Beyond Altruism: trust, fairness and social inclusion in deceased organ donor registration

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ABSTRACT

Despite decades of research and efforts to increase organ donation, the gap between the supply of and demand for transplantable organs continues to grow. Much of this research relies on models of individual prosocial behaviour, borne out of an almost ubiquitous framing of deceased donation as an altruistic “gift of life”. However, this framing has its limitations, in particular the assumption that individual personality traits and preferences drive donation.

This thesis takes an alternative approach to explaining donor registration behaviour. A collective, rather than an individual, conceptualization of deceased donation is argued for, in which the parameters of inclusion and fairness (as antecedents to trust and commitment) are key factors in donor registration behaviour. This conceptualization was empirically tested. First, a series of focus groups of five different migrant populations was conducted in the Gulf State of Qatar. This was followed by a pilot survey, and later a wider study involving Australian participants that tested a collective model of intentions to register. Registration behaviour was subsequently compared with an individual (theory of planned behaviour) model typically used in organ donation studies.

The results of the studies highlight the need for investment in donor registration to move beyond communication campaigns that focus on improving attitudes or self-efficacy towards organ donation. Policies focused on strengthening society members' relationships with social institutions and fostering inclusiveness offer scope to increase the uptake of registration in the community.
DECLARATION

This is to certify that

(i)  The thesis comprises only my original work towards the PhD,

(ii) Due acknowledgement has been made in the text to all other materials used,

(iii) The thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

........................................

Emma Tinning

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To my husband and son and to my parents
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INTRODUCTION

1. Context

Organ transplantation is used to treat an array of end-stage, life-threatening illnesses including kidney, heart, lung, liver, and pancreatic diseases, and a single deceased organ donor can provide organs for up to eight people and tissue for many others (American Transplant Foundation, 2016). However, while the need for organs for transplantation continues to grow, deceased donation rates remain relatively stable in countries with established programs such as the UK, the USA, and Australia (Cotter, 2011), leading to a well-documented shortage of organs available for transplantation worldwide (Global Observatory, 2016).

Research finds widespread public support for the concept of deceased donation (Weber & Martin, 2006). However, high levels of support have not tended to translate to similar levels of donor registration in countries operating explicit consent or “opt-in” donation systems (Abadie & Gay, 2006). Less than half of American adults (Ladin, 2016) and less than a third of UK (UK Government, 2013) and Australian (Australian Organ Donor Register Statistics, 2016) adults have registered as donors. In addition, large differences exist in willingness to donate between population groups, with ethnic and minority group less likely to register as donors than other groups (Morgan et. al., 2013). The failure of over half of the adult population in these countries to register comes despite decades of research and concerted education and promotion campaigns aimed at increasing deceased donation rates (Abadie & Gay, 2006).

The ongoing challenge of translating positive attitudes towards deceased donation into donor registration has resulted in scrutiny of the framing of deceased donation in the public domain (for example, Batten, 1992; Healy, 2004; Moorlock, Ives, & Draper, 2013; Schweda, Wöhlke, & Schicktanz, 2009). Framing exerts a powerful influence on responses to issues in the public sphere (Chong & Druckman, 2007; Hallahan, 1999; Kahneman, 2003). The widespread acceptance
of deceased donation today belies the profound transformation of the conceptualisation of death required by the advent of donation and transplantation (Lock, 2002; Healy, 2004). Indeed Joralemon (1995) suggests that the framing of donation as a "gift" "make(s) use of the culturally familiar to legitimize the way we think and act toward the human body" (p. 342). Today, the framing of deceased donation as an altruistic “gift of life” (Zeiler, 2013) is almost ubiquitous in the policies and promotion underpinning organ donation and transplant systems (Lauritzen, McClure, Smith, & Trew, 2001; Siminoff & Chilag, 1999). It is also deeply embedded in the meanings attached to the donation of other bodily materials, such as blood, semen, and oocytes (Tober, 2001; Raymond, 1990; Holland, 2001).

Yet, the reliance on altruism to explain deceased donation has been challenged by those who advocate market-based approaches to increase donation rates (Mahoney, 2009; Matas, 2008), and those who argue that the efficacy and efficiency of donation and transplant systems are more influential than individual personality traits and preferences (Healy, 2004; Salim et al., 2011). Others argue that donor registration is best understood as an interdependent behaviour founded on reciprocity (Schweda et al., 2009), or a collective behaviour—an act of social solidarity (Etzioni, 2003; Murray, 1987). As evident in these few examples, the framing of donation dictates how the “problem” of an insufficient supply of transplantable organs to meet demand is understood. Importantly, framing also dictates the solutions that may be offered to public issues (Calvert & Warren, 2014), with different conceptualisations of deceased donation pointing to different policy approaches. Consequently, the public framing or conceptualisation of deceased donation has a material impact on how motivations for registration are understood (Robertson, 2004) and the approaches taken to increase donation.
2. Research aim and questions

To that end, the aim of this thesis is to examine the influence of framing deceased donation as a collective behaviour on understanding motivations for and barriers to registering as a donor, with a focus on the roles of trust and social inclusion in driving donation behaviour. While there are a number of discussions of deceased donation as a collective behaviour (Etzioni, 2003; Murray, 1987; Siegal & Bonnie, 2006), this thesis aims to move beyond a theoretical repositioning to interrogate why such a collective framing provides an optimal account of deceased donation and what it means in terms of addressing the low registration rates evident in many opt-in systems. The thesis examines three main research questions:

1. What is the justification for a collective conceptualisation of deceased donation when framing donor registration in the public domain?
2. What insight does such a conceptualisation provide into drivers of and barriers to registering?
3. How can these insights be used to help increase donor registration?

This thesis is composed of four papers and a discussion chapter. The papers include one conceptual paper and three empirical studies (one qualitative and two quantitative). Each paper serves as a basis for future publications and thus is largely treated independently, although the two quantitative studies are both founded on the collective model of donor registration developed for the thesis. Each of the papers will be briefly outlined now.
Paper 1

Paper 1 examines the first of the thesis's research questions, regarding the justification for a collective account of organ donation. In doing so, the paper offers a theoretical examination of deceased donation and registration that provides the foundation for the proposed collective account of donor registration behaviour (and the subsequent empirical studies). The paper takes an exchange approach to donor registration, drawing on Barbara Meeker's (1971) "decision rules" categories of exchange to explore how three different rules—altruism, reciprocity, and group gain respectively—influence the way donor registration is conceptualised.

Drawing on theories of social identity and resource exchange, the paper identifies the characteristics of donation and transplant systems that justify the framing of donor registration as a collective behaviour. Importantly, this collective conceptualisation accounts for the influence of institutional trust (Petersen, 2002; Siminoff & Arnold, 1999; Russell, Robinson, Thompson, Perryman, & Arriola, 2012) and social inclusion (Morgan, Mayblin, & Jones, 2008; Mossialos et al., 2008) in donor registration. These factors are shown to influence donation attitudes and behaviour, but are largely missing from theoretical models of donation behaviour. The reconceptualisation presented in this paper also shifts the locus of donor registration behaviour from individual traits and preferences to the social and institutional settings in which deceased donation and transplant systems operate. Thus, the paper argues, increasing donor registration requires us to move beyond merely improving attitudes towards donation to instead ensure equitable access to social institutions and promote social inclusion within countries.
Paper 2

Paper 2 relates to the thesis’s second research question, focusing on the drivers of and barriers to registering as a deceased donor in a collective account of deceased donation. The paper reports the results of a qualitative study undertaken among five migrant populations in the gulf state of Qatar. Ethnic minority populations are shown to be less trusting of organ donation and transplant systems and are less likely to register as donors. Such populations are also at increased risk of social exclusion. Thus the setting allowed an exploration of key factors identified in Paper 1 as relevant to a collective conceptualisation of donor registration, including trust, inclusion and identity. Unlike the majority of donation and transplant systems, Qatar’s system affords access to transplantation for non-citizen residents, so the possible influence of inclusion in an organ donation and transplant system was also examined.

The study indicates that perspectives on donation are principally founded on norms and practices relating to living (largely illegal) donation within the temporary migrants’ home countries. Participants had less understanding of deceased donation and transplantation and very few were aware of Qatar’s system. In addition, participants remained focused on home, maintaining narrow social relationships with other migrants of the same nationality, and having few interactions with Qatari citizens or institutions. The findings highlight the challenge of building knowledge of and investment in deceased donation among migrant populations, particularly where institutional and social settings foster exclusion of some population groups.
Paper 3

Paper 3 further examines the drivers of and barriers to registering, as well the final research question regarding how the insights from a collective account of donation may be used to drive donor registration. In doing so, the paper reports the results of two quantitative studies (n=345 and n=887) testing a behavioural model—the model of Collective Donor Behaviour (CDB). As the lack of knowledge of deceased donation and transplant systems in the migrant groups studied in Qatar made the population ill-suited for testing a model of donor registration behaviour, the samples were derived from the Australian population. Australia is a multicultural society with a long established deceased donation and transplantation system.

Building on the theoretical conceptualisation of donor registration outlined in Paper 1, the CDB places trust at the centre of donor registration behaviour—specifically trust in other society members and trust in institutions—founded on inclusion and fairness respectively. These factors have been shown to influence both attitudes towards donation and donation behaviour, but are not typically incorporated into models of registration behaviour.

Both studies support the efficacy of the collective model in explaining variance in behaviour. The studies also demonstrate normative commitment—perceptions of an obligation to register—to be strongly associated with donor registration. This suggests that appealing to collective responsibility may help drive donor registration, an approach that offers an alternative to the construction of donation as an individual “gift”. However, the findings also indicate that the effectiveness of appeals to collective behaviour will depend on perceptions about the trustworthiness of both the organ donation and transplant systems and other people in society, and that negative interactions with social institutions or experiences of social exclusion will negatively impact an individual's willingness to register.
Paper 4

Paper 4 also further examines drivers of and barriers to registering in a collective account of donor registration as well as how such insights may help increase donor registration rates. Having demonstrated the efficacy of the CDB model in Paper 3, this paper compares the CDB with an established behavioural model—the Theory of Planned Behaviour (TPB). The TPB is the foundation of numerous organ donation behavioural models, for example, the Organ Donor Model (Horton and Horton, 1991), the Organ Donor Willingness Model (Kopfman & Smith, 1996), and the Organ Donation Model (Morgan, Miller, & Arasaratnam, 2002). It is also directly used in a range of organ donation studies (Hyde, Knowles, & White, 2013; Rocheleau, 2013; Bresnahan et al., 2007). The study compares the two models in a sample of non-donors in relation to registration intentions (n=514). These donors were then followed up three months later (n=272) in relation to subsequent donor registration.

When comparing the CDB with the TPB, it is shown that the collective model is indeed a viable way of predicting registration intentions and behaviour, suggesting alternative decision-making pathways based on social and institutional relationships. Thus, the paper challenges long-held assumptions about the attitude intention pathway predominant in health and prosocial behavioural studies. In doing so, the CDB provides a level of specificity about drivers of donor registration behaviour not found in the TPB. In particular, the collective model locates registration behaviour within a social and institutional context, providing a behavioural account of known barriers to donor registration such as mistrust, perceived inequities within organ donation and transplant systems (Denvir & Pomerantz, 2009; Minniefield, Yang, & Muti, 2001; Siminoff & Arnold, 1999), and social exclusion (Morgan, Hooper, Mayblin, & Jones, 2006; Morgan et al., 2008).
3. Discussion and conclusion

Each of the papers that comprise this thesis examines donor registration in the context of broader social structures and norms that serve to encourage or discourage participation. The discussion chapter then places the research undertaken for this thesis in the broader context of institutional theories, which move beyond individual psychological accounts of behaviour to focus on the processes by which the norms, practices, and rules that guide behaviour are established in society (Scott, 2004). Institutional theories bridge the gap between accounts that depict behaviour as a product of individual, rational decisions and those that see action as a function of social structures and socially enforced norms (Granovetter, 1985). In doing so, this thesis demonstrates the importance of considering donor registration neither as a function of individual traits and preferences, nor as a preordained universal norm. Instead, the thesis advocates focusing on building trust, both in the institutions underpinning deceased donation and transplant systems and in other society members to increase donor registration.
4. STRUCTURE OF THESIS

**Paper 1** – Conceptual framework

**Paper 2** – Qualitative study Qatar.

**Paper 3** – Quantitative study. CDB model pilot and retest.

**Paper 4** – Quantitative study. CDB model comparison with TPB.

Discussion
PAPER 1

Deceased organ donation registration: altruism, reciprocity, or group gain?

Abstract

This paper addresses the first of the thesis’s research questions, regarding the justification for a collective account of donation.

Donation and transplant systems worldwide face the ongoing challenge of meeting the growing need for transplantable organs. While deceased donation is almost ubiquitously associated with altruism, this paper argues for a collective account of deceased donation and donor registration. Taking a “decision rules” approach, the paper examines how three alternate rules or norms (Meeker, 1971)—altruism, reciprocity and group gain—provide alternative explanations for deceased donor registration. Drawing on theories of social identity and resource exchange, the paper identifies the characteristics of donation and transplant systems that justify the framing of donor registration as group gain, and thus a collective behaviour.

A collective conceptualisation suggests alternative motivations for and barriers to donor registration, that also account for the significance of trust and social inclusion in willingness to register. Such a framing shifts the locus of donor registration behaviour from individual traits and preferences to the social and institutional settings in which deceased donation and transplant systems operate. Thus, the paper argues for moving beyond a focus on improving individual attitudes as a means of increasing registration rates. Instead, efforts should be focused on issues of access to social institutions and fostering social inclusion within countries.
1. Introduction

Over the past three decades, organ transplantation has been transformed from an experimental therapy to a relatively common treatment for end stage organ failure (Healy, 2007). While the need for transplantable organs continues to grow, deceased donation rates are relatively stable (Cotter, 2011). In 2014, donation rates fulfilled less than ten percent of the estimated global need (Global Observatory, 2016). Less than one percent of the deaths occur in circumstance that would allow for donation (Thomas & Klapdoor, 2008); even so it is estimated that only 10-20 percent of such deaths result in donation (Farsides, 2010).

Deceased donation systems operate under informed consent (opt-in) or presumed consent (opt-out) systems. In opt-in systems, citizens express explicit consent to deceased donation by registering; in opt-out systems, consent is presumed unless a citizen explicitly registers an objection. The majority of continental European nations adopt an opt-out approach, while countries such as the USA, Canada, Australia, and the UK (excluding Wales) operate opt-in systems (Abadie & Gay, 2006; Rudge, Matesanz, Delmonico, & Chapman, 2012). Despite decades of concerted education and promotional campaigns, high levels of professed community support for organ donation has not translated to similar levels of donor registration in opt-in systems (Abadie & Gay, 2006). In the USA, nearly 95% of American adults surveyed profess their support for organ donation, yet less than half are registered donors (Ladin, 2016). Equally, there are large differences in donation behaviour between population groups (Morgan, et al., 2013).

The disparity between general support for donation and donor registration has resulted in renewed scrutiny of the framing of deceased donation in the public domain, from the legislative structures and policies underpinning donation systems to the promotion of donor registration. Richard Titmuss (1970, 1997) recognised the significant impact of framing on donor behaviour over forty years ago in his seminal work on blood collection systems, where he argued that commercial incentives undermine intrinsic motivations by reframing donation as
an economic exchange. Donation as a “gift of life” is another such framing—a metaphor evident in deceased donation policies (for example, the USA’s Uniform Anatomical Gift Act (1968), which regulates the donation of organs, tissues, and other human body parts), and promotions in nearly all organ donation systems worldwide (Guibet-Lafaye & Kreis, 2012). Siminoff and Chillag (1999) state “The metaphor suits the transplant community because it is easy to understand and readily conveyed to the public, and because it maps onto cultural ideals about altruism” (p. 40). However, the value of attributing donation to individual altruism is frequently challenged by both those who advocate market-based approaches to increase donation rates (Mahoney, 2009; Matas 2008; Nadal & Nadal, 2005), and those who argue that the efficacy and efficiency of the donation systems themselves influence donation rates (Healy, 2004).

Others suggest the “gift” of organ donation is better understood as an exchange rather than a unidirectional act of giving (Murray, 1987; Shaw, Bell, & Webb, 2012). This approach, drawing on gift exchange (Mauss, 1967) and social exchange (Blau, 1964; Emerson, 1976) theories, focuses on the reciprocal nature of deceased donation and transplantation systems (Burkell, Chandler, & Shemie, 2013; Schweda et al., 2009). Such accounts see giving behaviour as being founded on social relations and driven by societal norms and obligations (Simmel 1950). Thus, reciprocity offers a useful counterpoint to the altruism metaphor, marking donation as an interdependent behaviour. Reciprocity in deceased donation includes dyadic (between donor and recipient) and collective (between society members) accounts. There are also various other collective accounts of deceased donation. These include donor registration as a social dilemma (Glannon, 2009), whereby individual self-interest is seen to undermine collective gains, and normative discussions of donation as a moral obligation for all society members (Etzioni, 2001). However, beyond these self-interested and normative arguments, theories of group behaviour have the potential to provide additional insights into the collective nature of deceased donation and thus motivations for and barriers to registering. Given the progressively diverse and sometimes fragmented nature of many societies, focusing on the role of group behaviour in encouraging or discouraging participation in collective action may be key to increasing donor registration.
To that end, this paper examines how three alternate exchange “decision rules” (Meeker, 1971)—*altruism, reciprocity*, and *group gain* respectively—provide different explanations for deceased donor registration. Drawing on theories of social identity and resource exchange, the paper identifies the characteristics of donation and transplant systems that justify the framing of donor registration as a collective behaviour. Importantly, this collective conceptualisation accounts for the influence of institutional trust (Petersen, 2002) and social inclusion (Morgan et al., 2008) in donor registration, factors shown to influence donation attitudes and behaviour, but that are largely missing from theoretical models of donation behaviour. This reconceptualisation shifts the locus of donor registration behaviour from individual traits and preferences to the social and institutional settings in which deceased donation and transplant systems operate. Thus, the paper argues that increasing donor registration requires us to move beyond just improving attitudes towards donation to actually ensuring equitable access to social institutions and fostering social inclusion within communities.

The paper is organised as follows: first, the paper provides a brief background on exchange theories and Meeker’s decision rule approach to social exchange. Next, it examines the impact the three different decision rules—altruism, reciprocity, and group gain—have on the conceptualisation of deceased donation and the act of donor registration. It then further investigates the salience of group gain to deceased donation from two theoretical perspectives—social identity and resource-based theories—to demonstrate how and why donor registration is optimally founded on the group gain decision rule. The paper concludes with a discussion of the implications for public policies in relation to deceased donation and transplantation, and how to promote donor registration in the public domain.
2. Background

2.1 Exchange theories

Exchange theories are premised on the belief that all interactions in life are best understood as exchanges. Social exchange theories developed from the anthropological works of Mauss (1967), Malinowski (1932), and Levi-Strauss (1969) in relation to gifts and other exchanges in non-western societies. These were taken up and interpreted across multiple disciplines including sociology, (Blau, 1964; Emerson, 1976; Homans, 1958), psychology (Thibault & Kelley, 1959) and economics. While there are numerous perspectives on social exchange, most theorists see social exchange as involving interdependent transactions that generate obligations between parties (Cropanzano & Mitchell, 2005). Blau (1964), for example, describes social exchange as “the principle that one person does another a favor, and while there is a general expectation of some future return, its exact nature is definitely not stipulated in advance” (p. 93). These diffuse obligations are seen to create ongoing patterns of social exchange between participants (Molm, 2010). Social exchange has been a central conceptual paradigm for understanding behaviour across a range of domains (Konovsky & Pugh, 1994; Smith, Bolton, & Wagner, 1999; Tyler, 2003). Nonetheless, criticisms are levelled at social exchange theories, particularly in relation to the assumptions that exchange relationships are founded on individual self-interest (Elster, 1991; Turner, 1991; Levi, 1991) and that calculative reciprocity is the primary decision rule underpinning exchange (Cropanzano & Mitchell, 2005).

2.2 Decision rules of social exchange

Decision rules are the principles adopted by participants when making exchanges (Emerson, 1976). Barbara Meeker (1971) takes a decision rule approach to social exchange, arguing that human behaviour can be predicted by 1) the value of that behaviour to a person, 2) his or her perception of the alternative behaviours available, 3) expectations of the consequences of these alternatives for both the individual and others, and 4) a decision rule, which Meeker (1971) defines as a “a kind of social norm telling him how the first three
Social norms are context-dependent, socially-derived rules that are followed conditionally (Bicchieri, 2008). The nature of exchanges, which involve both giving and receiving, has seen the norm of reciprocity (minimizing the difference between what is given and what is received) typically identified as the salient decision rule in social exchanges (Croppanzo & Mitchell, 2005). However, Meeker’s theory identifies other decision rules at work, including rationality (maximizing one’s own benefit), altruism (maximizing the exchange partner’s benefit), competition (maximizing the difference between the exchange partners’ benefits), status consistency (ensuring benefits are allocated according to the status of the partners), and group gain (maximizing the total benefit that accrues from the exchange between partners). In accordance with theories of exchange, Meeker’s typology is grounded in rational choice; the decision rules represent an optimum choice under a particular set of conditions. However only the rationality decision rule strictly reflects the self-interest assumption typical of rational choice. Thus, Meeker avoids conflating rational choice with self-interest.

According to Meeker (1971), decision rules are “neither mutually exclusive nor exhaustive with regard to the choices they prescribe, nor does each necessarily lead to a unique outcome” (p. 491). The goal (the ultimate aim of the exchange) helps determine which rules are appropriate and compatible. For example, within the donation literature, four main decision rules are evident—rationality, altruism, reciprocity, and group gain. While rationality underpins discussions of financial incentives for living donation (Arnold et al., 2000; Erin & Harris, 2003), which is not the subject of this paper, altruism and reciprocity dominate discussions of deceased donation, with group gain also evident in calls for a communitarian approach to donation (Etzioni, 2003).

3. Decision rules and deceased donation

3.1 Altruism

As noted, within the literature and in the public domain, deceased donation is overwhelmingly associated with altruism. Altruism refers to the behaviour of
caring strangers—acts of help directed towards needy individuals or groups with whom the giver shares no relationship and has no expectation of return (Batson & Powell, 2003). Thus, the altruistic decision rule applies to unidirectional behaviour—there is no reciprocity involved (Meeker, 1971).

3.1.1 Altruism and deceased donation

Behavioural models of donor registration, such as the Organ Donor Model (Horton and Horton, 1991), the Organ Donor Willingness Model (Kopfman & Smith, 1996) and the Organ Donation Model (Morgan et al., 2002) typically attribute donor motivations to individual altruistic personality traits and preferences. For example, the Organ Donor model identifies altruistic attributes, such as being helpful, cheerful, forgiving, loving, and courageous, as key predictors of willingness to donate. Indeed, deceased donation appears to epitomise altruism—organs are given to desperately unwell, anonymous recipients with no apparent possibility of reciprocity (Batten, 1992). The potentially life-saving impact of deceased donation also involves promotion campaigns that depict donors as superheroes coming to the rescue of transplant recipients (Zeiler, 2013). In opposition to this view, some have suggested that deceased donation hardly qualifies as altruism at all, yet alone heroism, given that the donor is already dead when donation takes place, and hence involves no sacrifice on the donor's part (Robertson, 2004).

Communication campaigns that promote altruistic donation tend to conflate the act of registering with the act of donation itself; campaigns call on people to “save a life”, “become a donor”, or “be a hero” through registration (Zeiler, 2013). However, most registered donors ultimately do not die in circumstances that would allow donation (Thomas & Klapdoor, 2008). Lauritzen et al. (2001) argue against exaggerating the significance of organ donation, suggesting instead that appeals should stress the “ordinariness” of donating. Similarly, exaggerating the relationship between registering and subsequent donation understates how many potential donors are necessary for a thriving deceased donation and transplant system, which may in turn negate perceptions of responsibility to register. This has implications in terms of the extent to which donor registration
might be considered a necessary act, as opposed to a supererogatory act of altruism—laudable but nonetheless beyond moral obligation (Hester, 2006).

3.2 Reciprocity

A major theme in the literature on deceased donation relates to interpreting the “gift of life” as a reciprocal act (Daar, 2000; Robertson, 2004; Siegal & Bonnie, 2006). Goulder (1960) suggests that reciprocity is a fundamental social norm that spans different cultures, and Cropanzano and Mitchell (2005) argue that the reciprocity decision rule dominates theoretical and empirical interpretations of social exchange. Different exchange structures influence the nature of the reciprocity involved. While dyadic exchanges are more likely to involve tit-for-tat reciprocity, the diffuse nature of generalised exchanges within groups creates uncertainty about when and by whom an act will be reciprocated (Glenane-Antoniadis, Whitwell, Bell, Genguc, 2003). Indeed, generalised exchanges are evident in acts as diffuse as stopping to help a stranded motorist or reporting a burglary in the neighbourhood (Takahishi, 2000). While such behaviours involve no expectation of return as such, people may act in the belief that if the tables were turned, other society members would come to their aid, reflecting a karma-like approach to reciprocity (Cropanzo & Mitchell, 2005).

Different forms of reciprocity are also seen to influence the value attributable to exchanges; while tit-for-tat behaviour is concerned primarily with instrumental benefits, the uncertainty inherent in generalised exchanges creates a symbolic value in addition to any material gain (Komter, 2007; Singelmann, 1972). This symbolic value arises from participation in the face of uncertainty, which demonstrates trust in the people involved. Such symbolic value is shown to build solidarity within groups (Molm, 2010; Molm, Takahashi, & Peterson, 2000). Equally, the reciprocity decision rule is tied to perceptions of fairness, where the difference between what is given and received by partners in an exchange is to be minimised (Meeker, 1971). Indeed, fairness or justice perceptions, such as distributive (fair allocation of resources), procedural (fair processes in relation to decisions), and interactional justice (fair/respectful communication), are
central concepts in studies of exchange in relation to prosocial group behaviour (Tyler & Blader, 2003; Tyler, Degoe, & Smith, 1996).

3.2.1 Organ donation and reciprocity
Within the organ donation literature, the reciprocity decision rule is interpreted in a range of ways. The first relates to the relationship between the (deceased) donor and the recipient, rather than to registration per se. In this reading, the reciprocal nature of organ donation and transplantation is identified as a burden on recipients, who are in the impossible position of being indebted to—but unable to pay back—the (deceased) donor for the “gift”, leading to feelings of guilt (Fox & Swazey, 2001; Siminoff & Chillag, 1999). Within living donation, the pressure on family members to donate and the debt it creates between donor and recipient is described similarly as a tyrannical gift (Scheper-Hughes, 2007).

A second interpretation of reciprocity ties donor registration to transplantation access (Gubernatis & Kliemt, 2000; Jarvis, 1995). A number of studies (Burkell et al., 2013; Dijker, Nelissen, & Stijnen, 2013; Schweda & Schicktanz, 2009) suggest that participants find it theoretically appealing to link willingness to donate with willingness to receive an organ, as it satisfies “certain fundamental intuitions of justice and fairness” (Schweda & Schicktanz, 2009, p. 417). Several studies also find the reciprocity decision rule is an effective way of motivating donor registration (Robertson, 2007). For example, a 2015 study undertaken by the UK Government’s Cabinet Office Behavioural Insights team found that communication campaigns appealing to fairness and reciprocity were the most effective way to prompt donor registration among people applying for driver’s licences or paying vehicle tax. Testing a variety of messages, the study found that the prompt “If you needed an organ transplant, would you have one? If so, please help others” resulted in the largest number of new donor registrations (UK Government, 2015).

The reciprocity principle underpins the donation and transplant systems in Israel and Singapore, in which access to transplantation is prioritised for those who have previously registered as donors (Burkell et al., 2013). Despite broad theoretical support for the principle of reciprocity, a review of studies regarding
attitudes towards reciprocity-based organ donation systems found that only half of the participants were supportive of the approach (Chandler, Burkell, & Shemie, 2012). Those opposed expressed concern about the fairness of reciprocity-based systems in practice, including the potential for discrimination against people who are unwilling to donate for legitimate reasons—religion, culture, psychological factors, socioeconomic vulnerability, or social exclusion (Chandler et al., 2012). Critics of priority systems also suggest that some populations in society may have good reason to mistrust donation and transplantation systems, and punishing non-donors simply exacerbates existing disadvantages (Almassi, 2014; Goering & Dula, 2004).

An additional critique of reciprocity-based priority systems for registered donors is that reciprocity may take different forms, with people giving to society in a range of ways that are not necessarily directly related to organ donation (Chandler et al., 2012). Implicit in this criticism is the construction of deceased donation as generalised exchange (Prottas, 1993). This third interpretation of reciprocity within deceased donation sees donor registration as a way of “giving back” (Mossialos, et al., 2008) or “paying forward” (Healy & Krawiec, 2012) benefits received during one’s lifetime. The existence of generalised exchange defies rational/utilitarian constructions of behaviour, yet the tendency to pay generosity forward is evident both in experimental studies (Simpson & Willer, 2015) and in everyday life (Willer, Flynn, & Zak, 2012). There appears to be few instances of communication campaigns explicitly identifying donor registration as generalised exchange, but one such example is a Donate Life USA campaign run annually during the festive season (Thanksgiving and Christmas) using the message “Give thanks. Give Life.”

3.3 From generalised exchange to group gain

Donor registration framed as generalised exchange blurs the boundary between the reciprocity and group gain decision rules. Generalised exchanges are collective behaviours marked by the most diffuse of obligations between society members—the obligation to help on the understanding that others in society would do the same if positions were switched (Takahashi, 2000). Participants in
generalised exchanges are thus effectively “co-operators in a societal solidarity contract” (Mau, 2004, p. 64). That said, the terms of such a contract are open to interpretation—a general obligation to help does not tell us to which situations this obligation applies. In this respect, generalised exchange is open to the criticisms levelled at accounts of prosocial behaviour based on individual or personal values or norms—being too vague to provide real guidance about how to behave in concrete situations (Schwartz, 1973). In opposition to norm-based accounts of helping, situational approaches see context, rather than personal beliefs or social norms, as the most important determinant of helping behaviour (Anker & Feeley, 2011). For example, the Bystander Intervention Model (Darley & Latane, 1968) suggests that people will act when they see a need to, take responsibility for, and know how to, help. Alternatively, norms and context may work in tandem, with personal norms becoming salient under particular circumstances—including knowledge of the consequences of one’s actions and believing one has a responsibility to act (Schwartz, 1973; De Groot & Steg, 2009). These situational accounts of helping behaviour highlight the role that context plays in determining whether or not people will act, and it is the context—the nature of deceased donation and transplant systems—that makes group gain a useful way of framing donor registration beyond generalised exchange.

3.4 Group gain

The group gain decision rule is designed to produce maximum benefit for a bounded social group (Meeker, 1971). As such, group gain is theoretically less concerned with individual gains and losses than in collective outcomes. Group gain does not require that each individual benefit from a behaviour, only the group overall. However, theories of collective behaviour are rarely founded on the group gain decision rule; rather collective behaviour is typically framed as a series of individual rational decisions (Oliver, 1993). The predominance of the rational self-interested actor in accounts of collective behaviours can be traced to Mancur Olson’s influential book “The Logic of Collective Action” (1965), in which the author proposes “rational, self-interested individuals will not act to achieve their common or group interests” (p. 2). According to Olson, large group collective actions are doomed to fail; the individual benefit gained from
participating is simply too small. Olson’s work set in train a body of theoretical and empirical research into social dilemmas—resources from which the whole society benefits if everyone contributes, while at an individual level non-cooperation is the dominant choice (Hardin, 1968; Yamagishi & Sato, 1986). Social dilemmas pose a tension between individual and collective interests (Simpson, Irwin, & Lawrence, 2006), resulting in a temptation to “free ride”, that is, neglecting to contribute while taking from a collective resource (Yamagishi & Cook, 1993). Some have attributed the failure to meet the growing need for organs through deceased donation to the free rider problem—people failing to register to donate while being willing to take from the collective pool of deceased donor organs if required (Chandler et al., 2012; Glannon, 2009).

Solutions offered to social dilemmas are typically designed to increase the value of individual participation, turning an “apparent dilemma into a non-dilemma by manipulation (conscious or automatic) of the consequences accruing to the individual for cooperation or defection” (Dawes, Van de Kragt, & Orbell, 1988, p. 85, emphasis in original). Thus, solutions to collective resource problems make collective benefits a by-product of private objectives (Macy, 1991; Oliver, 1993). Dawes et al. (1988) identify four main solutions to social dilemmas: Leviathan (state-sanctioned punishment for defection), reciprocal altruism (enlightened self-interest), mutual coercion (socially-sanctioned punishment), and socially-instilled conscience and self-esteem (intrinsic rewards for participation), each of which may be used to prompt participation in collective action. The sanctions imposed on non-registrants in Israel and Singapore is an example of a Leviathan solution, while aligning registration with heroism exemplifies socially-instilled conscience and self-esteem. Nonetheless, there are many examples of collective behaviour under both experimental conditions and in real life even in the absence of individual incentives to do so (Rothstein, 2001). That said there are many instances of individual interests trumping collective action (Douglas 1987). As Elinor Ostrom (2014) notes, decades of “extensive empirical research could be summarised with the weak statement that ‘some groups do and some groups do not succeed in overcoming social dilemmas to achieve collective action’” (p. 235), raising the issue of how and when group gain becomes a salient decision rule for group actions. The paper now draws on two theoretical approaches to
collective behaviours—social identity and resource-based theories—to help answer this question.

4. Group gain, social identity, and resource exchange in relation to donor registration

4.1 Social identity

Social identity theory (Tajfel, Billig, & Bundy, 1971) and self-categorization theory (Turner, Oakes, & Haslam, 1994) see collective behaviour as a consequence of group identification. According to these theories, people have both personal and social identities, and while the former leads people to make decisions in their own individual interests, the latter leads to “in-group” behaviour—actions that favour the group at the expense of an outgroup (Tajfel et al., 1971). Tajfel et al. (1971) posits that such in-group behaviour is a product of a fundamental human drive to maintain a positive self-identity; because one’s identity derives in part from one's group or social category, emotionally investing in a group is central to self-esteem. According to such theories, cooperation is a result of “the shared and mutual perception by in-group members of their interests as interchangeable” (Turner et al. 1987, p. 65). This is because inclusion in groups reduces social distance between members, blurring the distinction between individual and collective interests, such that group members attach greater weight to group benefits than individual ones (Kramer & Brewer, 1986). A range of studies show group identity to be a predictor of cooperative behaviour in existing social groups such as within neighbourhoods and universities (Buchan, Croson, & Dawes, 2002; Dawes et al., 1988) and within groups based on arbitrary criteria (such as preferences for different types of art) established solely for experimental purposes (Charness, Rigotti, & Rustichini, 2007; Van de Kragt, Orbell, & Dawes, 1983). That said studies by Yamagishi & Kiyonari (2000) and Simpson (2006) found that group cooperation does not necessarily rely on the merging of self and other interests; rather groups are a “container for generalized reciprocity” (Yamagishi & Kiyonari, 2000, p. 116).

Footnote:
1 Note that self-identity theory is different to the general concept of “social identity” found in discussions of social development (Haslam et al., 2010).
allowing a reasonable expectation of favourable treatment by other group members.

Building on social identity theory, Lawler and colleagues (Lawler et. al., 2001; Lawler & Thye, 1999) propose that collective exchanges are based on emotional attachment to the group. This approach views the emotions (positive and negative) produced by the exchange process as being attributed to the social unit (the group), encouraging or discouraging participation in group exchanges. Two main conditions affect the degree to which group identity influences group behaviour in exchanges: 1) non-separability, that is, the effect of individual contributions are difficult to distinguish, and 2) perceived shared responsibility for the outcome. Together, these factors determine the “jointness” or interdependence of the exchange task. Kramer and Brewer (1984), for example, demonstrate that social identity motivates collective behaviour only when a superordinate identity based around a common resource in which participants have a shared fate is made salient. Group membership alone is not a sufficient condition for participation in a collective act (a subordinate or lower level group identity does not motivate participation); it is interdependence in relation to a specific task that determines behaviour. Importantly, the work of Lawler and his colleagues and Kramer and Brewer points to the influence of the resource itself on collective behaviour: the group gain decision rule is more likely to be enacted in relation to resources that the group members recognise depend on their collective contributions. In this respect, focusing on the resource sheds further light on the characteristics of deceased donation and transplant systems that influence the extent to which group gain is an effective decision rule in relation to donor registration.

4.2 Collective resources

Early exchange theorists recognised that different types of exchange involve varying levels of interdependencies among actors (Thibaut & Kelley, 1959; Blau, 1964). Resource exchange theory (Foa & Foa, 1984) extends the work of these theorists, proposing that the resources themselves determine the characteristics of the exchange and thus the value attributable to that exchange. Foa and Foa’s
categories of resources include love, money, status, information, goods, and services—some more concrete, others more symbolic or intangible; some more universal, others more particular. In Foa’s and Foa’s model, for example, fungible resources (those in which the value remains stable irrespective of its source—such as money) are contrasted with non-fungible resources (those in which the value is entirely dependent on who it comes from, such as love). This approach becomes relevant when considering the value attributable to donor registration, which is discussed later in the paper.

Accounts of collective behaviour take a different approach, identifying two main types of resources in collective action: 1) common pool resources, which require people to ration their use of an existing collective good, such as water consumption and grazing on public land, and 2) public goods, which require people to contribute to the good, such as radio stations funded by public subscriptions and donating blood (Hardin, 1968; Yamagishi & Cook, 1993). These resources are both theoretically different and invoke different kinds of behavioural responses (Ostrom, 2003). For example, prospect theory suggests that people are more averse to losing an existing resource than failing to gain a new one (Kahneman & Tversky, 1979) and thus people may find it harder to behave with restraint in a common pool dilemma (that is, to not overuse an existing resource) than to contribute to a public good (Brewer & Kramer, 2003). Deceased donor organs are public resources (Prottas, 1993), making donor registration a public goods type of collective action. A key assumption of public goods is their non-excludability—anyone can benefit irrespective of whether or not they contribute. Olson (1965) believed this problem to be intractable in large groups, in which individual contributions would make little difference and where benefits would be divided into smaller and smaller amounts. Olson’s account of participation in large-scale collective action presumes that the attributes of various collective resources are homogenous, that is, the way they are produced and allocated—and hence the rules that govern their production and allocation—are the same irrespective of the good (Ostrom, 2003). Such assumptions are challenged by a range of theoretical and empirical research demonstrating that public resources may be both produced and allocated in a range of ways (Granovetter, 1978; Macy, 1991; Oliver & Marwell, 1988; Van de
4.2.1 The production of collective goods

Oliver and colleagues (Oliver & Marwell, 1988; Oliver, Marwell, & Teixeira, 1985) identify different types of production functions for different collective behaviours, which are determined by the way that contributions translate into units of collective good. A production function illustrates the value of individual contributions (for example, individual organ donor registration) relative to the total benefits produced in terms of collective goods. A linear production function, for example, ascribes equal value to each contribution—theoretically, the value of the first contribution is the same as the last. Other production functions place greater weight on initial contributions (a “concave” production function), while for others, the reverse is true, that is, initial contributions have smaller incremental benefits compared with later contributions (a “convex” production function). The latter production function is “characterized by positive interdependence: each contribution makes the next one more worthwhile” (Oliver & Marwell, 1993, p. 63). Public resources with convex production functions are, therefore, more likely to require widespread participation; the value of a single contribution depends largely on the contributions of a sufficient number of others. Health-related public goods, such as vaccination, have such a production function. Herd immunity requires a particular threshold of people to be vaccinated within a community, which ranges from 83-94 per cent dependent on the disease (May & Silverman, 2003). At the extreme, public goods may have an “all or nothing” production function, in which a certain threshold of contributions must be reached in order for the good to be produced at all (Croson & Marks, 2000; Van de Kragt et al., 1983, ). For example, collective action in relation to global warming is identified as having such a production function, with a ceiling temperature rise identified above which catastrophic environmental effects are deemed likely (Lenton, Held, & Kriegler, 2008; Russill & Nyssa, 2009).

2 Though, an individual vaccination does also have a direct value independent of other contributions: one child vaccinated = one child with immunity, even if a threshold for collective immunity is not reached.
In the case of deceased donation, translating contributions (donor registration) into units of the collective good (transplantable organs) is a non-linear process because, as mentioned, the vast majority of people who register will not go on to become donors. Few people die in circumstances that enable donation, with less than one percent of hospital deaths amenable to possible subsequent organ donation (Thomas & Klapdor, 2008). Thus, deceased donation has a convex production function—the value of an individual donation in terms of producing transplantable organs depends on achieving a certain number of registrations. Consequently, organ donation and transplant systems are required to operate on a national or regional scale to achieve the scale required for registrations to translate into actual donation. For example, the Lifesharer network (Life Sharers, 2006), a privately organised deceased organ donation and transplant scheme that commenced in 2002 and shut down in 2016, failed to produce a single donation despite having 15,000 members. Returning to Lawler’s (2001) criteria for group cooperation, donor registration is characterised by a high level of non-separability, that is, the effect of an individual contribution is not only indistinguishable from the collective—the effect of each contribution depends on the behaviour of the collective.

### 4.2.2 The allocation of collective goods

Deceased donation and transplant systems also challenge an inherent assumption about the allocation of collective goods in social dilemma theories; that at an individual level, the supply (contribution) and consumption of goods is inextricably linked, that is, those who contribute will also consume the public good. This idea, founded on the non-excludability assumption in relation to public goods, is the basis for Olson’s (1965) suggestion that the larger the group involved, the smaller the benefit derived for each participant. However, contribution and consumption are not necessarily connected in all public goods. Building on Foa and Foa’s resource exchange theory, Galvin and Lockhart (2012),

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3 Given that family wishes are almost always adhered to irrespective of whether a potential donor has registered (Bramstedt, 2013; Downie, Shea, & Rajotte, 2008), achieving a sufficient number of organs for transplant also relies on certain number of families willing to authorise donation of a loved one’s organs. Families authorise donation in over 95% of cases where the deceased is a registered donor; hence this theoretical discussion of the "production function" relates to registration.
for example, distinguish between different kinds of public goods on the basis of two attributes—fungibility and divisibility—demonstrating how those attributes influence the allocation of resources. Fungibility refers to the extent to which the value of a good is stable irrespective of who possesses or consumes it, while divisibility refers to the extent to which a good is dividable into smaller amounts. Money is an example of a good that is both highly fungible and highly dividable—the value of $10 remains, theoretically at least, stable regardless of who possesses it and is easily dividable into smaller and smaller amounts as the number of people it is shared between increases. Galvin and Lockhart (2012) call these continuous universal goods. The inverse of such goods are those in which the value depends on who possesses it and those that cannot simply be divided to accommodate a greater number of recipients, which Galvin and Lockhart (2012) name discrete idiosyncratic goods. The authors identify medical care and education as examples of discrete idiosyncratic goods. Using the case of a hip replacement, Galvin and Lockhart note not only is hip replacement surgery valuable only to someone who needs it (and is in fact detrimental to someone who does not need it), it is not valuable (or even possible) to perform half or a quarter of the surgery on two people should more than one person need a hip replacement.

Turning to donor registration and the allocation of donated organs, the relationship between the production and allocation/individual consumption of the public good is weak (though priority systems for registered donors attempt to theoretically strengthen this link). A greater number of potential participants in deceased donation and transplant schemes does not decrease the amount of the good available at an individual level; in fact, it achieves the opposite, providing a greater number of potential donors. This is because donated organs are both idiosyncratic—that is, only valuable to someone who needs a transplant—and discrete, that is, organs (other than livers) are not divided into smaller and smaller units. As transplant surgery is utilised only by those who require a transplant, most people, registered or otherwise, will not draw on the pool of organs and thus not individually benefit from the resource. This has the effect of uncoupling supply from allocation and consumption, challenging the assumption that large-scale collective endeavours necessarily involve
diminishing individual benefits, or that individual benefits are the driving force behind collective behaviour in relation to all public goods.4

The conclusion that may be drawn from the relationship between a resource’s attributes and collective behaviour is that group gain is a desirable, if not necessary, decision rule for some kinds of public goods—namely those that almost entirely depend on mass participation and those in which individual gain is not a defining feature of participation. These are goods for which societies take shared responsibility, and thus they do not have the characteristics of private goods. Deceased donor organs are such public goods; once removed from the deceased donor, they belong to the state (Prottas, 1993) and they cannot be gifted to a specific individual but are allocated according to set criteria to those on waiting lists. The widespread acceptance of organs as public goods is demonstrated by the failure of proposals for directed donation (the capacity for a deceased donor to specify what kind of person should be allocated his or her organs) to gain traction (Pennings, 2007; Truog, 2005; Wilkinson, 2003). In this way, donor registration differs to “altruistic” acts, in which people decide to whom they would like to direct their charity (for example, one can choose to support a particular child sponsorship organisation over another, then choose the nationality, region, gender, age, and even birthdate of the child). Consequently, theories of collective behaviour that are a scaling up of individual interests offer an insufficient account of motivations to register as a donor.

5. Deceased donation as public goods – the roles of trust and social inclusion

Having established why it makes sense, theoretically, to consider donor registration as a group gain activity, this paper now considers the implications of

4 An alternative way of assessing the value of deceased donation is to attribute individual value to the existence of the system rather than the consumption of the resource, that is, an organ transplant. This is the approach taken in contingent valuation (Carson, 2012), which used to value public environmental resources, such as the existence of national parks, that few people ever use. Note that contingent valuation is critiqued on the basis that what people are valuing is the “feel good” factor or “warm glow” of caring about the environment rather than the resource itself (Hausman, 2012; Kahneman & Knetsch, 1992).
this approach in relation to motivations for and barriers to registering as a
donor. Meeker’s (1971) decision rules identify normative context as central to
understanding individual behaviour, reflecting the approach of other scholars
interested in the relationship between norms and rational choice (Elster, 1991;
Levi, 1991; Ostrom, 2014). Such theorists are methodological individualists who
are also concerned with the actual contexts—political, social, and historical—in
which decisions are made. This paper draws on the accounts of contributions to
public goods by one such theorist, political scientist Margaret Levi (1991, 1998),
to examine drivers of donor registration. Levi proposes that contributions to
public goods have both normative and instrumental bases, which she describes
as “duel utilities”—the desire to contribute to the social good and the wish to
ensure that one’s needs are met as far as possible. According to Levi (1991),
people are contingent consenters in relation to public goods: “each citizen’s
action is affected by the actions of both other citizens and of state actors” (p.
135). Levi sees willingness to contribute as dependent on belief in the worth of
the good, trust that the institutions responsible for the good will actually deliver
them, and trust that others are also willing to contribute, that is, feeling that one
is not a “sucker”, contributing when others do not. Rothstein (2001) describes
these two forms of trust as two social dilemmas faced by people when
considering contributing to public goods. Consequently, both institutional and
social relationships are significant to donor registration behaviour as discussed
now.

5.1 Institutional trust

Levi and Rothstein’s focus on institutional and social structures reflects
Granovetter’s (1985) work in relation to the “embeddedness” of individual
decisions in cultural and institutional structures. Granovetter argues that this
embeddedness provides constraints and incentives that fundamentally influence
individual behaviour, and thus it makes no sense to consider behaviour outside
the context in which it takes place. The delivery of public goods is almost
ubiquitously mediated through institutions (Mau, 2004), both public and
(increasingly) private. Indeed, deceased organ donation and transplantation is
necessarily highly institutionalised, supported and regulated by what Steiner
(2003), calls an "imposing set of political, legal, economic, medical and relational institutions" (p. 160). Drawing on Granovetter's (1985) work, Healy (2004, 2007) identifies a range of institutional factors—hospital resources and processes for example—that influence the number of organs ultimately collected from deceased potential donors. Mossialis et al. (2008) also find a relationship between donation and transplant systems' organizational settings (that is, opt-out versus opt-in) and donor registration. Beyond effectiveness and efficiency, the need to trust the institutions charged with carrying out donation and transplantation represents (in Rothstein's terms) a "social dilemma" that has the potential to overwhelm normative beliefs about the need to contribute to social goods.

Rothstein (2001) also argues that public goods (such as welfare), which have long-term horizons, require people to trust not only the current but also any future institutions/governments charged with delivering those goods. This characteristic is particularly evident in donor registration, which involves inherent uncertainty about whether or not an individual will ultimately become a donor because donation takes place only in specific circumstances. Deceased donation occurs as a result of the loss of life after a catastrophic injury or illness, typically involving the declaration of brain death (though donation after cardiac death is becoming more common (Bastami et al., 2013)). Consequently, registered donors need to trust the institutions underpinning donation and transplant systems into the future, because becoming a donor may well entail end-of-life treatment in an unknown hospital followed by declaration of death by unknown medical staff.

The significance of trust in deceased donation is demonstrated by an array of studies that found institutional mistrust in relation to becoming a donor (including fear that registered donors may receive suboptimal care and/or have life-saving care withdrawn prematurely) is a barrier to donor registration (for example, Russell, 2012, Siminoff, & Arnold, 1999; Brown, 2012; Goldberg, Halpern, & Reese, 2013; Robinson et al., 2012). Equally, perceptions that transplant systems are unfair—that they are systematically biased against the poor and ethnic minority groups (Boulware, Troll, Wang, & Powe, 2007; Morgan
—suggest that perceived injustice in the allocation of donated organs is a barrier to donating. These studies also found that mistrust of organ donation and transplant systems stems in part from negative perceptions of healthcare and other social institutions and unsurprisingly, mistrust is particularly prevalent in minority populations (Morgan et al., 2013). Nonetheless, institutional mistrust is frequently attributed to lack of knowledge or myths about donation (Hyde, Wihardjo, & White, 2012), with an implicit assumption that increased knowledge is sufficient to overcome mistrust. Equally, institutional trust appears in few models of donor behaviour, though studies of donation intentions in the African American population by Robinson et al. (2012) and Morgan (2006) found a relationship between institutional mistrust and unwillingness to donate.

5.2 Trust in others

The other of Rothstein’s (2001) dilemmas—the need to trust that other society members will contribute—is an archetypal social dilemma. That said, it does not necessarily follow that responses to such dilemmas are founded on individual self-interest. As already discussed, group membership may facilitate trust in others through the merging of individual interests with those of the collective, or by providing reassurance that one will be treated fairly by the group (Brewer, 2008; Brewer & Kramer, 2003). However, theories of group behaviour rely on an implicit assumption of inclusion—one trusts other group members precisely because one is included in the group. As a consequence, the extent to which the group gain decision rule is seen as applicable in a given circumstance is likely to depend on the extent to which an individual recognises himself or herself as part of a group whose interests are served by participating. Indeed, research demonstrates that inclusion increases cooperation between people and willingness to participate in prosocial activities (Hillebrandt, Sebastian, & Blakemore, 2011), while exclusion is associated with a decrease in trust and lower participation in collective actions (Twenge, DeWall, Bartels, Ciocarluca, & Baumeister, 2007). Studies also suggest that perceptions of social exclusion do impact on attitudes towards deceased donation; those who do not feel part of a society feel more negatively about donation (Morgan, Adams, Seed, & Jones,
These findings suggest that the social context in which donation decisions are made does influence willingness to register as a donor.

6. Discussion

Understanding the decision rules that apply to deceased donation behaviour has the potential to provide new insights into the drivers of donor registration and to suggest alternatives ways of framing donation registration in the public arena. Deceased donation may have become inseparable from the idea of altruism but, as demonstrated through Meeker's (1971) decision rules, it offers an incomplete account of donor registration behaviour. A number of critics suggest the framing of deceased donation through altruism stems from an historical attempt to make organ donation palatable to the public (Healy, 2007), using the gift metaphor to “legitimize what is in fact a profound transformation in the way we think about and act toward the human body” (Joralemon, 1995, p. 342). Joralemon characterises the altruistic gift metaphor (as well as the property rights metaphor used to advocate for commercial living donation) as a “cultural transplantation” (p. 342). This entails powerful images and priorities from one domain of social life being adopted for organ transplantation to make it appear congruent with the cultural values and meanings associated with that domain. Indeed, organ donation is frequently likened to charitable giving and volunteering, with models of donor behaviour typically founded on models of individual prosocial behaviour, such as the Theory of Planned Behavior (Horton & Horton, 1991; Hyde, Knowles & White, 2013; Robinson et al., 2012). Nonetheless, altruism is a fairly weak predictor of donor registration overall (Wakefield, Watts, Homewood, Meiser, & Siminoff, 2010; Nijkamp, Hollestelle, Zeegers, van den Borne, & Reubsaet, 2008), and appeals to altruism have arguably thus far failed to mobilise the public to register in sufficient numbers.

The shift to reciprocity-based accounts of deceased donation recognises donor registration as an interdependent behaviour. The reciprocity decision rule is founded on equity considerations—ensuring a balance between what is given and received. Appealing to donor registration as a matter of fairness taps into the
reciprocity decision rule, which may be a fruitful avenue for encouraging registration. Beyond fairness considerations, the group gain decision rule aims to maximise the collective benefit, which as this paper has demonstrated, is distinct from individualistic accounts of group behaviour. Consequently, the effectiveness of framing registration as a group gain activity depends on the extent to which society members acknowledge their joint responsibility in relation to donation, and the extent to which people understand that their individual interests are tied to/inseparable from those of society.

Lawler and colleagues’ (Lawler, 2001; Lawler et al., 2001; Lawler & Thye, 1999) account of social identity theory in group exchange suggests that a potential means of fostering group gain lies in promoting a superordinate social identity in relation to deceased donation and transplant systems. Superordinate identities subsume lower level group categorisations (such as family, team, or ethnic membership), promoting trust and cooperation, and allowing disparate social groups to work together towards specific goals (Gaertner & Dovidio, 2012), such as meeting the need for transplantable organs. A communications campaign founded on group gain would, for example, stress the collective nature of donation and transplant systems and the need for participation by all population groups within a community. It would also stress the small number of deaths that result in donation, making it clear that the highest possible number of registrations is essential.

However, the success of fostering a superordinate, collective identity around donation and transplantation depends on the extent to which it is congruent with the broader experiences of society members. Group behaviour is fundamentally tied to notions of inclusion and exclusion (Abrams, Hogg, & Marques, 2004). Groups rely on the construction and maintenance of symbolic and social boundaries (Lamont & Molnár, 2002). Symbolic boundaries are conceptual distinctions that generate a collective identity by stressing the similarities between group members (and conversely the differences between non-group members). Social boundaries such as social exclusion, racial, and class segregation are the manifestation of these symbolic boundaries, whereby group membership dictates access to and distribution of resources (Lamont & Molnár,
As a consequence, creating a superordinate identity around deceased donation is likely to be a challenge for populations who are already outside these symbolic and social boundaries—that is, those who are not represented in a nation’s collective identity and who receive an inequitable share of society’s resources.

A key question raised by this paper is, therefore, whether it is possible to foster a sense of inclusiveness around donation and transplant specifically, in the absence of broader social inclusion. Research undertaken with the Caribbean population in London (Morgan et al., 2008) suggests that this may be a difficult task. The study found that in the face of perceptions of exclusion and mistrust of social institutions, ethnic identity becomes an important influence on attitudes towards donation. The authors argue that while people have multiple identities, some experiences make ethnic identity more salient and encourage them to act in accordance with that identity. Hence, reluctance to donate and a desire to be buried in the Caribbean, expressed by some participants (even those born in the UK) seems to be a way of asserting ethnic identity in response to social marginalisation brought about by migration. On the other hand, research in relation to blood donation in an African migrant population in Australia (Polonsky, Brijnath, & Renzaho, 2011) finds experiences of racism, lack of media representation of non-white communities, and negative encounters with the blood donation staff led participants to believe that mainstream Australia simply did not want their blood. The authors suggest that engaging the African migrant population in blood donation requires a greater representation of Africans within marketing campaigns as well as communications specifically aimed at African communities, while acknowledging that the issue of broader social exclusion remains. In a related paper, Polonsky, Francis, and Renzaho (2015) point to the potential for participation in collective activities such as blood donation to actually facilitate perceptions of broader social inclusion, suggesting a mutually reinforcing relationship between social inclusion and participation in collective action. Thus, fostering perceptions of a shared fate in relation to deceased donation and transplantation and a shared responsibility to register may possibly increase perceptions of social inclusion if barriers such as mistrust
and beliefs about the unfairness of transplant allocation policies can be overcome.

7. Conclusion

The group gain decision rule suggests alternative drivers of registration behaviour, invoking the mutual responsibility associated with the provision of other public goods, such as welfare, healthcare, and education, rather than the empathy associated with discretionary acts of charity or other prosocial behaviours. Contributions to public goods pool social risks and redistribute resources between groups (Mau, 2004) in recognition of the mutual obligations between society members, the very point made by Titmuss over forty years ago in relation to blood donation systems. These mutual obligations, however, depend on community trust in institutions and each other (Rothstein, 2001). The success of fostering a norm of group gain in relation to deceased donation and transplant systems, therefore, will depend on the extent to which diverse populations take on a superordinate, collective identity in relation to registering. In the absence of cues that reinforce the inclusiveness of donation and transplant systems specifically and in the face of social systems that reinforce social exclusion more broadly, building institutional trust and trust in other society members represents a challenge. However, in making explicit the role of underlying social institutions and relationships, this paper demonstrates the limitations of focusing on improving individual attitudes or self-efficacy to effect behavioural change in relation to donor registration and possibly other public goods. Rather, ensuring equitable access to and favourable interactions with social institutions and fostering a sense of belonging to a community may well be central to increasing donor registration rates.
This paper discusses the thesis's second research question, focusing on the drivers of and barriers to registering as a deceased donor in a collective account of deceased donation.

Organ donation and transplant systems are organised around citizenship, with organ transplantation typically not granted to non-citizens. However, globally-increasing labour migration and refugee flows challenge the idea of citizenship as a means of delineating access to resources, such as donated organs. Currently, little is known about the attitudes of temporary migrants towards organ donation and the role of institutional norms and practices on perceptions of deceased donation in such populations. Temporary migrant populations are also vulnerable to social exclusion, a factor shown to influence attitudes towards donation in permanent ethnic minority populations. Thus temporary migrant groups may offer important insights into barriers to participation in deceased donation and transplant programs in socially divided societies.

This paper presents the results of a qualitative study (n=44) undertaken among five temporary migrant populations in the gulf state of Qatar—Indian, Filipino, Sri Lankan, Bangladeshi and Nepali. The study aimed to explore knowledge and perceptions of deceased organ donation and the potential influence of social norms and practices, mistrust, and social exclusion on attitudes towards donation. Taking a theoretical thematic analysis approach, the study found that participants' understanding of and expectations around donation are based on a different institutional logic to Qatar's voluntary unpaid system. First, participant perspectives on donation are principally founded on norms and practices relating to living (largely illegal) donation within the temporary migrants' home countries. Second, Qatar's inclusive system appears to be at odds with
participants’ expectations of life in Qatar, which is characterised by a lack of interaction with Qatari citizens and institutions and narrow social relationships founded on shared nationality. The participants’ overwhelming lack of knowledge regarding the country’s donation system highlights the challenge of reaching migrant populations that have limited relationships with their broader society. Thus, the paper concludes that the promotion of deceased donation requires us to address these clashing institutional logics by investing in the wider integration of temporary migrants.
1. Introduction

Organ donation and transplant systems worldwide face an ongoing challenge of meeting the need for deceased donor organs, as transplant waiting lists continue to grow (Klein et al., 2010). The shortage of organs is particularly significant for ethnic minority populations, who tend to be over-represented on transplant waiting lists in Europe, Australia, and the USA (Malek et al., 2011; Rudge et al., 2007; Cass et al., 2003). This is partly due to the higher prevalence of end-stage renal failure stemming from chronic diseases in these groups and the subsequent need for kidney transplants (Callender et al., 2002). Ethnic minority populations are also less likely to register as donors or to provide in-hospital consent to the donation of a loved one’s organs (Morgan et al., 2013). Because donated organs are more likely to go to recipients with a shared ethnicity, these lower donation rates further exacerbate the problem of waiting times for transplantation in ethnic minority populations (Davies, 2006).

Studies of donation among ethnic minority and migrant populations have largely been undertaken among permanent residents or citizens in countries with well-established deceased organ donation and transplant systems (Morgan et al., 2013). Within such systems, organ donation is highly institutionalised, both in the sense that there are well-established legal processes in place to enable deceased donation (for example, legislation and donor registration systems), as well as accepted social norms and practices that encourage deceased donation. Institutional theory (Scott, 2004) identifies these as the organisational settings and the institutions (rules, norms, and routines that guide social behaviour) of deceased donation and transplantation respectively. However, competing institutional logics—contradictory practices and beliefs about institutions (Thornton & Ocasio, 2008)—may influence donation behaviour. For example, organizational settings around donation differ across various cultural and national groups, and institutions relating to deceased donation may be at odds with other institutional norms and practices. These include religious norms (Padela & Zaganjor, 2014; Wakefield, Reid, & Homewood, 2011), ideas about death and brain death (Lock, 2002), and cultural practices around the body, including beliefs about the need to be buried “intact” (Hayward & Madill, 2003;
Wong, 2010). Lower donation rates in migrant populations may stem in part from these different norms, beliefs, and practices.

Other studies suggest that beyond these competing institutional logics around donation, factors including mistrust (Russell et al., 2012; Kurz et al., 2007) and social exclusion (Morgan et al., 2008) discourage deceased donation among migrant and other ethnic minority populations. Mistrust is evident in fears about the treatment of potential donors in hospitals, for example, that life-saving treatment will be withdrawn prematurely from registered donors (Denvir & Pomerantz, 2009; Siminoff, et al., 2006). It is also manifest in perceptions that donated organs are allocated unfairly, for example, that the rich, famous, and white receive priority for transplants (Siminoff et al., 2006). Such perceptions of organ donation are particularly pervasive within minority populations that have historically experienced racism and social exclusion (Denvir & Pomerantz, 2009; Petersen, 2002; Siminoff et al., 2006).

Social exclusion refers to the systemic denial of particular groups or individuals of access to social institutions and relationships (Hillebrandt et al., 2011; Popay et al., 2010). Within the donation literature, studies have found a relationship between social exclusion and perceptions of both blood (Polonsky et al., 2011) and organ (Morgan et al., 2008; Mossialis, 2008) donation. For example, research regarding donation attitudes and behaviour among the Caribbean population in the UK (Morgan et al., 2008) found that perceptions of racism, exclusion, and negative interactions with social institutions were associated with reluctance to donate. The researchers suggest that in the face of this marginalisation, ethnic identity becomes of central importance, as is evident in participants’ desire to be buried “at home” in the Caribbean, even among those born in the UK. Morgan et al. (2008) see the role of ethnic identity in the reluctance to donate to be less about cultural practices per se, and more about the marginalisation that arises from belonging to an ethnic minority group. Consequently, lower donation rates in migrant populations may be associated with both beliefs, norms, and practices and negative experiences of social institutions that discourage migrants from registering as donors or consenting to the donation of a loved one’s organs.
Less is known about how temporary migrant populations perceive deceased donation. It is estimated that around 244 million or 3.3 percent of the world’s population live and work outside their country of birth (United Nations Population Fund, 2016). Some are temporary workers who maintain close social and economic links with their home country and intend to return home (Ottonelli & Torresi, 2012). Increased refugee flows also leave vast numbers of people legally stateless, affording them limited rights in host countries (Malkki, 1995). Bauböck (2012) describes these temporary populations as “partial citizens” (p 667), living between two nations, often with limited access to their host country’s resources and opportunities for participation in civic life.

Organ donation and transplant systems are organised around citizenship, with organ transplantation typically not granted to non-citizens (Fortin & Williams-Jones, 2013), with some exceptions (for example, if no suitable citizen recipient for an available organ can be found). The favouring of citizens over non-nationals (permanent or temporary) for organ transplantation has been justified precisely on the basis that citizenship confers privileged access to society’s resources, particularly those as scarce as transplantable organs (Prottas, Jonasson, & Kleinig, 1986). However, mobile populations globally pose a challenge to traditional notions of citizenship (Basok, 2004), raising questions about the legitimacy of basing access to organ transplantation on citizenship status, particularly given the contributions made by non-citizen workers to their host countries (Fortin & Williams-Jones, 2013). In addition, although uncommon, non-nationals such as temporary migrants and unauthorised permanent residents can and do become organ donors after death (Martin & Fadhil, 2014). Such disparities have led to calls for equitable access to transplantation for non-citizen residents (Fortin & Williams-Jones, 2013; Goldberg, Simmerling, & Frader, 2007; Martin & Fadhil, 2014).

Thus, temporary migrant populations might be considered participants in deceased donation systems, particularly those who remain in the host countries.

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5 For example, in 2014 two asylum seekers living in Australia on temporary protection visas (which require persons recognised as refugees to reapply to protection every three years) became organ donors (one after self-immolation).
for the long term. How such migrant populations make sense of deceased donation is unknown. Equally, while temporary migrant populations are at risk of social exclusion in their host countries (Basok, 2004), it is unclear whether, and how, social exclusion may influence attitudes towards donation.

1.1 Aims of the research
To that end, this study aimed to explore the knowledge and perceptions of deceased organ donation among a number of temporary migrant populations and the potential influence of norms and practices, trust, and social exclusion on attitudes towards donation. The research was guided by the ideas that there may be a range of institutional practices that influence perceptions of deceased donation in such populations and that the vulnerability of temporary migrants to social exclusion may influence engagement with the cause of organ donation. Because in most countries access to transplantation is typically granted on the basis of citizenship, the study also aimed to explore migrant perceptions of a donation and transplant system that explicitly affords access to transplantation for non-citizens.

2. Methodology

2.1 Context
This study was undertaken among five migrant groups (Filipino, Sri Lankan, Bangladeshi, Nepali, and Indian) in the wealthy Gulf State of Qatar. Qatar has an extremely ethnically diverse population, and 85-90 percent of the estimated 2.2 million residents are non-citizens (De Bel-Air, 2014). Qatar’s donation and transplantation system, outlined in the 2010 Deceased Donation Accord (DDA), allows access to transplantation for all residents regardless of citizenship status, with a focus on encouraging donor registration in all residents (Martin & Fadhil, 2014). The DDA aims to reduce the number of Qatari residents undergoing transplant surgery abroad through achieving “self sufficiency” in relation to organ donation and transplantation, that is, a sufficient supply of donor organs from a population to meet the transplantation needs of that population (Martin & Fadhil, 2014). Self-sufficiency in relation to organ donation and transplantation relies on the existence of a sufficiently large pool of potential organ donors to
meet the local need for transplantable organs; hence achieving self-sufficiency in Qatar necessarily depends on the participation of the country's large number of non-citizen residents. The DDA differs to the county's overall approach to non-citizens, which is marked by clear differences between the rights afforded to citizens and non-citizens and a lack of interaction between the two groups (Fargues, 2011). Many workers in Qatar are vulnerable to social exclusion as a result of disparities in access to legal rights (Gardner, Pessoa, & Harkness, 2014; Zahra, 2014), employment and accommodation conditions, and cultural and linguistic barriers, particularly where migrants are from outside the Gulf region (Gardner et al., 2013; Zahra, 2014). Consequently, the setting provided an opportunity to explore the potential effect of inclusion in a donation and transplant system within a context of broader social exclusion.

2.2 Sampling

Data was collected through eight semi-structured focus group discussions held with five temporary migrant populations in May 2015 in the capital of Qatar, Doha. The use of focus groups enabled a broad-ranging discussion around donation and life in Qatar, which is appropriate given that little is known about perceptions of organ donation in these populations. The data was collected as part of a larger study of attitudes toward the health system and organ donation in Qatar that included permanent Arab populations and Qatari citizens. Indian, Filipino, Sri Lankan, Nepalese, and Bangladeshi participants were recruited for the study because they comprise the largest non-Arabic populations currently residing in Qatar and, together, they represent diverse experiences of working and living in Qatar.

Participants were recruited in April 2015 at shopping malls in Doha, by recruiters from each of the nationalities sought. Booths were set up over several weeks with posters providing general information about the study in the language most commonly spoken in each group (Malayalam, Tagalog, Sinhalese, Nepali, and Bengali). Recruiters did not approach shoppers until they expressed an interest in the study by approaching the booths, at which point the prospective participants were provided with a plain language statement to
read. Those interested provided their contact details and were contacted by telephone several weeks later to organise the focus groups. Efforts were made to schedule the meetings at times amenable to the largest possible number of those contacted. A significant barrier to participation in the study was the long hours worked and limited recreation time of many potential participants. Consequently, many of those contacted were unable to attend the focus group meetings. Because most of the Bangladeshi and Nepali workers in Qatar are male, few Nepali and no Bangladeshi women were recruited to the study.

2.3 Data collection

The focus group interviews were held at the Qatar Organ Donation Centre (known as Hiba), which is part of the Hamad Medical Corporation, during the weekends (Friday and Saturday) in an attempt to accommodate the long working hours of migrants during the week. The groups were nationality- and gender-specific to accommodate cultural norms within a number of the ethnic groups participating in the study, in particular Muslim participants. Interviews were conducted in the language most commonly spoken by those in each group. The interviews were conducted by staff from Hiba of the same nationality as the interview participants, with the exception of the two Sri Lankan group interviews, which were conducted by an Australian citizen of Sri Lankan origin.

Each facilitator received training regarding conducting focus groups, which consisted of three to four sessions held over a two-week period. The training program drew on international experience of similar training for multilingual focus group facilitators, as outlined by Maynard-Tucker (2000). This included an initial session providing an introduction to the foundations and ethics of qualitative research, discussion of the roles and tasks of the facilitator, a review of the interview guide and translation of the guide into each of the languages. A second session covered the preparation of the introductory speech, training regarding probing techniques and a discussion of approaches to difficult participants, followed by role playing both in English and in the language of each of the facilitators. Several subsequent sessions were dedicated to role-playing and the refining of facilitators’ introductory speeches, interview questions and probing techniques. As recommended by Squires (2009), the interview guide
was tested in the languages of the participants during facilitator training to ensure it retained its meaning once translated into each of the languages.

Focus group interviews lasted between 90 minutes and two hours. Each focus group facilitator was provided with the same interview guide (provided in Appendix 1 of Paper 2), which included questions regarding life and work in Qatar, general knowledge of and attitudes toward organ donation, and Qatar’s organ donation and transplant system. The demographic data collected during the focus groups was limited to occupation, length of stay in Qatar, and marital status (with some missing data).

2.5 Data analysis

Coding and analysis of the data took place in English. Prior to analysis, recordings were transcribed in the original language and translated into English by five different translators (not the facilitators). All data was de-identified to ensure participants’ anonymity. Analysis of the data was founded on the theoretical thematic analysis approach (Braun & Clarke, 2006). This approach involves analysis driven by a specific theoretical interest/perspective—the potential influence of migrant experiences and perceptions on deceased donation behaviour and attitudes. Thus, analysis focused on a number of factors already identified from the organ donation literature—cultural and religious ideas about donation, social exclusion, belonging and trust—with a view to examining their potential role in deceased donation behaviour in the context of Qatar. However, in practice, analysis shifted between deductive and inductive processes as themes were identified during the analysis. This corresponds with Kirk and Miller’s (1986) point that good qualitative analysis alternates between inductive and deductive processes, as tentative hypotheses are arrived at and amended or abandoned in the process of analysis.

Analysis took the five-step approach outlined by Braun and Clarke (2006): 1) familiarisation with the data, 2) generation of initial codes, 3) searching for themes, 4) reviewing themes, and 5) defining and naming themes. The author of this thesis undertook the primary analysis for the study. Two additional researchers also independently reviewed the data and identified themes, which
were compared and refined until consensus was reached (Ryan & Bernard, 2003).

To avoid influencing participants’ attitudes, facilitators did not answer questions about donation raised during the focus group but responded to participants after the discussions were formally concluded. Data from the Indian women’s group was excluded from analysis in this paper, as the translation revealed that the facilitator might have overly influenced the discussion.

2.4 Ethics

Ethics approval was obtained by the University of Melbourne (ID 1443280.1) and the Hamad Medical Corporation. Facilitators received permission to record the discussion and participants were provided with 100 Qatari Riyals (approximately AUD $30) in recompense for their time, in addition to travel costs. Costs associated with recruiting participants and running the focus groups were met by the Hamad Medical Corporation, as were transcription and translation costs. Hamad also met the travel and accommodation costs of two additional researchers (not the author) involved in the study.

3. Findings

3.1 Participants’ characteristics

Focus group participants were: Indian (5 male), Filipino (5 male, 7 female), Sri Lankan (5 male, 4 female), Nepalese (11 male, 3 female), and Bangladeshi (4 male) community members. They included a mix of long and short-term stay migrants (range: 3 months–19 years) and reflected known population demographics in Qatar (De Bel-Air, 2014). Thus male participants in lower income jobs were more likely to be in Qatar alone for shorter stays, while female participants tended to be married with children and residing in Qatar for longer periods. Female participants included a mix of housewives, office workers, and healthcare workers but (with the exception of Filipina female participants) were likely to have been sponsored in Qatar by their husbands.
Male worker occupations varied, with Nepali, Bangladeshi, and Sri Lankan males more likely to be employed in construction or other low-income jobs, Indian male participants included a mix of office and manual workers and Filipino men tended to have office or professional jobs. Participants’ religious beliefs also varied, with many of the Bangladeshi, Indian, and Sri Lankan participants identifying as Muslim, some Sri Lankan participants identifying as Buddhist, and Filipino participants identifying as Christians. Four of the 44 participants identified themselves as registered donors in Qatar.

3.2 Conceptualisations of donation

3.2.1 Living donation

When the topic of organ donation was initially discussed, most participants across each of the focus groups spoke about living donation rather than/deceased donation. Indeed, many participants seemed to presume that organ donation related mainly, if not solely, to living donation. As noted by one participant (Filipina, female, nurse, 2-year stay):

Because when people think of organ donation, it seems ... mostly they think that the person who donates is alive and is willing to give one of your kidneys, or part of your liver. They do not know that you can donate after life.

In particular, participants in each group spoke about illegal kidney sales in their home countries, some with direct experience of illegal selling (for example, relatives or friends buying or selling organs). One Bangladeshi, (male, supermarket worker, 15-year stay) said that his uncle had sold his kidney in Singapore in order to pay for his house, but had died a year later, though the participant did not know whether his death was a consequence of the nephrectomy. He also suggested, “In our country, the transplant is only in exchange of money”.

Others described seeing newspaper advertisements or hearing rumours about people being kidnapped for their organs or being fooled by organ vendors—as
one participant described “I have heard in news that people are duped. They are told that they will receive money for it, they will just take it out, and you will be as before” (Nepali, male, construction worker, length of stay not identified). Similar, another participant (Nepali, female, office worker, length of stay not identified) stated:

We know about such organ donation [living donation] from Nepal. We have mostly heard about it happening in India. Somebody donated their kidney to somebody else and so on. They also publish advertisements and interested people go and donate their kidneys. We have never been involved directly in such matter but we have heard about it.

Participants also aligned “donating” with organ selling, identifying poverty as a motivation for “giving”, as identified by one participant “They are taken to India, removed kidney, and given two hundred thousand rupees. They go, as they are in dire need of money and they are assured that they can live normally and won’t die” (Nepali, male, occupation and length of stay not identified). Similarly, another participant (Filipina, female, teacher’s aid, 9-year-stay) explained:

For many of them [poor Filipinos], giving their organs as donors becomes their means of livelihood because of poverty, to help alleviate their poverty. That is already a big thing for them. That is why they become donors.

In addition to organ selling, a number of participants spoke of knowing people who had purchased kidneys in their home countries, expressing a belief that the only way to obtain an organ transplant is to buy an organ. One participant mentioned “He [a friend in India] bought from outside or something else [when his mother was unable to donate due to incompatibility], I am not sure. Anyway you have to give money if you want to get it” (Indian, male, craftsman, 7-8 year stay).
However, although some participants knew of people receiving transplants in their countries, participants also identified organ transplantation as a procedure for the wealthy, with the poor lacking access to basic health care in their home countries, let alone organ transplantation. One participant (Filipino male, supervisor in construction company, 10-year stay) suggested:

The way I see it, it seems that those who have the money are given priority to be recipients of organ donations. The rich more than the poor. It is hard to accept mostly, but the people with money receive donations ahead of those with no money.

Likewise, a Filipino female participant, (teacher’s aid, 9-year stay) suggested that a transplant would be a “hopeless case” for people in the Philippines, due to the cost, while a Sri Lankan male (accountant, 18-month stay) noted that if you have money in Sri Lanka, you can buy a transplant at any time in a private hospital.

The prevalence of experience and/or knowledge of (largely illegal) living donation practices was also reflected in the concerns and fears expressed by participants regarding donation. Participants in many groups expressed concern regarding the impact of personally becoming living donors, as explained by this Filipina female (unemployed, sponsored by sister, six month stay):

You can donate one of your kidneys, but what if the other one has a problem afterwards? Of course, it is also frightening, but if you get to think about it, it will be so good if you would be able to save a life, but likewise, you have to take the risk because you will be donating, but what about you in the end?

This fear also expressed itself through the lack of trust in medical and organ donation and transplant systems. An Indian male participant (supermarket worker, 9-year stay) described how he and the other participants feared that if they had surgery for any reason, they would later discover that one of their kidneys was missing. Another Indian male (craftsman, 7-8 year stay) suggested that he and the other participants were “shocked” about being asked to sign the
consent form to participate in the study, and suspicious that they were also consenting to donate (until reassured). Three participants noted that their families warned them to be careful before coming to the focus groups. One participant mentioned “Today, as I was talking on phone with my wife’s sister, I told her that I am going to a program in the afternoon, dealing with organ transplantation. Then she warned me not to sign or commit to anything” (Indian, male, craftsman, 7-8 year stay).

Thus, rather than the mistrust of deceased donation, which was identified as a central theme in minority population attitudes towards donation (Brown, 2012; Goldberg et al., 2013; Morgan et al., 2013), participants cited risks of living donation as a significant concern.

3.2.2 Deceased donation
While the majority of participants in each focus group said they had heard of deceased organ donation (with the exception of the Bangladeshi male group, most of whom professed to know nothing about deceased donation), overall there was an incomplete or lack of understanding of deceased donation among many participants. A number of misconceptions emerged, such as a belief that living eye donations occurred, and that head transplants were possible. The amount of knowledge about deceased donation varied between nationalities. Bangladeshi male participants and Nepali participants demonstrated little knowledge of organ donation, which may reflect both education levels of the participants and negligible deceased donation programs in these countries (Moniruzzaman, 2012; Ruit et al., 2002). As one participant stated, “No. I’ve have never heard of it [organ donation], but of course heard of blood requirement and transfusion of blood from an individual to another” (Bangladeshi, male, labourer, 3.5-year stay). Similarly, another participant stated “This is the first time I am hearing about organ donation. What kind of donation is this and who receives it? Who benefits from such donation and where does it go? I don’t exactly understand what organ means” (Nepali, female, occupation and length of stay not identified).
Equally, some participants who had heard of deceased donation appeared not to understand what donation involves: “Transplantation means once our organ is taken from our body, it has to be joined to another person’s body. The proper way of doing it, I am not aware whether it is an operation or not” (Indian, male, document controller, length of stay not identified). Similarly, another participant (Nepali, male, occupation and length of stay not identified) explained:

I have heard several things from my friend, a person got his hand amputated in Saudi and an Indian gave him his hand. Similarly, another one I heard in from a Sri Lankan co-worker that some Japanese came there and donated his eye.

However a number of Sri Lankan and Filipino participants demonstrated an accurate understanding of deceased donation, as one participant (Sri Lankan, male, accountant, 18-month stay) suggested:

But … when you donate an organ, it entails a big complicated process. Doctors cut open your body and it is a serious thing. You can either donate while you are living because you have two kidneys or else you can donate after your death.

Several Filipino female and male participants reported the media as being a source of knowledge about deceased donation, discussing Filipino actor Mike Sotto, whose corneas were donated after his death. Most Filipino participants (male and female) also demonstrated an understanding of the registration process in the Philippines. As one participant (Filipino, male, supervisor, construction company, 10-year stay) stated:

I already read that in the license of the Philippines, there is something written there at the back that in case something happens within that year, like an accident, you would be willing to give or donate your organs. It’s there in the back, asking whether you agree or not.
Overall, with the exception of the Filipino male and female groups, few participants knew much about deceased organ donation and transplant systems within their own countries. For example, one of the participants registered in Qatar noted “Organ donation has been asked to me only after I came to Qatar. I have not heard any questions asking whether I was ready for organ transplantation anywhere other than Qatar” (Indian, male, document controller, length of stay not identified).

A number of participants also suggested that people were unaware of deceased donation in their home countries, “I don’t think people in Sri Lanka know a lot about (deceased) donation and transplantations” (Sri Lankan, female, student, 16-year stay).

### 3.2.3 Attitudes to deceased donation

Despite a lack of detailed knowledge about deceased donation practices, each of the focus groups generally expressed positive views about the idea of deceased donation. No respondent raised the issue of brain death and none expressed significant superstition about deceased donation, although one Filipina female (nurse, 2-year stay) suggested people might be afraid to sign a donor card in case they were then killed for their organs. A number of participants also expressed reservations related to the body based on religious beliefs. Overall, participants in each of the focus groups identified deceased donation as an act of beneficence, as demonstrated by one participant: “Once we are dead, let our organs help someone to lead a better life … I don’t need eyes once I am dead. There are many people who need eyes. Let me do something good for them” (Indian, male, supermarket worker, 9-year-stay).

Another participant (Filipino, male, labourer, 1-year stay) stated:

In my case, donating is a good idea because the lives of others are prolonged. Like I am also on the road, I do not know what could happen because the car is fast. If on the spot, I lost all my chances to survive, I also want to be able to help others. This way, I can give anything, rather than it will be wasted.
The depiction of donation as a way of helping others was consistent across all religions, including Buddhism, Islam, and Christianity. Consistent with previous studies regarding the influence of religion on attitudes toward donation (Khalaila, 2013; Rocheleau, 2013), participants who identified themselves as Muslim (from India, Sri Lanka, and Bangladesh) expressed varied views about the permissibility of deceased donation under Islam. Some participants believed it was “haram” or forbidden to interfere with a deceased body. For example, one participant (Indian, male, supermarket worker, 8-year stay) suggested:

There are many wise people in the Islam religion. We have to know all their views, what is told in the Quran. Someone in ancient days remarked, once we are dead, even if a mosquito comes and sits on our body, it is very painful. So imagine the pain if we remove an organ as such. So Muslims will have a general tendency to back out from organ donation.

Others believed that the duty to help others was a central tenet of Islam or that donation was beyond the remit of religion, as this participant (Bangladeshi, male, labourer, 15-year stay) described:

I do not believe in religion in this regards, if I am able to save some one's life with one of my body part and he is again able to get back to work, I feel that is more important and bigger than religion.

One Sri Lankan male participant (driver, 6-year stay) believed that Buddhism not only supported but actually encouraged donation. He mentioned learning in school “about certain Jataka stories, how giving is appreciated and demonstrated by Buddha.” Several participants suggested that religion should not influence donation decisions. For example, a Sri Lankan female (office worker, three-month stay) suggested:
I don’t think Buddhism, Christianity, and Islamic religions make an impact on donation. I think it has to be the personal choice. I don’t think religion can force or impact you. It is your life and it is your choices to donate.

3.2.4 Qatar’s donation and transplant system
While participants were largely supportive of the concept of deceased donation (despite their relative lack of knowledge), the majority of participants knew little about Qatar’s donation and transplant system, with the exception of the four registered donors. Although familiar with Qatar’s system, each participant who identified themselves as registered donors in Qatar demonstrated some misunderstanding of the system. These misunderstandings point to participants believing that registering as a donor bestowed various individual benefits.

Two of the registered participants suggested that access to transplantation in Qatar was conditional upon registering as a donor. One Indian male (document controller, length of stay not identified) referred to registration as being a “member” of a “scheme”, noting:

That is, when we have a need, if we want people to be willing to help us, we should also be bound to help them when they need it. It’s a give and take. Only if we give, we get. We don’t know what’s in store for us. When we become a donor, there is a chance that we might become a receiver too.

Another (Indian, male, labourer, 8-year stay) explained:

The organ donation card [Qatar’s organ donor registration card] is useful in two ways. One is that we can donate organs. The second is that we don’t know what will happen to us tomorrow. We don’t know what is going on inside us. We can seek the help of others through this organ donation card. Thus we can donate and receive organs with the help of organ donation card.
One participant expressed a belief that his registration extended benefits to his immediate family in the home country, possibly reflecting a misunderstanding of the DDA, which provides funding for medically-fit related live donors to travel to Qatar for the purposes of donating to Qatari residents only (Al Kuwari et al., 2014). As one participant (Filipino, male, office worker, 3-year-stay) suggested:

> Their offer was that you will donate when you die. Then if anyone from our immediate family would have a problem, Hamad [Qatar’s health system] will help. They will bring our family member here, he will get treatment here.

Another registered donor (Bangladeshi, male, occupation not stated, 6-month stay) felt that being a deceased donor in Qatar was a way of avoiding the costs to his family associated with returning his body to his home country should he die (though employers in Qatar are legally required to repatriate the bodies of deceased workers):

> I guess as I would die, if the body is to be sent back home it would require a lot of money and the money would be required to be collected, instead I can donate my body and donate my kidney.

In addition, a newly arrived Sri Lankan female (office worker, 3-month stay) who was not a registered donor stated that she had no idea about Qatar’s system because “we don’t have citizenship here”, suggesting that she considered donation and transplants to be associated with citizenship. Overall, however, most participants were simply unaware of the existence of Qatar’s donation and transplantation system.

### 3.2.5 Life in Qatar

Participants were also asked about their lives in Qatar, including experiences of work and accommodation as well as socializing and friendships. It was notable that there was an almost complete lack of mention of Qatari citizens or comparison of migrant and citizen lives, with only a handful of participants explicitly speaking about Qatari citizens. One participant noted a lack of
friendships with Qataris: “Those people whom I don't have freedom [to make friends] with, from my experience are Qatari people. Arabic people. I don't have them as friend still now” (Indian, male, supermarket worker, 8-year stay). Numerous participants (Indian and Sri Lankan males) also brought up being unable to socialize on their days off due to “family day” policies, that prohibit single men from entering the malls (the primary location for spending leisure time) where Qatari citizens and married migrant workers shop.

However, those from the Nepali male focus group spoke of disparities in their treatment in Qatar, both in comparison to Qatari citizens and other workers. As one Nepali male (labourer, length of stay not identified) suggested “If I had to say, we are looked upon as inferior, which is what bothers me. Maybe because of being Hindu, Nepalese, or foreigners.” Similarly, another Nepali male (occupation and length of stay not identified) suggested “In comparison, 90 percent of us come in low privileged compare to other nationals in salary or everything.”

Nepali males were also the only group to explicitly question differences between the rights afforded to citizens and workers. For example, one Nepali male (labourer, length of stay not identified), who perceived there was differential access to healthcare, stated “The development is possible because of us and money; we are the people who did it [built the healthcare centres] so there should not be difference between labourers and others”.

However, other than these few instances, participants largely framed their experiences of life in Qatar through comparisons with their home countries, not with Qatari citizens. For example, many participants spoke about feelings of security and freedom in Qatar in comparison to home, with one participant (Sri Lankan, female, student, 16-year stay) stating:

It’s very peaceful here. There is no fear to live in Qatar. It’s not like in Sri Lanka. Even when sleeping and going to places, travelling, we don't have to feel fear about anything. Even when going out in the night, we don't have to feel fear about anything. We can do our work freely.
Others reported difficulties living in Qatar in comparison to home, including lack of freedom, poor salaries, and inadequate accommodation, as one Bangladeshi male (occupation not stated, 6-month stay) suggested:

> I find the life here not as good as it is back in my country. The climate here differs, so does the environment as compared to our country. Here I have to share my living room, the place where I work, my company does not compensate me with adequate salary. So if all the points are weighed, the life in Qatar is not so fascinating. Again there is no freedom to work anywhere and everywhere as per your wish, so overall it is not so great here.

The role of the home countries in framing life in Qatar is also evident in the reasons given for working in Qatar. These include saving money or earning enough to get married or to buy land. While a small number of participants (married women sponsored by their husbands) cited lifestyle reasons for being in Qatar, the rationale for living in Qatar for the vast majority was described largely in economic terms, as explained by one Filipino male (civil engineer, 7-year stay):

> So in my case, salary wise, the salary here is really much higher, it’s triple what I received in the Philippines … But of course, if you would think of your future, it would still be happier to be in the Philippines with your family. So that factor in being an OFW [Overseas Filipino Worker] you had to bear with time … so you can send money to the Philippines and support your family’s needs. So you just make sacrifices.

Equally, Qatar was seen as a temporary arrangement for many participants, even for some staying for many years, which seemed to help a number of participants manage the negative aspects of living in Qatar (for example, poor accommodation and working conditions, missing home, and so on). As one Sri Lankan male (accountant, 3-year stay) stated:
In Qatar for the job that I do, I can earn a lot more than I could earn in Sri Lanka. It is really for financial reasons that I have come here. And I don’t have plans to stay here for a long time. I have some plan to achieve in Sri Lanka [by working in Qatar] and once that aim is achieved, I am going to go back and settle back in Sri Lanka.

3.3.6 Employment conditions

While participants across all of the focus groups cited similar reasons for living in Qatar, views about work appeared to depend on the kind of work undertaken. It was also clear that migrant worker access to resources in Qatar is mediated through employers. For example, participants spoke of the type of accommodation provided (apartments versus labour camps), the choice of flatmates (shared nationality versus other nationalities) and access to healthcare services (via employer provision of the healthcare card that affords access to medical care) being dependent on their employers. Consequently there were differences in accommodation, working hours and working conditions across participants.

Filipino participants (who were mainly employed in professional and semi-professional roles) expressed largely positive views about work, including high salaries compared to home and reasonable accommodation, as one participant described “With me, it is a bit okay because I am with Qatar Petroleum, and the salary is good. The benefits we get are also good: medical, education, almost everything is there, so you don’t feel at a disadvantage” (Filipino, male, electrical technician, 15-year stay).

Other groups, such as Sri Lankan, Nepali, and Indian males, expressed frustration over the Kefala system, which binds workers to the employers who sponsor them (Gardner et al., 2014), as stated by this Sri Lankan male (housekeeper, 2.5-year stay):

The rule in Qatar is that if you are working in a company called X, even if you get a better job offer from a company called Y, you cannot go to the second company. The company X has to give a no objection letter.
releasing you for the company Y. But more than 95% of the companies don’t give that release letter. So whether you like it or not … you have no choice other than working in the same company. Otherwise you have to go back to Sri Lanka, spend two years there, and then apply again to come to Qatar. And more than that if you ask for a release and if the management does not want to release you, then you get a problem with them anyway. And after that it would become difficult to work there.

Many participants across the focus groups also raised the issue of treatment of other workers, and the vulnerability of low paid workers, as described by this Indian male (craftsman, 7-8 year stay):

That is a pathetic situation. You can see the work sites here. In this climate, also those workers have to climb up and do their work and will be getting only 800 riyals. Those higher officials sitting in an air-conditioned room though, they have their own tension, but don’t have much physical work to do, will be getting 1000 or 10,000 salary. Everyone can’t be given the same salary … still …

Similarly, a Sri Lankan female (student, 16-year stay) stated:

I think life in Qatar depends on the kind of work you do in Qatar. If you look at the road workers’ life, you can see that they lead a pretty difficult life. You know, hamdulla [praise be to God], I have a pretty good life. I am blessed to have a pretty good life. But there are lots of people who are suffering here.

However some participants expressed a level of fatalism around the differences in work conditions between different migrant groups, possibly reflecting hierarchical arrangements in the home countries, as described by one participant “Those who have, they have; those who don’t, they don’t … that’s it” (Indian, male, supermarket worker, 8-year stay). Similarly, another participant (Sri Lankan, female, officer worker, 3-month stay) said:
What I can see especially in this season is that because of the high heat, the labourers really suffer a lot. I think those who are not very intelligent get a very low salary. But in Sri Lanka too, there are lots of people like that. We feel pity for those people.

3.2.7 Social relationships
Throughout discussions about life in Qatar, a consistent theme emerged across all focus groups relating to the importance of developing and maintaining social relationships with migrants from the same country. For example, participants identified living with others of the same nationality as particularly important, as one Sri Lankan male (accountant, 18-month stay) demonstrated:

> When you come here on that type, then the tendency is to find a place that you can get more Sri Lankans or with other Sri Lankans. The reason is that then you can live with the people who talk your language and who live according to your own culture.

Another Sri Lankan (male, housekeeper, 2.5-year stay) spoke of his despair on arriving in Qatar to find no other Sri Lankans at his accommodation:

> But the place that I stayed did not have anyone from Sri Lanka and I had no one to even to talk to. I did not even know how to cook. And I didn’t have a big salary to buy my meals from out. So I called my mother in Sri Lanka and cooked. I was even crying when cooking thinking about my mother.

Fellow expatriates were identified as a substitute for family across many of the groups. A number of Nepali males spoke about relying on friends when sick because, “we don’t have family here to take care [of us]” (Nepali, male, occupation and length of stay not identified). According to this Filipina participant (office worker, 8-year stay) who was living with her children and other Filipina women:
It’s like because we are here abroad, we do not have a choice, we have to adapt ourselves to what we now have here. But in our culture, it is quite hard to live in a house with people who are not your relatives. But in a way, eventually we also become close to each other, and it’s like developing our own family here.

While a few female participants with children spoke of friendships with migrants of other nationalities (formed through their children’s schools), participants largely relied on friendships with migrants of the same nationalities, speaking about having shared language, religious beliefs, and food (though many had colleagues from different countries). Friendships with other nationalities were identified as difficult due to cultural differences, as this participant described: “You see my relation with them cannot be as I would have it with a fellow person of my own country” (Bangladeshi, male, occupation not stated, 6-month stay). Equally, one Sri Lankan male (accountant, 18 month stay) noted:

So in the work place you can have those people from other cultures as friends. But outside work it is even difficult to have friends from other cultures. You know its because the way those people from other cultures socialise and the way we socialise in our Sri Lankan culture are very different. We don’t really settle into good friendships often with people from other cultures. In the way that we all socialise there are different restrictions that we have to adhere to. And when it comes to food sometimes its difficult to like foods from other cultures. I don’t like to say the names of the countries and cultures specifically but for example if you take the Filipino and Nepalese cultures you can see that it is difficult to eat them [the food from these countries]. We don’t really like them [the food] at all.

Participants also identified maintaining cultural links to home as important, facilitated by organised cultural activities. Participants from the Philippines, Sri Lanka, and India spoke of attending functions at associations and churches of their home countries. As described by one Sri Lankan female (housewife, 18-year stay):
Ever since we have started living here, every year there are lots of associations being created, especially Sri Lankan school associations by Sri Lankan expatriates and that’s a really good thing. Apart from these, there are many other festivals like Buddhist religious festivals and other festivals. If you ask me about Christian religious festivals, there are festivals organised by Sri Lankan Christians.

Equally, several long-term residents expressed fears about loss of their culture, as described by this Filipino male (electrical technician, 15-year stay):

The negative aspect that I observe here is that my children seem to have a different culture. Of course they already know that they got used to this place. They are not aware of the real traits and traditions of our country, the kind of life that we have there. That is the fearful aspect, of course we won’t be here for the rest of our lives. When we get the chance, we will go back to our country.

Thus, overall, participants across each focus group described life in Qatar as segregated, not only between citizens and non-citizens, but also by migrant nationality.

4. Discussion

The study aimed to explore whether and how institutional norms, beliefs, and practices of different migrant populations and their experiences of life in Qatar influence attitudes towards deceased donation. In addition, the potential impact of Qatar’s inclusive donation and transplant system on both attitudes towards donation and registration behaviour was of interest. However, slightly different albeit equally interesting themes emerged from the focus groups.

Other than the religious beliefs of some of the Muslim participants, institutional practices around deceased donation did not emerge as a major theme in the focus groups. Nor was medical mistrust in relation to deceased donation evident
in any group, other than in the Filipino female group. Instead, much of the discussion across each of the focus groups was directed towards (largely illegal) living donation in their home countries, despite many of the participants residing in Qatar for extended periods. While many participants expressed positive sentiments about the idea of deceased donation, discussion about actually donating focused largely on the potential risks associated with living donation. This tendency of participants to draw on home for their understanding of organ donation echoes the findings of Polonksy et al. (2011) regarding the influence of cultural beliefs on shaping attitudes to blood donation in the African migrant population in Australia. However, in this study, participants’ ideas about donation go beyond cultural, religious, or social beliefs, reflecting the institutional norms and practices around donation in their countries, characterised by (frequently illegal) living donation and a lack of access to transplantation for the poor (White et al., 2014). Given that many of the participants’ home countries are known as organ vending and transplant tourism “hotspots” (Shimazono, 2007), the focus on living donation is understandable, particularly given that some of these same countries lack established deceased donation and transplant systems.6

In light of these findings, the lack of knowledge regarding deceased donation among participants is in some ways unsurprising, although given that many of the participants had lived in Qatar for extensive periods, more knowledge of deceased donation had been anticipated. Qatar’s (relatively new) organ donation and transplantation system is based on established voluntary unpaid systems, such as those in Europe and the USA, rather than those in surrounding or nearby countries such as Saudi Arabia and Iran, which permit organ sales (Ghods & Savaj, 2006). Qatar’s equity-based system also differs to the institutional arrangements, norms, and practices of participants’ home countries, with participants describing inequitable and frequently illegal systems that exploit the poor and favour the rich. However, the participants’

6 Although corneal donation is common in South Asia, deceased donation is otherwise negligible in Bangladesh (Moniruzzaman, 2012) and Nepal (Ruit et al., 2002), and rare in Sri Lanka and most Indian states (Abraham et al., 2010) and in the Philippines (Danguilan et al., 2012; Gatarin, 2014).
assumptions about donation (that is, illegal living donation) highlight a possible misalignment between the principles underpinning Qatar’s system and the expectations around donation and transplantation of many of the migrant populations on whom the system will ultimately depend.

The participants’ lack of knowledge regarding Qatar’s organ donation and transplantation system and their focus on donation as it occurs in their own countries may reflect the strength of the participants’ ties to their home countries and lack of relationships with Qatari society. Consistent with Adam and Page (2005), the findings suggest that most participants see life in Qatar as a means to an end; migration to Qatar is largely a way of earning money in the face of poverty and unemployment at home (Gardner, 2012). This view is characteristic of workers undertaking temporary migration, which Ottonelli & Torresi (2012) suggest requires “bracketing many essential components of one’s life while living and working in the host society in order to advance an overall life plan and long-term goals that will be realized at another time and in a different social space” (p. 209).

However, the “bracketing” of life in Qatar, evident in participant responses, is perhaps also an inevitable consequence of Qatar’s approach to non-citizens, which Fargues (2011) characterises as “de jure” and “de facto” separation. The former relates to the legal provisions that differentiate between the rights afforded to citizens and non-nationals; the latter to the lack of interaction between the two groups. Unlike other nations in which long-term residency confers increasing rights and a pathway to citizenship (Miller, 2008), migrants in Qatar retain their temporary status irrespective of length of stay. Babar (2014) argues that the increasing reliance on migrant labour (skilled and unskilled) to develop Qatar over the past few decades has resulted in a heightened need to maintain a distinct “Qatari” identity, one that is used to dictate access to the country’s (considerable) resources. The notable lack of discussion of Qatari citizens across the focus groups (Nepali male group excepted) points to the differential treatment between citizens and non-citizens being deeply embedded in the relationship that participants have with the society. This reflects Brusle’s
(2010) contention that migrants in Qatar do not attempt to become integrated into broader Qatari society, as they know it is simply unfeasible.

Equally, the participants in the study appear to have less a relationship with the State of Qatar per se than their individual employers. This finding reflects the State’s overall approach to migration, which is based on private sponsorship of temporary workers. The study shows working hours, living conditions, leisure time and access to healthcare are dependent more on individual employers than state regulations (DeBelAir, 2014). These findings echo those of Preibisch’s study of Mexican seasonal workers in Canada, which found employers exerted high levels of control of workers, with worker freedom dependent on the “subjective goodwill of the employer” (Preibisch, 2004, p 212). However Preibisch’s study also found social contact between workers and citizens in rural communities and social support for workers from individual citizens and citizen groups reduced worker dependency on employers, a theme that did not emerge in this study. Consequently, both the structural and social separation of citizens and non-citizens, and the relative lack of state involvement in migrant worker lives indicates that Qatar’s equity-based organ donation and transplant system may be misaligned with the participants’ expectations and experiences of Qatar generally. This suggests beyond the influence of donation practices in their home countries, migrant expectations regarding donation and transplantation in Qatar may be influenced by their everyday experiences of living in the country.

Overall, participants’ strong focus on their home countries and lack of interaction with Qatari institutions suggest that building knowledge of and investment in Qatar’s deceased donation and transplant system is likely to be an ongoing challenge. Migrant workers are in Qatar on a temporary basis: low-paid workers stay an average of 5.5 years (Gardner et al., 2013), though many stay for longer periods (Babar, 2014), with little to bind them to country. While participants in this study seldom directly discussed issues related to inclusion in Qatari society per se, they did identify inclusion in nationally-specific communities as vital to migrant life. Inclusion in these migrant communities appears to be a means of maintaining their own national identity, with shared language, food, and cultural practices creating strong community bonds. Such bonds were shown to provide
social support and in some cases, substitute for the care typically given by family members. As in Morgan et al.’s (2008) study among the Caribbean population in London, ethnic identity may be a means of maintaining a sense of self in response to marginalisation and exclusion, and/or may simply be an inevitable consequence of temporary migrant life.

5. Implications

The findings of this study have some implications for programs that aim to increase deceased donation in migrant populations. First, while there were a small number of donors, the study’s findings offer an interesting contrast between participants’ general perceptions of deceased donation as an act of altruism/benevolence and the framing of registration as a transactional exchange expressed by the participants registered in Qatar. Siegal and Bonnie (2006) argue that donor registration is best understood as a social contract between society members. However, in divided societies, such a framing may not resonate with those who are excluded from society—regardless of the reason for the exclusion, be it ethnicity, citizenship, status, or poverty. It may well be the case that framing donor registration as a transaction, that is, focusing on access to transplantation in return for registration, could resonate with such populations in the absence of this broader social contract. That said, the small number of registered donors and overall lack of knowledge about Qatar’s system ultimately makes it difficult to draw too many conclusions about motivations for registration.

Second, migrant beliefs about and attitudes toward donation may be based not only on religious beliefs and cultural practices, but also on the institutional arrangements, norms, and practices in migrants’ home countries. Consequently, encouraging deceased donation in migrant communities requires an understanding of these experiences and the delivery of education programs that clearly address the concerns of migrant populations. In addition, the very

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7 Certainly, in Singapore and Israel, in which access to transplantation is prioritised for previously registered donors (Burkell et al., 2013), registration is legally framed as an explicitly transactional exchange, an approach that is nonetheless critiqued for potentially exacerbating entrenched social exclusion disadvantage (Goering, 2004).
low penetration of Qatar’s multi-language donation and transplant campaigns in the study sample points to the potential difficulty in reaching migrant communities in relation to donation. Although this may be exacerbated by the temporary nature of the migrant population in Qatar, in this sample, knowledge of the system was as negligible in long-term residents as it was for the newly arrived. The closed nature of the individual migrant communities, which seem an inevitable consequence of Qatar’s institutional and social structures, appear to be a barrier to connecting with these communities. While Qatar’s social divisions are sharper than in most countries (Malecki & Ewers, 2007), all nations whose institutional and social settings foster exclusion may find it equally difficult to gain traction around donation in minority communities.

6. Limitations

Most qualitative research approaches are able to accommodate cross-language designs (Squires, 2009), and focus groups offer researchers an opportunity to access marginalised groups (Halcomb, Gholizadeh, DiGiacomo, Phillips, Davidson, 2007) such as migrant workers. Nonetheless, conducting research in five different languages in Qatar posed significant challenges. First, the setting of the study required the use of non-professional focus group facilitators. While the use of bilingual healthcare worker facilitators helped build trust between the participants and the facilitators (Davidson et al. 2004), it also influenced the depth of the data obtained from the focus groups. Each facilitator used the same interview guide to help structure the focus group, however, in practice some facilitators were able to elicit richer, more expansive responses from the participants compared to others (though this may also be a function of differences in the makeup of various groups). Equally, inconsistent demographic data was collected in cases where facilitators did not explicitly ask participants and the information was not volunteered unprompted. For example, the Nepali facilitator did not ask any of the participants how long they had lived in Qatar, nor their occupations, although some of this information was volunteered. In addition, facilitators neglected to ask about the education status of the participants, although the differences in types of employment suggest varying levels of education. Equally, it is important to acknowledge that the process of
translating inevitably influences the data. The use of translators for the five languages was, however, necessary, and although it may have resulted in a degree of loss of nuance in the data, the analysis took a narrative rather than a phenomenological approach. Consequently, the analysis was concerned not with the way in which participants used language to describe their experiences but with the overall picture captured by the data. This corresponds with Squire’s suggestion that narrative analysis should be used for translated data due to fewer methodological issues resulting from the process of translation (Squires, 2009).

Another limitation of the study relates to the recruitment process. In the first instance, it was not possible to recruit any of the unknown number of low-paid migrant workers employed to work in private homes, a difficulty also faced by other researchers in Qatar (Gardner et al., 2013). These workers, who are largely female, work extensive hours with relatively little freedom, and are reported to be among the poorest in Qatar (Nagy, 1998). Equally, potential participants (those who expressed initial interest during the recruitment process) who did not ultimately attend the focus groups largely cited working hours as the reason for not participating, even though the focus groups were held on weekends. Consequently, the focus group attendees are likely to be different to those who did not participate. For example, the sample may have had a degree of privilege relative to the migrant population in Qatar, as evidenced by the female population, many of whom were sponsored by their husbands. Despite this, the aim of focus group research is not necessarily to gain a representative sample of a population but to enable the examination of issues in some depth. The discussions in this study provide important insights into how these populations might conceive of donation and their experiences as migrants.

7. Conclusion

It is believed this is the first study to explore the attitudes of multiple temporary migrant populations toward donation and transplantation. While the findings relate to the experiences of a small number of temporary migrants in Qatar,
ultimately, globally-increasing labour migration and refugee flows (Castles, 2006; Miller, 2008) challenge the way that many societies are conceptualised and what it means to be socially included. As such, this study of non-citizens in Qatar may offer important insights into some of the issues that many societies will face in the future in relation to the provision of public goods, such as organ donation, in diverse/divided communities. Future research may provide more insight into the extent to which the mistrust of deceased donation and transplant systems identified in previous studies is rooted in experiences from migrants’ home countries in addition to experiences within institutions in the host countries. The small number of registered donors in this study and participants’ lack of knowledge about donation made it impossible to draw conclusions about the effectiveness of equitable access to transplantation as motivation for donor registration. Thus, additional research is required to determine the potential for promoting equity within donation and transplant systems as a method of encouraging donor registration in all populations, both temporary and permanent.
PAPER 3

Trust, inclusion, and commitment: introducing a model of Collective Donor Behaviour

Abstract

This paper examines the third research question, regarding drivers of and barriers to registering and the final research question regarding how the insights from a collective account of donation may be used to drive donor registration.

Behavioural research within organ donation largely frames donor registration as a product of individual altruistic traits and preferences. While factors beyond individual altruism have been shown to influence donation behaviour, including collective norms, institutional arrangements, trust, and inclusion, they are seldom incorporated into models of donation behaviour. This research aims to address this gap by applying a novel donor registration behavioural model—the model of Collective Donor Behaviour (CDB)—to test the efficacy of moving beyond individual accounts of donor registration. The CDB identifies registration as a function of affective commitment (emotional attachment) and normative commitment (obligation) to the cause, stemming from trust in other society members and trust in institutions. These two forms of trust are founded on inclusion and fairness perceptions respectively. The model was tested in two samples—the first a pilot study of n=345, the second a main study of n=887.

Confirmatory factor analysis found constructs derived from the CDB had convergent and discriminant validity in both the pilot and main studies. Structural equation modelling shows the model accounts for 48.7% and 37% of variance in registration behaviour in the pilot and main studies respectively. Normative commitment to the cause of donation is found to be strongly associated with registration, and both institutional trust and trust in others foster normative commitment. Therefore, interventions aimed at increasing donor registration rates should focus beyond the cause and look at ways to
facilitate individual positive experiences with institutions and strengthen community bonds.
1. Introduction

Encouraging deceased organ donor registration remains an ongoing challenge in nations with opt-in systems. A range of factors are associated with willingness to register as a donor. These include demographics (such as age, socioeconomic status, gender and religion), beliefs about the body, past behaviour and personality traits (Falomir-Pichastor et al., 2013). For example, registered donors are more likely to be young, educated women with higher socioeconomic status, who are not religious or squeamish about donating and who are altruistic and have positive attitudes towards deceased donation (Nijkamp, et al., 2008; Wakefield et al., 2010).

Behavioural models are also used to predict and explain variances in donation behaviour, including registration and willingness to discuss donation with family (Hyde, Knowles, & White, 2013). Models of donor behaviour largely draw on theories of prosocial or “helping” behaviour, premised on the construction of organ donation as an altruistic act (Healy, 2004). For example, Horton and Horton’s (1990, 1991) Organ Donor Model, the Organ Donor Willingness Model (Kopfman & Smith, 1996) and the Organ Donation Model (Morgan et al., 2002) all build on the Theory of Planned Behavior (TPB), in which behaviour is seen as a function of individual positive or altruistic attitudes and intentions. Other models focus on the role of social and cultural norms in driving donation behaviour, such as the relationship between perceived social responsibility to donate and cultural and familial norms (Park et al., 2009; Park & Smith, 2007; Alden & Cheung, 2000) and the role of moral norms in encouraging registration (Godin, 2008). Numerous studies build on these existing models to incorporate additional factors shown to influence donation behaviour, such as religion (Rocheleau, 2013), squeamishness (or the “ick” factor) (Morgan et al., 2008) and superstition (or the “jinx” factor) O’Carroll et al., 2011). An advantage of the use of behavioural models is their focus on direct drivers of donor registration. However the ability to predict donation behaviour through behavioural models is inconsistent, with positive attitudes being the only consistent predictor of donation intentions and behaviour (Nijkamp, et al., 2008; Wakefield et al., 2010).
In addition, altruism is shown to have a weak relationship with willingness to donate (Nijkamp, et al., 2008; Wakefield et al., 2010), and the reliance on altruism to explain donor registration has been criticised for providing an overly narrow account of donor motivations (Batten, 1992; Healy, 2007; Moorlock et al., 2013; Robertson, 2004; Saunders, 2012). Indeed, research identifies a range of factors beyond individual traits and preferences as influencing donation behaviour, including the institutional settings that underpin donation and transplant systems (Mossialos, et al., 2008) and the efficacy and efficiency of these systems (Healy, 2004; Salim et al., 2011).

Deceased donation has also been identified as an interdependent behaviour viewed through an exchange theory lens (Etzioni, 2003; Schweda & Schicktanz, 2009; Shaw et al., 2012). Such interpretations see the "gift of life" not as a unidirectional act of benevolence from one individual to another, but as part of a social system (Etzioni, 2003) underpinned by reciprocal obligations (Siegal & Bonnie, 2006) or generalised exchanges among society members. Generalised exchanges involve diffuse obligations between society members, as opposed to tit-for-tat transactions (Blau, 1964). Gift exchange (Levi-Strauss, 1969; Mauss, 1967) and social exchange (Blau, 1964; Emerson, 1976; Wiebe, 1951) theories identify such exchanges as the foundation of societies. Less about individual transactions, generalised exchanges are "systems of social solidarity" (Giesler, 2006); the glue that holds societies together. Through exchange theory, donor registration can be seen as a collective behaviour, an act that "affirm(s) a number of vital social values including our solidarity with others in our community, and our vision of human flourishing" (Murray, 1987, p. 37).

Less optimistically, deceased donation is also portrayed as a social dilemma (Chandler et al., 2012; Glannon, 2009). Social dilemma theory depicts the collective provision or maintenance of public resources as a conflict between individual self-interest and the collective benefit (Hardin, 1968). Consequently, individuals are tempted to "free ride" off the contributions of others, leading to an inevitable depletion of the resource (Kollock, 1998). Taking a rational choice approach to collective behaviour (Olson, 1965), social dilemma theory pits
individual interests against those of the collective, with contributions to public goods and indeed other acts of generalised reciprocity between society members being theoretically inexplicable. Yet this dim view of collective action is belied by the fact that people do contribute to public goods and engage in acts of generalised exchange every day (Ostrom 2014, Douglas 1987), including registering as deceased organ donors. This disparity between theory and practice highlights the potential limitations of individual self-interested accounts of collective behaviour and the need for alternative ways of conceptualizing collective action.

In response to these limitations, a range of theorists highlight the role of institutional contexts—social, political, and historical—in shaping individual behaviour (Elster, 1991; Levi, 1991; Mau, 2004; Ostrom, 2007, 2014; Rothstein, 2000, 2001), and the intersection of rational choice and social norms in collective action. Margaret Levi (1991, 1998) warns against attributing collective action in relation to public goods to either purely altruistic or purely self-interested motivations. Instead, Levi argues that both instrumental and normative interests influence contributions to public goods. Levi sees these as “dual utilities” at work—the desire to ensure individual needs are met and a normative belief in the value of contributing to the public good. Furthermore, Levi sees contributions to public goods as a kind of social bargain between individuals, governments, and other society members, hinging on two forms of trust—trust in the institutions charged with delivering the public good and trust that other society members will also contribute. Taking up Levi’s work, Rothstein (2001) identifies the need to trust both 1) institutions and 2) other society members, as two forms of social dilemmas facing individuals when they are contemplating contributing to public goods.

This paper builds on Levi’s conceptualisation of collective action, presenting the findings of two studies based on a behaviour model—the model of Collective Donor Behaviour (CDB)—centred on trust (a pilot of n= 345 participants and a full study of n=887 participants). The CDB model draws on Levi’s and Rothstein’s accounts of participation in public goods as well as exchange-based theories of prosocial behaviour (Dawes et al., 1988; Konovsky & Pugh, 1994; Lawler et al,
2001; Tyler & Degoey, 1995) to predict donor registration. In doing so, the model addresses criticisms regarding the failure of altruistic accounts of donor registration to acknowledge the institutional context in which deceased donation behaviour takes place, as well as capturing the interdependent nature of deceased donation and transplant systems. Drawing on the exchange literature in relation to groups and prosocial behaviour (Foddy & Dawes, 2008; Lawler et al., 2001), the model posits that perceptions of justice (Sargeant, Ford, & West, 2006; Tyler & Degoey, 1995) and social inclusion (Hillebrandt et al., 2011) are key antecedents to two forms of trust, which drives commitment to the cause of organ donation and donor registration.

This paper makes a number of theoretical and managerial contributions. First, the CDB provides an alternative framework through which to understand donor registration, one that addresses the limitations of altruistic accounts of donation behaviour. While others have described deceased donation as a collective behaviour, for example, Etzioni (2003) argues for a "communitarian" approach to deceased donation, this paper goes a step further by determining how, if at all, a collective account may help to explain motivations for and barriers to registering. Second, the CDB demonstrates that there is a role for trust in donor registration behaviour, a factor evident in attitudinal studies of donor registration but largely absent from behavioural models of donor registration. Third, the study's findings suggest that positioning deceased donation as a collective act may be an effective way to motivate donor registration, offering an alternative to the construction of donation as an individual "gift". However, the findings also indicate that the effectiveness of appeals to collective behaviour will depend on perceptions about the trustworthiness of both organ donation systems and other people in society, and that negative interactions with social institutions or experiences of social exclusion will negatively impact an individual's willingness to register. The focus on individual positive attitudes towards donation, prevalent in many models of donor behaviour (for example, Horton & Horton, 1991; Hyde et al., 2013; Rocheleau, 2013), comes at the expense of fully considering the key role of social and institutional structures on behaviour. Consequently, increasing donor registration is likely to require us to
look beyond individual traits and preferences to address issues such as social exclusion and inequitable access to social resources.

This paper begins by introducing the theoretical framework of the CDB model and proposes a number of hypotheses concerning the degree to which institutional trust and trust in others influence donor behaviour. This is followed by a description of the research methodology and results. The results section is divided into two sub-sections: the first outlines the results of a pilot test of the model, and the second outlines the results of the main study of a larger sample based on the refined model. The paper then follows with a discussion of the findings and the implications of the research in relation to efforts at increasing donor registration. It concludes with the strengths and limitations of the study, and suggestions for further research.

2. Framework and hypothesis

The framework of parameters and the hypothesized relationships tested in the model of CDB are described as follows, and are shown in Figure 1. As noted earlier, the CDB draws on Levi's (1991, 1998) and Rothstein's (2001) accounts of participation in public goods, as well as the literature relating to group behaviour, including theories of social identity (Dawes et al., 1988; Lawler et al., 2001; Tajfel et al., 1971), justice (Konovsky & Pugh, 1994; Moorman, 1991; Sargeant et al., 2006; Tyler et al., 1996), and social inclusion (Bradford, 2014; Hillebrandt et al., 2011; Twenge et al., 2007).
2.1 The role of trust

Trust is one of the most significant concepts in theories of both collective behaviour and social exchange (Cook, 2005; Molm et al., 2000). Trust can be defined as “voluntary action based on expectations of how others will behave in relation to yourself in the future” (Gilson, 2003, p. 1454). While trust in social exchange and social dilemma theories generally relates to an assessment of the behaviour of other participants (Yamagishi & Cook, 1993), the collective model includes two objects of trust: trust in others and institutional trust.

2.1.1 Trust in others

In the collective model, trust in others relates to trust between group members, which facilitates cooperation (Brewer, 2008). Foddy and Dawes (2008) describe this kind of trust as “social assurance” (p. 57). Such trust operates between particularised trust, which is trust in known others, and generalised trust, which is trust in everybody in relation to everything—also characterised as a moral view of the world (Kramer, 1999). Trust in others, which Brewer (2008) calls depersonalised trust is founded on 1) perceptions that one is part of a group and that others recognise and accept one as group member, and 2) an assumption
that group members will behave fairly towards other group members. In the collective model, trust in others captures the trust between society members in relation to organ donation and transplantation, that is, beliefs that other society members are also willing to register as donors and not free ride.

2.1.2 Institutional trust
In the CDB, institutional trust relates to perceptions regarding the trustworthiness of the institutions that underpin deceased donation and transplant systems. Exchanges, both economic and social, are embedded in cultural and institutional structures that provide constraints on and incentives for behaviour (Granovetter, 1985). The provision of public goods is almost inevitably mediated through institutions (Mau, 2004), and studies consistently indicate that institutional mistrust is a barrier to donation. This institutional mistrust includes fears that physicians may withhold or prematurely withdraw life-saving treatment for registered donors (Brown, 2012; Goldberg et al., 2013), and perceptions that some groups, such as the rich and famous, get preferential access to organ transplants (Boulware, Troll, Wang, & Powe, 2007; Morgan & Cannon, 2003).

2.2 Justice and institutional trust
Fairness perceptions have been shown to influence institutional trust and collective behaviours in relationships in the workplace (Konovsky & Pugh, 1994; Moorman, 1991), community policing (Bradford, 2014), interactions with government bodies (McComas, Tuite, Waks, & Sherman, 2007), and the justice system (Tyler, 2003). Perceptions of fairness facilitate institutional trust by reassuring people about the justness of institutions, that is, that they can and will deliver on their promises. Fairness relates to three forms of justice: distributive (the allocation of resources), procedural (the processes by which decisions regarding resource allocation are made), and interactional (the manner in which decisions are communicated) (Smith et al., 1999).

As it has been shown that trust in organ donation and transplant systems is influenced by perceptions of the health system (Morgan, 2006; Russell et al,
justice perceptions in the CDB relate to perceptions regarding the distribution of health resources (distributive justice), the fairness of the processes governing healthcare (procedural justice), and the fairness of interactions with medical/healthcare staff (interactional justice) such that:

**H1a**: Distributive justice within the health system is positively associated with institutional trust in the organ donation and transplant system.

**H1b**: Procedural justice within the health system is positively associated with institutional trust in the organ donation and transplant system.

**H1c**: Interactional justice within the health system is positively associated with institutional trust in the organ donation and transplant system.

### 2.3 Social inclusion and trust in others

Inclusion is a basic assumption of theories of collective behaviour. Theoretically, those participating do so because they belong to/are included in a community or group with a shared interest in behaving collectively, and thus group members can be trusted (Yamagishi & Kiyonari, 2000). Inclusion is identified as a primary human need (Sheldon & Gunz, 2009) that has been shown to increase cooperation between people (De Cremer & Stouten, 2003; Hillebrandt et al., 2011) and willingness to participate in prosocial behaviours (Twenge et al., 2007). In the case of donor registration, as with many public goods dilemmas, the group extends to the society in which organ donation and transplantation systems operate.

There are several theoretical accounts of the relationship between social inclusion and trust in others. The first, social identity theory, posits that group membership helps to form and maintain a positive self-identity (Tajfel et al., 1971). Trust in other group members is, therefore, based on emotional ties to the group, ensuring affective commitment to the group and desire to further the interests of that group (Lawler et al., 2001). The second account sees the group as a "container for generalised reciprocity" (Yamagishi & Kiyonari, 2000, p. 116), with trust within groups based on participants having a reasonable expectation
of favourable treatment from other members (Brewer, 2008). This leads to the hypothesis:

**H2a:** Social inclusion is positively associated with trust in others.

### 2.4 Social exclusion and depersonalised trust

Conversely, exclusion has been shown to decrease trust (Hillebrandt et al., 2011) and participation in collective behaviours (Twenge et al., 2007). Emerging research suggests that perceptions of social exclusion do impact negatively on attitudes towards deceased donation; those who do not feel they are part of a society are less inclined to donate (Morgan et al., 2008). Similar results are evident in an Australian study of blood donation among African migrants, which found that perceptions of social and institutional racism led to respondents being less likely to donate blood (Polonsky et al., 2011). Therefore:

**H2a:** Social exclusion is negatively associated with trust in others.

### 2.5 Institutional trust and trust in others

Evidence suggests that institutional trust can facilitate trust between society members by encouraging fair and just behaviour in communities (Levi, 1998; Rothstein, 2000). Institutions help set the tone of a society; where institutions are perceived to be corrupt and ineffective, trust between society members is likely to be low. Conversely, where institutions are seen as fair and just, people have some basis to trust others. Hence:

**H3:** Institutional trust is positively associated with trust in others.

### 2.6 Trust and commitment

Within generalised exchange, demonstrations of trust are shown to build solidarity and commitment (Molm, 2010; Morgan & Hunt, 1994). Commitment is a psychological attachment to a goal (Meyer, Stanley, Herscovitch, & Topolnytsky, 2002). Meyer & Allen (1991) identity three types of commitment within exchange relationships—affective, normative, and continuance. Affective commitment relates to an emotional attachment to and identification with an
organisation. Normative commitment denotes perceived obligation to an organisation, while continuance commitment relates to the perceived costs associated with leaving an organisation. In respect to prosocial behaviour, these can be understood as wanting to act, feeling obliged to act, and needing to act respectively.

In the case of registering as a donor, affective commitment may manifest itself in feelings of attachment to the cause of donation. For example, donation promotion campaigns that utilise narratives of real organ donors and transplant recipients attempt to encourage registration by fostering affective commitment (Kopfman, Smith, Ah Yun, & Hodges, 2009). Appeals to normative commitment are evident in the portrayal of deceased donation as a moral obligation (Savulescu, 2003). The call for a “communitarian” approach to donation exemplifies this approach, for example, Etzioni (2003) argues that the preferences of non-donors need to be changed through “moral persuasion, community appreciation of good conduct, and gentle chiding of those who do not do what is considered right” (p. 5). Continuance commitment is typically studied in relation to employer/employee relationships, referring to commitment based on the perceived costs of leaving an organisation (Meyer et al., 2002) and thus has a strategic basis (Geyskens, Steenkamp, Scheer, & Kumar, 1996). This form of commitment may be evident in donation and transplant systems that employ the threat of sanctions to encourage donation. Such systems operate in Israel and Singapore where previously registered donors are prioritised for transplant surgery (Burkell et al., 2013). However, continuance commitment is unlikely to be an outcome of either trust in others or institutional trust as it is founded on utilitarian assessments of the costs of the benefits of participating versus not participating. Equally, as a one-off behaviour, it is unlikely that registered donors will withdraw their consent to donate. Consequently, continuance commitment is excluded from the CDB.

The relationship between institutional trust and normative commitment is founded on theories of generalised exchange. Institutional trust fosters normative commitment by creating a relationship of mutual obligation or a norm of reciprocity (Gouldner, 1960). For example, perceptions of fair treatment are
shown to foster institutional trust in organisations, creating a generalised exchange relationship between the employee and employer, fostering perceived obligations towards the organisation (Konovsky & Pugh, 1994). Within the prosocial literature, trust in charitable institutions is shown to be a key antecedent to commitment to donating (Sargeant & Lee, 2004). When an institution's values are perceived to reflect those of an individual, institutional trust may also promote affective commitment. For example, affective commitment is shown to be an important factor in continuing public sector employment (Liou, 1994). Thus:

**H4a:** Institutional trust is positively associated with normative commitment to the cause of deceased donation.

**H4b:** Institutional trust is positively associated with affective commitment to the cause of deceased donation.

Trust in others is also hypothesized to be positively associated with both affective and normative commitment. Generalised exchanges are based on recognition of the interdependence of interests between people (Yamagishi & Kiyonari, 2000). As per institutional trust, the relationship between trust in others and normative commitment is explained by generalised exchanges promoting perceived normative obligations to the group. Consistent with social identity theory, trust in others may also facilitate affective commitment to the cause of organ donation because trust promotes affective bonds within groups, encouraging commitment to furthering a group's interests (Lawler et al., 2001; Lawler & Thye, 1999). Thus:

**H5a:** Trust in others is positively associated with affective commitment to registering as a donor.

**H5b:** Trust in others is positively associated with normative commitment registering as a donor.
2.7 Commitment and donor registration

Commitment is shown to be a reliable predictor of prosocial behaviour (Meyer & Allen, 1991; Sargeant & Lee, 2004), though there are differences between the strength of the relationship across the forms of commitment (Meyer et al., 2002). Affective commitment is identified as having a strong influence in helping behaviour such as organisational citizenship behaviour (Meyer & Allen, 1991) and blood donation (Bednall, Bove, Cheetham, & Murray, 2013), which suggests that affective commitment will influence donor registration behaviour. However, it is likely that normative commitment will also have a strong relationship with donor registration, as feelings of obligation via the norm of reciprocity prompt donor registration.

H6: Affective commitment to the organ donation cause is positively associated with donor registration.

H7: Normative commitment to the organ donation cause is positively associated with donor registration.

3. Methodology

3.1 Setting

Data collection for this study took place in Australia, a country with a well-established opt-in deceased organ donation and transplant system. The Australian population is ethnically diverse, with 28 percent of the population born outside the country (Australian Bureau of Statistics [ABS], 2015). About ninety percent of the population is of European descent, with a further eight percent of Asian descent (ABS, 2013).

3.2 Sample

A market and social research company was engaged to collect data for the main study using a convenience sample of panel data. The firm engaged is ISO26362 and ISO20252 accredited. Further information regarding the firm and its approach to panel recruitment can be found in Appendix 1 of Paper 3. This sampling method was chosen in order to obtain a broad range of respondents,
with the sample weighted to the profile of the Australian adult population. Behaviour modelling studies are frequently undertaken using university student samples (Peterson, 2001); however, it was anticipated that a more broadly representative sample would be preferable for the collective model to be tested in order to allow for adequate variance in responses. Thus, based on Australian Bureau of Statistics Census data, the sample was weighted according to gender, age range, and geographic location by state as well as capital city versus other location.

3.3 Sample size

Two samples were collected for this study. The first was a small sample (n=345) for a pilot study, which was estimated to be sufficient to test the reliability and validity of the survey items. For the main study, based on the percentage of donors in the Australian adult population (approximately 32 percent) and the number of pathways in the model, it was estimated that a sample size of approximately 800 would ensure sufficient power to achieve statistical significance in accounting for the variation in donor registration status across the sample. An initial sample of n=1055 was collected.

Prior to data analysis, a test for Mahalanobis distance was undertaken (Tabachnick & Fidell, 2001) to look for multivariate outliers. In the pilot sample (n=345), no outliers and no missing data were identified. In the main study sample, 24 multivariate outliers were detected. Inspection of the response pattern to the set of items associated with each measure revealed that these outliers had uniformly selected the middle category (neither agree nor disagree) in over ninety percent of the items, suggesting that they had not complied with the survey’s instructions. Consequently, these cases were excluded. One hundred and forty two respondents who stated that they were unsure of their registration status were also removed from the sample, leaving a sample of n=887 for the main study. Respondent profiles for the pilot and the main study are listed in Appendix 2 of Paper 3.
3.4 Data collection

Data for the pilot study was collected by an online survey over seven days in September 2015 and for the main study over 10 days in March 2016. An email invitation to participate in the survey was sent to the online panel, in the form of a plain language statement developed for the study. The online survey included questions about donation registration status, perceptions of the health and organ donation and transplant systems, perceived social inclusion and exclusion, and a range of demographic information.

3.5 Measures

Measures were adapted from previous studies to ensure they were applicable to the organ donation context, and all items were assessed using a seven point Likert scale ranging from strongly agree (1) to strongly disagree (7). The survey instrument is available in Appendix 3 of Paper 3. Justice perceptions were adapted from Blader & Tyler (2003) and sample items include “In Australia everyone has fair access to healthcare services” (distributive), “The Australian health system has rules in place to make sure that everyone is treated fairly” (procedural), and “I am treated with dignity in my encounters with medical staff” (interactional). Social inclusion and exclusion items were adapted from the two-dimensional General Belonginess Scale developed by Malone, Pillow, & Osman (2012). Sample items include “I feel accepted by others in Australia” (inclusion) and “I feel like an outsider in Australia” (exclusion).

Institutional trust in organ donation and transplant systems was measured using items from previous studies relating to trust and organ donation (Robinson et al., 2012; Siminoff, et al., 2006). Sample items include “If doctors know I am an organ donor, they won't try to save my life” and “I trust that hospitals use donated organs as they are intended to be used”. Trust in others was adapted from Molm, Collett, & Schaefer (2007) who measured trust in generalised exchange, for example, “I can rely on people in Australia to register as donors”.

Commitment measures were adapted from Allen and Meyer's (1990) commitment scale and include “I really feel the organ shortage problem is my
own” (affective commitment) and “I feel a personal responsibility to register as a donor” (normative commitment). Lastly, donor registration status was self-reported as yes, no, or uncertain. The Department of Human Services, which administers the Australian Organ Donor Register, was contacted regarding the possibility of verifying registration status. However, independent verification was not possible due to privacy requirements.

Note that in Australia, registering as a deceased donor is typically a two-step process that involves registering an intention to donate online, followed by signing a consent form sent to those who register intent (unless signed consent is obtained directly, for example, during organ promotion campaigns in public spaces). This process was implemented in 2005 when a single national register replaced a range of other methods for registering as a donor (for example, driver’s license, holding a donor card, and the existing Australian Organ Donor Register) (Hyde & White, 2009). It is estimated that nearly seventy percent of current Australian registrations (4.27 million out of approximately 6.23 million registrations as of June 2016) derive from intent rather than consent (Australian Organ Donor Register, 2016), meaning that for the majority of registrations, only the first step of the process has been completed. Given that the majority of Australian registrations derive from intent, the survey does not differentiate between intent and consent registrations when asking about registration status.

3.6 Control variables

The study controlled for a number of individual level factors shown to be relevant to deceased donation behaviour. These include organ donation knowledge, religiosity, beliefs about the body, and past experiences relating to donation and/or transplantations (Falomir-Pichastor et al., 2013). Knowledge about organ donation and transplantation is associated with increased willingness to register (Sander & Miller, 2005), as is past experience with donation or transplantation (Rumsey, Hurford, & Cole, 2003), while the belief that the body should be buried whole is negatively associated with willingness to register (Stephenson et al., 2008). Evidence regarding the role of religion as an influence on donor registration is mixed, with studies showing both positive and
negative associations with donor registration (Newton, 2011). The rational for the controls was to isolate the effects of the constructs of interests. For example, it was important to ensure that institutional trust was not largely a function of knowledge about deceased donation and transplantation, or that past experience, religious beliefs or beliefs about the body were not the main drivers of affective and normative commitment and donor registration behaviour.

3.7 Data analysis
Data analysis was undertaken using MPlus v7. The analysis follows the recommended two-step approach to testing the hypotheses (Gerbing & Anderson, 1988). This includes establishing the unidimensionality and reliability of the measures before testing the hypothesized relationships via structural equation modelling. Logistic regression was undertaken with maximum likelihood estimation procedures. Model fit was assessed with chi-square ($\chi^2$), the comparative fit index (CFI), the root-mean-square error of approximation (RMSEA), and the standardised root mean square residual (SRMR). A value of less than two for the ratio of $\chi^2$ to the degrees of freedom indicates a well-fitting model. CFI greater than 0.90 indicates a good fit to the data (Tabachnick & Fidell, 2000). RMSEA values less than .06 and SRMR values less than .08 are generally considered a good fit (Hu & Bentler, 1999).

For the confirmatory factor analysis, values above the minimum range of 0.7 are seen to confer composite reliability as recommended by Bagozzi and Yi (2012). Also, as per Bagozzi and Yi, the average variance extracted (AVE) should exceed the recommended 0.5 for all measures. Discriminant validity is determined according to the criteria established by Fornell and Larcker (1981) with the square root of the AVE to exceed the correlations between all pairs of latent constructs, and maximum shared variances (MSV) and average shared variance (ASV) to be smaller than the AVE for each construct.

Because all of the measures for the study were gathered through a single survey, the potential for common method variances was assessed using Harman’s one
factor test, which uses exploratory factor analysis to assess whether a single factor accounts for the majority of covariance between items.

3.8 Ethics approval
Ethics approval for the study was obtained by the University of Melbourne (ID1545343.1) in August 2015. As per the ethics approval, all potential participants received an electronic copy of the plain language statement (PLS) prior to commencing the study. The PLS stated clearly that clicking on the link to the study indicated consent to participate.

4. Results – pilot study

4.1 Confirmatory factor analysis
Results suggest that the model is a good overall fit ($\chi^2$ (df = 791) = 1764.310, p = .000, CFI = .906, RMSEA = .060, SRMR = .061). As shown in Table 1, all factor loadings were statistically significant and above the cut-off value of 0.5. Composite reliability was demonstrated (all values = >7CR). Thresholds for discriminant validity outlined in the methods section were achieved for all constructs, with the exception of procedural justice. Consequently, the construct was removed from subsequent analysis. The Harmon’s test showed low likelihood of common method variance with ($\chi^2$ (df = 819) = 7357.972, p = .000, CFI = .369, RMSEA = .152, SRMR = .157).
### Table 1. Confirmatory factor analysis – pilot study

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Note. p < .001 for all.
Note the diagonal shows the square root of the AVE.

### Table 3. Confirmatory factor analysis – main study

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<td>7. Affective commitment</td>
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<td>8. Normative commitment</td>
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Note. p < .001 for all.
Note the diagonal shows the square root of the AVE.
4.2 Hypothesized relationships

The findings presented in Table 2 suggest that the hypothesized structural model fits the data well $\chi^2(df = 763) = 1483.294$, $p = .000$, CFI = .928, RMSEA = .052, SRMR = .083. The model explained 48.7 percent of the variance in donor registrations.

<table>
<thead>
<tr>
<th>Standardized path coefficients for the structural model.</th>
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<td>Distributive justice</td>
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<td>Knowledge</td>
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<td>Affective commitment</td>
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<td>Normative commitment</td>
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Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Table 2. Pilot study – hypothesis testing: predictors of registration status

Of the two justice perceptions, distributive justice was non-significant (H1a: 0.060, NS), while interactional justice was significantly associated with institutional trust (H1c: 0.35 $p < .001$). As hypothesized, social inclusion was significantly positive (H2a: 0.28, $p < 0.001$, and social exclusion (H2B: -0.14 $p < 0.001$) negatively associated with trust in others. The hypothesized relationship between institutional trust and trust in others was also significant (H3: 12 $p < 0.05$). Institutional trust was significantly associated with both affective (H4a: 0.19 $p < 0.01$) and normative (H4b: 0.46 $p < 0.001$) commitment. Likewise, trust in others was significantly associated with both forms of commitment (H5a: 0.29 $p < 0.01$; H5b: 0.51 $p < 0.001$). However contrary to expectations, in this study,
affective commitment was not positively associated with registration behaviour (H6a: p<0.08, N.S.) whereas normative commitment was strongly positively correlated with donor registration (H6b: 1.16, p<0.001).

**Main study**
The survey administered in this study was almost identical to that used in the first study with the exception of two variables. In an attempt to address the lack of discriminant validity of procedural justice in the pilot, the main study used an alternative set of justice scales adapted from Colquitt (2001) (available in Appendix 4 of Paper 3). Sample items include “I have as much access to hospitals as everyone else” (distributive justice), “I am able to query decisions about my care in hospital (procedural justice), and “I am treated with dignity in my encounters with hospital staff” (interactional justice). The new items were designed to improve the validity of the scale by providing a more specific frame of reference (hospital care as opposed to the health system generally) for respondents. To improve its parsimony, social exclusion was removed from the model. This is because the construct was deemed redundant, given the presence of social inclusion in the model (see Figure 2).

**5. Results – main study**

5.1 Confirmatory factor analysis
Results suggest that the model is again a good overall fit $\chi^2$(df = 944) = 3199.782, p = .000, CFI = .954, RMSEA = .048, SRMR = .044. As depicted in Table 3, all measures show high reliability and convergent validity. Results support the discriminant validity for all measures except for procedural justice, which despite the new scale, were cross-loaded with distributive and interactional justice. Consequently, procedural justice was eliminated from the subsequent analysis (see Figure 2).
5.2 Hypothesized relationships

The findings, presented in Table 4, suggest the hypothesized structural model fits the data well. $\chi^2 (df = 796) = 1628.152$, $p = .000$, CFI = .946, RMSEA = .045, SRMR = .078. While in the pilot the model explained 48.7 percent of the variance in donor registration in this second study the model explained 37 percent of the variance in donor registration, a lower but still strong result.

### Standardized path coefficients for the structural model.

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<th>Institutional trust</th>
<th>Trust in others</th>
<th>Affective commitment</th>
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Note. * $p < .05$, ** $p < .01$, *** $p < .001$

**Table 4. Main study – hypothesis testing: predictors of registration status**
The relationship between distributive justice and institutional trust in the main study was shown to be significant (H1a: 0.11 < .01), albeit weaker than the relationship between interactional justice and institutional trust (H1c: 0.37 < .001). Social inclusion was positively associated with trust in others (H2a: 0.23, p<0.001). Institutional trust and trust in others were significantly associated (H3: 0.15, p<0.001). Institutional trust was significantly associated with both affective (H4a: 0.57, p<0.001) and normative (H4b 0.57 p<0.001) commitment. Likewise, trust in others was significantly associated with both forms of commitment (affective H5a: 0.21, p<0.001, normative H5b: 0.14, p<0.05).

The relationship between affective commitment and registration was significant (H6a: 0.33, p<0.01.), as well as the relationship between normative commitment and donor registration (H6b: 0.74, p<0.001). While in the pilot, institutional trust and trust in others were shown to have similar strength relationships with normative commitment, in the main study the relationship between institutional trust and commitment is markedly stronger than the relationship between trust in others and commitment.

6. Discussion

The study results support the efficacy of the proposed collective model of donor registration, although there were some differences between the pilot and the main study. In the pilot, distributive justice was non-significant, possibly because judgments about distributive justice are more likely to relate to specific instances (the fairness of pay for example), than perceptions of an organisation overall (Moorman, 1991). Thus, participants may have had difficulty assessing the fairness of resource allocation across the whole health system. In contrast, perceptions of personal interactions with healthcare staff were positively associated with institutional trust. This may be because when people are unable to make judgments about larger institutional procedures and distributive processes, perceptions of personal interactions may serve as a proxy for overall judgments about organisations (Moorman, 1991). With the inclusion of new justice measures in the main study, distributive justice was found to be significant. This may have been a result of the narrower scope of new measures
(hospital care as opposed to the health system), or it may due to the larger sample size used in the main study (nearly three times that of the first study), allowing weaker relationships in the model to achieve significance.

While affective commitment was non-significant in the pilot, the main study showed a small but significant relationship between affective commitment and registration. Once again, the difference in the findings between the two studies may be a result of the larger sample size allowing weaker relationships in the model to achieve significance.

6.1 Theoretical implications
Together, these two studies contribute to the organ donation literature by applying theories of collective behaviour to test the influence of two forms of trust on donor registration behaviour: 1) institutional trust, and 2) trust in others. The findings suggest that the CDB model is a useful one. The final model includes key factors associated with collective action, namely justice perceptions, inclusion, trust, and commitment. The theoretical contribution of these studies is threefold.

First, utilizing theories of exchange to develop a collective model of registration behaviour presents an alternative to an altruistic account of donation, which Zeiler (2013, p177) argues downplays “the reciprocal dependence between the self and the other as concrete, specific individuals” (p. 177). Within the literature, there are two main constructions of deceased donation as an interdependent act. The first sees donor registration as a way of giving back to society generally, with deceased donation being a solidarity building exercise (Etzioni, 2003; Murray, 1987). For example, Mossioli et al.’s (2008) research found an association between perceived social support and willingness to donate, reflecting a willingness to “give back” for social support received. The second identifies donation as a reciprocal responsibility, linking willingness to donate with willingness to accept a transplant. Several studies suggest that people do identify donation as a reciprocal obligation (Burkell et al., 2013; Schweda et al., 2009) and the reciprocity-based systems operating in Israel and Singapore (in which
previously registered donors and/or their families receive priority access to transplants) are based on this premise (Burkell et al., 2013). These two forms of interdependence align with Levi’s (1991) account of participation in citizenship behaviour as involving both normative (giving back to society) and instrumental (getting back and not being exploited) motivations, both of which are captured by the CDB model.

Second, the CDB identifies two forms of trust relevant to donor registration behaviour—institutional trust and trust in others. These reflect two key relationships at work in collective action—one between an individual and the institutions that underpin organ donation, the other between an individual and other society members. Deceased organ donation and transplant systems require the highest possible number of registered donors, few of whom will ultimately become donors (Thomas & Klapdor, 2008), making trust in institutions and other society members crucial to meeting the need for transplantable organs.

The CDB model supports the role of trust in others as influencing donation donor registration, although the difference between the strength of this effect in the pilot and main studies warrants further investigation. Both studies also found a significant relationship between institutional trust, normative commitment to the cause of donation, and donor registration. This finding is consistent with attitudinal studies showing that mistrust of organ donation and transplantation systems negatively influence willingness to donate in minority and ethnic populations (Morgan, et al., 2013; Russell et al., 2012; Siminoff & Sturm, 2000). This mistrust is sometimes attributed to lack of knowledge about deceased donation (Hyde et al., 2012), with increased knowledge seen as a means of overcoming reluctance to donate (Morgan & Cannon, 2003).

However mistrust is largely absent from existing donor behavioural models. Two exceptions are Robinson et al.’s, (2012) and Morgan’s (2006) studies of donation intentions among African Americans. Both studies found that religion and mistrust to a significant degree were negatively associated with willingness to donate (though both studies suggest different pathways to donor registration to the one proposed in this paper, focusing on attitudes and intentions). The small
number of theoretical models that incorporate trust may be a consequence of trust operating as a “silent background” (Miształa, 1996), exerting a positive but invisible influence on the behaviour of those who have no reason to mistrust institutions or other people. As Almassi (2014) points out “it can be easy for those who are privileged to enjoy rational trust to discount its fragile nature, and hard to understand why those people we justifiably consider trustworthy to be regarded differently by others” (p. 1).

The results of this study correspond with the work of Sargeant et al. (2006) in relation to charitable donations. Drawing on relationship marketing, Sargeant et al. (2006) found that trust in charitable organisations was a key determinant of the amount of money donated. The authors argue that this trust is essential because people cannot directly assess how well their charitable donations are spent and so must rely on the organisation delivering the services. Donor registration involves an additional element of uncertainty because registration is a behaviour with a long-term horizon—that is, one registers with no idea whether, when, or under what circumstances donation will actually take place. Consequently, registered donors must trust the institutions that underpin organ donation and transplant systems now and into the future. Such trust relates to the safety of organ donation—that physicians will not withhold or prematurely withdraw life-saving treatment for registered donors (Siminoff & Arnold, 1999; Russell et al., 2012; Brown, 2012; Goldberg et al., 2013; Siminoff et al., 2006). Additionally, trust is relevant in the fairness of the allocation of donated organs—that the system is not biased against the poor or minority groups and/or biased in favour of the rich and famous (Siminoff, et al., 2006; Boulware et al., 2007; Morgan & Cannon, 2003).

Another key difference between registration and other forms of prosocial behaviour lies in the one-off nature of donor registration. Charities typically rely on ongoing behaviour—regular donations or volunteering (Penner, Dovidio, Piliavin, & Schroeder, 2005)—and thus focus not only on prompting initial participation but on retaining those donors or volunteers (Bussell & Forbes, 2002; Sargeant & Woodcliffe, 2007). A key driver of ongoing prosocial behaviour is commitment, both normative and affective (Naskrent & Siebelt, 2011), with
affective commitment developing as the “cause” becomes integral to an individual’s identity (Tidwell, 2005). The idea of “being” a blood donor, for example, is reinforced each time an individual goes to donate. However, research suggests that affective commitment is less important to an initial prosocial act, becoming salient only when people repeat that behaviour on an ongoing basis (Callero & Piliavin, 1983). Consequently, affective commitment is likely to be less significant to one-off behaviour, demonstrated by the results of this study, which show affective commitment to be non-significant in the pilot and weakly significant in the main study. Indeed, even defining registration is difficult; Horton and Horton (1991) characterise it as “the acceptance of an idea about an altruistic act that has a very low probability of ever being completed” (p. 1047), which arguably poses a challenge to establishing affective commitment to registering.

The third theoretical contribution, therefore, is to demonstrate that normative commitment is likely to be the more important driver of donor registration. The results of the study demonstrate strong pathways between justice perceptions in relation to health/hospital care, institutional trust, and normative commitment, as well as strong links between social inclusion, trust in others, and normative commitment. These results indicate that donor registration may to be driven by perceived obligation, rather than an emotional connection to the cause of organ donation, which has implications when considering the promotion of registration in the public domain, as discussed next.

6.2 Managerial implications

Beyond theoretical implications, the findings have several implications for policies and programs aimed at increasing donor registration. First, framing donor registration as a collective obligation may be an effective way to motivate registration behaviour beyond the altruism message. Altruistic acts are supererogatory—laudable but unnecessary acts (Hester, 2006), negating any obligation to donate. The depiction of donors as altruistic “heroes”, for example, promotes the idea of donation as an extraordinary act (Zeiler, 2013). In contrast, a collective approach sees deceased donation a consequence of a perceived
obligation to society, either to reciprocate benefits received from or to further the interests of the society.

The findings also highlight that the effectiveness of appeals founded on collectivity will depend on both institutional trust and trust in others. Those who experience negative interactions within the healthcare system or perceive social exclusion are less likely to identify donor registration as an obligation or indeed to feel an emotional connection to the cause. Thus, the collective model may help to explain why ethnic and other minority groups who have experienced prejudice and negative interactions with social institutions are less likely to register as donors, despite acting equally, if not more altruistically, in other areas of life, such as in charitable donations (Siminoff & Arnold, 1999).

These findings suggest that improvements in organ donation registration rates may require the strengthening of both institutional trust and trust in others. Given that most people have no direct interaction with organ donation and transplant systems, institutional trust relies on past positive interactions with medical staff. The significance of positive interpersonal experiences in this study is consistent with studies that find the perceived value of healthcare relates not only to instrumental outcomes but also to patient experiences within healthcare settings, such as being treated with dignity and respect in medical encounters (Mooney, 1998; Ryan, 1999). Consequently, campaigns aimed at increasing knowledge are unlikely to instil trust in deceased organ donation and transplant systems in the face of ongoing negative interactions within healthcare settings.

The findings also demonstrate that trust in others regarding organ donation is best built through a sense of belonging in society. Several studies found a relationship between attitudes towards donation and social inclusion/exclusion. For example, Morgan et al.’s (2008) qualitative study undertaken among the Caribbean population in London found that reluctance to donate may reflect a

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8 For example Siminoff and Arnold (1999) report that African-American persons across socioeconomic levels were more likely to volunteer or make a charitable donation than any other ethnic group.
sense of dislocation and feelings of not truly belonging to British society. Equally, Polonsky et al.’s (2011) research in relation to blood donation in African migrant communities in Australia revealed that participants felt marginalised and excluded from mainstream society with little public representation of non-white communities. The study also found that perceived exclusion from the blood donation system specifically (that is, a perceived reluctance to accept African blood) serves to further reinforce this social exclusion. Thus, social exclusion and reluctance to donate are caught in a vicious cycle. The authors suggest that including diverse population groups within donation marketing campaigns may address the perceptions of exclusion, while acknowledging that tackling broader social exclusion requires a wider change in cultural norms and beliefs across society. Consequently, encouraging deceased donor registration through increasing perceptions of social inclusion is likely to require more than inclusive marketing campaigns. That being said, fostering a sense of inclusion within organ donation and transplant systems, such as emphasizing that all population groups belong to a pool of potential donors and potential recipients, may be a useful starting point.

7. Limitations and further research

This paper demonstrates that a theoretical approach based on collective theories is a viable way of understanding donor motivations to register. However, it has limitations that future research may address.

First, the study design involved necessary concessions in the choice of sample groups to ensure an adequate sample size and sufficiently robust data to test the CDB model. While it was initially intended for the research to be undertaken among migrant communities in Qatar (in line with the sample population in Paper 2), the lack of registered donors in Qatar made this approach unfeasible. Thus, it was necessary to shift the location of the research to Australia. Further, as a result of the costs and logistical difficulties associated with conducting the surveys in multiple languages across diverse migrant populations in Australia, the samples for both the pilot and main studies were drawn from the general population and the surveys were written in English. The sample was dominated
by respondents born in Australia or those who had migrated from either the United Kingdom or New Zealand. Consequently, there were an insufficient number of respondents from other ethnicities to stratify the sample by ethnicity. That said, sample collected is broadly representative of the Australian population, with over 70 percent of citizens born in Australia (ABS, 2015) and around 90 percent being of European descent (ABS, 2013).

A second limitation relates to use of an online panel for data collection. This approach enabled a broad representative sample of the Australian population to be surveyed. Nonetheless, despite internet access being widespread in Australia—approximately 86 percent of all households have internet access at home and 97 percent of homes with children under 15 (ABS, 2016)—online panel data collection is subject to bias towards people with ready access to technology. Therefore, the study potentially excluded recently arrived migrants and those in tenuous financial positions or transient living conditions. In addition, panel data may be subject to response bias, with the risk of participants providing responses that they believe the researchers want. Equally, panel samples may be subject to practice bias, given that the online panels are well-rehearsed in responding to surveys (Duffy, Smith, & Terhanian, 2005). Further data collection should, therefore, include surveys administered in situ to capture a broader range of possible respondents. Another limitation is the reliance on self-reported registration status. All variables in the study were collected through a single source—an online survey—and thus may be subject to common method variance. Despite the author’s best efforts, it was not possible to independently verify the registration status of respondents with the Australian Organ Donor Register. While Harmon’s one factor test (a statistical procedure designed to identify common method variance) was applied to the data, it does not guarantee a lack of common method variance (Podsakoff, 1986).

Further, while the study demonstrates the efficacy of the collective model overall, it is yet unclear whether the model is more effective than other models at predicting donor registration behaviour. Future studies could address this limitation by comparing the collective model with typical models of donor registration. In line with the initial focus of the research, future research may
also assess whether the collective model is more applicable to specific population groups, given that factors such as trust and inclusion are known to be pertinent to minority populations. Equally, future research may be able to assess whether the collective model of donor registration is able explain a broader range of collective behaviour, such as blood donation, or whether the nature of deceased donation and transplant systems make donor registration a unique behaviour.

8. Conclusion

Recognising deceased donation as a collective behaviour has the potential to provide fresh insight into factors that influence donor registration, in particular trust in the institutions that support organ donation, and trust in other society members. Beyond altruism, reframing donation as collective act provides an important context within which to understand the reluctance to donate noted in a range of populations for whom trust and social inclusion are ongoing concerns. It also provides researchers and policy makers with an opportunity to rethink the strategies used to encourage donation, and to address the way in which individuals perceive the institutions that support organ donation, and how they perceive their own place in the wider community.
PAPER 4

Donor registration: a comparison of the model of Collective Donor Behaviour and the Theory of Planned Behaviour

Abstract

This paper examines the third and fourth thesis research questions, regarding drivers of and barriers to registering in a collective account of donor registration, and how such insights may help increase donor registration rates.

This paper presents the results of a longitudinal study comparing the model of Collective Donor Behaviour (CDB) with the Theory of Planned Behaviour (TPB) in relation to both organ registration intentions (n=514) and registration behaviour (n=274). Few organ donation studies compare different behavioural models, despite the importance of these models in understanding the drivers of behavioural change in relation to donor registration. The two models propose different pathways to donor registration. The CDB identifies registration as a function of affective commitment (emotional attachment) and normative commitment (obligation) to the cause, stemming from trust in other society members and trust in institutions. These two forms of trust are founded on inclusion and fairness perceptions respectively. The TPB identifies behaviour as a function of individual attitudes, perceived behavioural control, subjective norms, and intentions.

Confirmatory factor analysis shows the constructs derived from both the CDB and the TPB to have both convergent and discriminant validity. Structural equation modelling also finds both models are effective at predicting donor registration intentions (44.3% and 47.5% of variance respectively) and donor registration behaviour (34% and 40% respectively), albeit via different pathways. The TPB identifies registration as primarily founded on perceived pressure from important others (subjective norm) and positive attitudes. In contrast, the CDB views donor registration as a function of perceived obligation.
(normative commitment), founded on trusting institutional and social relationships, which are in turn a product of perceived fairness and social inclusion respectively. Thus, the CDB provides a level of specificity about drivers of donation not found in models based on attitudes and intentions. The CDB highlights the need for interventions to move beyond a focus on improving attitudes to focus on building community inclusiveness, addressing mistrust in transplant systems, and fostering a shared fate in relation to donation and transplantation.
1. Introduction

Organ transplantation is an important and often life-saving treatment for an array of end-stage diseases (Lauritzen et al., 2001). While living donation is increasingly used for kidney and liver transplants, overall, organ transplant systems remain reliant on deceased organ donation in Europe, the USA, and Australia (Global Observatory, 2016). However, in many countries with opt-in deceased donor systems, deceased donor registration rates are insufficient to meet demand (Siegal & Bonnie, 2006). This inadequacy is despite ongoing public communication campaigns and decades of academic work dedicated to understanding what drives donation behaviour (Falomir-Pichastor et al., 2013).

Theoretical modelling is a key research tool used to predict and explain variances in donation behaviour, including registration (for example, Anker & Feeley, 2011; Farsides, 2010; Hyde et al., 2013) and willingness to discuss donation with family (for example, Hyde & White, 2010; Park & Smith, 2007). Models such as Horton and Horton’s (1991) Organ Donor Model, the Organ Donor Willingness Model (Kopfman & Smith, 1996) and the Organ Donation Model (Morgan et al., 2002) focus on factors such as attitudes, knowledge, values, and norms to predict donation behaviour. Such models build on established behavioural theories, including the Theory of Reasoned Action (TRA) and the Theory of Planned Behaviour (TPB) (Fishbein & Ajzen, 2010). The TRA identifies attitudes, subjective norms, and intentions as key predictors of behaviour under volitional control. This was later expanded in the TPB to include perceived behavioural control—the perceived ease or difficulty in performing a behaviour—to capture those behaviours not under volitional control. Along with the previously identified models of donation behaviour, numerous studies use the TPB directly to model donation behaviour. These studies include willingness to register as a donor (Bresnahan et al., 2007; Hyde et al., 2013; Rocheleau, 2013) and willingness to discuss a donation decision with family members (Hyde & White, 2009). An advantage of behavioural modelling is its focus on direct drivers of donor registration rather than distal factors such as demographics (Falomir-Pichastor et al., 2013). However, the predictive ability of behavioural
models is inconsistent, with positive attitudes being the only consistent predictor of donation registration intentions (Nijkamp et al., 2008).

Despite these limitations, relatively few studies that model donor registration behaviour challenge the underlying assumption that the behaviour is a function of individual values and preferences (Healy, 2004). Fewer still test the efficacy of individual models against alternative accounts of behaviour. Instead, theoretical or practical gaps in models, such as the TPB, tend to be filled by the inclusion of further variables (Sniehotta, Presseau, & Araújo-Soares, 2014). The dearth of studies that challenge and compare different theoretical approaches has been identified as a key problem in moving health-related behavioural research forward (Noar & Zimmerman, 2005). Weinstein and Rothman (2005) argue that despite thousands of health behaviour studies, advances in theories have been modest, with few substantive improvements to existing theories. This argument appears relevant to organ donation research, where individual attitudes, norms, and intentions remain the dominant way of conceptualizing donation registration behaviour.

To address this gap, this paper presents the results of a quantitative study based on a collective model (the CDB) in which trust, justice perceptions, and social inclusion influence individual donor registration decisions. This CDB (which was tested in Paper 3) is compared with the TPB in relation to both registration intentions and registration behaviour. In doing so, the paper makes a number of contributions. First, the paper establishes that the CDB is indeed a viable way of predicting registration intentions and behaviour, suggesting an alternative decision-making pathway based on social and institutional relationships. Second, in demonstrating the CDB model of donor registration to be as effective as the TPB, the paper challenges long-held assumptions about the attitude intention pathway dominant in health and prosocial behavioural studies. Third, the strength of the association of normative commitment with donor registration suggests that a perceived obligation to forward the interests of the community, founded on institutional trust and trust in other society members, helps to drive donor registration. Thus, the CDB accounts for the role of known barriers to registration, such as medical mistrust and social exclusion. These findings
suggest that increasing donor registration rates requires us to consider the interactions of individuals with social institutions and communities. Thus, the CDB identifies specific factors beyond attitudes that deceased donation policies and communication campaigns can address.

The paper is structured as follows. First, it provides a brief review of the TPB within the deceased donation literature. Second, the paper presents the CDB (discussed in Paper 3), as well as the TPB model. Subsequently, both the CDB and a TPB-based model are tested, comparisons are made, and implications are discussed. Last, limitations and potential directions for future research are provided.

### 2. The Theory of Planned Behaviour

The Theory of Planned Behaviour (TPB) (Fishbein & Ajzen, 2010) and the earlier Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975) were developed in social psychology to explain and predict behaviour. The TPB identifies intention as an immediate antecedent to behaviour, which is in turn determined by attitude (a function of beliefs about the likely costs and benefits of performing a particular behaviour), subjective norm (perceived pressure from important others in relation to the behaviour) and perceived behavioural control (perceived capacity and autonomy to act). The strength of the TPB is seen as lying in its parsimony, which allows it to be applied across a range of domains (Rocheleau, 2013). The model is commonly used in relation to decision-making in various health contexts (Newton, Ewing, Burney, & Hay, 2012), including alcohol consumption (Norman, Armitage, & Quigley, 2007), exercise (Bryan & Rocheleau, 2002), safe sex (Reinecke, Schmidt, & Ajzen, 1996), and smoking cessation (Norman, Conner, & Bell, 1999), as well as prosocial behaviours such as recycling (White, Smith, Terry, Greenslade, & McKimmie, 2009), blood donation (Giles, 2004; Robinson, Masser, White, Hyde, & Terry, 2008) and charitable donations (Knowles, Hyde, & White, 2012; Smith & McSweeney, 2007). A meta-analysis of the TPB across a broad range of behaviour found that the theory accounts for around 39% of variance in intentions and 27% of variance in behaviour (Armitage & Conner, 2001).
Although the TPB is parsimonious, this has been identified as a potential limitation of the model (Perugini & Bagozzi, 2001), as it omits important predictors specific to particular domains. To address this weakness, Azjen (1991) proposed additional domain-specific variables be added if they significantly improve the explanatory power of the model in a particular context.

Within the organ donation literature, studies based on the TPB incorporate variables such as religion (Robinson et al., 2012; Rocheleau, 2013), self-identity (Terry, Hogg, & White, 1999), past behaviour (Rocheleau, 2013), and anticipated regret (Godin, Bélanger-Gravel, Gagné, & Blondeau, 2008), as well as further normative constructs including moral (Hyde et al., 2013), personal, and social norms (Park & Smith, 2007). Even so, the effectiveness of the TPB in predicting donor registration intentions and/or behaviour is mixed. For example, Hyde et al. (2013) found that the TPB alone accounts for around 61 percent of donation intentions, rising to 74.6 per cent with the addition of self-identity and in-group altruism. Rocheleau (2013) found that religious attitudes and past behaviour increase the efficacy of the TPB, with a standard model accounting for 48 percent of variance in donor registration increasing to 69 percent with the additional variables. However, a number of studies found that non-cognitive beliefs about donation were more salient than the TPB's social-cognitive approach. For example, Morgan et al.’s (2008) study of American adults found knowledge, attitude, and subjective norm to be weak predictors of donor registration, with non-cognitive beliefs such as the so-called “ick” factor (disgust at the idea of donation) and the “jinx” factor (superstition) the strongest predictors of failure to register. O’Carroll et al.’s (2011) study found similar results, with TPB constructs failing to distinguish donors from non-donors, while non-cognitive beliefs accounted for a significant variance in registration behaviour. In addition, the study found that asking about anticipated regret lead to a significant increase in registration intentions. Consequently, it is not entirely clear which constructs in the TPB have the greatest influence on donation registration behaviour.

2.1 The TPB and norms

The normative aspect of the TPB is one of the most frequently modified
components in organ donation studies. Across a range of domains, subjective norm is shown to be the weakest construct in the TPB, resulting in its frequent omission from studies or subsequently in data analysis (Armitage & Conner, 2001). The subjective norm’s low level of explanatory power led Azjen to conclude that the primary predictors of behaviour are in fact personal factors—attitude and perceived behavioural control—not norms (Azjen, 1991). A main criticism of the subjective norm is that it ignores the role of other norms that influence behaviour (Mielewczyk & Willig, 2007). To address the limitations of the subjective norm (perceptions of what important others think an individual should do), various organ donation studies incorporate descriptive (the actual behaviour of important others), personal or moral (internalised beliefs about the fundamental rightness of wrongness of a behaviour), and social or group norms (implied or accepted rules about how group or society members should behave).

As is the case with the addition of other variables to the TPB, results from organ donation studies that incorporate additional norms vary. Some studies found moral norms to be significant predictors of donor registration (for example, Godin et al., 2008; Hyde & White, 2009), while others did not (for example, Hyde et al., 2013). Park, Shin, & Yun (2009) found social norms to be significant predictors of differences in donor registration behaviour between different cultures, while Alden & Cheung (2000) found no differences. Hyde and White (2013), however, found the norm of in-group altruism—a preference for helping a narrowly-defined group of family and friends as opposed to strangers—to be associated with a decreased willingness to donate. This suggests that the way in which group norms affect donor registration depends on precisely who is considered as included in the “group”. The inconsistency in the findings regarding the role of norms in these studies also highlights the potential limitations of adding constructs to the TPB that alter the foundation of the model.

2.2 From the individual to the collective

The inclusion of social or group norms marks a shift in the assumptions that underlie the TPB. Indeed, Terry & Hogg (1996) argue that the inclusion of the
subjective norm in the TPB reflects a misunderstanding of the role of norms in influencing behaviour. In their judgment, the TPB conceptualises norms as external prescriptions/rules that influence individual behaviour, while norms are in fact accepted or implied rules about behaviour that exist within a group (Terry & Hogg, 1996; Turner, 1991). Accordingly, perceptions about how others think an individual should behave are less relevant than group norms—“the context specific attitudes and behaviours appropriate for group members” (White et al., 2009, p. 139). Drawing on social identity theory (Tajfel et al., 1971), Terry, Hogg, and colleagues (Terry et al., 1999; Terry, Hogg, & McKimmie, 2000) argue that group norms work by transforming individual behaviours into collective ones. While individual behavioural accounts assume that attitudes are formed by an assessment of the individual costs and consequences of the behaviour, weighted by the value placed on these consequences (Ajzen, 2011), in contrast, social identity theory (Tajfel et al., 1971) and self-categorization theory (Turner et al., 1994) view collective behaviour as a consequence of group identification. Drawing on social identity theory, Lawler et al., (2001) identify several factors that influence situations when group norms are likely to drive collective behaviour: the extent to which individual contributions are difficult to distinguish, and the level of perceived joint responsibility for the outcome (Lawler et al., 2001; Lawler & Thye, 1999), that is, where there is a high level of perceived interdependence in relation to the behaviour.

Terry et al.’s (2000) interpretation of the TPB through social identity theory views behaviour primarily as a function of group interdependence. This arguably marks a significant departure from the theory’s individualistic foundations, raising the question of whether the TPB is in fact the most useful vehicle for modelling collective behaviour. It also highlights the need for a deeper understanding of the mechanisms at work in collective behaviour. The TPB identifies attitude as central to behaviour, which is based on assessments of the individual costs and consequences of acting or not acting. Interdependent theories of behaviour, such as the group gain decision rule in social exchange (Meeker, 1971) and social identity theory (Lawler et al., 2001) suggest that behaviour stems from one’s place in the group and the extent to which one’s
interests are intertwined with those of the collective. As such, a range of factors related to collective behaviours, and that go beyond individual attitudes, perceived behavioural control (PBC) and subjective norms, may be key to understanding donor registration behaviour.

3. Framework and hypothesis

3.1 Model of Collective Donor Behaviour (CDB)

The CDB model developed seeks to account for donation as a collective behaviour. Drawing on the work of political scientist Levi (1991, 1998) in relation to public goods as well theories of exchange (Blau, 1964; Emerson, 1976), two forms of trust are central to the model—trust in the institutions that underpin deceased donation and transplant systems and trust in other society members. The CDB also draws on theories of exchange to identity two pathways to commitment to the organ donation cause. The first is between justice perceptions and institutional trust, the second between social inclusion and trust in others. Paper 3 provides an in-depth discussion of the hypotheses, shown in Figure 1.

![Figure 1. Model of Collective Donor Behaviour](image)

Figure 1. Model of Collective Donor Behaviour
3.2 Theory of planned behaviour

As shown in Figure 2, the study uses a standard TPB model (attitudes, subject norms, and perceived behavioural control). Given the inconsistent findings regarding the influence of additional constructs in the modelling of donor registration based on the TPB (discussed previously), the standard model was deemed most appropriate for the purposes of comparison.

![Figure 2. Theory of Planned Behaviour](image)

4. Methodology

4.1 Setting

Data collection for this study took place in Australia, a country with a well-established opt-in deceased organ donation and transplant system. The Australian population is ethnically diverse, with 28 percent of the population born outside the country (ABS, 2015). Around 90 percent of the population is of European descent, with a further 8 percent of Asian descent (ABS, 2013).

4.2 Sample

A market and social research company was engaged to collect data using a convenience sample of panel data. This sampling method was chosen in order to gain a broad range of respondents, with the sample weighted to the profile of the
Australian adult population according to gender, age range, and geographic location by state as well as capital city versus other locations.

4.3 Sample size

Two samples were included in this study. The first comprises the subset of n=514 self-identified non-registered participants from the sample of n=1055 collected for Paper 3. A follow-up of the n=1055 sample yielded n= 272 valid responses from non-registered participants. Respondent profiles for the study are provided in Appendix 1 of Paper 4.

4.4 Data collection

The study included two waves of data collection (see the flow chart of sampling process at Figure 3). During the first wave data was collected by an online survey over 10 days in March 2016. An email invitation to participate in the survey was sent to the online panel in the form of the plain language statement (PLS) developed for the study. The online survey included questions about donation registration status; perceptions of the health, and organ donation and transplant systems; perceived social inclusion; and the TPB constructs of attitudes, subjective norm, perceived behavioural control, and intentions; as well as a range of demographic information.

Confidentiality requirements meant that the market and social research company used could not re-contact participants based on their individual responses. Consequently, during the second wave of data collection, the entire study sample (described in Paper 3) of n=1055 was re-contacted by the market and social research company in June 2016, three months after the initial study, in order collect a follow-up sample of the non-registered donors. This follow-up yielded n=659 responses. Of these, n= 340 stated they had identified themselves as non-donors in the first survey. Collation of the datasets from the first and follow-up survey revealed that 16 respondents were multivariate outliers that had been removed from the analysis in the prior study. For a further 42 respondents, discrepancies were found between responses to the first and follow-up surveys (for example, stating they were not sure about registration.
status in the first survey and identifying as a non-registered donor in the second). Consequently, these were also removed, leaving a sample of n=272. This sample was asked if they had registered as donors since completing the first survey. Those who had not registered since the first survey were offered the opportunity to click on a link to the Australian Organ Donor Register to register an intention to donate organs. Last, respondents who clicked on the link to the website were asked whether they had registered. Registration status was self-reported as it was not possible to verify registration status with the Australian Donor Register.⁹

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⁹ The Australian Commonwealth Department of Health was contacted regarding the possibility of cross-matching data with the Australian Organ Donor Register, however confidentiality requirements precluded this. The Department was also asked about the possibility of tracking participants who clicked on the link to the Australian Donor Register (ADR) to confirm whether the online form had been filled out. Because the ADR website uses secure certificate encryption strategies, tracking participants past the point of survey exit was also not possible.
4.5 Measures

Measures for the CDB were adopted from previous studies and all items were measured on seven-point Likert scales ranging from strongly agree (1) to strongly disagree (7). The survey instrument is provided in Appendix 2 of Paper 4. A full discussion of the measures can be found in Paper 3. For the purpose of comparison with the TPB, the model specifies intentions as the dependent variable in phase one of non-registrants.

Measures for the TPB model were adopted from previous TPB studies (Newton, Newton, Ewing, & Burney, 2013) and were also measured on Likert scales ranging from strongly agree (1) to strongly disagree (7). The TPB survey instrument is provided in Appendix 3 of Paper 4. In line with Fishbein and Ajzen's (2010) most recent iteration of the TPB, the subdomains for each construct were incorporated into each of the scales. Accordingly, attitudes include both experiential (“To me being or becoming a registered donor is unpleasant/pleasant”) and instrumental (“worthless/valuable”) items. The subjective norm includes injunctive (“The people in my life whose opinions I value would approve of me being a registered organ donor”) and descriptive (“Most people whose opinion I value have registered”) items. The perceived behavioural control includes capacity (“It is easy to register as a deceased donor”) and autonomy (“Whether or not I am or become a registered organ donor is entirely up to me”) items. Intentions were measured using three items (for example, “I intend to become a registered organ donor”).

4.6 Control variables

As outlined in Paper 3, a number of factors shown to be relevant to deceased donation behaviour are controlled for in the study. These include organ donation knowledge, religiosity, beliefs about the body, and past experiences relating to donation and/or transplantations (Falomir-Pichastor et al., 2013).

4.7 Data analysis

Data analysis was undertaken using MPlus v7. The analysis followed the recommended two-step approach to testing the hypotheses (Gerbing &
Anderson, 1988). This includes establishing the unidimensionality and reliability of the measures before testing the hypothesized relationships via structural equation modelling. Logistic regression was undertaken with maximum likelihood estimation procedures. Analysis of registration was undertaken using full information maximum likelihood (FIML) estimation procedures, which uses the full n=514 sample, with missing data on the registration variable, as recommended by Graham (2009). Model fit was assessed by the following indicators: chi-square ($\chi^2$), the comparative fit index (CFI), the root-mean-square error of approximation (RMSEA), and the standardised root mean square residual (SRMR). A value of less than two for the ratio of $\chi^2$ to the degrees of freedom indicates a well-fitting model. A CFI greater than 0.90 indicates a good fit to the data (Tabachnick & Fidell, 2000). RMSEA values of less than .06 and SRMR values of less than .08 are generally considered a good fit (Hu & Bentler, 1999).

For the confirmatory factor analysis, values above the minimum range of 0.7 are seen to confer composite reliability as recommended by Bagozzi and Yi (2012). Also, as per Bagozzi and Yi, the average variance extracted (AVE) should exceed the recommended 0.5 for all measures. Discriminant validity is determined according to the criteria established by Fornell and Larcker (1981), with the square root of the AVE exceeding the correlations between all pairs of latent constructs, and maximum shared variances (MSV) and average shared variance (ASV) being smaller than the AVE for each construct.

Because all of the measures for the study were gathered through a single survey, the potential for common method variances was assessed using Harman's one factor test, which uses exploratory factor analysis to assess whether a single factor accounts for the majority of covariance between items.

There is no method for comparing non-nested models estimated using a Maximum Likelihood estimator, and consequently the analysis does not include a formal comparison of the CDB and the TPB. Instead, the models were evaluated
by how well they fit the data, the variance explained in intentions and their capacity to predict and explain registration (Gerend & Shepherd, 2012).

4.8 Ethics approval
Ethics approval for the study was obtained by the University of Melbourne (ID1545343.1). As per the ethics approval, all potential participants received an electronic copy of the PLS prior to commencing the study. The PLS stated clearly that clicking on the link to the study indicated consent to participate.

5. Results – CDB and TPB on intentions

5.1 Confirmatory factor analysis
Results suggest that the CDB is a good overall fit ($\chi^2$(df = 704) = 2508.016, p = .000, CFI = .957, RMSEA = .050, SRMR = .045). Because the model had been tested previously and adjustments were made (such as the removal of procedural justice from the model), no further changes were required.

Initial analysis indicated that the TPB model was a good overall fit, ($\chi^2$(df = 153) = 8933.219, p = .000, CFI = .94, RMSEA = .065, SRMR = .06). However, investigation of the modification indices indicated that the model fit would be improved by removing one of the subdomains from each of the constructs ($\chi^2$(df = 120) = 442.001, p = .000, CFI = .964, RMSEA = .051, SRMR = .046). These are the experiential subdomain of attitudes, the descriptive subdomain of the subjective norm, and the capacity subdomain of perceived behavioural control.

The improvement in model fit with the removal of the experiential subdomain of attitude—registering as a donor would be pleasant/unpleasant etc.—may be indicative of the lack of effort required to register as a donor. Thus, registering as a donor is less likely to invoke perceptions of enjoyment or un-enjoyment, than behaviours that may involve a level of discomfort such as blood donation or exercise. In the case of the subjective norm construct, the descriptive norm—whether important others are registered as donors—is likely to be less relevant to behaviours that are not easily observable (Gerend & Shepherd, 2012). Because donor registration status is not easily observable in the way that some
behaviours are (such as exercise or smoking), people may be less aware of or less influenced by others’ donor registration status. A number of organ donation studies founded on the TPB include the injunctive component of the subjective norm only (for example, Godin et al., 2008; Hyde et al., 2013). Last, the capacity subdomain of perceived behavioural control—knowing how to register—was removed, as autonomy (for example, perceptions regarding the likelihood of the person’s family rejecting registration decisions) was identified as the more salient domain.

A combined model (the CDB and the TPB) was also analysed to assess the possibility that both sets of variables would provide a good model fit. The results demonstrated that the combined model was a very poor fit ($\chi^2$(df = 1196) = 2827.818, $p = .000$, $CFI = .956$, $RMSEA = .036$, $SRMR = .045$). As the Confirmatory Factor Analysis given in Table 1 demonstrates, the constructs from each model are distinct from each other, achieving discriminant validity, with composite reliability also demonstrated. The Harmon’s test showed low likelihood of common method variance with $\chi^2$(df = 1274) = 28104.853, $p = .000$, $CFI = .287$, $RMSEA = .143$, $SRMR = .156$. 

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Table 1. Confirmatory factor analysis – CDB and TPB

<table>
<thead>
<tr>
<th>Correlations among factors</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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<th>8</th>
<th>9</th>
<th>10</th>
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<th>12</th>
<th>13</th>
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<td>.24***</td>
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Table 1. Confirmatory factor analysis – CDB and TPB.
5.2 Hypothesized relationships

The findings presented in Table 2 suggest that the CDB fits the data well ($\chi^2$ (df = 918) = 1796.084, p = .000, CFI = .949, RMSEA = .043, SRMR = .076. The model explains 44.3 percent of the variance in donor registration intentions among non-registered respondents. All of the hypothesized pathways in the model were significant except affective commitment, with normative commitment demonstrating a strong positive association with donation intentions (0.87 p<.001).

Table 2. CDB hypothesis testing: predictors of registration intentions

<table>
<thead>
<tr>
<th></th>
<th>Institutional trust</th>
<th>Trust in others</th>
<th>Affective commitment</th>
<th>Normative commitment</th>
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<td></td>
<td>.29***</td>
<td>.27***</td>
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R         | .295 | .086 | .182 | .175 | .443

Note. * p < .05, ** p < .01, *** p < .001
Standardised path coefficients for the structural model

<table>
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<td>R</td>
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</table>

Note. * p < .05, ** p < .01, *** p < .001

Table 3. Theory of Planned Behaviour hypothesis testing: predictors of registration intentions

5.3 Discussion

Analysis showed one construct from each of the models to be non-significant. As found in Paper 3, the non-significance of affective commitment in the CDB suggests emotional attachment to the cause of donation is less relevant than perceived obligation to the cause. In the TPB, the non-significance of the PBC suggests that feelings of autonomy do not have an impact in relation to registering as a donor. The PBC construct relates to behaviour that may not be under volitional control (Armitage & Conner, 2001); thus it is most salient in decisions where power plays a role, such as safe sex (for example, feeling in control of the decision to use a condom) (Reinecke et al., 1996). The non-significance of the PBC in this study suggests that power over one’s decision-making in relation to donor registration is not salient in this sample.

Overall, the results of the analysis suggest that both the CDB and the TPB fit the data well and are able to predict donation intentions in non-registrants, albeit via different pathways. Both models, however, find a strong relationship between the normative components of their respective models (normative commitment and subjective norm), suggesting that perceived normative pressure influences intentions to act in this context. In the CDB, this pressure is shown to stem from perceived obligations to the group operating via positive experiences of the health system and institutional trust on one hand, and perceived social inclusion and trust in other society members on the other. In the TPB, this perceived pressure stems from perceptions about what important others think.
6. Results – follow-up study: CDB and TPB on registration

6.1 Hypothesized relationships

Having already established the reliability and validity of the two models in terms of registration intentions, their effectiveness in predicting donor registration behaviour was evaluated with a follow-up sample. Of the n=272 respondents, 12 stated they had registered with the Australian Donor Register since the first survey. A further 21 stated they had registered after clicking on the link to the Australian Donor Register during the follow-up survey. The results are presented in Tables 4 and 5.

<table>
<thead>
<tr>
<th>Standardised path coefficients for the structural model.</th>
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<tr>
<td>Attitude</td>
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<tr>
<td>Subjective norm</td>
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<tr>
<td>Perceived behavioural control</td>
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<td>Beliefs about the body</td>
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<td>Religiosity</td>
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<td>Knowledge</td>
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<td>Past experience</td>
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<tr>
<td>Intentions</td>
</tr>
</tbody>
</table>

R | .458 | .400

Note. * p < .05, ** p < .01, *** p < .001

Table 4. Theory of Planned Behaviour hypothesis testing: predictors of registration

The TPB predicted 40 percent of the variation in registration behaviour. Subjective norm had a strong relationship with intentions (0.88, p< .001), and attitudes had a weak but significant relationship with intentions (0.14, p<.05). Analysis found the PBC to be non-significant both as a direct effect on behaviour and via intentions.
**Standardised path coefficients for the structural model.**

<table>
<thead>
<tr>
<th></th>
<th>Institutional trust</th>
<th>Trust in others</th>
<th>Affective commitment</th>
<th>Normative commitment</th>
<th>Intentions</th>
<th>Registrations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distributive justice</td>
<td>.14**</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Interactional justice</td>
<td>.31***</td>
<td></td>
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<tr>
<td>Social inclusion</td>
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<td>.12*</td>
<td></td>
<td></td>
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<tr>
<td>Institutional trust</td>
<td>.23**</td>
<td>.34***</td>
<td>.43***</td>
<td></td>
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<tr>
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<td>Beliefs about the body</td>
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<tr>
<td>Knowledge</td>
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<tr>
<td>Past experience</td>
<td></td>
<td>.29***</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Intention to register</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.78***</td>
</tr>
</tbody>
</table>

\[R^2 = 0.443, 0.340\]

Note. * p < .05, ** p < .01, *** p < .001

**Table 5. CDB hypothesis testing: predictors of registration**

Initial analysis of the CDB omitted intentions to reflect the original model discussed in Paper 3. In contrast to the findings from Paper 3, the CDB (with intentions omitted) did not yield a significant result, possibly due to the low registration rate in the sample (33 registrations out of n=272) and the number of pathways to be estimated in the CDB model. However, once intentions were included, the model explained 34 percent of the variation in registration behaviour. All of the hypothesized pathways specified in the model were significant, once again with the exception of affective commitment. In particular, normative commitment was highly associated with intentions to register (0.78, p<.001).

6.2 Discussion

The improvement in the efficacy of the collective CDB model with the inclusion of intentions is consistent with a number of studies that compare the TPB with a domain-specific model—the Health Belief Model—(Bish, Sutton, & Golombok, 2000; Gerend & Shepherd, 2012; Şimşekoğlu & Lajunen, 2008). The findings are also consistent with research regarding the role of perceived responsibility in donor registration behaviour (Farsides, 2010), in which responsibility and determination were shown to be discrete factors, the latter resembling the
intention dimension of the TPB. The capacity of intentions to improve the efficacy of the model in predicting registration behaviour, thus, is unsurprising, given that it is the most proximate factor underlying behaviour (Armitage & Conner, 2001). This proximity led Gerend and Shepherd (2012) to suggest that when comparing the TPB with other models, it is appropriate to “level the playing field” (p9) by including intentions in the comparison model or excluding it from the TPB.

While both models were able to predict donor registration, they offer different accounts of behaviour. In the case of the TPB, the results suggest that intentions and subsequent registration are largely driven by perceived pressure from important others, with attitudes being a weaker predictor of intentions. This may be a consequence of a “crossover effect” from attitudes to normative beliefs and vice versa (Terry et al., 1999), with attitudes and normative beliefs influencing each other, rather being cognitively independent as proposed by the TPB. Alternatively, it may be that normative considerations are indeed the most significant component in donor registration decisions.

Within the TPB, the subjective norm is an externally prescribed norm, a function of the need for approval and acceptance by important others (Terry et al., 1999). In contrast, the normative component within the CDB—normative commitment—is a function of perceived obligation to the cause. Within the collective model, this obligation reflects a group or social norm that guides group behaviour within specific contexts (White et al., 2009). Terry et al. (1999) view group norms as a function of social identity, with “people... more likely to engage in a particular behavior if it is in accord with the norms of a behaviorally relevant group membership, particularly if the identity is a salient basis for self-definition” (p. 228). However, while social identity theory suggests that emotional attachment is a central driver of behaviour (Lawler et al., 2001), in this study, affective/emotional commitment does not translate into either intentions or behaviour. Thus, the CDB indicates that obligation over emotion drives donor registration in the sample. This suggests that some behaviours—those that primarily affect the group rather than the individual—may invoke perceptions of obligation rather than emotional engagement. In this respect, the
findings are similar to those of Godin, Conner, and Sheeran (2005), who find that intentions founded on perceived obligation are more likely to translate into behaviour than those driven by attitudes founded on the basis of perceived individual outcomes. Thus, perceived obligation (in this case, normative commitment) may drive donor registration independently of an individual’s desire to become an organ donor (Farsides, 2010).

7. Overall discussion

The aim of this paper was to compare a CDB against one of the most frequently used behavioural models in the literature. Behavioural theories serve an important function—helping researchers and policy makers understand the determinants of behaviour and the processes and drivers of behavioural change (Noar & Zimmerman, 2005). Despite this, comparisons of alternative theories are relatively rare; rather well-established/entrenched theories, such as the TPB, may be extended repeatedly, without necessarily interrogating the theoretical foundation of the theory (Sniehotta et al., 2014). An exception is Hyde and White’s (2009) comparison of the TPB and the Prototype Willingness Model (PWM) in relation to both registration and communicating registration decisions to the person’s family. The study found that a combined TPB/PWM model provided the best explanation for registering as a donor and discussing the decision.

One of the paper’s key contributions, therefore, is to challenge the assumptions that underpin the TPB by demonstrating that a collective model—founded on theories of exchange and collective action—offers an equally viable account of donor registration. If the aim of behavioural theories is to understand drivers of behaviour in order to effect positive change (Taylor et al., 2006), then the usefulness of a theory lies partly in its ability to provide insights that can be used to address barriers to positive behaviours. As such, a comparison of theoretical models should look not only, or even necessarily, at the variance explained to assess the respective value of the models (Weinstein & Rothman, 2005). Instead, the value of a model lies in how much it tells the researcher or policy maker about why an individual or group is more or less likely to behave in a particular
Consequently, evaluating the usefulness of each of the models in understanding donor registration behaviour requires us to assess what the constructs reveal about motivations for and barriers to donating. Herein lies another central theoretical contribution of this paper.

The parsimony of the TPB and its capacity to be applied across any behavioural domain is identified as one of its key strengths. However, the extent to which the TPB provides detailed insight into drivers of donor registration behaviour is questionable. For one, it is not clear that the hypotheses derived from the TPB are more than “essentially common sense statements which cannot be falsified” (Sniehotta et al., 2014, p. 2), that is, it is highly unlikely that people who feel positive about a behaviour and feel capable of doing it are less likely to intend to engage in a behaviour. In this study, positive attitudes about donation and perceptions about what others think is shown to be the primary drivers of intentions. The association between attitudes and intentions is arguably such a “common sense statement”—those who feel more positively about donation are more likely to intend to donate than those who feel negatively about it. The influence of norms in behaviour with a social imperative, such as organ donation, is also to be expected (Schwartz, 1973).

While this study used a standard TPB model, as noted, other studies include a variety of individual and social norms (Godin et al., 2008; Hyde et al., 2013; Park et al., 2009; Park & Smith, 2007), and cultural and social factors such as religion and cultural beliefs (Bresnahan et al., 2007; Bresnahan, Guan, Wang, & Mou, 2008; Robinson et al., 2012; Rocheleau, 2013; Stephenson et al., 2008) to increase the explanatory power of the model. However, doing so makes the model both less parsimonious and universal, and challenges a key tenet of the TPB—that behaviour is a function of individual calculations of the costs and consequences of the behaviour. This shift is epitomised by Terry and colleagues’ (Terry et al., 1999; White et al., 2009) theoretical re-interpretation of the TPB through social identity theory, in which group norms are seen to drive behaviour.
Starting from an assumption that deceased donation behaviour is best understood as a group behaviour, the CDB avoids the potential pitfalls of adapting an individual behavioural model, such as the TPB. Instead, the model draws on social exchange literature and theories of collective behaviour to suggest an alternative set of factors that drive donor registration—inclusion, justice, trust, and commitment, providing insights into registration behaviour not captured by the TPB constructs. Moving away from individual preferences to predict donation also locates registration behaviour within a social and institutional context. In doing so, the CDB provides a theory-driven behavioural account of known barriers to donor registration such as mistrust of and perceived inequities within organ donation and transplant systems (Denvir & Pomerantz, 2009; Minniefield et al., 2001; Siminoff & Arnold, 1999) and social exclusion (Morgan, Hooper, Mayblin, & Jones, 2006; Morgan et al., 2008).

Consequently, the CDB suggests that encouraging behavioural change in relation to donor registration requires us to move beyond improving attitudes to donation. Instead, it requires us to foster a specific normative commitment or a sense of collective obligation to register as a donor. For example, focusing on a collective responsibility to register and a shared fate around the issue may be a way to motivate those whose failure to register is founded on inertia rather than negative perceptions of deceased donation and transplantation. The collective model also highlights, however, that perceived responsibility to register stems from relationships with social institutions and other society members. Consequently, encouraging donor registration requires a consideration of the historical and ongoing experiences of different population groups with social institutions that shape perceptions of donor registration.

8. Limitations

While this paper demonstrates the usefulness of the collective model, a number of limitations to the study exist that future studies may address. The online panel used in the survey included a broad sample of the Australian population, however, online panels are inevitably biased towards people with ready access to the Internet and who are motivated to join panels (Duffy, Smith, & Terhanian,
2005). Consequently, some of the country’s more vulnerable populations were likely to be excluded from the sample. Given that minority groups, such as migrants and other ethnic minority populations, are less likely to register as donors, the potential omission of such groups has likely reduced the variance in responses. This suggests that the results may well underestimate the influence of social inclusion, justice, and trust on donor registration; even with the relatively high mean scores for these constructs, the pathways in the collective model of donor registration were significant. Nonetheless, future research may focus on assessing the strength of the collective model with minority populations in comparison with the general population.

Another consequence of the method of data collection chosen is the potential for common method bias. The potential for such bias is inevitable in online surveys in which responses cannot be validated by alternate sources, and as noted it was not possible to confirm registration status independently. While Harmon’s one-factor test was undertaken in this study, it does not guarantee a lack of common method bias. MacKenzie and Podsakoff (2012) identify seven factors that decrease the likelihood of participants being able to respond accurately to surveys, resulting in bias. These are: 1) lack of verbal ability, education, or cognitive sophistication, 2) lack of experience thinking about the topic, 3) complex or abstract questions, 4) item ambiguity, 5) double-barrelled questions, 6) questions that rely on retrospective recall, and 7) auditory-only presentation of items versus written presentation of items. In designing the survey, attempts were made to address each of these factors. In particular, every attempt was made to ensure that questions were worded simply and unambiguously and that the survey was visually simple and clear. As discussed in Paper 3, items for the collective model of donor registration were tested in a pilot study and refined where necessary (for example, the justice items) prior to the main study.

9. Conclusion

The aim of this paper was to assess the usefulness of the CDB model in relation to the TPB. The results demonstrate not only that the collective model is as good a fit as the TPB but that it also provides a level of specificity about drivers of
donor registration behaviour not found in the TPB. A central criticism of the TPB is that it provides little insight to guide the design of interventions to effect behavioural change (Schwarzer, 2015). In contrast, the insights found in the CDB relating the roles of justice perceptions, social inclusion and trust in fostering normative commitment to the cause of donation suggest a number of focus areas for policy makers and communication campaigns. These include building community inclusiveness, addressing mistrust in transplant systems, and fostering a shared fate in relation to donation and transplantation. As with many public issues, donor registration is embedded in broader social institutions that are beyond the capacity of any single policy or campaign to address. Challenging entrenched assumptions about individual drivers of donation behaviour is nonetheless a useful starting point.
DISCUSSION & CONCLUSION

1. Discussion

Meeting the need for organ transplants remains an ongoing challenge across donation systems worldwide. In some ways, organ transplantation has become a victim of its own success. The ability to improve and save lives through organ transplantation has increased dramatically over the decades as medical advances have made it a viable therapeutic option for a range of diseases (Rana et al., 2015). The increasing demand for organs, however, has not been matched by increases in deceased donation, and it is estimated that annually over 8,000 people in the USA alone die waiting for an organ transplant (OPTN, 2016).

Most deceased donation and transplant systems are underpinned by well-established organizational arrangements and institutionalized norms relating to donor registration and family authorization of the donation of a loved one’s organs. Yet the advent of deceased donation and transplantation entailed profound shifts in norms and practices around death and the body (Lock, 2002), which are now largely forgotten. The disparity between cultural and religious ideas about death and the concept of “brain death” essential to deceased donation exemplifies competing “institutional logics”, that is, “contradictory practices and beliefs inherent in the institutions of western societies” (Thornton & Ocasio, 2008, p. 101). Indeed, a number of commentators point out that aligning donation with altruism (a concept now inseparable from the idea of deceased donation) was an effective means of papering over such contradictions (Healy, 2007; Joralemon, 1995).

Donation and transplant systems now appear to be once again at a crossroad, with the current voluntary “altruistic” systems placed in opposition to the market, evident in calls for commercialized “donation” through the establishment of a regulated system for kidney sales (Matas, 2006; Friedman & Friedman, 2006). However, the usefulness of the altruism versus self-interest dichotomy to understand donation behaviour is questionable (Schweda & Schicktanz, 2014). In focusing on individual motivations, both altruistic and
market-based conceptualisations neglect to consider the possibility that donation and transplant systems are better understood through a collective lens, which is precisely the subject of this thesis.

This thesis aimed to answer three questions:

1. What is the justification for a collective conceptualisation of deceased donation when framing donor registration in the public domain?
2. What insight does such a conceptualisation provide into drivers of—and barriers to—registering?
3. How can these insights be used to help increase donor registration?

Paper 1 addressed the first question utilizing Meeker’s “decision rules” approach to examine the impact of framing deceased donation and donor registration through altruism, reciprocity, and group gain. The paper demonstrates that while altruism typically dominates discussions of deceased donation, within the literature, reciprocity is also increasingly identified as a useful way of conceptualising deceased donation. Beyond altruism and reciprocity, the paper advocates taking a group gain approach to donor registration, founded on the conceptualisation of deceased donation as a collective act. While accounts of collective behaviour tend to either depict behaviour as product of individual, rational decisions or assume that social structures and socially enforced norms largely dictate behaviour (Granovetter, 1985), this paper attempts to bridge these two theoretical worlds. Drawing on social identity theory, the paper argues that donor registration is more likely where there is a perceived joint responsibility in relation to donation and transplantation, and where people understand that their interests are intertwined with those of other society members. Consequently, this conceptualization shifts the focus from individual values to broader social norms and practices around collective behaviour. Doing so indicates the need to consider donation behaviour within the context of other social institutions that may reinforce or weaken norms around collective behaviour within society. Rothstein (2001), for example, demonstrates the influence of government institutions on collective behaviour, with institutionalized corruption undermining willingness to contribute to public goods. Within the organ donation literature, mistrust of healthcare institutions,
perceptions of racism, and exclusion similarly serve to undermine donor registration in ethnic minority populations, with norms around donating destabilized by experiences of broader institutions.

Paper 2 aimed to address the second question, regarding the insights that a collective framing of donation provides into drivers of and barriers to registering. Donation and transplant systems are a product of both organizational arrangements (the policies and processes governing the system) and institutions (the embedded social rules and practices that guide behaviour). The Qatar setting offered the opportunity to examine the process of establishing a deceased donation and transplant system in an ethnically diverse society. Thus, the setting enabled an exploration of known barriers to donor registration in ethnic minority populations, such as mistrust and social exclusion. Qatar’s approach to transplantation—allowing equitable access irrespective of citizenship status—also provided the opportunity to assess the potential for inclusiveness within deceased donation and transplant systems to encourage donor registration.

However, the findings from the study suggest that social norms and practices around deceased donation (the institutions) have not developed in tandem with Qatar’s implementation of a voluntary unpaid deceased donation system (the organisational arrangements). The research identifies several competing institutional logics at work in relation to organ donation in Qatar. In the first instance, participants’ conceptualisation of donation in terms of (illegal) living donation highlights the influence of the norms and practices from their home countries, in which voluntary deceased donation systems are weak or non-existent. Equally, the tendency to draw on home reflects competing institutional logics between Qatar’s inclusive donation and transplant system and the relationship of Qatari’s migrant workers with Qatari society overall. The research finds that workers largely perceive their lives in Qatar as transactional arrangements designed to further individual or family goals at home—an approach reflected in (and/or a consequence of) Qatar’s clear delineation between the privileges afforded to citizens and non-citizens. Thus, participants’ overall experiences are characterised by a lack of engagement with public
institutions and narrow social relationships founded on shared nationality that appear at odds with a socially inclusive donation and transplant system. Overall, the results from the study reinforce the need to consider individual donation behaviour within the context of broader social institutions that may facilitate or discourage participation.

Papers 3 and 4 aimed to further address the question of how a collective conceptualization of deceased donation influences the motivations and barriers attributed to donor registration and thus the implications for attempts to increase registration rates. These papers used the model of collective donor behaviour (CDB), developed for the thesis. The CDB model focuses on trust in other society members and trust in the institutions that underpin organ donation and transplantation, founded on social inclusion and perceptions of the healthcare system respectively. The model aims to address the striking lack of consideration of these factors in contemporary models of donor behaviour, despite qualitative and attitudinal research indicating their significance in donation decisions. Paper 3 demonstrates the viability of the CDB in explaining variance in donor registration, with both institutional trust and trust in others shown to be significant. The strength of normative commitment in the results was however unexpected, as a number of studies of prosocial behaviours, such as blood donation (Bednall et al., 2013) and organizational citizenship behaviour (Meyer et al., 2002), find affective commitment to be the more important driver of behaviour. The weak or non-significance of affective commitment in the research therefore indicates that donor registration may involve different motivations to those ongoing or long-term prosocial behaviours. This indicates that it may not be necessary to build an emotional attachment to the cause to encourage registration; rather it may be more appropriate to foster a sense of collective obligation. As demonstrated in this study, and others, trust is key to establishing normative commitment. In addition, organizational research suggests that normative commitment is strongest when individual and institutional values align (McCormick & Donohue, 2016). Therefore, building commitment to the cause of donation is likely to depend on instilling community trust in the institutions that underpin donation and transplantation systems to
ensure that these systems are seen to reflect community values, such as equity
and benevolence.

Paper 4 compares the CDB model with the most cited individual behavioural
model—the Theory of Planned Behavior (TPB). The findings show the CDB
model to be nearly as effective at predicting registration intentions and
behaviour as the TPB, though the two models suggest very different pathways to
registration. The results also demonstrate why the TPB remains a predominant
model in predicting behaviour, as it appears quite difficult to disprove the
relationship between attitudes, intentions, and behaviour. Nonetheless, when
considering the aim of modelling of health and prosocial behaviours—to offer
insight into drivers of behaviour with a view to effecting positive change—the
relative weakness of the TPB in providing in-depth accounts of behaviour
become apparent. Indeed, arguably a focus on improving “attitudes” has done
little to forward the cause of donor registration. While it could be argued that the
addition of numerous variables (religion, anticipated regret, moral norms) to the
TPB provide more specific insights into possible motivations for/barriers to
registering, such models still frame registration as essentially a product of
individual attitudes and values. For this reason, simply adding the collective
constructs from the CDB to the TPB, such as institutional trust, trust in others,
social inclusion, and fairness perceptions, was deemed inappropriate (and as
analysis shows, results in a very poor quality model). Instead, the CDB starts
from the premise that donor registration is a collective act, demonstrating the
significance of institutional and social relationships to fostering a sense of
collective obligation (normative commitment) to register as a donor. Thus, the
model offers an account of behaviour that hopefully suggests numerous potential
points of intervention (increasing trust, fostering inclusion, and so on).

One of the potential criticisms of the empirical results in Papers 3 and 4 is that
they frame collective action through the lens of methodological individualism
(Lars, 2002), namely, that they depict collective behaviour as a simple
amalgamation of individual level behaviours (Hodgson, 2007). However, this
thesis makes no claim that the collective nature of deceased donation can be
understood purely through the actions of individuals. Rather, the research takes
the pragmatic approach put forth by Coleman (1990, p5) in relation to the use of individual level data in the study of system level problems, that “the explanation [for a systems level behaviour] is satisfactory if it is useful for the particular kinds of intervention for which it is intended.” Thus, the research in this thesis considers the relationships that people have with social institutions to explore which factors encourage individuals to feel a collective responsibility to register, with a view to designing appropriate policy interventions. It does so with the recognition that complex collective problems, such as deceased organ donation, are unlikely to be solved easily.

A policy implication of the research outlined in this thesis is that organ donor behaviour may be affected by factors beyond the realm of typical organ donation policies and promotion and communication campaigns. Macro level policy settings that facilitate or hinder social inclusion and institutional trust, such as those relating to healthcare, employment, housing, education, immigration and social welfare, are likely to influence the extent to which people are willing to participate in deceased donation programs. In this respect, the research reflects well-documented links between positive health related behaviour/outcomes and socially equitable and inclusive societies (Wilkinson & Pickett, 2010). However, policy makers interested in increasing donor registration rates are unlikely to be able to effect significant macro level change; rather it may be necessary to build collective responsibility for deceased donation by focusing on building inclusion and trust within specific communities.

One of the aims of the research undertaken in Qatar was precisely to examine the potential for a micro level policy—that of equitable access to organ transplantation for all residents irrespective of citizenship status—to encourage donor registration in the face of macro level settings that may be a barrier to participation. Because Qatar’s broad approach to temporary migrant workers is one of overt differential exclusion (Castles, 1995), while its donation and transplantation policies and promotion campaigns aim to foster inclusiveness (Martin & Fadhil, 2014), the setting offered a unique opportunity to explore the interplay between macro and micro level settings in relation to donation
behaviour. The unanticipated results of the study—that ideas about donation and transplantation almost entirely related to (official and unofficial) systems at home and an overwhelming lack of knowledge of Qatar’s system among participants—however, made it difficult to draw any conclusions about the impact of Qatar’s approach to donation.

Nonetheless, several examples from the blood donation literature provide some insight into how micro level policies that promote either inclusion or exclusion may influence participation in donation programs. The first example relates to the development of a blood donation communication campaign focused on African migrant communities in Australia (Francis & Talenta, 2015). The campaign was developed in response to Australian research that found perceptions of racism and negative experiences with blood donation organizations resulted in a reluctance to donate in African migrants (Polonsky et al., 2011). Researchers developed and tested several potential ways of framing blood donation with African community members (Francis & Talenta, 2015). One approach, founded on research suggesting blood to be a highly symbolic product in Africa and closely linked to ideas of kinship, stressed the need for blood donors who are compatible with other African migrants. A second approach focused on the universal nature of blood donation and transfusion systems—that anyone, regardless of race or culture could be a donor and that this donated blood could go on to help or save anyone, regardless of race or culture. While the former approach focused on a narrow in-group defined by African heritage, the latter emphasised a wider in-group defined by Australian residency/citizenship. Researchers found participants overwhelmingly preferred the second approach—“blood from everyone, for everyone”—with blood donation seen as a way to affirm inclusion in Australian society (Francis & Talenta, 2015).

The second example is of a blood donation policy that reinforces perceptions of social exclusion within a migrant community. In 1983, the Canadian Red Cross implemented a policy (known as H4) of not accepting blood from Haitian immigrants, on the basis that Haitians were at increased risk of being AIDS carriers (Farmer, 2006). The H4 policy (which was not founded on credible scientific evidence) was withdrawn in 1985 (Farmer, 2006), however over
twenty years later, the effects of this exclusionary policy remain (Charbonneau & Y-Lang-Tran, 2015). Research has found within the Haitian community in Canada, the policy has undermined trust in blood donation and led to perceptions that Haitians are not welcome at blood donation centres, as well lingering anger at the stigmatization of the community (Charbonneau & Y-Lang-Tran, 2015). A consequence of the policy is a continued shortage of blood donation from the Haitian community.

Together, these two policy examples demonstrate how micro level policies may influence perceptions trust and inclusion in donation systems specifically, while simultaneously reinforcing perceptions of social inclusion and conversely social exclusion at a macro level. That said it is beyond the scope of this thesis to actually test potential policy and communication interventions informed by the findings from the research undertaken for the thesis; rather it identifies areas for future focus. For example, additional research would ideally further test the CDB model in population groups for whom issues of mistrust and exclusion are likely to be most salient. Future research may also examine the effect of different messaging with a view to assessing the effectiveness of appeals to collectivity and normative commitment to drive donation behaviour. Research in the UK found reciprocity messages to be an effective driver of registration (UK Government, 2013). A similar study could assess the effectiveness of messages that 1) focus on the characteristics of donation and transplant systems that make participation vital (for example, that most registrations do not ultimately result in donation) 2) stress the inclusive nature of donation and transplant systems, and 3) frame registration as a collective obligation. Another possible avenue for future research would be to assess the applicability of the CDB model proposed in this thesis in terms of behaviour relating to other public goods.

2. Conclusion

The thesis demonstrates the need to move beyond the focus on increasing knowledge and improving attitudes as a means of raising organ donor registration. Individual attitudes towards deceased donation cannot be
considered in isolation from the broader institutions that influence behavior. Scott (2008, p. 50) argues “institutions provide [both] guidelines and resources for taking action as well as prohibitions and constraints on actions.” To see deceased donation as a collective behavior requires acknowledging the powerful constraining force of social exclusion on behavior and the significance of social and institutional relationships in encouraging positive action. Consequently, increasing donor registration rates requires considering the place held in society by individuals and groups who are being called on to participate. Ultimately calls to collective action in relation to registration will not succeed in the face of negative perceptions of the institutions underpinning donation and transplant systems and everyday experiences that encourage divisions in societies. Given the shifting nature of societies world wide as people leave their homelands, whether by choice or necessity, fostering collective behaviour, such as donor registration, has never been more important, nor more challenging.
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PAPER 2: APPENDIX 1

Topic and question guide

Introduction/Icebreaker

- Please tell us your first name, where you come from and how long you’ve lived in Qatar).

Perceptions regarding work, the immigration process, friendships/socialization and the health system. Prompts

- What’s it like living in Qatar, how did you find work, could you tell us about your living arrangements/housing?
- Please briefly describe your experience of the immigration process.
- Can you tell us a little about your social life in Qatar? (Prompts if needed - For example, how did you make friends in Qatar? What nationalities are your friends?)
- How would you describe your interactions with Qatari or other non citizen residents?
- Please tell us about any experience you’ve had of Qatar’s medical system.

General knowledge and awareness of organ donation and the organ donation and transplant system in Qatar specifically

- Who has any previous experience of organ donation or transplantation here or elsewhere?
- What can you tell me about organ donation and transplantation?
- What is a deceased donor registry?
- Who do you think decides or should decide if a person can become an organ donor after death?
- What is an organ transplant waiting list? How do you get on this list if you need an organ?

Attitudes and intentions towards donation and transplantation

- Who has joined the donor registry here in Qatar? Elsewhere?
• Why have you joined/not joined here in Qatar?

Cultural and religious attitudes towards donation (If not prompted by previous questions regarding knowledge of organ donation and reasons for joining or not joining a donor registry)

• What does your religion say about organ donation?
• What do you know about organ donation in (country of origin – eg Nepal, Sri Lanka etc)?
• How do people generally view organ donation and transplantation in your country?
• How is it discussed publically – in the media or by public figures?

Conclusion

• The Organ Donation Center is going to be developing new strategies and materials to educate people about donation and encourage them to join the donor registry. What advice would you have for them about how to do this?
• What would be an effective way to encourage people from your country to join a donor registry?
• Is there anything else that anyone feels we should discuss that we haven’t talked about?
PAPER 3: APPENDIX 1

Market and social research company approach to sampling

Data collection for Papers 3 and 4 was undertaken by market and social research company QOR. QOR is a member of the Association of Market and Social Research Organizations and has been independently audited and accredited with ISO 20252 ISO 26362 and QSOAP ‘Gold.’

QOR sourced research participants for the studies from a consumer panel, comprising 120,000 members. The panel, which is used for research purposes only, is built from the First Direct Solutions Australian Lifestyle Survey, administered by Australia Post. QOR largely recruits panel members either via phone or post (only 30 percent of panel members are recruited online). The make up of the panel is designed to reflect Australian demographics in terms of age, gender and location (based on Census data).

Prior to joining the panel, potential members are required to complete an extensive profiling questionnaire, agree to the panel’s terms and conditions and provide consent to participate. Panel members are paid a small fee for each survey (AU$1 per five minutes) and are also entered into an annual $5,000 cash prize draw. The attrition rate for the panel is 4.6% per annum. The invitation only approach taken by the firm eliminates a large proportion of fraudulent responses and others are detected by a series of checks based on key data points (DOB, postcode, name, phone number, gender). Panel member information is updated or verified every six months.

Survey invitations to panel members are generic and do not include information about the subject of the survey, the type of respondent being sought or the client. There is a limit on the number of surveys panel members can participate in. This is a maximum of two surveys in any given month and a total of six completed surveys per year. Panel members are also excluded from completing more than one survey on the same topic in a three-month period (follow up surveys excepted).
The company reports approximately 71 percent of emailed survey invitations are opened, 37 percent of these are started and 32 percent are completed (a drop out rate of five percent). Validation checks undertaken by the company include time taken to complete the survey (any response under 50 percent of average is removed), comparison of profile variables with survey data, validation questions (two similar questions at the start and end of surveys to check for consistency) and verbatim checks.

QOR complies with ISO 20252 regarding the safekeeping and backup of client provided data as well as member data located in secure and multi-layer protected servers backed up on a daily basis.
# PAPER 3: APPENDIX 2

## Respondent profiles – pilot study

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# PAPER 3: APPENDIX 3

Respondent profiles – main study

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## PAPER 3: APPENDIX 4
Measurement instrument (with Means and Standard Deviations) – pilot study

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<thead>
<tr>
<th>Construct</th>
<th>Items</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
</table>
| Distributive justice | In Australia everyone has fair access to healthcare services.  
In Australia healthcare resources are shared fairly.  
The Australian health system treats everyone equally.  
In Australia the health system is equally fair to everyone.                                                                 | 4.6  | 1.54|
| Interactional justice | Medical staff give me an honest explanation for the decisions they make.  
Medical staff consider my views when decisions are being made on treatment.  
Medical staff do what is best for me.  
I am treated with dignity in my encounters with medical staff.  
Medical staff provide me with timely information about my care.  
Medical staff deal with me in a truthful manner.  
My interactions with medical staff have been positive.  
Medical staff respect my rights as a person.                                                                 | 5.32 | 1.19|
| Social inclusion | When I am with other people in Australia, I feel included.  
I have close bonds with family and friends in Australia.  
I feel accepted by others in Australia.  
I have a sense of belonging in Australia.  
I have a place at the table with others.  
I feel connected with others in Australia.                                                                 | 5.49 | 1.24|
| Social exclusion | I feel like an outsider in Australia.  
I feel as if people in Australia do not care about me.  
I do not feel like I belong in Australia.  
I feel isolated from the rest of the world.  
When I am with other people in Australia, I feel like a stranger.  
Friends and family in Australia do not involve me in their plans.                                                                 | 5.51 | 1.46|
| Institutional trust | If doctors know I am an organ donor, they won’t try to save my life.  
When patients are eligible to donate organs, doctors can be trusted to pronounce death correctly.  
I trust that hospitals use donated organs as they are intended to be used.  
I am confident that staff working in the Australian organ donation program are well trained.  
I could rely on hospital staff to care for me if I needed an organ transplant.  
I could rely on hospital staff to care for my family if they needed a transplant.                                                                 | 5.56 | 1.17|
| Trust in others | I trust that other people in Australia will register as donors.  
People in Australia are trustworthy when it comes to registering as donors.  
I can rely on people in Australia to register as donors.  
I can depend on other people in Australia to register as donors.                                                                 | 4.47 | 1.03|
| Affective commitment | I really feel the organ donation shortage problem is my own.  
I am more passionate about organ donation than other causes.  
Registering as a donor has a great deal of personal meaning for me.                                                                 | 3.78 | 1.23|
| Normative commitment | I feel it is morally right for me to register as a donor.  
I feel a personal responsibility to register as a donor.  
I would feel guilty if I did not register as a donor.  
I feel that if I am willing to accept an organ transplant I have an obligation to register as a donor.  
I would feel guilty if I changed my mind after registering as a donor.                                                                 | 4.71 | 1.31|
# PAPER 3: APPENDIX 5

Measurement instrument (with Means and Standard Deviations)—main study

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<tr>
<th>Construct</th>
<th>Items</th>
<th>Mean</th>
<th>SD</th>
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<tr>
<td>Distributive justice</td>
<td>I have access to hospital care I need.</td>
<td>5.26</td>
<td>1.15</td>
</tr>
<tr>
<td></td>
<td>I feel hospital resources are shared fairly.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I have as much access to hospitals as everyone else</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If I need to go to hospital, I can.</td>
<td></td>
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</tr>
<tr>
<td>Interactional justice</td>
<td>Hospital staff give me an honest explanation for the decisions they make.</td>
<td>5.38</td>
<td>1.22</td>
</tr>
<tr>
<td></td>
<td>I am treated with dignity in my encounters with hospital staff.</td>
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</tr>
<tr>
<td></td>
<td>Hospital staff provide me with timely information about my care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hospital staff do what’s best for me.</td>
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<tr>
<td></td>
<td>Hospital staff deal with me in a truthful manner.</td>
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<tr>
<td></td>
<td>Hospital staff respect my rights as a person.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social inclusion</td>
<td>When I am with other people in Australia, I feel included.</td>
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<td>1.23</td>
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<tr>
<td></td>
<td>I have close bonds with family and friends in Australia.</td>
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</tr>
<tr>
<td></td>
<td>I feel accepted by others in Australia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I have a sense of belonging in Australia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I have a place at the table with others.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I feel connected with others in Australia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social exclusion</td>
<td>I feel like an outsider in Australia.</td>
<td>5.41</td>
<td>1.53</td>
</tr>
<tr>
<td></td>
<td>I feel as if people in Australia do not care about me.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I do not feel like I belong in Australia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I feel isolated from the rest of the world.</td>
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<td></td>
<td>When I am with other people in Australia, I feel like a stranger.</td>
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<td></td>
<td>Friends and family in Australia do not involve me in their plans.</td>
<td></td>
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</tr>
<tr>
<td>Institutional trust</td>
<td>Hospitals use donated organs as they are intended to be used.</td>
<td>5.40</td>
<td>1.25</td>
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<tr>
<td></td>
<td>When patients are eligible to donate organs, doctors can be relied upon to pronounce death correctly.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The organ donation and transplant system is honest.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The organ donation and transplant system has high integrity.</td>
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<tr>
<td></td>
<td>Organ donation and transplant staff are competent.</td>
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</tr>
<tr>
<td>Trust in others</td>
<td>I trust that other people in Australia will register as donors.</td>
<td>4.53</td>
<td>1.22</td>
</tr>
<tr>
<td></td>
<td>People in Australia can be trusted to register as donors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I can rely on people in Australia to register as donors.</td>
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</tr>
<tr>
<td></td>
<td>I can depend on other people in Australia to register as donors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affective commitment</td>
<td>I am passionate about organ donation.</td>
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<td>1.52</td>
</tr>
<tr>
<td></td>
<td>Registering as a donor has a great deal of personal meaning for me.</td>
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<td></td>
</tr>
<tr>
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<td>I feel emotionally attached to the cause of organ donation.</td>
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<tr>
<td>Normative commitment</td>
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<td>I feel a personal responsibility to register as a donor.</td>
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<td>I feel obliged to register as a donor.</td>
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<td></td>
<td>I feel that if I am willing to accept an organ transplant I have an obligation to register as a donor.</td>
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<tr>
<td></td>
<td>I would feel guilty if I did not register as a donor.</td>
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## PAPER 4: APPENDIX 1

### Respondent profiles

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<td></td>
<td>25-34</td>
<td>16.3%</td>
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<td>35-44</td>
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<tr>
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<td>75+</td>
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<td>Level of education</td>
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## PAPER 4: APPENDIX 2

Model of Collective Donor Behaviour Measurement instrument (with Means and Standard Deviations)

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<tr>
<th>Construct</th>
<th>Items</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
</table>
| Distributive justice | I have access to hospital care I need.  
I feel hospital resources are shared fairly.  
I have as much access to hospitals as everyone else  
If I need to go to hospital, I can.                                                                                                           | 5.26 | 1.148|
| Interactional justice | Hospital staff give me an honest explanation for the decisions they make.  
I am treated with dignity in my encounters with hospital staff.  
Hospital staff provide me with timely information about my care.  
Hospital staff do what’s best for me.  
Hospital staff deal with me in a truthful manner.  
Hospital staff respect my rights as a person.                                                                                               | 5.37 | 1.21 |
| Social inclusion  | When I am with other people in Australia, I feel included.  
I have close bonds with family and friends in Australia.  
I feel accepted by others in Australia.  
I have a sense of belonging in Australia.  
I have a place at the table with others.  
I feel connected with others in Australia.                                                                                                   | 5.52 | 1.23 |
| Social exclusion | I feel like an outsider in Australia.  
I feel as if people in Australia do not care about me.  
I do not feel like I belong in Australia.  
I feel isolated from the rest of the world.  
When I am with other people in Australia, I feel like a stranger.  
Friends and family in Australia do not involve me in their plans.                                                                             | 5.41 | 1.53 |
| Institutional trust | Hospitals use donated organs as they are intended to be used.  
When patients are eligible to donate organs, doctors can be relied upon to pronounce death correctly.  
The organ donation and transplant system is honest.  
The organ donation and transplant system has high integrity.  
Organ donation and transplant staff are competent.                                                                                       | 5.40 | 1.24 |
| Trust in others | I trust that other people in Australia will register as donors.  
People in Australia can be trusted to register as donors.  
I can rely on people in Australia to register as donors.  
I can depend on other people in Australia to register as donors.                                                                             | 4.52 | 1.22 |
| Affective commitment | I am passionate about organ donation.  
Registering as a donor has a great deal of personal meaning for me.  
I feel emotionally attached to the cause of organ donation.                                                                                     | 4.40 | 1.52 |
| Normative commitment | I feel it is morally right for me to register as a donor.  
I feel a personal responsibility to register as a donor.  
I feel obliged to register as a donor.  
I feel that if I am willing to accept an organ transplant I have an obligation to register as a donor.  
I would feel guilty if I did not register as a donor.                                                                                         | 4.72 | 1.51 |
### Theory of Planned Behaviour Measurement instrument (with Means and Standard Deviations)

<table>
<thead>
<tr>
<th>Construct</th>
<th>Items</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude</td>
<td>To me, being or becoming a registered organ donor is:</td>
<td>5.72</td>
<td>1.43</td>
</tr>
<tr>
<td></td>
<td>Bad/good</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Worthless/valuable</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unimportant/important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjective norm</td>
<td>Most people who are important to me think that I should be a</td>
<td>4.32</td>
<td>1.31</td>
</tr>
<tr>
<td></td>
<td>registered organ donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The people in my life whose opinions I value would approve if I</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>become a registered organ donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>It is expected that I will become a registered organ donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most people who are important to me have registered as deceased</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>donors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most people whose opinion I value have registered as deceased</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>donors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most people who are important to me are willing to be</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>deceased donors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived behaviour</td>
<td>Whether or not I am or become a registered organ donor is</td>
<td>5.64</td>
<td>1.09</td>
</tr>
<tr>
<td>control</td>
<td>entirely up to me.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Whether or not I am or become a registered organ donor is within</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>my personal control.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I feel that I have complete control over whether or not I am</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>or become a registered organ donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>It is easy to register as a deceased donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I am or was confident about registering as a donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I know or knew how to register as a donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intention</td>
<td>I intend to become a registered organ donor.</td>
<td>4.29</td>
<td>1.79</td>
</tr>
<tr>
<td></td>
<td>I expect to become a registered organ donor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I am likely to become a registered organ donor.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Author/s: Tinning, Emma Elizabeth

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Date: 2016

Persistent Link: http://hdl.handle.net/11343/121867

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