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Donor Family Consent and the Behavioural Perspective Model

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DONOR FAMILY CONSENT AND

THE BEHAVIOURAL

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A radical behaviourist approach to exploring and stimulating organ donation consent

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Abstract

Organ transplantation is one of the greatest medical innovations of the 20th century, providing individuals facing death a hope of survival. In the context of the UK this life saving procedure is totally dependent on the altruism of the potential donor's family. Currently demand for transplantable organs outstrips supply, resulting in 1000 individuals dying each year. Donor family refusal has been consistently identified as the greatest obstacle preventing an improvement in donation rates. The need for new theory and theory driven methods in understanding donation consent has been highlighted in the existent literature. To date there is a notable absence of a theoretical framework that allows for both individual and external level factors to be analysed together, thus providing a truly holistic depiction of this complex human behaviour.

This thesis seeks to fill this notable gap by exploring donor family consent from a radical behaviourist perspective via the application of the Behavioural Perspective Model (BPM). Specifically this thesis documents a dual-phase sequential research strategy that seeks to answer three overarching research questions: (1) Can the decision to consent be understood as an operant process? (2) What patterns of reinforcement increase the likelihood of consent? (3) Can donor family consent be stimulated via behavioural intervention?

The first empirical phase utilises a case study approach in the exploration of donor family consent, drawing upon multiple sources of evidence (N = 55). The second empirical phase builds upon the findings of the first by utilising a novel simulated laboratory experiment methodology to examine how organ donation consent can be stimulated in different hypothetical scenarios based upon the eight contingency categories of the BPM framework (N = 50).

The results of the employed empirical strategy demonstrate the usefulness of the BPM as an interpretative device in this important health context and thus extend its applicability beyond the traditional consumer behaviour domain. Four key findings have resulted from the two empirical phases of this thesis: (1) the role and importance of positive learning history in influencing consent (2) the open behaviour setting preference of donation decision makers (3) the success of informational reinforcement in stimulating consent and (4) the role of pleasure in the consent process. This thesis complements existing organ donation knowledge by adopting a radical behavioural perspective. In addition to making a unique contribution to existing knowledge by offering a new theoretical perspective to this context, the findings of this thesis offer implications for social marketers on the ways in which consent may be stimulated.

Acknowledgements

Firstly I'd like to thank my supervisors Dr Michael Nicholson and Dr Sarah Xiao for their insight, patience and humour during my candidature. I am particularly grateful to Dr Sarah Xiao for her encouragement and support during the planning, data collection and final analysis of study two, her time and attention were always appreciated. I am also grateful to Dr Les Graham for giving me the opportunity to hone and develop my qualitative research skills whilst working on his EU funded project during my first year. This experience proved to be truly invaluable in my own data collection and analysis. I would also like to thank the Donor Family Network and the Live Life then Give Life charity for helping me in the recruitment process of the case study participants. I am also grateful to the Oxford University Health Experience Group for the access and use of their online database, which proved to be a rich source of secondary data.

On a personal note I would like to express a very special thank you to my mother Vanessa and my father Leo, who have provided me with advice and love through the whole process. I am so blessed to have such supportive parents, who have always nurtured my interest in human behaviour. I am also eternally indebted to my wonderful fiancé Ian. Without his love, encouragement and support over the years I would have never completed this work. I would also like to express particular thanks to my highly valued colleagues and much treasured friends, who have always been a source of much needed kindness, inspiration, support and laughter. They have never failed to lift my spirits, and spur me on. In particular special thanks go to Dr Emma "*Legend*" Black, Dr EY OH, Dr Naveena Praksham, Natalie "*Paddy*" Friswell, Jennifer Devonshire, Maria Thompson, Jane Willis & Lia Mckay.

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Dedication

This thesis is dedicated to

Calvin, Jennifer and Cynthia and their families ~ who gave so much for the benefit of others

&

My own wonderful family ~ past, present and future.

Table of Contents

List of Figures

List of Tables

Chapter One

Organ donation consent ~ an introduction

"Organ donation is complex and demanding for all involved because human bodies and organs have value to the individual, the family, the potential recipient, research, and society."

Sque and Payne, 2006, p.112

Introduction

Undoubtedly human organ transplantation is one of the greatest medical achievements of the 20th century. This remarkable procedure provides individuals who are facing death from end stage organ failure a hope of survival. Organ donation not only saves lives but also drastically improves the quality of lives for those who are living with long term debilitating illnesses. At present this life saving technology is entirely dependent on the altruism of strangers, who either choose to donate their organs by registering on the Organ Donation Register (ODR) or their families consent on their behalf after their death. At present demand for suitable transplantable organs far outstrips supply and the weak link in the chain of supply has been found to be potential donor families, who err on the side of caution and refuse when the wishes of their loved one is unknown (Yong *et al.* 2000; Martinez *et al.* 2001; Exley *et al.* 2002; Singh *et al.* 2004; Barber *et al.* 2006; Lopez *et al.* 2008; Anker & Feeley 2010). It is against this contextual backdrop that this thesis is set.

This chapter aims to provide the reader with a brief overview of the field of organ donation research, with specific reference to the context of the United Kingdom. The chapter begins with a definition of organ donation and provides the reader with a brief summary of the historical development of the procedure and what donation involves. The chapter then proceeds by providing the reader with a contextual background to organ donation, discussing the problem of donor supply the United Kingdom faces and how the current system of consent operates. The

following sections will discuss previous research areas concerning organ donation and donor family consent, before explicitly outlining the current gaps within the existent literature. The chapter will then introduce the focus of the present research, namely a behaviourist perspective of donor family consent. The guiding theoretical framework that this thesis is founded upon will be introduced, namely the Behavioural Perspective Model (Foxall 1990; Foxall 1997) and a justification for the adoption of this theoretical approach will be provided. The chapter concludes with an outline of the structure of the remainder of the chapters contained within this thesis in order to provide a route-map for the reader.

Organ donation ~ definitions and development

Organ donation is the donation of the biological tissue or organ(s) of a human body to a recipient in need of a transplant and in the UK is voluntary and founded upon the principles of altruism. The first successful kidney transplant from one twin brother to another took place at the Peter Bent Brigham Hospital, Boston in 1954 (Tilney 2003). Following the success of this landmark case, the technological development of transplant procedures moved rapidly, allowing for a dramatic increase in the frequency of these life saving procedures and a larger variety of organs and tissues viable for transplantation (Sque & Payne 2006). Due to modern surgical techniques and the use of immune-suppressive drugs a greater range of organs and tissues can now be successfully transplanted than ever before. At present each potential donor can improve the lives of up to nine individual recipients by donating their heart, lungs, kidneys, pancreas, liver, small bowel, as well as being able to restore the sight of up to two individuals by donating their corneas. In addition to the donation of major organs, since 1999 composite tissue transplants of hands and forearms have become a reality in some specialist transplant centres (Dubernard *et al.* 1999). In November 2005 the first ever face transplant was conducted in France by Bernard Devauchelle and Jean Michel Dubernard using skin from a tissue donor (Spurgeon 2005). This landmark case in the history of transplantation has raised numerous concerns relating to immune-suppression, the potential psychological impact on the patient and the consequences of any technical failure (Sque *et al.* 2006b).

The problem of supply in the UK

In the context of the UK demand for suitable transplantable organs outstrips supply. Each year approximately 1000 individuals lose their life in the UK whilst waiting for a suitable organ to become available, which equates to approximately three deaths per day (NHSBT 2013b). This situation is likely to worsen in the coming decades due to a predicted increase in the demand of transplantable organs due to various public health problems becoming more prevalent in the UK, such as obesity, alcohol abuse and diabetes (Nuffield Council on Bioethics 2011). In 1994 the NHS Organ Donor Register was established to improve donation rates in the United Kingdom, however to date only 31% of the population have registered their wish to donate their organs post-mortem (NHSBT 2013b).

In 2006 Barber and his colleagues undertook an extensive audit of NHS intensive care records as a part of a UK Transplant initiative to improve donation rates in the United Kingdom. The aim of this study was to determine the true potential for solid organ donation from deceased heart beating donors (Barber *et al.* 2006). The audit identified the number of patients who could be potential solid organ donors from intensive care units over a two year period and established obstacles that prevented donation from taking place. Over the two year period, April 2003 to March 2005, data was obtained on 46,801 deaths in 341 intensive care units in 283 different hospitals (Barber *et al.* 2006).

The study found that out of the 46,801 deaths recorded only 2740 were potential heart-beating solid organ donors, with 1244 of them going on to becoming actual donors (Barber *et al.* 2006). Interestingly the data shows that in 273 patients there was no record that organ donation had been considered and in 147 cases there was no record of relatives being approached for consent. This amounts to 15% of potential heart beating donors, however it must be stressed that lack of documentation of these stages does not necessarily mean a lack of consideration or approach. Of the relatives of 2320 potential heart beating donors who were approached for consent for donation, 41% refused consent over the two year period of this study. The study concluded that

family refusal was the biggest obstacle to improving organ donation rates in the UK (Barber *et al.* 2006).

Current consent system in the UK

In the context of the UK the law is clear on what forms organ donation consent may take. At the time of submission in England, Wales and Northern Ireland the provision for the removal of organs is set out in the Human Tissue Act 2004 and the Mental Capacity Act 2005. In the context of Scotland, the equivalent legislation is the Human Tissue Scotland Act 2006 and the Adults with Incapacity Act Scotland 2000. The Human Tissue Act 2004 states that if a person has, while alive and competent, given consent for some or all of their organs or tissue to be donated following his or her death then that consent is sufficient for the donation to go ahead. Once consent is established, next of kin should be advised of the fact and encouraged to respect the deceased's wishes (Human Tissue Act, 2004). Although by registering one's wishes on the NHS Organ Donor Register (ODR) consent is technically sufficient for donation to proceed, in reality the procedure is unlikely to take place without the explicit consent of the deceased's next of kin (Barber *et al.* 2006; Sque *et al.* 2006b; Vincent & Logan 2012). The Human Tissue Act (2004) details the forms of consent that are legal and valid in instances where the patient is deceased or lacks capacity, these include:

- A listing on the ODR or another applicable advanced directive;
- Consent obtained from a properly appointed representative who is acting on behalf of the patient by prior agreement;
- Consent or refusal from individual(s) in a qualifying relationship when the wishes of the patient are unknown;
- Witnessed statements of the prior views held by the patient.

The Human Tissue Act (2004) provides the legal and practical structure for seeking consent for organ donation. In the UK it is the responsibility of the healthcare provider to seek evidence of a potential donor's wishes concerning organ donation, and in cases where these wishes are unknown to discuss the option with their family or nominated appointed representative. This system of consent is what is classified as an "*opt-in*" system. This means that an individual must

actively express a wish to become a donor for the process of donation to take place (Thaler & Sunstein 2009). In reality the UK system of consent is a "*soft opt-in*" system, since it is standard practice to let relatives know if the person has opted in and doctors can decide not to proceed if they are faced with opposition from relatives (**Appendix 1**).

Even when the wishes of the potential donor are known through ODR registration, up to 10% of families of potential donor families refuse to consent, despite the existence of a valid and legal form of consent (Rudge 2007). At present it is accepted practice to respect these objections, despite the family having no legal right to overturn the wishes that the potential donor has expressed during their lifetime (Vincent & Logan 2012). When compared with countries across Europe, the UK has comparatively low organ donation consent rate o (Council of Europe, 2010). Consent rates for organ donation vary substantially between countries, and the reasons for this wide variation is still not fully understood, although cultural and infrastructural differences between countries do play a part (Council of Europe, 2010; Vincent & Logan 2012). For example evidence given to a House of Lords report that addressed the challenge of increasing the supply of organs within the EU suggested that, *pro rata*, Spain has three times as many intensive care beds as the UK, and also three times as many potential donors (House of Lords European Union Committee, 2008).

In 2006 the Department of Health established the Organ Donation Taskforce with the purpose of identifying the barriers to organ donation and formulating solutions to overcome these obstacles (Department of Health, 2008). In 2008 the Organ Donation Taskforce made 14 separate recommendations to support and improve donation rates in the UK. These recommendations included the need for a structured and systematic approach of the identification and referral of potential donors, the urgent requirement to identify and implement the most effective methods through which organ donation can be promoted and the urgent need to address outstanding legal and ethical issues concerning donation (Department of Health, 2008). On the issue of presumed consent otherwise known as an opt-out system of consent, the Taskforce recommended that the implementation of such a system should not be introduced in

the UK at the present time. They argued that such a system has the potential to undermine the concept of donation as a gift, to erode the trust in NHS professionals and negatively impact on overall organ donation levels in the UK. Despite this it was emphasised that an opt-out system of presumed consent has not been totally abandoned as a potential strategy in the future, and would be revisited and reviewed by the Taskforce again in 2013 (Department of Health, 2008).

In 2013, the Taskforce announced that it had achieved the 50% increase in donation levels that it set out as a goal in 2008. However, despite this success in increasing donation levels, this increase reflected an increase in approaches and not in family consent. The family refusal rate for organ donation remains still one of the highest in Europe, despite sustained efforts in the interim period to improve consent levels.

Sally Johnson, NHS Blood and Transplant's Director of Organ Donation and Transplantation, stated, *"Although I am delighted that we have made such big advances in the UK, we can and must do more. We need a transformation in donor and family consent to organ donation because the UK's family refusal rate remains one of the highest in Europe. Without that, there is only a limited amount more the NHS can do to offer further hope to those on the waiting list for an organ transplant."* (NHSBT 2013a)

In addition the Organ Donation Taskforce revisited the issue of an opt-out system of consent in 2013 and again concluded that further research was needed to assess the impact of an introduction of such a system across the UK (NHSBT 2013a). Most recently, during the summer of 2013 the Welsh Assembly passed a bill to introduce an opt-out system of consent into Wales for 2015; however the role potential donor families will play in the new system is still being debated (Human Transplantation (Wales) Act, 2013).

Previous research

Early research concerning organ donation focussed on what type of individual was more likely to become an organ donor and what types of family were more likely to provide consent when requested. Therefore this area of research was largely concerned on the distinctions between donors, non-donors and their families. Later research in the field of organ donation started to

examine the possible reasons for consenting or refusing donation, with a great emphasis on the role of attitudes, beliefs, subjective norms and intentions in relation to organ donation. This area of organ donation research has tended to heavily rely upon the use of social cognition models such as the Theory of Reasoned Action (Fishbein & Ajzen 1975) and the Theory of Planned Behaviour (Ajzen 1991) as a guiding theoretical framework. In more recent years researchers have turned their attention to the external factors that that may influence organ donation, such as the environment in which the decision is made and the impact of the media on the decision making process.

The existing organ donation literature can therefore be classified into two distinct categories: (1) studies examining individual-related factors influencing organ donation and (2) studies investigating external factors influencing organ donation. This fact demonstrates that the factors that influence organ donation have been largely examined in isolation with no theoretical framework to date being presented that can incorporate both the individual level and external level factors together. In addition comparatively little UK specific organ donation research exists, with the majority of existent research originating from a USA context. The UK specific studies that do exist are of good quality, providing rich insight into the phenomenon of organ donation and family consent; however these studies tend to solely rely upon qualitative research methods, small samples and/or archival data provided by NHSBT. A need for more research into organ donation decision making with a greater theoretical emphasis has been called for in the existent literature (Shanteau 1986; Shanteau 1988; Radecki & Jaccard 1997; Feeley 2007). The following sections aim to provide a brief overview of the individual level factors that have been identified in previous studies as influencing organ donation behaviour. This section will then be followed by a section dedicated to providing an overview of the external factors identified within the existent literature, before highlighting the evident gaps in current knowledge and understanding which this thesis seeks to fill.

Individual factors

In the existent literature a considerable amount of research has focussed on the pre-determinants of organ donation behaviour. These studies fall largely within two categories of research, individual difference research and attitudinal research, which has largely relied upon the use of social cognition models. Early research in the field of organ donation tended to focus on the individual difference between organ donors, non-donors and their families. Three of the earliest studies attempting to identify the characteristics and distinctions between those who donate and those who do not were conducted by Cleveland (Cleveland & Johnson 1970; Cleveland 1975b; Cleveland 1975a) and Johnson (Cleveland & Johnson 1970). These studies indicated that organ donors were more likely to be highly educated, less conservative, less religious and more positively inclined toward science than non-donors. In addition the results from these studies indicated that a higher percentage of donors were female (Cleveland & Johnson 1970; Cleveland 1975b; Cleveland 1975a). In the following decades subsequent research found no such relationship between gender and organ donation willingness (Parisi & Katz 1986; Amir & Haskell 1997; Besser *et al.* 2004). Other un-modifiable characteristics that have consistently been found to be associated with a positive organ donation outcome include a young age of the donor (Siminoff & Lawrence 2002; Rodrigue *et al.* 2006; Brown *et al.* 2010), ethnicity (Cleveland 1975b; Randhawa 1998; Darr & Randhawa 1999; Alden & Cheung 2000; Siminoff *et al.* 2001; Siminoff & Lawrence 2002; Morgan *et al.* 2006; Rodrigue *et al.* 2006; Wu & Tang 2009; Brown *et al.* 2010; Jacoby & Jaccard 2010), prior religious beliefs (Simmons & Simmons 1971; Horton & Horton 1990; Siminoff *et al.* 2001; Exley *et al.* 2002; Siminoff & Lawrence 2002; Afifi *et al.* 2006; Rodrigue *et al.* 2006; Brown *et al.* 2010) and trauma as the cause of death (Siminoff *et al.* 2001; Exley *et al.* 2002; Siminoff & Lawrence 2002; Afifi *et al.* 2006; Rodrigue *et al.* 2006; Brown *et al.* 2010). Findings in this area are not wholly consistent, which can often be attributed to the sampling strategies utilised by the study.

Another area within the individual factor domain that has attracted a great deal of attention in the literature is the role of social cognition variables such as attitude, subjective norm and

intention. A considerable amount of research has examined the influence of attitudes in organ donation. Within the existent literature attitude toward organ donation has been a central construct in the investigation of consent, and has been found under certain conditions to be associated with one's willingness to become a donor (Parisi & Katz 1986; Horton & Horton 1990; Horton & Horton 1991). Numerous attitudinal surveys have been conducted in various contexts, and the result consistently report that the overwhelming majority of respondents hold positive attitudes toward organ donation and transplantation. The general pattern that emerges from the attitudinal survey results is that over fifty per cent of the population surveyed hold positive attitudes towards donating their organs, a similarly large percentage is undecided, and a minority of individuals hold negative attitudes toward donation (Parisi & Katz 1986; Schutt & Schroeder 1993; McNamara *et al.* 1999; Yeung *et al.* 2000; Gross *et al.* 2001; Reddy *et al.* 2003; Bilgel *et al.* 2004; Barcellos *et al.* 2005; El-Shoubaki & Bener 2005). In the particular context of the United Kingdom, the most recent surveys indicate that approximately ninety per cent of the population are in favour of organ donation and possess positive attitudes towards the procedure (NHSBT 2013b). The question then arises as to why those who hold positive attitudes fail to covert this into actual behaviour by either registering to donate or by providing consent on behalf of their family? One possible explanation posited in the existing literature is that those who classify themselves as undecided have no intention to donate after their death, however expressing ambivalence is more socially acceptable than expressing an anti-donation position (Sanner 2006).

As well as examining the influence of attitudes held towards organ donation in isolation, previous research has attempted to construct decision making models in the context of both individual donation decision making and donor family consent (Horton & Horton 1991; Sque & Payne 1996; Radecki & Jaccard 1997; Sanner 2006; Morgan *et al.* 2008; Hyde & White 2009). One of the most influential in the specific context of the UK was constructed by Sque and Payne (1996). The theory of dissonant loss focused on the feelings and decision making process *within* the decision maker. Put simply it fell within the information processing sphere of social cognitive psychology. The proposed model depicted donor relative's experiences in relation to

providing consent in the UK and comprised of seven distinct stages. The researchers used a ground theory approach with the themes emerging directly from the qualitative data they had obtained. The results showed that donor families' experiences revolved around a process of conflict and resolution. The seven distinct stages included recalling, informing, hoping, realising, deciding, parting and coping. Although illuminating and rich in detail, this theory was descriptive in nature and provided little contextual or situational analysis, instead focusing its attention entirely on the experiences *felt* by the individual.

Other attempts to construct decision making models in the field of organ donation research have often relied heavily upon attitudinal theories and existing social cognitive models. The most commonly adapted model used within the organ donation literature is the Theory Planned Behaviour (TPB) (Ajzen 1991), which is a latter extension of an earlier social cognitive model called the Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975). Both models comprise of measures of an individual's attitude towards a given behaviour and subjective norm, defined as a measure of the perceived social pressure to engage in the behaviour in question. However, the TPB adds a further cognitive variable to those included in the original formulation of the TRA. This additional variable posits that along with attitude and subjective norm, an individual's perception of whether they can or cannot engage in a given behaviour determines behavioural intention. In the TPB this variable is defined as *perceived behavioural control* (**Figure 1**). It is important to emphasise that both the TRA and TPB predict *intention* to engage in a given behaviour rather than *actual* behavioural outcome. This fact leads to the common criticism levelled against the use of social cognition models to explain actual behaviour, an issue that will be discussed later in this chapter.
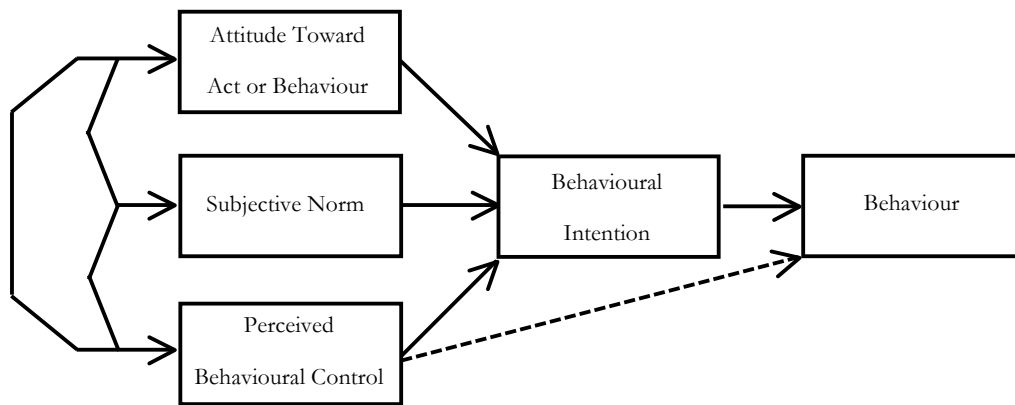
Figure 1. The Theory of Planned Behaviour (Ajzen, 1991).

The Theory of Planned Behaviour (Ajzen, 1991) has been extensively used in the field of organ donation research and has appeared both in its original formulation without amendment but also specifically adapted to include additional variables with the aim of increasing its predictive power, for example the inclusion of moral norm (Hyde and White, 2009) and non-cognitive variables such as the "*ick factor*" (O'Carroll, 2011). The TPB has been used to explore both personal donation decision making, e.g. whether to register as an organ donor (Burg *et al.*, 2000; Feeley *et al.*, 2005; Hyde and White, 2009) and family decision making on behalf of a patient (Radecki and Jaccard, 1997). Although it should be noted that in the latter context there is limited empirical evidence available due to the predominantly qualitative nature of the research field.

Despite the strengths and undeniable contribution of social cognition models in exploring the pre-determinants of organ donation behaviour, this approach takes little account of the environment in which the decisions are made, instead focusing solely on the factors that dwell inside the individual i.e. their attitudes and beliefs. Foxall himself has critiqued both the TRA and the TPB for their inability to account for what he calls the attitude behaviour-problem of consistency (Foxall, 2005). Put simply, the failure of positive attitudes to convert into actual behavioural action. Throughout his work Foxall has asserted that without taking into account the influence of situational and non-attitudinal elements, which are known to exert an influence over the strength of the attitude-behaviour relationship, the gap between attitude and *actual*

behaviour cannot be effectively bridged (Foxall, 1993). In this sense the weaknesses of current attitudinal theory have acted as a facilitator for the development of the Behavioural Perspective Model (BPM). In addition, in the particular context of the current thesis the strengths of the TPB model have been incorporated into study two through the construction of a devised learning history questionnaire based upon the TPB's measurements of attitude and subjective norm, an approach proposed by Foxall (Foxall, 2005).

External factors

In addition to the individual level factors identified in the literature discussed in the above section, various external factors have been shown to be influential in donor family decision making. Recent evidence from the existent literature suggests that there are factors relating to the consent request environment that correlate with a decision to either provide or refuse consent by potential donor families. For example, some of the more common contextual factors that have been identified as exerting an influence on consent include the family's interactions with medical staff (Douglass & Daly 1995; Siminoff *et al.* 2001; Cleiren & Van Zoelen 2002; Jacoby *et al.* 2005; Rodrigue *et al.* 2006; Jacoby & Jaccard 2010) the appropriateness of the setting in which the request is made (DeJong *et al.* 1998; Gortmaker *et al.* 1998; Cleiren & Van Zoelen 2002; Jacoby *et al.* 2005) and time related factors such as the time of the approach and the time given to the family to make the decision (Niles & Mattice 1996; Gortmaker *et al.* 1998; Siminoff *et al.* 2001; Siminoff & Lawrence 2002). In addition previous research has found that families who feel like they are being pressurised are less likely to provide consent to donation (Siminoff *et al.* 2001; Cleiren & Van Zoelen 2002).

A recent systematic review of twenty observational studies and audits conducted by Simpkin and colleagues (2009) found a series of so called "*modifiable*" factors that had either a statistically positive or negative effect on consent outcomes. These included information discussed at the request, timing of the request, perceived quality of care of the donor and the setting in which the request was made. They concluded that a larger scale intervention study was needed that tests what elements that might be modified to increase organ donation consent (Simpkin *et al.*

2009). To date no study exists that examines the influence of multiple intervention strategies on consent outcome.

Another external factor that has been shown to exert an influence in the context of the USA is the media's portrayal of organ donation and transplantation (Moray *et al.* 1999; Moloney & Walker 2000; Matesanz 2003; Harrison *et al.* 2008; Quick 2009). Previous studies have also highlighted the negative role the media can play by propagating myths surrounding organ donation, such as unfair organ allocation, and preying on the fears of the general public. To date no such relationship has been proven yet in the context of the UK, however this area is under-researched in the UK and anecdotal evidence implies that the media could possibly have a similar influence in donor family decision making.

Specific problems associated with donor family research

There are three well documented methodological issues associated with conducting donor family research. Firstly, donor family research is plagued with problems concerning access, with donor families being stringently protected by gatekeepers and rightly so. This however can have a negative impact on the size and quality of the data available regarding donor family consent. Most studies in the field of donor family research rely upon very small samples, which results in problems concerning the generalisability of results (Sque & Payne 1996). Secondly, much of donor family research is retrospective in nature, happening many months if not years after the event. Due to the retrospective nature of much of the qualitative obtained data in this field, there is the possibility that donor family participant's recollections of events may be prone to recall bias and therefore their reliability of the results obtained in these studies is uncertain (Yin 1994). Thirdly donor family research nearly exclusively relies upon self-selected samples. This sampling method presents a significant problem since a self-selected sample may include individuals who still have remaining issues about their personal bereavement experiences and want to the opportunity to resolve these through participation in research. This in turn may produce data that is unrepresentative of what can be deemed a normal bereavement experience

Gaps in the existent literature

Despite the undoubted contribution of the aforementioned research to our current understanding of both organ donation and donor family consent, there are a number of significant gaps within the existing literature that this thesis seeks to address. Firstly, as has already been noted within this chapter the field of organ donation research has to date lacked a strong theoretical base (Shanteau 1986; Shanteau 1988; Radecki & Jaccard 1997; Feeley 2007). To date research concerning organ donation decision making and behaviour has largely been one dimensional in nature, either examining the pre-determinants of behaviour *or* examining external factors. At present no theoretical model in the existent literature provides a contextual account of donor family decision making, instead showing a tendency to focus solely upon the pre-determinants of consent behaviour that dwell inside the individual. Feeley (2007) rightly argues that too often scholars "*go to the well*" and utilise social cognition models to conveniently accommodate their study factors when examining the issue of organ donation. New theory and theory-driven methods are desperately needed within the field of organ donation research in order to understand the complex decision making process of both individuals and their family. The field has become congested with the cognitive approach, which despite its significant contributions to organ donation research, has failed to adequately address the considerable gap between intention and actual behaviour. This thesis aims to fill this considerable void by adopting a holistic approach, where the cognitive and behavioural aspects are analysed together.

This thesis argues that the BPM offers one such model, since it allows for the individual factors to be examined through the learning history construct, and the external factors through the behaviour setting and situational elements. This results in a holistic picture of the behaviour under investigation. In addition the BPM possesses the capability of being able to accommodate the whole consent process, from pre-behaviour right through to post-behaviour consequences and evaluation. This is a truly significant advantage over existing models used in the literature, as the BPM possess the capability of being able to explore not only the motivations of the behaviour before action but to assess the reinforcing outcomes which could ultimately produce

answers on how organ donation can be stimulated. It is therefore solution orientated in its approach.

A second gap evident in the existent literature is that to date no study has examined the impact of different organ donation request situations on consent simultaneously. The need to examine the impact of different intervention strategies upon organ donation consent has been highlighted in the existent literature (Simpkin *et al.* 2009). Limited evidence exists on the potential impact of changing the scope of the behaviour setting through legislative changes (i.e. moving from an opt-in to an opt-out form of consent) or the use of non-altruistically focused incentives such as the payment of funeral expenses. This gap in the literature is possibly existent due to the fact that no framework to date has accommodated the examination of multiple consumer situations simultaneously. This thesis seeks to address this gap by examining the situational influence on organ donation consent. Put simply, how changing pattern of reinforcements and behaviour setting scope influence consent outcome.

Thirdly, another significant gap within the existent literature concerns the role of affective responses toward the organ donation request situation. Although positive affective responses have been noted within the existent literature, such as feelings of pride (Parisi & Katz 1986; van den Berg *et al.* 2005; Manzari *et al.* 2012), satisfaction (Parisi & Katz 1986; McIntyre *et al.* 1987; Manzari *et al.* 2012) and comfort (Batten & Prottas 1987; Soukup 1991; Cunningham 1993; Pelletier 1993; Sque *et al.* 2006a), to date no study has made any attempt at measuring the emotional responses of donor families towards the actual request for donation. This is perhaps unsurprising since it would be methodologically difficult to obtain and would raise a number of ethical issues. However this area warrants further investigation as the existent literature clearly implies that the potential donor family's emotional response towards the request environment may play a role in the final consent outcome. The present thesis will achieve this through a simulated donor request environment during the second empirical phase of this thesis, documented in chapter five.

A behaviourist approach to organ donation consent

In light of the research gaps highlighted in the previous section, the present research seeks to apply the Behavioural Perspective Model (Foxall 1990; Foxall 1997) of purchase and consumption to the context of donor family decision making with the principle aim of constructing a behavioural account of donor family consent through the application of the BPM and to identify a means in which organ donation consent maybe stimulated. The BPM is a radical behaviourist interpretive device that has Skinner's three term contingency at its very core. In particular the BPM asserts that human behaviour is directed towards the maximisation of positive reinforcement and the minimisation of aversive consequences. The BPM provides an account of individual choice founded upon the discipline of applied behaviour analysis (Foxall 1999). Conceptually the BPM stems from the Skinnerian premise that the behaviour of an individual is determined by the contingencies of reinforcement under which they are emitted (Skinner 1938; Skinner 1953; Skinner 1974). According to the BPM, aspects of a consumer's behaviour are predictable from two elements that exert situational influence: (1) firstly, the scope of the behaviour setting and (2) secondly, the utilitarian and informational reinforcement signalled by the setting as primed by the individual's individual learning history (Foxall 1999). For the purpose of clarity, in the context of the donor family consent situation, an individual's learning history refers to the primary decision maker's previous learning and experiences regarding organ donation and related behaviours/issues. It should be acknowledged that the term "*family consent*" can potentially be confusing, as it can in reality imply more than one person involved in the decision making process. However in the context of this thesis the term is used to denote the family member or legally appointed individual who is asked to provide consent on behalf of their family member. This person is typically the patient's spouse, parent or legally appointed individual who has been selected to make health decisions on their behalf.

One of the particular strengths of the BPM framework is that it firmly directs its attention toward the *actual* behaviour of providing consent to organ donation, rather than towards the pre-behavioural precursors of consent behaviour. Therefore it lends itself to being an ideal

framework to investigate the following aspects of donor family consent: (1) the interaction between an individual's learning history and the organ donation request situation, (2) the impact of the actual request situation on consent and (3) the patterns of reinforcement that increase likelihood of a positive consent outcome.

To date the BPM has been adopted to investigate a diverse range of traditional consumer behaviours, including consumer brand choice (Foxall & James 2003; Foxall & Schrezenmaier 2003; Foxall *et al.* 2004; Oliveira-Castro *et al.* 2005; Oliveira-Castro *et al.* 2006), consumers reactions to shopping environments (Foxall & Greenley 1999; Soriano *et al.* 2002; Foxall & Yani-de-Soriano 2005) socially responsible consumption (Davies *et al.* 2002; Foxall *et al.* 2006), illicit consumer behaviour (Xiao & Nicholson 2010) amongst others. To date the BPM interpretive device has yet to be adopted in the investigation of health choice behaviours, despite the fact that there is no evidence to suppose that the model's central variables will not be equally applicable.

The adoption of behaviourist approach to the investigation of donor family consent can be justified on four specific grounds. Firstly, as already highlighted in this chapter, despite the existing literature demonstrating that donor family consent is influenced by a wide range of *both* individual and external factors, to date a model that integrates all the possible contributing factors is notably absent. The BPM provides one such model, where both the individual level factors of the potential donor family can be examined through the learning history construct and the situational influences explored through the behaviour setting and situational variables. Therefore this model offers a truly holistic depiction of the behaviour under study, something which has been lacking thus far in the field.

The second clear advantage of adopting a behaviourist standpoint in this particular context is that the BPM is truly solution orientated. The BPM framework focuses on parts of the request and consent process that can be manipulated by policy makers and health practitioners. This is a distinct advantage over the traditionally used social cognition models, which solely examine pre-existent variables that reside inside the individual that are largely outside of the control of those

seeking to influence potential donor families. In contrast the BPM focuses on factors that can be controlled and altered, therefore providing a means of potentially stimulating organ donation levels via intervention. For example, by changing the mode of reinforcement signalled to the potential donor family. Due to this particular strength the BPM has the potential to be a valuable tool for social marketers, health care practitioners and academics alike.

A third clear advantage of the BPM framework is that it is contextual in nature. This in turn means that the actions of other parties within the immediate behaviour setting, such as the behaviour of medical staff, can be analysed on equal terms. This is particularly important advantage over traditional social cognitive models that have been previously utilised in this area, as they analyse the family's decision making process in isolation, with the actions of influential others being largely overlooked or grouped under the subjective norm. In the context of donor family requests and consent the actions of other parties within the environment have been shown to exert considerable influence over the final consent outcome (Douglass & Daly 1995; Siminoff *et al.* 2001; Cleiren & Van Zoelen 2002; Jacoby *et al.* 2005; Rodrigue *et al.* 2006; Jacoby & Jaccard 2010).

Fourthly, the use of the BPM in this particular context allows for the examination of donor family consent in different situations. This is achievable through the BPM's matrix of eight distinct contingencies which are characterised by the scope of the behaviour setting and the reinforcement pattern evident in the situation (Foxall 1990; Foxall 1997). The BPM matrix provides a theoretical and systematic way to map out the situations in which organ donation consent can occur and thus examine the situational elements that influence that behaviour simultaneously. Put simply, the BPM matrix can contribute to our understanding of *situational influence* on donor family consent

Finally, whilst the majority of studies have focused on the pre-determinants of donor family consent, such as the individual differences evident between donors, non-donors and their families or the measurement of social cognitive variables, radical behaviourism focuses exclusively on the *actual* behaviour of providing consent for organ donation rather than merely

the *intention* to engage in a behaviour. This is a considerable strength of this perspective since social cognitive theories often do not predict actual behaviour reliably and that intention to engage in a given behaviour is not indicative of actual behaviour since these intentions are not static and may change over time. Furthermore, attitudes can be affected by a wide range of individual biases (Bemmaor 1995; Morwitz 1997; Sun & Morwitz 2010).

For these aforementioned reasons, one being the solution-oriented focus of the BPM framework and the unique capabilities of the BPM in contributing to the gaps in the existent organ donation literature, radical behaviourism and more specifically the BPM has been chosen to guide the empirical phases of the present research.

Original contribution to knowledge

In sum the anticipated contribution of this thesis to existing knowledge can be summarised as the following:

1. Development of a detailed and contextualised account of donor family behaviour towards providing consent from a radical behaviourist perspective.

2. Theoretical contribution to the field of organ donation research by combining the pre-behavioural and the contextual determinants of donor family consent into one holistic model of donor family behaviour. Examining how learning history and situational influences interact with each other at the time of decision making.

3. Extension and adaptation of the BPM explanatory framework and typology of consumer behaviour via the application of the framework into a new health focused domain. This application offers a unique contribution to the on going development of the behaviourist approach to consumer health research and more specifically the BPM programme of research.

4. A practical contribution of providing the field of organ donation research with a typology of donor family consent based upon the BPM's operant classes of consumer behaviour. This typology allows for the mapping of intervention strategies, with the practical aim of stimulating consent.

Research objectives and methods of inquiry

This thesis seeks to examine the phenomenon of donor family consent from a radical behaviourist perspective via the application of the BPM. The principle objective of this thesis being to better understand the actual behaviour of donor families towards granting consent, the various types of learning history which inform these decisions and the environmental contingencies that shape this complex human behaviour. In light of these aims and objective the following research questions will guide the empirical phases of this thesis:

1) Can family organ donation consent be understood as an operant process utilising the BPM as an interpretive device?

2) What patterns of reinforcement are associated with likelihood of consent?

3) Can donor family consent be stimulated via behavioural intervention?

These research questions will be answered using a sequential mixed-method approach, which is outlined in detail in chapter three of this thesis. The first empirical phase adopts a case study approach, drawing upon multiple sources of evidence to construct a behavioural account of donor family consent via the application of the BPM as an interpretative device. The aim of the first empirical phase is to validate the BPM in this particular health behaviour context and to identify the pre-determinants and situational elements that influence of donor family consent. The second phase of the empirical investigation builds directly upon the first, to investigate how donor family consent may be stimulated. This phase of the research adopts a laboratory simulation methodology in order to examine *actual* consent behaviour across the eight contingency categories outlined in the BPM. In addition through a specifically designed learning history instrument the interaction between an individual's learning history and the request situation can be examined.

Thesis structure

This thesis is structured in the following manner. Firstly, chapter two provides the reader with an overview of the Behavioural Perspective Model. This chapter outlines the historical

background of the behaviourist paradigm, in which the BPM is located and then proceeds to introduce and discuss each one of BPM's central tenants, before applying it to the context of organ donation consent. Chapter three provides a description and justification for the overall research strategy adopted in this thesis. Chapter four and five then proceed to document the data collection, results and analysis of the two sequential studies, namely a case study approach to exploring donor family consent (chapter 4) and a laboratory simulation examining how best to stimulate consent (chapter five). Finally, chapter six provides an overall discussion of the research contained within this thesis, summarising the key research findings, discussing the theoretical, practical and methodological contributions of the present research, then concluding with the limitations of the thesis and avenues for future examination. The thesis concludes with a summation of the general applicability of this perspective to this unique context.

Chapter Two

Donor family consent ~ a behavioural perspective

"Pick any aspect of human existence, and you will find that behaviourism shows it in a new perspective"

(Baum 1994), p.181.

Introduction

Family refusal has consistently been identified as the biggest obstacle in improving organ donation rates in the United Kingdom (Harris *et al.* 1991; Jasper *et al.* 1991; Martinez *et al.* 2001; Barber *et al.* 2006). It is estimated that three individuals die every day in the United Kingdom as a direct consequence of the chronic shortage of suitable organs facing the National Health System (NHS). The present system of consent operational within the United Kingdom is defined as an opt-in system of consent. Put simply this means that an individual must actively express their wish to be a donor during their lifetime by registering on the NHS Organ Donor Register (ODR) which was established in 1994 and continues to be the primary method of expressing a wish to donate organs after death. As it stands 31% of the UK population have signed up to the Organ Donor Register (ODR), despite opinion polls consistently reporting that over 90% of the UK's population hold positive attitudes towards the procedure (NHSBT 2013b). In the absence of this form of consent the decision to donate often falls entirely on the potential donor's immediate family and as outlined in the previous chapter this can prevent donation from taking place. Past research has consistently found that families tend to err on the side of caution when the wishes of their family member are not explicitly known (Yong *et al.* 2000; Martinez *et al.* 2001; Exley *et al.* 2002; Singh *et al.* 2004; Barber *et al.* 2006; Lopez *et al.* 2008; Anker & Feeley 2010). Furthermore up to 10% of families, whose family member has registered their wish to donate by joining the ODR, subsequently refuse to provide consent and at present it is an accepted practice in the UK to respect such wishes despite the existence of a valid form of consent (Rudge, 2007). The ethical implications of this have been the focus of much debate

in recent years (Farsides 2012; Price 2012), however this complex ethical and legal issue is beyond the scope of this current thesis.

Against this contextual background, recent figures released by NHSBT show that approximately 40% of all approached families will deny consent for organ donation, a level that has remained unchanged despite an overall increase in donations in recent years (Barber *et al.* 2006; NHSBT 2013b). This rate of refusal is amongst one of the highest levels in Europe, third only to Estonia and the Netherlands (Council of Europe, 2010). It is likely that the need for suitable transplantable organs will increase in the future because of growing public health issues facing the UK such as obesity, binge-drinking culture and an aging population. Therefore improving our understanding of this complex human behaviour and formulating ways of stimulating consent amongst potential donor families is of paramount importance. As has been discussed in the introduction chapter of this thesis, research to date has primarily been concerned with the pre-behavioural aspects of donor family consent, such as the individual differences between donor and non-donor families and the attitudes and the beliefs held by decision makers in relation to organ donation and transplantation. In the existent literature these aspects have often been explored using social cognition models such as the Theory of Reasoned Action (Fishbein & Ajzen 1975) and the Theory of Planned Behaviour (Ajzen 1991). In addition to this, organ donation specific decision making models have also been formulated in the existing body of literature (Horton & Horton 1990; Sque & Payne 1996; Radecki & Jaccard 1997; Sanner 2006). However as chapter one outlined these have fallen within the social cognition domain and have given little attention to the role of the environment in the decision making process, instead examining the decision maker in isolation. A recent review has examined the role of modifiable environmental factors that can influence donor family consent; however these have been separated from individual level factors (Simpkin *et al.* 2009), thus again failing to provide a holistic depiction of the donor family consent decision making process.

Despite the undeniable contributions of the aforementioned approaches in furthering our understanding of this important human behaviour, it has been argued in the existent literature

that new theory and theory driven methods are desperately needed in the general field of organ donation research that can effectively bridge the attitude-behaviour gap that is clearly evident in this specific health context (Radecki & Jaccard 1997; Feeley 2007). At present no model has been presented in the literature that can incorporate *both* individual level factors and external level factors in the donor family making process. This is a significant gap in the existing organ donation literature, which this thesis seeks to address.

The primary objective of this thesis is to explore the issue of donor family consent from a behavioural perspective utilising the Behavioural Perspective Model (Foxall 1990; Foxall 1997) as its principle explanatory framework. As will be recalled from chapter one of this thesis, the adoption of a behavioural standpoint can be justified on four specific grounds, which are summarised below:

1. The BPM can incorporate both individual level and external level factors into the one holistic model which the field currently lacks.

2. The behavioural framework proposed is solution orientated, focusing on elements in the request situation that can be changed by external agencies instead of focusing solely on pre-existent variables that reside inside the individual.

3. The BPM allows for analysis of behaviour in context, with the actions of others in the behaviour setting being analysed on equal terms.

4. Radical behaviourism focuses exclusively on the *actual* behaviour of providing consent for organ donation rather than merely the *intention* to engage in a behaviour

For these four aforementioned reasons, one being the general solution-oriented focus of the model and the remaining three concerning the capabilities of the BPM in contributing to the existent gaps in the literature, radical behaviourism and more specifically the BPM has been chosen to guide the present research. Against this backdrop, the present chapter seeks to apply the Behavioural Perspective Model (Foxall 1990; Foxall 1997) in the construction of an operant account of donor family consent. Specifically, the chapter begins by outlining the historical origins and development of the behaviourist school of thought, with particular attention being

paid to key figures within the movement. The chapter then proceeds by introducing the Behavioural Perspective Model (BPM) as the proposed framework for the subsequent empirical work contained within this thesis. Each principle component of the BPM will be examined in depth and applied to the specific context of donor family consent, thus demonstrating its suitability as an interpretative device in the context of this complex human behaviour. At the end of each section, research propositions are presented that will serve as a guide in the empirical phases of this thesis, which are documented in chapter four and five. The present chapter concludes by providing a summary of the central argument of this thesis and restates the formulated research propositions presented within this chapter.

The historical development of behaviourism

The origins of behaviourism

The death of Behaviourism has been periodically announced for over fifty years by its opponents, despite the fact that the discipline is very much alive and continues to make significant contributions to the understanding of complex human behaviour, especially in applied settings (Sturmey 2008). As will be recalled, this thesis seeks to provide a behavioural account of donor family consent via the application of the neo-Skinnerian framework known as the Behavioural Perspective Model (Foxall 1990; Foxall 1997). Before an application of this model to donor family consent can be attempted, it is first important to provide the reader with a brief introduction to the behaviourist movement and the contextual background against which it emerged. With this particular aim in mind, the present chapter provides the reader with a brief account of the historical origins of the Behaviourist movement, with specific reference to key figures who have been vital to its development and growth over the past 100 years. The chapter will then proceed to highlight the distinctions between the two major brands of behaviourism, namely methodological behaviourism and radical behaviourism, and will discuss some of the more common critiques levelled against this branch of psychology before introducing the central framework which is utilised in this thesis.

Chiesa (1994) explains that psychology is a fragmented field with many different perspectives, each possessing its own distinct worldview (Chiesa 1994). In the early 1900s the Behaviourist school of thought emerged in the United States as a direct reaction against the so called rampant excesses of Freudian theory and the introspective method which had long been dominating the intellectual landscape (Moore 1995). Watson's (1913) famous address to Columbia entitled "*Psychology as the Behaviourist views it*" eloquently summed up the behaviourist approach to the study of human behaviour and showed the world how it staunchly contrasted from the psychological stance that preceded it:

"*Psychology as the behaviourist views it is a purely objective experimental branch of natural science. Its theoretical goal is the predication and control of behaviour. Introspection forms no essential part of its methods, nor is the scientific value of its data dependent on the readiness with which they lend themselves to the interpretation in terms of consciousness*" (Watson 1913).

Wozniak (1997) asserts that like many other origin myths, the story of Watson's founding of the Behaviourist branch of psychology is both oversimplified and unrepresentative of its true development, and argues that Watson was by no means the first individual to use objective, experimental methods in the study of behaviour nor was he the first to criticise psychology's over-reliance upon the concept of consciousness and the method of introspection (Wozniak 1997). The common depiction that academics suddenly flocked to Watson's perspective once he presented his "*behaviourist manifesto*" at Columbia in 1913 is both flawed and misleading of what actually took place (Samelson 1981). It took well over a decade for the psychological branch of behaviourism to gain substantial ground within American academia and when it did, it was not by converting the old guard but by attracting young psychologists (Wozniak 1997).

It can be argued that the first real purely objective studies of behaviour were undertaken by Douglas Alexander Spalding and Charles Darwin during the late 19th century. Spalding designed and undertook a series of experiments to distinguish instinctive behaviour from learned behaviour in animals (Spalding 1872). He achieved this by systematically manipulating an animal's experience, such as hooding or blind folding the eyes of a chick while it was still in its shell and then allowing it to see without impairment several days after hatching in order to

analyse its behaviour. Around the same time Charles Darwin (1877) illustrated the same attention to detail as Spalding in his work entitled a biographical sketch of an infant. In this work, Darwin varied the conditions of stimulation to an infant and recorded the related variation in the infant's behaviour. In one observation Darwin used a piece of paper to stimulate the sole of the infant's foot, reporting that the related variation in the infant's behaviour was to "*jerk it away, curling at the same time his toes, like a much older child when tickled*" (Darwin 1877). Despite being objective in their observations and experimental in their method, neither Darwin nor Spalding took steps to design apparatus to control their subject's reaction or quantify their responses; however their work did lay the foundation for future researchers who wished to quantify behavioural responses.

The first real attempt to quantify responses to stimuli was undertaken and recorded by Ivan Petrovich Pavlov (1849-1936). Pavlov was investigating the physiology of the secretion of mouth and stomach fluids by presenting dogs with food and measuring the subsequent secretions from their digestive tracts. During the course of this research, Pavlov stumbled across an intriguing phenomenon that would lay the foundations for the future development of behaviourist theory in the subsequent decades (Rachlin 1976). While conducting his now infamous experiment, Pavlov discovered that a dog could learn that the sound of a turning folk signalled the arrival of food, thus prompting the dog to salivate before the food had been physically presented. In what is now termed *classical conditioning* or *Pavlovian learning*, the neutral stimulus (NS) of the turning folk was repeatedly paired with the unconditioned stimulus (US) of the food, which in turn produced a conditioned stimulus (CS) that was able to evoke the conditioned response (CR) of salivation in the absence of food (Bolles 1979).

Inspired by Pavlov's findings, John Broadus Watson, the author of the Behaviourist Manifesto (1913), extended this principle of learned associated to the study of humans, where he conditioned responses in infants using the same techniques (Watson & Rayner 1920). During the now legendary "*Little Albert*" experiments, Watson and his assistant Rosalie Rayner succeeded in classically conditioning a white rat phobia in a small child (Watson and Rayner, 1920). The subject of the experimentation was a healthy, normal infant. The experiment

consisted of Watson producing a loud noise behind the child each time a white rat was presented to the child. This subsequently evoked an unconditioned response in the infant of falling over, crying, and crawling away. After three pairings, the animal alone elicited a fearful response in the infant. Furthermore Watson and Rayner (1920) put Albert through a series of generalization tests, in which he was presented with a white rabbit, a dog and a fur coat. In each instance Albert's fear transferred to these associated stimuli, a phenomenon defined as stimulus generalisation (Bolles, 1979). Through this experiment, Watson had successfully shown that through the procedure of associated learning, first introduced by Pavlov, the response of humans could be modified. Unfortunately Watson's academic career came to a swift end when he was dismissed from his post, surprisingly not for unethical experimentation on minors but for engaging in a frowned upon relationship with a colleague. Ultimately Watson's techniques found a home in the advertising industry where he developed marketing campaigns for the Walter J. Thompson agency. Despite his recognised professional success outside of academia during his lifetime, Watson's brand of behaviourism was ultimately unpopular in the academic world, largely on the basis it was seen to be unable to account for the complexities of human behaviour. It was not until the emergence of the discipline of consumer psychology during the 1960s that Watsonian techniques exerted any influence in the academic landscape (Buckley 1982). From that point onwards, classical conditioning became firmly entrenched within the consumer research landscape and was applied far beyond what is deemed traditional consumer contexts. For example previous research has applied Watsonian techniques to a vast range of diverse behaviours, including behaviours of social importance. For example poster campaigns on consumer recycling (Geller *et al.* 1973); encouraging patient compliance with medical appointments (Friman *et al.* 1985); encouraging safe sex (Honnen & Kleinke 1990); and the use of shocking imagery in road safety campaigns (Cope *et al.* 1988).

In brief, Watson's methodological behaviourism considers behaviour as merely a reaction to the external environment, a behavioural response to an environmental stimulus. This brand of behaviourism staunchly argues against any form of introspection and focuses its attention firmly on publically observable acts that can be objectified and quantified according to the scientific

method (Watson, 1913). As already discussed, Watsonian techniques have had a considerable impact on both traditional and non-traditional consumer contexts, however one could argue that Watson's greatest legacy was in inspiring the next generation of behaviourists, most notably B. F. Skinner (1904-1990) whose work on the three term contingency laid the foundation for the BPM programme of research that underpins this current thesis.

Radical Behaviourism and its deviation from Methodological Behaviourism

The second phase of the behaviourist revolution came with the rise of arguably the most influential of all post-Watsonian behaviourists, B. F. Skinner (Moore, 1995). Skinner's brand of behaviourism, known as *radical behaviourism*, is markedly distinct from Watson's methodological behaviourism, despite often being misrepresented within the literature as merely an extension of it (Moxley 1982; Catania 1984; Skinner 1984; Morris 1993; Malone & Cruchon 2001). Skinner shared Watson's staunch belief that that a science of behaviour was possible and that scientific psychology should concern itself solely with public and therefore observable acts of behaviour. However despite these shared beliefs Skinner deviated considerably from the stance of Watson and other early behaviourists in a range of fundamental areas that set the two brands of behaviourism firmly apart. These deviations not only differentiated these two brands in terms of theory but also had far reaching methodological implications that are of importance for this present thesis.

The first major deviation of radical behaviourism from its predecessor was that Skinner asserted that behaviours were not purely elicited by a stimulus but were emitted by the past consequences of a response (Catania, 1984). Put simply, that an organism's behaviour is shaped and maintained by its consequences (Skinner, 1974). The origins of Skinner's own approach in this area can be found in the seminal work of Thorndike (1927) entitled "*Law of Effect*" which formally expressed the theory that the effect of successful behaviour increased the probability of its future occurrence (Rachlin, 1976). Skinner reconceptualised Thorndike's *Law of effect* by arguing that animals were in fact learning behaviour-outcome associations rather than merely learning a series of stimulus-response associations (Thorndike 1927; Bolles 1979). This notion

departed considerably from Thorndike's own interpretation of the process, which argued that animals were in no way learning causation during the trial and error process in the laboratory experiment. In contrast, in Skinnerian *operant conditioning* the organism is learning that a given action will have a reinforcing outcome, for example that the click of the food dispenser signals to the animal to press the lever which will in turn release food that will satisfy hunger (Gross 2005). The following extract demonstrates Skinner's own thinking regarding behaviour-outcome associations:

"When a bit of behaviour is followed by a certain kind of consequence, it is more likely to occur again, and a consequence having this effect is called a reinforcer. Food, for example, is a reinforcer to a hungry organism; anything the organism does that is followed by the receipt of food is more likely to be done again whenever the organism is hungry. Some stimuli are called negative reinforcers: any response which reduces the intensity of such a stimulus—or ends it—is more likely to be emitted when the stimulus recurs. Thus, if a person escapes from a hot sun when he moves under cover, he is more likely to move under cover when the sun is again hot." (Skinner 1972)

As has already been noted in the above discussion Skinner's reformulation was a marked deviation from the early behaviourists, who posited that a response is *caused* by a stimulus, with the stimulus *eliciting* or drawing out a behavioural response (Nye 2000). In contrast within Skinnerian operant conditioning the response must be *emitted* before it can be reinforced, and therefore a behavioural response is determined by the consequences of behaviour, as depicted in the three-term contingency, which is the cornerstone of behaviour analysis (Foxall 1990) (**Figure 2**). Put simply consequences are the events that affect the likelihood that an operant behaviour will be repeated in the future (Bolles 1979; Baum 1994).

STIMULUS → RESPONSE → REINFORCEMENT

Discriminating stimulus   Response   Reinforcing stimulus
S^D R S^R
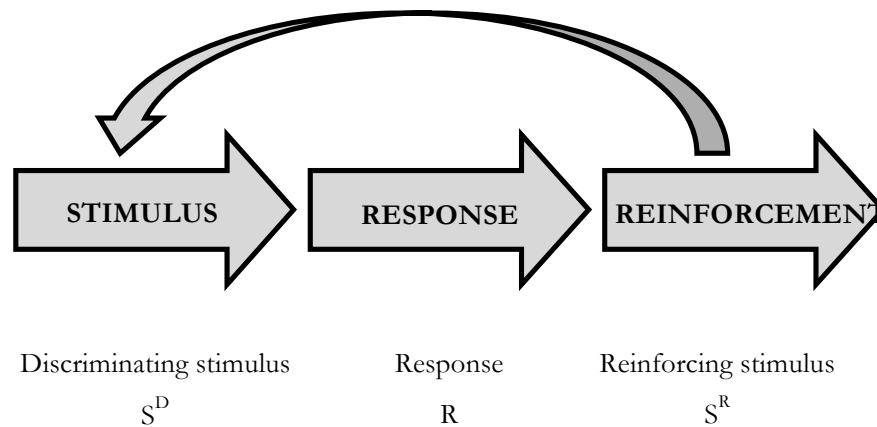
Figure 2. The three-term contingency.

In summary Skinner was still concerned with stimuli but not in the same *eliciting* manner as his predecessors. Skinner himself acknowledged the significance of classical conditioning, which he termed *respondent conditioning*, for interpreting behavioural responses that were elicited by initially neutral stimuli (Nye, 2000). However, Skinner's focus and interest would remain on the active, voluntary emitted responses rather than simple reflexive behaviours, which in a practical sense are the most important and frequent activities that humans engage in daily. Real-world examples of emitted responses include such fundamental human activities as working and communicating with others.

The second major deviation from Watson's more extreme form of behaviourism was that Skinner's own view of psychology accepted the inclusion of what was traditionally deemed by early behaviourists as internal events. Skinner considered such acts as behaviours in their own right and therefore argued that they were legitimate for investigation (Moore, 1995). As will be recalled from earlier in this chapter, Watson staunchly argued against the inclusion of what he deemed private and inaccessible events on the grounds that such acts were unable to be observed independently and quantified in accordance with the scientific method (Watson, 1913). Therefore Watson's methodological behaviourism sought to confine the science of psychology solely to the examination of events that could be independently observed and quantitatively measured. In contrast, Skinner's perspective on the status of internal events was markedly different, and this had far reaching methodological implications which set the two brands firmly

apart. Skinner himself stated that *"the part of (methodological) behaviourism I rejected was the argument that science must confine itself to events accessible to at least two observers and that behaviourism was therefore destined to ignore private events"*. (1984, p.579)

Skinner's position posits that if an internal event, or as he defined it *"the world within the skin"* could be shown to exert an influence upon behaviour at a given point in time, then it should therefore be classified as a public act of behaviour in its own right and included in an analysis of behaviour (Skinner, 1974). Put simply, Skinner believed that internal behaviours were not always private events *per se*. This is because he considered internal events such as deciding and thinking as publically verifiable in situations where they exert an evident control over behaviour. It is at this point that it should be highlighted that Skinner's emphasis was still on scientific enquiry without resorting to introspective methods; however there was a general acceptance that some private events should be considered public acts in their own right and therefore acceptable and legitimate for scientific inquiry. This distinguishing aspect of Skinner's approach to behaviour analysis has important methodological implications, most specifically in relation to the role of verbal behaviour in an analysis of behaviour.

As has been discussed in this section radical behaviourism considers private events such as deciding and thinking as the same as public events in all important respects as long as they independently observed and verified (Baum, 1994). However the question arises as to how one might access these events without resorting to introspective methods that are so abhorred by behaviourists? Skinner's answer comes in the form of *verbal behaviour,* the capacity of the human species to communicate through the medium of language. Skinner defined *verbal behaviour* as an operant behaviour that requires the presence of a listener for its reinforcement (Skinner 1957). This concept is of fundamental importance within radical behaviourism because of its ability to make the traditionally inaccessible accessible through the use of verbal reports. These verbal reports are viewed as behaviours in their own right and are controlled and maintained by the same contingencies as actual physical behaviour (Skinner, 1953, 1974, 1984; Foxall, 2005). By recognising the important role of verbal behaviour in human activity the radical behaviourist

position has provided a method by which to accommodate within the paradigm, facets of human behaviour that would have been previously deemed inaccessible, but via the capacity of language are deemed public and viable for analysis. Methodologically speaking this inclusion expands the researcher's toolkit in order to examine more complex human behaviour, an issue that will be discussed in great depth in chapter three of this thesis.

Criticisms of radical behaviourism

Despite the undeniable contribution of radical behaviourism in furthering our understanding of human behaviour, it has been widely and often erroneously attacked by its opponents (Day 1969; Bijou 1979; Moxley 1982; Catania 1984; Skinner 1984; Moore 1995; Malone & Cruchon 2001). Common criticisms levelled against the radical behaviourist position are often inaccurate and unfounded in nature, with many opponents misunderstanding and misrepresenting this distinct branch of behaviourist thought (Chiesa 1994; Palmer 2006).

Chiesa (1994) noted that there were common criticisms that have been levelled against radical behaviourism that stem from a fundamental misrepresentation of this school of thought. One of the most prevalent and worrying misunderstandings of Skinnerian behaviourism is that it is merely an extension of its predecessor, which leads to it being criticised for treating private events in the same manner as Watson's methodological behaviourism. To criticise radical behaviourism for ignoring private events or for equating it to a form of black box theory is to criticise it for something it is explicitly not. As highlighted earlier within this chapter Skinner himself made no dichotomy between public and private events, and even claimed that it would be foolish to ignore such an important facet of human experience (Skinner, 1974).

A second common criticism level against radical behaviourism is that it treats humans as passive organisms, and thus fails to account for the true complexity of human behaviour (Bijou, 1979). One could argue that the apparent simplicity of radical behaviourism is highly deceptive, with Skinner's inclusion of verbal behaviour allowing for ever more complex human behaviours to be explored. Furthermore the critique of radical behaviourism for treating humans as passive is

totally unfounded since in radical behaviourism the organism is in constant interaction with its environment, hence the term operant conditioning (Bijou, 1979).

Despite these criticisms of radical behaviourism, this approach continues to cast a clear and often unique light onto various aspects of human behaviour, and has been shown to make a considerable contribution especially in applied settings (Sturmey, 2008; Nye, 2000). The potential of behaviour analysis shedding light on numerous human problems is eloquently summed up by Leigland (2010) in the following extract:

"As a comprehensive, coherent, and useful science of behavior, behavior analysis should have relevance to any and all questions and investigations of human behavior, from the behavior problems of children diagnosed with autism to the verbal behavior of physicists as they work mathematically and also speak in nontechnical terms about quantum mechanics."

The Behavioural Perspective Model

Within the context of the United Kingdom the behaviourist perspective has seen somewhat of a renaissance through the emergence of the Behavioural Perspective Model of purchase and consumption, a radical behaviourist interpretive device that has Skinner's three term contingency at its heart (Foxall 1990; Foxall 1997). The BPM provides an account of individual choice founded upon the discipline of applied behaviour analysis (Foxall, 1999). Conceptually the BPM stems from the Skinnerian premise that the behaviour of an individual is determined by the contingencies of reinforcement under which they are emitted (Skinner, 1938, 1953, 1974). According to the BPM, aspects of an individual's behaviour are predictable from two elements that have situational influence: (1) the scope of the behaviour setting, (2) the utilitarian and informational reinforcement signalled by the setting as primed by the individual's individual learning history (Foxall, 1999, p.150). One of the major strengths of the BPM as an interpretative device is that it provides a contextualised account of choice by locating the individual's behaviour in time and space.

To date the BPM has been adopted to investigate a wide range of phenomena, such as consumer brand choice (Foxall & James 2003; Foxall & Schrezenmaier 2003; Foxall *et al.* 2004; Oliveira-Castro *et al.* 2005; Oliveira-Castro *et al.* 2006), consumers' reactions to shopping environments (Foxall 1999; Foxall & Yani-de-Soriano 2005), socially responsible consumption (Davies *et al.* 2002; Foxall *et al.* 2006) among others. The BPM framework has yet to be adopted in the investigation of health choice behaviours, despite the fact that there is no evidence to suppose that the model's central variables will not be equally applicable. As discussed in chapter one of this thesis one of the principle aims of this thesis is to produce a behavioural account of donor family consent through the application of the BPM and to identify a means in which organ donation consent maybe stimulated. To this end, the remainder of this chapter seeks to demonstrate the potential applicability of the BPM to this particular context by discussing each of BPM's central tenants and applying them to the context of family organ donation consent. At the end of each section a proposition regarding that variable will be stated with the intention that these will guide the two empirical phases of this thesis, which are documented in chapters 4 and 5.

Learning history

The concept of learning history is a central variable within the BPM schema as it interprets behaviour as occurring at the intersection of an individual's learning history and the behaviour setting. Foxall defines the concept of learning history as "*the reinforcing and punishing consequences of similar behaviour previously enacted in similar situations to that currently encountered*" (Foxall 2007). Put simply, an individual's learning history is the repository of all past experiences with a particular product or behaviour and their reinforcing and/or punishing consequences. This past experience helps the individual interpret the behaviour setting accurately, thus signalling the likely consequences of their behaviour within the situation they are currently presented with. Therefore prior learning establishes what will act as discriminate stimulus in the immediate behaviour setting (Foxall 2005). This means that even within the exact same behavioural setting, individuals will respond differently as a result of their unique learning history, which in turn will

dictate whether they approach or avoid the situation (Foxall & Greenley, 1999). For example, an individual who has experienced positive outcomes, such as a free cup of coffee or a bumper sticker when they have donated blood will be more likely to revisit a blood drive when they are given a flyer encouraging donations. In this example, due to the individual's positive learning history with the act of blood donation, the advertising flyer becomes a discriminative stimulus promoting the individual to act, which in this context is to provide a blood donation.

A person's unique learning history represents all personal factors that may influence their behaviour and comprises of three variables, (1) genetic history, (2) state variables and (3) individual learning history (Foxall 1994). Foxall defines the concept of genetic history as "*the product of an evolutionary past*" on an individual's current behaviour (Foxall, 1994, p.29). It stems from the premise that human behaviours have evolutionary origins, with some being more overt than others. For example behaviours that meet our basic needs on a species level such as the process of sourcing food will clearly have evolutionary roots as the behaviour in question ensures the survival of the organism by satisfying their need for nutrition. In the context of organ donation consent one could argue that in light of the existent literature, altruistic behaviour towards one's immediate social group or kin has strong evolutionary roots, since it promotes the survival of the group in times of scarcity (Hamilton 1964; Trivers 1971). Conversely, within the existent literature the concept of "*fear of death*" has been identified as a prominent obstacle to organ donation consent and this too has clear evolutionary underpinnings (Horton & Horton 1991; Radecki & Jaccard 1997; Siminoff *et al.* 2001). However as Foxall (1994) rightly emphasises, the genetic history of individuals is not empirically available in a direct sense and cannot be accurately measured. Due to this limitation this dimension of learning history has been disregarded from this thesis. Furthermore its inclusion would represent an over-complication and would move the scope of this thesis away from the actual behaviour of consent and back towards the antecedents of organ donation consent behaviour.

The second dimension of an individual's learning history outlined by Foxall is defined as state variables, which refer to the momentary factors that are present at the time of the behaviour in

question (Foxall, 1994). For example state variables can relate to the negative mood a customer is in whilst food shopping or the sudden feeling of sickness that an individual experiences which disrupts a trip to the cinema. All behaviours are potentially influenced by these so-called state variables, however because of their often fleeting nature they are incredibly difficult to capture. Foxall (1994) acknowledges the potential effects of state variables; however they are generally omitted from BPM research due to the difficulty in accessing and measuring them. Therefore following this line of argument this thesis also acknowledges the potential effect of state variables on the organ donor consent, but will make no attempt to explore them due to problems with reliably capturing them.

Individual learning history will be the most explicit personal variable considered within this thesis, since it exerts the most evident lasting influence over behaviour. In direct contrast to genetic history, individual learning history is not inherited but accumulated over the span of a lifetime. As will be recalled earlier in this chapter individual learning history accounts for an individual's predisposition to approach or avoid engagement in a given behaviour based on the behavioural outcomes of previous encounters with that or similar behaviours. In a behavioural analytic approach, this unique learning history accounts for the individuality of the decision maker (Foxall, 1994).

Before applying the concept of individual learning history to the context of donor family consent, it is important to address some of the difficulties associated with measuring the concept and how it differs from existing consumer behaviour models. Firstly learning history is not usually empirically accessible through direct observation, even to the individual involved (Foxall, 1990, 1994). Unlike in laboratory settings, where an animal can be observed from birth thus allowing full access and measurement of their learning history, researchers cannot track a human's full learning through observation. Therefore it has been proposed in the BPM literature that researchers may have to resort to the use of "*verbal surrogates*" from respondents in the form of attitudinal reports of prior behaviour and their consequence in order to reconstruct an account of their learning history (Foxall, 1995). More explicitly the BPM literature proposes the

use of existing models such as the Theory of Reasoned Action (Fishbein & Ajzen 1975) or the Theory of Planned Behaviour (Ajzen, 1991) as a sophisticated technology that can allow the researcher access to an individual's learning histories via an indirect means (Foxall, 1995, p.53). The use of verbal reports of attitudes and past behaviour has been effectively used in the existent literature to account for respondent's learning histories. For example Leek et al in their BPM study on situational determinants of fish consumption used consumer's attitudinal statements to reconstruct their consumption history (Leek *et al.* 2000). Therefore in instances where it is impossible to gain direct information about an individual's past experiences, attitudes can be justifiably used as a surrogate measure of past experiences.

Thus far this section has provided the reader with an overview of the different types of learning history identified within the BPM literature and has provided a justification for the focus on individual learning history due to the problems associated with access and measurement of the other forms. The section then proceeded to explain how the BPM's understanding of the effect of experience differs from existing consumer behaviour models. It is at this point that this chapter will now endeavour to link together the BPM individual learning history construct to the existing research regarding organ donation consent. The following section will discuss in detail individual learning history in the organ donation consent context with explicit reference to the existing literature in the organ donation field. The section will conclude with propositions that have been formulated in light of the existing literature, these will act as guide in the empirical phase of this thesis.

Learning history and organ donation consent

Attitude

As was discussed earlier in this chapter, in instances where accessing information about an individual's experience is unattainable, attitudinal statements can be used as surrogates since they express what an individual predicts will be the most likely outcome of engaging in a given behaviour. Therefore attitude is a measure of an individual's anticipated behavioural outcome of engaging in a specific behaviour formed through their experience with that or similar behaviours

(Foxall, 1995). Within the existent literature attitude toward organ donation has been a central construct in the investigation of consent, and has been found under certain conditions to be associated with one's willingness to become a donor (Parisi & Katz 1986; Horton & Horton 1990; Horton & Horton 1991).

Attitudinal surveys conducted in various contexts have consistently found that the overwhelming majority of respondents report positive attitudes toward organ donation. Generally, attitudinal surveys report that more than half the population surveyed are positive towards donating their organs, a large percentage is undecided, and a minority possess negative attitudes toward donation (Parisi & Katz 1986; Schutt & Schroeder 1993; McNamara *et al.* 1999; Yeung *et al.* 2000; Gross *et al.* 2001; Reddy *et al.* 2003; Bilgel *et al.* 2004; Barcellos *et al.* 2005; El-Shoubaki & Bener 2005). The exact percentages of positive, undecided and negative individuals vary from country to country, from subgroup to subgroup, however the overarching trends remains the same. In the particular context of the United Kingdom, the most recent surveys indicate that approximately 90% of the population are in favour of organ donation and possess positive attitudes towards the procedure (NHSBT 2013b). So the question arises why is there such a low conversion rate between individual attitude and *actual* organ donation consent?

It is well documented within the existent literature that positive attitudes and intentions towards a specific behaviour are not necessarily predictive of actual engagement in that behaviour, and this is particularly evident in the context of organ donation consent (Radecki and Jaccard, 1997). Prottas rightly emphasised that a willingness to express a positive attitude towards a socially approved activity is not the same as a willingness to make it concrete (Prottas 1983). Sanner (2006) found that those who reported they were undecided regarding organ donation within her sample reported discomfort levels closer to the group who were negative towards donation than those who were positive towards donation. Sanner (2006) argues that this result indicates that many of the undecided individuals were in fact a hidden negative group, who believed it was more socially acceptable to indicate hesitance over the issue rather than outright refusal.

There is also a growing body of evidence that demonstrates that individuals can hold both positive and negative attitudes toward organ donation simultaneously. Vincent and Logan (2012) state that factors determining consent outcome include *both* altruistic motives and negative psychological responses (Vincent and Logan, 2012, p.80). Two recent studies have identified a group of negative attitudinal variables coined as "*non-cognitive variables*", which have been shown to be a significant barrier to organ donation commitment (Morgan *et al.* 2008; O'Carroll *et al.* 2011). At this point one should stress that the term "non-cognitive" should not be taken literally as this term can be misleading. Both sets of authors believe that information processing does occur in relation to these variables and therefore they are still cognitive by definition, however the authors stress that these reactions are irrational and emotional in nature. These so-called non-cognitive variables include what has been termed the "*ick factor*", defined as a general disgust response to the notion of organ donation, the "*jinx factor*" which is a belief that registering to be a donor will hasten one's own death, medical mistrust relating to the belief that medical personnel will not try as hard to save individuals if they are donors and lastly the need to preserve bodily integrity (Morgan et al, 2008). Within the context of the UK, Morgan and colleagues' (2008) study was replicated by O'Carroll and his colleagues. O'Carroll and colleagues (2011) similarly reported that this set of non-cognitive variables were highly predictive in discriminating between donors and non-donors within their sample. This body of research corroborates the findings of a range of studies that have focussed on the reasons why donor families refuse consent when approached. For example a fear of dismemberment and disfigurement, (Martinez *et al.* 2001; Exley *et al.* 2002; Siminoff & Lawrence 2002; Barber *et al.* 2006; de Moraes & Massarollo 2009; Sotillo *et al.* 2009; Ghorbani *et al.* 2011) and a level of medical mistrust regarding the integrity of the process (Martinez *et al.* 2001; Anker & Feeley 2010; Ghorbani *et al.* 2011) have been identified as prominent reasons why potential donor families have denied consent.

From a behaviourist perspective, both negative and positive attitudes are acquired by an individual through their experience with the behaviour in question or similar behaviours. This can be acquired either directly through personal contact with the behaviour's contingencies or

indirectly through the verbal behaviour of third parties, such as the views of influential others such as immediate family. This subject will be explored more in depth later within this chapter when the role of direct and indirect experience with organ donation will be addressed.

Characteristics of donors vs. non-donors and their families

A substantial body of research within the existent literature has attempted to identify the characteristics of donor and non-donors and their families that are associated with positive and negative organ donation consent outcomes. The most common background factors identified in the literature are educational level, religious beliefs and the ethnic/cultural background of the potential donor and their family. Findings in this area of research have often been inconsistent, especially regarding the influence of education on organ donation, demonstrating the impact of the sampling strategy utilised by the researchers. In the following section each of these characteristics will be examined as a form of individual learning history. From a behaviourist perspective religion, cultural background and educational attainment are all acquired through experience during a lifetime. Furthermore the transmission of cultural and religious traditions constitutes a form of rule-governed behaviour.

Three of the earliest studies attempting to identify the characteristics and distinctions between donors and non-donors were conducted by Cleveland and Johnson during the 1970s in the USA (Cleveland & Johnson 1970; Cleveland 1975a; Cleveland 1975b). These studies indicated that donors were more likely to be highly educated, that is in possession of an education higher than a diploma, less religious and more positively inclined toward science than non-donors. More recent studies (Siminoff *et al.* 2001; Rodrigue *et al.* 2006) have found no significant association between educational attainment and family consent, however the role of religion has consistently be found to be associated with refusal. This is a somewhat surprising finding, since one might expect that religious individuals would be more inclined towards charitable acts of altruism due to their beliefs and therefore be more willing to donate, but early studies identified donors to be less religious than non-donors (Cleveland & Johnson 1970; Simmons & Simmons 1971; Cleveland 1975a; Cleveland 1975b). This could partly be attributed to the fact that these

individuals are uncertain about what their religion prescribes regarding the body after death. In the existent literature ambiguity regarding what the potential donor's religion dictates in relation to the body after death has been identified as a barrier to organ donation (Horton and Horton, 1990). This appears to still be the case a decade since this research, especially among ethnic minority groups in the United Kingdom. For example Randhawa (1998) reported that for UK Muslims an awareness of their religion's stance towards organ donation was an important influence in their decision making process. Within the sample of this study few were aware of the Fatwa issued in 1995 in support of organ donation. In reality religious faith does not constitute grounds for refusal since Islam, Christianity and Judaism are not formally opposed to the procedure. However, because organ donation is a relatively new medical advancement there is no explicit mention of the procedure in any sacred texts, therefore religious stances on the subject are purely based on interpretation. Furthermore the concept of brain stem death is incompatible with the beliefs of some Orthodox Jews and Catholics (Randhawa *et al.* 2012). In a recent interview study conducted with faith leaders in the UK, many stressed the fact that no-consensus regarding organ donation had been reached within their own faith group and that in reality there was a broad spectrum of opinion concerning the issue of organ donation and transplantation (Randhawa 2012). Therefore it is understandable that within certain religious groups, affiliates would err on the side of caution and refuse donation if they were unsure of the official stance of their religion on the issue of donation. Religious grounds are often cited as reasons for donor family refusal within the UK (Barber et al, 2006) and this theme is repeated in various contexts around the world (Yong *et al.*, 2000; Singh *et al.*, 2004; Anker and Feeley, 2010; Ghorbani *et al.*, 2011). What is not clear is whether these families have an informed view of their faith's stance based on upon teachings and/or debate from a religious leader or whether they are expressing their own personal interpretation of their faith. Both forms would constitute rule governed behaviour; the only distinction being one would be acquired from a regulatory figure within their faith group, whilst the other a self-imposed rule. These findings demonstrate the urgent need for religious groups to formally articulate their stance regarding organ donation and communicate these effectively with their followers.

Lastly another component of learning history that is often inextricably linked to religion but deserves separate treatment is the influence of ethnicity and culture on organ donation consent. Within the existent literature the association between ethnicity and organ donation refusal has been consistent and has been demonstrated in multiple contexts. Ethnic minority groups have repeatedly been found to be less likely to become organ donors, communicate their donation wishes to family members or provide consent for the donation of a family member when requested (Cleveland, 1975; Randhawa, 1998; Darr *et al.*: 1999; Alden *et al.*, 2000; Siminoff *et al.*, 2001; Siminoff *et al.*, 2002; Morgan *et al.* 2006; Rodrigue *et al.*, 2006; Wu *et al.*: 2009; Brown *et al.*, 2010; Jacoby and Jaccard, 2010). These findings are particularly problematic in the context of the United Kingdom, where individuals who are of Black heritage are approximately three times more likely than the general population to develop kidney failure, and the need for organs in the Asian community is four times higher than the general population (NHSBTb, 2013). Several studies investigating ethnic minority groups and attitude towards the issue of organ donation have reported cultural specific issues that argue against donation. For example, Alkhawari et al reported that various cultural specific issues arose when they conducted a study examining attitudes toward donation amongst Indo-Asians in west London (Alkhawari *et al.* 2005). These culture specific issues included a sense of the sacredness regarding the body, a fatalistic approach to illness, a belief that organs took on an independent role as '*witnesses*' to an individual's life on Judgement Day and an anxiety that the donor would have no control of the probity of the recipient of an organ (Alkhawari *et al.*, 2005). Other studies conducted with ethnic minority groups in the UK have argued that many of the barriers to organ donation are not entirely culture specific, for example concerns about leaving the body "*intact*" and medical mistrust (Morgan *et al.*, 2006). The evidence base within a UK context is somewhat embryonic with relatively few studies having been conducted in comparison to other contexts e.g. the USA. However what can be concluded from the limited evidence base is the need for an improvement in the provision of health information provided to ethnic minority communities is vital if the UK is to see an increase in donations among this segment of society.

Subjective norms and organ donation

Subjective norm is defined as "*a reflection of the demands of the situation conceptualised and measured as a set of beliefs about what the respondent believes a significant other thinks about the respondent's performing the behaviour in question*" (Foxall, 2005, p.87). Subjective norm represents a form of learning history since it reflects the extent to which a respondent feels social pressure to conform to the demands of the particular situation and demonstrates a history of compliance, or in some cases non-compliance with the perceived wishes of important individuals in a respondent's life. For example, subjective norm would be reflected in the statement "*my partner thinks that I should exercise regularly.*" In this context the statement demonstrates the respondent's perceived pressure to conform to their partner's wishes.

In the context of donor family consent, significant others would typically include the potential donor's family, friends and in some contexts the views of other influential individuals such as religious figures or senior members of a community. The importance of family agreement and approval regarding organ donation consent decisions has been consistently identified within the existent literature. Family disagreement regarding organ donation has been found to be a significant barrier to consent (Yong *et al.* 2000; Martinez *et al.* 2001; Singh *et al.* 2004; Barber *et al.* 2006; Lopez *et al.* 2008; Anker & Feeley 2010; Ghorbani *et al.* 2011), with the likelihood of refusal increasing with an increase in the amount of individuals involved in the discussion. One particular study conducted by Rodrigue et al. in the USA found that family disagreement occurred in 32% of donation approaches when multiple family members were involved during the request (Rodrigue *et al.* 2008). These families were less likely to consent to donation and took longer to make their final decision. This demonstrates that when other family members voice disapproval of the organ donation procedure, the decision maker is less likely to donate and more likely to conform to the social pressure within their family unit. Similarly, Barber et al (2006) report that in the context of the UK, relatives being divided over the donation decision has been cited as the primary reason for organ donation not taking place in 16% of all organ donation refusals during the audit period between April 2003 and March 2005.

Commentators, public health specialists and researchers alike have stressed that the remedy for this particular obstacle to improving donation rates is through the encouragement of discussion between family members during their lifetime about their wishes and intentions regarding organ donation. However prompting communication has been found to be difficult, with a lack of communication between individuals and their family about their organ donation wishes being identified as a considerable obstacle in improving donation consent rates across multiple contexts (Harris *et al.* 1991; Jasper *et al.* 1991; Radecki & Jaccard 1997; Martinez *et al.* 2001). This lack of communication has been attributed to several factors, including negative subjective norms in the form of perceived family disapproval of organ donation appears. The existing literature indicates that individuals are less likely to express their donation wishes to their significant others during their lifetime if they anticipate they will encounter objection or lack support for their donation choice (Thompson *et al.* 2004; Waldrop *et al.* 2004; Breitkopf 2006; Morgan *et al.* 2006). This is partly due to individuals wanting to avoid conflict with their family over the issue and having to justify their stance. The negative consequence of individuals not expressing their donation wishes with family members is significant, since families tend to err on the side of caution when wishes are unknown (Anker and Feeley, 2010). Previous research indicates that when a family is cognizant of the deceased's wishes they usually abide by them (Harris *et al.* 1991; Jasper *et al.* 1991; Burroughs *et al.* 1998; Martinez *et al.* 2001; Thomas *et al.* 2009), therefore promotion of these discussions should be paramount in any intervention strategy that seeks to increase family consent rates.

Direct and indirect experience and organ donation

Prior to a full discussion on the influence of direct and indirect forms of experience on organ donation consent; it is important to first reiterate the BPM's stance on the role of past experience in shaping future behaviour. Firstly the BPM argues that future behaviours are influenced by both the amount and the nature of past experience. This means that an individual will engage in a given behaviour, regardless of how limited their previous experience is, as long as that previous experience was rewarding enough to reinforce future repetition. For example,

an individual might purchase a particular brand of wine not because they are a wine connoisseur but because they have had one sip at a friend's house and liked the taste.

As discussed in chapter one of this thesis, organ donation is a relatively new and rare procedure in the United Kingdom, with a small number occurring each year. Consequently very few individuals possess direct experience with organ donation and transplantation. Most experience of the phenomenon and the issues that surround it are acquired indirectly via the verbal behaviour of third parties or through experience with similar behaviours. In the context organ donation direct experience with similar behaviours could feasibly include previous engagement with blood donation programs, Anthony Nolan registration, carrying a donor card or family discussion about the topic of organ donation. Relatively little research has been conducted on the role of direct and indirect experience on organ donation consent, especially in the context of the UK. Most studies have been conducted in the context of the USA and have primarily investigated the following sources of experience and its influence on organ donation committal: (1) the influence of knowledge, (2) mass media and its impact and (3) the influence of prior behaviour, in particular family discussions on the topic of organ donation. The following section will provide an overview of each these sources of experience within the existent literature.

Knowledge

Numerous studies within the existent literature have focussed on the role of knowledge on organ donation committal. One of the earliest and most influential pieces of research that focussed on the role of knowledge on organ donation committal was conducted by Horton and Horton (1990). They administered a survey measuring the public's knowledge regarding organ donation and transplantation within the context of North America. The study comprised of 21 true or false questions regarding factual knowledge about organ donation with a participating sample of 455 undergraduate students, 26 MBA students, and 465 people from the surrounding community. The resultant data identified four major knowledge deficiencies that served as barriers to organ donor committal. These knowledge deficiencies were identified as a lack of knowledge regarding what one's religion prescribed regarding the issue of organ donation, a lack

of knowledge regarding the term "*brain death*", a lack of knowledge regarding ethical policies surrounding organ procurement and a lack of knowledge concerning donor cards. Horton and Horton (1990) found that the concept of "*brain death*" posed the most significant problem among their sample. This finding in particular corroborates with the findings of several other investigators (Manninen & Evans 1985; Pearson *et al.* 1995; Franz *et al.* 1997; Burroughs *et al.* 1998; Siminoff *et al.* 2001; Siminoff & Lawrence 2002). Manninen and Evan found that many individuals did not fully understand that a declaration of brain death was required before kidneys and other organs could be removed for transplantation, and that this was a substantial barrier to donation (Manninen & Evans 1985). Other studies carried out on donor and non-donor family members report a lack of information regarding brain death criteria (Pearson *et al.*, 1995), a poor understanding of the meaning of brain death (Franz *et al.*, 1997, Dejong *et al.*, 1998) and confusion with other brain conditions such as comas and permanent vegetative states (Franz *et al.*, 1997; Siminoff *et al.*, 2001, 2002). This lack of knowledge indicates a lack of experience. This is unsurprising since these highly medical and technical terms are often outside of the realm of ordinary everyday experience for the average individual.

Franz et al (1997) undertook one of the few studies that have actually assessed the extent of respondent's knowledge regarding brain death. Franz and his colleagues carried out a cross sectional telephone survey of 164 next of kin of potential organ donors. Their findings indicated that a substantial number of donor participants were confused about whether their relative was truly dead, furthermore non-donating families had less understanding of brain death than donating families (Franz *et al.*, 1997). This finding implies that families with a greater degree of knowledge regarding brain death are more likely to go on to consent to organ donation than families with a lower degree of knowledge, a conclusion that is incredibly important from an intervention perspective. Franz et al (1997) then proceeded to ask their participants specific questions regarding the diagnosis of brain death, these included whether a person diagnosed as brain dead is a person in a coma or dead? The participants were then asked to state true or false to the following: i) whether it is possible for a brain dead person to recover from their injuries and ii) whether someone is brain dead is dead even if their heart is still beating. The authors

found that nearly 50% of donor and over 80% of non-donor respondents answered one or more of the basic questions about brain death incorrectly (Franz *et al.*, 1997). In response to the second statement regarding the ability of an individual to recover after brain death diagnosis, 20% of donor and 52% of non-donor respondents incorrectly agreed with this statement. These findings highlight that a lack of knowledge, which in turn demonstrates a lack of experience regarding brain-death ultimately poses a significant barrier to organ donation consent rates. An apparent lack of brain death knowledge is incredibly important from an intervention and public policy perspective, as it highlights the need for this aspect of the procurement process to be addressed and clarified for the benefit of the general public. From the above evidence presented a lack of knowledge and experience with the issues surrounding organ donation appear to inhibit organ donation considerably. Radecki and Jaccard (1997) argue that increasing knowledge regarding organ donation and transplantation may assist in dispelling myths about the procedure, may enable one to confront the issue and may facilitate effective decision making and promote discussion among individuals and their next of kin. This leads us onto the question how might individuals gain the knowledge needed to assist them in organ donation decision making? One important source of indirect experience that can potentially expand an individual's knowledge regarding organ donation is the mass media. This source and its potential influence on donation decision making is discussed in the following section.

The role of the media

In the absence of direct experience with organ donation, the existent literature has identified the mass media as an important source of information for the general public. The positive and negative impact of the media in informing the public about the general issue of organ donation has been highlighted by several studies (Moray *et al.* 1999; Moloney & Walker 2000; Matesanz 2003; Harrison *et al.* 2008; Quick 2009). Previous research has emphasised the mass media's often sensationalised portrayal of organ donation as being a significant barrier to organ donation committal in various contexts. For example Harrison et al (2008) argue that media portrayals of organ donation sensationalise the facts surrounding organ donation and play to the fears of the

general public. While national news broadcasts tend to focus on factually accurate events surrounding the issue of organ donation and transplantation, medical dramas such as House and Grey's Anatomy which boast huge international ratings depict crises such as the deaths of organ recipients due to undiagnosed diseases carried by donors (Harrison *et al.*, 2008). These negative depictions fuel the reservations individuals may already feel towards donation and transplantation. Furthermore in the absence of any direct experience with the issue, negative depictions can actually wrongly inform individuals of the facts surrounding donation. One study conducted by Morgan et al reported how storylines presented on entertainment television mirrored the actual reasons individuals were giving for not becoming donors, with family members actually reciting storylines from television episodes to justify their negative positions (Morgan *et al.* 2007).

In contrast, there are some researchers who view the media's role in a positive light, arguing that the media may be our best hope of educating the public about organ donation and subsequently increasing donation levels (Greenfield 1988; Matesanz 2003). Matesanz (2002) argues that the best way of influencing public opinion may be through the direct use of the mass media and stresses that this could be a useful way of addressing misconceptions regarding organ donation openly, and at the same time placing emphasis on the life-saving aspects of donation and transplantation. In the context of the UK relatively little is known about the influence of the media's portrayal of organ donation on the general public. However, it is not difficult to hypothesise a potential effect of this form of learning history upon donor family consent given research findings from a US context. In particular negative publicity surrounding organ donation (verbal behaviour) has the potential to act as powerful deterrent to organ donation committal, or at the very least make individuals faced with the decision extra cautious of committing to the act of donation. One poignant example of negative media coverage occurring in the United Kingdom happened during the summer of 2013 when a popular medical television drama called Holby City, ran a storyline depicting a mother's struggle to decide whether her brain-dead daughter should donate her heart. In one particular scene, the mother saw the organ harvest operation in progress, despite having withdrawn consent (BBC News, 2013). The

NHSBT responded promptly in a formal letter of complaint, stating that the episode was "*misleading*" and "*wholly inaccurate*" and stated that that as a direct consequence of the programme they had already been contacted by people asking to be taken off the Organ Donor Register (BBC News, 2013). This most recent incident highlights the potential threat of such negative publicity on organ donation levels in the United Kingdom.

Prior behaviour

The radical behaviourist standpoint assumes that an individual's current behaviour is shaped by their previous experience with that or similar behaviours and is resultant from the reinforcement or punishment incurred (Skinner, 1938; 1953). Previous experience primarily consists of engagement with the behaviour under investigation, and in instances where direct experience is limited it can include experience with similar behaviours. Within the existent literature numerous research studies examining various different human behaviours have consistently demonstrated that measures of prior behaviour improve predictions of current behaviour over those provided by attitudes, subjective norms and intention alone. For example, behaviours where this has been shown include smoking cessation (Marsh *et al.* 1983; Sutton *et al.* 1987); blood donation (Bagozzi 1981); seat belt use (Budd *et al.* 1984; Mittal 1988; Sutton & Hallett 1989), voting behaviour (Echabe *et al.*, 1988) and traditional consumer behaviour (East 1992; East 1993). These studies provide a convincing evidence base that indicates that prior behaviour exerts a strong influence on an individual's current behaviour.

As has already been highlighted elsewhere in this chapter, due to the relative newness and rarity of the procedure in the United Kingdom, very few people are in procession of direct experience of organ donation or the process. Therefore relevant prior behaviour in this context is concerned with behaviours that lead up to the act of donation. In the existent organ donation literature various sources of relevant prior behaviour have been identified, these include prior family discussions regarding organ donation and post-mortem wishes and having previously registered to be an organ donor (Burroughs *et al.* 1998; Brug *et al.* 2000). Another possible source of prior behaviour that may exert an influence but has received little attention within the

literature is prior engagement in similar behaviours, such as blood donation or other socially beneficial behaviours such as volunteering (Burroughs *et al.*, 1998). This is an area that has attracted limited attention within the existing literature, despite the fact that it is easy to hypothise a relationship between donor family consent and past engagement in similar socially beneficial acts. It is logical to assume that those who have previously received positive reinforcement from engaging in socially approved behaviours will be more likely to engage in other socially approved behaviours in the future when the opportunity presents itself. For example an individual who has engaged in blood donation programmes in the past and has received positive reinforcement for this behaviour in the form of thank you letters from the NHS and approval from their peers, they may be more likely to consent to the organ donation of their family member if the environmental cues signal a similar reinforcement.

This section has sought to demonstrate the applicability of the learning history construct to the context of organ donation committal and consent by drawing upon the existent literature. In light of the above discussion regarding learning history, this thesis proposes that this element of the BPM will exert a significant influence on donor family decision making and those in possession of a stronger more positive learning history will be more likely to consent compared to those with weaker more negative learning history. This section has demonstrated that although a wide range of literature exists regarding the role of attitude and subjective norm, there is limited amount of research on actual donor family consent in the context of the UK and much of which that does exists is of a qualitative nature. Which particular learning history dimensions will be most strongly evident in the context of the UK remains unclear, therefore the influence of the learning history dimensions identified in this literature review, namely attitude, subjective norm, direct and indirect experience, will be explored further in study one with the following proposition guiding this inquiry:

P. 1.1: Learning history will significantly influence donor family consent

Once the specific attitudes, subjective norms, direct and indirect experience has been identified in study one, the second empirical phase seeks to examine their influence on actual consent. The

second proposition P.1.2 follows the logic that significant differences in consent will be apparent between those in possession of positive history and those in possession of a more negative learning history regarding organ donation. Learning history being the total score of all identified elements in study one, measured via a learning history instrument. This will be empirically tested in the second phase of the research strategy, documented in chapter five of this thesis. This proposition is formally presented as:

P. 1.2: Likelihood of consent will differ between those with a positive learning history and those with a negative learning history

Behaviour setting and organ donation consent

The present section of this chapter will discuss the concept of behaviour setting and its application to the context of organ donation and family consent. Before attempting to apply this concept to the unique context of donor family consent, one must first define the concept of behaviour setting and outline its origins within the existent literature. The concept of a behaviour setting partly stems from the work of the ecological psychologist Roger Barker and his colleagues whose work emphasised the environmental determinants of behaviour (Barker 1968; Wicker 1979). In his classic work entitled ecological psychology (1968) Barker coined the term behaviour setting to denote the environmental units in which particular patterns of behaviour could be observed, irrespective of the individuals performing them. According to Barker, behaviour settings are *"stable extra-individual units with great coercive power over the behaviour that occurs within them"* (Barker, 1968, p.17). For example particular patterns of behaviour are evident in certain behaviour settings, such as worshipping in a church, waiting at the reception of a doctor's office or browsing in a clothes store. These patterns of behaviour are termed behavioural programmes and are considered a direct outcome of the built environment in which the behaviour occurs.
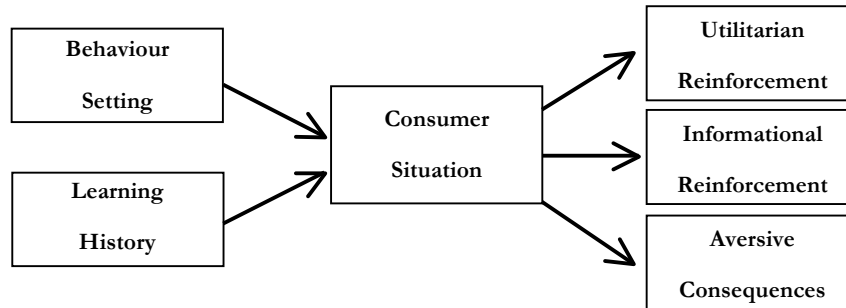
Figure 3. BPM framework (Foxall, 1990, 1997).

As depicted in the top left hand side of the BPM schema (**Figure 3**), one of the central tenants of the model is that of the behaviour setting. Within the BPM this term is subtly distinct from the definition proposed by Barker (1968). According to the BPM the behaviour setting represents the immediate environmental context within which the behaviour under investigation occurs. The term represents the unit of analysis within which to identify and classify all the environmental factors that may serve as potential discriminative stimuli for the individual decision maker. These discriminative stimuli serve as cues through their interaction with the individual's unique learning history, and signal the likely response outcome of the individual's particular choice (Foxall, 1993, Leek *et al.*, 2000; Soriano *et al.*, 2002;). Therefore whereas Barker's (1968) term represented a level of environment in which individuals would respond in a similar manner, the BPM's application of the term is more flexible, used to define the context of the behaviour in question and classify potential discriminative stimuli that comprise the setting.

Within the BPM account of behaviour, the discriminative stimuli that compose a behaviour setting can be classified as physical, social, temporal or regulatory in nature (Foxall, 1997). The BPM's stimuli categories of the behaviour setting owe much to Belk's (1974; 1975) categories of situational variables. According to Belk, the behaviour setting represents the interface between the individual (e.g. the decision maker) and the stimulus/object (e.g. the product, service etc.), with all the characteristics of the situation being termed as situational variables (Belk 1974; Belk 1975). **Table 1** demonstrates the applicability of this dimension of the BPM schema to the subject of this thesis by providing examples from the context of the organ donation request environment for each of the four behaviour setting variables. In the following sections each one

of the four variables, which comprise the behaviour setting, will be applied to the particular context of organ donation consent.

Behaviour setting variable	Examples in the organ donation request
Physical characteristics	The intensive care unit, medical machinery, waiting rooms, information booklets, hospital atmospherics e.g. alarms, medical personnel talking.
Social characteristics	Presence or absence of family and/or friends, doctors and nurses and their roles and attributes, religious figures.
Temporal characteristics	Timing of request, time given to make the decision to consent/refuse, amount of time given to explain process to the family by staff.
Regulatory characteristics	Hospital rules, regulations, instructions and protocols e.g. mandatory paperwork to be filled in by family, religious rites, legal aspects of the process, instructions and information given by medical personnel etc.

Table 1. Behaviour setting of the BPM applied to donor family consent.

The physical setting is the most evident dimension of the immediate environment (Belk, 1974). In a traditional consumer context this element includes the spatial location of the retail store, as well as the visual aspects of the in-store configuration of the products. It also may include the provision of information, as well as store atmospherics such as music, lighting and in-store design (Foxall, 2005). In the context of donor family consent, the physical dimension is primarily concerned with the physical elements evident within hospital and most often the intensive care unit. This environment would typically include the unit's waiting room, the unit's layout and lighting, the hospital's atmospherics such as alarms and medical machinery, as well as the physical appearance of the patient and staff. The influence of the potential donor's physical appearance on family decision making has received notable attention within the existent literature. Previous qualitative research in this area has consistently identified this as a particular barrier to donor family consent. Donor families often report that the physical appearance of the potential donor's body makes it harder for them to accept the diagnosis of death and consequently consent to organ donation (Sque *et al.* 2006a). More specifically the fact that the

potential donor's ventilated body is warm to touch, pink, twitches due to involuntary muscle spasms and is visibly breathing with a rising and falling chest is hard to reconcile with the fact that brain death has occurred. From an intervention perspective this element of the behaviour setting cannot be modified, since continued ventilation of the donor's body is needed in order to harvest organs that require a fresh oxygenated blood supply, most notably the heart.

The second dimension of a behaviour setting is categorised as the social characteristics of the environment. The social setting in which the behaviour occurs adds further depth to the environmental context (Belk, 1974). This dimension includes the presence or absence of other key actors within the behaviour setting, along with their specific roles, attributes and opinions. These individuals can become either discriminative stimuli or a source of reinforcement in their own right via their verbal or non-verbal behaviour (Foxall, 1990, 1997). In the context of donor family consent, the role and influence of other actors within the hospital environment is well documented in the existent literature. Specifically the influence of interactions with medical personnel and significant others, such as family members, has been highlighted. For example, it is a consistent finding that a perceived sensitive and empathetic manner or lack of, during organ donation discussions between medical personnel and the potential donor family is a discriminator between donor and non-donor families (Douglass *et al.*, 1995, Rodrigue *et al.*, 2006; Jacoby *et al.*, 2005; Jacoby *et al.*, 2010;).

The third dimension of the behaviour setting refers to the temporal setting. This dimension includes all time related effects within the immediate environmental context. For example in a traditional consumer context the temporal setting would include the time of day, week, as well as the season the behaviour under investigation was occurring. It can also be measured against a past or future event, for example pay-day (Belk, 1974; 1975). In the context of donor family consent the temporal element of the current behaviour setting would include the timing of the request, the length of time needed for the process of consent and the time given to families to say goodbye to the donor. In the existent literature the impact of the temporal element on donor family consent has been identified and been found to be significant in the ultimate

outcome. Previous studies have shown an association between consent being granted and the family being given what is deemed sufficient amount of time to consider their response (DeJong *et al.*, 1998, Siminoff *et al.*, 2001; Jacoby *et al.*, 2005; Rodrigue *et al.*, 2006; Rodrigue *et al.*, 2008).

Lastly within the BPM schema the regulatory setting denotes the rules that constrain behaviour within an environment. Simply put it is the amount of freedom an individual exerts in a situation. These rules can be self-imposed in nature or can come from a third-party such as a regulatory figure. Regulatory aspects of the environment can also be physical in nature such as a snake device in a bank to control queues (Foxall, 2005). In the context of donor family consent the regulatory setting could potentially have a strong impact on the final consent outcome via the verbal behaviour of family, friends or figures of authority present during the decision making process. As already demonstrated in this chapter, the behaviour of medical personnel and significant others has been found to be influential on the family's donation decision. Furthermore rules in the form of religious and cultural conventions and rites, such as concerns over maintaining bodily integrity have been cited as a common reason for refusing consent (Yong *et al.*, 2000; Singh *et al.*, 2004; Barber *et al.*, 2006, Anker and Feeley, 2010; Ghorbani *et al.*, 2011).

Thus far this section of the present chapter has demonstrated the applicability of the behaviour setting variables within the BPM framework to the context of the organ donation request environment. However at this point it should be emphasised that many aspects of the donation request environment are un-modifiable. Put simply due to the very nature of the behaviour in question many aspects of the environment cannot be changed or are beyond the control of the requester. For example many of the social aspects of the environment are beyond the requester's control or influence such as the behaviours of extended family and friends. In addition negative aspects of the physical setting, such as the appearance of the donor's ventilated body, which has been shown consistently to be a barrier to consent, cannot be overcome. Furthermore, due to the nature of organ donation and transplantation many of the temporal elements of the behaviour setting are fixed for medical and legal reasons. This leaves two elements that can be

fully controlled within the behaviour setting, (1) the regulatory behaviour of the requester and (2) the scope of the behaviour setting. The present research considers these two elements as inextricably linked, with the behaviour of regulatory figures in the request environment e.g. the requesters, dictating the scope of the setting and signalling the amount of freedom available to the decision maker. The behaviour setting scope variable is the focus of the next section within this chapter.

Behaviour setting scope and donor family consent

An important element of the BPM schema is the behaviour setting scope, a term first that was first coined by Schwartz and Lacey (1988) to represent the degrees of freedom an organism possesses in the behaviours they engage in. Schwartz and Lacey believed that all behavioural contexts could be defined and classified according to the relative degree of behavioural scope (Schwartz & Lacey 1988). As can be seen in **Figure 4**, according to the BPM literature the continuum of the behaviour setting scope ranges from entirely closed to entirely open in nature (Foxall, 1993). Along the continuum, an organism enjoys differing degrees of freedom, with those environments which are more restrictive in nature falling towards the closed end of the spectrum, and those environments where organisms can exert more freedom falling towards the open end (**Figure 4**). Foxall (1999a) states that in relatively closed behaviour settings, depicted as those that fall along the left hand side of **Figure 4**, the physical, social and regulatory elements within the environment are largely organised by individuals or organisations other than the decision maker. By their very definition, more closed behaviour settings encourage conformity to programmes of action that are deemed appropriate for the setting, e.g. queuing. In these types of behaviour settings the individual has a lesser degree of autonomy and must adhere to the rules of the environment.

Conversely, relatively open behaviour settings, depicted as those which fall along the right hand side of **Figure 4**, are absent from higher levels of social, physical and regulatory pressures. The decision maker is comparatively free to determine their own rules and course of action instead of being dictated to through environmental cues or external agencies. Of course social,

regulatory and physical discriminant stimuli are still present in more open behavioural settings; however they do not exert the same restrictive influence of more closed settings.
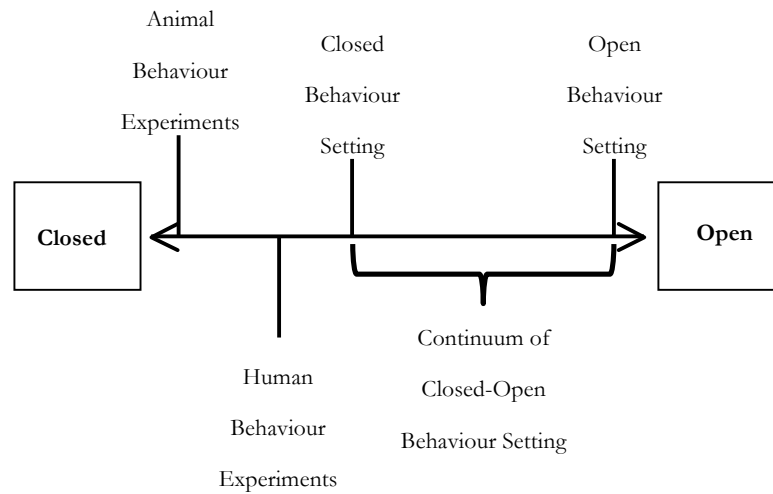
Figure 4. Continuum of the consumer behaviour setting (Foxall, 1993).

Unlike experimental animal laboratories where there are absolutes in the degree of freedom afforded to the organism, in the real world there are very few contexts in which human behaviour occurs that could be defined as totally closed or open in nature. One of the rare examples of a totally closed behavioural setting would be an environment devised for brainwashing. In direct contrast a totally open setting would have no constraints on the individual whatsoever which cannot exist in any society that adopts any form of legal or religious framework. In reality, the overwhelming majority of behavioural contexts fall somewhere *along* the continuum of behaviour setting scope, being defined as either relatively open or relatively closed. When the dimension of behaviour setting scope is added to the BPM'S operant classification of consumer behaviour, eight distinct contingency categories are generated that may control behaviour. **Figure 5** illustrates the eight contingency categories (CC) with the descriptive labels that Foxall has derived for each "CC" that reflects the type of behaviour that would be evident in that environment (Foxall, 1990, 2004).

	Closed ←——→ Open	
Operant classes	**Setting scope**	
Accomplishment	CC2 Fulfillment	CC1 Status consumption
Pleasure	CC4 Inescapable Entertainment	CC3 Popular Entertainment
Accumulation	CC6 Token-Based Consumption	CC5 Saving & Collecting
Maintenance	CC8 Mandatory Consumption	CC7 Routine Consumption

Figure 5. BPM contingency category matrix (Foxall, 1990, 2004).

In the context of organ donation consent the hospital setting in which donor family behaviour occurs could be defined as a relatively closed setting by nature. This is largely because the environment is under the control of external agencies to the decision maker, including doctors, nurses, administrators and even the government. Furthermore other dimensions evident within the immediate behavioural setting are restricting to the decision maker thus adding further to the closed nature of the environment. For example the potential donor families are restricted in the hours in which they are allowed to visit the hospital, the areas of the hospital they are allowed to access and frequent during their visit as well as the behaviours they are allowed to engage in whilst on the hospital grounds, such as the prohibition of smoking, mobile phone use and talking loudly with others. Put simply, the restrictions described are a combination of both the physical environment in which the decision making process is made, typically the ICU/ward of a hospital, and the discriminent stimuli that comprises the immediate behaviour setting,

including but not exclusively the medical personnel who interact with the decision maker and as will be discussed in later chapters, the physicality of the actual patient.

Despite the inherent closed nature of the overall hospital environment, potential donor families exert a high level of control and influence when it comes to providing consent and the request situation. As will be recalled from chapter one of this thesis, the current system of consent employed in the UK involves consent being obtained by an individual in a qualifying relationship, even in circumstances where consent has been obtained from the potential donor via their registration onto the ODR during their lifetime (Vincent and Logan, 2012). Therefore in the context of the UK the decision to refuse or provide consent rests entirely with the potential donor's family, who in approximately 10% of cases deny consent even though the potential donor is registered on the ODR (Rudge, 2007). At present it is accepted practice to respect such refusal despite the existence of a legally valid form of consent. For a complete discussion for the legal and ethical background to consent please refer to Price (2012) and Farsides (2012).

Additionally it should be noted that in unusual circumstances a even more open behavioural setting in the organ donation request environment may be possible. For example in instances where the decision making process could take place over a longer period of time in an environment outside of the hospital domain, such as the decision maker's own home. This type of situation would result in the decision maker exerting a higher level of control and freedom since they would not be party to the physical, social and regulatory stimuli within the hospital setting. However for the purpose of the current thesis the widely documented and far more common decision making situation has been adopted, where the family has limited time and where the decision making process takes place in the relatively closed and more restrictive hospital environment. This choice has been taken because the relatively closed hospital is the usual requesting setting for decision makers and therefore reflects the norm rather than the exception.

In light of the evidence currently available the request situation could be classified as being relatively open in terms of scope despite the inherent closed nature of the overall hospital environment. This is because the wishes of the family taking precedent over even the wishes of the deceased, thus affording the potential donor family a high degree of freedom and control. Against this backdrop there are growing calls from various parties for an introduction of a *harder* system of consent in the UK to tackle the problem of supply. The most common call from pro-donation factions is for the introduction of an opt-out system of consent where individuals would have to actively express a wish to *not* be an organ donor. As of summer 2013, the Welsh Assembly has passed legislation regarding the introduction of an opt-out system of consent but the explicit role families will take in the consent process remains unclear, especially in terms of whether they will be able to exercise a power of veto. To date little is known about the potential impact of an opt-out system on consent in the United Kingdom. This is a not insignificant gap as the introduction of such legislation would likely restrict potential donor families' perceived freedom of choice that in turn may have a negative effect on consent levels. This particular concern has been raised by the medical profession who have warned that such an introduction may make families feel pressured and erode the trust that has been built between patients and clinicians (Department of Health 2008). As part of its review of the available evidence regarding public support for an opt-out system consent, the Organ Donation Taskforce commissioned the centre for reviews and dissemination at the University of York to review the published literature on public attitudes to presumed consent. They found that among the eight UK surveys reviewed, there was considerable variation in the level of support for presumed consent, ranging from 30% to over 60%. The reviewers concluded *"the limited and incomplete evidence available from surveys suggests variable levels of support. In addition consideration needs to be given to potential variation in attitudes between different sociodemographic sub-groups"* (Rithalia *et al.* 2009).

In light of the above discussion it is proposed that the scope of the behaviour setting will significantly influence donor family consent, however the direction of the relationship is unclear at present due to limited and insufficient evidence in the existing literature. Therefore the

relationship between behaviour setting scope and consent will be examined in both empirical phases of this thesis with the following proposition guiding the analysis:

P2. The scope of the behaviour setting will significantly affect organ donation consent outcome

Situation specific emotions

Radical behaviourist view of emotion

Before discussing the role of emotion in the donor family request situation, one must first briefly outline the radical behaviourist stance concerning emotion and its relationship with behavioural response. Radical behaviourism holds low scientific significance to the role of emotions as antecedents to actual behaviour, maintaining that emotions in no way *cause* behavioural response. Radical behaviourists place emphasis on the fact that emotions are the consequence of behaviour, with feelings considered merely the by-products of behaviour rather than the *causes* of them (Baum, 1994, pp.103). Put simply emotions happen simultaneously to behaviour and are controlled by the same conditions (Skinner, 1953, 1974). For example a feeling of happiness will occur when a positive event happens to an individual, such as winning a prize, whereas a feeling of fear may arise in an individual as direct result of being in the presence of a dog. Seen in this light emotions or feelings arise from the same history of reinforcement and punishment that accounts for observed behaviour. That is emotions or emotional reports are the product of an individual's history with similar circumstances. To illustrate this point further we could take the example of the individual who experiences fear when presented with a dog. In this instance the individual in question had previously been bitten by a dog, and therefore the nervousness they feel when presented with the dog (emotion) and the obvious display of fear (e.g. crying) are two separate responses conditioned by the *same* discriminative stimulus, that being the past behavioural consequence of having been bitten by dog.

Despite this, within the radical behaviourist stance emotions do serve an important purpose for the observer. Skinner himself acknowledged that emotions could be used by observers for the

purpose of classifying behaviour (Skinner, 1953, pp.162-163). Skinner (1953) believed that by understanding the emotion that was felt by an individual at the time of an act of behaviour, the observer could identify the conditions that controlled that behavioural response.

Emotion and organ donation consent

As has already been alluded to earlier in this thesis, the organ donation request situation is recognised as a highly emotionally charged environment for all parties involved. It is an emotional situation for the potential donor family as they are faced not only with the painful news that their family member will not recover, but also faced with the difficult decision of having to provide consent on their behalf. In addition the situation can also be emotional for the medical professionals involved in the actual donation request, since the very act of requesting can be difficult with staff anxious not to cause any further distress to relatives (Fonseca & de Melo Tavares 2012). As discussed earlier in this chapter as part of the potential aversive consequences of organ donation, research has found that families often report a range of negative emotional responses towards the request situation, including fear, conflict and even disgust (Sque & Payne 1996; Sanner 2006; Morgan *et al.* 2008). As will be recalled these responses are commonly cited as the primary reasons why consent has not been granted for organ donation, thus demonstrating its powerful influence on the final consent outcome in the context of the UK (Vincent and Logan, 2012; Barker et al, 2006). However to date little attention has been paid to the role of positive emotional responses towards the actual organ donation request situation, despite the fact that a range of positive emotions have been identified in the literature. **Table 4** provides a summary of some of the more commonly reported positive emotions experienced by donor families.

Author(s)	Emotion reported by donor families
Manzari *et al.*, 2012; McIntyre *et al.*, 1987; Parisi and Katz, 1986	Satisfaction
Manzari, 2012; Van Den Berg *et al.*, 2005; Parisi and Katz, 1986	Pride
Sque *et al.*, 2006; Cunningham 1993; Pelletier 1993; Soukup, 1991; Bartucci, 1987; Batten and Prottas 1987; Buckley 1989; Morton and Leonard, 1979	Comfort

Table 2. Positive emotions reported in existent literature.

Despite the role of affective responses having been previously investigated in relation to individuals wanting to become a donor during their lifetime (Van den Burg *et al.*, 2005), to date no study concerning donor family consent has made any attempt at measuring the emotional responses of donor families towards the request environment. This is perhaps unsurprising since it would be methodologically difficult to obtain this information in situ and ethically improper to approach bereaved individuals at such a distressing time in their lives. However this area warrants further investigation as the existent literature clearly indicates that the potential donor family's emotional response towards the request environment may play a role in the final consent outcome. Given the above evidence it is logical to expect that donor family emotions will be closely associated with their final consent choice, as has been shown to be the case in other more traditional consumer choice behaviours. For example in the traditional consumer behaviour literature the emotional responses of consumers to service environments has been rigorously examined over the past decade, with consumer's emotional responses toward a consumer situation being consistently identified as directly related to a consumer's willingness to spend money, browse and consume (O'Shaughnessy & O'Shaughnessy 2003). In addition emotions have been shown to exert a considerable influence in a wide range of consumer behaviours (Andrade & Cohen 2007; Sivanathan & Pettit 2010; Griskevicius *et al.* 2011).

Emotion and the BPM

Following the above argument, this thesis will follow the precedent of previous BPM studies and employ Mehrebian and Russell's environmental psychology model (PAD) to investigate association between organ donation consent and individuals affective responses to request situations (Mehrabian & Russell 1974). Mehrebian and Russell's (1974) PAD model is an extensively used psychological instrument, which has accumulated a high level of empirical support within the existing consumer literature (Menon & Kahn 2002; Mummalaneni 2005; Ryu & Jang 2008; Li *et al.* 2009). Furthermore it has been successfully adopted in previous BPM research. Previous BPM research into situation-specific emotional responses has consistently found that Pleasure, Arousal and Dominance are related to all three elements of the BPM framework, namely utilitarian reinforcement, informational reinforcement and scope of the behaviour setting (Foxall, 1997; Foxall & Greenley, 1999; Soriano *et al.*, 2002; Yani-de-Soriano & Foxall, 2002). **Table 3** demonstrates the expected patterns of situational and emotion correspondence reported in the existent BPM literature.

Operant Class	Closed setting scope	Open setting scope
Accomplishment	+P +A -D	+P +A +D
Pleasure	+P –A -D	+P –A +D
Accumulation	-P +A -D	-P +A +D
Maintenance	-P -A -D	-P -A +D

Table 3. Expected pattern of situational and emotion correspondence.

At this point there is one particular issue concerning the application of the PAD model to the BPM that should be noted. As will be recalled from earlier in this chapter, radical behaviourism is founded upon the three term contingency which does not explicitly include the organism. In contrast Mehrebian and Russell's (1974) model is founded upon the stimulus-organism-response model, where the environment (S) prompts an individual's emotional response (O) which then

generates a behavioural response (R). Therefore in contrast to radical behaviourism, Mehrebian and Russell's (1974) PAD model emotions are considered *causes* as well as behavioural responses. This position seemingly contradicts the stance of emotions advocated in radical behaviourism. However it is important to note that Skinner himself did not order the omission of affective variables from an analysis of behaviour (Skinner, 1953). Instead he characterised emotions as *predispositions* to behave in a certain manner. Skinner (1953) also claimed that they were useful in helping the observer classify behaviour, in the respect of the circumstances that the behaviour occurred that in turn affected their probability.

"When we "arouse an emotion," we alter the probabilities of certain types of responses. Thus, when we make a man angry we increase the probability of abusive, bitter, or other aggressive behavior and decrease the probability of generous or helpful behavior" (Skinner, 1957, p.216).

Therefore this thesis follows this logic, and argues for the inclusion of affective responses in the analysis of organ donation consent behaviour on the basis that affective responses reflect consent *predispositions*, in Skinnerian terms.

In light of the present thesis investigation will start with first testing the relatedness of each of the PAD elements to the BPM's modes of reinforcement and setting scope in order to determine whether previously identified associations between PAD and the BPM will hold true in this health context (**Table 3**). Put simply, study two will test whether (1) *Pleasure* will be significantly higher in request situations maintained by high levels of utilitarian reinforcement rather than those maintained by relatively low levels, (2) whether *Arousal* will be significantly higher in request situations maintained by high levels of informational reinforcement rather than those maintained by relatively low levels and finally (3) whether *Dominance* will higher in request situations in which the scope of the setting is open rather than request situations in which the scope of setting is more closed. Therefore the following propositions will guide the analysis of study two concerning the PAD variables and their relationship with the BPM operant classes:

P3.1. Pleasure will discriminate between Accomplishment-Accumulation and Pleasure-Maintenance.

P3.2. *Arousal will discriminate between Accomplishment-Pleasure and Accumulation-Maintenance.*

P3.3. *Dominance will discriminate between Open and Closed consumer behaviour settings.*

Finally previous BPM studies have explored the possibility of relating emotional response to behavioural response by applying Staat's behaviourism (1996) (Foxall & Greenley, 2000; Foxall & Yani-de-Soriano, 2005). Staat's behaviourism posits that emotions can function as *both* antecedents of behaviour *and* behavioural response (Staats & Staats 1996). Previous BPM research has reported that emotions do act as antecedents to behaviour. Therefore following theses previous applications of Staats' (1996) behaviourism, study two examines the possibility of emotions serving as organ donation consent stimuli, and therefore an antecedent to behaviour. The following proposition will guide this investigation in the second empirical phase:

P4. *Affective responses will significantly influence consent behaviour*

Contingencies of reinforcement

As will be recalled from earlier in this chapter, the BPM schema conforms to the three term contingency which is at the core of Skinner's approach to behaviour analysis. This section of the present chapter now turns to right hand portion of the BPM framework that depicts three reinforcement outcomes, illustrated in **Figure 3**. According to the BPM, consequences signalled by the discriminative stimuli that compose a decision making environment can take three forms: *utilitarian reinforcement*, *informational reinforcement* and *aversive consequences* (Foxall, 1990, 1997). In the following sections each of these behavioural outcomes will be outlined and then applied to the specific context of donor family consent.

Utilitarian reinforcement consists of both the functional and economic benefits that are experienced by consumers and decision makers for adopting a certain course of action, such as the consumption of a product or the engagement in a certain activity. This term also includes the direct satisfaction that the good, service or behaviour yields to the consumer (Foxall, 2005, p.97). This concept corresponds to the use of utility in economics which derives from the psychology of hedonism (Black 1987; Griffin & Parfitt 1987). Therefore utilitarian reinforcement is not only concerned with the functional and practical performance of a product

or behaviour, it also includes the feelings that are associated with the ownership, consumption and engagement with said product or behaviour (Foxall, 2005). In earlier formulations of the framework the term hedonic reinforcement has been employed to denote the utilitarian reinforcement concept. However for the purpose of this thesis the latter formulation of utilitarian reinforcement has been maintained for two specific reasons. Firstly the term hedonic is synonymous with pleasurable experiences and sensations, and therefore does not seem a fitting label for the functional benefits experienced by decision makers in this serious and often distressing health context. Secondly, in recent years the incentivising of organ donation and of providing consent has been discussed and debated within the existent literature. Incentivising donation strategies that have been proposed in the literature have often included a prominent monetary element, more specifically in the form of the offer of payment of funeral expenses or a one off financial incentive as a token of appreciation (Nuffield Council on Bioethics 2011). Therefore in light of these developments, which have a very clear economic benefit for the donor and their family, the term utilitarian reinforcement is deemed more appropriate within this context and will be used in this thesis.

In a traditional consumer environment utilitarian reinforcement refers to the economic and tangible functional benefits that are a direct consequence of the purchase, ownership and consumption of a product or service (Foxall, 1999, 2005). For example, the utilitarian reinforcements of buying a Toyota Prius would include the obvious functional benefits associated with owning and using any car, namely the convenience of having door-to-door transportation. In addition the Toyota Prius model is a fuel efficient, low consumption vehicle and therefore there would be further utilitarian benefits of an economic nature. Lastly the actual pleasure and satisfaction that the owner derives from the driving of the vehicle would be an additional source of utilitarian reinforcement. With this definition of utilitarian reinforcement in mind, we now turn to the application of this concept to donor family consent. In this specific context, utilitarian reinforcement refers to the direct tangible benefits experienced by the organ donation decision maker, which in the UK is most commonly the immediate family of the potential donor. Nicholson and Xiao have argued that there are few utilitarian benefits evident

in the context of organ donation (Nicholson & Xiao 2011). However, in the existent literature on donor family consent three distinct potential sources of utilitarian reinforcement are clearly evident. The first identifiable source of utilitarian reinforcement in the existent literature is the direct comfort that donor families can derive from providing consent. Previous research has found that families report a sense of comfort in something good stemming from such tragic circumstances (Soukup 1991; Cunningham 1993; Pelletier 1993; Sque, 1996; Manzari *et al.* 2012). The second clear source of utilitarian reinforcement that can be identified within the existent literature is the personal satisfaction that can be felt by the donor family for facilitating the organ donation process (Parisi & Katz 1986; McIntyre *et al.* 1987; Manzari *et al.* 2012).

The third potential source of high utilitarian reinforcement would be the introduction of a system, which financially compensates donor families for providing consent. This is an area that has attracted much debate in recent years, with opponents claiming that the introduction of such of scheme undermines the ideal of altruism upon which the donation process is founded. At present only Iran has a legal centralised system for the payment of living donors (Vincent & Logan 2012), therefore little data exists on the real-life outcomes of such a system and whether or not it stimulates consent amongst potential donor families. Rodrigue et al (2006) conducted an interview study with 155 next of kin and found that 6% of donor families stated that they would have refused donation if that incentive had been offered. This finding implies that the introduction of such a scheme could potentially offend some, in particular those who are already distrustful or apprehensive about donation already.

Informational reinforcement consists of the symbolic, indirect benefits acquired by the decision maker that attests to the level of correctness or appropriateness of an individual's performance as a consumer and decision maker (Foxall 1999). It should be emphasised that the term informational can be misleading, since this form of reinforcement does not consist of information per se, but in feedback that is often mediated through the responsive actions of other individuals and is therefore a form of verbal behaviour as defined by Skinner (Skinner, 1957). In some circumstances the individual can provide their own informational reinforcement, which consists of the individual's own evaluation of their performance, and can be described as

pride. In these situations the individual becomes the *"other person"* in their private thoughts (Skinner, 1957). In a traditional consumer environment an example of informational reinforcement would be the purchasing of luxury branded goods, where the possession of the high status brand attracts admiration from third parties through which the owner gains social esteem. Therefore the self esteem and social status the owner gains are the symbolic rewards from ownership and consumption of these prestigious high status goods. In sum informational reinforcement is fundamentally social and verbal.

In the context of donor family consent, informational reinforcement refers to the symbolic and indirect benefits experienced by the donor family as a consequence of providing consent. Perhaps unsurprisingly due to the altruistic nature of organ donation in the UK numerous sources of informational reinforcement can be identified in the existent literature. Perhaps the most prominent source of informational reinforcement is the social approval bestowed on donor families by the wider community for their engagement in a socially approved activity. This approval can be seen most clearly in the portrayal of donor families in the mass media and in the feedback that this group receives from the medical profession, the recipients of donated organ, as well as the wider transplant community.

In terms of negative reinforcement, the BPM literature has traditionally used the general term *aversive consequences* to denote those behavioural outcomes that may decrease the behaviour in question of being repeated in future situations (Foxall 1999). In newer formulations of the BPM schema the term punishment has been used to the same effect, and is sometimes dichotomised into utilitarian punishment and informational punishment. However for purposes of clarity and compatibility with the existent organ donation literature the term aversive consequence(s) has been retained. This is largely because a range of unwanted or aversive consequences have been identified in the existent literature, however none of these could be deemed as punishing, especially since the behaviour they engage in is, by in large, socially approved. In the existent literature a wide range of aversive consequences that are a direct result of organ donation have been identified. One of the most prominent aversive consequences associated with organ donation in the existent literature is the distress experienced by donor families due the notion of

dismemberment. This has been shown to be a powerful disincentive to providing consent, with families often providing it as the main reason for refusing consent (Exley *et al.* 2002; Siminoff & Lawrence 2002; Barber *et al.* 2006; Anker & Feeley 2010). In a similar vein, another commonly reported aversive consequence in the existent literature is donor families' concerns over bodily integrity, which is deeply rooted in the belief that if integrity of body is breached serious afterlife consequences would be incurred to the donor (Barber *et al.* 2006; Morgan *et al.* 2008; O'Carroll *et al.* 2011). This particular aversive consequence has been classified as a non-cognitive variable that prevents donation (Morgan *et al.* 2008; O'Carroll *et al.* 2011). Another prominent aversive consequence that is consistently identified in the literature is the issue of family conflict. Put simply arguments and disagreements between family members on the topic of organ donation (Martinez *et al.* 2001; Singh *et al.* 2004; Barber *et al.* 2006; Lopez *et al.* 2008; Anker & Feeley 2010)

Based upon the varying levels of informational and utilitarian reinforcement present in a given consumer situation, four operant classes of consumer behaviour have been proposed in the BPM literature. These are depicted in **Figure 6** and are named *Accomplishment, Pleasure, Accumulation* and *Maintenance.* It should be emphasised that no operant class is totally devoid of either informational or utilitarian reinforcements, these are evident in all four operant classes in differing degrees along the continuum of high to low. In the following section each of these contingency categories will be discussed and then applied to the particular context of donor family consent, where amended classifications for each of the classes will be proposed.
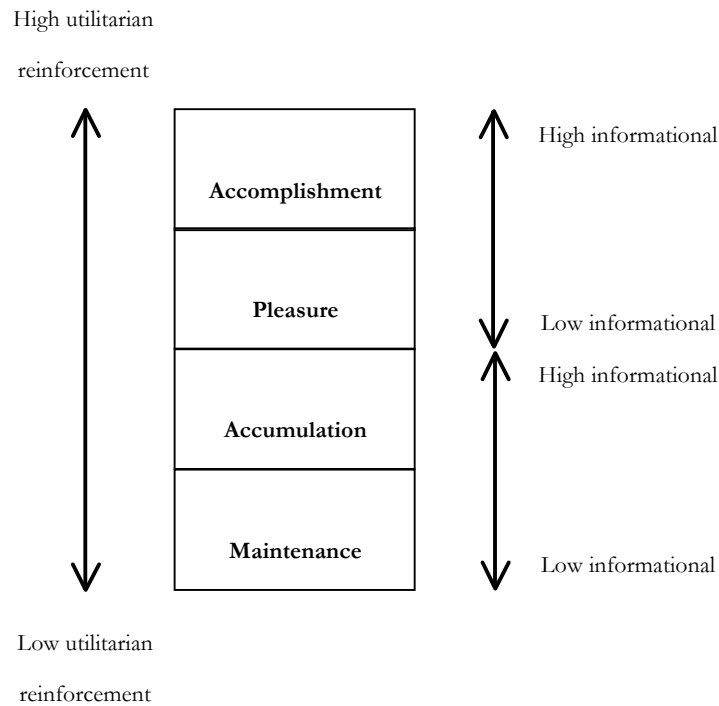
Figure 6. Operant classes of consumer behaviour (Foxall, 1990).

The *Accomplishment* operant class is maintained by maximum levels of both utilitarian and informational reinforcement. The *Accomplishment* class of behaviour would typically involve activities that would incur personal pleasure for the consumer, but also would result in social and economic status from the consumption of the high status good. In a traditional consumer context this operant class would involve the purchase and consumption of luxury brand goods. In the context organ donation and consent, the request within this operant class would emphasise the social status that could be gained from engaging in a socially approved behaviour. In addition this operant class would also consist of high utilitarian reinforcements, such as financial incentives for the donor family or an emphasis on the positive feelings that could be felt as a consequences of donation. Therefore this operant class is renamed *Societal Accomplishment* for the purpose of this thesis, reflecting the social approval and reward of providing consent for donation.

As **Figure 6** illustrates, the *Pleasure* category is maintained by high levels of utilitarian reinforcement but relatively low levels of informational reinforcement. Therefore within this operant class of behaviour activity is of a more indulgent nature. In a traditional consumer

context activities that would fall in this class would include the purchase and consumption of entertainment products and services that generate high levels of pleasure for the individual. In the context of organ donation, this operant class of behaviour would emphasise the direct satisfaction and comfort that donating would produce for the donor family, in addition to any financial incentives offered that would direct benefits to the decision maker, such as the payment of funeral expenses. Therefore this operant class has been renamed as *Incentivised donation* to reflect the incentivised nature of this category and the emphasis on self gratification.

The third operant class within the proposed BPM typology is the *Accumulation* class of behaviour. This operant class is maintained by high levels of informational reinforcement and relatively low levels of utilitarian reinforcement, therefore there are few direct tangible benefits for the decision maker with the reinforcements being largely symbolic in nature. Within this class of behaviour activities would typically involve collecting, saving and investment activities, which rely heavily upon the positive feedback of others. In the context of organ donation this operant class would emphasis the symbolic, indirect benefits associated with donation, such as the feedback that donor families would receive from recipients so they could see how their choice has improved the lives of other. In addition a collecting and saving element could be introduced, with donor families being offered a priority place on the transplant list if they should ever need one. This type of "*soft*" intervention has been proposed by the Nuffield Council on Bioethics (2011). In light of the nature of the Accumulation class, it has been renamed A*ltruistic donation* for this context. This new label reflects the non-functional, non-monetary benefits that can be derived from providing consent for donation and highlights the altruistic motivations behind the decision.

This takes us to the last of the operant classes defined within the BPM's typology of consumer behaviour. As will be noted from **Figure 6**, the *Maintenance* operant class is characterised by its relatively low levels of both utilitarian and informational reinforcement. Therefore behaviour in this operant class would typically involve the consumer satisfying their basic needs and/or obligations to society, for example purchasing and consuming items that meet basic human needs such as food or shelter or meeting civic obligations by paying tax. Therefore in the

context organ donation providing consent would be consider routine or even mandatory, with little utilitarian and informational reinforcements present. The emphasis would be in organ donation being a fundamental part of being a socially responsible individual, with families providing consent being an ordinary rather than an extra-ordinary occurrence. Therefore the Maintenance class has been renamed *Routine donation* to reflect the routine, ordinary and un-incentivised approach to organ donation that characterises this category. It could be argued that of all the operant classes, the *Maintenance* class is the one, which resembles the current UK system the most.
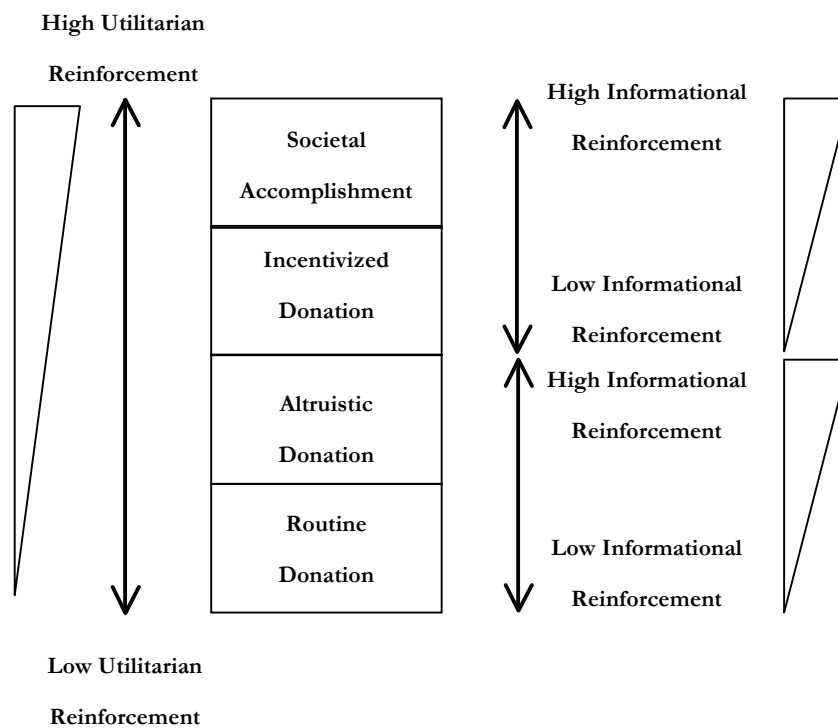
Figure 7. Operant classes of organ donation consent.

It is at this point in light of the above discussion that the formal propositions that will guide the empirical phases of this thesis regarding organ donation consent and patterns of reinforcement can be formulated. This section has provided the reader with an overview of modes of reinforcement proposed by the BPM schema and applied them to the context of organ donation consent. In light of the evidence presented in this section it is clear that organ donation consent is shaped by a combination of both utilitarian and informational reinforcement. However this behaviour appears to be primarily motivated by symbolic, informational benefits. Furthermore

policy makers have warned that if utilitarian benefits are too high some there is a risk of potential donor families refusing consent (Department of Health 2008). Therefore it is proposed that requests situations where informational reinforcement is high and utilitarian reinforcement are relatively low will be the most effective in stimulating consent. This proposition is formally expressed as:

P5.1. Altruistic donation (Accumulation operant class) will be the most effective in stimulating consent among donor families

Following the same logic it is proposed that situations that are low in both informational and utilitarian reinforcement will be the least effective in stimulating consent. This proposition is formally expressed as:

P5.2. Routine donation (Maintenance operant class) will be the least effective in stimulating consent among donor families

Lastly, the final proposition is based on the hypothesis that informational modes of reinforcement will be universally important to decision makers regardless of their learning history. As this chapter has discussed, informational modes of reinforcement such as social approval, positive feedback from family members and recipients of donated organs appear to be important to decision makers. In contrast this thesis proposes that utilitarian modes of reinforcement will only be important to decision makers with a high level of learning experience. This proposition has been formulated in light of the existent literature which has indicated that utilitarian reinforcements such as financial incentives may possibly be looked on with suspicion or deemed offensive by individuals who lack the requisite learning history, and therefore would not be deem such a incentive as important (Department of Health 2008; Nuffield Council on Bioethics 2011). These propositions are formally expressed as the following and will be examined in study two of this thesis:

P5.3. Informational modes of reinforcement will be equally important to both learning history groups

P5.4. Utilitarian modes of reinforcement will be more important to the higher learning history group than the lower learning history group.

Toward a behavioural interpretation of donor family consent

To summarise, the primary aim of this thesis is to explore donor family consent from a radical behaviourist perspective via the application of the Behavioural Perspective Model (Foxall, 1990; 1997). This chapter has sought to justify and develop a behavioural account of donor family consent by applying the BPM to this context in a systematic fashion, with each of the central tenants being discussed and subsequently applied to the chosen context of this thesis. The proposed explanatory account of donor family consent can be summarised into an analytical framework, which is depicted in **Figure 8.**
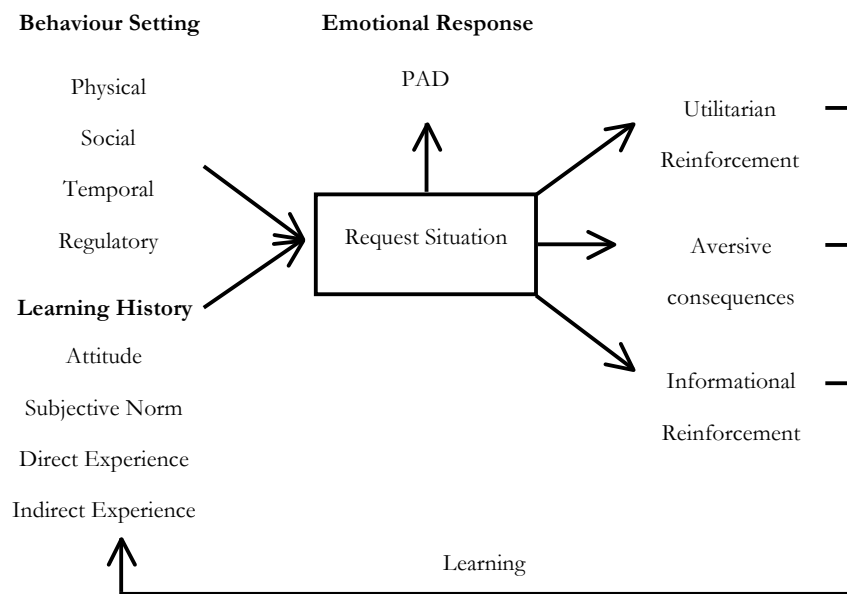
Figure 8. Proposed explanatory account of donor family consent.

In summary, the proposed analytical model is a subtle adaptation of the Behavioural Perspective Model (Foxall, 1990, 1997), with donor family consent outcomes being influenced by a range of individual level and external factors. The antecedents of organ donation consent behaviour is represented by the behaviour setting (physical, social, temporal and regulatory) and the four learning history constructs. In addition the organ donation consequences are shown as either

utilitarian, informational or aversive in nature. The request situation is located where the individual's unique learning history and the current behaviour setting meet thus depicting the influence of situations (Foxall, 1990, 1997, 2007). As can been seen in **Figure 8**, the individual's consent response occurs concurrently with their emotional response in accordance with Skinner's stance (Skinner, 1953). Lastly as stated earlier in this chapter, this thesis intends to also explore the possibility of affective responses functioning as antecedent stimuli by adopting Staat's (1996) behaviour. This proposition has been tested in previous BPM studies and has been proven to be relevant (Foxall & Greenley, 2000; Foxall & Yani-de-Soriano, 2005).

Chapter Three

Methodology

"A scientist may not be sure of the answer, but he's often sure he can find one. And that's a condition which is clearly not enjoyed by philosophy."

B. F. Skinner, 1974, p.120

Introduction

This thesis seeks to examine the phenomenon of donor family consent from a radical behaviourist perspective. The principle objective of this thesis being to better understand the behaviour of potential donor families towards granting consent, the various types of learning history which inform these decisions and the environmental contingencies that shape this complex human behaviour. As will be recalled from chapters one and two, this thesis aims to address the following overarching research questions that serve to guide the empirical phase of this thesis:

1) Can family organ donation consent be understood as an operant process utilising the BPM framework?

2) What patterns of reinforcement increase likelihood of consent?

3) Can donor family consent be stimulated via behavioural intervention?

This thesis began by introducing the issue of organ donation and the global shortfall of suitable transplantable organs with a particular emphasis on the context of the United Kingdom. Chapter two then proceeded with a review of the literature concerning the philosophical branch of psychology called Behaviourism, before presenting the Behavioural Perspective Model of purchase and consumption as a potential explanatory framework upon which to build the subsequent studies contained within this thesis. The Behavioural Perspective Model (BPM) was presented as the principle explanatory framework for this thesis since it is the key radical behaviourist framework currently available within the consumer psychology literature and offers

several distinct advantages over the existing social cognitive models commonly utilised in the field of organ donation research. The application of the BPM was justified for several reasons that are outlined in depth in chapter two; most notably its ability to examine both individual level and external factors that impact on the final consent outcome. A full justification of this approach was made in chapter two and preliminary research propositions, which serve as a guide to the empirical phases of this thesis, were presented in light of the existent literature.

This present chapter aims to document and justify the empirical strategy adopted within this thesis, which is a dual phase mixed-method approach. The chapter will begin by providing an overview of the radical behaviourist approach to scientific inquiry, which underpins the whole research strategy of this thesis. The chapter will then proceed to outline and justify the general research strategy of this thesis before discussing some of the training the researcher undertook in order to prepare for the role of researcher. The chapter continues by documenting the research procedures for the first empirical phase of thesis, an exploratory case study approach utilising the BPM as an analytical framework. In this section the various sources of evidence that were collected for study one will be discussed, as well as the analysis procedure, reliability and validity tests employed and the ethical issues that needed to be considered with this particular form of research. The research procedure for the second phase of this thesis, an experimental study into stimulating organ donation consent can be found at the beginning of chapter five. This structure was adopted in order to ensure clarity and cohesion for the reader. Put simply, so that the method of each study could be presented with their accompanying results.

The radical behaviourist approach to scientific inquiry

The philosophical stance which is adopted in any given research study has strong methodological implications for how the study ought to be conducted (Remenyi *et al.*, 2005). Burrell and Morgan (1979) state that all social scientists approach research via "*explicit or implicit assumptions about the nature of the social world and the way in which it may be investigated*" (1979, p.1). In **Figure 9** Burrell and Morgan's (1979, p.3) scheme for analysing the assumptions about the nature of social science is outlined. As can be seen from **Figure 9**, the two extremes at either

end of the spectrum represent the objectivist and subjectivist paradigms, each with their own belief system regarding (1) how the research views reality (ontological assumptions), (2) the nature of knowledge (epistemological assumptions), (3) the relationship between reality and humans (assumptions about human nature) and (4) on how best to acquire information from the world (methodological assumptions).

The Subjective-Objective Dimension

Subjectivist approach			Objectivist Approach
Nominalism	← Ontology →		Realism
Anti-positivism	← Epistemology →		Positivism
Voluntarism	← Human nature →		Determinism
Ideographic	← Methodology →		Nomothetic
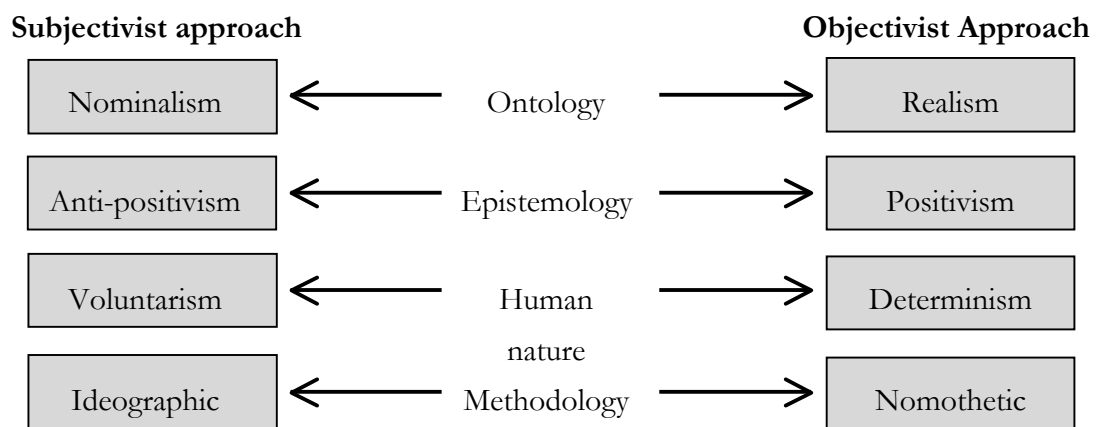
Figure 9. Objectivist-Subjectivist spectrum (Burrell and Morgan, 1979).

It should be emphasised that despite the fact that positivist and interpretative paradigms are often depicted as two opposing positions on the spectrum, one should not consider either of them as superior to the other as they both possess inherent strengths and weaknesses (Saunders *et al.*, 2007). It is for this reason that a growing number of researchers are calling for these "*opposing*" paradigms to be seen as complementary rather than mutually exclusive (Burrell & Morgan, 1979). This argument is firmly grounded in the assumption that through the application of both qualitative and quantitative approaches the weaknesses of one method can be offset by the strengths of the other (Creswell & Plano Clark, 2007). Therefore research that adopts a mixed-method strategy falls *along* the objectivist and subjectivist continuum, somewhere in the middle ground *between* the two extreme stances. This perspective is often associated in the literature with the philosophical paradigm of pragmatism, that ascribes to the belief that it is the research question alone that should drive the selection of the method(s) utilised in an

investigation believing that '*epistemological purity doesn't get research done*' (Miles & Huberman,1984, p. 21).

Against this backdrop, the BPM's approach to empirical investigation is based within the radical behaviourist view of science and its associated methodological standpoint. Whilst methodological behaviourists located within the scientific paradigm of logical positivism emphasised the hypothetico-deductive method, radical behaviourists have adopted a subtly distinct view of science firmly positioned within the philosophical sphere of pragmatism that is concerned with finding the most practical explanations for phenomena rather than the pursuit of a universal truth (Baum, 1994, p18; Moore, 1995; Leigland, 2010). Skinner's (Skinner, 1957, 1974) view of science saw the purpose of scientific inquiry as one of exploration rather than theory development, the primary goal being the better prediction and control of behaviour. Skinner (1974) regarded the hypothetico-deductive method as often counterproductive, limiting scientific development with its tendency of validating theoretical constructs simply because an experimental hypothesis had been repeatedly demonstrated within restrictive laboratory conditions, despite the underlying assumptions being potentially flawed. Put simply, the hypothetico-deductive method advocated by early behaviourists such as Watson may lead to the validation of explanatory fictions, the reproduction of results being seen as confirmation of a particular explanation of behaviour, regardless of it being true or not (Bolles, 1979).

The differences between the two brands of behaviourism regarding scientific inquiry have important methodological implications on how they believe science ought to be conducted. Early behaviourists methodologically placed emphasis on theory formulation and development through experimental procedures. By contrast, Skinner (1957, 1974) recognised that the complex nature of human behaviour was seldom suitable for formal experimentation within a laboratory setting; therefore he advocated a more pragmatic approach. Methodologically, Skinner still favoured quantitative measures like his predecessors due to their intrinsic objectivity. However unlike orthodox behaviourists, he did not disregard the use of qualitative methods, in particular in contexts where measurement was impossible or impractical to obtain. Traditionally

qualitative methods were permissible as long as they provided an explanation of behaviour that was independently observable and led to a consensus of interpretation by those observing them. Furthermore any results obtained from qualitative methods had to remain consistent with the 3-term contingency, which is at the very heart of the radical behaviourist's view of human behaviour (Foxall, 1995, 1997).

This more pragmatic view of scientific inquiry permits the inclusion of indirect methods of observation that were previously excluded by early more orthodox behaviourists, therefore expanding the behaviourist researcher's toolkit for exploring human behaviour. This chapter therefore documents the pragmatic mixed-method approach that is employed in this thesis, before discussing the case study methodology that has been adopted in study one. This research method includes the analysis of the verbal behaviour of donor families, both textual and oral in nature since humans have a unique ability to communicate through language, defined in radical behaviourist terms as verbal behaviour (Skinner, 1957). This linguistic capacity allows the researcher to have access to previously unobtainable internal events. Whereas orthodox methodological behaviourists would argue that donor family narratives are the product of mentalistic processes which they would deem subjective and unscientific on the basis that they cannot be empirically observed and measured, radical behaviourists would argue that the act of narration is an act of verbal behaviour in its own right, that would have been shaped by the donor family member's unique learning history and their subsequent reinforcing outcomes. In recent years an increasing number of behaviourist researchers have utilised qualitative methods, demonstrating its compatibility with a radical behaviourist view of scientific inquiry (Nicholson *et al.*, 2002; Nicholson, 2005; Xiao, 2006).

To summarise, radical behaviourism supports a mixed-method approach to empirical investigation, as long as it provides an explanation of behaviour which is consistent with the 3-term contingency as a flexible interpretive device. In seeking to validate the application of the Behavioural Perspective Model to the context of organ donation consent, the following section will outline the general research strategy adopted in this thesis before outlining the particular

research methodology utilised in study one, namely a case study approach which explores donor family experiences of consent using the Behavioural Perspective Model as an interpretive device.

General research strategy

This thesis adopts a mixed-method approach to the investigation of donor family consent from a behavioural perspective, via the application of the BPM framework. Mixed method research is defined as an approach to inquiry that combines both qualitative and quantitative forms of data so that the overall strength of a study is greater than either qualitative or quantitative research employed on its own (Creswell & Plano Clark, 2007). The mixed-method approach has several characteristics that set it apart from other research strategies that are employed in social science. Firstly this strategy is unique in the fact that it utilises both qualitative and quantitative methods within a single research project or a series of studies. The mixed-method approach is deeply rooted in the belief that it is neither helpful nor realistic to treat qualitative and quantitative approaches to research as incompatible opposites on the subjective-objective spectrum (**Figure 9**). Instead advocates of the mixed-method approach assert that this forced dichotomy between the positivist and interpretivist paradigms should be abandoned, with a practical and applied research philosophy being favoured to guide the methodological choices of the investigator (Creswell & Plano Clark, 2007; Creswell, 2009; Denscombe, 2010). Within the mixed-method approach qualitative and quantitative methods are seen as complementary, which once combined provide strengths that offset the inherent weaknesses evident when either qualitative or quantitative methods are used in isolation. Historically this is the primary argument for utilising a mixed method approach in the study of social phenomena (Jick, 1979). Mixed-method research is also considered to be inherently practical in nature. This is because this flexible approach allows the researcher to use all possible tools within their methodological arsenal to address a specific research problem, instead of gleaning to one paradigm and its traditionally compatible methods. This pragmatic worldview and approach opens the door to a wide range of possibilities for social scientists to explore and investigate human behaviour.

In the context of this thesis, the empirical phase adopts a sequential mixed-method procedure with equal weighting being given to each phase of the empirical process. This research strategy is traditionally depicted in the mixed-method literature as QUAL➔QUANT (Morse, 1991). This sequential strategy is commonly used in social science research, the intention being that the results from the first method (qualitative) will help inform the second method (quantitative). This design is particularly useful and well suited to contexts where the researcher needs to (a) explore a social phenomenon in depth and then measure its prevalence, (b) develop and test an instrument or (c) test aspects of an emergent theory (Creswell and Plano Clark, 2007; Creswell 2009).

A sequential QUAL➔QUANT mixed method approach was adopted for the research phase of this thesis for two important reasons. Firstly, the qualitative phase of data collection was exploratory in nature with two particular aims, one theoretical and one methodological. The first aim was to provide further validation of the BPM as an interpretative device in the specific context of donor family consent. This was to be achieved through the systematic application of the model's central tenants to the obtained case study data. Secondly the qualitative phase was to serve an important methodological purpose as it aimed to identify the pre-determinants of donor family consent, namely the particular attitudes, subjective norms, direct and indirect experience that influenced their decision making process, as well as the situational influences in the request environment. The resultant data from this first qualitative phase fed directly into the development and construction of the learning history instrument that would be utilised during study two (**Appendix 9**) as well as the design of the eight scenarios that would serve as stimuli during the laboratory experiment in study two (**Appendix 10**).

Study two served the purpose of quantitatively testing the respective influences of learning history, behaviour setting scope, emotion and reinforcement pattern on donor family consent. Therefore it built and expanded upon the results generated from the first empirical phase. A laboratory experiment was deemed the most appropriate design for the following reasons. Firstly an experimental methodology enables the experimenter to exert a high level of control

over the environment in which the behaviour occurs (Burns and Bush, 2002). Secondly an experimental approach allows the experimenter to specifically control the independent variables under investigation, so that cause and effect can be clearly separated (Beins, 2004). Lastly an experimental procedure is considered the gold standard of behaviour analysis and is methodologically favoured by behaviourists (Bailey & Bursch, 2002; Beins, 2004). A full description of the research design and strategy of study two is documented at the beginning of chapter five of this thesis.

Advantages and disadvantages of approach

In the existent literature three distinct strengths of the mixed-method approach to research have been emphasised. Firstly it has been argued that the mixed-method approach to research can provide a more comprehensive account of the phenomenon being investigated by providing multiple perspectives on a given research question (Creswell and Piano Clark, 2007; Creswell, 2009; Denscombe, 2010). It is argued that by encouraging and applying the use of both qualitative and quantitative methods, the researcher can achieve a fuller picture of the phenomenon under study, discovering new avenues and insights that may have been left undiscovered if one method was utilised (Tashakkori & Teddlie, 2003; Creswell & Piano Clark, 2007; Creswell, 2009; Denscombe, 2010).

Secondly a distinct strength of the mixed method approach is that it can lead to the triangulation of findings (Denscombe, 2010). Triangulation involves "*the practice of viewing things from more than one perspective*" (Denscombe, 2010, p.346) Achieving triangulation can increase confidence in research findings on the basis that they have been replicated using alternative methods. It can also contribute to a clearer picture of the phenomenon under investigation by highlighting discrepancies between datasets, thus indicating which areas warrant further investigation.

Thirdly mixed method research is a practical, problem driven approach to conducting social scientific research, which is highly appropriate to research conducted in health behaviours and contexts. This approach is flexible and allows the researcher to use all methodological tools available to answer a particular research question without constraint (Creswell & Plano, 2007;

Descombe, 2010). This "*what works*" approach is solution-orientated, and is highly compatible to the investigation of socially important behaviours.

Despite these commonly cited strengths of this approach, there are inherent challenges associated with implementing a mixed-method research strategy. Firstly, this approach can be incredibly time consuming, costly and hard to undertake. This is especially prevalent in the context of sequential studies where progression in a research project is entirely dependent on the success of the first phase of data collection. Driscoll (2007) argues that by combining the two types of data and the time and resources required for each, it may compromise sample sizes, resources and duration in order to make each study using these methods possible. Secondly through the application of mixed-methods the researcher can run the risk of finding incompatible and/or contradictory results that are purely the result of the methods employed (Onwuegbuzie & Johnson, 2004). This presents a particular problem in terms of how researchers ought to interpret conflicting results, and what weight should be placed on each method and their accompanying results.

In spite of the outlined problems associated with the mixed method approach, in the context of the present research, the advantages of adopting such a strategy outweighed the disadvantages. Therefore a sequential mixed method approach was implemented. The remainder of the chapter now turns to the implementation of the research design outlined above.

Preparation for the role of researcher

Due to the nature of the topic under examination three particular areas of preparation were deemed necessary prior to the start of data collection. The preparation that the researcher undertook prior to starting data collection included (1) a Cruse bereavement training course, (2) an advanced interview training course and (3) and a general programme of education regarding organ donation and transplantation protocol and surrounding issues.

Firstly during November 2010 the researcher attended a Cruse bereavement course in Manchester with the intention of quipping themselves with the relevant skills needed to interact

with bereaved individuals in a professional and sensitive manner. The course also aimed to equip individuals with the skills needed to provide comfort to individuals who are emotional and/or distressed. Participating in this course was a purely pre-cautionary measure since none of the case study participants had been recently bereaved, with the final interview sample consisting purely of individuals who had volunteered to participate and had previously spoken about their experiences. Nevertheless it seemed appropriate to err on the side of caution and be prepared for any eventuality. In addition, the bereavement course consisted of a section devoted to counselling skills such as the art of listening; paraphrasing; reflective summarising; and the use of open questions. These skills proved to be invaluable during the interviews themselves and added to the researcher's existing skills set that had been developed during an advanced interview training course at Durham University and through work as a qualitative research assistant on a multi-national project.

Secondly, as the interview process is an opportunity for the participant to seek information from the researcher, it was incredibly important for the researcher to be thoroughly informed about the subject under examination. Prior to the data-collection phase of this thesis it was of fundamental importance that the researcher became as informed as possible on issues surrounding organ donation and transplantation in the context of the UK. This was achieved through the immersion of the researcher in the existent organ donation literature, watching and reviewing recent documentaries on the topic, seeking information and advice from specialist charities and speaking to members of the organ donation and transplant community. This experience equipped the researcher with the needed knowledge and confidence to engage with donor families in the first empirical phase.

Ethical considerations of research

Ethical considerations for the participants

This research project was ethically approved by Durham Business School's Ethics Committee prior to its commencement during the spring of 2011. In addition to ensuring anonymity and

confidentiality to all participants, other ethical considerations were taken into account based on recommendations within the existent literature on the topic of organ donation research and bereavement studies in general. Unsurprisingly a significant amount of literature has focussed on the issues involved when interviewing participants about sensitive topics (Lee, 1993; Sque and Payne, 1996; Dickson-Swift *et al.*, 2006). Organ donation consent research falls within this remit, as it involves interactions with individuals who have had to make difficult decisions in the event of a family member's death. In addition, this death is often unexpected and/or accidental in nature, with little time occurring between the incident and the diagnosis of brain death, for example in the context of road a brain haemorrhage. For this particular reason recounting the circumstances under which organ donation consent has occurred can be potentially emotional for all involved, therefore it is of uttermost importance that the interviewer is prepared, knowledgeable and sensitive to the needs of the participant. The following section aims to cover the key ethical areas that required consideration before the data-collection phase commenced.

In the existent literature, researchers in the bereavement field have highlighted that those who are not able to tolerate talking about their experience will not (Parkes, 1990; Hutchinson *et al.*, 1994; Long-Sutehall *et al.*, 2011). Parkes (1990) assures researchers in the field of bereavement research that:

'Any bereaved people who are not ready to talk will decline the invitation to take part... I believe that most are glad to find that their experiences, however awful, can be of help to others" (1990, p. 36).

With this insight in mind the interview recruitment for the case study interviews was conducted through two organ donation charities, allowing potential participants to opt-into the study if they were interested and willing to contribute. This meant that the final sample consisted of individuals who had actively wanted to contribute to the study and felt able to talk about their decision making process and experience. Furthermore an extra stipulation was put into place as a pre-cautionary measure, that the participants could not be newly bereaved, that is bereaved during the previous 12 months. Parkes (1995) warns that the recently bereaved are a particularly vulnerable group and as a consequence the strong emotions they experience will shape their

judgement. This could potentially lead to them agreeing to take part in studies which they may later regret. Conversely, due to this heightened state of emotion they may refuse to join a study, which in another frame of mind they would be happy to participate in. Therefore for this reason a 12 month stipulation was put into place to protect this newly-bereaved group.

A key consideration in any research that involves human participants is informed consent. Parkes (1995) suggests that bereaved individuals invited to take part in research should receive a document that outlines the following in order to ensure that their consent to participate is informed. Parkes (1995) states that this document should include a full description of the study and what participation would entail for the individual, the identity and qualifications of the researcher and the organisation through which the research is being conducted, their rights as participants of the research project and confirmation of ethical approval. These criteria were rigorously adhered to in this research project in order to ensure that participant's consent to participation was truly informed.

Ethical considerations for the researcher

In addition to the ethical considerations that had to be made for the participants, certain ethical considerations also had to be made for the researcher in relation to two particular issues. Firstly as the case study interviews took place in the participant's homes and therefore outside of the control of the researcher this raised the issue of safety. Therefore it was of uttermost importance to ensure that prior to data collection information regarding the location, time and the anticipated length of the interview was given to a member of the researcher's department. A contact number was taken and once each interview finished the researcher confirmed its end and their safe return to the department with this individual. This protocol was rigorously adhered to and provided a chain of evidence regarding the movement of the researcher.

Secondly due to the potentially emotional nature of the subject matter being covered during the interviews, and the fact that these interviews would be played back over and over again during the analysis process, in line with recommendations in the existent literature a recovery window was left between each case study interview. Cowles (1988) recommends that reflective time for

the researcher is needed in the research timetable to allow for recovery between each sad interview experience (Cowles, 1988).

Study one objectives

There are three principle research objectives that the case study approach aims to address in study one. Firstly, study one aims to validate the Behavioural Perspective Model as a potential interpretative device for donor family consent in which to construct a radical behaviourist account of this phenomenon. Secondly, study one aims to substantiate the key determinants of donor family consent, both behavioural and contextual which have been identified in the literature review phase of this research. Thirdly, through analysis of donor family situational experiences and decision making, the results obtained will feed directly into the design, development and construction of the learning history questionnaire for study two, as well as the eight situational scenarios that will be used as visual stimuli for the experimental phase of this thesis. Therefore study one had both a theoretical and methodological purpose.

Research design of study one

A case study approach to exploring donor family consent

Yin (1994) defines a case study as "*an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident*" (Yin, 1994, p.13). Therefore a case study strategy is selected when the researcher deliberately wants to explore contextual conditions, believing that they may be highly significant to the phenomenon under examination. One of the strengths of the case study approach is that it relies upon multiple sources of information, with the data needing to converge in a "*triangulating fashion*" (Yin, 1994, p.13). Evidence from multiple cases is often considered to be more compelling and robust, as it follows replication logic (Heriott & Firestone, 1983). Furthermore a case study benefits greatly from the prior development of theoretical propositions to guide data collection and analysis. It has been argued that the case study is neither a data collection method nor a

design feature, but a comprehensive research strategy that comprises an all-encompassing method (Stoecker, 1991).

Study one employed a wide range of sources of evidence, this is because any finding or conclusion resultant from a case study is likely to be more convincing and accurate if it is based upon several different sources of information (Yin, 1994). The following sources of evidence were used in study one: semi-structured in-depth interviews with donor families (N = 3), secondary analysis of a secondary interview dataset with donor families obtained from Oxford University Heath Experience Group's online database (N = 13), analysis of recent publications regarding organ donation produced by bodies including NHSBT, the Nuffield Bio-ethical Council and the BMA (N = 4), and finally analysis of media stories and blogs that document donor families providing consent to organ donation (N = 35). This resulted in a total sample of 55 units for final analysis. **Table 6** outlines the associated strengths and weaknesses of each of the chosen sources of evidence employed in study one. In the following section the data collection methods utilised in study one will be addressed in more depth, with their associated strengths and weaknesses outlined.

Source of evidence	Strengths	Weaknesses
Documentation	Stable – can be reviewed repeatedly. Unobtrusive – not created as a result of the case study. Exact – contains exact names, references, and details of an event. Broad coverage – long span of time, many events, and many settings.	Retrievability – can be low Biased selectivity – if collection is incomplete. Reporting bias – reflects (unknown) bias of author. Access – may be deliberately blocked.
Archival records	[Same as the above for documentation]. Precise and quantitative.	[Same as the above for documentation] Accessibility due to privacy reasons.

Interviews	Targeted – focus directly on case study topic. Insightful – provides perceived causal inferences.	Bias - due to poorly constructed questions. Response bias Inaccuracies - due to poor recall. Reflexivity – interviewee gives what interviewer wants to hear.
Direct observations	Reality – covers events in real time. Contextual – covers context of event.	Time consuming Selectivity – unless broad coverage. Reflexivity – event may proceed differently because it is being observed. Cost – hours needed by human observers.
Participant – observation	[Same as the above for direct observations]. Insightful - into interpersonal behaviour and motives	[Same as the above for direct observations]. Bias – due to investigator's manipulation of events
Physical artefacts	Insightful into cultural features Insightful into technical features.	Selectivity Availability

Table 4. Sources of evidence used in case studies (Yin, 1994).

Semi-structured interviews

The first method of data collection employed by study one was semi-structured interviews with organ donor families (N = 3). Yin (1994) argues that "*interviews are an essential source of case study evidence because most case studies are about human affairs*" (Yin, 1993, p.85). Therefore the interview method allows the researcher a unique insight into the phenomenon of interest through the eyes of the participant. King (2004) suggests that the aim of any research interview is "*to see the research topic from the perspective of the interviewee; and to understand how and why they have come to this particular perspective*" (King, 2004, p.11). A well-informed respondent can provide invaluable insights and information about a topic of interest, which could not be obtained by any other method. In the

context of the topic of this thesis, interviews with donor families who had experienced the decision making process first hand was vital.

The semi-structured interview format was adopted for this study for the following reasons. Firstly, one of the benefits of semi-structured interviews is that they allow the researcher a degree of control in comparison to their unstructured counterparts. The semi-structured interview permits the researcher to probe deep into the world of the participant, whilst avoiding significant deviations from the topic of interest. Secondly this method is also flexible enough to allow the interview to deviate from the designed protocol when a relevant issue might emerge. Therefore this approach produces a rich, focused and contextualised understanding of the phenomenon of interest, whilst remaining incredibly flexible (Yin, 1994).

Despite the undeniable strengths of the case study interview as a data collection method for exploring complex human behaviour, it is also important to acknowledge the weaknesses inherent in this form of evidence, which are summarised in **Table 6**. Two particular weaknesses associated with the interview method need to be acknowledged in this particular study. Firstly interviews can be subjected to a range of biases, including recall bias, response bias and any bias on the part of the interviewer (Yin, 1994). In the context of this particular study recall bias and response bias were two potential weaknesses that needed to be considered. As a substantial amount of time had passed since the participant's decision making process, recall bias was a real possibility. Unfortunately this limitation could not be avoided, largely due to ethical reasons where it would have been unethical and impractical to obtain a sample from the newly bereaved (Parkes, 1995). The second form of bias that needed to be considered was response bias as this is a particular issue in any form of bereavement research where self-selected samples are common. This poses a particular issue since individuals who actively opt in to a study may not be representative of the larger population and may be using the study as an opportunity to discuss any outstanding issues (Sque, 1996). Again this limitation could not be overcome, since donor families are an "*elusive*" population who are incredibly difficult to obtain access to (Long-Sutehall *et al.*, 2011). Regardless of the limitations, the inherent strengths of this form of data

collection in exploring this type of social phenomenon deemed the method appropriate, especially since this study did not rely upon one source of evidence.

Interview recruitment

It has been widely acknowledged in the existent literature that bereaved families are an elusive group who are notoriously hard to access (Parkes, 1995; Long-Sutehall, *et al.*, 2011). This is partly due to the rigid constraints imposed by gatekeepers who vigorously protect this group due to concerns about oversampling and the potential harm which can be caused by insensitive researchers (Parkes, 1995; Sque and Payne, 1996). In addition very low response rates are common in organ donation research (Long-Sutehall *et al.*, 2011).

With the problem of access in mind, study one recruited the case study interview participants via two active UK based organ donation charities, The Donor Family Network and Live Life Then Give Life. A call for participants was published on their websites April 2011. Four donor families responded, three of which met the criterion for participation: (1) that they were the primary decision makers regarding their family member's organ donation, (2) that they had spoken about their experiences before and therefore they felt comfortable talking about the subject and lastly (3) that they had not suffered the bereavement within the last twelve months. The first criterion was formulated so that the decision process of the *actual* decision maker could be understood, instead of an account of a bystander, and the last two criteria were formulated on ethical grounds that have been covered earlier in this chapter. A description of these participants, together with their relationship to the donor and the details surrounding their consent can be found in **Appendix 2**.

Interview instrument

The interview instrument was developed in light of the existing literature concerning organ donation consent and was centred on the core tenants of Behavioural Perspective Model. As one of the objectives of study one was to validate the BPM as an interpretative device in this context, it was important to cover each of the individual BPM variables in depth during each case study interview in order to assess each variable's applicability in this context. Approximately

twenty minutes was allocated to each core variable within the BPM, namely learning history, behaviour setting variables, the request situation, utilitarian and informational reinforcements and aversive consequences (**Appendix 3**). The interview instrument was independently assessed by a behaviourist researcher prior to the commencement of data collection in order to assess its reliability.

Procedure

Each case study interview took place in the house of the donor family, as this was considered the most appropriate and comfortable environment for participants and is a common practice in the field of donor family research (Sque and Payne, 1996). The duration of each interview was between 90-120 minutes. This is a precedent set by other researchers who are active in donor family research field in the United Kingdom (Sque and Payne, 1996). Additionally it was also deemed to be the most comfortable time limit for both the researcher and the participant. Upon arrival at the donor's house, the participant was asked to read the information sheet provided, and to familiarise themselves with the aims and objectives of the study. Once this was done the participant was invited to ask any questions they had. During this time the participant and the researcher had an informal discussion about the topic and their general background. This was considered as valuable opportunity to build a rapport between the interviewer and the participant. The participant was then asked to sign an informed consent sheet, confirming that they understood the aims and objectives of the study and understood their rights. The informed consent sheet clearly outlined the participant's rights to anonymity and confidentiality, as well as emphasising their right to withdraw from the interview process at any time without needing to provide a reason (**Appendix 4**). Due to the sensitive nature of the interview topic, it was also emphasised that should they need to take a break at any point they should just indicate this immediately and the audio-recorder would be turned off. Once the participant indicated they understood the procedure and were happy to continue the interview began with the participant being invited to talk a little about their general background and their family, in particular the donor. This format allowed the participant time to build a rapport with the interviewer and get comfortable talking before covering the potentially more sensitive issues.

Secondary sources

Secondary sources of evidence play an explicit role in most case study topics and come in a variety of forms (Yin, 1994). In study one this type of evidence was utilised for several important reasons. Firstly collecting data from the public domain is considered unobtrusive to donor families and access was guaranteed. Therefore it overcame the two major obstacles that are often associated with organ donation research (Sque *et al.*, 2006). Secondly documents, in particular public blog entries and online case studies, provided the researcher with a very broad coverage of the topic, with different geographic regions, ethnic groups, age groups and experiences being represented in the final sample. The fact that a variety of different contexts could be examined in depth was considered a particular strength of this form of data collection. Access to this range of donor family experiences would have been impossible if any other method of data collection had been employed during this phase, for example surveys that are prone to low response rates, especially in bereavement research areas.

In the existent literature weaknesses associated with the use of secondary source material have been outlined in the literature, in particular in reference to the use of secondary interview material for analysis (Blommaert 2001; Mauthner *et al.*, 1998; Yin, 1994). Blommaert (2001) and Mauthner et al (1998) critique the use of secondary analysis on the basis that only through a personal involvement in data collection can a researcher truly grasp the relevant context that is needed to interpret the subsequent data. Put simply, Blommaert (2001) and Mauthner et al. (1998) argue that without a researcher having gone out and collected the data, much of what the participants mean may be lost. One could argue that this is less of a concern when segments of video footage of the original interviews are available to the researcher, as was the case for the Oxford University Health Experience Research Group's online dataset (N = 13). The benefits of using these rich sources of secondary data far outweighed the disadvantages in this particular context since the aim was merely exploration rather than explanation. Furthermore the use of secondary sources helped the researcher overcome the inherent access problems in this type of research.

Lastly another weakness associated with the use of secondary source is biased selectivity of sources of evidence (Yin, 1994). The researcher attempted to limit this bias by implementing a search strategy that yielded a broad range of secondary sources. Furthermore the researcher removed sources from the database for further analysis that demonstrated a strong bias (for example overtly negative, sensationalist portrayals of the request situation). However since the population of interest is incredibly elusive and small this particular weakness could not be totally avoided.

Data collection of secondary sources

Once the Behavioural Perspective Model was validated as a potential interpretative device through the initial case study interviews, the second phase of data collection for study one commenced. This involved searching for existing donor family experiences within the public domain. A purposive sampling technique was used when selecting data to be included in the final sample. Krippendorf (2004) states that unlike other sampling strategies, relevance sampling aims at selecting all textual units that contribute towards answering a given research question. Therefore the resulting sample is purely defined by the analytical problem at hand. Neuendorf (2002) states that this type of sampling strategy involves the researcher making a decision regarding what units are appropriate to be included in the final sample. In order to fulfil the primary aims and objectives of this study, units of analysis that were included in the final sample had to meet the following three strict criteria:

(1) Firstly all data included in the final sample had to include a description of the contextual background of the organ donation request, the donor family and the donor. This was so that the pre-determinants of the consent behaviour and situational variables could be identified in order to fulfil the methodological purpose of study one.

(2) Secondly the account had to be from the primary decision maker's perspective. This was so that the *actual* decision makers consent process could be analysed, as well as their interactions with the behaviour setting and their motivation for providing consent to organ donation.

(3) Thirdly any sensationalist stories which were overtly negative or overtly positive from the public domain were considered outliers and removed from the final dataset. This elimination was conducted in order to limit sampling bias which could potentially skew the findings of study one.

Thirteen donor family interviews (n = 13) were obtained from Oxford University's Health Experience Research Group's online database, which can be accessed at Healthtalkonline.org. Written permission via email was granted by the research group before the online resources were used for secondary analysis. This database includes thirteen donor family narratives regarding their decision to consent, with accompanying film footage of the interviews and therefore was an incredibly rich and detailed source of secondary data. An additional 35 donor family narratives were found within the public domain from a range of sources including online case studies from health websites including the NHSBT official website, newspaper coverage of donor stories, charity case studies and donor family blogs. A table providing an overview of the sources of evidence used in study one can be found in **Appendix 5**. The 35 sources were found using various search terms, and multiple engines. A detailed overview of the search terms used and the engines that were utilised can be found in **Appendix 6**. In addition to this recent research and policy documents in the public domain published by bodies such as British Medical Association, NHSBT, the Nuffield Bioethical council and NICE clinical guidelines were also analysed in order to analyse not only current policy but future interventions and strategy (n =4). This resulted in a final sample of 52 secondary units for analysis to add to the existing in depth interviews that had already been collected (n=3).

At present there is no universally accepted set of criteria for selecting the appropriate size of a sample in the discipline of content analysis (Neuendorf, 2002). Therefore data collection and analysis was continued to the point where saturation was achieved. Put simply, when the collection of new data failed to shed further light on the issue being investigated (Glasser & Strauss, 1967).

Artefacts – physical evidence

One source of evidence that was unanticipated in study one was the access to physical artefacts owned by the donor families. Yin defines artefacts as a form of physical evidence which can either be collected or viewed as part of a field visit and when relevant can be an important component in the overall case (Yin, 1994). In this particular context physical artefacts came in the form of an information booklet produced by the British Organ Donation Society that was given to a donor family during the organ donation request, copies of letters of thanks from the recipients of donated organs, correspondence from the hospital and certificates of appreciation as well as keepsakes given to families (e.g. the handprints of the organ donor taken before death).

These physical sources of information gave the researcher a unique insight into some of the physical stimuli that composed the request situation and the modes of reinforcements signalled to the families at the time of the request. For example the information booklet that was given to the donor family at the time of the request for consent and demonstrated the type of information that was presented to families whilst they came to their decision.

Analysis procedure

As has been stated earlier in this chapter the analysis procedure employed by study one was a form of qualitative content analysis. In recent years content analysis has been widely used as an analysis method in health studies (Hsieh & Shannon, 2005). Research utilising the content analysis method focuses on making inferences by systematically and objectively identifying specific characteristics within text (Stone, Dunphy, Smith and Ogilvie, 1966, p.5). Text data can be verbal, print or electronic form and can be acquired from a range of methods such as from narrative responses, interviews, focus groups, observations, or print media such as articles, books, or manuals (Kondracki &Wellman, 2002). Downe-Wamboldt states that the primary goal of content analysis is to provide "*knowledge and understanding of a phenomenon under study*" (Downe-Wamboldt, 1992, p. 314). Content analysis provides researcher's with a pragmatic and flexible method for developing and extending knowledge of human experience and is particularly well suited to exploring health phenomenon (Hsieh & Shannon, 2005).

Study one employed a directed approach or deductive approach to content analysis (Hsieh & Shannon, 2005; Potter & Levine-Donnerstein, 1999). Since the aim of the study was to explore the extent to which the decision to consent could be understood as an operant process, the Behavioural Perspective Model's central variables were used as categories to code the data. This strategy has been utilised in previous BPM research that has made use of qualitative data in the exploration of consumer behaviour (Yermekbayeva, 2011; Xiao, 2006; Nicholson, 2004).

Firstly the audio interview data collected during the case study interviews was transcribed and cleansed by the researcher, meaning irrelevant data was removed so that a reduced format was ready for analysis. A coding protocol was then formulated around the central variables of the Behavioural Perspective Model and assessed by two behaviourist researcher in order to validate the definitions and examples provided (**Appendix 7**). The resultant coding protocol contained 16 distinct codes, relating to each of the central tenants of the BPM framework. Once the coding protocol was complete and verified, coding of the 3 case study interviews commenced using the qualitative analysis software NVivo 9. Once these were successfully coded and the suitability of the Behavioural Perspective Model was validated, the second phase of data collection commenced. This included constructing a database in the NVivo 9 software which included the twelve interview transcriptions and video footage obtained from Oxford University's online database, Healthtalkonline.org, and searching for donor family narratives within the public domain using various media search engines and search terms, documented in full earlier in this chapter. This resulted in a final sample of 55 sources of evidence, 3 primary sources and 52 secondary sources, which were successfully coded.

Reliability and validity tests

In order to establish the reliability of the data obtained from study one a secondary coder was trained in the analysis procedure and carried out secondary coding of 20% of the final sample, in line with Neuendorf's (2002) recommendation of a minimum of 10%. Various standards and benchmarks have been proposed within the existent literature regarding an acceptable level of inter-coder agreement. For example Frey, Boton and Krep (2000) state that 70% agreement

between inter-coders should be considered as reliable, whereas Riffe, Lacy and Fico (1998) endorse a higher standard of between *"0.8 to 0.9"* (p.131). For the purpose of this particular study, Krippendorff's (1980) recommendation of reporting variables when their reliability is above 0.8, with only cautious conclusions made about reliabilities between .67 and .80, was adhered to (1980, p.147). Therefore all results and analysis documented in chapter four of this thesis met the 0.8 standard.

Yin (1994) proposes several case study tactics to test (a) construct validity, (b) internal validity, (c) external validity and (d) overall reliability (**Table 5**). In the context of this thesis the researcher adhered to the recommendations outlined by Yin (1994) depicted in **Table 5**. Several measures were taken by the researcher in order to ensure validity and reliability of results. These included the construction of a case study database in order to establish a chain of evidence, multiple sources of evidence being sourced and coded by two independent coders, sources being constantly checked and rechecked for thematic consistency from different as well as the same sources (Duneier, 1999, pp. 345–347) with only replicated findings being reported in the final analysis. For example, once the analysis of both datasets was completed, the findings of each dataset were compared in order to assess whether the same themes and patterns emerged from both the primary and secondary sources. What emerged when both data sets were compared was that the three semi-structured interviews that were conducted by the researcher exhibited many of the same themes and patterns that were evident in the secondary data. In particular the secondary data obtained from the Oxford Health Experience Group showed striking similarities with the three primary sources, with the exact same elements of learning history, behaviour setting variables and modes of reinforcement informing the organ donation decision maker's choice. This finding adhered to the replication logic advocated by Yin (1994) as an external validity tactic.

Test	Case study tactic	Phase of research in which tactic occurs
Construct validity	Use of multiple sources	Data collection

	Establish a chain of evidence	Data collection
	Have key informants review draft case study reports.	Composition
Internal validity	Do pattern matching	Data analysis
	Do explanation building	Data analysis
	Do time series analysis	Data analysis
External validity	Use replication logic in multiple case studies	Research design
Reliability	Use case study protocol	Data collection
	Develop case study database	Data collection

Table 5. Case study tactics for ensuring reliability (Yin, 1994)

Conclusion

This chapter has sought to document and justify the mixed-method sequential strategy that was adopted in the empirical phases of this thesis. This chapter provided the reader with a background to the behaviourist approach to scientific inquiry and sought to provide a rationale for the mixed method strategy used, documenting both the strengths and weaknesses of this particular approach. The chapter then proceeded by outlining the preparations the researcher undertook before commencing with the data-collection phase and discussed some of the ethical considerations involved with this particular type of research. The chapter continued by documenting the methodology of the first empirical phase of this thesis, an exploratory case study into donor family consent. The various sources of evidence that comprised the case study were explored, together with their inherent strengths and weaknesses. The analysis process that was employed by the researcher was outlined before an explanation of the reliability and validity tests that were undertaken.

The next chapter within this thesis documents the results and analysis that have resulted from the first stage of the empirical process. The chapter is structured around the central tenants of the BPM schema, with qualitative extracts provided under the major themes as supportive evidence. Due to the sequential nature of the research process, the first study lays the foundation for the second empirical phase, which aims to build upon and validate the results from the first. As will be recalled a full explanation and justification of the research methods utilised in the second empirical phase are presented at the beginning of chapter five of this thesis.

Chapter Four

Exploring donor family consent ~ a case study approach

"In their last hour they gave a lifetime"

Author unknown

Introduction

The previous chapter outlined the development and implementation of two sequential studies that are documented in chapter four and five of this thesis. Specifically, chapter three detailed the systematic and rigorous empirical investigation that aims to address three central research questions which guide this thesis:

4) Can family organ donation consent be understood as an operant process utilising the BPM as an interpretive device?

5) What patterns of reinforcement increase likelihood of consent?

6) Can donor family consent be stimulated via behavioural intervention?

This chapter aims documents the first empirical phase of this thesis, an exploratory case study investigation into the key determinants, both behavioural and contextual, of donor family consent. This chapter seeks to validate the application of the Behavioural Perspective Model (BPM) of consumption to the unique context of donor family consent. As will be recalled from chapter two, the BPM is a neo-Skinnerian model that stems from the premise that an organism is determined by the contingencies of reinforcement under which they are emitted (Skinner, 1938; 1953; 1974). In particular the BPM asserts that human behaviour is directed towards the maximisation of positive reinforcement and the minimisation of aversive consequences. Positive reinforcement is subjected to bifurcation, into high or low levels of utilitarian and informational reinforcement. This in turn generates four distinctive operant classes of behaviour, namely Accomplishment, Pleasure, Accumulation and Maintenance. For the purpose of this specific health context these operant classes were renamed in chapter two of this thesis. The renamed operant classes are Social Accomplishment, Incentivised donation, Altruistic donation and

Routine donation. The degree of openness or closure of the behaviour setting scope dichotomises each of the four operant classes into eight distinct contingency categories. For the purpose of this thesis the four operant classes were renamed to reflect this distinct context, with the new typology depicted in **Figure 7.** In order to make a decision regarding consent the next of kin has to rely upon the application of their unique learning history to identify environmental variables within the immediate setting that may serve as discriminatory signal of a likely consent outcome. Thus far this thesis has argued that because the BPM firmly directs its attention toward the actual behaviour of consent, rather than towards pre-behavioural precursors of consent it lends itself to being an ideal framework to investigate (1) the interaction between an individual's learning history and the request situation (2) the impact of the request situation on consent (3) the patterns of reinforcement that increase likelihood of a positive consent outcome.

This chapter begins by providing a brief summary of the key research objectives of study one, before providing a brief overview of the methods employed. A full description of the data collection process, analysis protocol as well as the reliability and validity tests that were untaken can be found in chapter three of this thesis. The chapter will then proceed to report the results and analysis of study one, structured around the central tenants of the BPM framework. At the end of each BPM variable, a summary is provided and the hypotheses relating to that variable will be stated in light of the findings. These will be subjected to further testing during study two of this thesis, namely a laboratory experiment examining how consent may be stimulated. The present chapter concludes with a section that provides an overarching summary of the key findings of the study one before introducing the next chapter.

Aims and objectives of study one

As will be recalled from chapter three, there are three research objectives that study one aims to address. Firstly, study one aims to validate the Behavioural Perspective Model as a potential interpretative device for donor family consent in which to construct a radical behaviourist account of this phenomenon. Secondly, study one aims to substantiate the key determinants of donor family consent, both behavioural and contextual which have been identified in the

literature review phase of this research. Thirdly, through the analysis of donor family situational experiences and decision making, the results obtained will feed directly into the design, development and construction of the learning history questionnaire for study two, as well as the eight situational scenarios that will be used as visual stimuli for this phase of this thesis. Therefore study one has both a theoretical and methodological purpose. This conforms to the outlined justification for adopting a sequential QUAL➔ QUANT design (Creswell, 1999; Creswell *et al.*, 2003; Creswell *et al.,* 2007).

Summary of methods

As detailed in chapter three, study one utilised a case study approach which drew upon multiple sources of evidence since. The following sources of evidence were used in study one: semi-structured in-depth interviews with donor families (N = 3), secondary analysis of a secondary interview dataset with donor families obtained from Oxford University Heath Experience Group's online database (N = 13), analysis of recent publications regarding organ donation produced by bodies including NHSBT, the Nuffield council of Bioethics and the BMA (N = 4), and finally analysis of media stories and blogs that document donor families providing consent to organ donation (N = 35). This resulted in a total sample of 55 units for final analysis. The full procedure regarding how these sources were obtained, together with their associated strengths and weaknesses is discussed in chapter three. It should be emphasised that the form of content analysis employed was more interpretive in nature, since the goal was simply to assess whether the data obtained conformed to the classic Skinnerian three-term contingency, and to examine the patterns in those selected units, with no attempt at generalisation being made to the broader population (Lijphart, 1971). Put simply, the primary aim was to gain a thorough insight into the behaviours of donor families in the unique context of organ donation consent and to construct an account of those behaviours in terms which would render them as "*explained*" (Baum, 1994).

Study one employed a directed approach or deductive approach to content analysis (Potter & Levine-Donnerstein, 1999; Hsieh & Shannon, 2005). Since one of the principle aims of the study was to validate the BPM as an interpretive device in this specific health, the BPM's central

variables were used as categories to code the data. As documented in chapter three, this strategy of thematic coding based on the BPM variables has been utilised successfully in previous BPM research that has included the analysis of qualitative data (Nicholson, 2004; Yermekbayeva, 2011). The resultant coding protocol contained 16 distinct codes, relating to each of the central tenants of the BPM framework. This can be found in **Appendix 6**.

In order to ensure reliability of the analysis of study one a secondary coder was trained in the analysis procedure and carried out secondary coding of 20% of the final sample, in line with Neuendorf's (2002) recommendation of a minimum of 10%. All findings included in this chapter achieved a 0.8 standard of agreement which is considered acceptable in the existent literature (Krippendorff, 1980; Riffe *et al.,* 1998).

Results and analysis

The following sections of this chapter report the results and analysis of study one. The chapter is structured around the central tenants of the BPM framework, with qualitative evidence from the dataset provided under each theme. Since this chapter did not adopt a quantitative approach to content analysis, frequency counts are not provided. However themes were only reported that occurred repeatedly within the sample, thus conforming to Yin (1994) logic of replication as a benchmark of external validity.

Learning history

P1.1 *Learning history will significantly influence donor family consent*

As discussed at length within chapter two of this thesis, a central precept of the Behavioural Perspective Model (BPM) is the concept of behavioural learning history. This variable centres on the premise that the behaviour of an individual evolves and develops during their lifetime as a direct consequence of their history of performing behaviours with their reinforcing outcomes. Foxall (2005) asserts that the importance of learning history has been substantiated by the repeated finding that prior behaviour is an important determinant of an individual's current behaviour. He argues that this finding should not be simply attributed to habit, since this is

merely an attempt to "*re-describe it rather than explain it*" (Foxall, 2005, pp.94). An individual's learning history is best understood as what an individual brings to a particular choice situation, in terms of their own unique set of experiences of performing past behaviours coupled with their positive and/or negative reinforcing outcomes. In situations where there is an absence of direct experience, the reinforcement may have been acquired through a third party via verbal behaviour. Put simply, an individual's learning history is the collective effect of rewarding and punishing outcomes of past behaviours. It is the application of this unique learning history upon the current behavioural environment that directs the individual's conversion of behaviour-setting variables into discriminatory stimuli.

Within this dataset four reoccurring sources of learning history were identified, (1) positive attitudes towards organ donation, (2) positive subjective norms (3) direct experience of the hospital environment and similar behaviours 4) indirect experience obtained through third parties, most notably the media and social acquaintances. These four themes reoccurred in the overwhelming majority of accounts within this dataset (90%), thus demonstrating the significant role learning history plays in the consent process. In this section each one of these sources of learning history will be discussed in turn with examples presented from the dataset.

Attitude

An individual's behavioural history can be captured in the attitudinal variable, which expresses what an individual predicts will be the most likely consequences of them engaging in a given behaviour (Foxall, 1995). Therefore attitude toward an object or activity is a behavioural outcome formed through an individual's prior experience with that object or activity and its resultant consequences. Attitude is generally understood to refer to an individual's evaluation towards an object, idea or behaviour. Within this dataset four positive attitudinal themes consistently emerged: (1) to reuse organs that were no longer needed, (2) to donate because it was the "*right*" thing to do (3) to provide consent because they would take an organ if needed and (4) that donating the deceased's organs brings a sense of meaning to their death. As discussed earlier in this thesis, attitudinal surveys have reported that approximately 90% of the

UK population hold positive attitudes toward the general issue of organ donation and transplantation; however this has failed to convert into actual consent rates with 40% of potential donor families refusing consent when requested by medical professionals (Barber *et al.,* 2006; NHSBT, 2013b). Therefore this section focuses on exploring the reoccurring attitudes that are associated with actual consent behaviour rather than intention to consent from a population who have not experienced the issue first hand, as many attitudinal surveys do. In the following section each one of these attitudinal themes will be explored in turn, providing evidence from the dataset as support.

(i)   Reusing organs that are not needed by the donor

The attitudinal expression that the donor's organs should be reused was expressed by the majority of sources. In this dataset a considerable amount of decision makers stressed the fact it would be wasteful not to donate useful organs, which could be beneficial to others. This theme of avoiding waste has been documented in the existing literature. An early study conducted by Batten and Prottas (1987) found that 75% of donor families within their sample felt that "*functioning organs should not be wasted*" (Batten and Prottas, 1987, p38). To elaborate this theme further the analogy of recycling was used by several donor decision makers within this data set. One case study interview participant used the analogy of a car being taken apart so that "*spare parts*" could be retrieved and used to repair other vehicles (source 14). In this instance it was a particularly fitting analogy since the case study participant was a car mechanic by trade, therefore this was a helpful way of him explaining his reasons for consent. Similar attitudes were expressed by another donor family interviewee who stated:

"The spirit had gone, and all we were looking at is the shell, so recycle the shell sort of thing, it made a lot of sense to me" (Source 5).

The concept of recycling being applied to the context of organ donation consent, as illustrated in these two examples, is particularly interesting. In one study conducted by Lauri (2008), participants likened organ donation to recycling. Lauri (2008) argues that because organ donation was a relatively new phenomenon and not very well understood by her sample the

participants of the focus groups made sense of the concept by comparing it with more familiar acts such as giving to charity and recycling. Sharp (2001) argues that in the United States organs and the process of organ donation have been reified through ecological themes that have been deemed appropriate. Sharp (2001) refers to two examples that have become popular, one is the slogan "*recycle yourself*" that is often accompanied by triangular symbol that is often found on recyclable goods in the US. The second example is what Sharp refers to as "the celestial recycling motif" with the slogan on bumper stickers that reads "*don't take your organs to heaven ... heaven knows we need them here*" (Sharp, 2001, p.122). From a behaviourist perspective it could be argued that this "*reusing*" attitude demonstrates the use of learning history experience from other socially responsible behaviours, in this case environmentally friendly behaviours. This learning history is being applied by the donor families because they lack direct experience with the issue of organ donation and therefore are utilising learning history which they deem appropriate to the situation they have been presented with.

A prevalent attitude among this dataset which was closely linked with the recycling analogy and the waste avoidance attitude was that the donor no longer needed the organs, therefore they should be donated and put to use by others. This sentiment is illustrated by the following three sources:

 "*They're no good to us when we go. Why not let somebody else get some use out of them.*" (Source 4)

"*She would have seen no sense in being buried or cremated with all her organs.*" (Source 44)

'*Just the thought of it: being cremated or rotting in a churchyard. I thought, "Well, at least this will go on and help someone"* (source 36).

These verbal statements demonstrate the pragmatic attitude held by donor families within this sample regarding not needing to preserve the body. Donor families within this dataset did not feel the need to preserve the body of their loved one, instead expressing an attitude that to not donate would be a waste of valuable and much needed organs. Fear of bodily mutilation and dismemberment has long been cited as a reason for refusal amongst potential donor families

(Exley *et al.*, 2002; Siminoff *et al.*, 2002; Barber *et al.,* 2006; Anker *et al.*, 2010; Ghorbani *et al.*, 2011). Most recently a small study in the UK with non-donor families found that one of the most prominent reasons cited as a justification for refusal was that they wanted to keep the donor body as "*whole*" (Sque and Galasinski, 2013). The results from this dataset demonstrate that those who consented to the organ donation did not possess the attitude that the body needed to be preserved and kept intact; instead they wanted the donor's body to be of use to others and felt that they should facilitate this process.

(ii)　　　Organ donation being "*right*"

A common attitude expressed within this dataset was that consenting to organ donation on behalf of their family member was considered to be the right thing to do. This particular attitude is well documented in the existing literature, with 90% of individuals in the UK expressing positive attitudes toward the act of organ donation in surveys (Coad, Carter and Ling, 2013; NHSBT, 2013b). Sque *et al.* (1996) reported that donor families within her sample reported some comfort in consenting to organ donation because they believed donation was the right thing to do in the circumstances. In a more recent study, "*doing the right thing*" was reported to be one of the main motivators for organ donation consent (Hogan *et al.*, 2013). The following two extracts are typical examples of this attitude within this dataset:

"*I knew it was right to do it. So I just let them take him*" (source 12).

'*I agreed to donating her organs. . . I thought it was the right thing to do*" (Source 45).

This attitude from a behaviourist perspective may be defined as a form of rule governed behaviour. As will be recalled from chapter two of this thesis, rule governed behaviour is behavior that occurs due to contact with rules that describe contingencies, and *not* due to prior contact with the contingencies the rule describe. For example, an individual can respond effectively to the rule "*do not ingest liquid as substance is toxic*" without ever having been directly in contact with the contingencies, that is, without ever having engaged in the behaviour of ingesting a toxic substance or of experiencing the negative consequences of toxicity. By

definition, an individual can comply with a rule, without ever having been in contact with the contingencies that it describes. In the case of organ donation, it appears that donor families are often complying with the socially propagated rule that organ donation is good and right, without having any direct contact with their contingencies. Where these rules originate from will be addressed in a later section within this chapter in the section that discusses the role of subjective norms and indirect experience.

(iii)   Organ donation being a reciprocal process

A commonly held attitude within this dataset was that organ donation was part of reciprocal process, an element of being a socially responsible individual. Donor decision makers within this dataset often stated that if one was willing to accept an organ, they should also be willing to donate one and this attitude informed their ultimate decision to provide consent for their family member. The following two sources demonstrate this "*reciprocal*" attitude:

"*I feel very strongly if someone had said your son could have an organ transplant and he would live, I would have taken it with open arms. And I think, if you're prepared to take it, then you've got to be prepared to give it as well. I'd hate to think that I was the cause of somebody not living because I was too selfish or upset not to go with that.*" (Source 2)

"*You'd take an organ for me and (name) if something happened to us. So I think you should be prepared to do the same thing back*" (Source 35).

Past research has demonstrated that in general people are more willing to accept an organ than to donate one (Sanner, 2006). A recent survey conducted in the UK found that despite 78% of individuals in their sample stating that they would accept an organ if needed, only 63% said they intended on being a donor after their death (Coad, Carter and Ling, 2013). This significant discrepancy between those willing to donate an organ and those willing to receive one is a national trend, where the majority of the UK relies upon the minority to donate organs for transplantation (NHSBT, 2013b). However, within this dataset donor families felt that it was their responsibility to donate, as they would happily accept one for themselves or their family.

To date this notion of reciprocity is something which has not been actively harnessed by policy makers, however there have been suggestions in recent years that those who register their intent to donate could receive a prioritised place if they ever where to need an organ (Nuffield Council on Bioethics, 2011).

(iv)   Organ donation bringing meaning to death

Another common attitude expressed within this dataset was that consenting to organ donation was an opportunity to bring meaning to the death of their loved one. One mother (source 2) stated that she thought organ donation could be "*something that would bring a real meaning for him (her son)."* This attitude was also mirrored in one of the case study participant's reasoning when he stated that his wife's death was in some ways was "*a tragedy, in others it was a victory*" (Source 15). This sense of bringing something positive and meaningful out of an otherwise tragic circumstance was evident in all sources within this dataset, thus highlighting this attitude's importance in the consent process for donor families. In the existent literature this theme is prevalent and well rehearsed. Donor families often report that the fact that organ donation brought meaning to their loved one's death was a highly motivating factor in their decision to consent (Batten & Prottas, 1987; Radecki & Jaccard, 1997; Sque *et al.,* 2006). This attitudinal statement is one avenue that could potentially be fostered by social marketers in promoting organ donation amongst the general public to increase the rate of family consent within the United Kingdom.

Subjective norms

Foxall defines subjective norms as representing "*a learning history which reflects the extent of social pressures to conform with the demands of situation and a history of compliance or non-compliance with the perceived wishes of a significant other*" (Foxall, 2005, p.87). In study one subjective norm was a significant component of learning history within this dataset, with decision makers stating that important others, including but not exclusive to immediate family members, were supportive of their ultimate decision to consent. In the overwhelming majority of sources, the importance of coming to a final decision with the input of significant others in mind was highlighted.

The following examples illustrate the importance of subjective norms in the consent process within this dataset:

"The rest of the family started to discuss times we had spent together, things we said to each other, things we believed in. It was at this point that the subject of organ donation was brought up. We all agreed what had to be done" (Source 22).

"I spoke to other family members and they all said, "If that's what you want to do, we'll go with that." Nobody had said, "No we don't want to," for any reason. We all felt that that was the right thing to do" (Source 2).

"We all carry donor cards. When they asked if they could use her organs, my wife and I said yes instantly" (Source 20).

Another interesting finding within this dataset was that once the decision to consent was made by the immediate family, the opinions of others such as the opinions of extended family were considered of little importance. Donation decision makers within this sample emphasised the fact that it was their ultimate choice to provide consent on behalf of their next of kin and that the opinions of individuals outside of the immediate family were not important and therefore not taken into account. The following example demonstrates how a mother, in the face of opposition from the donor's partner, felt that ultimately it was her decision since she was legally the next of kin. She expressed that she was comfortable with having to veto his wishes if the situation arose:

"There was a bit of a conflict between us and [donor's partner] because he was a bit sceptical. He didn't know if he really wanted us to donate her organs. But, as much as I'd said to him from day one, I would always talk to him. We would always discuss everything that needed to be discussed, because I was her next of kin I would overrule, if I wanted something and he didn't, I would overrule it" (Source 4).

Similarly one of the case study interview participants spoke about how extended family were not happy about the decision to donate but how this had little impact on his decision to consent since he felt it was his, and his sister and father's choice:

"They were not happy about it, but it was our decision." (Source 14)

The existing literature regarding the donor family decision making process has consistently emphasised the role and importance of subjective norms and organ donation researchers have incorporated the variable into their decision making modelling (Horton and Horton, 1991; Radecki and Jaccard, 1999; Hyde and White, 2009). Previous studies exploring the factors that impede consent rates have also identified family disagreement over organ donation as one of the primary reasons why retrieval has not taken place (Lopez Martinez *et al.*, 2001; Martinez *et al.*, 2001; Singh *et al.*, 2004; Barber *et al.*, 2006; Rodrigue *et al.*, 2008; Anker and Feeley, 2010; Ghorbani *et al.*, 2011). Although rare, family disagreement has prevented donation for taking place even when the potential donor has expressed a wish to donate during their lifetime via registration (Rudge, 2007). This finding further highlights the importance of positive learning history regarding the issue of organ donation in producing a successful donation outcome.

Direct experience

As will be recalled from chapter two of this thesis, learning history is a container of an individual's past experiences and their reinforcing consequences. An important element of this is an individual's direct experience with an object or behaviour. Direct experience refers to an individual's exposure to the contingencies of an activity or object and the consequences they have produced in the past (Foxall, 2005). In this particular context direct experience with actual organ donation is incredibly low. This is an unsurprising finding since the phenomenon is a relatively rare occurrence, with only 2143 donations occurring in the year 1st April 2011 to 31st March 2012 (NHSBT, 2013b). However donor decision makers within this sample were in possession of some relevant direct experience in the following areas (i) with similar or associated behaviours, for example blood donation, (ii) with the hospital environment and medical personnel and (iii) experience of being involved with family discussions regarding organ donation.

(i)   Engagement with similar behaviours

The first source of direct experience that was frequent among decision makers within this dataset was prior experience in engaging with similar behaviours, for example blood donation or having registered on the national organ donation register themselves. Previous studies have demonstrated that measures of past behaviour improve predictions of behaviour over those provided by attitudes, subjective norm and intention alone, for example giving up smoking (Marsh and Matheson, 1983; Sutton et al, 1987) and blood donation (Bagozzi, 1981; Charng et al, 1988). In this dataset past engagement with similar behaviours was an important element of the decision maker's learning history. From a behaviourist perspective, the likelihood of an individual engaging in a given behaviour is a function of past reinforcements in similar circumstances (Baum, 1994). Therefore, one may infer that donor families within this dataset had experienced positive reinforcements when engaging in similar behaviours, for example praise via verbal behaviour or personal satisfaction from donating blood and therefore brought this learning history to the donation request situation.

One father expressed that it was a natural decision for him and his wife to consent to their son's organ donation in light of their experiences with similar behaviours:

"I donate blood and we have both been on the donor register for most of our adult life" (Source 39).

Whilst another father of a donor stated that donating was something that he and his wife *"instantly"* consented to because they had both signed an organ donor card in the past, therefore consenting seemed like the obvious action in light of this history:

"We all carry donor cards. When they asked if they could use her organs, my wife and I said yes instantly" (Source 20).

(ii) Experience with hospital environment and similar injuries

A considerable number of donor decision makers within this dataset had experience of the hospital environment prior to the organ donation request. This direct experience often came

from having worked closely with the medical profession in the past or from the experience of witnessing similar injuries in the context of the hospital. One father who consented to the retrieval of his daughter's organs spoke of having been in contact with surgeons in the past and how this direct experience had helped him understand the process and the job the medics were doing:

"I knew and understood doctors, the challenges of their work. So often people are suspicious of them, of what they're up to, but I regarded them as essentially friendly" (Source 43).

Similarly one mother within this dataset had previously worked as a nurse, she had witnessed her own mother suffer the same injury as her daughter and this experience had helped her make sense of the situation she found herself in when he daughter fell seriously ill:

"And my mum had died of a brain haemorrhage. . . then when I looked at my daughter I knew there and then, being a nurse myself, that's exactly what was going on with her" (source 1).

Recognising the severity of the injury from previous experience with brain injuries helped another donor decision maker within this dataset. A mother who consented to the donation of her son's organs said that she recognised and accepted that he was irreversibly injured because she had direct experience of having had a relation who had suffered the same type of brain injury:

'We have a family member who suffered brain damage and the look was exactly the same" (source 39).

These extracts from the dataset demonstrate how previous direct experience of the hospital environment and of similar injuries had enabled these donor families to respond to the environment by providing consent. It is possible that without this direct learning history of similar environments and injuries these donor decision makers may have not been as equipped to make the final decision to consent.

(iii) Direct experience of family discussions about organ donation

Another source of direct experience identified within the dataset was family discussions about organ donation. This has been identified as one of the most important predictors of donor family consent in the existing literature (Borroughs *et al.*, 1998; Martinez *et al.*, 2001; Thomas *et al.*, 2009). Previous studies have found that once a family is aware of the deceased's wishes, they tend to honour them (Harris *et al.*, 1991; Harris, Jasper *et al.,* 1990). The majority of donor families in this dataset had discussed the issue of organ donation with the donor at some point during their life. Interestingly this discussion was often stimulated by a media story covering the issue of donation. The following examples from the dataset demonstrate that having had a family discussion at some point with the donor regarding the issue of organ donation, equipped them with the relevant learning history to make the decision to consent:

"There was an interview done on local television with this couple's daughter and she'd not been very well. And they were appealing for organ donation. And I'd said to him at the time, "Oh would you donate your organs?" And he said yeah he would because there'd be no point in keeping hold of them. So it was just an observation on the television and that. I didn't give it five, ten minutes thought. We'd just had this conversation, but when I look back after a couple of weeks later, that gave me the knowledge really to make the decisions that I made." (Source 7)

"We had discussed it in the past because. It was something that, because she did work for a while at the [hospital name], at the kidney unit. She did work there for a while. . . . She always said, "Oh well, they can have whatever of mine they want, they can, they can have in that respect." So yes it was something we were aware of" (source 15).

"We had spoken about organ donation a few times as a family and it was something she (the donor) was keen on" (source 20).

Previous literature has shown that if these discussions regarding donation wishes do not take place, families err on the side of caution and refuse to provide consent when requested (Yong *et*

al., 2000; Martinez *et al.*, 2001; Exley *et al.*, 2002; Singh *et al.,* 2004; Barber *et al.,* 2006 Lopez Martinez *et al.,* 2008; Anker & Feeley, 2010). NHSBT (2013b) have reported that family consent rates jump from 41% when wishes about organ donation are not known to over 90% when they are explicitly known by the donor family at the time of request. Research carried out by a YouGov survey across the UK found that half of those surveyed (52%) had not passed their organ donation wishes onto their friends or family (BMA, 2012). In light of these findings, one could argue that unless a drastic change is enforced and individuals are made to express their donation intentions to their family during their lifetime, this issue will remain a prominent obstacle to increasing consent within the UK.

Indirect experience

In the context of organ donation, where most individuals possess very limited amounts of direct experience due to its rarity, indirect experience plays a prominent role in an individual's learning history. Indirect experience is obtained primarily through third party sources via verbal behaviour. Foxall (1995) argues:

 "*We do not learn solely from direct experience of the contingencies; learning history also reflects observation and incidental learning without immediate reinforcement, the acceptance of rules handed down by others, and our tendency to devise our own rules based on observation and even imagination of contingencies as well as through the direct impinging of reinforcers and punishers*" (Foxall, 1995, p. 41).

There were two main sources of indirect experience identified from the dataset; these included (i) the media's coverage of organ donation (pro-donation campaigns, newspaper coverage and entertainment television) (ii) knowing people who had been affected by organ donation and transplantation.

    i)   Media coverage

Within this dataset a significant source of indirect experience was the media and its portrayal and coverage of organ donation. The existing literature has identified the media as an important source of information for the general public and emphasised the potential positive role it can

play in educating people on issue and facilitating family discussions (Greenfield, 1988; Matesanz, 2002). However, previous studies have also highlighted the negative role the media can play by propagating myths surrounding organ donation and preying on the fears of the general public (Maloney & Walker, 2000; Matesanz, 2003; Asher *et al.*, 2005; Quick, 2009; Harrison *et al.*, 2008). Morgan et al (2007) report that storylines presented on television mirror the actual reasons individuals give for not providing consent, with family members reciting storylines from television episodes to justify their position. Matesanz (2003) claims that organ donation rates dropped in the UK, France and Belgium when stories aired through the media that questioned brain death criteria highlighted the number of non-citizens who were on waiting lists or discussed rumours of illegal international organ trafficking.

In this dataset donor families reported mostly positive coverage of organ donation and transplantation in the media, namely medical programmes that highlighted the organ shortage crisis or human interest stories about individuals needing a transplant. Media coverage appeared to play an important role in prompting discussions about organ donation amongst the donor families in this dataset. For example one mother said that she and her first husband watched a programme about Anthony Nolan and his family. They were so touched by his story that they joined the organ donation register. She states that having watched the programme and subsequently discussed the issue with her first husband made agreeing to provide consent on behalf of their son easier:

"It was something that we'd all talked about as a family, and it had started many years ago with Anthony Nolan and his story. And my first husband and I at the time were very taken with this story. We were just drawn into it, and just felt so incredibly sorry for this family. And we both joined the register and so, in many ways, that made it easier for us to sort of talk about it at this point" (source 9).

Another mother within this dataset reported a similar experience, where watching a medical programme that contained organ transplantation had prompted a discussion:

"He'd (her husband) remembered a conversation (the donor) and I had whilst watching a medical programme on

TV where they were performing an organ transplant – (the donor) couldn't understand why people wouldn't donate their organs" (source 23).

These two sources demonstrate the positive role indirect experience through the media can play in the organ donation consent process. However, in this dataset there was one source of negative media coverage that 5% of the dataset mentioned as a concern, and that was allocation of organs to individuals like George Best, who was an alcoholic ex-footballer who received a liver transplant on the NHS but continued to drink until his death in 2005. One father explained how is first "*instinct*" was to refuse consent because he didn't want individuals like George Best being helped by his son's organs:

"I hated the thought that someone such as George Best, who'd abused their body, would get bailed out by my son's organs" (source 36).

George Best's liver transplant also was mentioned by two of the case study participants. A male case study participant said that the thought of an individual who continued to abuse their body receiving his mother's organs was something he didn't want; however he put those thoughts to the back of his mind and consented (source 14).

These examples illustrate that negative press coverage did have an influence in decision making process in these particular cases, however its impact was minimised due to the individuals being in possession of positive learning history components, such as positive attitudes and positive subjective norms. A study conducted by Pioli and Lawton of UK Transplant found no significant impact between negative press coverage surrounding events such as the Alder Hey organ retention scandal and George Best's transplant, and donation rates in the United Kingdom during that time period (UK Transplant, 2006). Although no evidence of a significant influence between negative press and consent levels could be found in Pioli and Lawton's study, the potential power of press coverage and awareness campaigns should not be underestimated. It is undeniable that positive organ donation media coverage can improve the public's general understanding and attitudes of issues surrounding donation, dispelling myths on the way and

therefore one could argue should be utilised more vigorously by the public health sector to improve donation levels in the UK.

ii)   Knowing people affected by donation

Within this sample there were donor families who had known people, either directly or indirectly, who had been affected by organ donation or transplantation. This served as a form of indirect experience for the donor decision maker, since the direct experience of others was passed onto the potential donor family through verbal behaviour or observation.

One mother within this dataset said that she had witnessed the transformation of her father's life due to a kidney transplant, saying that it made a big difference to his general quality of life and that had a positive impact on the whole of her family:

"My father had a kidney transplant, he was on dialysis, and then he had a kidney transplant when I was very young. He was only born with one kidney and he was basically very ill. And latterly he went onto dialysis and he got a kidney transplant that worked for about a year and a half. And also then the body rejected it and then he got another one, and that rejected right away. But there is a big difference to our quality of life, the whole family's quality of life when he got a new kidney. Before that we were tied to a kidney machine, or a dialysis machine three times a week" (source 1).

Similarly, one of the case study participants said that his nurse wife worked for some duration at the kidney unit of the local hospital. She had spoken about the dialysis process and how organ donation could change the daily life of recipients dramatically:

"I think working at the [hospital name] for that time, seeing people on dialysis and all the rest of it... it brought it home" (source 15).

Summary of learning history findings

This section has provided further validation for the four identified key components that comprise an individual's learning history, which feed into donor family consent decisions within this dataset. These have been identified as (1) attitude towards organ donation (2) subjective

norms toward organ donation (3) direct experience and (4) indirect experience. As demonstrated from the analysis of this dataset, the role of each of these learning history elements appear to have a significant role in the donor family consent process. Findings from this section have corroborated much of the existing literature regarding the role of experience, attitude and subjective norm in donor family decision making. These findings will now be utilised in the development of the learning history questionnaire that intends to measure learning history regarding organ donation in study two of this thesis.

In sum the analysis conducted on learning history from this dataset has provided further weight to the proposition generated from the existent literature discussed in chapter two of this thesis, that learning history will significantly influence likelihood of organ donation consent. In study two of this thesis this proposition will be further tested by exploring the relationship between these identified elements and consent and to examine whether significant differences in consent are evident between those who possess a more positive learning history (a high learning history score) and those with a more negative learning history (a low learning history score).

Behaviour setting & scope

P2. Behaviour setting scope will significantly influence donor family consent

As will be recalled from chapter two of this thesis, the BPM proposes that an individual's behaviour is jointly determined by the behaviour setting variables that comprise the decision making environment and an individual's unique learning history regarding the behaviour in question. The discriminative stimulus within the current behaviour setting activates an individual's learning histories through their prior association with the reinforcing and punishing consequences of engaging in the current behaviour. Therefore these stimuli play a vital role in the creation of meaning for the individual, signalling what contingent outcomes of the current behaviour are likely to be produced for the individual. The BPM schema outlines that there are four distinctive behaviour setting variables, namely physical, social, temporal and regulatory. In chapter two of this thesis, it was argued that the physical stimuli in which the donor family

decision making process takes place is largely consistent, with it taking place in a high dependency unit of a hospital. Therefore by its very nature the environment is more closed than a traditional consumer behaviour setting, with the individual's behaviour and choice limited.

In the following sections of this chapter each one of the behaviour setting variables will be analysed in turn with the objective of demonstrating the interpretative power of the BPM framework in this environment. As will be recalled in chapter two of this thesis, due to the unique nature of this health behaviour the physical, social and temporal elements of the consent process cannot be easily manipulated by the practitioner or interventionist in a meaningful way since these environmental constructs lie largely outside of their control. Therefore in the following section particular attention will be paid to the behaviour setting scope and the regulatory aspects of the decision making situation since these appear to have significant impact on consent behaviour and can be easily modified from an intervention perspective.

(i)   Physical

In a traditional consumer context the physical aspect of the behaviour setting includes elements such as the location of the institutional or spatial location, atmospherics within the setting, and visual depictions of merchandise and product attributes to name a few (Foxall, 1990). In the organ donation context consent happens in a very consistent environment, a hospital which comprises of wards, waiting rooms, beds, patients, medical machinery and hospital atmospherics such as alarms going off and nurses and doctors busily working. It could be argued that the physical behaviour setting is inherently negative due to its association with illness and this was reflected in donor family accounts within this dataset.

"We arrived at the hospital and were rushed up to the intensive care ward. It was absolutely packed with doctors and nurses looking grave and there was a really sad atmosphere about the place" (source 38).

"I remember looking round at the ward and to me standing there, there was no humanity on that ward. Everyone was doing their job professionally" (source 3).

As illustrated by the examples above the majority of donor families within this dataset generally described the actual physical environment in negative terms. The most distressing element within the immediate physical environment identified within this dataset was the physical appearance of the potential donor. This is largely to do with the fact that the donor still looked alive when the decision maker provided consent for donation. In the existent literature this negative physical element within the behaviour setting has been documented and can sometimes leave the decision maker conflicted (Sque *et al.*, 1996). The following examples from the dataset illustrate this particular physical element of the behaviour setting:

"It was very hard to take on board that he had died because he'd still got a rosy glow to his skin. He was still very warm and all the rest of it" (source 9).

"You turn around and you walk away but to me he was still warm and his chest was still going up and down, so therefore he was still alive" (source 7).

Unfortunately due to the nature of organ donation these negative physical elements cannot be removed or subdued. The physical environment in which the consent process takes place is inherently negative, since it is synonymous with illness and death. However, other features of the behaviour setting were reported to be positive by the overwhelming majority of donor families within this dataset, one of which being the social element, which will be addressed and discussed in the next section.

(ii) Social

The social feature of the behaviour setting includes the presence of other individuals and third parties within the environment (Foxall, 1990). In the context of organ donation consent the social element of the behaviour setting includes the presence of family members, friends and medical personnel within the environment. Unsurprisingly in light of findings regarding subjective norms, within the majority of donor family accounts in this dataset the social element of the behaviour setting was positive, with family members being supportive of the donor decision makers decision to consent and the staff being informative and perceived to be

supportive and empathetic. The following extracts illustrate the positive role of family and friends in the consent situation:

"I spoke to other family members and they all said, "If that's what you want to do, we'll go with that." Nobody had said, "No we don't want to," for any reason. We all felt that that was the right thing to do" (source 2).

"I think we were lucky in the point of fact that we had some very good friends with us at the hospital who came to [place name]. And then for the five days that (donor's name) was in between the two hospitals, there was certain people that visited every day, that spent the time with us, and have been our support" (source 4).

The positive role of hospital staff, in particular doctors, nurses and transplant co-ordinators in the social setting was evident in the dataset. Although difficult to quantify, a number of studies have drawn attention to the effect of wider aspects of care by staff involved in discussions with potential donor families (Douglass *et al.*, 1995; Jacoby *et al.*, 2005; Rodrigue *et al.*, 2006; Jacoby & Jaccard, 2010). It is a consistent finding that a sensitive and empathetic manner during these discussions is a discriminator between donor and non-donor families. In a recent study Jacoby and Jaccard (2010) found that families who felt that they had been treated with empathy, understanding and assurance were more likely to consent. Similar findings are reported within this dataset, the following examples from the dataset illustrate this:

"The donor co-ordinator team was first-class throughout. They were a great support to us" (source 20).

"(The co-ordinator) was extremely compassionate in what I could only describe as extremely emotional situation. She explained the process and went through the expected paper work and questions in an extreme warm and professional manner. Although she had a job to do I knew that she was generally concerned about me and my family's wellbeing. She went through the details of what would happen and ensured that I was okay with everything every step of the way" (source 21).

These examples demonstrate the important role of a positive social setting in contributing to a positive consent outcome. Unfortunately the attitudes and behaviours of the family and friends of the potential donor are outside of the control of health professionals in this setting. What

hospital personnel can ensure is that potential donors and their family experience as positive a service as possible within the hospital setting by adhering to the NHS donor family care policy (NHSBT, 2004) and NHS family approach best practice guidelines (NHSBT, 2013).

(iii)   Temporal

In a traditional consumer context the temporal features of the behaviour setting comprise of time related factors, such as opening times and the duration of promotions (Foxall, 1999). As will be recalled from chapter two of this thesis the temporal setting in the context of organ donation consent is substantially different and related primarily to timing of the organ donation request and the amount of time potential donor families have to process the situation. Many studies have demonstrated an association between consent and the family having sufficient time to process the information and consider their response (DeJong *et al.*, 1998; Siminoff *et al.*, 2001; Jacoby *et al.*, 2005; Rodrigue *et al.*, 2006; Rodrigue *et al.*, 2008). Within this dataset the temporal setting concerning the organ donation request was overwhelming positive. For example one donor decision maker explained that their family was given sufficient time to process the information and come to decision as a family:

"They took us to another room so we could have time to think about it while they went away. And they came back about ten minutes to fifteen minutes later" (source 13).

Similarly another example from the dataset demonstrates this common theme:

"We were left to ask the questions, to have our thinking time" (source 11).

Not one donor family within this dataset reported feeling rushed into their decision to consent; however a small number did report one negative temporal effect of consenting, namely having limited amounts of time with the donor. For example one donor family recalled how difficult it was when they took the donor away for the procedure:

"It was still difficult. At the point he died and we were still in the room because we were within a quarter of an hour of it being too late for them to do it. They had to take him more or less straight away, and that was really

difficult. I wanted to say, "No, no." I really felt when they were wheeling him out of the room, part of me wanted

to say, no, don't" (source 12).

This particular negative aspect of the temporal setting cannot be overcome due to the nature of the donation process. However, what can be controlled is how donor families are approached and treated by medical personnel. These findings support previous findings that how much time, space and support the family are given is crucial in achieving a positive consent outcome.

(iv)   Regulatory

The regulatory setting refers to "*self and other rules that specify contingencies*" (Foxall, 2005, p92). As will be recalled from chapter two, it is a form of rule-governed behaviour and is classified as a social phenomenon; however due to its importance it deserves separate treatment. The regulatory settings in the context of donor family consent is of uttermost importance, since most families lack experience in organ donation and are therefore looking to regulatory figures such as nurses and co-ordinators for guidance in order to direct their behaviour. In this context, positive regulatory input involves emphasising the benefits of organ donation, not only to society but to the donor family, whilst reassuring the family and reducing any fears or concerns they may have about the procedure.

Within this dataset positive regulatory behaviour setting elements were unsurprisingly prominent, with donor families reporting positive regulatory input from medical personnel whilst they facilitated the process. The following examples demonstrate the appreciation donor families had of the positive regulatory figures within the behaviour setting:

"This is when we were introduced to (name), a transplant co-ordinator at (hospital name). She told us everything

we needed to know and was very good at putting us at ease at such a difficult time" (source 22).

"But I had no concerns over the care that (donor) received. As a donor, he received equally good care as he would

as a patient who they were trying to save, to live. Because those organs were just as important as if he was being

treated to live. And as the co-ordinator [specialist nurse] once said to me, when she accompanied (donor) to the

operating theatre on the evening that the retrieval took place, he will be looked after just the same as if he was having any other operation because those organs are very, very precious to another person." (source 8).

I can only applaud them for being how they were. Then obviously (specialist nurse) and the team that came afterwards were so sympathetic but so informative" (source 14).

NHS policy recognises the importance and impact of positive regulatory behaviour in the consent environment. Most recently guidelines published by the NHS regarding best practice in relation to donor family approach emphasises the importance of using positive language when discussing the issue of organ donation and providing assurance to the family as to dispel any concerns they may have. The following extracts from the most recent guidelines (2013) illustrates this form of regulatory behaviour in practice:

"At all times, the language regarding donation should be positive, emphasising the potential benefits for recipients, their families and society in general. The known benefits to donor families in the longer term should also be mentioned" (NHS Family Approach Best Practice, 2013, p.13).

"Emphasise the care and respect shown to a donor at all times" (NHS Family Approach Best Practice, 2013, p.14).

The findings documented in this chapter find support in previous studies and have demonstrated the importance of the inclusion of specific explanations by regulatory figures within the consent discussion with potential donor families. These include a description of what the organ donation process involves (Jacoby *et al.*, 2005; Jacoby and Jaccard, 2010), emphasis of the benefits of donation and the potential help to others (DeJong *et al.*, 1998; Siminoff *et al.*, 2001) and reassurances over burial arrangements and fair organ allocation (DeJong *et al.*, 1998; Siminoff *et al.*, 2001).

(v)   Setting scope

As outlined in chapter two of this thesis, alongside informational and utilitarian reinforcements, the scope of the behaviour setting is an integral variable in the BPM framework. The behaviour

setting scope can vary from relatively open, where the individual is presented with multiple choices, to being relatively closed, presenting the decision maker with a restricted number of choices (Foxall & Yani-de-Soriano, 2005). Chapter two of this thesis argued that by its very nature the overall hospital environment is a relatively closed environment, where an individual's freedom is restricted, for example access to certain areas are closed off and visiting times are restricted to certain times of the day. However the present process of consent in the UK is relatively open within the closed hospital environment, with the potential donor family able to provide or deny consent as they please, even being able to override the potential donor's wishes. As was discussed earlier in this thesis, there have been calls for the system to become more restrictive via an opt-out system of consent. This would mean that potential donor families would be told that if their family member had not opted-out they would have no legal right to veto the process, however if strong objections were expressed the donation would be unlikely to proceed (Department of Health, 2008). This system would evidently be more closed on the spectrum, thus restricting potential donor families' choice in this difficult situation. Within this dataset donor families saw their freedom of choice as a positive element of the behaviour setting. Many expressed that they felt that the choice was theirs, and that no one pressured them into making the choice. The following examples from the dataset illustrate how the openness of the decision making process was seen as a positive by donor families in this dataset:

'It was then we met the lady who put forward the case for organ donation. There was no pressure at all" (source 36).

"We met 2 wonderful transplant co-ordinators who talked us through the process; I never felt rushed or forced to do anything I didn't want" (source 23).

"I then met [donor co-ordinator's name] who was our donor co-ordinator [specialist nurse]. And a lovely, lovely, lovely person. As were all the medical people, because at no time were we pushed, cajoled, persuaded. We just weren't. We were left to ask the questions, to have our thinking time" (source 11).

At present there is limited and incomplete evidence regarding the level of public support for a change in the consent system in the UK. The Welsh Assembly will be the first to introduce such

a system commencing in 2015 after a substantial publicity campaign has been conducted to inform individuals about the changes to the law. However within the existing literature challenges of the introduction of such a system have been highlighted (Randhawa *et al.,* 2010; Bramhall, 2011). For example some members of the medical profession have expressed concerns that the introduction of presumed consent may possibly damage the relationship of trust between clinicians caring for patients at the end of life and their families (Bramhall, 2011). In addition faith leaders have also expressed concern that it may lead to a backlash from members of the public who currently support the opt-in system of consent (Randhawa *et al.,* 2010).

Within this dataset donor families felt that consent was solely their decision to make and appreciated not being pressurised or cajoled into making a decision that wasn't right for them. Two donor families went as far as to express a negative response to the possibility of not being given this choice in the dataset:

"I truly believe that organ donation was the right thing for me. But that is my choice. No one else's. . . . . I can tell you from personal experience that donating an organ of a loved one is an incredibly traumatic thing to do. To take the choice away from someone, to force them to agree to it when they are in the midst of their grief, would be incredibly cruel" (source 38).

"It was our choice (to consent), no one else's (choice) to make" (source 14).

The findings from this dataset indicate a preference for open consent choice settings, where the potential donor family exercises a level of freedom. Restricted choice, possibly in the form of a soft-opt out system of consent, potentially could anger potential donor families especially if they lack a positive learning history in similar environments. This finding will be further scrutinised during study two to see whether consent levels are significantly higher in open behaviour setting situations.

Summary of behaviour setting and scope findings

This section has demonstrated the usefulness of the BPM as an interpretative device for the behaviour setting in which organ donation consent occurs. One of the advantages of the BPM is that it allows for all key actors within the setting to be analysed on equal terms, resulting in a rich contextual depiction of the consent process. As has been discussed earlier in this chapter, many of the behaviour setting variables cannot be manipulated or modified as they are unavoidable in this context, for example the inherently negative physical setting or the actions of family or friends of the deceased. The behaviour setting elements that can be controlled are the scope of the behaviour setting and the actions and verbal behaviour of regulatory figures. Through recent NHS improvements in protocol regarding donor family care, regulatory figures must approach the potential donor family in a certain prescribed manner that has been shown to be the most effective in increasing consent (NHSBT, 2013). The one element of the behaviour setting that appears to have a significant influence on consent but little investigation being undertaken thus far is the effect that restricting donor family choice would have on likelihood of consent in the UK. The initial findings from this chapter indicate that donor families show a preference for more open behaviour settings, where they feel they exert considerable influence. In light of the existent literature and the preliminary findings from this chapter it appears that donor families could potentially respond negatively if they felt restricted or pressurised to conform. This will be scrutinised further in study two in order to validate the hypothesised relationship between behaviour setting scope and likelihood of consent.

Contingencies of reinforcement

P5.1. The Accumulation operant class (Altruistic donation) will be the most effective in stimulating consent

P5.2. The Maintenance operant class (Routine donation) will be the least effective in stimulating consent

P5.3. Learning history will influence mode of reinforcement preference.

As discussed in chapter two of this thesis, the radical behaviourist standpoint presupposes that it is the contingency of reinforcement that is the primary factor in the generation of an

appropriate behavioural response. The Behavioural Perspective Model (BPM) conforms to the basic three term contingency which is at the very core of Skinner's approach to applied behaviour analysis. Reinforcement may take one of two principle forms, positive reinforcement, which increases the likelihood of the response being performed again, and negative reinforcement, in which the repetition of a response being performed again in the future is less likely. The BPM framework proposes that positive reinforcement can take one of two forms, a process branded as bifurification (Foxall, 1990; 1995; 1999). The resulting two modes of reinforcement are referred to as either utilitarian or informational in nature. A third category, defined as aversive consequences, is also presented within the BPM schema and refers to the negative outcomes that are incurred by the individual for engaging in a given behaviour. For example in the context of smoking cigarettes, the aversive consequences would include the health and financial costs associated with engaging in that behaviour.

The following sections will document the differing modes of reinforcement that have been identified within this dataset through the analysis process, namely the utilitarian and informational reinforcements of providing consent, and the aversive consequences associated with providing organ donation consent.

Utilitarian reinforcement

As will be recalled in previous chapter, within a traditional consumer context utilitarian reinforcement consists of the tangible functional and economic benefits that stem from the purchase, ownership and consumption of products and services (Foxall, 1995, 1999). In the context of donor family consent the utilitarian consequences of organ donation are not functional or economical in nature as is the case in more traditional consumer contexts. As discussed in chapter two of this thesis, utilitarian reinforcement in the context of donor family consent relates to the direct benefits experienced by the donor family as a consequence of providing consent. Foxall (2005) states that utilitarian reinforcement arises from the features of the product or service obtained in purchase or utilised during consumption. He argues that this corresponds to the use of utility concept within economics that refers to "*the direct satisfaction that*

goods and services yield to their possessors" (Gould & Kolb, 1964, p.303, p.740). Therefore in this context utilitarian reinforcement not only refers to the functional consequences of engaging in the behaviour of organ donation consent but also to the feelings associated with consent and the positive affect generated in the process (Foxall, 2005).

Recently it has been hypothesised by Nicholson & Xiao (2011) that in the context of organ donation only low levels of utilitarian reinforcement are evident due to the altruistic nature of the health behaviour. However, within this dataset three distinct sources of utilitarian reinforcement were identified, namely (1) comfort derived from organ donation, (2) personal satisfaction and happiness and lastly (3) the potential introduction of financial incentives by the government outlined in recently published documents (Department of Health, 2008; Nuffield Council on Bioethics, 2011; BMA, 2012). Each one of these identified sources of utilitarian reinforcement will be explored consecutively in the following section, drawing upon textual evidence from the dataset.

(i) Comfort

The first and most commonly cited source of utilitarian reinforcement within this dataset was the personal comfort derived from consenting to the donation of a loved one's organs. The theme of donor families finding comfort in the donation process is well rehearsed within the existent literature, with previous research consistently identifying this as a behavioural consequence of donor family consent (Batten & Prottas 1987; Buckley 1989; Soukup, 1991; Cunningham, 1993; Pelletier 1993). Holtkamp states "*without hesitation, families report that there is great comfort in knowing that something uplifting and noble came from the hateful death of a loved one*" (Holtkamp, 2002, p. 26). The following extracts from the dataset illustrate the comfort that donor families have reported has been derived from the consent process:

"When we watched them turn off the life support machine, it made it a bit easier knowing that she was going to save others. It really has been a comfort to us" (source 20).

"Knowing a number of people have been helped has been very much a comfort to us and we all think it's marvellous" (source 42).

"It was such a tremendous source of comfort. It was not such a complete loss" (source 44).

Sque et al (1996) in her qualitative study of donor families does not go as far as previous studies have and does not suggest that comfort is derived for donor families from the organ donation procedure, but instead from the sense of having done the "*right*" thing and facilitating in providing a valued gift. If this alternative interpretation is examined from a behaviourist stance, the positive outcome (i.e. comfort) is a direct consequence of the decision maker abiding by the rules. Put simply, the decision maker receives a positive behavioural outcome by the fact they have followed the rules set out by either themselves or others by engaging in a socially approved behaviour. Therefore providing consent can be seen as a form of rule governed behaviour, which donor families experience positive utilitarian outcomes from if they engage in it in the prescribed manner, e.g. by providing consent.

(ii) Happiness and Satisfaction

Another key source of utilitarian reinforcement identified within this dataset was the satisfaction and sense of achievement felt by donor families after they provided consent to the organ donation. Within this dataset families often reported positive affective responses as a consequence of providing consent to donation, for example feeling pleasure and happiness at being able to have the opportunity to turn an inherently negative experience into a profoundly positive one. In addition donor families within this dataset also reported a sense of achievement in being to facilitate the improvement of someone else's life. This direct benefit was one of the most commonly reported behavioural outcome of providing consent, thus illustrating its potential importance in the consent decision making process. The finding that happiness and pleasure was derived from the decision to consent corroborates with the existing literature that states that a sense of personal satisfaction can be derived by organ donation (Parisi and Katz, 1986; McIntyre et al, 1987; Manzari et al, 2012). The following extracts demonstrate the sense of

happiness and pleasure associated with providing consent felt by donor families within this dataset:

"But we get pleasure in knowing she's saved people's lives. That has really helped me and my family" (source 45).

"The knowledge that she has helped so many people makes me feel almost elated at times" (source 38).

"I cried tears of happiness, because it was (donor's name) that had saved his life" (Source 45).

(iii) Financial incentives

Financial incentives for organ donation consent could be perceived as the most literal form of utilitarian reinforcement possible. In the BPM operant typology of behaviour, this type of intervention would belong in the operant classes characterised by the highest levels of utilitarian reinforcement, namely Accomplishment and Pleasure. At present financial incentives play no part in the UK's current system of consent. Worldwide there it is only one example of a financially incentivised system and that is Iran's legal, centralised system for the payment of living organ donors. In recent years there has been much debate surrounding the potential introduction of financial incentives to promote organ donation amongst potential donor families in several countries. In the USA the Ethics Committee of the American Society of Transplant Surgeons concluded that to offer direct cash payments to potential donor families would violate the ideal standard of altruism which organ donation is founded upon. However they did conclude that a payment of funeral expenses or a contribution towards a chosen charity would be deemed acceptable (Arnold *et al.*, 2002).

In this dataset 5 documents mentioned the issue of financial incentives as a potential strategy to stimulate an increase in consent rates from potential donor families in the UK. The Nuffield Council on Bioethics (2011) concluded that the payment of funeral expenses could be ethnically justified arguing that a similar scheme already operates for those who donate their bodies to medical schools for educational purposes. The Nuffield Council on Bioethics states *"We recommend that NHS Blood and Transplant should consider establishing a scheme to test public response to the*

idea of offering to meet funeral expenses for those who sign the ODR and subsequently die in circumstances where

they could become donors" (Nuffield Bioethical Council, 2011, p.9-10).

A YouGov survey was conducted in the immediate aftermath of the Nuffield Bioethical Council's recommendations about introducing payment of funeral expenses and reported mixed findings regarding its general acceptability. YouGov surveyed 2,640 individuals, of that sample 47% supported the suggestion, 32% were opposed to it and 21% said they did not know. One question within the survey asked respondents whether they thought it would make people more or less inclined to sign up to the Organ Donation Register. The results found that 56% said they thought it would increase registrations, 1% said it would decrease registrations and 32% thought it would make no difference. The remaining 11% did not know. Most importantly of those who were not currently on the ODR, 58% said it would make no difference to them personally (YouGov, 2011). Similarly an interview study conducted in the USA by Rodrigue et al (2006), assessed the general acceptability of paid funerals with actual donor families. They found that 12% of non-donor families stated that they would have consented if an incentive had been offered to them at the time of the request. However despite this gain in the non-donor family sample, 6% of those families who had consented stated they would have refused if they had been offered an incentive.

If such as system were introduced in the UK, families would be faced with a literal economic and functional benefit since the financial burden of covering the cost of a funeral for their family member could be avoided once they provided consent for organ donation to proceed. Both the BMA and the Nuffield Council on Bioethics recommend further research on this issue since there is lack of conclusive evidence from a UK context on how well such as strategy would be received by the general public. Furthermore ethical concerns regarding this type of intervention have been raised. The BMA report (BMA, 2012) within this data set concludes:

"This public recognition of the selfless act of donation could be damaged in a system that offers financial reward to

the donor's family, even where those rewards are declined or, where accepted, were not the donor's principal

motivation. On a societal level, however, the system could be particularly beneficial for the poor, who are most anxious about covering their funeral costs, and so could be seen as another form of solidarity."

Currently findings from initial studies appear to indicate that such strategies are just as likely to hamper donation levels as they are to improve them. In study two of this thesis potential donor family's response to such an intervention will be empirically tested in a simulated donation request situation to see whether they influence consent, especially amongst those with a weak learning history.

Informational reinforcement

Informational reinforcement refers to the positive feedback an individual receives on his or her performance; it is symbolic in nature and is usually mediated by the responsive actions of others (Foxall, 1995, p.42). As will be recalled from chapter two of this thesis, this reinforcement may be received through two distinct channels. Firstly it may be explicitly informational in format, for example via a certificate or a statement informing the individual of their performance as a consumer or decision maker. Secondly it may also be received via the verbal behaviour of third parties, for example when an individual's decision is confirmed as the right choice by a friend, colleague or sales assistant. Informational reinforcement in a traditional consumer context results from the social status, prestige and acceptance achieved by engaging in the purchase and consumption of a product or service. It is therefore primarily of social significance, attesting to the "*correctness or appropriateness*" of an individual's behaviour (Foxall, 2005, p.97). In the context of organ donation consent the less explicit mode of informational reinforcement, via verbal behaviour, was more prevalent within this dataset. Three separate sources of informational reinforcement were identified within this dataset, namely (i) feedback from the hospital and recipients through letters of correspondence (ii) donor memorials and associated levels of pride in the donation behaviour and a (iii) symbolic legacy for the donor achieved through the act of organ donation. Each one of these sources of informational reinforcement will be addressed in turn, referring to extracts from the dataset as support.

    (i)   Feedback from recipients

The most common source of informational reinforcement for donor families within this dataset was correspondence from both the recipients of the donated organs and the hospital in which the donation took place. In the UK donor families are provided with anonymous information about the recipients of their family member's organs, this includes basic updates regarding the recipient's medical progress. However, donor families also often receive written communication from the recipients themselves or their family members. Colarusso (2006) argues that this feedback serves to affirm that the donor family's altruistic donation has saved the lives of others. This direct feedback allows donor families to assign meaning to the donation itself and make some sense of otherwise tragic circumstances (Colarusso, 2006). The majority of donor families within this dataset reported that these letters of correspondence reinforced their decision to donate the organs of their family member, whilst those who failed to hear back from recipients felt disappointed, an issue that will be explored later in the chapter. The following extracts from the dataset demonstrate the reinforcing outcome of receiving this form of feedback from recipients:

"When letters arrived from the women who received (donor's name) kidneys, I saw then that his death had served a purpose – that there had been some meaning to what had seemed to be such a senseless waste of his life" (source 18).

"On the final letter from the co-ordinator she enclosed another letter from one of the recipients, a gentleman called [name], who had received (donor's) lungs. And that letter was just absolutely wonderful. And, every now and again, I get it out and read it. And it was just so, so important to receive that. And this man had just gone through his life really, and how he had suffered from ill health from a baby, all through his life. And the huge difference that it had made to him, to receive this transplant. And that was just worth all the money in the world, it really was" (source 9).

"There isn't a day goes by when I don't think of my beautiful, clever, kind loving son, but also of the people he's helped - they bring me so much comfort and pride. My letters from the transplant co-ordinators and from one of the recipients and their family are very treasured" (Source 23)

"How can words alone ever convey the depth of gratitude we have of the selfless action of your son and family with

the immense gift of life that you have provided us. ....I had been told that only a new heart could provide me with any hope of a lifeline. It is only because of your son's heart that I can now lead a new life and see my daughter grow up. I remain mindful of the value of the loving gift of life your son has enabled me to have. I owe my life to him and I wish to honour his gift by utilising every moment of time with great respect and lead a life of service" (source 26).

This source of informational reinforcement was incredibly important to the majority of donor families within this dataset, with donor families reporting that it cemented their decision to consent, reinforcing the fact that they had made the right choice. In terms of the four operant classes of consumer behaviour outlined within the BPM literature, this type of feedback belongs in operant classes that are characterised by the highest levels of informational reinforcement, namely Accomplishment and Accumulation. Nicholson and Xiao (2011) hypothesised that the choice to be a donor during an individual's lifetime was a form of accumulation behaviour, since there was little direct benefit to the donor apart from the social symbolic feedback the individual gained through engagement with a socially approved behaviour. The findings surrounding informational reinforcement documented within this chapter provide adequate support for this hypothesis and can be extended to the context of family organ donation consent. One could argue that positive feedback from recipients as a source of informational reinforcement could potentially be used as a method of encouraging consent amongst potential donor families. At present recipients are encouraged to express their gratitude but this is not mandatory behaviour, meaning that some families will never receive feedback from the recipients. This in turn can have negative consequences for the donor family, which will be discussed fully in the section addressing the aversive consequences associated with consent. Ensuring that this feedback takes place and is promised to donor families as a part of the organ donation process could provide that vital final "*nudge*" in persuading consent amongst families who are borderline. Guaranteeing that donor families can see how their choice to consent has saved and improved the lives of others is a vital form of informational reinforcement and may be the one of the most promising "*soft*" strategies in improving donation rates in the UK without resorting to "*hard*" policy changes e.g. an opt-out system of consent.

(ii) Pride and the construction of donor memorials

Another common source of informational reinforcement within this dataset was a sense of pride felt by donor families in their loved one's accomplishment of becoming an organ donor and subsequently improving the lives of others. In addition there was also a sense of pride associated in the donor families' personal achievement of facilitating the process of donation through the act of consent. The theme of a sense of pride in association with becoming an organ donor or facilitating the organ donation process has been identified previously within the existent literature (Parisi and Katz, 1986; Van Den Berg *et al.*, 2005; Manzari *et al.*, 2012). Most recently a qualitative study conducted by Manzari and colleagues (2012) found that participants reported feelings of pride in having provided consent , expressions of being "*useful to humanity*" and in "*showing kindness to others*" were reported by donor families within this sample (Manzari *et al., 2012*, p.658-659). Within this dataset donor families reported the same expressions that they were proud not only of the achievement of the donor but also having facilitated such an important process. The following extracts from the dataset demonstrate these expressions of pride:

"Secretly I was very proud, then less secretly when we all confessed to the same feeling" (Source 25).

"I felt very tearful but also very proud" (Source 41).

One method of building upon this positive behavioural response could be through the creation of donor memorials in hospital grounds that honour both those who have donated their organs but also the donor families who consented. This would provide families with a physical space to channel their pride. Furthermore it would also give social status and accolade to the donor for having performed a socially responsible act and as such would be a strong source of informational reinforcement. This method of providing positive informational feedback from the transplantation community appears to be a move that would be welcomed by all parties involved. In recent years several organ donor memorials have been set up at hospitals and there is currently a fundraising project run by the Donor Family Network to construct an arboretum as a memorial for donors (Donor Family Network, 2012). However to date this is still a fairly

rare occurrence with few public memorials in existence. Within the dataset one organ donation specialist emphasised the importance of such memorials for organ donor families:

"The memorial would mean a lot to families, who feel the people that have saved lives through donation are heroes . . . They're publicly saying thank you to them for all they've done" (Source 33).

(iii) A symbolic legacy for the donor

The last prominent source of informational reinforcement identified within this dataset was organ donation being seen as a symbolic legacy for the organ donor. In some cases this notion was taken a step further, with donor families expressing the act of donation as a form of continuation for the donor through the lives of the recipients, symbolically a means for them to live on in the world. The notion of organ donation providing a legacy and a means of continuation has been documented in previous studies with donor families (Sque and Payne, 1996; Hogan *et al.*, 2013). The following examples from the dataset illustrate this form of informational reinforcement:

'She has left a lasting legacy and example to others, by being an organ donor" (Source 37).

"Look, one good thing is that he's been a multiple organ donor – the gift of life for six and sight for two is not a bad epitaph for a sixteen year old" (Source 10).

'(Donor's name) heart is still beating. . . . A part of him still lives on' (Source 39)

"It is like (donor's name) carries on. If not in the physical, then through his spirit with a new family. It's very, very special" (Source 26).

The healthiness of the "*living on*" and continuation motif as a source of motivation and reinforcement for the donor families has been debated within the existent literature (Sque and Payne, 1996; La Spina *et al.*, 1993). It has been argued that it may lead to an unhealthy attachment and identification between the donor family and the recipients of the donated organs. La Spina et al (1993) demonstrated how harmful a collapse of identification with donor families could potentially be. A more healthy approach could be the use of the legacy motif in

organ donation promotions. The notion of legacy taps into the notions of pride and bringing meaning to the life of the donor that have been identified as motivating factors earlier in this chapter. Again this is a means of harnessing these positive behavioural outcomes through the receiving of feedback from the recipients and the wider transplant community. This could be achieved through various sources, including public memorials, media reports, awards and detailed feedback regarding the progress of the recipients.

Aversive consequences

In the existent literature concerning the BPM the term aversive consequences is used to define the negative behavioural outcomes of engaging in a given behaviour. Therefore aversive consequences do not maintain behaviour; rather they reduce the likelihood and frequency of that behaviour occurring. As will be recalled from chapter two of this thesis, within the existent literature a range of potentially aversive consequences associated with providing consent to organ donation has been documented. Within this particular dataset three negative consequences were identified, namely (i) bodily mutilation of the deceased (ii) the long process of consent (iii) and a lack of feedback from the recipients.

(i)   Bodily mutilation

Relatives of potential donors expressing concern over bodily mutilation and disfigurement is well documented in the existing literature and is a well known barrier to organ donation committal and family consent (Parisi and Katz, 1986; Kopfman *et al.*, 1996; Exley *et al.*, 2002; Martinez *et al.*, 2001; Siminoff *et al.*, 2002; Barber *et al.*, 2006; Moraes *et al.*, 2009; Sotillo *et al.*, 2009; Anker and Feeley, 2010; Ghorbani *et al.*, 2011). The aversive consequence of bodily mutilation was identified in a substantial number of the donor family accounts, although as stated earlier within this chapter, the donor families' positive learning history in relation to organ donation was more prominent and therefore subdued any concerns they felt regarding mutilation. One could argue that without the requisite learning history to distil these anxieties, the fear of bodily mutilation and dismemberment may have been more salient in the potential donor family and thus preventing donation from taking place.   The following extracts

demonstrate that although all the families within this dataset consented to organ donation, many still possessed initial fears and concerns about bodily mutilation and dismemberment:

"To put it bluntly, he didn't want anyone slicing her up" (source 45)

"Instead I was letting her go to an operating theatre to die with strangers, to be cut up and taken apart" (source 38).

"My first instinct was: "keep the lad whole" (source 36).

This aversive consequence cannot be avoided as it is a fundamental element of the donation process. The donor's body must be cut and dismembered in order to retrieve the much-needed organs for transplantation. Sque *et al* (2006) have argued that those who find themselves in the predicament of having to make a decision regarding organ donation on behalf of a relative are most often reluctant to agree because they feel their relative has already suffered enough and want them to avoid any unnecessary medical procedure in which they will be cut. From a behaviourist perspective this could be remedied by the verbal behaviour of regulatory personnel, who stress that the donor will not feel any pain or discomfort. The very fact that donor families who have consented report fear of mutilation indicates how strong this behavioural response is and how important a barrier it is to the donation process.

(ii)   The distressing process of consent

Another prominent averse consequence identified within this dataset was the distressing process of providing consent for the donor family involved. This process included having to consent to turning off life support, consenting to each individual organ for removal, the lengthy process of filling in paperwork and the painful wait for the donation process to proceed. The following examples from this dataset illustrate this form of aversive consequence:

"We signed all the paperwork, which was probably the worst point for me because it takes such a long time" (source 8).

The bit I found quite daunting, but at the time I've got to say it's the kind of paperwork you have to do. You don't realise just how much paperwork you have to go through. We've committed to organ donation, that kind of, I felt was a lot. I know I can understand now, but at the time it was quite long and drawn out. And they're asking all these kind of different questions. I mean even me, at that point, I was thinking, "They need your organs" (source 1).

The transplant co-ordinator came to see us and she had a long talk with us. That was one of the worst parts of the whole experience because we'd already made the decision to donate the organs. Really I would have preferred to just be able to sign a form saying we have agreed to this, and we understand we could have been told all the details but we don't wish to know all the details. We just agree to it. But, instead of that, we had to sit through her telling us very kindly, very nicely, as compassionate as she could possibly be, but she still had to tell us in detail how and when everything would be done. Which is a hard thing to listen to" (source 2).

These aversive consequences that were direct behavioural outcomes of providing consent were often unanticipated by the donor families. Furthermore these negative outcomes were unavoidable by the hospital facilitating the consent process. This negative aspect of the decision making process is not well documented within the existing decision making literature and is only alluded to by donor family studies. This possibly is due to the fact these are un-modifiable features of the organ donation process, since all medical and legal protocols for consent must be strictly adhered to in the United Kingdom. These protocols are in place to protect all parties involved in the donation process to ensure that a sensitive, professional and ultimately successful donation and subsequent transplantation is achieved.

(iii)   The absence of feedback from recipients & hospital

One of the most interesting and prevalent forms of aversive consequence identified within this dataset was the disappointment, and in two particular cases anger, expressed by donor families who had failed to receive adequate feedback from the recipients of the donor's organs. There were also a small percentage of donor families within this dataset that felt that they also didn't receive enough information post-donation about the progress of the recipients from the hospital. These sources of informational reinforcement were deemed incredibly important by donor

families in this dataset, as discussed earlier the chapter. Donor families felt that they needed to know how the recipients were progressing with their new organs in order to be content with their decision to consent. The following example illustrates how one donor family felt about the lack of information received from the hospital after the first update post-donation had happened:

"And we didn't hear again. And I think we all felt we needed more, even if it was just once a year, to know how these people were doing. It just seemed very important" (source 9).

This response was expressed by several donor families within the dataset, who felt that there was a need to know more after the initial update from the hospital. This finding corroborates with existing literature, which has found that donor families need this source of feedback in order to reinforce their contentment with consent (Sque, 1996; 2006; Calarusso, 2006).

As stated earlier in this chapter, donor families receive anonymous information regarding the recipients of the donated organs, together with general information regarding their progress from the transplant co-ordinator. In many cases the recipient or the recipient's family will also send a letter of thanks expressing gratitude to the family and the donor for their decision to consent. As argued earlier within this chapter this is a much treasured and vitally important source of informational reinforcement for the donor family, providing them with the assurance that their decision to consent has improved the lives of many and validation that their sacrifice was worthwhile (Calarusso, 2006). In light of this, it is unsurprising that some families within this dataset expressed extreme levels of disappointment at not receiving any contact from some of the recipients of their family member's organs. In two particular instances, the donor families expressed their anger that they had not received contact from some of the recipients:

"Half a dozen people are alive through (donor's name) donation and we're only hearing about two. That's disgusting in my eyes. What happened to the other four? Like the lad who received (donor's name) lungs. What happened to him? The lad who received (donor's name) heart. What happened to them? The other person who received (donor's name) liver, what happened to them? The spleen. What happened to that? They're not telling us

and just like, "Oh look the two recipients who had (donor's name) kidneys are doing fine." Yeah and…" (source 5).

"I would have expected at least a letter saying thank you (from the recipient)" (source 16).

This form of aversive consequence could be easily avoidable by the implementation of mandatory yearly feedback from the recipients via the transplant co-ordination team that handled the donation process. This would be a guaranteed source of informational reinforcement for the donor family, demonstrating to them that their choice to consent has made a tangible difference to the recipient for which they are grateful and that their gift of consent had not been forgotten and was highly valued.

Summary of contingencies of reinforcement

This section has identified various sources of both utilitarian and informational reinforcement, as well as aversive consequences, which have helped and hindered the process of consent for donor families within this dataset. The utilitarian reinforcements of comfort, satisfaction and happiness experienced as a behavioural consequence of consent appear to be strong, indicating that a level of direct benefit should be emphasised during the organ donation request. However initial findings also indicate that too high a level of utilitarian reinforcement, possibly in the form of financial incentives, could potentially be damaging to consent rates, in particular amongst those who report medical distrust. High levels of informational reinforcement were present in all sources that comprised this dataset thus demonstrating its powerful influence in the consent process. Donor families within this dataset reported that feedback from the hospital and the recipient, as well as a sense of pride and a legacy of the donor all contributed towards a positive consent experience. This provides further support to the hypotheses generated in chapter two that where low levels of informational reinforcement are evident, such as in the operant class of maintenance (renamed routine donation), there will be a drop in consent levels and where it is high an increase in consent will be evident. In addition to this evidence from this dataset indicate that reinforcements that provide direct benefits to the donor family appear to be

the most frequently cited mode of reinforcement in the decision making process, for example the comfort derived from consent to donation, with other reinforcements being ranked as secondary to this. This will be further tested in study two, by examining the preferred mode of reinforcement amongst the experimental participants.

Conclusion

In conclusion study one has been successful in its aim to achieve the following:

1. To provide further validation of the BPM as a potential interpretive device for the context of donor family consent

2. To identify and validate the pre-behavioural determinants that are associated with consent through the learning history construct

3. To serve its methodological purpose in identifying situational elements that will be used in the design of the experimental scenarios in study two.

4. To identify and further validate the patterns of reinforcement which are associated with positive consent outcomes.

Firstly this chapter has provided validation of the applicability of the Behavioural Perspective Model in this unique health context, thus extending the BPM program of research. The BPM has been previously utilised in various traditional consumer contexts, however this is the first attempt to apply the framework to a health behaviour context. Through the analysis of donor family accounts and public policy documents, this chapter has demonstrated that the BPM is a useful and insightful interpretative device for identifying not only the pre-determinants of behaviour via the learning history construct, but also the contextual and behavioural elements of the decision making process, thus producing a truly holistic picture of the decision making process. As has been discussed in chapter two of this thesis, organ donation research to date has lacked a strong theoretical base (Shanteau, 1988; 1986; Radecki & Jaccard, 1997; Feeley, 2007). This chapter offers the BPM as an alternative theoretical framework to the social-cognition models that have dominated this research area to date. In light of the results of this preliminary

explorative chapter, this thesis argues that the BPM could provide future researcher with a truly holistic and contextual framework to analyse the whole donation process, from pre-behaviour right through to post-consent. This is in direct contrast to existing social cognitive models that solely focus on pre-behavioural variables.

Secondly study one has succeeded in the identification of the key pre-behavioural determinants of donor family consent. The following learning history constructs have been identified as being associated to the positive consent outcome within the existent literature and the findings reported within this dataset: (1) positive attitudes, (2) positive subjective norms, (3) direct experience with similar environments and related behaviours and (4) indirect experience obtained from third parties. These finding will feed directly into the development and construction of the learning history instrument that will be used in study two of this thesis. These four learning history elements will be empirically tested in study two in order to evaluate whether learning history has the hypothesised positive impact on likelihood of consent. Furthermore differences between those who possess high levels of learning history and those who possess low levels will also be tested systematically in study two.

Thirdly further support for the role of high levels of informational reinforcement in contributing to a positive consent outcome amongst potential donor families has been identified in this dataset. Due to the nature of the dataset utilised in chapter four the hypotheses formulated regarding these constructs will need to be further scrutinised during study two of this thesis, which is an experimental scenario study examining how to stimulate organ donation consent. If this is proven to have a strong relationship with consent as hypothesised this has implications for social marketers, public health practitioners and donor family support groups.

Lastly this study found some evidence regarding the positive impact of an open behaviour setting on consent. Donor families within this dataset consistently reported that they felt that the choice to consent was *their choice* and that having experienced no pressure from health professionals to donate contributed towards their positive consent outcome. Again due to the nature of the dataset employed in study one, this finding will need to be further tested in study

two of this thesis, to validate whether behaviour setting scope has a significant impact on likelihood of consent as predicted. If substantiated during study two this finding could offer some insight into the possible implications of introducing so called "*hard*" public health interventions, such as an opt-out law, that restrict the choice of donor families within this context.

Chapter Five

Stimulating donor family consent

"At this very moment enormous numbers of intelligent men and women of good will are trying to build a better

world. But problems are born faster than they can be solved."

B.F. Skinner, 1974, p.81

Introduction

This thesis seeks to develop a behavioural account of family organ donation consent via the application of the Behavioural Perspective Model (Foxall, 1990; 1997). The first step towards fulfilling this objective was documented in the previous chapter of this thesis. Specifically, chapter four documented the results obtained from study one of this thesis which explored donor family consent through a case study methodology, drawing upon multiple sources of evidence in order to formulate an operant account of this complex behaviour. The results from study one confirmed that the choice to donate one's family member's organs is influenced by a wide range of environmental factors and behavioural contingencies, therefore providing validation of this thesis's proposed behavioural interpretation of this behaviour. Study one also reported a relationship between the decision makers's unique learning history regarding organ donation and their willingness to provide consent, with the overwhelming majority of donor families within the sample reporting positive attitudes, subjective norms and experience in relation to organ donation. In addition study one also found a relationship between varying levels of utilitarian and informational modes of reinforcement and providing consent. The decision to consent involved both utilitarian and informational sources of reinforcement, however informational modes appeared to be prominent in the decision making process. Lastly the behaviour setting scope of the request was identified as an important factor in the decision making process, with families indicating a preference for more open settings where they elicited more control over the situation.

Therefore in light of the key findings summarised above, study one successfully fulfilled its methodological purpose of firstly providing further validation of the BPM as an interpretative device within this particular context and secondly by providing further support and development of the research propositions formulated in light of the literature review contained in chapter two. The present chapter now seeks to justify and document the second empirical phase of this thesis, namely an experimental investigation into how consent might be stimulated. The present study seeks to address research questions (2) and (3) of this thesis:

2) What patterns of reinforcement are associated with likelihood of consent?

3) Can donor family consent be stimulated via behavioural interventions?

As will be recalled from chapter three, this thesis adopts a sequential mixed method research strategy with the results of the first study informing the development of the second study. Therefore study two of this thesis builds upon the findings of study one by quantitatively examining how organ donation consent can be stimulated. This first step towards meeting this objective involves further testing the identified factors, namely learning history, reinforcement patterns and setting scope, quantitatively in an attempt to achieve triangulation between the findings from the literature review and study one. Additionally, study two will explore the influence of affective responses in relation to consent and examine whether previously identified patterns within the existent BPM literature hold in this particular health context. The primary intention of this study being the successful identification of the most effective methods of stimulating consent. Once identified these findings may have implications for academics, medical practitioners and social marketers alike that will be discussed at length in chapter six.

The present chapter is structured around the five propositions that have been formulated in light of both the literature review in chapter two and the results of study one. The following section will provide a summary of study two's formal research propositions, which guide the analysis of this second empirical phase. The subsequent section will then proceed to outline the adopted research design of study two and the approach to data collection and analysis that has been adopted. The strengths and weaknesses of this approach will be addressed and a

justification will be provided. The chapter will then proceed to report the results of the statistical analysis of the experimental data, which will be organised around the five key research propositions. The final section will provide the reader with a summary of key findings generated from the analysis of the data obtained during the second phase and will draw some preliminary conclusions in light of the evidence presented in this chapter on the most effective methods of stimulating donor family consent.

Study propositions

Study two aims to test the following propositions visually depicted in **Figure 10**. Firstly, by measuring the learning history of participants via a devised learning history questionnaire, study two will test *P1.1* and *P1.2* on the influence of learning history on likelihood of consent. Secondly, study two will test the hypothesised positive effect of an open setting condition on consent (*P2*). Thirdly, study two will examine the relatedness of emotions to the BPM elements to examine whether they hold true within this context *(P3)* and then will proceed to measure the influence of emotions on likelihood of consent *(P4)*. Finally, study two will test the proposed behavioural preferences of decision maker towards reinforcement patterns (*P5.1-5.2*); and test whether differences in reinforcement mode preference is evident amongst those with a higher learning history experience score compared with those with a lower learning history experience score *(P5.3-5.4)*.
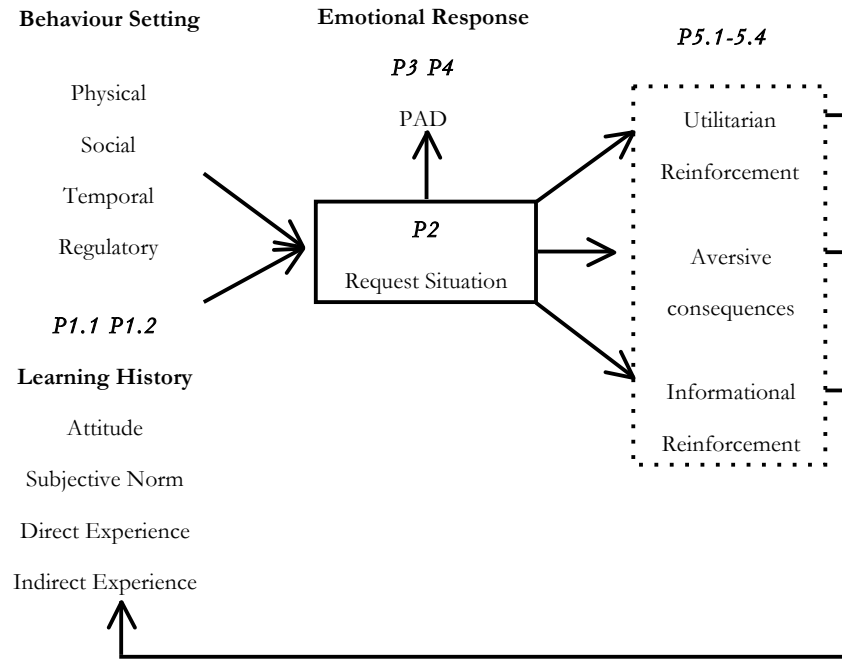
Figure 10. BPM Schema and study propositions.

Research design

Research instrument

Study two has adopted a laboratory experiment approach to test the respective influences of learning history, behaviour setting scope, affective response and reinforcement pattern on donor family consent. As will be recalled from chapter three of this thesis, the experimental method is considered the gold standard in behaviour analysis (Beins, 2004; Bailey & Bursch, 2002). In addition to the compatibility of an experimental methodology with the radical behaviourist paradigm, this approach to data collection has two distinct advantages over alternative methods. Firstly in circumstances where observation of behaviour in situ is impractical or impossible, simulated environments allow the researcher to gain insight into actual behaviour. Secondly an experimental methodology enables the experimenter to exert a high level of control over the environment in which the behaviour occurs (Burns and Bush, 2002). This in turn allows the experimenter to specifically control the independent variables under investigation, so that cause and effect can be clearly separated (Beins, 2004). As the primary objective of study two is to test

the propositions that have been formulated in light of both the literature review and the results obtained in study one of this thesis, a laboratory experiment was deemed the most suitable approach in answering the third research question posed regarding how organ donation consent might be stimulated from potential donor families.

Experimental design

Study two adopted a repeated measures quasi-experimental design. This research strategy is common in social scientific research when randomisation of treatment conditions is impractical (Fife-Schaw, 2000). In the methodological literature advantages of a repeated measures design over alternative designs are outlined. One of the key advantages of using a repeated measures design is that it allows the researcher to exclude the effects of individual differences that occur when using independent groups (Howitt & Cramer, 2011). For example individual differences such as IQ, age and personality can be excluded since they will remain the same over the course of the experiment. Therefore any observed differences could be attributed to the different condition rather than the individual differences of the participants. Another distinct advantage of adopting a repeated measures design is that because the same participants are used in all conditions it requires fewer participants than if an independent group design was used (Howitt & Cramer, 2011). This should result in a quicker and easier recruitment process. This was seen as a particular strength of this design considering the focus of this study is organ donation, which like other death-related areas of study is often prone to problems with recruitment and achieving adequate sample sizes.

Despite the aforementioned strengths of the repeated measures design, independent group designs have particular strengths in areas where repeated measures are found to be weaker. The use of the same participants in all condition can lead to difficulties in counteracting problems associated with ordering effects. For example an effect observed in results could be attributed to boredom, otherwise known as the *fatigue effect* (Cozby and Paul, 2008). This can affect both the concentration and performance of the participant and therefore have a significant impact on results (Bergh & Vrana, 1998). In addition observed effects could be attributed to practice,

causing the respondent's results to improve over time because they have been given repeated chances to practice and perfect the task set (Collie, Maruff, Darby & McStephen, 2003).

In the literature a prescribed solution to reduce ordering effects is known as *counterbalancing* (Field, 2009). This measure involves randomly assigning the order of the conditions participants are exposed to during the experiment. Once applied this counterbalancing measure should ensure that results obtained would be less likely to be affected by factors such as fatigue, boredom and practice (Howitt & Cramer, 2011). This measure was adopted in this study. Lastly another measure that can reduce ordering effects is for researchers to offer participant's opportunities to take a break during the experiment in order to counteract any fatigue or loss of concentration that may affect the results (Pan, Shell & Schleifer, 1994). This particular measure was not deemed necessary in the context of the present study two because the experiment only took between 25-30 minutes.

It is at this point within this section that the levels of analysis that were conducted will be discussed. The first level involved comparisons *between* those with high learning history experience and those with low learning history experience *(P1.2, P5.3 and P.5.4)*. These groups were formed based on the calculation of participant's learning history score, which were calculated from the results of the learning history questionnaire. Since learning history is a pre-existing variable that is outside the control of the experimenter, it cannot be classified as a true independent variable. As such, comparison between these two groups was based upon quasi-experimentation (Beins, 2004).

The second level involved comparisons *between* consent outcomes in open and closed behaviour settings in order to ascertain whether significant differences in consent were evident between the behaviour setting scopes *(P2)*.

Finally, the third level of analysis addressed the remaining propositions that were primarily related to the inter-relationships between variables, such as the learning history and consent *(P1.1)*, affective responses (PAD) and the BPM *(P3.1-3)*, affective responses and likelihood of consent *(P4)* and reinforcement patterns and likelihood of consent *(P5.1-P5.2)*.

Therefore study two adopted both a *mixed within* and *between* participants design, with learning history experience and behaviour setting scope being compared *between* groups, followed by *within* group comparisons on the remaining propositions *(P3.1-P5.2)*.

Stimuli materials

A total of eight situational scenarios were designed based upon Foxall's eight contingency categories (Foxall, 1990, 1997; Yani-de-Soriano and Foxall, 2002) and the situational details of organ donation consent presented in the literature and reported in study one of this thesis. The open and closed scenarios within a single operant class (e.g. accomplishment, pleasure, accumulation, maintenance) were identical apart from the behaviour setting scope (independent variable) being either open or closed in nature. In relation to the current study, the two situational elements of the behaviour setting which differentiate between more open (CC1, CC3, CC5, CC7) and more closed (CC2, CC4, CC6, CC8) organ donation request environments revolve around the level of perceived pressure from regulatory figures and whether or not there is an emphasis of the right of choice on behalf of the family. These two elements are reflected in the verbal behaviour of the regulatory figure in the scenarios used within study two. To clarify, within the designed hypothetical request scenarios defined as open, the regulatory figure emphasises the decision maker's right of choice and the lack of pressure to donate, and by doing so, affords the decision maker more freedom in the scenario. In contrast, in scenarios defined as closed, the regulatory figure restricts the perceived choice of the decision maker via an opt-out system of consent. This results in more perceived pressure to donate. At this point it is important to again acknowledge that the organ donation request environment is relatively closed behaviour setting by its very nature because of the discriminant stimuli that comprise the hospital which limit the freedom of the decision maker. However in this study open and closed scenarios are differentiated by the freedom/restriction of the behaviour setting signalled by the regulatory figure, the requester.

The eight situations were designed according to the examples and guidelines present within the existent BPM literature (Foxall and Greenley, 1999, Xiao and Nicholson, 2010, Yermekbayeva,

2011). Each situational scenario was presented to the participants via an audio-enabled PowerPoint slide. The scenarios contained a visual representation of the organ donation request situation as well as visual cues signalling the modes of reinforcement present in that contingency category e.g. a picture of a donor memorial wall or a cheque being written as a financial incentive. To enhance realism the experimenter's choice of visual representation was a black and white photograph. Each scenario depicted a medical specialist talking to two members of a potential donor family. In accordance with the manuals on the Picture-Frustration test (Rosenzweig, 1978) and the Thematic Appreciation test (Morgan and Murray, 1938; Morgan, 2003) the following measures were taken when developing the visual representations. Firstly the characters depicting the donor family members within the scenarios were mixed gender; this was to ensure that it was equally easy for male and female participants to identify with the depicted characters. Secondly all facial features of the characters in the scenarios were pixelated in order to produce a blurred effect. This measure was taken in order to ensure that participants were able to freely interpret the emotions of the depicted characters. Lastly the visual representations were photographed in black and white as to avoid any potential distraction in the participant's attention, for example distracting colours or unnecessary detail that added no meaning to the scenario. This methodological approach has been previously utilised by Yermekbayeva (2011) in her BPM study on m-advertising opt-in behaviour and proved to be a novel means of providing a naturalistic environment that enhanced realism for experimental participants. In previous BPM studies (Foxall and Greenley, 1998, 1999, 2000, Yani-de-Soriano and Foxall, 2002) text descriptors of scenarios representing each of the eight contingency categories have been utilised, therefore the participants were also given a textual descriptor to accompany each scenario. Full written descriptions of each scenario are detailed in the response sheet in **Appendix 10** and the visual representations can be found on the CD which accompanies this thesis.

Reliability and validity test for scenarios

The designed scenarios were rigorously reviewed and evaluated by a panel of five BPM experts over a three month period. The panel members were all deemed experts due their previous experience with the BPM and the accompanying literature. The panel consisted of two lecturers,

two post-doctoral researchers and one final year PhD student. The panel members were asked to classify the eight organ donation request situations into the contingency category they believed it belonged and to justify this decision in terms of pattern of reinforcement and behaviour setting scope. After two separate examinations of the scenarios a final agreement level of .85 was achieved thus confirming the instrument as valid. This particular approach to determining the validity of scenarios follows a precedent set by previous BPM research studies which have utilised either textual or visual consumer situations descriptors representing each of the eight contingency categories.

In order to test the reliability of the instrument the following tests were conducted on a pilot sample of ten participant responses. Firstly a paired samples t-test was conducted to compare dominance scores across the open and closed behaviour setting. A paired t-test is utilised when you wish to compare one group of participants under two different conditions (Field, 2009; Pallant, 2007). This test was conducted to check that the closed and open behaviour settings adequately represented the behaviour setting scope. There was a significant difference evident in Dominance scores between the open setting condition (M=35.8, SD=7.3) and the closed setting condition (M=28.9, SD=7.27); $t(9)$=- 2.88, p=.00), indicating that dominance scores are lower in closed settings and therefore demonstrating the validity of the setting scope representation within the instrument.

To assess whether Pleasure and Arousal scores varied across the four classes of behaviour in a similar manner to previous BPM studies, mean scores of both Pleasure and Arousal were calculated across the operant classes. The results of this indicated that differences were evident in Pleasure and Arousal scores across the four operant classes of behaviour and followed a similar pattern to those reported in the BPM literature (Foxall, 1997b). Therefore the instrument was deemed satisfactory to proceed with.

Learning history questionnaire

The learning history questionnaire that participants completed prior to the experiment consisted of four distinct sections measuring the following information: demographic information, direct

and indirect experience, attitudes and subjective norms. The learning history questionnaire was developed in light of the findings documented in study one and the literature review documented in chapter two of this thesis. The demographic section included variables that have been reported in the existent literature to exert influence upon consent outcomes, such as ethnicity (Cleveland, 1975 Randhawa, 1998; Dar *et al.*, 1999; Alden *et al.*, 2000; Morgan *et al.*, 2006; Wu *et al.*, 2009) and religious beliefs (Siminoff, Gordon *et al.*, 2001; Brown *et al.*, 2010). The experience section included fifteen items, which sought to measure the participant's experience of organ donation and related issues. This section included items that sought to measure whether participants had seen a televised organ donation campaign, previously engaged in the similar behaviours of donating blood or had discussed the topic with their own family. The attitudinal section consisted of eighteen items and was measured on a seven point likert scale ranging from strongly disagree to strongly agree. Eight items within the attitudinal section were negatively worded in order to help prevent response bias (Pallant, 2007). The attitude section included items measuring attitudes held towards the importance of body integrity, the social responsibility aspect of organ donation, perceptions of medical trust and the so called "*ick*" factor, which have all been identified in the existent literature as being important factors in the organ donation decision making process (O'Carroll *et al.*, 2011; Morgan *et al.*, 2008; Sanner, 2006). The learning history questionnaire initially was based upon an existent TPB questionnaire developed by Hyde and White (2009). This questionnaire was accessed by the researcher from the primary authors and then altered in light of the results of study one to reflect the particular aims and objectives of the current study. The final version of the learning history questionnaire used in this study can be found in **Appendix 9**.

Reliability and validity test

The learning history questionnaire was piloted on fifty individuals recruited via Durham Business School. This strategy resulted in forty nine usable questionnaires ready for statistical analysis. One response had to be discounted due to large parts having been left incomplete. In order to establish the reliability of the questionnaire instrument the internal consistency of the attitudinal and subjective norms scales was calculated using Cronbach's coefficient alpha. The

results were 0.85 for the attitudinal scales and 0.91 for the subjective norm scales. These results are well above the recommended 0.7 level and are therefore the questionnaire was considered reliable (Nunnally, 1978; DeVellis, 2003; Field, 2009).

In addition to the above test, 10 of the 50 participants within the pilot study were asked to partake in an informal feedback session regarding the instrument. During this session participants were asked to read the questionnaire items and re-iterate the meaning back to the experimenter. This was to ensure that the items were easily understood by the sample and that the questions were measuring what they were intended to measure. Participants also gave general feedback regarding the format and wording of the questions. In light of this feedback minor amendments were made to the questionnaire, such as a change of font style, size and layout.

Scenario response sheet

The scenario response sheet consisted of three sections. In the first section participants were asked to imagine they were the decision maker in the scenario and evaluate their emotions using the scales provided. The effective responses were measured using Mehrabian and Russell's (1974) Pleasure-Arousal-Dominance (PAD) scale.

Mehrabian and Russell (1974) developed the PAD model to describe the relationship between consumer behaviour and the environment. The authors propose a three dimensional view of emotion, that includes measures of Pleasure, Arousal and Dominance (PAD). The PAD model was developed to obtain the relationship between emotional responses to specific situations (Mehrabian and Russell, 1974). It asserts that it can effectively map any emotional responses to any given environment (Babin and Darden, 1995, Takahashi, 1995, cited in Wasserman *et al.*, 2000). Practically the instrument utilises semantic differential scales whereby Pleasure, Dominance and Arousal are measured along a single continuum (Mehrabian and Russell, 1974). For example, Pleasure is an emotional state measured on a continuum ranging from unsatisfied to satisfied, Arousal measured on a continuum ranging from relaxed to stimulated, and lastly Dominance measured on a continuum ranging from awed to important (**Table 6**).

Semantic differential measures of emotional state	Scale
Pleasure – happy/unhappy, pleased/annoyed, satisfied/unsatisfied, contented/melancholic, hopeful/despairing, relaxed/bored	9 point scale
Arousal – stimulated/relaxed, excited/calm, frenzied/sluggish, jittery/dull, wide awake/sleep, aroused/un-aroused	9 point scale
Dominance – controlling/controlled, influential/influenced, in-control/cared for, important/awed, dominant/submissive, autonomous/guided.	9 point scale

Table 6. Semantic differential measures of emotional state (Mehrabian and Russell, 1974).

As will be recalled from chapter two of this thesis, this scale has been successfully used in a range of previous BPM studies (Foxall, 1997b, 1997c; Foxall & Greenley, 1998; Soriano, Foxall, & Pearson, 2002; Yani-de-Soriano & Foxall, 2002). Furthermore this scale has received strong empirical support within the existent literature and has been applied successfully to numerous contexts (e.g. *Li et al.*, 2009; Menon & Kahn, 2002; Mummalaneni, 2005; Ryu & Jang, 2008).

In the context of the present study three of each of the six PAD items was inverted in order to minimise response bias and were presented in a random order. For each PAD dimension the responses were coded 1 to 9, with 1 being the least pleasing, arousing or dominant situation and 9 being the most pleasing, arousing or dominant situation. Therefore a total score for each dimension of PAD ranged from 9 to 54.

The second section asked participants to state what the likelihood of them consenting to organ donation would be in the particular scenario they had been presented with. This was measured on a likert scale of 1 to 7, with 1 being very unlikely and 7 being very likely. Explicitly this would serve as the independent variable in the analysis stage of study two.

The third section of the response sheet asked participants to state how important each mode of reinforcement was to them in the scenario they had been presented with. For example, ranking how important funeral expenses being paid were as an incentive. These items were measured on a likert scale 1 to 7, with 1 being not at all important and 7 being extremely important. This was measured so differences in reinforcement mode preference between the two learning groups could be assessed during the analysis for *P5.3* and *P5.4*.

Reliability tests for PAD scales

Despite the PAD scale having been already rigorously tested in the existent literature (Foxall, 1997b; Foxall & Greenley, 1999, Soriano, Foxall, & Pearson, 2002; Yani-de-Soriano & Foxall, 2002), it was deemed important to the establish reliability of the scale in the context of the present study before embarking on the data collection process. In order to assess the reliability of Mehrabian and Russell's (1974) PAD scales, internal consistency of the three dimensions, Pleasure, Dominance and Arousal was calculated using Cronbach's alpha coefficient. Ideally the Cronbach's alpha coefficient of a scale should be above .7 (DeVellis, 2003). The results of this procedure are summarised in **Table 7** below.

Variable	Number of items	Cronbach's Alpha
Pleasure	6	0.82
Arousal	6	0.70
Dominance	6	0.74

Table 7. Cronbach's alpha coefficient for PAD scales

In summary, all of the affective variables were found to have a good internal consistency, with Cronbach's alpha coefficients of between 0.7 and 0.82. Therefore the scales utilised in study two can be deemed reliable.

Participants

A convenience sample was utilised in study two of this thesis. Convenience sampling involves selecting sample units that are easily accessible to the researcher but not necessarily representative of the population. In the context of the present study there were two distinct advantages of adopting this approach to recruitment. Firstly this approach was adopted as it was the least time consuming and expensive of all recruitment strategies (Saunders *et al.*, 2003). Furthermore, due to the sensitive nature of the research topic it was anticipated that recruitment of a sufficient number of participants in the specified time frame could be a potential problem if other recruitment strategies were adopted. Therefore convenience sampling was deemed the best option for reaching a suitable sample size within a reasonable time frame.

The researcher recruited participants by publishing a general call for participation through their institution. This strategy was adopted because the researcher's institution employs a wide range of individuals who possess different backgrounds and experiences. This diversity was considered a distinct advantage of this sampling strategy. In the existent organ donation literature there is a tendency for researchers to rely upon student samples. This was something which the present study endeavoured to avoid as the 18-25 category which typically categories the student population would not be wholly representative of donor families in the UK.

An overall sample of 50 participants was achieved generating 400 individual situation cases for final analysis (n = 50 x 8 scenarios). The final sample consisted of 20 males (40%) and 30 females (60%). The age range and educational level of the final sample is summarised in **Figure 11 and Table 8**. One of the strengths of the sample achieved is that it is very diverse in terms of age and educational level, which was a distinct advantage of sampling from the general population rather than a student population. Furthermore organ donation typically involves individuals making choices on behalf of spouses, children and parents. Therefore it was particularly important that the middling age categories were well represented, since this age span typically tends to include individuals who have families and dependents that they would have to

make decisions for if the situation ever arose. Therefore the age distribution achieved in this sample is highly relevant, with the majority (68%) falling between the ages of 25-54
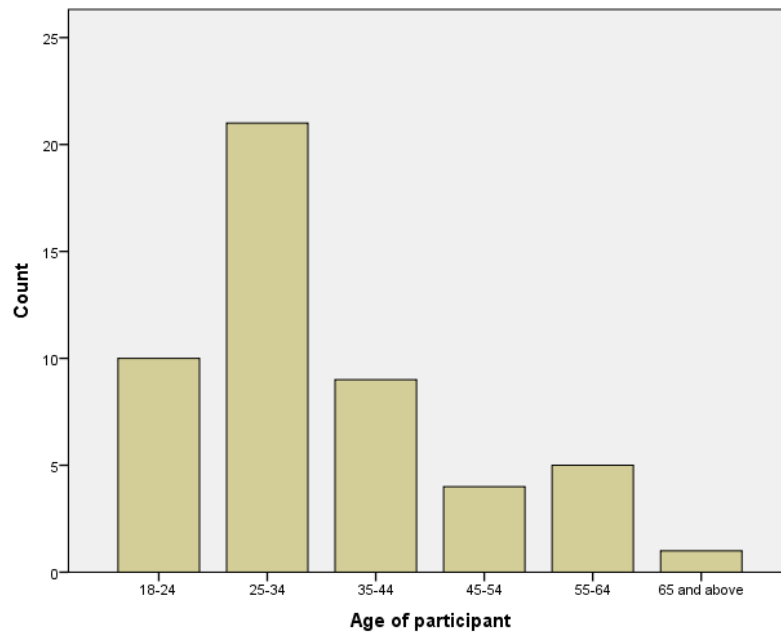
Figure 11. Age profile of sample

Educational level

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	GCSE level	4	8.0	8.0	8.0
	A-level	11	22.0	22.0	30.0
	Undergraduate degree	13	26.0	26.0	56.0
	Postgraduate degree	10	20.0	20.0	76.0
	Professional qualification	12	24.0	24.0	100.0
	Total	50	100.0	100.0	

Table 8. Educational level of sample

In order to limit biases within the sample several other measures were taken, apart from ensuring a good distribution of age and gender in the final sample. For this particular experiment it was also important to measure both participant's intension to donate and actual

donor registration to assess whether the overall sample was representative of the general UK population in terms of organ donation behaviour. Of the final sample, 32% had registered on the NHS organ donor register or had designated on their driving license their wish to donate (**Table 9**). At the time of the experiment, 31% of the UK population had registered on the NHS Organ Donor Register (NHSBT, 2013b). In addition, of the final sample 58% stated that they wished to be an organ donor after their death, 12% said they didn't and 30% said they were undecided on the matter. These figures are generally representative of the general population's intention to donate organs (NHSBT, 2013b).

Have you registered on the NHS organ donor register or designated on your driving license that you are an organ donor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	16	32.0	32.0	32.0
	No	34	68.0	68.0	100.0
	Total	50	100.0	100.0	

Do you wish to be a donor after your death?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	29	58.0	58.0	58.0
	No	6	12.0	12.0	70.0
	Undecided	15	30.0	30.0	100.0
	Total	50	100.0	100.0	

Table 9. Organ donation behavior of sample

Another demographic variable that needed to be measured to ensure representativeness was ethnicity. In the existent literature ethnic minority groups have been found to be less likely to register for organ donation, to become actual donors and to provide consent for the donation on behalf of their next of kin's (Randhawa, 1998; Darr *et al.*, 1999; Alden *et al.*, 2000; Morgan *et al.*, 2006; Wu *et al.*, 2009). Therefore it was important that the final sample of study two included a significant ethnic minority group which reflected the multi-cultural nature of the UK today.

Within the final sample 10% (n = 5) were from a non-white ethnic background. This can be deemed an adequate number since the most recent UK census found that 14.1% of the population were classified as originating from ethnic minority groups (Office for National Statistics UK Census, 2011).

In summation despite the inherent weaknesses associated with the adoption of a convenience sampling strategy, the researcher took several measures in order to limit sampling bias. At this point it also should be emphasised that the population of interest for study two was potential donor families in the UK. Therefore one could argue that a convenience sample strategy is justified on the grounds that all participants within the utilised sample had an equal chance of being exposed to the donor family consent situation on the grounds that anyone who lives in the UK of adult age could potentially be donation decision maker. Therefore the convenience sample utilised in study two provides a useful insight into the decision making process of potential donor families.

Procedure

The experiment was conducted in a computer laboratory with small groups of two to three people. The participants were asked to read the information sheet provided that outlined the aims and objective of the study, to sign an informed consent form **Appendix 8** and to complete a five page learning history questionnaire. Prior to starting the experiment, participants were given time to familiarise themselves with the response sheet and given the opportunity to ask questions.

Participants were then asked to view the PowerPoint slides and to complete the corresponding response sheet after watching each of the eight situations. The scenarios (operant classes) were presented in a random order as to minimise any possible carry over effects. This procedure generated 400 situation cases (responses of fifty participants to eight scenarios). In order to minimise the influence of outside effects (e.g. noise, other participants) the participants were asked to wear earphones while watching the PowerPoint slides. This particular measure helped participants to become fully immersed in the scenarios that were being presented with.

Furthermore it gave them the opportunity to listen to the audio more than once if they needed without disturbing others within their group. The experiment took between twenty five to thirty minutes to complete. Participants were then asked to provide a contact email address if they would like to receive a summary of the results once analysis was completed.

Ethical considerations

It is of fundamental importance that researchers have their participant's general welfare in mind when designing an experiment (Harris, 2002). In this section three particular areas are discussed in relation to the ethical considerations that had to be made by the researcher when designing the experiment documented in this chapter. In the following sections informed consent, debriefing and confidentiality are discussed in turn in relation to the present study.

Informed consent

The principle of informed consent is incredibly important in any form of research that involves human participants. Informed consent refers to providing potential participants enough information regarding a research project to enable them to make an informed decision about whether to take part or not. Therefore it is of uttermost importance to provide potential participant's with a clear and comprehensive information sheet prior to their participation. The American Psychological Association (APA, 2001, p.391) states researchers should "*use language that is reasonably understandable to research participants.*" This is to ensure that participants fully comprehend the nature of the research being undertaken, their rights as a potential participant and the potential consequences that may arise as a direct result of participation.

In the context of the present study, participants were given an information sheet that outlined the research's primary aims and objectives. It also outlined what participation in the experiment would entail for them. A copy of the information sheet can be found in **Appendix 8**.

An informed consent form was developed which highlighted the participant's rights. This included their right to withdraw at any time without giving reason and their rights to confidentiality and anonymity as a research participant (**Appendix 8**). Once participant's

confirmed their understanding of the experiment and had the opportunity to ask questions to the researcher, they were invited to sign the informed consent sheet.

Debriefing participants

At the end of the experiment time was made available to discuss any questions that the participants may have as a direct result of participation. The researcher anticipated that participation in the study may lead to some participants seeking information about organ donation. Therefore the researcher gathered information leaflets produced by the NHS regarding organ donation and information about how to join or remove registration. The collected leaflets covered some of the more common questions surrounding registration, the donation process, organ allocation and some of the common issues and concerns surrounding organ donation e.g. the compatibility of the process with certain religions. Of the fifty participants only one individual sought additional information regarding organ donation. In addition at the end of the response sheet, the participants were invited to put a contact email address down to receive results from the experiment. An overview of the key findings was sent to those who expressed a wish to receive results once data analysis and interpretation was completed. This element ensured that the research was a reciprocal process and the participant's gained something tangible from their participation in the study.

Data confidentiality

It is important for researchers to acknowledge that ethical considerations do not finish with the completion of the data collection phase (Harris, 2002). All data obtained from the data collection process of study two was stored safely and securely. Furthermore it was stored in a manner that ensured that confidentiality was maintained.

Data analysis and interpretation

The following sections are structured around the five key propositions that have been generated and developed in light of the literature review and the results from the first empirical phase. Each proposition will be discussed in turn, with the analysis procedure outlined, the statistical

results reported and discussed in light of the existent literature and where applicable the results of study one.

P1.1 Learning history will significantly influence likelihood of organ donation consent

Analysis procedure

Before conducting any statistical tests preliminary analysis was conducted using scatter-plots to firstly ensure no violation of the assumption of normality, linearity and homoscedasticity (Pallant, 2007). Furthermore scatter-plots were also used to visually assess the nature of the relationship between the two variables under investigation. As can be seen in **Figure 12,** the scatter-plot showed no such violations and as such it was deemed appropriate to proceed with further analysis. The relationship between learning history and consent was investigated using Pearson's product-moment correlation. Correlation analysis is used when a researcher wishes to measure the strength and direction of a linear relationship between two variables (Field, 2009; Pallant, 2007). In the context of *P1.1* the two variables the researcher wished to investigate were total learning history score and its relationship with likelihood of consent. In order to calculate this, an overall learning history score was calculated by adding together the scores of the following constructs within the learning history questionnaire: attitude, direct experience, indirect experience and subjective norms. In addition to the overall learning history calculation and analysis, the researcher also conducted a Pearson's product correlation for each of the individual constructs of learning history, namely attitude, subjective norm, direct and indirect experience in order to assess which particular dimensions of learning history had a strong relationship with likelihood of consent.

It should be noted that despite the well established relationship between ethnicity, religion and consent, study two conducted no separate analysis concerning these two variables. This is because of two important reasons. Firstly study two's focus was overall learning history, defined as an individual's collective experience towards organ donation and related behaviours, of which an individual's religion and ethnic background plays only a part. Furthermore the rule governed aspect of religion and culture is already captured in the study through the measurement of

attitude and subjective norm. Secondly, because of the small sample size achieved in study two (N = 50), only 10% of the participants were from ethnic minority backgrounds (N=5), thus making any further analysis of this variable problematic. Examining these aspects within the learning history construct could be a potential avenue for analysis in future research when a larger sample and more representative sample could be achieved, thus making comparisons more meaningful.
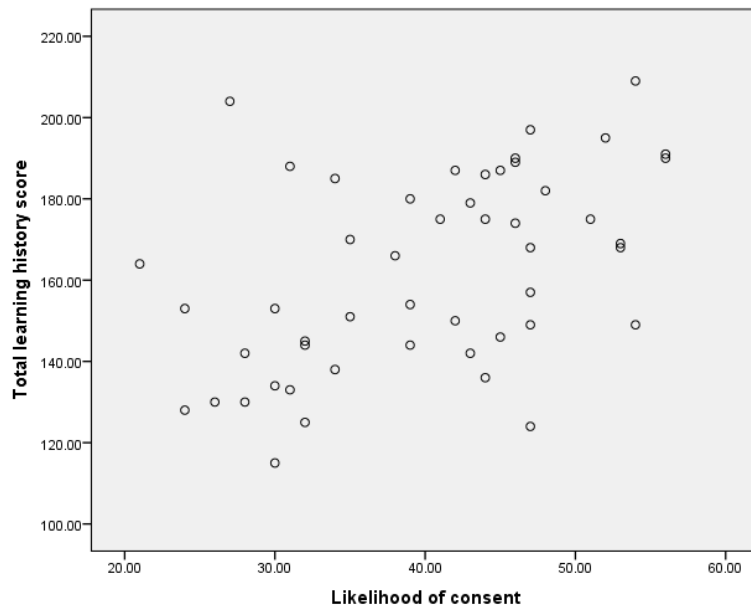
Figure 12. Learning history scatterplot

Correlations			
		Total learning history score	Likelihood of consent
Total learning history score	Pearson Correlation	1	.479**
	Sig. (2-tailed)		.000
	N	50	50
Likelihood of consent	Pearson Correlation	.479**	1
	Sig. (2-tailed)	.000	
	N	50	50

**. Correlation is significant at the 0.01 level (2-tailed).

Table 10. Pearson product correlation for overall learning history and consent

Correlations

		Likelihood of consent	Direct experience score	Indirect experience score	Attitude score	Subjective norm score
Likelihood of consent	Pearson Correlation	1	.242	-.020	.567**	.293*
	Sig. (2-tailed)		.090	.890	.000	.039
	N	50	50	50	50	50
Direct experience score	Pearson Correlation	.242	1	.548**	.367**	.404**
	Sig. (2-tailed)	.090		.000	.009	.004
	N	50	50	50	50	50
Indirect experience score	Pearson Correlation	-.020	.548**	1	.043	.377**
	Sig. (2-tailed)	.890	.000		.764	.007
	N	50	50	50	50	50
Attitude score	Pearson Correlation	.567**	.367**	.043	1	.712**
	Sig. (2-tailed)	.000	.009	.764		.000
	N	50	50	50	50	50
Subjective norm score	Pearson Correlation	.293*	.404**	.377**	.712**	1
	Sig. (2-tailed)	.039	.004	.007	.000	
	N	50	50	50	50	50

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 11. Pearson product correlations for individual learning history dimensions and consent.

Results

As shown in **Table 10**, the relationship between likelihood of organ donation consent and learning history was investigated using Pearson product-moment correlation co-efficient. Following Cohen's recommendations as a guideline for the interpretation of correlations overall learning history has a borderline moderate to strong positive correlation with likelihood of consent (r =.479, n = 50, p <.000) (Field, 2009). This finding provides further support for the results reported in study one of this thesis.

In addition to the above analysis, each of the four dimensions that contribute to the overall learning history score were investigated separately using Pearson product correlation in order to assess their relationship with likelihood of consent. The results indicate a strong positive correlation between attitude and likelihood of consent (r = .56, n = 50, p <0.01). A moderate positive correlation between subjective norm and likelihood of consent was also evident (r = .29, n = 50, p = 0.03). Similarly, a moderate positive correlation between direct experience and likelihood of consent was found, although the probability value did not reach significance at the conventional level (r = .24, n = 50, p = 0.09). Lastly, a marginal non significant negative correlation between indirect experience and likelihood of consent was detected (r = -.02, n = 50, p = 0.89).

Discussion

The first research proposition *(P1.1)* was concerned with assessing the relationship between learning history and likelihood to consent to organ donation in the request situations. *P1.1* proposed that learning history would significantly influence likelihood to consent. As will be recalled this proposition was formulated based upon both the findings of the literature review conducted in chapter two and the data resulting from study one of this thesis. It was hypothesised that learning history, which comprised of attitudes towards death and donation, subjective norms, direct and indirect experience would significantly influence likelihood of consent, with those reporting more positive learning history being more likely to consent. The results from the Pearson product-moment correlation analysis (**Table 10**) indicate that learning

history is significantly and positively correlated to likelihood of consent. Therefore in light of this result *P1.1* is strongly supported. The results thus validate the learning history dimension of the BPM schema, and demonstrates that donor family consent behaviour is largely contingency shaped. Put simply donor families appear to be strongly influenced by their previous experiences with organ donation and related issues. Where previous experiences are positive, likelihood of consent appears to be higher and where previous experience is more negative in nature, likelihood of consent appears to be reduced.

In addition to the above analysis concerning overall learning history, a Pearson product-moment correlation analysis was conducted for each of the four separate dimensions of learning history, namely attitude, subjective norm, direct and indirect experience. This was conducted in order to assess their individual relationship with likelihood of consent. As **Table 11** illustrates, attitude had the strongest relationship with likelihood of consent out of the four dimensions that constituted learning history in this study ($r = .56$, $n = 50$, $p < 0.01$). This finding is somewhat unsurprising and corroborates with the existent literature in this area which has consistently identified a relationship between positive attitudes and organ donation consent on both an individual decision making basis (i.e. personally deciding to be an organ donor) and within a family consent context (e.g. Horton & Horton, 1991; Morgan et al., 2001; Sanner, 2006).

As discussed in chapter two of this thesis attitude is a measure of an individual's anticipated behavioural outcome of engaging in a specific behaviour formed through their unique experience with that or similar behaviours (Foxall, 1995; 2005). In the context of the present study, the attitude construct included the measurement of the following items that have been identified in the existent literature as influential in organ donation consent process: attitudes toward bodily integrity, level of medical trust, the so called "*ick factor*" (Morgan *et al.*, 2008; O'Carroll *et al.*, 2011) and notions of pride, value and meaning derived from the donation of one's own or family member's organs (Sque *et al.*, 2006a). In the context of study two participants who reported lower levels of medical mistrust, "*ick factor*", the need for bodily integrity and the highest levels of general positive attitudes towards organ donation were more

likely to consent to the organ donation in all request situations. According to Foxall (2005), attitudes towards an object or behaviour are formed on the basis of past experiences and in a way represent internal rules held by the individual that may guide their future behaviour. Therefore in the context of organ donation consent, attitudes towards organ donation are an indirect measure of a participant's prior exposure to organ donation and related issues. Following this logic the more positive these prior experiences regarding organ donation and transplantation the more positive the attitudes held. The finding that attitude positively correlates with likelihood of consent also corroborates the results reported from study one of this thesis, where donor families within the sample used consistently reported a wide range of positive attitudes in relation to organ donation and transplantation. This finding leads inevitably to the important question of how to increase positive learning history amongst the general population? In the existent literature the media has been identified as one of the best means of educating the public on organ donation issues and in recent years the NHSBT has conducted a campaign seeking to increase ODR levels (NHSBT, 2013b). However, in the context of the current study 54% of participants stated that they had never seen a televised organ donation campaign (see **Appendix 11**). This figure indicates that despite increased efforts by the health sector to educate individuals through mass media, it is still not reaching some individuals.

The second dimension of learning history whose relationship with likelihood of consent reached significance was subjective norm. As will be recalled from chapter two of this thesis, this construct is defined as "*the perceived social pressure to engage or not engage in the behaviour*" (Ajzen, 1991, p188). In the context of organ donation consent, these "*important others*" are likely to be close family and friends. In study two this construct was measured by eight items relating to the attitudes of important others regarding organ donation, for example question 44 measured this construct with the following statement, "*most people who are important to me would approve of organ and tissue donation*". The results from the Pearson product-moment correlation (**Table 11**), indicate a moderate positive correlation between subjective norm and likelihood to consent (r = .29, n = 50, p = 0.03). This finding corroborates with previous research conducted in this area, which has found that subjective norms influences organ donation decision making. In the existing

literature the role and importance of subjective norm has been consistently identified in the donation decision making process, with organ donation specific models incorporating this variable (Horton & Horton, 1991; Radecki and Jaccard, 1997; Hyde & White, 2009). The power of both perceived and actual social pressure from important others in the decision making situation is illustrated by the fact that family disagreements concerning organ donation consent have been consistently cited as one of the most common reasons for refusal in the existent literature (Yong *et al.*, 2000; Martinez *et al.*, 2001; Singh *et al.*, 2004; Barber *et al.*, 2006; Lopez Martinez *et al.*, 2008; Anker & Feeley, 2010; Ghorbani *et al.*, 2011). Furthermore family disagreement has also been reported to have prevented donation from taking place even in circumstances where the potential donor has expressed a wish to donate during their lifetime via registration (Rudge, 2007). The finding that social norm is positively correlated to likelihood of consent also corroborates with the results from study one of this thesis, where the overwhelming majority of families said that consenting to donation was influenced by significant others, most notably the immediate family unit. Study two's finding regarding the relationship of subjective norm further highlights the importance of family discussions regarding organ donation.

Interestingly in the context of the present study, 42% of participants didn't explicitly know the donation status of their family members, with a similar percentage, 46%, having never actually discussed the topic of organ donation with their family. These results indicate that the majority of participants within this sample were not fully informed of their friends and family's *actual* organ donor status or wishes. Therefore the results from this sample are *truly* a perceived measure of social pressure, rather than what participant's actually know concerning the opinions and wishes of their family about organ donation. This finding highlights the particular importance of promoting family discussions regarding organ donation wishes amongst family members.

The third and fourth dimensions of learning history measured in study two were indirect and direct experience. In relation to direct experience, results from the Pearson product-moment

correlation analysis indicate a small to moderate positive correlation between direct experience and likelihood of consent; however this did not reach significance at the conventional 5% level (Field, 2009; Pallant, 2007). In relation to indirect experience, a marginal non significant negative correlation between indirect experience and likelihood of consent was detected (r = -.02, n = 50, p = 0.89). So far this thesis has argued that because organ donation is a fairly rare occurrence in the UK very few people have any actual direct experience of the organ donation process and therefore must rely upon other forms of relevant direct experience, such as experiences with similar behaviours and situations, for example, blood donation and prior organ donation registration (Burroughs *et al.*, 1998, Brug *et al.*, 2000). However despite a positive, moderate correlation being detected between direct experience and likelihood of consent, this failed to reach the conventional significance level therefore no definite conclusion regarding this dimension could be arrived at in the present experiment. As for indirect experience, which includes items such as media exposure and knowing individuals who are on the transplant list, no meaningful relationship could be detected in the present study. One possible explanation for this is that very few individuals, even those who reported otherwise high levels of learning history experience, reported any indirect experience in the present study.

P1.2. Consent will differ between those with a high level of learning history and those with a low level of learning history

Analysis procedure

The data was split into two equal groups, below and above the mean learning history score of the group. This process produced two equal groups that could be directly compared, one labelled high learning history group (above the mean score), and the other labelled low learning history group (below the mean score). An independent t-test was conducted with consent as the dependent variable and learning history (low and high) as an independent variable. An independent t-test is used in instances where a researcher wishes to compare the mean score on a continuous variable from two different groups of participants (Pallant, 2007; Field, 2009).

Frequency counts of organ donation consent across the four operant classes, between the two learning history groups were compared using contingency table analysis (**Table 12**). To prepare the data for contingency table analysis responses to the question "*what is the likelihood of you consenting in this scenario*?" was coded, with responses 1to 4 being classified as refusal and responses 5 to 7 classified as consent.

The final stage of the analysis involved separating the data by operant classes and performing an independent t-test for each of the four individual operant classes of behaviour.

Results

The t-test shows that there are significant differences in likelihood of consent between those with a low learning history score (M = 35.36, SD = 8.78) and those with a high learning history score (M = 44.72, SD = 7.66; t(47.14) = -4.01, p = .000). The magnitude of the differences in means was 9.36.

Group Statistics

	Total learning history score (Binned)	N	Mean	Std. Deviation	Std. Error Mean
Likelihood of consent	Low learning history score	25	35.3600	8.78389	1.75678
	High learning history score	25	44.7200	7.66768	1.53354

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Likelihood of consent	Equal variances assumed	1.468	.232	-4.014	48	.000	-9.36000	2.33195	-14.04870	-4.67130
	Equal variances not assumed			-4.014	47.140	.000	-9.36000	2.33195	-14.05091	-4.66909

Table 12. Independent samples t-test for learning history groups and consent

179

As can be seen in the **Table 13** below, out of 200 consent outcome for each learning history group overall consent across the 4 operant classes was 56.5% amongst the low learning history group and 86% amongst the high learning history group. The most effective contingency category in stimulating consent amongst the high learning history group was Pleasure a finding that will be discussed later in this chapter. In contrast, the most effective contingency category in stimulating consent among the low learning history group was Accumulation. The least effective for both groups was the maintenance category, with 46% consent amongst the low learning history group and 72% amongst the high learning history group.

	Low learning history score (n = 200, 25 views per operant class)	High learning history score (n = 200, 25 views per operant class)
Societal Accomplishment	29	45
% consent	58%	90%
Incentivised Donation	26	46
% consent	52%	92%
Altruistic Donation	35	45
% consent	70%	90%
Routine Donation	23	36
% consent	46%	72%
Total	113	172
% consent rate	56.5%	86%

Table 13. Consent rates across operant classes for low and high learning history groups

Lastly, consistent with the frequencies observed in the above table, there were significant differences in levels of likelihood of consent between the high and low learning history groups across all four operant classes. The findings of the t-tests are summarised below:

In the Societal Accomplishment (accomplishment) operant class there was a significant difference between the low learning history group (M = 8.96, SD = 2.44) and the high learning history group (M = 11.32, SD = 1.93; t(48) = - 3.79, *p* < .001).

In the Incentivised donation (pleasure) operant class there was a significant difference between the low learning history group (M = 8.56, SD = 2.59) and the high learning history group (M = 11.44, SD = 1.80; t(42.7) = - 4.55, *p* < .001).

In the Altruistic donation (accumulation) operant class there was a significant difference between the low learning history group (M = 9.88, SD =2.45) and the high learning history group (M = 11.92, SD = 2.41; t(48) = -2.96, p = .005).

In the Routine donation (maintenance) operant class there was a significant difference between the low learning history group (M = 7.96, SD = 3.07) and the high learning history group (M = 10.04, SD = 2.82; t(48) = -2.49, p = .016).

Discussion

Confirmation in the differences in likelihood of consent between the two groups across all operant classes has resulted in the *P1.2* being strongly supported. Within this particular sample those with a higher learning history score were more likely to consent across all contingency categories. This finding further highlights the vital importance of long term educational campaigns focused on organ donation and transplantation to improve the general population's overall learning history regarding these issues. A better informed population will potentially feel more confident about making decisions regarding organ donation which can only have a positive effect on overall donation rates within the UK.

In terms of which operant class was most effective in stimulating consent for each group, the findings of *P1.2* are intriguing and indicate differences in intervention preference between the two learning history groups, something which is explored later in this chapter (*P5.1-P5.4*). The most effective contingency category in stimulating consent amongst the high learning history

was the Incentivised donation contingency category, originally labelled the *pleasure* operant class. As will be recalled from earlier discussions contained within this thesis, this contingency category is characterised by its high levels of utilitarian reinforcement and relatively low levels of informational reinforcement. One plausible interpretation for this particular preference amongst those in possession of high levels of learning history is that they merely need that final "*nudge*" to make the leap and consent (Thaler & Sunstein, 2008). In the context of the present study this so called "*nudge*" is produced through the offering of immediate benefits to the decision maker. In this study, the *incentivised donation* operant class consisted of scenarios involving financial incentives being offered to the donor family, more specifically funeral expenses being paid in full. In general those with a higher learning history score were in possession of a more positive learning history regarding organ donation and past experiences with healthcare professionals, and consequently reported lower levels of medical distrust. Therefore this group did not treat financial incentives with distrust or disapproval but welcomed this approach, with an overall consent rate of 92% in this operant class amongst the higher learning history sample. At present the use of financial incentives to stimulate consent is one of the many strategies that are being discussed by various health research bodies, including most recently the British Medical Associations' publication on the issue (2013) and the Nuffield Council on Bioethics' publication regarding organ donation (2011). The one major issue that prevents this approach being implemented is primarily ethical in nature, with the Nuffield Bioethical Council concluding that the NHS should conduct a pilot scheme to test how the offer of financial incentives as a "*non-altruistic focused intervention*" would be implemented and how it would be received by the general public (Nuffield Bioethical Council, 2011).

Despite the success of the Incentivised donation operant class amongst the high learning history group for stimulating the consent, it was not as amenable to those who lacked a strong learning history. In direct comparison to the high learning history group, the Incentivised donation operant class was the second least effective for stimulating consent amongst the low learning history group, with only 52% providing consent. This finding could be attributed to the fact that this group tended to have reported higher levels of medical mistrust and sub-optimal

experiences will healthcare professionals. Couple this with generally more negative attitudes to the organ donation procedure, it is somewhat unsurprising that this group showed a propensity to treat financial incentives with suspicion and therefore be less likely to consent to donation.

The most effective operant class in stimulating consent amongst the low learning history group was *Altruistic donation* contingency category, originally labelled the accumulation class. This operant class achieved a 70% consent rate amongst the low learning history group, and achieved a 90% consent rate amongst the high learning history group. This operant class is categorised by its high levels of informational reinforcement and its relatively low levels of utilitarian reinforcement. In this study the *Altruistic donation* operant class offered the decision maker detailed feedback from the recipients of the donated organs, recognition through a memorial wall and a prioritised place for the donor family on the organ transplant list, thus reflecting the highly informational nature of these two contingency categories (CC5, CC6). In particular the prioritised place on the transplant waiting list represents a delayed benefit for the potential donor family which reflects the "*saving and collecting*" nature of Foxall's original accumulation category (Foxall, 2005). One explanation for this operant class being popular amongst the low learning history group is due to the soft approach it adopts. This operant class consists of nothing that could be interpreted as untoward concerning incentives being offered, furthermore it provides the donor family with an opportunity to see how their *gift* has improved the lives of others, provides recognition of this gift through a memorial wall and gives the donor family a tangible non-financial incentive through the prioritised place on the transplant list. Therefore this operant class is solely altruistic-focused, merely encouraging individuals to consent because it will change the lives of others. Furthermore this operant class recognises and rewards the act of donation in a way that does not call into question the trust between the medical establishment and their patients, nor does it devalue the gifting concept that is historically central to organ donation within the UK.

The Routine donation or maintenance class was by far the least effective for both groups, with a consent rate of only 46% amongst the low learning history group and 72% amongst the high

learning history group. This operant class is characterised by its relatively low levels of both utilitarian and informational reinforcement. As was discussed in the literature of the BPM earlier within this thesis, behaviours within these two contingency categories (CC7, CC8) are perceived as mandatory or routine in nature. As will be recalled from the literature review, traditional consumer behaviours that fall in this operant class relate to satisfying basic needs or societal obligations, such as buying food or paying taxes. In this study, the Routine donation scenarios emphasised the fact that organ donation was a routine procedure, and that it was part of being social responsible, therefore highlighting the civil duty aspect of providing consent. Basic incentives were offered to potential donor families in this operant class, including brief and basic information regarding the recipient's progress and a certificate of appreciation, therefore reflecting the low levels of both utilitarian and informational reinforcement that characterise this contingency category. Appealing to the participant's sense of social responsibility, whilst highlighting the routine nature of the procedure was the least effective approach, emphasising the need for introducing incentive focused inventions by policy makers in this particular context. NHSBT have stated that one of their aims is to see donation as a routine and usual procedure rather than unusual event in end of life care (Department of Health, 2011). The findings from this study indicate that potentially organ donation policy makers should tread carefully before introducing protocols that could be seen as de-valuing the gifting aspect of consent, as this could potentially hamper efforts to increase donation rates in the UK. In light of the results obtained from this study it could be argued that a long term educational plan would be needed before organ donation policy could effectively move towards a more *routine* policy attitude regarding organ donation.

P2. Situations where the behaviour setting scope is open will be more effective in stimulating consent than situations where the behaviour setting is closed.

Analysis procedure

As will be recalled from study one, this proposition was formulated on the basis that donor families tended to report that not feeling pressurised or rushed was an important element in

their decision making process. To formally test this proposition, a paired samples t-test was conducted to evaluate the impact of the behaviour setting scope on the likelihood of consent to organ donation. A paired sample t-test is used in instances where a researcher wishes to compare the mean scores for the same group of people on two or more occasions (Field, 2009; Pallant, 2007).

The data was split by open (CC1, CC3, CC5, CC7) and closed (CC2, CC4, CC6, CC8) scenarios, before likelihood of consent across the four operant classes was calculated.

Results

There was a statistically significant increase in consent in the open behaviour setting scenarios (M=20.9, SD = 4.61) compared to the closed behaviour setting scenarios (M=19.08, SD = 5.55), t = 3.39, p<.001 (two tailed). The mean increase in the dependent variable of likelihood of consent was 1.88 with a 95% confidence interval ranging from 0.76 to 2.99. The eta squared statistic (.18) indicating a large effect size.

Discussion

Based on the results obtained through the paired samples t-tests procedure that was conducted, the proposition that open behaviour settings stimulate consent more effectively than closed behaviour settings is supported. As will be recalled previous BPM studies have found a closed behaviour setting to be an effective tool in stimulating approach behaviour in consumers. However the context of this thesis is markedly different from a traditional consumer context which has been the usual setting for previous BPM applications. This particular finding provides further support for the results obtained during study one regarding the relationship between behaviour setting scope and providing consent. As study one of this thesis demonstrated, potential donor families value more open behaviour settings where they feel important, with a sense of autonomy. This is because an important element of the behaviour setting for the potential donor family is the sense that there is no pressure to donate and that they exert a large degree of freedom in the final outcomes. In the existing literature this aspect of the environment

has been alluded to, with donor family stating that a lack of pressure put on them to provide consent by health professionals was a positive element of the behaviour setting (Siminoff, *et al.*, 2001, Cleiren *et al.*, 2002).

In the context of the present study a closed environment was represented by scenarios depicting what would be deemed a *soft-opt out* system of consent. As will be recalled from earlier in this thesis, this term denotes that the potential donor is presumed to be a willing donor if they have not actively opted-out of the system. Therefore donation would proceed unless the family veto and object to organ donation. Conversely the open behaviour setting environment in this study was represented by scenarios where the donor family's freedom of choice was strongly emphasised.

The results obtained from the current study in relation to the influence of behaviour setting scope on likelihood of consent could potentially have implications for organ donation policy makers and healthcare professional in organ donation service domain.

Based on the results presented for *P2*, it could be argued that were any changes to legislation or protocol that were perceived to restrict the rights or freedom of choice of potential donor families could unintentionally have a negative effect on organ donation levels. Domínguez and Rojas (2013) recently evaluated the impact of the opt-out legislation change in Chile on donation rates 2 years after its implementation. They reported that in the context of Chile, the introduction of presumed consent legislation not only did not increase overall donation levels but appeared to have had a deleterious effect. This trend was reflected in an increase in family refusals and a high percentage of non-donors on the registry (Domínguez & Rojas, 2013).

In the context of the UK the Welsh Assembly has recently passed a human transplantation bill that would introduce an opt-out system of consent in Wales by 2015 (Human Transplantation (Wales) Act, 2013). In the context of a *soft opt-out* system, individuals over the age of 18 who haven't expressed a wish to *not* be an organ donor by actively opting-out of the NHS Organ Donation Register will be presumed to be donors. Potential donor families of those who haven't opted-out of the organ donation register will be reminded that unless they have strong

objections to organ donation the process of donation would go ahead. This type of system of consent evidently restricts potential donor family's choice, thus producing a more closed behaviour setting. In light of the evidence produced by both studies in this thesis, as well as the results of such a legislation change seen Chile, one could argue that this type of intervention could be damaging to overall consent rates without an adequate long term educational programme being conducted prior to implementation. At the time of submission, the role and extent of influence of potential donor families in the Welsh human transplantation bill was still being debated.

P3.1 Pleasure will discriminate between Accomplishment-Accumulation and Pleasure-Maintenance.

P3.2: Arousal will discriminate between Accomplishment-Pleasure and Accumulation-Maintenance

P3.3: Dominance will discriminate between Open and Closed consumer behaviour settings

Analysis procedure

As will be recalled from chapter two of this thesis, the above propositions (*P3.1-3.3*) were formulated in light of the existing BPM literature which has identified the following associations between PAD variables and the BPM typology of behaviour: that pleasure will be related to utilitarian reinforcement, arousal will be related to informational reinforcement and dominance related to the scope of the behaviour setting (e.g. Foxall, 1990; 2004; Foxall & Greenley, 1999).

Prior to conducting statistical analysis, the PAD scales were tested for reliability by calculating the internal consistency for each dimension of the scale. To test propositions *3.1-3.3*, a one way repeated-measure ANOVA was conducted with post hoc tests. For the post hoc test, the Bonferroni confidence interval adjustment was used (Field, 2009).

Results

The Cronbach's alpha coefficients for all of the PAD dimensions were above the recommended .7 level (Nunnally, 1978), therefore indicating a good level of reliability.

Table 14 presents the mean scores for each of the PAD scale dimensions across the eight contingency categories. The scores are comparable to those observed in previous BPM studies that have utilised Mehrabian and Russell's (1974) Pleasure-Arousal-Dominance (PAD) scale as a measurement scale (Foxall, 1997b).

Contingency category/ Mean PAD	Pleasure	Arousal	Dominance
CC1 (open)	34.56 (7.183)	31.30 (5.116)	32.92 (7.148)
CC2 (closed)	28.82 (8.462)	31.00 (6.321)	26.06 (6.215)
CC3 (open)	35.20 (6.824)	30.96 (4.045)	34.20 (6.054)
CC4 (closed)	27.54 (7.933)	30.10 (5.504)	27.56 (7.205)
CC5 (open)	35.86 (7.329)	30.60 (5.046)	34.30 (6.972)
CC6 (closed)	32.44 (4.947)	32.26 (4.947)	28.24 (6.811)
CC7(open)	30.30 (7.693)	30.46 (4.527)	30.30 (7.693)
CC8 (closed)	24.06 (6.698)	31.90 (6.411)	25.40 (8.261)

Table 14. Mean scores for PAD dimensions

The results from the Mauchly's test of Sphericity indicated that the assumption of sphericity had been violated. Therefore the Greenhouse Geisser correction was applied (Field, 2009). The results show that there were significant differences across the eight contingency categories for both Pleasure (F = 21.89, p < .001) and Dominance (F = 16.46, p < .001). However there were no statistically significant differences for Arousal across the eight contingency categories (F = 1.72, p = .12).

In light of the significant differences in Pleasure and Dominance mean scores across the contingency categories, unplanned post-hoc pairwise comparisons were performed, using the Bonferroni adjustment for multiple comparisons (Field, 2009). The results of which are reported in the **Tables 15 and 16** below.

As **Table 15** illustrates, there were significant differences as predicted in 50% of the comparisons conducted for the Pleasure operant class. The remaining 50% the results either failed to reach significance or were not observed (CC1>CC5, CC1>CC6, CC2>CC7) in the predicted pattern, for example CC1 was not observed to be more pleasurable than CC5. **Table 16 and Figure 13** also demonstrates that the proposed relationship between Dominance and behaviour setting score exists in this particular context. The results match the predicted pattern, with participants reporting to feel more in control in open settings and more submissive in closed. Only two comparisons failed to reach significance, CC7>CC4 and CC7>CC6.

Expected differences CC1-4>CC5-8	Results
CC1>CC5	NOT OBSERVED
CC1>CC6	NOT SIGNIFICANT
CC1>CC7	SIGNIFICANT
CC1>CC8	SIGNIFICANT
CC2>CC5	SIGNIFICANT
CC2>CC6	NOT OBSERVED
CC2>CC7	NOT OBSERVED
CC2>CC8	SIGNIFCANT
CC3>CC5	NOT SIGNIFICANT
CC3>CC6	NOT SIGNIFICANT
CC3>CC7	SIGNIFICANT
CC3>CC8	SIGNIFICANT
CC4>CC5	SIGNIFCANT
CC4>CC6	SIGNIFICANT

CC4>CC7	NOT OBSERVED
CC4>CC8	NON SIGNIFICANT

Table 15. Pleasure across contingency categories

Expected differences CC1,3,5,7> CC2,4,6,8	Results
CC1>CC2	SIGNIFICANT
CC1>CC4	SIGNIFICANT
CC1>CC6	SIGNIFICANT
CC1>CC8	SIGNIFICANT
CC3>CC2	SIGNIFICANT
CC3>CC4	SIGNIFICANT
CC3>CC6	SIGNIFICANT
CC3>CC8	SIGNIFICANT
CC5>CC2	SIGNIFICANT
CC5>CC4	SIGNIFICANT
CC5>CC6	SIGNIFICANT
CC5>CC8	SIGNIFCANT
CC7>CC2	SIGNIFICANT
CC7>CC4	NON-SIGNICANT
CC7>CC6	NON-SIGNIFICANT
CC7>CC8	SIGNIFICANT

Table 16. Dominance across contingency categories
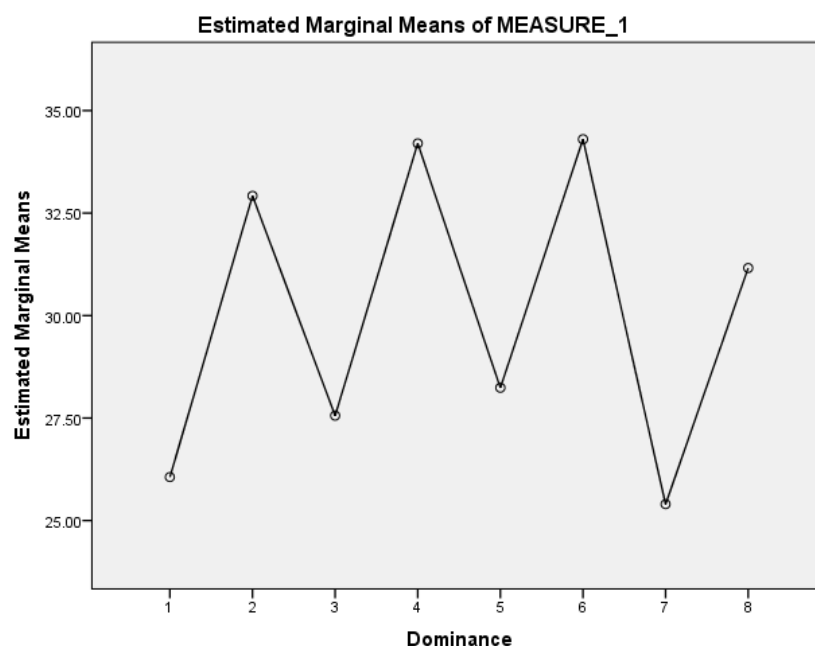
Figure 13. Dominance across contingency categories

Discussion

In light of the results obtained through the above analysis, *P3.1* and *P3.2* have been rejected. As illustrated in **Tables 15 and 16**, multiple comparisons of Pleasure and Arousal have shown that in the particular context of donor family consent these dimensions were not directly related to informational and utilitarian patterns of reinforcement. **Tables 15** and **16** illustrate the post-hoc tests results that show that Pleasure and Arousal levels have considerably deviated from the expected pattern outlined in the existent BPM literature (e.g. Foxall & Greenley, 1999).

Therefore these results indicate that levels of Pleasure and Arousal are not solely related to levels of informational and utilitarian reinforcement. One possible interpretation of the results obtained could be Pleasure and Arousal are in fact independent emotional reactions to the service being provided instead of purely responses to the environment.

Despite this, the proposed relationship between the behaviour setting scope and Dominance appears to exist (**Figure 13**), with participants within this sample reporting to feel more in control and dominant in situations characterised as open behaviour settings and more

submissive in situations characterised by closed behaviour settings. Therefore in light of this finding proposition 3.3 is supported.

P4. *Affective responses will significantly affect likelihood of consent.*

Analysis procedure

To test this proposition, the data was split by operant class and Pearson product-moment correlation coefficients were assessed in order to better understand the strength of the associations between affective responses and likelihood of consent. A two tailed significance test was used as the existing literature has presented conflicting findings on the influence of dominance on behaviour (Foxall, 1997b; Foxall and Greenley, 1999).

Results

	1	2	3	4
1 Pleasure	-	-	-	.439**
2 Arousal	-	-	-	.024
3 Dominance	-	-	-	.009
4 Likelihood of consent	.439**	.024	.009	-

** Correlation significant at the 0.01 level (2 tailed)

Table 17. Societal accomplishment Pearson correlation matrix

	1	2	3	4
1 Pleasure	-	-	-	.300*
2 Arousal	-	-	-	-.023
3 Dominance	-	-	-	.011
4 Likelihood of consent	.300*	-.023	-.011	-

*Correlation is significant at 0.05 level (2 tailed)

Table 18. Incentivised donation Pearson correlation matrix

	1	2	3	4
1 Pleasure	-	-	-	.583**
2 Arousal	-	-	-	.237
3 Dominance	-	-	-	.216
4 Likelihood of consent	.583**	.237	.216	-

**Correlation is significant at the 0.01 level (2 tailed).

Table 19. Altruistic donation Pearson correlation matrix

	1	2	3	4
1 Pleasure	-	-	-	.560**
2 Arousal	-	-	-	-.182
3 Dominance	-	-	-	-.039
4 Likelihood of consent	.560**	-.182	-.039	-

**Correlation is significant at the 0.01 level (2 tailed).

Table 20. Routine donation Pearson correlation matrix

Discussion

Based on the results of the Pearson product-moment correlations, proposition 4 can only be partially supported. Pleasure was positively and strongly associated with likelihood of consent across all operant classes, which is consistent with the existing BPM literature that has found that Pleasure influences approach behaviour in a variety of consumer settings (Donovan & Rossiter, 1982; Baker *et al.*, 1992; Donovan *et al.*, 1994; Sherman *et al.*, 1997; Li et al., 2009). This observation is also consistent with the findings reported later in this chapter regarding the analysis of *P5.1-P5.4* which found the Societal Accomplishment operant class to be one of the most effective in stimulating consent amongst the whole sample, regardless of learning history.

The identified relationship between pleasure and consent is an interesting finding and could potentially have practical implication for social marketers and healthcare professionals seeking to increase donation levels. The context of organ donation is recognised as in inherently sad situation for all those involved in the process. However the findings of this study imply that direct pleasure may be derived for the potential donor families through the act of providing consent. In light of this one could argue that social marketers and public health policy makers should place more emphasis on the direct comfort and personal satisfaction that can be derived by donor families in these often tragic circumstances. This finding corroborates with the results in study one, that found the overwhelming majority of donor families report that they felt a great deal of comfort in knowing they had facilitated the process of consent.

As far as the Arousal and Dominance dimensions are concerned, study two has mixed and inconsistent findings across all the operant classes which are summarised in the **Tables 17-20** above. Arousal and Dominance were not significantly associated with likelihood of consent in any of the operant classes. In the Accumulation class of behaviour they were moderately and positively associated with likelihood of consent, but failed to reach a level of significance. In all other operant classes only marginal, insignificant relationships were detected. This issue has been experienced by other BPM researchers apply PAD to new consumer behaviour contexts (Yermekbayeva, 2011).

One potential explanation for this finding is that the Arousal and Dominance items used in the PAD instrument were problematic for the sample to interpret in this unique context. In hindsight, items such as jittery, dull, aroused, awed and frenzied could be potentially difficult in an organ donation request scenario. Furthermore, it could be argued that for some participants the hospital environment is inherently closed by nature, therefore dominance items such as in-control and dominant would be difficult to place in this context. As can be seen from the results of *P2* discussed earlier in this chapter open settings were more effective in stimulating consent than closed settings. Despite this, dominance variable failed to be significantly correlated with consent. This further indicates a problem for participants in applying this concept to this particular context. This problem was not detected during the pilot stage of this study; however this was conducted on a very small sample (n = 10). Therefore one potential avenue for further research would be to investigate possible revisions of the terms used in the current version of the Arousal and Dominance scales, in order to achieve better fit between the measurement instrument and the context under study. This will be discussed further in the limitations and future research sections of chapter six.

P5.1. Accumulation (altruistic donation) will be most effective in stimulating organ donation consent

P5.2. Maintenance (routine donation) will be the least effective in stimulating organ donation consent

P5.3. Informational modes of reinforcement will be equally important to both learning history groups

P5.4. Utilitarian modes of reinforcement will be more important to the higher learning history group than the lower learning history group.

Analysis procedure

To test this *P5.1* and *P5.2,* the data was separated by operant class, mean scores and standard deviations for each operant class were calculated, as illustrated in the table below. A one way repeated-measures ANOVA was conducted with post hoc tests to assess whether there were significant differences in likelihood of consent across the operant classes. A one way repeated-measures ANOVA is utilised when a researcher wishes to measure the same subjects who have

been exposed to two or more different conditions measured on the same scale (Pallant, 2007). For the post hoc test, the Bonferroni confidence interval adjustment was used (Field, 2009).

To test *P5.3* and *P5.4*, an independent t-test was conducted to compare the mean importance scores of the high and low learning experience groups concerning utilitarian and informational modes of reinforcements. For example the importance each learning history groups assigns to utilitarian modes of reinforcement such as financial incentives, and informational modes of reinforcement such as memorials. Before conducting the t-test, total utilitarian reinforcement scores and total informational reinforcement scores were calculated.

Results

Operant class	N	Mean	Std. deviation
Accomplishment	50	10.14	2.48
Pleasure	50	10.00	2.64
Accumulation	50	10.90	2.62
Maintenance	50	9.00	3.10

Table 21. Mean scores for likelihood of consent across the contingency categories

Table 21 presents the mean scores for likelihood of consent across the eight contingency categories. As can be seen from the table, Accumulation operant category stimulated the highest mean likelihood to consent scores, followed by Accomplishment, then Pleasure, with Maintenance appearing the least effective of all four operant categories. To test whether these differences were significant, a one way repeated measure ANOVA was conducted. The results from the Mauchly's test of Sphericity indicated that the assumption of sphericity had been violated. Therefore the Greenhouse Geisser correction was applied (Field, 2009). The ANOVA procedure identified significant differences in likelihood of consent across the operant classes (F =, 12.28, p =.001). As can be seen in pairwise comparison **Table 22** illustrated below, the results indicate that there were significant differences in likelihood of consent between all operant classes apart from between Accomplishment and Pleasure, and Accomplishment and Accumulation

Measure: MEASURE_1

(I) Consent Operant class	(J) Consent operant class	Mean Difference (I-J)	Std. Error	Sig.[b]	95% Confidence Interval for Difference[b]	
					Lower Bound	Upper Bound
1	2	.140	.219	1.000	-.463	.743
	3	-.760	.285	.062	-1.544	.024
	4	1.140*	.349	.012	.181	2.099
2	1	-.140	.219	1.000	-.743	.463
	3	-.900*	.279	.013	-1.667	-.133
	4	1.000*	.331	.024	.091	1.909
3	1	.760	.285	.062	-.024	1.544
	2	.900*	.279	.013	.133	1.667
	4	1.900*	.397	.000	.808	2.992
4	1	-1.140*	.349	.012	-2.099	-.181
	2	-1.000*	.331	.024	-1.909	-.091
	3	-1.900*	.397	.000	-2.992	-.808

Based on estimated marginal means

*. The mean difference is significant at the .05 level.

b. Adjustment for multiple comparisons: Bonferroni.

Table 22. Repeated measures ANOVA testing differences in consent across the operant classes

To assess the level of consent in each operant category, likelihood of consent score were collapsed into two categorical variables, with scores above 8 classified as consent to request and scores below 8 classified as refusal to consent (**Table 23**). The results indicate that the Accumulation operant class is by far the most effective in stimulating consent across the whole of the sample. As illustrated in **Table 23**, this is followed jointly by Accomplishment and Pleasure, with the Maintenance operant class being by far the least effective in stimulating consent amongst this sample. Therefore in light of this evidence *P5.1* and *P5.2* are supported.

Operant class	Consent (%)
Accomplishment	68%
Pleasure	68%
Accumulation	78%
Maintenance	54%

Table 23. Consent across operant classes

Table 24 illustrate the results of the independent t-test that was conducted to assess the differences in importance that the high and low learning history groups assigned to informational and utilitarian modes of reinforcement. As can be seen, differences were evident between low learning history group (M=99.28, SD=31.1) and high learning history groups (M=109.04, SD=30.7); t(47.9) p = .27 (two tailed) regarding the importance of informational modes of reinforcement, but failed to research significance at the conventional level.

In contrast, significant differences were evident between high and low learning history groups regarding the importance they assigned to utilitarian modes of reinforcement. The high learning history group ranked utilitarian modes of reinforcement as more important (M = 65.8, SD = 15.13) than the low learning history group (M = 55.2, SD = 13.85); t(47.6) = p = .01(two tailed)

In light of these results, *P5.4* is supported, whilst *P5.3* is rejected on the basis that differences were observed between low and high learning history groups regarding importance assigned to informational reinforcement but failed to reach the conventional significance level. Due to the mean difference failing to reach the conventional significance level no definite conclusion regarding this could be arrived at in the present experiment.

Group Statistics

	Total learning history score	N	Mean	Std. Deviation	Std. Error Mean
Total importance score utilitarian	low learning history group	25	55.2000	15.13550	3.02710
	high learning history group	25	65.8800	13.85436	2.77087
Total importance score informational	low learning history group	25	99.2800	31.17360	6.23472
	high learning history group	25	109.0400	30.73201	6.14640

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference		
									Lower	Upper	
Total importance score utilitarian	Equal variances assumed	.869	.356	-2.602	48	.012	-10.68000	4.10379	-18.93122	-2.42878	
	Equal variances not assumed			-2.602	47.629	.012	-10.68000	4.10379	-18.93288	-2.42712	
Total importance score informational	Equal variances assumed	.761	.387	-1.115	48	.270	-9.76000	8.75500	-27.36310	7.84310	
	Equal variances not assumed			-1.115	47.990	.270	-9.76000	8.75500	-27.36320	7.84320	

Table 24. Independent t-test between learning history groups concerning reinforcement modes

Discussion

In light of the results obtained from the performed analysis, *P5.1-5.2* is supported. As can be seen from the results the altruistic donation operant class was by far the most effective in stimulating donor family consent, with 78% of the participants within this study reporting they were likely to consent to organ donation in scenarios 5 and 6. This operant class appeals to most people, regardless of learning history as it consists of nothing that could be interpreted negatively.

In contrast, the Maintenance operant class was the least effective, only securing 54% consent rate. This operant class highlighted that organ donation was a routine procedure, could provide some comfort to donor families and was part of being socially responsible. This finding implies that the United Kingdom may not be ready for this type of approach. A long term educational programme would be needed if this line of promotion was adopted.

Overall these findings illustrate the effectiveness of so called soft intervention strategies as a means of stimulating donor family consent. Practically, this means pursuing altruistic-focused interventions that highlight the benefits of organ donation whilst offering a non-financial but highly valuable incentive, such a prioritised place on the transplant list if the family were ever to need an organ.

Regarding *P5.3* and *P5.4*, the results obtained from the independent t-test procedure show that differences are evident between the low learning history group and high learning history group regarding the importance they assign to informational modes of reinforcement, however these differences failed to research significance at the conventional level. Therefore little can be concluded based on these results of the present experiment, and therefore *P.5.3* is rejected at the present time. In contrast, significant differences were evident between high and low learning history groups regarding the importance they assignment to utilitarian modes of reinforcement. The high learning history group ranked utilitarian modes of reinforcement as more important than the low learning history group. As will be recalled, in this study utilitarian reinforcements in included financial incentives and the direct satisfaction and comfort that the donor family gain

from providing consent. The results obtained add further weight to the conclusion that those with a higher learning history are more comfortable with hard intervention strategies that are not altruistically focused in nature. In contrast those who are in possession of a lower learning history level assign a lower level of importance on these non-altruistically focused interventions as a motivating force to provide consent for donation. As will be recalled from previous chapters, concerns have been raised by various medical bodies globally about the impact of non-altruistically focussed interventions in trying to stimulate consent. Most recently, the Organ Donation Taskforce (Department of Health, 2008) warned that such an intervention could erode the trust between the medical profession and their patients. The results from this study provide some empirical evidence to support this claim. As those who reported higher levels of medical mistrust, lower levels of positive past healthcare experience and more negative attitudes towards the procedure showed a distinct preference for informational modes of reinforcement and assigned significantly less importance to utilitarian modes when compared with the higher learning history group. Therefore in light of these findings, it could be argued that such an introduction is just as likely to hamper organ donation levels, as it is to improve them, especially amongst those who have a lower level of learning history.

Summary of key findings of study two

(i)   The role of learning history in the consent process

Study two has provided further support regarding the importance of positive learning history on organ donation consent, in particular the role of positive attitudes and subjective norms in the decision making process. There were significant differences in consent rates across all operant classes between those who possessed a high learning history score and those in possession of a low learning history score. As will be recalled the learning history score consisted not only of attitudes and subjective norms but also measured direct and indirect experience. The findings from this chapter highlight the importance that must be given to campaigns that endeavour to improve the general population's attitudes toward organ donation and transplantation. Campaigns should also continue to promote family discussions regarding post-mortem wishes,

as this form of direct experience is vital in producing positive consent outcomes. Improvement regarding the population's attitudes and subjective norms can only be achieved through sustained long term educational campaigns regarding the importance of organ donation and the importance of communicating one's wishes with those who ultimately will be approached for consent.

Another key finding from study two was that once learning history score were taken into account, there was a difference in reinforcement pattern preference, with the higher learning score group preferring the Pleasure or "*Incentivised Donation*" operant class and the lower learning history group preferring the Accumulation or "*Altruistic Donation*" operant class. This finding is interesting and illustrates further that those with a higher learning history appear to be more comfortable with hard intervention strategies that include financial incentives. One possible interpretation of this finding is that this group is equipped with enough positive learning history regarding organ donation and transplantation, which they have accumulated through past experiences. Therefore they tend to be less suspicious of this type of intervention strategy. Conversely those who lack this positive learning history treat this sort of intervention with suspicion, which in turn can result in a negative consent outcome. If these findings are replicated, this could have potentially important implications for policy makers if replicated in the future. In particular, this finding could help inform what type and level of intervention should be adopted by the health sector in stimulating consent. One could argue that on the basis of these findings, that without a long term educational campaign prior to implementation, the financial incentivisation of organ donation in the UK could be particularly damaging in groups that lack a strong positive learning history regarding organ donation issues. Therefore one could stress that practitioners and policy makers should tread with caution when considering the introduction of hard incentives.

(ii) *Influence of open behaviour setting scope*

Study two has also provided further evidence of the influence of behaviour setting scope on donor family consent. Results from study two build upon the initial findings of study one that

open behaviour settings are more effective in stimulating donor family consent compared with more closed behaviour settings. This finding corroborates with the results reported in study one that potential donor families acknowledged that the fact that they felt no pressure to donate was an important factor in their decision making. Therefore the results from study one and two of this thesis indicate that in order to stimulate potential donor family consent, families should be made to feel as though they have a large degree of control within the consent situation, as any attempt to control or restrict their freedom of choice may hamper donation levels.

(iii) *Altruistic donation operant class most effective for stimulating consent*

Another key finding from study two was the identification of the operant classes that were most effective in stimulating consent from potential donor families. For the overall sample, the Accumulation operant class, renamed the *Altruistic Donation* category for this particular context, was the most effective in stimulating consent. This operant class is characterised by its relatively low levels of utilitarian reinforcement and high levels of informational reinforcement. In this study this operant class consisted of *soft* incentives including regular and detailed feedback from recipients of the donated organs and a prioritised place on the transplant list. This soft approach appeals to people with or without a positive learning history as it directly benefits the donor family without resorting to incentives that could fuel levels of mistrust toward the medical establishment. In light of the findings from this chapter it could be argued that this type of incentivisation is the safest option when pursuing an intervention strategy, as this approach is unlikely to cause a backlash and a subsequent drop in organ donation levels.

(iv) *Routine donation operant class least effective for stimulating consent*

In addition to identifying Accumulation as the most effective operant class in stimulating donor family consent, study two also identified the Maintenance category as the least effective, regardless of learning history score. This is an interesting finding, since this particular contingency category resembles the current system of consent request operating in the United Kingdom, with families offered basic and anonymous information regarding the recipient of the donated organs and are informed that the act of donation can be a comfort to families at a

difficult time. This result highlights that individuals may need a higher level of reinforcement to encourage organ donation consent, in the form of informational reinforcements such as a prioritised place on the transplant list.

Other findings

(v)   *Problems with the application of PAD in this context*

This chapter has produced somewhat mixed results regarding the application of the Pleasure Arousal Dominance scale (Mehrabian and Russell, 1974) to the context of the organ donation request environment. In study two, Pleasure has been found to positively and significantly correlate to likelihood of consent to organ donation, thus corroborating with previous BPM studies that have reported Pleasure to be strongly associated with approach behaviours (Foxall, 1997b; Foxall & Greenley, 1999; Yani-de-Soriano *et al.*, 2002). No significant association could be detected between Dominance or Arousal and likelihood of consent. However, empirical evidence supported the proposition that the Dominance dimension of the scale would differentiate between open and closed settings, with participants reporting higher levels of control in open settings and lower levels of control in closed. Study two also found no evidence to support the proposition that the Pleasure and Arousal dimensions of PAD are related to informational and utilitarian modes of reinforcement as previous BPM studies have (Foxall, 1997b; Foxall & Greenley, 1999; Yani-de-Soriano *et al.*, 2002). However this should not be considered a weakness, since study two's context was markedly distinct from previous applications of the scale, which have been traditional consumer environments. One potential explanation for this finding is that PAD was utilised in study two not to measure affective responses to the environment itself, but emotions toward a behaviour/service being offered to the donor family. Therefore the association between these two dimensions and the respective reinforcements may have been lost.

Conclusion

In conclusion study two has been successful in its aim to achieve the following:

1. To provide further validation of the influence of learning history on consent outcomes

2. To empirically test the hypothesised influence of open behaviour settings on organ donation consent.

3. To empirically test the influence of different patterns of reinforcement on consent outcome.

4. To test the influence of affective response on consent

Study two sought to test the effects of the determinants of donor family consent identified in the literature review of this thesis and study one. The study adopted a novel methodology of picture representation, which included photographic images presented on PowerPoint slides with embedded audio messages. This approach had previously been successfully used by in the existing BPM literature (Yermekbayeva, 2011) and was specifically adapted for this study to enhance realism for the participants. The adoption of this methodological approach has differentiated this study from previous applications of PAD, which have presented different consumer situations in purely textual format (e.g. Foxall, 1997b; Lutz & Kakkar, 1975; Mehrabian & Russell, 1974). Within the organ donation literature consent has only be able to be examined retrospectively due to the sensitive nature of the topic, relying upon qualitative techniques after the event. This novel methodology has allowed consent outcomes to be examined at the time of decision making, a distinct advantage over previously utilised methodologies.

In summary, study two has provided further support to the important role of learning history in organ donation consent outcomes. In addition, the findings from this chapter have also provided further support for the most successful operant class in stimulating donor family consent regardless of learning history. Study two has also highlighted the caution that should be taken before implementing protocols or interventions that are perceived to restrict donor family control or autonomy, as this may hamper donation levels. Furthermore it could be argued in

light of the results obtained in this study that any introduction of financial incentives should only be introduced after long term educational campaign has been conducted, as study two has revealed that consent levels fall amongst those with a lower learning history in situations where non-altruistically focused incentives are employed.

Chapter Six

A radical behaviourist approach to understanding & stimulating donor family consent

"Let us try to teach generosity and altruism, because we are born selfish."

Dawkins, 1976, p.3

Introduction

This thesis set out to examine the socially important behaviour of donor family consent from a radical behaviourist perspective, via the application of the BPM. The principle goal being to better understand the situational influences of this complex behaviour and to identify ways in which it may be stimulated. By way of consolidation, the purpose of this final chapter is to provide the reader with an overarching discussion of the main findings reported within this thesis, and to consider the implications of the two empirical studies for organ donation practice and research, in both a theoretical and practical sphere. The structure of the present chapter is as follows. Firstly the present chapter will provide the reader with a restatement of the aims, objectives and justifications of approach of the research undertaken. The chapter will then detail how these objectives were met through the sequential mixed method research strategy that was employed in this thesis. The chapter will then proceed with a full discussion of the key findings from the two empirical phases. The following section will then discuss in detail the particular research contributions of the present research to existing knowledge in the field of both BPM and organ donation research. The theoretical, practical and methodological contributions of the present thesis will each be addressed in turn. The next section of this chapter will then explore some of the limitations of the present research and will provide recommendations on how some of these issues could be addressed in the future research. The penultimate section of this chapter will discuss potential avenues of further research in light of the research contained within this thesis. The present chapter will conclude with a section that discusses the overall suitability of a

radical behaviourist approach to understanding and stimulating donor family consent, a restatement of the strengths of this particular approach and how this perspective can contribute to future programs that seek to stimulate organ donation consent rates in the United Kingdom.

In the following section of this chapter a brief overview of this thesis's objectives and research strategy will be outlined, before an exegesis of the key findings resultant from this thesis is provided. The chapter will then continue by outlining the unique contribution to current knowledge this thesis has made, before proceeding to document the limitations of the empirical research.

Overview of research objectives and justification of approach

As has been discussed at length in this thesis, the primary aim of this research was to provide a behavioural account of donor family organ donation consent via the application of the Behavioural Perspective Model (BPM) of purchase and consumption. As previously discussed in chapters one and two, the existing literature concerning donor family consent has lacked a strong theoretical base, with researchers often "*going to the well*" and reaching for existing social cognitive models, such as the Theory of Planned Behaviour (Ajzen, 1991) to conveniently accommodate their study's factors (Feeley, 2007). A model which incorporates *both* the individual level and external factors that influence the donor family decision making process is notably absent from the existent literature. In addition previous studies have either shown a tendency to focus solely on the pre-determinants of behaviour that reside within the decision maker (i.e. attitudes), or to exclusively focus on the external factors that may influence the decision maker. A holistic model that accounts for *both* the individual level factors as well as the situational factors has yet to be applied to this important health context. Furthermore a model which also allows the researcher to investigate the donation decision making process from a pre-behavioural standpoint right through to post-behaviour evaluation and behaviour is markedly lacking. These aforementioned gaps in the existent literature are not insignificant, and are addressed in this thesis via the application the Behavioural Perspective Model (Foxall, 1990, 1997) to this unique context.

As will be recalled from chapter two of this thesis, the BPM is a neo-Skinnerian model with the three term contingency at its very heart (Foxall, 1990, 1997). Conceptually the framework stems from the Skinnerian premise that the behaviour of an individual is determined by the contingencies of reinforcement under which they are emitted (Skinner, 1938; 1953; 1974). Put simply, it is the consequences of an action or related behaviour that determine whether repetition will occur. The BPM asserts that an individual's behaviour can be predicted from two elements of the model that have situational influence: (1) the scope of the behaviour setting, (2) the utilitarian and informational reinforcement signalled by the setting as primed by the individual's individual learning history (Foxall, 1999, p.150).

As discussed in chapter two of this thesis the BPM framework was selected due to the distinct advantages it possessed over existing models that have been utilised in past donor family research. Firstly as already noted, despite the existing literature consistently demonstrating that the decision to consent by families is influenced by a wide range of *both* individual level and external factors, to date a model that integrates all the possible contributing factors is notably absent. The need for a stronger theoretical base has been identified in the existent organ donation literature, which has emphasised the need for new theory and theory driven methods in the field of organ donation research (Shanteau, 1988, 1986; Radecki and Jaccard, 1997; Feeley, 2007). The present thesis has argued that the BPM provides one such model, where both the individual level factors of the potential donor family can be examined through the learning history construct and the situational influences explored through the behaviour setting variables. Therefore this model offers a truly holistic depiction of the behaviour under study.

Secondly the BPM framework is inherently solution orientated, since it focuses its attention towards situational elements that can be manipulated and altered as to increase likelihood of consent. In the context of the present study this means elements of donation process that can be manipulated and changed by policy makers and organ donation requesters. This is a distinct advantage over existing models in the organ donation literature that solely examine pre-existent variables that reside inside the individual and therefore are beyond the control of those who

seek to increase donation. One such example is the potential to modify the patterns of reinforcement presented to the potential donor family in the request situation as a means of stimulating consent, such as offering financial incentives or providing informational feedback on performance. Unlike traditional social cognition models such as the Theory of Planned Behaviour (Ajzen, 1991), which focus purely on factors pre-existent within the decision maker which are largely outside of the control of those seeking to influence potential donor families, the BPM focuses on factors that can be controlled and altered, therefore providing a means of potentially stimulating organ donation levels via intervention. Due to this particular strength the BPM has the potential to be a valuable tool for social marketers, health care practitioners and academics alike.

Thirdly the BPM is a framework that allows for the analysis of the decision maker's behaviour in context. This means that the actions of other parties within the immediate behaviour setting can be analysed on equal terms. This is particularly important advantage over traditional social cognitive models that have been previously utilised in this area, as they tend to analyse the family's decision making process in isolation, with the actions of other influential actors within the immediate environment being largely ignored or grouped erroneously under the subjective norm category. In the context of donor family consent the actions of others within the request environment have been shown to exert considerable influence over the final consent outcome (Douglass, Daly *et al.*, 1995; Siminoff, Gordon *et al.*, 2001; Cleiren, Van Zoelen, 2002; Breikopf *et al.*, 2005; Rodrigue, Cornell *et al.*, 2006; Jacoby & Jaccard, 2010). However how these external factors interact with the individual decision maker's unique learning history has not been addressed in the existent literature to date.

Lastly, whilst the majority of studies in the existent literature have focused on the pre-determinants of donor family consent, such as the individual differences evident between donors, non-donors and their families, or the measurement of social cognitive variables such as attitudes and intentions, radical behaviourism focuses exclusively on the *actual* behaviour of providing consent for organ donation. This can be considered a particular strength of this

perspective, since social cognitive theories often do not predict actual behaviour accurately, and that an intention to engage in a given behaviour is not indicative of the *actual* behaviour of providing consent, especially since these intentions are not static and may change over an individual's lifetime. In addition, attitudes can be affected by a wide range of individual biases (Bemmaor, 1995; Morwitz, 1997; Morwitz & Sun, 2010). Therefore because the BPM firmly directs its attention toward the *actual* behaviour of consent, rather than towards pre-behavioural precursors of consent it lends itself to being an ideal framework to investigate (1) the interaction between an individual's learning history and the request situation (2) the impact of the request situation on consent (3) the patterns of reinforcement that increase likelihood of a positive consent outcome.

Against this background, the present thesis proposed three overarching research questions that would serve as a guide for the empirical phases of this thesis. The research process aimed to assess whether the BPM is a viable interpretive framework for this unique context and to identify situational influences and patterns of reinforcement that were associated with providing consent to organ donation. The final objective of the research being to successfully identify the most effective way of stimulating consent from potential donor families. The three overarching research questions were formally expressed as:

1) Can family organ donation consent be understood as an operant process utilising the BPM framework?

2) What patterns of reinforcement increase likelihood of organ donation consent?

3) Can donor family consent be stimulated via behavioural intervention?

Overview of research strategy

To address the aforementioned research questions that guided this thesis a mixed-method sequential research strategy was adopted. This approach was utilised as this particular design is useful and well suited to contexts where the researcher needs to (1) explore a social phenomenon in depth and then measure its prevalence, (2) develop and test an instrument or (3)

test aspects of an emergent theory (Creswell *et al.*, 2007; Creswell, 2009). In the context of the present research all three of these outlined reasons were applicable, therefore a sequential mixed method research strategy was deemed the most appropriate.

The first empirical phase utilised a case study approach, drawing upon multiple sources of evidence (n = 55) to explore the donor family decision making process. The aim of study one was threefold in nature. Firstly study one aimed to address research questions one by providing evidence to validate the BPM as an explanatory framework in the context of donor family consent. Secondly study one sought to validate the pre-determinants of consent behaviour that had been previously identified during the literature review in chapter two, so that a learning history instrument could be designed for the subsequent study. Thirdly study one sought to identify situational factors that influenced donor family consent outcomes, as to inform the design of the eight scenarios that would represent the eight contingency categories within Foxall's (1990, 2005) consumer behaviour typology, and to also help refine research propositions regarding the relationship between individual BPM constructs and consent outcome (i.e. behaviour setting and consent).

The second empirical phase employed a laboratory experiment approach to address the third research question regarding how donor family consent might be stimulated. Therefore the second phase of this thesis built and expanded upon the results generated from the first study. Study two served the purpose of quantitatively testing the respective influences of learning history, behaviour setting scope, emotion and reinforcement pattern on donor family consent. The influence of learning history was measured via a specifically developed learning history questionnaire which was designed in light of the literature review conducted and documented in chapter two and the results obtained from study one. The laboratory experiment employed a repeated measures design, where all participants (n = 50) were exposed to eight different organ donation request scenarios, which represented the eight contingency categories of the BPM typology of behaviour. This generated 400 situations for final analysis (50 x 8 = 400), the results of which are documented in chapter five of this thesis.

In the following section the present chapter will provide a brief overview of the key findings that have emerged from the data obtained from the sequential, dual phase research strategy that has been outlined above. Five key findings have resulted from both phases of the data collection process and have corroborated with much of the existent literature regarding donor family consent. The specific implications of these findings will be discussed in a later section concerning the contribution of this thesis to both the BPM programme and organ donation research in general.

Overview of key findings

Validation of the BPM's applicability as an interpretive device in donor family consent

Firstly the present research has provided validation of the BPM framework in the particular context of donor family consent. Until this point, the BPM has only been empirically applied to traditional consumer contexts, such as consumer brand choice (Foxall & James, 2003; Foxall & Schrezenmaier, 2003; Foxall, *et al.*, 2004; Oliveira-Castro *et al.*, 2005, 2006;), consumers reactions to shopping environments (Foxall & Greenley, 1999; Soriano *et al.,* 2002; Foxall & Yani-de-Soriano, 2005), socially responsible consumption (Davies *et al.*, 2002; Foxall, Oliveira-Castro *et al.*, 2006), and illicit consumption (Xiao and Nicholson, 2011) amongst others. To date the BPM framework has yet to be adopted in the investigation of health choice behaviours, despite there being no reason to suppose that the model's central tenants would not be equally applicable in this context. As discussed at length in chapter one and two, one of the principle aims of this thesis was to produce a behavioural account of donor family consent through the application of the BPM and this was achieved through the sequential dual-phase research strategy employed by this thesis.

Both study one and two have demonstrated the suitability and strength of the BPM as a flexible interpretive device when applied to this unique health context. Specifically study one has illustrated the applicability of the BPM's central tenants to the context of donor family consent, by showing that the decision to provide consent for organ donation is influenced by a wide

range of individual level and external factors, as depicted in the BPM schema. Through the analysis of donor family accounts and public policy documents (n = 55), study one demonstrated that the BPM is a useful and insightful interpretative device for identifying the pre-determinants of consent behaviour via the individual learning history construct, but also in exploring the contextual and situational elements of the decision making process that may influence consent behaviour. Through the systematic application of the BPM study one was able to achieve a truly holistic picture of the whole consent process, something which to date has been notably lacking in the existent organ donation due to the tendency of researcher's to depend on social cognition models. The strength of the BPM in this context is illustrated by the fact that all elements specified in the schema were evident in the donor family narratives that were utilised in study one. Furthermore the BPM scheme afforded the analysis of the whole consent process, from pre-donation right to post-donation evaluation.

In relation to study two, the BPM's eight contingency categories of consumer behaviour were effectively applied to the donor family consent context. Specifically, the four operant classes and eight individual contingency categories (CCs) proposed in the BPM literature were shown to be a novel means of mapping the differing approaches to stimulating organ donation consent in the UK that have been proposed in resent organ donation policy literature (Department of Health, 2008; Nuffield Council on Bioethics, 2011; BMA, 2012). In particular the four distinct operant classes that have been set out in the BPM typology of consumer behaviour have been shown to be an excellent means of depicting the spectrum of possible organ donation intervention strategies, from soft altruistic focussed intervention strategies right through to more hard lined individual benefit focused ones, such as the use of financial incentives. This particular aspect will be discussed further in more depth in the section that outlines the practical contributions of the research documented in this thesis.

It can therefore be argued that this thesis has fulfilled its primary research objective of producing an operant account of donor family consent via the successful application of the BPM schema and accompanying typology of behaviour to this health context.

The importance of learning history in donor family consent

The second key finding obtained from the body of work contained within this thesis is that an individual's unique learning history has fundamental importance and influence in the donor family consent process. As will be recalled from earlier chapters in this thesis, a central precept of the BPM is the concept of an individual's unique behavioural learning history. This variable centres on the premise that the behaviour of an individual evolves and develops during their lifetime as a direct consequence of their history of performing behaviours with their reinforcing outcomes (Foxall, 1997, 1990). The results obtained from the sequential research strategy employed in this thesis not only affirm the important role of learning history in the consent process, but also have demonstrated that it can affect an individual's preference of intervention type. Put simply, depending on the level of learning history experience an individual possesses at the time of the request, different methods of stimulating their consent will be preferred.

In study one various types of learning history were identified as being associated with a positive organ donation consent outcome. Within the dataset (n = 55) four reoccurring sources of learning history were identified, (1) positive attitudes towards organ donation, (2) positive subjective norms (3) direct experience of the hospital environment and similar behaviours 4) indirect experience obtained through third parties, most notably the media and social acquaintances. These four themes reoccurred in the overwhelming majority of accounts within this dataset (90%), thus demonstrating the significant role learning history plays in the donation consent process. However despite the overwhelming positive learning history held by those in the sample, some negative aspects of learning history were also evident. Specifically donor families in the dataset reported concerns over negative press coverage in the media and fears regarding dismemberment and organ allocation (the *George Best* effect). This particular finding corroborates with the existent organ donation literature regarding concerns about dismemberment (Exley *et al.*, 2002; Siminoff, Lawrence, 2002; Barber *et al.*, 2006; Ghorbani *et al.*, 2011) and the impact of the media on organ donation consent and refusal (Moray *et al.*, 1999; Maloney & Walker, 2000; Matesanz, 2002; Asher *et al.*, 2005; Harrison, Morgan and Chewning,

2008; Quick, 2009). These findings also demonstrate that organ donation decision makers can hold *both* positive and negative attitudes towards organ donation simultaneously, and that consent depends on which elements a triggered during the request situation.

In the second empirical study each participant's learning history was assessed via a specifically developed questionnaire, which sought to measure their attitudes, subjective norms, direct and indirect experiences towards organ donation. As will be recalled this learning history questionnaire was designed and developed in light of the conducted literature review documented in chapter two and the results obtained from the exploratory case study documented in chapter four. The results obtained from the analysis of study two validated the proposition that learning history significantly influenced likelihood of organ donation consent. In the sample used in study two those with higher levels of learning history were more likely to consent to organ donation when requested across all operant classes, whereas those who reported lower levels of learning history were less likely to consent across all scenarios. When tested the differences in consent between the two learning history groups were statistically significant across all four operant classes, thus demonstrating the powerful influence of learning history in the final consent outcome. This finding coupled with the qualitative findings reported in chapter four of this thesis, highlight the vital importance of improving the general population's overall learning history regarding organ donation and related issues through the implementation of long term educational programmes.

Another intriguing finding concerning learning history that emerged from study was that those with high and low levels of learning history differed in their preference of pattern of reinforcement. The highest level of consent achieved for the high level learning history group was in the Incentivised donation operant class, with a consent rate of 92 % being achieved. In contrast this operant class was the second least effective class in stimulating consent amongst the low learning history group, with a consent rate of 52 % being achieved. The most effective operant class for stimulating consent from the low learning history group was altruistic donation class, with an overall consent level of 70%. These findings demonstrate that learning history

influences what pattern of reinforcement appeals to the decision maker, with those equipped with higher levels preferring highly utilitarian reinforcement and those with lower levels preferring highly informational reinforcement. One interpretation could be that individuals who are equipped with a higher level of learning history may be more tolerant towards more aggressive intervention strategies, such as the offering of financial incentives because they possess the relevant history that makes them less likely to be offended or suspicious of such inducements. Conversely, those who lack the requisite learning history may treat such hard intervention strategies with suspicion due to possessing lower levels of medical trust, as well as less favourable attitudes and subjective norms towards organ donation. In the existent literature concerns have been raised about the introduction of financial incentives to stimulate consent, on the basis that they could potentially hamper donation levels by undermining the gifting aspect of organ donation whilst jeopardising trust between the medical profession and patients (Department of Health, 2008).

Open vs. closed behaviour setting scope

A third key finding obtained from the data of both study one and two was that individuals in both studies reported a preference for more open behaviour settings, regardless of their level of learning history. As will be recalled, the scope of the behaviour setting is an integral variable in the BPM framework, varying from relatively open, where an individual is presented with multiple choices and exerts a great degree of control, to being relatively closed in nature with the decision maker only being presented with a restricted number of choices and exerting relatively little control in the environment (Foxall & Yani-de-Soriano, 2005).

In both phases of the empirical investigation present in this thesis, decision makers consistently reported a preference for more open settings where they felt they exerted more control in the environment. In study one donor families reported that not feeling pressurised or rushed by medical staff during the decision making process was an important aspect of the behavioural environment and contributed towards their final decision to consent. Furthermore donor families within the dataset reported that they felt that the decision to consent to organ donation

was theirs alone, thus demonstrating the level of control they felt they were entitled to exert in the environment as close family of the potential donor.

The results obtained during study one were corroborated by those reported during the second empirical phase. In study two of this thesis the influence of the behaviour setting scope on likelihood of consent was empirically tested. The resultant data showed that open behaviour settings (CC1, CC3, CC5, CC7) were more effective in simulating consent than their closed setting counterparts (CC2, CC4, CC6, CC8) across all operant classes. As will be recalled from earlier chapters in this thesis, previous studies have found that potential donor families who feel pressurised are less likely to consent when requested (Siminoff *et al.*, 2001, Cleiren, Van Zoelen, 2002), and that families who are given sufficient amounts of time in an unpressurised manner are more likely to consent (Dejong *et al.*, 1998; Siminoff *et al.*, 2001; Haddow, 2004; Jacoby *et al.*, 2005; Rodrigue *et al.*, 2006, Rodrigue *et al.*, 2008). Therefore the findings of both phases of the empirical strategy documented in this thesis corroborate and build upon these previous studies, offering a fresh perspective.

The results reported in this thesis concerning the influence of behaviour setting scope highlight the care that should be taken by policy makers before introducing any changes to the organ donation consent process that may be interpreted to restrict the much valued freedom of choice donor families feel they are entitled to. This particular issue will be discussed later on within this chapter in the section which addresses the practical contributions and implications of the present research.

The role of pleasure in donor family consent

A fourth key finding resulting from the empirical investigation documented in this thesis concerns the role of pleasure in the organ donation consent situation. In both phases of the empirical investigation, direct pleasure and satisfaction from facilitating the donation process was identified as a direct benefit for donor families. In study one the vast majority of donor families within the sample reported positive feelings of satisfaction, comfort, pride and pleasure which stemmed directly from the knowledge that they had facilitated the consent process and

that something good had resulted from the tragic death of their family member. The feeling of comfort, satisfaction and pride derived directly from providing consent to organ donation has been reported in the existent literature (Parisi and Katz, 1986; Sque and Payne, 1996; Van Den Berg *et al.*, 2005; Manzari *et al.*, 2012). However it has been emphasised that this is not comfort necessarily derived from the decision makers doing something of value but instead from facilitating their loved one's wishes (Sque and Payne, 1996).

The second phase of the research process sought to empirically test the association between affective responses to request situations on organ donation consent through the application of Mehrabian and Russell's (1974) environmental psychology model (PAD). The results obtained from study two indicate that the Pleasure dimension of PAD is strongly and positively associated with organ donation consent. This finding corroborates with much of the qualitative evidence presented in the existent donor family literature, where previous qualitative studies have identified positive emotions being felt by donation decision makers as a direct consequence of having provided consent for donation (Parisi and Katz, 1986; Van Den Berg *et al*, 2005; Manzari *et al*, 2012). However to the researcher's knowledge this is the first time that this association has been empirically verified through quantitative measures. This finding is particularly interesting and warrants further research in the future, as it could have potentially important implications in the sphere of social marketing and organ donation request practice, something which will be discussed in greater depth later in this chapter regarding the practical contributions of the present thesis to the field of organ donation research.

Situational influences and donor family consent

The final key finding produced by the empirical work contained in this thesis was that different situations produce varying levels of consent. Although donor family consent occurs across all operant classes, certain categories were more effective in stimulating consent than others regardless of the level of learning history possessed by the decision maker. The most effective operant class at stimulating consent amongst the whole sample utilised was the Altruistic donation class, traditionally known as the Accumulation class in the BPM literature, which

achieved an overall consent rate of 78 %. As will be recalled this particular class is characterised by its high levels of informational reinforcement and relatively low levels of utilitarian reinforcement. Therefore in this particular health context this consumer class of behaviour should be classified as altruistically focussed. In study two the Altruistic donation operant class consisted of scenarios that offered delayed, high informational reinforcements to the decision maker. This included informational reinforcements such as a prioritised place on the transplant list for them and their family to safeguard their future health, a donor memorial to acknowledge the gift and detailed and regular feedback from the recipients so that they could build a relationship with the recipient and see how their gift had changed and improved the lives of others. These soft, altruistically focussed incentives were the most effective in stimulating consent from both high and low level learning history groups, thus illustrating the powerful potential of informational reinforcement in stimulating high levels of consent from potential donor families.

In direct contrast the least effective operant class for stimulating donor family consent was the Routine donation class of behaviour. This operant class merely achieved 54% of consent from the overall sample, regardless of learning history. This figure is approximate to the current level of consent reported by the NHS (NHSBT, 2013b), and in many ways reflects the current approach used by the NHS, which at present does not offer many tangible inducements to donate for potential donor families. As will be recalled from earlier in this thesis, this operant class is characterised by relatively low levels of both utilitarian and informational reinforcements and is traditionally known as the Maintenance category in the BPM literature. The Routine donation scenarios presented to participants during study two consisted of a very basic offering to the decision maker, thus reflecting the low levels of reinforcement present in both CC7 and CC8. In the Routine donation scenarios, participants were offered basic and anonymous information regarding the recipients, an acknowledgement of appreciation and it was highlighted that organ donation was a routine procedure that may provide some comfort to the donor family. In addition it was emphasised that organ donation was part of being socially responsible. These two operant classes intended to reflect the routine nature of organ donation, something

which was not effective in stimulating consent. This is an interesting finding, since the Department of Health has emphasised that their ultimate aim is for organ donation to "*become a usual rather than unusual event as part of end-of-life care across the NHS*" (Department of Health, 2011, p.7). The results obtained from study two indicate that this aim may be a long way off from fruition, and that a long-term educational programme is needed in order to change individual's view of organ donation as a special gift. This is supported by the results reported in study one, where donor families emphasised the gifting aspect of the donation process, and the specialness of providing a chance of life for others. Arguably by emphasising the routine and ordinary nature of organ donation, policy makers could be inadvertently undermining the gifting aspect of donation, and the sacrifice donor families make by providing consent.

As for the other operant classes, the Societal accomplishment class was the second most effective in stimulating consent regardless of learning history, achieving an overall consent rate of 68%. This provides further evidence and weight behind the conclusion that high levels of informational reinforcement are needed in order to stimulate organ donation consent, especially amongst individuals who do not possess a strong learning history. It also highlights that high levels of utilitarian reinforcement are tolerated by lower learning history groups once high levels of informational reinforcement are also present, therefore demonstrating that the key to stimulating consent is positive feedback from the hospital, recipient and society, something that will be discussed in greater depth later in this chapter.

Lastly as will be recalled from earlier this chapter the Incentivised donation operant class produced mixed findings regarding its effectiveness in stimulating consent, achieving the highest rate of consent amongst those with a high level of learning history 92% and achieving the second lowest rate of consent amongst those in the lower learning history group 52%. Again, this highlights the importance of informational patterns of reinforcement for lower learning history groups, and the fact that higher levels of learning history make individuals more robust to harder intervention strategies.

Research contributions

The following sections will discuss in detail the original contribution the present thesis has made to existing knowledge to both the donor family consent research sphere and the development of the BPM programme. The contributions contained within this thesis are threefold and can be classified as either (1) theoretical (2) practical or (3) methodological in nature. Each one will be discussed in turn are and are contained in the following sections of this chapter.

Theoretical contribution

The present section will discuss the theoretical contributions that the present thesis has made to both the field of organ donor family research and the ongoing development of the BPM research programme. Firstly the sequential empirical investigation presented within this thesis has made a theoretical contribution to the BPM programme of research via the application of the framework to a health behaviour which falls outside of the domain of traditional consumer contexts which have been previously explored using the framework (e.g. Foxall & Greenley, 1999; Leek *et al.*, 2000; Foxall & James, 2003; Foxall & Yani-de-Soriano, 2004; Xiao & Nicholson, 2011). Through this application and adaptation of the BPM framework and its accompanying typology of consumer behaviour, this thesis has contributed to the ongoing development of the behaviourist approach to consumer research. As discussed earlier within this chapter, the present thesis has provided further validation of the BPM as an interpretive device in this particular health context, thus demonstrating the framework's flexibility and applicability to a wide range of contexts outside of the traditional consumer environment domain.

Secondly the work documented in this thesis has also made a theoretical contribution to the wider organ donation research field by providing a theoretical framework that incorporates *both* individual level and external factors in the decision making process. The field of organ donation research has been routinely criticised for its lack of strong theoretical base (Shanteau, 1986, 1988; Radecki & Jaccard, 1997; Feeley, 2007). Furthermore, when theory has been utilised it has

shown a tendency to look at aspects of the decision making process in isolation which has often resulted in a fragmented depiction of the behaviour under investigation. The BPM fills this considerable gap by providing a theoretical framework that allows the examination of both the individual level factors that influence consent behaviour through the learning history construct, and the situational elements through the behaviour setting variables and reinforcement patterns. Furthermore the BPM possesses the unique capability of being able to examine the whole consent process from pre-consent behaviour right through to post-consent evaluation and behaviour in the one model.

The BPM also offers a novel and comprehensive typology of consumer behaviour through the BPM matrix that has been successfully adapted in this thesis to reflect the unique context of organ donor consent. This typology can be successfully used to map intervention strategies for stimulating consent. In the one typology of behaviour all patterns of reinforcement are addressed, including hard lined personal incentive focussed interventions where the benefit to the individual decision maker is highlighted (CC3, CC4), to more soft altruistic focussed strategies where the incentives are more informational in nature (CC5, CC6), and all combinations of both informational and utilitarian reinforcement in differing degrees (CC1, CC2, CC7, CC8). Furthermore with the addition of behaviour scope dimension, open and closed environments add another facet to intervention strategies by indicating the level of choice and freedom presented to the decision maker.

Lastly, the present thesis has provided a theoretical contribution in so far as through providing empirical evidence of donor family consent in different situations. More specifically, the BPM matrix has provided a theoretical and systematic method to investigate donor family consent behaviour in various request situations. One existing knowledge gap in the donor family literature is that this behaviour has not been investigated across different situations simultaneously, despite the fact that previous research demonstrates that situational influences are critical to donor family behaviour. For example, the family's interactions with medical staff (Douglass, Daly *et al.*, 1995; Siminoff, Gordon et al, 2001; Cleiren, Van Zoelen, 2002; Jacoby *et*

al., 2005; Rodrigue, Cornell *et al*, 2006; Jacoby and Jaccard, 2010), the appropriateness of the setting in which the request is made (DeJong, Franz *et al.,* 1998; Gortmaker*, et al.*, 1998; Cleiren, Van Zoelen, 2002; Jacoby, Breikopf *et al.*, 2005) and time related factors such as the time of the approach and the time given to the family to make the decision (Gortmaker *et al.*, 1998; Siminoff, Gordon *et al.*, 2001; Siminoff *et al.,* 2002). As already noted, one plausible reason for this deficiency may be that to date there was no sufficient model existent in the literature that could successfully map out all the possible types of donor request situations e.g. a model that allowed for comparisons between opt-in and opt-out behaviour settings and differing modes of incentives.

It should be stressed that the behaviourist approach adopted in the present thesis is not intended to replace the cognitive approach which to date has dominated the field of organ donation research, but should instead be seen as complementary approach to the existent perspectives.

Practical contributions

The work contained within this thesis has numerous practical contributions, most notably for health care practitioners working in the field of organ donation, health care policy makers, as well as for those who work in social marketing practice who seek to promote organ donation to the wider population.

Firstly this thesis has provided a novel means of mapping potential intervention strategies for increasing organ donation consent. The typology consisting of the four operant classes of organ donation behaviour founded upon the BPM typology of consumer behaviour. As will be recalled these operant classes of behaviour can be distinguished depending on the pattern of relatively high/low utilitarian reinforcement and relatively high/low informational reinforcement which maintains the responses of which these classes are composed (Foxall, 1997, 1990). In addition to the four outlined categories of organ donation behaviour, once the dimension of behaviour setting scope is included in this operant classification of behaviour, an eightfold categorisation is produced as depicted in the BPM contingency matrix. Therefore it is an ideal

typology for effectively mapping hard and soft intervention strategies, such as soft strategies that rely heavily upon informational reinforcement belonging in the Altruistic donation category or hard strategies that rely heavily upon utilitarian reinforcement belonging in the Incentivised donation category. It is also effective in mapping potential legislative changes as the closed behaviour setting reflects restricted and/or mandatory choice, and the more open setting an opt-in system of consent.

A second element of this thesis that has strong practical implications are findings obtained from study one and two regarding the relationship between behaviour setting scope and organ donation consent. In both phases of the adopted research strategy there was a strong preference for more open behaviour settings. Donor families in the first phase consistently reported that having control over the final decision, and not feeling pressurised or rushed into providing consent were important factors in the decision making process. As will be recalled this association was then tested in the second empirical phase. In study two, open settings were characterised by an emphasis on the decision to consent being solely the family's thus emphasising the control they had over the situation. In direct contrast the closed settings of study two were characterised by the emphasis being on the fact that the potential donor had not opted-out of ODR and therefore if no objections were made by the family the process would precede, thus restricting the perceived control of the family in that situation. The resultant data of this study indicate that regardless of learning history level, open behaviour settings (CC1, CC3, CC5 and CC7) were consistently more effective in stimulating organ donation consent across of all operant classes. One of the more practical implications of this finding is that policy makers should tread carefully before implementing any changes in donor family protocol or legislation that may be interpreted as restricting or impeding the freedom of choice currently enjoyed by donor families faced with this difficult situation. The findings from both study one and two indicate that any restriction on donor family freedom of choice is likely to hamper donation levels.

A third element of this thesis that may have practical implication is the finding from study two that pleasure is significantly and positively associated with organ donation consent. This result could have potential implications for both social marketers and health practitioners who seek to increase organ donation registration and family consent. One strategy for stimulating consent could involve highlighting the pleasurable aspects of providing consent for organ donation in social marketing materials, such as highlighting the personal satisfaction, comfort and pride that may be derived from facilitating the process. From a health-practitioner perspective, highlighting the comfort and satisfaction that is often reported by donor families could be an element in the request discussion.

A fourth area from this thesis that has practical implications are the results obtained from study one and two regarding the role of learning history in the donation consent process. In both phases of the empirical investigation contained within this thesis, positive learning history was identified as highly influential in producing a positive consent outcome. In study two those who possessed a higher level of learning history were more likely to consent across all operant classes. This finding highlights the importance of educating the general public on the issue of organ donation, in order to dispel the myths surrounding the process and alleviate the common fears associated with the procedure of donation. Of particular concern in this study was that of the fifty participants who partook in the second phase of the research, over half had never seen a televised organ donation campaign despite the fact that at the time of the experiment one was running on television. This raises the important question of what is the best means of educating the general public about organ donation? This subject is beyond the scope of the current thesis, however results from the first phase of the empirical process indicate that the general media could have a strong role to play in increasing donation and prompting discussions amongst families. Only by confronting the myths and fears associated with organ donation head on through documentaries and educational programming will an improvement in the general public's learning history be achieved.

Finally, the findings within this thesis highlight the importance of providing high levels of informational reinforcement to potential donor families in the form of high levels of feedback and recognition during the post-donation period. Study one highlighted the fact that feedback was vital to donor families, especially from the recipients of the donated organs. Letters of correspondence from the recipients were considered to be treasured items by donor families and sources of great comfort and pride. Those donor families within the sample utilised in study one who failed to receive this feedback were disappointed and in some cases angry. At present writing to one's donor family is entirely voluntary but strongly encouraged. In light of the results obtained from this thesis, one of the practical implications is that this form of feedback should become a mandatory aspect of the donation process, so that the families who provide consent receive something valued back as part of a reciprocal process.

Methodological contribution

As will be recalled from chapter five of this thesis, donor family research is notoriously difficult to conduct due to common problems encountered by researchers in relation to access with relevant populations. In the context of the UK, studies in the field of donor family research have historically relied heavily upon retrospective accounts via qualitative interviews or on NHS archival data to inform their investigations of consent or refusal. For the second phase of the empirical investigation conducted for this thesis, the researcher wished to examine potential donor family decision making in situ. As observation of real-world organ donor family decision making was out of the question for various ethical and practical reasons, the researcher needed to formulate a novel means of simulating the donation request environment so that *actual* consent behaviour from potential donor families could be examined.

The result was a novel methodology of picture representation that included photographic images presented on PowerPoint slides with embedded audio messages. This approach had been previously utilised by Yermekbayeva (2011) in the context of m-advertising opt-in behaviour, and was adapted for the purpose of study two to enhance realism and immersion for the participants. The adoption of this particular design has differentiated this study from previous

BPM research that has presented consumer situations in purely textual format (e.g. Foxall, 1997b; Lutz & Kakkar, 1975; Mehrabian & Russell, 1974). As already noted, within the donor family consent literature consent has only been able to be examined retrospectively due to the highly sensitive nature of the topic. The novel methodology that has been adopted in study two has allowed consent outcomes to be examined at the time of decision making, a distinct advantage over previously utilised methodologies in the field of organ donation decision making.

Limitations of research

The previous sections have outlined the various contributions that this thesis has provided to current knowledge of donor family consent and in furthering the BPM programme of research. It is now at this point necessary to consider the limitations of the present thesis.

The first limitation of this thesis is methodological in nature and involves the nature of the sample utilised in study one. Firstly study one relied upon multiple sources of information including in depth interviews with a self selecting sample whose decision to consent had happened at least 12 months prior and the analysis of secondary sources such as secondary interview datasets, donor family blogs, online case studies and media interviews. The nature of the dataset raises some limitations. Firstly as the case study interviewees were a self-selecting sample they cannot be deemed to be representative of donor families per se. Furthermore in the bereavement research literature it is stressed that caution should be used when drawing conclusions from self-selecting samples as they may of opted into a study in order to discuss any unresolved issues surrounding their own experience and bereavement and therefore may not reflect a general experience (Sque, 1996). Secondly, the use of secondary sources such as secondary interview datasets, donor family blogs, online case studies and media interviews cannot be deemed as entirely representative of the phenomenon since a purposeful rather than a random sampling strategy was used when selecting units for analysis. However, it should be emphasised that the type of content analysis that was employed during the analysis phase of study one was more interpretive in nature. The goal being to simply describe the textual data that had been obtained by direst reference to Skinner's three-term contingency, and to examine

the themes, trends and patterns in those selected documents, with no attempt at making generalisations (Lijphart, 1971). The aim of study one was simply to gain insight into the behaviour of donor families in the organ donation consent environment and to construct an account of those behaviours in terms, which would render them as "*explained*" (Baum, 1994). Put simply, the primary aim of study one being to validate the BPM as an interpretative device in this unique context.

Another limitation of the present thesis is concerned with use of a convenience sampling strategy in study two. As will be recalled from chapter three of this thesis this strategy was employed for two important reasons. Firstly this approach was adopted because it is the least time consuming and expensive of all recruitment strategies (Saunders et al., 2003). Secondly, due to the sensitive nature of the research topic under investigation it was anticipated that recruitment of a sufficient number of participants in the specified time frame could be a potential problem if other recruitment strategies, such as probability sampling, were adopted. However despite the strengths of this strategy there is one important limitation associated with convenience sampling, namely it cannot be deemed representative of the population of the UK and therefore it can be accused of being un-generalisable beyond the sample utilised. In the context of study two, it should be stressed that the researcher made every attempt to limit bias in the sampling strategy by ensuring that the sample was highly diverse in terms of age, gender, ethnicity and education. Furthermore the researcher made every attempt to make sure that the sample utilised reflected the general population in terms of organ donation behaviour. In particular this meant ensuring that the level of organ donation registration evident at a national level was represented in the final sample, which at the time of the experiment was 31%.

Lastly another key limitation regarding the methods used in the documented research strategy involves the fact that study two consisted of a simulated request environment designed by the researcher that consisted of one behavioural setting rather than a real life organ donation request context. During study two, donor family consent was examined in eight request situations that were designed by the researcher to represent the patterns of reinforcement evident in the eight

contingency categories that make up the BPM matrix. These scenarios consisted of the one physical behaviour setting, a request scenario within a hospital and therefore do not reflect instances of more open settings, e.g. rare situations where the decision making process can be made at home. Although observing and measuring this complex behaviour in a naturalistic setting would have been preferable, it was impossible due to various ethical and practical reasons. Therefore a simulated environment offered the best alternative and was adopted as the approach to data collection in study two. It should be emphasised that the reinforcements included in the scenarios were drawn from existing proposals in the existing literature, such as financial incentives, donor memorial walls, certificates of appreciation etc and the designed setting of the hospital reflected an ordinary request scenario instead of more usual settings which would not be representative of the norm e.g. decision maker's home. This ensured that realistic reinforcements were presented to participants during the scenarios. In addition, it has been argued that in some instances the effects created in laboratories will be even stronger outside the laboratory, rather than weaker without the artificiality (Coolican, 2009).

Avenues for future research

In light of the results obtained through the sequential dual phase research strategy documented in this thesis, three particular avenues for future research have been identified by the researcher. Firstly, building upon the work that is documented within this thesis, the logical next step would be to examine the process of donor family consent in a real-life context, either through direct observation of the request process or through accumulating evidence via a donor family diary. This form of data collection would overcome some of the limitations outlined in the previous section. This form of data collection was beyond the scope of the present thesis for various ethical and practical reasons and would be a difficult and lengthy process to obtain; nevertheless it could prove to be an interesting and illuminating piece of research especially in a context where an opt-out system had been introduced in the UK (e.g. Wales from 2015). In this context the researcher could examine how the limiting of the scope of the behavioural setting has influenced donor family's decision making.

A second avenue for further research would be investigation of the role of the hospital and their staff in reinforcing organ donation consent behaviour and their relationship with donor families. In the existing BPM literature the bilaterally-contingent relationship between the marketing firm and the consumer has been proposed (Foxall, 1999). This process can be adapted to the context of the donor family consent, where the activities of the hospital and staff are similarly an operant process, concurrent with the Skinnerian three term contingency.

Requester

| S^D | $\rightarrow$ | R | $\rightarrow$ | S^R |
| Reinforcement | | Response | | Stimulus |

| S^R | $\leftarrow$ | R | $\leftarrow$ | S^D |
| Stimulus | | Response | | Reinforcement |

Potential Donor Family
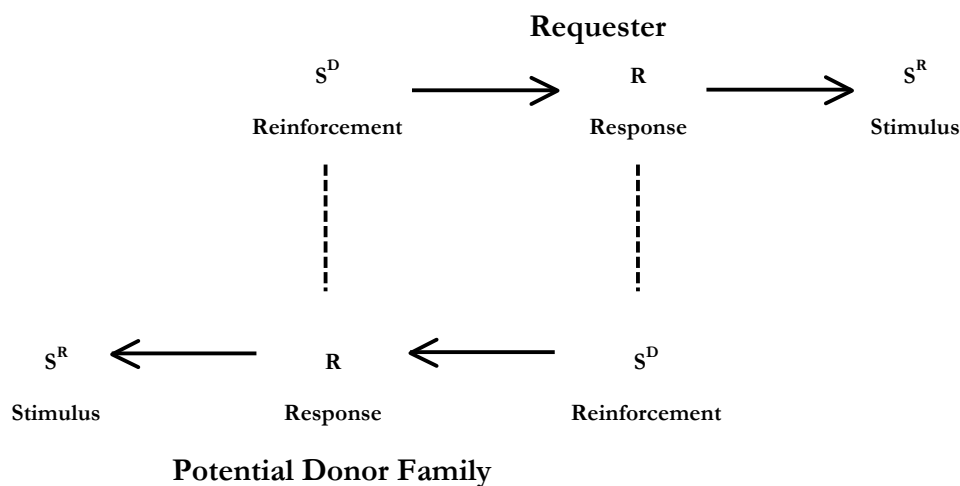
Figure 14. Adapted bilaterally contingent relationship between requester and donor family (Foxall, 1999)

The current thesis has shown that through the donor request situation a similar bilaterally contingent relationship exists between the hospital and the potential donor family to that proposed in the BPM between the marketing firm and the consumer (Foxall, 1999). In the organ donation request situation the requester signals the likely consequences that will result from a particular course of action, which in this case is consent or refusal. Depending upon the donor family's response, the hospital will engage in a series of activities, e.g. highlighting the benefits of donation, which will in turn be either positively or negatively reinforced by subsequent donor family responses. As illustrated in **Figure 14**, the behaviours of both the donor family and the hospital are interdependent and bilaterally contingent upon each other. An interesting avenue for future research would be to examine the actual training guidelines and

protocols used by transplant co-ordinators during their approach of donor families for consent, in order to explore this bilaterally contingent relationship in further depth.

Lastly, a third avenue for further research would build directly upon the findings of study two, to further investigate the role of pleasure in donor family consent and explore the possibility of revising the existing PAD scales for this particular context in order to try and achieved a better fit between the scales and the context under investigation. As already highlighted in study two of this thesis, the application of Mehrebian and Russell's (1974) PAD scales has produced mixed findings. The pleasure dimension of the scales was found to be strongly and positively correlated to consent across all operant classes. This is the first time to the researcher's knowledge that the relationship between pleasure and consent has been quantitatively measured and verified. This relationship warrants further investigation as it has potential implications for organ donation promotion and practice, which has been highlighted earlier in this chapter. A larger scale quantitative study measuring this pleasure dimension is one possible avenue of further research, possibly combined with a qualitative phase exploring the pleasurable aspects of donation process.

As for the other two dimensions of the PAD scale, one interpretation for the mixed findings of study two was that participants found it difficult to apply the terms used in the arousal and dominance scale to this particular context. Specifically, terms like jittery and aroused seemed problematic to participants in the final study, an issue that has been encountered by other BPM researchers (Yermekbayeva, 2011). Therefore in light of this, one potential avenue for further research would be the development and refinement of these two dimensions for this particular context, in order to achieve a better fit between the scales and the context under investigation.

A behaviourist view of donor family consent

In sum this thesis has sought to examine donor family consent from a behaviourist perspective, utilising the Behavioural Perspective Model (Foxall, 1990, 1997) as its principle explanatory framework. The principle objective of this thesis being to better understand the behaviour of

potential donor families towards granting consent, the various types of learning history which inform these decisions and the environmental contingencies that shape this complex and vitally important human behaviour

As noted in the introduction of this thesis, potential donor family refusal has consistently been identified as the biggest obstacle in improving organ donation rates in the United Kingdom (Radecki & Jaccard, 1997; Martinez *et al.*, 2001; Barber *et al.*, 2006; Vincent & Logan, 2012). Against this backdrop figures released by NHSBT show that approximately 40% of all approached families will deny consent for organ donation, a level that has remained unchanged despite an overall increase in donations in recent years (Barber *et al.*, 2006 NHSBT, 2013b). The direct consequence of this comparatively low rate of refusal is that three individuals die every day in the United Kingdom, which amounts to approximately 1000 per year. Therefore improving our understanding of this important human behaviour and formulating ways of how consent might be stimulated from potential donor families is of paramount importance. As has been discussed in the introduction chapter of this thesis, research to date has primarily been concerned with the pre-behavioural aspects of donor family consent, often utilising social cognition models such as the Theory of Reasoned Action (Fishbien & Ajzen, 1975) and the Theory of Planned Behaviour (Ajzen, 1991). Furthermore very little attention to date has been given to the role of situational influences on the decision making process, instead examining either the decision maker or the environment in isolation. The need for a stronger theoretical base has been identified in the existent organ donation literature, which has emphasised the need for new theory in the field of organ donation research (Shanteau, 1986, 1988; Radecki and Jaccard, 1997; Feeley, 2007). At present no theoretical model has been presented in the existent organ donation literature that can incorporate *both* individual level factors and external level factors in the donor family making process. This is a significant gap in the existing organ donation literature which this thesis has sought to address via the application of a behaviourist standpoint.

In conclusion, through the systematic application of the BPM explanatory framework to this unique health behaviour this thesis has presented an account of behavioural analysis of donor family consent. Subject to the limitations presented earlier within this chapter, the presented account appears to be both viable and comprehensive. Furthermore the empirical strategy has yielded considerable insights into (1) the learning history that informs these difficult consent decisions, (2) the environmental contingencies that shape donor family consent behaviour and (3) the nature of the situations in which donation decision makers will or will not provide consent. It has therefore fulfilled its three research objectives outlined in chapter one. This thesis has also offered contributions to both our current understanding of donor family consent and to the on-going development of the BPM research programme by extending its sphere of applicability into the health behaviour domain. By extending the BPM's applicability to the health domain this thesis has expanded the research possibilities future BPM researchers. Furthermore this thesis has been solution-orientated and has provided valuable insights into possible ways in which organ donation consent might be stimulated from potential donor families. This has potential implications for future researchers, social marketers and health-care practitioners alike. Lastly, this thesis has demonstrated that despite the death of behaviourism being episodically announced over the past 50 years, this branch of psychology is still alive and holds the capacity to bring fresh and unique insights into complex forms of human behaviour, as a complementary perspective to existing dominant paradigms.

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Appendices

Appendix 1

Table i) <u>Different consent systems used around the world (Organ Donation Taskforce, 2008)</u>

Option	Details
1: A 'hard' opt out system	Doctors can remove organs from every adult who dies – unless a person has registered to opt out. This applies even if relatives know that the deceased would object to donation but had failed to register during life. Example: **Austria.**
2: A 'hard' opt out system which does not cover some groups	Doctors can remove organs from every adult who dies – unless a person has registered to opt out <u>or</u> the person belongs to a group that is defined in law as being against an opt out system. Example: **Singapore where Muslims chose to opt out as a group.**
3: A 'soft' opt out system	**Option 3a: No need to consult relatives** Doctors can remove organs from every adult who dies – unless a person has registered to opt out <u>or</u> the person's relatives tell doctors not to take organs. It is up to the relatives to tell the doctors because the doctors may not ask them. Example: **Belgium.** **Option 3b: relatives should be consulted** Doctors can remove organs from every adult who dies – unless a person has registered to opt out. it is good practice for doctors **to ask the relatives** for their agreement at the time of death. Example: **Spain.**

4: A 'soft' opt in system (current system employed in the UK)	Doctors can remove organs from adults who have opted in. it is up to each person to decide if they want to opt in. it is normal practice to let relatives know if the person has opted in and doctors can decide not to proceed if faced with opposition from relatives.
5: A 'hard' opt in system	Doctors can remove organs from adults who have opted in. It is up to each person to decide if they want to opt in. relatives are not able to oppose the person's wishes.
6: A choice to opt in or opt out	**Option 6a:** people **can** register their choice to opt in or opt out.
	Option 6b: people **must** register their choice to opt in or opt out.

Table ii). International consent rates for deceased donation in 2009 (Council of Europe 2010).

Country	Consent rate %	Country	Consent rate %
Estonia	52.4	Poland	88.8
Greece	83.6	Romania	37.5
Ireland	82.7	Spain	83.6
Italy	69.6	United Kingdom	59.7
Latvia	54.2	Cuba	85.5
Lithuania	69.6	Israel	54.1
Malta	90	Turkey	31.3
The Netherlands	52.9	Venezuela	73.6

Appendix 2

Case study ID	DF1
Location	Staffordshire
Date of interview	10/07/11
Age	35
Marital status	Married
Religious affiliations	Church of England
Ethnicity	British
Relationship to donor	Son
Gender	Male
Donor's name, gender and type of donation	**********, female and multi-organ donor
Date of donation	31 May 2005
Recruited from	Donor Family Network call for volunteers
Other interesting information	He was able to provide the original letter from transplant co-ordinator and information guide that was given to him and his family at time of request. He was also able to show me the letters he had received from recipients. He knew the founder of the Donor Family Network before the incident and subsequent request. He and his wife are registered donors.

Case study ID	DF2
Location	Buckinghamshire
Date of interview	02/09/11
Age	62
Marital status	Widowed
Religious affiliations	Church of England
Ethnicity	White British
Relationship to donor	Husband
Gender	Male
Donor's name, gender and type of donation	**********, female and multi-organ donor
Date of donation	2007
Recruited from	Donor Family Network call for volunteers
Other interesting information	He was able to provide the original letter from transplant co-ordinator and show me the keepsakes he was given by the co-ordinators. He showed me some letters from the recipients of his wife's organs.

Case study ID	DF3
Location	Preston
Date of interview	31/08/11
Age	35
Marital status	Single
Religious affiliations	NA
Ethnicity	White British
Relationship to donor	Mother
Gender	Female
Donor's name, gender and type of donation	**********, male and multi-organ donor
Date of donation	Summer 2008
Recruited from	Donor Family Network
Other interesting information	Her son had been in a car accident and subsequently became a multi-organ donor. He was the face of Transplant Week in 2008. Had set up a memorial website and had been involved in road safety campaigns.

Appendix 3

Understanding family organ donation consent – interview protocol

Introduction to the research aims, outputs, confidentiality and consent statement.

Duration: 60 – 90 minutes approximately

I.   **About you and the donor**

- General background of the participant and the donor:

    1. Relationship to donor

    2. Age

    3. Gender

    4. Religion

    5. Education

    6. Occupation

    7. Ethnicity

    8. Activities or involvement in charities/community based projects/ blood donation

    9. Donor status before the event.

II.   **Narrative of events leading up to donation request:**

    1. What type of injury was sustained by the donor?

    2. Where was the donor taken? Intensive care unit, accident & emergency or other?

    3. Time period hospitalised? Hours? Weeks?

    4. How were the family updated and by whom?

5. Level of explanation / information given by health professionals

III.   Learning history

1. Prior to the request had the family any direct experience of organ donation or transplantation?

2. How much knowledge did the family have prior to the request?

3. What was the family's main source of information?

4. Were they aware of a national donor shortage?

5. Had they seen any campaigns? Can they remember which ones?

6. Had they any form of education regarding organ donation during school years?

7. Had they come across any stories in newspapers or television that addressed the issue of transplantation?

8. Had the family discussed the issue of organ donation prior to the donation request / process?

9. Were any of the family registered on the organ donation register prior to the donation request?

IV.   Behaviour setting

Temporal aspects of the donation decision

1. How long between diagnosis of brain death and donation request (if applicable)?

2. Did the family perceive this as a suitable time frame or not? Explanation?

3. How long did the donation decision take the family? Explanation?

Physical aspects of the donation decision

1. What was the physical environment like?

2. Impressions of the hospital and ward?

3. Feeling toward medical equipment, tests and protocols?

Social aspects of the donation decision

1. Who was involved in the donation decision? Family? Friends?

2. During the process did extended family and friends visit / offer advice/ support?

3. What was your relationship like with the health care professionals?

Regulatory aspects of the donation decision

1. If family member belongs to an organised religion, did any religious rules have an impact on the donation decision?

2. Any self imposed rules? Where do they stem from? Family? School?

V. Perceived costs and benefits of donation

1. Why did you ultimately choose to donate? Explore each reason and where it stems from.

2. Did you or any family member involved in the donation decision have at any point have any reservations about consenting to donation? If so what were they and where did they stem from?

3. Where there any unforeseeable / unknown consequences of consenting to donation? Explore.

Appendix 4

Durham University

CONSENT FORM

Understanding family organ donation consent

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is confidential and voluntary and that I am free to withdraw at any time, without giving reason.

3. I agree to take part in the above study.

Please initial box

	Yes	No
4. I agree to the interview being audio recorded	☐	☐
5. I agree to the use of anonymised quotes in academic publications	☐	☐
6. I agree that my data gathered in this study may be stored (after it has been anonymised) in a specialist data centre and may be used for future research.	☐	☐

_____   _____   _____
Name of Participant   Date   Signature

Alexandra Rose Castagnino
_____   _____   _____
Name of Researcher   Date   Signature

Understanding family organ donation consent

This project is examining organ donation and, in particular, the experiences of families giving consent. It is an important area of research because 42% of families decline to give consent, despite 90% of the population feeling positive about organ donation, and we need to understand the reasons behind this discrepancy better. The project is searching for family members who have been through the experience of having to make a donation decision and who are willing to talk about aspects of their experience. The interviews will be informal and not too intrusive. The researcher is interested in the environment in which decisions are taken and the ways in which this, together with family members' background and experiences, influences the final decision.

Call for volunteers to participate in this study

This project is concerned with donor families' experiences and background and the donation decision. By learning about what you and other donor families have experienced, we hope to find out more about the environment and the donation decision. I am therefore asking relatives to share their experiences and any thoughts they have regarding transplantation during a 90 minute meeting at a mutually agreed time. Anything you may say during the study would be treated as confidential. Your name will not be recorded anywhere within the study, and of course, you would be completely free to withdraw at any time.

If you are interested in taking part in the study, or are generally interested in discussing the research, you can find out more by emailing Alexandra Castagnino at a.r.castagnino@durham.ac.uk. Any help would be hugely appreciated. The study is being fully supervised by Dr. Mike Nicholson and Dr. Sarah Xiao.

Appendix 5

Source origin, name	Source type	Reference number
Healthtalkonline Oxford health experiences group, interview 7	Secondary interview source	1
Healthtalkonline Oxford health experiences group, interview 10	Secondary interview source	2
Healthtalkonline Oxford health experiences group, interview 13	Secondary interview source	3
Healthtalkonline Oxford health experiences group, interview 14	Secondary interview source	4
Healthtalkonline Oxford health experiences group, interview 15	Secondary interview source	5
Healthtalkonline Oxford health experiences group, interview 16	Secondary interview source	6
Healthtalkonline Oxford health experiences group, interview 17	Secondary interview source	7
Healthtalkonline Oxford health experiences group, interview 18	Secondary interview source	8
Healthtalkonline Oxford health experiences group, interview 19	Secondary interview source	9
Healthtalkonline Oxford health experiences group, interview 21	Secondary interview source	10
Healthtalkonline Oxford health experiences group, interview 25	Secondary interview source	11
Healthtalkonline Oxford health experiences group, interview 26	Secondary interview source	12
Healthtalkonline Oxford health experiences group, interview 30	Secondary interview source	13
Case study interview 1, (ID. DF1 CW)	Case study in-depth interview	14
Case study interview 2, (ID. DF2 FD)	Case study in-depth interview	15
Case study interview 3, (ID. DF3 JP)	Case study in-depth interview	16
NHSBT case study, (ID. J.T.)	Secondary source	17
NHSBT case study, (ID. P.M.)	Secondary source	18
NHSBT case study, (ID. C.B.)	Secondary source	19
BHF case study, (ID. D.B.K.)	Secondary source (charity case study)	20
BTS case study, (ID. V.V.)	Secondary source (charity case study)	21
LLTGL case study, (ID. AD)	Secondary sources (charity case study)	22
LLTGL case study, (ID. GH)	Secondary source (charity case study)	23
LLTGL case study, (ID. MW)	Secondary source (charity case study)	24
Donor family blog, (ID. GB)	Secondary source (blog)	25
Donor family blog, (ID. EAHC)	Secondary source (blog)	26
Donor family blog, (ID. J&A)	Secondary source (blog and filmed	27

interview)		
Organ donation scotland case study (I.D. LT)	Secondary source (case study)	28
Organ donation scotland case study (I.D. G.M)	Secondary source (case study)	29
Welsh health Board case study (I.D. Od.)	Secondary source (case study)	30
Organ donation scotland case study (GPB)	Secondary sources case study	31
Media coverage I.D. AG	Secondary source	32
BBC coverage, (ID. R.T.)	Secondary source	33
Newspaper interview - ID. CM	Secondary source	34
Newspaper interview - ID. GG	Secondary source	35
Newspaper interview - ID. HS	Secondary source	36
Newspaper interview - ID. JL	Secondary source	37
Newspaper interview - ID. LA	Secondary source	38
Newspaper interview - ID. LG	Secondary source	39
Newspaper interview - ID. MW	Secondary source	40
Newspaper interview - ID. PH	Secondary source	41
Newspaper interview - ID. SH	Secondary source	42
Newspaper interview - ID. Nic.	Secondary source	43
Newspaper interview - ID. R.H.	Secondary source	44
Newspaper interview - ID. Sto.	Secondary source	45
Newspaper interview - ID. SC	Secondary source	46
Newspaper interview - ID. Asq.	Secondary source	47
Newspaper interview - ID. BB	Secondary source	48
Newspaper interview - ID Cad.	Secondary source	49
Newspaper interview - ID Cor.	Secondary source	50
Newspaper interview - ID PP.	Secondary source	51
NICE clinical guidelines	Published document	52
Nuffield Council of Bioethics document (2011)	Published document	53
British Medical Association document	Published document	54
Organ donation taskforce documents (2008 & 2013)	Published document	55

Appendix 6

Online search strategy

The following key search terms were used in a variety of established search engines in order to source as much relevant secondary material as possible concerning organ donor family decision making. When using searching engines, boolean searches can be used to develop search more precise queries, thus increasingly the probability of relevant material being generated from the search. Boolean searches can increase the accuracy of your results because they specify relationships between keywords or phrases. The most commonly used Boolean operators are: **AND**, **OR**, and **NOT**.

1. "Donor family story" **OR** "account"

2. "Organ donation family" **AND** "story" **OR** "account"

3. "Organ donor family" **AND** "case study"

4. "Organ donation case study"

5. "Organ donation" **AND** "decision making"

6. "Organ donor" **AND** "family" **AND** "decision"

7. "Organ donation" **AND** "family" **AND** "decision" **OR** "consent"

8. "Organ donation" **AND** "relative"

9. "Organ donor story" **AND** "decision" OR "consent"

10. "Organ donation" **AND** "next of kin"

The following search engines were utilised during the search process:

1. Google

2. Excite

3. Blekko

4. Yippy (formerly known as Clusty)

5. Bing

6. Highbeam

*All secondary sources that met the criteria specified in chapter 3 were included in analysis until a point of saturation was met.

Appendix 7

<u>Coding Guide</u>

Node label: Learning history +

Definition: An individual's learning history is the collective effect of rewarding and punishing outcomes of past behaviours. Positive learning history can come in many forms, for example having read about positive organ donation stories in the media, having personally witnessed the benefits of organ donation, watched TV programmes etc. It can also come via the verbal behaviour of third parties, for example a close acquaintance expressing they want to be a donor.

Example: *"We had talked about organ donation and he said he wanted to help others after he died"*

Node label: Learning history -

Definition: An individual's learning history is the collective effect of rewarding and punishing outcomes of past behaviours. Negative learning history can come in many forms, for example negative press coverage of organ donation, staunch religious beliefs that prevent organ donation, negative attitudes towards donation. It can also come via the verbal behaviour of third parties, for example a close acquaintance expressing opposition to being a donor.

Example: *"Sometimes you hear things like they don't try as hard to save you if you have a donor card"*

Node label: Physical setting +

Definition: The physical setting is usually the most evident aspect of the behavioural environment. In this context the physical setting would comprise of the intensive care unit, including the layout of the ward, the physical appearance and demenour of the patient and staff, as well as atmospherics and machinery. Any positive aspects of these elements would be classified as Physical setting +

Example: *"We were put into a private room so we could have time to think and discuss things as a family"*

Node label: Physical setting -

Definition: The physical setting is usually the most evident aspect of the behavioural environment. In this context the physical setting would comprise of the intensive care unit, including the layout of the ward, the physical appearance and demeanour of the patient and staff, as well as atmospherics and machinery. Any negative aspects of these elements would be classified as Physical setting -

Example: *"He was still warm and his chest was going up and down, he didn't look dead"*

Node label: Social setting +

Definition: The social setting adds further depth to the immediate environmental context. In the context of organ donation consent the social setting would comprise of other key figures, such as transplant co-ordinators, ICU nurses, doctors and

extended family. Positive social setting would refer to positive aspects of these individuals or interactions. For example helpful and supportive staff, family agreement on donation etc.

Example: *"The transplant co-ordinator was amazing, she never rushed us and explained everything clearly"*

Node label: Social setting -

Definition: The social setting adds further depth to the immediate environmental context. In the context of organ donation consent the social setting would comprise of other key figures, such as transplant co-ordinators, ICU nurses, doctors and extended family. Negative social setting would refer to negative aspects of these individuals or interactions. For example family disagreement surrounding organ donation, opposition to organ donation decision, abrupt staff etc.

Example: "*We kept being interrupted on the ward by staff who didn't seem to be bothered***"**

Node label: Temporal setting +

Definition: The temporal perspective refers to time-related effects. In the context of organ donation consent the temporal perspective could include the time of request in relation to diagnosis of brain death, the speed at which a decision must be made or the general length of the process. Positive temporal setting refers to any positive aspects of these elements. For example next of kin being given time to make a decision, not being rushed.

Example: *"They didn't rush us, they gave us plenty of time to come to a decision"*

Node label: Temporal setting -

Definition: The temporal perspective refers to time-related effects. In the context of organ donation consent the temporal perspective could include the time of request in relation to diagnosis of brain death, the speed at which a decision must be made or the general length of the process. Negative temporal setting refers to any negative aspects of these elements. For example next of kin being rushed to make a decision or the process of consent being very long.

Example: *"They process was very long. Too long in fact. It cost us valuable time with our loved one."*

Node label: Regulatory setting +

Definition: This refers to *rules* that restrict behaviour within a behaviour setting and can be imposed by the individual or by the intervention of a third party. Positive regulatory setting refers to positive aspects of these elements, for example a transplant co-ordinator providing the family with information regarding the process, put their mind at ease.

Example: *"The transplant co-ordinator gave us lots of information and answered all of our questions"*

Node label: Regulatory setting -

Definition: This refers to *rules* that restrict behaviour within a behaviour setting and can be imposed by the individual or by the intervention of a third party. Negative regulatory setting refers to negative aspects of these elements, for example a transplant co-

ordinator not providing the family with adequate information regarding the process of transplantation or a doctor saying that they must make a decision as the life support will be turned off.

Example: "*I didn't feel like I had enough information from the doctors and nurses. They just left us really.*"

Node label: Utilitarian +

Definition: Functional reinforcement represents the direct positive benefits experienced by the decision maker, which can be utilitarian or hedonic in nature. For example payment of funeral expenses may be classified as a form of functional reinforcement due to the utilitarian benefits the decision maker may receive. Another example may be direct benefits felt by the decision maker, such as comfort and pride.

Example: "*I felt so much comfort from the whole process*"

Node label: Utilitarian -

Definition: utilitarian - represents the direct costs experienced by the decision maker, whether they be utilitarian in nature or hedonic. For example decision makers having their time with their next of kin cut short because of time constraints, lengthy process of consent involving large amounts of paperwork, having to hear what will happen during the process of transplantation, having to turn off the life support machine etc.

Example: "*The whole process was so long and they went through some gory aspects which I felt I didn't need to know.*"

Node label: Informational +

Definition: Informational reinforcement refers to the symbolic, indirect benefits acquired by the decision maker for engaging in a behaviour. This could be in the form of positive feedback from important others or gaining status or recognition from performing a behaviour.

Example: "*The positive feedback we got from the staff was amazing*"

Node label: Informational -

Definition: Informational punishment consists of the symbolic, indirect aversive consequences acquired by the decision maker. This could be in the form of negative feedback, or the breaking of religious rules etc.

Example: "*I was always told that the body should be kept whole, otherwise there would be afterlife repercussions.*"

Node label: Scope open

Definition: The behaviour setting scope refers to the amount of control and/or freedom an individual enjoys in an environment. An open behaviour setting is therefore an environment where an individual enjoys a great deal of freedom and control, such as a supermarket where the consumer has a wide range of options.

Example: *"They told us that it was 100% our choice and that we could take as long as we need."*

Node label: Scope closed

Definition: The behaviour setting scope refers to the amount of control and/or freedom an individual enjoys in an environment. A closed behaviour scope is therefore an environment where an individual enjoys relatively little freedom or control, such as a bank where the individual only have a few pre-defined options and must abide by certain rules.

Example: *"I really felt quite pressured. They were very restrictive in the amount of time they gave us."*

Appendix 8

Information sheet

Family organ donation consent: a scenario based study

This study is part of a research dissertation focusing on organ donor family behaviour and consent. The aim of this study is to examine participants' past experiences, attitudes and the attitudes of important others towards organ donation and how this helps individuals make decisions regarding the organ donation of relatives.

Participants will be asked to complete a short survey regarding their attitudes and experiences regarding organ donation which takes approximately 5 minutes to complete. Participants will then be asked to watch 8 different scenarios about requesting organ donation whilst completing a corresponding questionnaire that measures your responses to that situation. This is to examine the participant's response toward the setting in which the behaviour takes place and the pattern of reinforcement which that particular setting emits.

The completion of the questionnaire and scenarios should not take you more than **30 minutes in total**. You can, if you wish, get a copy of findings of this research by emailing me at **a.r.castagnino@durham.ac.uk.** The anonymity and confidentiality of this survey is fully guaranteed. The data collected will only be used for academic analysis and if published will not be identifiable as yours. Your contribution is greatly appreciated.

Consent form

Tile: Organ donation consent: a scenario based study

Please initial box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that the information provided by me will be held anonymously and confidentially, such that only the experimenter can trace this information back to me individually. I understand that I can ask for the information I provide to be deleted/destroyed at any time.

3. I understand that I can withdraw, without giving reason, at any time

_____   _____   _____

Name of Participant   Date   Signature

Alexandra Rose Castagnino

_____   _____   _____

Name of Researcher   Date   Signature

Appendix 9

Learning history questionnaire

Organ donation questionnaire

*1. What is your age?

○ 18 to 24

○ 25 to 34

○ 35 to 44

○ 45 to 54

○ 55 to 64

○ 65 and above

*2. What is your gender?

○ Female

○ Male

*3. What is the highest level of education you have completed?

○ No formal qualification obtained

○ GCSE level and equivalent

○ A-level and equivalent

○ Undergraduate degree

○ Postgraduate degree

○ Professional qualification

*4. Please state your occupation

[   ]

*5. What is your relationship status?

○ Single

○ Married

○ Cohabiting

○ Separated

○ Divorced

○ Widowed

Organ donation questionnaire

＊6. What is your ethnic group? (As classified by ONS)

○ White British

○ White Irish

○ Any other White background

○ White and Black Caribbean

○ White and Black African

○ White and Asian

○ Any other mixed/multiple ethnic background

○ Asian or Asian British - Indian

○ Asian or Asian British - Pakistani

○ Asian or Asian British - Chinese

○ Any other Asian background

○ Black or Black British - African

○ Black or Black British - Caribbean

○ Any other Black background

○ Arab

Other (please specify)

[   ]

＊7. Which religion do you identify with most strongly?

○ Anglican/Church of England

○ Roman Catholic

○ Protestant

○ Other Christian denomination

○ Islam

○ Judaism

○ Hinduism

○ Buddhism

○ Sikhism

○ Spiritual no formal religion

○ No religion

Other (please specify)

[   ]

Organ donation questionnaire

*8. To what extent do you consider yourself a spiritual/religious person?

○ 1 Small extent   ○ 2   ○ 3   ○ 4   ○ 5   ○ 6   ○ 7 Great extent

*9. Do you wish to be an organ donor in the event of your death?

○ Yes

○ No

○ Undecided

Personal experience

In the following section you will be asked about your own experience regarding organ donation and related issues.

*10. Have you thought about organ and/or tissue donation before today?

○ Yes

○ No

*11. Do you know anyone who has had an organ and/or tissue transplant?

○ Yes

○ No

*12. Have you personally known anyone who was an organ and/or tissue donor upon their death?

○ Yes

○ No

*13. Do you know anyone who is on a transplant waiting list?

○ Yes

○ No

*14. Have you discussed the topic of organ donation with your family?

○ Yes

○ No

*15. Have you registered on the NHS Organ Donor Register, or designated on your driver's license (or other document) that you are an organ and/or tissue donor?

○ Yes

○ No

*16. Have any of your family registered on the NHS Organ Donor Register or designated on their driver's license (or other document) that they are an organ and/or tissue donor?

○ Yes

○ No

○ Don't know

*17. Have any of your friends registered on the NHS Organ Donor Register or designated on their driver's license (or other document) that they are an organ and/or tissue donor?

○ Yes

○ No

○ Don't know

*18. Overall how would you rate your knowledge of the topic of organ donation?

○ 1 Poor   ○ 2   ○ 3   ○ 4   ○ 5   ○ 6   ○ 7 Excellent

19. What has been your main source of information about organ donation?

○ Television

○ Newspaper

○ Film

○ NHS

○ Friends

○ Family

Other (please specify)

[   ]

*20. Have you ever donated blood?

○ Yes

○ No

*21. Do you engage in activities that are for the benefit of society? (e.g. volunteering, charity work, monthly direct debit to charities, charity runs)?

○ Yes

○ No

Organ donation questionnaire

✱22. Do you watch any hospital dramas on television? (e.g. Holby City, Casaulty, House, Scrubs, ER).

○ Yes

○ No

✱23. Have you seen a televised organ donation campaign in the UK?

○ Yes

○ No

24. How would you rate your past experiences with health professionals?

| ○ 1 Very negative | ○ 2 Negative | ○ 3 Somewhat negative | ○ 4 Neither negative or positive | ○ 5 Somewhat positive | ○ 6 Positive | ○ 7 Very positive |

Attitudes

In the following section you will be asked about your own attitudes toward organ donation on a scale of 1 being strongly disagree and 7 being strong agree.

✱25. It is unnatural to prolong life by replacing organs and tissues

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

✱26. Individuals have no responsibility to donate their organs and tissues

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

✱27. The thought of having an operation to remove my organs and tissues after I die makes me feel uneasy

| ○ 1 Stongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

✱28. The thought of a member of my family having an operation to remove their organs after their death makes me feel uneasy

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

29. The body should be kept whole for burial

☐ 1 Stongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

*30. Organ donation helps to give meaning to death

☐ 1 Strongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

*31. I am not the type of person orientated towards donating their organs after death

☐ 1 Strongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

*32. I would not accepts organs or tissues into my own body

☐ 1 Strongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

*33. Pledging to donate organs and tissues after my death would make me feel proud

☐ 1 Strongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

*34. Consenting to donate organs and tissues after the death of a family member would make me feel proud

☐ 1 Strongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

*35. I am the type of person who would donate their organs after death

☐ 1 Strongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

36. Doctors may not try so hard to save the lives of organ donors

☐ 1 Strongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

37. Sometimes medical procedures are done on people without their consent

☐ 1 Strongly disagree   ☐ 2 Disagree   ☐ 3 Somewhat disagree   ☐ 4 Neither disagree or agree   ☐ 5 Somewhat agree   ☐ 6 Agree   ☐ 7 Strongly agree

Organ donation questionnaire

*38. Individuals have a responsibility to donate their organs after death

○ 1 Strongly disagree   ○ 2 Disagree   ○ 3 Somewhat disagree   ○ 4 Neither disagree or agree   ○ 5 Somewhat agree   ○ 6 Agree   ○ 7 Strongly agree

*39. Individuals have a responsibility to donate the organs and tissues of their immediate family after death

○ 1 Strongly disagree   ○ 2 Disagree   ○ 3 Somewhat disagree   ○ 4 Neither disagree or agree   ○ 5 Somewhat agree   ○ 6 Agree   ○ 7 Strongly agree

*40. Individuals have a responsibility to honour the donation wishes of their immediate family

○ 1 Strongly disagree   ○ 2 Disagree   ○ 3 Somewhat disagree   ○ 4 Neither disagree or agree   ○ 5 Somewhat agree   ○ 6 Agree   ○ 7 Strongly agree

*41. I would not donate the organs of my immediate family if their wishes were not known

○ 1 Strongly disagree   ○ 2 Disagree   ○ 3 Somewhat disagree   ○ 4 Neither disagree or agree   ○ 5 Somewhat agree   ○ 6 Agree   ○ 7 Strongly agree

*42. If I am willing to recieve an organ I should be willing to donate one

○ 1 Strongly disagree   ○ 2 Disagree   ○ 3 Somewhat disagree   ○ 4 Neither disagree or agree   ○ 5 Somewhat agree   ○ 6 Agree   ○ 7 Strongly agree

Attitudes of others

In the following section you will be asked about the attitudes of important individuals in your life. 1 is strongly disagree and 7 is strongly agree.

*43. The people in my life whose opinions I value would approve of organ and tissue donation

○ 1 Strongly disagree   ○ 2 Disagree   ○ 3 Somewhat disagree   ○ 4 Neither disagree or agree   ○ 5 Somewhat agree   ○ 6 Agree   ○ 7 Strongly agree

*44. Most people who are important to me are in favour of organ donation

○ 1 Strongly disagree   ○ 2 Disagree   ○ 3 Somewhat disagree   ○ 4 Neither disagree or agree   ○ 5 Somewhat agree   ○ 6 Agree   ○ 7 Strongly agree

*45. Most people in my life whose opinions I value would want to be an organ donor after their death

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

*46. My immediate family think being an organ donor is positive

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

*47. My immediate famly think being an organ donor is valuable

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

*48. My immediate family think being an organ donor is unfavourable

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

*49. My immediate family feel uneasy about organ donation

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

*50. Those people who are important to me are undecided about organ donation

| ○ 1 Strongly disagree | ○ 2 Disagree | ○ 3 Somewhat disagree | ○ 4 Neither disagree or agree | ○ 5 Somewhat agree | ○ 6 Agree | ○ 7 Strongly agree |

Appendix 10

Study two response sheets with descriptors

Date ....

Initials ....

Scenario 1

You and a family member have been invited to a specialist's office to discuss the potential organ donation of your close relative. The office is professional with pro-organ donation posters on the wall.

The specialist states that your relative has not opted out of the organ donation register during their life. The specialist advises you that legally you have no right to veto, however if you were to veto it is unlikely donation would proceed. Therefore unless you have strong objections to organ donation the process should proceed.

The specialist gives you a booklet entitled "The Gift of Life" which contains the benefits of organ donation.

The specialist states that families often report that consenting to donation is a source of great comfort at a difficult time.

The specialist informs you that you will have the opportunity to receive updates from the recipients of your relative's organs, through letters, photos and meetings. This will allow you to see how your gift has improved the lives of others.

As an incentive all of your relative's funeral expenses will be covered in full and your generous gift will be acknowledged publically through our Donor Memorial Wall.

Scenario 1

Q 1: Imagine you are the decision maker in this scenario, you feel. . .

Annoyed	1	2	3	4	5	6	7	8	9	Pleased
Autonomous	1	2	3	4	5	6	7	8	9	Guided
Relaxed	1	2	3	4	5	6	7	8	9	Bored
Calm	1	2	3	4	5	6	7	8	9	Excited
Satisfied	1	2	3	4	5	6	7	8	9	Unsatisfied
Melancholic	1	2	3	4	5	6	7	8	9	Contented
Despairing	1	2	3	4	5	6	7	8	9	Hopeful
Happy	1	2	3	4	5	6	7	8	9	Unhappy
Frenzied	1	2	3	4	5	6	7	8	9	Sluggish
Awed	1	2	3	4	5	6	7	8	9	Important
Dull	1	2	3	4	5	6	7	8	9	Jittery
Aroused	1	2	3	4	5	6	7	8	9	Un-aroused
Controlling	1	2	3	4	5	6	7	8	9	Controlled
Stimulated	1	2	3	4	5	6	7	8	9	Relaxed
Influenced	1	2	3	4	5	6	7	8	9	Influential
In-control	1	2	3	4	5	6	7	8	9	Cared-for
Sleepy	1	2	3	4	5	6	7	8	9	Wide - awake
Submissive	1	2	3	4	5	6	7	8	9	Dominant

Q2: What is the likelihood of you consenting in this scenario?

1	2	3	4	5	6	7
Very unlikely	Unlikely	Somewhat unlikely	Neither unlikely or likely	Somewhat likely	likely	Very likely

Q3-8: How important was each one of the following?

3. Funeral expenses being paid as an incentive

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

4. Recognition through the donor memorial wall

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

5. Updates from recipients through letters, photos and meetings

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

6. Pro-donation posters

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

7. Gift of life information booklet outlining the benefits to recipients

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

8. Donation being a source of comfort for donor families

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

Scenario 2

You and a family member are in a comfortable family waiting room. There are pro-donation posters on the wall. A specialist has come to discuss the potential organ donation of your close relative.

The specialist asks if you would consider organ donation as an option for your relative? The specialist emphasises that the choice is entirely up to you and that there is no pressure to donate.

The specialist gives you a booklet entitled "The Gift of Life" which contains the benefits of organ donation.

The specialist states that families often report that consenting to donation is a source of great comfort at a difficult time.

The specialist informs you that you will have the opportunity to receive updates from the recipients of your relative's organs, through letters, photos and meetings. This will allow you to see how your gift has improved the lives of others.

As an incentive all of your relative's funeral expenses will be covered in full and your generous gift will be acknowledged publically through our Donor Memorial Wall.

Scenario 2

Q1: Imagine you are the decision maker in this scenario, you feel. . .

Annoyed	1	2	3	4	5	6	7	8	9	Pleased
Autonomous	1	2	3	4	5	6	7	8	9	Guided
Relaxed	1	2	3	4	5	6	7	8	9	Bored
Calm	1	2	3	4	5	6	7	8	9	Excited
Satisfied	1	2	3	4	5	6	7	8	9	Unsatisfied
Melancholic	1	2	3	4	5	6	7	8	9	Contented
Despairing	1	2	3	4	5	6	7	8	9	Hopeful
Happy	1	2	3	4	5	6	7	8	9	Unhappy
Frenzied	1	2	3	4	5	6	7	8	9	Sluggish
Awed	1	2	3	4	5	6	7	8	9	Important
Dull	1	2	3	4	5	6	7	8	9	Jittery
Aroused	1	2	3	4	5	6	7	8	9	Un-aroused
Controlling	1	2	3	4	5	6	7	8	9	Controlled
Stimulated	1	2	3	4	5	6	7	8	9	Relaxed
Influenced	1	2	3	4	5	6	7	8	9	Influential
In-control	1	2	3	4	5	6	7	8	9	Cared-for
Sleepy	1	2	3	4	5	6	7	8	9	Wide - awake
Submissive	1	2	3	4	5	6	7	8	9	Dominant

Q2: What is the likelihood of you consenting in this scenario?

1	2	3	4	5	6	7
Very unlikely	Unlikely	Somewhat unlikely	Neither unlikely or likely	Somewhat likely	likely	Very likely

Q3-8: How important was each one of the following?

3. Funeral expenses being paid as an incentive

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

4. Recognition through the donor memorial wall

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

5. Updates from recipients through letters, photos and meetings

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

6. Pro-donation posters

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

7. Gift of life information booklet outlining the benefits to recipients

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

8. Donation being a source of comfort for donor families

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

Scenario 3

You and a family member have been invited to a specialist's office to discuss the potential organ donation of a close relative. The office is professional.

The specialist states that your relative has not opted out of the organ donation register during their life. The specialist advises you that legally you have no right to veto, however if you were to veto it is unlikely donation would proceed. Therefore unless you have strong objections to organ donation the process should proceed.

As an incentive all your relative's funeral expenses will be covered in full.

The specialist states that families often report that consenting to donation is a source of great comfort at a difficult time.

You and your family will receive a certificate of thanks acknowledging your consent for donation as well as brief, basic and anonymous information regarding the recipients and their progress.

Scenario 3

Q1: Imagine you are the decision maker in this scenario, you feel. . .

Annoyed	1	2	3	4	5	6	7	8	9	Pleased
Autonomous	1	2	3	4	5	6	7	8	9	Guided
Relaxed	1	2	3	4	5	6	7	8	9	Bored
Calm	1	2	3	4	5	6	7	8	9	Excited
Satisfied	1	2	3	4	5	6	7	8	9	Unsatisfied
Melancholic	1	2	3	4	5	6	7	8	9	Contented
Despairing	1	2	3	4	5	6	7	8	9	Hopeful
Happy	1	2	3	4	5	6	7	8	9	Unhappy
Frenzied	1	2	3	4	5	6	7	8	9	Sluggish
Awed	1	2	3	4	5	6	7	8	9	Important
Dull	1	2	3	4	5	6	7	8	9	Jittery
Aroused	1	2	3	4	5	6	7	8	9	Un-aroused
Controlling	1	2	3	4	5	6	7	8	9	Controlled
Stimulated	1	2	3	4	5	6	7	8	9	Relaxed
Influenced	1	2	3	4	5	6	7	8	9	Influential
In-control	1	2	3	4	5	6	7	8	9	Cared-for
Sleepy	1	2	3	4	5	6	7	8	9	Wide - awake
Submissive	1	2	3	4	5	6	7	8	9	Dominant

Q2: What is the likelihood of you consenting in this scenario?

1	2	3	4	5	6	7
Very unlikely	Unlikely	Somewhat unlikely	Neither unlikely or likely	Somewhat likely	likely	Very likely

Q3-8: How important was each one of the following?

3. Funeral expenses being paid as an incentive

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

4. Donation being a source of comfort for donor families

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

5. Certificate of appreciation

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

6. Basic and anonymous information regarding the recipient's progress

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

Scenario 4

You and a family member are in a comfortable family waiting room. A specialist has come to discuss the potential organ donation of their close relative.

The specialist asks if you would consider organ donation as an option for your relative? The specialist emphasises that the choice is entirely up to you and that there is no pressure to donate.

As an incentive all your relative's funeral expenses will be covered in full.

The specialist states that families often report that consenting to donation is a source of great comfort at a difficult time.

You and your family will receive a certificate of thanks acknowledging your consent for donation as well as brief, basic and anonymous information regarding the recipients and their progress.

Scenario 4

Q1. Imagine you are the decision maker in this scenario, you feel. . .

Annoyed	1	2	3	4	5	6	7	8	9	Pleased
Autonomous	1	2	3	4	5	6	7	8	9	Guided
Relaxed	1	2	3	4	5	6	7	8	9	Bored
Calm	1	2	3	4	5	6	7	8	9	Excited
Satisfied	1	2	3	4	5	6	7	8	9	Unsatisfied
Melancholic	1	2	3	4	5	6	7	8	9	Contented
Despairing	1	2	3	4	5	6	7	8	9	Hopeful
Happy	1	2	3	4	5	6	7	8	9	Unhappy
Frenzied	1	2	3	4	5	6	7	8	9	Sluggish
Awed	1	2	3	4	5	6	7	8	9	Important
Dull	1	2	3	4	5	6	7	8	9	Jittery
Aroused	1	2	3	4	5	6	7	8	9	Un-aroused
Controlling	1	2	3	4	5	6	7	8	9	Controlled
Stimulated	1	2	3	4	5	6	7	8	9	Relaxed
Influenced	1	2	3	4	5	6	7	8	9	Influential
In-control	1	2	3	4	5	6	7	8	9	Cared-for
Sleepy	1	2	3	4	5	6	7	8	9	Wide - awake
Submissive	1	2	3	4	5	6	7	8	9	Dominant

Q2: What is the likelihood of you consenting in this scenario?

1	2	3	4	5	6	7
Very unlikely	Unlikely	Somewhat unlikely	Neither unlikely or likely	Somewhat likely	Likely	Very likely

Q3-8: How important was each one of the following?

3. Funeral expenses being paid as an incentive

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

4. Donation being a source of comfort for donor families

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

5. Certificate of appreciation

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

6. Basic and anonymous information regarding the recipient's progress

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

Scenario 5

You and a family member have been invited to a specialist's office to discuss the potential organ donation of their close relative. The office is professional with pro-organ donation posters on the wall.

The specialist states that your relative has not opted out of the organ donation register during their life. The specialist advises you that legally you have no right to veto, however if you were to veto it is unlikely donation would proceed. Therefore unless you have strong objections to organ donation the process should proceed.

The specialist passes you a booklet entitled "The Gift of Life" which contains the benefits of organ donation.

The specialist states you that you will receive regular updates from the recipients of your relative's organs. You will communicate with them through letters of correspondence, photographs and meetings. This will allow you to see how your gift has improved the lives of others. It will also give you the opportunity to build a relationship with the recipients.

Furthermore your gift will be recognised publically through our Donor Memorial Wall. You and your family will also receive a priority place on the transplant list, thus safeguarding your family's future.

The specialist states that some families find donation a source of comfort.

Scenario 5

1. Imagine you are the decision maker in this scenario, you feel. . .

Annoyed	1	2	3	4	5	6	7	8	9	Pleased
Autonomous	1	2	3	4	5	6	7	8	9	Guided
Relaxed	1	2	3	4	5	6	7	8	9	Bored
Calm	1	2	3	4	5	6	7	8	9	Excited
Satisfied	1	2	3	4	5	6	7	8	9	Unsatisfied
Melancholic	1	2	3	4	5	6	7	8	9	Contented
Despairing	1	2	3	4	5	6	7	8	9	Hopeful
Happy	1	2	3	4	5	6	7	8	9	Unhappy
Frenzied	1	2	3	4	5	6	7	8	9	Sluggish
Awed	1	2	3	4	5	6	7	8	9	Important
Dull	1	2	3	4	5	6	7	8	9	Jittery
Aroused	1	2	3	4	5	6	7	8	9	Un-aroused
Controlling	1	2	3	4	5	6	7	8	9	Controlled
Stimulated	1	2	3	4	5	6	7	8	9	Relaxed
Influenced	1	2	3	4	5	6	7	8	9	Influential
In-control	1	2	3	4	5	6	7	8	9	Cared-for
Sleepy	1	2	3	4	5	6	7	8	9	Wide - awake
Submissive	1	2	3	4	5	6	7	8	9	Dominant

Q2: What is the likelihood of you consenting in this scenario?

1	2	3	4	5	6	7
Very unlikely	Unlikely	Somewhat unlikely	Neither unlikely or likely	Somewhat likely	Likely	Very likely

Q3-8: How important was each one of the following?

3. Pro- donation posters

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

4. Gift of life information booklet outlining the benefits to recipients

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

5. Regular communication with recipients

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

6. Recognition through the donor memorial wall

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

7. Prioritised place on the organ donor transplant list

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

8. Donation being a source of comfort for donor families

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

Scenario 6

You are in a comfortable family waiting room with a family member. There are pro-donation posters on the wall. A consultant has come to discuss the potential organ donation of their close relative.

The specialist asks if you would consider organ donation as an option for your relative? The specialist emphasises that the choice is entirely up to you and that there is no pressure to donate.

The specialist passes you a booklet entitled "The Gift of Life" which contains the benefits of organ donation.

The specialist states you that you will receive regular updates from the recipients of your relative's organs. You will communicate with them through letters of correspondence, photographs and meetings. This will allow you to see how your gift has improved the lives of others. It will also give you the opportunity to build a relationship with the recipients.

Furthermore your gift will be recognised publically through our Donor Memorial Wall. You and your family will also receive a priority place on the transplant list, thus safeguarding your family's future.

The specialist states that some families find donation a source of comfort.

Scenario 6

1. Imagine you are the decision maker in this scenario, you feel. . .

Annoyed	1	2	3	4	5	6	7	8	9	Pleased
Autonomous	1	2	3	4	5	6	7	8	9	Guided
Relaxed	1	2	3	4	5	6	7	8	9	Bored
Calm	1	2	3	4	5	6	7	8	9	Excited
Satisfied	1	2	3	4	5	6	7	8	9	Unsatisfied
Melancholic	1	2	3	4	5	6	7	8	9	Contented
Despairing	1	2	3	4	5	6	7	8	9	Hopeful
Happy	1	2	3	4	5	6	7	8	9	Unhappy
Frenzied	1	2	3	4	5	6	7	8	9	Sluggish
Awed	1	2	3	4	5	6	7	8	9	Important
Dull	1	2	3	4	5	6	7	8	9	Jittery
Aroused	1	2	3	4	5	6	7	8	9	Un-aroused
Controlling	1	2	3	4	5	6	7	8	9	Controlled
Stimulated	1	2	3	4	5	6	7	8	9	Relaxed
Influenced	1	2	3	4	5	6	7	8	9	Influential
In-control	1	2	3	4	5	6	7	8	9	Cared-for
Sleepy	1	2	3	4	5	6	7	8	9	Wide - awake
Submissive	1	2	3	4	5	6	7	8	9	Dominant

Q2: What is the likelihood of you consenting in this scenario?

1	2	3	4	5	6	7
Very unlikely	Unlikely	Somewhat unlikely	Neither unlikely or likely	Somewhat likely	Likely	Very likely

Q3-8: How important was each one of the following?

3. Pro- donation poster

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

4. Gift of life information booklet outlining the benefits to recipients

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

5. Regular communication with recipients

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

6. Recognition through the donor memorial wall

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

7. Prioritised place on the organ donor transplant list

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

8. Donation being a source of comfort for donor families

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

Scenario 7

You and a family member have been invited to a specialist's office to discuss the potential organ donation of a close relative. The office is professional.

The specialist states that your relative has not opted out of the organ donation register during their life. The specialist advises you that legally you have no right to veto, however if you were to veto it is unlikely donation would proceed. Therefore unless you have strong objections to organ donation the process should proceed.

The specialist emphasises that it is a routine procedure to procure organs from the deceased.

You and your family will receive a certificate of thanks acknowledging your consent for donation as well as brief, basic and anonymous information regarding the recipients and their progress.

The specialist states that some families find donation a source of comfort.

The specialist also says that organ donation is an element of being socially responsible.

Scenario 7

1. Imagine you are the decision maker in this scenario, you feel. . .

Annoyed	1	2	3	4	5	6	7	8	9	Pleased
Autonomous	1	2	3	4	5	6	7	8	9	Guided
Relaxed	1	2	3	4	5	6	7	8	9	Bored
Calm	1	2	3	4	5	6	7	8	9	Excited
Satisfied	1	2	3	4	5	6	7	8	9	Unsatisfied
Melancholic	1	2	3	4	5	6	7	8	9	Contented
Despairing	1	2	3	4	5	6	7	8	9	Hopeful
Happy	1	2	3	4	5	6	7	8	9	Unhappy
Frenzied	1	2	3	4	5	6	7	8	9	Sluggish
Awed	1	2	3	4	5	6	7	8	9	Important
Dull	1	2	3	4	5	6	7	8	9	Jittery
Aroused	1	2	3	4	5	6	7	8	9	Un-aroused
Controlling	1	2	3	4	5	6	7	8	9	Controlled
Stimulated	1	2	3	4	5	6	7	8	9	Relaxed
Influenced	1	2	3	4	5	6	7	8	9	Influential
In-control	1	2	3	4	5	6	7	8	9	Cared-for
Sleepy	1	2	3	4	5	6	7	8	9	Wide - awake
Submissive	1	2	3	4	5	6	7	8	9	Dominant

Q2: What is the likelihood of you consenting in this scenario?

1	2	3	4	5	6	7
Very unlikely	Unlikely	Somewhat unlikely	Neither unlikely or likely	Somewhat likely	Likely	Very likely

Q3-8: How important was each one of the following?

3. Emphasis that it is a routine procedure to procure organs

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

4. Certificate of appreciation

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

5. Basic and anonymous information regarding the recipient's progress

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

6. Donation being a source of comfort for donor families

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

7. Organ donation being an element of being socially responsible

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

Scenario 8

You and a family member are in a comfortable family waiting room. A specialist has come to discuss the potential organ donation of a close relative.

The specialist asks if you would consider organ donation as an option for your relative? The specialist emphasises that the choice is entirely up to you and that there is no pressure to donate.

The specialist emphasises that it is a routine procedure to procure organs from the deceased.

You and your family will receive a certificate of thanks acknowledging your consent for donation as well as brief, basic and anonymous information regarding the recipients and their progress.

The specialist states that some families find donation a source of comfort.

The specialist also says that organ donation is an element of being socially responsible.

Scenario 8

1. Imagine you are the decision maker in this scenario, you feel. . .

Annoyed	1	2	3	4	5	6	7	8	9	Pleased
Autonomous	1	2	3	4	5	6	7	8	9	Guided
Relaxed	1	2	3	4	5	6	7	8	9	Bored
Calm	1	2	3	4	5	6	7	8	9	Excited
Satisfied	1	2	3	4	5	6	7	8	9	Unsatisfied
Melancholic	1	2	3	4	5	6	7	8	9	Contented
Despairing	1	2	3	4	5	6	7	8	9	Hopeful
Happy	1	2	3	4	5	6	7	8	9	Unhappy
Frenzied	1	2	3	4	5	6	7	8	9	Sluggish
Awed	1	2	3	4	5	6	7	8	9	Important
Dull	1	2	3	4	5	6	7	8	9	Jittery
Aroused	1	2	3	4	5	6	7	8	9	Un-aroused
Controlling	1	2	3	4	5	6	7	8	9	Controlled
Stimulated	1	2	3	4	5	6	7	8	9	Relaxed
Influenced	1	2	3	4	5	6	7	8	9	Influential
In-control	1	2	3	4	5	6	7	8	9	Cared-for
Sleepy	1	2	3	4	5	6	7	8	9	Wide - awake
Submissive	1	2	3	4	5	6	7	8	9	Dominant

Q2: What is the likelihood of you consenting in this scenario?

1	2	3	4	5	6	7
Very unlikely	Unlikely	Somewhat unlikely	Neither unlikely or likely	Somewhat likely	Likely	Very likely

Q3-8: How important was each one of the following?

3. Emphasis that it is a routine procedure to procure organs

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

4. Certificate of appreciation

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

5. Basic and anonymous information regarding the recipient's progress

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

6. Donation being a source of comfort for donor families

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

7. Organ donation being an element of being socially responsible

1	2	3	4	5	6	7
Not at all important	Low importance	Somewhat unimportant	Neither unimportant or important	Somewhat important	Important	Extremely important

Thank you for taking the time to complete this study. Your contribution is greatly valued. If you would like a copy of the results please write your email address below:

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Appendix 11

Descriptive statistics for study two sample

Gender of sample

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	20	40.0	40.0	40.0
	Female	30	60.0	60.0	100.0
	Total	50	100.0	100.0	

Educational level of sample

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	GCSE level	4	8.0	8.0	8.0
	A-level	11	22.0	22.0	30.0
	Undergraduate degree	13	26.0	26.0	56.0
	Postgraduate degree	10	20.0	20.0	76.0
	Professional qualification	12	24.0	24.0	100.0
	Total	50	100.0	100.0	

Ethnic group

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	White British	34	68.0	68.0	68.0
	White Irish	5	10.0	10.0	78.0
	Any other white background	6	12.0	12.0	90.0
	Asian or Asian British - Indian	1	2.0	2.0	92.0
	Asian or Asian British - Chinese	1	2.0	2.0	94.0
	Any other Asian background	3	6.0	6.0	100.0
	Total	50	100.0	100.0	

Religion

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Anglican/C of E	12	24.0	24.0	24.0
	Roman Catholic	12	24.0	24.0	48.0
	Protestant	2	4.0	4.0	52.0
	Other Christian denomination	4	8.0	8.0	60.0
	Hinduism	1	2.0	2.0	62.0
	Buddhism	1	2.0	2.0	64.0
	Spiritual no formal religion	2	4.0	4.0	68.0
	No religion	16	32.0	32.0	100.0
	Total	50	100.0	100.0	

Do you wish to be a donor after your death?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	29	58.0	58.0	58.0
	No	6	12.0	12.0	70.0
	Undecided	15	30.0	30.0	100.0
	Total	50	100.0	100.0	

Have you registered on the NHS organ donor register or designated on your driving license that you are an organ donor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	16	32.0	32.0	32.0
	No	34	68.0	68.0	100.0
	Total	50	100.0	100.0	

Have you discussed the topic of organ donation with your family?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	27	54.0	54.0	54.0
	No	23	46.0	46.0	100.0
	Total	50	100.0	100.0	

Overall how would your rate your knowledge of the topic of organ donation?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very poor	4	8.0	8.0	8.0
	poor	11	22.0	22.0	30.0
	somewhat poor	10	20.0	20.0	50.0
	4	14	28.0	28.0	78.0
	somewhat good	5	10.0	10.0	88.0
	good	5	10.0	10.0	98.0
	excellent	1	2.0	2.0	100.0
	Total	50	100.0	100.0	

Have you seen a televised organ donation campaign in the UK?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	23	46.0	46.0	46.0
	No	27	54.0	54.0	100.0
	Total	50	100.0	100.0	

What has been your main source of information about organ donation?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Television	14	28.0	28.0	28.0
	Newspaper	10	20.0	20.0	48.0
	Film	1	2.0	2.0	50.0
	NHS	11	22.0	22.0	72.0
	Friends	8	16.0	16.0	88.0
	Family	4	8.0	8.0	96.0
	Other	2	4.0	4.0	100.0
	Total	50	100.0	100.0	

Appendix 12

Glossary of PAD scale terms

Annoyed	feeling moderate anger or impatient
Aroused	feeling interested, responsive or desire to do something
Autonomous	feeling independent and not controlled by others or by outside forces
Awed	feeling of amazement and respect mixed with fear that is often coupled with a feeling of personal insignificance or powerlessness
Bored	feeling tired and impatient because you have lost interest in somebody/something or because you have nothing to do
Calm	feeling peaceful and without anxiety or strong emotion
Cared-for	feeling having needed care and attention
Contented	feeling peacefully happy and satisfied
Controlled	feeling guarded, kept in check and not expressed fully or at al
Controlling	feeling able to exercise power or authority over something
Despairing	feeling or showing loss of hope or miserable
Dominant	feeling in control
Dull	feeling no interest or excitement
Excited	feeling enjoyment or pleasurable anticipation
Frenzied	feeling wildly excited or out of control
Guided	feeling being lead by somebody in the right direction
Happy	feeling or showing pleasure, contentment, or joy
Hopeful	feeling fairly sure that something that is wanted will happen
Important	feeling having value or significant
In-control	feeling able to direct a situation, person, or activity
Influenced	feeling being influence on; behaviour, development, action, or thought

Influential	feeling able to have a powerful effect on people and what they do, or on events
Jittery	feeling anxious or edgy , making rapid jumpy movements
Melancholic	feeling or tending to feel a thoughtful or gentle sadness, gloomy
Pleased	feeling or expressing satisfaction or pleasure
Relaxed	feeling no strain or tension, and not exerting much strain or force on anything else
Satisfied	feeling pleased or content
Sleepy	feeling quiet and not very lively or exciting
Sluggish	feeling slow to react or respond to stimulation
Stimulated	feeling able to rouse to action or effort
Submissive	feel giving in or tending to give in to the demands or authority of others
Un-aroused	feeling lack of interest or desire
Unhappy	feeling not pleased or satisfied
Unsatisfied	feeling unhappy or displeased
Wide-awake	feeling completely awake and alert