Title   Examining Relationships Between Deceased Organ Donations, Gift Exchange Theory and Religion

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EXAMINING RELATIONSHIPS BETWEEN DECEASED ORGAN DONATION, GIFT EXCHANGE THEORY AND RELIGION: PERSPECTIVES OF LUTON POLONIA

By

Chloe Sharp

A thesis submitted to the University of Bedfordshire, in partial fulfilment of the requirements of the degree of Doctor of Philosophy

September 2012
'You have never really lived until you have done something for someone who can never repay you.' (Unknown)
GLOSSARY

Donation after Brain-Stem Death (DBD) - the recovery of organs for transplantation after 'death following the irreversible cessation of brain-stem function' (A Code of Practice for the Diagnosis and Confirmation of Death, 2008, p.11).

Deceased Organ Donation – organs can be removed, if someone has pledged their wish and relatives have consented to this. The organs that can be removed after death for transplantation are organs including heart, lungs, liver, kidneys, small bowel and pancreas and tissues including skin, bone and corneas. Organs that can be removed after death for research are the brain, tissue, organs including those above and the large bowel, bladder and prostate. Organ donation is independent from tissue donation in the case of this study.

Donation after Circulatory Death (DCD) – describes the recovery of organs for the purposes of transplantation after 'death following cessation of cardio-respiratory function' (A Code of Practice for the Diagnosis and Confirmation of Death, 2008, p.11).

DVLA - The UK driver and vehicle licensing agency responsible for holding up-to-date records for drivers and vehicles.

End-Stage Renal Failure (ESRT) - kidneys can no longer function at a level for everyday life.

Human Tissue Act (1961, 2004) – this Act regulates the removal, storage and use of organs and tissue, outlines the remit for the Human Tissue Authority, regulates other aspects such as licensing, codes of practice and trafficking.

Human Tissue Authority – a UK non-departmental public body that regulates the removal, use and disposal of human organs, tissues and bodies for uses such as medical research and transplantation.
Living Donation – reference to kidney donation, the kidney is removed from a healthy living person and transplanted into another living person who may have ESRT. Other bodily materials that can be removed when living are blood, liver lobes, stem cells, eggs and sperm for research and forms of treatment.

Migrant – an individual who moves from one country to live in another, for a number of reasons including political, economic or to change one’s surroundings by choice.

National Health Service (NHS) – the UK’s free healthcare system which is funded by the government.

NHS Blood and Transplant (NHSBT) – a health authority that is responsible for the optimal supply of blood, organs, plasma and tissues and the quality and effectiveness blood and transplant services.

NHS Organ Donation Taskforce – identifies the barriers to organ donation and has recommended actions to improve organ donation rates within the legal framework.

Nuffield Council of Bioethics – examines ethical questions around medical research and developments in medicine and biology.

Opt-in System – individuals register their wish to become an organ donor.

Opt-out System/Presumed consent – individuals register their objection to being an organ donor.

Organ Donation – the removal of organs from an individual who has died or who is living for transplantation purposes, for example, kidney, heart and lungs. This is different from tissue donation where tissue is removed that includes cornea, skin, bone and heart valves.

Organ Donor Register (ODR) – this is where details are stored where someone has pledged to be a donor after death. A person can sign up to the organ donor
register via the organ donation website, Boots Advantage card, GP registration and DVLA applications.

**Persistent Vegetative State (PVS)** - 'Someone in a PVS can show signs of wakefulness...but have no responses to their surroundings.' (NHS Choices, 2012)

**Pole** - A Polish man or women.

**Poltransplant** - in Poland, this organisation is under the authority of the Minister of Health and is responsible for collecting and storing organs, cells and tissue, similar to that of NHSBT.

**Wielka Orkiestra Swiatecznej Pomocy** – an established Polish charity where money is raised annually in Poland, around January, for hospital equipment.

**United Kingdom Transplant (UKT)** – is the Directorate of NHS Blood and Transplant.
EXAMINING RELATIONSHIPS BETWEEN DECEASED ORGAN DONATION, GIFT EXCHANGE THEORY AND RELIGION: PERSPECTIVES OF LUTON POLONIA

ABSTRACT

Currently there is a critical shortage of transplantable organs in the UK. The existing evidence base highlights that cultural and religious norms can hinder familial consent and uptake of registration as an organ donor, particularly within ethnic minority groups. There is a dearth of information relating to the Polish community in the UK. Since the expansion of the European Union and the potential and consequent economic migration of Poles to the UK, this community presents a potential significant contribution to the active transplant waiting list, NHS Organ Donor Register and requests made for organs for donation on behalf of a relative.

The aim of the study was to examine in depth, the perceptions of the relationship between deceased organ donation, gift exchange and religion. Due to the exploratory nature of the study, grounded theory methodology was used and one to one interviews were carried out with 31 participants who were recruited using a purposive convenience sampling strategy. This approach allowed for the collection of rich and deep data in a hitherto under-researched issue with the Polish community in the UK.

To contextualise the key findings of the relationship, an in-depth analysis of settlement patterns, helping behaviour and experiences of and attitudes toward religion was conducted. The relationship between religion and gift-exchange was perceived to interact in different ways with deceased organ donation depending on the context. For the individual making an end-of-life choice, gift exchange impacted on the perception of the organ as a gift and whether reciprocity was expected, religion shaped views of the need for the body after death and social and cultural norms influenced the view of the 'typical' donor and family discussion of donation. For the relatives, social, religious and cultural norms impacted on death rituals and the conceptualisation of the dead body and experiences of a relative's death.

This study contributes to an understanding of the social, cultural and religious norms toward deceased organ donation from a Polish perspective and the implications for policy, health promotion and clinical practice.
AUTHOR'S DECLARATION

I declare that this thesis is my own unaided work. It is being submitted for the degree of Doctor of Philosophy at the University of Bedfordshire.

It has not been submitted before for any degree or examination in any other University.

Name of candidate: Chloe Sharp

Signature: C. Sharp

Date: 21 September 2012
DEDICATION

I wish to dedicate this work to my parents, who have always believed in me and to my husband, Simon who has helped me emotionally and financially through my PhD, I really could not have done this without him. Shortly after finishing my PhD, Simon and I welcomed our daughter Emma to the world.
ACKNOWLEDGEMENTS

I am indebted to the Polish community in Luton and Dunstable for all of their help, time and support, in particular Polska Szkola w Luton-Dunstable (Polish Saturday Community School), the priests and congregation at Polska Parafia Luton i Dunstable (Polish Catholic Church) and the adjoining Mother and Toddler group.

To all of the participants in this study, I appreciate you giving up your time as this study would not have been possible without you.

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CHAPTER ONE: SETTING THE SCENE

1.1 Introduction

This chapter presents a brief background to the study and the purpose of the research. Initially the research problem and rationale for the research will be explained. Following this, a research question is posed and to answer this question, aims and objectives are stated.

1.2 The Research Problem and Rationale

I became involved in this study through a three year PhD studentship joint funded by NHS Blood and Transplant and the University of Bedfordshire. Before I embarked on this journey, I had worked and studied across human resource management, pedagogy and health. Through the University of Bedfordshire, I had completed my BSc (Hons), PGCE and Masters in Psychological Approaches to Health and Management. My Masters dissertation had investigated the lay representations of young people from Central and Eastern Europe towards HIV/AIDS.

This thesis occurred at a time where there were debates surrounding organ donation as a 'gift' due to a potential change in policy to presumed consent and research from the Nuffield Council of Bioethics that had found that the public were willing to accept funeral costs (2011b). These questions were being considered due to the wide gap between the supply and the demand for organs. To address this gap, previous research (i.e. Exley et al., 1996; Hayward and Madill, 2003) had explored the views of Black African, Black Caribbean and South Asian communities across the UK to examine the attitudes towards donation. Within these studies, it had been found that religion often played a contradictory role. It was believed to encourage donating after death as a form of helping others, but these beliefs were juxtaposed with the perceptions that religion discouraged organ donation, based on definitions of brain stem death and the need for the body in the
afterlife. In a similar vein, religion advocates helping others and from a policy and historical stance, deceased organ donation is couched in gift rhetoric, promoting organ donation as a 'gift' and the 'gift of life' (Department of Health, 2011; Nuffield Council on Bioethics, 2011; NHSBT, 2013).

With this gap in the literature in mind, this thesis examined the perceived relationships between deceased organ donation, gift exchange theory and religion from a viewpoint of the Polish community in Luton. This relatively new and growing ethnic minority group’s perspective has been underrepresented in the literature. At this point, it is noted that from an essentialist perspective in terms of ethnicity, the use of a ‘Polish perspective’ can be problematic. Based on the essentialist view, where ‘everyone experiences the world in substantially the same way; but everyone’s subjective knowledge about the world is socially derived’ (Pfeffer, 1998, webpage). People from Poland, therefore, from an essentialist view belong to this social group, where there is a sharing of the ‘essence’ of Polishness that is fixed and stable. However, it may be argued that the Poles who are living in Luton and Dunstable are a heterogeneous group whose identities are dynamic in their interaction with gender, religion and culture.

The ‘research problem’ which is the basis of this thesis, is how deceased organ donation, gift exchange theory and religion were perceived to interact from a Polish perspective. This problem was examined for a number of reasons, firstly, little was known about the Polish migrant views toward deceased organ donation, gift giving and religion as individual components or how they connect with each other. The views of the Polish community in the UK should be represented because since the European Union (EU) enlargement in 2004, the Polish community in Luton has grown as reported in Luton Council statistics, the local media and national
academic literature plus there are signs that Poles are settling in the Luton and Dunstable area. In addition, there are known health issues among this group, which are alcoholism, substance misuse and hypertension (Mills & Knight, 2010; Kreft, 2010; Coakley, 2011) leading to a possible increase on the demand for liver, heart and lung transplants. As Rios et al. (2009) found in their study of East Europeans' migrants in Southern Spain attitudes toward living donation that the increase in migrants could lead to a higher number of non-natives on transplant waiting lists and non-native families being requested to consent to organ donation. This could be applied to the UK, however there is no data available to show the demand that Polish migrants are putting onto the transplant list and the number of Polish families are being approached for organ donor requests.

Secondly, although the relationships between deceased organ donation, gift exchange and religion had been briefly explored in the literature (i.e. Randhawa, 1998; Al-Khawari et al. 2005), an in-depth approach has not been taken of all three. In previous literature, it had been found that among ethnic minorities in the UK, mainly among the South Asian, Black African and Black Caribbean population, religion could have an impact on views towards donation (i.e. Sheikh and Dhami, 2000; Morgan et al. 2010). However, this finding had been the outcome of a number of studies that explored views toward organ donation where religion was found to be a factor in the findings. Religion was not fully investigated thus providing a limited and facile, but indicative view on the role of religion in donation. These points will be discussed in the literature review in more detail.

Thirdly, the relationships that had been examined in more detail in the literature were gift exchange in relation to official textual religion advocating helping others, such as Bible or Qur'an passages in relation to organ donation. There has not been previous research that had
investigated all aspects together, to identify how religion, deceased organ donation and gift-exchange theory may all connect.

1.3 Research Question

To explore this research problem in further detail, the following research question was asked - 'How do the Polish migrant community in the UK perceive the relationship between deceased organ donation, gift exchange and religion?'

1.4 Aim

To explore the relationship between deceased organ donation, gift exchange and religion in the context of the Polish migrant community in Luton.

OBJECTIVES

- To describe knowledge and attitudes toward deceased organ donation.

- To examine the role of gift exchange theory in deceased organ donation.

- To identify social, cultural and religious factors in deceased organ donation.

1.5 The Structure of the Thesis

In the second chapter, a wide and extensive literature review aimed to understand the current debates around donation and transplantation, attitudes toward deceased organ donation within the Black and Minority Ethnic (BAME) community in the UK and the strategies that NHSBT have taken to engage the public, in particular ethnic minorities. To try to engage the general public, NHSBT used the metaphor 'gift of life' and terming the
organ as a form of 'gift' has led to debate through the lens of Mauss's gift exchange theory.

There are a number of gift theories but the key element to Mauss's theory is reciprocity, this is examined in closer detail. Reciprocity is problematic in deceased organ donation as the donor is deceased and the donor family provided consent for the transplantation to occur. At this point, altruism and social capital were introduced to better understand reciprocity in deceased organ donation. Altruism advocates no reciprocity and the possibility of donating for purely altruistic reasons are discussed. Social capital lends itself to the argument as it builds upon social exchange theories where reciprocity can have wider benefits to society in the form of social solidarity where active members of society are civically engaged to help the 'common good'.

In the context of the BAME community in the UK, one of the biggest barriers to deceased organ donation is religion. The literature review examines religion and religiosity to better understand the reasons behind religion discouraging donation. Here, religion is viewed as a social and cultural phenomenon to investigate the role that they play in shaping how Polish migrants perceive donation.

The third chapter details the methodological framework for the study. The literature review illustrated that there was little research that had focussed on gift exchange and religion in relation to deceased organ donation as religion had been found as an outcome when investigating attitudes toward donation. With this in mind, a richer understanding of these issues was sought and a qualitative approach was taken to address this. Grounded theory methodology was used due to the exploratory and qualitative nature of the study. To arrive at a deepened understanding of the way in which grounded theory was used, a framework by Crotty (1998) provided guidance on the epistemological and ontological philosophies and
theoretical perspective that underpin this methodology. Following this discussion are details of the data collection including the interview guide, sampling technique, recruitment strategy, coding and analysis and ethical issues.

Following this discussion are details of the data collection including the interview guide, sampling technique, recruitment strategy, coding and analysis and ethical issues.

The proceeding chapters show the findings and an analysis of these data in relation to the literature. Chapter four outlines the findings of the study: settlement of Poles in Luton and Dunstable, their views toward altruism and giving to others, experiences and views toward religion, how giving to others and religion interact, attitudes toward deceased organ donation for the self, pre-death and post-death, where the family make decisions about donation and finally, the role of social capital. The penultimate chapter, chapter five analyses these data in the context of past literature on and discusses the descriptive conceptual map that was developed through data collection.

The key finding that informed the conceptual map is perceived relationships are context bound. Relationships between deceased organ donation, gift exchange theory and religion differed when an individual was considering donation after death for the self to when a family were deciding upon donation for a relative. The final chapter, chapter six summarises and concludes the thesis where there is an outline of the contribution to the field, limitations of the study, suggestions for policy and future research.
CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

A Straussian constructivist grounded theory methodology was used for the study and this allowed me to conduct a literature review prior to conducting the fieldwork and will be expanded upon in more detail in the methodology chapter.

This chapter is going to provide an overview of the debates within the literature within the field of deceased organ donation, a theoretical account of Mauss’s gift exchange theory and how it is applied to deceased organ donation and a social constructionist view of religion. In addition to these concepts, social exchange theory, social capital and altruism are examined beside gift exchange theory to deeper analyse the role of the gift and reciprocity in deceased organ donation and its social implications. Alongside religion, religiosity is going to be explored as this provides an insight into individual experiences of religion parallel to religion on a macro level. These will be examined individually and together as follows; gift exchange theory, altruism and social capital and religion; deceased organ donation, religion and religiosity and deceased organ donation and gift exchange theory.

2.2 Conducting the Literature Review

The literature for this PhD was accessed through the search engines PubMed, Science Direct, SCOPUS, EBSCOHost and Google Scholar, plus the Open University, British Library, Cambridge University, London School of Economics and the University of Bedfordshire libraries. I used a number of key word combinations in my searches across these sources such as ‘deceased organ donation and religiosity’ and regularly conducted searches throughout the PhD to ensure I kept abreast of recent literature. I also referred to reference lists at the end of books and journal articles,
published in reputable journals and most commonly cited literature in and outside of the UK. I felt my search was thorough and I developed an IT-based system that helped me organise the hundreds of books and articles that I had catalogued and read and I wrote an article to help other PhD students (Sharp, 2011).

I read widely across each topic area, which led to a deep understanding of the theoretical aspects. I could critically read the literature as I had read around the philosophical standpoint the author was coming from to evaluate how their research or theoretical perspective could contribute to the literature review. When looking at the relationships between deceased organ donation, gift exchange and religion in the literature search, exclusion and inclusion criteria were applied to ensure that the literature was relevant. For example, when exploring religion and deceased organ donation, I applied inclusion and exclusion criteria and focussed on ethnic minority groups in the UK as the study was being conducted in the UK. In addition, I excluded other concepts that related to religion in my search such as spirituality as I focused on religiosity and religion.

Across the literature, there was a mix of qualitative and quantitative studies and I took this into account when drawing upon the research. For example, some studies had assessed attitudes toward donation through questionnaires, the benefit of this method is that a high number of participants can take part however, pre-determined questions can limit the depth of the research and the conclusions that are drawn from the results.

Overall, I felt that this literature review was conducted systematically and comprehensively, I read a wide range of literature and successfully kept track of this that informed future reading as I could easily identify gaps. However I am aware that there may be limitations to this literature review as I do not have a background in medicine, anthropology or sociology.
2.3 Deceased Organ Donation

A Nuffield Council on Bioethics (2011a) information booklet illustrated that for deceased organ donation, the brain, bladder, large bowel and prostate are used for research purposes. For treatment, corneas, skin and bone can be recovered and for transplantation purposes organs including heart; lungs; liver; pancreas; small bowel and kidneys are used. For the purposes of this study, the solid organs recovered for transplantation were the focus of the study.

DECEASED ORGAN DONATION PATHWAYS

Organs have generally come from Donors after Brain stem Death (DBD) where patients have died according to neurological criteria, set out by the Academy of Royal Colleges in their publication 'A Code of Practice for the Diagnosis and Confirmation of Death' (2008). There are tests to determine brain stem death and these tests must be carried out by two doctors who have been practising for more than five years plus one of the doctors must be a consultant. The tests include satisfying criteria that the causes of death are irreversible and examination of brain stem function which includes the pupils' reaction to light, corneal reflexes and cough reflexes where there is no reaction (A Code of Practice for the Diagnosis and Confirmation of Death, 2008).

Brain stem death was accepted as a diagnosis of death in 1976 in the UK however there have been issues in relation to the acceptance of brain death in some countries as a definition of death, such as in Japan, which may have influenced the progression of transplantation. In Israel, brain death is only accepted with the use of electronic equipment is used as opposed to reliance on doctors, as decided upon after a rabbinical debate in 2008 (Shtrauchler, 2009). In 2011, debate sparked again after the death of a famous football player in Israel, where it was concluded that death
was defined as the cessation of breathing but did not include the continuation of breathing on a respirator, this was considered a ‘breakthrough decision’ (Lev, 2011, webpage).

The DBD pathway as a source of donation is well established, but high survival rates in road traffic accidents, improved facilities in Intensive Care Units (ICU) (Buckley, 2000) and in neuro-surgical medicine have had an impact on the number of DBD donors available. The second source of donors, which is less established, is Donation after Circulatory Death (DCD). DCD is certified when 'the individual meets the criteria for not attempting cardiopulmonary resuscitation, attempts at cardiopulmonary resuscitation have failed and treatment aimed at sustaining life has been withdrawn because it is not in the patient's best interests' (Academy of Royal Colleges, 2008, p.2). The person is observed for five minutes for absence of cardiac function through an 'absence of central pulse on palpation', 'absence of heart sounds on auscultation', 'a systole on an ECG monitor', 'absence of pulsatile flow using direct intra-arterial pressure monitoring' and 'absence of contractile activity using echocardiography' (Academy of Royal Colleges, 2008, p.2).

CURRENT DEBATES

Organ donation and transplantation may be seen as controversial topics but it is an area that is relatively new as transplants only began in the 1950s and 1960s and is an area that is developing. Both sources of donors, DCD and DBD, carry their own ethical and moral issues, but the current debates in transplantation are whether elective ventilation should be used (BMA, 2012; Meikle, 2012), legal issues of non-heart beating donation and heart donation (Department of Health, 2009) and providing the public the opportunity to give informed consent (Meikle, 2012).
Currently, there is a high demand for solid organs for the purposes of transplantation and the Organ Donation Taskforce (ODT) report (2008) outlined that the UK has one of the lowest rates of organ donation in the developed world, meaning that many people die whilst on the waiting list. The need for organs for transplantation in the UK is growing due to an ageing population and the potential increase of Type 2 Diabetes, as this disease progresses can lead to End Stage Renal Failure (ESRF) that is treated by dialysis or a kidney transplant. There are over 10,000 people in the UK waiting for a transplant and three a day will die waiting as there are not enough organs available (Organ Donation online, 2012b). Ninety percent of the UK population agree with organ donation in principle, but only 29% of the population are on the NHS Organ donor register (ODR), although this number is rising (NHSBT, 2011). Sixty five per cent of the population said that they would be willing to donate, but 40% fail to register their wishes to donate on the ODR (NHSBT, 2009).

**Incentives and Reciprocity in Organ Donation**

Initiatives to increase organ donation registrations have been widely debated, such as donation to charity (Hippen, 2009; Omar, 2011), individuals receiving tax credits (Peterson and Lippert-Rasmussen, 2011; Quigley, 2012) and families being paid for organs, based on there being a black market which could be legalised (Harris, 2003; Radcliffe-Richards *et al.* 2003; Radcliffe-Richards, 2003, 2008, 2012). Transplant tourism, where organs are bought on the black market or travelling abroad to receive an organ transplant, may have become alternatives for those waiting on long lists for a transplant. However, Scheper-Hughes (2000, 2007) and Scheper-Hughes and Wacquant (2003) criticised paid donation as a policy, suggesting that it commoditised body parts, contributing to inequality as the poor would give to the rich, women would give to men and the Third World would give to the First World. In addition to equality, market
systems have also been criticised for destroying the sense of community (Parry and Bloch, 1991) and being unethically feasible (Ross, 2009).

The Nuffield Council on Bioethics (2011d) recently created an intervention ladder based on altruism and non-altruism motivations where altruistic motivations may be increased through education and receiving gratitude and non-altruistic motivations are met through receiving financial benefits. Being paid for organs is a policy that exists in Iran as individuals are able to sell their kidneys and personally meet the recipient of their kidneys to negotiate a price, contributing to closing the gap between supply and demand of organs (Major, 2008). This comes at a cost to the donor who may benefit from the money earned but it may not be enough to cover short-term financial problems. Recipient families may also try to negotiate prices down as they also have to meet the costs for medication for the patient (Ghods and Savaj, 2006). Goodwin (2006) argues for a mixed strategy, for altruistic living donation and a market-based deceased organ donation approach. She believes that having a mixed approach would help build a sense of community as well as providing incentives to donate posthumously.

'Nudges' and Presumed Consent

Recently, it could be argued that there is beginning to be a shift away from altruism, not only in the literature but by policy makers, due to the implementation of ‘nudging’ people to donate, the consideration of incentives to donate in the form of funeral expenses from the Nuffield Council on Bioethics (2011b) and the debate around presumed consent in Wales, one of the constituent countries of the United Kingdom.

The government introduced ‘nudges’ as recommended by behavioural economists (Thaler and Sunstein, 2008). Thaler and Sunstein (2008) argued that communities can be created online where organ donation is
supported in this virtual environment, in turn ‘nudging’ others to become donors. Currently, this ‘nudge’ encourages people to make a mandated choice about donation when registering with the DVLA for a driving licence, an initiative that already exists in the USA. The existence of nudges are contested by Whyte et al. (2012) who argue they are not taking into account individual perceptions of meaning that can influence the individual’s responses to nudges. Moseley and Stoker (2010) stated that ‘nudges’ do influence civic behaviour as there is the notion that often individuals do not make decisions due to procrastination. Where there has been discussion that has not facilitated about organ donation, there was little difference in views. They purported from a paternalistic perspective, the state should be helping individuals to make decisions through discussion and educating the public and not in the form of these prompts.

At the time of this study, Wales was currently consulting upon the introduction of a presumed consent policy. Presumed consent has been argued to be a favoured alternative to the current opting-in policy by Adabie and Gay (2005). Currently, there are moral and ethical issues that have been raised by religious leaders in Wales who disagree with this policy about presumed consent (BBC news, 2012a). This is also supported by Randhawa et al.’s (2010a) findings that religious leaders generally have concerns about opting-in policy and generally support opting-in policy.

By assuming that everybody is a donor, unless a person ‘opts-out’, presumed consent is argued to take away the ‘gift’ and altruistic element of donating organs (BBC news, 2012a) as the individual is permitting the state to over-ride autonomous rights (Godbout, 1998). The Human Tissue Authority stated that the family has no right of veto over the wish of the recently deceased person. However, in practice, the families are always asked for consent and do, in effect, have right of veto over the individual’s wish or the state’s (Randhawa, 2011). Having a presumed consent policy
would therefore not deal with the current issue of low levels of family consent.

**Engaging the Public**

There were a number of key themes overall in the literature internationally linking with barriers to organ donation these were: lack of knowledge about organ donation (Basu et al. 1989; Shanteau and Harris, 1992; Martinelli, 1993; Radecki and Jackard, 1997, 1999; Morgan and Miller, 2001; Rumsey et al. 2003; Sanner, 2006); lack of knowledge of brain stem death (Gillman, 1999; DuBois and Anderson, 2006); lack of family discussion (Sanner, 1994; Verble and Worth, 2000; Blok, 2006); lack of trust in medical professionals (Cleveland and Johnson, 1970; Sanner, 2006); death anxiety (Kastenbaum and Aisenberg, 1976; Parisi and Katz, 1986; Pham and Spigner, 2004; Sanner, 2006); and the negative influence of stories in the media (Gross et al., 2001; Lauri and Lauri, 2005; Feeley and Vincent, 2007). One of the largest barriers in deceased organ donation is family consent.

Family decisions are complex and there are four significant factors according to Payne et al. (2004) who drew upon the work of Sque et al (2003) and Sque’s (1996) model of conflict. Sque and colleagues suggested that the factors influencing organ donation are: knowledge of the donor’s wishes; family’s view of death and donation; giving meaning to death and negative or positive hospital experiences. The UKT National Potential Donor Audit (PDA) found that between 2007 and 2008, 40% of families refused consent for their deceased relative’s organs to be donated and within Black, Asian and Minority Ethnic (BAME) communities, this level of family refusal was higher and stood at 70% (PDA, 2008).

The BAME in the UK population currently represents a high proportion of those on the transplant waiting list but are under-represented on the ODR.
South Asian, Black African and Black Caribbean individuals are three to four times more likely than British White people to develop ESRF (Organ Donation Online, 2012a). To address this national shortage and to engage the BAME population, the NHS Blood and Transplant (NHSBT) plans 'to increase organ donation by 60% in 2016-2017 and sustain and improve thereafter' by finding 'opportunities to achieve self-sufficiency in donation and transplantation across the UK, taking into account the changing donor pool' and changing 'public behaviour with regard to organ donation, especially among BME [Black and Minority Ethnic] communities' (2012, p.3). This is relevant to this study as the case centres on an ethnic minority group. However, due to the way that the NHSBT currently measures BAME behaviour with regards to organ donation, the Polish are not represented in their figures, making it impossible to speculate how many Poles are on the ODR or the waiting list. This is an area that should be addressed in the future.

Currently, the 'gift of life' is used by the NHSBT in its leaflets to inform people about organ donation, encouraging them to 'Leave the gift of life today' alongside the message in another campaign forming the basis of their most recent media campaigns launched in February 2011 (NHSBT website, 2012a). NHSBT is currently running the 'Prove It' campaign and 'Real People, Real Lives, Real Action' campaign. The 'Prove It' campaign advertisements showed the same person as a healthy individual and as a person in need of a transplant and invited people to become an organ donor to 'prove' they were willing to give in practice. This relates to gift exchange theory, in that there is an obligation to give that may be reciprocated as well as altruism, or giving without expecting a return as there may be no reciprocation in the form of an organ if that individual needed one.
The 'Real People' campaign was a road show that included NHSBT staff and celebrities who visited shopping centres, local markets and places of worship in Black and South Asian communities, to raise awareness. Cramp (2012) at the first NHSBT National Organ Donation Congress in March 2012, criticised the relevance and applicability of the road-shows as they neither properly engaged the local community leaders nor tailored messages to the local communities. Taking a community-led approach has been an intervention that is viewed to be best suited to the Black and South Asian communities (Callendar, 1987; Darr and Randhawa, 1999; Randhawa, 2005). This demonstrates that using community-led campaigns cannot take a 'one-size-fits-all' and the importance of making information relevant to the community who information is being targeted toward.

This section has examined deceased organ donation and some of the current debates within this field. One area that has been touched upon is engaging the public through the ‘gift of life’ discourse and the notion of altruism in engaging or not engaging society. The next section is going to discuss how altruism links with deceased organ donation.

2.4 Altruism

Altruism is going to be discussed before gift exchange theory as organ donation is considered to be altruistic for current UK opting-in policy as there is no form of reward for donating. However, altruism has been argued to be used inconsistently across the Department of Health, Nuffield on Bioethics and NHSBT (Moorlock, 2013). Considering altruism alongside Mauss’s gift exchange is not unique as other theorists juxtaposed both concepts when examining organ donation (Lamanna, 1997; Healy, 2006; Gill and Lowes, 2008; Shaw, 2010).

Organ donation may be argued to be altruistic in the sense that it is a type of ‘unilateral’ gift (Godbout, 1998), a form of charity (Peters, 1986;
Gerrand, 1994; Lock, 2002; Sýkora, 2009), a civil duty (Peters, 1986), a type of sacrifice (Bataille, 1988; Mongoven, 2003; Sque et al., 2006), benevolence (Ferguson et al., 2008), generosity (Komter, 2010) or an agnostic gift (Sherry, 1983) all of these acts expect no form of reciprocity.

Altruism is defined as a pure concern for the increase of the positive welfare of another (Farsides, 2009). The concept of altruism has been debated within philosophy (Plato; Aristotle; Rand 1964; Nietzsche 1888) to be motivated by self-interest and economists (Kolm and Ythier, 2006) argue that helping another is a rational decision where costs and benefits to the 'helper' are assessed. The social psychologist Batson (1991) believed that concern to help another person was driven by empathy toward the individual.

Simmons (1991) has argued that separating self-benefits such as feeling better about oneself is difficult to distinguish from concern with the individual one is helping. With this in mind, it shows the difficulty in defining what self-interest is in deceased organ donation, for example, whether donating to feel better about oneself or enabling a family to better cope with the death of their relative are the motivations to help rather than having the recipient's welfare in mind.

The debate around the motivation behind helping others is not limited to increasing the welfare of the individual in need but helping the collective as a society or as a species. Sociobiologists suggest that altruism is a human trait that is instinctive, driven by protecting the species (Trivers, 1971; Novak, 2006; Dawkins, 2006) termed 'reciprocal altruism' (Pinker, 1997), the motivation here is helping the collective. In the case of organ donation, if a person is able to help other humans who may otherwise die of organ failure, this may be motivated instinctively through reciprocal altruism.

Helping the collective was highlighted by social policy scholar Titmuss (1971) who found in his study that duty motivated people to give blood
through a desire to help the common good. Altruism in terms of helping
the collective was considered by Batson (1994) who coined the terms
'collectivism' and 'principlism' (Farsides, 2009). Collectivism is where there
is a concern for the collective, for example making donations to charity or
the welfare state. Principlism is where the individual acts altruistically to
uphold a moral principle, such as 'do unto others as you would have them
do to you' (Luke 6:31). For example, someone may want to donate their
organs as they may perceive it to be upholding the principles of
Christianity.

Psychologists have highlighted the disadvantages of altruism, which are the
free-rider effect and the bystander effect (Darley and Latané, 1968). In the
case of deceased organ donation, these concepts have similarities in that
individuals expect others to be altruistic and that the individual themselves
do not have to be. Both free-riders and bystanders may accept organs but
would not donate as they benefit from the altruism of others.

It has also been debated as to where altruism originates, whether it is a
personality trait, is taught or is environmental based on social norms. From
a social constructionist perspective, there is the notion that humans have
to be taught to behave in altruistic ways to exercise moral reasoning
throughout childhood from sources such as family and school (Eisenberg,
1982, 1986; Frow, 1996). Learning to be altruistic was a concept that
Titmuss agreed with and suggested that social policy needed to provide
opportunities to act altruistically and social networks between strangers
could provide a way of creating social relationships generated, for example,
by blood donation. From a sociological stance, the investigation of altruism
in relation to organ donation is driven by norms, as highlighted by the
economists but not solely motivated empathy as Batson suggested.
Simmons (1991) cited Etzioni's (1998) paradigm illustrating that people are
'normative-affective beings' (p.13) where decisions are determined more
by conformity to norms and emotions than balancing pros and cons, as argued by economists who were influenced by rational choice theory\(^1\). Etzioni claimed that individuals want to balance morality with self-interest therefore altruism is a way of conforming to norms.

Overall, this section shows the complexities of teasing apart altruism and egoism and the motivation behind helping strangers, whether it is to help oneself, help the individual in need or to contribute toward the collective. The difference between altruism and gift exchange theory is reciprocity. Gift exchange is going to be discussed next, this introduces the obligation to reciprocate, which links with the altruism-egoism debate.

### 2.5 Gift Exchange Theory

The ‘gift of life’ is a metaphor that has been used by NHSBT in engaging with the public and has been explored by a number of theorists who have extrapolated Mauss’s (2002) gift exchange theory onto organ transplantation (Sque and Payne, 1994; Gerrand, 1994; Ben-David, 2005; Healy, 2006; Sque et al. 2006, 2007; Gill and Lowe, 2008) and blood donation (Titmuss, 1971). Mauss was a French anthropologist and functional sociologist, influenced by the work of Durkheim. Mauss studied gift exchange rituals within archaic societies, such as Polynesia and found that there were three main obligations within the gift relationship; the obligation to give, the obligation to receive and the obligation to reciprocate. Through these ritualised practices, or potlatches, power, honour, duty, obligation, respect and self-interest were established or maintained (Strathern, 1992).

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1. Rational choice theory advocates that individuals are ‘rational’ and make choices after weighing up the pros and cons. Its pioneering founder Homans (1961) suggested that its social application is exchange theory.

2. Functionalism is a sociological perspective whereby society is viewed on a macro scale, meaning that ideas are generalised to wider society and norms and moral values are based on consensus that people learn as they grow up. Functionalists believed that every section of society had a function and is a complex system that unites to promote social solidarity.
Lamanna (1997) argued that the title of Mauss's gift exchange theory is confusing because a gift has no reciprocity and exchange does have reciprocity. Exchange theories have had an impact on Mauss's work such as anthropologist Malinowski's (1922) work. Malinowski studied the Trobriander Islands and described the 'kula ring' which is 'an overseas networks of exchange relationships that link Trobrianders with people living on other islands of the Massim region' (Weiner, 1988, p.9). This is where items are exchanged but there is not an immediate return as reciprocation takes time.

Mauss influenced the work of Levi-Strauss (1969) who wrote *The Elementary Structures of Kinship* exploring exchange relationships of women and families in non-Western cultures. Malinowski, Mauss and Levi-Strauss were the predominant founders of exchange theory. A form of exchange theory is social exchange theory, which suggests that items that are exchanged build social cohesiveness (Simmel, 1950; Ekeh, 1974), social relationships and social networks (Granovetter, 1973, 1983; Simmel, 1978; Frow, 1997; Cheal, 1988), social responsibility (Caplow, 1982, 1984) and social solidarity (Hobhouse, 1906; Thurnwald, 1932; Ben-David, 2005; Komter, 2005, 2006).
Mauss's theory is the only theory that considers the gift and exchange, but there have been a number of gift theories. Godbout and Caille (1998) penned *The World of the Gift*, showing the importance of the gift in modern society alongside capitalism; Godelier (1999) in his book *The Enigma of the Gift* reassessed sacred objects as gifts; Komter (1996) emphasised power to create inequalities and social disintegration through gift practices; Strathern (1988) highlighted gender inequality in gift exchange; Cheal (1986, 1988) juxtaposed gift transactions and moral economy; Bourdieu (1991) stressed power or 'symbolic capital' in gift exchanges; Gregory (1982), Weiner (1992) and Deguchi (2002) focused on the idea of inalienability in gift relationships; Derrida (1992) argued that gifts are instantly forgotten making a continual exchange unlikely and Hyde (1984) applied gift theory to literary texts. Werbner (1990) analysed the Punjabi gift economy 'lena dena' (taking and giving) in the UK which explored community building to exchanges for marriage.

Taking into account all of these gift theories, each theory offers a unique view of giving gifts and reinforces the conflicting and delicate nature of gift giving for the giver and recipient for maintaining bonds. In addition, the circumstances in which a gift is given, such as who gives the gift, when the gift is given, how the gift is given and who the recipient of the gift is can affect the gift relationship. In the case of organ donation, Mauss's theory is the most suitable as it takes into account aspects of exchange such as the obligation to give, receive and reciprocate that come from giving a gift, whereas the other gift theories focus on outcomes of giving gifts or the position of gifts in personal relationships or capitalism. Reciprocity is the key component in exchange theory and is an integral part of Mauss's theory. Mauss's theory can be applied to organ donation in a number of ways including how the recipient feels about reciprocating the 'gift', whether the donating families expect a form of reciprocation and if a return is possible if a migrant's family donate in another country,
particularly viewed through the lens of generalised exchange that will be discussed later in this chapter.

The Maussian gift has been argued to encapsulate the ethos of giving in transplantation and has been used in public campaigns and policy (Titmuss, 1971; Sque et al. 2006; Gill and Lowes, 2008), but it is criticised for being too simplistic (Siminoff and Chillag, 1999) and problematic for the recipient who may feel coerced into receiving the gift and paying back the gift explained as the ‘tyranny of the gift’ by Fox and Swazey (2002). Applying gift exchange theory directly does not take into consideration the significant differences between archaic societal gift relationships and the organ donation process, such as the existence of gatekeepers in deceased organ donation (Sque, 1996), whereas in gift exchanges, as Mauss observed, gift relationships were personal. Also, in the gift exchange process, the potlatches were regular, ritualised events, but deceased organ donation happens once and at a time when someone dies. The sociologist, Healy (2006) highlighted that in Mauss's study gifts were not anonymous, which is the case in organ donation and transplantation.

**RECIPROCITY**

The obligation of reciprocity is a key aspect of Mauss's theory; he found that when gifts were reciprocated, they were returned with interest, meaning the gifts value increased over time as the exchanges continued. This is useful for the present study as it illustrates the role of the gift in maintaining and sustaining relationships, but the role that it plays in a one-off organ donation is unclear. As aforementioned, Fox and Swazey (2002) argued that the recipient may want to reciprocate, in Maussian terms the reciprocation should match or be more than the gift that was received but in organ donation this is not possible.
Recipients may feel the need to repay the donor family as the donor is deceased, due to reciprocity being a moral norm (Gouldner, 1960; Murray, 1987; Cheal, 1988; Komter, 2007) and the combination of generosity and self-interest when reciprocating (Komter, 2007). Lamanna (1997) argued that reciprocity may be a way of the recipient relieving a sense of guilt. Lamanna suggested that reciprocation is the 'dark side' of transplantation where recipients may feel reluctant to receive help, that accepting a deceased organ can have a negative influence on their body image compared to receiving a living organ. The recipient may have the burden of reciprocity, which may in turn result in destructive behaviour if the individual feels that it is impossible to achieve equity in this 'gift relationship' meaning that the recipient may not maintain the organ through lifestyle and medication. In terms of repayment, the recipient may give gifts to nurses but the exchange may be reversed as the donor family may have their grief eased through donating their relative's organs (ibid).

To add to the complexity of the deceased donor-recipient 'gift exchange', the NHS play a role after the transplantation has occurred as the SN-OD writes to the donor family to thank them for their donation and gives them an update of the progress of the organ, but this 'thank you' is not coming from the recipient but the NHS. This is highlighted by O'Neill (1993), who suggested that there were multiple exchanges that occur in a gift exchange relationship. This notion may link with deceased organ donation and the transplantation process as there are multiple exchanges that occur in between the donor's initial and the recipients' final exchange. Godbout (1998) illustrated that there are smaller exchanges occurring between the organ donor and the organ recipient. These are paid employees, such as Specialist Nurses in Organ Donation and Clinical Lead in Organ Donation, who may not view the organ as a gift, but as an item in a process.
GENERALISED EXCHANGE

To build on reciprocity, generalised exchange will now be discussed as I feel that this may play a role in this argument. When a donor family donates their relative's organs, the organs are being given to a number of recipients anonymously. This creates the dilemma within exchange theory as to where the reciprocity lies, whether the recipient should repay the donor or whether it is treated as a social good as Boas (2011) argues, where the recipient has been helped and in return the recipient helps society by donating organs and other people will be helped in the future. Viewing the organ as an item in an exchange where the recipient has to 'balance' the exchange by contributing to society will be discussed further through exchange theory.

There are a number of different forms of exchange; generalised, direct and indirect and balanced and negative. Generalised exchange theory had been developed by exchange theorists Sahlins (1978), Levi-Strauss (1969) and Malinowski (1922), they suggested that exchanges can be indirect and generalised.

Indirect and Generalised Exchange

In generalised exchange, there is the 'chain-generalised' form of exchange developed by Levi-Strauss (1969). This is where benefits flow unidirectionally until the benefits are returned to the original giver as found in the Kula ring (Malinowski, 1922). Ekeh (1974) built on Levi-Strauss's direct and indirect reciprocity theory, he suggested that direct exchanges are made up of high levels of emotional tension and egoism, concerned with the level of fairness of the exchanges made and there is a low level of solidarity. However, indirect exchanges consist of low levels of emotional tension, a collectivist intention and high levels of solidarity.
Takahashi (2000) coined the term pure-generalised exchange; this refers to unstructured giving, in that there is no set direction of reciprocity. He applied this notion to blood donation and explained that A may give to B in one instance but to C in another. I suggest that for deceased organ donation, A may enhance the lives of nine people in one instance at one point in time. These recipients may ‘pay it forward’, for example to strangers to help other people, perhaps those affected by organ failure and transplantation or to try to encourage people to sign up to the ODR. An example of this was on Channel 4’s ‘Battlefront’ (2011) where two friends had been affected by organ donation as their siblings had received transplantations. With the backing of the British pop singer, Alexandra Burke, they encouraged teenagers to sign up to the ODR at the UK’s Underage Festival.

In the ‘prove it’ campaign as discussed earlier, individuals may be prepared to receive an organ and should be willing to give one. However, Yamagishi and Cook (1993) and Takahashi highlighted the limitations of generalised exchange that is the ‘free-rider effect’, an issue highlighted by Šýkora (2009) in deceased organ donation based on altruism earlier. Yamagishi and Cook and Tahashi also argue that low levels of trust and solidarity can influence generalised exchange. This links with social capital theory in terms of levels of trust in the NHS and organ donation contributing towards social solidarity through civic engagement and will be discussed later in this chapter.

**Generalised, Balanced and Negative Exchange**

Sahlins (1978) argued that exchanges can be placed on a continuum from ‘generalised’ to ‘balanced’ to ‘negative’ exchange. Komter (1996) and Sahlins (1978) suggested that ‘balanced’ exchange is where exchanges end in equivalence and equity of reciprocity. It ‘resolves problems of collective action and binds communities. It transforms individuals from self-seeking
and egocentric agents with little sense of obligation to others into members of a community with shared interests, a common identity and a commitment to the common good’ (Adler and Kwon, 2002, p.25). This may not apply to organ donation as highlighted by Fox and Swazey (2002) through the tyranny of the gift; where it is not possible to pay back an equivalent gift. Balanced reciprocity is different to gift exchange theory’s obligation to reciprocate because the return is expected to be immediate rather than delayed as Mauss had discovered. In the case of organ donation, it may apply to donor families receiving a form of repayment in exchange for donating their relative’s organs to ‘balance’ the ‘exchange’.

Negative reciprocity is where reciprocity is expected to be equal but is not, there is no reciprocation and exchanges are motivated by self-interest (Sahlins, 1978). In the case of this present study, the donor family may feel unsure about giving their relative’s organs if there is no direct benefit to them. This returns to the previous arguments where there are policy debates shifting away from altruism towards self-interest motivated policy such as paid donation and the NHS paying for the donor’s funeral. Komter (1996) argued that negative reciprocity is common among strangers and is held to be dominated by suspicion and exploitation. It may be that donor families do not want to donate their relative’s organs to strangers as they are suspicious as to who is going to receive them and how they will treat them and also how the NHS will allocate them as the family has no control over this aspect.

There has been little research of the Polish perspectives in gift exchange in past research, bar one study by Gibraith (2003). She found that during Communist occupation in Poland, social networks were used to obtain scarce items and, post-communism, networks are still used, but more so to obtain work. To thank individuals for helping him or her get a job, they would give them a gift however; this could be seen as a ‘bribe’ because
they want that individual to help them again in the future. Now, discussion will turn to the application of altruism and Mauss’s gift exchange theory by Titmuss and Healy to explore how these have been examined by other scholars in relation to blood and organ donation.

A GIFT RELATIONSHIP OR ALTRUISM? TITMUSS AND HEALY ON DONATION

To discuss the distinction between the gift relationship and altruism, the study by Titmuss and Healy’s review of donation will be analysed to better understand the application of these concepts. In 1971, Titmuss, a social policy scholar, conducted a comparative study of blood donation between the UK and the USA, drawing upon the work of Mauss. He was criticised for his use of gift exchange theory in his study, Tutton (2004) found that Titmuss’s use of Mauss’s theory was ‘tokenistic’ (Leach, 1971) and it had been argued that the welfare state cannot be deemed to be a ‘gift’ domain (Frow, 1996). At the time, the UK voluntarily gave blood and the USA paid individuals to give blood. Titmuss supported the UK system because he concluded that the market-driven system caused waste as shortages and surpluses were created, as well as worse quality blood; it was bureaucratic and inefficient; it was exploitative as the blood was distributed from the poor to the rich; and it was degrading as altruism was replaced by self-interest and personal satisfaction (Le Grand, 1997).

Tutton (2009) explained that organ and blood donation policy in the 1960s and 1970s was influenced by Mauss’s theory and the implication that gifts had social bonds. Tutton argued that Titmuss was in favour of the altruistic blood system as this fell in line with his liberal-socialist political views of the welfare system. However, it could be argued that Titmuss’s findings are outdated, currently UK modern society has not experienced war and has a marketised welfare system.
Goodwin (2006) shed new light on Titmuss’s findings, she found that Titmuss had argued that blood was mainly from African Americans who were taking payment and blood was distributed to White Americans. Goodwin found that as blood across races is different, which was perhaps unknown at the time of Titmuss’s study as screening was not advanced. This may be the reason why the blood was seen by Titmuss as ‘contaminated’ in the USA. This major flaw could have implications as to whether the results of this study are still relevant in today’s society as racial attitudes have changed, although this could be challenged, screening is more advanced and attitudes towards altruism may be different (Goodwin, 2006). This also highlights Scheper-Hughes’s (2000, 2007) and Scheper-Hughes and Wacquant’s (2003) argument that commodifying body products can lead to inequality.

Titmuss’s (1971) key finding was that giving blood was a unique form of giving but he was not oblivious to humans acting for selfish gains and the possibility of people being taught to be altruistic and exercise moral choices, he termed the donors as not being ‘idealised altruists’ (ibid, p.116). For him, ‘None of the donors’ answers was purely altruistic as no donor type can be depicted in terms of complete, disinterested, spontaneous altruism. There must be some sense of obligation, approval and interest, some feeling of “inclusion” in society; some awareness of need and the purposes of the gift’ (p.306). Titmuss explained that donors were giving blood in an impersonal environment and it can be painful, the givers do not want a gift in return and it was based on anonymity as there were no expressions of gratitude. As has been found when exploring altruism and Mauss’s gift exchange theory, there are many perspectives on altruism and motivations to act prosocially and from a Maussian perspective, giving is expected to be met with reciprocation. Titmuss found that there was no pure altruism, that there is some other self-interest motivating giving blood, but not necessarily a return ‘gift’. He agrees with
the sociological perspective on altruism, where this may be socially constructed and learned through socialisation and social norms. By adding social capital to this analysis later in the chapter, Titmuss’s findings of wanting to feel included in society will be explored further.

Sýkora (2009) purported Titmuss viewed the donors as being pure altruists who saw blood donation as a form of charitable giving which, in turn created social solidarity, without considering the notion of reciprocity. Sýkora also suggested that Titmuss’s charitable model may be linked with the Christian concept of agape, (giving to the unfortunate) where no reciprocity is expected. However, I disagree with Sýkora as Titmuss himself did not view blood donation as a purely altruistic act and drawing on the work of Batson (1991) highlighted earlier, Sýkora’s ideas link with collectivism and duty, which may be argued not to be altruistic as the individual’s welfare is not in mind, but the common good. Also, it may be too simplistic to suggest that charitable giving creates social solidarity as has been found in the previous section. Titmuss may be drawing upon exchange theory instead as he suggests social solidarity is a result of exchanging items due to reciprocity a non-existent phenomenon in altruism, making it difficult to create social bonds.

**Healy**

More recently, Healy (2006), a sociologist, expanded on Titmuss’s work when he compared altruism with the market for blood and organ donation. For Healy (2006), the NHS played a key role in blood donation as it creates the bond to wider society and enables donors to give their blood. Healy argued ‘the ways in which society organises and structures its social institutions...can encourage or discourage the altruistic in man’ (p.225). This may be where some of the current problems lie, as 70% of the population have not signed up to the ODR showing that the NHS has not
been successful in invoking people to altruistically donate organs (NHSBT, 2012).

In addition to the NHS not fully encouraging altruism, Healy (2004) highlights that the logistics of altruism for blood and organ donation is hindered due to organisational issues. In his article, *Altruism as an Organizational Problem*, he suggested that that there are different forms of altruism.

![Figure 2: Different Forms of Altruism: The Case of Organ Donation](image)

**Figure 2: Different Forms of Altruism: The Case of Organ Donation**


Healy’s figure above illustrates the relationship between different forms of altruism and social organisation. In the case of organ donation, the frequency for individuals is low and the degree of institutionalisation is high. As Healy explains, it is an area of little academic attention but research does show that altruism within socially organised contexts increases the likelihood of the pro-social behaviour. He cites Drake et al.’s (1982) research who found that if people were directly asked to give blood, they were more likely to and highlighted that the findings are similar in
research where people are asked for monetary charity donations. Having this direct approach to asking people about donation links with the current 'Real People, Real Lives, Real action' (Organ Donation website, 2011) campaign where the NHS is talking to people about organ donation. Healy's work shows the differences in the forms of altruism but his work was based on the organ procurement system in the USA and may be limited in its application to the Polish migrant community in the UK.

In addition to the problems of engaging the public to register as a donor, is the experience of donation itself as it is not an everyday event, as outlined above, it is a 'one-shot' occurrence. Healy (2006) argued that the 'cultural account of donation' should help families who have to make a decision about donation to cope with this. He suggested that resources provide a framework for people to understand what their ideal 'feeling rules' are to experience their emotions as opposed to allowing these to dominate their decisions about donation (Hochschild, 1983).

In March 2012, new organ donation and religion leaflets were launched by NHSBT, this would be a form of the 'cultural account of donation'. Individuals could learn if his or her religion would allow and support the donation of relatives' organs and how this is supported by textual religion and religious leaders' views about helping others. This information may form part of the 'feeling rules' and establish religious norms around donation. For the non-religious, these leaflets would not contribute to these 'feeling rules' but other literature on organ donation may such as giving the gift of life and the 'prove it' campaign.

These leaflets may have limited impact as Healy is suggesting that individuals should detach themselves from emotional reasons to donate. Before the family has even got to the hospital, they would perhaps already have formed their own theories and attitudes towards donation. Also, the donation decision happens at an emotionally-charged time and having
leaflets about how one ‘should’ feel may have an unhelpful effect if they are not experiencing the expected thoughts and feelings they thought they would. In addition, the literature is readily available on the organ donation website and family members may have already seen the campaigns and information, these may not contribute toward the ‘feeling rules’ at the time the decision about a relative’s organ is made as these currently are part of organ donation rhetoric.

The analysis of the literature so far has focussed on deceased organ donation in relation to gift exchange theory and altruism where it highlighted limitations that social capital theory may be able to partially address. Attention will now turn to social capital theory.

2.6 Social Capital Theory

Limitations of gift exchange theory, altruism and exchange theories have led to the inclusion of social capital theory in the present study. In relation to deceased organ donation, gift exchange theory does not explain the reasons why individuals may feel the 'obligation to give' organs and are either motivated to help others in need, to benefit oneself or help the collective.

The ethos of giving may engage the public but Mauss's exchange theory, altruism and exchange theories do not go far enough in providing an explanation as to what could motivate Polish migrants to donate organs in a foreign country. I believe that social capital theory will address these issues and provide a deeper understanding of the motivation to give, such as sense of belongingness in a foreign country.

Aspects of social capital theory have been used in migration research such as the investigation of social networks (Ryan, 2010; Pollard et al. 2008). Ryan (2010) found that recent migrant Poles have had an economic impact on the UK and had strong social networks that they relied upon for jobs
and accommodation once in the UK. The use of social networks between 2004 and 2007 were more important for recent migrants than the pre-2004 cohort. However, the pre-2004 cohort may not have experienced the rapid growth of social networks that are not as well developed (Pollard et al., 2008). I agree that social capital marries together the ideas of the social effects of the gift, civic engagement, social solidarity (Adam and Roncevic, 2003) and migration, providing a more in depth analysis than only taking into account gift exchange theory and altruism.

**SOCIAL CAPITAL THEORISTS**

Social capital theory has been largely developed by three main scholars; these are Bourdieu (1980) Bourdieu and Wacquant (1992), Coleman (1988, 1990) and Putnam et al. (1993) Putnam (2000a).

<table>
<thead>
<tr>
<th>Levels of analysis</th>
<th>Bourdieu</th>
<th>Coleman</th>
<th>Putnam</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual / class faction</td>
<td>➢ Titles / names</td>
<td>➢ Citizenship</td>
<td>➢ Memberships in voluntary organizations</td>
</tr>
<tr>
<td></td>
<td>➢ Friendships / associations</td>
<td></td>
<td>➢ Voting participation</td>
</tr>
<tr>
<td>Family / community</td>
<td>➢ Citizenship</td>
<td>1.0 Family size</td>
<td>➢ Newspaper readership</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.0 Parents' presence in the home</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.0 Mother's expectation of child's education</td>
<td></td>
</tr>
<tr>
<td>Community / region</td>
<td></td>
<td>4.0 Family mobility</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5.0 Church affiliation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Memberships in voluntary organizations</td>
<td></td>
</tr>
</tbody>
</table>

Table 1: Social Capital Theorists

Source: ‘Contemporary authors’ level of study of social capital’, Claridge (2012) (with permission from the author)

Bourdieu’s social capital is ‘the sum of resources, actual or virtual, that accrue to an individual or group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and
recognition’ (Bourdieu and Wacquant, 1992, p.119). His theory is individualistic, it suggested that people must earn social capital and the individual benefits from the capital gained from each connection (Bourdieu, 1980).

Coleman (1988, 1990) defined social capital differently to Bourdieu, for Coleman the focus was on groups as opposed to the individual. As a functional sociologist, Coleman believed that social capital played a function in society that was ‘obligation and expectation, trust, information, norms and penalties that discourage their transgression, relational authority and social organisation and social network’ (as cited in Poder, 2011, no page number). Coleman married together the micro and macro levels within society in his social capital theory believing that social capital linked with reciprocity and trust on a micro level and was the basis for social consensus on a macro level (Siisäinen, 2000).

Finally, Putnam et al. viewed social capital as being ‘features of social organisation, such as trust, norms and networks, that can improve the efficiency of society by facilitating coordinated actions and cooperation for mutual benefit’ (1993, p.169). For Putnam et al. (1993) and Putnam (2000a), social capital increased the likelihood of collective action, such as civic engagement and viewed social capital as a product of civic culture. Putnam’s (2000a) theory of social capital links with the aforementioned generalised exchange theory where a person may help someone and expect a favour to be reciprocated in the future by another person when it is required. Putnam (2000a) distinguishes between different types of social relationships; these are ‘bridging’ and ‘bonding’. Bridging is connections across a number of networks such as work friends and acquaintances and bonding is the connection between people of similar backgrounds such as age or people who are family and friends. Woolcock (2001) added ‘linking’ where connections are made outside one’s communities enabling a wide
range of resources to be accessed. Social networks are seen as a resource in social capital theory but also as a way of exploring community groups via ‘bridging’, ‘bonding’ and ‘linking’ and norms within these social groups. With regards to organ donation, social networks could be used as a source of information (Callender, 1987; Coleman, 1988; Darr and Randhawa, 1999).

Polish migrants may ‘bridge’ their social relationships via modern social networking sites such as Twitter and Facebook. Transnational virtual networks may influence the social networks that migrants have in the UK linking them to Poland. Social networking media was not accounted for when the theory was developed. In addition to ‘bridging’ is ‘bonding’, Putnam and Fukuyama (2001) considered religious institutions to be a source of social capital. Polish migrants may come together through similar religious backgrounds, such as the Polish Catholic Church in Dunstable. Finally, ‘linking’ may apply to connections that Polish migrants make outside of their Polish networks, with non-Polish migrants.

Putnam’s (2000a) theory best sits within this study as it considers the individual agent and their interaction with their social environment, which connects with the social constructionist approach taken for this thesis. However, Putnam’s theory was based on his research on bowling clubs in the United States of America (USA), meaning that there are challenges in how far the theory can be applied to Polish migrants in the UK. In addition, Putnam is a functionalist sociologist and Siisiäinen (2000) argued that he focuses on the ‘integrative functions of voluntary associations’ which was influenced by ‘American “pacific functionalism” of the 1960s’ (p.5). Therefore, Putnam viewed social capital as playing a role in society and its
function can be influenced negatively by such factors as an attrition of volunteering and rise of multiculturalism.

In 2000, Putnam argued that individuals becoming time poor due to working long hours for both parents in nuclear families, increased travel times to the workplace, television and age as younger generations are less likely to belong to clubs, vote or read newspapers. In a recent news article, Putnam (2011) argued that multiculturalism also contributes to the deterioration of social capital. However, the meaning of ‘multiculturalism’ is problematic as it may be viewed in one way in an American context and in another form in a UK context.

Drawing upon this functional perspective and linking it with the social constructionist approach I am taking, I am interested in how participants view these aspects of social capital as a ‘social reality’ from their experiences, such as club membership, volunteerism, multiculturalism, their constructs of ‘community’ and social networks and views towards UK as a host society in the way they link with organ donation.

SOCIAL CAPITAL AND DECEASED ORGAN DONATION

Social capital adds a new dimension to the relationship between deceased organ donation, altruism and gift exchange theory as it considers the productive outcomes of positive social relationships through social trust, norms and networks (Szreter, 2000). Healy (2006) had tentatively linked organ donation and social capital from Putnam’s et al.’s (1993) perspective suggesting that ‘It is possible that organ donation lines up with other measures of associational activity and social capital more broadly’ (p.136).

Analysing social capital in relation to deceased organ donation has not been widely researched. Recently, I evaluated social capital and deceased

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4 Multiculturalism is a problematic concept to define according to Modood (2007) as its meaning can change depending on the political climate of a country. However, it is outside the remit of this study to focus on the definition of multiculturalism.
organ donation from a theoretical perspective a recent book chapter
(Sharp and Randhawa, 2012). It was suggested that social capital theory
can be connected to deceased organ donation on a micro, meso and macro
level. The micro level considers the individual in relation to the social
networks that he or she is part of. The meso level relates to the
neighbourhood and the local NHS services within the community. The
macro level takes into account the wider societal aspects such as the social,
economic and political aspects around deceased organ donation policy and
the imagined ‘other’ who is the perceived organ recipient.

In addition, as seen in Table 2, Sharp and Randhawa (2012) use Uphoff’s
(1999) structural and cognitive levels of social capital, where structural
social capital can be observed but cognitive social capital cannot, to
illustrate how organ donation may be viewed in relation to social capital
aspects, such as trust, networks and civic engagement.
<table>
<thead>
<tr>
<th>Structural</th>
<th>Cognitive</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sources and manifestations</strong></td>
<td><strong>Norms, values, attitudes and beliefs</strong></td>
</tr>
<tr>
<td>Rules and roles, networks and procedures.</td>
<td>Towards organ donation</td>
</tr>
<tr>
<td>Organ donation and transplantation process/</td>
<td>(myths/concerns, helping behaviour and morals)</td>
</tr>
<tr>
<td>Healthcare team training</td>
<td>influenced by religion, culture, and society</td>
</tr>
<tr>
<td><strong>Domains</strong></td>
<td><strong>Civic culture</strong></td>
</tr>
<tr>
<td>Social organisation</td>
<td>Society/Stories in the media about donation?</td>
</tr>
<tr>
<td>NHS Blood and Transplant/Government/Local</td>
<td></td>
</tr>
<tr>
<td>hospitals/Transplant Team</td>
<td></td>
</tr>
<tr>
<td><strong>Dynamic factors</strong></td>
<td><strong>Trust, solidarity, cooperation and generosity (Sense of belongingness)</strong></td>
</tr>
<tr>
<td>Horizontal and vertical linkages</td>
<td>Reasons for engaging with deceased organ donation</td>
</tr>
<tr>
<td>Networks within the organ donation and</td>
<td></td>
</tr>
<tr>
<td>transplantation process</td>
<td></td>
</tr>
<tr>
<td><strong>Common elements</strong></td>
<td>Expectations that lead to cooperative behaviour</td>
</tr>
</tbody>
</table>

Table 2: Social Capital and Deceased Organ Donation


Taking social capital theory into account in the present study extends the concept of the organ as a gift to demonstrate that organ donation could be mediated by many other factors such as trust in strangers, past experiences with the NHS and whether participants might view donation as a form of social responsibility in a country that is not their home country. Experiences of migration could have an impact on whether Polish migrants...
would want to act civilly, such as prejudice, racism, trust in UK institutions and sense of belonging in Luton.

Social capital theory will aid the examination of organ donation within society, whether aspects social capital is a source of motivation to donate, for example feeling included and accepted in one's neighbourhood or host society, or alternatively individuals want to contribute towards society through donation.

Social capital stresses the importance of community and society and the social benefits of giving, in this case an organ, towards social solidarity. As discussed earlier, if the motivation to give organs shifts towards helping the common good, there is still the issue of the bystander effect and the free-rider effect where others can benefit from the pool of organs. However, as Putnam argued, to benefit from the organs, one has to earn the capital to access resources and this can relate back to reciprocity-based policy or to solidarity or 'club' based policy (Nickerson et al., 1998) where 'everyone is in it together' (Nuffield Council on Bioethics, 2011c). This 'club' based policy currently exists in Israel, where there is the policy that if an individual is a registered organ donor, he or she has priority on the transplant waiting list.

Social capital is not an exchange theory as such but in some ways it is similar to indirect and generalised exchange theory, therefore it could be argued that there is an 'implicit exchange'. For example, if one trusts the NHS and conforms to values and norms to help the common good, he or she would then donate their organs as it is expected that an organ could be available when needed. The notion of solidarity in organ donation is supported by Portes (1998) who suggested that solidarity could be a source of social capital because if individuals are willing to take an organ if it is required, this is a form of 'bounded solidarity' as people need to donate to access resources. Komter (2006) studied the gift and the concept of social
solidarity together and argued that for organ donation, there is no reciprocity as payback is delayed to some future time in case the person needs the organ and they hope that other people are willing to give.

However, social norms of this ‘implicit exchange’ and ‘bounded solidarity’ are problematic in relation to the current social norms of donation where one agrees with donation in principle but does not necessarily discuss it with their family or sign the organ donor register (Moseley and Stoker, 2010). As those illustrated in Table 2, social norms are important but these are difficult to change as they are deeply rooted. Also, if there is the perception that one feels negatively about the conditions as outlined in Table 2, this could adversely affect views towards organ donation. This was highlighted by Morgan et al. (2010) who found in their study of Black Caribbean migrants in the UK that organ donation is hindered by feelings of marginalisation from UK society, this links with a sense of belonging; this could be argued to be a cognitive form of social capital.

Here, it is argued that social capital can gain insight into the motivation to donate organs as opposed to viewing the organ as a social good. It frames current discussions around organ donation such as reciprocity-based and club based policy approaches and highlights the importance of trust and social norms in donation. The current and previous sections in this chapter have focused on deceased organ donation, gift exchange theory and how altruism and social capital contribute towards the analysis of donation. The final element of the study to be discussed is religion and religiosity.

2.7 Religion

Religion is the final aspect of the study that will be examined, as was highlighted in the aims of the study. Religion had been highlighted in previous literature to have an impact on deceased organ donation. In previous studies (i.e. Exley et al. 1996; Randhawa, 1998), it had been
claimed that religion could either encourage donation through helping others in need or hinder donation through the perceived need for the body to be buried whole.

Religion has been examined prolifically across a number of fields including philosophy, anthropology, psychology, phenomenology and sociology (Hinnells, 2005). A sociological perspective best suits this study as it considers religion within society and fits in with the social constructionist approach to the present study. Riesebrodt and Konieczny (2005) explained that within the sociology of religion, there are three classical paradigms; Marx (1878/1964) Durkheim (1915/1965) and Weber (1922/1963).

As a social constructionist approach was applied to this study, this section will discuss the Durkheimian paradigm as he influenced the writings of Berger and Luckmann (1967), which will be discussed later in this section. According to Berger and Luckmann, Durkheim adopted the dialectic perspective of society from Marx and Weber’s subjective meanings from social reality and social action (Verstehen). Durkheim’s work is relevant for this study as opposed to Marx’s and Weber’s because Durkheim viewed religion as a social phenomenon, where religious groups would contribute toward social cohesion. However, Marx viewed religion as part of oppressive social structures that were alienating individuals. Weber perceived religion as being driven by charismatic leaders making religion a ‘sect’, able to drive social change as a result of his analysis of religious and economic performance of Protestantism and capitalism.

**DURKHEIM’S VIEW OF RELIGION**

In his book, *The Elementary Forms of Religious Life*, Durkheim (1915/1965) studied pre-modern societies of aboriginal Australians and Native Americans and argued that the findings of his research from these societies represented patterns of religion across all societies. Durkheim was not
interested in the individual experiences of religion, but the communal bonds as a result of participating in religious practices. He found that both these communities wanted social cohesiveness and solidarity and, through religion, a sense of community and commonality was achieved. Durkheim proposed it is the non-divine community which is ‘god’, which humans ‘need’. He suggested that religion ‘is indeed from society that it [religion] draws all its strength, but it is not to society that it binds us: it is to ourselves’ (Durkheim, 1984, p.122). Through society, expectations and values are framed and protected as these are believed to be what the ‘gods’ will, as opposed to humans within that community. He suggested that when society is participating in religious activities that it is in reality, worshiping society.

Durkheim purported religion has shaped worldviews, these are influenced by ‘social facts’ such as time, which originates from religion. Religion gave humans a social structure and a sense of collective consciousness, Durkheim viewed religion as ‘a unified system of beliefs and practices relative to sacred things, that is to say, things set apart and forbidden – beliefs and practices which unite into one single moral community, called a Church, all those who adhere to them’ (Durkheim, 1915/1965, p.47).

For Durkheim, there were certain elements of religion that were common across cultures, these were the ‘sacred’ and the ‘profane’. The sacred were objects and behaviours that were deemed religious or spiritual. The profane describes everything else in the world that does not have a religious value. Although these two are demarcated, they interact with one another and depend on one another. For example, the Catholic Church deems the crucifix and the behaviours and actions in mass to be sacred.
Durkheim’s work is couched in structuralism\textsuperscript{5} and functionalism and he suggests that religion plays a function universally. From a structuralist perspective, social reality is believed to exist independently of humans. However, from an epistemological stance, this is an objectivist way of viewing reality and this is not in line with the standpoint taken for this study. However, it is possible for these theories to contribute towards the relativist ontological perspective taken for the present study, as this structural-objectivist approach considers the social aspects in relation to religion. From a functionalist perspective, these theories contribute towards the social constructionist approach taken as Linking with social capital theory, which also takes a functionalist view. I was interested in how religion was perceived to contribute towards social solidarity and relate to deceased organ donation and gift exchange theory.

In modern society, Durkheim argued that traditional religion will not play a function, but it will be rational and express the sacred values and needs within society. Religion may take a new form in the form of individualism where the state is the head of this ‘cult’. Durkheim’s paradigm lends itself to this study as it considers religion to be the product of humans and how religion contributes towards the social construction of ‘social facts’. In this study, this sheds light on the ways in which religion may have influenced the participants’ social constructs including the way that the body is viewed, whether it was perceived as a ‘sacred’ object and how this influences organ donation and religious death rituals and the ways in which donation may be perceived to impact on these.

**BERGER AND LUCKMANN’S VIEW OF RELIGION**

More recently, Berger and Luckmann (1966) penned the influential book *The Social Construction of Reality*, which was referred to in the first

\textsuperscript{5} Structuralism ‘focuses on the objective structures of language and culture that give shape to human action’ (Ritzer, 2003)
chapter. Berger and Luckmann were influenced by Durkheim and also took a structuralist perspective. Berger and Luckmann (1966) viewed reality as 'dialectic', where they saw 'Society as a human product. Society is an objective reality. Man is a social product' (p.79). They believed that people go through a continual process of externalisation, objectification and internalisation. Externalisation is where individuals expressed themselves through activities that create objects, these objects had a character independent of the individual who made it, and this is objectification. Finally, they argued that individuals are the product of society as the objects that have been created affect other individuals. Overall, they viewed society as a product of humans and humans as a product of society.

Berger (1967) drew upon the collaborative work in *The Sacred Canopy* that explored religion as a social construct. He suggested that religion satisfies humans' need for order and consistency. He argues that culture can be maintained in society if people internalise cultural concepts. Berger suggests that in pre-modern society, religion provided a 'sacred canopy' that formed a perspective for that society. This 'canopy' provided meaning to that society, which individuals' constructed as 'reality'. In modern society, institutions have separated themselves from religion, causing society to become differentiated and leading to religion losing its 'plausibility structure'. For 'reality' or 'knowledge' to be plausible to an individual, it must have a plausibility structure and a social structure. Berger (1967) suggests that this decrease in plausibility structure has led to secularisation where there are a number of different worldviews, pushing religion from the public to the private sphere... Berger's view has been contested, in particular in relation to secularisation. Davie (2001) argues that religion does still play a significant role in Westernised, modern society. However, Berger and Durkheim both purport religion is being pushed into the private sphere and is perhaps being internalised through cultural concepts that have origins in religion, therefore, the notion of 'folk
religion may play a role in this study. This explores how official, textual religious teachings and cultural practices are interpreted by the individual.

As George Bernard Shaw said, 'There is only one religion, though there are hundreds of versions of it.' (Page unknown) Folk religion highlights this further in addition to Berger and Durkheim, illustrating that there are many different factors that contribute to the social construction of religion and may be experienced differently by each individual. This is not problematic for this study as it is taking a relativist ontological viewpoint, meaning that multiple social realities and social constructions exist.

Luckmann (1967) wrote *The Invisible Religion* and argued within that religion was less prominent in modern society; however, Berger suggested that secularisation left a space in the public sphere however, Luckmann (1967) disagreed. Luckmann (1967) thought that non-institutional religion has flourished in turn creating 'invisible religion' where individuals construct their own identity and worldview. Luckmann (1990) argued that modern social constructs of religion are moving away from transcendental religion towards 'immediate' religion. He suggested that within the private sphere, there is a shift towards solipsism, where the individual's own mind is in existence, where religion is individualistic aiming for self-realisation and self-expression. This last aspect of Luckmann's view on religion does not fit in line with the ontological perspective taken for this study, but

Folk religion is made up of customs of organised religions but they are outside the official teachings and practices (Bowman, 2004). Yoder (1974) defined folk religion as 'the totality of all those views and practices of religion that exist among the people apart from and alongside the strictly theological and liturgical forms of the official religion' (p.14). Folk religion is also known as 'popular religion' which Lanternari (1982) explained as:

'[a] set of beliefs and practices arising from the intersection of a complex dynamic: (1) the dialectics between official religion (i.e. ecclesiastical religion) and popular religion (Vrijhof and Waardenburg, 1979); (2) dialectics between bourgeois and intellectual forms of religion and the non-Enlightenment and/or illiterate forms of faith; and (3) the dialectics between the official and dominant culture (i.e. that of the dominant classes and elites) and the culture of the lower strata of society: poor people, workers and marginalised social groups of developing societies' (in Parker, 1998, p.199-200).
more in line with ontological idealism, where there is no external reality and reality is within one’s mind.

In terms of this study, Berger (1967) and Luckmann (1967) both provide a perspective on the way in which religion can be constructed. Within modern society in the UK, there is religious pluralism, particularly evident in Luton, which is a multi-faith and multi-ethnic area. It could be argued that there has been a shift toward secularisation on a national level, as the state has separated itself from the Church of England in the UK after the Enlightenment in the 18th Century however entering into a discussion of church-state relations and secularisation is outside the remit of this study. What was important in this study was the impact that society and community had on individual constructs of religion from a Polish perspective as they had come from a Catholic country to secularised UK society.

When discussing how religion is experienced by the individual to gain a further insight into their social constructions. Religiosity is appropriate as it encapsulates individual expression of religion such as church attendance and prayer, known as extrinsic religiosity (Allport and Ross, 1967). Intrinsic religiosity explains how a person lives and experiences religion (ibid). Batson et al. (1993) add to these two forms of religiosity and suggests ‘quest’ which is religion as an open-ended search. Allport and Ross (1967) developed these forms of religiosity for the Religious Orientation Scale, which suggests that religiosity can be objectively measured, taking a positivist perspective which contradicts the social constructivist position taken in this study. Attempts to measure it have been made through a number of scales such as the religious attitude scale (Armstrong et al. 1962) and the post-critical belief scale (Hutsebaut, 1996).

Using these forms of religion in this way can link with Berger and Luckmann’s externalisation, objectification and internalisation process. It
could be argued that religiosity is the individual expression of their
religious beliefs through externalisation, either physically through church
attendance or through abiding by religious tenets as part of everyday life to
contribute towards their social constructs of religion. With a social
constructionist perspective of religion and the role of religiosity in mind,
discussion will now turn to these aspects in relation to deceased organ
donation.

2.8 Religion and Deceased Organ Donation

Few studies about organ donation have taken a social constructionist
perspective to religion and religiosity. A number of studies have linked
religiosity with organ donation as opposed to religion (Rumsey et al., 2003;
Stephenson et al., 2008; Morse et al., 2009); many of these investigated
this relationship through quantitative methods such as questionnaires and
self-reported surveys. This is a limitation as the studies may have drawn
upon a more positivist view towards the connection between religion and
organ donation as the studies have tried to illustrate that there is external
validity in religion as it can be measured on a scale (See Appendix One).

The studies by Rumsey et al. (2003), Stephenson et al. (2008) and Morse et
al. (2009) have not been consistent with the way in which religiosity is
measured (See Appendix One). However, what can be drawn from the
results of these studies is that religion may have an indirect link with organ
donation shaped by views held of the body and the acceptance of one’s
decision about donation by family, friends and religious community is
significant. Also, these studies imply that religiosity can be measured and
this may be because Allport and Ross’s (1967) definitions have come from a
positivist stance. However, this study used only qualitative tools, that is,
open-ended questions about religiosity.
In previous studies (see Appendix One) the connection between deceased organ donation and religion has been examined through the inclusion of different ethnic groups in the UK and the results have shown that religion can have an impact on donation. These studies have not intentionally investigated the role of religion or religiosity on organ donation but through qualitative methods of inquiry the finding has been elicited that there are religious norms that can have an influence on views towards organ donation.

Some of these studies are questionnaire based, which has already been raised as a limitation due to differences in theoretical perspectives, but there were qualitative studies which took a similar data collection approach to this study. Overall, what can be found from all of this literature is the role that ethnicity and culture plays in the perception of the role of religion in deceased organ donation. What can be gleaned for the purposes of this study, is that religion has a significant impact on constructs of the body, death rituals, the preferred imagined recipients of organs and the perceptions of important ‘others’ on one’s donation views. These studies have not outlined religion to be one of the objectives or defined what they mean by religion as for all of them, the main focus has been attitudes towards organ donation. However religious and cultural findings could be argued to have been a sub-objective in these studies as the majority of studies have selected their sample based on faith and ethnicity. These studies have also highlighted social constructs that individuals have about the NHS and deceased organ donation. In addition, the studies aided the present study as there were similarities in the findings.

Although the studies did not set out to investigate religion, altruism or gift exchange and the studies used a range of methods from questionnaire to focus group, the findings across the studies indicated how in this present
study, religion, altruism and gift exchange indicated how the participants may view the relationships. There are similarities between Catholicism and the religions highlighted in these studies such as teachings to help those in need. Although there are significant differences between the sample groups and the participants in this study, for example Catholic death rituals and official religious rules such as ‘fatwas’.

There is very little research illustrating the lay perspectives of Polish views toward deceased organ donation. One study in Poland by Jakubowska-Winecka et al. (2006) found through a survey of 1000 Poles, that the majority of participants were positive and supportive of donation, those who were not, called ‘opponents’ did not inform their family of their view of donation, did not want religious leaders to discuss organ donation, and lacked trust in medical professionals and their skills. Those who were supportive were open about the issue, familiar with or accepting of brain death and wanted more information about the medical procedure of organ donation.

2.9 Religion and Gift Exchange Theory

A finding raised in the previous section is that religion may helping people cope through donating a relative’s organs, for example, Sikh participants were confident that their religion supported donation as an act of helping others (Exley et al., 1996; Randhawa, 1998). Across all major religions, helping others through gift giving is supported. For example, within Islam, the Qur’an suggests that individuals give zakât or help others through sadaqât (Homerin, 2005). Nanji (2001) suggests that almsgiving ‘draws upon the ideals of compassion, social justice, sharing and strengthening the community’ (p.64).

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7 Since submitting this thesis, there had been a new study by Perenc et al. (2012) that found that in Poland, university students had a generally positive view toward deceased organ donation in principle, but many were not registered organ donors.
The connection between religion and a person’s helping behaviour has been debated. The link between charitable giving and volunteering of religious persons has been researched with mixed results as to whether religious people are more helpful than those who are not religious (i.e. Ruiter and Dirk De Graf, 2006; Reitsma et al., 2006; Ecklund and Park, 2007; Monsma 2007; Graham and Haidt, 2010). In addition, there have been theological debates about how altruism can apply within religion context (i.e. Gardner, 1954; Murphy, 2006; Harvey, 2001). To summarise this, Neusner and Chilton (2005), in their book *Altruism in World Religions*, examined the relationship between altruism and religion. Generally, they argued that it was difficult to apply religious scripture to the notion of altruism as this concept was secular and fairly new relative to when religious scriptures were written. Scripture has implied altruism but does not teach the doctrine of altruism. There may be problems applying scripture to giving, altruism and organ donation from a religious perspective without taking it out of its original context and having the appearance that ancient religious scripture had been stretched too far to apply to new biotechnology by religious leaders.

When the connection between gift exchange and religion was discussed with the participants, this focused on the ‘real-life’ experiences that the individual had, through the question ‘Some studies suggest that people who are religious are more likely to want to help others they do not know, do you agree?’ From a social constructionist perspective, the study was interested in the participants’ social constructs of how gift exchange and religion connected in terms of what aspects of religion, whether it be teachings or scripture, participants perceived related to helping strangers and what form of helping they discuss.
2.10 Polonia in the UK: A Brief History

It should be clarified at this point that the term 'case' was applied solely to describe the context of this study, this is the Polish community in Luton. The Polish community provided the milieu for the exploration of the topics and how they related to one another within its 'real-life' setting (Yin, 1994).

Migration from Eastern Europe has occurred for much longer than the 2004 EU enlargement as Polish migrants have been joining the UK for over a century (Jazwinska and Okólski, 2001; Morawska, 2002; Duvell, 2004; Górný and Ruspiní, 2004; Triandafyllidou, 2006, 2009; Garapich, 2008). The following sections explore the three main waves of migration to the UK; these are post-Second World War, post-1989 and post-2004.

POST-SECOND WORLD WAR MIGRATION: POLITICAL

The Polish Resettlement Act (1947) enabled Polish migrants who fought in Western Europe to settle in the UK. By 1951, 160,000 Polish citizens were settled in the UK and people continued to settle until 1989 as families joined those in the UK to escape political unrest in Poland (Sword et al., 1989; Górný and Osipović, 2006).

After the Second World War, around 150,000 displaced persons and Polish soldiers settled in the UK. They achieved a high level of 'institutional completeness' (Breton, 1964) through the creation of schools, media and churches (Garapich, 2008). When analysing this group's experiences of migration in previous studies, a number of themes emerged:

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8 Rainey (2013) explained that the Poles had made a significant contribution to the Allied war in terms of providing resources and intelligence. After France fell in 1940, the exiled Polish Prime Minister and government founded an office in London and brought 20,000 soldiers and airmen with them. This meant that Poles made up the largest percentage of non-British RAF troop in the Battle of Britain and by 1945, 150,000 Polish troops were under the command of the British Army. At the end of the war, Churchill stated that the British were indebted to the Polish and pledged to give Poles freedom and citizenship in Britain. Wanting to escape from the Communist government in Poland, many Poles did not want to return to Poland, meaning that the Polish Resettlement Act 1947 was passed, which was the first mass immigration law.
'a long story about getting to the UK, views of the nation as the most treasured possession, mythologisation of the state, history and their own personal histories, knowledge of Polish history, active participation in church and religious ceremonies, recognition of the importance of the Polish language as a mother tongue of future generations and sense of community' (Galasińska, 2010, p.942).

There were values that were attached to migration for post-war migrants as political migration was viewed as superior to the later economic migration in Polish emigration ideology (Garapich, 2008). The Polish national identity was affiliated with religion, language and home land, and leaving one’s home land was viewed as a tragedy (ibid). Mobility was seen as a threat to the moral order because morality was believed to exist in the home land and emigration was viewed in moral terms. This is why political migration was viewed by the post-war migrants, in a better light than economic migration as political emigration was seen as a sacrifice but economic migration was believed to be cowardly and evil (ibid).

This dichotomy, according to Garapich was based on Christian ideology of the body and the soul, in turn reducing individual motivations to “ideas” vs. bread, the emigration ideology has the capability of creating a hierarchy of migrants’ (p.130). It is kept alive through cultural meanings that are revitalised through the sharing of memories of wartime experiences and rituals that emphasise the Polish government-in-exile (Garapich, 2008). Galasińska (2010) explained that the Polish church is a place in which cultural needs are met because so much symbolic capital is attached to them.

The post-war migrants did make up the majority of Polish migrants living in the UK prior to 2004 and as they settled in the UK, there are now second and third generations (Stenning et al., 2006). There may, therefore, be young Polish people living locally who are second or third generation and who may have very different views from migrants of similar age who have come to the UK recently.
POST-1989 MIGRATION: POLITICAL

Galasińska (2010) explained that before 1989, it was very difficult to leave the country and head for the mythological West as visas for the UK were very restricted. In the early 1990s, after the fall of the Iron Curtain and the rise of Polish Solidarity, many Polish nationals left but had to have an invitation to the UK and it was left to the discretion of immigration officials whether to admit them.

Once in the UK, they found it difficult to identify with the migrants already in the country as their social and class background was very different (Garapich, 2008). Garapich cited Joly (2002) who described post-war migrants as 'Odyssean refugees' to explain the conflict based on class differences from the same ethnic background. She described them as:

‘Actors who were not just victims of the structure of conflict in their country of origin but were positively committed to the political struggle and project of society in their homeland; they also brought this project with them into exile so that they are committed to a collective project in the homeland despite the defeat they have suffered...return is their objective with the aim of continuing the project...for Odyssean refugees include not necessarily all nationals of the same origin but all who were engaged in the same political struggle’ (in Garapich, 2008, p.132).

After the fall of the Soviet Union, the Odyssean refugees, had nothing to which to attach their identity, as what they knew about their home country had changed whilst they were in the UK (Garapich, 2008). At this time, boundaries were constructed to maintain Polish group solidarity and preserve their ideology. Currently, post-war migrants view themselves as purist Polish nationals but this group is dying out and their social clubs and newspapers are closing down (Garapich, 2008).
POST-2004 MIGRATION: ECONOMIC

The changes in the EU structure meant that Poles were able to come to the UK for economic reasons after 2004. For the post-2004 Polish migrants, there were significant ‘push’ and ‘pull’ factors behind migrating to the UK. Ravenstein (1885, 1889) hypothesised that migration is motivated by factors which are ‘pushing’ people away from their country of origin and ‘pulling’ them into another country. Push factors may be poor living standards and economic opportunities and pull factors may be the labour market and better economic opportunities. Drinkwater et al. (2009) suggested that a ‘push’ factor was a high level of unemployment in Poland. Bielewska (2011) explained that the post-2004 migrants were born in a baby boom in the 1980s which contributed towards the problems of entering the labour market in Poland. In 1989, after the fall of the Soviet Union, unemployment rates increased quickly. Young people were affected most by the rates of unemployment due to ‘insider’ and ‘outsider’ labour markets (ibid). The ‘insider’ labour market succeeds in growing markets and ‘outsiders’ are employed in declining industries or are not able to enter the alternative labour market as they have the incorrect skill set. The freedom of movement due to the expansion of the EU enabled the Poles to migrate and work in the UK without a work permit.

Burrell (2010) highlighted that the ‘pull’ factor of the UK was the labour market opening up once Poland had joined the European Union. Burrell (2010) showed that in a number of reports, young people who are highly educated, who wanted to experience a different way of life and improve their English, have been the most common demographic group that come to the UK. She cited Galasińska and Kozłowska (2009) who argued that for Polish migrants, migration is not to find a ‘better’ life, but a ‘normal’ life, which is a social construction in Poland about what is ‘normal’ in the West (Burrell, 2010). White (2009) found that family decisions to move abroad
were motivated by improving the quality of their children's lives. Burrell (2010) found in her review of Polish migration research that the motivations to move abroad were not necessarily economic but about enabling them to go on an exciting journey or to develop their skills.

Bielewska (2011) found that Poles typically enter the UK labour market through three routes; being an au pair, a job offer before leaving Poland and through the migrant network. Through personal observations for this Polish community case, there were Polish au pairs who had migrated outside of Luton to affluent areas such as Harpenden to gain employment. For Bielewska understanding the routes for coming to the UK was significant in understanding views towards other Poles. She explained that many migrate through institutional methods before coming to the UK, leading to independence from social networks within the initial stages of migration. This helped inform the study recruitment strategy as I could go through institutions such as workplaces, recruitment agencies and the University to advertise the study.

Since EU enlargement, the Polish community in the UK has grown significantly. According to Pollard et al. (2008), the UK received one of the most concentrated in flows of voluntary migrations from Poland to date. Between 2004 and 2007, the Polish population had grown six-fold and became the largest group of foreign-born nationals to move to the UK (Pollard et al. 2008). However, it is debated whether Polish migration is falling or has remained constant, perhaps due to negative changes in the economic climate, as there are indicators of settlement. The most recent

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9 Since submitting this thesis, the Census 2011 data has showed that Polish is the second most prevalent language spoken in England and Wales, plus Poles were found to be the second most common foreign-born population in the UK (BBC News, 2012b). In addition to these data, other indicators have showed signs of settlement, as highlighted in a recent news article such as the availability of Polish food has increase where Waitrose has begun to stock Polish food an increase in marriages between Poles and British people, plus more Poles becoming British house-owners, a growing number of road-signs in English and Polish and hundreds of Polish bars, pubs and clubs (Rainey, 2013).
report by the Office of National Statistics (2011) showed that there were half a million Polish nationals in the UK in 2010.

Overall, recent Polish migrants were thought to be a mixture of young graduates and having up to high school level education and working in unskilled work. Some data have shown that Polish citizens coming to the UK post-2004 were young, for example 72% were between twenty and twenty nine years old and a large proportion is made up of university graduates (24%) who are mainly from small towns (41%) (Fihel et al., 2006). Pollard et al (2008) found that the Polish population are on average 26 years old, 43.8% are female, 63.6% are employed in unskilled occupations and the median school leaving age is 19 (Labour Force Survey 2004-2007). Sumption (2009) identified that the characteristics of Polish migrants changed between 2004-2007, the average age decreased slightly, education level decreased slightly but not significantly, the number of females increased and those being married declined. This informed the first sample of participants to be part of the study as per theoretical sampling used as part of grounded theory methodology.

Post-2004 migrants were thought to return home to re-join their family and friends after earning money in the UK (Pollard et al., 2008). This group was suggested to be individualised, market orientated and entrepreneurial (Garapich, 2008), this may mean that there is little sense of unity and community spirit among the Poles. These ideals are very different from previous Polish migrant’s views and this has caused a generation gap but also a cultural and class gap (ibid). Galasińska (2010) suggested that this group has established itself differently compared to previous migration waves, through the use of technology-based networking and creating its own generation’s identity. The way in which the ‘new’ Poles interacted with the ‘old’ Poles is the focus of Galasińska’s (2010) study. She explored ‘gossiping’ in Polish clubs and found that, like the findings of Garapich
(2008) of the post-1989 migrants, the older generations distanced themselves from the new migrants and the new group are not interested in other migration waves. The post-1989 migrants sit awkwardly between wanting approval and criticising the other groups but distanced themselves from both. Galasinska concluded that they all struggle with the 'other' and different versions of 'Polishness'. Galasinska also explained that the post-2004 migrants viewed migration as very difficult; she highlighted two themes in Polish migration literature that are significant. Firstly, the feeling that migrating was an important and difficult decision and secondly it was not a group experience, but an individual one, meaning that there were no symbolic ‘Polish’ locations to which they were attached. Once in the UK, they found it difficult going to places which were governed by post-war migrants. This shows that having a shared ethnic identity does not constitute post-war migrants and post-2004 migrants to belong to ‘one’ unified group or community.

The issue with previous literature on Polish migration, particularly for the post-2004 migrants is that the research focussed on the economic aspects of migration (Fihel et al., 2006; Pollard et al., 2008; Sumption, 2009). These data and information gleaned from these sources have helped to build a picture of the Polish community in the UK, but it could be argued to be skewed as some sources were funded and conducted by Institute for Public Policy Research (IPPR) as opposed to academic literature. There are also the sociological aspects of migration experiences (Garapich, 2008; Galasinska, 2010) and social networks (Ryan, 2010), where the narratives of migrants have been explored. However, the applicability of these narratives may be limited as the geographic locality is different to Luton and Dunstable where little research of the Polish community has been conducted. It highlights some aspects of migration that link with social capital theory such as social networks and club membership.
This section has provided a brief overview of the three most recent waves of Polish migration. Attention will now turn to Luton, the area of the study and away from Polish migration in general in the UK.

2.11 Luton and Dunstable Polonia as a Case

Luton and Dunstable (a neighbouring town) Polonia is a significant size. The Daily Mail (2009) found that in Luton and Dunstable, there could be between 6,000 and 10,000 Polish migrants (Luton on Sunday, 2009). To put this speculative statistic into perspective, in Luton in 2010 the Pakistani population was 24,200, the Bangladeshi population was 13,750, the Indian population was 12,250, the Black Caribbean was 10,150 and the Black African was 9,600 (Luton Population Projects, 2012).

There is little data about the numbers of Polish migrants in Luton including data from the Luton council report:

‘Luton schools admitted 450 children of Polish origin in 2006 alone – highlighting that dependant data from the WRS [Workers Registration Scheme] is seriously flawed. But this also serves as evidence that immigrants (in this case, Polish) are “putting down roots” in Luton’ (Luton Council Report, 2007).

The WRS was a flawed scheme as it was not mandatory to sign up to it, making the data indicative at best. Those who did register onto the WRS found it to be costly and time-consuming and the whole programme ceased in April 2011. These out-of-date and inaccurate data posed as a challenge to the study due to the lack of data to construct a profile of the community, such as the average length of stay and age of the Polish migrants that could help inform sampling.

Based on WRS applications made between 2004 and 2007 in Luton, A8 (Accession 8) migrants\textsuperscript{10} were shown to be working predominantly as

\textsuperscript{10} A8 describes the countries that joined the EU in 2004, these were the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia.
process operatives (34%), packers (24%) and warehouse operatives (16%) (Luton Council Report, 2007). These ONS data were in line with previous research that showed Poles were generally in low-skilled work (Labour Force Survey, 2004-2007). These data also indicated that there were families perhaps settling in the area as their children were attending school.

The Luton Council report highlighted that the levels of WRS registrations may be as low as 57% among A8 migrants (p.34). The Luton Borough Council report showed that new National Insurance (NI) numbers, another form of migrant registration, grew from 20 to 2,530 between 2002 and 2006 in the UK (Luton Council Report, 2007). However, the report showed the flaws of using new NI numbers as studies show that NI registrations are low among A8 workers at forty six per cent (p.34). This means that less than half the A8 workers were registering and accounted for within local council reports. Therefore an up-to-date figure is currently unavailable, but in spite of the limitations of the availability and the reliability of these data, indicators showed that the Polish community in Luton and Dunstable is significant and would be a suitable case for the present study.

The local Polish community were visible in Luton and Dunstable town centres and there were a number of shops selling Polish food. This was more visible in Luton, where there was a Polish deli, barbers and restaurants, however Luton is larger than Dunstable as Luton has 191,800 inhabitants (ONS, 2008) compared to Dunstable which had 35,120 inhabitants in 2009 (Central Bedfordshire, 2011). This map shows the population of Poles across the UK based on WRS data (Figure 3). In spite of these data being flawed and a little dated, they illustrate that Luton and Dunstable has a dense population of Poles.\footnote{Since submitting the thesis, the Census 2011 data has been released showing that there is a high density of Poles around London, particularly in Slough (BBC news, 2012a) (Figure 4).}
Figure 3: Poles as a percentage of all Worker Registration Scheme registered A8 nationals, May 2004-December 2006

Source: Bauere et al. (2007) p.9

Country of origin: India Poland Pakistan Ireland

Key: Percentage of foreign-born residents

<table>
<thead>
<tr>
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<th>0% - 1%</th>
<th>1% - 3%</th>
<th>3% - 5%</th>
<th>5% - 7%</th>
<th>7% - 9%</th>
<th>More than 9%</th>
</tr>
</thead>
</table>

Figure 4: Census 2011 Data: Percentage of foreign-born population
As well as inaccurate data, an additional challenge to gaining an accurate picture of the Polish community was the temporary migration patterns described in previous literature. There were stories in the national media during the study, for example Prof Iglicka (2010) from Warsaw’s Centre for International Affairs, in a BBC news report stated that despite the worsening economic climate, Poland has tried to encourage people to return through its involvement in a European infrastructure investment fund and a strong exchange rate. She added that there has been government campaigning around Wroclaw to entice Poles to stay in Poland to start a career (BBC news, 2010). Pidd (May 2011) reported that Poles are staying in the UK as it is a better economic situation than in Poland, particularly as most come from small towns in Poland where unemployment levels are high. But to contradict these findings, in a Guardian news report (April 2011), Gentlemen suggested that migration peaked in 2006 and, since the economic downturn, people were returning, however this is difficult to quantify.

Bielewska (2011) highlighted that the Polish migrants have flexible and temporary migration patterns. She suggested that coming to the UK enabled options to be open, although initially Poles generally had been perceived to stay for less than three months or were unsure of how long they would stay in the UK. The migration patterns could not be categorised as settlement but ‘fluid’ (p.22). Eade et al. (2006) categorised the migration patterns of the Polish workers in London as Storks, Hamsters, Stayers and Searchers. Storks are seasonal migrants who visit the UK for two to six months each time. Hamsters visit the UK only once and stay to improve their income to take back to Poland. Stayers remain in the UK but the most common in their research were searchers who wanted to remain flexible and work in Poland and the UK depending on the career opportunities. These types of migration may rely on transnational networks which operate over time and space, making networks complex (Ryan et al., 2008).
Information technology and the Internet are having an impact on this, through social networking sites ties can be maintained resulting in an 'illusion of closeness' with family and friends in Poland (Toruńczyk-Ruiz, 2008). There is evidence of settlement in the UK in other studies, such as Metykova (2007), Parutis (2007) and Rabikowska and Burrell (2009).

The Polish community in Luton were a suitable case for this study as they could offer a perspective on deceased organ donation, gift exchange theory and religion that has not been investigated before, for a number of reasons. Firstly, some African, Caribbean and South Asian countries have had historical links with the UK as they were Commonwealth regions, such as the West Indies or countries, such as Nigeria and India. Poland and the UK are not connected through the Commonwealth country but by both world wars. In World War I, the UK built prisoner camps for Poles in London and in World War II, both countries fought on the same side against Germany.

Secondly, Polish migrants were coming to the UK in a different technological environment compared to previous migration waves. Poles were arriving in the UK in the technological era of social media, such as Facebook and Twitter and cheap international calls, perhaps making connections to home easier to establish and maintain than earlier waves. Thirdly, Poland is very close, in relation to the other countries of origin for ethnic minorities in the UK, so it is easier for Poles to return home within a short timescale, particularly in Luton as there is the London Luton Airport with regular flights to Poland.

Fourthly, Poland was a communist country and has in recent history become more 'Westernised' as it has become a democratic country with a free market. This has influenced unemployment rates in Poland, as has joining the EU, where the movement of labour is easier, the UK may be
seen as a place to earn a good wage, a significant ‘pull’ factor. Also, this may have an influence on the way that giving gifts is viewed as in current communist countries, where gift giving may be seen as a way of life to get what is needed for everyday life. It may also have had an impact on the collectivist/individualist view of society, moving from collectivism where there is a strong sense of community, to individualism where individuals are expected to take care of themselves and their immediate family (Hofstede, 2001). Fifthly, Poland is known to be a Catholic country as the previous Pope, John Paul II, was Polish and from a recent poll in Poland a 95% of Poles regarded themselves as Roman Catholic (Ministry of Foreign Affairs, 2011). The other ethnic minority groups in the UK have represented Muslim; Sikh and Anglican Church perspectives on deceased organ donation, having a Polish view could add a Catholic perspective.

Luton Polonia as a case has been established as the context in which the relationships between deceased organ donation, gift exchange theory and religion were explored. Now, each of these aspects will be discussed in turn, in different combinations of pairs and all together.

2.12 Summary

The literature review took an in-depth view of previous empirical research and theoretical perspectives on deceased organ donation, gift exchange theory and religion and the additional concepts of social capital theory, altruism and religiosity.

Deceased organ donation is a significant problem as the demand for organs is not being met by supply. Maussian gift exchange theory is to be used for this thesis and a key aspect of this theory is the obligation for reciprocity. Past literature had found that extrapolating Mauss’ theory onto a biotechnological process had its challenges, such as it being too simplistic
but at the same time being able to understand some of the difficulties that the recipient may be facing. To offset this, altruism was considered as this has also been used in policy for organ donation and there is no obligation for reciprocity. However, the antithesis of altruism is egoism, this may have an influence on the obligation to reciprocate and non-altruistic based policies.

The aspect of reciprocity in exchange theory is thought to have social implications and to examine this further, social capital theory was included. This considers many aspects of giving towards the common good through civic engagement such as club membership, sense of belonging and trust. Religion was explored from a social constructionist perspective and considered alongside religiosity, a social psychological concept but through the constructionist lens.

The literature indicated that there is a little detailed statistical information about the in and out flows of Poles and much of the literature has focused on social networks, the economic contribution of Polish migrants and experiences of living in the UK and working in the UK. There was little research regarding health issues of Polish migrants. Attention will now turn to methodology that will detail the justification for the use of qualitative research and a grounded theory methodology and experiences of data collection when exploring the public health issue of deceased organ donation among the Polish community in Luton.
CHAPTER THREE: METHODOLOGY

3.1 Introduction

The methodology chosen to study the perceived relationship between deceased organ donation, gift exchange theory and religion was grounded theory. For an in-depth inquiry into the perceived relationships, the qualitative tools one-to-one interviews and small group interviews were used to gather data. Once data was collected, grounded theory coding and analytical processes were applied. This chapter presents a discussion from the philosophical and theoretical perspectives underpinning grounded theory to the arrival of the decision to use qualitative research tools. Crotty's (1998) model is used to frame understanding.

3.2 Crotty's Model

A challenge faced when conducting a literature review of the appropriate methodology to answer specific research questions is the plethora of definitions of epistemology and ontology and theoretical perspectives (Spencer and Snape, 2003; Guba and Lincoln, 1994) that may shape study design. Crotty's model provides a framework to present the process of decision making related to research methodology. Crotty’s model will frame the discussion but the definitions of other scholars will be incorporated but under the categories that distinguished. Crotty clearly defined epistemology, theoretical perspective, methodology and methods:

Methods: the techniques or procedures used to gather and analyse data related to some research question or hypothesis.

Methodology: the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes.
Theoretical Perspective: the philosophical stance informing the methodology providing thus providing a context for the process and grounding its logic and criteria.

Epistemology: the theory of knowledge embedded in the theoretical perspective and thereby in the methodology.

Crotty provided a level by level figure that showed how each element impacted on one another to lead to the justification and reasoning behind the decision to use a specific methodology and methods.

Figure 5: Four elements of the research process

Source: Crotty (1998) p.4
Crotty provided a table to illustrate samples of forms of epistemology, theoretical perspective, methodology and methods:

<table>
<thead>
<tr>
<th>Epistemology</th>
<th>Theoretical Perspective</th>
<th>Methodology</th>
<th>Methods</th>
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<tbody>
<tr>
<td>Objectivism</td>
<td>Positivism (and post-positivism)</td>
<td>Experimental</td>
<td>Sampling</td>
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<td>Interpretivism</td>
<td>research</td>
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<td>scaling</td>
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<tr>
<td>Subjectivism</td>
<td>• Symbolic interactionism</td>
<td>Survey research</td>
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<tr>
<td>(and their variants)</td>
<td>• Phenomenology</td>
<td>Ethnography</td>
<td>Questionnaire</td>
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<td></td>
<td>• Hermeneutics</td>
<td>Phenomenologic</td>
<td>Observation</td>
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<td>Critical Inquiry</td>
<td>Grounded theory</td>
<td>• participant</td>
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<td>Feminism</td>
<td>Heuristic inquiry</td>
<td>• non-participant</td>
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<td>Postmodernism</td>
<td>Action research</td>
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<td>Discourse analysis</td>
<td>Focus group</td>
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<td>Feminist</td>
<td>Case study</td>
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<td>standpoint research</td>
<td>Life history</td>
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<td>Etc.</td>
<td>Narrative</td>
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<td>Visual ethnographic methods</td>
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<td>Etc.</td>
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Table 3: Crotty's (1998) List of samples for each category

Source: Crotty (1998) p.5

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3.3 Developing a Research Design

Figure 6 below provides an outline of the organisation of the methodological chapter and the epistemological and ontological philosophy, theoretical perspective, methodology and methods chosen. The proceeding sections will discuss the justifications and logic behind the decision for each element of the research process framed by Crotty's (1998) model.

![Figure 6: The study's research process](image)

**Figure 6: The study's research process**

*Source: Adapted from Crotty (1998)*

ONTONOLGY AND EPISTEMOLOGY

The first element in Crotty's model is ontology and epistemology and a relativist ontology and constructivist epistemology underpinned the research for this study. This section will explain the reason for the choice of these philosophical stances taken.
Ontology is the nature of 'being', of human existence and reality (Marsh and Furlong, 2002). Blaiklie (2007) suggested that ontology is made up of assumptions and perceptions that individuals make about their social reality, what is ‘real’ and how this is experienced. For this study, the focus was on the Polish participants’ views of their social reality.

There are a variety of positions within ontology, these being predominantly realism and idealism with variants of these positions such as critical realism, materialism, subtle idealism and relativism (Guba, 1990; Snape and Spencer, 2003). Ontological realism is the existence of an external validity that is independent of our beliefs and there is a clear demarcation between beliefs and the way the world is (Snape and Spencer, 2003). Critical realism is similar to realism but is influenced by idealism, which will be discussed later in this section, it is where reality is known through socially constructed meanings but external reality exists (Snape and Spencer, 2003). Materialism is a variation of realism, meaning that it considers eternal reality to exist, however it considers tangible objects to be ‘real’ and the intangible world, such as what exists in people’s minds comes from the material world.
Taking a stance influenced by realism would not be appropriate for this study as it suggests that there is an external way of validating how an individual views deceased organ donation and how this relates to religion and giving gifts, altruism and social capital. This stance was not conducive to this study as I was not objectively measuring views toward religiosity or attitudes toward donation and giving gifts. The study instead examined subjective views that cannot be externally validated.

Ontological idealism differs significantly from realism. Idealism assumes that there is no existence of external validity as reality is only known through the mind and meanings that are socially constructed (Spencer and Snape, 2003). There are two variations of this; subtle idealism and relativism. Subtle idealism is where reality is only known through meanings that are socially constructed and shared and there is a collective mind (Spencer and Snape, 2003). Relativism assumes the social constructionist perspective but does not assume that there is one shared reality, rather that there are a number of alternative constructions (Spencer and Snape, 2003). Mills et al. (2006) suggested that relativism rejects the existence of 'objective reality' and argues that notions such as 'rationality, truth, reality, right, good or norms must be understood within a world where there are multiple realities shaped by context' (p.2).

My standpoint was that the social realities of the participants were socially constructed, meaning that taking an approach shaped by ontological idealism was appropriate. The main variations between idealistic perspectives are whether meanings are individual or collective. I represented the views of the collective but also reported the alternative views where one or a few participants did not agree with the majority instead of dismissing these.

Ontology is concerned with the 'what is' but epistemology embodies 'what it means to know' (Crotty, 1998, p.10). Epistemology is the way in which
the world is viewed and made sense of, there are three predominant positions; objectivist, constructivist and subjectivist (Crotty, 1998). An objectivist position ‘holds that meaning, and therefore meaningful reality, exists as such apart from the operation of any consciousness’ (Crotty, 1998, p.8). Crotty explained that objectivism goes hand-in-hand with positivism, used with a quantitative approach. As with the dismissal of the ontological realist position, this study took a qualitative approach and would not be taking an objectivist view as subjective perceptions were being explored and the stance of this thesis is that these cannot be measured or externally validated.

Constructivists purport that there is no human knowledge as ‘truth or meaning, comes into existence in and out of our engagement with the realities in our world...Meaning is not discovered, but constructed’ (Crotty, 1998, p.8). The ontological perspective taken for this study supposed that social realities were constructed by the individuals that were influenced by their interaction, engagement and interpretation of their cultural and social environment. The construction of meanings is in the minds of the individuals themselves these are being constantly revised and the meanings themselves were not discovered (Denzin and Lincoln, 1994; Guba and Lincoln, 1994). At this point, it is clarified that social constructionism is the overall philosophical approach that is taken for the study and constructivism is the constructing of social realities in the interviews.

Within this constructivist epistemological position, ‘realities are social constructions of the mind, and...there exist as many such constructions as there are individuals, although clearly many constructions will be shared’ (Guba and Lincoln, 1989, p.43). In stating that social constructionism is the ‘construction of social reality rather than the “social construction of reality”’ they highlighted ‘the idea that society is actively and creatively
produced by human beings’ (Marshall, 1994 in Crotty, 1998, p.54). This figure below illustrates the social construction of reality.

![Social construction of reality](image)

**Figure 8: Social construction of reality**

*Source: Flick’s (2004) Construction and interpretation as means of access to the world of experience*

Berger and Luckman (1966) suggested that ‘reality’ is created through externalisation, objectification and internalisation. Externalisation is where cultures and societies make sense of the world, objectification is how these constructs are perceived as being ‘out there’ and internalisation is where the objectified world is understood and maintained through socialisation. The participants who took part in the study had spent the majority of their life in Poland within Polish society and culture and this could have had an impact on how gift giving, religion and deceased organ donation were constructed. Constructions about organ donation, religion and gift exchange could have been shaped by Polish history and cultural practices and living in Britain may have had little impact on their

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12 Socialisation is a 'process in which specific convictions, notions, beliefs, practices, values, norms, et cetera (i.e. 'knowledge' present in the dominant culture) is transmitted to future generations to enable them to participate in the prevailing social life' (Vermeer and van der Ven, 2006, p.206).
constructs. For example, Catholicism is the dominant religion in Poland and could be assumed to have had an impact on deceased organ donation in, for instance, whether it is accepted and encouraged. This construct is on a societal level, influenced by the Catholic Church and internalised by individuals through socialisation through the church, schools whose curriculum would be influenced by Catholicism, and perhaps family and friends who may be sharing and reinforcing the constructs learned.

According to Furseth and Repstad (2010), Berger and Luckmann’s (1966) work derived from the overlapping of symbolic interactionism and phenomenology, that were both popular in sociology in the 1960s (Conrad and Barker, 2010). Phenomenology was discounted as an approach for this study as the focus is not on one phenomenon. However, in relation to social constructionism, phenomenology illustrates how ‘meanings of phenomena do not necessarily inhere in the phenomena themselves but develop through interaction in a social context’ (Conrad and Barker, 2010, p.567). This study was interested in how individuals have arrived at their ‘social reality’ through social, cultural and religious norms.

Stainton Rogers and Stainton Rogers (2001) saw social constructionism as ‘taking a critical stance towards knowledge; seeing knowledge as history-, culture- and domain-specific; viewing knowledge as created and sustained by social processes; and recognising that knowledge implicates action’ (p.161). It may be assumed that in the case of this study for example, the participants’ experiences of gift giving could have been shaped by religious practices such as Holy Communion and history, such as Communism. In addition, deceased organ donation could have been influenced by the Polish history of deceased donation, the Catholic acceptance of defining death for donation and societal views towards donation influenced by health campaigns.

13 Source: Ministry of Foreign Affairs (2011) found that 95% of Poles belong to the Roman Catholic Church
In line with Stainton Rogers and Stainton Rogers (2001), context is significant as constructs are influenced by cultural and social norms, in this case Polish culture and society but also UK culture and society from a migrant's perspective. This is where constructs created by Polish migrants become complex as the socially and culturally shaped normative beliefs in Poland may be different to British ones. The participants would have experienced two cultures with a different history of donation, gift giving and religion, with each migrant wave perhaps spending their youth in Poland. This present study focussed on the UK context, but participants did draw upon Polish examples or compared perceived differences between UK and Polish practices to illustrate their experiences.

The final epistemological stance is subjectivism, which is where 'meaning does not come out of an interplay between subject and object but is imposed on the object by the subject...in subjectivism meaning is created out of nothing' as opposed to constructivism where meaning comes from something (Crotty, 1998, p.8-9). This standpoint asserts that knowledge comes from the subject's mind, free from external influence. This approach was not relevant to this study because the standpoint is that 'reality' is constructed and is 'learned' and reinforced through socialisation, which is external and exists in the social and cultural environment.

THEORETICAL PERSPECTIVE

The second element in Crotty's model is theoretical perspective and an interpretive theoretical perspective was chosen based on relativist ontology and constructivist epistemology. This section will describe the justification for the decision for this theoretical perspective.
There are a number of research paradigms; positivism, post-positivism, interpretivism, pragmatism, participatory and post-modernism (Crotty, 1998).

Positivism is where reality is framed by natural law; the aim of positivist research is that the ‘truth’ is discovered (Guba and Lincoln, 1994). For this study, there was no ‘truth’ that was being discovered as social constructs and multiple realities were discovered. Post-positivism suggests that imperfect ‘reality’ is assumed because the phenomenon is complex (Guba and Lincoln, 1994). This was not relevant to this study as this links with objectivity where a phenomenon is externally validated and can be measured and complexities are taken into account. However, in this study, social realities and constructs were examined that are not measurable or possible to externally validate.

Interpretivism holds the view that meanings are constructed as individuals interact with the world because humans understand the world through their own experiences (Crotty, 1998). This theoretical perspective was most relevant as it fell in line with the ontological and epistemological approach taken for this study.
Post-modernists argue that there are no fixed meanings as ‘meanings’ are a manifestation of time and place. It is not possible for a researcher to produce an extensive account because if he or she tried to, it would suppress diversity (Snape and Spencer, 2003). This theoretical perspective in some ways links with the constructionist perspective as social constructions and individual schemas are fluid and can be influenced by time and place. However, this theoretical perspective was dismissed because the aim of the study was to examine meanings that are constructed within a Polish migrant context in Luton and Dunstable at one point in time that would impact on how ‘meaning’ is manifested.

A participatory theoretical perspective assumes that research is emancipatory that helps individuals free themselves, which often starts with problematic issues within society and its main focus is to bring about change in practice (Crotty, 1998). Although this study was born out of the resource problem of the supply of organs, the aim of this study is not to bring about change in practice. Therefore, this theoretical perspective was inappropriate as the focus of this study is to examine the relationships between deceased organ donation, gift exchange theory and religion.

Pragmatism assumes that researchers can choose what research tools they need to use to meet the needs of the study, there is no ‘one’ way of viewing reality and truth is what makes sense at the time (Crotty, 1998). This will be examined further in the data collection section.

From all of the theoretical perspectives available, the most suitable to the aims of the study is interpretive. This perspective assumed the social world and researcher influenced one another. However, the limitation of this perspective is untangling the extent to which the findings are influenced by the researcher, who is central in grounded theory, making it difficult for the research to be free from biased. This shared ‘reality’ that is co-created with the researcher can be examined further through symbolic
interactionism (Crotty, 1998). Symbolic interactionism was developed by Mead (1934/1962) and it 'focuses on the meanings of events to people and the symbols they use to convey that meaning' (Baker et al., 1992, p.1355). For groups to function meanings are shared through language and socialisation, with these social meanings being continuously developed in social interactions, making reality fluid and dynamic (Chenitz and Swanson, 1986). In this study a qualitative approach will be taken to gain in depth information as there has been little research on this particular community in this context.

To meet the aims of the study, it has been argued that a constructivist epistemology, relativist ontology and interpretivist theoretical perspective were used. The next section will discuss the methodology and theoretical framework utilised.

**METHODOLOGY**

Using Crotty's model for designing research the sections above have highlighted the centrality of a constructivist epistemology, relativist ontology and interpretive theoretical perspective for developing a research design. This section builds upon these approaches and shows how they have influenced the research methodology.

Grounded theorists Strauss and Corbin (1998) stated a methodology is 'A way of thinking about and studying social reality' (p.3). The methodology used for the research was constructivist grounded theory and influenced the approach used for studying the perspectives of the Polish community. Grounded theory methodology advocate specific ways of data collection, the sampling strategy used and coding and analytical techniques, which can arrive at the conceptual map that visually represents the findings.
Grounded theory was developed by Glaser and Strauss (1967) at the University of San Francisco in California when studying dying patients in hospital. Grounded theory may be defined as ‘a systematic, inductive and comparative approach for conducting inquiry for the purpose of constructing theory’ (Charmaz, 2006; Charmaz and Henwood, 2007 in Bryant and Charmaz, 2007, p.1). Symbolic interactionism influenced Glaser and Strauss in their interpretation of ‘what society is, how it works, and what aspects of it need to be investigated in order to understand particular social situations’ (Baker et al., 1992). Grounded theory is rooted in symbolic interactionism (Strauss and Corbin, 1994) and the researcher is investigating the social processes that are interacting (Hutchinson, 1993). Thus taking a grounded theory approach was appropriate for this study as it takes an inductive approach in uncovering the participants’ views toward the relationship between deceased organ donation, gift exchange theory and religion.

Glaser and Strauss’s (1967) purist, classical grounded theory methodology begins without a literature review but a broad subject which is investigated through qualitative methods. The issues that arise through the fieldwork
are further investigated in simultaneous analysis through constant comparison and literature review. Future participants are selectively chosen through theoretical sampling and fieldwork is complete when saturation has occurred. However, over time, this classical grounded theory has changed, with the split between the original creators of the theory acting as the catalyst. Strauss developed his own method with Corbin, which differed from the Glaserian approach that was closer to the original methodology.

Annells (1997a, 1997b) argued that Glaser’s classic grounded theory may be referred to as ‘critical realist’ ontology and ‘modified objectivist’ and Strauss and Corbin’s (1998) approach took a ‘relativist’ and ‘subjectivist’ position (Ghezeljeh and Emami, 2009). This is in line with the current study, which took a relativist ontological stance. However, the theoretical perspectives differ as this study took an interpretivist approach as opposed to a subjective approach. This was overcome by taking a constructionist grounded theory approach as developed by Charmaz (2006), which builds on the Straussian framework. Strauss and Corbin’s perspective may be seen as ‘the reformulated grounded theory’ that advocates ‘objective external reality, aiming toward unbiased data collection’ (Ghezeljeh and Emami, 2009, p.17). Strauss and Corbin argued that their approach was epistemologically both post-positivist and constructivist as there are multiple ‘truths’ (Mills et al, 2006). This study did not take a Glaserian classical approach to grounded theory, but one that was influenced by Strauss and Corbin (1998) and Charmaz (2006).

The major differences between the Glaserian and Straussian approaches to grounded theory is linked with the coding paradigm and advocates an absence of a literature review as the research process starts with an ‘abstract wonderment’ and not taping the interviews but to rely on written notes and for the interviewer to talk as little as possible (Haslam, 2011).
The Glaserian method stresses emergence of the data but the Straussian approach takes a systematic approach, allowing interviews to be taped and transcripts to be coded to generate theory. According to Flick (2004), there are four main features within social interactionism, in which grounded theory is embedded, these are ‘Verstehen [the interpretive examination of social phenomenon (Elwell, 1996)] as epistemological principle, reconstructing cases as starting point, construction of reality as basis and text as empirical material’ (p.66).

When considering a grounded theory approach to doing a literature review, there are conflicting views between Glasserian and Straussian positions. A Straussian viewpoint advocates an initial review of the literature as '[i]t stimulates theoretical sensitivity, it provides a secondary source of data, it stimulates questions, it directs theoretical sampling and it provides supplementary validity' (McGhee et al., 2007, p.336). A Glasserian perspective is where no literature review is conducted at all but data collection is directed by the data and participants. By considering both Glasserian and Straussian approaches, I took a combination of these perspectives. Doing a literature review is something that is influenced by the ‘researcher’s ontological perspective, previous background and knowledge of the topic area, the researcher’s existing level of research experience and the need to meet ethics committee requirements’ (McGhee et al., 2007, p.341).

I decided to do a literature review for this study to make a significant contribution toward the field. I was aware of the research that had already been done, learnt from this and created aims that built on the current knowledge as opposed to talking to the Polish community about organ donation that may not have led into other areas in which previous researchers had highlighted as significant. Like the Glaserian method, a literature review was continuous throughout the study to review links with
existing theories to the model (Hutchinson, 1993). In addition, from a practical perspective as highlighted by McGhee et al., as a PhD student, I had to write reports for the PhD process for the university to progress to PhD from MPhil and to pass the ethics committees and a literature review was needed for these reports.

**Constructivist Grounded Theory**

Using a grounded theory method has been argued to be the most appropriate for this study, however within this approach there is constructivist grounded theory, which was developed by Charmaz (2006). Her approach studies individuals in their natural environment as constructivism supports the individual’s view of reality as constructed and invented by the individual, each having different views of reality. Constructivist grounded theory views data and analysis as a product of shared experiences and the researcher’s relationship with the participants (Ghezeljeh and Emami, 2009). It is argued that that the data and its analysis are social constructions in themselves (Charmaz, 2000, 2006). Data analysis reflects a specific culture, time and location, researchers have to be self-aware in their preconceptions and openly express how they influence the research (Charmaz, 2006). Data are constructed through a continuous interaction between the researcher and the participant and the interpretative understanding the researcher makes of the participant’s meaning of reality through analysis (Charmaz, 2000, 2006). This approach is very relevant for this study as the ontological and epistemological perspective, from which this thesis is drawn, parallels Charmaz’s.

**Rejection of Phenomenology and Ethnographic Methodology**

The methodologies of phenomenology, ethnography and grounded theory were all considered as they fitted within the constructivist epistemological position (Mertens, 2005). By using an ethnographic methodology, the focus
would be on the Polish community and not on the relationships between organ donation, gift giving and religion, which is the primary aim of the study, making an ethnographic methodology irrelevant for this study. A phenomenological methodology assumes that the phenomenon is a lived experience, which some aspects of the study were, religion for example but not the main aspect of the study which was deceased organ donation. Thus, a phenomenological methodological approach was also not appropriate for this study. I did consider methodology slurring through merging grounded theory and phenomenology (Baker et al. 1992), however this was not viewed as conducive to the aims of this study.

METHODS

The final level of Crotty’s (1998) model is methods; there are a number of different types of research method or ‘tools’ including questionnaires, participant observation, interviews and focus groups.

![Diagram of methods](image)

Figure 11: Methods

Source: Adapted from Crotty (1998)

The most appropriate methods for this study were qualitative tools of inquiry as this study took an epistemological constructivist and ontological relativist stance and interpretive theoretical approach, meaning
questionnaires and other quantitative methods were not suitable as these methods were positivist. Participant observation was not relevant because I was not examining behaviours within a certain environment, but wanted to gain a Polish perspective on the meaning of the perceptions of deceased organ donation, gift giving and religion and their relationship. The most appropriate methods were focus groups and interviews for data collection. In grounded theory, data collection is part of an on-going cycle where the aim is to create the core construct, sub-core construct and categories. The core construct explains what is happening in the data (Haslam, 2011) and is the central point of grounded theory.

Figure 12: Grounded Theory Process

Source: Adapted from Haslam (2011)

Focus Groups and Interviews

Focus groups are an organised gathering where participants can discuss how concepts interact; it is this discussion between the participants which
constitutes research data (Kitzinger, 1994). Kitzinger argued that group work is significant for ‘grounded theory development – focusing on the generation rather than the testing of theory and exploring categories which the participants use to order their experience’ (Kitzinger, 1994, p.108). Focus groups were appropriate as a method in this study as they identified community norms, recognised issues quickly so that they can be discussed and clarified in detail, but the depth of information was less than one-to-one interviews and difficulties in managing the group’s dynamic. For this study, the approach taken was to explore the social realities and social constructions, therefore identifying social, cultural and religious norms for deceased organ donation, religion, gift-giving, altruism and social capital.

Individual interviews are ‘directed conversations’ (Lofland and Lofland, 1984, 1995) and there are two positions on in-depth interviews according to Kvale (1996), the first is a ‘miner metaphor’ where the knowledge is ‘buried’ in the interviewee and ‘a traveller metaphor’ where the researcher is on a journey trying to understand the participant’s lived world from their view.

**DATA COLLECTION**

There were in total 3 small group interviews and 21 one-to-one interviews and interviews lasted approximately an hour to an hour and a half and were typically at the University of Bedfordshire Park Square campus for students and staff and at the participant's home. There were three samples of participants overall, the first sample was recruited through the University of Bedfordshire, the second sample was recruited through community networks and the Mother and Toddler group that adjoined the Polish Church in Dunstable. Data collection was between May and November 2011.
Data collection and the recruitment of participants were challenging as I am a non-Polish speaker and there was reticence from the post-Second World War Polish migrants to take part in the study. In addition to issues with recruitment and data collection was the challenge of using grounded theory for cross-cultural research. This section reflects the pragmatic approach taken that reflects the flexibility of grounded theory in exploratory research such as adapting data collection tools and changing recruitment methods for different sample groups.

**Pilot Study**

Before data collection occurred, focus groups were intended to be used as a method therefore the pilot study was a focus group with students from the University of Bedfordshire. The group interview was made up of four women who had heard about the study through the University of Bedfordshire and were either working or studying there. From the literature review, I had decided to make a group interview up of young, well-educated Polish people who could speak English as guided by the literature. Local data also suggested that the majority of local Polish migrants worked in low-skilled work, such as warehouse operatives, but these were not the first group to be part of the study because I wanted to thoroughly test the interview guide in English and discuss the detailed makeup of the Polish community to inform the theoretical sampling, the official data on local Poles being unreliable.

From this initial group interview, it began to emerge at a practical level, the difficulty of arranging groups as Poles worked and studied long hours and it was problematic setting up a group interview in reality among strangers. I had set up one group with each of the participants individually but a few of the participants knew one another. Also, I believed that one female participant withdrew from the first group interview as when I initially discussed the topics with her, she was very sensitive about her religion as
she was atheist and although she said this was not a problem, she did not show up to the group interview. I contacted her the next day and she said that she was ill, this may have been the case, but it made me think that perhaps it was not just deceased organ donation that was a sensitive issue, but religion and being a non-believer that she had been concerned about when I was discussing her participation in the study was an issue, which I later found was stigmatised in Poland (Tyrala, 2011). For these reasons, I decided to continue the data collection using individual interviews and if people felt uncomfortable doing this they could invite their friends and I would conduct small group interviews or paired interviews. There were limitations to doing this as individuals who invited their friends may have similar values and attitudes but it was also advantageous as people were open and comfortable talking about sensitive issues and challenging each other’s views.

**Sampling Strategy**

Choosing a sample based on the literature is called theoretical sampling, Strauss and Corbin (1998) split into stages of ‘open sampling, relational and variational sampling, and discriminate sampling, which correspond directly with their stages of open, axial and selective coding’ (in Breckenridge and Jones, 2009, p.116). Strauss and Corbin (1998) believed that sampling is based on the openness of the interview which guides the sampling process.

A purposive convenience sampling strategy was used. Purposive sampling is 'A form of non-probability sampling in which decisions concerning the individuals to be included in the sample are taken by the researcher, based upon a variety of criteria' (Oliver, 2006, webpage). Initially the literature review informed the first sample where there was the assumption that Polish migrants were young and educated. After interviewing students, sampling moved onto low-skilled workers and young families as it emerged that these were the most visible group in the local area. The third sample
was the post-war migrants who were included to incorporate a different perspective on the relationship as a group who had been in the UK for a number of years. Below is the inclusion and exclusion criterion that was used to guide the sample. Before the sample was recruited, saturation was reached in each sample, a concept that will be discussed later in the chapter.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria changed as the data collection, analysis and coding developed as new themes emerged that led to different criteria being required for recruitment.
<table>
<thead>
<tr>
<th>Sample</th>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First Sample</strong></td>
<td>Post-2004 Polish migrant</td>
<td></td>
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<tr>
<td></td>
<td>Spoke English</td>
<td></td>
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<tr>
<td></td>
<td>Living in Luton</td>
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<tr>
<td><strong>Second Sample</strong></td>
<td>Post-2004 Polish migrant</td>
<td>Students</td>
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<tr>
<td></td>
<td>Low-skilled workers</td>
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<td></td>
<td>Parents of young families</td>
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<td></td>
<td>Spoke Polish and English</td>
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<td></td>
<td>Living in Luton and Dunstable</td>
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<tr>
<td><strong>Third Sample</strong></td>
<td>Post-war Polish migrant</td>
<td>Students</td>
</tr>
<tr>
<td></td>
<td>Living in Luton and Dunstable</td>
<td>Parents of young families</td>
</tr>
<tr>
<td></td>
<td>Low-skilled workers</td>
<td></td>
</tr>
</tbody>
</table>

Table 4: Inclusion and exclusion criteria of sample
Sample Size

In total, there were 31 participants who took part between June and November 2011. The first (in pink), second (in purple) and third sample (in blue) are colour-coded in the table below.

<table>
<thead>
<tr>
<th>No</th>
<th>Code</th>
<th>Gender</th>
<th>Age</th>
<th>Sample</th>
<th>Occupation</th>
<th>Education</th>
<th>English Level</th>
<th>Children</th>
<th>Views Toward Religion</th>
<th>Weekly Church Attendance</th>
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<td>22</td>
<td>3</td>
<td>Student</td>
<td>BA</td>
<td>Proficient</td>
<td>0</td>
<td>Catholic</td>
<td>Once</td>
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<td>11</td>
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<td>2</td>
<td>FG F</td>
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<td>7</td>
<td>Admin</td>
<td>Master</td>
<td>Proficient</td>
<td>1</td>
<td>Catholic</td>
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<td>FG F</td>
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<td>Proficient</td>
<td>0</td>
<td>Catholic</td>
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<td>I1 F</td>
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<td>Student</td>
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<td>Student</td>
<td>BA</td>
<td>Proficient</td>
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<td>Non-Believer</td>
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<td>42</td>
<td>18</td>
<td>Teaching Assistant</td>
<td>Master</td>
<td>Proficient</td>
<td>2</td>
<td>Catholic</td>
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Table 5: Sample of Participants

**Recruitment**

As the sampling strategy developed, the recruitment strategy changed to attract the sample that met the inclusion and exclusion criteria. This section will outline the recruitment of each sample.
Recruitment of First Sample

The literature had intimated that majority of Poles were Roman Catholic therefore it was assumed that the majority of Polish migrants attended the only Polish-speaking church in the area, in Dunstable, the neighbouring town to Luton, and would be a good source for a cross-section of the Polish community in terms of differing lengths of stay.

Polish Church in Dunstable. With the assumption based on the literature review of Polish migration that Poles are religious as a starting point, I contacted the local Polish Catholic Church in Dunstable. In May 2011, a working relationship was beginning to be established with the Polish church in Dunstable. Starting the relationship with the Polish church was not easy, luckily one of the Polish individuals that I had contacted earlier, a contact I had, had tried to engage the church in a study with two prestigious universities in the UK and Poland. With her experience in mind, I knew that I could not informally call, email or go and visit the church uninvited, but that the initial contact had to be formal. A letter was written to the priest from my supervisor and we arranged a time for me to call the priest to set up a Sunday meeting where my supervisor and I would go to visit him (see Appendix Two). Unfortunately, we only just missed him as he had to go to another Catholic church in Milton Keynes, but we did speak to the mother and daughter who ran the bar at the time, whose father/grand-father had set up the church. They assisted me greatly in this study and suggested that I returned the following week to try to see the priest again. On reflection, I had not realised that the priest may have benefited from the letter being in Polish, but at the time I did not have a Polish translator and there were individuals at the church who were bi-lingual.
Unfortunately, the next week when I returned he was not available. I had previously made contact with the Head teacher for the Polish Saturday School and had met him to gain a better understanding of the Polish community. He was also present on my second visit and said that I could go along to the Children’s Masses and speak to people about my study. This was great news as I thought that as I had not spoken to the priest I would not be able to do the study. The Head teacher said that before I came, I should write a letter to parents giving them information about the study that would go out in their newsletter that week before the summer holidays began. I wrote a letter in English and he translated it into Polish and this was printed out, put into envelopes and sent to parents. The week after the newsletter went out, there was the Children’s Mass that I went to and begin recruiting participants for the study.

**University of Bedfordshire.** At the same time, I began recruiting at the University of Bedfordshire, as it was crucial that I attracted the students before the summer term ended. I put up a poster at the University (see Appendix Three) and contacted the Polish society at the University. It emerged, however that the Polish society was not active although they were very helpful in letting their friends know about the study. The marketing department at the University of Bedfordshire allowed me to put posters up in glass cases close to the library, one of the busiest areas.

An incentive of a £20 voucher for the Luton Mall was to be given to those who took part in the study. There are a number of limitations for the use of incentives such as research participants being coerced or persuaded into doing research, potentially affecting the motivation for the candidates to take part and introducing power relations (Grant and Sugarman, 2004). In spite of these limitations,
using incentives in the present study are outweighed by the benefits. The benefits included evoking participants to be motivated to take part in the research and to encourage their friends to take part.

Community Networks. At this point, I networked through email with Polish migration PhD students and researchers such as Helen Lowther, an English researcher who had really immersed herself amongst the Polish clubs and societies in Newcastle. I wanted to find out more about how other people had approached participant recruitment within the Polish community, particularly as an ‘outsider’. Helen’s ethos was to be a familiar face in the local Polish community as it would be easier to get participants if she was not a stranger. She attended film evenings, food festivals, and Polish restaurants and to communicate with them she learned Polish. I thought that was a good idea and learned some Polish but it was very difficult as it is so different from English and French.

I had some ‘warm’ connections with the Polish community through friends and meeting people at the University of Bedfordshire conference in July 2010, I emailed them and gained their view of the Polish community in Luton. I decided not to be too immersed with the Polish culture as I did not want to become too familiar and did not want them to become reserved in their answers if they were worried about confidentiality.

The pilot focus group had been recruited through the University of Bedfordshire Polish society and student and staff networks. The Polish community at the university was relatively small and although the participants had been contacted separately through different networks, they knew one another. This pilot focus group
enabled the interview guide to be tested and to test the card-sorting exercise, which will be discussed later in this chapter.

After the initial few interviews and group interview, it was clear that my first assumptions of the Polish community were very different to the participants' 'social reality' of the Polish community. The main difference was that the post-1989 group was not visible; there was one participant who was 42 years old who took part and was the only post-1989 Pole that I could access as they were very difficult to find. Also, the post-war group were very small and only existed within the church as their other organisations such as the Polish clubs had closed down. In addition, the second and third generations were not very visible, the only second and third generation Poles that I had met were the two women that worked at the Polish club, and this group was also difficult to access. Within the post-2004 group, there were a range of different 'clusters' of groups based on the reasons for coming to the UK.

**Snowballing Technique.** Within the post-2004 group, the Polish students and staff at the University were forthcoming in helping me find people to take part in my study such as their friends who were Polish. This is a form of purposeful sampling, called 'snowballing' (Bluff, 2005) and involved initial participants being asked to 'suggest others whom they [knew were] in the target group and who could be invited to take part' (Bowling, 2009, p.409 ). Although it is also a convenient form of sampling, it may be argued to be biased as negative cases should be included to provide different views to develop a balanced argument. However, in terms of negative cases, this would be difficult to define for this study as I was not
investigating one phenomenon or behaviour but examining multiple realities.

For this study, snowballing was beneficial on the one hand as it enabled potential participants to come forward for the study as their friend had taken part, but on the other hand, the individual would have heard their friend's experience of the interview process. This is a negative aspect to snowballing as the individuals sometimes researched me or looked into organ donation as they knew that they were being asked about it. This was problematic because the participants did not come to the study with what they would have originally known about organ donation as they had deliberately learned more about it before the interview, thus not truly representing views towards donation in this study. Although I was not testing their knowledge, their constructions may have been affected as constructions are fluid and may be shaped by new information.

Also, through snowballing, there was a risk that recruiting a participant's friends who may hold similar views restricting the breadth of views. In reality, however, this was not the case, for example, two cousins took part and their experiences of Luton and views towards deceased organ donation and religion were very different. Through the constant comparison method of analysis, it had become clear that no new categories were emerging among this predominantly post-2004 group. In addition, it had been found that the University staff and student population were a minority within the Polish community. The majority of Poles in the area were found to have a young family or were low-skilled, non-English speaking and young, this mirrored the Luton Council data and I
decided to change my sampling strategy to include non-English speaking Poles in low-skilled work or who had a young family.

Recruitment of Second Sample

Changing my sampling strategy meant that recruitment methods had to adapt as it had become clear that Poles generally socialised with other Poles who had come to the area for a similar reason. One of the participants of the first part of the study was an English language teacher and had enabled me to speak to his students. I tried to produce posters in Polish however, it was clear that my lack of Polish language and use of online translators was impacting how effective my recruitment strategies were, as the posters were being checked by Polish friends of friends and I did not want to keep relying on them. I decided to recruit a translator to help me and who would later conduct the interviews. The translator helped me produce leaflets in Polish and she translated all of the recruitment materials, so that when someone was interested in taking part we could move quickly in setting up an interview. The translator helped me to further my working relationship with the priest and build up contacts at the Children’s Mass as discussed earlier.

Polish Church in Dunstable. In July 2011, the recruitment of families was influenced by the summer holidays as the majority of Poles had gone back to Poland meaning that the Polish Saturday School was on their holiday break and the Polish Catholic Church was very quiet. I decided that the translator and I should go and visit the priest to build foundations for September, when Poles would be back in the area. When we discussed the study, at first he was unsure about it and wanted to see all of the documentation and interview questions. These had all been translated into Polish and this was beneficial as he did not speak English well. By the end of the discussion, he was happy to support the study.
At a later meeting with him, we had an impromptu discussion about different aspects of the study such as Catholic death and church attendance among the Poles in Luton and Dunstable. This initially was not part of the methodology but the opportunity arose where he wanted to discuss the thesis with me and give me information. I felt that at this point, he would be able to give me a different perspective on some of the themes that were arising in the study. This worked well as speaking to key leaders within the Polish community provided new information. I had already discussed the community with the Head teacher who was a significant figure and I perhaps should have planned to have interviewed the priest too. However, this may have been difficult due to the changeover of the priests. There was one priest who left near the beginning of my study and it was the second priest who had replaced him who I had met.

In August 2011, no data were collected and recruitment resumed in September 2011. The translator and I spoke to the church members after Mass at the Polish club where there was a licensed bar or tea and cakes in the church hall. Many of the families that were present after the Children’s Mass organised by the Polish Saturday School, did not speak English well and having the translator was key to explaining the study to recruit participants. The post-war migrants were also there after Mass and they did speak English but chose to speak Polish with the translator.

It was thought that after a number of trips to the Children’s Mass at the Polish Church that some parents may take part, but they all silently withdrew, in that they did not respond to me or the translator emailing or calling them to set up taking part in the study. The explicit support by the priests shown at the mother and toddler
group was not shown at the Children’s Mass; it was limited as they were not willing to suggest that families take part. However, the Head teacher did request that families take part, for which I was extremely grateful but having the priest show his support in Mass may have had a greater impact on the recruitment for the study as his endorsement may have carried more weight.

I attended the mother and toddler group at the church. The priest had on one occasion walked with us into the mother and toddler group, explicitly showing his support for the study. The priest may be described in this situation as a ‘cultural broker’ (Galasińska, 2011, personal communication) as he was the link between myself and the potential participant.

The mother and toddler networks snowballed, but not as quickly or as widely as the University networks. Due to the participants through the mother and toddler group mainly living in Dunstable, the geographical area for the study was expanded to incorporate Luton and Dunstable. The mother and toddler network was very small and using this network was beneficial as someone was likely to know another who took part.

**Raising Awareness of the Study in Luton.** In addition to going to the Children’s Mass, myself and the translator used other methods to recruit participants. These included speaking to parents at the mother and toddler groups; putting posters in Polish (see Appendix Two) at the Polish deli and shops in the town centre selling Polish food; asking local recruitment agencies to give out leaflets, which were smaller copies of the poster; having my own Organ Donation study Facebook page; networking on Facebook and distributing leaflets through workers at Amazon, ASOS, Pratt’s Bananas (all large employers of Polish workers from Luton) as
opposed to going through the employers directly; advertising the study in Polish on the local Luton Polish magazine Facebook page; and going through the translator’s wide social network.

The only difficulty I met was through the recruitment agencies in Luton, where unfortunately I was unable to put a poster up about the study as they had a policy against this and against the storage of any of my leaflets for Polish applicants who came in for factory work.

Although my recruitment posters were posted around Luton and I had started to network through Facebook, not all of these recruitment methods were successful. The ‘cold’ methods such as networking on Facebook and leaflets and posters had a low response rate.

The translators used their personal community networks to help recruit participants for the second sample. The translator at the time worked in a customer service role and took any opportunity to speak about the study to another Polish person living in Luton who she met at her day job or running chores in the area. The translator’s social network had limitations as she was a University student who was a professional translator and her friends were mainly linked to the University and spoke English well, she generally did not socialise with Poles who were non-English speaking. It was through her Polish friends and some English friends who worked in warehouse jobs that enabled access to non-English speaking Poles.

The translator’s networks worked well, however, the disadvantage to using this was that I had not met them and could not meet them when recruiting as I did at the church. The translator was keen for the interviews to move quickly and at times it felt like she was trying to decide who would take part. This was problematic as the
translator was talking to people about the study and setting up dates. On one occasion, she had set up a date without my consent and I explained that no-one can take part unless the participant had completed the recruitment form that included their length of stay and job role, which I assessed and then decided if the interview would occur. Not all of the people that she suggested were suitable at this stage of the study, for example, if they were a member of University staff as these participants would have been part of the first sampling stage. Recruiting through the translator's network was a challenge as I had to keep her motivated and interested in the study as she was key in helping to recruit participants. Having a translator act as the 'middle-man' did slow the process down, but participants responded better to a ‘warm’ contact who was Polish rather than a ‘cold’ contact who was English and did not speak Polish.

I felt that the translator and I could have had some influence on participant recruitment, as we were both female in our 20s. This may have had an impact as I found that more females who were in their 20s and early 30s came forward than males. This may have been due to females being comfortable talking and vocalising their views on these issues to another female.

Recruitment of Third Sample

At this point, the data collected from the English speaking and non-English speaking Poles led me to decide to recruit participants who had been in the UK for much longer than the post-2004 Polish migrants. I wanted to find out whether age or generational differences, different reasons for coming to the UK and a longer time in the UK would influence how participants viewed the relationship between deceased organ donation, religion, gift giving, altruism and social capital.
These participants were recruited through the priest who had invited the translator and me to a post-war lunch which occurred after Mass. I had met a few of the people who attended this lunch before as I had been to the Children’s Masses a few times when a group of post-war women and men were present. At the end of the meal, the priest announced the study which I outlined in English and the translator said in Polish. There were many questions after in relation to the Catholic Church’s view towards organ donation and transplantation. Two of the participants had come to England after the Second World War and one of the participants had been born in the UK after the war.

Previously, an incentive in the form of a £20 voucher for the Luton Shopping Mall had been given to the participants taking part however, it was clear that this was not attractive for this group as it was difficult to get them involved. Since the initial contact with the congregation after Children’s Mass, the translator and I had spoken individually to the older migrants who were having tea and cake. At the first meeting, they were reticent to take part in the study and the leader on the table said that no-one would be interested. Every time the translator and I went to the Children’s Mass, we spoke to the older migrants but they remained unwilling to take part. When discussing with them the reasons why, some said that they were too old to take part in research or were not able to donate as they were older and their views would not be helpful, although the translator and I did explain that their input was significant to the study.

It was decided that a donation worth £20 be given to the church for each older participant who took part and this was announced at the lunch where the post-war participants were recruited. It is unknown as to whether it was the change in incentive or our presence at the lunch with the endorsement of the priest that led to the participants taking part. Those who were from the post-war group had been involved in the setting
up and buying of the church and giving a donation best suited these participants. The final interview guide (Appendix Four) was adapted for the post-war migrants as it was considered due to their age, they may tire quickly. This turned out to be the case, particularly for those in their mid-80s and early 90s.

One-to-One and Small Focus Group Interviews

This section is going to explore the developing interview guide, the challenges that examining social capital presents in the interview guide and the card sorting exercise in the interview.

The Interview Guide

My role as the interviewer in these interviews was to ‘map’ the participant’s perspective on the issues and subsequently ‘drill’ into the participant’s views on organ donation, gift exchange and religion through probing questions, such as ‘why do you think that?’ This was because I wanted to gain a fuller picture of the ‘reality’ and the constructs of helping others, gift giving, religion and deceased organ donation among the Polish participants. The participants were then able to guide the data collection to some extent because new issues that arose that I had not considered previously could be ‘drilled’ into. From a constructivist grounded theory perspective, Charmaz (2006) argued that an interview is ‘contextual and negotiated’ (p.27) where participants may also request information. This occurred in this study, particularly when discussing organ donation and brain stem death.

The interview guide changed and developed throughout the data collection process (see Appendix Four). In the first interview guide, I did not include
social capital because I focused on the main aspects of the study, such as religion, gift exchange and organ donation. I did not feel confident at that point that social capital should be included as it had not been discussed in the context of deceased organ donation before. At the end of the group interview, I discussed this notion with the participants who thought that it made sense to consider how someone feels when they have migrated to a new country and whether they trust the NHS so this was added in the subsequent interview guides.

The interview guide and conceptual map had developed throughout the data collection process. The final interview guide was made up of prompts as opposed to open ended questions and the interview was a discussion around the themes that had emerged (for samples of English and Polish interviews go to Appendix Five). Changing and developing the interview guide throughout the process was beneficial as new themes could be explored, however, it was problematic as the guide cannot be too long and not all the questions were standardised across the interviews, meaning that some data may have been lost.

Within deceased organ donation, the main healthcare professionals involved are the Specialist Nurses in Organ Donation (SN-OD), Clinical Lead in Organ Donation (CLOD), Nephrologists and Transplant Surgeons. To add to the relevancy of this study, I visited the local SN-OD\textsuperscript{14} from the Luton and Dunstable hospital based close to the Intensive Care Unit to discuss the different aspects of the process of deceased organ donation, gift rhetoric and the role of religion. I asked about aspects of donation that I thought I may be asked by the participants, such as what the body looks like after organs have been removed, also I learned more about the process itself.

\textsuperscript{14} In a discussion with the SN-OD, it was highlighted that it would be useful for practitioners to be aware of who is influential in decisions about organ donation in the family and this question was added to the interview guide.
and how death is diagnosed. I gained a better understanding of the local
demographic who become organ donors and reasons for refusing and the
role that giving gifts and religion plays. The SN-OD was also the point of
contact for the participants in the debriefing letter in case they had any
questions about donation locally.

Challenges of Social Capital for the Interview Guide

There have been few social capital and health studies that have use
qualitative research methods. Kawachi et al. (2008) found that there had
been no qualitative studies of social capital and health before 2001
(Mackinko and Starfield, 2001). Kawachi et al. (2008) cite 11 qualitative
studies that deal with social capital and health and three of these were
conducted in the UK.

Campbell and Giles (2001) interviewed 37 residents in a South England
town, here Putnam's social capital was being tested in a British urban
environment. It was found that Putnam's concept does not encapsulate
lived experiences of residents. Campbell (2002) interviewed 25 African-
Caribbean participants to explore the impact of ethnic identity on
participation in local community networks, social capital here was viewed
as Putnam's civic engagement but results were interpreted based on
Bourdieu's theory that emphasises differential access and inequality
reproduction. Finally Cattell (2001) interviewed 100 residents in inner-
London and social capital was viewed from Putnam and Coleman's
theoretical perspectives. It was found that participating in social networks
is beneficial but not enough to explain negative effects on health.
The most relevant of these qualitative studies is the work conducted by
Campbell and Giles (2001) and Campbell and McLean (2002) as this was
conducted in Luton (Campbell, 2001). The interview topic guide in
Campbell et al.'s (1999) study was a discussion of a social capital questionnaire, the areas were 'Empowerment' (i.e. self-efficacy, social support and social networks) and life history (i.e. family and community).

I do not feel that Campbell's topic guide would be suitable for the present study and will therefore be drawing upon the work of Narayan and Cassidy (2001) (Figure 3) and the Office of National Statistics (2012) social capital questionnaire that are both in line with Putnam's social capital indicators for the United States. Putnam (2000b) measured social capital through community life, engagement in public affairs such as voting, community volunteerism, informal sociability and social trust (Productivity Commission, 2003).
Figure 13: Dimensions of Social Capital

Source: Dimensions of social capital, adapted from Narayan and Cassidy (2001)

The Office of National Statistics (ONS) (2012) provided a ‘Guide to Social Capital’ and a ‘Question Bank’, demonstrating how the UK government viewed social capital. The ONS questionnaire and questions were not applicable in this study as they were not conducive to the philosophical stance taken in that the assumption was social capital could be objectively measured. However, the 'Question Bank' themes were drawn upon to inform the interview guide such as social engagement in local groups and social cohesion.
Card Sorting Exercise in the Interview

I gave consideration to using instruments within the focus groups such as Q Methodology and vignettes. Q methodology is used to study the viewpoints of the participants and to rank these, I was going to use statements that were from the literature review and the participants had to order these in terms of their relevance. However, this is a time consuming exercise and it was decided that just as much depth could be gained from not using this tool. Vignettes are stories that are framed to tackle sensitive issues and in this case it could be used to discuss brain stem death or death rituals. These were not used but statements were discussed instead if they had not been covered in the interview. Statements that were used included ‘The body needs to be whole when someone dies’. It was thought that these better directed discussion and covered a wider range of issues that were raised in the literature. In addition to these statements, cards were utilised with key words on such as ‘organ donation’ and ‘gift’, to help guide the interview and set expectations at the start as to what will be discussed. The cards were used at the end by the participant to arrange in a visual way how the participant would show overall, how they thought organ donation, gift exchange and religion related, thus forming the primitive stage of the conceptual map building.

There was a card-sorting exercise that was part of the interview this was a visual way of the participants at the end of the study to give an overview of how deceased organ donation, religion and gift exchange related with each other. However, in group interviews there was consensus as to how the cards would be sorted that worked in smaller groups but in one-to-one interviews, the participant decided how he or she believed the cards should be arranged.
Non-English Speaking Participants: Use of Polish-English Translators

For the non-English speaking part of the data collection process, I recruited a local Polish-English professional translator. Before the translator began interviewing participants, I had ensured that the translator had enough information about the study, such as the aim and objectives to feel comfortable with conducting the interviews. The translator had been a participant in the study, which was beneficial as she knew what to expect from the interview and how it felt to be interviewed. The translator was a professional translator and has significant experience in this area but not in academic interviewing. To help the translator, I gave her a copy of detailed notes from the focus group workshop course about conducting interviews and a copy of a report showing the background to the study. One of the last English interviews was conducted with the translator, to give her experience of interviewing as the next interview would be entirely in Polish.

In addition to this main translator, a whispered translator was used; her role was to repeat exactly what the participants were saying in ‘real-time’, which I then noted. In previous literature, Brislin (1970) suggested that in cross-cultural research, the translation of transcripts should be done by two translators separately to ensure the interpretation is as close as possible. However, due to time and budgetary limits, this approach was not deemed practical. To overcome these limits, having two translators present at the interview and debriefing afterwards enabled me to ascertain consensus and discrepancies on translation within the interview. The transcripts that were returned were compared to the notes that I took when the whispered translator was translating and I was able to compare translations. Overall, there were no significant differences between the notes and the translated transcripts as coding was based on events that
arose in the interview as opposed to line by line analysis that could have only been done with the transcripts. Haslam (2011) explained that notes can be used as a source of data.

At the Centre for Research on Nationalism, Ethnicity and Multiculturalism (CRONEM) conference in 2011, I had spoken with Louise Ryan, a prolific researcher and writer on Polish migration. She suggested that a Polish PhD student would be able to do the interviews, however I did not follow this advice but this highlights the ways in which other non-Polish speaking researchers may deal with the issue of translation.

This is a challenging area as there were few resources or organisations to turn to for this kind of translation. When discussing with the translator, who worked on the present study, the issue of a non-professional translator conducting and translating the interviews, she stressed that it was imperative to know an area well before embarking on the project as there were technical terms and she had to be aware of the degree that she could interpret the messages. For example, if one is to interpret a book, the general meaning of the book is portrayed, but for academic research there must be little interpretation as the participant’s voice must be heard, not the translator’s. The translation should be detailed and accurate and should be close to the meaning, these are guided by translation rules that a lay Polish person may not know. She suggested that a translator should be involved in academic research that is an experienced translator and can learn interviewing, as opposed to an inexperienced translator who is experienced in interviewing. She found the translation of meaning time-consuming in this study. The interpreter could not translate the key message that the participant was expressing but simply say in English as close to Polish verbatim as possible, having as little influence on the data as possible. I did not want to have the translator’s summary of answers to
analyse, but to take notes of what the participant was saying. van Nes et al (2010) argue that language expresses meaning and social reality is expressed through language (Chapman, 2006). This causes an issue when translating Polish as close to English language as possible (van Nes et al., 2010). In this research, the translator was very clear when a phrase did not directly translate and tried to keep the meaning of the participant's response as close as possible. For van Nes et al. (2010), use of translated quotes for purposes of qualitative research can be problematic. This was the reason for a whispered translator and why detailed notes were taken to compare to the transcript to try as far as possible to ensure that the meanings conveyed in the interview were the same and that I could be confident when using translated quotations.

Using translators was challenging to some extent in terms of relationship building with the participants and the influence this may have had on the interview style in two languages by an ‘insider’ of the study, in this case myself as I was the researcher and an ‘outsider’ of the study, the translators as they had been recruited to assist with the fieldwork and were not as immersed in the study. As a non-Polish speaker, it was difficult for me to build a rapport with the participants due to the language barrier and the translators had to put the participant at ease and make him or her feel welcomed. Having the interviews conducted in two languages by an ‘outsider’ and an ‘insider’ to the study, may have had an impact on the data collection. As an experienced interviewer who is an ‘insider’ to the study, I felt comfortable with the interview guide, leading to a relaxed and ‘directed conversation’ that covered the main topics and expanded into new areas. Also, when the interviews were conducted by me in English, these were generally conducted in different locations at the University and a couple of times at the participant’s home. Having an ‘outsider’ to the study conduct the interviews in a foreign language highlights the
challenges of using grounded theory, as closeness to the participants and data had to be maintained. There is little guidance and literature about these issues (Willgerodt et al., 2005). This was the reason for recruiting a ‘whispered translator’ as I did not want the translators to have an overly dominant influence in the interviews. It was imperative that through the whispered translator, I gained an accurate insight into the interview, the themes that emerged and how these related to the previous set of interviews and the opportunity to ‘drill’ into responses.

The Polish interviews generally took place in participant’s homes, as most of the Poles were not familiar with the University. At the English interviews, there was only one researcher as opposed to the Polish interviews where there were two or three. These were the main translator, the whispered translator and me. Having whispered translation may have been distracting to the participants or influenced the formality of the interview environment. These differing locations and number of researchers across the series of interviews may have had an impact. For those interviews conducted in Polish, having three ‘researchers’ may have created a formal environment, in turn this may have influenced how comfortable and open the participant felt in the interview. However, to overcome this, we created an environment that was friendly and open as the translators built up a rapport with the participants. There was plenty of water and food and as much time as the interviewee(s) needed, this was generally an hour and a half to two hours for the interview.

Post-war Participants

I interviewed two post-war participants who had arrived in the local area as a result of the Resettlement Act in 1945. Both of the interviews were conducted at the participants’ homes. At this point in the data collection process, the conceptual map that represented the views of the participants
was becoming established and to develop it further I wanted the views of
post-war participants on this. The interview focused on this and the
experiences of migrating to the local area after the war, experiences of the
post-2004 participants and reflections of changes of the Polish migrant
community in Luton and Dunstable. Both of these interviews were
conducted in Polish as they felt more comfortable with this.

One participant was a second-generation Pole as her parents had come to
the UK after the war and her views were very similar to the non-English
speaking participants and English-speaking students. She was included as I
was at this point interested in a long length of stay and older age since
most of the migrants I had previously spoken to had been in their 20s and
30s. I had met one young second generation migrant in the Polish club,
generally second generation migrants were not very visible.

It was at this point no new data were emerging. Theoretical saturation is a
key aspect of grounded theory as this is when data collection, coding,
constant comparison and analysis ceases as new themes are no longer
emerging (Cutcliffe, 2000). I am aware that 31 participants may be
relatively small to reach saturation, however, as Hennink et al. (2011)
argue, the number of participants in qualitative studies tends to be smaller
as the number of participants is guided by saturation points. Also, it was
intended that the study ‘symbolically represented’ the Polish community as
opposed to statistically representing the community. Symbolic
representation is where the sample composed reflects the diversity that
meets prescribed criteria (Ritchie et al. 2004).
Challenges of the Use of Translators in Cross-Cultural Grounded Theory Research

The fluidity and flow of the interview was different between the English and Polish interviews. The Polish interviews had to be more structured as the translator was not immersed in the study. The translator translated the most recent interview guide into Polish, which was always being changed and developed. Giving the interview guide in advance to translate ensured there was a flow to the interview and it kept to a reasonable time, rather than it stopping and starting with me asking a question in English and it being translated into Polish. Taking detailed notes enabled me to expand at the end of the interview into new areas that emerged and to check areas where there may be ambiguity or where there had not been enough probing into finding out more about an interesting point.

It was challenging for the translator to know what to expand on as she was not as immersed in the project as I and I did not want her to have an influence on the areas of data collected, meaning that this was to be led by me at the end. However, Edwards (1998) disagrees with this and suggested that researchers are no more informed about what to expand on in the interview than the interpreter. As the researcher, I had spent a long time conducting the literature review and devising the interview guide and I felt better informed to decide what to continue with or move away from.

When the interview was over, I would have a discussion and debrief with the translators to understand their views on how the interview went and these were added to my notes. I would then develop the interview guide for the next interview. This was challenging for the translator as updating and changing the interview guides took time and the message in the question had to be captured in Polish when there was sometimes not an
equivalent Polish word or phrase. Also, the translators had found that some English words did not translate into Polish, such as ‘would’ and ‘should’, meaning that the questions had to be shaped to closely mirror the English version and this was time-consuming. The translator ensured that the whispered translator had a copy of the questions as some of the wording was different and it would be easier for the whispered translator to keep up with the Polish interview.

The translators were key in the process but the whispered translator had a full-time job and could not attend all of the interviews. In this case, the translator would translate what the participant had said and I would ask the next question and this would be translated. This occurred for one interview and it did interrupt the flow of the interview, but this interview was near the end of the data collection process. The majority of questions were around the map and participant’s opinion on how the map was constructed and explain their reasoning behind their view. This was not an ideal situation, but I had to stay close to the data as I was testing the conceptual map.

In addition to the practical challenges of using grounded theory with translators is the impact that language barriers and different interviewers have on the data from a constructivist grounded theory perspective. From a constructivist perspective, having two different interviewers with different backgrounds may have had an influence on the constructs that were being established in the interviews. To overcome this, I ensured that I had a clear interview guide and was aware of what the translator was saying to the participant as this may have influenced the participant’s perspective. I asked the translator to ‘drill’ further if a participant was being brief in their responses, however this did not always happen and I returned to the areas I needed clarifying at the end of the interview. I also
requested that the translator did not show any reaction to responses that could be seen as judgemental as this could have influenced how the participant constructed their ‘realities’. In practice, having a clear interview guide and whispered translator enabled me to stay close to the data. This was evident through the analysis as there were a number of similarities between responses of this set and the previous set of participants.

When it came to analysing the Polish transcripts, the responses were as full as the English interviews as I had been able to probe further in some areas and the questions that the translator had were pre-determined and open. The notes that I had taken from the whispered translator and debrief with the translators enabled me to make informed decisions about participant selection, the areas that needed to be expanded on or tested in future interviews and the point that saturation had been reached. Having the notes of the interview was imperative as waiting for translated transcripts to return would have significantly prolonged the data collection process. It was important that the interviews were set up quickly as snowballing was being used to recruit participants and keeping momentum going was imperative. However, language is part of the way in which individuals portray their social construction and having a Polish translator could have had an impact on this. The translator generally spoke in a formal way and this was reflected in the language used in the transcripts and this may not have been as the interviewee had phrased it originally, although this is a speculative observation. In the study, language is active in shaping social constructs and could have had an impact on coding and analysis. The interviews had included a card sorting exercise, this exercise entailed the participant or participants to arrange the cards visually to represent the relationships between deceased organ donation, religion and gift exchange at the end of the interview. There were more than three cards to arrange and the titles of each card included society, altruism and community. This
exercise was viewed as a primitive step toward the final descriptive conceptual map and enabled me to receive direct feedback from the participants of the final map to ensure that it represented their views. However, in the Polish interviews, the direct meaning of the card may have been lost in translation as the topics are complex and the translated term may carry different meanings and context in Polish. The interviews were conducted at the participant's home but two were at the university. The non-English speaking participants generally felt more comfortable having the interviews conducted in their home and for some, with a sibling or friends.

Grounded Theory Coding and Analysis

Grounded theory coding is built upon a reflexive approach through memo writing to allow for transparency of critical decisions and informs the coding. Coding may be computer assisted or could be pen and paper system, initially many codes are generated and these are filtered into core categories and sub-categories for the final conceptual map.

Reflexivity and Memo Writing

Before coding and analysis are discussed, memo writing will be examined as this feeds into the coding process. What is core to grounded theory is reflexivity and memo writing; these show the researcher the impact that he or she may be having on the data (Berger and Kellner, 1981; Hutchinson, 1993; Backman and Kyngas, 1999). Strauss and Corbin (1998) stressed that memos should be conceptual and not about individuals or events from the interviews. Coding relies on the researcher being honest and open in their reflexivity. Because the researcher plays a core role in grounded theory methodology, coding bias is a potentially significant
weakness of grounded theory. From a social constructivist perspective, it could be argued that my own social constructs of the topics discussed may have had an impact as in constructivist grounded theory; it is the participant and the interviewer who are co-constructing.

Being reflexive is also part of the interpretivist perspective taken in this research as findings are 'influenced by the researcher's perspective and values, thus making it impossible to conduct objective, value free research, although the researcher can declare and be transparent about his or her assumptions' (Snape and Spencer, 2003, p.17). However, the researcher can be too reflexive and stifle the creative process, leading to a lack of theory, Glaser (2001) terms this as a 'reflexivity paralysis'. To overcome 'reflexivity paralysis', I allocated one to two hours in the morning to think about the study and consolidate my thoughts before commencing with further coding and analysis. I discussed the study with others and wrote down thoughts and reflections so as not to dwell on them too much. When analysing the findings it was important to keep questioning my thoughts and constructs I saw emerging and to ensure there was evidence for it. This is the biggest challenge in grounded theory, as the researcher is core to the data collection, sampling strategy and analysis. At this point, it may be highlighted that the study had taken a Straussian perspective of grounded theory as I was active and coding was rigorous and the credibility of the descriptive conceptual framework is based on the rigour of the method. As opposed to a Glaserian method where the credibility of the study is whether the theory can be verified, the researcher is passive and coding is less rigorous. Haslam (2011) warned researchers of 'incidence tripping' (workshop notes), where phrases or concepts are blown out of proportion to perhaps sensationalise data and could skew relationships between categories, this links to objectivity vs. subjectivity as discussed earlier. To overcome 'incidence tripping', phrases or concepts were included in
subsequent interviews to test whether I had put too much emphasis on an idea when it was not something generally shared among other participants. For example, when reflecting on an interview, one of the interviewees had mentioned that he would only donate in Poland as he would be likely to know the person who received the organ. If I had sensationalised this response, I could have made a relationship between ‘place’ and ‘organ donation’, however I did not want to make incorrect assumptions. I added this statement to the interview guide and tested it with subsequent interviewees and a range of answers emerged from ‘Only willing to donate in Poland’ to ‘Not mattering where a person donates’.

In this study, a number of reflective personal journals were kept throughout the data collection process, within these journals there was also reflection upon existing literature and talks at workshops and conferences that I had attended. In grounded theory Haslam (2011) suggested that data can include the researcher’s observations about the community, although for this study, observations were not the core qualitative method some had been noted as this formed part of my view of this community. I was able to keep track of the research journey and any obstacles that had been tackled throughout the process (see Appendix Six for examples of memos).

Grounded Theory Coding

Whilst the data are being generated in grounded theory methodology, coding and analysis is occurring alongside data collection. Computer programmes such as Nvivo and Atlas.ti can be used in grounded theory for data analysis (Lonkila, 1995) as Atlas.ti was designed with this approach in mind. There are debates concerning the use of computer programmes in coding and analysis, from it increasing the quality of qualitative data (Dey,
to having a negative impact on how the data are interpreted (Mehmetoglu and Altinay, 2006). I had a personal preference to opt for pen and paper for coding and analysis as it made me feel more immersed in the data. The cards were ordered and re-ordered a number of times to create the categories and sub-categories. These were entered onto a table in Microsoft Word where frequency was also logged to ascertain how common a construct was and which cases were unique (see Appendix Seven) to help build the conceptual map and identify the main and sub categories.

There is a range of coding procedures within grounded theory methodology; microanalysis, axial coding, selective coding and theoretical comparisons. Open coding is defined by Strauss and Corbin (1990) as ‘the process of breaking down, examining, comparing, conceptualising and categorising data’ (p.6). Initial meaning is given to the data; codes with similar meanings are linked and renamed to create abstract meanings (Bluff, 2005). It starts the process and initial codes that then invoke more data collection. Charmaz (2006) explained that there may be issues with some aspects of coding such as codes being too general or out of context.

In the interviews, the questions were open and transcripts were read line by line to begin analysing the emergence of interesting data or incidents. From a Straussian perspective, it may be argued that data is forced through having structured questions. Coding line by line, or action coding, invoked me to consider the meaning that is attached to the data, to challenge it, spot gaps and is part of the constant comparison method of data analysis (Charmaz, 2000). For example, initially I had considered length of stay to be a significant factor in views toward organ donation in relation to social capital, however, this was challenged and through constant comparison I
found that responses of those who had been in the UK for 3 months to 62 years evidenced few differences in attitudes and knowledge of donation.

Haslam (2011) highlights the importance of naming the codes, as they should be conceptual rather than descriptive and they should be labelled with a gerund to keep codes in the present continuous tense and to some extent behavioural. This is reflected in subsequent chapters in the reporting of interview findings. He also explained that the source of the code should be written alongside the label with the date and a definition explaining the code. There should be an indicator of the behaviour, such as examples from the research context and links to other codes as they develop. There were hundreds of codes on squares of paper and these were grouped into loose categories and sub-categories for the next stage of coding. For example, one of the main categories was ‘Organ Donation and Giving Gifts’ and the sub-categories were ‘Organ donation is a gift’, ‘Repaying the donor family’, ‘Repaying others in the future’, ‘Receiving reward’ and ‘The Recipients’ View’.

Axial coding is the development of the main categories and their sub-categories (Megmetohgi and Altinay, 2006). Throughout the axial coding process, the emerging themes were validated by (1) comparing the information with the other informants, (2) comparing the emerging themes with the information obtained through observation and secondary analysis of documents from and about the organisation, (3) checking the validity of the choice of themes with selected informants, particularly with the insider (gatekeeper)’ (ibid, p.22). This is where constant comparison is used, which is where I compared new to previous data and ensured that the themes were from the data (McGhee et al., 2007). A challenge to using this is time as transcribing interviews can take many days and sometimes interviews were scheduled close together due to time restrictions of the participants.
and the momentum built up through snow-balling. To overcome this, notes were taken from the interview, memos were written and previous categories were referred to when creating the new interview guides. Charmaz (2000) suggests that selective coding uses the initial codes, making coding focused and conceptual rather than line by line and categories are designed more precisely. When I was analysing the data, I read the transcripts and coded based on conceptual incidents as opposed to coding every line.

Throughout open coding and axial coding, memos were written that led to the final categories, these were discussed earlier. When creating categories, there is debate about them emerging from the data or being ‘forced’ by the researcher (Glaser, 1992), to avoid forcing they should be tested deductively (Glaser, 2001). This was highlighted when exploring ‘incidence tripping’. These initial codes were collated and grouped into categories; this also showed how common and strong categories were and highlighted any views outside the main categories. For example with the category ‘Donating is an altruistic decision’, the frequencies were counted to help see how common the categories were as well as highlighting the alternative views as multiple realities were explored, this information was entered onto a table in Microsoft Word.

Finally, selective coding, where the core category is chosen and other categories are related to it, integrates the axial categories to lay the foundation for the conceptual map. The inter-relationships are explored further and the memos play an important role here, they help make sense of the data through highlighting conflicting issues, overlapping elements and relationships between key concepts (Megmetoghi and Altinay, 2006). This relates to the map that was developed that visually showed the
relationships between the key concepts and overlapping elements and will be discussed in more detail in terms of its evolution in Chapter Five.

*Strauss and Corbin's Story Line*

As Strauss and Corbin explain, 'The core category must be the sun, standing in orderly systematic relationships to its planets' (1990, p.124). The storyline is part of the process of selective coding in Strauss and Corbin's grounded theory that is informed by the reflective memos and guides theory generation. The story is the central phenomenon and the line is the conceptualisation of the story, the storyline is the core category. The approach that I used was to reflect on the themes that were emerging as social constructions as opposed to searching for cause and effect or processes.

Initially I felt that the story that the data was telling was temporal constructs, in that it was guided by space and time such as Polish references to geographical and virtual spaces and used past, present and future tenses. As the evolution in Appendix Twelve demonstrates, the storyline changed from distances; relationship distance were represented in the card sorting exercises as participants had to visually show how close or how far away concepts were, if they were present at all, to hierarchy of relevance and importance to context. As the data collection and coding progressed, the core category became the context of the relationship between organ donation, gift exchange and religion in the emergent conceptual map. The core category had an impact on the primary objective of selective coding, which was to explain the storyline (Strauss and Corbin, 1998) and in this study is demonstrated by the sub-categories in the conceptual map as explained in Chapter Five. The selective coding process is shapes the order and organisation of the core and sub-categories around the core category.
3.4 Rigour and Trustworthiness of Grounded Theory

Validiry and reliability relates to quantitative research more commonly, however, the integrity and quality of quantitative research is imperative. Chiovitti and Piran (2003) believe that many studies describe rigour in qualitative research, for grounded theory, this was covered in Glaser and Strauss’s (1967) chapter on ‘Credibility of Grounded Theory’. Chiovitti and Piran outline the practical standards of rigour which are important in qualitative research (Rose and Webb, 1998; Maggs-Rapport, 2001; Whittemore et al., 2001; Davies and Dodds, 2002).

Increasing the credibility, auditability and fittingness of grounded theory methodology is important to improve the rigour of the research. Credibility refers to the trustworthiness of the data (Carpenter Rinaldi, 1995) and can be achieved by allowing participants to ‘guide the inquiry process’, ‘check the theoretical construction generated against participants’ meanings of the phenomena’, ‘use participants’ actual words in the theory’ and ‘articulate the researcher’s personal views and insights about the phenomenon’ (Chiovitti and Piran, 2003, p. 430). Auditability refers to the reader to reach the same conclusions as the researcher (Carpenter Rinaldi, 1995) and can be achieved by specifying ‘the criteria built into the researcher’s thinking’ and ‘specify how and why participants in the study were selected’ (Chiovitti and Piran, 2003, p.430). Finally fittingness relates to the ability to transfer the findings to other, similar groups (Carpenter Rinaldi, 1995) and can be achieved through delineating ‘the scope of the research in terms of the sample, setting, and the level of the theory generated’ and ‘describe how the literature relates to each category which emerged in the theory’ (Chiovitti and Piran, 2003, p.430). In this study, to allow for trustworthiness and auditability of the data, there are excerpts of
the interview and examples of memos and coding that have been included in the thesis to allow for a reasonable level of transparency (see Appendix Five, Six and Seven).

In addition to trustworthiness and transparency of the analysis is assurance of analytic rigour to ensure that data were not selectively used and that the researcher's own position did not overpower the participants' voices. The steps that I took to guard against selectively using the data were during the coding process, frequency of the codes guided the categories to represent the stronger themes as opposed to the sub-categories. There was no inter-rater or member or expert checking of the coding and analysis and could be argued to be a weakness of the data. However, grounded theory coding processes do not acquire rigour through triangulation (Mertens, 1998) as constant comparison is used throughout the data collection process and is fed into the interview guides to test the categories and sub-categories toward the conceptual map that the participants are commenting on. Grounded theory is a cyclical process where the codes affect the data collected and each feedback into one another, this in turn could be argued to increase analytic rigour.

The safekeeping of data was important for this research. All data was kept on an encrypted memory stick and the translator was sensitive to the confidentiality of the data as she had an MP3 recorder with the interviews on and data were deleted once the transcribing was completed. All data were kept for two years for the purposes of accuracy and evidence for the PhD process and will be deleted November 2013.
3.5 Reflections on Grounded Theory Methodology for Cross-Cultural Research

Using a grounded theory methodology presented two challenges. The first was the presentation of the research and secondly the definition of theory as an outcome of grounded theory methodology.

Grounded theory provided the methodology to explore the relationship between deceased organ donation, gift exchange theory and religion. Taking a Straussian perspective enabled me to apply a systematic approach to the research process. Charmaz (2006) and Strauss and Corbin (1990; 1998) are more prescriptive in their approaches to grounded theory when compared to Glaser and Strauss (1967). On a practical level, applying grounded theory needed further guidance on the depth of the literature review as it is required for PhD purposes and for the interview guide, the interview itself, coding, memo-writing and theoretical sampling.

As seen in Figure 12, the grounded theory process is cyclical; data is collected, coded and analysed and this directly affects the interview guide and sampling strategies. However, reporting for PhDs are completed in a linear fashion and does not take into account the true timeline of the project and the critical decisions made regarding the interview guide and sampling choices.

Also, I found that the notion of 'theory' is problematic in grounded theory. Strauss and Corbin (1990) defined theory as:

'A grounded theory is one that is inductively derived from the study of the phenomenon it represents.' (p.23)
The Oxford dictionary (year unknown) defined it as:

'A supposition or a system of ideas intended to explain something, especially one based on general principles independent of the thing to be explained' (webpage)

In this study, a conceptual map emerged from the data that visually represented how deceased organ donation, religion and gift exchange theory related within the context of the Polish migrant community in Luton and Dunstable.

3.6 Ethics Process and Principles

The study was co-funded by NHS Blood and Transplant and the University of Bedfordshire, however, I do not have a contract with NHSBT nor did I meet with them, meaning that there were no conflicts of interest. The overall aim of the thesis was not instrumental, in that I was not investigating how to increase deceased organ donation as a result of the study. The aim was to explore how the Polish community viewed the relationships between deceased organ donation, gift exchange theory and religion.

For sociological research, there is guidance for ethical practice and principles from the British Sociological Association (2002) and the Social Research Association (2003). The British Sociological Association (2002) state that ethical research should uphold professional integrity, researchers have responsibilities toward their research participants, that relationships with research participants ensure that the wellbeing of the participant is protected and that the research practices ensure consent, anonymity, privacy and confidentiality. The Social Research Association (2003) widens the ethical principles in research and purport that the
researcher has obligations to society, funders and employers, colleagues and subjects.

The posters and information about the study made clear that the interview was going to be based on organ donation. The information was in English and Polish and was given to the participant at least 24 hours before the interview to give the individual ample opportunity to read through it and ask questions prior to data collection. At the interview, a consent form was completed with the participant in English or Polish and statements were initialled after being discussed. This consent form showed that the participant were aware of their rights to withdraw and stated that the individual agreed with the interview being recorded and the responses would be used, at some points verbatim, for the purposes of the thesis. In this study, participants were provided with information about the purpose of the study, expectations of the duration of the interview, potential wider benefits of the study, the funding body, their rights to obtain informed consent as far as possible and the use of the data in the dissemination of findings (See Appendix Nine). To protect identity and for confidentiality of data, all participants were given a pseudonym to anonymise the data in the transcripts.

After the interview, a debriefing letter was given to the individual with follow-up information about organ donation and contact details myself and the Specialist Nurse in Organ Donation (SN-OD) from the local hospital, who had agreed to give participants further information if there were queries or talk to someone about donation (see Appendix Nine). I also gave my supervisor's email in case the participant had any concerns or complaints about any aspects of the study or their involvement.

Guidelines can be limited as ethical issues for qualitative research can affect all parties in the research process. The next sections will discuss the
ethical challenges that were faced in this research from three perspectives; the researcher's, the translators' and the participants'.

3.7 Ethical Issues Related to the Study

There were three main ethical issues that arose in the study; these were the effect of the research on the participant, the researcher-translator-participant power dynamic and the effect of the research on the researcher.

THE EFFECT OF THE RESEARCH ON THE PARTICIPANT

The aim of the thesis was to examine the relationship between deceased organ donation, religion and gift exchange theory and later social capital, altruism and religiosity were added. Each of these key elements could be argued to be sensitive in their own right. This section discusses the challenges in discussing sensitive and personal subjects.

Interviews were conducted in pre-booked interview rooms at the new campus in Park Square where water, tea and coffee were available. Alternatively, interviews took place at participants' houses where they had been most hospitable and had made cakes to eat and a cup of tea to drink whilst the interview was happening. This made me and the translator or on some occasions, just me, feel very welcomed and like a 'guest and not merely as an inquisitor' (Finch, 1984, p.73).

The opening gambit of the interview was a conversation about migration and experiences of living in Luton and Dunstable and migration. Migration could be argued to be a sensitive and emotional issue as it is a discussion of being separated from family, home country and culture and a threat to identity in a foreign country due to major life changes (Timotijevic and Breakwell, 2000).
One of the negative experiences that a few of the participants raised about living in Luton and Dunstable were xenophobic attitudes displayed through racism and prejudice were experienced by some participants in Luton and from peers from the Polish community who had been jealous of their successful 'friends'. Gunaratnum (2003) suggested that when participants are discussing racism in a 'psycho-social space' of the interview, there are feelings of 'safety' and 'danger' and the 'power relations' between the interviewer and the interviewee are multiple and moving. These issues were not 'drilled' into further as it was outside the remit of the interview. I tried to ensure that the research environment felt 'safe' in that it was confidential 'space' where the participant could express their feelings without feeling judged.

Going back to the interview guide, questions moved onto giving gifts and altruism, these concepts may not be considered sensitive topics in their own right. However, when talking about these subjects with the participants in the context of migration, this changes the sensitivity of these topics. The participant is considering their own helping behaviour and may lead them to question their own level of engagement in the UK. Some of the participants had volunteered in the UK and others viewed helping behaviour to be the same whether in the UK or Poland. However, in the framework of social capital, helping behaviour could become an indicator of belongingness, settlement in the area and an acceptance of being part of the local Luton and Dunstable community outside of close friends and family networks.

Interviewing participants about deceased organ donation was the main topic in the interview. I had previously spoken to the local Specialist Nurse in Organ Donation (SN-OD) (Appendix Ten) and had learned about the processes of transplantation and the most common questions in case I was asked about donation and transplantation. In some cases I was asked and
became a source of information about donation and transplantation in the interview. This in some ways meant that the interview was an exchange of information as opposed it being one-sided.

Talking about organ donation meant an inevitable discussion about death, either one's own death or the death of a relative. Death is a well-documented sensitive topic (Lee, 1993) as it elicits an emotional response for the interviewer and the interviewee. In previous research in Sweden, Sanner (2006) reflected that from her interviews about organ donation, discussing death meant that the participant had to accept their own mortality and that the interviewer must be considerate to death anxiety and be aware of the uneasiness of the topic and be empathetic.

One of the findings was that some participants avoided talking about death and that it was a 'taboo' subject. One of the participants had said that their mother had found it too upsetting discussing death and organ donation as it meant discussing the death of their child. Some of the participants seemed 'matter-of-fact' about discussing death as it was 'part of life' and were candid and frank in expressing their views toward this topic. There was an almost detached way of discussing death. One participant joked about funerals; 'In Poland, it is usually about 2-3 days, because we don’t burn the bodies, we just put them in the coffin and then put them in the cemetery...So, they’d have to be kind of 'fresh'!' (FG1I2). Another participant joked about the soul migrating the body after the transplant; 'I personally, if it [the transplant operation] was happening to me, I don’t think it would bother me because as far as I’m concerned and if my little soul has gone up somewhere and say, look at the state of that! (laughs) Whoa!' (I19).

When discussing death, funeral arrangements were considered as participants had to think about how their family would deal with their death if they wanted to donate in the UK and how their migrating to the UK
may have had an impact on their family in Poland. Migrating to the UK is largely driven by economic reasons due to high levels of unemployment in Poland. As highlighted in the present study, there are low levels of mobility in Poland and migrating for some participants had meant separation between parents and grandchildren. Issues of separation meant that migration is an emotive and sensitive topic, particularly when discussing death in this context. It could have left the participants after the interview considering these aspects in more depth and what migration for economic reasons has meant for their family in Poland, particularly if the individual were to die.

In the present study, participants took part in a discussion about religion and it was discovered that this was a highly sensitive subject that subsequently led to a change in data collection tools. In Poland, a self-reported survey found that 95% of the population were Roman Catholic (Ministry of Foreign Affairs, 2011) and there seemed to be an underlying pressure to continue the Catholic faith in spite of individuals being Catholic or a 'non-believer'. Being a 'non-believer' seemed to be emancipating for the individual once outside of Poland as there was little pressure to attend church and views toward God appeared to be flexible and one could return to church to pray to revisit their faith and rekindle their relationship with God. However, working long hours, socialising and living in a secular society for some created distance between Polish participants and the church and God. Alongside this emancipation of deciding one's own faith status was a sense of shame that came with not being Catholic. Some participants would state that they were Catholic on the recruitment form but be open about their doubts about Catholicism but wanted to continue the 'tradition' through their children as it was part of their heritage and culture. Discussing religion with participants evoked many different types of emotions and was not sensitive in the way that it was upsetting and
emotive but that it was sensitive as it was deeply personal (Lee, 1993) and Catholicism is rooted in Polish culture and identity.

Deceased organ donation, gift exchange, altruism, social capital, religion and religiosity are personal, emotive, concrete and abstract subjects and thinking through how the relationship between them was challenging for the participants. Participants had to remember what life was like in Poland in a political and historical sense as for some they came to the UK in the war-time, Communist or post-Communist times and compare this to present life in the UK. Participants considered social, cultural and religious aspects of helping, being part of a 'community' in Poland and in the UK and attending church in childhood. Participants also had to consider family currently and in the future, in the UK and in Poland. Participants had to reflect on their childhood, family and upbringing, their church attendance and experiences of religion and predict, for example how their family would react to their death, their length of stay in the UK and what this is dependent on. They also had to think through the abstract, such as organ donation after death, consenting to donation of their relative, sense of belonging and identity and the concrete for example, current social networks and friends and examples of helping behaviour.

In past literature, being part of the interview process has been found to be positive for participants in discussing and thinking through topics that they would not otherwise have thought of in detail (Gair, 2002) and to reflect on 'taboo' topics such as death (Dickson-Swift et al., 2006; Rowling, 1999; Bourne, 1998; Johnson and Macleod Clarke, 2003). For participants, thinking through aspects of deceased organ donation such as the practical aspects of funeral arranging and the processes of donation with the opportunity to ask questions may have given participants a clearer understanding of the situation, a benefit cited by Bourne (1998), Rager (2005), Orb et al. (2000) and Simmons (2007).
Being part of an interview can be tiring and participants can experience burnout and fatigue, particularly due to the nature of the topics discussed. This was experienced by the participants, translators and I, this meant that adhering to an hour and a half to two hours maximum was important. However, the closing question of the interview, the turning off of the MP3 recorder and giving of the debrief letter did not necessarily mean the end of the interview for the interviewer as thoughts around the subjects could linger (Goodrum and Keys, 2007; Warr, 2004) but this can be applied to the interviewees who are left with many questions as it could be the first time that they had thought through these topics in such detail or at all.

**RESEARCHER-TRANSLATOR-PARTICIPANT POWER DYNAMIC**

Before the interviews took place, I felt that there was already a researcher-participant power dynamic as the main criterion for participation was ethnicity and this can be an issue in qualitative research (Ali and Kelly, 2004). As my research was focussing on Polish migrants, this could incite feelings of suspicion in addition to the topic of the interview, which was deceased organ donation, a health issue that could have influenced participation (Liu, 2012). It may have been assumed that I was trying to increase organ donation from this community as I was a researcher from a local university where the research was being sponsored by NHSBT but this was not my intention and this was explained to potential participants.

In cross-cultural research, it was suggested that the interviewer and the interviewee are 'matched' based on similar ethnicity by Gunaratnum (2003) as participants would be more likely to express what they think. I did not intend to 'match' the interviewer-interviewee but had to recruit a translator to conduct the interviews because I could not speak Polish. When coding the transcripts, there was a similar level of information given between the Polish translator doing the interview or when I did the interview.
In qualitative interviews, it has been argued that there is an unequal power relationship between the interviewer and the interviewee (Melville, year unknown). This power imbalance could lead to exploitation of the interviewee and highlights the impossibility for fully informed consent (Darra, 2008). This is a challenge that arose in the present study with the Polish translators as the Polish community. Some of the participants were recruited through networks and this created a challenge in the interviewer-interviewee dynamic between the participant and the Polish translator. The translator was working on the research in a professional domain but could be argued to be a 'peer researcher' as she was part of the Polish community and knew some of the participants as acquaintances.

The power inequality aspect arose due to the translator being the interviewer as I decided that this meant that the interview would flow better than translating each question in turn and a good rapport with the participant could be developed. However, the interview situation may have put the translator in a position of power as at one point, she felt that she could ask what she wanted. One of the interviews involved a participant who was a Jehovah's Witness, converted from Catholicism since coming to the UK. This is an area that the translator found interesting and within the flexibility of a semi-structured interview guide meant that she felt she could ask more questions about this as she was aware that one of the aims of the study was to examine religious factors in deceased organ donation. Through the whispered translator, I became quickly aware that this was happening and gave her cues to move on and was something that was addressed in the debrief to be prevented in future interviews. This was an important issue to address as I did not want the participants to feel exploited in the interview.

Outside of the interviewer-interviewee relationship, particularly in the recruitment stage of non-English speaking participants, I felt that there was
power inequality between myself and the translator as she was the 'insider' to the Polish community and I was the 'outsider'. This was an experience that has been shared by Murray and Wynne (2001). The interpreter could easily access the Polish community through networks and at one point of the recruitment process was setting interviews up that I had not consented to as I had to ensure that the participant met the inclusion/exclusion criteria of the sampling process as I was using theoretical sampling. This was addressed with the translator and was overcome as she then ensured that she referred the participants to me first.

THE EFFECT OF THE RESEARCH ON THE RESEARCHER

Talking about death through thinking about one's own death or a relative's death and what happens to the body can incite highly emotional responses (Lalor et al., 2006) as death is a commonly feared experience (Johnson and Macleod Clarke, 2003). As the interviewer, I could react to the stories and feelings of considering the death of a close relative as I am not solely a data collection tool (Hubbard et al., 2001).

Hochschild (1983) and Dickson-Swift et al. (2009) purport the researching of sensitive topics to be 'emotional work'. Melville (year unknown) argues that this 'emotional work' can have a concerning impact on the research assistants. The two translators who assisted with the non-English speaking participants and I always met and discussed the interviews after to give them an opportunity to discuss with them their feelings about the interview. This enabled the two translators 'space' to privately talk about the topics in the interview as they could not discuss it elsewhere due to confidentiality. Having opportunities to debrief is suggested by Beale et al. (2004). To help cope with this 'emotional work', Cowles (1988) suggested that the researcher should be cautious as to how many interviews are conducted per week due to emotional exhaustion. This is something that was found with the present study, there were no more than two interviews.
a day and interviews were usually every other day. This was not only to prevent emotional exhaustion, but pragmatically for the purposes of developing the conceptual map, I needed time to analyse the data to allow for constant comparison and develop the interview guides.

Dickson-Swift et al. (2008) argue that participants in sensitive research may become vulnerable as they are opening themselves to being changed by the research and that this also may be true for the researcher. This is potentially an issue from the potential research as some of the participants had considered deceased organ donation but other had not, some had discussed organ donation with their family and others had not. It may be argued that those who had not considered deceased organ donation or discussed it with their family may have been affected through opening themselves to the interview. The individual may be affected in different ways for example, the individual searches for more information from the debrief letter, about organ donation and talks about it with their family. As data collection took a constructivist grounded theory approach and it was a form of 'directed conversation', the participants sometimes asked questions about organ donation processes. This can be positive in that information can be given to the participants about certain aspects of the research. However, if an individual was unhappy about any aspect of organ donation he or she had learned about organ donation, such as the family had the right of veto about donating organs or that Poland had an opting-out policy, it may result in them being upset about organ donation.

Dickson-Swift et al. (2006) discusses the 'blurred boundaries' between the interviewer and the interviewee when researching sensitive topics and how the researcher may be affected by opening themselves up to the topic at hand. I found that some aspects of the interviews sensitive, such as participants were discussing donating their relative's organs, how their relative would feel about donating their organs and also some negative
experiences of living in Luton and Dunstable. I empathised with them in the interview, but I overcame opening myself up to these sensitive topics by becoming desensitised through reading deeply around these areas in the literature review and not thinking more about these areas after the interview.

Keeping a journal helped me cope with the feelings that I had after the interviews. Journals have been cited as useful in sensitive research (Darra, 2008; Glaze, 2002; Goodrum and Keys, 2007). Debriefing with the translators was imperative as it gave them a 'safe space' to reflect on the interviews.

3.8 Summary

The structure of this chapter has been guided by Crotty's (1998) model to guide discussion around the epistemological and ontological position taken, the theoretical perspective, methodology and methods used. This chapter has detailed the data collection stage of the study through the initial assumptions of focus groups to adapting data collection methods to one-to-one interviews to small group interviews made up of friends or family. As a grounded theory methodology was used, theoretical sampling informed the sampling strategies and this chapter has shown the three phases of sampling and how these participants were recruited. Once interviews had been carried out, these were transcribed, coded and analysed using grounded theory methods to develop the descriptive, conceptual map. This chapter finished with a reflective consideration of ethical issues of interviewing about sensitive topics.
CHAPTER FOUR: FINDINGS

4.1 Introduction

Chapters Four and Five turn their attention to the findings and analysis of the study. This chapter reports the findings of the study and is organised by the themes of the study. These themes were settlement, altruism and gift giving, religion, attitudes toward deceased donation pre-death, attitudes toward donation post-death and the role of social capital. See Appendix Eleven for an overview of the themes and sub-themes of this chapter.

4.2 Settlement

As discussed in the previous chapter, the most visible migration waves in Luton and Dunstable to emerge were post-war and post-2004 migrants. The visibility of these two groups was a continuing theme in this study.

'I think that especially in Luton and Dunstable and Bedford we have two groups of Polish immigration, one is a lot of people who stayed after Second World War, many like pilots and, and military, they stayed after the Second World Ward and then we have the second group, which is quite a big group of people who arrived after 2004, after Poland joined the European Union' (FG113, Student and Administrator, Post-2004).

A HISTORICAL CONTEXT

After the war, an agreement through the Polish Resettlement Act (1947) had been set up to enable Poles to settle in the UK, meaning that it would have been a 'one-time' event, making visits to Poland after the war difficult as one participant stated:

'Now, it is completely different to Poland, when I went in 1940, because I went there 13 times in Poland- you had to buy a 2 week coupon from the Embassy in London, from the Polish Embassy in London to stay at a hotel to live, otherwise they wouldn't give a visa.' (I20, Retired, Post-war)
The Polish Resettlement Act (1947) enabled Polish migrants who had fought in Western Europe, to settle in the UK. Previously, before settling in the UK, over 1.5 million Poles were forced by Soviet troops to go to other countries (Bielewska, 2011) those in Luton and Dunstable had been to India, Russia and Africa.

'The majority of Poles were the ones who walked across Russia, yes? They later, eh walked across India a lot, through Africa, like my wife did, yes? Well and the majority came here and so a lot came here, eh they had to first sign a contract in order to come here.' (I21, Retired, Post-war)

The post-war migrants presently living in Luton and Dunstable started setting up their Polish community in Marsworth, outside Tring (A on the map) and Aylesbury (Brown, 2011).

![Figure 14: Map of Post-war Settlement](Source: Google maps)

At the parish in Luton and Dunstable, in the time of Communism after the war, there had been occasions where allegedly, the Communists had secretly taped church meetings and Masses which occurred at the church. Communism had caused a divide among the parishioners as Communists
were not allowed to attend church, but it was believed that some had
attended church to recruit other communists for the Regime Embassy in
London.

‘Communism was very active and they had their own here, who
worked for Communism, yes? And everything was done here in such
a way that people were not aware about what is actually happening
at the parish, and then we were getting deeper, and deeper, we
came to the conclusion that everything is the work of
Communism...[I]t came to the extraordinary general meeting... I
knew that there will be a secret taping, and that, because before
mass the Priest said that one is not allowed to secretly tape, yes?
And, then it came to the extraordinary general meeting and the
leader kept the side of the reds\textsuperscript{15}, as they were called’ (I21, Retired,
Post-war)

\textbf{POST-2004 MIGRATION}

The participants overall suggested that the Polish community was made up
of groups of students, workers in low-skilled occupations who spoke little
English, ‘benefit tourists’ and families, the most visible according to the
participants are families and workers in low-skilled job occupations.

‘[M]ost of the Polish community is people who are not too well
educated, factory workers, err, um, doing some basic jobs’ (I6,
Student, Post-2004)

‘I have been here seven years now and I am more or less aware of
this society, and as of late I think that there are many more families
because, in the beginning, when we first moved here, basically there
were singles...I very rarely encounter students to be honest’ (I9,
Housewife, Post-2004)

‘[T]here isn’t that many Polish students, so they’re not really seen, I
mean, I’ve been here for three years and I know maybe two Polish
people that I speak to on a regular basis...I think that the
community that is seen the most is people, I don’t know, late 20s,
early 30s, often with one child, like new families that are kind of
here to start a family. That is a person that you’d see the most I’d

\textsuperscript{15} In Poland Communists are called “Red/Red’s” in slang; all movements and all government material
of such regimes were red (the Soviet flag, The Nazi’s flag, banners etc.- in Poland the eagle of the
then Polish flag was not allowed to have a crown; putting the crown back on the flag was a
significant event.)
say. Then there is the bad side, like all the people that didn't make it, just hanging about drinking and it's a bit embarrassing, that is another thing that they can see I think um, so that's probably what a lot of Polish people, the kind of Polish people that are coming here right now.' (I1, Student, Post-2004)

In personal communication with a potential participant who did not take part in the study, she was a current PhD student at the University of Bedfordshire, below are her observations of the Polish community.

'The Polish population in Luton - this is a very specific community: on one hand students and on the other hand low skilled workers with little education (and linked to it, little social awareness) and poor English. Especially, the latter, I fear, may have particular views (I would have hoped rather quite different to other groups of Poles). There is also a huge discrepancy between people from the cities and people from the countryside, especially in terms of religion. While religion has never played any important role in my life and most of the people I encountered in my studies and career in Poland, I was often surprised with the level of church engagement and following literally (and often blindly) what a priest says in rural, remote parts of Poland, when on holiday for example.' (Anon, personal communication)

The Motives for Migrating: Successful Western Economy

The main motivation for coming to the UK was to earn money.

'\textquotesingle [I]t's just easier to make a living here to be honest, I mean, I just know for a fact that some people find it difficult to make a living in Poland, especially if they have families, um because if you compare the relation between what you earn and what you spend on living, in Poland, it's so much different than here\textquotesingle ' (I5, Administrator, Post-2004)

For those who had earning money in mind, it was highlighted by one participant that parents may move to where the work is and the consequences of this can be detrimental for their children's education and the learning of English language.

'\textquotesingle It's constant, people are always going back and new people are coming in and people are going back and people are coming in and it's very, I can see within the school where children are coming in
and then going back...children suffer...they haven’t really got, finished education in Poland and without the language, they can’t really succeed here, so it takes a long time for children, although they do learn very quickly, you know to actually access the English curriculum takes a long time to be a proficient English speaker and to do GCSEs in English so it’s, it’s not easy.’ (I4, Teaching Assistant, Post-1989)

Coming to the UK to earn money may have been influenced by the way that the UK is perceived in Poland as a ‘promised land’ based on those they have seen who have earned money and had a good quality of life. This mythological perception and illusion of material success may have been evidenced by people going to Poland and showing their success in the UK in material form such as expensive clothing and jewellery. This was highlighted by one participant:

‘I come across a lady who came here and things were going from bad to worse and she was ready to go back to Poland, but once again her family in Poland are saying, “You are going to come back with empty hands?”...It is a lot of pressure that you are here and you’re earning megabucks...they go to Poland and obviously people say, oh yeah, he went to England and this is what he, you know, what he was able to achieve in such a short period of time, maybe we should try, and people are going because they think that they will be as successful as their neighbour, but the reality of life in here is different and you do really have to work hard’ (I4, Teaching Assistant, Post-1989)

Length of Stay: Intention to Stay for the Short-Term

It was commonplace for the length of stay in Luton and Dunstable to be mediated by the amount of money that was earned in the UK. However, one participant highlighted that staying in a certain area may also be affected by economic reasons.

‘Sometimes people do stay for a couple of years, there are cases when people are staying longer than a couple of years but you have to consider their circumstances, if they’ve got the job and they are contracted in their work and they are willing to stay in here, but they will be searching for a job, so the moment that the job opportunity comes in um, Sheffield or Liverpool...we need money to
pay for this and money to buy food, they have to take that into consideration and move so, because it’s such a high mobility, they constantly move, I understand that would be hard for Luton Council to get the real picture of how many Polish people we have in Luton.’ (I4, Teaching Assistant, Post-1989)

Length of Stay: Longer-term Settlement

For many of the participants, there had been the intention to stay in the UK for a short time but this changed to a much longer period.

‘[W]e [Her and her husband] decided that we are going to build our future together in a new country, that’s why we decided to move to England, to try something, to try to find a job and then make some money and come back after two or three years, but (laughs)...It never happens.’ (I15, Housewife, Post-2004)

There was also a desire to settle as some participants had met their partner in the UK, got married and wanted to build a future together.

‘[T]hat’s why we decided to move to England, to try something, to try to find a job and then make some money and come back after two or three years, but...It never happens.’ (I15, Unemployed, Post-2004)

It was perceived that in Poland it can be difficult to be employed but in the UK, there were more jobs available. Staying in Luton and Dunstable was seen as an attractive financial option as opposed to returning to Poland as one could get financial assistance from the government in the UK if one is unemployed. Alternatively, there was a preference for British culture and way of life as British people were seen to be friendlier, less strict and serious, compared to Polish people in Poland.

‘The ones who have stayed, basically have got sucked into the structure, and don’t see themselves being back home, I can’t imagine myself being home, and well, because I’m young I could still go back and do something, but...’ (I10, Warehouse Worker, Post-2004)
When asked about going back to Poland to live, many said that they felt that Poland had changed since they last visited, this may make it less attractive to return.

'[M]aybe I want to stay forever, maybe I want to build a future here, then I start seeing that difference, clearly, that in Poland, my God they are very sad, and wherever you go, most of them, they rude...England is a different country and it's like, the Poland, before they were like England, many years, so I can see now, the positive thing in Luton that people are very kind, and some of them, most of them are helpful.' (15, Female, 29, Post-2004)

POST-WAR AND POST-2004 POLISH MIGRANTS’ LIVED EXPERIENCES OF LUTON AND DUNSTABLE

The experiences of living in Luton and Dunstable were discussed with the post-war and post-2004 participants in line with social capital theory, to gain an insight into sense of belonging, social networks, perceptions of the Luton and Dunstable community, trust and civic engagement.

Overall, the participants who took part in this study came from many different locations in Poland, this observation may demonstrate that there is no chain migration; this is where migrants come from one area in one country to live in another area in another country. This is illustrated by the Pakistani community in Luton, who largely come from Azad Kashmir (Ali, 1999). This may have implications for the formation of social networks and community groups in Luton amongst the Poles in Luton and Dunstable.
Figure 15: Map of Participants' Place of Origin

Sense of Belonging

The majority of the participants had positive experiences of living in Luton and Dunstable and felt that the local community were friendly and welcoming.

'I think that the easiest example is that people [in England]...say 'Hello, How are you?' Yes, so that you can say to anyone who is practically a stranger, yes? And, eh if you don’t want to get deeper into the matter you just say 'It's ok, I'm fine'- and in Poland it is that way that you can't do something like that.' (111, Factory Worker, Post-2004)

'People here are cool, and everyone at work is nice-at least most of them are nice people, and they try to help and there isn’t any hostility or things like that, so it’s rather positive.' (113, Warehouse Worker, Post-2004)
On the other hand, one participant had experienced prejudice from British people because they were a Polish person.

‘[F]or the toddler group in my area, which is here...I can sometimes feel like some of them mm, some of them doesn’t want to talk to me, like er, she’s not English, so it’s like oh, oh so it’s better for them to focus on on, like own community, like English community.’ (115, Unemployed, Post-2004)

One participant had highlighted high rates of mobility in Luton and Dunstable compared to their experiences in Poland and the impact on local community spirit.

‘[I]n England, it’s different, that because people, ehm move around a lot and there is high mobility, ehm society is constantly changing therefore there is no, there’s no like one group that sticks together.’ (118, Housewife, Post-2004)

Few believed that there was as high a rate of mobility in the UK as people move to where the work was, this would not occur as frequently in Poland as some families may stay in the same village or city their entire lives.

‘In Poland, actually, when you live within the community you tend to stay in one place for most of your life or you spend your life until university...if you are not going to do further education, you just basically stay within the same community and it’s probably slightly different in England because to have one solid community when everybody knows each other, it’s, um, well, it depends on which town, but London or Luton when movement is so big, the, probably you don’t have the spirit of community anymore because it is changing constantly.’ (17, Teacher, Post-2004)

For one participant, a consequence of high mobility was the difficulty she found in meeting friends.

‘Poland to come to England, so that was, leave my family, leave my friends, everything, so everything was (exhales), that was really stressful, so and then, every time when I couldn’t find friends, like really good friends, and they been people who are coming and going away, every time when I thought that ‘oh, that guy is very good, that guy will be my friend’, or something I was thinking like ‘I can count on you’, but I couldn’t, so that was very like, a shock, it’s like, oh my God, this is England, everybody is coming and going
away and everybody just feel lonely, that's how I feel for a long time, lonely.’ (115, Unemployed, Post-2004)

Although the Polish community was said to be ‘big’ (FG112) by the majority of participants, it was not a community that Polish migrants felt part of.

Not wanting to be part of the local Polish community may be influenced by English language proficiency, giving some Polish people the choice in using Polish facilities or British facilities, as highlighted by a few participants. This quotation is from a participant who was a proficient English speaker:

‘I do speak to Polish people, but nothing besides that, so, well you know, I came here, not to live in Poland...So maybe it gives them [other Polish migrants] some kind of sense of security um, I would go to a Polish hairdresser so I wouldn’t strive to explain what hairdo I’d want, um or something like that or, don’t need to go to a Polish hairdresser, er so maybe that is the difference.’ (13, Student and Waiter, Post-2004)

A few of the participants highlighted the downside of being part of a visible Polish community as some can tarnish the rest of the Poles with a bad reputation and was perceived by the participants for British people to be cautious when interacting with Polish people.

‘There are different people who came here to get job, or, mm, they can’t, well they can’t be bothered to find a job and all these opinions and stigma and then you meet Polish students, you have all the series of thoughts, all these automatic thoughts in your head, ‘they are this’, ‘they are that’, and they don’t want to work and yeah, it’s my, well, it’s unfair and it’s not always nice’ (FG111, Student, Post-2004)

SOCIAL NETWORKS

Social Networks: English Language as a Gateway

In Luton and Dunstable and from the views of the participants, workers in low-skilled work may not speak English fluently as they are surrounded by other Polish workers in the workplace and at their accommodation.
‘I do believe that they [workers] for example, do struggle to learn the language and you do see situations where they work in warehouses or factories and just Polish people amongst Polish people, I mean they speak Polish and not English, but they only have each other’ (I4, Teaching Assistant, Post-1989)

One participant went on to express that she learned English to improve her employment opportunities. This participant has made the decision to learn English as she wanted to stay in the UK and improve her employment prospects.

‘I am here and I don’t know English, that is not an excuse, that is something like, should push me to looking for my future here, so I start study English classes first, from beginning then, intermediate and advanced and then I started looking for different types of work, like office jobs or something like this...I always believe that I need to keep going to learn something, learn new skills, so that’s why I decided I need to start building my future, not in a warehouse (laughs) but something different.’ (I15, Unemployed, Post-2004)

**Social Networks in a Multi-Ethnic Community**

Some participants had come to the UK to stay with wider family connections, such as a cousin. One participant said that her and her husband, ‘we came to, to our family but it wasn’t like our family, they are my husband’s cousin’ (I15, Housewife, Post-2004). Many participants agreed that social networks had been loosely made before coming to Luton as friends or relatives may be living there already, making it more attractive as it was a ‘tried and tested’ route of migration and location.

‘My cousin knows that person and it makes you feel safer, there’s a stronger community over here already and I think that some people may feel a little bit, in case something happens, that they’ve got someone to turn to, because obviously they are in a foreign country, it does make them feel uncomfortable in many ways, for example, if their English is not very good’ (I1, Student, Post-2004)

'I chose Luton by chance, as I came here with a friend from uni, whose brother-in-law was already here, so he, we could say, gave us a certain level of support, and he helped us in the beginning to give us a safe start.’ (I11, Factory Worker, Post-2004)
Once in Luton and Dunstable, Poles generally had small inter-personal networks as there seemed to be a lack of opportunity to meet other Polish people other than through work or university. This may explain the reason why networks in the recruitment stage were dependent on reasons for coming to the UK such as university students telling other students about the study.

‘[P]eople do cluster themselves within certain categories, so let’s say, you have the typical Polish worker stay with Polish workers and people who let’s say, to pursue an education and are here and are working, but I think that’s normal, because you have nothing in common with each other and if at, for example, at university, um, you stuck together because you knew, there were girls that all came from one university so they all knew each other so, prior to arrival, um, I think it makes it easier because you have that comfort, of being with someone, I wouldn’t want to say of your kind, but basically the kind that is a little bit of home abroad, it’s your little comfort pillow.’ (12, Student and Administrator, Post-2004)

The only exception, highlighted by a few of the participants, being two formal organisations, the Polish church and adjoining Polish club in Dunstable. Here, Poles came together to form small communities, regardless of the reason for coming to the UK but having commonality through religion.

‘I think in Dunstable there is a Polish society club so they want to be unified, they want to spend time themselves as if, kind of like the Asian communities do, that it’s just a big, closely knit community.’ (12, Student and Administrator, Post-2004)

Alternatively, an individual’s social network may be linked with English language, as being able to speak English may expand an individual’s network across a wider range of communities as they are able to access non-Polish speakers and this may limit those who are unable to speak English.

Also, in Poland, the majority of the population is White and coming to Luton has enabled them, particularly if they are able to speak English, to
meet people of a wide range of backgrounds and learn more about different cultures and religions as highlighted by one participant.

‘In Poland, I haven’t seen the other cultures, other religions, maybe just a few person when I came here, I saw a lot of Muslims, a lot of err, Indian people and when I work with the Muslim people, I start to speak with him, how this with his religion and their rules and how it is’. (116, Customer Services, Post-2004)

It was perceived by some of those who spoke English well, that a lack of English language had led to the creation of ‘little Poland’ (13, Student and Waiter, Post-2004) as Polish people had found it difficult to integrate with non-Polish speaking people. This was thought to influence the opportunities available to a Polish migrant and the extent to which someone had to rely on friends or family to translate as suggested by one participant.

‘They [the Polish migrants] manage to create something, like a little Poland let’s say, but they help each other, let’s say, share information, what to do, how to deal with problems...NHS or something, how to solve things, so they help each other, it appears that they have a good, strong community’ (13, Student and Waiter, Post-2004)

Some individual social networks were small as participants only spent time with their friends or family in Luton and Dunstable and did not widen their social networks greatly as they felt that they did not need to meet more people across the Polish community.

‘When it comes to Polish people I think that most of our friends are those people that we actually met at the University, so we basically meet from time to time when we are going out but when it comes to other people like families or those who actually work, for us, it’s like, it’s kind of difficult to even meet them because obviously you see a lot of people in Luton, but it’s just, you don’t want to go there and you know, just to start to talk to some random person, you need to get to know them better, students are those people who we, yeah, spend time with.’ (FG214, Student and Administrator, Post-2004)

‘All of my free time I either spend with my brother, because I live with him, and well in general my brother is my best friend, so we get
on really well, and well, with my girlfriend... and that’s it. And, eh, recently my cousin came over for holiday, and well... he had an opportunity to stay, and he did, and, eh so that is my circle of friends.’ (112, Warehouse Team Leader, Post-2004)

Polish migrants not feeling a part of or not being able to socialise out of their already established group of friends, may be due to competition between other Poles and jealousy and feelings of envy as one participant described.

‘[T]here are many Poles here, and I would tell you this, that in ninety nine per cent of them I see that jealousy, that envy, that if someone has it a bit better than them, that they will not speak to them; simple... we came to a house which we shared with 18 people, and we found work really fast, and they had, well they had work from some agencies, and they came around once a while, and basically it came to this that, listen, that we would do our laundry and people would take the clothes lines down, just so we wouldn’t have anywhere to hang our clothes, yeah? They envied us so much.’ (112, Student and Administrator, Post-2004)

Polish migrants may have had to adapt their views of their fellow Poles in England as being jealous and competitive may not have been as common in Poland as it is in England. However, this had not been the case for all of the participants, some said that Poles did help other Poles, but this may be limited to the initial period when someone had just moved from Poland.

‘I have had a few bad experiences with Poles, especially here in England; in Poland, no, but here, I keep my distance from Poles and I agree with the popular conception that ‘Poles will throw you pigs’ [meaning that Poles will do everything to make sure that you do not succeed or tarnish your reputation]’ (111, Factory Worker, Post-2004)

‘[T]here is a competition, they want to be better than the other person and I think there is an old Russian saying you know, God had appeared to a man and he says ‘Oh well your prayers has been answered, you can wish for um, anything’, you know, ‘you want but remember that whatever you get, your neighbour will get twice as much and the man says, take my eye and of course the neighbour will lose both’ (14, Teaching Assistant, Post-1989)
4.3 Altruism and Giving to Others

This section is going to outline helping and giving to others including altruistic, empathetic and egoistic motivations, acting civically and comparing a collectivist communist environment to a post-communist individualistic society.

ALTRUISM AND PUTNAM'S VOLUNTARINESS

Altruism, for most of the participants, was believed to be something that is learned at school and at home.

'[J]ust watching my parents, the way they were, not just the Polish community but with everybody, it’s the kindness and thinking about other people’ (I19, Retired, Post-war)

'[B]ecause if you have I don’t know, full family and happy child who then learn how to help others then it’s much easier to role model and do something the same because it is something that you are used to’ (I7, Teacher, Post-2004)

For some, there was an innate need to want to help others, making helping others being part of human nature or part of an individual’s personality.

'[S]ome people offer help out of the generosity of their heart that they don’t expect anything in return, however some people do help with the expectation of something in return, it depends on the person’ (I18, Housewife, Post-2004)

'I think it [helping others] comes from the inner need to help’ (I10, Warehouse Worker, Post-2004)

The majority of participants viewed giving gifts and helping others as being part of Polish culture.

'I would say [that giving gifts is] connected with parts of culture that we give each other gifts for our birthdays, that we give each other gifts on holidays’ (I10, Warehouse Worker, Post-2004)

'[B]ecause Christmas um, it’s like really old Polish tradition that you always have one spare chair and plate and you just wait until
someone knocks on your door then you just, need to invite this person in.’ (17, Teacher, Post-2004)

A couple of participants highlighted how competitive gift giving has become for special events, such as Christmas and Holy Communion and how this has changed since people have started to have money after communism.

‘[W]hen you had first communion or something that you would get gifts but, well, obviously bigger than other occasions for last 10 years or something, it just came to the point in Poland when it is absolute madness. You know, kids who are 9 I think when they have it, they just receive the most expensive bikes, laptops, cameras and you know, it’s just a race to who has got better gift actually and the whole point of first communion is lost, it is about gifts and not about religion and it’s happening probably the same with Christmas that it is about gifts, not about religion anymore.’ (17, Teacher, Post-2004)

**EMPATHY**

Paradoxically, some participants said that they would help other Poles, as previously participants had said that Poles would generally not help others Poles. Those who said they would help is because they could empathise with other Poles, for example struggling to speak English when first arriving in the UK, as the individual had experienced that him or herself, perhaps showing that competitiveness and jealousy may exist in some areas but not all of Luton and Dunstable Polonia.

‘I’ve got that drive because I came here to this country and I don’t have anyone to speak, there were no one to speak to, so I know what it’s like for some of the people who are arriving here, they don’t have the extended families, they didn’t have support of their friends and close family and they didn’t know the language, they didn’t know any papers they were receiving, it was hard for them, I think for that reason it was empathy and um, I tried to do as much as I could’ (14, Teaching Assistant, Post-1989)

‘[T]here was this um, girl who started the course with me here, but I just knew her from, her face from the classes and once we had a chat and she told me about her very difficult situation because she was renting house from people who didn’t treat her well to start with, he was a bit afraid of the guy, he kept asking for more money,
so I just told her you pack your stuff and you’re moving in with us, because in a way, it wasn’t a person from the street and I can trust her because it’s still a part of my community, my student community, well she was Polish, she didn’t have to be Polish’ (15, Student and Bar Worker, Post-2004)

It was commonplace for helping others to be motivated by empathy. Many of the participants suggested that people would help other people in a certain situation, so one should help another person in that situation; this could equally be the principle of reciprocity. For example, in the situation described above where a Polish person may help another Polish person as he or she understands what it feels like to come to the UK to find work.

‘I think that this is kind of like wishing like there were a person who can help them when they were in that position, so, I think that they just have a really good understanding of those needs.’ (13, Student and Waiter, Post-2004)

For a few, helping others was motivated by having experience of a certain issue or life experience.

‘[S]ometimes by helping, you don’t really know who is helping unless it is to someone we really know but, as you said, if it is someone that we don’t really know and it is some sort of organisation or something, I feel uncomfortable, because I don’t know these people, they might not be worth it. It sounds horrible but it’s just, a long time I felt like this, um, but then on the other hand, I changed my mind when my friend committed suicide during the summer and we decided to, well, we all signed up, all my friends signed up to a charity who helps people with problems, like depression and stuff like that. And I’m quite happily giving money each month for stuff like that but I guess I feel like that’s needed, but well, you, I think it all depends on what you go through in life’ (11, Student, Post-2004)

A few of the participants had given money or food directly to the rough sleepers on the street and most of the participants felt that their help was not appreciated, perhaps did not trust the individual in need with their money or were worried about helping strangers.

‘[I]f I see a beggar, I would, I wouldn’t straight away give the money to them because, um, I wouldn’t trust that it wouldn’t go for
alcohol...Um, when there were some charity events at the University, I always took part but it was always I knew that this was the kind of charity that, I know that they wouldn’t spend the money on whatever, but it’s that I can trust that the money will be used for a good cause, um, yes so, maybe not that easily, it depends.’ (I5, Student and Bar Worker, Post-2004)

'[S]ometimes I find it hard to help strangers, like I remember still when I was in Poland, there was a situation that on one of the bus stops, one guy was blind and he needed help so basically I went there but I was a little bit scared, I don’t him and I don’t know how he is going to react, but is he going to get upset that someone is trying to help him or something and it was fine but there was that little bit in me that felt a little bit afraid of doing so.’ (FG212, Student, Post-2004)

But one participant had a positive experience of giving money to someone on the street.

'[W]hen I used to be a student when I was walking to the University there was an old, um Jamaican man who used to beg and I quite liked the way he approached people and asked for money, and if I had spare change, 50p, £1, I always give it to him and it come to the point we knew each other (laughs) he knew that he could get that pound from me.’ (I4, Teaching Assistant, Post-1989)

EGOISM

There was a mixture of views as to whether individuals should be repaid for helping others. The majority of participants did expect reciprocity, either something in return for helping others or to give something if someone had helped them.

'I think that...that it has become normal in our culture that if someone does a favour for someone then they expect something in return, and it is the same with gifts, so everyone thinks that it is obvious that that’s the way it is.’ (I14, Teaching Assistant, Post-1989)

'Well if somebody helps you, you are grateful and I’m sure you feel like whenever the person needs some help, you want to help because I, not like um, unpleasant, but you may just feel grateful and you want to return the favour, in terms of giving gifts, it’s a bit difficult, like I don’t like receiving things because I have this inner
Some participants did not expect a reward for helping in any way.

'There is always this type of debt of gratitude and I believe that such debts of gratitude are the hardest to pay off...perhaps there is a greater satisfaction when you give a gift to someone you don’t know because you’re not expecting them to return it [the favour].’

(I9, Housewife, Post-2004)

'When you help someone you help them out of your own will and I gave someone to help someone and nothing else, right? I don’t want any gifts and I basically help people out of my own will.'

(I13, Warehouse Worker, post-2004)

Some participants thought that people help others for selfish reasons, such as increasing someone’s self-esteem.

'I mean that helping, helps yourselves more than others I think because you want to feel better, you want to do, I don’t know how to explain this, you do it for yourself.'

(FG12, Administrator, Post-2004)

'I think that most of people are doing that just for the sake of helping others because it makes them feel better about themselves, you know, it is rewarding, I feel better if I’ve helped someone.'

(I6, Student, Post-2004)

Alternatively, one participant felt that people gave gifts to help themselves, making the gifts act as a bribe.

'People gave gifts in order to have an impact on whether or not they get the job... after I obtained that thing I thought that I could give a small gift to show my gratitude, because that is what I felt coming from myself.'

(I11, Factory Worker, Post-2004)

**POLAND: FROM COLLECTIVISM TO INDIVIDUALISM**

This sub-heading comes from Hofstede’s (2001) categories of cultures where some are collectivist, where individuals expect at their relatives or communities to look after them in exchange for loyalty to their family and community. Individualism is where individuals take care of him or her and
their immediate family only. For the older participants aged thirty and above, Communism was viewed as a time when people helped each other the most, more than they do today as it shaped the way of life in Poland at the time.

‘Communism was a blessing because during the communist time, you had more chance that people would help each other...people were helping each other on a big scale’ (I4, Teaching Assistant, Post-1989)

There was a sense among some of the participants, that Polish people have become more individualistic.

‘[T]en or twenty years ago we had the end of communism and communism did try to make us feel like a big family, they had their own way to do it, but that was their purpose to make people equal, egalitarianism, um, but somehow we are not like that, I think that we’re becoming more individualistic like Western countries in a really nick of time, now, yeah because when we were in communism, we could call Poland a collectivistic country, a bonding, a big family, now it disappeared, even within my family, family is just my father, my mother and my sister, I don’t call them my family how my parents see it...I think that we’re kind of separated into really small groups, even within family, um, and it’s, I think it’s because of the pressure of individualism coming to our country like, you have to look for things for yourself you have to be, not like we, I think that’s happening quite dramatically now.’ (I3, Student and Waiter, Post-2004)

Although Polish people were seen to becoming more individualistic in Poland, helping others was seen to be embedded in traditions that are old and new by few of the participants.

'[I]t’s like really old Polish tradition that you always have one spare chair and plate and you just wait until someone knocks on your door then you just, need to invite this person in at Christmas, when it is Christmas Eve dinner together’ (I7, Teacher, Post-2004)

‘We have this big event [Wielka Orkiestra Świątecznej Pomocy] and we all collect money for seriously ill children to get new machines into hospitals. Once a year, in January... and it is kind of amazing, how many people get involved in it, lots of young people get involved in money collection and lots of people gift money, so I don’t
know why they do that, I always do it. I think it’s a very good thing to help, especially children.’ (FG111, Student, Post-2004)

CIVIC ENGAGEMENT

Many participants felt that they did not trust strangers in the UK, but there were a couple of participants who did trust strangers. However, when discussing helping strangers in society and being an active citizen who is civic minded, many believed that Poles should participate in British society as if they were living in Poland.

‘[W]e’re here now so we should do everything as if we were living in Poland or wherever else you’re from, wherever you’re from, you should be doing whatever you can to give, you know, to be a part of something because again, we need to help, we expect it but you should be at least able to consider helping in some kind of way and contributing to society.’ (11, Student, Post-2004)

'I live here, study so I part of society, whether I like it or not, I am part of it, so I should, well, if I were back at home, I’d do something, but I am here and I should also do something for these people [those in need living in the UK]' (FG1F1, Student, Post-2004)

However, some participants said that they were more willing to help those that they knew, such as people they knew through university, work or their children, rather than strangers.

‘I’m more willing to help to people who I know a little bit, so um, there was this, um, girl who started the course with me here, but I just knew her from, her face from the classes and once we had a chat and she told me about her very difficult situation because she was renting house from people who didn’t treat her well to start with, he was a bit afraid of the guy, he kept asking for more money, so I just told her ‘you pack your stuff and you’re moving in with us’, because, in a way, it wasn’t a person from the street and I can trust her because it’s still a part of my community, my student community, well she was Polish, she didn’t have to be Polish, she was in my study group, so I knew that I could trust that she wouldn’t do anything too stupid’ (15, Student and Bar-Worker, Post-2004)

‘I’d rather help a friend but probably not only (them), I’d probably help a third party as well.’ (110, Warehouse Worker, Post-2004)
4.5 Religion

This section is going to outline views toward Catholicism, attending the Catholic Church in childhood, Polish Catholic culture and practicing and non-practicing Catholics in Luton and Dunstable.

**CATHOLICISM AS PART OF POLISH CULTURE AND TRADITION**

For many participants, religion was seen as individual and personal. Most of the participants went to a Roman Catholic Church when they were growing up and, for some, they felt they were pushed into it by their parents though this was not always the case.

'I was raised Roman Catholic and at some point I realised that I am mostly attending just because I want to satisfy my parents' expectations because some parts, like during Mass for example, sometimes I felt a bit boring... but then I've realised it teaches you lots of good stuff, which you can adapt... I still find myself Roman Catholic, I just don't know whether I am a good one!' (FG213, Student and Administrator, Post-2004)

'I think that, because of my background, that religion was inflicted, like pushed on me, rather than me learn it and understand it and make my own mind up' (12, Student, Post-2004)

Whether a Polish person is very religious or not, continuing the Catholic tradition with their children was important as was giving their child the choice of whether to be religious, when discussing this issue with mothers.

'I have a child now, I want him to go into this tradition, but I will show him and tell him everything in my way' (15, Unemployed, Post-2004)

'Well, I am full of faith. Faith, hope and love are my kind of life doctrines, which I try to keep to. I teach this to my children, and I raise them in such a spirit. In general, I believe that religion is very important to us.' (19, Housewife, Post-2004)
One post-war participant had said that the Holy Communion used to be very difficult to achieve as one had to prepare for this over two years and take an exam, however this is no longer the case.

'Maybe because we, as old people and before World War II, because we approached our first holy communion, you had to attend religious teachings for two years, and to approach your First Holy Communion you had to be 11 years old...Because, back then you couldn't do it like today that young children don't understand. And we had to pass a religion exam, yes? And then we were allowed to go to our First Holy Communion, yes?" (121, Retired, Post-War)

PRACTICING CATHOLISM IN THE UK

Luton and Dunstable are multi-ethnic and multi-faith towns with a number of places of worship ranging from Seventh-Day Adventists Church to a Hindu temple to Jewish Synagogues. It could be confusing to find a Catholic church, as highlighted by one participant. However, the availability of churches did not play a role in church attendance, it was suggested by one participant, that if someone wanted to attend church then s/he would find the means to do so.

'[F]or a Polish person coming to the UK, it's er, suddenly from being in a country where mainly, the main religion is Christianity and we've got mostly just one type of churches, there are others, but it's a minority, coming to actually Luton and seeing a couple of church but every one of those churches are a different religion actually and that maybe is confusing, we've got one church in Luton that actually has a Polish priest but when I told that to a lot people, they didn't know even that something like that was in Luton, I think um, a lot of people don't know of which church to go to that or that in some other culture, mostly Christian Catholic churches but there are differences, so they might be scared of that really.' (18, Student and Teacher, Post-2004)

The strengths of religiosity among the participants varied from devout Roman Catholics to atheists. Those who said that religion played a large role in their life attended church weekly, either the English Catholic Church in Dunstable or Luton, or attended the Polish Catholic Church. Many of
them felt that they needed to go to church. Most of those who attended church, preferred not to go alone because in Poland, church was attended as a family and there were Sunday rituals surrounding this, such as eating breakfast and lunch together and going for a walk after Mass.

‘It’s important to have something to keep you in the right place’ (FG111, Student, Post-2004)

‘It feels different [attending church in the UK] and I do get a need to kind of go to church every now and then, so I think it became stronger like the need to start practising again’ (11, Student, Post-2004)

Those who stated that God played a significant role in their lives felt that God was omnipresent, that He could be reached outside of the church walls by people who do not attend church but prayed regularly.

‘Oh, I believe that God is somewhere there and he always takes care of you and even if you don’t think about him, even if you don’t pray every day and stuff, he is still there and he looks after you, whatever you do if you do good things or bad things, he always, you know, he knows you, he knows whether you do it on purpose and stuff and even, you know, if you commit a sin or something, you know, he knows that you are a good person and you can be forgiven or something like this, he is kind of important, even if you don’t think about him, I’ve got the feeling that he’s there and he looks after me anyway.’ (FG214, Student and Administrator, Post-2004)

From personal observations, many post-2004 migrants go to the church on Sunday and the congregation is so large that they cannot all fit into the church, meaning that some people have to worship from the outside church steps. I also observed that the Polish Saturday School Children’s Masses were attended predominantly by young families. One participant said that attendance helped her children gain access to the areas only Catholic upper school.

'I was going to the church and also er, when the first child arrived, we had to go to church to make sure that the priest supports our application so he can get into a Catholic school.' (I4, Teaching Assistant, Post-1989)
Those who attended the English Catholic churches were mixed in their feelings towards it, some felt that they were friendly and open and had visited them for their friends’ children’s christenings, but they lacked a sense of community and preferred to attend church in Poland. A few of the participants had commented on the differences in Catholic customs between England and Poland, such as Christmas. Some of participants felt that the language in which Mass was carried out, acted as a barrier in connecting with God.

‘Well let’s say, it’s [English Catholic Church] different! It’s not only because of the language but it’s the different customs as well, um, I think that still, I’m kind of attached to the way that the Mass is conducted in Poland than here, at the beginning it was quite fascinating’ (FG214, Student and Administrator, Post-2004)

‘[I]t doesn’t matter how well you speak [English], when you speak a certain language, but there are certain things that I am never, that I will never feel so strongly about, like praying in Polish, I mean English, praying in Polish, it seems like I’m praying but in Polish, even if I say it in English, even though I understand the words, I’m still kind of don’t feel like I’m communicating with God’ (l1, Student, Post-2004)

Religion and attending church was viewed by most of the participants to be more common among older people. The perception was held that older people were reaching the end of their lives and wanted forgiveness and they had more time than younger people to go to church.

‘Because, it’s the same that old people in Poland, and in particular the ones who attend church, and it’s as if church plays a really big role in their life and in this type of moment in their life it happens that they have a big, huge impact and influence the older people.’ (l14, Shop Assistant, Post-2004)

‘[T]here is only one person in my family that really goes to church, um, which is my grandpa, but he goes to church because kind of like, when there is a need, there is a willingness to go to church...he didn’t go to church ever and when he got older and he got health problems, and other problems, he went to church.’ (l3, Student and Waiter, Post-2004)
'I believe that somebody who is older, they believe like the end is coming very quick and they start believing that it's time to start thinking about this period, it's time to start thinking about dealing with if anybody's there, it's time to er, fix everything that I've done wrong to people, to anybody else, so I believe they are looking for excuses and explanations of everything they've done wrong in church, or in their sins, they believe that's going to be mm, like forgiveness for them, from the God-side, that's why I believe.' (115, Housewife, Post-2004)

When discussing the new wave of migration with the older Poles, they had mixed views towards the younger Poles, one post-war participant could empathise with them in their struggles of settling in the UK, but the other post-war participant did not like their attitude towards the church and thought they lacked respect for it and viewed it closer to a social club than a place of worship.

‘The young have other problems and an old person like me, who doesn’t have to worry about work, doesn’t have to worry about anything, then the church is number one to me, yes? And the young? They only go to church on Sundays, they went, but here is work, but there you have to raise the children and there isn’t that, no, that doesn’t want to or something, such a situation is in England here too. It’s not like it was back in the day in Poland, that you had to drop everything because you had to go to church, now everything has changed.’ (120, Retired, Post-war)

NON-PRACTISING CATHOLICS IN THE UK

Those who said that the Catholic Church played some role in their lives in Poland had found that it was common for church attendance to decrease whilst in the UK. Church attendance decreased for a number of reasons, including lack of time due to long working hours, feeling tired on Sunday mornings, people around them in the UK not being religious and not feeling pressured from family to go to church.

‘There is not my family here, nobody is in my ear, talking to me like to, to church, this is something, the other thing is that sometimes you work hard yeah...they [Poles] work hard for the whole week and
sometimes they don’t want to go to church, they are too tired, they are just like me, they are lazy.’ (115, Unemployed, Post-war)

A few participants had a connection with God that was rekindled every so often and His role in their life came and went, rather than Him having a constant role.

‘Have you ever had like a best, best friend that is abroad and you can’t see him or her very often but every, I don’t know, three, four months you write emails to each other and you feel reconnected and you feel like it’s great, like they have been there all the time, um, and sometimes, it’s been another four months passing by and you think oh I’m going to talk to him or her, it’s going to be alright and the other person is a bit upset, like oh, you haven’t talked to me for three months, I’ve missed you, and somehow it is just a little bit like that, I don’t think about God on an everyday basis but sometimes I have things in my head, you know and I think God’s an amazing thing, and an amazing thing, just as it is and you’re like thinking about it, like coming back to it, it’s just like coming back to the roots of your religion and your traditions but then it disappears again and every now and then I think I’m being a bad Catholic, maybe I should think about God more often, but it doesn’t appear on a regular basis, so it’s just a bit, comes and go, but I’m not agnostic, I still believe that thing exists, that God exists.’ (FG213, Student, Post-2004)

A few participants commented that non-attendance at church led to the person being a ‘sinner’ in Poland. However, most participants attended church for religious or social events such as weddings and Holy Communions, regardless of their religious persuasion.

‘I would go to church every Sunday or almost every Sunday, um, I’ve done all the services and things like that, mm, but probably like at the end of High School or maybe beginning of studies, it was just, less and less and less and now it’s maybe, I’d go to church during Christmas, Easter or any family occasions like wedding or baptisements or something like this, it’s not really often and, um, it’s probably because in Poland, religion is strictly connected with church, so like, um, (...) mm, it’s like the centre of everything, especially in, um, little villages and towns and things like that, that’s the most important building probably and, er, for its slightly different ways, religion is one thing that, probably that one thing and church is probably slightly different so.’ (17, Teacher, Post-2004)
'There is definitely less people going to church especially young people, well erm, I think that the main priority for young people is actually going out, somewhere going out for a party, meeting people and church is something that it's very boring and that is what keeps young people out of the church.' (18, Student and Teacher, Post-2004)

NON-BELIEVERS

Some participants who said that religion, the Church and God did not play a role in their life, or who were atheists, had decided upon this as adolescents but had labelled it or decided upon it once they were in the UK as they were around people who were not religious.

'I noticed my surroundings[in the UK] that less people are religious and that became a regular surrounding that I wasn't around religious people so that became, at one point, I started questioning religion and I made my mind up about it' (110, Warehouse Worker, Post-2004)

One participant's mother assumed that being an atheist may be a phase, but that she will return to it later.

'Catholicism is our tradition, but I do understand what you say and it, she kind of said, between the lines that she understands that I'm an atheist and that I don’t believe in this but in later life I would reconsider it because it is the tradition of the family' (12, Student and Administrator, Post-2004)

For non-believers, there were contradictory messages between religious teachings and 'real' life experiences. Many participants had observed other people regularly attending church but not living a Christian lifestyle.

'I've seen too many cases where with people, especially places like Poland where most, the majority of society are declared to be religious, they say 'oh yeah, we're Catholic', I don't know if it's a pressure from the society to say that or, you know, I don't know how truly religious they are and how seriously they consider whatever religion tells them to do, um, because I've seen too many cases where I've seen people do everything against what Catholicism says and they seem like hypocrites.' (1, Student, Post-2004)
'My gran used to go to our church when I was, as I little girl I would follow her and go to the church and listen to Mass and stuff like this, but the church has finished and go back to a normal routine and there was a time when I was very confused because although the church is teaching you that you have to be this, that and the other, the life was telling me a different story, so whatever the church said, it was clashing with the reality of life' (I4, Teaching Assistant, Post-1989)

A few participants suggested that the religious leaders manipulate religious teachings depending on the message they are trying to portray to their lay congregation.

'I it was changeable depending on what priest wanted to, um, make you feel about particular thing, so at the same time, God is very merciful and everything and at the same time he can punish you or just check your faith and bring some bad luck onto you or something, so it depend, depending on what priest wanted to, um, from you to, to think about issue, or to do something, they would kind of adapt it toward.' (I5, Student and Bar-Worker, Post-2004)

Until this point, this chapter has outlined the findings of experiences of living in Luton and Dunstable, social capital, gift giving and helping others and religion. Attention will now to the perceived relationships between gift exchange theory, altruism, social capital and religion.

### 4.5 Relationships between Gift Exchange Theory and Religion

When discussing communities in relation to social capital, many saw religion or the church as a way of bringing people together, in this case Polish migrants at the Polish Catholic Church in Dunstable. Religion and community were thought to come together by some through sharing the same religion, which offered charity to the needy or help in a general sense to friends made through the church.

'But I do think that these two [religion and community] can influence helping others, giving gifts and organ donation because a community can exist without religion but religion cannot exist.
without a community. So I think that community is most important
and it just brings in other aspects, such as religion, well, the
religious part of community might want to help others and give
gifts, maybe not all of them would want to give organs away but I
think that essentially that community is the most important.’ (12,
Administrator, Post-2004)

‘[W]hat in the church I would say that I meet up with a particular
group of friends with whom I also, I also meet up with at home. I
also have a different circle of friends who I can say that church is not
the most important thing to them, and they do not go to church
often, yes? And, well, at school I have such people there, who I do
not know very well and I don’t know what I could say about them,
but there is a nice mix of nationalities so...’ (19, Housewife, Post-
2004)

The relationship between religion and religiosity and helping others was
mixed, but the majority of the participants felt that religion did not
influence whether people helped others.

I am under the impression that there are many such people who go to
church, and listen to what the Priest has to say [about biblical stories
such as The Good Samaritan], but I don’t know if they apply this to life
afterwards.’ (19, Housewife, Post-2004)

'[R]eligion teachings you like, priests tell you in the church you know, you
are supposed to help others and everything but I don’t think that it
actually has such a strong influence over the people who attend Mass.'
(I5, Student and Bar Worker, Post-2004)

But some participants believed that religious teachings and God do
encourage people to help and love others. However, this could be a
combination of the church, school and parents in these teachings being put
into practice.

'I think that people who are more religious help regardless of
whether or not it’s a good deed- which is liked by God, I mean you
don’t believe in God, so your life is guided by materialism.' (112,
Warehouse Team Leader, Post-2004)

'T[He] religion is more of a theory and at home you see the
practice.’ (FG113, Student and Administrator, Post-2004)
Regardless of the strength of one’s religiosity, religion was commonly viewed as a source of morality, to make someone a better person and helping others was a form of moral behaviour.

‘[R]eligion is trying to help you to be a better person and trying to teach you to do something, do something good for other, it’s this way so when you do something good.’ (I16, Customer Services, Post-2004)

‘Well, in Poland, they [the Church] certainly embed it (in your brain) from an early age that you have to be good, and so on, and so on, and so on, so I am sure it had some kind of impact’ (FG312, Personal Shopper, Post-2004)

4.6 Attitudes toward Deceased Organ Donation: Pre-Death

Themes arose for the consideration of deceased organ donation pre-death including lack of knowledge about donation and registering as an organ donor, the thoughts behind donating one’s own organs, perceiving the organ as an 'altruistic gift' and discussing registering and organ donation with family.

LACK OF KNOWLEDGE ABOUT DONATION AND REGISTERING

The participants were asked what they knew about organ donation and their experiences of it. For the majority of participants little was known about all of the organs that could be donated and what transplantation entailed. One participant said that ‘almost nothing’ (I10) was known about organ donation or which organs were removed for transplantation. The majority of participants had little experience of donation, many did not know anyone who had had a transplant or who needed one. One participant illustrated that information or experience of organ donation may influence a person’s view more so than religion.

‘[S]o from religion, it’s not really something that you hear about and not something that, um, definitely not, I can’t think how religion would help people, to get people to do that because it’s not something they talk about, however, mm, yeah I mean, it’s
definitely a personal decision, it's not strictly a religious decision but it can be influenced by it. It'll be mainly personal circumstances or the things that happen to you or someone you know and you're kind of making your decision based on what you've been through, what you've heard and what information you have about how easy it is to be done.' (I1, Student, Post-2004)

There were three participants who were aware of the opting-out policy in Poland where they were given opportunities to 'opt-in', although they should have been given the option to 'opt-out' as they were already donors.

'I never knew about it [opt-out], that's really cheeky of the Polish government! No, like... I think that's not, it's not a proper, it shouldn't be like that.' (I6, Student, Post-2004)

'So yes they [the Polish government] assume otherwise they [Polish people] wouldn't donate otherwise, well this is my opinion, but carry on! (Laughs) I may be wrong! I think that it's a fantastic idea, I think that England should do the same, but everyone is, you know, assumed organ donor and people don't have to make a decision, you know it has been decided upon them.' (I4, Teaching Assistant, Post-1989)

Some participants were not aware of how to become a donor in the UK or whether they were a donor in Poland. For the older participants, organ donation was a pledge that someone made in their Will as opposed to signing up through the other methods, such as Boots or the DVLA. However, most of the participants had opted in, in the UK through their GP, online, through the DVLA or Boots.

'Well, when I was signing up with a GP here, I immediately filled everything out, that, eh, after death they can take everything from my body, so I have all that done.' (FG311, Warehouse Worker, Post-2004)

'In England, I mean in Poland I was already registered and when I moved to England, I wanted to register straight away here,....basically a friend told me what to do and how to register...on the Internet basically.' (I14, Shop Assistant, Post-2004)
Level of English language was raised as an issue in accessing the organ donor register; however this was not commonplace as a few participants suggested that learning about donation could be achieved on the Internet where there is information available in Polish.

‘Maybe it’s because they don’t even know this word, what it means ‘donation’? They filling in an application and they just, leaving the space, leave this blank, its like ‘what is donation? Never mind, I’m going to leave it’, maybe it’s because of this, maybe it’s because they don’t know the language enough to understand what it is writing in an application form, and yeah, yeah, maybe they are not educated.’ (115, Unemployed, Post-2004)

Many participants highlighted that organ donation is not a topic that was discussed at school or in church:

‘[C]hurch may encourage sometimes, and may be make people aware of it because well, they have a special way of communicating information. There are some people, when you hear something in church, you absolutely listen to it and you have to do it.’ (FG111, Student, Post-2004)

‘[I]t wasn’t even a discussed topic when I was at school, even when I was at school in Poland, you didn’t really talk about it, organ donation never came up.’ (12, Student and Administrator, Post-2004)

Many participants suggested that organ donation is a topic that has recently become well-known in Poland in the past couple of years, one participant highlighted that this may be due to the EU expansion and advertising has improved due to Western consumerist influences.

‘[I]n Poland through last couple of years, probably because we are learning as well from other European countries and loads of people have actually moved out, started travelling and came back...they’ve seen how you can build people’s awareness through adverts and things like that, probably 20 years ago you wouldn’t have any adverts, I don’t know, don’t drink and drive and now there is plenty of them... it’s a slow process, but it’s changing I would say, probably 25 years ago if you would say organ donation in Poland there would be seventy per cent would say no, not because they wouldn’t like to or they wouldn’t, um, be able to but they didn’t know and they
would probably be scared, I didn’t know about it, I didn’t hear about it so it’s probably best that I say no, just in case in a way, so.’ (11, Student, Post-2004)

Older persons were thought by many not to be aware of organ donation, as they were not brought up with it, with the exception of one participant. This perception of the older Poles was not reflected when discussing donation with this group as they were as much aware of organ donation as the younger Poles.

‘I mean, everyone has a TV at home, and I think they are more established, and I don’t think these are the times that people live in a dark garden, as even people in villages have TV...everyone has a TV and to some extent someone knows something about it’ (118, Housewife, Post-2004)

Some had seen the organ donation advertisements in the UK, but most of the participants had not. When discussed as to where they had to go to learn about organ donation, they suggested the hospital where a person would need to have psychological tests done to register, blood collection points, go on to the Internet and maybe ask their friends who were at medical school. Many thought that organ donation should be learned about at school, to help people make a choice early in life.

Many of the participants had learned about organ donation through the film ‘Seven Pounds’ (‘Seven Souls’ in Poland) (2008) or Polish television programmes:

‘From some TV campaign or even some TV series, we used to have a lot of TV series about hospital life and doctors and I think that they liked to touch some social issues so one of those was about organ donation’ (FG113, Student and Administrator, Post-2004)

‘I think that it [the media] would make many people more aware of what kind of help this is to others, and how it affects them later, and how many, many people lives they could obviously save. I think that yes, yes that this type of education is needed very much, people
change their views through such...have you ever seen the movie “Seven souls”’’ (I9, Housewife, Post-2004)

It was commonplace to want more information about organ donation.

‘I’d like to know more, but there is no, mm, information about that, spread anywhere, just, I can hear there is more, mm, how to say that, there’s more occasions when they ask us if we want to be donors, but no-one really making...Any explanations, and people are scared to do this...Because they don’t know how this works, basically first what I was first thinking about was like, here in, err, brain dead, and they taking their organs for someone, but you didn’t, you know, people they, they might have hope that they are still alive, so they don’t want to end up alive because they signed a piece of paper and no-one waits for them to wake up from a coma or...’ (I17, Vet Technician, Post-2004)

Campaigns about organ donation were not currently reaching all of the Polish community:

‘[D]espite all of the campaigns, people don’t know about it, it’s not like people will decide, I am going to donate organs, I am going to go to the NHS and sign something! It should be more like the NHS or any other organisation should go out to people and give them the opportunity, like look, have you ever considered?’ (FG213, Student, Post-2004)

One participant had had experience in Poland where there had been a campaign where ‘they gave out cards in our high school, so we could all sign it, so they gave us some information to decide’ (FG111, Student, Post-2004).

Community events could help raise awareness about donation and also what people in their geographical area thought about deceased organ donation. Some of the participants wanted to know more about what people in their local area thought about donation.

‘I think if people talked about it more often as a group, um, then perhaps we would have a better understanding, but people don’t, it’s not a subject that people bring up unless somebody says something.’ (I19, Retired, Post-war)
‘[S]ociety can also have an impact on it [organ donation] because somewhere it is commonly known that if it gets brought down to something normal’ (118, Housewife, Post-2004)

To reach the Polish population, organ donation, it was suggested by some of the participants that it should be in the media:

I17 (Vet Technician, Post-2004): [R]un a campaign about this or something. I think if some celebrities ran a campaign about this because in Poland, one guy from a band, he’s got, he needed a marrow transplant and his girlfriend was a celebrity as well and she ran campaign and they register so many people, they registered marrow donors because of them and I don’t know if they opened any.

I16 (Customer Services, Post-2004): Foundation

I17: I don’t know if they opened any foundation but like people reading about this, people can know that there is no harm and pain with this.’

I16: Newspapers, tabloids, they are reading about this and people just see this, oh its good help, nothing, cost me.

THINKING ABOUT GIVING ONE’S ORGANS POSTHUMOUSLY

Making decisions about one’s own organs was a ‘personal choice’ (120, retired, post-war) for nearly all of the participants. One participant highlighted that this was her decision because it was her body:

‘I thought I’m an adult now, nobody tell me what I should do with my body or not, I tick yeah, everything yeah, any part of my body and I was thinking, mm, I’m proud! What would say my family, but this is my decision, I put the signature on and this is my decision.’ (115, Unemployed, Post-2004)

For some of the participants, deciding to be a donor is made over a long period of time with deep consideration, but for a couple of participants, it was a quick decision, ‘I didn’t even think about it, because it’s quite clear for me that, why not?’ (FG111, Student, Post-2004)

Individual factors were thought to have an impact such as accepting one’s mortality and making plans for after one’s death, life experiences and age.
The majority of participants did not want to think about their own death but some accepted their own mortality and viewed death as part of life.

'I'm not one to think about death...I think that's how most people will think...I think some people are frightened to die' (I19, Retired, Post-war)

'I think that I have an issue with that [organ donation] and accepting mortality and that's, when you're signing this, it's like the next step because it makes you think that, err, mm, makes you think that it's really happening, that you can't skip this in your life, I think that there is a big connection between this, because it links one to another.' (I17, Vet Technician, Post-2004)

Many believed that religion helps people cope with one's own death as it provides reassurance for what happens when someone dies.

'I think that the aim of religion is to give people support, to help people cope or even think about dying, I think that this is kind of like mental support that, don't worry about your death because, the party, you know, starts after that, so it's really important, I mean if I believe in God it would be much more easier to think of death, but if you think well, yeah, some insects are going to eat me and that's it, the end, that's horrible, people who are religious actually believe they get that support' (I3, Student and Waiter, Post-2004)

'I think that this is something greater than me and that you know some things don't happen by accident and that you know there has to be someone who is just you know, putting you in the right place at the right time very often and you know it gives me some sort of security that for example, um, if that one day that I'm going to die, I believe that there will be something afterwards, and it gives me some sort of courage and um, I'm not so afraid of dying or sometimes I doubted that, 'oh what will happen if I'm going to die?'' (FG212, Student, Post-2004)

Some participants who had children suggested their perspective changed on organ donation as having children is a significant life event.

'I think that I'm more likely to give organs now I've got a baby than before when I didn't have a baby.' (FG112, Administrator, Post-2004)

Younger people were assumed by many participants to have different priorities and would not consider organ donation or one's own death.
‘I think young teenagers...thinking about me at that age now, I wouldn’t have even thought about it, not that they did it then...I think when a child is about 18, they have a different perspective on life don’t they?...they are young adults and a lot of them have their own opinions in the sense.’ (119, Retired, Post-war)

‘[Y]ou are young and you’re teenager, you’re looking for parties, your friends are most important and you are not thinking about anything else [such as death or organ donation], but you’ve, when time is going, you’re growing up and you are more mature, you see what is happening. You start losing people around you.’ (117, Vet Technician, Post-2004)

Some participants suggested that people, who are old, could not donate their organs. This is an issue that arose when trying to recruit the older participants as they said that they were too old to donate and could not understand their contribution to the study.

‘I was in the opinion if you’re old, you don’t think about donation because it’s all broken so to speak’. (119, Retired, Post-war)

DECEASED ORGAN DONATION AS AN 'ALTRUISTIC GIFT'

Many of the participants viewed donating organs as a gift.

‘[I]t is the most beautiful gift you can give I think...Someone’s life...Help.’ (FG212, Student, Post-2004)

‘I think there is nothing more altruistic, mm, gift, than giving an organ to someone, I don’t know I won’t benefit from it personally but I’m signing up to it’ (16, Student, Post-2004)

Viewing organs as a gift is in line with the ‘gift of life’ metaphor that was suggested to aid society in engaging with organ donation (Sque and Payne, 1994; Gerrand, 1994; Ben-David, 2005; Healy, 2006; Sque et al. 2006, 2007; Gill and Lowe, 2008). Nearly all of the participants did not expect anything back in their lifetime for registering as an organ donor as it is about helping others and it is a gift that cannot be repaid or compared to any other form of giving such as giving money to charity or volunteering.
'[W]hen one donates an organ, one does it out of love to another' (121, Retired, Post-war)

'[W]hy be selfish and go six feet under where you're going to decompose and there is going to be nothing of you, but each organ can save one life but to save them you only need that one organ, so you could be helping and saving loads of people' (12, Student and Administrator, Post-2004)

'[O]rgan donation is of the highest rank [of helping others]' (113, Warehouse Worker, Post-2004)

Some participants, when comparing living to deceased donation, saw a lower level of risk with the latter as the family were donating another person's organs. This could influence the type of 'gift' that the organ is, based on its source and the cost or risk it was to someone. For some, living donation was viewed as a form of 'sacrifice' as opposed to deceased donation.

'[O]rgan donation from a living person to a living person is well, a person that gives...his organ or whole organ, he actually makes himself not 100 per cent...I know there are problems after that, I know that a person that gives one of their kidneys towards another person, they are actually lowering their, mm, their, um, health actually might, um, sorry... let's say with a kidney, there's another working kidneys he has to come four or five times to hospital and spend five hours being stuck on a machine just being able to live and some people can't even move from their beds if some of their organs have failed, so helping a person like that is, major improvement for the person, there is a lot of risk with that.' (18, Student and Teacher, Post-2004)

It was commonplace for donation to be perceived as a way of helping humanity.

'[W]ith organ donation, why shouldn't you give it to someone that you don't know or have any feeling, it's another human being, black, white or whatever, you know, that family is suffering, they need help.' (119, Retired, Post-war)

'[Y]ou think about save someone's life rather than thinking, she's Japanese or she's Black, my child is dying, nobody cares if he is Black or not, I just want him alive, I don't care, you know, so for me, no preference.' (115, Housewife, Post-2004)
Helping humanity may be a form of empathy because if a person can help another who is suffering. It could be them and they would want help, it connects people together and was highlighted by a couple of participants.

‘I think that like, life is changing and it is full of twists and you never know when you’re going to need the help, so I am always thinking, if I am the one which is willing to give, if, I hope that when I’m going to be needing it, hopefully not, but if it may happened then I hope that somebody is going to be there because they have the same choice, that they are willing to, to give, so.’ (FG113, Student and Administrator, Post-2004)

However, aside from the religious teachings of helping others, religion was thought by some of the participants to have little to no influence on organ donation, except for Jehovah’s Witnesses for whom it was thought to be an issue. In fact, Jehovah’s Witnesses can receive and give organs but cannot receive and give blood (Oliver et al., 2011).

‘I think Jehovah Witness, they are not allowed to transplant blood, so probably they are not allowed to donate organs, so maybe if you have that strong religious belief maybe not, other than that, all other religions involve helping each other, so, it shouldn’t be a problem.’ (I7, Teacher, Post-2004)

Catholicism was viewed to support organ donation by the majority of those in the study with the exception of a couple of participants who were unaware of how their religion viewed donation. Although two participants believed that Catholicism was against organ donation. It was thought by the majority of participants that donation is showing love to others, which is in line with Catholic teachings. A couple of participants said that God would not reward the individual in Heaven for donating their own organs, as the intention to donate is to help those in need and not to benefit from the act.

‘I’m not sure if it's [organ donation] got too much to do with religion, I mean the fact that you want to do it is probably, could be, part of what religion tells you to be like as a Christian, but I mean like, obviously our religion doesn't mention anything like that in any
shape or form, so I guess that it can’t come straight from there, it might come from the background of a culture and, you know, awareness of how much, you know, how much it could help others, um yeah, I think that’s the main reason.’ (11, Student, Post-2004)

‘[I]n the religion we’ve got some guidance and they are saying that you should help other people and that you should respect other people and you should do everything to help them and...if you think this can actually influence you to agree to be a donor I think’ (FG24, Student and Administrator, Post-2004)

Most the participants did not have a preference for the recipient of their organs after they died in the UK.

‘[R]eligion would come into that, in the sense that I am [not] God, why should I decide, you know, the doctors will decide on the person then, they’re not, the only reason why they decide is because if they are a blood match and who is the best person to, so I don’t, they would want to make that sort of decision, no, it’s like you say, why should we? You’re not, you know, so.’ (119, Retired, Post-war)

‘I don’t have a problem with that [who receives the organs], and I don’t care who gets them [organs]...basically meaning, I could donate here and in Poland.’ (113, Warehouse Worker, Post-2004)

There were a few who believed that homophobia and racism could influence the decision to donate in the UK.

‘[L]et’s not fool ourselves most people are in Poland White and that’s it, true? And here we have a broad selection of people from various ethnic backgrounds and, well, basically I know people who are racists and for simple reasons people don’t know whether their organs go to black people or to white people, and I think that’s why they don’t want to donate their organs.’ (110, Warehouse Worker, Post-2004)

Many were not comfortable with the idea of getting paid for their organs as it was thought that the organ would lose its value as a gift and the recipient and donor would enter into an exchange, meaning that altruism is no longer the motivator.

‘I don’t think it’s [receiving money] a good idea, it would lose all the beauty of this amazing gift, if you pay somebody for that, then I don’t know, its, it’s just, well (laughs) it’s business to do and when
we talk about our body and organ donation we shouldn’t talk about any business and any money actually, that’s just my opinion.' (Post-2004, Student, Female, 22)

'I don’t think that it’s the right way to do it [getting repaid to donate], because at the end of the day, I mean, we were born to like, we didn’t work for it... it’s [receiving help toward funeral costs] still a payment you put it as the costs towards a funeral or a holiday but (laughs) I don’t think it’s right, it’s just something in a way, even something religion says that, for instance Catholicism says that you can’t take away your own life because it’s not yours, kind of to take it away, it is yours but you can’t take it away' (Post-2004, Student, Female, 22)

However, paradoxically, many agreed with receiving a reward for donating, such as funeral costs from the government.

'If I couldn’t afford to pay for my funeral cost, by somebody in a close relationship, then, yeah, that would be good, if yeah, for example, they say that, mm, the other family that they need this part of body, I would never take the money for this, I would feel like, oh my God, probably they would spend a lot of money on the treatment and for that person and now I am expecting them to pay me for my husband’s heart or something, no, I would be like, no, that would be more like a transaction, like money transaction, I wouldn’t feel good, for me, for myself, but if somebody, like a government, paying for my funeral costs and it doesn’t cost the family which are going to get my husband’s part of the body for example, yeah?’ (115, Unemployed, Post-2004)

'That [receiving funeral expenses] would actually be a good idea, and it could also be successful, and like people could sign up to the list because they could think that my family could have better options, for example.' (Post-2004, Warehouse Team Leader, Male, 24)

However, one participant highlighted that it may be reassuring to know that you are going to do something good in the future and this is a reward in itself.

'I mean since you can’t get any big reward, after you donate the organ maybe it’s like when you sign the paper, that you’re going to donate an organ at some point, it’s a bit of a selfish deed, you feel very good that you are going to do something great and maybe this
is your reward, you are going to feel good about what you’re going to do, at some point probably.' (FG213, Student, Post-2004)

ATTITUDES TOWARD FAMILY DISCUSSION

Whether the participants had discussed organ donation with their families was mixed. Some had spoken to their family about organ donation and their wishes but many had not. A few participants suggested that talking about donation is not easy; one participant said that people would rather talk about other things such as ‘plotka’ (gossip); another said that talking about death is taboo and another participant suggested that as donation is linked with death, people did not like thinking about death and dying, particularly with their close relatives, as it is an emotive topic.

‘[T]his [organ donation] is taboo subject, people don’t want to talk about it because it’s linked with death and our life, death is not good fun, we try to have good life and things like this, death, ‘Oh no, let’s change the subject’, we want to be happy, don’t talk about death and death is compared to donate.’ (116, Customer Services, Post-2004)

‘I think like back home, we are quite open about this, if something happens, we all want to donate our organs and I think my parents and my brothers and, like for us it was kind of important because, let’s pretend we’re brothers, like me, they are really active, they do a lot of sports, they study this, so they are skiing, cycling, I don’t know, canoeing and doing a lot of stuff, so I don’t want to say that they are in a risk group, kind of it was obvious that if something happened, just take as much as you can and as much can help, so I think it’s the same now with my boyfriend or with my friends, they know that if something happened to me, just, just, yes definitely.’ (FG113, Student and Administrator, Post-2004)

The majority of parents’ views towards donation were positive, a couple of participants said that their grandparents’ were also positive and a few of the participants said that these views would influence their perspective on organ donation and a couple of parental views were known to be negative. For a couple of participants, their friends’ and family’s views on donation would not change their opinion.
'My parents would probably donate their organs...I know that my mum would surely donate her organs after death, and well, she would—she would like, I mean that's what she would, and I'm sure my dad would—or at least I think so.' (I13, Warehouse Worker, Post-2004)

4.7 Attitudes toward Deceased Organ Donation: Post-Death

There was a distinction between thinking about donation for the self and for a relative and attitudes toward deceased organ donation after a relative had died included the conceptualisation of the act of consenting to donating a relative's organs, the body and the pragmatic issues of funeral practices.

PERCEPTIONS OF DONATING A RELATIVE’S ORGANS

Two of the participants said that they would be prepared to donate their partner's organs at this difficult time.

'I saved somebody’s life and I am proud of this, more like this, yeah, I’m proud that I did it, that I have enough strength to decide in this very bad situation, that I want to give somebody who is in my family, somebody else donor’ (I15, Unemployed, Post-2004)

Some of the participants said that the decision to donate is difficult if the person’s wish isn’t known.

'I think it’s a very hard decision, if, for example, you've got your mum or dad or your sister is dying and you know she is in the condition that she is not able to make that decision that you have to make it for her and I think that it is up to you, it is up to the family whether they want to agree or not, it may be very difficult for a family to decide rather than for your own, I don’t know, I’ve never ever thought about it before but I think, for me, it would just be easier to sign whether I want to do it or not, it's fine, but if my parents are supposed to do it then it would be a very hard decision for them.’ (FG2I4, Student and Administrator, Post-2004)

It was thought by a couple of participants that donating their relative’s organs would help the family cope with the recent loss of their loved one.
‘[C]ertainly it is a difficult decision to make for someone else, first of all, because if someone really died, it is difficult to come to terms that they are gone, and then cope with the fact that there is a piece of that person living on in someone else, well it’s something very difficult; however it depends on one’s approach, as it’s like people say there is always that glimmer of hope that maybe you’ll meet that person, and by keeping a part of your loved one, who has passed away...it also works the other way around that if maybe I help someone, eh, I don’t know, not as much as myself, but maybe my children may need the same type of help, let’s hope that that type of person will be found, and who is in the state to help.’ (11, Factory Worker, Post-2004)

Some participants said that the family should honour the person’s wish at the difficult time of deciding to donate. One participant was not aware that the family was able to over-ride their wish to donate.

15 (Student and Bar Worker, Post-2004): Even if I said, like you said, I was a potential donator, they [the family] could just say we don’t agree, we want to keep her organs and keep her body in the ground just like that.

CS: Yeah they can do that.

15: Oh, interesting.

A couple of participants said that they had become organ donors to prevent their family to have to make the decision about donating their organs. One participant said that being an organ donor should be a legal contract that the family cannot change.

‘I think that if people are really serious, they should make it a legal document, that doesn’t cost them anything to have anything, as soon as you say legal, the lawyer takes the money, make something that it’s taken out of your hands, I think it would make it easier because that person has made, I mean, if something happened to me, I think if I had a legal document saying I want some parts of my body to be donated, and the girls would then have to respect that, they haven’t got to make that decision, but they have to respect my wishes, because the doctor won’t come up to them and say, ‘oh’, you know, ‘your mother said that she had a donor card’, they might go, ‘sod off and leave her alone!’ I’ve just died or am dying, they don’t want to talk about it, you know? I know the doctor has to ask
It was perceived by some participants that nurses did not ask people about organ donation at all. There were some concerns about the level of perceived support that the family would get to make the decision and after the transplantation occurred.

>'You know, what is the procedure? You know, um, do they, when, well, say something happened to [my daughter], would I then might have to, or might need counselling? Because you know I've just made a decision, do they just say 'thank you very much, good bye?' My head's going, ‘Have I made the right decision? Have I done this?’, so you know, I think that you need that after help, you must do, surely.' (I19, Retired, Post-war)

Decisions of organ donation were also linked with decisions about donating after a relative's death, in particular brain stem death. There was confusion between this and persistent vegetative state (PVS).

>'It's a problematic thing. As we said, in Poland when the family has to decide, well if you didn't sign the consent, well you have to decide, so like if you said, brain death....So they have to decide if pull the plug' (FG1F1, Student, Post-2004)

For some, the family would be hoping for a miracle that the individual woke up due to this misconception of brain death being reversible. One participant highlighted that it would be difficult to donate as the person still looks alive.

>'I mean the doctor would say, 'yes they are brain dead' or 'we've got to keep them alive because of the heart, blah blah blah', but are they really dead, do you know what I mean? So most people must ask themselves that question, when they've got, especially a child, well, it would have to be someone close to you or the doctors won't be asking you, you know, is there always that doubt that the person isn't quite dead.' (I19, Retired, Post-war)
Many perceived little risk in donating but this confusion of brain stem
death and PVS led one participant to suggest that people were killed in
order for the doctors to get organs for other people.

‘[I]t depends at what stage that they are not saving you anymore,
because I don’t want to be kept as a vegetable, you know, if I’m
really in a bad state and, you know, my mind may never be, I may
not be aware that I am still there, and then I don’t mind because it
would, you know, it’s nothing, but if there is still a chance for me to
have a normal life, to be mentally stable in a normal way so I know
what is going on around me, even if I am not fully able to do
everything and I am still living, I don’t want to risk it, I need to read
up a bit more about what stage they can say, um, we leave it, we
put her for donation because if I find those, um, the process, um, like
based on really good assumption then I would be willing to sign up
for it but first I need to know what are the risk and what is the
procedure for that.’ (15, Student and Bar Worker, Post-2004)

CONCEPTUALISING THE DECEASED BODY AND
TRANSPLANTATION

A few participants suggested that the family would not want their relative’s
body to be cut open as although it is an upsetting thought but at the same
time, was considered to be helping others. One participant thought that
Polish families would be ‘selfish’ and keep the organs in the body.

‘[T]heir loved one hasn’t got cold yet, and they have to think about
their body being violated in such a way.’ (10, Warehouse Worker,
Post-2004)

A number of participants said ‘why not?’ (FG111) be a donor as they would
no longer need their body parts when they have died. The majority of
participants believed that the organs will not be needed after one’s death
and the body does not have to be intact after death. However, some
believed that the body should be whole after death or did not want the
body cut open either for religious or personal reasons.

‘[W]ell we won’t after our death, we won’t need them anyway,
that’s my thinking, that we won’t need them anymore, so we might
as well, um, give them to somebody who will need them, really I think that would be the main reason to do it, just to do that, towards helping other people.’ (18, Student and Teacher, Post-2004)

‘[I]t’s down to the whole religion thing like what my grandmother said to my mother that ‘God made you like this, God didn’t make you with one kidney or no kidney’ so you go back the way you came out sort of thing was her argument, so that was a bit influenced by religion I guess.’ (12, Student and Administrator, Post-2004)

A couple of participants believed that the doctors would not have any respect for the body but one participant said that doctors do have respect for the body. One participant compared organ donation to being unnatural in a Frankenstein-like sense, which is a finding that arose in Sanner’s (2006) work among the Swedish population.

‘The other thing is that some people have this, although some people can be too attached to their body in a way depending on what they believe in and I think that sometimes it’s not explainable but some people may just fear it because they think that they will be cut, that they won’t be buried in this body anymore, some people have different phobias, they are afraid of this point, of being cut after they are dead you know, but I think that some people have not well explained, but just, you know, worry and may not feel comfortable with it, but I’m sure that some people would feel this way.’ (15, Student and Bar Worker, Post-2004)

Being operated on after one died was not an issue for many of the participants, highlighted by one participant.

Many saw the body as being a vessel for the soul and this encouraged a positive view towards donation.

‘[I]t’s a part of my religion that says for instance, there is a soul, body and everything and the soul is supposed to go to heaven...I don’t think that it’s got anything to do with your soul going to heaven and then you can do it because I said that would do that, when they are alive they give their organs...I don’t think it’s wrong to do it when you’re alive, I don’t think that it’s more acceptable from a religious point of view when you’re dead because your soul is not in your body any more’ (11, Student, Post-2004)
Those who believed in the body and soul thought that the soul goes to Heaven or another world and leaves the body quickly.

"[O]ur soul takes on a different body...And well, it (the other body) is in some world, and I don't think that I believe in reincarnation and that, for example that the soul returns to us, on Earth, in the form of a different body...well, to that of life after death, it goes to that different world and stays there." (19, Housewife, Post-2004)

Some participants thought that the body carried no soul.

'I don't think in terms of soul and body...we have a conscience, but I don't think in those in sort of terms.' (14, Teaching Assistant, Post-1989)

Among the participants, there were a number of different interpretations of the Resurrection in Catholicism, such as what happens to the body and soul upon death. Only a few of the participants thought that views towards the Resurrection would influence views towards donation. Some participants believed that there is no Resurrection, no life after death and no body and soul.

'[T]here is not going to be a Resurrection, I'm sorry, no, well if there was, we'd be severely overpopulated in this world by now.' (12, Student and Administrator, Post-2004)

Many of the participants said that organ donation is a way of the family prolonging the life of their relative because their relative's heart is beating in another person and this was viewed as being comforting, unnatural or making it difficult for the family to say goodbye.

'Someone continues to live on and I think that is still life more on the positive rather than negative and you can feel that a part of that person still lives on.' (18, Housewife, Post-2004)

'It's just the feeling, that some part of you is living in someone else, it's something that I don't think even as humans it is something that we are comfortable with, it's a fairly new thing you know, so I think that it's going to take a lot of time for us to feel comfortable, I mean obviously, it happens to us and I'm guessing as a family we'd be grateful because we get to save someone that we love, but then in
general as a problem or an issue in society, I think it might be quite difficult to get used to the fact that, I don't know, we're just able to kind of mix and match and it's great, but is it right to do?' (1, Student, Post-2004)

However, the donor him or herself, in his or her lifetime may have a different perspective about their family saying goodbye to them if they had donated their organs.

'They would be able to say goodbye, because the real me is here, and, eh, that is just a body, so when my brain dies-basically I just died and it (the organs) can work in someone else, but not me.' (13, Warehouse Worker, Post-2004)

A couple of the participants did not think that the personality of the donor is transported with the organ. There was one participant and through personal observations when talking to potential participants about the study and organ donation in general, who made references to TV shows showing people who had received other people's organs and believed that the transference of the donor's characteristics into the recipient occurred.

'There was a programme about this guy who got the heart of this motorcyclist fanatic and all of sudden he needed more adrenaline in life and he started doing things that he would never dare to do because he never, he was never a person who was up for bungee jumping or something but all of a sudden he needed more adrenaline, and there is other things in history, where all of a sudden people are wanted to have different types of food and I don't know if that is true and I don't know if that is anything that we can specifically say is a fact but even the thought that someone lives there with a part of your loved one, may be, it may be difficult in terms of that, you know, it's often that you don't know because it's protected, the identity is protected, I think there is a reason for it and I think that people obviously try to get into contact and it's kinda hard to deal with because I don't think, there is a feeling that you say goodbye to someone that died, but then you can't really do it if you know that part of him or her is still alive in someone else's body, it doesn't give you the opportunity for full closure I don't think, so it's really difficult.' (1, Student, Post-2004)

A few of the participants said that the eyes and heart had no special meaning and would not have a problem in donating these from their
relative, but one person did think there was special meaning in organs and tissues.

'They [the eyes and the heart]...it's all without any difference to me.'
(I13, Warehouse Worker, Post-2004)

FUNERAL PRACTICES

Some of the participants had come to the UK with their family, such as their cousin, sibling or parents. For those whose family was in Poland, it was expected that the body is returned to Poland in order for the families to visit the body on All Souls Day. Many suggested that their family would donate their organs in the UK or outside of Poland. A couple of participants said that their family would not be willing to donate their organs in the UK or outside of Poland.

'I was absolutely sure that I wanted to donate my organs and, back in Poland, but in the UK, I don't know, it's much more difficult because if something happens to me here and back at home, of course they would like to bury me in Poland, so they would have to transfer my body and there are lots of practical issues around it' (FG111, Student, Post-2004)

'I believe that, mm, they, if I would die, that they would think that I would not want to donate because I have, haven't seen him for a while, I want him home, as he left Poland, I won't give any part of his body to anybody in England, maybe something like this... Maybe it is because they don't know England, maybe it is because they were saying something bad about English experience... If that happened in Poland, ok, but this is England, we don't know this, it's better to have back them here, plus another thing is that they want a quick, quick funeral.' (I15, Unemployed, Post-2004)

Rituals surrounding death in Poland is traditionally an open-casket burial according to most of the participants. It was mixed as to whether the individual is concerned about their own appearance in their coffin; however the majority suggested that appearance would not be an issue to affect donation. A couple of the participants said that open-casket burials are becoming less common.
‘But depending what you’re going to donate, if you’re going to donate your skin, or, something then, the coffin wouldn’t be able to be open.’ (FG212, Student, Post-2004)

‘[Y]ou’re buying the best clothes and, you try to look as good as possible [in the coffin]! (Laugh) If that’s the right thing to say! I think that it is quite a strong tradition about funerals.’ (FG113, Student and Administrator, Post-2004)

Funerals are arranged very quickly in Poland, usually within a few days of the person dying. This quick arrangement of the funeral was not thought to influence the family’s decisions or views towards donation by many except for one participant. One of the participants said that families prefer quick burials because there is a superstition that if a body is present over the weekend, the deceased person will take another person with them.

‘[I]n Poland, they are ringing us, saying, ‘when is this funeral? I have no time!’ It’s like, what! It’s his funeral, if you don’t want to come, then don’t come, I have to ask my boss if I can get holiday or not, it’s like, if you don’t want to come, then don’t come, I won’t be planning everything for you because you are waiting for the funeral and I need to be suitable for you, but some people are thinking like this, you know, somebody has died, quick! Quick! That needs to be quick. In Poland, it needs to be quick.’ (115, Unemployed, Post-2004)

The family consenting to donation was suggested by one participant to be making the end of life and the funeral more meaningful as they had been able to help others.

‘[T]he whole thing about organ donation and people that might be reluctant to do it, it’s about what is important, so do you want to have, I don’t know, a brilliant funeral, or do you want to have a meaningful funeral, that’s why it’s so deeply rooted within our personality, our family ok because let’s say you have a really stiff, short of money in a society, a poor society or something like that I doubt whether you would agree for her son to be taken their organs and you would think about the scars and things like that, she would have a vodka party over there, you know what I mean, I just, but if you, it’s just, it depends on what is more important for you, it’s just a couple of scars right? Anyway, the person still wears a suit so, but who knows.’ (13, Student and Waiter, Post-2004)
4.8 The Role of Social Capital and Deceased Organ Donation

Social capital was later applied to the study and was not part of the original aim of the study. It was added to better understand the impact of social networks, social norms, trust and overall civic engagement. Here, participants viewed donation only to be aiding the individual and not a civic act and trust in the UK national healthcare system had some bearing on views toward organ donation based on past experiences but at end-of-life there was a lack of control in being able to trust healthcare professionals as the team would be doing what it could to save the individual.

HELPING THE INDIVIDUAL NOT CONTRIBUTING TOWARD SOCIETY

Many thought that organ donation was about helping an individual, not the community or society.

'I never thought I want to be society with the England community if I would give a donor like they would look at my like oh yeah, she is really good because she give a donor, no it's not, it's more like I don't care what they say if they communicate with me, if they talk to me, it's just human, it's a human for me.' (Il15, Housewife, Post-2004)

It was highlighted by a couple of participants that society is too large to be brought together by donation, it may have worked when there were smaller groups of people but it is difficult to bring together society.

'[I]n small communities and in small societies like in a village or something like that when everybody knows everybody then their sense of community may be stronger because all lived their life together...if you feel that you are part of the community and one of your neighbours is dying because they need a kidney, you might be willing to give it away, um, you know that you know that how the neighbour of the family is suffering, because it's, you, because you see the pain and ok you can live with one, that may be willing to help more but in bigger communities, I think that is difficult to
have so much trust, you know and to be able to um, imagine what those people would feel to be interested in those people whatsoever you know.’ (15, Student and Bar Worker, Post-2004)

A couple of participants thought that it would be difficult to bring people together on a societal level as the UK is multicultural and there is little common ground to base health campaigns on. This links with the finding of the contested meaning of ‘community’ in the previous chapter, in terms of how this is difficult to define and therefore link to building social relations through donation.

‘Well, if someone has strong feelings about being part of a community, like, mm, well, if someone identifies himself really strongly with, er, being British for example, then on some level it may make that person want to donate to British people in the country or something like that, that is possible and understandable, but it doesn’t, I wouldn’t think on that level, I would rather think on a personal level and I wouldn’t think about community because, as I said before, there are no borders, it is so big, it’s not a community any more, community for me is my family and friends, it may be 30 or 40 people that I am close to, the rest is people that I don’t know, it wouldn’t make a different to me, where in the world I was to be honest, realistically. So I don’t think that, um, well, I wouldn’t donate an organ in order to help the community because I don’t identify with the community. I would donate in order to help the person.’ (16, Student, Post-2004)

Social capital suggests that giving as a form of civic behaviour can have wider benefits for social solidarity and social relations. However, amongst participants in this study, the implications that deceased organ donation had for improving solidarity and relations on a local geographical community level was viewed to be limited. Creating small communities through identification based on similar experiences was thought to be an example of organ donation bringing people closer together by one participant.

‘[If you have the same experience as someone else then it makes you somehow similar in a way and people might have the need, like people who had, um, their organs given by someone else, they might feel a need to be in between other people who had the same
situation and that might make them closer because that might make them understand what they went through during the period of waiting for the organ and after the surgery and every other thing. I think that it does create bonds, I think that people who have cancer as well, like people can understand what they are going through and they can understand what’s happening with them and how they feel and they are very close because of the experience that they get, so I think that it’s like.’ (FG212, Student, Post-2004)

Donating was also viewed by some participants as bringing families together, rather than the nation as a few participants explained that donation is a private decision.

‘[I]t would but on an individualistic level, let’s say, um, a Polish family, a son is dying because of something and, I don’t know, Russians, not too dissimilar, British family donates an organ to that boy, on an individualistic level the Polish family would have a really strong, positive attitude towards British because of that but not necessarily as a bigger picture because of that family got a kidney that doesn’t mean that me as Polish would think the same thing. It has to be a close relationship between a donor and recipient to make that bonding.’ (13, Student and Waiter, Post-2004)

The individual perspective of being in a ‘community’ was discussed with the participants in terms of their sense of belonging and the relationship to donation. For many participants, deceased organ donation was linked to belonging to society.

‘I think [belonging] it can [link] because, I don’t know, I just think that when there is a good atmosphere you feel more comfortable with things and, for example, if you feel secluded or negative or whatever from the start you’re not going to want to participate in anything, you’re going to want to go back home, you’re not going to mix with society because you see no point but because, if it’s welcoming and people are willing to listen to you and try new things, and you will hear people out and hear what they’ve got to say, um, yeah, I do think that, open society that is warm and welcoming and kind of influencing someone towards organ donation.’ (12, Student and Administrator, Post-2004)

Although a sense of belonging to a ‘community’ is viewed as significant for many participants, the geographical location in which someone donated
did not matter and many were willing to donate in the UK although a few would only donate in Poland.

‘I think if you really want to be donor, I don’t think, you don’t think about place you live in. I don’t know how it works but I never thought about this, that when I signing my donor card, that my organs are going to this hospital, because your accident can happen anywhere, so they stay there that they are transporting organs with a helicopter, you know to someone who is first in the queue...So, there’s not people from Luton, but from whole UK I think, so.’ (17, Vet Technician, Post-2004)

One participant said that their ethnic identity was an issue for them, considering it to be ‘in-between’ (14) being Polish and English. This was further investigated in relation to one’s sense of belonging and views towards deceased organ donation though most said that it did not matter.

‘When you are foreign in England, you think should my organs go back to Poland to help and save lives there or help people in England where I live, I mean for me, it wouldn’t make a difference, a person’s life is a person’s life, well if one of my organs would save a life in England or in Poland or between evens, so I wouldn’t have a problem with that, but I can see that might be an issue here. Some of the people in the Polish community might see it as a problem, they would rather help their own country rather than people in England.’ (18, Student and Teacher, Post-2004)

Also, one participant suggested that their experiences of living in Luton and Dunstable had an impact on their self-esteem and, in turn, influenced whether they would donate their organs.

‘I registered again, erm, because I changed my GP and I changed the area, and I registered to the new health centre, I ticked none somehow, I think that was after bad experience in England, that was bad period in my life, of a very bad experience in England, and I thought none! Never! I would rather die and not give anything to anybody, they can die with me! I was thinking like that really! I was.’ (115, Unemployed, Post-2004)

In addition to ‘communities’ and sense of belonging in Luton and Dunstable, trust in the NHS was discussed with the participants. For Healy (2006), the NHS played a key role in organ donation as it facilitates the
process and altruistic tendencies. In social capital theory, trust in governmental institutions can influence civic behaviour. Therefore, how individuals felt about the NHS and whether they trusted the health care professionals, may play a role in their views towards donation. A few post-2004 Poles had had negative experiences with the NHS and a couple had had positive experiences. A couple of participants did not trust the NHS staff to save their life, which is a popular concern that has arisen in previous studies as outlined in the literature review.

‘If you say that you have to voluntarily, um, come to them and say that you are willing to be a donator, it may be even more difficult because as people agree to the, I'm not [sure] what the procedure is there, so it is hard to tell but I think it's still quite tricky, because then it was a small amount of people that are willing to give their organs when they are dead, um, they, yeah, they may be a bit afraid that it would be too tempting to do it and decide to take off this wire or whatever, just to stop saving you further and they think, ok, they may not do anything they can, you know, they may not find strong enough for you.’ (IS, Student and Bar Worker, Post-2004)

A few of the participants did trust NHS staff to save their life as an individual would not necessarily have a choice at the time. It was thought by a couple of participants that the experiences that people have with the NHS do not influence donation. However, many were more comfortable with Polish doctors as many had family members or friends who worked in healthcare and were aware of their training.

‘[A]s far as I know, something like organ donation doesn’t, isn’t based on the opinion of one doctor, it’s like many, many doctors. I think that it’s a proper board making a decision, which are totally scared of anything against law or something, so I think they may take some precautions, they make sure that you are going to die or that you are dead already, um, before they can take anything, I mean if you don’t trust NHS about your health, who would you go to?’ (IS, Student and Waiter, Post-2004)

A couple of participants raised the issue of corruption and unfairness which influences whether one trusts governmental institutions.
The level of corruption, yes absolutely, particularly, in the um, aspect of medicine, you know, if you don’t have money, who cares, die you know, because, organ, maybe, erm, organ donation maybe organ transplant, if you know there is a list, but sometimes for some reason, some people can jump at least, you know, because they have money and they know, you know where the money should go and how to get on the top of the list, that’s a common practice in Poland, the doctor wouldn’t talk to you if you wouldn’t give him money, things have changed because now they have special police, well not police, but there are people in Poland posing that they are a patient and trying to bribe the doctor and of course if the doctor accepts, then he has to face the music basically.’ (14, Teaching Assistant, Post-1989)

TRUST IN THE NHS

One aspect of social capital theory is trust in the governmental organisations such as the NHS. The Poles were mixed in their views towards the NHS, some had negative experiences and did not trust the doctors’ abilities and others had positive experiences. There were a few that returned to Poland to use the healthcare system there.

‘I don’t tend to go there [the GPs] at all, I just do all my check-ups and things in Poland...it’s easier for me to go to Poland during the holidays and actually do the check-ups and whatever I want, just pay and have it done and that’s it, because here it’s just really, really complicated to get an appointment’ (17, Teacher, Post-2004)

Some of the participants raised the issues of trust in health care professionals, after a story broke in the news a few years ago with regards to the paramedics in Poland.

‘I heard that there was this big issue, um, maybe you know seven years ago or something? Definitely when I was still in high school, some people weren’t saved by those people who drive ambulances...Yes, paramedics, and those paramedics would go to the hospital which is furthest away or delay just to make those people, um, you know organ donators because it would be too late. I heard there was this big issue um going on, a big affair that they did for money, so and others could use those organs, so.’ (15, Student and Bar Worker, Post-2004)
4.9 Summary

This chapter described the findings of the study by theme. The first part of the chapter provided the context by exploring the social, cultural and religious norms of migrating to the UK and voluntariness. The second part of the chapter examined attitudes toward deceased organ donation, the relationship between gift exchange theory, altruism and religion and the role of social capital. These findings will now be analysed in the next chapter.
CHAPTER FIVE: DATA ANALYSIS AND THE CONCEPTUAL MAP

5.1 Introduction

The previous chapter showed the attitudes and beliefs that were held by the participants toward the social, cultural and religious norms of altruism, gift-giving in everyday life and in the context of organ donation, settlement patterns and social networks and views toward deceased organ donation. This chapter will analyse the findings of Luton and Dunstable Polonia to inform the social and cultural context. This is important as it demonstrates the social, economic, political, historic, religious and cultural milieu in which the findings exist. Following this, there is analysis of altruistic and gift giving behaviour within the Polish community and lived experiences of religion as a migrant in Luton and Dunstable. After this chapter has analysed the settlement, altruistic and giving to others and religion themes in the findings in turn, the way these relate to deceased organ donation are analysed. Following this analysis is the presentation of the conceptual map that visually represents the perceived relationship between deceased organ donation, gift exchange theory and religion.

5.2 Social and Cultural Context: Luton and Dunstable Polonia

Social constructions can highlight the social ‘realities’ but can also demarcate groups due to divergences in opinions. In this case, the significant differences between post-war and post-2004 migrants’ views are shaped by the reasons for migrating to the UK and the circumstances in Poland that led them to settle in the UK.

When comparing the post-war and post-2004 migrants, differences between the ‘old’ and ‘new’ Poles is thought to represent a cultural and class gap (Garapich, 2008), creating a divide between the two groups within the Polish community. He suggested that political migration was viewed by the post-war migrants to be superior to economic migration
within Polish emigration ideology. He argued that the Polish national identity was affiliated with religion, language and homeland and leaving this was a tragedy. Mobility was viewed by ‘old’ Poles as a threat to the moral order as morality was believed to exist in the homeland, leading to emigration being judged in moral terms. Garapich found that as political migration was viewed as a sacrifice, economic migration comparatively was seen as cowardly and evil. This was not found in the present study but illustrates some of the thoughts and assumptions that could be being made by the post-war migrants towards the post-2004 migrants in this study.

The significant differences between the social, political and cultural environment that post-war and post-2004 migrants have come from to Luton and Dunstable, I thought would demarcate the two groups. However, from the findings of this study, these variations in migration experiences has led to differences in collective consciousness in the sense of the Poland that they had left but there were similarities in the ways in which altruism, religious identity and social networks were viewed.

**POST-WAR MIGRATION**

By 1951, 160,000 Polish citizens were settled in the UK (Sword *et al.*, 1989; Sword, 1996; Górný and Osipovič, 2006), this was a significantly lower number of Poles compared to the half a million Poles in the UK in 2011 (ONS, 2011). Sword (1996) explained that Polish migrants were housed in vacated accommodation that was previously inhabited by US or Canadian troops. Locally, the Marsworth camp provided temporary accommodation where the Polish citizens could live in barracks and ex-army housing; those that could stay there had been invited to stay in the UK by the Foreign Secretary.

*Sword et al.* (1989) suggested that 85% were Roman Catholic and for the post-war migrants attending Mass at church was continued once in the UK,
they held the first midnight mass in 1947, and this still happens today. The parish in Dunstable started in 1953, where the post-war migrants first went to the St. Joseph’s church in Luton where the Mass was conducted in Latin, as it was at that time; nowMasses in England are generally in English. In 1967, the Polish church in Dunstable called Our Lady of Częstochowska was established. Casanova (1994) explained that Our Lady of Częstochowska was a symbol of Catholic resistance to Communism.

In addition to the church, other organisations were established such as the Stowarzyszeni Polskich Kombatantow (SPK), a club for ex-servicemen, a Saturday morning school and a scout troupe. The SPK had recently been shut down and sold as the post-war community is declining. Bielewska (2011) who conducted a study about migration among the Polish community in Manchester, explained that the SPK soldiers during the Second World War were a resistance army that were organised in occupied Poland across the country and in parts of Germany and the Soviet Union. These soldiers were captured by the Germans after the Warsaw Rising and were freed by the British. Polish soldiers were then part of the British army and were viewed by communists as politically suspicious. The Polish community may be argued to have ‘institutional completeness’ (Breton, 1964) as a result of the organisations that have been established. Institutional completeness explains the extent to which a community is self-sufficient to meet their own social, psychological and spiritual needs.

Galasińska (2010) had studied the migration narratives of the post-war migrants and found:

‘a long story about getting to the UK, views of the nation as the most treasured possession, mythologisation of the state, history and their own personal histories, knowledge of Polish history, active participation in church and religious ceremonies, recognition of the importance of the Polish language as a mother tongue of future generations and sense of community’ (p.942).
Galasińska highlighted the sense of ‘Polishness’ through the continuation of Polish traditions and Polish language. She explained that the Polish church is a place where cultural needs are met because symbolic capital is attached to them. Galasińska showed that symbolic capital (Bourdieu, 1986) is earned from social capital and comes from the availability of resources to an individual, which may be based on power or recognition. Bourdieu’s view of social capital is individual and it depends on the individual how much social capital they have, based on the connections that they have worked to make.

Post-war migration to Britain also differed from other major migrant groups at the time (Sword et al. 1989). Sword et al. explained that Polish migrants:

‘...came for the most part in organized, disciplined groups (including schools and hospitals, as well as military units). They were part of a structured social grouping with its own political and military leadership and a sizeable cultural and literary elite...Unlike subsequent immigration waves from former British colonial territories, the Polish newcomers had few traditional ties with Britain and little familiarity with English language and culture...the majority of the Poles were unwilling settlers in the sense that, with the defeat of the Axis powers, they had expected to return to their homeland. Many harboured a strong sense of resentment towards the British for having “sold them out” to the Soviets at Yalta’ (1989, p.28-29).

Bielewska (2011) found that among the post-war migrants, networks were significant as English language was limited when they first arrived. Being part of the Polish community was important after the war and migrants bought houses close to one another. The organisations that were created by post-war Poles were found by Bielewska (2011) to no longer meet the needs of the post-2004 migrants and of those who attended them did so as they are the only available options in the area. She found that ‘They are not accustomed to the collective form of national identity rooted in early twentieth-century traditions, where a strong sense of patriotism was mixed
with a strong collective religiousness' (Bielewska, 2011, p.30). Her findings illustrate the strong collective consciousness among the post-war Poles in terms of their national identity of the Poland they left and a strong sense of religiousness, illustrated by the set-up of the Polish church which is still attended by post-war Poles. The organisations that were set-up by the post-war Poles were commonly created by Poles who settled in groups across a number of English towns, according to Sword (1996). He explained that the Polish Catholic Church, SPK, Polish Saturday School and Scout clubs were generally part of the 'structures' of Polish community in the UK.

What can be learned from these previous findings is that the post-war Poles, in the Luton and Dunstable area have similarities to other post-war groups that were included in other studies located in other areas in the UK. There were a small number of Polish migrants after the war; they largely arrived in organised groups for political reasons making this wave significantly different from the post-2004 migrant group. In Luton and Dunstable, the role of the church and the Polish club is central in the continuation of collective consciousness of Polish history and culture as they remember it, through social events were traditions are continued. Through the post-war social networks, the collective consciousness is being sustained through their interaction, language and communication.

**POST-2004 MIGRATION**

This section is going to draw upon the results of the motivations behind migrating to the UK and social networks.

**Motivations for Migration**

The majority of participants came to the Luton and Dunstable area for economic reasons due to the freedom of movement of labour after the EU enlargement. Unlike the post-war migrants, post-2004 migrants were free
to go between the UK and Poland. This freedom has led to fluid and temporary migration patterns meaning that their options remain flexible as to how long they decide to live in one country. However, Eade et al. (2006) in their study of Poles in London, found that those who were ‘searchers’ had open options depending on career opportunities and this was part of their identity in that they defined themselves as Polish but were positive about British meritocracy, perhaps linking with a construct of what constitutes a ‘normal’ life as referred to earlier. They found that Poles criticised their fellow Poles as the majority had maintained ties in the UK and Poland, in particular ‘storks’ and ‘hamsters’.

Many of the Poles were 'stayers' in this study but kept a connection in Poland through using Polish organisations, most notably, the church in their home town, as one participant stated, but generally the use of health facilities as there was a preference for the Polish healthcare system, linking with the trust in NHS finding. Other participants may be described as 'stayers' as they were beginning to accept that they wanted to build their future in Luton and Dunstable and families wanted their children to remain in English education.

Alternative migration patterns explained by participants were other Poles they knew who were 'storks', in that they work in the summer in the UK to raise money for university and 'hamsters' who were described by the participants as those that come to the UK to raise money for building a house or a wedding in Poland and then returned to Poland. For some participants, they described their friends whose plans in Luton did not change and they went back to Poland, in line with the Polish proverb 'everything is good, but it’s better at home' (I20). This is similar to Pollard et al.’s (2008) findings who suggested that Poles come to the UK for economic reasons and return home.
Small Inter-Personal Social Networks

Post-2004 migrants have established their own formal organisations in addition to the post-war migrants' organisations (Polish Church and Saturday Morning School). Across Luton and Dunstable, the post-2004 Polish community have their own online and print magazines (wLuton.net and Magazyn Lokalny respectively), wedding businesses, delis, restaurants, business groups, barbers, hairdressers, taxi companies and additional clubs at the church including youth club, choir, traditional dance troupe and the Rosary circle. It is possible, at Cardinal Newman, the only Catholic Upper School in Luton and Dunstable, to take a Polish GCSE. However, these are generally to contribute toward 'institutional completeness', expanded on in the section, as opposed to the building of formal social networks as it was found that across the Polish community, migrants generally have small, informal, inter-personal networks.

For the post-2004 migrants, social networks are significant as many participants knew someone in the Luton and Dunstable area who had 'tried and tested' migrating to the area. This was not an issue for post-war migrants as they had little choice but to locate in this area due to the way that Polish settlement operated at the time. Moriarty (2011) found that informal social networks have played a traditional role in Polish migration, such as family chain migration, as opposed to geographical chain migration, as Poles rely on informal familial connections and informal references for jobs. In addition Bielewska (2011) found that social networks were a short-term answer as resources are soon established and an individual can distance themselves from their social networks. This is illustrated in the present study by one participant who had come to London to stay with her husband's cousins but soon moved away from them when jobs and accommodation had been sourced.
Bielewska (2011) highlighted a significant feature of post-2004 Polish migrants, which is experiencing migration as an individual, not as a 'Polish migrant'. She found in her study that migrants did not want to be a part of the Manchester Polish community. However, in Bielewska's findings it is not clear as to which 'community' these participants are referring to. In the present study, English language proficiency and commonality had an impact on the use of social networks whilst in Luton and Dunstable. Bielewska's participants may have been referring to the informal social contacts that were initially made that over time that they would distance themselves from as they perhaps began to develop other networks, as this was the case in the present study.

Taking an individualistic view to migration experiences was also found by Moriarty (2011). She suggested that migration is a form of 'self-development' or mobility as the 'project of self-realisation' (Kennedy, 2010) and coming to the UK could be a springboard for travelling to other countries. This individualistic and independent view of Polish migration may be more applicable to those who are able to speak English as they do not need to rely on Polish community social networks.

Brown (2011) asserted that for the post-2004 Poles, Poland is their 'home' as that is where their family is based. Poles generally maintain regular contact with their families in Poland through Internet and cheap telephone calls. She cited Baldassar (2008) who called this 'virtual co-presence' which cannot be likened to physical, face-to-face contact. It had been found in this study that the Polish migrants wanted to stay in Luton and Dunstable because their connection to Poland could be easily maintained. Polish migrants saw 'place' in a post-modern sense where boundaries between geographical locations are fuzzy due to active networks and connections in both the UK and in Poland. This is mainly due to open forms of
communication through social networking sites, such as virtual links through Facebook and Twitter and physical links through the availability of short-haul flights from London Luton Airport to Poland. It was initially thought that by having networks and connections across two countries, that their level of civic engagement may be lower as they were still tied to Poland. However, this was not the case, as with the length of stay, having transnational networks did not significantly impact on one's sense of belonging or civic behaviour in the UK.

**Institutional Completeness**

Breton’s (1964) 'institutional completeness' has been previously highlighted as it refers to the structures and organisations within an ethnic community, in the case of the Polish community in Luton and Dunstable; this included the long-established Polish Church and Club and Polish Saturday Morning School plus new businesses such as the Polish dells. In addition to these, Breton (1964) argues that when a migrant goes to another country that the individual needs to rebuild networks and that these are used to satisfy one's needs such as gaining employment, attending church and learning a new language and that the migrant may turn to the institutional structure within their ethnic community or the individual may go outside of this, to the native community, having an influence on the social networks and integration of the individual.

Breton (1964) found that firstly, the ethnic community were socially or culturally different from the host country were able to have their own structures and organisations to satisfy the needs of the migrants, in particular the level of language. Secondly, the resources available among the ethnic group were both associated with levels of institutional

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16 This section was added post-viva.
completeness and finally, patterns of migration, whether it is individual or group migration.

In relation to the Polish community in Luton and Dunstable, there have been organisations and structures put into place that satisfy the Polish migrants needs such as the Polish Church, Polish club, Polish delis, Polish hairdressers, Polish-English language school and Polish Saturday Morning School. However, there were organisations that the participants used that were outside of these institutions such as the University of Bedfordshire, the NHS, places of work and a local entertainment venue called Hat Factory. It was also found that the degree of English language proficiency had an impact on the degree of social networks and integration of the individual. For example, it was found that those who were able to speak English could create personal affiliations with individuals from other ethnic backgrounds. English language proficiency was thought to have an impact on the use of facilities outside of the Polish community.

The second factor influencing institutional completeness are resources and Breton (1964) found that a high level of manual workers can link with a high level of institutional completeness. It had been found in the present study that there was a high prevalence of low-skilled workers in Luton and Dunstable. However, it would be misleading to incite whether there is a high level of institutional completeness based on the findings of this study, this is an area of research that could be done in the future.

The patterns of migration within the Polish community are different, the post-war migration wave was mass group migration and the post-2004 migration is individual. This may frame the arguments within the literature of the divisions between post-war and post-2004 migrants as found in the Literature Review chapter.
'Community' and High Rates of Mobility

White (2011a) suggested that most émigré communities have tensions within them and it would be understandable if they were not cohesive. On the one hand she explained that there is pressure to integrate with the UK society, competition for jobs and strain of the migration process which may impact on friends and families. On the other hand, Poles want friends who are also Polish as it may be difficult to make friends with British people and there is a need to share information and support one another. White explained that newcomers from Poland may have limited social capital due to small social networks and solidarity comes from sharing the same ethnicity.

The word ‘community’ is contested (Howarth, 2001), as it is a concept which is abstract and fluid, giving ‘our daily practices, our political differences and our understanding of ourselves significance’ (p.224). Popple (1995) argued that there are different forms of community, these are based on ‘locality or territory’ or ‘commonality of interest or interest group, such as the black community or Jewish community’ (p.4). However, Mayo (2000) explains that defining community based on locality existed in the past that had common values of solidarity, but that these communities may have been imaginary. Mayo (2000) argued that in the British context, traditional ‘community’ is based on neighbourliness and reciprocity among working-class communities. Communities of ‘interest’ or ‘identity’ is based on shared meanings (Lash, 1994) that are socially constructed (Castells, 1997). Anderson (1983) purported community based on national identity, these ‘imagined communities’ share communal feelings, but the bonds are imagined.

It was difficult for the participants to define what ‘community’ meant as I had not given them a definition of the term as a starting point. For them it
took a number of forms; locality such as Luton and Dunstable, their
neighbourhood or their home town; identity such as fellow post-war Poles,
同胞学生，同胞从学校或母亲和托儿所
club; being a Catholic or a Pole; organisations such as university, church
和母亲和托儿所团体; 血缘关系，例如家庭和密友; 或
virtual such as through Facebook. For the participants, ‘community’ was
linked with geography such as their local neighbourhood but largely
identity, such as fellow students or kinship such as friends or family that
they arrived in the UK with or knew in the area. Also, one may be part of a
‘community’ in more than one sense, for example through identity as being
a student at the university and organisation such as the University. This
was considered upon much later reflection of the data and was not
examined further with the participants as the fieldwork had ceased.

Eade et al (2006) found that ethnic identity was individually constructed,
shaped by occupation, education and class. The concept of class was not
highlighted in the present study, although it may be implicit. When well-
educated and English-speaking Poles were speaking of other Poles who
could not be ‘bothered’ to get a job or worked in low-skilled work and did
not speak English, they may in some sense be viewed to be a lower class as
they would be considering to be part of a different social group or ‘class’.
These individual constructions may reinforce ‘in-group’ and ‘out-group’
divides between ‘communities’ within Luton and Dunstable Polonia.

‘Community’ made the exploration of social capital challenging as when
there was discussion of sense of belonging for example, this would be
linked to their notion of community. From a community of locality
perspective, linking social capital, sense of belonging and place attachment
has been argued by Pooley et al. (2005) to be a psychological construct of
social capital. This highlights that the way that individuals feel in their
neighbourhood is important to their sense of belonging within it. Generally
participants felt safe and liked living in Luton and have had positive experiences of the Luton and Dunstable population. However, in terms of community of identity, participants generally did not feel that they belonged to the Polish ‘community’ in Luton and Dunstable solely based on shared ethnic identity. They felt that they did belong to their communities based on shared interest, such as fellow students or social groups based at the church.

There were multiple social ‘realities’ and theories among the participants as to what constituted a community and whether they felt that they belonged to it and would help others. This was a concept that in hindsight should have been clarified before the fieldwork commenced or was an area that should have been given more attention in the fieldwork. However, as Howarth (2001) purported ‘community’ is a contested word and has been viewed from a number of perspectives in the literature, with their own limitations. Generally, it was found that Poles sharing an ethnic identity was not enough to constitute a community due to the conflicts within this such as competition for jobs and differences in English language ability. There were a number of small ‘communities’ that had shared experiences and meaning, for example Polish student community and the Polish parents at the Children’s Mass. It is too simplistic to assume that shared ethnic identity led to a sense of solidarity among Poles, this is perhaps why other studies have found that ‘Poles do not help each other’ (Ryan et al., 2009) as they may have begun with this assumption.

**Ethnic Identity and Belonging**

When the Polish migrants came to Luton and Dunstable, they may have had to reflect on their own ethnic identity. Eriksen (2002) stated that ethnicity is an ‘aspect of social relationship between agents who consider themselves as culturally distinctive from members of other groups with
whom they have a minimum regular interaction. It can thus be also identified as social identity (based on contrast vis-a-vis others) characterised by metaphoric or fictive kinship' (p.12). More recently, Cooley's (1956) 'looking glass self' and Winnicott's (1967) 'social mirroring' concepts explain that the self-evaluation of ourselves reflects others' view towards the self. This illustrates the interactions that the individuals are having with their social environment in the UK and the effect that it is having on how they view their Polish identity within the Luton and Dunstable context.

Ryan (2010) explored how Poles viewed their ethnic and social identity in the UK. Religion was viewed as part of their ethnic identity by some and others viewed their identity as being based on their national identity. Polishness and Catholicism interlink, however, and the relationship between identity, religion and ethnicity is complex. Ryan found that Polish churches in London were important for some to show their Polishness and Catholicism and rituals performed there helped the transition from Poland to the UK, Christmas and Easter helped maintain Polish rituals. Ethnic identity was discussed with the participants as some studies have shown that Catholicism is part of Polish ethnic identity. The post-war migrants may have viewed religion as a stronger part of their ethnic identity as they set the Polish church up, however, it may have been due to wanting to keep hold of their Catholic heritage.

In the present study it was found that although Poles may be White, it was perceived by the participants that there was some degree of prejudice held by British people, which had been contested by some Poles. For example, some Poles were not visibly seen to be working and this may create a stigma towards Poles generally by the local community, media reports about Polish people ‘taking’ jobs and also the behaviour of those at an English speaking mother and toddler group excluded the Polish woman.
This has been highlighted in research by Burrell (2009) who suggested that there is a presumption that cultural capital will be accrued as Poles are White and Christian, however this has not the case. She outlined that Poles had been discriminated against and exploited. She highlighted that whiteness is a ‘mutable category, and that newcomers, regardless of their physical colour, are not readily accepted as ‘white’ (Burrell, 2009, p.8).

Bielewska (2011) suggested ethnic identity enabled Polish migrants to form a positive link with the host country. In Poland, ethnically the population is homogenous and class differences through socio-economic status are fairly recent. This is something that was raised by the translator, who said that there are few class differences in Poland. When this is compared to England, where there are class and ethnic distinctions, Poles want to be part of the White working or middle class and avoid areas dominated by South Asian or African migrants. However, in the present study, it was found that the Bury Park area, currently a predominantly South Asian area, is a common location for post-2004 Poles to live, but it was unclear as to whether this was an economic necessity or choice for example due to knowing people in the area.

The notion of ‘belonging’ has been highlighted in Morgan et al.’s (2010) comparative study of the Black Caribbean community in the UK and those living in Barbados, who found that those residing in South London had more attitudinal barriers to donation than those who lived in Barbados. They suggested that this was due to marginalisation and lack of belonging that influenced the level of participation in civic society and was mediated by income equality and decreased public trust. A lack of belonging, as a migrant was also found by Campbell and McLean (2002) to have an impact on trust and social networks. They found, in their study of African Caribbean individuals in the USA, that this group were less likely to donate organs as they felt a lack of trust in institutions and their social
relationships, and participation was limited to their community networks. This links to the issues that arose in the Luton and Dunstable Polonia analysis chapter in terms of the difficulty in defining ‘community’ and an individual’s social network. Lack of trust in the NHS has been raised among the participants and will be discussed later, however, this and feeling part of their smaller ‘communities’ of identity for example have not been found to negatively impact views toward donation.

In addition to individuals exploring their own ethnicity, Poles expressed their views of how Poles are being perceived by the local Luton and Dunstable population. For post-war Poles, they perceived the Luton and Dunstable community to have a positive perception of them as they were accepting and welcoming. A few participants suggested that some post-2004 Poles can contribute towards a detrimental view of Poles from the local community as not being ‘bothered’ to get a job.

Also, the social constructions that the UK public have of Poles may influence how Poles interact with British people and reflect on their own ethnic identity. Social constructions of Poles may be influenced by the media. There had been negative headlines about Polish migrants in the UK, for example, Polish Migrants Online (2010) outlined that Stephen Fry had suggested Polish people were anti-Semitic and homophobic and this website also cited media stories about factory workers and fruit and vegetable pickers who had to speak Polish and not English to work at a particular workplace, illustrating positively discrimination in favour of Polish workers. Garapich (2008) argued that the Polish community is not a homogenous group as may be perceived by the UK, but there is great diversity, such as differences in education and knowledge of English language, also found in the present study. Differences in English language parallels Bielewska’s (2011) findings that suggested the view held by the UK public is that migrants are not well-educated and solely interested in
low-paid work, this view was not convergent with the migrants who were coming from Poland. Many spoke English and 72% had finished secondary school or had a degree (Grabowska-Lusinska and Okolski, 2009).

These British social constructs of Polish migrants link with Hall’s (2007) theory of the ‘West and the Rest’ which explores the social construction of ‘the other’. Non-Western society would be considered the ‘East’ which, in this case, would have been Poland as geographically they are in Eastern Europe. Eastern Europe according to Wolff (1994) is an invention that was created in the period of Enlightenment by Westerners. Todorova (1997) studied the Balkans and suggested that, to Westerners, this area is not completely European and is semi-oriental, -developed and -civilised. Said (1978) coined the term ‘orientalism’ which is ‘a set of discursive practices through which the West structured the imagined East politically, socially, military, ideologically, scientifically and artistically’ (Buchowski, 2006, p.463).

This is significant for this study because British people and my social constructs of Poles as a British researcher may have preconceptions about the Poles who may be viewed, as Tadorova explained, as not completely European because they have only very recently joined the EU and are becoming westernised after Communism. This was the picture that was being painted in the media and by the Western world of Polish people. The perceptions that the UK public have toward Poles could shape the experiences that Polish migrants have in the host country. These social constructions of ‘the other’ may influence the way that British individuals view and behave towards Poles and, in turn, how the Poles experience and feel about living in the UK and consequently may impact on their intended length of stay and social networks and sense of belonging and acting civically.
Brown (2011) suggested that differences between the post-war and post-2004 migrants are influenced by the ways in which each group expresses their ‘diasporic belonging’. Her study took place in High Wycombe, a town close to Luton and to the location of the post-war settlement camp in Marsworth. Brown argued that both post-war and post-2004 migrants viewed their homeland in different ways, which affects how they view their own ethnic identity through food, religion and language. She found that the post-2004 migrants felt homesick and post-war Poles felt nostalgic towards their home country as borders have changed since the war. In the present study, both of the post-war migrants came from what would now be Ukraine and not Poland.

Perceptions of Living in Multi-Faith and Multi-Ethnic Luton and Dunstable

In addition to shaping one’s own ethnic identity, Polish migrants were also shaping their views of other ethnic groups. Luton in particular is a multi-faith and multi-ethnic area, in comparison to Poland, which has a largely White, Christian population. For the Poles, this may have had an impact on their experiences of other ethnic groups as it may have been the first time that they have interacted with them and formed their perceptions. Many Polish migrants, commonly those who spoke English, did integrate with non-Poles. For one participant, coming to an area that was multi-ethnic was a ‘pull’ factor as she perceived her chances of employment as being improved. This was found in another study, as Eade et al (2006) had found that Poles in London viewed multiculturalism as being an asset.

Nowicka (2010) found in her research of Polish migrants in London and the Midlands that diversity is foreign to Poles as Poland is homogenous and the UK is super-diverse. In Polish culture she highlighted that there may be some ‘ignorance towards other cultures and even xenophobic reactions to
them’ (p.26). This shows in the findings from this study, where there is openness to other ethnicities, though this may not exist across all clusters that make up the Polish community in Luton and Dunstable, such as those who do not speak English and cannot communicate with people across different ethnic groups.

Integrating with other cultures links with Putnam’s (2011) earlier comment about how multiculturalism erodes social capital. However, this finding questions this too because if individuals across different cultures are creating social networks, they are in turn creating social capital as ties and bonds are being created. However, this may depend on levels of education, the extent to which people feel they are in competition with others for jobs and so forth.

Bielewska (2011) found in her study that the issue of ethnicity had emerged, as Polish migrants who were living in Manchester felt closer to White British people than those from South Asia or Africa. She highlighted that ‘racial categorisation’ is a theme within Polish migrant identity, as they experience other cultures in the UK more so than they did in Poland. Viewing themselves as ‘white’ is part of their identity formation and enables them to link better with the host society than other migrant groups (Eade et al. 2006). In the present study, this may have implications as Polish migrants may feel part of British society as they are ‘white’ and this forms part of their identity, however some may struggle with linking with other migrant groups which may explain why there are prejudicial views towards other migrant groups and whether they would donate organs to them.

5.3 Altruism and Gift Giving

As previously discussed, the different ‘communities’ within Luton and Dunstable Polonia had their own social networks, as opposed to a general
social network connecting all Poles across Luton and Dunstable. However, using social networks was seen as a resource for receiving help or giving help to others as they could empathise with others within their own 'communities'. This may explain why many of the participants had negative experiences within their own ethnic community in that there was a reticence to helping a fellow Pole as this connection was weakly based on shared ethnic identity. However, a number of Poles were willing to give to strangers directly by helping rough sleepers, volunteering at charitable events or giving money to charity.

For Putnam et al. (1993), organised religion was a source of social capital which would encourage civic behaviour outside of the church. However, this is quite a general view as it has been seen that Poles are selective to some extent about who they help and have a preference for helping those within their own 'community' or strangers that they could empathise with. As will be discussed later in this chapter, participants had a wide degree of views toward religion and, as previously reported, a minority of Poles in Luton and Dunstable attended church. Making a connection therefore between an organised church group and civic behaviour may be significantly limited in its 'real-life' application.

Gift giving was generally viewed by the majority of participants in the study to occur at specific events such as birthdays and Holy Communion and over time, competitiveness of gift giving has increased between neighbours and friends. This has led to children receiving expensive presents at these events. Komter (2006) found in Amsterdam that gift giving is complex and context-bound as it depends on the gift given, the circumstances in which the gift is given and to whom the gift is to be given. Generally, participants agreed with the Maussian gift, that reciprocity underpins gift giving and also doing favours for others.
ALTRUISM THROUGH SOCIALISATION

People's motivations for helping others was discussed in the literature review, and participants highlighted it may be due to having an altruistic personality or being taught to be helpful by parents and church. These findings link with the view that altruism is a human trait, perhaps linking with the sociobiologist's view and that it is learned, in the vein of social constructionism. From a social constructionist view, altruism is learned. Viewing altruism as something which is learned links with the notion of altruism being a social construct as a result of an individual's interaction with their social and cultural environment. The participants suggested the sources of learning about altruism were church, school and parents. These would inform the individuals' attitudes toward altruism and giving to strangers, through observing helping behaviour carried out by their parents, their parents teaching them to help others and didactic teachings learned at church or school. The priest at the Polish Church in Dunstable said that helping others and religion connect through Catholic theology. The main teachings were based on love; the Old Testament says that people are built upon others, that we are one. We cannot love God if we cannot love others.

5.4 Religion

Catholicism is the core religion in Poland and this section will explore Catholicism in Poland and Catholicism and experiences of religion in Luton and Dunstable.

CATHOLICISM IN POLAND

For many of the participants, attending church in Poland when growing up was the norm. There has been little research about non-believers in
Poland, bar one study by Zrinščak (2004) who found that non-believers were a minority in Poland. As noted in the methodological chapter, the perceived stigma of being a non-believer was believed to have led to one participant withdrawing from a group interview.

It has been reported that 95% of Poles were Roman Catholic (Ministry of Foreign Affairs, 2011), but this is misleading as the sociologist Knoblauch (2011) showed, at the European Sociological Association (ESA) Conference, as the number of Poles who attended church was 2.6% very often, 19.5% often, 37.8% occasionally and 29.1% rarely. Knoblauch's (2011) statistics showed that around 30% did not attend church, which is nearly as many as those who occasionally attend church. This may indicate that church attendance is not necessary to show that one is Roman Catholic and one did not necessarily have to attend church to show that he or she believed in God. It may be assumed that one has a relationship with God outside of church, putting more emphasis on the form of intrinsic religiosity in Poland.

Alternatively, there may be social pressure to self-report being a Catholic due to the stigma attached to being a non-Catholic as religion is part of Polish culture and tradition. For some post-war and post-2004 migrants, church attendance in their childhood was forced upon them by their parents or grandparents. This links to the earlier finding of the importance of continuing the Polish tradition of Catholicism as the majority of Poles attending church in Luton and Dunstable are young families. For post-war migrants, they reflected that there were no other distraction such as the TV or computer games and those attitudes towards going to church have changed in that in modern society people are more relaxed about church attendance and question religion and religious leaders. This was also highlighted by post-2004 migrants who suggested that Catholicism is changing in Poland, that it is declining and non-attendance at church is becoming accepted. This illustrates a difference in social and cultural
environment between the post-war and post-2004 migrants in relation to social norms of church attendance in Poland.

An issue that was raised by some of the participants was that church can make one’s life difficult as it is controlling and prescriptive in how people should raise their children or use contraception. The Catholic churches in Poland were seen by a couple of participants to be linked with politics and scandals, making people want to separate Catholicism from the Church. Most of the participants saw the priest as influential, although not as controlling or influential in the UK, this may be because the churches are the core of the community in some villages in Poland, some people have lived there all their lives and what the priest says is the ‘truth’. This was perceived by many to be the case for the older generation as some participants said young people were likely to question religion.

**CATHOLICISM IN LUTON AND DUNSTABLE**

The Institute for Public Policy Research (IPPR) published *Faith in the Nation* (2009) and suggested that Polish migrants will have a significant effect on Catholicism in the UK (Murphy O’Connor, 2009). He explained that there are ‘over half a million Catholics from Poland and they alone will certainly change the face of British Catholicism. The growth of ethnic chaplaincies, especially in London, offers a support that is familiar but as with previous migrations, integration into existing communities is already taking place through school and work’ (p.29).

However, this speculative view was not evidenced in this study as there were around 500 Poles that attended Mass (Luton on Sunday, 2009) and this is around 30% of those currently living in the area, which is higher than the number of Poles who often attend church in Poland. The priest from the Polish Church in Dunstable explained that the Ministry of Foreign Affairs (2011) figure is incorrect as this classification is based on Baptism.
There were multiple social ‘realities’ of religion in Luton and Dunstable, mediated by a number of factors including English language proficiency, strength of religiosity, working hours, choosing to attend the English or Polish Catholic Church and if the individual has children.

In Luton and Dunstable, there were differences in the availability of Roman Catholic Churches compared to Poland, which can be described as ‘location-specific capital’ by DeVanzo (1981). In the local area, there is an English Catholic Church and a Polish Catholic Church in Dunstable and two English Catholic Churches in Luton, one of which has a Polish priest and all services at both churches are conducted in English. The availability of churches was not a significant factor in whether Polish migrants attended church in the present study.

It was found that Roman Catholicism is viewed as a tradition that is passed on to future generations and this is facilitated by the Polish church. However, it had also been found that families prefer their children to attend Catholic schools in the area, where there are many Catholic lower schools and one upper school, meaning that it is competitive to enter. This was also found by Bielewska (2011) who suggested that many were aware of the Polish church but few attended regularly. Those that did had children where the parents wanted to continue Catholicism and many sent their children to the Polish Saturday school.

For those that did attend church, it was found by Brown (2011) to be part of the Pole’s weekly routine that reminded them of home and was a social event, similar to those that took part in this study. She noted a hierarchy in the church, which was highlighted by one participant who said that, in Poland, the ‘sinners’ sit at the front of the church. However, Brown found that those who contribute less to the church sit further to the back and that post-2004 Poles are not included in this hierarchy. This was not something that was found in this study as I did not attend any services;
however in Poland an individual who did not attend church was viewed to be a ‘sinner’.

There were a few participants who attended an English Catholic Church in Luton and Dunstable instead of the Polish Catholic Church. Those who attended the English Catholic Church all spoke English proficiently and attendance may not be an option for those who cannot speak English as they would not be able to access Mass. This may relate to the finding that migrants prefer to have an individual migration experience where they are immersed in English culture as opposed to Polish traditions. Alternatively, it may relate to the ‘communities’ that they chose to be part of, that they wanted to practise religion, but not with other Poles.

5.5 The Conceptual Map

Throughout the series of interviews and group interviews, there was a card sorting exercise, this acted as the primitive stage of the evolution of the map as it showed how the participants would sort the significance of the issues which had been previously discussed in the interview. This was then developed further into different conceptual maps until the final map was created (see Appendix Twelve).

Throughout the literature review, deceased organ donation has been examined from either an individual perspective by understanding organ donor register behaviour or from a family perspective, through gaining an insight into donation experiences. The conceptual map places these two contexts together, one that has been experienced which is the individual perspective and one that has not, highlighting the expectations that the Polish participants have if they were to make decisions about their relative’s organs. The role that religion, social capital, altruism and religiosity play differs within these two contexts.
Here is a picture of the final conceptual map that visually represents the findings. The core construct is context with the themes that connect to these sub-constructs feeding into the core construct.

![Overall Conceptual Map](image)

Figure 16: Overall Conceptual Map

Viewing the differences in contexts of the map can be analysed through ‘sacred’ and the ‘profane’. Davies (2006) explored the sacred and the profane in biotechnology to explain the two forms of reasoning. The profane is elicited in views towards the body transformation that technology enables, the sacred is viewed as unnatural or people playing God. The first form of reasoning is ‘sacred’ and is ‘principled, rational and disembodied deliberation expected and accepted as publicly warrantable reasonings around organ transplantation’ (p.431). This could be likened to the first context where individuals may consider organ transplantation from a rational and objective perspective in their lifetime. However, within the family context, rationality may change due to the circumstances of grief and loss. Davies (2006) suggests that the irrational reasoning is considered to be ‘profane’, which ‘contracts the specialist divisions of labour around the institutional forms and discourses of organ transplantation’ (p.431).
Through the analysis of the data, there were a high number of codes and through the coding process were grouped by themes. The themes with the highest frequency of codes were viewed as the core constructs and sub-constructs were linked to the core constructs. To ensure that the participants' views were being represented, feedback was received from the participants about these constructs and sub-constructs through the process of the conceptual map development. The discussion will take each context in turn, starting with the individual context.

THE INDIVIDUAL CONTEXT: MAKING AN END-OF-LIFE CHOICE

Each branch of this figure illustrates the construct and sub-constructs of the map within the context of the individual. These branches are not all of equal value as some were considered to be more important than others.
Those in the dashed lined boxes are sub-constructs linking with the main constructs in the blue boxes.

**Donors' and Non-Donors' Characteristics**

A 'typical' donor was described by the participants to understand further the social norms around donation. Menzel (1990) believed that deceased organ donation should be 'the norm'. The power of normative beliefs and influence has also been found in other organ donation studies, such as Radecki and Jaccard (1997) who suggested normative beliefs influenced the willingness to become a donor. Moseley and Stoker (2010) argued that the current social and cultural norm is to agree to organ donation in principle, but not to sign up to become an organ donor and that there is no social sanction in shaming, for example, for those who are not donors or who refused the donation of their loved one’s organs. Hyde and White (2010) explained that the views of others’ actions are influential in organ donation. They found that people make judgements about who does and does not donate organs as well as those benefiting from organ donation. The way in which an individual assesses likeness between the typical donor and oneself was found to influence willingness to behave in a particular way (Gibbons et al, 1995).

It was perceived that individuals considering donating and not donating were influenced by age, life experiences and acceptance of their own mortality; religiosity was viewed to play little or no role. There has been little research with regards to effect that having children has on donating.

There were no differences in views towards organ donation across varying degrees of religiosity and views toward Catholicism. In previous studies, as outlined in the literature review chapter, Allport and Ross’s (1967) forms of religiosity linked religion and organ donation emerged as a variable in the findings of previous studies when focussing on specific ethnic minority
groups. This highlights the difficulty of identifying the direct relationship between one’s religiousness and views toward organ donation. It also demonstrates that the relationship between one’s religion and organ donation is shaped by wider cultural and social norms such as the social construction of the body upon death that is shaped by religion and culture, echoing the findings of Stephenson et al. (2008) and the way in which organ donation is framed.

In this study, religious leader’s views were generally not viewed to have an impact on organ donation as this topic is not currently being discussed at church. This study highlighted that the participants were sceptical about religious leaders, that biblical references can be moulded to suit the message that the religious leader is trying to portray. It was also highlighted that these biblical references are dated and may not fully apply to reality. Previous research had found that the views of religious leaders were significant (Rumsey et al., 2003; Jindal et al., 2003). However, this study and previous studies have found that religious leaders can play a role in raising awareness about donation (Jindal et al., 2003). This is an interesting finding in relation to social constructionism as religious leaders may play a role in creating the religious norms toward donation, in particular whether it is supported or not by that religion. The majority of the participants suggested that Catholicism would support organ donation however many had made this assumption based on the teachings to help others as it generally had not been discussed by religious leaders.

In relation to age, in Poland, Sadowska et al. (2007) found that the majority of the participants in their study, in particular the young population, were aware of organ donation, but not fully aware of all of the organs that were donated. They showed that 99% of those aged between 18 to 24 years old were willing to donate their organs upon death and the rest of the
population were between 77% and 81% willing. They concluded that the younger population were more likely to be aware of organ donation, which is parallel to that in the UK with 58.8% of those on the ODR being under 40 years of age (Vincent and Logan, 2012). Previous studies of ethnic minority groups in the UK that have focussed on organ donation behaviour have not found a person’s age to be a significant factor within ethnic minority groups in the UK (Sheikh and Dhami, 2000; Morgan et al., 2010). However, Exley et al. (1996) did find that among Sikhs in the UK, older generations were more resistant to deceased organ donation than younger generations. Jindal et al. (2003) found that, within the South Asian community in Glasgow, knowledge about organ donation decreased as age increased.

Among the younger participants, it was viewed that age influenced levels of knowledge and attitudes among the older participants, however when discussing organ donation with the older participants, there was a similar level of awareness and views toward organ donation. This was informed by the assumption that organ donation is a new phenomenon and that older people would not be aware of it. However, across the older participants, there was the belief that age had an impact on being eligible for being a donor as it was suggested that organs would not be used after a certain age. This perception, I believe had an influence on the recruitment of older participants. When trying to recruit them, they said that their organs could not be used as they were old and unhealthy, therefore giving them no reason to take part in the research, although it was explained that their input was important. The perception of the usefulness of one’s organs after he or she dies in old age relates to Bekkers’s (2006) resource theory of human capital. This is the ‘personal characteristics which make people productive in the labour market and in which they may invest’ (p.349). She considered health to be an aspect of human capital and health is a resource for organ transplantation as donors must meet specific criteria to
be eligible to donate. Due to the lack of donors, ‘marginal’ donors are being used where donors are over 60 years old, thus age may be less of a criterion in donation than the health of the organ (Cohen and Persijn, 1997).

In relation to acceptance of one’s mortality, this links with death anxiety according to Sanner (2006), who critically evaluated organ donation literature. She found that death anxiety is regarded as a natural reaction as it exists as a survival function but the intensity of the reaction differs between individuals. The core issue that one will no longer exist evokes fears including the fear of dying and the moment of death (Kastenbaum and Aisenberg, 1976). Even talking about death is seen to tempt fate, decrease hope and may not be respectful to the person who is ill (Pham and Spigner, 2004). Cleveland and Johnson (1970) found that individuals who were resistant to donating had a fear of death, did not want to contemplate this and were more likely to believe in life after death.

In the current study, there was the perception that a sense of immortality existed among young people and that older people had to begin facing their mortality this also linked with church attendance to pray for forgiveness before going to Heaven. There were multiple ‘realities’ of what happens with a person’s soul in the afterlife. Sanner (2006) found that as a defence mechanism, one may feel a sense of immortality meaning that one will find it difficult to imagine no longer existing. Sanner found that a belief in the afterlife may reduce anxiety of death for those who hold a religious view of the after-life as rewarding, but those who were not religious viewed death as lonely and a punishment (Hooper and Spilka, 1970). Based on the findings of this study, linking religiousness with reduced death anxiety may be too simplistic, as it was found that there are multiple strengths of religiosity and ‘realities’ of the Resurrection.
Deceased Organ Donation: Knowledge and Misconceptions

Many of the participants had only been in the UK for an average of seven years meaning that their social and cultural environment in the UK and Poland would both have largely informed views toward donation, as they had lived in Poland most of their life. To contextualise this, here is a brief history of organ donation and transplantation in Poland. Poland has had a different journey with the development of organ donation and transplantation compared to the UK, as Poland started later. In Poland, organ transplantation started in 1966 with the first kidney transplantation, similar to that in the UK, where the first kidney transplant occurred in 1960. However, the development of organ donation in Poland was delayed due to legalities concerning kidneys as these were required for post-mortem examinations. DCD donation was the most common source of donors as brain death was not permissible as a form of death. However, due to complications in DCD procedures, organ donation was unsuccessful (Rowinski and Paczek, 2002). Also, in Poland organ transplantation was viewed negatively by nurses who consider it to be a taboo subject (Orzet-Nowak et al., 2005) and being a transplant surgeon was not viewed as a desirable occupation because it is a business which is ‘not honoured at all’ (Perner et al., 1996, p.12) due to the extra effort and work that must be undertaken. Although, this is a dated paper and from the participants’ perspectives, organ donation awareness has increased in recent years and this change may also be a reflection of developments within the Polish transplant community.

In 2005 the Polish government passed a law to regulate transplantation procedures and the system of final familial consent within the presumed consent policy. With regards to this opt-out policy in Poland, Rowinski and Paczek (2002) found a lack of understanding of this among the Polish public. This was shown in the present study where it was not widely known
that Poland had an opt-out policy and that the UK's policy was different. Some participants had applied their 'common-sense' knowledge from Poland to the UK and, for example, had considered donation to be an 'opt-in' process in Poland and had opted-in in the UK. This illustrates that perceptions that were formed in Poland may be extrapolated onto British systems, such as registering to be a donor.

There were a low number of transplants that occur in Poland, which according to Nowacka (2003) is due to a lack of understanding of transplantation by the public. There were 1900 patients waiting for an organ in 2008, but only 427 donors were identified (Pszenny et al., 2008). In opinion polls in Poland, 90% of the Polish community supported transplantation in 2003, similar to the recent figures in the UK, but this dropped to 74% in 2005 (Public Opinion Research Centre, 2003, 2005). This was reflected in this study, as the majority of Poles were aware of the concept of organ donation and transplantation, but not details about which organs can be removed and they had a simplistic idea of the process of transplantation.

In previous research, having low levels of knowledge within ethnic minority groups and general populations about organ donation is not uncommon. This phenomenon is cited across the literature on deceased organ donation in the Western world, such as in the UK (Exley et al., 1996; Ahmed et al., 1999; Randhawa, 1998, 1999, 2001, 2005; Darr and Randhawa, 1999; Sheikh and Dhami, 2000; Davis and Randhawa, 2004; Morgan et al., 2008, 2010, Saleem et al., 2009), in the USA (Manninen and Evans, 1985; Basu et al., 1989; Horton and Horton, 1990, 1991; Radecki and Jackard, 1997; Siminoff and Chillag, 1999; Morgan and Miller, 2001, 2002; Rumsey et al., 2003; Sander and Kopp Miller, 2005; Morgan et al., 2008) and within Europe (Sanner, 1994, 2006; Lauri, 2001; Blok, 2006). These low levels are thought to be linked with misconceptions about organ donation, such as
medical staff not trying to save one’s life if they are aware they are a donor (Lauri, 2001; Sanner, 2006). A high level of knowledge has been found to link with a positive view of donation (Sander and Kopp Miller, 2005).

Gross et al. (2001) cited Sanner et al (1998) who found that those who are undecided about organ donation are grouped into four categories: ‘hidden negatives’ where people don’t accept organ donation but will not state this, those with misinformation which can be clarified, those who need time to make the decision and those whose personality trait is indecision. Gross et al. suggested that the first and last subgroup were unlikely to be responsive to health campaigns. Many campaigns have attempted to increase knowledge, but without adequate success, they claimed that campaigns should include better information and reflection on life and death (Gross et al., 2001).

The media had been cited as a source for information about organ donation, such as the film ‘Seven Pounds’. In the UK, there had been stories in the news about mistakes being made in matching the donor’s wishes to the organs taken (BBC news, April 2010). Parisi and Katz (1986) cited a number of studies that identified the inconsistency in the reporting of organ donation in the media, from giving life to receiving poor medical attention (p.567-568) and may contribute to the ambiguity towards donation. It can work both ways, as Lauri and Lauri’s (2005) found that where donors were perceived as caring, it is reinforced by the positive issues raised in the media (Feeley and Vincent, 2007).

Views of deceased organ donation highlight the issues of lack of knowledge and confusions around the ‘facts’ of donation and how to become a donor. This illustrates that the incorrect information coming from sources such as the media can have a negative effect on representations of donation. However, many of the participants had friends who were medical professionals or who had signed up to be a donor in the UK and had
encouraged them to donate. This demonstrates that having information from sources who are medical professionals or who have registered to donate can positively influence views toward donation.

Lack of knowledge toward organ donation may be related to the state of organ donation and transplantation in Poland where donation was not generally widely known, but as discussed, this is not uncommon across many countries. This may be due to organ donation being an uncommon procedure as there were no participants who knew anyone who had donated or received a transplant. In previous studies, in particular with South Asian and Black Caribbean and Black African participants, who are at higher risk of Type 2 Diabetes and ESRF, who are three to four times more likely than a White person to require an organ transplant, these participants were more likely to know someone who had received or given an organ (Ahmed et al., 1999).

In spite of this lack of knowledge, deceased organ donation was generally supported in principle and in practice by some who had registered to be a donor. One limitation of this study is that participants may have taken part that were comfortable talking about donation and agreed with it. It was not part of the objectives to explore who were donors and who were not donors in the UK; this information was volunteered by the participants. This additional information may have indicated if the participants generally were pro- or anti-donation, which may have had an effect on whether these findings were skewed.

Trust in the NHS

Trust was discussed with participants as this was highlighted in previous literature to be significant in social capital (Putnam, 2000a), in particular trust in the NHS and in healthcare professionals. There had been a range of positive and negative experiences of the NHS and healthcare professionals.
including GPs and A&E staff. The majority of participants preferred to return to Poland to use the health facilities there than use British alternatives which they mistrusted. This has been found by Moriarty (2011) who discovered that among the Polish community in Belfast, Poles accessed services in Poland such as hairdressers, retail, doctors and the dentist, as there was more trust in these professions.

Participants raised the story in the media about paramedics not saving lives and financially benefiting\(^{17}\), illustrating that trust issues do not solely lie in the British healthcare system. Preferring the Polish healthcare system to the British healthcare system is not singly due to mistrust but has been found to link with ease of access to specialist services (Jadczak, 2009), familiarity with processes such as being accustomed to receiving antibiotics (Ignaszak-Szczepeaniak et al., 2009) and difference in doctor-patient relationship where the GP in Poland is more authoritative (Tonkin-Crine et al., 2011).

However, a mistrust in healthcare professionals is not uncommon as it has been found in a number of previous studies (Parisi and Katz, 1986; Belk, 1990; Callender et al., 1991; Davidson and Devney, 1991; Dominguez et al., 1991; Hall et al. 1991, Lange, 1992; Tolodo-Pereyra, 1992; Youngner, 1992; Thompson, 1993; Sanner, 1994, 2006; Schutte and Kappel, 1997; Stevens, 1998; Guadagnoli et al., 1999b; McNamara et al., 1999; Siminoff and Arnold, 1999; Alden and Cheung, 2000; Reubsaet et al., 2001; Hayward and Madill, 2003; Alkhawari et al. 2005; Morgan et al., 2006, 2010). Negative views linking with healthcare professionals had included concerns about organs being taken whilst the donor was alive, were found as a barrier in previous studies (Hall et al., 1991; Lange, 1992; Rene et al., 1994; Exley et al., 1996; Stevens, 1998; Siminoff and Chillag, 1999) and the belief that if

\(^{17}\) There had been stories in the media in Poland where paramedics were purposely killing patients as they were paid for the corpses by funeral homes. This practice was known as 'skin-hunting' and there were 5,000 deaths that were suspected to be involved (BBC online, 2003).
they were found to be an organ donor, less attempts would be made to save their life (Watts, 1991; Gallup Organisation, 1993; Lauri, 2001).

Sanner (2006) explained that distrust can link with death anxiety, as discussed earlier. If an individual is involved in an accident in the UK, he or she would have little control over who treated them found in the present study. This was identified by the participants who were assured that there was a strict protocol about diagnosing death. Sanner explained that organ donation may occur in the case of brain death and one must trust the health care professionals in handling this process, i.e. brain death is a real death and there will be no premature death to access organs although people become suspicious as they would have no control in this situation. This distrust of medical professionals may be a reaction to the complex and specialised medical world which is alien to the lay person.

There was the belief that the British NHS cannot be trusted due to negative experiences with GPs and A&E, these may be framed by the individual’s expectations and values embedded within the Polish healthcare system. There were multiple ‘realities’ of how this lack of trust would extend to healthcare professionals being in control if one died and was eligible to donate. There were theories that the physicians would hasten their death or not declare them fully dead before taking their organs, however these may be fears that relate to death anxiety. There were other theories that one does not have a choice but to trust healthcare professionals when one dies as one would not be able to go to Poland as the emergency services and hospital in the UK would have to be in control.

The ‘Altruistic Gift’

The notion of the ‘altruistic gift’ is paradoxical to some extent as altruism does not expect reciprocation and Lamanna (1997) highlighted that a ‘gift’ has ‘no strings attached’, in terms of the Maussian gift however, the gift is
part of a fair exchange and reciprocity is expected as help is met with help. Among the participants, there was the perception that the organ was an ‘altruistic gift’, where no reward was expected in a monetary form but help toward funeral expenses would be accepted. This links with balanced reciprocity (Sahlins, 1978) as discussed in the literature review, implying a form of exchange that the Maussian gift expects, this finding is supported by Ben-David (2005) who argued that the Western way of viewing the organ is as an altruistic act but also as a Maussian gift. This could be due to the libertarian paternalistic political milieu where personal incentives are not ‘aimed at forcing people to do things, but are aimed at "structuring" people’s decisions so that they choose healthier options’ (Oliver, 2009, webpage) or in the case of organ donation, the option that could affect the individual in the future if he or she needed an organ.

Altruistic aspects of organ donation were in line with Piliavin and Charng’s (1990) review of altruistic research, where the participants linked with organ donation and altruism based on altruistic personality and mood.

Shaw (2008) conducted research in New Zealand and interviewed lay persons and in 2010 interviewed organ donation specialists to find out their perspectives of gift in relation to body tissue and she found that the notions of the gift and altruism were influenced by the tissue being donated and who was the recipient. This is similar in the present study, not in as much as the particular organ that was being donated, but who the recipient was as this was conceptualised in other ways than an abstract stranger in need and will be discussed later in this chapter.

Shaw’s studies have lent itself to the analysis by highlighted discrepancies between the lay person and healthcare professionals in the way that the gift discourse within the organ donation context is viewed. Organ donation specialists may be making assumptions on behalf of their patients that the word ‘gift’ may not be appropriate due to the Maussian connotations
which is why it is not used in family conversations. However, both the lay person and organ donation specialists may concur in the view that the ‘gift’ in the context of donation and transplantation is viewed to be altruistic and unilateral and not seen in the Maussian sense. In addition, academics and policy makers of organ donation who have studied the gift, may ‘take-for-granted’ their knowledge about the Maussian gift and the connotations behind this term, which may not be the same for a lay person. This may skew the analysis of the ‘gift’ in relation to organ donation as healthcare professionals and academics are aware of the reciprocal assumptions behind it, but this may not be the way this is viewed by a lay person.

It has been argued that altruism can be stated to be a reason to donate, but this could be due to this notion being socially constructed within organ donation and reinforced by policy (Batten, 1990) which is culturally transmitted (Healy, 2006) through health campaigns and information provided through NHSBT. The ‘gift of life’ rhetoric has also been used to frame organ donation, perhaps explaining some of the confusion between organ donation being a gift or an altruistic act. The paradigms within organ donation has been framed may also shape views toward organ donation, such as viewing it as a gift and altruism simultaneously but not being aware of the differences between these two concepts. The message from government should be clearer in organ donation as to whether it is an altruistic act or a self-interested act as the Maussian gift implies, where a reward is accepted.

Within the participants’ views in this study, reciprocity in the form of help toward funeral expenses was accepted, negating the altruistic aspect of organ donation because the individual’s welfare is no longer the motivation to donate. At the time of the study, there were stories in the media of funeral expenses being paid as a result of Nuffield Council on Bioethic’s (2011) research. Therefore, the media could have contributed to
the participants' view of the 'norms' of what can be accepted within the context of organ donation.

Sykora (2009), Seigal and Bonnie (2006) and Nadel and Nadel (2005) have all suggested self-interest based incentives including giving priority to patients on the waiting lists who are registered organ donors, or providing incentives, such as help with funeral costs. However, Seigal and Bonnie argued that bioethicists rebuked this concept as it is not in the ethos of organ donation. Receiving funeral expenses was accepted, but financial payment was not viewed in the same way (Kittur et al., 1991; DeJong et al., 1995; McFarland et al., 1997; Nickerson et al., 1998). In the present study, participants felt that receiving financial payments was generally wrong as it would engage people in organ donation for the wrong reasons, such as wanting a new car. Pragmatically, this was viewed as problematic in terms of who would receive the payment and the final sum of money based on the value of the organ. However, Hayden (2007) suggested that there is a shift in public discourse regarding donation, towards reciprocity and being paid. Sanner (2006) suggested that there is a general acceptance towards the rule of reciprocity within organ donation, in that people wanted to receive more than they wanted to give. However, she believed this could be due to psychological discomfort, for example, death anxiety as previously discussed. This acceptance of reciprocity and shift towards self-interest based policies may be being reflected through the participants' views as the current status of organ donation is in a state of flux, particularly at a time where the Nuffield Council on Bioethics is suggesting funeral costs are paid. The participants' were mirroring the debates in health campaigns and media such as altruistic and gift rhetoric, in addition to funeral costs being acceptable but not payment. This illustrates the complexities of the individual-social dialectic relationship, in terms of which influences which.
In addition to this gift-altruism argument is the notion of ‘sacrifice’, which Shaw (2010) argued to be congruent to organ donation, as opposed to the term ‘gift’. This was also suggested by Sque et al. (2006), who researched the experiences of bereaved families who had made decisions about their relative’s organs for donation. Sque and her colleagues were influenced by the work of Mongoven (2003) who likened organ donation to being a form of sacrifice for the family. Mongoven suggested that the bereaved family has to make a difficult decision to ‘relinquish the guardianship and protection of the corpse to allow the cutting up of the body and the removal of organs, albeit through a standardised surgical procedure, for the benefit of the recipient’ (Sque et al. 2003, p.122).

Mongoven’s (2003) terms motivational and cultic, where the motivation element is the intention behind the sacrifice which is giving another person the ‘gift of life’. The cultic dimension is the process of this occurring, for example certifying death and the donation surgical process. Sque et al. found that sacrifice was interpreted by bereaved families in terms of ‘letting go’ of their relative and the way that the donation operation was perceived.

In the present study, this was not the case, the donating of a relative’s body or their own body were not viewed as forms of sacrifice. The term ‘sacrifice’ was only likened to living donation where the individual is in effect taking a health risk as for example, he or she could be living with one kidney. For the participants, giving organs after death was not a sacrifice as the body was not perceived to be required when an individual dies and their organs could be used as a resource to help others. Few highlighted that there were meanings attached to organs, which has been highlighted in other studies and when discussing body metaphors, donation was viewed as a form of recycling or a body with parts that were not needed. This will be discussed in further detail later but illustrates that there is no
significant ‘attachment’ or meaning to particular organs, hence donation was not viewed as a sacrifice.

**Donating to UK Society**

There was the view in the present study that organ donation was a private decision and would not have an impact on social cohesion or social solidarity as the process involved the donor and recipient. Carsten (2000), a social anthropologist, developed the notion of kinship and suggested the concept of ‘relatedness’ between the donor and the recipient and eradicates the divide between biological, nature and social relatedness. Kinship is not only the basis for biological and marital ties but how people define and express the concept of kinship organ donation here could be considered an extension of kinship. Alnæs (2001) investigated the relationship between kinship and deceased organ donation. She found that organ donation changes forms of kinship to a form of relatedness between the donor family and recipient in terms of deciding to donate and after donation. Sharp (1995, 2006) developed the notion of ‘fictive kinship’ to explain the need that donor families have in wanting to make contact with the recipient to reciprocate the donation. This illustrates that stronger bonds may be made on a small scale, between the donor and the recipient as opposed to on a larger scale as suggested by gift exchange and social exchange theory.

These smaller networks would create small communities outside of the family where people may share their experience of donation with others with similar experiences and this was highlighted by the participants in this study who suggested that organ donation would only bring certain people together rather than the nation. This links with the notion of biosociality (Rabinow, 1992), which is where new social groups are created through medical technology. Rabinow and Rose (2003) argued that:
'The creation of new social subjects and groups occurs when people identify with bio-medical, genetic categories and start to generate self-imposed obligations specific to their embodiment in the light of new knowledge available to them about their condition' (p.5).

Although social capital was not viewed to link with organ donation as a form of increasing capital, many participants thought of donation as a way of contributing or investing by helping others in the community of locality and UK society in a general sense, as opposed to belonging and experiences in living in Luton and Dunstable motivating donation. In addition, community-based events were suggested to find out what other people think of donation, meaning that it could be social norms that are key in organ donation, as a point of reference and to find out more about those living in their locality in relation to organ donation.

**Donating to Humanity**

There was a dichotomy of views where it was believed religion not influencing helping others through donation and religion encouraging helping others through donation. Taking the first theory, that religion does not influence helping others through donation could be explained through everyone being a human and having vulnerable bodies making all humans have something in common, thus invoking a sense of solidarity and empathy. Turner (2001) explained that human vulnerability is the grounding for human rights. Suffering, in this case experienced by the potential organ recipient, is a ‘feature of vulnerability’ (p.279) and is ‘an important prerequisite of membership of a moral community, the notion that sympathy is the social glue of society characterised by precariousness’ (p.278). This links to the previous section on the ‘altruistic gift’ and who the individual is envisaging as being the recipient of the organ. Preferences will be later discussed in the next section, generally there was a view in the present study, that death and illness can happen to anyone at any time and
they may need an organ one day and should be prepared to give one. This could be argued to be giving in the most general and abstract sense to the collective and not an individual, perhaps for those who are comfortable with helping the common good as opposed to specific individuals. Religion having no influence may also link with the previous section of the social norms and framing of organ donation as a gift and form of altruism through policy and health campaigns.

In the second theory, where religion does influence helping others through organ donation, this was suggested to be a general teaching through church as opposed to applying Biblical scripture and parables, which currently informs the NHSBT guides on religious perspectives towards donation. These can be linked to Healy's (2006) argument that these inform ‘feeling rules’, which are norms as to how a person should feel in a given situation. Some of this literature recently published by NHSBT shows the standpoint that religion has on organ donation. Helping others is part of the literature, for example, Dr Barry Morgan, the Archbishop of Wales is quoted as saying that ‘Giving organs is the most generous act of self-giving imaginable’. In terms of the ‘feeling rules’ or norms which the families may not be familiar with within a foreign, clinical environment regarding organ donation, the literature may help guide the family in the organ donation context as it is likely they have not experienced it before.

The leaflets that have been provided by the NHSBT to structure the religious ‘feeling rules’, may not be enough as they rely on religious parables. It is too simplistic to suggest that as someone holds X religious views, that parable Y will put their mind at rest as it shows an ‘official’ link between religious tenets of helping others and organ donation. There are many denominations within a major religion, which are shaped by culture, for example this study has shown that English and Polish Catholicism are very different. The previous chapters also showed that there are many
strengths of religiosity and interpretations of aspects of religion such as the Resurrection and God. These leaflets may help some people who are uncertain if their religion supports donation, but the decision is influenced by other elements such as cultural views of the body, death rituals and most significantly other family members.

Religion influencing helping through organ donation may be explained through the Polish Catholic social construct ‘duty of solidarity’ invoking Catholics to help those close but also those who are distant. Mullard and Spicker (1998) explained that this religious form of solidarity teaches followers that they are socially responsible for helping others as it is their duty to God and others in society. This is not solely a Catholic tenet, as there are similar teachings in other religions, such as Islam where ‘He who saves one soul is as if he has saved all of humanity’ (5:32) and one of the five pillars of Islam, Zakat, is giving to the needy. Sýkora (2009) argued that Titmuss’s charitable giving model had parallels with agape, the Christian teaching of helping those in need. Generally it was assumed by the participants that Catholicism would support donation as it advocates helping others.

Baum and Musielak (2008) researched the role of Catholicism and education in relation to transplantation in Poland. They showed that, in Poland, 95% of Poles self-proclaimed to be Roman Catholic and that the Catholic Church support organ donation, the Pope suggesting that is an act of ‘caritas’ (love) and compassion. In the Poland through the Public Opinion Research Centre survey in 2005, 63% believed that organ transplantation was supported by Roman Catholicism. Baum and Musielak found that the role of religion in transplantation influences how liberal or conservative one’s views are. They found that the majority had a liberal view on religion and transplantation. They highlighted that as far back as 1956, the Pope has supported transplantation as a form of treatment for
diseases where no other treatment is available and church documents such as the Evangelium vitae from 1995 views organ donation as a heroic act. This could be informing the participants' perceptions that religion can be linked to encouraging donation through the Pope supporting donation. Although there is the Polish social teaching to help humanity that can be applied to organ donation and it is generally viewed that Catholicism does support donation, there are further limitations. Nevertheless brain stem death was accepted and organ donation is viewed as a positive act. However, in spite of teachings to help others, for specific religions there was a barrier, in particular Jehovah Witnesses\textsuperscript{18} and Muslims where the norm to keep the body whole was more significant.

In addition to helping humanity being a social construction of Polish Catholic teachings reinforced through the church, it could also link with 'religious communities' that are assumed to help one another extending to beyond this 'community'. Putnam \textit{et al.} (1993) believed that religious 'communities' were a source of social capital; however this is based on the assumption that religious individuals are more likely to help one another, although this is yet to be established within the literature. Lamanna (1997) cited Ehilstain (1990) who suggested that sacrifice and social obligation are exercised within communities of religion and ethnicity where these relationships are extended to humanity (Menzel, 1990) or society (Putnam \textit{et al.}, 1993). Belk (1990) also agrees with this suggesting that the 'extended self' is society.

The findings of this study suggest that communities are created based on commonality, it has been highlighted in this study that shared ethnicity is a basis for unity. Therefore, these explanations where religious communities

\textsuperscript{18} There had been a story in the media in 2010 where a teenager who was a Jehovah’s Witness died as he refused a blood transfusion as this was against his religion. This same logic was assumed to be applied to organ donation, however, this is not the case as Jehovah’s Witnesses are allowed to give and accept organs as all blood from the donor is removed.
are argued to be a source of social capital as their values extends beyond the community are too simplistic as community formation is complex, meaning that the assumption to extend values is limited as it may be based on social norms of giving as previously argued.

Requested Allocation: The Conditional Gift

Having a preference for the recipient for one’s organs was highlighted by a minority of the participants, where a few individuals wanted to request the allocation for their organs either by having their own exclusion criteria, such as sexuality or ethnicity, or meeting the recipient. This has been found in previous studies and may be influenced by negative experiences of non-Polish ethnic groups in Luton and Dunstable.

Requesting a preference for the recipient has been found in previous studies, such as Randhawa (1998), Bennett and Savani (2004) and Kenten et al. (2011). Randhawa (1998) concluded from his study of the South Asian population in Luton that there was a preference to donate to those with ‘biological and sociocultural bonds’ (p.1952) or in the ‘faith’ family (Kenten et al., 2011). This indicates a preference that an individual may have to donate to others ‘like them’, either their family members or others of the same ethnicity. In Bennett and Savani’s (2004) study of White, Asian and Afro-Caribbean communities in London, they found that the minorities of each ethnic category had a preference for the location of their body parts, either going to a young person, to go to people ‘like them’ or belonging to the same ethnic group or religion. For many of the participants in the present study, religion was seen to restrict donation among certain religious groups such as Jehovah’s Witnesses and Muslims. Muslims were thought not to be able to donate as it was considered that the body had to be looked after within Islam and had to be buried whole, linking with the initial constructs. This illustrates that the social norm for Jehovah
Witnesses and Muslims is ambiguous in relation to donation and it is not only Muslims but non-Muslims who are unsure whether they can donate.

The extent to which someone integrated with different cultures and ethnic groups was highlighted by some participants to perhaps positively influence views towards donation and whether a person would have preferences as to a recipient. However, one participant believed that feeling belonging in society does not matter because the geographic location in which someone dies and donates could be anywhere. This illustrates that some religions and cultural groups may perceive rules as to who can receive organs and whether individuals can give. For Poles who come from a largely White Catholic country, their views of other ethnic groups may be formed whilst in the UK. This may be informed by lay theory and attribution theory where individuals are deducting their own theories based on their experiences of interacting with the social and cultural surrounding, informing their views of who could possibly receive their organ and whether they feel comfortable with this, based on their experiences and interactions with other ethnic groups in the area, highlighting the sensitive issue of racism. It may also relate to the notion of 'community' and belonging to this 'community' and feelings towards donating outside of the 'community'. Previous studies have illustrated that individuals are not comfortable donating outside of 'communities of identity' such as religion and kinship. In the case of this study, some participants were not comfortable donating to others who were not in the same community of identity such as other ethnicities. Homophobia was raised as an issue and the lessons learned here could be extended to

19 The impact that donating in foreign country can have may be illustrated by the 'Nicholas Effect'. An English family, Reg Green and his family, were on holiday in Italy and their seven year old son Nicholas was killed by highway robbers. The family decided to donate his organs into the Italian procurement system. This had a profound effect on organ donation and transplantation in Italy, by raising awareness of the issue and organ donation has increased. It is called the 'Nicholas effect' because it illustrates helping the 'common good' across nationality boundaries.
individuals having preferences for donating to others based on their sexuality.

**Body after Death**

The body upon death has been briefly mentioned in previous sections and will be discussed further in terms of metaphors, cultural views of the body and the need for body totality. The body, in terms of religious holism is discussed by Campbell (1998) who suggested that the body has been theorised throughout theological literature and it is viewed to carry much symbolism. She cites Gold (1996) who outlines:

>'The body, from a scientific viewpoint, is a source of knowledge of physical development, aging, and disease. From a religious perspective, the body is understood as a sacred object, being created in the image of God...The scientist values the body instrumentally, as a means to acquire knowledge; the believer values the body intrinsically, for being an image of God (in Campbell, 1998, p. 276-277).

Within Christianity, the body viewed in its totality as tied to personal identity and religious metaphors of sacrality are used relating to the body, such as 'temple' (Campbell, 1998, p.277). The body is viewed from many different religious angles as is the body's relationship to the self and the status of body parts. The body is viewed as a vessel and if others can benefit from the organs from the body, they can be used.

The findings of this study did not find a strong connection between the body and soul, although this dichotomy was apparent. There were a number of individual theories of the 'reality' of this. Some believed that there was no 'soul' but a conscience and others believed that the soul would part and go to Heaven. The body was viewed as 'sacred' or a 'temple' for non-Catholics among the participants as the body was generally viewed as a form of vessel for the soul that one does not need after death. Those who believe that death is the end of the body and soul
or that the body separates from the soul are less anxious than those with transcendence beliefs (Sanner, 2006). In the present study, it was found that there were no significant differences in death anxiety existed across individuals who were devout Catholics to atheist. Sanner (2006) suggested that these beliefs are not tied to religion per se, but are drawn from a variety of belief systems and quasi-scientific concepts. Death may be viewed being an escape as there is further existence after death.

In addition, Sanner’s (2006) findings around death anxiety links with the other constructs and sub-constructs found in this study, illustrating the complex and interactive nature of representations of organ donation, the body and religion. She suggested that the belief in life after death through the resurrection or reincarnation for example, is also a defence mechanism. This ‘symbolic symbolism’ (Sanner, 2006, p.139) is a reconciliation as opposed to a denial of death. However, decisions regarding issues after death may be a problem and could be triggered when considering organ donation. Religion was perceived to act as a way of individuals reconciling death as they were looking forward to the Catholic form of the afterlife. There were many forms of the Resurrection but Reincarnation was not raised. It may be challenging therefore, to link the Resurrection with accepting death because there were a number of different versions of it.

Metaphors of the dead body were discussed with the participants and the majority saw the body in organ donation as a form of recycling organs and body parts that are no longer required. One participant saw organ donation as Frankenstein-like, which was also found by Sanner (2006), and another participant saw the body as a machine with spare parts, another metaphor argued to exist by Belk (1992).

Social representation theory (SRT) has been used to investigate organ donation, SRT accounts for how social environments can contribute to an
individual's taken-for-granted, common sense knowledge and was founded by Moscovici (1961). When investigating social representations of organ donation in Australia, Maloney and Walker (2002) found that organ donation was best understood through two ‘opposing’ images. These were the ‘gift of life’ as previously discussed and the body as a machine. However, from the findings of this study, it could be argued that these images are too simplistic from the discussion of what ‘gift’ means from a lay perspective in relation to organ donation. This study has shown that the body is not viewed as a machine with spare parts but a body with parts that are not needed after death and could be ‘recycled’. It is claimed from the findings in the present study, that the social and cultural environment has been shaped by religious views toward the body as there was a strong theme of a Catholic perspective on the body among all the participants. It was commonplace to view the body as not being needed after death for the afterlife, either in Heaven or the Resurrection, this logic was applied to organ donation in that it was suggested that organs should be used as they would only be ‘wasted’ by being buried with the body, linking with the metaphorical perspective.

Lauri (2009) found the following in her Malta-based study investigating the social representations of organ donation in relation to social representations of the body and metaphors describing the body. For example, the social representation ‘I own my body’ linked with the metaphor to describe the body as a ‘machine’ which was linked with recycling, a positive attitude toward donation. From Lauri’s work, there are a number of similarities of metaphors and social representations that were found in the present study. However, in the present study, the metaphor of the organ being a gift does not match up with the body being a gift from God or being a treasured possession as the body was not viewed in this way, but as simply not being needed after one dies.
Lauri's (2009) findings closely mirror the outcomes of this present study and the findings bear some similarity to the findings of the present study:

- **Normative context** - there was a lack of information; social influence from the church, media and interpersonal sources; motivations such as altruism and charity; fears including taking risks and mutilation.
- **Decision making** – decision to sign the donor card.
- **Death and body image** – death anxiety; body image; afterlife; sacredness of the body; and miracles.
- **Ethical issues** – declaration of death; choice of recipient; abuses and exploitation; opt-out system.
- **Medical issues** – faith in doctors; experimentation and research.

Religious and cultural constructions of the body and organ donation can be illustrated in other studies of ethnic minority groups in the UK. Al-Khawari et al. (2005) in his study of UK Muslim Indo-Asians found that the dead body was viewed to be sacred by the participants, meaning they were unwilling to donate. Hayward and Madill (2003) found that many Muslims were concerned about the intactness of the body and, in their focus groups, discussed whether the body was given back to Allah physically or metaphysically. They found that Muslim men considered an Islamic burial important and Gatrad (1994) is cited who suggested Islamic customs are important. Sheikh and Gatrad (2000) purported it may be more for the relatives to help them in the bereavement process. Exley et al. (1996) focused on the South Asian community in Coventry, UK and found that Sikhs were concerned with the ‘mutilation’ of the body and that missing organs would affect reincarnation. Lam and McCullough (2000) found that there are religious reasons around body totality within the American Chinese community in the USA. Religion is an integral part of a person’s identity and religious persons rely heavily on religious guidance to help
them make decisions (Batson, et al., 1993) especially related to integrity of
the body (Radecki and Jaccard, 1997; Gillman, 1999). In Sweden, Sanner
(2001) found that those who were neither willing to receive nor give
believed in the reincarnated body and that ‘every molecule of the body
would be needed in the next existence; one could not start a new life with
a transplantation if some organs were donated when one died’ (p.1495).
This illustrates that the social construction of the body has been
significantly influenced by religious and cultural views of the body and its
requirement in the afterlife, which is applied to donating organs. In the
USA, Simmons et al. (1970) found that those who are less likely to believe
in life after death were less likely to view the body as sacred and oppose
conventional funeral practices. However, in this study, believing in life after
death seemed to play no significant role in traditional death rituals and the
way the body was viewed.

This reticence to donate based on the social construction of the body from
a religious perspective however, may be limited. It may be that some
individuals are not comfortable with the idea of the dead body, either
theirs or their relative, to be operated on to have organs removed. This
was what Sanner (2006) termed as an ‘anti-donation reaction pattern’. She
discovered that people found it difficult to distinguish between the living
and the dead body. People may react to this by feeling a sense of
immortality and that keeping the body intact means that life can continue.
Sanner also found that respecting the dead body was another anti-
donation reaction pattern. This had been highlighted in the present study
as there were mixed views of whether healthcare professionals would
respect the dead body. Sanner suggested that there is the belief that the
body should not be interfered with as it is disrespectful and the deceased
should rest in peace. However, the procedure for organ donation is
performed in a respectful manner. The significance of the corpse may be its
connection to ‘symbolic survival’ (Toynbee, 1976). In life, the body and self
are not separable and treating the body with respect may be linked back to expressing respect for the individual before they died. Wanting the body whole for non-religious reasons linking with organ donation has been found in previous studies. Alden and Cheung (2000), in their research in Hawaii, found that there was a general concern about body integrity after death. In McNamara et al.’s (1999) American study of White, Hispanic and African-American participants, there were concerns about the disfigurement of the body. Morgan et al. (2004) and Stephenson et al. (2008) found that bodily integrity is a strong predictor of the intention to donate.

Overall, it was viewed that the body was not needed after one’s death and that it should be used as a resource to help others as the organs and the body will not be needed in the next life. It may be argued that there is a connection between other constructs in the map, for example this view of not requiring the organs may link with donation as an altruistic act as the organs are not required and may be used to help a person in need.

Family Discussion about Registering as a Donor

Family refusal is a significant issue in deceased organ donation with 40% of families refusing to donate organs (Sque et al., 2007). Lack of family discussion and lack of organ donation registration contributes towards family refusal (Sque et al. 2008) as Griffiths (2012) also showed from the National Audit Data who presented at the first NHSBT Organ Donation Congress. She highlighted the most common reasons with 19.2% due to not knowing their relative’s wishes, 18.8% being against donation and 12.3% not wanting further delays due to the donation process. Talking to one’s family and friends about organ donation has been found to be a factor in giving consent because if a person has spoken to their family or signed the NHS donor register to show their wish to donate, the family is more likely to follow their wishes (Morgan and Miller, 2001). This was
highlighted by the participants in this study as a number of participants suggested that families should honour a person’s wish if they have said that they wanted to be a donor. A few participants said that it was a difficult decision that had to be made quickly and would be harder if the person’s wish is not known. Participants generally did not want to think about what happens when they die, lack of discussion among families about organ donation have been found by Guadagnoli et al. (1999) and Siminoff et al. (2001) to be due to a number of reasons such as readiness to discuss donation, family understanding of brain death and who raised the topic.

When the SN-OD or consultant speaks to the family about organ donation if the decision to withdraw treatment has already been made, there is a specific list created by the Human Tissue Authority which informs them of who is spoken to first about the decision to donate. The ways in which the medical team approach families about donation is mixed across Trusts and hospitals, but this discussion is outside the remit of this study. When discussing with the participants in this study who would make the final decision, there was not a particular family member, such as an elder, who would make the decision, but the potential donor’s next of kin, who may be a father or partner. In previous studies, the family decision makers have been elders of the family (Randall, 1991; Exley et al. 1996).

Vincent and Logan (2012) found that the most common reasons for family refusal were the relatives not wishing the individual to have surgery on the body, there was uncertainty about the individual’s wishes, disagreements among the family, dissatisfaction with the healthcare staff and process, inability to accept death and lack of understanding of brain stem death. It was challenging for the participants to be specific about the issues of giving consent as they had no experience of organ donation and transplantation from a family’s perspective. The majority of participants thought that their
families would donate their organs. They believed that the difficulties for the family would be the hope that the person is not dead, not being able to say goodbye, if a child died before a parent, family having to build a relationship with the recipient, nurses not approaching families about donation and having little support for the donor family after the donation has taken place. Nurses not approaching the family may be due to nurses’ perspectives in Poland, as many of the participants had friends or relatives who were nurses or doctors in Poland. It was found that nurses in Poland were not familiar with the details of transplantation, such as differences between diagnosing brain death and donating, most had little experience with donation and considered the topic to be a taboo (Orzel-Nowak et al., 2005).

Religion is commonly cited as a barrier to organ donation, Lesoeurs et al. (2009) looked at the communication between transplant coordinators and potential organ donor migrant families in France and this illustrates some of the issues migrant families have around organ donation. The reasons for refusal are the ‘fear of mutilation, doubts regarding reality of death of a family member and a difficult relationship with host culture’ (p.631). Refusals occur among migrants who are faithful to their culture from their home country and communities. Communication is an issue with migrants and causes of refusal were hard to find.

Lesoeurs et al. (2009) surveyed 30 coordinators in 22 hospitals and found that communication was an issue; and religion was found to centre on difficulties in donation. Religion was used frequently as a reason for refusal nonetheless it could be used to hide personal feelings or the inability to make a decision. Lack of solidarity was an issue, the coordinators felt that there was a feeling of diminished solidarity with the host country and traditional values had to be reaffirmed. This was also linked with ‘level of instability, lack of social consideration families feel’ (p.633). Lack of
solidarity was coupled with the fear that death rites would not be able to be performed and the necessity to conform to culture of origin as they were afraid of reactions of their own community. The findings of this study build on the results of Lesoeurs et al.'s (2009) study and suggest that from a social capital perspective, other aspects in addition to solidarity can be examined such as civic engagement and belongingness from a migrant perspective. It was found that there was a feeling of solidarity on a humanity level as opposed to a societal level. However, the participants in the present study were willing to civically engage as they generally felt a sense of belonging in Luton and Dunstable and perhaps this was not felt by the participants in Lesoeurs et al.'s study.

The low donation rates of minorities is not solely their issue, some studies have shown there is prejudice from health care professionals and approaches about organ donation are made on fewer occasions (Siminoff and Sanders-Sturm, 2000; Siminoff et al., 2003; Pietz et al, 2004; Al-Sebayel and Khalaf, 2004; Sander and Kopp Miller, 2005; Epstein and Ayanina, 2005; Rodrigue et al., 2006). Feld et al. (1998) suggested that perceived ethnic and religious barriers to organ donation discourages health care professionals from speaking to potential families as they want to avoid offending them.

Fears of the organ donation discussion had been investigated by Verble and Worth (2000, 2002) who found that there were four fears in their 2000 study, ‘the prospective donor expressed a desire not to donate, donation is a hard decision to make for someone else, the body needs to be buried whole, and the donor may not really be dead’ (2002, p.188). A further three fears from their 2002 study, Verble et al (2002) found ‘a concern about the fairness of the system, the body part being connected with the soul, and the loved one needing the part in the next world’ (2002, p.188). Some of these fears had been expressed by the participants, such as
donation being a difficult decision, the donor not being dead and fairness of the system, however with regards to the soul and body parts being needed in the next world, this was not the case in the present study.

Sque et al. (2008) found in their review of the literature that families refused donation as they think that the deceased suffered enough or do not want the body to be cut. In an earlier study, Sque et al. (2007) suggested that families refused to give consent for a number of reasons including protecting the dead body, the circumstances at the time of death, a lack of knowledge about the donation process, the donation discussion and to being able to witness the observable ending of life. Also the type of donation that may occur, whether it is DCD or DBD, may influence consent rates as they each have their own issues, such as accepting brain death for DBD, or accepting long waiting times for DCD. As discussed earlier, Sque et al. (2008) in her review of the literature, states the issue of ethnicity has arisen as a factor in the declination of organ donation in addition to other factors such as the family not making a united decision in the UK, not being satisfied with the care at the hospital and not being able to cope with such a decision and wanting to be present when the ventilator is turned off. Vincent and Logan (2012) show that there is a 63% consent rate for DBD and a 57% consent rate for DCD.

Some participants wanted to help their family by signing the register to protect them from deciding. This raised issues of lack of knowledge of the family, having the right of veto at the point of donation and registering as a written, legal contract between the individual and the NHS, making the consent phase easier for families by not having the option to veto an individual’s wish has also been found by Irving et al. (2012). The Human Tissue Authority do suggest that the donor’s wish is not changed by their next of kin, but in practice, the donation protocol is to always discuss donating with the family who may wish not to follow the donor’s wish. The
majority of the time however, the wish is followed if it is known. This highlights the issue of the health care professional’s views vs. a lay person’s views. The individual may have registered their wish to be a donor and may have done this to make it easier for their family. However, health care professionals would not feel comfortable going forward with donation without the family’s consent. This may be due to ethical or moral issues or protecting the family. But it is a decision that is made at a difficult point as the family are grieving.

There was a general reticence to discuss organ donation with one’s family. This lack of discussion leaves a significant gap in the family’s knowledge about the relative’s view towards donating and consequently the family may not want to donate their relative’s organs in case the individual was against it. However, many of the participants had discussed organ donation with their family, this was sometimes prompted by watching a television programme or film which raised the issue. For one participant, her siblings took part in extreme sports and the perceived risk had prompted the family to have a discussion to consider as a family what they wanted to happen after their death. This illustrates that familial attitudes towards accepting death and preparing for one’s death are positive. Many of the participants had seen Seven Pounds, Grey’s Anatomy or ‘real-life’ television series on medical issues where organ donation arose, which was the catalyst for family discussion for a number of participants. This highlights the significance of the media in triggering family discussion and perhaps the importance of the messages that are being portrayed in film and television about organ donation.

**Summary of Individual Context**

The individual context has framed the shared cognitions and conflicts within collective views regarding the relationship between deceased organ donation, gift exchange theory and religion. These have highlighted the
'theories' that the Polish participants had that were most significant in the relationship between the three aspects of the study within an individual context.

Within some of the constructs and sub-constructs, there were theories that were contradictory such as the perceptions of the altruistic gift and the body upon death. This highlights the multi-layered and complex nature of the relationships between deceased organ donation, gift exchange theory and religion. For example, the social and cultural context has shaped the way in which organ donation is viewed, such as a ‘gift’ as a form of altruism but also through recent media coverage, an act that could be repaid through a contribution to funeral expenses. From a theoretical perspective, untangling the differences between the gift and altruism is through the notion of reciprocity, but from a lay perspective, reciprocity was not highlighted as the difference, it was simultaneous with altruism as individuals are helping patients at the NHS and the NHS is helping families, help was repaid with help.
THE RELATIVES' CONTEXT: THE RELATIVES' DECISION TO GIVE CONSENT

Death Rituals

The importance of ritualised behaviour around death is highlighted from an anthropological perspective by Richardson (2000) and Banbury (1999). Richardson analysed the history of death rituals and found that the protection of the body resonates throughout historic death customs. The cadaver is no longer a person and there is the expectation from the family that the body will be treated with care and respect by the health care professionals. Banbury argues that in modern society, death rituals bring
families close together and are ‘processual’ (p.113) where the deceased and the relatives are undergoing transformations into their new roles within the family.

Funerals in Polish culture are quickly organised and the deceased are buried in graveyards in Poland close to the family but relatives from all over the world who have migrated come to the funeral. In the UK, this differed as funerals were not as quick and it was assumed that the body would be sent back to Poland and buried near their family who would visit the grave on All Souls Day. These death rituals may be performed by the church and may fall in line with official religious teachings, however, other aspects such as a quick burial and visiting the grave on All Souls Day may be cultural practice. One participant explained that the deceased are buried quickly due to the superstition that the dead need to be buried before the weekend or they will take someone with them. Overall, the death rituals were not viewed to be hindered by the organ transplantation process.

However, this has not been the case in the study of other ethnic groups, in Morgan et al.’s (2010) it was found that participants wanted their body to be buried ‘whole’ in the Caribbean or in a Caribbean style funeral in the UK. They suggested that burials and funerals symbolised the reconciliation of their divided identity in their life. Woo (1992) found that Asians from Singapore had a desire to bury their dead whole. Lauri (2006) argued that burial traditions were a barrier to organ donation as there are notions as to what makes a decent funeral. Where people are buried in the ground, body totality is common.

This perception connects with the previous view of the body upon death within the individual context where the body is perceived not to be needed after death. However, previous studies highlight issues such as divided ethnic identity for migrants in the UK and body totality is needed for traditional burials. The participants suggested that their funeral traditions
would be adhered to as their body would be sent back to Poland and buried there and did not perceive donation to significantly interfere with this process.

In Japan, Lock (2002) in *Twice Dead*, found that Buddhism supports organ donation on the basis that this form of treatment saves lives but Buddhists are not comfortable with the notion of the ‘gift of life’ as within Buddhist culture as reciprocity was embedded in tradition. Death is an event that is socially determined and not a specific moment and the way in which the spirit and body are perceived makes autopsy and brain death criteria controversial (Lock, 2002).

**Experiencing a Relative’s Death and Conceptualising the Deceased Body**

The family must make the decision to donate or not to donate at an emotionally charged time. Sque and Payne (1996) illustrated the stages that the family may go through from recalling ‘the last time we were together’; informing ‘finding out something is wrong’; hoping ‘waiting for a diagnosis’; realising ‘becoming aware things are going wrong, realisation of death’; deciding ‘confirmation of brain stem death, donation decisions’; parting ‘saying goodbye’ and coping ‘dealing with grief and donation’ (p.1361).

In relation to these stages, the participants’ views focussed on the latter parts such as hoping, parting and coping. Within the hoping stage, there was the perception that the individual may wake up, within the parting stage, organ donation was viewed to evoke magical thinking through families being unable to say goodbye if a person was ‘living’ on in someone else and conceptualising the dead body and coping was viewed to relate to organ donation being a way of dealing with grief.
The perception of the individual potentially waking up due to the confusion between brain stem death and PVS is dealt within the perceptions of brain stem death; this section is going to focus on the ‘parting’ stage. The donor relative’s experiences were thought by some participants to evoke ‘magical thinking’, this is where individuals may think in a fantasy-type way about what will happen to the organs once transplanted in the recipient and what has happened to the ‘soul’ of the individual once they have died. Sanner (2001) found this in her study in Sweden where she used the idea of ‘magical thinking’ where ‘Magic presupposes that an object or a person can be influenced by supernatural forces, not by natural laws’ (p.1497) and this affects how people feel about the transference of the deceased’s qualities into another person through their organ. She explained that this ‘magical thinking’ is common, even in today’s Westernised society, citing superstition as an example. The participants in the study suggested that life is prolonged in another person. However the majority of participants felt that there was no significant meaning in tissues and organs such as eyes and the heart, however this is not supported in previous research (Exley et al., 1996; Verble and Worth, 1997; Ahmed et al., 1999; Kaba et al. 2005).

Specific organs were not thought to hold special meaning, however, the donor’s general personality was viewed to be transferred through transplantation through the donor ‘living on’ leading to difficulties for the family in saying goodbye. The notion of the donor ‘living on’ in the recipient connects with Mauss’s ‘spirit of the gift’ and Malinowski’s *hau*, where the gift has a ‘hold’ over the recipient as part of an identity had transferred with the item. The concept of ‘living on’ has been found in previous research, such as Sque and Payne (1996) who found that if an individual has an unsuccessful transplant, there may be a sense of loss felt by the donor families and recipient, this was thought to illustrate an unconscious exchange where the donor’s personhood was transferred in the organ, especially an organ such as the heart. They also found that it
was difficult for families to donate some body parts as they have symbolic meaning, such as the corneas as eyes were seen as the windows to the soul. Families that believe that by donating organs, part of the person lives on can be fundamental in the decision making process (Fox and Swazey, 1978). Batten and Prottas’s (1987) conducted a study with organ donor families and found that 68% believed that their deceased relative would live on in someone else. Healy (2006) explained that this phenomenon is in journalistic literature and organ donation professionals in America use this notion as a way of recruiting organ donors. Personality transference through organs was also found in this study as media stories had been highlighted as the source of ‘knowledge’ that this could occur, however this has been anecdotal and there has been no scientific evidence to justify this phenomenon.

Haddow’s (2005) view of embodiment could be considered here, as the family has to adjust their views of their loved one’s body to no longer being alive. She explained that the Cartesian view of embodiment is linked with a detachment where the dead person is no longer attached to their body. However, from a holistic perspective, there was a view that the living person and the dead body were connected. Haddow found that families considered the embodiment of the newly deceased person as a mix of Cartesian and holistic, in a number of ways such as concern for the body’s integrity and the identity of the living person. She created the following table to illustrate the connection between death, embodiment and organ donation.

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20 A Cartesian view stems from the dualist philosophical view of the body where the body is treated separately from the ‘soul’ or ‘self’ by Descartes.
Table 6: Death, embodiment and organ donation

Source: Haddow (2005) p.108

What can be learned from Haddow's table that can be applied to the present study is the way in which the body is generally viewed by the Polish community. If this table represented a continuum, the majority of participants in the context of the individual would be classified in section iv as many said 'why not?' to donation as they do not need their body after death. This illustrates a Cartesian view of the body where there is a perceived separation of the body and self, or body and soul, upon death and the body is no longer required. However, within the family context, the view of the body and self may be mixed between level 'iv', where the person is believed to have gone to Heaven and the level 'iii' as it may be difficult for families to distinguish between the newly-dead person and their living identity, taking a holistic embodiment perspective on the body. This may be influenced by magical thinking and irrational thoughts at a difficult time.

Brain Stem Death and Catholic Death

There was the belief that the person was not certified dead from brain stem death and the family could be hoping for a 'miracle' that the patient would wake up, this confused PVS and brain stem death, bringing in perceived ethical issues around euthanasia for the family. The lack of
understanding of brain stem death had been found in the review of the literature by Sque et al. (2008) and found in studies (Manninen and Evans, 1985; Horton and Horton, 1990, 1991; DeJong et al. 1998; Franz et al., 1997; Siminoff et al. 1999, 2004). Brain stem death has been a highly contested issue within religious circles (Veith, et al., 1977; Ota, 1989; Lecso, 1991; Faltin et al., 1992; Zycinski, 1996; Gillman, 1999; Askoy, 2000; Healy, 2006; Mandel, 2011).

In her study about the use of religion in deciding about organ donation, Röcklinsberg's (2009) found that some Christian participants were unsure about organ donation, partly due to the definition of brain death which conflicted with their view of what constituted a 'person', their body and soul and when life ends. Some Christians supported the brain death definition but were unsure of organ transplantation based on theological reasons, such as not killing and respecting God's plans. But some Catholics did not accept brain death as they suggested it was suited to favour transplantation and the real death occurs once the organs have been removed. Participants overall however, did not see religious issues with brain stem death, but this is not the case in other research. In the present study, it was found that brain stem death was viewed to be a form of Catholic death and there were no significant issues with this definition.

The Recipient and Reciprocation

The motivation behind giving organs is to benefit those who are in need and in the case of organ transplantation, this is the recipient. There was the assumption that the relationship between the donor family and recipient would not be anonymous, but this is not the case in reality. The donor family will be made aware of the characteristics and progress of the recipient. A letter usually comes from the SN-OD within a couple of weeks of the donation to provide the family with a follow-up of the progress of the transplantation. The recipient of the organ was not thought to matter
to the donor family, in terms of having a preference as to who the recipient is according to a couple of participants, unlike in the individual context where preference was highlighted.

Through an altruism lens, there were no expectations from the donor families to have a repayment from the recipient as a result of receiving the organ. From this viewpoint, it was considered that families who receive help through funeral costs will be removing the burden from the recipient who may feel they have to repay the family, as they have received something from the donation. However, from a Maussian gift perspective, there is the obligation to reciprocate when a gift is received. It was considered by participants that the families would view the organ as a form of help but the recipient would be more likely to view it as a gift as they had been waiting for it and they receive great benefit from the organ. The recipient may struggle with the repayment; this was discussed in the first chapter where the recipient may feel the ‘tyranny of the gift’ (Fox and Swazey, 2002). In this way, the Maussian gift is useful for analysing the feelings and obligations that the recipient may be facing. The tyranny of the gift may link with Bourdieu’s (1986) ‘symbolic capital’ of honour and prestige. In the case of organ donation it may describe power in this relationship as an individual may feel guilty about the organ as a person has died to give it to them and they may feel that they owe a debt to the giver, in this case the donor family. It may also put pressure on the recipient to accept the organ and to care for the health of the organ.

It was suggested by the participants that the recipient would not be able to repay the donor family as returning the equal value as the organ they received would be challenging. In terms of the Maussian gift, the recipient would have to repay the donor family the equivalent with interest, but this is not possible. Participants explained that a solution to this would be that the recipient would give back to society in a general sense, through the
notion of 'paying it forward', which is very similar to the social exchange notion of 'generalised reciprocity' (Sahlins, 1978). This may be in a number of forms such as raising awareness about the organ disease to prevent others from needing a transplant and raising awareness about organ donation in general to encourage people to consider signing up to be a donor. This is also supported by Gerrand (1994) who suggested gifting in organ donation as a way of motivating people to help others in need. However, the concept of 'paying it forward' could cease if the recipient perceived there to be an equity and fairness in the exchange between the donor family and the NHS who had reciprocated on behalf of the recipient. The debate surrounding reciprocity may be argued closer as to whom the parties in the 'exchange' are, whether it is the donor family and the recipient or the donor family and the NHS.

Boas (2011) suggested that organ donation is a form of 'restricted altruism' as opposed to 'generalised altruism' that is similar to the notion of generalised exchange. Boas found that organs were considered to be personal gifts as opposed to social goods and the effect of altruism is restricted, as it is based on a one-to-one relationship rather than generalised giving. Viewing an organ as a social good for the common good may be too abstract and difficult to comprehend, making it more difficult for people to feel empathy, the key motivator for altruism. This is something that Batson et al. (2001) found when studying community involvement. Having boundaries for the criteria of the recipient may be put in place by some individuals who would like to choose their recipient if they view their organ as a personal gift to a person who may have to conform to religious and cultural practices to care for the organ.

**Summary of the Relatives’ Context**

These constructs illustrate the everyday thinking, lived experiences and lay theories of what the participants feel that the family would experience
when donating a relative's organs. These constructs highlight the practical aspects of death such as arranging the funeral and irrational thinking in a time of grief such as conceptualising their relative's dead body. Also, the conceptualisation of the recipient is more 'real' as in the individual context, it is an abstract person in the future that someone is helping but in the relatives' context, there is a shift in perspective to how the recipient will deal with the gift and possibly reciprocate.

5.6 Summary

This chapter began with an analysis of the social and cultural context of Luton and Dunstable Polonia to better understand what 'community' means to them, the formation of social networks, intended length of stay and ethnic identity and belonging. Altruism and gift giving were analysed and it was perceived that altruism was largely learned through socialisation. There were a plethora of religious experiences and views toward religion emphasising the personal and individualistic nature of religion and religiosity.

The conceptual map demonstrated how deceased organ donation, gift-giving and religion related:
Overall, this conceptual map has highlighted the differences in perceptions of deceased organ donation in two different contexts. Within the individual context, an individual registers their wish to become a donor and the findings of the study showed that this is mediated by a number of factors; the way the body is perceived after death; family discussion of organ donation; whether organ donation is altruistic or repaid; a preference for a recipient; the perception of who a typical donor is; experiences of the NHS and levels of knowledge of deceased organ donation.

From a relatives' perspective, there are different considerations as this is the point where the family would have to consider donating the organs of their loved one. This may be influenced by the perception of death rituals and practices and whether organ donation has an impact on these; the emotions and feelings of the family at this point in time that could have an effect on how the body and 'spirit' of the individual is conceptualised; if death and brain stem death are accepted as forms of death and finally if the family have preferences for the recipient of their relative's organs.
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6.1 The Journey from the Aims to the Conceptual Map

At the beginning of my journey, I set out to examine deceased organ donation, gift exchange theory and religion individually, in relation to one another and overall. I decided to take each part of the question independently to create a deep understanding and then could see which aspects were highlighted when they were asked to relate them. I did not think that by looking at the relationships from the beginning would give a deep insight as I wanted to understand the context and background of each component and I do not think that this would have arisen if I just looked at how they overlapped. Subsequent chapters have shown how this journey has developed. The introductory chapter outlined the aims of the thesis and the epistemological, ontological and theoretical approach that shaped the chapters that followed.

The journey from the aims to the conceptual map was not straightforward as I had started this thesis with little knowledge of deceased organ donation, gift exchange theory and religion. The more I read in the literature review, the more it emerged that the ways in which these elements interacted was more complicated than anticipated. I was unsure at the beginning in which field the thesis would sit, as many different perspectives could have been taken on this PhD, such as psychological, viewing the attitudes behind organ donation and framing it in a health belief model or theory of planned behaviour, and perhaps measuring religiosity using psychological measures and examining how these reacted. After much reading, it was decided that a multi-disciplinary approach would be taken, however, over time, the thesis leaned more towards a sociological perspective. This was the point at which social capital theory was considered, in order to take into account wider social aspects to examine further the altruistic argument of helping the collective and also
the wider social implications of gift giving and exchanges. When I conducted a literature review on deceased organ donation, I decided to include altruism from a multi-disciplinary perspective as the literature referred to charitable giving and helping others.

One of the biggest challenges of the thesis was that the relationship between deceased organ donation, gift exchange theory, altruism, social capital and religion had not been investigated and with respect to the Polish community. The literature that provided the foundation was problematic in many ways such as the ways in which religiosity or religion had been defined. This was being confused with ethnicity as the studies had predominantly set out to explore attitudes towards donation and not the role of religion and gifting or helping others intentionally but it arose in their findings. When investigating religion in the literature, this was challenging as it has been investigated and theorised in many fields including philosophy, psychology and sociology and previous studies that found religion to be a factor did not necessarily state from which theoretical perspective or field their arguments were drawn. In addition, after reviewing each element individually, I took each element in pairs such as gift exchange theory and organ donation, or altruism and religion. I wanted to keep an open mind for the fieldwork and did not hypothesise how these elements would relate.

Through a literature review, it was decided to take a grounded theory approach for the thesis and it was found that a social constructionist approach best fit the study. With a constructionist grounded theory approach in mind, the interview guide was developed from the findings in the literature review and was continuously developed throughout the fieldwork. The questions set out to be exploratory and open to examine the social constructions that the participants had through methods that enabled rich data to be collected.
Through the fieldwork, my conceptual map began developing and the relationships between deceased organ donation, gift exchange theory and religion began to become clear. Having done a literature review helped me identify areas to include in my interview guide although I felt that I knew too much theory making it difficult to view my study from a lay perspective. The wording that I used in the interview guide was tested through the group interview to check it was not too ‘academic’. I also found I was beginning to change my perspective on some of the literature that I had read because it was now being contextualised by my findings but also some of the findings contradicted the literature and theory. For example, the way in which the Maussian gift is viewed is clear that there is a form of reciprocity that follows, however the findings of the study showed that viewing the organ as a 'gift' from a lay perspective did not necessarily mean that reciprocity did follow.

I have briefly outlined here how the study changed over time, through the literature review and fieldwork and some of the challenges I faced. From a personal perspective, my journey had developed my skills as a researcher, for example finding and adapting recruitment methods, interview skills, networking skills and analytical abilities. I overcame unforeseen obstacles such as a lack of interest in my study from the Polish community and learning to take criticism and advice and take a more flexible and reflective approach.

6.2 Contribution to the Field

Through taking social constructionist lens to present the findings from a grounded theory approach, it is argued that by going considerably further, beyond attitudes and perspectives towards organ donation, this thesis has made a contribution in a number of ways:
CONTRIBUTION TO THEORISING ORGAN DONATION

- Social constructionism was used to gain a deeper insight into lay understandings of donating and the conflicts a Polish and UK setting.
- The conceptual map showed how deceased organ donation was viewed to relate with religion, religiosity, social capital, altruism and gift exchange theory.
- The study highlighted the multitude of definitions and interpretations of the term ‘community’ and how this may impact on the conceptualisation of the recipient.
- The study argued the importance of separating the individual and relatives’ context when examining deceased organ donation.
- The conceptual map could be transferable to different ethnic groups, to examine the social constructs that they have within these contexts and the way in which these are significant and interrelate.
- The differences of a theoretical concept of ‘gift’ and ‘altruism’ and the lay understanding of the ‘altruistic gift’, which could be used to reward donors.
- The initiative of cultural, religious and social norms in shaping social constructs and attitudes and beliefs towards the body and death in organ donation.
- The lack of current family discussion and the significance of individuals being aware of the norms within their family toward donation.
- Having a lack of information about deceased organ donation but still supporting it in principle.
- The relevance of trust in the NHS and its procedures for defining death and allocation of organs for transplantation.
• The importance of knowledge of social, cultural and religious norms and social networks for the organisation and the planning of content for community events.

RESEARCH POPULATION

• There is very little research discussing the settlement patterns and community formation of the Polish community in the UK (ref). This is one the first research studies that presented some settlement context for the Polish community. Research finding give a clearer picture of Luton and Dunstable Polonia that was not WRS or NINO based, but is from a Polish perspective from people living in the area.

• A significant contribution to the literature on migration histories of the Polish community in the UK.

• The study offers an insight into the experiences of the Poles in Luton and Dunstable in relation to living in the area from the perspectives of social capital, religion and helping others.

• The experiences of living in Luton and Dunstable as a Polish migrant and one’s ‘community’ in evoking organ donation.

• The study provided the basis for comparing the Polish community with other migrant communities/settlers in the UK as and provides a basis for comparison of access and utilisation of health care services.

KEY CONTRIBUTIONS

The most important contribution that the thesis has made is the use of social capital theory in relation to deceased organ donation as this had not been analysed together before as most emphasis had been placed on Mauss's gift exchange theory. However, by taking into account social capital in the deceased organ donation debate it widens it to include
reasons why people would give organs, particularly migrants where other considerations such as sense of belonging and trust in governmental institutes should be considered.

In addition to the use of social capital as contributing to the body of knowledge on deceased organ donation, are the findings of the Polish migrant population and new information about the way in which deceased organ donation is conceptualised from their perspective. This contributes in a practical way for healthcare professionals to regard the findings of the study when having conversations about organ donation with Polish migrant families.

This thesis contributes towards increased cultural awareness of the Polish migrant community and their attitudes toward deceased organ donation which could have some bearing on the clinical environment by improving cultural competency when approaching Polish migrant families. Overall, the thesis has contributed toward a further understanding of understanding diversity as Polish migrants have been a neglected group in discussions and conversations around organ donation. A limitation of the NHS Organ Donor Register and active waiting list is that data on race and not ethnicity is collected and it could be problematic to assume that everyone who is 'White' is White British and not to include White ethnic minorities.

6.3 Constraints

There were a number of constraints to this study, a number have already been discussed. An additional constraint however, was my lack of knowledge in the area of deceased organ donation, gift exchange and religion before I embarked on this PhD studentship and had very little personal experience with organ donation or the Polish community. Although this was a constraint, it could be argued to be a strength because
I began the study without any preconceptions and had an open mind in terms of the direction that the study could take. However, this multi-disciplinary approach has allowed me to view the relationships between deceased organ donation, gift exchange and religion from many different perspectives whilst deciding on the most appropriate stance to take. This wide range of reading across many fields has been challenging but was helped by detailed audits trail.

The thesis took a constructivist grounded theory perspective and the biggest challenge to taking this approach was the involvement of translators, having transcripts translated and not being able to hear first-hand what the participant's had said. Although measures were taken to overcome this, as I had a whispered translator, I lost the way in which the participant phrased their views in their own language however the interpreter tried as best she could to translate closely to the words used. This was one of the biggest limitations to the data collection as I was unable to use in vivo codes, where codes are direct quotes from the participant.

Another constraint of the study was the sample as I had restricted the geography to the Luton and Dunstable area, where there are unique characteristics to the area such as London Luton airport, University of Bedfordshire and being close to London. The Poles in this area had not been involved in academic research before, meaning that I had significant barriers to overcome. If I had involved a wider geography, such as London, there are Polish organisations that have been involved in research previously and this may have made it easier to recruit participants. I would have been able to explore experiences of Poles living in the city and those who chose to live within the proximity of London. There may have been significant differences in social capital issues such as sense of belonging, what the term ‘community’ meant, experiences of living in the UK and trust
in strangers and the NHS. However, by restricting the geography of the sample group, I have been able to consider factors that relate to Luton and Dunstable in my analysis, such as the local facilities, demographics and Polish history of the area; therefore there must be caution when applying it to the wider Polish migrant community in the UK.

In addition to the geographic location of the sampling, there is a constraint to this study based on the number of females who took part in this research. This could have occurred for a variety of reasons, for example, I am a young, female and perhaps others who were 'like me' were comfortable talking to me. This is supported by Ritchie and Lewis (2006) who argued that feminist researchers claim that there may be an affinity that exists between women interviewers and participants. This is also argued to be the case for interviewer and participants being of similar ethnicity, which affected the non-English speaking part of the data collection. Having 22 out of 31 of the participants being female may have skewed the findings in terms of ethical reasoning and perhaps views and experiences of helping and giving gifts to others.

The sampling strategy used was limited as I focussed on different groups within the Polish community but did not encompass the views of significant gatekeepers formally, in that the meetings were logged through making notes rather than recorded and transcribed. When I did speak to two key gatekeepers, I had focussed on aspects that related to them, such as when I spoke to a key informant, a Polish priest (See Appendix Thirteen), I discussed religion in detail in relation to donation and the Polish migrants who attended the church, but did not widen my discussion to encompass his views on all areas of the study. I think it would have been beneficial to have had the key informants' perspectives on key aspects of my study as they are 'experts' in their areas and would have been able to contribute
toward the development of the model or to provide detail to better contextualise or contrast some of the views held by the lay persons.

Finally, I did not capture the number of donors and non-donors who took part in the study and in hindsight this could have added to the study. Having this information could have added to the analysis in terms of the participants' donor or non-donor status and how it linked with their overall attitudes, for example if the majority were donors could explain the general positive attitude toward donation. I did not add this to the study originally as my main aim was not to focus on the instrumental aim of donation through increasing donation but purely to examine the perceived relationship between deceased organ donation, gift exchange and religion.

6.4 Directions for Policy: Grass-Roots Approach to Increasing Awareness through Social Networks

In deceased organ donation, social networks have a dual purpose, they can be a source of information about donation and for the health care professionals to find out next-of-kin details if individuals are migrating to the UK with their friend or relative as well as being a way of disseminating information.

Taking a grass-roots community-led approach to accessing local social networks to increase awareness about organ donation is not a unique idea. Increasing knowledge has been done on a community level within schools (Cantarovich et al., 2000; Reusbeut et al., 2001, 2004, 2011; Piccoli et al., 2004; Milaniak et al., 2010) and faith groups (Callender et al., 1995, 1997; Miles and Callender, 1997; Clarke-Swabey et al., 2012; Jotkowitz, 2004). NHS Blood and Transplant have supported community events as described in the introductory chapter.

Utilising established community social networks to disseminate information used to shape social norms and constructs through updating
social constructs is a method that Darr and Randhawa (1999) found in their study of organ donation among the Asian community in Luton. However, as Cramp (2012) argued, the way in which the NHSBT is raising awareness in ‘communities’ currently is not relevant to the individuals. Therefore the social, cultural and religious norms should be addressed at these community events to ensure that the messages are framed in a relevant context.

It was found that there was lack of consensus of the definition of ‘community’ therefore it cannot be assumed for example that Polish people are homogenous and unite because they share the same ethnic identity and religious background; it has been found this ethnic group are heterogeneous. There are many smaller communities within Luton and Dunstable Polonia that have formed based on shared identities such as reasons for coming to the UK. Appealing to ethnic groups therefore, may have its limitations as opposed to appealing to smaller ‘community’ groups that share identity where their values and attitudes may be similar. The confidence that the public have in the organisation of organ donation links with the findings in this study of trust towards the NHS. In addition, Poles are more accustomed to speaking to specialists as opposed to general practitioners in the context of community activities, therefore local SN-ODs and CLODs and potential organ recipients could be involved in raising awareness as they all have direct experience in organ donation and transplantation.

More needs to be done to increase levels of awareness within the Polish community and it is suggested that a grass-roots community-led approach is taken. However, as social capital has been a theme running through this thesis, the limitations of accessing social networks is acknowledged. Campbell and McLean (2002) researched the impact of ethnic identity on participation in the African-Caribbean community in health promotion.
events through the lens of Putnam's social capital theory in a multi-ethnic South England town. They suggested that some health promotional strategies do include community participation in three forms: community representatives aid design and implementation of health services; local people participate in projects to improve health and local neighbourhood groups should participate in local community networks.

Campbell and McLean (2002) found that African-Caribbean people were more likely to have inter-personal networks and had integrated into the local neighbourhood. Obstacles to community participation were experiences of social exclusion and African-Caribbean viewed their community to lack cohesiveness as opposed to the Asian community where there were perceived solidarity. Lack of solidarity and collectiveness is similar across the Polish community as found in this study as inter-personal networks are more common and group membership was also low, a factor of social capital that Putnam (2000a) heavily emphasises. Campbell and McLean (2002) suggest that obstacles to participation in community networks are acknowledged and also that local community participation could be undermined by the way that ethnic identity is constructed within the context of British society.

There would be challenges to accessing the Polish community as there are few formal organisations, particularly in the Luton and Dunstable area and this was evident when trying to recruit participants for the study. As found in Campbell and McLean's (2002) study, Polish and African-Caribbean migrants have small and informal networks. Deciding upon the content of the event, the level of appropriate information to lead to informed consent when considering deceased organ donation and the involvement of local organ donation professionals and patients could be argued to be further practical issues of these community events that can be tackled by understanding the social, cultural and religious norms of the community.
RELIgIOUS ORGANISATIONS AND RAISING AWARENESS

In this study, religion was viewed to play a little role in donation, however within the Polish community the Polish church is an important formal organisation and could be a platform for discussing donation with this community.

Vincent et al. (2011) suggested that religious leaders could be advocates for donation, as all major denominations of religion support donation. However, this may be problematic. Religious leaders could discuss organ donation with their congregation, however, the topic may not be viewed as a priority according to Randhawa et al. (2010b). The key part of the conceptual map in the present study was the way in which the body was viewed and that this could be shaped by religion. Therefore, religious leaders could give information about the body after death in relation to deceased organ donation for not only one religion but all major religions to illustrate that there is not the onus on only one religious group to consider organ donation. Plus information about how the body will look after transplantation, the idea of the person 'living on' in another person, funeral arrangements and death rituals post-transplantation and the support that the church could give at this time.

Many participants in the present study said that strong figures such as priests have a strong influence in the formulation of public opinions. The role that religious leaders play in increasing awareness of organ donation is however challenging as generally participants did not view them to be relevant as it is a personal or hospital issue. Jakubowska-Winecka et al. (2006) found that 87% of the participants in this study were willing to donate upon death, those that did not support organ donation associated it with injury and psychological trauma leading to avoidance behaviour, not wanting it discussed in church. They also did not want the Catholic Church to discuss the topic in classes, sermons or in any other place. Those who
supported organ donation, had an ‘open approach’ (p.12) to it, had
discussed it with their family and believed that the Catholic Church should
advocate donation as a form of helping one’s neighbour. From the health
provider’s perspective however, religious leaders are the ‘cultural brokers’
and this is the link between the faith group and the outsider that I
discovered in my fieldwork. It had also been found that organ donation was
seen to be a ‘hospital issue’ as opposed to a subject that was discussed in
church as it was not viewed as a religious issue.

Social constructs refer to the understandings of the everyday world and on
the processes of how these are shaped. Family discussion is important as
this has an impact on family consent levels and is a source of socialisation
that shapes social constructs through interpersonal and social
communication as a source of information.

6.5 Directions for Policy: Using Mass Media to Increase
Awareness

To overcome some of the challenges of grass-root community-led events,
the mass media could help increase awareness about organ donation,
however follow-up information should be available in Polish.

There have been previous studies that have used social representation
theory in relation to organ donation. Moloney and Walker (2000a, 2000b,
2002), Lauri and Lauri (2005), Lauri (2009) and Morgan (2008) have
suggested the significance of mass media in the shaping of social
representations. Moloney and Walker (2000a, 2000b) found that social
representations toward organ transplants were significantly influenced by
the mass media and information campaigns (Lauri and Lauri, 2005).
Morgan (2008) connected interpersonal conversation, perceptions within a
community and mass media campaigns in her view of social representation
theory in organ donation. She highlighted from her study the difficulty in
trying to change social representations once established, something that Moscovici had highlighted as a limitation of social representations. This is something that Kenten et al. (2011) raised, although this was from a Bourdieu perspective, in that habitus can be changed, but this takes time. However, this is contradicted by the ‘transformation’ stage of representations which keep representations fluid and flexible, shaped by new experiences and information. Sanner (2006) illustrated by improving facticity, facts should be emphasised which can reduce underlying fears and misconceptions about organ donation. For example, a corpse does not feel anything and people’s lives can be saved through organ transplantation. In addition it has been found that there needs to be confidence from the public in the organisation of organ donation (Strenge, 1996; Cohen and Wight, 1999; Lloveras, 1999).

What can be learned from the above and findings of this study is the important role of mass media in shaping individuals’ perceptions and attitudes. This has been highlighted in the present study, but not as key constructs within the conceptual map. The previous work on viewing organ donation through a social representation lens has purely focussed on organ donation and not the aspects that are taken into account in this study, illustrating why the results differs significantly.

Moloney (2001) evaluated mass media contributing toward social representations of organ donation and found that media is influential in providing a context of donation for the lay person. It was thought by some participants that mass media negatively portrays organ donation and that some people may use films and television as a source of knowledge and information about the topic. The film ‘Seven Pounds’ (2008), a film where an individual commits suicide to donate his organs, was cited a number of times by participants. Generally it was found that Polish people do not access the British media where most advertisements were aimed at the
recent organ donation campaign. When discussing reaching the Polish community, it was suggested that local Polish magazines could be used for providing information about organ donation, also cinemas as Poles generally do not own TV and Facebook. Facebook is currently being utilised by NHSBT (NHSBT, 2012), however this is in English and that may limit who has access.

The campaigns currently are not giving the participants enough information and more was needed. The poster and television element in the recent organ donation campaign showed individuals who were transplant patients. It may be argued that this most recent campaign focuses on the transplant aspect of organ donation as opposed to the donor. It may be seen to be linking with ‘fear appeal’ (Janis and Feshbach, 1953), that organ failure can happen to anyone and guilt that this is happening to people and only a small percentage of the population are helping. According to Burnett and Wilkes (1980), fear appeals are little help. Wang (2011) focussed on anticipated guilt in donation and found that guilt can turn to empathy and family discussion (Basil et al., 2008; Lindsey, 2005).

Mass media may not be currently used to its fullest potential in prompting family discussion, changing social norms, as they are fluid, and raising awareness about deceased organ donation. It may be used to create a culture where donation is the norm, which is how the media is utilised in Spain. The Spanish donation system currently has a high conversion rate of donors. In the Spanish mass media, positive stories are featured regularly and transplant coordinators are media trained (Matesanz, 2001) as negative stories can create the ‘Panorama effect’ where there was controversy around brain death in the 1970s (ibid). Quick et al. (2007) reinforces Matesanz’s finding and argues that there is a link between media and organ donation rates, meaning that the media does have an
impact on views towards donation. Morgan et al. (2010) analysed television story lines and found that those who had already decided to donate were not influenced by the stories but those who were not donors were significantly influenced by negative organ donation stories. Lauri and Lauri (2005) found that from a social representation perspective, before the campaign, donors were perceived to be young but after a campaign, donors were seen to be generous and educated people. Non-donors before the campaign were seen as uncaring and after the campaign were believed to be uninformed, older and uneducated. Also, individuals may feel compelled to help another if they are more aware of the issue, this has been found by Bennett and Savani (2003), who found in their study of English and Pakistani communities, that knowledge about donation was linked with altruism.

Having these reminders and prompts could also keep organ donation ‘fresh’ in individuals’ minds and perhaps encourage them to find out more about the subject or make a decision about it. Evoking family discussion would be a measure of success (Southwell and Yzer, 2007). These prompts should be relevant to the individual, in the case of the Poles, it was suggested by the participants that to reach the Polish population, advertising should be done at the cinema because many did not own a TV or watch British programmes, information could be displayed on billboards, prompts could be on social networking sites which could be endorsed by Polish celebrities, perhaps soap celebrities as this is what happens in Poland. In Australia, Hyde and White (2009) found that having a prompt, such as the media, about registering to donate could also act as a cue to discuss organ donation with the family. The NHSBT Organ Donation website could be better utilised as presently there is no information on the organ donation in Polish and there is no data on how the Polish migrants are represented on the waiting list in relation to the Organ Donor Register. Through personal communication with the Department of Health’s
Transplant department, I found out that there is a reciprocal agreement in terms of paying for organ transplants between Poland and England. This means that if a transplant occurred in England, the Polish government would pay for it. For Polish migrants, if a Pole wants to donate in the UK one must join the register and de-register when leaving (Evans, 2011).

6.6 Future Research

There are a number of areas for future research;

- The conceptual map may be tested among different ethnic groups to gain a further insight into differing social constructions.
- To examine the conceptual map with Poles living in different areas of the UK, a nationwide study or a different ethnic minority group.
- To test the conceptual map in a quantitative form using scales and to compare this with the qualitative results for religiosity, social capital, altruism and organ donation.
- To do further investigation into the influence of ethnicity, religion and culture in relation to views towards the body and cultural practices of death and organ donation.
- To do further research on the lay perspectives of the Maussian gift and altruism in deceased organ donation and compare these to health care professional views.
- To research the role of the mass media in the formation of social representations toward organ donation amongst Poles in the UK.
- To explore the term ‘community’ in relation to social capital and deceased organ donation.
- To examine further the use of the words gift and altruism in policy and health campaigns for deceased organ donation.
- To explore normative influences on deceased organ donation amongst Poles in the UK.
• An examination of views toward living donation in relation to gift exchange theory, social capital, altruism and religion.

• To investigate spirituality and deceased organ donation from a religious perspective in relation to the meaning of life and views of the deceased body.

• To evaluate the experiences of Polish families in the UK who have donated their relatives' organs.

• Further research on the causes of death of Polish migrants that result in deceased organ donation and the extent to which accidents at work and poor health and safety contribute.

• Experiences of approaching Polish and East European migrant families from a Specialist Nurse in Organ Donation's perspective to understand further reasons for family consent and family refusal.

• To further examine the role of social capital and health across Polish migrants in the UK.

6.7 Conclusion

At the outset of this journey, examining the relationship between deceased organ donation, gift exchange and religion appeared logical and straightforward through the hypothesis that religion supports helping others and one form of this is organ donation. Through the literature, this simplistic view began to get more complicated whilst becoming more immersed in the theoretical debates for example, the definition of the terms ‘gift’, ‘exchange’ and ‘religion’.

Once the epistemological, ontological and theoretical perspectives were decided upon, these debates started to become clearer through a constructivist lens. Throughout the fieldwork, some themes had arisen that I had not found in the literature whilst others had been found prolifically in previous literature. Over the course of the interviews and group interviews, I began to develop the Polish context for the conceptual map.
Little was previously known about the Polish community in Luton and Dunstable, there were indicative statistics through the Luton Council and local media and signs of settlement through the rising visibility of Poles and the number of Polish shops. This study gained an insight into what it was like to live in Luton as a Polish migrant, what the Polish 'community' was like, what role religion played in their lives and their perspectives on altruism and gift giving. This provided the backdrop for the conceptual map.

The conceptual map demonstrated the interrelationships between deceased organ donation, gift exchange theory and religion from a Polish perspective. There were a number of key findings that emerged through this conceptual map, for example, the significance of social, religious and cultural norms in shaping perceptions held toward deceased organ donation and the body. As a result of these findings, it was suggested that views toward organ donation were shaped through mass media and social norms within the 'community' as there was found to be a lack of knowledge towards organ donation and mixed levels of family discussion. The findings of the conceptual map could also help shape the mass media messages as health care professionals will be aware of the different constructs of organ donation, the gift, the body, religion and social capital.

The aim of the thesis was to examine the relationships between deceased organ donation, gift exchange and religion. This thesis shows that these relationships are intertwined, interdependent and complex. Overall, the role of gift exchange, altruism and social capital in relation to organ donation is that donating is viewed as an altruistic act, but to further engage Poles, a reward may play a significant role. It was predicted that the social effects of gift exchange, civic engagement and helping the collective would play a significant role in deceased organ donation. This study shows that motivations vary in donation, but generally organ donation was
viewed as a way of helping the collective on a humanity level as opposed to societal although it was noted that the limitation of this was that the exchange and benefits are on an individual level. In terms of the role of religion, there was a variety of strengths of religiosity across the participants and overall religion was not viewed to play a significant role in organ donation. However, indirectly, it had an impact on the way the body was viewed in terms of the body not being needed after death and general teachings of religion to help and love others was in line with Catholic tenets. In terms of what can be learned about engaging the Polish community, organ donation specialists should be available at community events to give information about organ donation and the mass media can play a role in prompting family discussion through positive stories on donation and transplantation.
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Appendices

Appendix One: Tables of Organ Donation Studies
## Religiosity and Organ Donation

<table>
<thead>
<tr>
<th>Authors and Date</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morse et al. (2009)</td>
<td>Mixed methods with self-reported behaviour measured on Likert-scales with a national sample of 972 participants in the USA, predominantly White, and personal observations with 72 participants of an individual with a next-of-kin</td>
<td>They aimed to explore the link between religiosity, as defined by Allport and Ross (1967), and organ donation and found that individuals' religiosity is positively correlated with anxiety, influencing ways in which family views are sought on organ donation and the perceived relation to one's organ donation decisions.</td>
</tr>
<tr>
<td>Stephenson et al. (2008)</td>
<td>A survey approach with 4,426 participants</td>
<td>With the aim of exploring the role of religiosity, as considered by Allport and Ross, and religious norms when becoming an organ donor, they concluded that attitudes towards donation were weakly linked with religiosity however there was a strong link between bodily integrity, where the body is believed to stay intact upon death, and the willingness to donate.</td>
</tr>
<tr>
<td>Rumsey et al. (2003)</td>
<td>Organ Donation Attitude Survey (ODAS), with 190</td>
<td>This study explored the influence of religiousness, but not in Allport and</td>
</tr>
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</table>
undergraduate students Ross’s terms, and knowledge on attitudes to donation, it found that the role of religion was linked with the level of church attendance and if their religious community and religious leader were perceived to support donation.

Table 7: Religiosity and Organ Donation

**Ethnicity and Organ Donation**

<table>
<thead>
<tr>
<th>Authors and Date</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Al-Khawari et al. (2005)</td>
<td>Observed and interviewed 141 UK Muslim Indo-Asians in West London</td>
<td>It emerged that Muslims believed the body was sacred and the organs acted as ‘witnesses’ on Judgement Day, which led to unwillingness to donate organs</td>
</tr>
<tr>
<td>Exley et al. (1996)</td>
<td>Interviewed 22 participants from the local Sikh community in Coventry, UK</td>
<td>Sikhism is concerned with helping others and organ donation was seen as a way of expressing altruism. There were concerns about the body being cut up and mutilated and missing organs may have an impact on the reincarnation process. Few participants were aware that Sikhism supported organ donation as they...</td>
</tr>
<tr>
<td>Authors</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Ahmed et al. (1999)</td>
<td>A structured questionnaire that was asked in person to 100 South Asian adults in Southall, Middlesex. The majority of these participants were Sikh, Hindu and Muslim</td>
<td>They found that it was commonplace to be aware of organ donation, forty per cent knew someone on renal dialysis and eleven per cent knew someone who had received a transplant. Religion played a role for seven respondents in becoming an organ donor and six of these were Muslim as they were unsure whether their religion supported transplantation.</td>
</tr>
<tr>
<td>Sheikh and Dhami (2000)</td>
<td>25 British Muslims in London to complete a questionnaire</td>
<td>They found that the large majority felt that Islam forbade organ donation, they felt the body was sacred and is owned by God and only God can make decisions about the body, as organs act as ‘witnesses’ as they did not want someone to ‘contaminate’ their organs with pork, alcohol or cigarette smoke.</td>
</tr>
<tr>
<td>Jindal et al. (2003)</td>
<td>A questionnaire among the Asian community in Glasgow</td>
<td>Many were unsure of their religion’s stance on donation and religious leaders were seen as instrumental in raising awareness.</td>
</tr>
<tr>
<td>Randhawa (1998);</td>
<td>Eight focus groups and 64 individual interviews</td>
<td>Many did not know what stance their religion took on organ donation and...</td>
</tr>
</tbody>
</table>
Darr and Randhawa (1999) based on a questionnaire, with the Asian population in Luton who were Hindu, Sikh and Muslim few had heard of the ‘fatwa’ that allowed it. Those who were of Sikh faith were confident that their faith supported it. Only two out of thirty two Muslim participants were aware of the ‘fatwa’ passed by the Muslim Law Council in 1995 that allowed organ donation. The Muslim respondents were found to rely greatly on religious doctrine to inform their decisions on organ donation. They found that other reasons for uncertainty were lack of knowledge around transplantation procedures and the appearance of the body before the burial. Darr and Randhawa (1999) extended their analysis on this research and found that community networks were important in disseminating information and sharing experiences about organ donation.

<p>| Hayward and Madill (2003) | This study used a grounded theory method and conducted four focus groups in the North of England with Muslim men and women and White men and women, these groups were split by | They found that organ donation was viewed to have a cost to the individual, Muslims of Pakistani origin perceived these costs to relate to their religious beliefs such as ‘meddling with natural order’ (p.393). However, White English participants suggested that personal cost is their |</p>
<table>
<thead>
<tr>
<th>Gender</th>
<th>Distrust in the NHS.</th>
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</thead>
<tbody>
<tr>
<td>Davis and Randhawa (2004)</td>
<td>Eleven focus groups with Black Caribbean and Black African individual living in Lambeth, Southwark and Lewisham (LSL). They found that there was a general lack of awareness about organ donation and information was not easily available. There was a level of superstition, mistrust and fear for the majority of the participants that if someone carried a donor card, they would not have their life saved. Stories in the media had negatively affected their trust towards health care professionals in the NHS.</td>
</tr>
<tr>
<td>Morgan et al. (2006)</td>
<td>Questionnaire completed by 1536 respondents across four general practices in South London by Black Caribbean, Black African, Indian, Pakistani, Bangladeshi and other Asian groups. Religion, particularly Islam was related to concerns of bodily integrity. Muslims perceived organ donation to be disrupting the dead. Many were unwilling to donate outside of the immediate community.</td>
</tr>
<tr>
<td>Morgan et al. (2010)</td>
<td>Questionnaire based approach which included 327 participants in Barbados, 338 Black Caribbean migrants and 805 White participants at three private general practices in South London. They found that those from Barbados were positive about deceased organ donation due to the informed consent policy. However, those from south London had mostly negative attitudes due to social disadvantages leading to feelings of marginalisation and low sense of belonging.</td>
</tr>
</tbody>
</table>
Radecki and Jaccard (1997) critically reviewed the literature on organ donation from a psychological perspective and suggested that religious beliefs, cultural beliefs, knowledge beliefs, altruistic beliefs and normative beliefs all influence an individual’s attitude towards becoming a donor which, in turn, influences their willingness to sign the register. They found that religion was viewed as a barrier to donation, particularly for Jehovah’s Witnesses and Orthodox Jews. Those who have open casket burials were thought to not donate due to fears that donation will delay funeral proceedings and the absence of organs will influence the individual’s quality of afterlife. Cultural beliefs according to the reviewers included levels of knowledge about donation, awareness of the need for organs, trust in medical establishment, concerns about one’s life not being saved, not assuring specified recipients and a lack of communication between the families and the healthcare professionals. They also suggest that transplantation is not supported by Asian cultures due to superstition in everyday life, death anxiety, the need for body totality and the belief that Asian religions do not support donation.

Table 8: Ethnicity and organ donation
Appendix Two: Letter to the Priest
Rev. Czeslaw Osika S.Chr.
17 Victoria Street,
Dunstable,
Beds,
LU6 3AZ

Dear Rev. Czeslaw Osika S.Chr.,

Firstly I would like to thank you for taking the time to read this letter, I appreciate how valuable your time is.

I am writing to you with reference to my PhD student, Chloe Sharp who is carrying out a study into the views of the Luton Polish community of organ donation, religion and helping others. The aim of this study is not to increase or promote organ donation among the Polish community but to find out more about their opinion of it.

Currently there is a large shortage of organ donors and there are a number of reasons why this may be, from being unaware of the option of donation to a concern that health care professionals may not try to save one's life.

There has been extensive research into South Asian, Black African and Caribbean and White British communities in the UK; however there has been very little research into the East European and Polish community. Since 1995, I have conducted several studies into the views of the South Asian community in Luton which has directly impacted Health Policy, Chloe aims to have a similar result with the Polish community.

Luton has been chosen as an ideal location for carrying out this research due to the diverse Polish community, which includes those who have recently arrived in the UK as well as generations that established the community after the Second World War.
Religion often plays a key role in a person's perspective of organ donation and studies have shown that religious teachings can differ greatly in their approach to donation. Some inspire helping others, meaning a positive approach to organ donation, whilst others have concerns about the effect on the body in the afterlife. This study aims to give more information about how the Polish community view the connection between religion, helping others and organ donation.

We would very much like to meet with you to get your advice and insight into how we could involve the local Polish on the mornings of either the 1st, 2nd or 3rd June 2011 at your Church?

Chloe will call you on Monday 30th May to confirm, alternatively you can reach me at gurch.randhawa@beds.ac.uk.

Yours sincerely

(Signed)

Professor Gurch Randhawa
Appendix Three: Recruitment Poster
Czy jesteś z Polski?

Czy byłbyś zainteresowany wzięciem udziału w badaniu?

What do I need to do?
You would need to take part in an interview about your views on organ donation, religion and giving gifts and how you think they link.

Why is it good for me to take part?
You will be given a £20 voucher for taking part to spend at any shop in the Luton Mall Shopping Centre. The information from the study will help the NHS and me understand more about organ donation, religion and gifts.

Where?
It will take place in Luton.

Do I have to be religious?
No, you can take part if you do or do not follow a religion.

What if my English is not very good?
I will arrange for a translator to come along or you can bring someone to translate for you.

How long will it take?
The group discussion will take between 1-1 1/2 hours.

For further information or to volunteer for this study, please contact
Chloe Sharp - chloe.sharp@beds.ac.uk
Czy jesteś z Polski?

Czy byłbyś/zalazergować zainteresowany wzięciem udziału w badaniu?

**Jak wziąć udział?**

Must zgłosić się na spotkanie naukowe przeprowadzające dyskusje o poglądach związanych z: pośmiertnym oddawaniem narządów, logiką kryjącą się w teoriach wymiany prezentów, religią.

**Po co brać udział?**

Osoba która weźmie udział w badaniu otrzyma bon towarowy o wartości £20 do wydania w Centrum Handlowym Luton Arndale, po zakończeniu spotkania. Zebrane dane pomogą NHS rozumieć więcej o tym co Polacy myślą odnośnie pośmiertnym oddawaniu narządów, religii, sprawianie innym prezentów.

**Gdzie?**

Spotkanie odbędzie się w Luton.

**Czy muszę być osobą wierzącą?**

Nie. Osoby każdego przekonania religijnego mogą włączyć udział.

**Co jeśli nie znam języka angielskiego?**

Dla osób potrzebujących tłumacza, będzie tłumacz lub możesz przyjść z kimś który mówi po angielsku.

**Jak długo trwa spotkanie?**

Rozmowa potrwa między 1- 1½ godziny

Jeśli jesteś zainteresowany obranie udziału w tym badaniu naukowym i chcesz uzyskać więcej informacji na temat badania, proszę skontaktować:

Chloe Sharp - chloe.sharp@beds.ac.uk
Appendix Four: Interview Guides
Interview Guide I

Polish migrant's experience

- Why did you decide to come to Luton?
- Do you like or dislike living in Luton? Why?

Altruism and gift exchange

- What does the word 'gift' mean to you?
- Why do you think people give gifts?
- Why would you give a gift to someone you didn't know?
- Why would you help someone you didn't know?

Religion

- What role has the Church had in your time that you have been in Luton?
- Tell me about the role that religion, God and the Church play in your life generally.

Religion, gift exchange and altruism

- How do you think religion and helping others you don't know are linked?
- How do you think religion and giving gifts are linked?

Deceased organ donation

- What have your experiences been of the NHS since you've been in Luton? (Doctors? Hospital?)
- Do you agree or disagree with the use of technology in medicine, for example, helping women have children and growing cells for bone marrow transplants?
- What do you know about organ donation and transplants?
Where did you learn about organ donation?

In your view, do you think there is a high demand for organ donation and transplants?

What concerns do you have about organ donation?

Deceased organ donation, altruism and gift exchange

Do you think there is a link between that organ donation after death and gift giving and helping others?

Would you give your organs after you've died? Why?

Would you mind who your organs would go to? (If yes, why?)

Do you view organ donation as giving a gift that without wanting anything in return? (If no, why?)

Does giving organs to others influence community spirit?

How do you think the recipient would feel about receiving a donated organ? (Why would they feel good? Why would they feel bad?)

Where do you think an organ recipient would want their organ to come from? A person who has just died? A living person? An animal? An artificial organ?

Religion and deceased organ donation

How does your religion view organ donation?

Do you think that your faith would influence whether you would be a donor or not?

What role, if any, do you think the Church should play in relation to organ donation?

Religion, altruism, gift exchange and deceased organ donation

To summarise, you have mentioned that organ donation, helping others and giving gifts are linked by.... you have also mentioned that religion's
view on organ donation is... and religion's view towards helping others is....

Overall, how do you think they all link together?

Statements

I am now going to show you some statements and I want you to tell me whether you agree or disagree with them:

• The body is a gift from God and it is possible to give parts of the body to others when someone dies.
• Helping others by donating organs will be rewarded by God.
• I am scared about death and dying.
• The body and soul separate upon death, so organs can be given to those who need them.
• If someone dies because their brain is dead, meaning no oxygen or blood is going to their brain, but their body is being sustained by machines, they are able to donate organs.
• The body needs to be whole when someone dies for a successful Resurrection.

Any other questions or comments?
Interview Guide II

Polish migrant's experience

• What do you think attracts people from Poland to live in Luton? (Why did they move here?)

• Can you tell me a little about who makes up the Polish community in general who live in Luton? (Students, families, people here for work)

• Overall, have you had negative or positive experiences of living in Luton?

Altruism and gift exchange

• Would you give your time and money to someone you didn’t know? (Volunteering? Giving money to charity?)

• Can you tell me about gift giving in Poland compared to the UK? (Or other cultures you've experienced in the UK? Such as Indian or Pakistani?) Towards strangers?

• What do you think motivates people to help others they don’t know? And giving gifts?

• What do you think deters people from helping others they don’t know? Giving gifts?

• Do you think that people always expect something back when they help someone or give gifts? (Why?)
Social capital and altruism

- Can you tell me about some of the groups that you belong to? (People in your neighbourhood? People in the same job? Family? Polish friends? Friends from other ethnic backgrounds? Church-based groups? Virtual groups such as on Facebook?)

- Which group do you feel you are closest too and feel part of the most? Do you see and speak to them often? Within this group do you help each other?

- Which group do you feel you feel the least close and part of? Why? Do you help each other? Do you speak to them often?

- Do you feel that if you help each other within your family and close friend groups that you would help others you wouldn’t know? Or is helping down to the person and situations?

- Met a lot of people through travelling/those kind of life experiences, meet lots of people – does that make you feel you belong?

Religion, Religiosity and Spirituality

- Tell me about the role that religion, God and the Church play in your life generally (How often do you go to church? How would you explain your relationship with God? What role does God have on everyday decisions? Have your religious views changed over time or since you’ve been in Luton? Why is religion important to you? Do you go on pilgrimages? Would you say that you are part of the religious community in Luton?)
• Do you feel that the religion is changing within Poland? Polish people living in the UK? (Church attendance? Polish people going to English Catholic churches? Differences between English and Polish Catholic traditions?)

• How do you view the meaning of life? The meaning of death? Views towards the Resurrection and afterlife?

Religion, Culture, gift exchange and altruism

• Some studies suggest that people who are religious are more likely to be generous and want to help others or give gifts, that they do not know, do you agree? (Such as giving time or money or donated items like clothes or food. What about the role of religious teachings such as The Good Samaritan or helping others as an ‘act of love’ that may be taught at school or church, do they influence whether people are helpful? Is helping others rewarded in any way by God? How? How are these things taught in relation to family upbringing and school? Is helping others part of being a ‘good’ Catholic?)

• Do you think that helping others or giving gifts is part of Polish culture perhaps instead of being linked to religious teachings? (Why? How is it tied into customs and traditions?)

• Do you think that whether people would help others has changed over time in Poland and in the UK since you’ve been here? (Globalisation, Westernisation)
Deceased organ donation

- Can you tell me what you know about organ donation and transplants? (Which organs are removed? What happens with these? Where did you learn about this? Do you know anyone has personally had experience of organ donation?) *Organs that are donated can be lungs, heart, liver, kidneys, small intestine, pancreas and corneas and can help up to 6/7 people*

- Do you know how to become an organ donor after you die in the UK? Poland? (Would this way of signing up encourage or discourage people to register?) If organ donor in Poland, would you be an organ donor in the UK?

*Donating in the UK – you can sign up when you apply for a driving license, a Boots advantage card, register at a doctors or through the organ donation website. (You would need to opt-in whilst in the UK and then opt-out when you left.)*

- Have you seen any of these? Do you have to update your drivers license when you are in the UK?

*The process in the UK is different from that in Poland, in the UK, you have to choose to sign up to it, but in Poland, you have to sign out of it.*

- Why do you think people would sign up to donate their organs after they have died in the UK?
- There is a large demand for organs and many individuals die waiting for them, why do you think that people do not donate an organ in the UK?

In Poland and in the UK, the families are always asked and it is their decision whether the organs are donated or not. If the family knows their loved one’s wishes, it may make their decision a little bit easier.
• How do you feel about this? Is organ donation something you have spoken about with your friends or family? What do your parents and grandparents think of it?

• How do you think that movies and the press have influenced people's views on organ donation?

• Have you thought about finding out more information about organ donation?

Deceased organ donation, altruism and gift exchange

• Earlier we spoke about gift-giving, would you consider an organ to be a gift? Why? What is it a similar gift to? (Is organ donation when someone giving an organ when they are living a different type of gift than when a family donates an organ of their loved one? Is it a gift if organ donation is presumed? If an organ is not a gift, how would you describe it? (charity, generosity, sacrifice)

• Is helping others, in terms of what you said earlier about volunteering or giving money to people you don’t know through charities for example, is this similar in any way to giving organs? (Are there different forms or levels of helping others? Are the reasons why people give organs to help others for different reasons?)

• Is the person who died altruistic or is it their family or both?

• There are not enough people donating organs, there are long waiting lists for people who have organ failure and need a
transplant. Do you think that altruism is enough to base organ donation on?

• What difficulties do you think the family face in relation to organ donation, when they are asked about it? (Timing? Loved one being physically part of someone else? The parts of their loved ones are living in other people? Whether they know whether it is what the person wanted? Many people taking part in the decision?)

• Have you seen the UK or Polish organ donation campaigns? How do you think they could be better?

*Explain about gift exchange theory – a cycle of obligation to give, receive and reciprocate – show them the card with this figure on.*

• Do you think that people may be obliged to give organs? The recipient obliged to receive them? Would they always want it? How to reciprocate to the family?

• How do you think that the cycle of exchanging gifts links with organ donation when someone dies? (from the family’s perspective, the recipient’s and the recipient’s family perspective? Donor when they are alive – feel better about themselves? Pay it forward, help others as they or their loved one has been helped)

• Some studies suggest that people who register as organ donation should be repaid, how do you feel about this? (Such as getting priority on the organ waiting list?) What if the family was repaid by receiving help with funeral costs? Is signing up as an organ donor a way of repaying them? Would it make a difference to the recipient
whether the organ was given to them if someone was paid or
donated it? Organ trafficking – is it an issue in Poland?

Religion, Culture and deceased organ donation

• Can you tell me about the view that Catholicism has towards organ
donation? (Why would it be against it? Why would it support it?
Where did you learn about it? Which religious teachings would be
relevant? What role do religious leaders play? Should they be
talking to their congregation about it? None as it is an individual
decision? Catholic views towards the body – is it a gift from God?)

• (In the news recently, the Pope said that he would donate organs,
but the Vatican is against it because they say his body belongs to
them as it may become a relic in the future. What influence do you
think has on organ donation amongst Catholics?)

• Would organ donation be rewarded by God? Is the body a gift from
God?

Social capital, gift exchange, altruism and deceased organ donation
(Social Trust/Civic Engagement)

• How do you think giving in the form of organ donation could be
linked with the groups that you have just explained? (Would it
increase levels of trust within local community? Would it impact on
how people identified with other people? Is it not possible due to
high mobility, people don’t get to know their neighbours? Feel part
of something?)

We’ve spoken about groups on a small and immediate level, now we’re
going to talk about society, so sense of community on a wider scale.
• Do you think that giving in the form of organ donation helps to create a wider sense of community spirit within society outside of the smaller immediate groups you have just explained? (Why? Do you think that people trust strangers?)

• Tell me what you think about organ donation as a way of ‘doing your bit’ for the greater good? And whether it would make you feel more connected to UK society? (Way of providing organs to people who need them because one day that person may need one? Would registering as an organ donor be influenced by whether people felt that they belonged to society?)

• How does this idea link in with helping others and giving gifts?

Religion, altruism, gift exchange, social capital and deceased organ donation

Overall, how do you think they link together? You don’t need to include all of them.

Statements about organ donation (These may have been previously discussed)

I am now going to show you some statements and I want you to tell me whether you agree or disagree with them:

• I do not feel very strongly about organ donation and have not thought about it before.

• I would donate because I can imagine the people that I would be helping within UK society.

• Organ donation is a moral issue for the individual and the family.

• Someone may worry about how they look at their open-casket burial may influence whether people would become organ donors.
• I don’t like the thought of operations or hospitals and don’t want to be operated on after I die.
• Considering organ donation is a way of dealing with your own death and I don’t feel comfortable thinking about death and dying.
• Organ donation is not natural.
• The body and soul separate upon death, the body is just a vessel for the soul, so there is no problem for organs to be donated.
• The length of time I think that it takes the soul to leave the body and then organs being removed is a concern to me.
• I would have an issue donating my own eyes or heart as I think they carry special meaning.
• If I am an organ donor in Poland, I am automatically an organ donor in the UK.
• I feel like I do not have any control of whether I am an organ donor or not.
• Jesus Christ sacrificed himself, organ donation has similarities to this.
• I have no preference as to who my organs would go to.
• For people to become organ donors, it is not a quick, snap decision it is deeply and rationally consider and discuss it with friends and family.
• I would not want someone to interfere with my body when I have died.
• Organ donation is a form of charity, a one-way gift, and generosity.
• I would be worried that there would be a risk that my life would be shortened if I was in a coma or in a vegetative state and organs were taken to help save others.

The medical team do not know whether you are organ donor until you have died and the decision is made whether to donate organs or not. It is illegal to shorten someone’s life because they are in an irreversible coma as this is
called Euthanasia. If someone has died because they are brain dead, which is a medical definition of death, the same as if someone died when their heart or breathing stopped, then the family may be asked whether they would consider donating that person’s organs. What are your thoughts on this?

- I do not trust the NHS and would not expect the health care team to save my life, especially if they knew I’m an organ donor.
- I am only registered in Poland because I trust the healthcare system there more than the UK.
- How people view their national identity, for example, if people feel they may feel they are not British or not Polish, but something ‘in-between’, this may influence whether they would donate organs to either country.

Any other questions or comments?
Interview Guide III

Individual

Human nature and wanting to help other people as humans

- Upbringing - learned how to help others through parents and church - theory and practice
- Previous blood donor
- No preference for the recipient or place for being a donor - UK or Poland.
- Donating to help other humans in need, as they empathise with them, not a gift that has to be repaid, just won’t need them when dead.
- Inner need to help others by giving life and saving life.

The Person

- Level of maturity - questions about life and death and helping others as may be grateful for own life and feel lucky as have good health and life experiences.
- Opportunities to access organ donor registration - GP - moved out/starting family and drivers licence as over 18.
- Familiarity with medical technology
- If have family as gives different perspective on life.
- Stage in life / Moral and psychosocial development / Religious beliefs – Table
- Positive experiences of the NHS and trust in NHS healthcare professionals
- Level of English language (meeting others of other cultures/religions – accessing information)
- How someone feels about themselves – if depressed or happy
Body after Death

• Not wanting to waste organs as won't be needing them, organ donation is like recycling the organs rather than gifting as there is no repayment, they are given to someone else in need.

• View that the body is not needed after death - a vessel for the soul - not the same everywhere as some religions view the body as a temple.

• Comfortable with body being operated on upon death.

• Comfortable with body appearance after donation in one's coffin.

• Don't need body totality when someone has died.

• Not an age limit on donation.

Knowledge of Organ Donation (why do/don’t donate)

• Learned from media - TV shows/newspaper stories/biology at school – generally not seen campaigns but is more openly talked about in UK.

• Personal experience of organ donation – if someone has given/received organs that they know.

• Knowledge of how to become an organ donor/which organs are removed/not seen as risky.

• Concerns/misinformation about donation such as taking organs when haven't died, or killing someone for 6/7 organs as nurses know that person is a donor/body not treated with respect.

• Religion teaches you morals, right from wrong and organ donation is the right thing to do. It is this aspect that links to donation, not teachings or what leaders say.

• Thought and time someone has to become an organ donor.

• Catholicism supports donation.
• The organ is a gift for the recipient as they have wished and waited for it, not the donor or donor family as this is a way of helping someone.
• Anyone can be an organ donor anywhere, place doesn’t matter, organs are distributed nationally, not just locally.

Views towards Mortality and Death
• Generally, Polish people accept death as a part of life – cultural views about death and dying
• Positive attitude and comfortable with own death (may be religious reason) and planning what happens after it.
• Comfortable talking about death with family.
• Accepts that anything can happen at any time.
• Accept both medical definitions of death – brain stem death and circulatory death

Morals
• Helping others depends on the person – altruistic personality
• Religion teaches people morals, to be good people, it is a good base, helping others is a general view and religion can give people the opportunity to help others.

Family and Friends

Becoming a Donor
• Views of one's own family has an influence on whether someone is negative or positive about donation.
• Talked about organ donation with family so they are aware of their wish.
• View of the local priest (in Poland)
Making Decisions about Donating a Loved One’s Organs

- Would accept funeral costs from the government, if donated a loved one’s organs, but not money.
- Mystical thinking in that the personality of the loved one will live on in someone else.
- Family back in Poland would donate their loved one’s organ in the UK and want the body to be transported to Poland.
- Selfish if families don’t donate but is a difficult time and find it hard to let go.
- Facing the death of a loved one.

Polish Customs and Catholicism

- The Church’s view and the Pope’s view have little influence on organ donation but it is assumed Catholicism supports it.
- Teachings to help others may extend to becoming an organ donor.

(Expand more on customs and rituals around death and funerals)

Traditions When Someone Dies

- Location of the body in Poland with families, after donation.
- Arrangement of the funeral – quickly – could be in the UK
- Burial and death customs are to be followed by the family.

* * * * * * * * * *

However, it is not clear how these fit in (if they do at all):

Individual

- Experiences in the UK – safe/belonging, mixing with other cultures, stigma – positive or negative experiences of living in UK.
- Experiences of helping others – negative/positive - volunteering/donating to charity
• Reason why came to UK – level of investment or commitment in UK
  – if going back to Poland
• Where individual is from in Poland – more information about
  donation in cities than villages.
• Accessing British media
• Religion has little influence on helping others – religious people
  aren’t necessarily more helpful than non-religious people in
  experience.

Religion
• How religious someone is – if become nonbeliever/how religious
  someone is and was.
• Relationship someone has with God.
• How often someone attends church in Luton.
• What religious leaders say about donation.
• Belief in the afterlife/Resurrection – how someone feels towards
  death

The Body and Death
• Concern that organs are taken when haven’t died properly.
• The role of priests in the rituals around death – have any role in
  organ donation – should they?

Older generations
• Religiosity and Polish customs may be more important for older
  generations.
• May be less familiar and comfortable with medical technology
Family

- The family may not want to donate because they are not able to say goodbye to that person as part of their loved one is living on in someone else.
- Family not here – influence on church attendance – family may want person to go back complete to Poland as UK is alien and visit grave on All Souls Day – November 1
- Nurses not asking families

Community and Society

- To help someone in need and expect the favour to be returned in the future by someone else when needed.
- The view that some religions may not be able to donate such as Muslims and Jehovah Witnesses.
- Organ donation as giving back to society.
- People being selfish – individualistic – not wanting to help others.
- Raising awareness about donation within local communities.
- High level of mobility in the UK, difficult to get to know neighbours.
- Organ donation is Poland is becoming more well-known and talked about.

Giving Gifts

- Expect anything back for helping others whilst alive for being donor? Money? Small token gift?
- Whether someone views an organ as gift, which is different from any other gift but could be compared to living donation. However, some have said that living donation is more of a gift as the person is alive and affecting their health to help someone else.
Interview Guide IV

Migration Experiences

- Tell me about your experiences of coming to the UK after the war.
- Were there many people here from the post-1989 after the fall of Solidarity?
- What are your views towards the recent Polish migration? (As they are coming to the UK for different reasons – economic and not political)
- Do recent Poles have different expectations about the UK? Why?

Role of religion in their life

- Tell me about the history of the Polish church in Dunstable.
- Tell me about the Polish community in Dunstable and Luton generally (how big was it? What else did you set up in addition to the church?)
- What were your experiences with other communities in this area apart from other Polish people?
- Tell me about the role that God, the church and religion has played throughout your life.
- Some people have said that there is a generational difference in how religious people are in that older generations are more religious than younger generations, do you agree with this? Why?
- Some of the people that I have spoken to in their 20s/30s have become non-believers since coming to the UK or during their adolescence in Poland, either they have questioned religion or don’t have time to go to church anymore once they are here. Is this a generational difference or do people become less religious and then come back to it at different times, such as when they have family or as they get older?
Helping Others

- Have you seen any changes in whether people help others since you’ve been in the UK? (Were people more helpful after the war than they are now?)
- Some studies have said that religious people are more helpful, do you agree with this? Why?

Organ Donation

- What do you know about organ donation?
- Why do you think people are donors/not donors?
- Do you think that religion influences organ donation? How?
- Do you think that people expect anything back for being a donor? Why?
- Which Polish customs around death may influence decisions around donation?
Appendix Five: Interview Excerpts
Excerpt of Interview with English participant

I: So I suppose they would be reasons why people would donate, they want the organ to be available if they needed it, and also you are helping other people that are dying.

R: It’s more like, yeah, it’s more like thinking like, my husband doesn’t need this anymore, it won’t help anymore because he’s died, but this might be helpful for somebody else, is it a child? Or a teenager, or anyone else his age, that would be more suitable, it’s still somebody is waiting for this, that is the main reason, he doesn’t need this anymore, that won’t help him as he has gone, you know.

I: Why do you think that some people wouldn’t want to donate?

R: They still feel relationships, they feel like they don’t want to share with your body with anybody else, that’s what I believe, that I would give you, anyone, your mine, whatever, I don’t want to look at you like they are cutting you, I don’t want to imagine you like they are cutting you and taking something from you and giving it to someone else, maybe it’s just because of this because they feel big relationships, this relationships too big, it’s just that they don’t realise that, it won’t help them, if somebody has gone there’s other help that they need, like psychology therapy because the body won’t help them, because it has gone, that is what I believe.

I: So when you are talking about the body being cut, do you think any of that links with Catholic views around burial?

R: Maybe it is about general opinion in Poland, it’s more like, mm, I don’t know, it’s more like a hermetic word, like Poland, they have, it’s Poland, they don’t see difference, they don’t see like how people live in different countries, how they deciding about their lives, how they are deciding about careers, how they decided about education, they don’t see this, in Poland, people live in one schedule, and if something is wrong in this schedule, then everybody just pointing, different than us! It’s like you’re different than us, you’re not sticking with us! It’s something like this, rather than thinking like, this is your life, this is your decision and you will do whatever you will do, nobody will pushing you, nobody will punching you, that’s how, I believe that still in Poland, its this schedule, it’s this schedule that is like a pattern, which we mm, we are growing up in this pattern, we see how our parents growing up, see how they deal with the problems, how they deal with different kinds of situation and we repeating the same, this is something like this, because our parents are our teacher, this is the first teacher, this is the main teachers, whatever
they do, whatever they have attitude, their characters, we are copying, we are similar to them.

I: If someone wanted to be buried whole, it would be because that is what everyone else is doing and if they didn’t do that, then they’d be looked at differently, is that what you mean?

R: Yeah, it is more like a tradition, because they like to see, go to the cemetery, the whole family is coming, they cry, then after that, they going drinking, you know, because this is like a family’s party then, after all these things, like the church and the cemetery, and er, whatever they go into the home, they party, they eating, they drinking, most of them drink alcohol, it’s like a strange, it’s like, when I was a kid I was thinking like strange, why are they laughing? Two hours ago they were crying! I was like what the hell! I know that they laughing now because they are drunk, but it’s like, I was thinking this is bad when I was bad, but when I was growing up, I was think, I was somehow copying this pattern because, everybody when they look at you, you’ve been doing something different than them doing, the family, and they were saying, what has happened to Agneitza? She’s started to be very rude! They start thinking oh like, something bad is happening with her, because I would have my own opinion yeah, because I said, now listen, I don’t like this or listen, I don’t care what you think about this, but I’m going to do this my way and it was like, no, no, there is something wrong with her! (Laughs)

I: If for example something happened and your family had to make a decision, would all the traditions stop them, I just wondered if they would say I don’t want to donate because I need her back here, we want to bury her here quickly because that is the tradition, or if they would think?

R: Yeah, some of this is like, I can give you er, example, we won’t donate even in hospital, my father has died, he had a cancer yeah, but don’t believe that they even ask in the hospital, do you want to donate? Because nobody asked us, but he had a cancer, but never mind, I believe that in Poland, they are ringing us, saying, when is this funeral? I have no time! It’s like, what! It’s his funeral, if you don’t want to come, then don’t come, I have to ask my boss if I can get holiday or not, it’s like, if you don’t want to come, then don’t come, I won’t be planning everything for you because you are waiting for the funeral and I need to be suitable for you, but some people are thinking like this, you know, somebody has died, quick! Quick! That needs to be quick. In Poland, it needs to be quick.

I: It’s within 2/3 days or something?
R: Yes, never mind that you want to, say goodbye to that person, get used to that situation, no, that needs to be quick, no time for emotion, no time for thinking, planning, then there will be emotion, like after all, your coming back to the home and people starting crying, start you know realise, this person has gone, before you get used to that, before the funeral, but after the funeral, it's like yeah, getting used to that.

I: With regards to some of the traditions, because if someone becomes a donor, they have a list of people they speak to and the family is always at the top, so say for example if someone is here and their family is in Poland, who would be the main decision makers in the family? The older generation, if they are very influential or if it would be the parents and they wouldn't listen to the grandparents? I wondered who would be making the decisions.

R: I hope not! I believe that people in Poland and they have some die in England, they want the body to go back to Poland and do the funeral for the family and for themselves, I believe that mm, they, if I would die, that they would think that I would not want to donate because I have haven't seen him for a while, I want him home, as he left Poland, I won't give any part of his body to anybody in England, maybe something like this.

I: Is it because they don’t know England.

R: Maybe it is because they don’t know England, maybe it is because they were saying something bad about English experience, you know, I don’t know, but I can hear like Polish people who have never been outside Poland, they saying some, you know, only bad things, oh you got this, it’s like, they are not persuaded about England, they are not persuaded that this is something good for you, come back to Poland, what are you doing there? You know, maybe it’s because from, you know making decision, it would be something good, it’s just because it’s England, that’s it, maybe that’s how they would feel, no, this is England, if that happened in Poland, ok, but this is England, we don’t know this, it’s better to have back them here, plus another thing is that they want a quick, quick, quick funeral.

I: Would it matter about what Catholicism thought about organ donation? If it supported it or not?

R: Another thing is like, I don’t know how it is about politics, what they are thinking about this, but in the youngest, like teenagers and people my age, changing this opinion, I used to think I would never donate anything, when I used to live in Poland I used to think
that, nobody asked me, nobody educated me about donation, nobody, they didn't ask, never, in health centre, hospital, never, they don't talk about these things, nobody is preparing you for those things that that might happen, would you help, I don't know what it is like now as I haven't been in Poland, but it's like the old, oldest people over 40, they are like, no, this is like your body, it's saint, saint, this is your body, otherwise you will be in hell if someone cut you, some people talking about this bullshit. (Laughs) Ok, some older people you know, but now it is changing you know, people are more educated and people are thinking, their own opinion is changing now, but it's still like, most of young people, they still believe in this pattern, they are still afraid to talk about what they thinking about different opinions, because in Poland, it's it's a lot of village, people that live there are less educated than people who live in a town, it's everywhere like that, but still, in some part of Poland, you can imagine, people in the village don't have electricity, so.

I: Donation, isn't going to be something they think about!

R: Donation? Mm, they are thinking about waking up, going to work, coming back, go to the church, every day, on their knees, coming back, so yeah, they have a pattern, their life is like a pattern, most.

I: You said that in Poland you hadn't heard anything about donation, have you heard about it more since you've been in the UK?

R: Yeah, when I signed the register in the health centre to the GP, the first thing in the application under my details was like, would you donate any of your part of your body, which one? Then tick, and it was kidney, heart, lungs and everything else, yeah so.

I: If you hadn't heard very much about it, what made you want to donate?

R: I thought I don't care, I don't care, I can donate, I was young and I was thinking I was in England, nobody cares, nobody asked me, they asked, they said this is confidential, this is your choice, so, I thought I'm an adult now, nobody tell me what I should do with my body or not, I tick yeah, everything yeah, any part of my body and I was thinking, mm, I'm proud! What would say my family, but this is my decision, I put the signature on and this is my decision, yeah and then some how, when I registered again, erm, because I changed my GP and I changed the area, and I registered to the new health centre, I ticked none somehow, I think that was after bad experience in England, that was bad period in my life, of a very bad experience in England, and I thought none! Never! I would rather die and not give anything to anybody, they can die with me! I was thinking like that really! I was. But, when I register here, I thought, yes, I'm getting older, and I ticked yeah.
I: If that bad experience was that something that you had um, was it in your
neighbourhood or?

R: It's not that, but everything, workplace, if I go to the shop, if I was struggling with
my benefits or anything or had a bad day and somebody was very rude to me, so that was
very bad experience you know, in, like you know, sometimes you have periods in life when
everything is wrong, everyone is wrong, it's like, I was thinking oh my God, my life is
rubbish, you know, I was thinking what I'm doing wrong? You know, but you know, and it
starts to getting better, I found the psychology, I went to the psychologist and said, I'm
struggling, I'm not dealing with this, something is wrong and then she explained to me,
this, this and this and I had something like a small therapy which was three or four visits,
that helped me, that's realised me now that I'm not struggling, I'm not the only person
and it's not because I'm Polish, it's because I'm not the only person in the world who feels
like that, because it was too much stress, which caused all these feelings and bad
experience and then I start thinking and I go back to reality, go back to the right way and
now I'm thinking like, never mind, I could be English, Chinese, Japanese, I don't know,
Bulgarian, I don't care, it's just like, if I die I don't need this body, that is what I'm thinking.
Excerpt of Interview with Polish participant conducted by the translator:

Translated Version

DB: Eh, now we will proceed to the topic of faith, spirituality and piety, and did religion play a part in your childhood?

I13: In my childhood, well...

DB: Well, when you were growing up.

I13: Well, when I was growing up I went to church every day, and well, every Sunday, and my family and I tried to make an effort, and in general I believed in God, and what they taught us about religion and other stuff, but...

DB: And what kind of role does religion play in your life now?

I13: Well, now I probably don't believe as much as I did as a child, and even more so, I wonder about if it's all not just a big scam, and that all that bible stuff, but well, I just try to go to church when I can, and well it's only 45mins of your day amongst all those hours, and I like to zone out in the church.

DB: Mhm. And why did you begin to doubt religion? Do you, for example, have some atheist convictions in you?

I13: Yes. Exactly, basically, the older I was the more I began to think about religion and I wondered if there was any sense in believing, and if someone didn't just make this up and well, obviously, religion there never was such a thing, and it never existed, and from the very beginning of existence, so basically the older I grew, the more I started to wonder about it.

DB: And, eh, when you began to question—did these thoughts begin to come when you lived in Poland? Or when you moved to Luton? Like, for example, did you begin to wonder about certain things after a specific point in time?

I13: I believe that not. In Poland, I began to wonder about this, and it wasn't that I arrived here, in a new place that I began to think about it. So, basically I was fifty-fifty we can see.

DB: But you have mentioned that you try to at least make it to one mass a week, do you attend mass in Luton or Dunstable?

I13: No, I don't go (at all).
DB: Nowhere, aha.

I13: (I only attend) Only in Poland.

DB: And how would you describe your relationship with God, at present?

I13: At present? Well, I pray every day, and that's about it.

DB: Mhm. Ehm, and do you thin that religion has changed in Poland?

I13: Mmm, yes, I think that less people believe, that less believe, and yeah, that's pretty much how it is.

DB: Mhm. And, ehm in Poles' living in Luton, have you noticed that less/little attend church?

I13: Here in Luton? I haven't noticed such a thing.

DB: Aha, and do you not think that religious beliefs are changing in Poland, and that people are turning to a different religion or that they basically stop...

I13: NO, somehow I haven't noticed such a thing.

DB: Aha. And, ehm have ehm, have you in some way noticed that the church has changed, that eh, religion and Catholicism have changed in children or that it has changed from generation from generation? Have you noticed any differences, for example?

I13: I don't think so, I mean, I have a younger brother but he is not in school yet, and now, I don't know what relations/approaches are towards religion, I haven't noticed such a thing.

DB: And, ehm, what is your opinion about resurrection?

I13: No, well, ehm I don't think there is such a thing and that is final.

DB: And, ehm, what do you think happens with our...

I13: body

DB: (with our) body...after death.

I13: With the body after death? Mmm, I don't really have a clue about what happens, really.

DB: Mhm.
I13: Basically, it’s one big mystery and that’s it.

DB: Ehm, some have this feeling of security through their faith in God, and that God will look after them after their death, and that is why people are not afraid to die - what do you think about this?

I13: Well, in general, it is true, but what do I think - I do not think this way, I do not believe in this, that their will be good, and that I am afraid that I don’t go to church and that I afraid of what will happen to me after death, or that something bad will happen to me, because I believe that after (donating my organs) I still have a chance with God, so... in all...

DB: Eh, now I will proceed to religion and helping others.

I13: Mhm.

DB: Some studies have shown that the more religious people are the more willing and eager they are to help others (in need) and that they hand out financial assistance, or they organize some charitable events to help (such as clothes drives) regardless of whether if they know the person or not, and, eh, for example, do you agree with this statement or no?

I13: No. I believe that it doesn’t depend on religion, and that everyone - that everything depends on the person, and the person’s personality, and from the person’s character and that it has nothing to do with the church or whether they believe in something or not, it basically depends on the person.

DB: And what kind of role do religious tales, about, for example, the good Samaritan play? How/ does it influence people to help others?

I13: I think that it does.

DB: In what way?

I13: Well, when you read it to children, I believe that it gives a form of/track of thought and that later that person is more willing to help a poor person/a person in need and that it strengthens one’s will to help.

DB: Mhm, and eh, some believe that helping others is linked to, sorry that it isn’t linked to religion and that this is a biological process or that it depends on how you were brought up at home, do you agree with this?
I13: Yes. Yes, it's just like I said earlier, and well- I agree with this.

DB: OK, well let's proceed to organ donation and the NHS- NHS is the acronym for the British National Health Service.

I13: Oh, I didn't know that.

DB: Well, yeah, basically the British National Health Service, have you had any experience with it?

I13: No, no- I haven't.

DB: Aha, Ok, cool.

I13: At least, not yet.

DB: And, ah, mmm....

I13: I hadn't had any (experience) with the Polish one either.

DB to CS: Should I ehm what do I do know, cause if he's not heard of the NHS in England

CS: Has he heard about it at all?

DB: No, I just told him now, and he didn't know what the NHS was

CS: Oh, all right ok-are you thinking about registering with a doctor?

DB: Do you have any intention of signing up with a GP here?

I13: No.

CS: Ok. The NHS is a free health system here.

I13: Free? We have. Yeah, but I never...

I13: I never get ill, so...

DB: He said he never gets ill so he doesn't need it and he said he doesn't even go to the GP in Poland.

I13: I'm a very healthy person.

CS: Oh, ok right so you must be really healthy (laughs)

DB: Should I just skip over to...
CS: Yeah, just skip over.

DB: Eh can you tell me what you know about organ donations and transplants?

I13: Eh, like, what is my opinion on the matter?

DB: Eh, like in general, do you know what organs are removed, what do you know about it?

I13: Aha, OK.

DB: DO you know what happens to them (the organs)?

I13: Eh, well, there must be some kind of agreement, yes?

DB: Eh...mmm...

I13: Or not always? (laughs)

DB: There should usually always be an agreement, if not them...(laughs)

I13: Eh, well I know that the kidneys are taken without a problem, and, eh, the heart, and something in the eye, eh, I think it’s the iris or something like that, I don’t remember, I mean I’m not sure.

DB: Aha, well, I will mention it in a minute.

I13: And, eh, wait, wait, wait, the liver- I think.

DB: Aha, and well, so- how do you know that some organs are harvested and not others?

I13: Those, meaning that what, I was correct?

DB: No, meaning those that you have named. For example, how do you know that those organs are harvested, and how do you know that they are harvested; I mean you don’t go to a GP...

I13: (laughs) Eh, well, no, but I know this from biology class, and well I’ve also read about a lot of this (stuff).

DB: Ok, well, so I will show you what is harvested. Basically, after death...after death you can donate your brain, some tissue(s), ehm, your retina, and ehm skin and bones. And from organs, you can donate your heart, lungs, ehm liver, small intestine, large intestine, your bladder, and you’re your prostate.
I13: Well, that’s quite a bit.

DB: And, well, how do you think a person obtains an organ?

I13: Eh, but, you mean, when someone isn’t alive anymore?

DB: Eh, yes, like when someone has died, and then someone accepts those organs, and so, how do you imagine the person who accepts those organs feels?

I13: Eh, well, normally. They got an organ, they got a second shot at life, and they should be even more happy/pleased about that.

DB: Mhm, and do you know how to become an organ donor in England or Poland?

I13: No, I have no idea. I only donate blood... but about organ donation, I have no idea.

DB: Mhm. And have you attempted to find out more information about organ donation?

I13: No, but I think I will have to do this shortly, as it interests me a lot... in the sense that I would like to donate an organ when I’m still alive, like for example, a kidney.

DB: Aha.

I13: So, for example, not for money or any od the such, but just to help someone in order to save their life, you know what I mean, right?

DB: That is a very pleasant thing to hear, and now I will tell you how to become an organ donor in England?

I13: Oh, yes- that is a very interesting thing (to know).

DB: Eh, aha ehm, do you have a Polish driver’s license?

I13: I do.

DB: A, eh, have you renewed it in England?

I13: No, no, no

DB: Aha. Very well, in England you can become an organ donor when you apply for a driver’s license or when you exchange you Polish one for an English one, and, eh I don’t know if you know that we (in Luton) have a shop in the shopping centre called „Boots“ ...

I13: Yeah, it’s possible I have seen it.
DB: Eh, well there, you can obtain a card called the Boots advantage card, and, eh you can become a donor that way. Also, when you sign up with a GP, he gives you a form to fill out, or, for example you can sign up with the English NHS online when you're living here, and when you emigrate you can opt-out of the list.

I13: Aha, so in any case, I can sign up at any moment.
Appendix Six: Examples of Memos
Luton Polonia – June 2011

Findings from the discussion with Head teacher from the Polish Saturday School, first focus group with the young, post-2004 females, second focus group of females who were mainly religious and interviews with six post-2004 females and two post-2004 males have led to the view of Luton has significantly changing.

The way in which I see the Poles in Luton has changed, look at Poles in Luton in clusters, views from each cluster should be symbolically represented. These clusters are university students, families where males are typically working and females are typically at home, single people with low levels of education, in low-skilled work, here to earn money only, do not speak English and Catholic Polish parishioners. Haven’t been to the church yet, there may be post-1989, post-war and second and third generation Poles there.

The sampling strategy is changing because the original sampling strategy of focus groups based on length of stay is not working, due to majority of Poles are non-English speaking, it is difficult to put focus groups together, students are not a true reflection of the Polish community in Luton.

Recruitment Strategies – October 2011

I’ve interviewed five people so far, which has taken one month to get – 1 family (from church) and 4 workers. They didn’t make the announcement at church again, the Head teacher wasn’t there and it was another wasted visit.

There is a post-war dinner on the 30th October and will need to find out the time, but I can make an announcement then about the money being put towards the church or a day trip.

Through networking, leaflets have gone into Amazon through a participant on Sunday. The recruitment strategies are difficult, I have tried recruitment agencies, networks at Sainsburys by distributing leaflets to workers, posters at delis and going to the church but with little fruition.

Other places I can try are hotels, bars, the airport; doctors surgeries and cleaners at the university. Also I could ask the priest to put the study in their newsletter, but this has taken a long time to do.
Views on Religion Codes – July 2011

Religion links with people – family, home, community, space and time, religion changing for some and not for others. A shift in views towards church by the young people – sceptical. Don’t agree with all teachings, priests are influential, church is problematic, reality and teachings contradict each other, controlling. Teachings – after life after death, own view on Resurrection, life can’t be pointless, a nice place awaits one, don’t believe in Resurrection.

Many Pole opposites on views toward religion – on a continuum, i.e. do believe or don’t believe or church attendance or relationship with God outside church. Very complex, in addition – political aspect. Have differences in time, people, space and place.

Religious upbringing – church attendance in Poland (links with tradition/family/belonging and language) – in the UK they don’t have this (links with tradition/family) – in a different place. People are important – don’t want to go alone – community – they feel in Poland but not in UK. Space and time – how can beliefs and values apply here? Are they transferrable or get suspended?

Reflections on Religion and Altruism – November 2011

After the interview yesterday, we were speaking about Muslims and Black African and Black Caribbean church goers – it seems to be that religion is a way of life, but not in the case for Poles, similar to British people in that regard. It appears that there are issues around education, death, empathy and altruism that are most relevant.

Altruism isn’t enough by itself – need empathy and education. Why should it be that altruism, empathy and education are treated separately?

Different ethnic groups have had different histories – in America, African-Americans – don’t trust system, history of slavery and inequality but in the UK, Poles have had come to the UK in different waves but not had these issues – different history – limited in how compare their views.
Appendix Seven:

Example of Table of Codes and Frequency
## Deceased Organ Donation, the Body and Death

### Categories, sub-categories and open codes across all of the participants’ views

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-Category</th>
<th>Open Code</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donating is a personal decision</td>
<td></td>
<td>Donating is a personal choice</td>
<td>I3, I10, I12, I14, I15, I19, I16, I17, FG1, I20, I19</td>
</tr>
<tr>
<td>Donating is a way of helping the human race</td>
<td></td>
<td>Donating is about being human and helping another mother or child, people are people, brothers and sisters</td>
<td>I12, I15, I11, I14, I16, I17, I7, I3, I2, I1, I19</td>
</tr>
<tr>
<td>Social capital and organ donation</td>
<td>Communities</td>
<td>Transplantation may create communities of support</td>
<td>I8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Donating may bring the family together, not the nation</td>
<td>FG1, I1, I8, I3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Communities/media/society should talk about organ donation more</td>
<td>I19, I18, I17, I16</td>
</tr>
<tr>
<td>Belonging</td>
<td></td>
<td>Donating is not linked with belonging to society</td>
<td>I6, I10, FG3, I18</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Donating based on belonging in a community/society</td>
<td>FG1, I3, I2, FG2, I10, I14, I5, I8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Being aware of community views and raising awareness through communities</td>
<td>FG1, FG2, I5, I7, I1, I12, I13, I15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Donating is a private decision and can’t bring</td>
<td>I2, FG1, I16</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>people together</th>
<th>Organ donation is about helping an individual and knowledge, not the community</th>
<th>I6, I5, I8, I4, FG1, I20</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Meeting/experiencing other cultures and ethnic groups in the UK may influence donation</td>
<td>I2</td>
</tr>
<tr>
<td></td>
<td>Donating as a way of contributing/investing/helping others in the community or society</td>
<td>I8, I14, I9, FG3, I21</td>
</tr>
<tr>
<td></td>
<td>Not knowing anyone who is a donor or recipient</td>
<td>I9</td>
</tr>
<tr>
<td></td>
<td>Making donation the norm would be beneficial</td>
<td>I18</td>
</tr>
<tr>
<td>Voting</td>
<td>Donating and voting do link</td>
<td>I14</td>
</tr>
<tr>
<td></td>
<td>Donating and voting don’t links</td>
<td>I11, I13</td>
</tr>
<tr>
<td></td>
<td>Giving organs is not linked with trust</td>
<td>I10, I14</td>
</tr>
<tr>
<td></td>
<td>More people should be publicly talking about donating across different communities</td>
<td>I13, I15, I16, I15</td>
</tr>
<tr>
<td>Migration issues and donating</td>
<td>Integrating into society is not linked with organ</td>
<td>FG2</td>
</tr>
<tr>
<td></td>
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<tr>
<td>-----------------------------------------------------------------</td>
<td>-----------------------------------------------------------------</td>
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</tr>
<tr>
<td><strong>donation, place doesn’t matter</strong></td>
<td><strong>Integration influencing donation</strong> I1, I2, I3</td>
<td></td>
</tr>
<tr>
<td><strong>People being generally reluctant to donate in Poland</strong> I2, I6</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family willing to donate who are back in Poland</strong> FG3, I14, I18, I16, I17, FG1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family not willing to donate who are back in Poland</strong> FG1, I15</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Muslims don’t integrate as well and limits if can donate</strong> I17</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Organ donation as a commitment to the UK</strong> I1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Organ donation is not a commitment to the UK</strong> FG3</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethnic identity not linked with donation</strong> I4, I10</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Place</strong></td>
<td><strong>Only willing to donate in Poland</strong> FG1, I10, I12</td>
<td></td>
</tr>
<tr>
<td><strong>Willing to donate in the UK</strong> I13, I11, I14, I15, I19</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Not mattering where donate</strong> I10, I18, I16, I17, FG3, I9</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Donating is an altruistic decision</strong></td>
<td><strong>Not expecting anything from donating</strong> I3, FG2, I4, I5, I2, I6, I7, I8, FG1, I10, I9, I19, I20, I21</td>
<td></td>
</tr>
<tr>
<td><strong>Organ Donation and Giving Gifts</strong></td>
<td><strong>Organ Donation is a gift</strong></td>
<td><strong>Donating organs is the best gift</strong></td>
</tr>
<tr>
<td>------------------------------------</td>
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</tr>
<tr>
<td></td>
<td><strong>Organ isn’t a gift but a way of helping, can’t be returned</strong></td>
<td><strong>I10, I12, I13, I15, I16, FG3, I19</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Living donation is a sacrifice, a bigger form of gift as risk was involved</strong></td>
<td><strong>I9</strong></td>
</tr>
<tr>
<td><strong>Repaying the donor family</strong></td>
<td><strong>Thank the donor in a small way</strong></td>
<td><strong>I8, I5</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Human nature to want</strong></td>
<td><strong>I14</strong></td>
</tr>
<tr>
<td>Repaying others in the future</td>
<td>Paying it forward as effected by donation</td>
<td>I6, FG2, I8, I6</td>
</tr>
<tr>
<td>-------------------------------</td>
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</tr>
<tr>
<td>Repaying others in the future</td>
<td>Having experience of donation and obligated to donate</td>
<td>I9, I10</td>
</tr>
<tr>
<td>Receiving reward</td>
<td>Donating for money would increase donation</td>
<td>FG2, FG1</td>
</tr>
<tr>
<td>Receiving reward</td>
<td>Being given money for deceased donation is wrong and loses value as gift, create market, spend on wrong thing</td>
<td>I1, I4, FG1, I17, I18, I3, I110</td>
</tr>
<tr>
<td>Receiving some kind of reward for donating</td>
<td>I3, FG2, I2, I8, I1, I5, I7, I12</td>
<td></td>
</tr>
<tr>
<td>Should not be given funeral costs as enter into an exchange/ do it to help</td>
<td>I15, FG3</td>
<td></td>
</tr>
<tr>
<td>Funeral costs from the government would encourage more donors as helps family</td>
<td>I17, I15, I10, I11, I18, FG3, I9</td>
<td></td>
</tr>
<tr>
<td>Priority on waiting lists would be difficult to manage</td>
<td>I11</td>
<td></td>
</tr>
<tr>
<td>Family should have</td>
<td>I13</td>
<td></td>
</tr>
<tr>
<td><strong>Recipient's view</strong></td>
<td>Recipient will have renewed appreciation for life</td>
<td>FG3</td>
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<tr>
<td>----------------------</td>
<td>---------------------------------------------------</td>
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</tr>
<tr>
<td>Recipient wouldn't care if person was paid</td>
<td>I6</td>
<td></td>
</tr>
<tr>
<td>Recipient views as gift, not donor as waited long time for it</td>
<td>I2, I1, I10, I11</td>
<td></td>
</tr>
<tr>
<td>Less pressure on recipient to repay as family already got something</td>
<td>I9</td>
<td></td>
</tr>
<tr>
<td><strong>Blood donation</strong></td>
<td>Being/willing to donate blood in the UK and willing to donate marrow</td>
<td>I13, I17, FG3, I19</td>
</tr>
<tr>
<td></td>
<td>More aware of blood donation than organ donation</td>
<td>FG3</td>
</tr>
<tr>
<td></td>
<td>Not a blood donor in the UK</td>
<td>I11, I14</td>
</tr>
<tr>
<td><strong>Age/Life Stage</strong></td>
<td>Deciding about donating is fluid and influenced by age and maturity and era brought up in</td>
<td>I18, I16, I17, FG3, I15, I2, I7</td>
</tr>
<tr>
<td></td>
<td>Having children changes your perspective on this issue</td>
<td>FG1, I18, I16, I19</td>
</tr>
<tr>
<td></td>
<td>Young people not thinking about donation</td>
<td>I10, I17, FG3, I19</td>
</tr>
<tr>
<td></td>
<td>No age limit on</td>
<td>I18</td>
</tr>
<tr>
<td>Age limit on donating, can be too old to donate</td>
<td>FG3, I13, I21, I2, PO, I19</td>
<td></td>
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<tr>
<td>Seeing organ donation as an adult decision about one's body</td>
<td>I15, I12</td>
<td></td>
</tr>
<tr>
<td>People getting older and experiencing death and priorities change</td>
<td>I16, I17</td>
<td></td>
</tr>
<tr>
<td>No divide in older or younger people who decide to donate</td>
<td>I18</td>
<td></td>
</tr>
<tr>
<td>Older generations not aware of donation, not brought up with it</td>
<td>I16, I18, I17, I19</td>
<td></td>
</tr>
<tr>
<td>Older generations are aware of donation</td>
<td>I19</td>
<td></td>
</tr>
<tr>
<td>Friends, parents and grandparents' views influencing one's thoughts on donation/knowing wish</td>
<td>I18, I9, FG1, I7</td>
<td></td>
</tr>
<tr>
<td>Friends views won't change opinion on donating</td>
<td>I10, FG3</td>
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</tr>
<tr>
<td>Parents not being supportive of donation as had negative experiences of the NHS?</td>
<td>FG3, I2</td>
<td></td>
</tr>
<tr>
<td>Grandparents being supportive</td>
<td>I13, I14</td>
<td></td>
</tr>
<tr>
<td>Upsetting topic to</td>
<td>I11</td>
<td></td>
</tr>
<tr>
<td>Family discussion</td>
<td>Talking to family about donation to find out wishes</td>
<td>I12, I15, I9, FG1</td>
</tr>
<tr>
<td>-------------------</td>
<td>----------------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td></td>
<td>Not spoken to family about donation, isn't something people talk about</td>
<td>I18, I10, I11, I16, FG2, I1</td>
</tr>
<tr>
<td></td>
<td>Talking about donation isn't easy, people would rather gossip <em>(plotka)</em></td>
<td>FG1, I1, I19</td>
</tr>
<tr>
<td></td>
<td>Difficult talking about donation as thinking about loved one dying, especially if parent</td>
<td>FG3, I19</td>
</tr>
<tr>
<td>Deciding to be a donor</td>
<td>Deciding so the family don't have to</td>
<td>FG1, I4</td>
</tr>
<tr>
<td></td>
<td>Needing psychological tests to donate</td>
<td>FG1, I6, I5, I11, I14</td>
</tr>
<tr>
<td></td>
<td>Only thinking about donation when someone has died/is dying (making easier)</td>
<td>I16, I18, I4, FG2</td>
</tr>
<tr>
<td></td>
<td>Not a topic that people think or talk about</td>
<td>I16, I9, I7, I6, I8, I15</td>
</tr>
<tr>
<td>Topic</td>
<td>Reference</td>
<td></td>
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<tr>
<td>----------------------------------------------------------------------</td>
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<td></td>
</tr>
<tr>
<td>How someone feels about themselves – depressed/happy</td>
<td>FG3, I18</td>
<td></td>
</tr>
<tr>
<td>Feeling strongly about donation</td>
<td>FG1</td>
<td></td>
</tr>
<tr>
<td>Can take a long time to decide</td>
<td>FG3, I17</td>
<td></td>
</tr>
<tr>
<td>Deciding to donate is a quick decision</td>
<td>I14, FG1</td>
<td></td>
</tr>
<tr>
<td>Deciding to donate is a moral decision</td>
<td>FG3, I18, I9</td>
<td></td>
</tr>
<tr>
<td>Donating is a formality</td>
<td>FG3</td>
<td></td>
</tr>
<tr>
<td>Once decided, won’t change mind</td>
<td>FG3</td>
<td></td>
</tr>
<tr>
<td>Views towards medical technology may influence decision</td>
<td>FG3</td>
<td></td>
</tr>
<tr>
<td>Needing to meet person who receives organ to judge if deserving</td>
<td>I12</td>
<td></td>
</tr>
<tr>
<td>Can’t judge if people are deserving, not God</td>
<td>I19</td>
<td></td>
</tr>
<tr>
<td>Deciding to donate if have experience of organ transplantation</td>
<td>I19</td>
<td></td>
</tr>
<tr>
<td><strong>Family deciding about a loved one</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deciding to donate is the whole family’s decision</td>
<td>I5, I12, I9</td>
<td></td>
</tr>
<tr>
<td>Father would be final decision maker</td>
<td>I14</td>
<td></td>
</tr>
<tr>
<td>Husband decide about</td>
<td>I18</td>
<td></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Wife</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Children decide about parents</td>
<td>118</td>
</tr>
<tr>
<td>Family needing psychological help</td>
<td>115</td>
</tr>
<tr>
<td>Would donate loved one’s organs</td>
<td>115, 11</td>
</tr>
<tr>
<td>Makes end of life more meaningful</td>
<td>13</td>
</tr>
<tr>
<td>Donating is not first thought if someone is dying</td>
<td>FG2, 13</td>
</tr>
<tr>
<td>Donating could help the family to cope</td>
<td>115, 11</td>
</tr>
<tr>
<td>Recipient of the organ won’t matter to the family</td>
<td>117, 11</td>
</tr>
<tr>
<td>Decision to donate should be taken away from family, should be legal agreement</td>
<td>111, 11, 19</td>
</tr>
<tr>
<td>Family should honour person’s wish</td>
<td>118, 11, 17, 18, 19</td>
</tr>
<tr>
<td>Not aware that family’s wish over-rides individual’s</td>
<td>15, 19</td>
</tr>
<tr>
<td>Questioning whether family given support for a short while after donating</td>
<td>19</td>
</tr>
<tr>
<td><strong>Magical thinking</strong></td>
<td></td>
</tr>
<tr>
<td>Personality of donor not transplanted</td>
<td>FG3, 11</td>
</tr>
<tr>
<td>Person is not living in</td>
<td>110</td>
</tr>
<tr>
<td>Difficulties for family</td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
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</tr>
<tr>
<td>Eyes and heart having no special meaning</td>
<td>I13, I14, I9</td>
</tr>
<tr>
<td>Prolonging life as heart beating in another person (comforting or not natural)</td>
<td>FG3, I4, I15, I18, I1</td>
</tr>
<tr>
<td>Organs have some emotional meaning</td>
<td>I1</td>
</tr>
<tr>
<td>Family hoping for a miracle that they wake up (killing for organs-taken alive)</td>
<td>I17, I9, I19</td>
</tr>
<tr>
<td>Can’t say goodbye as person living on in someone else</td>
<td>FG2, I1</td>
</tr>
<tr>
<td>A paradox as one family is grieving and the other is praying</td>
<td>FG2</td>
</tr>
<tr>
<td>Difficult decision for family that has to be made quickly</td>
<td>I1, I11, I9, I2</td>
</tr>
<tr>
<td>Not wanting to donate person’s organs as just died</td>
<td>I20</td>
</tr>
<tr>
<td>Donating is harder if the wish of person isn’t known</td>
<td>I9, I10, I21</td>
</tr>
<tr>
<td>Difficult if person is child and died before parents</td>
<td>I13, I18, I16</td>
</tr>
<tr>
<td>Donor family building up relationship with recipient family (lack of anonymity)</td>
<td>I13, I15, I17, I16</td>
</tr>
<tr>
<td>Barriers to donation</td>
<td></td>
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</tr>
<tr>
<td>Difficult but would be proud to have done it</td>
<td>I15</td>
</tr>
<tr>
<td>Difficult as person still looks alive</td>
<td>FG3</td>
</tr>
<tr>
<td>Having little control over what is taken</td>
<td>I6</td>
</tr>
<tr>
<td>Nurses not asking about organ donation</td>
<td>I2, I19, I15</td>
</tr>
<tr>
<td>Donating being like Frankenstein</td>
<td>I6</td>
</tr>
<tr>
<td>Organs taken when still alive</td>
<td></td>
</tr>
<tr>
<td>Not respecting the body</td>
<td>FG1, I1</td>
</tr>
<tr>
<td>People are scared about donation</td>
<td>I20</td>
</tr>
<tr>
<td>Risk involved in donation</td>
<td>I10, I5, I10</td>
</tr>
<tr>
<td>People killing others to get organs</td>
<td>I10</td>
</tr>
<tr>
<td>Fear about being a donor</td>
<td>I17</td>
</tr>
<tr>
<td>Homophobia/ Racism influencing decision to donate</td>
<td>I12, I10, FG2</td>
</tr>
<tr>
<td>Risk in the other person’s body rejecting organ</td>
<td>I11</td>
</tr>
<tr>
<td>Not wanting to give organs to strangers, but people know</td>
<td>I12</td>
</tr>
<tr>
<td>Corruption and unfairness on</td>
<td>I12</td>
</tr>
<tr>
<td>transplant list</td>
<td></td>
</tr>
<tr>
<td>Going to take time when everyone is comfortable about medical technology</td>
<td>I1, I7</td>
</tr>
<tr>
<td>Length of time to donate may put people off</td>
<td>I21</td>
</tr>
<tr>
<td>Positive aspects of donating</td>
<td>Donating is saving lives/ extending life, highest form of help</td>
</tr>
<tr>
<td>Owning the organs and deciding what happens to them</td>
<td>I8, I6, I5, I1, I15</td>
</tr>
<tr>
<td>No risks in donation</td>
<td>I1, FG1, I7, I8, I14, I13, I15</td>
</tr>
<tr>
<td>Organ donation is like giving life</td>
<td>FG1</td>
</tr>
<tr>
<td>Body is treated with respect</td>
<td>FG3</td>
</tr>
<tr>
<td>Seeing organ donation as heroic/saintly</td>
<td>I13, I1</td>
</tr>
<tr>
<td>Donating is quite similar to other types of helping such as volunteering</td>
<td>I14</td>
</tr>
<tr>
<td>Seeing donation as amazing and special</td>
<td>I11</td>
</tr>
<tr>
<td>No preference for recipient</td>
<td>I18, I15, I9, FG1, I7, I5, I19</td>
</tr>
<tr>
<td>Topic</td>
<td>Description</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Believing everyone should donate</td>
<td></td>
</tr>
<tr>
<td>Death</td>
<td>In Denial</td>
</tr>
<tr>
<td></td>
<td>Not wanting to think about own death/in denial</td>
</tr>
<tr>
<td></td>
<td>Talking about death when someone is dying</td>
</tr>
<tr>
<td></td>
<td>Talking about death is taboo</td>
</tr>
<tr>
<td>Accepting Mortality</td>
<td>Accepting own mortality/death as part of life</td>
</tr>
<tr>
<td></td>
<td>Comfortable talking about death</td>
</tr>
<tr>
<td></td>
<td>Accepting own mortality is linked with organ donation as can happen at any time</td>
</tr>
<tr>
<td>Thinking about loved ones die</td>
<td>Thinking of a child or loved one die is hard</td>
</tr>
<tr>
<td>Experience of loved ones die</td>
<td>Friend committed suicide</td>
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<td></td>
<td>Loss of close relative</td>
</tr>
<tr>
<td>Views of what happens when die</td>
<td>Soul floats away</td>
</tr>
<tr>
<td></td>
<td>Angels accompany soul</td>
</tr>
<tr>
<td>Brain Stem Death/Godly death</td>
<td>Accepting brain stem death as a form of death</td>
</tr>
<tr>
<td></td>
<td>Brain stem death and comas being mixed up and thinking of Euthanasia</td>
</tr>
<tr>
<td><strong>Burials/Funerals</strong></td>
<td>Appearance in one’s coffin influences donation</td>
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<tr>
<td></td>
<td>Don’t fully understand brain stem death compared to Godly death</td>
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<td></td>
<td>Appearance in the coffin doesn’t influence donation</td>
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<td></td>
<td>Arranging funerals is not affected by donation</td>
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<td></td>
<td>Funerals organised quickly, emotions happen after funeral</td>
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<td></td>
<td>Burial is tradition</td>
</tr>
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<td></td>
<td>Superstition about having body over the weekend, take a person with them</td>
</tr>
<tr>
<td></td>
<td>Body after donation to returned to Poland so can visit on All Souls Day</td>
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<tr>
<td></td>
<td>Donating may get in the way of a quick burial</td>
</tr>
<tr>
<td></td>
<td>Burials can take a while to arrange in cities</td>
</tr>
<tr>
<td></td>
<td>Open-casket funerals becoming less popular</td>
</tr>
<tr>
<td><strong>The need for more information</strong></td>
<td><strong>TV/Movies</strong></td>
</tr>
</tbody>
</table>

427
<table>
<thead>
<tr>
<th>Finding out information</th>
<th>Blood collection point</th>
<th>FG3, I10, I17, I9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning about donation/brain death through TV shows/movies (Grey’s Anatomy and 7 pounds)</td>
<td>FG1, I3, I1, I16, I12, I11, I9, I18</td>
<td></td>
</tr>
<tr>
<td>Awareness increasing in Poland</td>
<td>I2, FG1, I15, I11</td>
<td></td>
</tr>
<tr>
<td>Awareness in Poland not increasing</td>
<td>FG3</td>
<td></td>
</tr>
<tr>
<td>Awareness of demand for organs</td>
<td>FG1, I15</td>
<td></td>
</tr>
<tr>
<td>Organ donation in the media makes people think about it and increase knowledge</td>
<td>I17, I13, I16, I19</td>
<td></td>
</tr>
<tr>
<td>Would not find out more information about it, even if signed up</td>
<td>I10, I17, I9</td>
<td></td>
</tr>
<tr>
<td>Have to want to find out about it, people don’t tell you</td>
<td>FG3, I17</td>
<td></td>
</tr>
<tr>
<td>Go onto the internet to find out more</td>
<td>I12, I16</td>
<td></td>
</tr>
<tr>
<td>Learning from friends in UK/friends at medical school</td>
<td>I14, FG3, I2</td>
<td></td>
</tr>
<tr>
<td>Learning at school, early in life so can decide</td>
<td>I13, I17, I11, I16, FG1, I2</td>
<td></td>
</tr>
<tr>
<td>Campaigns</td>
<td>Adverts being seen</td>
<td>FG1, FG2, I14, I20</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>-----------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Adverts not being seen</td>
<td></td>
<td>FG1, FG2, I10, I11, I12, I13, I9</td>
</tr>
<tr>
<td>Ideas to reach Poles through billboards/internet/celebrities as don’t have TV or read paper</td>
<td>I14, I16, I12, I17, FG3, I15</td>
<td></td>
</tr>
<tr>
<td>In Poland, motorcyclists are automatically donors</td>
<td></td>
<td>I18, I11</td>
</tr>
<tr>
<td>Seen information about funeral costs in the media</td>
<td></td>
<td>I15</td>
</tr>
<tr>
<td>Knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being aware of most the organs removed</td>
<td>I3, I11, I12, I13, I14, I15, I17, I6, I5, I20</td>
<td></td>
</tr>
<tr>
<td>Lacking knowledge about donation</td>
<td>I4, FG1, I5, I7, I2, I19, I15, I11, I9, I10, I18, I17</td>
<td></td>
</tr>
<tr>
<td>Information and misinformation influencing donation</td>
<td>I10, I11, I14, I16, I17, I9</td>
<td></td>
</tr>
<tr>
<td>Wanting more information about it</td>
<td>I11, I12, I18, I15, I17, I18, I19</td>
<td></td>
</tr>
<tr>
<td>People from Polish villages would not have spoken about it</td>
<td>I11</td>
<td></td>
</tr>
<tr>
<td>The body is given structure after organ removal</td>
<td></td>
<td>I6</td>
</tr>
<tr>
<td>Language</td>
<td>Policies and Opting-In</td>
<td></td>
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</tr>
<tr>
<td>Not filling in forms as not understanding 'donation'</td>
<td>Not being aware of opting-in in the UK</td>
<td>I15, I18</td>
</tr>
<tr>
<td>Language not mattering as can look on the internet in Polish</td>
<td></td>
<td>I17</td>
</tr>
<tr>
<td>Not understanding TV adverts</td>
<td></td>
<td>FG3</td>
</tr>
<tr>
<td>Trust and Healthcare Professionals</td>
<td>Not trusting Polish paramedics</td>
<td>I5, FG1</td>
</tr>
<tr>
<td>Negative experiences of the NHS influence donation</td>
<td></td>
<td>I18, FG3, I12</td>
</tr>
<tr>
<td>Positive experiences of NHS</td>
<td></td>
<td>I11, I14</td>
</tr>
<tr>
<td>Not trusting NHS staff to save life</td>
<td></td>
<td>FG3</td>
</tr>
<tr>
<td>Trust NHS staff</td>
<td></td>
<td>I10, I12, I17</td>
</tr>
<tr>
<td>Experiences of the NHS not influencing donation</td>
<td></td>
<td>I17, I9</td>
</tr>
<tr>
<td>Experiences of NHS influencing donation</td>
<td></td>
<td>I18</td>
</tr>
<tr>
<td>Knowing medical students in Poland and being more comfortable with their level of training</td>
<td></td>
<td>I10, I15, I2, FG3, FG1</td>
</tr>
<tr>
<td>No experience of the NHS</td>
<td></td>
<td>I13</td>
</tr>
<tr>
<td><strong>Opting-In</strong></td>
<td>Being aware of opting in in England</td>
<td>I1, FG2</td>
</tr>
<tr>
<td>--------------</td>
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<tr>
<td></td>
<td>Not knowing how to opt-in – Boots/GP/online</td>
<td>I12, I9, I13</td>
</tr>
<tr>
<td></td>
<td>Has opted in in the UK – GP/online/Boots</td>
<td>I9, I11, I14, I12, I15, FG3</td>
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<tr>
<td></td>
<td>Not having the opportunity to sign up</td>
<td>I10</td>
</tr>
<tr>
<td></td>
<td>Not knowing how to ‘opt-in’ in Poland</td>
<td>I18, I9</td>
</tr>
<tr>
<td></td>
<td>Registering is confidential</td>
<td>I15, FG3</td>
</tr>
<tr>
<td></td>
<td>Has ‘opted-in’ in Poland</td>
<td>FG3, I7, FG2, I4</td>
</tr>
<tr>
<td></td>
<td>Organ donation seen as something that is put in someone’s will, not signing the register through different means</td>
<td>I20, I21</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Opting-Out</strong></th>
<th>Opting out is preferred</th>
<th>FG2, I4, I10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Aware of opt-out in Poland</td>
<td>FG2, I4, FG1</td>
</tr>
<tr>
<td></td>
<td>Not aware of opt-out in Poland</td>
<td>I4, FG3, I13, I18, I9</td>
</tr>
<tr>
<td></td>
<td>If donor in Poland, automatically donor in UK</td>
<td>I13, FG3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>The Body</strong></th>
<th><strong>God and the Body</strong></th>
<th>Sharing body as it is not yours</th>
<th>I3, FG1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Body not a gift from God</td>
<td>I4, I1</td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
<td>Reference(s)</td>
<td></td>
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<tr>
<td>Protecting the Body</td>
<td>People being selfish and not wanting others to have their organs</td>
<td>I9</td>
<td></td>
</tr>
<tr>
<td>Body Totality/Waste</td>
<td>People being selfish and not wanting others to have their organs</td>
<td>I9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not needing organs after die, someone else can use them/ not waste them</td>
<td>I10, I11, I13, I18, FG3, I14, I15, I16, I17, I4, I2, FG1, I9, I3</td>
<td></td>
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<tr>
<td></td>
<td>(don’t need body after death)</td>
<td></td>
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<td></td>
<td>Need for body totality/ don’t want body cut open</td>
<td>FG2, I1, I2, I5, I6, FG3, I11, I15</td>
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<tr>
<td></td>
<td>(Personal/religious/age)</td>
<td></td>
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<tr>
<td></td>
<td>Family not wanting body being destroyed may be upsetting but helping someone</td>
<td>I17, I11, I15</td>
<td></td>
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<tr>
<td></td>
<td>Family not being allowed to see body after donation</td>
<td>I16</td>
<td></td>
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<tr>
<td>Operated on after death</td>
<td>Not wanting to be operated on</td>
<td>PO</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Being operated on after death doesn’t matter</td>
<td>FG3, I13, I9, I10, I18</td>
<td></td>
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<tr>
<td></td>
<td>Wouldn’t notice that has been operated on after death</td>
<td>FG3</td>
<td></td>
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<tr>
<td>Metaphors</td>
<td>Body as machine with spare parts</td>
<td>I13</td>
<td></td>
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<tr>
<td></td>
<td>Body as form of recycling</td>
<td>I17, I14, I18, I16</td>
<td></td>
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<tr>
<td>Cartesian View</td>
<td>Religion and organ donation</td>
<td></td>
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<td>------------------------</td>
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<tr>
<td>Not believing in soul</td>
<td>FG1, I1, I3</td>
<td></td>
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<td></td>
<td>Body as a vessel for the soul</td>
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<td></td>
<td>FG1, I1, I3, I5, I7</td>
<td></td>
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<tr>
<td>Religion and organ donation</td>
<td>Generations young people may listen to priest more about donation</td>
<td></td>
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<tr>
<td></td>
<td>I18, I12, I14</td>
<td></td>
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<tr>
<td>Leaders</td>
<td>Strong figures such as priests have strong influence to formulate opinion</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>I18, FG2, I2, I3, FG1, I10</td>
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<tr>
<td></td>
<td>Church leaders having little influence</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>I14</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Priests not raising issue as seen as hospital issue</td>
<td></td>
<td></td>
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<td></td>
<td>I15</td>
<td></td>
<td></td>
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<td></td>
<td>Donation not mentioned in Mass</td>
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<td></td>
<td>I14</td>
<td></td>
<td></td>
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<td></td>
<td>Would not talk to priest about decision to donate</td>
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<td></td>
<td>I9</td>
<td></td>
<td></td>
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<td></td>
<td>Church could promote donation</td>
<td></td>
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<td></td>
<td>I9, I10, I12, I21</td>
<td></td>
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<td></td>
<td>Pope can't donate as body is sacred</td>
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<td></td>
<td>I11, I12, I19</td>
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<tr>
<td>Rewarding Donation</td>
<td>God would not reward donating</td>
<td></td>
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<td></td>
<td>I10, I12</td>
<td></td>
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<tr>
<td>Religion having an influence</td>
<td>Religion having no influence on donation</td>
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<td></td>
<td>FG1, I1, I8, I6, I7, I20, I21, I19, I18, I9, I16, I12, I13</td>
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<td></td>
<td>Religions restricting donation such as Jehovah Witnesses and</td>
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<td></td>
<td>FG1, I1, I6, I5, I18, I13, I14</td>
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<tr>
<td>Category</td>
<td>Description</td>
<td>References</td>
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<tr>
<td>Islam</td>
<td>Religious teachings on helping others and loving others like yourself may influence donation</td>
<td>FG2, I2, I3, FG1, I18, I17, I12, I9, I16, I21</td>
<td></td>
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<td></td>
<td>Islam the body has to be looked after and want it whole</td>
<td>FG3, I17, I18</td>
<td></td>
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<tr>
<td></td>
<td>Impact of religion on decision to donate is individual</td>
<td>I18</td>
<td></td>
</tr>
<tr>
<td>Cultural</td>
<td>Donating is cultural not religious</td>
<td>I1</td>
<td></td>
</tr>
<tr>
<td>Catholicism</td>
<td>Catholicism supporting donation</td>
<td>FG1, FG2, I1, I3, I10, I21, I13, I14, I9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unaware of Catholicism stance</td>
<td>I15, I19</td>
<td></td>
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<tr>
<td></td>
<td>Catholicism being against donation</td>
<td>I3, I10</td>
<td></td>
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<tr>
<td></td>
<td>Donating is showing love to others</td>
<td>I12, I21</td>
<td></td>
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<tr>
<td>Catholic death</td>
<td>Resurrection not influencing donation</td>
<td>FG1, I1, I2</td>
<td></td>
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</table>
Appendix Eight: Ethics Report and Approval
Institute for Health Research

Research Proposal Ethical Approval Form (RS1_RA1_IHR)

Complete this form and submit it to the Institute for Health Research Ethics Committee.

- Under graduate and post graduate students should attach a copy of their full proposal.
- Staff should attach (or include below) an abstract of their research proposal.
- All applicants should include any consent forms or information sheets, and data collection tools you intend to use with your participants.
- If the intention is to work and specific agencies or establishments the applicant should attach copies of any letters of agreement with those agencies/establishments.

Provide as much information as you are able to on this form and answer the questions as fully as you can. INSTRUCTIONS FOR SUBMISSION ARE TO BE FOUND BELOW THE SIGNATURE PANEL TOWARDS THE END OF THIS FORM

ALL staff and students MUST obtain ethical approval BEFORE beginning any fieldwork

All proposals:

Name: Mrs Chloe Sharp

Contact email/phone: chloe.sharp@beds.ac.uk / 01582 743737

Date: 06 May 2011

Title of Proposal: To examine the relationship between deceased organ donation, gift exchange and religion: A case study of Polish migrants in Luton.

Fieldwork: 23rd May

Anticipated Start Date: Project: 28th September 2009 2011
Anticipated Duration of project: 3 Yrs: 0 Months

Is the project to be externally funded? YES NO

Student proposals:

Supervisor Name: Professor Gurch Randhawa and Dr Kathryn Ellis

Award studied for: PhD

N.B. Before completing this form you should read the NHS National Research Ethics Service Guidance available from http://www.nres.npsa.nhs.uk/applications/guidance/[Applications from other disciplines such as psychology or social studies should read the ethical guidance relevant to their discipline]

Undergraduate and Postgraduate students should complete this form in consultation with their supervisors

What are the key aims or objectives of your research? (Provide a brief summary in bullet points)

Objective 1: To examine the different factors relating to perceptions of deceased organ donation among Polish migrants in Luton.

- To gain an insight into perceptions and misconceptions of deceased organ donation.
- To examine the motivation behind giving organs.
- To analyse the concept of the gift and gift-giving.
- To analyse the concept of altruism and motivation behind altruistic acts.
- To critically evaluate religiosity and the role religion plays in deceased organ donation.
- To critically evaluate gender differences in perceptions of gift giving, deceased organ donation and religion.
- To analyse the role that migration factors, such as length of stay and sense of belonging, have on views towards giving, deceased organ donation and religion.

Objective 2: To examine the inter-relationship between these factors.

- To analyte how gift exchange theory interacts with social capital, organ donation and religion.
To evaluate how religion, religiosity, gift exchange, altruism, social capital and organ donation all connect.

To examine whether migration factors or gender factors have impacted on the perception of the interaction between these elements.

What is the key question your research will address?

The key question that the research is addressing is 'what is the interaction between gift exchange theory, deceased organ donation, social capital, altruism, religiosity and religion?' There have been a number of studies which have examined the relationship between gift exchange theory and deceased organ donation or gift exchange theory and social capital. Other studies, with mixed results have linked altruism with religion and religiosity. However, these concepts have not been examined together. I am going to be taking a case study approach and will be asking Polish migrants their view on the interaction between these elements.

Who is your target group or sample?

The target group for this study are Polish migrants from Luton, Polish migration to the UK has increased significantly since the EU enlargement in 2004. In Luton, one of the areas with a high number of Polish migrants, eighty four per cent of Working Registration Scheme applications were from Polish nationals. In addition to a high number of Polish migrants in this area, there is an established group of post-war migrants. After the Second World War, soldiers who did not return to Poland stayed in the UK and were temporarily housed, one of the sites was in Marsworth, near Dunstable and it is from this camp that the Polish community grew, including Polish mass and Polish Saturday School. Presently, there are ex-servicemen clubs that exist in Luton and Dunstable showing that they still reside in Luton today. In addition to post-2004 and post-war Polish migrants, a wave of migrants came to the UK post-1989 after the collapse of the Soviet Union. Therefore, my sample are post-war, post-1989 and post-2004 migrants, the sample will be grouped depending on how long they have stayed in the UK for, for example, 7 years or less, 8-22 years or longer than 23 years. The sample will be split based on sex, White (2011a) found that there is gender inequality in Poland due to conservative and Catholic gender roles within this sample group. In addition to this, it has been found between
sexes that there are differences in ethical reasoning (Davies, 2006).

The Polish group has been chosen for a number of reasons, firstly, there is very little research representing the views of Polish migrants on each issue and the examination of the interaction of them; organ donation, religion, social capital, gift giving and altruism. Secondly, there have been a number of studies that have shown the perspectives of South Asian and Black Caribbean and Black African migrants in the UK in how they view organ donation and their perspectives on altruism and religion are elicited. However, this research illustrates predominantly Anglican and Islamic views as opposed to Roman Catholic views. Thirdly, the post-2004 Polish migrant group have been migrating to the UK in large numbers and there are signs that they are settling, therefore organs may be needed for Polish patients. This means that their views should be represented to provide health care professionals an understanding of their religious and cultural views towards donation and gift giving within this context.

What data collection methods will you use?

Focus groups (between 12-18)

Answer the following questions by checking ‘yes’ or ‘no’ and supplying any additional information as required

1) Does the study involve children (anyone under 18 years), vulnerable participants or those who are unable to give informed consent? [Please consult the notes on researching with children and young people and the list of those who may be considered ‘vulnerable’ at the end of this form before completing]

NO

• If YES: Explain what steps will be taken to ensure that participants understand what participation will mean

• If YES: Have/will researchers been CRB checked? (obligatory)

YES

NO

• If you are researching with children/young people, what is your target age group?
2) From whom will consent be sought and how is consent to be given? (It is anticipated that written consent will be sought in most circumstances)

Consent is sought from each participant and consent is written. Participants will be provided an information sheet which they have 24 hours to read before signing the informed consent sheet.

3) Is participation voluntary?

YES

4) Will it be necessary for participants to be involved without consent? (e.g. covert observation in public places)

NO

5) Will the study make use of gatekeeper(s) to access participants?

YES

6) Will the study include participants or involve accessing information or case files pertaining to those who are part of your client group, case load or with whom you are working?

NO

- If YES: How will you obtain their consent to use information about them, access their files or otherwise participate?

7) Will the study be exploring ‘sensitive’ topics? [Please consult the list of what may constitute a ‘sensitive’ topic given at the end of this form]

YES

8) Will the research investigate involvement in any illegal activity?

NO

9) Will any incentives or rewards be offered for participation?

YES

- If YES: Explain the nature of the incentives or rewards

Participants will be offered a £20 Luton Mall voucher for taking part, no travel expenses will be offered.
10) Is the research likely to cause any distress to participants?
    NO

11) Will arrangements be made to support participants after their involvement
    in fieldwork if necessary?
    NO
    • If YES: Please explain the nature of the arrangements

12) Will the research involve intrusive interventions? (e.g. provision of drugs to
    participants, hypnosis, physical exercise, blood or tissue sampling)
    NO

13) Will the research involve any participants from the NHS (patients or staff)
    NO
    • If you have answered YES to this question you MUST additionally submit
      your proposal to the National Health Service Local Research Ethics
      Committee via the Integrated Research Application System (IRAS):
      https://www.myresearchproject.org.uk/

14) Will the study involve clients or workers of a Local Authority?
    NO
    • If you have answered YES to this question you should additionally seek
      the permission of the relevant Local Authority Research Governance
      Committee.

15) Will ethical approval for the project be sought from any other source?
    NO
    • If you have answered YES to this question please give details and
      forward the letter of approval to the Chair of Ethics Committee of IHR
If in doubt about completing any aspect of this form, consult your supervisor or, where appropriate, a member of the IHR Ethics Committee

16) Summarise below any ethical issues involved in your proposed research and state how you intend to address them, paying particular attention to any of the questions above to which you have answered 'yes'..

If your research involves fieldwork with human subjects provide details of:

- how you will gain informed consent,
- how you will ensure confidentiality and deal with disclosures of harm or illegal activity,
- how you will inform participants about the purpose of the research and dissemination of findings, who will have access to the data,
- what steps will be taken to ensure the safety of researchers and participants,
- what mechanisms you will employ to enable participants to withdraw from the research if they should wish to do so,
- how you will store the data you collect and what you will do with it on completion of the project.

[NB. If it is envisaged that data will be processed outside of the research team (e.g. external transcribers) a confidentiality agreement may be required.]

Please see the attached files to illustrate how I will achieve the above.

Applicant declaration

I understand that I cannot begin any fieldwork until the application referred to in this form has been approved by all relevant parties. I agree to carry out the research in the manner specified. If I make any changes to the approved method I will seek further ethical approval for any changes.

Signed (Applicant): C. Sharp Date: 06 May 2011
Signature of Supervisor/ Director of Studies (N.B. This is NOT required for staff applications)

........................................................................................................ Date: ..........

**Note to supervisors:** Signing this form certifies that in your opinion, the project described here is ethical under Departmental and NHS guidelines. Do **NOT** sign if you are unsure or if the student has not attached complete details of the research design and methodology.
Appendix Nine: Consent Forms and Participant Information

Pack
Recruitment Form (English Version)

Dear Participant,

Thank you for showing your interest in taking part in this study. Please complete the information below so I am able to choose the most suitable group for you.

<table>
<thead>
<tr>
<th>Question</th>
<th>Please write your answers in this column</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you male or female?</td>
<td></td>
</tr>
<tr>
<td>How long have you been in the UK for?</td>
<td></td>
</tr>
<tr>
<td>How long have you lived in Luton for?</td>
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</tr>
<tr>
<td>Are you confident in speaking English in the group discussion?</td>
<td></td>
</tr>
<tr>
<td>If no, are you going to bring someone to translate for you or would you prefer a translator?</td>
<td></td>
</tr>
<tr>
<td>Which dates are you not available?</td>
<td></td>
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</tbody>
</table>

Please let me know when you will be available by putting a 'X' in the box:

<table>
<thead>
<tr>
<th>Date</th>
<th>9-10</th>
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</table>
Please let me know your contact details for me to contact you on to arrange the group and let you know if there are any changes.

<table>
<thead>
<tr>
<th>Mobile Telephone Number</th>
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<tr>
<td>Home Telephone Number</td>
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<td>Email Address</td>
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</table>

I will contact you very soon to arrange the group discussion and look forward to meeting you. Thank you very much for volunteering to take part in my study.

Yours Sincerely

Mrs Chloe Sharp
Recruitment Form (Polish Version)

Drogi Uczestniku,

Dziękuję za okazanie zainteresowania moim badaniem naukowym i za wzięcie udziału w nim. Proszę wypełnić poniższy formularz, aby móc ustalić spotkanie.

<table>
<thead>
<tr>
<th>Płeć</th>
<th>Męska/żeńska</th>
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<tr>
<td>Jak długo mieszkasz w Anglii?</td>
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</tr>
<tr>
<td>Czy jesteś osobą religijną? Jeśli tak, to jakiej wiary?</td>
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</tr>
<tr>
<td>Jak długo mieszkasz w Luton?</td>
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<tr>
<td>Czy mieszkasz w Luton sam, lub z rodziną?</td>
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<tr>
<td>Czy potrafisz mówić po angielsku na tyle by, przeprowadzić tą rozmowę po angielsku?</td>
<td>Tak/Nie</td>
</tr>
<tr>
<td>Jeśli nie, czy znasz kogoś kto by przyszedł z tobą by przetłumaczyć twoje odpowiedzi?</td>
<td>Tak/Nie</td>
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<tr>
<td>Jeśli nie, czy wymagasz by tłumacz był obecny podczas rozmowy?</td>
<td>Tak/Nie</td>
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Proszę umieścić odpowiedzi w tej kolumnie.
Które dni/godziny są nieodpowiednie aby, zorganizować spotkanie?

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Poniżej proszę zaznaczyć swoją dostępność krzyżkiem, to pomoże mi w ustaleniu dzień i godzinę spotkania:

Proszę podać swoje dane kontaktowe, aby móc się skontaktować z tobą by ustalić/potwierdzić konkretny termin spotkania.

<p>| | |</p>
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<td>Adres mailowy</td>
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Wkrótce skontaktuje się z tobą by móc zorganizować spotkanie. Bardzo dziękuje za zainteresowanie moim badaniem, oraz za chęci spotkania się ze mną.

Z poważaniem,

Mrs Chloe Sharp
Information about the group discussion and interviews

An Invitation to Take Part in the Study

Not much is known about the Polish views towards organ donation and as a member of the Polish community, you are invited to take part in this study. Before deciding whether or not you want to take part, please read this information sheet to learn more about the research and what it involves.

Overall, it will involve answering some questions about deceased organ donation, religion and giving gifts in a group discussion or interview. It will take about 1-1 1/2 hours and will take place at a local venue to suit all of those who take part.

Why do this research?

The reason why this research is being done is to find out more about what the Polish community thinks about deceased organ donation, religion and giving gifts and if there are any links between these. This research will help create a picture of the attitudes, knowledge and experiences of the Polish community towards deceased organ donation, religion and giving gifts. This is an academic study and it could make a difference to health policy.

Why have I been chosen?

You have been invited to take part in this study because you are a member of the Polish community, which is the basis for inviting people to take part. The groups will be split up depending on how long you have been in the UK for in total.
Do I have to take part in this research?

You do not need to take part in this research, it is entirely voluntary and is your choice. By taking part you are helping to improve the knowledge about the views of the Polish community towards deceased organ donation, religion and giving gifts.

What happens if I do take part?

If you do decide to take part, you will need to give me your contact details and I will let you know about the dates and times other people can do and I will organise the group discussion. If you are doing an interview, I will sort out a time, date and place with you that suits you. The interview will last approximately an hour and will be conducted in English.

It will be important for you to give your personal opinions about the topics and these will not be judged in any way. There are no right and wrong answers to the questions. The information that you give will be tape recorded and your answers will help build a picture of the views and experiences of the Polish community and deceased organ donation, religion and giving gifts. You will remain anonymous, this means that your name will not be used, you will be given a code number (FG1 P1 for example). In the final write up of the study, there is no possibility of you being identified in any way.

What do I need to do?

You will be given at least 24 hours to read this information sheet to give you enough to make a decision about whether you want to be included in the study. If you do, you need to come to the venue, on the day and time organised, to take part in a group discussion or interview about deceased organ donation, religion and giving gifts. I will take your contact details to arrange the group or interview, these will be kept confidential and will not be used in any way to identify you. All personal details will be destroyed once the fieldwork is complete. During the group discussion or interview, you do not have to answer all the questions and you can leave at any time.

Travel expenses and a 'Thank You' gift

Travel expenses will not be given, however the venue will be in Luton so that it is convenient for everyone to get to. To thank you for your time if you choose to take part in
the entire group discussion or interview, at the end, you will be given a token worth £20
to spend at the Luton Mall.

What are the benefits of taking part?

Taking part in the group discussion or interview will not necessarily benefit you directly,
but the information that we get from this study will help me and the NHS understand
more about the Polish community and how deceased organ donation, religion and giving
gifts are viewed.

What are the risks of taking part?

The topics that will be discussed may raise feelings that could be upsetting for some
people (see Sensitive Topics below). A cost to you to taking part in this study will be your
time, this group discussion or interview will last between 1-1½ hours, but if you want to
leave at any time you can.

Getting your consent to take part

Taking part in the study is completely voluntary, it is your choice. You will be asked to
confirm your consent to take part by signing a form that has statements with boxes which
you initial to show that you agree and have given consent. These statements are to show
that you are aware that the interview is taped, that you understand this information and
the aims of the study; it also confirms your understanding that you can withdraw at any
time by letting me know in the discussion that you would like to leave.

The anonymised data (names or anything that can identify individuals are removed) are
securely stored for two years and then destroyed. Some of the data may be written
verbatim (word for word) in the write up of the study. The discussion is recorded so that I
can talk to the group without having to take notes. I will answer questions about this
information sheet or about the study at the beginning of the group discussion or
interview, but can answer them earlier if you contact me through my email address
(chloe.sharp@beds.ac.uk). If you are willing to take part in the study, you will be asked to
sign the consent form.

Sensitive topics

Some of the questions may make you feel sad or upset, especially questions around death
and perhaps the process of organ donation itself. Although these are sensitive topics and
questions around them can be difficult to answer, please bear in mind that unless we can
understand your views about organ donation after death and how these relate to religion and giving gifts, it will not be known how these are viewed and no suggestions can be made to improve health campaigns or access to information about organ donation.

**What if I am worried about my English?**

The group discussions or interviews will be conducted in English, if you are not sure about taking part because you are not confident in speaking English, do not worry as a Polish translator will be at the group discussion or interview. You can bring a friend or relative to translate for you instead if you prefer, but they will not receive a voucher, you may share your voucher with them. Please let me know if you are worried about your English and whether you want to bring someone with you to translate.

**What if I want to stop?**

If after reading this information sheet you decide you want to take part and then change your mind, you are not obliged to continue, you can withdraw at any time without explaining why. You are able to stop part of the way in the group discussion or interview. The information that you provide will be removed from the transcripts (written up data from the group discussion) and there is no possibility of you being identified. The information from the interview will be completely destroyed.

**What if something goes wrong?**

If you are unhappy about any aspect of the study or your treatment as a participant in the study, you should speak to my study supervisor, Professor Gurch Randhawa – gurch.randhawa@beds.ac.uk. If you wish to complain formally, you can do this by contacting the Pro Vice-Chancellor of Research, Professor Carsten Maple – carsten.maple@beds.ac.uk.

**What happens to the information that I give?**

All the information that is recorded at the group discussion or interview will be transcribed and analysed. The themes from the analysis will be included in the study and to illustrate some points, some of the responses will be included that are verbatim, but your identity will not be attached to these. The information will be kept in a secure and locked location and will be used for this study only. The data will be stored under the Data Protection Act (1984) and will be destroyed two years after collection. This study is funded by NHS Blood and Transplant and they will consider the conclusions drawn from the study.
How can I find out the results of the study?

The study is due for completion in September 2012. If you are interested in finding out the results, please contact me at chloe.sharp@beds.ac.uk at this point and I can provide you with a summary of the results and conclusions drawn from the study. It may be made available in the University of Bedfordshire library where it is possible to view the study in its entirety.

What happens next if I decide to take part?

If you are interested in taking part in this study, please contact me at chloe.sharp@beds.ac.uk and I will email you a form to fill out letting me know more information about you so I can organise the best group for you to go in to. I will call or email you to arrange a suitable time and day to come along to the place that the group discussion or interview will happen. Any questions or concerns that you may have can be discussed with me.

Who is organising and funding the study?

NHS Blood and Transplant have provided funding for this research for the University of Bedfordshire to carry out, I am a PhD student and this study is my PhD. A PhD is a three year research degree. The PhD is supervised by Professor Gurch Randhawa who is an expert in organ donation and has conducted a lot of research in this area, to find out more about him, please go to http://www.beds.ac.uk/research/ihr/staff/gurch-randhawa.

Who has approved this study?

This study has been approved by the University of Bedfordshire Ethics Committee.

Further information and taking part in the study

If you would like to take part in this study or want any further information, please contact me at chloe.sharp@beds.ac.uk or telephone me on 01582 743737.

Thank you for reading this information.
Dear Participant,

Thank you for taking the time to take part in this study.

**Project Information**

This study is being undertaken by the University of Bedfordshire on behalf of NHS Blood and Transplant, which is part of the NHS. Very little is known around the views of people from Poland and organ donation. The aim of this study is to find out about the role and relationship between organ donation, religion and giving gifts.

I would like to discuss your general opinions NOT personal experiences, your opinions will not be judged in any way. Only the overall findings of this study will be fed back to NHS Blood and Transplant, no individual information will be provided it is completely anonymous.

**Consent to participate:**

1. I confirm that I have read and understood the information sheet and aims of the study above and have had the opportunity to consider this and ask questions which have been fully answered.

2. I understand that the information I provide will be treated confidentially, and that it will be anonymous. I understand that the data will be locked in a secure place and then destroyed in accordance with the Data Protection Act (1998).

3. I understand that my participation is entirely voluntary and I am free to withdraw from the research at any time and for any reason. I am aware that if I do decide to withdraw, any data obtained up to that point will be destroyed.

4. I understand that I am free not to answer any questions that I do not wish to.

5. I understand that the interview will be audio taped and that some quotations may be used verbatim in the write up of the study and am happy for this to happen.

6. I agree to take part in this study about organ donation, religion and giving gifts.
Please complete the following questions:

1. I am male/female
2. Age_________
3. Where in Poland are you from?____________________
4. Highest education qualification____________________
5. Occupation____________________
6. Length of stay in UK in total____________________
7. Reason for coming to the UK____________________
8. What is your religion?____________________
9. Do you attend church? Yes/No
10. How many times a week do you attend?_________
11. How many children do you have?____________________

Please sign to confirm the information above is correct and to confirm that you understand and agree to the above.

__________________  ___________  __________________
Name of Participant  Date        Signature

__________________  ___________  __________________
Name of Researcher  Date        Signature

__________________  ___________  __________________
Name of Researcher  Date        Signature

Many thanks,

Chloe Sharp, PhD Research Student
Dear Participant,

Thank you for your time today. All of the information that you have disclosed will be treated in the strictest confidence and will be kept anonymous.

If you feel you have been affected by this topic and would like to speak to the donor co-ordinator at the Luton and Dunstable hospital, contact Alia Rashid (Alia.Rashid@nhsbt.nhs.uk).

If you are interested in finding out the outcome of this study or have any questions relating to the study, please contact me on chloe.sharp@beds.ac.uk. If you have any complaints about your treatment as a participant in this study, please contact Professor Gurch Randhawa (gurch.randhawa@beds.ac.uk).

If you would like more information on organ donation and religion, the following websites are also very useful:

www.organdonation.nhs.uk

www.bbc.co.uk/religion/religions/christianity/christianethics/organs.shtml

Thank you again for your time,

Chloe Sharp

PhD Research Student
University of Bedfordshire
Appendix Ten: Notes from the Conversation with the SN-OD
Potential donor – the medical team speak to the family if it is not in the best interest to continue care – judging from the family whether they are taking in what you are saying. Introduce transplant – option for OD – may or may not check the ODR at this point – if the patient is on ODR – their wish is discussed. If they are and the family refuse – ask them why? Usually it is because they don’t have enough information. Explain the process – better understanding usually are on board. They can refuse legally even if on ODR – the patient gives consent but the family can’t override this. Need to give it authorisation. Ethically the trauma can be greater then don’t want them to go through an more.

Things people are usually unhappy with – think that limbs will come back in a box. They assure them that it is not like that and they can have an open casket funeral if they so wish. Lack of knowledge to the process. No religious barriers. Depends on the decision maker in the family – have to use the HTA hierarchy but everyone must all be in agreement.

Negative view of ODT from patients and HCP – vultures and grim reapers. Developed a long contact model – spend more time – make light of the situation. Each family is very different in their needs. The nurse’s attitude does have an effect. There is a debate if wishes should be overridden.

It is important at the time that their loved one is gone – don’t care about anyone else – even saving other people’s lives.

Don’t use ‘gift’ or ‘help’ or any of those terms in the discussion – but these may be in their minds from health promotions. Families watch BSD testing, find it helps. Nothing relating to faith comes in as a barrier. Give them a leaflet about OD but not about religion. Means they can read about it and feel they are doing something.

Muslim feel that the soul/person hasn’t gone and that they are out of the body looking over it.

Misleading states if there is an increase on the ODR as families can still refuse OD – more family discussion is needed. Look at Spain’s approach.

Death rituals important – Muslim family do last bathing.

Email – Academy of Medical Royal Colleges – Code of Practice for the Diagnosis and confirmation of death. Patient assessment. Consent. Diagnosis of BSD.
Appendix Eleven: Themes in Findings Chapter
<table>
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<tr>
<th>THEME</th>
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<tr>
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<td>• Post-2004 Migration</td>
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<td>• Post-war and Post-2004 Polish Migrants' Lived Experiences of Luton and Dunstable</td>
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<td>• Social Networks</td>
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<td>Altruism and Gift-Giving</td>
<td>• Altruism and Putnam's Voluntariness</td>
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<td>• Empathy</td>
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<td>• Egoism</td>
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<td>• Poland: From Collectivism to Individualism</td>
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<td>• Civic Engagement</td>
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<td>Religion and Religiosity</td>
<td>• Catholicism as Part of Polish Culture and Tradition</td>
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<td>• Practicing Catholicism in the UK</td>
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<td>• Non-Practicing Catholics in the UK</td>
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<td>• Non-Believers</td>
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<td>• Lack of knowledge about donation and registering</td>
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<tr>
<td>and Religion</td>
<td>• Thinking about giving one's organs posthumously</td>
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<td>• Deceased organ donation as an 'altruistic gift'</td>
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<td>• Attitudes toward family discussion</td>
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<tr>
<td>Attitudes toward Deceased Organ Donation:</td>
<td>• Perceptions of donating a relative's organs</td>
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<td>Pre-Death</td>
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460
| Deceased Organ Donation: Post-Death | • Conceptualising the deceased body and transplantation  
| | • Funeral practices  
| The role of social capital | • Contributing toward society  
| | • Trust in the NHS  

461
Appendix Twelve: Evolution of the Conceptual Map
Here are two examples:

![Diagram](image-url)

Figure 20: Card sorting by participant: Example one

This participant had clustered organ donation, giving gifts and altruism together, showing that he or she perceived these to have the most significant links to each other across the themes discussed in the interview. Community and religion were also thought to have an influence but were placed further out as they were viewed to relate less to organ donation, giving gifts and altruism.

![Diagram](image-url)

Figure 21: Card sorting by participant: Example two

Here, the participant has shown that organ donation is linked with society and local community, showing these aspects of social capital were significant. Religiosity was placed
a away from organ donation, society and local community, showing that this has an influence but it is not as important.

The next stage of the map development built upon these data collected, which were coded and analysed and created the constructs and sub-constructs of the final map. The constructs and sub-constructs that emerged were tested and developed over the subsequent interviews and were shown to the participants who would comment on the map, as opposed to the card sorting exercise. Below is first map that was developed.
Figure 22: The first map
This first map was based on concentric circles as it represented levels of importance how the relationship between deceased organ donation and the other elements in the study related. The concentric circles shows these levels of importance, the individual is at the centre of the circle as individual differences such as levels of religiosity, experiences in helping others, accepting of mortality and views towards their own body were thought to have most influence over views toward donation. The widest ring was thought by the participants to have least importance in donation, this was religion and religious leaders. Catholicism did not overtly support donation and participants had had little experience within the church of discussing the issue.

A limitation of this shaped map was how scholars from different fields would interpret the map. Also, the concentric ring map had been originally developed by Burgess (1925) to explain social structures and this map may be easily misinterpreted to show for example different social contexts as spaces of how relationships exist rather than significance.

The next map moved away from this shape to an inverted pyramid and could be viewed as a 'slice' of the onion shaped map as it showed levels of importance in a hierarchical form.
Figure 24: The second map: Later version
This later version of the inverted pyramid showed that deceased organ donation, gift exchange theory and religion were most important at the individual and cultural level and less significant at the religious level. The individual’s views towards deceased organ donation may be influenced by feelings towards death and dying, knowledge of donation and altruistic motivations to help influence an individual’s views towards donation and the experience of donating a loved one’s organs. Finally, there is a religious level which explores rituals around death may be connected with donation on a religious and cultural level as it links with the way the body is viewed, and whether it should be buried whole.

There was a shift again in the thinking behind the shape of the map as on further reflection and analysis, the notion of context was thought to add a further dimension to these relationships that had not been highlighted in a previous conceptual map. This contextual aspect meant that this inverted pyramid shape would no longer be suitable.

The earliest version of this map is this:

![Figure 25: The final map: Earliest version](image)

This map considers the interaction of organ donation, gift exchange and religion in an individual space, for example, the way in which gift exchange and deceased organ donation may link because the individual may view the organ as a gift. It is also a concept that may be abstract because it is a decision that would be made after an individual dies and they would not therefore experience it. Overall, this map illustrates that the Polish community view donation in two contexts and the relationship between gift exchange, altruism, social capital, religion and religiosity can be shaped by many factors, making these relationships fluid and complex. Within the constructs of the branches there would be sub-constructs to illustrate significance as highlighted in previous maps. Below is the map in its final stage.
Social Representation of Donating to Society and Humanity

Individual Social Representations

Social Representation of the Donor and Donor's Characteristics

Donating to Strangers

Social Representation of the Allogeneic Donor

Social representation of Trust in the NHS

Brain Stem Death and Catholic Death

Death

Donating to UK Society

Family decision about registering as a donor

Social Representation of Death

Individual Context

Donating to Humanity

Socio- and Macrocultural Context

Requested Allocation: The Conditional Gift

Deceased Organ Donation: Knowledge and Misconceptions

Figure 26: The final map: Finished version

This map shows the main constructs in dark blue and the sub-constructs in white boxes with a dotted outline.

After suggestions from the examiners in the viva, the final map looked like this:

Figure 27: Map Post-Viva
Appendix Thirteen: Notes from the Conversation with the Priest
Church attendance

Older people and children going to church more and teenagers and young adults generally do go to church less. There are many factors involved, school, upbringing, ethics, children veering away, law and discipline in attending church, children have more control about going to church, those going to university are coming away. In the UK, some lose their faith, others gain their faith and may become more religious. There are 15,000 Poles in Luton and Dunstable and around 500 go to church.

In St. Albans there is a greater population and few attend church. Around 8% of the Poles are religious. In Poland 90% are said to be Roman Catholic but this is misleading as this classification is based on baptisms but only 30-35% attend church. (Parents attend as want their children to continue the traditions)

Children in Poland, their grandparents and parents are asking them about church and what they studied in bible class, there is more of a pressure to be Catholic.

Many children are baptised as parents think in a magical way, that the devil is entering the child.

Helping others

Catholic theology - early times, the main teachings are based on love, people misinterpret the church's view to help, but it comes from love. Humanitarianism is linked with religion. Jesus in need was fed as see others as themselves and want to help, reciprocated in this way. The old testament says that people are built upon others, that we are all one. We can't love God if we can't love others. There is a quote that says that if you can't love what you see then you can't love what you don't see.

Serve and help others - Jesus passed on the message of love. Lots of people forget how it was formed.

The body and death

Not needing the body after death, Jesus came back in the same body but it was modified. Plato said that his body was the prison for the soul, that the body is disgusting and good riddance to it. The other way is to help others that comes out of love, perhaps the view of not wanting to waste the body is linked with the latter.

When someone dies, they go to heaven on two wings - faith and logic.

The issue with organ donation is that it is an advanced technology in advanced countries and priests haven't said much about it apart from it is an act of love but lack of speaking about it links with lack of education and knowledge about it, it is
almost taboo. At the dinner this was highlighted as the church's view was questioned.

If people don't ask or know they have their own stance but the devoted will know.

The body is supposed to be intact as when you are resurrected you have your own body it is modified. You can give your organs but not all of them like skin and bones as you will need them. Jesus's hand scars - sign of love. Body resurrected is the one used in Heaven when it was at its best - see this in the pictures of the Virgin Mary.

Being buried is linked with having respect for the body - scattering ashes is disrespectful and ungodly.

Fenixon - wrote about euthanasia

Tanatologia - teachings about death and the phenomenology of death, theological views of death

John Paul II - pontifs - highest documents of the church

Evangelium vitae - death and organs

Abstract (English) Bortkiewicz Pawel - Tanatologia. Zarys problematyki moralnej (Thanatology. an outline of moral issues) Adam Mickiewicz University. Vol 29. p. 304

Heidigger - radical view of death.