practices were supportive and appeared engaged, both the GP and Practice Manager met with the researcher at the beginning of the study and during the three monthly follow up visits to supply more materials and feedback ODR audit figures, motivate and sustain activity. The two other practices agreed to be involved but were unavailable throughout the 12 months for additional meetings, and only the Practice Manager was present in the start-up meeting.

8.2.2 Results

It was disappointing to report that not one new ODR was recruited by any of the five GP practices.

Number of new ODR recruited by GPs over 12 months = 0
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Brief informal written (email) feedback on the process of ODR recruitment was received on behalf of the three supportive practices once the 12 month observation period had expired. The study materials had indeed been made available but no person had approached their GP to discuss organ donation, despite posters throughout the practice encouraging them to do so. Practice Manager comments suggested that maybe some people would come forward if such information material was available all the time, but apart from advertising the information literature, they could not see 'what else we can do' to help.

‘During the study we have information in all the clinician rooms and waiting area, if anyone was interested the reception staff could guide them. I know that we didn’t recruit any patient’s this time, but maybe if the information was in practice all the time via leaflets and posters, patients may take more notice.’ (Manager, Practice 1)

‘We had put leaflets and posters in reception and all the clinicians had been brief on what the campaign entailed. I am not really sure why there was not a good response, we can still advertise in reception but other than that I am not sure what else we can do.’ (Manager, Practice 2)

A further comment indicated that patients that registered with GPs were asked to Opt in to organ donation on the patient registration forms, but it was perceived by the Practice Manager that the majority leave this blank because they do not feel comfortable because of religious beliefs.

‘At the moment all our patients during the registration process have the option to opt in for organ donation via the GMS1 form. The Majority of the South Asian patients choose not to fill this section in or decline being any sort of donor. The patients do not feel comfortable in this due to cultural and religious reasons. I believe that there should be some sort of national campaign to raise awareness amongst South Asian population about becoming a donor, as this can help save millions of lives. It would be beneficial if we can have leaflets in all languages to put at reception desk and if there is CD that we can play on our LCD in Urdu and Bengali about awareness.’ (GP, Practice 3)

Indeed the above comment from a GP indicated a lack of awareness that the leaflets supplied were in different languages, suggesting minimal engagement was offered to the study, with little knowledge of the study materials readily available.

The initial education approach proposed by the researcher was proactive in that GPs raised the topic and openly discussed it with their South Asian patients taking the initiative themselves, however GPs from all five centre’s at the outset declined this approach as impossible to incorporate within a GP consultation surgery. Reasons for this were that;

‘When the patients are visiting us with their illness it is not our priority and organ donation topic’

'...discussing organ donation may give them negative impression on their health status'

*'...as it is more related to religion we do not feel confident to discuss with patients'
'I (GP) am not confident about the process and religious stand to approach, but if a patient ask me and start the conversation I will discuss this further.'*

The modified approach was reactive and relied on South Asian people believing organ donation was relevant to them and bringing it up in an already rushed consultation. What was interesting was the comment that suggested one GP perceived there to be religious barriers to organ donation, which they did not feel confident to discuss. It was never the intention of the study to encourage GPs to answer religious or cultural uncertainty questions posed by patients; but simply to reinforce the education of susceptibility of the South Asian population to developing CKD and the increased demand, and need for donor organs from the same ethnic group. What this comment reinforced was that the GPs had not been prepared or equipped to deliver the organ donation information and indeed to first increase their own awareness and knowledge of the topic. This could have been alleviated through appropriate cultural and religious training regarding the myths of organ donation, to provide them with the confidence to embed organ donation within consultations with people from varying faith groups.

Despite the poor result, the position of trust that GPs hold with the public cannot be underestimated and the belief given to this health professional could potentially be a very useful tool to encourage and increase organ donation amongst South Asian people. Participant's interviewed in Phase One, reinforced the idea that GP education and raising awareness would be beneficial.

'My GP never mentioned about organ donation. I will listen to the GP. GP's are always right. No they are not taking that initiative.' (4FM)

'If the GP's taking leading role, it is a good idea' (6MM)

'If we can start from somewhere where we go and see for regular symptoms, the foundation and stepping stone could be GP's for awareness, and then we can take it from there.' (7MM)

GP and the local Trusts could play a role in raising awareness like smoking awareness.' (8FM)

Certainly organ donation draws perceived religious tension within a discussion where discussing fasting with diabetics does not. Questions posed regarding religion should simply be directed to religious leaders, but a lack of confidence and knowledge in the topic prevents such a discussion starting.

Interest was shown, by the President of the Royal College of General Practice, following a study presentation (at UK Kidney Week, May 2014), to rethink on how best to take such an approach forward. She believed the opportunity should not be wasted but a different approach taken, building on the trust held by a GP. Recommendations on how this can be achieved are presented in Table 33.

Table 33 GP and Primary Care Recommendations

<p>GP and Primary Care Recommendations:</p> <ul style="list-style-type: none">• GP ODR recruitment approach to be redesigned but not abandoned• Provide culturally sensitive and religious training to primary care staff to increase confidence of GPs and others to discuss and recruit ODR• Recruitment to ODR proactively as new members register within all primary care sites• Consider financial incentive similar to other quality outcome targets set in primary care• Audit presence of and promote organ donation literature within all primary care sites - as directed by the DoH and Government in 2001, still not widespread practice• Develop national large scale primary care organ donation recruitment project• Gain the support and ownership for the initiative by GPs

8.3 Education and Training of Specialist Nurses in Organ Donation (SNODs)

8.3.1 Gaining Access and Education Workshop

The education was designed and introduced as a direct response to evidence of the need to train and educate health professionals to approach the families in a culturally sensitive manner (Rizvi and Naqvi 1995; McKay and King 2004; Randhawa 2013). The workshop and education support aimed to deliver sensitive, cultural and religious training to the North West team of SNOD's, increasing knowledge, awareness and confidence to approach South Asian families whose family member could be a potential cadaver organ

donor. The original education initiative was to educate the whole organ donation team within ITU to encourage a proactive, coordinated and confident approach to all appropriate South Asian families. However, taking the advice of the North West SNOD Manager and the Steering group discussions it was agreed to focus on the SNOD team as they were the designated person often responsible for approaching the next of kin. The SNOD team manager facilitated access to the group through one of their three-monthly team meetings, allowing the whole half day session to be developed into an education workshop.

The North West SNOD's team was met on the 19th of March 2013 by the researcher and two of the steering group members (South Asian Transplant Consultant and Muslim Religious Leader) during their team meeting. From a regional team of 27 SNOD's, the attendance at the three-monthly meeting was dependent on workload, at this workshop 16 SNODs were available to attend. The workshop provided a balance between face to face lecture and the provision of accurate information, stimulating discussion and answering questions as to what to do if, based on SNOD experiences in practice (Table 34).

Table 34 Example of workshop content

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|---|
| <ul style="list-style-type: none">• Presentation of Phase One study results: highlighted mistrust of the medical team and lack of knowledge and awareness amongst people of the South Asian community, experience of interviewee from South Asian family not being approached• Use of body language to show respect (for example when sitting down do not cross legs as most of the South Asian elders consider that as a sign of disrespect)• Using appropriate culturally acceptable terminology (for example if the organ is not transplanted it will be '<i>incinerated</i>' the term is not acceptable in most South Asian cultures, may represent disposing without respect, alternative terminology suggested to provide reassurance of appropriate disposal and dispel mistrust of misuse of organs)• Difference in culture and religion explained (the use of the word 'Asian' to collectively describe very different groups of individuals with different beliefs, culture and traditions which are important to understand and to be able to distinguish between)• Religious clarification and expert support (What to do if people request religious clarification – refer to religious leader and scholar, making better use of Trust |
|---|

Chaplains, often accessible 24hrs a day)

- Providing accurate information on how their family member's body will be respected and taken care before, during and after the donation operation.
- Providing options of spending time with their family member once organ donation is agreed
- Reassurance about time (overcome and dispel the common myth that if they agree to organ donation there will not be a delay in releasing the body)

8.3.2 Workshop Discussion and Experiences

The SNODs were open and receptive to the education and training. The results from Phase one of the study generated an interesting response, with SNODs particularly about the mistrust in the medical team, and the perceived misuse of donated organs for research without the consent and knowledge of the family.

Many SNODs were misinformed regarding the South Asian community and they collectively perceived that being Asian indicated one ethnic group and people from the from Muslim religion. Thus the education raised the importance of taking the time to understand the different backgrounds of individual families their cultural and religious beliefs, prior to approaching them to consider organ donation. Asking them questions of what they believe would clarify what information is needed to reassure and support their decision. Cultural competence on behalf of the health professional was required to ensure respect and dignity when approaching different families from different Asian cultures.

The Muslim religious leader (an Imam and steering group member) explained about the perceived pressure of time (the body to be buried before sunset) and discussed the explanation given in the Holy books, what the circumstances were when it was mentioned in Qur'an, and offered advice on how to overcome this barrier, indeed encouraging contact with the local religious Scholar. SNOD's discussed the challenges they have faced in the past: including: *identifying the next of kin, male domination when making the decision, coordinating big families with many elders, all of which want to be involved in the decision making*. Solutions on how best to manage religious and cultural situations in practice were discussed and 'what to do if' questions posed and answered collectively between the Transplant Surgeon, Imam and researcher. Direct feedback from the SNOD

attendees at the close of the workshop indicated a very positive benefit and consensus that the session helped increase their confidence in approaching the Asian families, with a deeper understanding. SNOD's suggested an appropriate information leaflet with culturally sensitive and relevant religious information would be really useful for them to distribute and discuss with families.

The plan was to regularly meet with the SNODs, potentially two or three times over the 12-month observation period to reinforce and extend the cultural and religious education of the organ donor professional's. Unfortunately, due to the SNOD's busy schedules and shortages of staff, a further session within one of their planned team meetings was not possible in the time frame. Although regular meetings were held with North West SNOD'S team manager to discuss the study progress and take forward suggestions for future practice.

An alternative approach provided access to SNOD's and Transplant Surgeons at the North West organ retrieval team meeting, where the Imam and researcher presented the study results, raised awareness and stimulated both religious and cultural discussions. Indeed discussions with ITU staff at the outset of the study stimulated awareness in the topic; verbal feedback from a leading North West ITU consultant identified that *'this study has made the team rethink about organ donation approach to the BAME families (ITU consultant).'*

8.3.3 Audit of Cadaver Organ Donation Rates

A retrospective and prospective audit of cadaver organ donation rates was undertaken from all ITU sites across the North West region, with information monitored and collated by the NHSBT audit team. This is normal practice for NHSBT to manage donor activity data from the ITU sites, so research ethical approval to access to this anonymous Trust data was sought from NHSBT and was not necessary from the NHS ITU sites. Data was observed for 24 months prior to the education workshop (2011-2013) and for 12 months post workshop (2013-2014).

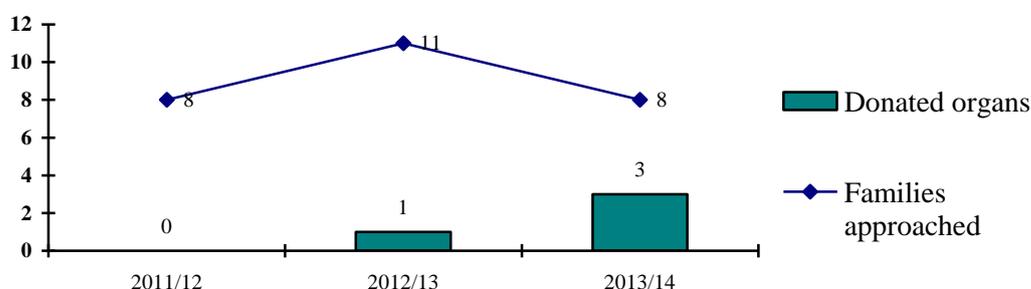
8.3.4 Results

Whilst it is impossible to directly prove that the education of the SNODs influenced organ donor activity a small increase in the number of South Asian organs was reported over the observation study period.

Increase in South Asian cadaver organs from 1 to 3 during study period

It was important to recognise that the annual number of Asian cadaver organs donated throughout the North West ITU sites is low in number (Figure 32). The retrospective audit identified that prior to the study commencing (2011-2012) eight Asian families were approached for organ donation consent and not one family agreed for donation to take place. The following year (2012-2013) 11 families were approached, but only one family provided consent and proceeded with donation. After the educational workshop, donor activity during the study period (2013/2014) highlighted that 8 potential Asian donor families were approached and three families' consented to organ donation (Figure 32).

Figure 32 North West South Asian cadaver donor activity



Qualitative evidence regarding cadaver organ donation experiences was gathered formally within the participant interviews where appropriate but also through discussions with people met through the networking. One interview participant from a highly educated background, had recently lost her Mother, and she reported her father had refused consent for organ donation, because of religious uncertainty, which could have been overcome by a Hindu priest being available to talk through concerns.

'I think if there was a Hindu priest there and if he has said okay to donate and it is good thing to do my Dad would have said yes for my Mom's organ donation, I think you will get more people donating if it happens in that way.' (1FH)

One of the South Asian donor families who agreed to in communicate their experience in a media interview stated that:

‘The family decided to donate five organs (heart, liver, lungs, kidneys and eyes) since five is a significant number in the Sikh religion. This desire was mainly put forward by my brother in light of my mother’s strong Sikh faith, giving nature and how she put others before herself in so many aspects of her life, even though the SNOD offered opportunity to donate more organs, but as this was their religious preference they kept it as only 5.’ (MFH)

The examination of why families of potential cadaver donors refuse consent is recorded by SNODs and monitored by NHSBT (Table 35). Twenty-three more South Asian people could have donated their organs over the last three year period, freeing up a possible 46 Asians from needing to have daily or alternate day dialysis, given the ‘gift of life’. However, the notion that donation is against religious and cultural beliefs, remains the largest barrier to not providing consent by South Asian families in the North West. Indeed nine organs, equivalent to 18 kidneys were lost to this misinformed belief, just in the last three years (Table 35).

Table 35 Reasons for Asian families to decline organ donation consent

Asian Donor Activity	2011/2012	2012/2013	2013/2014	Total
Family Approached	8	11	8	27
Family Consented	0	1	3	4
Reasons why donation was refused				
Did not believe in donation	1	1	0	2
Against religious/ cultural beliefs	1	6	2	9
Family divided over the decision	0	1	2	3
Patient suffered enough	1	0	0	1
Strong refusal-probing not appropriate	3	2	0	5
Other	2	0	1	3
Total	8	10	5	23

The need to provide sustained religious and cultural reassurance, with the topic being discussed openly and encouraged within each ethnic community by religious leaders, before a family are faced with a difficult decision, will help to address and overcome this problem. This increases the evidence that SNOD's need to be culturally competent and receive mandatory training, not to be able to answer questions related to religion but to be able to understand and identify when a cleric, Imam or priest need to be invited to dispel myths, offer religious clarification and advice. A religious or community leader may help a family to make the organ donation decision with confidence and reassurance at what is a very difficult time. A field note captured a comment by a SNOD at the North West Organ Retrieval meeting in Manchester.

SNOD from North West team reinforced how important she thinks this study is as they meet lot of Asian families and most of the time it is a challenge discussing organ donation topic. NORS Meeting @MRI, Manchester, Field Note: 3/7/2012

The South Asian donor family who agreed to make a media film of their experience to encourage others identified a that there was not enough information available for South Asian people in ITU, but at the same time described a very detailed information sheet that was not culturally specific and not helpful at the time of trying to make the decision.

'There is not enough information for Asian families in the intensive care areas regarding organ donation and also the process was very rushed.' (South Asian Donor Family)

'Information sheets provided to families have too much information's to understand at the difficult time and it is not religious/cultural specific.' (South Asian Donor Family)

The issue of meeting the information needs of donor families was discussed with SNOD's, ITU consultants at the researcher's Trust and steering group members. It was decided that developing an information leaflet for South Asian families would be useful. During a networking event the researcher met a family member from South Asian background who consented for their loved one to be a deceased organ donor. She reinforced that information was not available from her experience and made suggestions as to what questions she had wanted answering and what should be included in a family information booklet. Suggested questions were formatted and accurate and informative answers

gathered from; the NHSBT website, professional and religious experts, and lay steering group members.

The leaflet was constructed, content agreed by all members of the steering group and the resource made available to the SNOD's North West Manager for approval and dissemination to assist SNOD's to provide the right information at the right time. However, for the SNODs to be able to use the simple information leaflet (Appendix 11), it required printing approval from NHSBT. The leaflet was sent to NHSBT communication department for the approval, but as they are planning to review their own family information booklet in practice, the approval process is still pending. Such an information leaflet endorsed by religious leaders will provide the SNOD's with a useful tool in everyday practice. Within this current Opt in system, the only way to improve the poor South Asian cadaver organ donation rate is to ensure that families have the information they need, that is both religious and culturally sensitive, to answer the questions they have, access to a religious or community leader for reassurance, and more importantly they are approached by the right skilled and trained clinicians to provide the best possible support (NHSBT 2013) (Table 36).

Table 36 Recommendations for SNOD's and ITU teams

SNOD and ITU Recommendations:

- Provide culturally and religion sensitive information, leaflet, access to video of other peoples experiences, the donation process, and religious clarification
- Provide mandatory culturally sensitive and religious training to SNODs and where appropriate ITU staff to increase confidence in approaching South Asian families and offering a high level of reassurance of the donation process
- Develop a relationship with donor families to overcome issues of medical mistrust and ensure reassurance with respect to handling the family members body
- Consider theoretical models of organ donation education – perceived susceptibility and severity, barriers and actively promote benefits of donation – ‘gift of life’, organ matched to another South Asian, helping ethnic community
- Involve and set up support network of community leaders and hospital clerics and chaplains willing to offer religious clarification across the North West

8.4 Peer Education Increasing Knowledge and Awareness

8.4.1 Peer-education – what, when, where and how

During the initial stages of the study (Jan 2012 to May 2012), prior to commencing the Phase One questionnaire survey the researcher spent time to network and develop relationships within the community, identify key South Asian religious and social leaders in the North West, to begin a good rapport. The content of the peer education sessions were developed and informed from the phase one study findings and the review of the barriers within the literature. The threats, perceived severity and susceptibility, barriers and perceived benefits (expectations) from the theoretical models generated a framework to better understand the purpose of the targeted education, information and awareness campaign that was introduced (Table 37).

Table 37 Peer education in the community

	<p>289 events attended over 24 months</p> <p>Type of event:</p> <ul style="list-style-type: none"> Religious events = 127 (23 Muslim, 24 Hindu, 8 Sikh, 12 Jain, 1 Nepal, 56 Christian, 3 multi-faith) Social community events = 134 Health events = 24 University or student events = 4
	<p>Core education content:</p> <ul style="list-style-type: none"> Perceived severity, susceptibility – threat of CKD, scarcity of organs, plight of South Asian community, transplant waiting time Perceived barriers – religious clarification, respect in handling donor body, Perceived benefits – helping South Asian people, gift of life, way of serving God, real success stories
	<p>Key strategies:</p> <ul style="list-style-type: none"> Introduced by someone known and trusted Pre-meeting with key gate keepers to develop relationship and trust Information provided before a meeting to reassure gate keepers and agree content Communication, patience and persistence Nothing too much trouble, no meeting too small, no invitation to present, discuss, or support refused



Key success factors:

- South Asian network co-ordinator with passion, understanding and deep cultural knowledge of different communities
- Introduction and recommendation through respected community member
- Dedicated time to develop sustainable relationships and networks
- Support of respected experts, religious scholars, professionals, community leaders, CKD patients and families
- Use of different media – South Asian press, real stories of benefit
- Flexibility and availability at short notice

The researcher attended 289 community events and gatherings, the majority of which took place within the North West, but as the campaign became more well known requests to deliver education in other areas across the UK were unable to be refused (Table 37).

Meetings involved engaging with many different communities and indeed wider than the remit of the original study and included; Hindu, Muslim, Sikh, Jain, Nepal, and Christian groups. The majority of peer education events took place in the Christian community. Number of attendees in each meeting varied from 20 to 1,000. Larger meetings whilst useful at targeting large crowds of people at one time, it was not easy to have deep conversations with people to encourage people to register as a donor.

For example, during a Manchester Mela, supported by NHSBT outreach peer education team, where more than 5,000 South Asians attended over two days and there were eight volunteers with team on both days. Working from 10 am till 6pm, the team managed to register 256 individuals on the ODR. Compared to a smaller religious gathering where only the researcher was present, with the approval of the religious leader, which was attended by only 126 South Asians. Gaining permission to do a 30 minute presentation, and answer direct questions, 76 individuals were registered on the ODR.

Providing information in a closed environment and the opportunity to discuss and clarify the concerns along with the direct support from religious leader influenced

the individual's decision making process informed and prompt which reflected positive on the ODR. Field Note: 27/05/2013

Attending these events enabled the researcher to raise awareness on shortage and the severity of organ donation along with South Asian community's susceptibility of developing kidney failure and the benefits of joining the ODR. These sessions helped to generate discussions among the South Asian community members and spread the Gift of Life message. Even though study was going to concentrate only at North West region, as the study became popular researcher started getting requests from other parts of the UK too.

Important key education messages were communicated, using leaflets, talking to people, formal presentation to the group, answering questions, discussing people's concerns and providing reassurance and information to increase knowledge and awareness. For most of the peer education participants it was the first time they had heard key messages on the scarcity of organs and the need of the South Asian community, for example:

- In the UK 3 people die every day waiting for an organ (i.e. more than 1,000/year)
- Nearly 5000 people die each year in circumstances where their organs could be donated and less than 1500 actually go on to donate.
- Better match and outcome if the donor and recipient from same ethnicity
- South Asians are more prone to develop CKD
- Blood group and tissue type match
- More than 10,000 patients on the waiting list in total and 17% are South Asians

This type of information attracted attention and for some was enough to encourage them to register as a donor, but also it confirmed earlier findings that in this study being highly educated did not correlate to having an increased awareness of organ donation facts and accurate information. For example both a health professional (Chest Physician) and politician from the Pakistani community commented that:

'I was not aware that 17% of transplant waiting list were Asian, when we are represented less than 6% of total population and under represented on the ODR, I will join the register today.', Field note: 18/8/2012

'I was not aware it is better outcome if an Asian donor matched with an Asian recipient due to their genes match, even though I had involved in many community health education events as a political leader I was never aware about this information, we need to inform this kind of vital information to our community.'

Field Note: 16/11/2013

8.4.2 Peer Education Team

It was invaluable to have the experience and knowledge of the steering group participants to give up their valuable time, not only to participate in study meetings but also to dedicate time outside their work to educating and influencing the perceptions of the communities to which they belonged, at peer education events. Predominantly the core educators were the researcher, the Muslim hospital chaplain, a CKD patient, Transplant patient (wife and husband), and different transplant surgeons.

Prior to any education being delivered it was important the team were also educated before going out in the community, so the perceived susceptibility, severity barriers and benefits were explored within the first few steering group meetings. At times it felt like we were discussing the same issues but it was important for people to explore their own understandings, and beneficial to listen to others to enrich the understanding of the different South Asian communities. Consensus within meetings on the way forward unified the education team. Constant feedback of activity and results, communication by the researcher and follow up of networks and contacts kept members engaged with the study, certainly when benefits to increasing organ donation began to be realised.

8.4.3 A Reciprocal Relationship with NHSBT

One of the strengths of the study was the support and guidance received from NHSBT, which included valuable and active representation on the steering committee, providing information literature and ODR forms with specific study codes, analysing and generating study audit reports to measure impact and supplying paid volunteers to support education events. Without such a strong dedicated audit and communication team supporting the whole peer education approach throughout the 24 months there is no doubt the education approach would not have been as successful. However, the relationship was not one sided,

but reciprocal, and NHSBT received direct benefit from the study, the impact captured by feedback from the NHSBT ODR Manager (and steering group member) (Table 38).

Table 38 Summary feedback from the NHSBT ODR Manager

'Since 1999, NHSBT has implemented many interventions to register more Asian donors but from 2012 till 2014 Asian registrants on the ODR reached 4638, this was an increase of 1264 new Asian registrants in a 24 month period in the North West region alone.

Although the study was initially aimed at the North West region, Agimol went on to campaign throughout the UK with no financial or time incentives to increase awareness of organ donation, dispelling myths and gathering support along the way.

In 2011/2012 there were no Asian deceased donors from North West but in 2013/2014 there were 3 Asian donors. Another achievement was that she managed to facilitate two altruistic donors along with stem cell donor recruitment. The outcomes of this study will be beneficial to the ethnic minority patients waiting for a transplant.

Agimol has:

- devoted many hours to this study and stretched herself and others to ensure that any potential avenues to increase awareness of organ donation amongst ethnic minority groups is sought*
- Gathered evidence and key information that will help NHSBT and others to campaign more effectively*
- has put together leaflets that are specifically targeted at the ethnic groups ensuring that the information is relevant and up to date.*
- formed many influential relationships along the way which has led to partnerships for NHSBT and an increase in registrations*
- provided NHSBT with key information in regards to how to gain support among the ethnic groups, what their expectations and barriers are*
- put together an educational package that she has started to rollout for Specialist Nurses working in organ donation which provides essential information about approaching ethnic families to obtain consent for organ donation'*

The researcher acted as a feedback mechanism for NHSBT, direct from the people in the community highlighting issues with the NHSBT website communicated and discussed at a peer education session with approximately 40-50 people from the Blackburn Muslim Women's Group. After clarifying and presenting an overview of the scarcity of organs and the waiting list for transplants one lady who expressed concern regarding the religious

information on the NHSBT website and contact details of experts for advice. Her experience is captured with a field note.

One participant whose son was a transplant recipient expressed a real concern from NHSBT religious clarification on the website and the people to contact. From the Muslim religion and while promoting the message among her community, to help her son, she has been asked many religious related questions, so wanted some clarifications, so she tried contacting the Muslim religious leader which NHSBT mentioned as point of contact for religious and Fatwa clarifications. She had a very negative experience, according to her she might have tried more than 75 times to get through and when she got through the person was really angry and instructed her never to call him again and not interested in organ donation topic. Blackburn Muslim Women's Group, Field note: 11/05/2013

Giving information that is not accurate or useful can have a negative impact on influencing attitudes to organ donation. Following the meeting the Communications and Marketing team of NHSBT was contacted, on advice from ODR manager (steering group member) identifying the two issues raised by the peer education participant. The religious site was not up to date, with the Muslim point of contact inaccurate and out of date, and the Imam mentioned that the organisation listed as contactable regarding discussing issues of the Fatwa is not contactable and doesn't exist anymore. The NHSBT assured that they would act on the points raised and contact the named individuals.

8.4.4 Results

Peer education was extremely successful at increasing the number of South Asian registered organ donors, through the delivery of culturally sensitive organ donation information, providing reassurance and enabling time for people to ask questions and receive answers to overcome perceived barriers. Over a 24 month period the researcher monitored activity using coded forms that she posted directly back the NHSBT to be entered on the database. The researcher kept accurate record keeping and reports registering 2,874 people across the 289 (large and small) community events.

2,874 South Asian people registered as new ODR during 289 peer education sessions
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Unfortunately the researcher did not obtain the formal coded forms during the first 6 months of study period and was instructed to write the code on manually. It was only when the report was received in Jan 2013 from NHSBT regarding ODR registrants that the discrepancy in numbers was identified, with 522 missing forms that had been submitted not being recognised with the code. The ODR Manager was unable to rectify the mistake and the forms submitted could not be traced back or recognised to the study as part of the final NHSBT number. But permission was obtained from the ODR manager to include that missing 522 in the study related documents. Also during the two Mela South Asian events in Manchester (2012 and 2013) the researcher was supported by the NHSBT outreach team. For them to be funded the forms for the event had to be coded differently as there was cost implications to NHSBT. Rather than lose the opportunity of raising awareness at the event this was accepted but not ideal for measuring the accurate study impact.

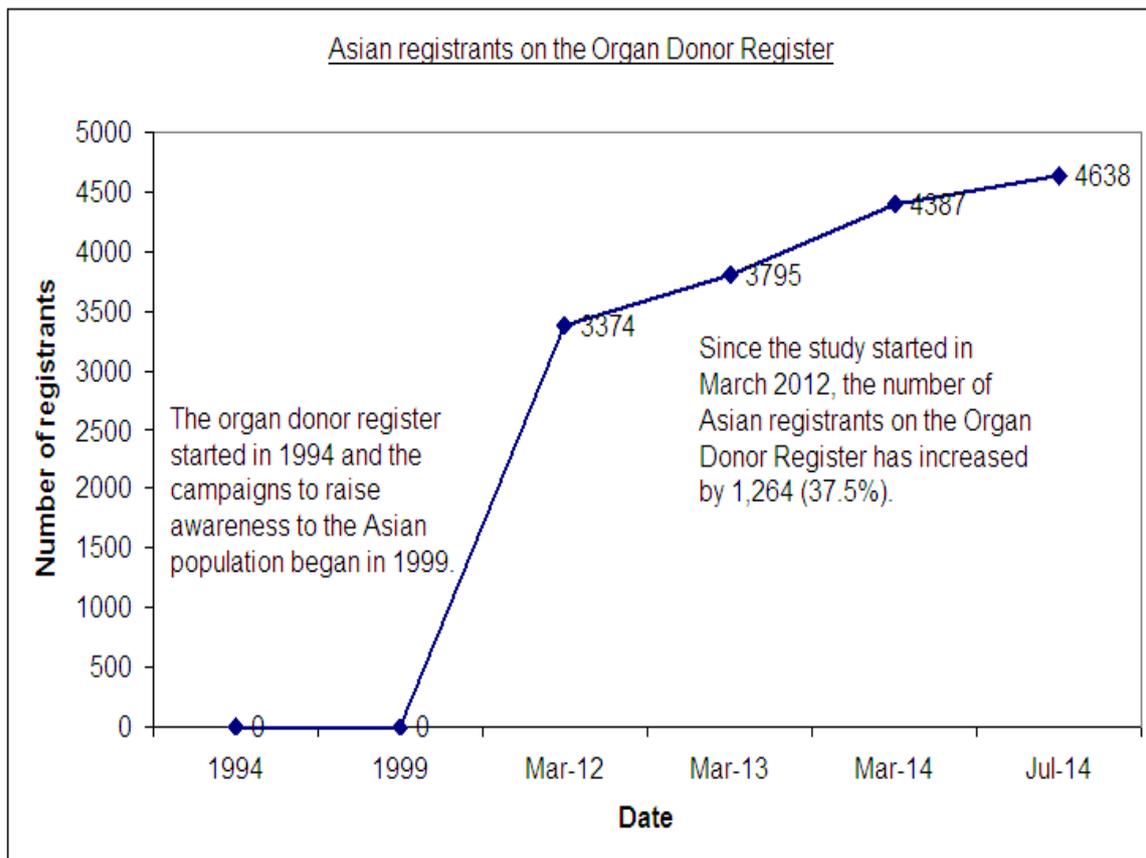
Also following a presentation at the Hospital (Trust Governor’s meeting), Trust Chairman and the Lead Governor requested to publish an article about this topic in the Trust Members Newsletter. Researcher informed NHSBT regarding the interest expressed by the Trust Governors, which was supported by NHSBT and provided a different code to track the record. Article was written by the researcher and cited a story from a transplant patient along with ODR form which was coded. Trust Newsletter was send to 13,500 members with ODR forms, through this initiative NHSBT received 131 ODR forms (Table 39).

Table 39 Completed ODR forms returned to NHSBT

Time frame (24 months)	Events	Number of ODR forms collected	Number of ODR forms coded/Not coded/Different code
May 2012– Nov 2012	76	674	152 Study Code/ 522 Not coded
Dec 2012- Nov 2013	124	1065 (i.e. Including 131 Trust Newsletter code + 265 NHSBT outreach code)	669 Study Code 396 Different code
Dec 2013- Sept 2014	89	870 (i.e. Including 302 with NHSBT outreach code)	568 Study Code/ 302 Different Code
Total	289	2874	1785 Coded/ 1089 Uncoded or Different code

The final figures generated by NHSBT demonstrated a considerable increase (1,264) although did not capture the accurate number of South Asian donors recruited within the North West region during the study period. However, since year 1999, NHSBT has implemented many interventions to register more South Asian donors and over 15 years has managed to register over 3374 South Asian donors. The current campaign has increased the number of South Asian registered donors by a further 37.5% in just 24 months in the North West region alone to 4638 (Figure 33).

Figure 33 Total of Asian organ donor registrants in the North West



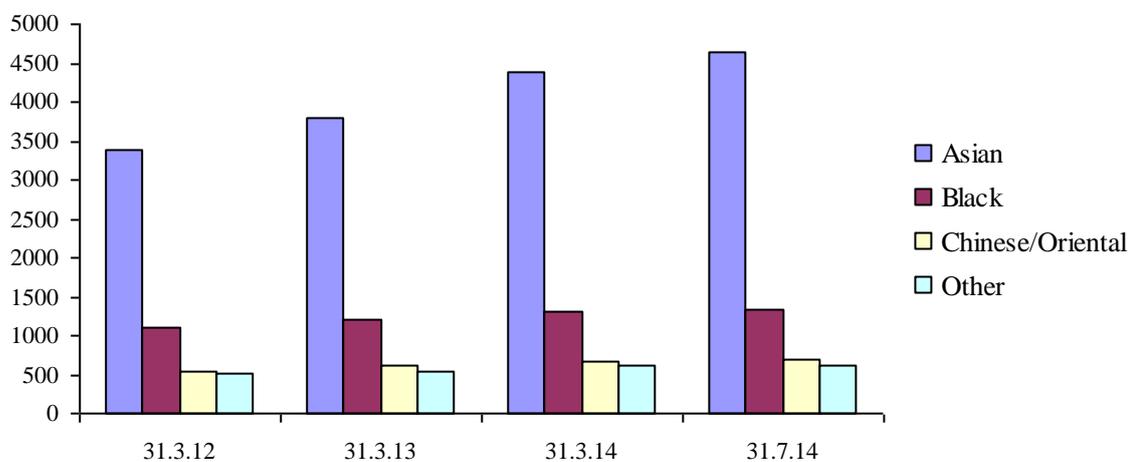
Indeed there may be more South Asian registered organ donors than the figures portray, as often when people are recruited or join the organ donor register, one third of registrants do not report their ethnicity making it impossible to accurately measure the actual number of South Asian organ donor data. This may need reviewing by NHSBT to set up a system that prevents people progressing without stating ethnicity, although this could in turn create a further barrier to joining the ODR (Table 40).

Table 40 Number Asians currently registered with reported ethnicity

	Registration number			
	to 31.3.12	to 31.3.13	to 31.3.14	to 17.7.14
Ethnicity Reported	439,613	470,691	500,365	506,743
Ethnicity Not reported	1,402,977	1,477,691	1,557,604	1,580,987
Total number	1,842,590	1,948,382	2,057,969	2,087,730
Asian	3,374	3,795	4,387	4,638
% of reported	0.77%	0.81%	0.88%	0.92%
% of Total	0.18%	0.19%	0.21%	0.22%

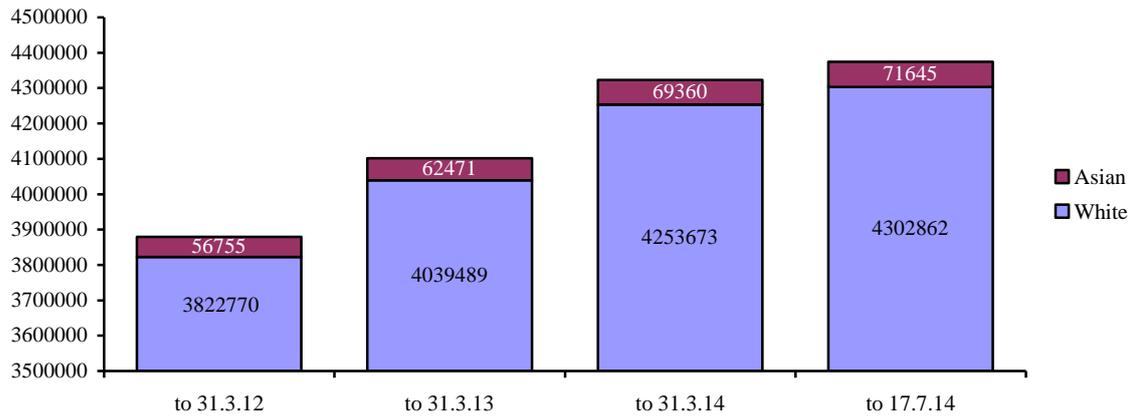
The activity across other ethnic minority groups was explored to examine if an increase had been seen across all BAME groups not just those in the study target population. Indeed there may have been local campaigns that the team had not been aware of. Figure 34 indicates that whilst there has been a dramatic increase in the number of Asian people joining the ODR other BAME groups have not experienced the same intensive activity, confirming that the intervention of the education approach had significantly directly influenced the number of ODR Asian registrants.

Figure 34 North West ethnicity ODR data for the UK



As the study became popular among the South Asian community, researcher was invited to attend many events throughout UK (109). Although this activity was not measured as part of this study, it will have influenced the overall ODR rate increases in the UK during the 24 months of the education approach (Figure 35).

Figure 35 Overview of ODR increase for UK during study period



8.4.5 Best Practice Rules of Engagement

From the development of the network there were key strategies engaged that influenced the success of the relationship, whether it progressed and sustained through to gaining access to a community group, religious leaders, community politician or influential leader, or being invited to further events in the same community. There were a number of different ways in which communities were approached through different forms of gatekeepers (discussed in next section), but there was also strategies used that formed best practice rules of engagement (Table 41).

Table 41 Examples of developing best practice engagement rules

Event, Experience and Activity – Field Notes	Key Rules of Engagement
<p>27/05/2012</p> <p>1. Pre-meeting with event organisers, educated about scarcity of organ donation and community's susceptibility of CKD, benefits of joining the ODR. Committee members acknowledged first time have been notified, wanted to do their best to support the issue.</p> <p>2. Wrote an article about the organ donation shortage in the native language and provided a small video clip reinforcing the severity and susceptibility.</p> <p>3. Published article 3 days prior to the meeting and prepared the audience, informed readers if they want to join the ODR and support this good cause, they will be able to do so during the</p>	<p>Pre-event meeting with editorial team</p> <p>Identify key information to generate passion for cause</p> <p>Publish information to get people thinking prior to an event</p> <p>(Influence of South Asian Press)</p>

<p><i>meeting in presence of an expert for clarification.</i> 4. 182 individuals registered from an event attended by 400</p>	
<p>18/08/2012</p> <ol style="list-style-type: none"> 1. Meeting with community leader in advance before the event 2. Community leader keen to promote this message 3. Advertised the facility of ODR registration along with his own special request for people to join the register via social media and advertising material 4. 134 individuals registered from an event attended by 200, people more willing and already informed 	<p>Pre-meeting with community leader</p> <p>Gain support for cause and educate key influential people</p> <p>Pre-event advertising via social media by the influential community leader</p> <p>(Influence of Community Leader)</p>
<p>27/05/2013</p> <ol style="list-style-type: none"> 1. Meeting with religious leader and discussion on the topic 2. Gain access and permission to have 30 minutes during one of their religious group session 3. Religious leader introduced the researcher to the group and his positive view on organ donation 4. Informed the group that he was willing to clarify any religious concern if anyone has following the education session –more convincing than health professional 5. 15-20 minutes presentation on the topic by the researcher and 15 minutes question and answers, led by the religious leader 6. 18 individuals registered from an event attended by 26 	<p>Pre-meeting with religious leader</p> <p>Educate then gain support for cause and permission to access group</p> <p>Endorsed by South Asian Scholar in respected position</p> <p>Availability of Religious Leader to support the education with positive religious interpretation -</p> <p>(Influence of Religious Leader)</p>
<p>26/04/2014</p> <ol style="list-style-type: none"> 1. Researcher introduced to the event organisers by the Transplant patient who holds influential role in local South Asian association 2. Group already aware of topic and impact of CKD from the patient belonging to their community – need for organs more real 3. Patient endorsed and supported education provided 4. Local champion (transplant patient) enabled access to future events 5. 46 individuals registered from an event attended by 70 	<p>Recommended introduction by respected member of community</p> <p>Pre-meeting with local organisers to confirm purpose of education</p> <p>Use of ‘real’ life experience - inside group supporter</p> <p>(Influence of ‘real’ person/patient within community)</p>

The key rules of engagement included; meeting and preparing group organisers prior to an education session being scheduled, gaining their support for the cause, confirming content of the education and information to be presented, gaining permission to access the people within the community group, using influential people in the group to endorse and actively promote organ donation, allowing people time to answer and ask questions, using an influential community of religious leader to clarify cultural/religious understanding (not a health professional). One of the most crucial activities throughout the engagement was the need to ensure the person making the decision to register as a donor was certain it was the right decision for them, it was completely voluntary and the person had no doubts, signing

someone to the ODR would have been counter-productive if they had changed their minds shortly afterwards, or had felt pressured to register.

Intelligence gathered from the Steering Group identified the importance of ensuring that the people who had influence within a community, a religious or political leader, were educated at the outset to gain their support. This type of peer education took place using pre-meetings, prior to accessing the wider group. In addition two formal peer education sessions were also introduced and developed with Muslim Religious Scholars (described later).

Steering group discussion following examining the questionnaire finding regarding options of Opt out system, comment from group member indicated: 'people are not opposed to opt-out but more against being forced to make a decision and opposition by Muslim religious scholars on the grounds of the sacredness of the human body' Group suggested an education session for religious leaders to educate to discuss the merits of organ donation and influence wider their teaching within the community by involving umbrella organisations (Bolton Council of Mosques, Lancashire Council of Mosques, Trafford Council of Mosques, Manchester Council of Mosques.) to influence religious teaching. A religious representative explained that 'there is lack of consensus amongst scholars, particularly when solutions are not clearly stated, more people, more opinions and different interpretations, so these issues need to be discussed and addressed through education and the use of media.' Steering Group Meeting, Field note: 12/09/2012.

A further communication that supported the need to educate the religious leaders as their own knowledge and understanding of organ donation was lacking was reinforced by a personal communication of the Muslim Hospital Chaplain (and steering group member) who reflected on his own knowledge and learning before becoming a member of the peer education team.

"Our initial discussion around organ donation was the main reason I decided to find out more about organ donation from an Islamic perspective. The statistics we had discussed had a profound effect on me and I decided to learn more about my communities' perceptions on this topic. This led to interesting discussions with fellow Imams, Muslim Doctors and the youth. All these discussions convinced me that organ donation was something that the Muslim community needs to be made

aware of and encouraged to donate. Personally, I have joined the register myself and even used my Manchester Evening News column to bring this topic to the forefront nationally. I do believe the many events, interviews, debates and discussions we have been involved in has gone a long way in promoting organ donation amongst the Muslim community.’ Personal Communication, Mr. Siddiq Diwan, Muslim Hospital Chaplain, Imam and Steering Group Member”

The best practice rules developed throughout the study when engaging with any individual (whatever their position within the South Asian community) were focused on a set of values to respect and trust through establishing the credibility and trust of the researcher by providing honest accurate information; and respect the hierarchy of a community, respect difference of informed opinion, and ensure informed consent.

8.4.6 Peer Education Recommendations:

- Peer education increases organ donation and needs to be introduced as a national education strategy
- Using key theoretical concepts organises and focuses education to target specific perceptions within communities
- Develop and ensure best practice rules of engagement (credibility, respect and trust)

8.5 Networking and Building Sustainable Relationships

The key to the success of all the different education approaches was the extent of networking and building of successful positive relationships throughout the South Asian communities within the North West. Indeed it is recognised now that if GPs within the North West had been approached prior to the study, to develop ideas and have a passion for the topic, the education intervention could potentially have demonstrated a degree of success. In addition increasing the relationship and networking with all the SNODs (not for the want of trying) could have potentially influenced cadaver donation.

Peer education within the community could not have been implemented without establishing community networks and taking the time to build and establish strong relationships with community and religious leaders, and the South Asian people. The evidence captured of this journey, through field notes and direct communication (verbal or

through email) identify a series of different successful strategies that influenced how and if the researcher was able to engage a particular community, these included:

- Optimising the Steering Group membership
- Community and Religious Leader influence
- Making the most of every opportunity – real life stories

8.5.1 Optimising the Steering Group membership

It cannot be stressed enough the valuable role the Steering Group made to this study and the education of the South Asian community regarding organ donation. The Steering group membership was not exclusive some members engaged more than others and some dropped in and out. What was a critical success factor from the outset was identifying and engaging key influential people, without which networking would have been a much greater challenge.

The group was formed with 15 members from different health professional disciplines, community, religious and political leaders from Asian origin. Key to networking was the willingness of the steering group member to introduce and recommend the researcher to their community, gaining access to their influential leaders (political or religious), or the fact that the member themselves were an important and respected member of the community (Table 42).

Table 42 Three examples of access to networks

Person	Action	Wider access
Muslim Hospital Chaplain, Imam	Letter of introduction to Muslim Scholars in North West (1.5.13)	Access to different Muslim Scholars and their communities
Transplant Surgeon	Introduced to patient who was Ahmadiyya Muslim Group Leader	Introduced by patient to wider International Ahmadiyya Muslims and approval obtained from leaders to attend their Charity Walk and their national Conference in London

Steering Group Member (Community Leader)	Invited to Soul Searchers Meeting, Bolton (8.12.12) networking among the GP's and community leaders	Introduced to a GP who is the chair for one of the South Asian radios, offered a chance to take part in one of their talk show to discuss about organ donation and its need
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The different activities of the steering group membership inviting the researcher to meetings, introducing her to other people and other networks enabled wider and more comprehensive relationships to be developed, although recognising still after two years there were many more community groups with which to continue to network and expand.

8.5.2 Community and Religious Leader Influence

One of the key strategies of networking was to identify people of influence within the community whether this was a religious or political leader. A number of key South Asian Mayors and councillors offered their support to the project and endorsed the education in the community at different events (Figure 36).

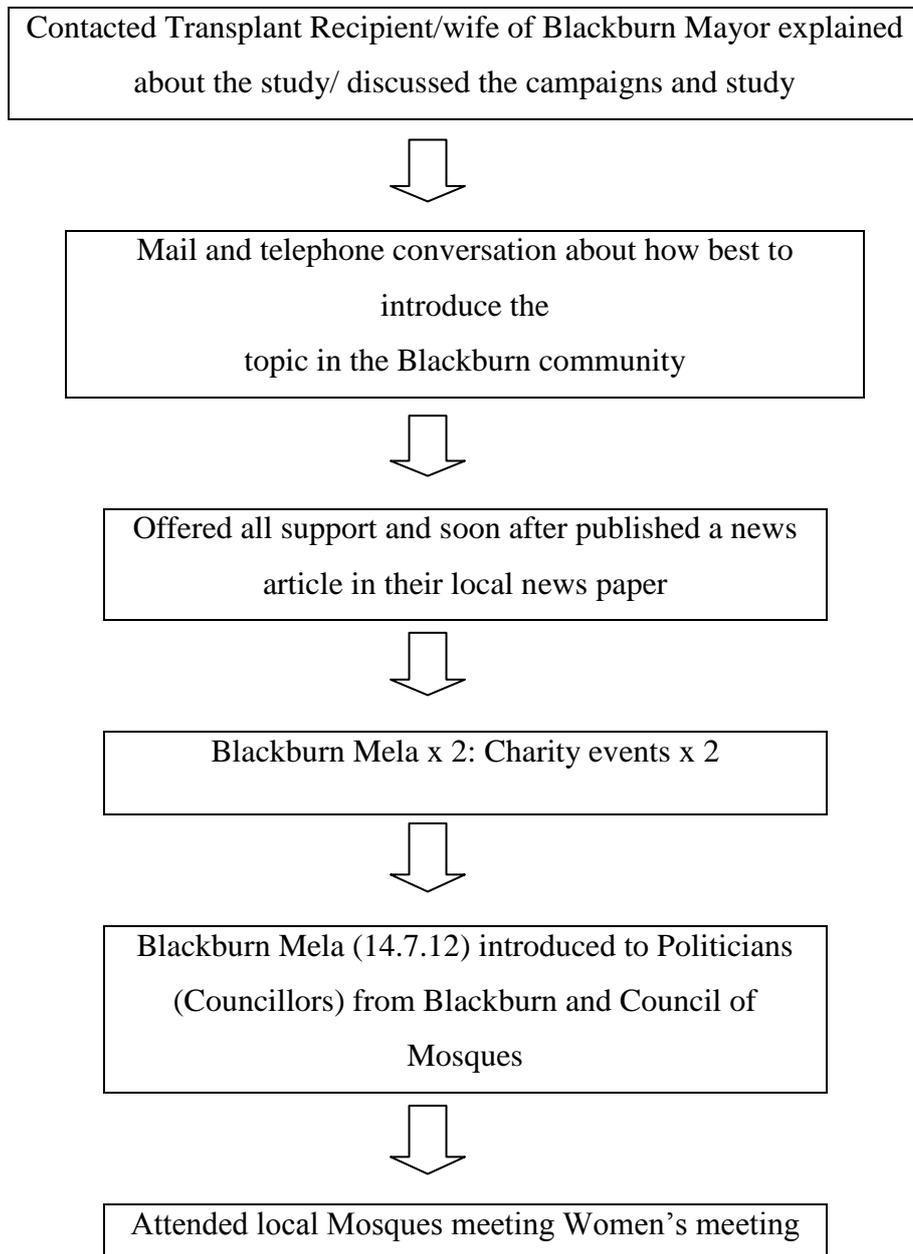
Figure 36 South Asian Mayors and Councillors



The support from the Blackburn Mayor, Mr. Salim Mulla, was particularly important as the perceived susceptibility and severity of CKD and waiting for a transplant was particularly relevant to his family. His wife had not long since received a transplant and

both were happy to promote her story to communicate the inherent need of the South Asian people with CKD. Mr Mulla kindly used his networks to connect and communicate the study with the Blackburn community, through religious events, charity evenings, wider through other councillors (Figure 37).

Figure 37 Networking with Blackburn Community



The networking was a great success certainly because the person involved had the political power and respected position among the community members, and his 'real life' experience increased the importance and meaning when he engaged with people, as he

discussed firsthand the suffering of his wife with CKD, waiting for transplant for over seven years and the difference the transplant has made on her life. Working together with the researcher, as a peer educator he was able to effectively spread the organ donation message throughout his community and the community he was serving as Mayor, to make a great impact on raising awareness. He commented that working together was the key to successful networking:

'I would like to support this work. Health professionals alone cannot do the awareness on organ donation topic among the Asian community. She has involved: Asian medias in conveying this important message, and she was successful by conducting radio talk shows, TV documentary, Newspaper articles, and involving GP's with relevant materials and information's to promote organ donation' Mr. Salim Mulla, Blackburn Mayor

Similar approaches were made to leaders of other organisations, some through cold calling, contacted and a pre-meeting arranged following the best practice rules of engagement. Many of the leaders unaware of the perceived susceptibility and severity of need for the South Asian community, once informed more often than not their participation and agreement to engage followed (see examples of field notes below).

Met the president prior to the meeting, who offered me to help and arranged a well known person from the community to assist me on the day. As she was from the group and known to many who attended the meeting, her presence with me allowed me to make great networking among the leading members. Indian Association Independence Day, Manchester, Field Note: 18/08/2012

Met the president of the organisation once and made regular contacts through phone, he introduced me to the group and managed to convey the message and was accepted positively, also networked with North Manchester Councillors. NORMA Event, Greater Manchester, Field Note: 5/01/2013

Religious leaders were engaged through different strategies; for the Christian religious leaders, communication with a Fr. Davis Chiramel from India, an influential (Chairman, Kidney Federation of India) and important religious figure supportive of organ donation was invited to visit the UK (Figure 37, Appendix 12). Accompanying the educators to

Christian meetings certainly raised awareness, gave importance to the topic and clarified any religious misconception towards organ donation.

Figure 38 Fr. Davies meets Christian religious leaders



To gain access to the Hindu community the educator/researcher organised and met with the Poojari (Hindu Priest) and the Temple committee leader twice prior to the community meeting, so they could explore the issue and understand the motives of the researcher clearly before agreeing to allow access to the community. His decision to give permission was captured in a field note at a meeting in the Temple.

Poojari (Hindu Priest) and the Temple Committee leader meeting to explain purpose of the study prior to meeting the community. Poojari commented 'as this is great human service and costing human life I will give all the support, in the past I did not know about the seriousness of the problem.' Even though I am not a Hindu I was given permission to enter in the Temple and attend their Pooja (religious rituals) and was introduced to their community. Poojari stated to me that 'human religion lies in your heart and you are a great human doing this great service to save lives, so it does not matter whether you belong to Hindu religion or not to attend our Pooja' Gita Bhavan Temple Anniversary Pooja, Manchester, Field Note: 18/06/2012

Similarly, Mr. Zilur Rahman (Social Secretary at Bangladesh Assistant High Commission Office) once the evidence behind the reason for the study was explained he was extremely really keen to support the work, and introduced and opened up his networks with some of the Bangladeshi community leaders and medical professionals.

A great success and fantastic achievement for the peer education team and a clear endorsement of the importance of the study topic, was the organisation and implementation of two Muslim Scholar Organ Donation education meetings, the first time such an event has taken place in the North West. The event was first proposed at the Blackburn Mela when the researcher met different Muslim Scholars and the Council of Mosques. They felt the religious uncertainty required deeper discussion and indicated a meeting of 10-12 Scholars would help clarify the issues.

This idea was taken forward with the support of a member of the Steering Group (the father whose child had a kidney transplant), the Muslim Hospital Chaplain and Transplant Surgeons. The initial meeting was held in March 2014; was attended by 35 Muslim Scholars mainly from the North West, but also had representation from Birmingham and London (Figure 39). It lasted over three hours with a mix of pertinent presentations and discussion.

Figure 39 1st Muslim Scholar's meeting in the North West



The peer educator presented the study; the networking and engagement of the community activity, attendance at over 250 meetings, registering over 2000 South Asian people on the register, the results of the questionnaire, and educated the community on the severity and need of the South Asian community. Surgeons presented an overview of organ donation the process from cadaver donation to transplantation, to gain a deeper understanding of the handling and management of the deceased body and determination of 'brain death.' To

reinforce the impact of CKD a patient presented their experience and a living donor discussed their donation experience.

The ‘real life’ religious questions posed to the educators from the Muslim community were presented as a basis to stimulate discussion and ascertain religious consensus, starting with for example ‘*I do not have any personal objection against organ donation, but I am not sure my religion allows this or not.*’ The event was reported by the BBC Asian radio. The outcome was so positive attendees expressed the importance of building on what they had begun to discuss and requested further meetings to be organised.

A second meeting was organised in May 2014, to form a committee to take the message forward, this was attended by 18 members, with additional invited representation from NHSBT and Faith Management Action Plan committee (Figure 40).

Figure 40 2nd North West Scholars meeting at Manchester



A realistic set of outcomes were agreed (Table 43) and it is hopeful to continue these meetings, sustain support, engage the Muftis to allow the religious ‘grey area’ to be clarified and agreed.

Table 43 Outcomes of the Muslim Scholar's meetings

- Need further clarification on brain death diagnosis, to present accurate information on this topic
- Need to engage Muftis (Very senior Muslim Scholar's from the UK), Islamic Universities, Academia and Imam's to discuss and find a solution on organ donation decision and to clarify the grey area and spell out the reticence
- Use and engagement of Asian media and networking among the local Mosque leaders would be the best local approach

It was clear from this approach engaging the religious scholars, as we have known for some time, is key to gaining support and raising awareness within a community. Members of the steering group reinforced this issue indeed one member shared an experience of a TV programme raising organ donation awareness which had completely overlooked religious involvement and caused considerable harm to engaging people positively with the topic. This allowed the researcher to learn from and avoid past mistakes.

One of the group members had experience of doing a live TV programme on organ donation but did not invite a religious scholar to take part, which received so many complaints that donating organs was against their religion, that it was forced to stop transmitting. This was reinforced within the subsequent discussion among the steering group members where it was perceived that 'the obstacle to organ donation lay in the misunderstanding of religious beliefs which required sensitive handling within education sessions so as not to undermine the authority of the Imam and their role'. It was also suggested a similar TV or radio debate if staged well with religious Scholars support it would have a great impact. Experience shared by AMM, Steering Group Meeting, Field Note: 25/05/2012

However, networking with people on a national level highlighted that even today the same mistakes are being made with respect to understanding the culture and importance of engaging religious scholars within the South Asian community, with their extensive sphere of influence they have, seen with the introduction of the Opt out system in Wales.

'My thoughts are based on the discussions I have had with the agency appointed by the Welsh Government (Cognition) and the leadership team of the Muslim Council of Wales (MCW). I was impressed to learn of the extensive amount of

outreach Cognition had undertaken over the course of 18 months and the network of influential contacts that they had established. However, despite the positive response on the surface they have found it difficult to secure active engagement and commitment from local Shariah scholars and Imams. In some cases, having agreed slots to speak with the management committee to address the congregation not being allowed in at the 11th hour. The feedback from MCW is that they felt disenfranchised from the process and whilst cannot guarantee an active response their networks and connections are with the key decision makers and this carries enormous weight. I am pleased to say that I have managed to get them back around the table and there is now a desire on both sides to work more closely together...’ Mr Ali, Steering Group Member of Faith Action Plan.

The member of the Faith Action Plan Steering Group reinforced the earlier warning that health professionals or key community networkers must not take on the role of educating people of the religious aspects of organ donation this must always be reinforced by the appropriate religious scholar or priest.

‘The approach must always focus on providing factual information about the challenges patients on waiting lists face and not the issue of permissibility within the faith. Yes... it’s important to have the appropriate documentation to support the current religious viewpoint but never to try and explain the rationale behind the Religious edict (Fatwa). The last thing any outreach worker wants to be accused of is leading individuals down a path that is against Islam.’ Mr Ali, Steering Group Member of Faith Action Plan.

One of the weaknesses of previous campaigns has been the focus on religious issues and not the perceived susceptibility of the community and severity of need for South Asian CKD patients. The religious edicts should only be discussed by a religious leader. An active member of the steering group and a religious scholar summed up the ignorance of people trying to address religious issues:

‘How do you feel if one of the religious scholar comes and teaches a transplant surgeon on how to do a transplant, we feel it is the same way when health professionals comment on religious perspective’ SMI, Steering Group Member

Therefore the networking, working together approach is crucial to any campaign and a team of health professionals, religious leaders, politicians, respected community members, people with 'real life' experience are needed to take the education of this multi-dimensional topic forward. This potentially highlights the needs of a team approach in ITU to increase cadaver organ donation rather than one SNOD without the support or influence of the religious and community leaders.

8.5.3 Making the most of every opportunity - real life stories

The philosophy of the campaign and networking was to make the most of every opportunity no matter how small. Two work colleagues introduced the researcher to two different groups. The first was a small community meeting attended by other health professionals, with an aim to try and help save more patient lives. The group accepted the cause positively and the majority of attendees joined the ODR, but a comment by a nurse reinforced the need to educate health professionals as well and not assume they are an informed group.

One nurse participant commented that; 'I thought they may stop treatment if I sign up the ODR that's why I did not join the register, but now I understand how the record is maintained, so I will join the register.' Kannada Community Meeting, Manchester, Field Note: 18/08/2012

The second was a meeting amongst the black community, where a work colleague was an influential leader. She was so inspired after the meeting that she has taken on the challenge of spreading the word and educating others, and she continually asked for more and more materials as she distributes information throughout the community.

There was nothing more powerful than a patient who has experienced CKD, had a transplant or is on the waiting list, standing up and discussing their own experience, suffering and journey, particularly if the person is known to the community. Examples have been captured earlier with Mr Mulla (Blackburn Mayor) and his wife and the transplanted patient (Figure 37). The patient being part of or known to a community increased the likelihood of gaining access to the community group and increased the meaning of the topic. Being prepared to attend the smallest and most unlikely of events, like a cricket tournament (Table 44) provided wider contacts the most passionate response.

Table 44 Making the most of every opportunity - power of patient experience

Event, Experience and Activity	Wider Networking Impact
<p>Field Note:18/05/2014</p> <ol style="list-style-type: none"> 1. <i>Friend of a cricket tournament organiser diagnosed with CKD</i> 2. <i>Request sent to the researcher to conduct a session during their national cricket tournament attended by 14 teams</i> 3. <i>Introduced the researcher by the tournament organiser to the individual team's captain also explained about his friend's health.</i> 4. <i>Researcher provided a small session to individual teams during their break time without interrupting the game.</i> 5. <i>Most of the team leaders had a role in their local community association, so they requested similar education event to conduct among their local community</i> 6. <i>Most of the players were young, understanding the desperate need of more donors, reflected on their own role to promote this message and requested the researcher to provide forms and information materials to educate their family and friends</i> 7. <i>One of the players worked for NHS, when the researcher explained the voluntary work she is doing to save our community, he expressed his wish to be a volunteer too.</i> 8. <i>78 ODR registrants from total 100 players</i> 	<p>Personal experience of cricket organiser and gatekeeper</p> <p>Influencing role of respected individuals from the community</p> <p>Passion and explanation of need and severity for South Asian community increased support</p> <p>NHS volunteers and young people to become local champions to spread the Gift of Life message</p> <p>Making use of every opportunity</p>

8.6 Passion, Knowledge and Ethnicity of the Educator

There is no doubt that the passion and dedication of the educator is crucial to ensure the campaign is believable, engage people, and communicate the honest and worthwhile reasons why such an initiative is important to get people to connect with the topic. With this culturally and religious sensitive topic the educator being extremely knowledgeable on organ donation, of South Asian descent, with a clear understanding and cultural and ethnic respect for the idiosyncrasies of the different communities, dismantled most barriers from the outset. One question raised by a community leader was ‘*What is your benefit of doing this campaign and why you are doing this?*’ which when the researchers professional role was explained and the issues faced by South Asian people with CKD, that her role being

voluntary to help the community and NHS, the leader indicated a different level of trust, respect and understanding and was keen to offer support. Not all people are convincing and this is a skill that educators in the community need to possess, but gaining the trust of the people being educated, is key to the learning that takes place and the notice taken of the topic. The feedback from other people on the Steering group recognised such skills present in the researcher, a success factor that needs to be acknowledged.

'I'd also like to emphasize the importance of having a role of networker who is passionate about the topic and from same ethnic background to maintain the relationship with community and religious leaders in order to promote the Gift of Life message as she was successful. It is important to have the knowledge and passion to maintain the relationship among the leaders, then only we can get access to their communities. Importance is that an individual may be a very influential in the community and passionate about the topic to act as networker but if we do not have that in depth knowledge on the topic there is a high possibility of developing some bias in the topic and can cause some negative impact for this very sensitive topic, so we have to balance when we choose volunteers and networker leader for this specific topic.' Mr. Salim Mulla, Blackburn Mayor

'Agimol has devoted many hours to this study and has stretched herself and others to ensure that any potential avenues to increase awareness of organ donation amongst ethnic minority groups is sought. I can honestly say that I have never met an individual more dedicated to a study...and the outcome of this study will be beneficial to the ethnic minority patients waiting for a transplant... will be beneficial to many as well as to NHSBT and I would like to personally thank her for her dedication to her work and this study.' NHSBT ODR Manager

'I do believe your passion and untiring efforts have produced amazing results and long may their continue!' Mr Siddiq Diwan, Muslim Hospital Chaplain

For the successful organ donation campaigns educators need to be identified who is passionate and knowledgeable on the organ donation topic and at the same time who understand the communities perceptions and level of knowledge on organ donation. These qualities, honesty, trust, passion, same ethnicity, enabled the researcher and members of the peer education team, to obtain support and trust from the different community religious

and political leaders, which opened many new doors through which to conduct peer education.

However there was an incident where the importance of training educators became apparent, and raised concerns regarding the level of training of those people registering people to the ODR, as misinformation can de-motivate as quickly as motivate someone to a good cause. A field note captured an event where an NHSBT campaigner (paid volunteer to assist in ODR registrations) put off a person considering joining by their lack of enthusiasm and lack of knowledge.

Large Mela event, NHSBT kindly supplied a number of paid volunteers to help register new people to the ODR at the peer education event. A male Asian convinced with the cause and need to be an organ donor got the form to register. As he was filling in the form he asked the question how do you maintain the anonymity of my details, NHSBT campaigner provided the answer 'I am not sure', so he immediately declined to complete the form. I approached the person apologised for the miscommunication and explained I work for NHS and can I clarify your doubt, he said no as he can't trust my team members who did not know how the confidentiality is maintained so if he provides his details people may misuse it. Need to ensure level of understanding and education of volunteers and educators. Manchester Asian Mela, Manchester, Field Note: 25/08/2012

8.7 Awareness Campaign – Use of Media

The use of digital and social media influenced and enhanced the spread and uptake of the campaign messages throughout the South Asian community, but could have been used more proactively. Different strategies were used to increase awareness through social and digital media, Newspaper articles, TV, Radio, Facebook page and developing a study website and web links to other sites (Appendix 13). The digital media started with Media students from the university developing videos for the website of patients' experiences waiting for a transplant, how organs are matched and tissue typed, and the different multi-disciplinary team perceptions of why organ donation was important including religious opinion. These videos were uploaded to the study website and social media sites and been viewed by more than 2,000 individuals, but also provide a sustainable resource for future campaigns (Table 45).

Throughout the campaign when people searched the key words South Asian organ donation the study website name was the first to be shown on a *Google Search*, a contributing factor why the website received over 5000 visitors since the start of the study (Table 45). The Facebook group was much less used and not found to be well populated certainly we were unable to stimulate an online discussion on the topic, although it was useful as a mechanism to pass out wider messages to other people’s followers about the website. Many local and national broadcasting companies including BBC and ITV recognised the study and telecasted the interview with the researcher, which again focused on reinforcing education to increase the perceived susceptibility and increase awareness of organ donation and the need for transplantation, with religious experts focusing on clarifying religious uncertainty. From one ITV programme (From the Heart), where the researcher took part with other health professionals and patients, achieved a great success. Following this ITV programme 52,810 individuals joined the ODR which impacted the BAME register too, rising by 2.6%.

Table 45 Examples of Key Digital and Social Media Strategies

   	<p>Study Website - 5179 visitors www.southasianorgandonor.org.uk</p> <p>Recorded interview in South Asian media in the native language: 2615 online views</p> <p>Multi-disciplinary and Muslim Religious Scholar You Tube Video explaining the scarcity of donors 1637 online views http://www.youtube.com/watch?v=aU7AcGEUPc8</p> <p>2012 Best Nurse Award by the British Malayali Group</p> <p>Various South Asian Radio Talk shows</p>
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  	<p>and News paper articles</p> <p>ITV Organ Donor Report impact:</p> <p>Total 52,810 registrants (BAME 2.6%)</p> <p>Sikh TV</p> <p>(Sanghat TV, Series on Organ Donation- Let's make Dofference</p>
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The Muslim Chaplain (Imam), Transplant surgeon and researcher attended a radio talk show in Bolton (ISHAAN Radio, 30/12/2012) a many questions received were related to religion and the respect provided to the body during while organ retrieval. The success of the talk show and the valuable information passed through the network enabled further sessions to be planned. When talking with the North West people it was apparent despite earlier campaigns their knowledge was poor, many had not seen a campaign before or even heard about organ donation signifying this campaign is not enough and there is still an enormous amount of work to do. The South Asian press were used effectively by publishing a news item at the time of the phase one questionnaire and advertising the web link to enable on-line completion, which stimulated over 300 additional completed questionnaires and in turn ODR's through the website.

The work by the researcher was recognised by the British Malayali Group, the South Indian Community residing in the UK, and she was awarded the Best Nurse Award 2012. This award was advertised on the website and within different newspaper articles to communicate the achievement and further endorsements were received from different community representatives.

'Agimol, you did really great, well done!!! Very moving message in Punjabi & English, and we've had very good feedback -- the testimonials are worth capturing in

a central repository, and as my family all aligned on registering after watching, I feel it would be great to measure the outcome/results.’ Personal communication, Mr. Inderjit S. Bhogal, Sikh Coaching Ltd

‘Dear Ajimol, Read about you in the Manorama daily. It was an inspiring story. Congrats & all the best for all your endeavours. I am Assistant Professor with Amrita College of Nursing, Kochi. Your urge to serve, that's what makes you special. People like you are in best position to motivate the new generation. It would be great if you can spend some time with our students during your next vacation as a guest speaker, if your time permits. I've put the article in the student's notice board to motivate them.’ Personal communication Lekha Viswanath.

Table 46 South Asian Network and Engagement Recommendations

South Asian Network and Engagement Recommendations:

- Educators and networker from South Asian community with appropriate knowledge skills - consider Team approach to education using influential leaders to spread word
- Respect community and religious leaders and work with them gaining their participation to influence and endorse education and campaign messages
- Identify and engage the right people, who are respected and trusted and have wider networks to infiltrate and influence people within the wider community
- Engage the help of patients to gain a deeper understanding of the plight of people with CKD using patient stories to make the topic ‘real’ and meaningful to people
- Network at every invitation and opportunity as the smallest event can create widest spread and network impact
- Use digital and social media to disseminate key messages of the importance of the topic, the need of the South Asian community and the plight of people with CKD using patient stories to make the topic ‘real’ and meaningful to people

8.8 Summary

The focus of this penultimate chapter has been to draw together the key findings of the study approaches and make sense of what impact it made to the scarcity of organ donor from South Asian community. There was clear overwhelming evidence contributing new knowledge, understanding and suggestions to take this approaches forward in future to

increase the organ donors from South Asian community. The study is the largest study of its kind in the UK among South Asians, which identified the barriers, then implemented the education approaches to deal with the barriers and measured the impact. This study helped to identify the basic issues around the organ donation topic from the South Asian community and their preferences and priorities for information. Explained how the researcher implemented education approaches with GP's, SNOD's and community. It undoubtedly identified the failure of GP's approach due to the lack of interest, confidence and misjudging the organ donation as religious issue rather than a health related topic. But the SNOD's and peer education approach was successful as the researcher obtained help, support and guidance from religious and political leaders to implement and progress with interventions. Plus this study enabled to recognise what works better and what not works and why and it bodes well for future service development around organ donation topic.

Key Points

- GP's education initiative unsuccessful in this study, but remains as a great potential
- Health professionals (GP and SNOD's) training need on culture and religious aspect
- Identified 3 key peer education approaches i.e with the support of religious leader, community influencing individual and using South Asian media.
- Respect the community and their leaders during the net working
- Make the most of every opportunity to engage with community
- Value of an South Asian coordinator with knowledge and passion

The next Chapter takes the discussion forward and examines the findings of the study with the current evidence base to identify what new knowledge has been uncovered and what recommendations will inform future policy, practice and research. .

9 DISCUSSION

9.1 Introduction

The original premise of this study was that to identify why there is scarcity of South Asian organ donors from the North West of the UK and how we can increase the organ donors from South Asians. The novelty of the current study is evident - this major study conducted in the UK, focusing on organ donation, was first of its kind to identify barriers, implement and evaluate the impact of the education approaches among the three major ethnicities within South Asian community as part of single study. This study provides an in depth knowledge on this topic, generates a clearer understanding of the issue and offers guidance on how to tackle this problem effectively.

The findings indicated that, in the population studied, culture and religion play a much less prohibitive part in influencing the organ donation decision than previously suggested, but there is a desire to be aware of the religious stances so that people can make a more informed decision. But the emphasis should clearly be on a reconsideration of the presently inadequate knowledge among the public along with lack of confidence among the health professionals in approaching with organ donation topic and the influencing role of community and religious leaders among South Asian community.

This chapter draws together some suggestions and discusses the study findings alongside existing evidence in an attempt to overcome the shortage of South Asian organ donors. This study has identified areas which need attention from the Government officials, NHSBT, health professionals, community and political/religious leaders to improve the current deceased organ donation and registration system among the UK South Asian population. In the following passages, the researcher explains in detail the issues and key themes derived from this study. It should be noted that while the themes are discussed here individually, in practical terms they are interdependent, with a great deal of overlap between them. The chapter concludes with a discussion of the strengths and weaknesses of the study.

9.2 Key themes

9.3 Positive Impact of Educating South Asians on organ donation using HBM frame work

9.3.1 Perceived barrier

9.3.1.1 Community Need

A review of literature reiterates that this study is the largest ever in the UK among the South Asians, providing an in-depth understanding on the community's perceptions and awareness on organ donation. Baines et al. (2002) notify that there is a tendency to consider Asians as a homogenous group, with a particular set of beliefs, attitudes and opinions but it is important to identify the individual differences between members of the Asian community in any publicity campaign. It was identified in early 19th century that South Asian immigrants in the UK are distinctly different from the UK native population and it is crucial to be aware of their desires, needs, and goals (Mark and Kitayama 1991; Castles and Miller 2003). As explained in Chapter Seven and Eight, one of the highlight of this study is the importance of concentrating on the community education need to meet the lack of awareness barrier and to improve the knowledge on organ donation among the South Asian community. The importance of concentrating on community education need is supported by the literature review by Deedat et al. (2013) on effective interventions to increase ethnic donors informing community based education has a higher level of success in terms of verified registration than those solely relying on the mass media.

But unfortunately current efforts to encourage organ donor registration in the UK have only some community engagement (Deedat et al. 2013) and it remains as one of the main barrier to overcome in the organ donation campaign. The minimal engagement of the current organ donation campaign among the Asian community was experienced by the researcher during the Phase Two of the study, as majority of community leaders and participants revealed that they never had any education sessions in their community about organ donation in the past. As identified by Karim et al. (2103) "one size fits all" approach will not fit to better inform the ethnic minority groups living in the UK regarding organ donation and this remains as one of the major barrier. It is also noted that organ donation education is effective in the minority community when conducted in the familiar community settings by appropriately trained individual (Deedat et al. 2013).

9.3.1.2 Education need

Consideration of highly educated individuals being less aware about organ donation topic is a concern from this study as there are previous studies stating contradictory information. Studies by Conesa et al. (2003), Haustein et al. (2004), Bracellos et al. (2005) among the general population in the UK explains that higher levels of educated participants were more supportive of deceased organ donation because of their greater knowledge and awareness of the importance of the topic. But worryingly, study by Gaugher et al. (2013) among Asian University students in the UK, identified the lack of awareness and little knowledge about the organ donation topic. One of the participants in the interview mentioned that even though she had seen campaigns on their university campus she did not feel the campaign was specifically targeted for South Asians. One and half decade before, it was identified that future organ donation rate from the South Asian community will be directly influenced by the attitudes and beliefs developed in the younger Asian community (Ready 1998). But as evident from this study, the education need among the youngsters remain as an outstanding issue and this may be a missed opportunity to provide community specific organ donation teaching and to promote the Gift of Life message. This is supported by Trompeta (2008) suggesting the incorporation of organ donation education in high schools is necessary to reinforce and maintain high knowledge and awareness among youngsters such that they may influence and raise organ donation awareness in their parents and families too.

It is explained that *“Knowledge about organ donation is a strong predictor of attitudes toward organ donation, individuals with more knowledge about donation being more likely to accept organ donation and to be identified as a potential donor”* (Wakefield 2011: pp-164). This was identified from this study; even though increased education status did not positively affect the attitude/willingness to join the ODR, the increased knowledge on the organ donation topic positively influence the willingness to join the ODR by the Indian Hindu community. It is mentioned by the previous researchers that, the general public should not be held alone responsible for the unwillingness to donate organs but the health system and health care providers are responsible and it is important to implement an effective approach regarding health education on organ donation (El-Shoubaki and Bener 2005; Alghanim 2010).

Difference in the knowledge among the South and North based South Asian community in the UK is another concern from this study which was identified by Poonia (2006). Also, Morgan et al.'s study from 2006 on attitudes to kidney donation from South (i.e. London) region identified that ethnic minority respondents (83%) were more aware about the urgent need for kidney donors compared to White respondents. But this study identified that 57% participants from the North West were unaware about the urgent need of kidney donors, this reflect that the campaigns on organ donation need among BAME community is limited in the North of the UK compare to the South. But it's interesting to note that the well informed community of this study i.e. Indian Hindu's were more willing to join the register which challenges the Morgan et al. (2006) finding of increased knowledge about organ donation not making a positive attitude to join the ODR in the South.

Several studies dealing with the barriers and opinions of organ donation among the BAME community from the late 19th century was identified from the literature (Exley et al.1996 Morgan et al. 2006; Ahmed et al. 1999; Razaq and Sajad 2007; Alkhawari et al. 2005; Bennett and Savani 2004; Kraim et al. 2013). As mentioned in Chapter Four when comparing the results of study by Exley et al. (1996) and Karim et al. (2013), barriers for organ donation among South Asian community remains similar as detected two decades before. Lack of knowledge and religious uncertainty on this topic were highlighted along with worries about receiving inadequate healthcare after donation and lack of family support. Again these barriers were highlighted through this study as well, so it supports the finding from Karim et al. (2013) informing that the South Asian community living in the UK is untouched to the current organ donation campaigns and needs a more in-depth scrutiny.

9.3.1.3 Mistrust

It was clearly identified from the questionnaire survey and interviews that it is essential to clarify the mistrust in the medical system and people's unwillingness to donate their organs to outside one's immediate community. As Symvoulakis (2009) explains, distorted beliefs, negative or ambivalent attitudes, indifference and lack of knowledge and trust in health care systems often are more harmful than chronic diseases and potentially cost lives. So this study clearly identify that it is vital for the health care workers to focus on this mistrust and lack of information and focusing on how this situation can be reversed for the

purpose of increasing donation consent rates in the future. Thus there is a need for culturally sensitive communication by the health professionals to remove the various misconceptions in the minds of the public regarding organ donation along with increasing the access to the organ donation services. One of the reasons for this ignorance and negative attitude could be as mentioned by the participants in the interview that most of the Asian countries do not have a successful deceased organ donation programme in place (Mithra et al. 2013; Ansari 2007; Vatsala 2004), and organ donation is understood as a Western concept (Cheng 1992). Moreover, organ trafficking messages and misuse of organs may have given them a negative impression as well (Shroff 2009; Nosheen 2007; Moazam 2007; Noorani 2008; Moniruzzaman 2012; Moazam 2011; Mustafa 2012).

Reason for unwillingness to donate their organs to outside one's immediate community (Gauher et al. 2013) could be as recognised from the literature; immigrant ethnic minority's feeling of marginalisation, prejudism and institutionalized racism (Klinken and Noble 2000; Castles and Miller 2003; Macpherson 1999) making them being unscrupulous (Silove 2003). This ongoing construction of immigrants as different or invisible, disadvantaged or dishonored could be the reason for strong levels of their community bonding and dense network of ties that hold families and ethnic groups together (Putnam 2000; Morgan et al. 2006). But this barrier could overcome by explaining the successful match between the donor and recipient of the same ethnicity.

9.3.1.4 Next of Kin

Another barrier identified from the literatures is that even though Asian community are sympathetic and supportive of organ donation, they are reluctant to discuss their wish with the older members of the family or to provide their next of kin consent, as they feel it may cause distress among the family members and may feel going against the wishes of their elders (Razaq and Sajad 2007; Bapat et al. 2009; Gauher et al. 2013; Exley et al. 1996). This was confirmed by one of the interview participant in this study informing that he will override the next of kin's wish to be an organ donor due to his own (not the deceased) religious and personal believes. With the current Opt-in system in the UK evidence suggests education is needed not only for the next of kin but for people registered on the ODR, to ensure their family are aware of and respect their wishes to donate when they die, to prevent consent being refused (NHSBT 2013).

9.3.1.5 Religion

Findings from the Phase One questionnaire and interviews provided important information regarding the views and perspectives of South Asian people. It was observed that the willingness to donate organs was higher among Hindus and Christians than Muslims and the difference was found to be statistically significant ($P < 0.001$), the same was identified by the study (Mithra et al. 2013) which conducted among the South Indians in India. Also it is important to notice that even though Bangladeshi Muslims were the least knowledgeable about the possibility of leaving the organs for transplant after death, Pakistani Muslims expressed more concerns and reluctance to join the ODR compared to Indian and Bangladeshi Muslims.

It is evident that while most religions are positive about actions taken to save other's lives there is less support apparent for organ donation since some religious beliefs apparently anticipate bodily resurrection requiring a complete body for the afterlife (Dawson 2000). This study revealed that ethnicity or religion is not a barrier but has concerns about organ donation, particularly among the different Muslim faith secondary to the concern on the ownership of the body and instructions from the religious leaders. This is despite the declaration by leaders from all the major faith groups in the UK that there are no religious prohibitions against organ donation (Rudge et al. 2007). However, respondents may not have been aware of these views, also differences between beliefs and practice, with deceased donation perceived by many Muslims as disrupting their honouring of the dead (Hayward and Madill 2003).

One solution would be for the transplant community to more actively engage with religious leaders, especially when it has been reported that, across the major religions, there are very few cases where organ donation can be seen to be inconsistent with religious edicts (Cooper and Taylor 2000). It was identified from the study that among the Muslim religion there were different views and understanding on organ donation from the religious perspective. This was identified by Razaq and Sajad (2007) who expressed that this difference in Islam may be the reason that available Fatwa on organ donation do not make any impact among the Muslim Groups.

There is considerable uncertainty from the religious perspective particularly among older people and people of Muslim faith who commonly required guidance from religious

leaders (Morgan and Bradby 2014). But a respectful, cultural approach with trust which demonstrates an understanding of the religious sensitivities carries significant weight in breaking down barriers particularly with the elder generation (Takeshita et al. 2002). Having support from religious groups is mentioned as an important factor in overcoming the donation barrier among ethnic community (Horton and Horton 1990). Even though it was recognised 25 years ago, unfortunately one could not identify any active, successful and sustained interventions in place apart from the recent publication by NHSBT on “Faith Action Plan”, which is awaiting implementation and evaluation.

The support from religion and religious leaders is recognised in other European countries too. A report published by the Dutch National Institute for Health Promotion and Disease Prevention (NIGZ) in 2009 informs that non-Western immigrants, to whom the majority of Muslims in the Netherlands belong, are less often donors and less positive about organ donation. The report added that this negative attitude has partially to do with the uncertainty of this group about the stance of their religion towards organ donation and their need of support from religious leaders (Van Thiel and Kramer 2009). Randhawa et al. (2010) study performed among the faith leaders in the UK indicated that organ donation is currently not a priority for many faith and belief groups, and that there is a need for a much greater level of engagement to address this issue.

But getting help from the religious leaders to deliver the message in some of the orthodox religious groups in the study during education session and transmission of their knowledge certainly facilitated the individual’s decision making process for whom the stance for their faith is an important issue and had very positive outcome. One comment received was “*I was not sure about organ donation and my religious stand, but now I have been told by my religious leader that it is permissible according to my faith, I am happy to join the ODR*” (Young South Asian Muslim).

9.3.1.6 ODR access and knowledge

Other finding from this study is that some people were supportive and agreed with organ donation, but they have not registered on the ODR, due to the lack of knowledge on how to access and register on ODR. This is not only the minority community’s issue, the study among young British adults by Coad et al. (2013) identified that even though most participants were in favour of organ donation, fewer had signed up to the ODR. The

availability and access to donor cards issue among minority communities in the UK has been highlighted in 2001 by Connect Report. Since then NHSBT acted on this issue and implemented many interventions including promotion via GP centres, public places, driving licence etc. But this study revealed that the issue among the South Asian community in accessing and knowing how to register still persist.

Availability of ODR forms and the opportunity to complete registration process immediately during every education events may be one of the reasons for success in the current study, as the researcher provided the opportunity during every event for the participants to complete the registration instantly. Success of this approach is evident from literatures as well. Study by Alvaro et al. (2011) noticed an increase in organ donor registration rates by providing an immediate opportunity to complete registration process at community event, compared with the use of a generic slogan and offering general information about organ donation (86% vs 54%).

As explained by previous studies (Siminoff et al. 2001; Wong 2010) participants expressed their concern about disfigurement of face by donating their eyes. This concern could be overcome by explaining the options available on ODR and letting people know that they can opt into donating some rather than all of their organs along with reassurance from medical team. It is evident from this study that better awareness of organ donation and its various aspects can improve the motivation among the South Asian community to donate as suggested by Saleem et al. (2009).

9.3.1.7 Perceived Susceptibility and severity

One of the important factors identified from the peer education sessions and literature was that South Asians are unaware about their susceptibility and severity of CKD and find it difficult to understand their communities extended waiting period for transplantation due to the scarcity of best matched organ donors who is from same ethnicity; how many die on the waiting list and how their lives are affected (Callender and Miles 2001; Alkhawari et al. 2005; Morgan et al. 2006; Gauher et al. 2013). So it is important to educate the community that organ donation is their own community's need, which may act as a motivator. It was identified by Exley et al. (1996) that South Asian community's over representation on the transplant waiting list is crucial information to be provided to raise awareness on organ donation. But unfortunately one and half decades later following this

suggestion, organ donation campaigns still do not provide this crucial information. For most of the peer education participants, it was the first time they heard about the severity and the susceptibility of CKD and scarcity of organ donation facts and figures as mentioned in Chapter Eight.

As explained by Saleem et al. (2009) awareness and motivation will go hand in hand in promoting organ donation message among the Asian community. So it is important to provide the vital information on their susceptibility and severity of CKD to promote the organ donation message. It was also suggested by one of the family member who consented for her Mom's organ donation that *“by addressing the serious shortage of organs and the gap between the number of organs donated and the number of people waiting for a transplant, particularly among Asians living in UK, we can save more lives (South Asian donor family)”*.

From the interview participants there were some concerns about the choice of donor, in forming their preference to donate only to specific religious or age group. Concerns about donated organ allocated to only rich and famous people were explained by Spigner et al. (2002) among high school students. While researcher cannot be sure that this is a commonly held view, from experience she can say that it may not be an exceptional one. It is likely that greater awareness of the need for organs within specific communities might help encourage people with similar views to review their stance on organ donation due to their strong community bonding.

9.3.2 Perceived Benefit

One of the important aspects of promoting organ donation message among South Asian community is by explaining the benefits of organ donation which will enable them to make informed choices (Saleem et al. 2009). As explained above lack of knowledge on organ donation topic is directly influencing their awareness on perceived benefit of joining the ODR. Also, making individual to understand the possibility of saving lives by joining the ODR could provide them a feeling of hero which could act as motivator to join the ODR and influence the decision to donate (Parisi and Katz 1986; Quick et al. 2010). As explained by Morgan et al. (2006) due to the strong community bonding, educating on best match and successful outcome if the donor and recipient are from same ethnicity may act as motivator as they may identify joining the register as benefit to their own community.

9.3.3 Cues of Action to tackle the scarcity of South Asian organ donors

9.3.3.1 Opt out / presumed consent

As South Asian community is not responding to current organ donation campaigns (Karim et al. 2013) to understand the perceived severity and the susceptibility of CKD and the benefits of joining the ODR, it is vital to look into cues of action to tackle this challenge. One of the solutions could be reviewing and changing the current policy of organ donation in the UK, (Gauher et al. 2013) maybe by implementing opt out or presumed consent system. But, opt out system has been opposed by the health professionals in the UK very strongly (Koffman 2000) from early 20th century. But this study strongly suggest to relook the opt out implementation as it was opposed by only 18%, remaining 57% said Yes and the rest 25% mentioned Not know or Not care either way. This result is supported by Rithalia et al. (2009) who conducted a systematic review on opt out opinion among the general public in the UK. The review identified that even though most people opposed an opt-out system prior to 2000 in the UK, since then four studies conducted among the general public revealed that on average 60% of people surveyed are in favour of donation by presumed consent.

Proportion of participants who stated that they would agree to donate their own organs is 44% more than double of those signed up to the ODR (17%). There could be several reasons for this: perceived difficulty of signing up to the ODR, not knowing how to register, lack of information about what is required to join the register or just that signing up is not a priority. Many of these issues could be overcome and this gap could be reduced by introducing the opt-out (presumed consent) system of organ donation or the system of automatic consent registration (Coad et al. 2013).

From the study sample it is important to note that, even the individuals who declined to join the ODR also agreed with implementation of opt out system if it is implemented following the adequate education among the community. So if the community and religious leaders could be educated on the implementation of opt out system and its benefit, this could be successfully implemented.

Awareness on opt out system is not only BAME issue but as the study by Coad et al. (2013) among young British adults also recognized that only a minority of participants

were aware of the proposed opt-out system for donation. One of the major and promising change in national organ donation system noted during the study was that; in July 2013 the majority of Welsh Assembly voted in favour of an opt out system and it was confirmed that such a system would come into force by 2015 (note this Bill was passed after the Phase One of study period).

9.3.3.2 Live donation

As identified from this study and previous studies, people are more willing to make a living donation to a family member than a donation after death (Boulware et al. 2002; El-Shoubaki and Bener 2005), while religious reasons were commonly cited as barriers (Barcellos et al. 2005; Bilgel et al. 2004; Hai et al. 1999; Hyde and White 2007; Lam and McCallough 2000). Thus another cues of action to tackle the shortage of Asian donors which is identified from the previous and this study is to promote live donation to their loved one (El-Shoubaki and Bener 2005). Only 8% of South Asian participants disagreed with live donation if needed for their loved one. Also it is mentioned that live donation can be considered as selfless giving, as there is no barter of commodities involved (Sque and Payne 1994) which is praised by all the religions.

But interestingly it is noted from the researcher's transplant unit that there is a clear indication of lack of Asian live donors (Table 47). Data from 2010-2013 from one centre clearly explain that even though it is possible to obtain above 40% transplants from live donors generally when it comes to the Asian patients data, it remains low as 4 to 7%. Particularly, it is worrying in the case of paediatric data as it is evident that more than 62% of children are fortunate to have a live donor option generally but unfortunately the Asian CKD paediatric group has only 7% of live donor support. When this data and result from phase one of the study is compared, it is very contradictory and there is a need to ask the question are we making use of this resource to its potential and as health professionals are we exploring this option to our Asian patient's family members?

Table 47 Transplant Activity 01/01/2010 to 31/12/2013

Year 2010-2013	Total Transplants	Asian recipients	Total Live donor transplants	Total Asian live donor transplant
Adult	859	122 (14.4%)	353 (41.8%)	36 (4.2%)
Paediatric	71	18 (25.4%)	44 (62%)	5 (7%)

(Adult and paediatric) at ManchesterUniversityHospital

But, even though on one hand it seems well to encourage live organ donation to save CKD patients and to provide a high quality life by just focusing on the donated organ itself in the sense of gift (Gerrand 1994), on the other hand, recipients found accepting the donors offer grueling, because of concern for their donor's wellbeing (Gill and Lowes 2008). This grueling experience is explained by one of the study steering group members son, who received a live donor transplant commented in an media interview as part of the study that *"potential donors were my uncles whose kids are close to me so God forbid if something happens to them (my uncles) what do you say and how do you go about it, at the end of the day it's only me affecting now let me suffer, with my moral beliefs how do I take this"*. This indicates the need to consider the recipients emotional dilemma in accepting the live donor option and their mental health (Schweitzer et al. 2003; Razaq and Sajad 2007). This also places one in the track to realize that deceased donation will be the best resource to make use as the recipient will not be having the dilemma of their loved one going through the operation for them when they are alive and to face the dilemma of something going wrong with the relative in the future.

So it is important to acknowledge that even though living donation is expressed by participants as one of the solution for this growing problem, there are various barriers to overcome. Emotional dilemma of the recipient (Gill and Lowes 2008), overcoming the other family member's pressure and overriding the willing individuals consent to donate to their loved one that is including donating to their own child (Hayward and Madill 2003) and religious concerns (Oliver et al. 2011). The reluctance to accept the live donation may not be based so much on medical grounds but more on psychological grounds (Henderson et al. 2003) of the recipient. So expert handling social and psychological issue (Rodrigue et al. 2007) of the donor and recipient could be vital need along with religious clarification in promoting live donor transplantation. Also, providing a culturally sensitive approach by

the health professionals may be a solution to reassure the recipient, as it was identified that using Asian live donor coordinators influenced in increasing living donation rates among Asians (Windmill et al. 2005).

9.3.3.3 Community and religious leaders

Community leaders, high social profile figures from the community are advocated as the best promoters for organ donation (Reitz and Callender, 1993). In order to increase public debate and user engagement in this issue, it has been suggested that key figures, religious leaders and role models trusted by the community and from within communities will increase the trust and greater acceptance by the community members on this topic (Baines et al. 2002; Morgan et al. 2006; Saleem et al. 2009). Vital and positive role of religious and community leaders among Asian community on organ donation awareness is a well known fact from previous studies (Exley et al. 1996; Saleem et al. 2009; Gauher et al. 2013). But unfortunately it is impossible to prove from the literature, how the current organ donation campaigns are making use of this potential source and how this can be successfully implemented or the evaluation of its impact. But this study implemented this vital opening for education and evaluated the positive impact of this intervention. Continuous level of engagement and grass root level of education by religious leaders and role models from within the ethnic minority communities is imperative (Karim et al. 2013).

Whilst speaking to the SNOD's based in the researcher's hospital about organ donation issues, they commented that majority of South Asian families will request to wait before they make a decision to get an advice from their local religious leader regarding the donation. Most often the family will come back with a negative answer stating that due to their religious believes they will not be able to agree for deceased organ donation. Study conducted by Randhawa et al. (2010) with the leaders of the three Muslim organisations in the UK revealed the extent of work required at grass roots level within their communities to encourage organ donation. Scholars did not have adequate knowledge on organ donation need and was unaware about the NHSBT leaflet on Islam and organ donation (Randhawa et al. 2010). It was clear that leaflets and policies alone would not be an effective solution if it is not serving the purpose of reaching the community.

9.3.3.4 Passion, knowledge and method

It was identified that in order to address the sensitive health issues, medical educators need to be aware about the cultural differences and how these differences affect their health needs (Vaugh et al. 2009). As the researcher/educator is from the South Asian community and was aware about the health related concerns of the community, she was accepted and supported by the religious and community leaders as their own community member which enabled the easy access, networking and to gain trust from the community during the campaign. Even though previous studies explained that increased knowledge on organ donation did not positively influence the Asian community's decision to join the ODR Morgan et al. (2006), the current study reveal that if one could increase the knowledge in a culturally sensitive manner by the community based approach provided by an individual who the community trust, there is a positive impact and influence on the South Asians. By reflecting on the positive results explained in Chapter Eight and looking at the literature (Karim et al. 2013, Exley et al. 1996), the researcher can confirm that it is important to provide the education on organ donation topic among the South Asian community by a person who they trust, concentrating on the perceived susceptibility and severity of CKD and the benefits of joining the ODR.

One of the comment received by a South Asian religious leader is that *“in the past we have been approached by a health worker who is not from an Asian background and requested to have an opportunity to speak to the congregation about organ donation, but as I was not sure about the intentions and the rationale for his approach I did decline the permission, but now I understand from you so I will definitely support your campaign (Hindu religious leader)”*. It is important to be approached by an educator or promoter, who the community will accept and listen to. As noted by the researcher's experience, it is important to build relationships based on mutual trust, mutual respect and mutual responsibility in addition to the need to identify individuals who have a personal connection with their local community before planning the education session.

Another key aspect to be mindful while educating South Asian community on organ donation topic is their preference for oral face to face presentation as the desired method of education as well as the education provided by individuals from their own community (Exley et al. 1996). Success of this approach is experienced by the researcher in this current study. The researcher/educator who is a health professional with in-depth

knowledge on CKD, organ donation, allocation and transplant and who can speak their language and sharing some of their community members stories acted as motivator and influenced the South Asian community to join the ODR. It is reported that in Birmingham (UK) outreach events were identified as more successful in challenging active rejection of organ donation than visual or radio elements (Coleman 2012), as it is easy to clarify the doubts/worries and provide details on the issues surrounding organ donation. Moreover, through education, it is possible to address key misconceptions about organ donation. It also has the potential to highlight the personal impact individuals can have by either donating their own organs or agreeing to donate on behalf of their loved ones (ODTF 2008).

From the interviews and discussion during peer education session it became apparent that other health campaigns such as cancer research, stroke, blood donation, smoking cessation etc are more familiar to the South Asian community but not organ donation. This was identified by Gauher et al. (2013) which is regrettable that current organ donation campaigns do not reach the South Asian community, even though other health campaigns have been effective with very same population, especially when NHSBT has taken many initiatives to promote organ donation among BAME community. So it is important to look into the current organ donation campaigns and to examine whether it has been effective in addressing the factors/concerns expressed by the South Asian community in this study.

Even though there were some difficulties at the initial stage of the study to approach the hard to reach communities like Bangladeshi and Sikh, by obtaining the community and religious leader's support through the researcher's continuous engagement with them and passion to save lives, the researcher managed to develop a positive networking among these communities during the second phase of the study which is reflected positively on the ODR. So it is vital to recognize the need of prominent team to continue and nurture the good networking which was established as part of this study to a national base to achieve the aims of TOT 2020 strategy (NHSBT 2013) as mentioned in Table 48.

Table 48 Taking Organ Transplantation to 2020

TOT 2020 Recommended: Specific Action	Responsibility
Develop national strategies to promote a shift in behaviour and increase consent and test progress with regular public surveys.	UK Health Depts, NHSBT
The relevant Government Health Departments should explore with Education Departments the possibility of incorporating donation and transplantation into schools curricula.	UK Health Departments
All Governments should provide regular reports to Parliament/Assembly on progress in their nation. Health Ministers should have duty to promote organ donation and transplantation effectively leading to a significant improvement in public attitudes and consent for organ donation.	UK Health Departments
Develop a community volunteer scheme to support Trust/Health Board donation committees to promote the benefits of donation in local communities', particularly amongst groups with little tradition of organ donation.	NHSBT, voluntary sector
Increase BAME communities' awareness for the need of donation, to benefit their own communities and provide better support for people in these communities to donate.	NHSBT, voluntary sector, professional bodies, DoH

A detailed strategy: Improving donor conversion rates (NHSBT 2013 pp16)

9.3.3.5 Role of Media

Role of media was identified by most of the participants in the study and importance of concentrating on Asain specific media was highlighted. Targeting minority ethnic press and media is a potentially effective way to relay the organ donation message (Exley et al. 1996; Connect Report 2001; Feeley and Vincent 2007; Morgan et al. 2006; Quick et al. 2009). Through this study it is clear that, even though this promising opportunity has been identified many years ago, effective implementation of this resource is minimum in our current BAME organ donation campaign.

One of the reasons for successful organ donation transplantation programme in Spain is that they consider media as one of the cornerstones for the organ donation and transplantation programme (Rada 2013). It is mentioned that most Spanish health

journalists acknowledge that the ideal communication department to deal with organ donation topic is the Organisation National de Transplante's (ONT) one, which is available for journalists, health administrations, or health professionals 24 hours a day (Rada 2013). Positive media interest can have a significant effect on organ donation rates (Pacheco et al. 2009), but negative media reports may provide negative impression to the viewers. The negative impact of media as mentioned by the participant's during the interview that, story of individuals continuing to be alcoholic even after the successful liver transplant will challenge the individual's willingness to join the ODR. In Spain, ONT actively promotes positive news related to organ transplants or makes sure that journalists have a reliable source to confront negative information, as donations drop when negative issues occur (Rada 2013).

The first systematic review of evaluated interventions to increase organ donor registration and knowledge of organ donation among minority ethnic groups by Deedat et al. (2013) identified that, mass media interventions alone reported no significant change in the intention or willingness to register but educational interventions either alone or combined with mass media approaches were more effective in increasing registration rates. Success of this approach is experienced by the researcher; as she attended seven South Asian radio shows and TV documentaries as well as managed to give few interviews to South Asian news papers. Media engagement enabled the researcher to develop a supportive and promising net work to spread the organ donation in the local communities.

There is an imperative need to introduce and normalise the organ donation topic in all South Asian media's as regular and positive news, not just during the transplant week. It is also important to concentrate on the BAME channels and websites, so that people are earlier on exposed to this topic and not in the emotional context of ITU/impending death of loved ones. There is also the need to equip the public with information on organ donation and its benefits via radio talk shows, TV documentaries, News paper articles, magazine stories etc. But it is important to have the NHSBT to provide a service to check the contents of the stories before it is published as Spanish ONT perform (Rada 2013) to assess the reliability and validity of the matters provided.

9.3.3.6 Accept but not to Give

It was identified from previous studies that even though individuals express their reluctance to donate, when asked about receiving an organ if they are in need, majority mentioned they would accept it (Razaq and Sajad 2007). One of the frequently heard comments in the UK from non South Asian ethnic groups in the transplant field is that *“if Asians are not willing to give why they should receive?”* researcher herself witnessed and heard this question many a time. As mentioned in Chapter Eight, interestingly during the Phase One of the study few participants commented on negative attitude of their own community i.e. “Receive but not to Give” and the importance of attempting to change this behaviour through education.

It was suggested by Razaq and Sajad (2007) that it is necessary to implement a harsher regime among Muslims in the UK to tackle the shortage of organ donors by recommending the transplantation access only to individuals who are willing to be a donor. This could act as motivator among Asian community which could stimulate more to join the ODR identifying this benefit. Also it is suggested to review the current legal status and organ donation policy in the UK (Razaq and Sajad 2007). One option could be the implementation of Israel approach, by prioritising the patients if the patient or their families who are already on the register or have been actual donors. It is the thought of the researcher that it is not an unfair system to implement as it is important for each individual and their family members to take equal responsibility with NHS to look after their health and at the same time to serve the society they are living in. Especially when UK Government insist to have the individual contribution in other field in order to obtain the benefit like pension, allowances etc, it is essential the contribution towards organ donation to be counted towards the individuals and their family’s benefits.

Following the steps of HBM in educating South Asian community on organ donation enabled to provide the self confidence and knowledge which is reflected on the ODR, 2,874 South Asian organ donor registrants over the 24 months period, 2 altruistic donors and increased deceased donor rate from the North West.

9.4 Health professional training and cultural competence

Another comment the researcher heard was the medical and nursing teams' hesitancy to approach the South Asian donor family during the difficult stage. One of the Muslim participants who agreed with organ donation mentioned that, "*during my father's last stage in intensive treatment unit none of the medical team approached me or my family regarding the organ donation (Muslim)*". This comment was supported by Griffin and Bratton (1995) who mentioned that lack of discussion by health care professionals with families of the potential donor as a reason for lower donation rates among Black families in the UK. There is lack of published studies pertaining to UK healthcare professional's willingness and attitude to approach ethnic minorities, majority of studies are from US and looking at Black community. So in order to find an answer to the question raised above by the potential donor family member more research is needed in the UK to investigate why there is disparity in approaching Asian families. Study done by Siminoff et al. (2003) and Guadagnoli et al. (1999) suggest that in a comparison of Black and White families experience of donation in the USA, Black families were viewed by the health professionals as less receptive to donation than White families as they were less likely to have spoken to an organ procurement representative and given less opportunity to discuss the decision to donate. Half of the organs eligible for donation usually cannot be used due to the disinclination of the deceased patient's family due to the attitude of the health care personnel (Rizvi and Naqvi 1995).

Mckay and King (2004) explained that it is important for health care professionals to understand that they have an important role and should be aware of organ procurement policies and be educated enough for contacting the family of the dead person. But unfortunately in the UK health professionals are not fully trained to contact the families from the different cultural and religious background (Randhawa 2013). But whatever the approach, an essential component is the involvement of a team of healthcare workers who are sensitive to the values and the traditions of each individual group and able to clear any misconceptions about organ donation (Van Embden *et al.* 2008). It was suggested by Irving et al. (2012) that staff members who have a role in approaching families to request consent for donation could be more effective through awareness programmes and resources about religious concerns. ODTF report published in 2008 also insists on training the health professionals who approach the family with organ donation, on cultural and religious aspect. Even though this suggestion was published in 2008, 5 years down the line

the researcher could not identify evidences on any systematic approach taken place to educate the health professionals on cultural and religious based organ donation approach.

Interesting information learned from Spanish successful approach is that the Transplant coordinators in Spain receive communication courses to deal with families and with the media. This enable them especially when controversial issues such as brain death or organ trafficking must be discussed (Rada 2013). The ONT also organizes an annual meeting where transplant coordinators and journalists share experiences and has a best practice guide for organ donation and transplants which is freely available in several languages on its website (Rada 2013). It is identified by Guadagnoli et al. (1999) that hospital staff's perceived perception, disposition among Black families and language barrier (Perera and Mamode 2011) play a vital role in identifying and approaching potential ethnic donor. This could be tackled if the health professional is from the same ethnic background of the donor.

One of the steering group member and ITU consultant commented that “While SNODs are highly respected and valued, there is nevertheless some acknowledgement that SNODs are predominantly white, female, and either Christian or of no particular faith, we need to do more to encourage uplift in numbers of nurses from BAME and different faith groups”(ITU Consultant). Following the comment to clarify this, researcher contacted NHSBT team to identify the total number of SNOD's who are from BAME community. Unfortunately the request was declined by NHSBT due to their staff's data protection, so unable to confirm the statement from the steering group member. But it explains underrepresentation of SNOD's from different ethnic and religious background is a concern among the health professionals. This concern was reported in Faith Engagement and Organ Donation Action Plan (2013) and the action plan response by NHSBT for this stated that “NHSBT will support SNOD regional managers across the UK (or ideally identify a BAME SNOD lead for each region) to enable them to share best practice with Organ Donation Committee Chairs and help them achieve their potential outreach/public engagement role or build on the work already being carried out locally”(NHSBT response to publication of the Faith Engagement and Organ Donation Action Plan, Action Point 11). Even though this action plan was discussed in December 2013 and arrangement was to deliver this action by September 2014, unfortunately researcher could not identify any BAME SNOD's appointment or plans implemented among the North West SNOD's team.

It was suggested that health professionals especially GP's who hold a respected position within the community ideally who could speak the community's language could be the educators for organ donation (Exley et al. 1996). But, unfortunately concerns of GPs lack of confidence to approach the South Asian community with this topic is an outstanding issue. From the discussion from GPs and other health professionals, it is evident that some health professionals assume that they are responsible for religious clarification if any of their patients raise this concern. It was difficult to identify any literatures to support or refute this.

Is it the health professional's role to clarify religious concern? It is known that health professionals are not religious experts, but from the researcher's experience, some health professionals act as religious experts and comment on the religious rules. This tendency can be easily identified by checking any of the organ donation social media or digital medias discussions and information site. The researcher witnessed a few events where the health experts who are non Muslim talking about Fatwa's without knowing the religious ruling and the in depth sanctity of the words used. As explained in Chapter Eight there is a concern among the scholars on the role of health professional in discussing religious ruling on organ donation. The religious edicts can be discussed by a religious leader only as they are the Scholars in the field and equipped to face the religious challenges raised by the public.

From the study it is reflected that even though communities feel the role of GPs are vital in promoting organ donation, GPs and the practice managers does not understand/appreciate their vital role in promoting organ donation message generally and specifically among BAME community. Few participants in the study mentioned about their wish to have the discussion with their GP's due to their trust factor and long relationship from health care aspect and felt that GP's provide correct information. These comment were supported by Symvoulakis et al.(2009), demonstrating that the implementation of family practice driven information and educational campaigns about organ donation and transplantation has the potential to increase the numbers of new donors. Maybe the DoH needs to tackle this issue as soon as possible working with practice managers and GPs. Moreover, there is the need to look into cultural and religious training program for GPs, as it was identified from the study that GPs do not feel comfortable or knowledgeable enough to discuss the organ

donation topic. Training need on organ donation topic is identified in the recent study by Ward et al. (2013) among the GPs in Ireland.

9.5 NHSBT-BAME education: National approach

9.5.1 BAME campaigns- *Should it be Paid or Volunteer/Attitude of the educator*

It is identified that peer educators who are contracted or volunteer are flexible, highly adaptable and acting as gatekeepers to access the BAME community and addressing health issues (Jain 2014). But it is interesting to note that even though these peer educators were challenged by some of the community members informing what they were doing was against their religion but they were determined with confidence in what they were doing and carried on (Jain 2014). But from the researchers own peer education experience, even though she conducted education sessions in orthodox religious group, she never been challenged from the religious perspective. One reason could be that if any questions expressed from the religious aspect, the researcher requested to discuss this matter with their religious leaders as the researcher is not a religious scholar. Also, the presence or permission obtained to meet with community and rapport maintained through the networking and thus the introduction of researcher to the community by the religious leader helped to overcome the challenging behaviour from different religious group. Enormous impact on South Asian community and their preference of learning about this sensitive topic through support from religious bodies and in religious surrounding is identified by Exley et al. (1996). As discussed in earlier chapters it is important for the educators to approach religious aspect with caution, as they are not the experts in this field and to obtain the support from religious leaders on campaigns. Access to any religious community gathering was obtained by the researcher through the leaders which provided a mutual respect and value feeling by both parties.

Another major concern noticed by the researcher is the attitude and knowledge of BAME campaigners. Two of the researcher's campaigns were supported by the NHSBT outreach team. But from the researchers experience in the field, this approach raised some concerns. Organ donation is very sensitive topic and should be handled with knowledge and experience, unlike the rule of commercial business. When, an outreach team member asked about the confidentiality of the data by a potential ODR, the answer provided was "*I am unsure*" and that resulted the individual declined to join the ODR. This kind of

untrained campaigners will misrepresent the ODR volunteers, so it is high time to review the current BAME campaigns. This raises concern about should campaign be a voluntary or paid and if it is by paid volunteers, do they need to have appropriate training and guidance.

Unfortunately apart from Jain's (2014) study which is mentioned above, there were no studies identified about the attitude of organ donation campaigners from the UK, how to involve them in national campaigns and the impact of their input. But from experience of the researcher and positive impact it made on the ODR by involving steering group members i.e. CKD/transplant patients and religious/political leaders may be a solution this issue. Forming a nationwide registry for willing volunteers including health professionals and patients and appointing a community network coordinator who is already active in the community may be a key to take this drive forward. But if the education sessions are provided only by the patients and families there may be concerns about bias, but the presence of an expert health professional from transplant field will help to overcome this bias and convey the organ donation message from real experiences. Such that the researcher makes the comment that there is a great role for the transplant personnel joining hands with transplant recipients and CKD patients in spreading the Gift of Life message.

This highlights the need for national South Asian link workers network to facilitate education within the community and as discussed in Chapter Eight, it is important to concentrate on small and big events. With the current NHSBT campaign it promotes big gatherings due to their resource supply and finance input, but when one concentrate's only on big gatherings it may be difficult to rely the message in the midst of other fun fare, the ODR topic may sound bland. But, there is a definite way of raising awareness among the public by putting up a banner or providing some leaflets. For small gathering, the message can be passed on promptly and with minimum resource, such as smaller group of volunteers.

9.5.2 Sustainability in education among BAME community

The DoH conducted national research in the year 2000 and launched its awareness-raising campaign for the Black African Caribbean community in March 2002. Amongst the recommendations are: an active community education drive, including health promotion, targeting schools, colleges, universities and churches setting up a volunteers' network

including black transplant recipients, patients waiting for transplants and family members, who would be empowered to spread the message of donation in their community. The project manager Cynthia Davis mentioned following the project that “*Now what we need to concentrate on in our local project is education* (Davis 2003, pp.15). Following the suggestion twelve years down the line it is arguable whether any of this initiative is successful, reflecting Black registrants on ODR as there are only 71,645 Black registrants on the ODR (NHSBT, 2013). Previous NHSBT policy recommendations have highlighted local engagement strategies (ODTF 2008) and NHSBT actively promotes engagement among the BAME community at the local level through road shows in shopping centres and places of worship. But result from this study shown that more than 50% of the participants who took part in the study have not heard or seen about organ donation topic so, it challenges this initiative and questions whether this initiatives have reached its full potential or not.

Therefore this raises the question of the gap between research policy guidelines and implementation. As explained in Chapter Three, DoH and NHSBT have produced many policies and projects in last two decades to address this growing issue of shortage of BAME donors. It is imperative to evaluate the implementation of approaches to appreciate the practicality and feasibility of such approaches recommended by study findings, prior to initiating any further studies. It is identified from this study the need for sustainability in education, local networkers, to sustain and manage key community relationships to avoid the short lived, forgotten funded initiatives gone before. Researcher is aware that the networking established through this study is in danger of being lost if continued funding cannot be identified. It is evident that in last three years NHSBT has written many documents to promote BAME campaigns like ODTF report 2012, TOT 2020 etc. From researcher’s knowledge, in last three years working along with very passionate and knowledgeable community and religious leaders who were supporting the study, they were not involved in any decision making process.

It is high time to reflect on the finance resource spend on these campaigns to evaluate whether the resource is spend cost effectively and is reaching the intended community. For example from the researchers personal experience in last two years she managed to attend more than 250 different campaigns, spend 60% days off and annual leave to accomplish this and managed to register nearly 3,000 South Asians on to the ODR, but has not been

provided any financial incentive for the time or travel cost by the NHSBT. It would have been easy to notify the increase in the ODR registration from the North West in last two years but unfortunately none of the authorities apart from the study steering group member who is ODR manager commented on the impact of the study. Even though every projects and policies comment on the huge amount of financial resource they have allocated to spread this organ donation message among the BAME community, it is very difficult to reflect and comment on the impacts it made and what the finance resource spend on. Acknowledging and appreciating the selfless efforts taken by individuals will be a great action which can be done by the authorities without much cost which will serve as a motivating factor for individuals to serve the community more.

One such example undertaken in this study by the researcher was that the researcher requested the NHSBT to provide an acknowledgment and appreciating certificate to present to the community leaders or Associations when they took the initiative to conduct the peer education session. This request was granted by NHSBT, and the certificate was obtained. Researcher put this certificate in a frame, presented it to the leaders following the education session and acknowledged them for their efforts. This small costless incentive and appreciation allowed to provide a value feeling and enabled to maintain a very positive professional rapport. It also helped to achieve seamless support and network among the community.

9.6 Strengths and Weaknesses

Largest study in the UK to identify the lack of awareness among South Asian community on organ donation topic and concentrating on different community rather than routinely identified religion and ethnicity. Given the overwhelming data that emerged from this study it could be argued that a combined approach of both qualitative and quantitative methods is by far the most effective research strategy. It enabled to understand and to provide an in-depth knowledge and explore reasons why organ donation within the South Asian community in the North West of the UK is much lower than that of other ethnic groups as well as to identify the perceptions of presumed consent and the cultural/religious influences on this topic. It is proven from this mixed methodology; triangulation can improve validity, stability and overcome the bias inherent in one perspective (Daymon and Holloway 2011). This approach overcame the problem of quantitative findings where there is a lack of context with which to explain findings and added a broader more representative

dimension to the findings which cannot be achieved from the smaller sample used within qualitative interviews, creating meaningful data. The strength of information accumulated from the in-depth interviews from the participants who declined to join the ODR, provided added dimension to the understanding and suggestions to implement the education approaches to tackle the scarcity of South Asian organ donors which cannot be underestimated.

Strong barriers were identified; participant's suggestions were used to successfully implement the education approaches to tackle this issue with support from religious and community leaders which enabled to make a huge impact on the South Asian ODR from North West. Semi structured face-to-face interviews, although labour intensive, provided openness on this sensitive topic and two individuals expressed their wish to join the ODR following the interview, even though that was not the focus of the interview. Though identified barriers remains common across studies, this study provided vital information from the community perspective on this topic.

The ethnicity and passion of the researcher were positive attributes of the study such that the participants felt free to contact for further advice and help. This also enabled the researcher to register people on to the ODR and to get some suggestions from the participants on how to improve the current issue on poor deceased organ donation from South Asian people. Moreover this provided the opportunity to get access to all the religious and community groups.

Academic researchers are sometimes perceived as being remote from the day to day realities of delivering health care, and the results of research do not always reach those who could benefit (Morris et al. 2005). In here, this study need to be an example of sharing the result and working with effective collaboration between researchers, health professionals, community, religious and political leaders along with support of media resulting in health benefits to renal patients and NHS. Even though it was suggested in the 19th century the importance of religious and community leaders' role in educating South Asian community on organ donation (Exley et al. 1996; Reitz and Callender 1993), no clear evidences was available on the impact of this approach. But this study clearly identified and emphasised the positive impact of this approach by increasing the ODR registrants. Moreover, it also identified that input from experts from the same community

and same culture helped to alleviate the barriers on organ donation among the South Asian community.

The study also acknowledges the successful use of HBM theory to make the positive impact on ODR by addressing and tackling the scarcity of organ donors from South Asian community by explaining the importance of looking into perceived severity of organ shortage, susceptibility of South Asians CKD and the perceived benefit of joining the ODR to help the community instead of concentrating on barriers when planning the education programme for the community through cues of action to enable them to achieve self efficacy.

The study also accentuate the positive impact of identifying the key experts in steering group from the outset i.e. from planning of the proposal to evaluating the results and measuring the impact. The experts' input in each step of the study by providing the critiques, guidance and networking enabled to strengthen the study. Approval to use the questionnaire from Morgan et al. (2006) saved considerable time as it was already piloted and tested. Furthermore the review of the tool provided by steering group members added to the validity and reliability of the tool and to ensure items were accurate. But the analytical process was complex requiring expert statistical support. Although the translated questionnaires and translators for interview were available to target the non English speakers, unfortunately only six individuals used the translated version and none used translator service for interview. Therefore there is a chance of missing Non-English speaking individuals' views and perception. Same was remarked in the study by Exley et al. (1996) which raise concern about the importance or need of spending resources on translation service if it is not Asian community's preference to communicate via translators or translated questionnaires.

9.6.1 Sample

The study managed to recruit 907 participants, nearly double of targeted sample, making this study the largest study conducted among the South Asians in the UK on the topic of organ donation. A weakness of the study sample was the composition and failure to recruit representative sample from different communities. Even though the researcher attempted to obtain the equal sample from different religion and ethnic group during Phase One, it was unsuccessful to reach Bangladeshi and Sikh community. Due to this reason the

sample provided is not a representative of the population of interest in different aspects such as community (ethnicity and religion), age and education. The distribution of data across communities, age and education groups are considerably different. One of the solution for this limitation for future researchers is to dedicate more time to make the networking among this hard to reach communities prior to commencing the study. As per the researcher experience, by spending more time and constant communication, the researcher managed to develop a good networking among the Bangladeshi and Sikh community during Phase Two of the study. The ethnicity of the researcher may also have influenced the response rates.

Invitation to be part of Faith Action Plan UK and requests received from Muslim community to engage in their health education acknowledges the value of the rigorous and comprehensive evidence generated from this research thesis, signifying that it was timely and responsive to a gap in the knowledge base. It is easy to have many leaders in the field but seldom are there committed and passionate workers. It is imperative to have both: leaders with a vision and workers with a passion for the subject. No study is worthwhile, if the findings are not implemented and those implementations evaluated. There is concern that many projects and studies are merely ‘reinventing the wheel’ and does not necessarily contribute to any reflective changes in the community. It is hoped that this study will help the authorities to reflect on the current policies and projects and work with the evidence gathered in this study.

9.7 Summary

The focus of this penultimate chapter has been to draw together the key findings of the study and make sense of what the data revealed. Even though prior researchers had identified the barriers of organ donation among the South Asian community in the UK and the challenge faced by South Asian CKD patients of long waiting due to the scarcity of Asian organ donors, this study provided the overwhelming evidence contributing to new knowledge to the South Asian community’s need of education on organ donation topic and their preferential way of learning about this topic. The study also provides an in-depth knowledge on how the education approach should be targeted and the importance of involvement of religious and key individual leaders with the support from a health

professional from transplant and South Asian background to promote organ donation message among South Asians.

The study has shown that it is possible to give a positive view on organ donation topic among South Asian community if it is delivered on an individual community level by individuals whom the community can trust. Peer education session need to concentrate on perceived severity of organ shortage and perceived susceptibility of developing CKD along with perceived benefits to the South Asian community by joining the ODR through cues of actions that meets the needs of South Asian community rather than concentrating on general campaign. A deeper and more effective education session can be provided if the educator is from the same ethnic background who understands the community's established conventions, knowledge from their home country on this topic, religious and cultural values and their priorities.

The study acknowledged the weakness of the current organ donation education programmes and recommends a different educational approach concentrating on public as well as primary and secondary health professionals in order to improve the organ donation rate in the future. It is important to note the hesitancy to equip GPs and SNODs with information on how to deliver and approach South Asian families with organ donation topic will lead to lack of confidence on their part to discuss or approach the individuals with this topic. So it is vital to target the education among GPs and SNODs as early as possible. The wealth of information gleaned from this study will inform and direct the evidence base for practice and enhance information for organ donation campaign in future.

This study evidently recognized the need of three groups i.e. (i) society - including religious and political leaders and key individuals, (ii) health professionals - including primary and secondary care, (iii) NHSBT, Government officials and Commissioners working together and supporting each other to educate and reassure the South Asian community on organ donation. This team work is essential in the UK in order to obtain and to match the world-class performance in organ donation and transplantation to reach 74pmp donor rate i.e. 58 transplants for every 100 patients on the list from current 39 deceased donor transplants for every 100 patients on the transplant list at year end (TOT, 2020). Researcher is hopeful that through the education approaches mentioned in this study and support from political, religious and health professionals, the desired 74pmp

donor rate can be achieved. Whilst the study was successful in achieving its aim, it has also highlighted the need and scope for future research on the organ donation topic among the South Asian community particularly concentrating on suggested education approaches which are implemented in this study. Based on the strong evidence generated recommendations for future research, practice and policy are presented in the final chapter.

10

RECOMMENDATIONS AND CONCLUSIONS

10.1 Introduction

This study has examined and explored the perceptions of the South Asian people with regard to organ donation; identified and implemented different education approaches, and measured the impact on the increased number of organ donors within the North West Asian community. There was a clear justification at the start of this study from the outset identifying the importance of increasing the South Asian organ donors in the UK and the desperate need of finding solutions for this issue, as the current BAME campaigns are untouched in Asian community (Karim et al. 2013). Even though NHSBT and DoH identified these issues two decades ago and introduced recommendations to deal with the problem, the solution or best practice has not yet been identified, although educational strategies identified within this study reinforce and support a consistent approach to take forward to tackle this challenge.

The choice of the study emerged through a specific interest and passion of the researcher, a transplant nurse, and it is this passion that has driven the success and wide reaching campaign networks established, through which to continue to educate this ethnic minority group. Indeed there is no doubt the researcher, being South Asian, and her knowledge and understanding of the topic and community's need was a considerable strength to this study. Educators of communities, whether these are health professionals, leaders or local champions need to be trained and equipped with the skills and knowledge, alongside values and respectful behaviour that enables effective communication and sustained relationships based on trust. Working with the community, drawing on the influence of leaders, or people within the community suffering with CKD, that encapsulates the severity of the disease and the need for organs, making the issue 'real' and impossible to ignore.

Both nationally and internationally the Transplant world is looking to identify a solution for the scarcity of deceased organ donors especially from South Asian community, this study offers evidence of best practice education approaches that will certainly help tackle this problem. In addition, as the researcher been contacted by many religious, political and experts from the transplant field to educate their community and to share the success of the

approaches taken as part of the study acknowledges the value of the rigorous and comprehensive evidence generated from this research thesis, signifying that it was timely and responsive to a gap in the knowledge base.

By exploring barriers on organ donation from the community's perspective and understanding their education need enabled to implement different education approaches to meet South Asian community's and health professionals' education need. The empirical evidence base on what approach worked and which approach did not work is informed through this study which was previously unknown, that illuminates the need of identifying the best education approaches among the South Asian community. It is this crucial evidence that will inform NHSBT and facilitate the development of future policy.

Strength of this study is that it fulfilled recommendations from the previous studies. Deedat et al. (2013) suggested that for future there is a need for rigorously conducted studies to assess the impact of specific facets of knowledge and robust intervention studies on ODR and to that take account of the population's readiness to sign the donor register. With approaches ranging from personal interaction and discussion with members of the lay community and facilitating a sign-up process in practice (Deedat et al. 2013). Furthermore, Karim et al. (2013) recommended future opinion sampling should use a combination of electronic/paper surveys, in multiple sub continental languages if possible, and to have a steering group of key opinion makers who can drive the project and encourage targeted and comprehensive sampling cohort. This study built on this recommendation and moved it forward generating an evidence base for future research. Also, Shahbazian et al. (2006) from Iran, recommend that to identify the public attitudes toward deceased organ donation it is important to evaluate the differences between the ethnicities and their beliefs in organ donation studies. As the researcher managed to concentrate on individual communities rather than concentrating on religion or ethnicity this study result becomes more reliable.

Kidney transplantation is highly cost-effective particularly in relation to NHS spends, and is the treatment of choice for many patients with CKD than dialysis therapy. If the transplant rates increase, it will have a beneficial impact on resources and enable patients currently on dialysis to enjoy increased quality of life. The results of this study have a potential to be are beneficial long-term to both the NHS and the people it serves,

particularly those with CKD. Through increased transplantation the NHS is able to provide cost effective and quality treatment for their organ failed or failing patients who are on the transplant waiting list. This study has increased the number of people registered as organ donor which will over time increase the transplant rate in the UK, through increased deceased organ donors from South Asian people. Recommendations naturally emerged from the findings of the study and are presented here as suggestions to improve future organ donation awareness campaigns among the South Asian community, inform and influence national policy and the scope for further research.

10.2 What this study adds

From the outset it was clear the literature was scant examining the scarcity of South Asian organ donors from the North West of England. Indeed there are very limited UK studies looking at the different ways to educate the South Asian community and measuring the impact of educational campaigns amongst South Asians people to promote organ donation. This thesis contributes to both these areas as well as presents a comprehensive methodology, a representative study population (the largest to date in the UK), and findings relevant to local and national health policy.

The literature review on barriers identified religion and ethnicity as major factors on which to focus organ donation education, but this study looked beyond the historical context in which they were presented. This study fostered a deeper understanding of the perceived susceptibility and severity and benefits of organ donation, examining the community needs rather than concentrating on perceived religious and ethnic barriers, although these featured within the education approaches on organ donation.

The study draws on the theory of HBM and uses the concepts throughout the education approaches which offer a concrete and simple framework to better understand the priorities for education and the key focus of the messages provided. Focusing on the susceptibility and severity was more meaningful, effective and engaging for communities at the outset than religious and ethnic barriers. The deeper theoretical exploration of perceptions generated a clearer understanding as to the theory behind planned behaviour towards organ donation and how planned behaviour could be influenced.

Reluctance to donate outside one's immediate community is reflected in the study, but this needs to be built on as a strength and such a practice and belief encouraged to some degree to allay fears and increase ethnic matched donors. Indeed this study highlighted how living donation could be increased and encouraged as an alternative way to increase donated organs to enable people to observe the visible benefit of 'gift of life' compatible to their underpinning beliefs of helping and giving a chance of life. Apprehension and mistrust around organ and tissue donation needs to be continually addressed and health professionals need to take responsibility to continue to facilitate education that alleviates such fears. Success of this study highlighted the importance of planning and applying the education approaches on organ donation topic '*with*' South Asian community by engaging community expertise and leaders instead of implementing '*on*' the community.

What was clear from this study was that highly educated South Asian people are not knowledgeable about organ donation even some health professionals have a limited understanding. Indeed it was clear that young people growing up in the UK had limited knowledge and lacked awareness, often influenced by family beliefs and community elders. This reinforced the need for education within School and Universities, using South Asian social and digital media, and education that targets the whole family, particularly to influence and support the next of kin decision for cadaver organ donation.

This study has just scratched the surface and awareness campaigns need to be continuous, the networks and relationships built on not left to die out once a campaign comes to the end of the funding. The lack of sustained education since the first campaign in 1996 is testament enough that a campaign every so often is not effective. This study presents an evidence base that a team approach is necessary, working together between health, government organisations, BAME community leaders, religious scholars and researchers to provide a consistent and strong united front that organ donation must be a positive choice for the South Asian people. Piloting of education approaches among GP's and SNOD's highlighted the need of exploring this options further and identified their key role in assisting to resolve the scarcity of South Asian organ donor concern.

There is a seemingly endless amount of research yet to be realised before health professionals on Collaboration between community/religious leaders and

passionate/knowledgeable transplant personnel's from the same ethnicity to promote the Gift of Life message.

10.3 Recommendations for Policy and Practice

- Appointing and funding of passionate and knowledgeable South Asian health professionals, or trained local champions as networker/coordinator/educator for community education among South Asian groups in order to reduce the bias, instill trust and confidence in the factual information provided
- Concentrate on the importance of communities rather than ethnicity and religion to distinguish what the term organ donation means and the dimensions surrounding the concept. Future research should concentrate more in depth examination of individual communities influencing factors on organ donation decisions.
- A change is recommended to the current approaches used to meet the information and education needs of health professionals especially SNOD's who are dealing with organ donation topic and approaching South Asian families, a team approach of educating the whole organ donation team would be beneficial to ensure a consistent confident approach.
- Utilise and build on the positive, trustworthy and influential role of GP's in the South Asian community. Educate GPs and roll out education to the whole practice team to foster organ donation for all people registered with primary care practice. UK national study with the ownership and involvement of GPs from the outset leading the project would increase GP engagement and acceptability of the study.
- Further develop the information booklet with NHSBT's approval to be implemented effectively and provide pertinent information's to South Asian families prior to approaching the organ donation topic.
- UK wide implementation of different education approaches is recommended and evaluating the impact of the approaches using coded forms and actual deceased donor rate provide a comprehensive research strategy to generate meaningful data surrounding the topic of organ donation among the South Asian community in the UK.
- Role of the South Asian coordinator and involvement of religious and social leaders from Asian background is the important areas to be considered in the future development of organ donation campaigns among BAME community.

- A combined mixed methods approach, utilising both quantitative and qualitative is recommended to obtain the wider knowledge and in depth understanding of organ donation topic among South Asian community and to identify the preferred method of education manner as the most effective and comprehensive research strategy to generate meaningful data and recommendations on the sensitive and growing issue of lack of organ donation by BAME community.
- This study acknowledged that the adoption of HBM as the appropriate theoretical framework to raise awareness and increase South Asian organ donor studies. As it is necessary to educate the community on perceived severity, susceptibility and benefit to overcome the perceived barriers through cues of action in order to achieve the self efficacy.

10.4 Strategies to move forward

- Appoint a South Asian networker nationally and develop a team of educated networker's who are trusted and respected in the community and building up their own influence within communities
- Implementation of Opt out following education in the community to ensure people fully understand what it means.
- Increase education among South Asian community using HBM theory to raise awareness on the scarcity of South Asian organ donors and severity of CKD.
- Partnerships and collaboration with religious and community leaders, maintain and sustain communication and working together with their support
- Involvement of South Asian networker, religious and community leaders to support the society and individuals, NHS hospitals and staff, NHSBT and Commissioners to achieve the Taking organ Transplantation to 2020 strategy (NHSBT 2013).

10.5 Plan for the future following the successful study

The emerging and subsequent findings of the study will be communicated to the BAME campaign within the NHSBT.

10.5.1 Dissemination within Clinical networks, regional/national clinical groups

The analytic phase brings researchers answers to the questions posed in the first phase of the project. However researcher's responsibilities are not complete until the study results

are disseminated (Polit and Beck 2004). After completion of this proposed study, the reports will be presented to the UK transplant authorities, National Service Framework (renal) team, NHSBT group and the trust transplant team. Also the article will be published in the Royal College of Nursing Journal, Transplant Journal and Nursing Standards. This report will be presented in the National Transplant symposium and will be using this as tool to explain and encourage the importance of educating people about deceased organ donation; also this will be disseminated among the trust staff and authorities. Moreover this result will be informed to the religious, community leaders and participants if they contact the researcher to find out the outcome of the study.

There will be direct feedback of the research study findings within the Transplant co-ordinators network at a regional and national level. Naturally occurring platforms, such as the Trust Audit Day, National Organ Retrieval Team Meeting, Intensive Care Unit study days (across different sites), GP practice and network meetings, Transplant Alliance Meeting, and Transplant Nurses Education Day will be used to disseminate the findings and encourage sustained activity and roll out after the study is completed.

10.5.2 Conference Presentations

Three national conference presentations are planned, reporting on different aspects of the study to appropriate audiences, accessing strategic events such as the British Renal Society conference, National Transplant Association conference, and on an international level, the European Dialysis and Transplant Nurses Association/ European Renal Care Association.

10.5.3 Peer reviewed Publications

A minimum of three peer reviewed publications are envisaged following the study.

1. A methodological paper that reports the impact of the different pilot interventions to increase organ donors and cadaver organ retrieval within this hard-to-reach group
2. A paper that enhances clinician understanding of South Asian peoples' views of organ donation, to inform current practice
3. Finally, a policy paper discussing ethnic minority perceptions of presumed consent to directly inform national strategy for organ donation in the future.

10.5.4 Future research

The researcher plans to expand this area of research particularly within ethnic minority groups to enhance kidney donation within hard to reach communities. Depending on the success of a particular education approach the team would seek funding for national roll out of a particular recruitment method, or replication of methods for alternative hard to reach groups from the National Institute of Health Research (NIHR) funding stream. This would further help develop the profile of the early career researcher and sustain research capacity building within the NHS.

10.6 Concluding Remarks

The study has achieved much more than it set out to do. It has generated a rigorous, high quality evidence base grounded from the South Asian's perspective that: identified barriers that are pertinent to understand in order to tackle the scarcity of South Asian organ donors. Developed and tested three different education approaches to deal with and promote South Asian organ donor registrants and actual donors. Demonstrated that South Asian communities have preferences on how the organ donation message is delivered via religious leaders, GP's, social and political leaders, media and school/university education. Also it has identified that peer education approached, networking and establishing partnerships are effective in embedding education within the communities, but need to be sustained and funded to make a real difference overtime.

Prior to undertaking this research, I had always thought research as tedious only undertaken by 'academics and gown up in the higher educations'. I was not able to place research into a clinical context. But this research activity has revolutionised my understanding of the term. I learned how the clinical placement could be an impetus for research activities; and learned that learning can be both asynchronous and synchronous. Though initially I found this task very challenging especially while seeking ethical approval process, performing networking and doing the data collection, overall the process was enlightening as well as productive. As an ordinary human being I use to think that you as a single individual can't influence the people to change their way of thinking or attitudes. But the experience from this study taught me that if you do something with a real interest and with pure good will, and with right supervision as well as guidance, you can achieve great success and positive outcome which will help others and through that you

can improve the well being of the society and enable the NHS system to perform at their high standard level. The study findings provide researcher with a platform upon which to build, a platform that itself was built from postulations and research originating from passion and knowledge. The value of looking wider than the current practices and evidences when dealing with sensitive topic like organ donation among the ethnic groups was clearly evident in this study result.

The uptake of the findings as integral evidence upon which to generate a guideline for future NHSBT awareness campaigns among South Asian community and their willingness to discuss the suggestions of the study to implement in the future practice is an encouraging outcome. More than that the 2874 new registrants in 24 months individually driven campaigns and two altruistic donors along with slight increase in the South Asian deceased donors from North West was an accolade of the highest standing, one that made all the hard work worthwhile. The aim of this study was to make a difference and increase the number of organ donors amongst South Asian people, which I certainly did.

Appendix 1 SEARCH STRATEGY

Set#	Searched for	Databases	Results
1	southasia*.mp.	Ovid MEDLINE(R) <1946 to October Week 3 2013	3440
2	Asia		21905
3	"TissueandOrganProcurement"/		12572
4	organdon*.mp.		6427
5	Transplantation/		7454
6	transplant*.mp.		491662
7	3 or 4 or 5 or 6		496832
8	1 or 2		24562
9	7 and 8		256
10	9 keep		54
1	organ don*.mp.	PsycINFO <1987 to October Week 3 2013>	667
2	organ donation.mp.		579
3	exp Organ Transplantation/		2007
4	transplant*.mp.		4800
5	1 or 2 or 3 or 4		5128
6	south asia*.mp.		2557
7	asia.mp.		3931
8	6 or 7		6150

9	5 and 8		12
10	9 and keep		5
1	organ don*.mp.	CINAHL	2105
2	organ donation.mp.		1446
3	exp Organ Transplantation/		10130
4	transplant*.mp.		29857
5	1 or 2 or 3 or 4		30558
6	south asia*.mp.		1400
7	asia.mp.		4642
8	6 or 7		5360
9	5 and 8		49
10	9 and keep		9
1	organ don*.mp.	British Nursing Index	262
2	organ donation.mp.		256
3	exp Organ Transplantation/		601
4	transplant*.mp.		1224
5	1 or 2 or 3 or 4		819
6	south asia*.mp.		280
7	asia.mp.		2127
8	6 or 7		2321
9	5 and 8		8

10	9 and keep		4
1	all(transplant) AND all((south asia* OR asia)) AND all((organ donation OR organ don*))	Applied Social Sciences Index and Abstracts (ASSIA)	192
2	To keep		53

Organ dona* and South Asia* CINAHL=6 Organdona* and Asia* CINAHL =17

Organ dona* and South Asia* MEDLINE= 7 Organ dona* and Asia* MEDLINE = 90

Organ donation and South Asia* PsychoINFO= 4 Organdonation and Asia* = 7

Organ donation and Asia* PsychoINFO = 17 Organ donation and South Asia* BNI = 2

Organ donation and South Asia* ASSIA =11 Organdonation and Asia* ASSIA = 350

Further searches for academic and grey literature were made using search engines using Search strategy terms:

1. exp ‘‘Tissue and Organ Procurement’’/

2. exp ‘‘Tissue and Organ Harvesting’’/

3. ((organ or organs) adj3 donor*).ti,ab..

4 ((cadaver or deceased) adj2 (donat* or harvest*).ti,ab.

5. ((deceased or dead) adj2 (donat* or harvest*).ti,ab.

6. ((organ or organs) adj3 (donat* or procure* or harvest*).ti,ab..

7 (race or racial or ethnic* or asian* or indian* bangladeshi* or pakistani* or nonwhite* or multiracial or mult racial).tw.

8 (culture or cultural or faith* or relig* or sikh* or hindu* or muslim* or islam* or christian* or buddhis*).tw.

9 (barrier* or prohibit* or custom or customs or factor* or interest* or disinterest* or objection* or opposition or decision* or decide or deciding or allow* or agree* or disagree* or willing* or unwilling or moral* or ethics or ethical or attitude* or behaviour or behavior* or knowledge or education* or opinion* or belief* or emotion* or motivat* or demotivat* or choice* or acceptab* or accessib* or inaccessib* or regist* or provision or availab* or aware* or perception or perceive* or view* or perspective* or inhibit* or influenc* or misunderstanding or misunderstood or consent or reluctant or reluctance or disparity or disparities or family or families or relative*).tw.

Appendix 2 CRITICAL APPRAISAL FRAMEWORK

	Adapted from HCPRDU (2001) Framework	In line with NICE (2007)
Clear Aims:	<p>Are the study aims appropriate for the review and inclusion of the study?</p> <p>Do the study aims to find out the reasons for scarcity of South Asian organ donors, look at factors influencing this, individuals concerns, or suggesting a solution for promoting organ donation from South Asians?</p>	<p>Clear (+)</p> <p>Unclear (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Study Type	<p>What type of study is it?</p> <p>Is this appropriate to answer the study questions or aims?</p> <p>Has the type of study design been clearly outlined and a rationale provided as to why this approach was considered the best?</p> <p>Could a better approach have been utilised?</p>	<p>Clear (+)</p> <p>Unclear (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Literature Review	<p>Is the literature review comprehensive?</p> <p>Does it generate an argument for the current study?</p> <p>Does it draw out the pertinent points?</p> <p>Does it identify theories to consider?</p>	<p>Well covered (++)</p> <p>Adequatelyaddressed(+)</p> <p>Poorly addressed (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Perspective	<p>Is the perspective obtained relevant to the study group?</p>	<p>Well covered (++)</p> <p>Adequatelyaddressed(+)</p> <p>Poorly addressed (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Sample selection	<p>Is the selection of participants transparent?</p> <p>Have all variables within the sampling population been considered? Is a random or non-random method applied and is this appropriate?</p>	<p>Good (++)</p> <p>Adequate (+)</p> <p>Poor (-)</p>

	<p>Could the sampling method have been improved?</p> <p>Are the inclusion and exclusion criteria appropriate to achieve the aims of the study?</p> <p>Have certain groups within the sample been excluded and is this appropriate?</p>	<p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Sample Size	<p>Is the sample size and composition representative of the target population?</p> <p>Have sufficient participants been recruited?</p>	<p>Good (++)</p> <p>Adequate (+)</p> <p>Poor (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Method	<p>Is the method adopted explicit and appropriate?</p> <p>What are the good points and bad points of the approach?</p> <p>Is the method based on previously validated studies? Are previously validated tools considered and are they appropriate?</p> <p>Is the method of data collection appropriate to answer the study aims?</p> <p>Could the methods have been improved?</p> <p>Have ethical issues and consent been considered and described?</p>	<p>Good / Clear (++)</p> <p>Adequate (+)</p> <p>Poor (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Fieldwork	<p>How the fieldwork is performed, is it described insufficient detail to be clear?</p> <p>When, where, for how long, and to whom, does the fieldwork target?</p> <p>Are there any problems with the way the fieldwork was approached?</p> <p>Who is performing the fieldwork is there potential for researcher bias? How is the reliability and validity of the data guaranteed?</p>	<p>Well covered (++)</p> <p>Adequately addressed(+)</p> <p>Poorly addressed (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Analysis	<p>Does the study have an appropriate analytical approach and is it transparent?</p> <p>Have the correct statistical tests been applied?</p>	<p>Good / Clear (++)</p> <p>Adequate (+)</p> <p>Poor (-)</p>

	<p>Have appropriate qualitative approaches been applied? Are steps taken to verify and maintain the reliability and validity of the data emerging within the analytical process?</p> <p>Who performed the data analysis and is there any potential researcher bias?</p> <p>Have appropriate computer software been utilised?</p> <p>Is there theoretical sensitivity?</p>	<p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Results/ Findings	<p>Is there evidence to support the results/findings emerging?</p> <p>Are statements and conclusions supported by relevant evidence?</p> <p>Are the findings discussed in relation to the current literature?</p> <p>Are theoretical and methodological issues/connections discussed and extrapolated from the findings?</p> <p>Are these appropriate?</p>	<p>Well covered (++)</p> <p>Adequately addressed(+)</p> <p>Poorly addressed (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Limitations	<p>Do the strengths of the study out-weigh the limitations? Do the weaknesses of the study invalidate the findings and conclusion?</p> <p>Could this study be replicated?</p> <p>Are there any suggestions that could to make it a better, more reliable study?</p>	<p>Well covered (++)</p> <p>Adequately addressed(+)</p> <p>Poorly addressed (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>
Generalised	<p>Is it possible to transfer or generalise the findings to a wider population or different setting/disease group?</p>	<p>Good (++)</p> <p>Limited (+)</p> <p>Poor (-)</p> <p>Not addressed</p> <p>Not Reported</p> <p>Not applicable</p>

Overall Quality Rating: based on combined ratings of individual sections

High / Good (++)

Medium / Average (+)

Low / Poor (-)

Not Applicable

Overall quality rating is done looking at the Study aims, Sample judgement based on sampling framework, participant selection and representative of target population, number of participants recruited and to the answer why the study is appropriate or is the result can be generalised.

In line with NICE (2007) quality assessment indicators, each section of the study was given a judgement of good (++) , appropriate/adequate/average (+), or poor (-) depending upon the quality of the work and descriptions provided within the paper. The positive and negative aspects of each paper are stated and the relevance to the developing study identified.

21 Chosen studies are from:

UK = 10

USA= 3

India = 1

Pakistan =1

Malaysia = 3

Comparative studies = 2

Appendix 3 CRITIQUE OF SAMPLE

Overall Quality Rating: NICE-2007

In line with NICE (2007) over all quality assessment and rating is done as High/Good (++), Appropriate/Adequate/Medium/ Average (+), or Low/Poor (-) depending upon the quality of the work and descriptions provided within the paper. The positive and negative aspects of each paper are stated and the relevance to the developing study identified looking at the individual sections:

- Study aims and to the answer why the study is appropriate or is the result can be generalised.
- Sample judgement based on sampling framework, participant selection and representative of target population, number of participants recruited
- Method judgement based on methodology, description of fieldwork, recruitment method, data collection methods and analysis framework

21 Chosen studies are from:

UK = 11

USA= 3

India = 1

Pakistan =1

Malaysia = 3

Comparative studies = 2

Study	Type	Main aim	Participants group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Gaughan et al. (2013)	Qualitative study Focus Groups and Semi structured interviews	To study the factors influencing the attitudes toward organ donation among younger (age 18-25) generation of UK educated Indians and Pakistani's	Indian and Pakistani University students from medical and non medical background who had their secondary school education in the UK	Convenience sampling, purposive sampling Stratified sampling	Not clear 58 interview participants, not clear about the total sample as it is mentioned 9 focus group with 5-8 participants	Not clear	Studied the subgroup of medical and non medical Indian and Pakistani university students' attitude towards organ donation. Suggestion provided to do more studies in distinct groups rather than combining them. It identified that lack of awareness exists among the educated future potential donors.	Good (++)
Karim et al (2013)	Quantitative Questionnaire survey	A survey of South Asian attitudes to organ donation in the United Kingdom	South Asians residing in the UK Indian-238 Pakistani and Bangladeshi-318	Not clear	556	Study web link posted on internet based forum groups and emailed to South Asian groups. Paper based questionnaires were distributed in Mosques, Temples and Gurdwaras	South Asian population in the UK is a heterogeneous cohort with individualized attitudes to organ donation that are subject to religious, socio cultural and environmental pressures	Average (+) Participation bias has led to the results of this survey deviating toward the views of younger and better educated South Asians & ignores the views of less interested South Asians

Study	Type	Main aim	Participants group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Tumin et al (2012)	Quantitative study Questionnaire	To identify the factors that influences Malaysian persons with a tertiary level of education on their willingness to donate organs	Several locations; University, campuses, hospitals and restaurants 65.1% Muslims, 9.5% Christians , 9.0% Hindus 16% Buddhists, 0.4% other	Not mentioned clearly	1311 total sample but only 688 selected with tertiary education	Multiple, not mentioned accurate number of locations	Explained about the importance of targeting better educated to narrow the gap between organ demand and supply	Average (+) Rationale for selecting tertiary educated sample is not justified and result cannot be generalised.
Sims et al (2012)	Qualitative Focus Group	Overcoming barriers for registering as organ donor among minority ethnic group	DonaTE study including Nigerian, Caribbean, Indian, Pakistani and Bangladeshi Community in London	Not clear	22	Not clear	These groups have specific concerns about organ donation which in turn influences their willingness to register. Addressing this requires opportunities for different groups to engage with information that is relevant to them.	Good (++)
Abidin et al (2012)	Quantitative Questionnaire	To assess the attitudes, knowledge and understanding of health professionals in Malaysia	Doctors, nurses and medical assistants. 66.7% Muslims 59.1% Malay	Convenient sample	462	Two territory hospital in Kuala Lumbar	Identified the need of continuing medical education and increasing awareness on brain stem death among the health professionals	Good (++)

Study	Type	Main aim	Participants group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Clarke-Swabby (2010)	Qualitative-Focus group and Questionnaire survey. (Only questionnaire survey included as focus group did not have any Asian representation)	Understanding the cultural beliefs surrounding organ donation	Caribbean, African and Asian communities In South London 25 women 24 men and 7 data missing	Not mentioned clearly	49	Not clear Local Library within the BME community in Lewisham, Southwark and Lambeth	Identified the need of improving the effectiveness of the current organ donor system, by building on public's awareness and understanding organ donation and the associated benefits of transplantation	Average (+) Result cannot be generalised to Asian population in the UK due to the small sample representation from Asians
Wong (2010)	Qualitative Focus group discussion	To identify the factors limiting organ donation among, Malay's, Chinese and Indians and to promote acceptance of organ donation in a multiethnic Asian community	General public from Klang Valley area of Malaysia Malay 47% Chinese 36% Indian 22%	Not clear	105	Venues varied Universities, Offices, participants home	In-depth understanding on diversity of cultural and religious concerns regarding organ donation across culturally diverse community. Identified the role of religious and community leaders in promoting organ donation.	Good (++)
Bapat et al (2010)	Quantitative study Questionnaire	To understand the awareness, attitudes and beliefs among medical postgraduate students in South India	Medical Postgraduate students; 62% Christian 36% Hindus 2% Muslims	Not mentioned clearly. Said that out of 143 students 123 Consenting participants were recruited	123	1	Study was well presented apart from the sample selection. Clearly explain about the need for incorporating the topic deceased organ donation into the medical curriculum.	Good (++)

Study	Type	Main aim	Participants group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Park, Smith and Yun (2009)	Quantitative Questionnaire	To identify ethnic differences in intension to enrol in a state organ donor registry and intension to talk with family about organ donation	Current or former employees of companies in manufacturing or and service industries located in the Midwest of the United States 75.1% White Americans 12.33% African Americans 2.24% Hispanic Americans 2.11% Native Americans 1.55% Asian Americans	Convenient sample Various work places	2896	Various work place venues via responsible person from each area of work	The differences to enrol organ donor register were small among different ethnic group but the relationship between attitudes was stronger among Asian Americans and weaker for African Americans than for White Americans	Average (+) (Bias in the sample and recruitment)
Saleem et .2009)	Quantitative study Questionnaires in selected public areas of Karachi, Pakistan	To determine the knowledge, attitude and practices regarding organ donation in a selected adult population in Pakistan	People attending the market place in Karachi, Pakistan	Not clear	408	Five conveniently selected market places in Karachi, including Tariq Road, Saddar, Bahadarbad, Clifton and market areas in the vicinity of Stadium road	Better knowledge may ultimately translate into the act of donation. Effective measures should be taken to educate people with relevant information's with involvement of media, doctors and religious scholars	Good (++)

Study	Type	Main aim	Participants group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Razaq and Sajad (2007)	Cross sectional study Questionnaire survey	To explore the opinions of Muslims towards organ donation in Birmingham , UK	Muslims attending University, Gym and local community	Not clear	97	Not clearly mentioned	This study points out the lack of knowledge of religious ruling among Muslims. People aged 40 or over identified as less aware about the organ donor register	Average(+) Bias in the sample and the validity of the results as questionnaires were filled by the interviewer.
Edwards , Essman and Thornton (2007)	Quantitative Questionnaire	To assess racial and ethnic differences in medical students (US) knowledge, attitudes, and behaviours regarding organ donation	First and second year Medical students		500	Three Ohio medical schools-Case, Western Reserve University School of Medicine, The Ohio State University College of Medicine, and the Ohio University College of Osteopathic Medicine (US)	Minority medical students were less willing to donate	Average (+) (Bias in the sample and those less willing to donate may have responded)

Study	Type	Main aim	Participants group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Morgan et al (2006)	Quantitative Study Questionnaire survey	To establish current knowledge of kidney donation recruitment	People attending GP centre at Lambeth Primary care trust. White - 808 (52.6%) Black Caribbean-338(22.0%) Black African – 192 (12.5%) Asian – 33 (2.1%)	Convenience sample (Individuals attending GP practice)	1536	4 GP centres	Eventhough the aim was identify the attitudes to registering as a donor among ethnic groups in the UK, more than 50% participants were White and there were only 2.1% Asians	Average (+) (Sample is not representative to achieve the study aim especially Asians, as they were only 2.1%)
Alkhwari et al (2005)	Qualitative study using grounded theory. Three approaches.Participant observation, Focus group and in depth individual interviews	Attitude towards transplantation in the UK Muslim Indo Asians in West London	UK Muslim Indo Asians	Participants were selected using a theoretical or purposeful approach	141	Initiated at one of the 15 Islamic centres in West London and repeated at two other centres to test and validate the findings	Identified the need to provide the health information to this community in a culturally sensitive way	Good (++)
Bennett and Savani (2004)	Quantitative Questionnaire	To identify what factors will influence people willingly to agree organ donation and relatives to agree donation	Three areas in Greater London 118 Asians, 112 Afro-Caribbean, 106 White, 53% Muslims and 15% Christians	Random sampling	336	Street locations around underground stations in various part of London	Government needs to initiate large scale education programmes in order to inform the public about the actualities of organ donation. And there are no critical differences in attitude towards body part transplantation among various ethnic groups.	Average (+) (Sampling bias and the location of the study ,as it is street location)

Study	Type	Main aim	Participants group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Hayward and Madill (2003)	Qualitative Focus group interviews based on grounded theory	To explore the meaning of organ donation among two ethnic groups (Whites and Pakistani's) in North of England	People living in North of England; 5 Muslim women 5 Muslim men 9 White women 8 white men	Not clear Recruited via organisations and community centre in Leeds, UK	27	Not clearly mentioned	This study helped in weighing the costs and benefits of organ donation. This was related to religious consideration and family concerns as well as moral judgement of scientific and medical conduct	Average (+) Sampling not clear and small sample size
Spigner et al (2002)	Quantitative questionnaire survey (35 questions)	To assess knowledge and opinions about the process of human organ donation and transplantation among American Teenagers	High School students African American-107 White- 80, Asian American-73, Hispanic American-10 Indian American- 2, Pacific Islander-9, African-8. Middle Eastern-3, Alaska Native-2	All students from three schools during their regular class room session enrolled in health and science classes.	247	3 School sites	Identified the accurate need for up to date culturally sensitive youth oriented health education that emphasizes family discussion about organ transplantation is needed	Good (++)
Ahmed et al (1999)	Interview Survey	To canvas opinions from all the groups that represents the Indian subcontinent in Britain.	Street survey at main thoroughfare of Southall, Middlesex among the South Asians,	Not mentioned clearly. Street survey	100	1	Study well presented and they had sample from all the religious group including Sikh. Got suggestions from participants on how to improve the current system.	Good (++)

Study	Type	Main aim	Participants group	Sample selection	Sample size	No. of Sites	Appropriate / why	Overall Quality Rating
Exley et al (1996)	Qualitative Small interviews (even though it is from 1996, chose as this study is from UK among Sikh)	To identify the attitudes and beliefs within the Sikh community regarding organ donation	From local Sikh community in Coventry, UK	Judgemental sample	22	Various setting within the community as per participants convenience	Identified that campaign on organ donation by DoH failed to reach the intended sections of the population. Needs more resources to reverse the current situation	Good (+)
Morgan et al (2013)	Review and synthesis of quantitative and qualitative studies	Attitudes to deceased organ donation and registration as a donor among ethnic groups in North America and the UK.	14 Quantitative and 12 Qualitative papers	Not applicable	Not applicable	Not applicable	Identified the greater emphasis on organisational and service related barriers and changes required to enhance ethnic minorities access to registration as a donor and consent to deceased donation	Good (++)
Perera and Mamode (2011)	Review the available evidences along with recent data from UK transplant	This study considers the current situation for Asians in the UK who require a renal transplant and how the current excess of Asians awaiting transplantation might be addressed	The available evidence along with recent data from UK transplant	Not applicable	Not applicable	Not applicable	The interaction of biological, cultural; and organisational factors affecting Asian patients needs to be considered carefully to ensure that these patients are not disadvantaged. Improving organ donation rate among Asians in the UK need a cohort strategic interventions including cultural education to the healthcare providers	Good (++)

Appendix 4 QUESTIONNAIRE

(Questionnaire used by Morgan et al. 2006)

Research code:

Identification number:

This Questionnaire asks your views on kidney donation.

Everything you tell us will be treated as strictly confidential.

Please tick the box in answer to each of the following questions

Section A

1. Did you know that it is possible to leave your kidneys for transplant in somebody else after your death?

Yes No

2. Do you know someone who has received, or is waiting to receive a kidney?

Yes No

3. Have you ever thought about donating your kidneys after your death?

Yes, I have thought about it seriously Yes, but not very seriously

Not sure No, I have never thought about it

4. Have you ever discussed donating your kidneys with a partner, family member, or friend?

Yes No

5. Are you registered on the NHS organ donor register and/ or do you carry a donor card?

Yes (please go to question 7) No

6. Would you be willing to register as a kidney donor, and donate a kidney for transplant after your death?

Yes, definitely Yes

Not sure No No, never

In some countries there is an ‘opt-out system’ which means it is lawful to take the kidneys from any adult who has just died, unless that person had specifically forbidden it while they were alive.

7. How would you feel if this kind of system was introduced in the UK?

I would strongly support it I would support it

I would not care either way I do not know how I would feel about it

I would oppose it I would strongly oppose it

Section B: Below are statements that reflect what people think and feel about organ donation. Please read each statement and decide how much you agree or disagree with it. There are no right or wrong answers. Your opinion is valued.

8. If I were a kidney donor, I would not mind who received my kidney after my death.

Strongly agree Agree

Disagree Strongly disagree

9. It is important to me to know that I could give someone else a chance of life after my death.

Strongly agree Agree

Disagree Strongly disagree

10. I worry that medical teams may not try as hard to save the life of a person they know has agreed to donate their organs.

Strongly agree Agree

Disagree Strongly disagree

11. I am uneasy with the thought of my body being cut up after my death.

Strongly agree Agree

Disagree Strongly disagree

12. Donating my organs is a way of serving God.

Strongly agree Agree

Disagree Strongly disagree

13. I worry that if I agree to donate my organs for transplant, they might be used without my consent for other purposes like medical research.

Strongly agree Disagree

Agree Strongly disagree

14. Registering to be a donor or carrying a donor card is like tempting my own death.

Strongly agree Agree

Disagree Strongly disagree

15. Donating your organs when you die is a good thing to do.

Strongly agree Agree

Disagree Strongly disagree

16. An intact body is needed for the life hereafter.

Strongly agree Agree

Disagree Strongly disagree

17. There is currently an urgent need for more kidney donors. Have you seen, read, or heard about this need from any of the following sources:

Television Radio

Newspaper Magazine

Leaflet Poster

Religious leader

18. How well informed do you feel about registering as a kidney donor?

Very well informed Fairly well informed

A little informed Not very well informed

Know nothing about it

19. It is becoming increasingly possible to donate one of your kidneys while you are still alive to a close relative. If a close relative of yours needed a kidney transplant, would you be willing to consider becoming a live donor?

Yes, definitely Yes

Not sure No No, never

Some information about you

20. What is your ethnic group?

Asian or Asian British

Indian Pakistani Bangladeshi

Any other Asian background

(please describe) _____

21. What kind of education did you receive?

Primary education

Secondary education Further education – commercial or technical

University or polytechnic education No school education

22. Are you?

Male Female

23. What is your religion?

Muslim Hindu

Christian Sikh

Other

24. What is your age? _____

25. Are you?

In paid employment (please state occupation) _____

Student

Retired/ Not working (please state previous occupation) _____

Thank you

Date: Research code:

Identification number:

REPLY SLIP:

I am happy to be contacted further to discuss my possible participation in the research study described in the letter.

My contact details are:

Name _____

Address _____

Telephone No: _____

Appendix 5 INVITATION LETTER

Central Manchester University Hospitals 
NHS Foundation Trust

Study Title: Increasing Organ Donation in the North West South Asian Community through Strategic Intervention

Dear participant,

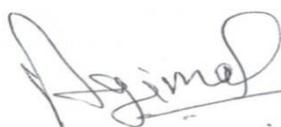
My name is Agimol Pradeep and work as transplant recipient coordinator at Central Manchester Foundation Trust. I am currently doing PhD Study at University of Salford. I am conducting a research study as part of the requirements of my PhD programme, and I would like to invite you to participate. The study is to find out why there is a scarcity of Deceased Organ Donors from South Asian background community.

I am inviting you as a member of the South Asian community to take part in my research study. Attached is an information sheet explaining; the research study I would like you to complete and how you could participate in different ways?

Please read it carefully and telephone me if you have any questions (see below). If you are happy to be involved please send back the completed questionnaire.

You can access the information's online as well; our study web address is **www.southasianorgandonor.org.uk**

With kind regards,



Agimol Pradeep,

Transplant Recipient Coordinator, CMFT, Oxford Road, Manchester, M13 9WL.

Tel no: 07886922313

Email: **agimol.pradeep@cmft.nhs.uk**

Appendix 6 PARTICIPANT INFORMATION SHEET

Version-1, Date:

Research code:

Identification number:

What to do if you do not understand or read English?

If you do not understand or read English then help is available to translate and help you understand the information below and guide you through the information sheet.

For a translation service for the following languages:

Urdu, Hindi, Bengali

Please telephone: 07886922313

Project Title:

Increasing Organ Donation in the North West South Asian Community through Strategic Intervention

You are invited to take part in a research study. Before you decide you may wish to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please contact Agimol Pradeep (contact details below).

Purpose of the Study

I am inviting you to participate in a research project that will find out why the members of South Asian community do not register for organ donation. Kidney failure is a major health issue in the Asian population and kidney transplantation is a way of treating this disease. Of those patients waiting for a kidney transplant 14% are South Asians. However, only 1% of people registered on the organ donor register are South Asians, donation rates are low among Asian people which means South Asian people have to wait on average twice as long as a white person for a kidney transplant. White patients wait on average 722 days, Asian patients wait 1496 days and Black people wait 1389 days. Indeed one in eight people who died waiting for a transplant in 2006 were of African-Caribbean or South Asians. This study is trying to find out the reasons for this poor organ donation after the end of life and develop interventions to increase organ donation.

Why have I been invited?

You have been chosen at random as a member of the South Asian community in the North West because we are interested to understand your views of organ donation.

Do I have to take part?

No, your participation is entirely voluntary. It is up to you to decide whether or not to take part. If you choose not to take part you can dispose of the study information and we will not contact you again.

What will I have to do if I choose to take part?

There are two ways that you can be involved within the research study. You can answer a questionnaire asking about your views regarding organ donation, which should take approximately 5-7 minutes to complete. Then post the questionnaire back to the researcher in the pre-paid self-addressed envelope. We will presume when receiving a completed questionnaire from you that you are happy for your answers to be used as part of the research study.

If you are happy to be involved further you can complete the reply slip and detach it from the questionnaire and send this back to the researcher indicating you are happy to be contacted further to take part in an interview. The researcher will then contact you to arrange a convenient time and place for you to meet together to be interviewed, this can be at your home, your GP surgery or religious centre if you prefer. The interview should take approximately one hour but no longer than two hours and will be tape recorded. You will be asked to sign a consent form prior to the interview to ensure you are happy to be involved. The purpose of the interview is to explore your perspective of organ donation within the South Asian community.

We are providing on the organ donation register throughout the study to people within the South Asian community so we can increase the number of registered donors. You may see organ donor registration forms at different events associated with the research study. However your registration on the organ donor register is completely voluntary and at no point will you be expected to register on the organ donor register as part of your participation within this research study. Therefore, you can complete a questionnaire and take part in an interview but do not have to become an organ donor.

Will I get paid for my involvement?

The completion of the questionnaire is voluntary there is no payment or expenses available to people who participate. However if you agree to take part in an interview we would reimburse any travel expenses you may incur from your participation in the research.

What are the side effects of the study when taking part?

There are no known side effects.

What are the possible benefits of taking part?

There are no benefits to you individually but this may help people in the future. The results of this project will help to understand the reasons for poor organ donation within the South Asian community identify ways in which organ donation could be increased and raise the awareness among general public of the importance of organ donation. We can only achieve this by asking the people within the South Asian community what they think and developing ways to increase knowledge and understanding to overcome the shortage of organs.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time without any effects on you. If you decide after sending through your questionnaire that you no longer want your information to be involved then you can contact the researcher. She will then ask you for the number on the top of the patient information sheet which is the same as the number on your questionnaire. If you can provide this number your questionnaire will be removed and your data will not be used within the research. Also if you wish to withdraw you interview

information you can use the same number that is written on the top of the information sheet and ask for your interview to be removed from the study. You can do this at anytime

What if there is a problem?

If you have a problem with the research at anytime you can report this to the researcher (contact details below). If the problem you have relates to the way in which the research is being undertaken then you can report this to the researchers supervisor: Dr Paula Ormandy , Email: p.ormandy@salford.ac.uk or telephone: 0161 294 0453

Will my taking part in this study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential, the information you provide through your questionnaire will be anonymous using a unique research code. If you send in your name and address details on the reply slip this information will be kept safe on a password protected computer, accessed only by the researcher and the research supervisor. This information will only be used for the research and will not be shared with anyone outside the research group which consists of me, my supervisors and hospital research committee. You should not put your name on the questionnaire. If you do not feel comfortable handing your survey back directly to the researcher , you may also send this via the pre paid self-addressed envelope attached with questionnaire please.

Will my GP be informed?

No, your GP will not need to be informed regarding your participation in this study.

What will happen with the results of the study?

Results will be published in scientific journals or presented at conferences. When the findings of the study are reported the opinions and perspectives of South Asian people will be discussed as a group with the identity of individual people being anonymous.

Who has paid for this research?

The British Renal Society and NOVARTIS Pharmaceuticals have provided some research funding to complete the study.

Further information and contact details

Agimol Pradeep, Transplant Recipient Coordinator,

CMFT, Oxford Road, Manchester, M13 9WL

Tel no: 07886922313

email : agimol.pradeep@cmft.nhs.uk

Appendix 8 MEDIA PARTICIPATION CONSENT FORM

Central Manchester University Hospitals



NHS Foundation Trust

I hereby give my consent to be interviewed.

Please enter date of interview session:

Name : _____

Home Address: _____

Daytime Telephone Number: _____

Participant's Date of Birth: _____

Signature of Participant: _____

Re-use of interviews/photographs/film clips

Please be aware that with external agencies, such as newspapers and TV companies, we cannot control re-use/repeat.

Appendix 9 POSTER FOR GP CENTRES



7,593 people in the UK
are **waiting** for
an **organ transplant!**
1,834 of the total number are
Black and Asian people!



Need more Asian organ donors

1571 Asians waiting for a kidney donor



**Give life...Live life...Doctor donates
kidney...**

“Being a physician I felt I should be a role model. I wanted to promote organ donation to other people in the Asian community” (Dr Tony Akbar, GP)



**Accept life...Live life...I have had a
kidney transplant...**

“We need your help. Not enough people from the South Asian community are signed up to the organ donor register” (Wajid Iqbal, Kidney Patient)



The wife of a Blackburn Councillor received a kidney transplant after waiting six-years, making her start to feel healthy again (Councillor Mulla and wife Sayeeda)

Speak to your GP today become an organ donor

For more information please contact Agimol Pradeep on 07886922313 or mail agimol.pradeep@cmft.nhs.uk

Appendix 10 FIRST LEVEL INTERVIEW ANALYSIS

1. Religious beliefs on donation / Gods will to live or die/ scarcity

There is no firm religious barrier, there is nothing i read or heard from religious leaders, I rise in my faith, I am not grown up with you cannot be organ donor. Nothing religious. It s more the idea I associate with religion and culture. Carrying a donor card in Hindu faith believe that if you carry things or do certain things it's like Tempting my own death, tempting fate. If you carry it fate will come and find you and give you premature death. I know the rational part says it is silly but cautious part says just to be sure (1FH)

Probably i may not recollect what i have said before, probably may be in last one year also i might have changed my opinion. Main reason i said was more of it to the religious reason. There was not very much idea on religious perspective on organ donation. Of course there is a good move going in the Muslim religion about organ donation and more clarity coming about, which is not established yet, as far as i know, may be lack in the knowledge. (3MM)

It is hard for Muslim to donate. We especially in Muslim religion we have to listen, whatever say in Quran it's always right. We will listen, all Muslim will donate, but i am not sure about it. If the clarification comes from religious leaders I will donate (4FM).

As I am from Muslim culture, obviously there is a belief that you cannot be a kidney donor, so that's all it is really, and we all believe that you can't be a donor and that's what everybody believes. It is not personal or individual reluctance, it is because of the religion. (5FM)

I am not sure, I think I may have heard or read somewhere that it is not possible for us from the religious perspective. Allah, God created this body for us, we should not disfigure the body, we should not meddling with our body like tattoo. That's my understanding, even organ donation I think that do as well. It's like with medicine say it is haram for us with alcohol, for medicinal purposes you can take it. While you are living may be. If it's permissible through religion, i will consider it. It is the religious ankle I want to clear about it. Scarcity of donors-I mean it's in the hands of the creator at the end of the day, so i don't have any problem. What's going to happen it will happen and it's to be it is to be. If people die due to the organ failure it will be Gods purpose (6MM).

For me if it religious comes to it and it says you are allowed to donate your organ, then if need to be.(6MM)

I would be unclear of it as well. There is also an Islamic point of view which I have got to be very careful on about and the life perspective as well I have to be exactly careful on. Weighing out the options I would recommend if a lay person ask me I will ask the person if you can and has opportunity to ask the senior scholars than I, who will then try and give you an exact reason opinion yes or no. if its yes then I will go yes, if its no I will of the opinion as well no. at the moment I can only give you such kind of assurance as it is grey area, and still waiting for my seniors which the question has passed on to them to give me an insight and to pas some light into it. What's happening and how far we into the investigation and then whether it's yes or no answer.(7MM)

At this moment in time my believe is that, I wouldn't go on to transplant waiting list, I may act differently if I was in that situation. But as it stands, well, If God wills me to be here, I will be here without kidneys, my cousin she is here for 25yrs, and she is alive. She is on the list for 25yrs, and she survived 25yrs, she is on dialysis, and had two failed transplants. The way I see,

Whichever way God wills it.(8FM)

Yes, my religion has got bit an influence on this (my decision). Again with as every religion you have the choice.(8FM)

I do not know whether the religion allows or not allows. That is the reason I am not registered. Yes definitely religion plays a role in making the decision.(9FM)

Religious understanding I have been told that you are not allowed to accept or give any organs. But in this stain age we need to move forward and I agree with organ donation.(10FM)

2. Personal beliefs on organ donation and what happens after death

I agree with organ donation would happy to receive an organ. But something spiritually tied in religion that is stopping me from agree to register myself as an organ donor. If my son wanted/needed an organ straightaway i would not even think twice, it will be same but my practical mom will come. It's just i put so much emphasis on people can move on spiritually in their life so i don't want that risk to happen.

I do think if part of your physical part and not cremated, there is risk that the sprit will cling on to this life and will not be able to move on. (1 FH)

But if I could talk to my partner okay that sounds bit right its just because in my head so much having been raised with that I can't almost get away from it. (1 FH)

I think it important that at that time also at that everything has to work so fast, getting organs raw, that can't comprehend that you lost someone that was there yesterday full of beans and now part of them has to go to someone else. I think that you can't comprehend the fast pace of everything.(1FH)

Ideas of having you cut open things like that, i wanted to preserve myself. I have seen post-mortem and things like that i have seen the way they do it, that put me of completely so i did not want to donate my kidneys at that particular time i was filling questionnaire.(2FC)

After you die you don't know what happens to you, you just go back because of one of your organs if somebody can live that's a good thing to do. (2FC)

When you gave me the questionnaire i did not research about the religious aspect of it, I was still believing in my myth about organ donation and the religious percept. It must have changed now, recently I have seen the chaplain here doing a project on this actually, and i may change my perspective on it in the future. as a human being i cannot see a reason for not to donate my organ. So the answer of no might have changed to Yes. Why should i take to underground when I am dead, nobody is going to use, anyway God does not want it back. (3MM)

I do not have any personal objection to this (6MM).

Personally I wouldn't agree myself or family members to do as well for organ donation. Because my belief is that we are born with this organ and when we leave this world we have to go with this as well unless it has to be removed for health purpose, nothing should be taken away from you.

Its very delicate subject, its not for everyone, some of them may say i don't want even to talk about it. (6MM)

Perspective of organ donation varies, how I will answer. As personal point of view openly i will say i don't have a clear answer as yet, that I can give you, whether yes or no.(7MM)

As my personal point of view, if I have to look at the life today and the high expectations of organ donation, I have been in and out of the hospital, I lost my father secondary to multi organ failure and he did not receive any organs or replaced and he lost his life. Also I have friends and families who have had organs replaced looking at their situation I thought very deep into this situation, and I said if we say no to organ donation the question arises will that person survive, will he live on and if we donate an organ to him aren't we give him a lifespan of another 20 or more years, aren't we give him a life to live, because had he he try to live with a damaged or fractured organ what's the life span on that, bringing that into the consideration and its life threatening moment, this is my personal view, organ donation should be given from the Muslim community, that is my personal point nothing from the scholars or any sectors of Muslim community. If I have look at the broad spectrum yes, if it's a life threatening moment yes I would agree if its not life threatening again it's a grey area.(7MM)

Personally I would only donate my organ to a family member and they have to be Muslim. If it's a outsider, the way I see it is if the God's intention is that, then that's what its people can survive without them. This may sound really bad at this moment in time. It's just that with my organ what is the guarantee that they are going to have a life. It could reject and I have seen the rejection.

All my views are more personal. If I needed a transplant I will take only from my family members and may be another Muslim. Not everybody is compliant with eating and things like that, I take care of what I eat, I watch in terms of whether it is halal, the ethical values, where the food come from things like that, I watch everything that goes into my body, not everybody does that . And you don't know how it's going to react to it. Having something from somebody else, it becomes part of you. So part of somebody else become part of you. I don't agree with it. I find it very difficult accepts.(8FM)

As a person I think I would do especially if it was an immediate family even as extended family I would come forward as a live donor. But the deceased donation I don't know that something very new, may be may be something that I will consider its new it's a gray area with religious aspect and everything. If it's your family you wouldn't give up your life would you? (10FM)

3. Family beliefs/ next of kin / generation differences

My mother died two years ago, she always wanted to donate her organs as her brother-in-law received a kidney. When she died my dad was next of kin he refused, he did not want part of his wife's body to go somewhere else.(1 FH)

Minute you start drifting away your spirit start leaving you, this helped me to get through my mother's death. Knowing that she moved on, she is happy and had a good life and will have composedly rewarded in next life. That's why partly i could understand why my dad said no. My sister was very upset, saying mum wanted to donate her organs. But i could understand if her part of the organs left behind and her spirit cling on. My dad's decision more. Which is really silly? When they came home when they mentioned about the hospital staff approaching about organ donation my sister was really upset saying my mom wanted to be an organ donor and I could understand and I told her that dad is next of kin (1FH).

If he (partner) is on the register, i would not override that. And that's because the disclaimer there is that he is not Hindu and he is Protestant. So he is Very difficult and he would have thought very carefully. He does only think really carefully things he wants to do it. if he put himself on

the register he would have really want to do it (1FH).

If my son dies i do not think I could donate his organ even if there is a baby next to him and his mom saying that he is waiting for an organ, because i think it's more about my son's body being interfered with, I think it may be selfish, in an honest way. (1FH).

There could be restrictions from family Donating organs there could be negative points from my family, because of awareness could be an issue, if we can make them understand and tell them the reason and the scarcity and how people are suffering and if they are also aware of it i think they would agree. But i think what I would be and what i decide is what happens to me.(2FC)

But there is a family restrain, if i am dead and somebody telling my parents or family that you are not getting the body, if i have not convinced my parents or family that actually okay, after my death you wont get the body, they will be upset. So basically practicality of consents within the family. Within my family with my wife it may be easy but for my parents may be it will be difficult. In the old generation there is actually, they always still live in same well, they have not come out of it. So awareness may be a lacking factor. (3MM)

Actually the new generation, when the old generation vanishes from the world it may change. (3MM)

I was aware about the organ donation, but if you ask my parents they may not be aware.

I think the new generation will be more and more willing to donate. Its like blood donation, my sister is a blood donor (5FM).

I would object that person's consent. No, I am acting that persons best interest , I know that person made that wish but now he is not here so he can't make that decision so i am making it for his best intention on his behalf. Unless, if my view and thinking was different, if i am completely with idea of organ donation then I will say yes. All depends on what my thinking at that time. If I say yes, you should carry on organ donation, yes go ahead with it. All depends on the individual left behind (6MM).

4. Mistrust of medical team

I did think to myself that they kept her alive to get her organs, part of me was kind of because one of the first thing they did when they said we are going to turn the machine off was ask about organ donation, they took my dad to a room and said that we are underrepresented and bla bla... would you like to. I think they kept her alive for organs really. In a way I am quiet angry about that because that was paying for her, her spirit was struggling to move on in those few days when she was kept alive when shoe should not have been, it was hard for us too. But she would want to go straight away and she wouldn't want that unconscious and left in limbo for those three days. (1FH)

And that the doctor, actually the other doctor who saw us was an Asian who said I don't know why they did that if it was me I would not have done, they should not have done that. That made us to think Oh well why did they do that, she had a heart attack and left us aside on X mas day. They phoned me couple of days later, and first I thought may the doctor did not want our Mom to die on Xmas day no they may be thinking it will not be good for them. But, then there were other people dying on the ward on xmas day. It was about saving the organs not saving the person, yes I got bit spectacle it may not be true. (1FH)

5. Religious beliefs at death - Intact body for second life – spirit leaving body — ownership

of the body – Reincarnation

We believe the body has to be intact as it came. You don't want to risk part of the body, It's important for Hindus we get move on to the next life. Even though we believe that body is shalom and the spirit goes as soon as it dies, it's almost like you don't want leave your part of the body lying around with if the spirit cling on that part and the body can't move on to the next life, and i know that kind part of our religious thinking and religious beliefs about recantation. I do think if part of your physical part not cremated, there is a risk that the sprit will cling on to this life and will not be able to move on.(1 FH)

Allah created us in the perfect form. So why do anyone change it for. That will affect even after my death, after I die i do not believe in leaving behind, that's my personal perspective. (6MM)

Still no, I wouldn't do if I was dying and they want to donate my organs to somebody else to give them a life, I personally will say no. because I was given birth with this and I want to go with everything.. Allah has given this body to me, and personally I do not think that my burial is incomplete without all my body part. I understand that when you die your soul goes up and the rest of the body is in the ground still. This body does not belongs to me, this belongs to him up there, He has given to me He trusted me to look after it and to go back with it. That's the way I see it.(8FM)

6. Myths of donation

Yes, there are still myths around. That can be sorted out by education. I think there is also people don't trust medical authorities as well as they should do like there was that baby organ donation scandal happened few years before and where organs been kept and all. (1FH)

Also mentally, i don't know it may play a part on, you know once you pass away for the family you are living behind, they may say he was a donor, so organs are here, they may not come into terms with it not some of it kept in hospital and where you keep it and some of it's gone to grave, so they are not getting full closure. Especially if its heart or eyes, they may say he has got my..... heart or eyes, some may play a part in their back of their mind, someone out their with my partners or husbands heart (6MM).

I do not have any myths, because it should not be working one side it should be working both ways.(7MM)

7. Awareness and knowledge of donation/ education needs

Yes, I know, we are underrepresented. That we have problems with match, and I knew that from my Uncle.... (1FH)

My understanding is Organ donation is something that you donate one of your organs to another person, it can be done when you are alive or once you are death as well which is helping somebody live and when somebody is in need of an organ to prolong their life (2FC).

When i filled the questionnaire, i wrote no, because the idea of organ donation i had very less knowledge about especially about donating the organs after death i have not heard much about. Back at home I am from India we have seen relatives donating to relatives (2FC).

Awareness is an issue. When people are not aware of things they can go negative on it. When a depth understanding and awareness is given, people can change their mind because they know what is there and what is next and they have people to talk to. Now a days we have lot of medias

and things like that (2FC)

See, at the end of the day everyone knows about organ donation, its a matter how you take it. Its a very simple. Unless and until I need an organ I never think about others life, everything about our own lives . We have not crossed that boundary, start about thinking others life, not yet, we still think about our lives and then the family. There is no time to think beyond family. I do not think there is any difference between health professionals and layman; both are in the same boat. Everyone think about our lives and I think the issue is same. (3MM)

I am aware about the scarcity of Asian donors. People know about it, but something that is not spoken about like diabetes, blood pressure or something like that.(5FM)

Very very briefly, nothing in detail. I know it happens but I do not have any personal experience or through any friends or families. No experience at all. I never heard during my schooling about organ donation, so the education need is there.(6MM)

I mean organ donation is last thing in people mind any way, I have not come across anyone talking about it. I have been working in health care for 17 years and met so many people, but no never the case. All our customers are non whites, not many Asian customers in the nursing home, but still never been talked about organ donation. In fact I never heard working in care home in last 17yrs, so i don't think any of Asians heard about (6MM).

Not really to be frank and honestly during my school, college and university I have not heard about organ donation. Only When I went to study educated islamically I was told about organ donation, because at the same time we answer question and queries, so I came stumbled the cross organ donation, when its triggered I started looking into, because it is triggered me. And I started educating myself. The education system I went through here did not educate me about organ donation.

Awareness and education will speed up my generation and generation before and after me will then acknowledge organ donation. So it will be wonderful if we can have an education tool. I can do it from Islamic point of view and from the country's point of view from the Mosque itself. but before we start education awareness is important. If I go around there will be many with strange view. Lay persons in this country do not have enough knowledge on this.(7MM)

I heard about organ donation, I got couple of family members suffering with kidney disease. I got a cousin, she is in Leicester, she is always in and out of hospital she had two failed kidney transplants and one almost killed her, and she is in and out of hospital for operations. So I have seen it and I have seen the effect it has on them. Never in my schooling had I heard, in university I have seen odd campaigns here and there. Nothing ever been specifically delivered to us. (8FM)

I have heard about organ donation. But not from school. I am always out and about and heard from people like you.(9FM)

I have heard about it. I know about organ donation, but not much; just know that it does happen. I understand that kidneys can be transplant from live patient to live patient person or somebody who is not deceased but like brain dead or something. No I did not hear about organ donation during my schooling. Especially coming from Asian background there will bit oblivious on what's going on outside the world. Like you learn from your Mom, my mom didn't get to teach me about all this organ donation so its very new to me, but I speak to my children about organ donation other aspects of life aspects etc which I did not have from my Mom. So its the different generation.(10FM)

8. Disfigurement of dead body

I would say nothing on my face only because we have open coffin, when my son see my body basically. If I have an eye missing i think he will struggle with it, I don't mind anything else missing as it is all covered. (1FH)

Believe me after my death I am not worried about anything, if you want to bury me or keep in the museum i don't care. The whole issue is about the souls if you believe in God, if there is some sort of life after death, it will be about the soul, so I am not bothered about the disfigurement. (3MM)

9. Religious advice and instruction /Religious leaders lack of knowledge/ Lack of clarification / Grey area

But I do think if my Dad spoken to from the religiously and given more information he would have changed his mind. Basically what we are working is mythology and things have been passed down basically from the people who grew up in like the villages who didn't really t know much about organ donation and that's what we are working with now, not kind of facts and science of it so I think if we can get some clarification that will change our view (1 FH).

Religious leaders have a role in this. I don't know much about other religion, but from my religious perspective, actually it was never been discussed in the past. Every religion when you are evolved the more discussion was the present of that time not the future of that time. So the future discussion was not happening in much of the religion, if it was there it can be there in my religion too. I might have completely misunderstood; I did not learn my religion much. Because I learned only basics of my religion if you do dig into my religion there will be Fatwas related to this, stating that you can do this and do that. So my ignorance is the problems not the religion. It is misinterpreting or people may not have the knowledge. (3MM)

I heard from my religion, so i am not sure exactly what and i don't think it is allowed in religion. Donating from dead body it is not allowed, I heard from my religious leader it is not allowed. May be hopefully proper study will clarify this. May be now days they use donation, so i am not sure (4FM)

I have seen patients benefitted from transplant and waiting for transplant, so obviously there must be Asian donors out there, but in this particular area nobody is donor to tell you the truth, because this is belief. This is told to us by religious leaders (5FM).

In the Muslim community, we don't even allow autopsy, so i do not know it depends. I mean different people have different believes. Its an education thing. It's like my mom and dad say different. i think they need more education on. My mom may say no,no but then i will say why don't mom and this is the reason. I think they need more education on this side of it and they will understand it. If he (religious leadrs) is educated he will probably have more options to give to the community, if he says no we won't do it. I think they need to be more aware about it, if they know how it is done and aware about it (5FM).

I would rather say from the religious perspective, which needs an in-depth investigation to it. As from the junior scholar the amount of knowledge I have and the level of understanding I would hand over to senior scholars than myself who are well experienced in this field to then they will investigate in length then they will get back to us whether yes or no. that is the answer we are looking for it today, it is grey area, either black or white. From my perspective it is grey area, with my lack of knowledge and experience so I will hand over to my senior scholars who will

investigate themselves in depth and try and exactly find out and will come back to us whether yes or no, if its yes we needs reason behind it if it's no we need reason behind it too.(7MM)

Yes I am aware about the Fatwas, but there are parts of scholars said yes and some said no, so it is 50:50 situations. It's their own personal view. I heard yes but I am not still condemned want a thorough investigation still needs to go in and we want a decisive answer rather than a 50:50(7MM)

I think it should come from religious leaders. In due course I got meeting with some of the scholars I am trying to exactly find out, I have my own questions for the senior scholars to give an affirmative answer to rather than keeping me in grey area. So that I can at least pass on to the many people out there who want to donate but then at least let us not make it as one way street. If I can get a confirmation from the religious perspective, then I will be able to give to the entire community. And the community will accept the organ donation. Lets not take one-way path.(7MM)

Religious leader could play a role but they hardly want to get involved because of the different interpretation and different views on it, so there is a massive conflict about it. But I know that if I want to donate and to think about it if I go to my local mosque leader he will advise on but he won't tell what to do, he will just advise. It will be my personal decision. What we call it as harem, which is, we pray certain things from the Quran in the night and every morning we pray and you see in your dream whether it is good or bad, within three days we get an answer. And if it's meant to be it will come in your dream as positive light or positive feeling. . So them factors play in making that decision. I do not think any religious leader will have any direct impact on this.No, I have never heard any religious leaders saying it is not permissible. .(8FM)

Religious understanding I have been told that you are not allowed to accept or give any organs. But in this stain age we need to move forward and I agree with organ donation.(10FM)

10. Approach by medical team to donate next of kin

My Mom had a heart attack it was a massive sudden heart attack. . She never regained conscious, she was brain dead, she wouldn't be able to function fully.. They resuscitated her and her heart going on the scene. When we got to hospital two days later one of the doctor said i don't know why she was resuscitated they should have let her go, she has reached that dangerous stage they should not have revived her. she had a heart attack and she was clinically dead for so long so there would have been serious damage. No one said anything but I am very spectacle about organisations and medical professionals, sorry but that's the research I am doing. I did think to myself that they kept her alive to get her organs, part of me was kind of because one of the first thing they did when they said we are going to turn the machine off was ask about organ donation, they took my dad to a room and said that we are underrepresented and bla bla... would you like to. I think they kept her alive for organs really.(1FH)

Yes, my dad felt bit discomfort when they asked, straight away he said no, my brother was with him.(1FH)

11. Media misinterpretation/ negative influence of donation

I think sometime we hear this horror story like George Best, celebrity he got liver and what did he do drink drink.... Media does and always will i think some time some Trust are not accountable.(1FH)

It's to do with media, its shame because many of our early generation in to bollywood, and they

have so common stories coming up, you know if you give someone eye and he got my eyes, any so much of silliness, the media plays and they get so much drawn into it and they will think its happening for real, because Bollywood does play a vital role in many Asians life. You have to target them into main source of informations. If its bollywood it is bollywood,. Whatever works, you cannot target everyone form same ankle.(6MM)

Also I don't think there is much discussion about this in media anyway especially targeting Asian community. you get lot of this, Islam channels , Asian channels, so many of them i don't think any of this channels I have seen say anything about organ donation. That is the main sort of information they get. Even radios, news paper never mentioned about organ donation. . Majority doesn't know what's happening out there. I think if we can concentrate on Asian Medias, that's the only way to get them. That's what i think anyway.(6MM)

It is a sensitive topic so I will be very careful about the media itself, we have to be very careful about the wordings, we cant be too bold or too lineate we have to find a balance in our approach. we can use community hubs ad mosques on health education. When we start educating health we can actually educate on organ donation. Obviously not encouraging because we got this tense issue, but we can educate on why we need organ donation their side effect etc. If it's a correct education approach and we have to watch the sensitivity of the topic soothe are not putting anybody off either. (7MM)

12. Misuse of organs – choice of donor

When I am dead i have no control who gets my organ, family does not have a control and we cant say that the organ can go to only this person only i would hate to think that part of my body has been given to someone who is going to waste it. I know majority of cases the person would appreciate it but i still think about the George Best cases. Or someone who does not deserve having it and person who is does not deserve getting it and he is not passing the **karma** on and getting them (1FH)

Also, But I will be really carful about whose it goes to as well, i will probly say if its close family then, that's my personal view, nothing from religious. it's just my thinking , if its my close family but not to anybody else i don't think I will (6MM)

Personally I would only donate my organ to a family member and they have to be Muslim. If it's a outsider, the way I see it is if the God's intention is that, then that's what its people can survive without them. This may sound really bad at this moment in time. It's just that with my organ what is the guarantee that they are going to have a life. It could reject and I have seen the rejection.(8FM)

Not everybody is compliant with eating and things like that, I take care of what I eat, I watch in terms of whether it is halal, the ethical values, where the food come from things like that, I watch everything that goes into my body, not every body does that . And you don't know how its going to react to it.. Having something from some body else, it become part of you. So part of somebody else become part of you. I don't agree with it. I find it very difficult accepts.(8FM)

13. Receive but not give!/ Asian community mentality

I agree with organ donation would happy to receive an organ. But something spiritually tied in religion that is stopping me from agree to register myself as an organ donor . its horrible....errr if its because i would take an organ and if my son would take one if needed, that's the kind of dilemma.(1 FH)

If my son dies i do not think I could donate his organ even if there is a baby next to him and his mom saying that he is waiting for an organ, because i think it's more about my son's body being interfered with, I think it may be selfish, in an honest way. I Support organ donation and transplantation, there is something spiritually linked to my religion practising where i accept.(1FH)

my dad was willing to accept, but not to give but he was very serious in his views (1FH)

When it comes to that point i don't know how i will react. When you are in die need, i don't know how i will react, i would be on the waiting list,.(2FC)

I think we should donate. If someone prepared to giveit i think i should. But I am not sure donating from dead person think it is not better.(4FM)

I do not really think receiving and live donation is a problem.(5FM)

I am not sure on that one to be honest. If I am still alive or anyone still alive too, support some one who is in need you can give whilst you are alive not after you pass away, nothing at all. While living may be yes. Especially we need to educate our Asian community, because we like to take but they don't like to give. God forbid if it happens to me if I was in need of an organ, why they are like this, why they are not giving to me. I am sure everyone will be same . But when it is time to give, its not for me they will move it back. Its just the way our mentality is, to change that we need to put lot of effort, if its permissible from Islam (6MM).

This is a very difficult situation, If it's a dire need necessarily life threatening situation I would say yes, but if itsn't it's a grey area.(7MM)

Yes, I am very aware about the Asian community, that they are very reluctant to give, but when its come other way around sadly they are very quick to take on, that's when I paused to them asking if you are very so stronger against organ donation but when you are in need of transplant you are quick to run to NHS and put yourself on the organ waiting list, random persons from somewhere will have perfect organ and that organ is inside you and then you don't question. I think we have to work in harmony together has to be a good human being and to help others and to progress in our life if we can help someone else to have a good life I think that's become our duty as well.(7MM)

I have been told that you are not allowed to accept or give any organs. But in this stain age we need to move forward and I agree with organ donation. If it's your family you wouldn't give up your life would you?(10FM)

14.Policy of donation - Opt out/opt in perceptions/

I heard about it, it's kind of like part of being on the register, still it bit serious commitment given that i am not still not sure about and how I feel about. I would straight away opt out for two reasons. 1. For my beliefs 2. another reason that's too much control that the Government is having more on my body and life they have for them to opt me in . Too much control of them having on my body. To make that point I will straight away opt out. And if in case I change my mind I may opt in later. (1FH)

If there is a way of signing up in the criteria saying this age, lady with children and Asian and who appreciated life i would prefer them to have organs i have control of where my organs goes to, greater control over that i think that would help me to feel ease spiritually. I can say to the sprit that yes I am consented to that someone has not taken away from me without my permission

i have consented to take that part of my body to go to someone and I am happy with that so that means my spirit is not clinging on to that so I can move on (1FH).

To be honest the only thing it will make me sign up on the ODR is as if there is a scheme is introduced, where it is said you can decide who gets your organ, and you can name someone my partner or son that make sure that the person gets the organ and if they don't get that organ that they get compensated or something. so i have sort of some kind of control over who gets that organ and under what circumstances and there will be someone for me in place that is a promise, i am dead so i can't make sure that been fulfilled but i can name someone that the promise is fulfilled. I would suggest a blank page for the individual to put down their wishes like in my case i want to give to 20-30, has children, has come from certain background has approached life, does not drink, keeps fit. I don't want to give life to someone who wastes it basically. I would say it more widely for me not just gender and age, much more wide for me it's more about their approach to their life and where they are with their life and what they are going to do their life (1FH).

Only time will tell. I don't think earlier on i would have opted out, but now with being aware of need and what you can do to a person after you dead and gone and if you can help somebody that's what God want in this world . You are here to be a blessing if I am blessing even after my death yes i will go for it and agree with opt out (2FC)

I don't know really. Well, I am 50:50. So for example, I don't know how the system works out. If i am not sign up will they be able to take my organs, so if I opt out of it they may not. So I don't know, I never thought about. I might not object. Before, it was different, but now people believed in that.(5FM)

I heard about it. It's not fair, automatically you are getting organ donation system. But as an individual you should be aware of it what's going around you , if that does come into force and u can opt out you can say straight away, Yes I don't want to be part of it and opt out . Especially with the Asian they are very laid back and let it happen until the last minute and they will say i don't want this anymore (6MM).

If the connotation on it I will fear of it. For Eg; I don't want and I know it is the law of the country and have not opt out of it the request I made before I died if I don't want any part of my body to be removed and I should be buried and it should be that way only and that's how it should be.

Flipping the coin some people who wish to donate their organs ad how to donate.

Firstly we need to start with awareness that is the first aspect of it secondly education.

We need people to be aware about organ transplant and organ donation. There are people out there from Muslim community who will agree with organ donation from personal opinion. I would suggest it is the awareness and education We need to educate small big, male female we need to educate every single person regarding organ donation. And then afterwards choice is made organ donation. If its opt out system it will be the persons responsibility to do it whenever he pleases to do it.I wouldn't say its bad thing, from my own personal point, after the education and awareness person will have sufficient amount knowledge to decide whether he want to stay in opt out or to remain inside the system for transplant. Otherwise if it's no education and awareness then that person is already in the system and that person will start argument and then it will become extremely ugly. So I think to begin with awareness and education and then having an opt out system is perfectly fine from my personal point on one condition that person has given

two tools, education and awareness.(7MM)

I do not agree with it. Because everybody not knows about it, Due to the cultural and linguistic barriers not everybody knows that. Like my 70yrs old grandma who has not many of her family members here, they are not aware so when she goes back, as she automatically opted in, she has been opened, no I do not agree with it. I do not think you will ever be able to raise the enough awareness for everybody to know that they have been opted in and they have to be opted out. I see this with other things as well in life, simple things like benefits, I was working in the benefit system as an occupational therapist, although there is massive awareness people are still not aware. Some people take advantage about it and some people not aware. (8FM)

I agree with it, it depends people have different views. Even if it becomes a national law some people may be happy and some still not be happy. People may say why should we this is my own body I can do whatever I want. It shouldn't be national thing; everyone should have their rights.(9FM)

I am not very happy to hear about this, I did not know about this. I am not very happy to hear about bit. There must be lot of people who have not heard about it. They might have not It is something you are forced into it. I wouldn't agree with it.(10FM)

15. Live donation

Yes i believe in live organ donation. I got a relative who benefitted from organ donation, he is alive, he was about to die because he rcd an organ he is alive, he lives in Bolton, he survived and doing very well. if a family member needing one i will be a happy to receive and give one. (1 FH).

I would have second thoughts about it because of the Pain after that. I have worked in transplant unit before and i have seen son donating to father and the kidneys got rejected so both of them lost their kidneys so all that in your mind. Only when time comes you would decide on something like that.

If its something that i have to do I will do it.(2FC)

I have seen a patient receive from brothers and sisters kidney donor to them. I think they will go far as siblings and family members. So live donation is allowed.(5FM)

But while alive if any of my close family i will consider it. Yes I will be willing to a live donor to my close family.(6MM)

That would bring back situation which I wasn't put in. I will question as a scholar, we are happy to do blood transfusion, from myself to another person with same blood group, we are happily do it; I am a living body, for my personal opinion I am alive likewise if we can live with one kidney and passing it on to another person in your family saving that person's life yes I will go for it.(7MM)

Live donation, I will definitely and happily give to my family member. (8FM)

I think its something that it's very new to me, if it was my immediate family I would donate my organs as live donor. It's still very new to me; there is lot that I would need to understand risks and everything. As a person I think I would do especially if it was an immediate family even as extended family I would come forward as a live donor.(10FM)

16 Knowledge from their home country
Back home in Bangladesh also we have not heard much about it.(5FM)
Back at home in india people are not that aware,. (2FC)
17. Opinions different approaches/strategies (GPs/peer education/ SNODs/ religious leaders)
I think if there was a Hindu priest there and he has said okay to donate and it is good thing to do he (my Dad) would have said yes, but I don't know, only may by my dad was in a vulnerable stage and he looked up to like religious leaders he would have respected i don't know it's 50-50 . Because its just see the medical practioners and as much as you do see them and thank them for saving person's life and doing the good work they do. And still you think that now the body has gone now all they wanted is organs. And I think if someone like the religious leaders, make that it easier, if it happens to me it may influence my decision and make bit easier. I don't know kinds of the emotions are all over the place at that time. i think you will get more people donating if it happens in that way (1FH).
My GP never mentioned about organ donation. I will listen to the GP. GP's are always right. No they are not taking that initiative.(4FM)
If the GP's taking leading role, it is a good idea (6MM).
If we can start from somewhere where we go and see for regular symptoms, the foundation and stepping stone could be GP's for awareness and then we can take it from there.(7MM)
Religious support for SNOD,s, Yes, it would. if it's yes from Islamic point of view and the Imam preset in the distress and daunting if we have a religious scholar who you can actually lean on and comfort your self from the Islamic point , yes they will be relieved if Imam as a back bone support to make decision. if we have more and more people like hospital imams to support families can get the moral support, to make the final decision with doctors the family will be condemned, because the decision will make strong. They already know it is allowed in the Islamic perspective and there is a religious leader to support, so two in two make the decision strong. This will be a very good idea.(7MM)
GP and the local Trusts could play a role in raising awareness like smoking awreness.(8FM)
Imam with SNOD:Yes definitely, we feel more comfortable making the decision.(9FM)
18. Suggestions on how to improve current system – senior scholars etc
Speak to religious leaders and talk to them brief to them about organ donation issue. I think, Certainly our spiritual leader i don't think he is really upon the organ donation, I don't think i think he will have the same views, he is an elderly gentleman and had training in India. May be some kind of close consultation with them about their views may could they help, having some kind organ donation awareness day in religious places .In my previous work place they have the blood transfusion van. May be doing something like that. We always see in the town centre having an information stand. It is literally about informing people; even we need to challenging people about their views on organ donation. Once i sit down and talk about it you do rethink and your rationale you do overcome like the fear (1FH).
Having support from the religious person will be definitely a good idea. May be in Opt in opt out

did come into force much more details then you know spiritually what it means. If you can work very closely with them some discussion with them and raise the issue and more work in the community education. If i was more educated my dad might have changed my decision. Also experiences may be like my my Mom saw my uncle getting the benefit and it was her sisters husband so she felt it more. Mom going through the leukaemia treatment (bone marrow match) all her sisters helping out, (1FH)

Its i would suggest to speak in the language people understand, it's like if you go professionally and tell them this is what and normally if you get down to their level of understanding and tell then what happens , reality and how people are suffering thing like that i think there will be change.

It takes time any concept/change will take time for people to accept. there is any change there is resistance first. it takes time, when people understand and they will overcome resist and they will start aware of it and start donating. I haven't heard much about, i don't think media or any kind of medias has spoken about transplant and so much lately. May be more its because communication, people have really got into it. Earlier on it was like just propaganda, and it has to be given. i think people have taken more initiative to understand about it. I have heard people saying straight away negative and resistant some of them were agreeing. So i think if more of to their level understanding, if we speak and give them awareness then maybe we could take the negative away.(2FC)

So The best way is actually do an awareness to the religious leaders with the chaplain or whoever is so called religious leader in their mass media communication and Fridays prayers and let them take the lead to discuss this further quoting Fatwas relating religion, there will be definitely Fatwas related to every related aspects of life, so it will be there. If they can tell the people that this is what Allah been told and there is fatwa or Hades related to this and there is no harm in doing this. People may take on board, rather than you going and saying actually it is there. There was a discussion here on Fridays lunch time prayers, and as far as i am aware he is collecting some data, what the data will do is that it will come out with more articles and Fatwas on it, so that will completely clear my ignorance on this. This will help me to convince my parents actually that in religion it is said that we can do this way, so forget about the rest of the things, you will get my body back, they will just take my organs. But without that knowledge i will not be in a position to amend that decision on my parents. (3MM)

Probably rather than a study time a wide mass media awareness will be better than anything else. If you see in mass media, there are lot of people who are in the need of an organ people may start to think about it rather than you take me to a study day. I do not have time for it, i have to find free time, which is lacking , it's a hazzle. Probably mass media awareness it will be far better than anything else (3MM).

If you look at the charity organisation the work in here like children's charity, so often you see pictures of Somalia and Ethiopia. Which has much more influence on somebody coming and telling that there is poverty in Somalia. Then you are forced to give something, because you have seen the pictures there, people are struggling. Probably that will be the best way, as far as I am concerned, my perspective. Rather than study day, mass media communication you are showing people who are suffering with kidney failure and if you showing youngsters suffering with heart disease and they are waiting for heart, that probably would have created much more awareness and sympathy for myself. I think organ donation has much to do with awareness and sympathy than anything else. Then you know actually there is a human being suffering there and he may leave with my heart if i am dead. You cannot educate the people, It is awareness. It is the

awareness not the education. Other option is that with strong religious leader's organ donation team can produce the leaflet with this religious guidance and that should be authenticated. So the literate can read it.(3MM)

I think they need to be more aware of this. If we can do leaflets in different languages, they will be able to read it, and see that. They think that they will cut you up and that's it they will take your kidney off, i think this is the image they are getting of it. If they know how and when is it done and especially the belief of it, i think lot of people might come forward especially the youngsters they probably will come forward. I have not heard much about, Not really during my education. I remember like we use to get a little card you could sign it and then you could be a donor, otherwise as i said this is something which is least spoken about, nobody talks about it , unless it happens to you or your family and you realise, it's not something people talk about (5FM).

Also when it come to education We need to show two sides of the story , one to into giving, and you have to put it say if in my case if you are in need, what would you think, think in that, may be psychological way, may be it work, i don't know its an option (6MM).

I think it should be like awareness should be more, from the school it should be more part of curriculum like anything else I think for eg; smoking and stuff. (8FM)

Suggestions: Just carry on what you are doing; giving your views out to everybody has their own views about organ donation. And working hard towards it and May be getting the community together to talk about it. (9FM)

I think its more about educating people I believe anyway. Education, school, university, advertisement, I found lot of information just from tv commercials like on stroke and what kind of signs to look out for meningitis. What kind of signs to look out for kidney donation May be do an advert and let the people know the benefits of live donation (10FM)

Appendix 11 ASIAN FAMILY INFORMATION BOOKLET



Central Manchester University Hospitals 
NHS Foundation Trust



What is organ donation?

Organ donation is the gift of an organ to help someone who needs a transplant. The generosity of donors and their families enables over 3,000 people in the UK every year to take on a new lease of life.

More info: www.southasianorgandonor.org.uk Or www.organdonation.nhs.uk

Or contact Agimol Pradeep, Transplant Recipient Co-ordinator Telephone: (0161) 901 2531, Mobile: 07825 142 221 , Pager: 07659 521 453 Email: agimol.pradeep@cmft.nhs.uk

Why are even more donors needed from the Asian community?

Every day three people die while waiting for an organ transplant and many others lose their lives, before they even get onto the transplant list. There is a serious shortage of organs and the gap between the number of organs donated and the number of people waiting for a transplant is increasing. This situation is worst among Asians living in UK.

Asian people living in the UK are three times more likely to need an organ transplant than the general population. This is because these communities are more susceptible to illnesses such as diabetes, kidney and heart disease which may result in organ failure.

Donated organs need to be carefully matched to the recipient to ensure blood and tissue groups are compatible. An organ is more likely to be a close match and a transplant much more likely to be successful, if the donor and recipient have the same ethnic origin.

Unfortunately, while there is an urgent need for donor organs from the Asian community, less than 2% of those on the NHS Organ Donor Register are Asian. This drastically reduces the chances of finding a successful match. It also means Asian people generally have to wait longer than a white person for a kidney transplant.

How does the medical team know your loved one has really died?

Organs are only removed for transplantation after a person has died. Death is confirmed by doctors at consultant level who are entirely independent of the transplant team. Death is confirmed in exactly the same way for people who donate organs as for those who do not.

Most organ donors are patients who die as a result of a brain haemorrhage, severe head injury, or stroke and who are on a life support machine in a hospital intensive care unit. In these circumstances, death is diagnosed by brain stem tests. There are very clear and strict standards and procedures for doing these tests and they are always performed by two experienced doctors.

The ventilator provides oxygen which keeps the heart beating and blood circulating after death. These donors are called heart beating donors. Organs such as hearts, which deteriorate very quickly without an oxygen supply, are usually only donated by a heart beating donor. Patients who die in hospital but are not on a ventilator can, in some circumstances, donate their kidneys and other organs. They are called non-heart beating donors.

Can I be sure doctors will try to save my loved ones life if I agree for donation?

Health professionals have a duty of care to try and save life first. If, despite their efforts, the patient dies, organ and tissue donation can then be considered and a completely different team of donation and transplant specialists would be called in.

Can you be kept alive with machines?

If brain stem death has been confirmed machines cannot keep you alive. In these cases a ventilator will keep the body supplied with oxygen and this means the heart will continue to beat and circulate blood. This preserves the organs so they can be donated for transplant. When the ventilator is turned off the heart will stop beating within a few minutes.

Does donation leave the body disfigured?

Organs and tissue are always removed with the greatest of care and respect. This takes place in a normal operating theatre under sterile conditions by specialist doctors. Afterwards the surgical incision is carefully closed and covered by a dressing in the normal way. Only those organs and tissue specified by the donor or their family will be removed.

Is it possible for family to see the body after donation?

Families are given the opportunity to spend time with their loved one after the operation if they wish, facilitated by the specialist nurse. Arrangements for viewing the body after donation are the same as after any death.

Does being a donor cause delays to funeral arrangements?

The donation operation is performed as soon as possible after death, causing no delay to funeral arrangements.

Are there religious objections to organ and tissue donation?

None of the major religions in the UK object to organ and tissue donation and transplantation. If you have any doubts, you should discuss them with your spiritual or religious adviser

Islam

One of the fundamental purposes of Islamic law is the preservation of life. Allah greatly rewards those who save the lives of others.

‘Whosoever saves the life of one person it would be as if he saved the life of all mankind’. Holy Qur’an, chapter 5:32

In 1995, the UK based Muslim Law (Shariah) Council resolved that: the medical profession is the proper authority to define signs of death. Current medical knowledge considers brain stem death to be a proper definition of death. The Council, on the basis of the rules of the Shariah, accepts brain stem death as constituting the end of life for the purpose of organ transplantation and supports transplantation as a means of alleviating pain or saving life.

The person’s next of kin, in the absence of a donor card or an expressed wish to donate their organs, may give permission to obtain organs from the body to save other people’s lives and this must be given freely without reward, trading in organs is prohibited.

This is supported by Muslim scholars from some of the most prestigious academies of the Muslim world, such as: The Islamic Fiqh Academy of the Organisation of Islamic Conference (representing all Muslim countries), The Grand Ulema Council of Saudi Arabia, The Iranian Religious Authority, and The Al-Azhar Academy of Egypt; who call upon Muslims to donate organs for transplantation.

Hindu Dharma

There are many references that support the concept of organ donation in Hindu scriptures. Daan is the original word in Sanskrit for donation meaning selfless giving. In the list of the ten Niyamas (virtuous acts) Daan comes third. The law of Karma decides which way the soul will go in the next life. The Bhagavad Gita describes the mortal body and the immortal soul in a simple way like the relationship of clothes to a body:

‘As a person puts on new garments giving up the old ones the soul similarly accepts new material bodies giving up the old and useless ones’. Bhagavad Gita chapter 2:22.

Sikhism

The Sikh philosophy and teachings place great emphasis on the importance of giving and putting others before oneself.

‘Where self exists, there is no God. Where God exists, there is no self’. Guru Nanak, (founder of Sikh faith, and first of ten Gurus) Guru Granth Sahib (Sikh Holy Scripture)

Appendix 12 MEDIA IMPACTS AND REPORTS

ITV IMPACT REPORT

Hi Agimol,

Just thought you might be interested to see the results of our From the Heart Campaign which you so kindly helped us with. As you can see from the figures released from NHSBT, it was a huge success. And particularly gratifying is the fact that the Granada region had the biggest impact (outside of the channel islands). Thanks again for helping to facilitate the filming, Kind regards, Mel. Mel Barham | Reporter/Presenter | Broadcast | **ITV plc** Tel: 07825 281142 | Mel.Barham@ITV.com

Please see below the links of the articles and videos, more can be seen on my study website

http://www.youtube.com/watch?v=S_ScbQXPP4Q Sangham TV

<http://www.kidneysforlife.org/nurse-education/agimol-pradeep-msc/>

<http://www.youtube.com/watch?v=xMW4vMdS75U> Interview in Malayalam

<http://www.britishsouthindians.co.uk/agimol-pradeep-best-nurse-2013-by-british-malayali/>

<http://southasianorgandonor.org.uk/>

[South Asian Organ Donation: VIDEO](#)

<http://vimeo.com/59574631> <http://vimeo.com/59742620>

<http://www.itv.com/news/granada/2013-02-13/from-the-heart-shortage-of-ethnic-minorities-on-the-donor-list/>

<http://public.ukcrn.org.uk/search/StudyDetail.aspx?StudyID=13095>

<http://www.salford.ac.uk/chsc/about/nursing-midwifery-and-social-work-news/award-for-nurses-contribution-to-organ-donation>

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<http://www.cmft.nhs.uk/media-centre/latest-news/our-transplant-coordinator-voted-best-nurse.aspx>

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Appendix 13 LETTER FROM FR. DAVIES



KIDNEY FEDERATION OF INDIA

01 Oct 2014

Ref:

To whom it may concern

Date:

It is quite common to see students pursuing their passion for studies, achieving higher and higher educational diplomas, degrees and doctorates. But it is difficult to see someone who undertakes studies for the benefit of common man or the public.

I have often dreamt of a global family of organ donors, a family nurtured in altruism which transcends caste, creed and colour and to realise this, I conduct retreats, talks, seminars and symposiums in different countries. This is how I encountered Agimol Pradeep, who was compelled to find out why the South Asians in UK waited more than the Caucasians for a Kidney transplant, what barriers were out there and what can be done. Such a query, resulted in her undertaking her PhD and she started her campaign to enlist South Asians on the organ donor register.

I was overwhelmed by her passion, sincerity and genuineness to improve the plight of the South Asian Kidney patients, to improve transplant rate and to increase the number of organ donors. It is no wonder to me that she was able to register nearly 3000 Asian donors with her three year study, a fact collaborated by the chair of the NHSBT. Moreover, since the start of the study from no deceased Asian organ donor to 3 Asian deceased donors from the North West region. Her campaign extended to stem cell donor recruitment as well.

Again it is not a wonder that her initiative was contagious and people from the South Asian community sought her out to request her to give talks, clarify their doubts and dispel the prevailing myths about organ donation. Media – television, newspapers and radio - welcomed her talks and interviews. With no financial or time incentives for her campaign, she rallied from North to South, from East to West, to increase awareness of organ donation. It also had an international impact, with her giving talks to Schools of Nursing in India and appearing for interviews in leading newspapers and magazines in India.

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I was able to follow her in her campaigns and gain an undertaking of how the system worked in UK with intention of incorporating best practices in my campaigns in India. Her networking and influential relationships helped to forge relationships, form partnerships and foster community engagement. Joining hands with her in her endeavor, I was able to witness the passion and devoutness with which she organised events; her enthusiasm was contagious and inspiring. The real outstanding achievement for the submission of Proposal to the Chief Minister of Kerala to develop a Government lead deceased organ donation programme in Kerala to assist me in developing an infrastructure for deceased organ donation programme.

To see her effectively juggle work, family life, studies and her campaigns without compromising any aspect of her life was remarkable and evident in the strong support she received from her family, feedback received from her supervisors and examiners regarding her studies and the acknowledgment of her leadership qualities from her employers. She was nominated NHS North West Leadership Academy Recognition Awards. This I believe, could be because of her information leaflets specifically targeted at the ethnic groups and her educational package for Specialist Nurses working in organ donation on how to approach ethnic families to gain consent for organ donation.

Her dedication served as a stimulant to my campaigns in India and abroad and it was a privilege to meet such a person like Agimol Pradeep, toiling for the common good. I have no doubt her study has influenced and touched many and will continue to do so as the ripples started will continue to enlarge and cover the entire ocean of humanity. Along with offering her thanks her for all her efforts and help, I wish her all the best for her study.

Thanking you,

Yours faithfully,

Fr. Davis Chiramel - Chairman

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