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Social Capital and Deceased Organ Donation

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1. Introduction
At present, the UK has one of the lowest numbers of deceased donors when compared to other European countries at 12.8 per million people (pmp) to the EU average of 17.8 pmp (Council of Europe, 2007). To tackle this, the NHS Blood and Transplant’s (NHSBT) strategic plan 2011-2014 aims ‘to increase organ donation by 60% in 2013-14 and sustain and improve thereafter’, by seeking ‘opportunities to achieve self-sufficiency in donation and transplantation across the UK, taking into account the changing donor pool’ (p.11).

Deceased organ donation policy to address this has been argued across a wide range of fields, such as medicine, philosophy and social sciences to try to seek a way to increase Organ Donor Register numbers. The current system is an opt-in system, whereby an individual expresses their wishes to become a donor and what organs to donate through the Organ Donor Register. The aim to increase organ donation so significantly by the NHSBT, may be an indicator that the current system is not working. To try to remedy this, ‘nudges’ have been implemented, where individuals have to compulsory declare their wishes on their driving license as suggested by behavioural economists (Cabinet Office, 2010). When an individual applies for their driving license, they have three options; ‘yes, I would like to register, I do not wish to answer this question now and I am already registered on the NHS Organ Donor Register’ (Directgov online, 2011). Other more overarching policies have been considered in the literature such as paid donation (Radcliffe et al., 1998; Erin and Harris, 2003) and presumed consent (Lawson, 2008) to try to increase numbers as they have been viewed to gain a higher number of donors pmp in other countries.

This chapter will provide a way of viewing current and potential policies through applying a social capital viewpoint. The first part of this chapter will provide a brief overview of social capital and its most prolific writers. Gift exchange theory and aspects of social capital will be analysed in the second part in relation to deceased organ donation, for example, trust, reciprocity and social networks. This section will also consider prosocial behaviour, civic engagement and active citizenship from the social capital perspective. The third and final part will focus on the limitations, challenges and opportunities that face the application of social capital to deceased organ donation and organ donation policy.
2. Development of social capital theory

One of the main challenges to the use of social capital is the plethora of definitions, interpretations and forms of measurements (Claridge, 2011). Social capital has, however, become popular in recent years and has become significant in politics and governance, in particular the ‘Big Society’, in Mr Cameron’s attempt to promote ‘socially integrated behaviour’ (Guardian online, 2010). Attention will now turn to brief outlines of the approaches of the main theorists; Bourdieu, Coleman and Putnam.

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Source: Claridge (2011) web page (with permission from author)

Table 1. Social Capital theorists and different levels of analysis

2.1 Bourdieu

Social capital is viewed as ‘the sum of the resources, actual or virtual, that accrue to an individual or group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition’ (Bourdieu and Wacquant, 1992, p.119). The underpinnings of social capital were viewed as social networks and relationships according to Bourdieu, built on class and social hierarchy. His ideas were influenced by the work of Marx as he believed that social capital highlights conflict and power (Field, 2003). Social capital was something that individuals had to work at and the value of individual ties depended on the amount of connections they had and the capital gained from each connection (Bourdieu, 1980). Field (2003) argues that Bourdieu’s views of social capital neglected any exploration into the ‘dark side’ of the concept and is orientated towards being individualistic.

2.2 Coleman

Coleman’s work differed from Bourdieu’s, as Bourdieu’s focused on the outcome of the individual rather than the group or societies (Claridge, 2011). Coleman (1988; 1990) defined social capital as ‘the set of resources that inhere in family relations and in community social organisations and that are useful for the cognitive or social development of a child or young person. These resources differ for different persons and can contribute an important
advantage for children and adolescents in the development of their human capital’ (Coleman, 1994, p.300).

Coleman was a functionalist sociologist believing that every section of society has a function. Functionalists view society on a macro scale, making their theories generalised about wider society, and norms and moral values are based on consensus that are maintained through socialisation. Social capital for Coleman was a function, it was seen to be in the shape of ‘obligation and expectation, trust, information, norms and penalties that discourage their transgression, relational authority and social organisation and social network’ (Poder, 2011, no page number). Attributes of social structures can encourage or inhibit social capital, such as altruism. These are utilised by individuals within society and for Coleman, social capital was an ‘unintended result’, it was something that individuals could have if they invested in social structures. Social capital may be viewed as a resource because it is created by the norm of reciprocity, reciprocity through networks, rather than on an individuals, where relationships are influenced by trust and shared norms (Field, 2003).

Coleman argued that sociological and economic concepts can be married together to create links between micro and macro levels within society. He was influenced by the work of Becker, an economist who applied economic principles to education, family and health through the perspective of rational choice theory. Rational choice theory purports that individuals act in their own interest and interactions are viewed as exchanges. Coleman argues that individuals and society are interdependent and individuals are motivated by egoism, relationships are created and sustained to become social structures and resources for individuals. Rational choice theorists believed that individuals were agents who wanted to satisfy their own self-interest. However, Coleman suggested that it is social relations that help ‘establish obligations and expectations between actors, building the trustworthiness of the social environment, opening channels for information, and setting norms that endorse particular forms of behaviour while imposing sanctions on would-be free-riders’ (Coleman, 1988, p.102).

Social capital for Coleman was a way of explaining how people are able to cooperate with each other against the tide of the assumptions made by rational choice theory. Coleman viewed social capital as a way of contributing to human capital, which links with education and health. He believed that social capital contributes towards collective action, Coleman argued that social capital was a public good that is created by and benefits from all of those who are part of the structure (Field, 2003), therefore co-operation is required as it is in the individual’s self-interest.

2.3 Putnam

According to Putnam, a political scientist, social capital is characterised as ‘features of social organisation, such as trust, norms, and networks, that can improve the efficiency of society by facilitating coordinated actions and cooperation for mutual benefit’ (1993, p.169). Putnam’s notion of social capital are ‘moral obligations and norms, social values (especially trust) and social networks (especially voluntary associations)’ (Siisäinen, 2000, p.1). Social capital increases the likelihood of collective action by ‘increasing the potential costs to defectors; fostering robust norms of reciprocity; facilitating flows of information, including information on actors’ reputations; embodying
the successes of past attempts of collaboration; and acting as a template for future cooperation’ (Putnam, 1993, p.173).

Putnam’s notion of social capital was influenced more by Coleman than Bourdieu’s ideas of social networks. Putnam viewed civic culture as a way of determining the success of democratic performance, being made up of a society that has high levels of trust, solidarity and a public who were interested in public affairs. Civic culture is founded on generalised reciprocity, this is where a person may help someone and expect the favour to be returned in the future by someone else when it is needed. This brings together the individual and the collective as the consequences for both are positive. Generalised reciprocity is a notion that has been previously explored by social exchange theorists such as Sahlins (1978).

Putnam et al. (1983, 1993) suggested that generalised reciprocity is unequal within society due to differing socio-economic statuses (Almond and Verba, 1963). The difference between civic and uncivil society is heavily influenced by Coleman’s (1988) view of social capital, in particular networks, trust and norms of reciprocity. Putnam suggests that the demise of social capital in the United States of America has contributed towards an increase in crime and violence and an ineffective health care system as ‘For a variety of reasons, life is easier in a community blessed with a substantial stock of social capital’ (1995, p.67). In societies where there is generalised reciprocity, collective action is taken based on networks and civic culture and sustained more through reciprocal social relationships than voluntary associations. The decrease in social capital in the USA may be traced back to de Tocqueville according to Field (2003), who also felt that a high level of civic engagement improved democratic societies. The decline of social capital may be due to four reasons; individual’s being time poor due to long working hours for both parents in families, increased travel times, television and age as younger generations are less likely to belong to clubs, vote and read newspapers (Putnam, 2000).

Putnam is well-known for his ideas of ‘bridging’ and ‘bonding’; bonding social capital is good for ‘undergirding specific reciprocity and mobilizing solidarity’ (Putnam, 2000, p.22-23), between people with similar backgrounds such as a similar age or religion, or are family and friends (Woolcock, 2001). It serves as ‘a kind of sociological superglue’ in maintaining strong in-group loyalty and reinforcing specific identities, however, it reinforces homogeneity (Field, 2003). Bridging is ‘better for linkage to external assets and information diffusion’, and provides a ‘sociological WD-40’ that can ‘generate broader identities and reciprocity’ (Putnam 2000: 22-3). Connections are across a number of networks, such as work friends or acquaintances (Woolcock, 2001) bringing people together from diverse social divisions where, ties are weak according to Granovetter (1973) and structural gaps exist (Burt, 1995).

Bonding creates a sense of belonging but bridging creates positive societies. Putnam (1995) views bonding and bridging as being ‘reinforced reciprocally’ (Poder, 2011, page unknown). Both are appropriate for meeting different needs of individuals, bonding is beneficial for maintaining and reinforcing in-group relations and identities, whereas bridging is beneficial for linking external assets and disseminating information that generates reciprocity (Putnam, 2000). In addition, Woolcock (2001) has added linking social capital where connections are made with individuals far outside of one’s community, reaching a wide range of resources.
Siisiäinen (2000) explains that trust in society is ‘generalised trust’ and links with generalised reciprocity. Trust links with the notion that individual agents help the common good because they trust that their action is ‘rewarded’ through the development of collective social relations (Newton, 1999). Generalised trust is the basis for ‘brace reciprocity’ and networks, ‘trust creates reciprocity and voluntary associations, reciprocity and associations strengthen and produce trust’ (Siisiäinen, 2000, p.3-4). In turn, this creates civic culture, breaking this cycle through actions such as disorder or not trusting society, creates non-civic culture. Putnam did have difficulty explaining where social trust began, it is complex and within post-industrial societies can come from two sources; reciprocity and civic engagement Putnam et al. (1993). He has been criticised for his lack of clarity of where social capital begins and how it can be maintained (Misztal, 2000) and assumes there are links between trust and social networks (Sztompka, 1999).

Field (2003) argues that Putnam’s theory resonates with Durkheim’s ideas of solidarity, his theory differs from Coleman and he is clear in not basing his ideas on rational choice theory. Putnam disagreed with Tönnies notion of Gemeinschaft (organic community) and Gesellschaft (social organisation). He believed that family was less important than the coming together of different and distinct groups (Putnam et al., 1993) and collective action could be achieved through these ‘horizontal’ ties. Putnam and Coleman highlight the significance of social relationships where high levels of social capital may make up for lack of economic resources (Ryan et al. 2010).

3. The bigger picture

Up to this point, the main theorists’ views have been briefly explained, now attention will turn to gift exchange theory and the finer details of social capital in relation to deceased organ donation, such as trust, reciprocity, social networks and civic behaviour. It may be noted that a definition of social capital that applies to deceased organ donation has not been specified as a result of the brief descriptions of the three theorists’ approaches. Each of the approaches will be drawn upon as they all contribute towards the analysis of deceased organ donation, however Putnam’s theory may be the most relevant, as it draws upon community level approaches.

3.1 Gift exchange theory as a starting point

Social capital may be considered a modern manifestation of gift exchange theory, devised by Mauss (1923). After observing archaic, money-less societies, Mauss postulated three obligations within gift relationships; the obligation to give, the obligation to receive and the obligation to reciprocate. Gift exchange theory carries some similarities to social capital, in that exchanges have wider implications for social relations and the creation of social cohesion and the key aspect of Mauss’s theory, reciprocity. Gift exchange theory has been widely applied to deceased organ donation and transplantation (Sque and Payne, 1994) as it has been described as the ‘gift of life’ in previous health campaigns. It is believed to apply because the notion of the gift encompasses the ethos of giving, however, it has been criticised for being a simplistic and misleading metaphor (Siminoff and Chillag, 1999) and coercive (Schepers-Hughes, 2007).

Social capital has been analysed in relation to gift exchange theory by Dolsma et al. (2008). They suggested that social capital results from ‘concrete interaction (gift exchange)
between concrete individuals’ (p.322). A gift exchange creates a relationship that can be revisited at a future point in time and could be referred to as social capital (Bourdieu, 1986; Nahapiet and Ghosal, 1998). Gift exchange plays a significant role in the creation of social relations and networks (Cheal, 1988; Gouldner, 1960). Social capital itself may be the byproduct of the obligation to repay, featured in Mauss’s theory where the recipient repays back society rather than the individual through generalised reciprocity (Dolfsma et al. 2008), this may not be immediately. Giving gifts creates social indebtedness which perpetuates the exchange process (Belk and Coon, 1993). Social capital is the reciprocal aspect of the gift exchange process, according to Coleman (1994) the repayment can be used when they require it, however trust and the context will influence this. Dolfsma et al. (2008) outlines that social capital as an outcome of the gift exchange system enables an understanding of the creation, maintenance and demise of social capital. The obligation to repay is the key to the creation of social capital.

Lessons that can be learned from the gift exchange theory analysis in relation to deceased organ donation are the ‘tyranny of the gift’ (Fox and Swazey, 2004) and the ‘spirit of the gift’ (Mauss, 1923). The ‘tyranny of the gift’ explains the burden that the recipient feels when reciprocating the gift as they may want to repay the donor, however they are no longer alive and it is not possible to repay them in equal terms as Mauss’s theory prescribes. With regards to social capital, recipients may consider ‘paying it forward’, either becoming a donor or creating voluntary associations to help others. This notion links with Putnam’s generalised reciprocity.

With regards to the ‘spirit of the gift’, this provides a mystical sense to the gift as this concept in relation to organ donation suggests that the identity of the giver is carried in the gift. This is one of the challenges that come with giving organs to anonymous strangers. In terms of social capital, this may make the connection between the donor and recipient stronger than other forms of formalised prosocial behaviour and perpetuate the need to reciprocate.

At this point, it may be said that helping behaviour, prosocial behaviour and altruism may be defined differently (Bierhoff, 2001). Helping is where individuals support one another,
prosocial behaviour is where the action is intended to benefit the welfare of the recipient, not driven by professional obligations and the recipient is a person, not an organisation. Altruism is a type of prosocial behaviour is constrained by the motivation of the individual’s empathy. These definitions according to Bierhoff (2001) may be useful in defining further the type of behaviour that is being displayed by donors and donor families. Donors give organs to help others and this may be motivated by altruism, this is one of the challenges that Titmuss found in his work on blood donation and will be discussed later.

3.2 Social capital and deceased organ donation: Giving the ‘gift of life’

From an extensive literature review, it is suggested that social capital can provide a useful way of viewing deceased organ donation and its policies, using lessons from gift exchange theory as a springboard. Social capital considers the multi-layered links within society such as micro-, meso- and macro (Schuller et al., 2000)(Table 2). For example, the micro level considers the individual and psychological theories, such as self-efficacy, and influences on decision making on health behaviours (Campbell, 2002). The micro-level may also account for the socio-demographics and socio-economic status of the individual such as their level of income and education. These may in turn have an impact on the kind of community that the individual resides in, whether they feel safe and they belong to this community and also their access to health services and specialist service information, such as organ donation and transplantation. The meso level is community, this may be in the form of neighbourhood groups, taking urbanisation into account, the social environments within these communities and the perceived norms. Existing communities could hold potential for health promotion in accessing groups of people and tailoring messages. Communities may be in the form of neighbourhood groups or business acquaintances (Narayan and Cassidy, 2001). The macro level takes into account wider society such as social, economic and political aspects and in relation to deceased organ donation may be influenced by the imagined ‘other’ who may be the organ recipient, a stranger in society. It could take into account the social norms of organ donation and laws, policies and governing bodies around organ retrieval.

<table>
<thead>
<tr>
<th>Micro</th>
<th>Individual</th>
</tr>
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<tbody>
<tr>
<td>Meso</td>
<td>Group/Community</td>
</tr>
<tr>
<td>Macro</td>
<td>Society</td>
</tr>
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</table>

Table 2. Different levels of social capital

From Table 3, it is possible to see from the items highlighted in green, that deceased organ donation spans across different levels of society and social capital theory at different points in time. There is the point when the individual signs the register, the family consenting to donation, the donation process and the repercussions of the donation in a social sense. Heffron (2000) explains the different types of ties, these are strong (repeated) or weak (temporary); vertical (through hierarchical structure) or horizontal (decentralised authority); open (civic engagement) and closed (protected membership); geographically wide or close; instrumental (membership for individual needs) or principled (membership as solidarity). Reasons for donating are complex as it may involve many factors on different levels as illustrated by Table 3.
Table 3. Amended conceptual map of social capital

Moseley and Stoker (2010) suggested the social norms at present is for people to agree with organ donation in principle, but not to sign up to become organ donors, there is no social sanction in shaming for those who are not donors. Also, there may be perceived sanctions for becoming donors, which may link with the disapproval of family members whose beliefs may be based on myths of organ donation, illustrating the need for education and family discussion.

To some degree, the organ transplantation process is a type of bridging social capital as it is bringing together people across different networks, the ties are weak as the connection occurs once but at the same time is strong as characterised by the ‘spirit of the gift’. They are vertical as the process occurs through the NHS hierarchical structure, and is instrumental as it fulfils the needs of the recipient. After the transplantation event, individuals would have experienced organ donation, either donor families or recipients may create organisations to help and support one another.
Morgan et al. (2006) commented on social capital in relation to the cohesiveness of local communities and ‘bonding’ social capital within these, leads to the unwillingness to donate outside of them. This may be due to low levels of bridging, where ties are loose with other social groups and cultural differences may the way that imagined others in society are perceived. Another explanation may be due to kinship and group belonging, this limits exchange with outsiders. Their view of social capital would link in the diagram to signing to be a donor in that there may be a perception that organs only should be given to kin or those within the same group, this may be religious or ethnic for example. Their research was based on White, Black Caribbean, Black African, South Asian and mixed race, the majority of respondents being White. This may also link with national identity, multiculturalism, racism and prejudice.

This connection where there is a preference of organs going to kin or others that individuals are familiar with could link with Lam and McCullough (2000) work where ‘social distance’ described this phenomenon. Social distance was illustrated by participants who stated that they would be ‘willing to donate organs to people similar to themselves before they will donate to strangers at large. This is an issue of similarity to and distance from the individual based on family ties and kinship, rather than a matter of racial prejudice’ (Lam and McCullough, 2000, p.455-456).

### 3.3 Structural and cognitive social capital and organ donation

Organ donation may be considered to fit Uphoff’s framework as it views social capital as being structural and cognitive. According to Uphoff (2000), structural social capital are rules, roles, procedures and networks that contribute towards mutually beneficial collective action (MBCA) and cognitive social capital are mental processes that are reinforced through culture and are in the form of norms, beliefs and values contributing to MBCA.

The structural element of social capital may relate to the procedures around becoming an organ donor, the organ removal and transplantation process and networks within this process between the donor family, health care team and recipient. The cognitive aspect of social capital may relate to the norms and beliefs towards organ donation. Uphoff explains...
that these two forms of social capital are interdependent, the structural aspects can be observed but the cognitive aspects cannot.

<table>
<thead>
<tr>
<th>Sources and manifestations</th>
<th>Structural</th>
<th>Cognitive</th>
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<tbody>
<tr>
<td></td>
<td>Rules and roles, networks and procedures.</td>
<td>Norms, values, attitudes and beliefs</td>
</tr>
<tr>
<td></td>
<td>Organ donation and transplantation process/ Healthcare team training/ Stories in the media about donation</td>
<td>Towards organ donation (myths/concerns, helping behaviour and morals) influenced by religion, culture, and society</td>
</tr>
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<table>
<thead>
<tr>
<th>Domains</th>
<th>Social organisation NHS Blood and Transplant/Government/Local hospitals/Transplant Team</th>
<th>Civic culture Society</th>
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<tr>
<th>Dynamic factors</th>
<th>Horizontal and vertical linkages Networks within the organ donation and transplantation process</th>
<th>Trust, solidarity, cooperation and generosity (Sense of belongingness) Possible reasons for donating organs</th>
</tr>
</thead>
</table>

Common elements | Expectations that lead to cooperative behaviour


Table 4. Structural and cognitive levels of social capital

It may be argued that individuals are not fully informed as they are not being told in detail about organ donation through the adverts and when signing up to register. At this point, it is emphasised that organ donation is a personal decision that should be fully informed, the term ‘cooperative behaviour’ is part of this model and it is not advocated that organ donation is this as it would suggest coercion. This model illustrates the interaction between the structural aspects and cognitive aspects. Cognitive aspects of social capital in relation to deceased organ donation.

The structural and cognitive forms of social capital are evident in Bourdieu, Coleman and Putnam’s work at a descriptive level, however, not at an analytical level (Uphoff, 2000). Uphoff believed that roles and rules, as well as norms, values and attitudes produce expectations about the way in which people act. According to Healy (2006), these expectations of how the donation process should be experienced may be facilitated by ‘cultural account of organ donation’, where there are ‘feeling rules’ (p.117). In other words, literature provided by the hospital is intended to guide individuals in how they should be feeling about donating organs and the expectations that other actors, such as other family members, health care teams, have of them.

Networks are viewed by Uphoff as patterns of social exchange that exist over time and are perceived to be important for social capital. In relation to organ donation, exchange of information may be viewed as a form of social capital. In the study by Darr and Randhawa (1999) social networks were viewed to be key in disseminating information about organ donation. This
may be linked to social capital because according to Coleman (1994), information provides a basis for action. Thus, if information is being circulated based on falsities or myths, such as the need for body totality, this may influence the action that individuals take.

The property of social capital raises interesting questions, some forms of social capital are "collective goods", they are not owned property of those who are benefitting from them (Coleman, 1988). This is an interesting notion because it begins to question the property of organs. This is usually debated within the literature about the commercialisation of organs. However, if organs are viewed as "collective goods" because they are given to strangers who are part of the wider collective, would it be the individual who owns it or the donor family?

In relation to welfare policy, Le Grand (1997) suggests that human motivation and behaviour impacts on policy. Those who ‘finance, operate and use the welfare state are no longer assumed to be either public spirited altruists (knights) or passive recipients of state largesse (pawns); instead they are all conserved to be in one way or another self-interested (knaves)’ (p.149). This may suggest that individuals are motivated by their self-interest and this may have implications for organ donation policy. These type of self-interest based arguments link with the beginning of the chapter for payment or reward based donation policies.

3.4 Social capital and blood donation

By taking these aspects into consideration, when looking at organ donation’s current and alternative policies through a social capital lens, it may explain the issues of altruistic donation and potential issues in the use of alternative policies. Social capital has not yet been applied directly to deceased organ donation in this sense, however it has been applied to health in terms of quality of life and wellbeing (Campbell, 2002). The closest comparison that can be made is to the account of applying social capital to blood donation. Alessanderini and Carr (2007) found that social trust is currently low in Australia due to increased alienation but through participatory policy-making, this has had positive implications for blood donation as individuals feel involved. Alessandrini et al. (2007) suggests that social capital should be considered in blood donation but recognises the demographic factors which will impact on it.

Blood donation is viewed as the benchmark of the measurement of levels of social capital alongside voting behaviour according to Mohan et al. (2004). Blood donation and voting have similarities because individuals visit a centre to perform the action, but for deceased organ donation it is in two private forms. The individual filling in a form to illustrate their willingness and the families making a decision about their recently deceased loved one. Both decisions are made in an isolated environment, where it may not be further spoken of, making it difficult to sow the seeds for social capital to flourish. The individual’s decision may be made impulsively when given the chance, when ‘nudged’ on the DVLA form or presented with opportunities on the GP registration form or Boots Advantage card form. Aside from these opportunities, individuals may not consider organ donation deeply if they were undecided when asked on the forms. But for others, deep consideration may be needed before signing the forms and they may forget about signing up altogether. The decision for the family is made at a time of great difficulty and at some stage of the bereavement process.

Putnam (2000) prosocial behaviour which is formal such as blood donation, benefits strangers, and can be viewed as an indicator of social capital. Social capital has been linked
with blood donation and organ donation by Mohan et al. (2004) who view donation as a measure of social capital and was compared with electoral behaviour. They illustrate the limitations of the studies that showed links between blood donation and social capital. It may be that blood donation has been linked with electoral behaviour as forms of measuring social capital, perhaps because they are both public acts in that for both one goes to the polling station or the bloodmobile collection point to perform the act. Organ donation, however, is private and may not be viewed as a measure for social capital because it is performed by donor families and not the individual. However, signing the organ donor register may be a measure of social capital because it is the individual's confirmation of their wish logged on the ODR where the statistics about UK donor numbers are available. This comparison may be limited though as, blood donation and voting is something that can be done a number of times in one's lifetime, organ donation may help someone at some point in the future, if their family allow it. Blood donation and voting are personal decisions, but donation is a family decision. Blood donation and voting have tangible outcomes that the individual can experience, but organ donation is something that happens after one dies.

3.5 Analysis of individual aspects of social capital in relation to organ donation

3.5.1 Norms

Moseley and Stoker (2010) in their research, they challenge the social norm and civic behaviour based on information circulated within networks. In their study, there was an information exchange within existing virtual social groups such as blogs and Twitter where one’s decision to become an organ donor was told to others. Education has been a source for sparking family discussion in a recent Maastricht programme in The Netherlands (Reusbaet et al., 2011), whereby adolescents were educated in organ donation and they spoke to their families about it, rather than leaving it to older generations and parents to raise the topic with their children. Raising awareness and educating people about donation had a direct impact on engagement with organ donation. For example Vinokur et al. (2006) showed that pupils shown educational materials about organ donation were more likely to contact the organ donor registry. Through a social capital lens, the key is not just about educating people, but the ongoing information exchanges that occur within social networks.

3.5.2 Generalised reciprocity

Adler and Kwon (2002) suggested that generalised reciprocity ‘resolves problems of collective action and binds communities. It transforms individuals from self-seeking and egocentric agents with little sense of obligation to others into members of a community with shared interests, a common identity and a commitment to the common good’ (p.25). From this perspective, low organ donation may be viewed as a social problem that can be solved through collective action, knowing that this act will help others and will build up a sense of community and contribute towards the 'common good'. Rather than an individual issue, where past research has focussed on attitudes and behaviours in decision making, perhaps organ donation could be looked at from a wider perspective that helping a stranger will not only help one person, but many others.

Portes (1998) argued that it was obvious why the "recipients" of social capital wanted the benefits of it, but what about the "donors", what motivates them? He argued that a tie did not constitute returned benefits, he supported Putnam's et al. (1993) notion of trust and norms in motivating "donors". This has been dismissed by critics who believe that individuals are
egoistic (Adler and Kwon, 2002). But Portes (1998) suggest that individuals are motivated by 'consummatory' motives which are 'deeply internalised norms, engendered through socialisation in childhood or through experience later in life by the experience of a shared destiny with others' (Adler and Kwon, 2002, p.25). Another motive may be 'instrumental' which are norm based, influenced by rational choices and obligations created through gift exchange or what Portes calls 'enforced trust' by the broader community.

Coleman referred to social capital contributing to the sanction of free-riding; this is a phenomena that Šýgora (2009) has expanded upon in his chapter 'Altruism Reconsidered'. This links with Trivers (1971), an evolutionary psychologists work and social exchange theory where individuals would receive the benefits of others without providing any input. For altruistic systems to be successful, such as organ donation, free-riders should be sanctioned (Šýgora, 2009, p.31) and may be problematic for social capital because it would stagnate the reciprocal element. But, it may spur on social capital and reciprocation as the individual may feel guilty taking something that they were not willing to give.

Source: Organ Donation online (2011a)

Diagram 3. Advert as part of current campaign

In this poster, one can see that if one is willing to take an organ they should be willing to donate. The emphasis has moved away from the notion of the gift and towards obligations and reciprocity. This the byproduct of social capital and later stage of the giving process
rather than focusing on the creation of the 'gift relationship'. However, this image may be
seen as a way of making individuals feel guilty and emotionally blackmailed into donating
and focuses on the recipient rather than the donor and reasons to donate such as altruism. It
does not currently promote reciprocity in the form that will promote social cohesion and
contribute towards society. In Alessandrini’s (2007) research, 1.7% donated blood as they
felt guilty, most people donated blood as they felt they were socially responsible (24.6%),
received personal satisfaction (28.3%), wanted to give back to the community (31.3%) and
wanted to do good (13.8%). These notions relate to civic engagement and helping the
common good which will be explored later in the chapter.

3.5.3 Trust

Within social capital, trust is a perception that the individual has towards known others in
their immediate and wider communities, but also towards strangers and wider society. The
definition of trust is problematic as it varies across disciplines. Tonkiss and Passey (1999)
ilustrate that social capital theorists view trust as instrumental in economic terms, but imply
moral and normative values in the way that the term is used in everyday language. They felt
that trust is a feeling on an informal level that influences social action and interaction. Trust is
a recurring issue in social capital as it prompts the creation of social networks which are
sustained through common values as individuals can rely on each other (Furbey et al., 2006).

However, Beem (1999) states ‘Trust between individuals thus becomes trust between
strangers and trust of a broad fabric of social institutions; ultimately, it becomes a shared set
of values, virtues, and expectations within society as a whole. Without this interaction, on
the other hand, trust decays; at a certain point, this decay begins to manifest itself in serious
social problems… The concept of social capital contends that building or rebuilding
community and trust requires face-to-face encounters’. (p. 20)

Gilchrist (2004) found that social capital is a ‘collective asset made up of social networks
based on shared norms and trust and mutuality’ (p.4). This illustrates the importance of
social networks in the creation and sustaining of social capital. Social capital accounts for
perceptions of trust in society and strangers which may impact feelings of belonging and
wanting to help others through organ donation. Putnam (2011) recently theorised that
multiculturalism and migration has contributed to the decline of social capital in the UK. In
a sense deceased organ donation decisions may link to one’s national sense of belonging,
trust in society and strangers and perhaps wanting to express criteria for preferences for
recipients of one’s organs if they fear that their organs may go to a community that they
have had negative experiences with.

Homans’s (1950) suggested that gift exchange generated social cohesion and people may
invest in relationships. Social capital may be an outcome of exchange relations through
social interactions. Gift exchange literature purports that the initiation, maintenance and
possible decline of social capital can be understood through this model (Dolfsma et al. 2008).
Within the gift relationship, there is an element of ‘trust’ in that the gift will be put to its
appropriate use and also the gift will be reciprocated.

3.5.4 Social solidarity

Solidarity is a notion that has been given attention in bioethical issues according to Nuffield
Bioethics online (2011) and is being examined further. The term is viewed to be ambivalent,
but may ‘inform questions on bioethics where philosophical and policy issues do not turn
only on individualised ethics’ (webpage). However, social solidarity can be defined as ‘the integrative bonds that develop between persons and the social units to which they belong. Solidarity is potentially composed of both behavioural and affective components, but as research on social networks has shown, the two are frequently unrelated – structural or situational factors may encourage or constrain behavioural interaction independent of the strength or closeness of the relationship’ (Molm et al., 2007, 207).

Through analysing Mauss’s gift exchange theory, Douglas (1990) suggested that it is in the interests of the members of the collective to participate and exchange gifts and services with others (Komter, 2005). This links with social capital and the notion that deceased organ donation is in the interest of individuals. More organs will be available, meaning that individuals will benefit from this ‘resource’ if they require an organ if they are ill. By collectively dealing with the issue, the byproduct of this may be the strengthening of social relations and the building of social solidarity. Mauss (1923) concurs that gifts create social bonds and in an analysis of Titmuss’s work, Rose (1981) suggested that the NHS assisted the social solidarity of Britain. Titmuss (1971) in his study compared paid and unpaid blood donation in the USA and UK respectively and found that the UK blood quality was better. It is debated whether Titmuss suggests that altruism was a motivating factor behind donating blood, or whether it was other, more selfish factors such as increasing individual’s self-esteem. However, his work heavily influenced policy on blood and organ donation policy.

The main criticism of Titmuss's work is the notion that donation is based on pure altruism, similar to that of charitable giving, without obligation to reciprocate. Sýgora (2009) added that giving to charity benefits the altruistic and egoistic motives, Komter illustrates ‘feelings of being morally obliged to return a gift and not purely altruistic motives are the main psychological impetus to reciprocal giving’ (2006, 46-48). She found the motives behind giving, the role of gratitude helped maintain social relations and refers to Simmel’s work, ‘By mutual giving, people become tied to each other by a web of feelings of gratitude. Gratitude is the motive that moves us to give in return and thus creates the reciprocity of service and counterservice’ (Komter, 2006, p.67). Reciprocity is a key factor in the creation of the ‘cement of society’ (ibid, p.203).

Putnam (2011) recently argued that the lack of homogeneity, in the shape of multiculturalism in Western societies is leading to atomised societies, not cohesive ones. Diversity was considered to strengthen social capital, but Putnam challenges this. At this point, it may be theorised that social and national identity and to some extent, for migrants or second generation migrants, ethnic identity may play a role. Perhaps linked with multiculturalism is the fragmentation of what ‘Britishness’ or ‘Englishness’ is, this is another area entirely and is outside the scope of this chapter, but is worth acknowledging at this point.

3.5.5 Altruism

Altruism is ‘to act on concerns for others’ welfare as well as their own’ according to the social psychologist Farsides (2007). Altruism has been defined earlier in this chapter and, but this definition highlights self-interest behind altruistic acts. Durlauf and Fafchamps (2004) did view a link between altruism and social capital ‘One… claim often made in the literature is the idea that social capital favors altruism and raises concerns for the common good – the ‘touchy-feely’ side of social capital… Even a minor increase in altruism can raise social efficiency, [as shown] in a standard Prisoner’s Dilemma game…Altruism provides an efficient solution to
free-riding – a principle that most religions seem to have discovered centuries ago.’ (Durlauf and Fafchamps, 20-21). Free-riding is a weakness in altruism (Sýgora, 2009) and in social capital (Adler and Kwon, 2002). Smith (2007) believes that the link between altruism and social capital may be a two-way relationship, social capital may encourage altruism, facilitate reciprocity and perpetuate further interaction, creating further social capital.

Sýgora (2009) suggested that deceased organ donation is a form of charity, similar to that of alms-giving found in religion. However, charity is perhaps a uni-lateral form of giving, whereas lessons from gift-exchange theory when applied to deceased organ donation would suggest that some level of reciprocation exists from recipients. Individuals may not be able to fully repay the donor family, however, they would be able to help others in the future, through ‘paying it forward’, as mentioned earlier when discussing generalised reciprocity.

Whether altruism exists is debatable, from a socio-biological perspective such as Dawkins or an economic viewpoint, such as Adam Smith, both fields converge their views that individuals act for their own self-interest. But altruistic acts may be strategic according to List (2007) in that individual’s help people only if they are to be benefited in some way. Komter (2006) found that the individual’s expressed altruistic motives, such as love and solidarity but it is gifts may have a ‘strategic aim’. Gifts benefit a person in need but simultaneously appease the donor’s conscience.

However, if altruism does exist, Alessandrini (2007) highlights that it is socially constructed (Bishop and Rees, 2007; Healy, 2006) and Rushton (1980) argues that it is something that is taught and practiced. Titmuss (1970) found that none of the donor’s answers were completely altruistic, there was ‘some sense of obligation, approval and interest, some feeling of “inclusion” in society; some awareness of need and the purpose of the gift’ (p.238). More recently, Healy (2006) argued institutional and individual aspects of altruism and suggests that it was the NHS which collected the blood that created the bond to wider society and enabled donors to give their blood for personal reasons and to help the general demand. He states ‘the ways in which society organises and structures its social institutions...can encourage or discourage that altruistic in man’ (p.225). Etzioni (2003) suggests that ‘it cannot be stressed enough that the reference here is not to altruism, which critics correctly point out often is an insufficient motive for action... Rather reference is making organ donation a part of one’s sense of moral obligation, something one cannot look in the mirror or face friends without having lived up to’ (p.1).

The Behavioural Insights Team, part of the Cabinet Office, influenced by behavioural economics suggest that people make choices in their own interest, especially when unaware of the facts Thaler and Sunstein (2008). In relation to organ donation, they suggest a libertarian paternalistic approach, libertarian where there is no government coercion and paternal as the government are able to nudge. The government is trying to create prosocial behaviour and have created the behavioural insight team, aka the ‘nudge unit’. Halpern (2005) suggests that social networks aspects could be combined with behavioural economics.

Smith, a medical scholar, suggested there are four attributes of altruism; ‘a sense of personal responsibility for another’s well-being...a sense of compassion for another...a sense of empathy...an uncalculated selfless commitment to the needs of others’ (1995, p.787). The consequences of altruistic acts are ‘a vicarious pleasure in the welfare or happiness of others; a sense of relief when another’s needs appear to be met; good equated with caring for
Social Capital and Deceased Organ Donation

Social Capital and Deceased Organ Donation

3.5.6 Civic engagement and civil society

Civil society is the connection between welfare and citizenship and active citizenship is the crux of civil society because it addresses the obligation towards the common good and builds a ‘good society’ of trust, compassion and participation. Civil society includes the ‘market, and “kinship, family and community systems” ... and “the education system, the union movement, local government, the media, voluntary organisations and ... the church”’(cf. Sibeon, 1997, p.81). However, in the 1990s there was a debate around civil society, whether it is based on civic trust and goes back to collectivism as it purports a new form of communitarianism (Etzioni, 1994; Fukuyama, 1995). Communitarianism ‘...seeks to make organ donation an act people engage in because they consider it their social responsibility, something a good person does, akin to volunteering’ (Etzioni, 2003, p.1).

The Borrie Report (1994) states that social capital is made up of institutional relationships of civil society which is built upon solidary individualism and active citizenship and includes extended families, community groups and religious organisations (p.307-308). Beveridge suggested New Labour’s focus on active citizenship is a response to globalisation pressures. The sense of social citizenship should be based on agreed principles on rights, duties and responsibilities of the state and individuals to maintain state welfare in the future (Pratt, 2006). To some degree this is still the current political agenda as Cameron’s Big Society advocates community and empowerment through social action (Cabinet Office, 2011).

If civic engagement is part of social capital, then who owns it? Putnam was reluctant to ascertain whether it was a private or public good, ‘Social capital has both an individual and a collective aspect—a private face and a public face. First, individuals form connections that benefit their own interests. One pervasive stratagem of ambitious job seekers is “networking,” for most of us get our jobs because of whom we know, not what we know—our social capital, not our human capital... If individual clout and companionship were all that there were to social capital, we’d expect foresighted, self-interested individuals to invest the right amount of time and energy in creating or acquiring it. However, social capital also can have “externalities” that affect the wider community, so that not all the costs and benefits of social connections accrue to the person making the contact... Social capital can thus be simultaneously a “private good” and a “public good.” (Putnam, 2000, p.20).

3.6 Grass-roots approach to health promotion

As social capital does emphasise the importance of communities, this would naturally lead onto the recommendation of a grass-roots approach where messages are tailored to established communities. Schuller et al. (2000) explains that social capital may be used in this functionalist way but social capital itself does not encourage this. Health care professionals, local community leaders and organ recipients from the local community to
attend events to increase awareness of organ donation and promote discussion. Social networks are emphasised in social capital, networks can be created and established through making contact with communities, such as neighbourhood or religious. Overall, the sum will be greater than all parts.

Taking a grass-roots method to promoting organ donation is not new, by taking a social capital stance, its importance as an approach is emphasised. Darr and Randhawa (1999) in the UK and American scholars such as Callender (1989) and Hall et al. (1991) advocate a grass-roots approach. Recently Whitelaw (2011) in the Guardian argued that face to face events help, as taking a grassroots approach has helped elsewhere. They illustrate that in July 2009, Kidney Research UK had a Peer Educator programme which was tailored to their audience, it was either religious in nature or for Joe Bloggs on the street, and started people talking about it through social networks. Social networks are a key element of information dissemination, people share experiences and information but for organ donation it may be wrong information which may be perpetuating the current situation as there is lack of knowledge. In addition, Channel 4's 'Battlefront' is taking a 'grass-roots' approach to increasing awareness amongst teens at the UK's Underage Festival, backed by Alexandra Burke, a pop singer.

Organ donation online (2011b) showed that in their campaigns aimed at Black African, Black Caribbean and South Asian groups, they were hosting events at shopping centres, faith sessions, facebook social media, thus linking in with social capital. These sources pull upon ethnic minority groups, further research may be required as to how indigenous population feel, as resources may be seen to be focusing away from them. Hosting events are not just a method of raising awareness, but may have wider implications such as increasing trust (Beem, 1999), particularly in organ donation, helping to dispel myths which may circulate social networks and act as a source of social capital in an information sense.

Through the grass-roots approach, social capital is formed through a bottom-up approach to promotion and engagement, as opposed to a one-size-fits-all top-down approach. NHSBT would be sending the message that the NHS will come to the community to speak to people about donation rather than people having to come to them or briefly consider it as part of a form filling exercise. For some people, it may be a big decision as it encapsulates many factors such as religious, cultural and social concerns. Individuals may have many unfounded issues about donation that they have nobody to speak to about when filling in the forms. People are time poor, as Putnam pointed out and are bombarded with adverts on a regular basis, organ donation adverts may be being lost and may not be relevant. However, it may be expensive and time-consuming to put events like this together. Information would have to be tailor made to each group and staff would have to make time to be available, when they are already extremely busy. Also, which groups that are targeted to be given information would have to be justified and the impact of the event may be difficult to measure.

In addition to a grass-roots approach, education should be increased and information held on the organ donor register could be analysed. Children could become more involved in organ donation education, recently reported Adams (2011) as they are viewed to be more altruistic at this age. As argued before, altruism is in itself a contested issue, but through educating children, it may spark discussions about death and organ donation with parents. Through education, social norms may be challenged as myths are dispelled. Geographic information from the Organ Donor Register may enable the mapping of where the donation 'hot spots' are and how these correlate with social capital in these areas, strong and weak.
4. Opportunities and limitations

4.1 Opportunities

Through the social capital lens, it may be possible to consider the current and potential policies in a different way. The Organ Donation Taskforce (2008) illustrated that presumed consent was considered due to erosion of trust between patients and health care professionals. When the aspect of trust is considered through a social capital lens, its importance is magnified. Presumed consent removes the altruistic and reciprocal element, which could potentially, if capitalised upon, contribute towards a civic society. This may be similar if organ donation was to be commercialised, it would remove reciprocity.

4.2 Limitations

Social capital takes into consideration a wide variety of factors that were not considered through gift-exchange theory. As it may exist on a number of different levels in different forms, there are a number of challenges and questions to face when applying social capital to deceased organ donation:

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<tr>
<th>Limitation</th>
<th>Explanation</th>
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<tbody>
<tr>
<td>Encouraging preference-based donation?</td>
<td>Does social capital highlight the limitations of ‘gifting’ organs, in that people do not feel comfortable donating to people who may be different from them? Portes (1998) explained that people are willing to give up something for another person in the same social structure and Randhawa (1998) highlighted preferences to donate organs to other individuals that they have biological or sociocultural connections with. These issues link with Putnam’s bonding social capital, therefore, preference-based donation, whereby individuals can choose who their organs go to in a multi-faith, multi-cultural society. It is something that is being considered in living donation (Dor et al., 2011) however, it may exacerbate in-group identities, fragmentation and alienation within the UK.</td>
</tr>
<tr>
<td>How much social capital?</td>
<td>As a relatively small number of transplants are occurring, how much social capital could be built from it? There are low levels of organs available and more transplants would be possible if more organs were available and in the long run could be a source of social capital.</td>
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<tr>
<td>Low levels of societal trust</td>
<td>There may be low levels of trust in strangers and society (World Values Survey, 2006) and may link with issues of social distance, as people would want to help those they know before strangers. It may be naïve to think that people will contribute so readily to people they do not know to help the common good, does it link with rational choice theory and strategic decisions in that there is no perceived benefit from helping strangers?</td>
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### Limitation Explanation

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<th>Limitation</th>
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<tr>
<td><strong>Reciprocity</strong></td>
<td>The reciprocal element can only come from those who have received organs. Is the current number of people on the organ donor register a measurement of social capital? How accurate is this data? Family refusal rate may decrease this. Further analysis is required, such as who make up the demographics of these individuals that have signed up.</td>
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<tr>
<td><strong>Community</strong></td>
<td>How do individuals define community, is it possible to make ties across borders, local communities and neighbourhoods through grassroots events? The ties would be ‘weak’ as they would not be repeated over time, but it would increase education.</td>
</tr>
<tr>
<td><strong>Social and health inequality</strong></td>
<td>Is social capital reproducing class through limited access to health information about organ donation through DVLA and Boots advantage card? Those who are at the lower spectrum may not drive or afford to shop at Boots.</td>
</tr>
<tr>
<td><strong>Social media</strong></td>
<td>Is Twitter, facebook and blogging over-used for networking or an untapped source for raising awareness about donation? According to a social capital blog, America is changing the way that social capital is being measured and now includes 'frequency of using the internet to express opinions about political and community issues' (webpage).</td>
</tr>
<tr>
<td><strong>Human capital</strong></td>
<td>Do individuals feel that they can donate, if people are ill or old they feel they cannot according to Bekkers (2006). People should be made aware that people can donate into old age and with certain illnesses in a way that would discourage them from viewing donation in a negative way.</td>
</tr>
<tr>
<td><strong>‘Dark side’ of social capital</strong></td>
<td>Does organ donation highlight power struggles? Is there too much focus certain groups of the population such as BME and can this make indigenous population feel excluded?</td>
</tr>
<tr>
<td><strong>Unsuccessful transplants or transplants that last for a short time</strong></td>
<td>Would these potentially erode trust or the reciprocal aspect of organ donation as social capital is temporal?</td>
</tr>
<tr>
<td><strong>Role of the media</strong></td>
<td>TV, news and film may be the source of information about organ donation rather than community leaders at present. There may be inconsistency in messages about donation, there should be more positive stories and it should be less sensationalised, like that in Spain. The media could highlight that donors are good citizens, making this the social norm, rather than organs being gift or hero due to the implications of these terms.</td>
</tr>
<tr>
<td><strong>Future of transplantation</strong></td>
<td>Transplantation is ever expanding into unexplored areas, people may not feel comfortable about the future of donation. Perhaps if it was in the public domain and individuals participated in it policy making, people may feel comfortable about its progression.</td>
</tr>
</tbody>
</table>
Can it fit in with the Big Society?  
The Big Society may be viewed as an ethos of creating a community-led and empowered nation. Organ donation may be seen as a concrete example of how to help many other people in society and be socially responsible and contribute to the common good.

Current economic Milieu  
In hard times, budget cuts may be seen to be eroding society, such as decrease in social housing and cuts in benefits, perhaps leading to more social instability and movement, decreasing the likelihood of the maintenance of established communities. However at the same time, lack of economic resources may increase levels of social capital.

Unclear as to building and maintaining it  
There are deeper issues that underlie social capital such as roles of families, which are becoming broken.

Social norm  
This is to accept organ donation in principle but not to donate, there is no sanction for not donating, if donation was the norm, would people feel coerced into giving?

A romantic or Marxist idea?  
Putnam argued that social capital has demised due to being time poor, lack of membership to clubs and not reading the newspaper. Does that mean that coming together as a country to help tackle the issue is a romantic idea or a Marxist idea in that people will unite in what they believe in? Would people believe in it enough, even after being educated about it?

Lack of national identity  
There may be a feeling that there is a lack of national identity in Britain which manifests itself in difficulty to help strangers and may challenge the notion of pulling together to tackle the problem of donation. However, this may not be the case, as helping those in need may be viewed as helping the human race or ‘brothers’ and ‘sisters’ and national identity is not part of it.

Individualistic Society  
Social capital may be lower in individualistic societies such as the UK (Hofstede, 2011), which may challenge the creation and maintenance of it through donation.

Table 5. Limitations of links between social capital and organ donation

5. Conclusion

Social capital offers a unique and useful way of examining deceased organ donation and to simultaneously consider many aspects that may be inhibiting the success of altruistic approaches to donation. This is a theoretical position on the connection between social capital and deceased organ donation and does not claim for these to be empirically founded in any way. Social capital is a cohesive and holistic way of viewing deceased organ donation as it marries together micro, meso and macro levels of analysis and illustrates the importance of building up an individual’s trust in society and in organ donation. It is not denied that there are many flaws to this theory, it is a malleable concept, making it flexible...
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to facilitate the notion of deceased organ donation but its elasticity can lead to it being
difficult to fully apply to all areas. The purpose of this chapter is to highlight organ donation
as a form of civic engagement and illustrate why gifting and altruistic donation may be
difficult to facilitate in a society that may have low levels of cohesion, trust, sense of national
identity and community. The author hopes to evoke discussion through viewing deceased
organ donation through a social capital lens to consider many other factors that are not
considered through gift exchange and altruism, that they perhaps are cogs of a bigger
machine.

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Transplantation has succeeded in prolonging the lives of those fortunate enough to have received the gift of a body organ. Alongside this life-saving development, there lies another sadder side to the story - there are not enough organs to meet the ever increasing demand. This not only places an increasing emotional and physical burden among the waiting patients and families but heaps a great financial burden upon health services. This book provides an analysis and overview of public policy developments and clinical developments that will hopefully ensure an increased availability of organs and greater graft survival. Medical, policy, and academic experts from around the world have contributed chapters to the book.

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In order to correctly reference this scholarly work, feel free to copy and paste the following:
