

# Blood and organ donation: Health impact, prevalence, correlates and interventions.

| Journal:         | European Health Psychology Society                    |
|------------------|---|
| Manuscript ID    | GPSH-2018-0582.R3                                     |
| Manuscript Type: | Psychology and Health                                 |
| Keywords:        | Blood Donation, Organ Donation, Altruism, Reciprocity |
|                  |   |

SCHOLARONE™ Manuscripts

Ferguson E, Murray C & O'Carroll RE (2019) Blood and organ donation: health impact, prevalence, correlates, and interventions. Psychology and Health p. 32. https://doi.org/10.1080/08870446.2019.1603385

**Blood and Organ Donation** 

Blood and organ donation: Health impact, prevalence, correlates and interventions.

#### Abstract

Objective: Without a supply of blood, health services could not meet their clinical needs. Similarly, organs for transplantation save and transform lives. Donations are acts of generosity that are traditionally seen as altruistic, and accordingly, interventions to recruit and retain blood and organ donors have focused on altruism. We review the predictors, prevalence and correlates of these two behaviours, how effective interventions have been, and draw common themes. Design: Narrative review. Results: We highlight that both recipients and donors benefit, and as such neither blood nor organ donation is purely altruistic. We also highlight health problems associated with both types of donation. In evaluating interventions, we highlight that a move to an opt-out default for organ donation may not be the simple fix it is believed to be and propose effective interventions to enhance the opt-in default (e.g. social media updates). We show that incentives, text messaging, feedback and a focus on prosocial emotions (e.g., 'warm-glow', 'gratitude') may be effective interventions for both blood and organ donation. Interventions designed to reduce fainting (e.g., water pre-loading) are also effective for blood donation. **Conclusions**: We conclude that affect is key to understanding both types of donation and in designing effective interventions.

#### **Definitions**

# What is Blood and Organ Donation?

People's health is influenced, in part, not only by their own behaviour (e.g., diet) but also by the behaviour of others. Some aspects of people's behaviour negatively impacts other's health (e.g., passive smoking), while other aspects have dramatic life changing benefits. Such life changing benefits are exemplified by blood and organ donation. Blood and blood products are derived from (1) whole blood donations (i.e., giving 450mls of blood), or (2) apheresis donations (e.g., where blood is drawn, platelets and plasma extracted, and the blood replaced in the donor minus these products). Organs similarly come from two avenues of donation: posthumous and living. Living donations are further divided into directed donation towards a family member, and *non-directed* (so called 'altruistic') donation towards a stranger (Table 1). All forms of blood and organ donation are traditionally viewed as altruistic. However, how strong is the evidence for the claim of altruism?

Altruism – Behavioural Definition: For all types of blood and organ donation, people give voluntarily, without personal gain, at some personal cost, to help a stranger in need (Ferguson, 2015; Ferguson & Lawrence, 2015; Ferguson & Masser,

2018; Steinberg, 2010). Specifically, whole blood and apheresis donors give blood voluntarily to benefit a stranger in need, but also pay a cost in terms of time, effort, blood loss, and undergoing a medical procedure. Posthumous organ donation occurs after death. Under an opt-in system (see later) there may be some emotional cost to registering on the organ donor register (ODR), as it forces the individual to confront their own mortality and bodily integrity (Morgan, Miller & Arasaratnam, 2002; Morgan, Stephenson, Harrison, Afifi & Long, 2008). Living organ donors can donate a kidney or a lobe of either their liver or lung. This incurs significant cost in terms of medical procedures, loss of an organ or part of an organ, and pain and recovery from surgery. For directed organ donation, there may be additional costs in terms of social interactions with relatives where the donor may feel coerced or obliged to donate (Gill & Lowes, 2008; Sharp & Randhawa, 2014)<sup>1</sup>. Evolutionary biology defines altruism as a behaviour that increases the fitness of the recipient (i.e., longterm survival and fecundity) at a cost to the donor's fitness (Bshary & Bergmüller, 2008; Sober & Wilson, 1998). Behaviourally, all types of blood and organ donation fit

<sup>&</sup>lt;sup>1</sup> There may also be an additional cost as in some cases the donor finds out that they are not actually related to their relative.

this definition. However, while behaviourally an act may appear altruistic, it may not be motivated exclusively by the needs of others (Sober & Wilson, 1998).

Altruism – Motivational Definition and Considerations: *Psychological altruism* focuses on the motivations underlying helping behaviour (Sober & Wilson, 1998).

Motivational definitions of altruism across economics, psychology and philosophy converge on the idea that *pure altruism* is either a preference, or an ultimate desire, to maximize the welfare (utility) of others, by reducing their suffering, at a personal cost, without personal benefit (Andreoni, 1990; Batson, 1991; Nagal, 1970). So, are blood and organ donors motivated by *pure altruism* or is there some *personal benefit*?

Ferguson (2015a) suggested a framework to understand and model these motivations that maps the mechanisms of altruism (MOA) derived from psychology, economics, biology, sociology, and philosophy (e.g., Andreoni, 1990; Batson, 1991; Fehr & Fischbacher, 2004a, 2004b; Fehr & Schmidt, 1999; Nowak, 2006) onto blood and organ donor motivations, preferences and behaviour. Drawing on the MOA

approach, behavioural economic analyses<sup>2</sup> of blood and organ donor preferences has revealed that both are not purely altruist (Ferguson, 2012a; Ferguson, 2015; Ferguson & Lawrence, 2018; Ferguson, Zhao, O'Carroll & Smillie, 2018). Rather blood donors are motivated by a general prosocial preference towards 'warm-glow' (Ferguson, Farrell & Lawrence, 2008; Ferguson, Taylor, Keatley, Flynn & Lawrence, 2012a). Warm-glow describes the feelings of positive affect that arise as a consequence of helping (Andreoni, 1990, 1995). Furthermore, Ferguson, Atsma, de Kort, and Veldhuizen (2012) identified a preference in blood donors they termed 'reluctant altruism'. Reluctant altruists help because they do not trust others to help. This is particularly the case in a context like blood donation where 96% free-ride on the generosity of the 4% of the eligible population who donate blood at any one time. The idea of reluctant altruism further suggests that blood donors are more likely to act when they perceive others as acting unfairly. Consistent with this, blood donors

<sup>&</sup>lt;sup>2</sup> The MOA approach recommends that behavioural economic games are used to assess these mechanism so as to avoid social desirability effects when simply asking people why they donate blood or register to be an organ donor (Ferguson 2015a; Ferguson & Lawrence, 2015).

have been shown to have an increased tendency to punish unfairness (Ferguson & Lawrence, 2018).

While for some there may be emotional costs to signing the organ donor register (Morgan et al., 2002, 2008), as the donor is deceased, the actual personal physical cost for posthumous organ donation is zero. This has led some to question its pure altruistic nature (Moorlock, Ives & Draper, 2014). Ferguson et al. (2018) reasoned that if this were the case, organ donors should have a preference for costless helping in general. Consistent with this reasoning, in a series of economic games to assess costless and costly helping, organ donors gave more generously in a costless game. Thus, some people may be drawn to posthumous organ donation due to its relative costless nature.

Directed living donors may feel coerced or obliged to donate to loved ones, which undermines the voluntary nature of the behaviour (Gill & Lowes, 2008; Lennerling et al., 2003). The non-directed donor also may gain personal benefits in terms of pride, admiration by others or self-esteem (Roff, 2007). In both cases, therefore, the notion of pure altruism is undermined.

Thus, we can see that all forms of blood and organ donation may be better described as acts of impure altruism.

## Impact of Blood and Organ Donation

For blood and organ donation there are impacts both on the donor (or their family) as well as the recipient, as discussed below.

#### **Blood Donation**

Impact on the Recipient: Health services could not operate without a continual supply of blood. This is used to treat a wide range of illnesses and disease processes. For example, from whole blood, red blood cells, among other things, are used to treat anaemia, sickle cell disease, thalassaemia, blood loss following surgery and trauma in child-birth, as well as in palliative care. White cells are used to treat immunodeficiency conditions. platelets to treat clotting deficient conditions (e.g., leukaemia) and immunoglobins and albumin, derived from plasma, to treat infections, as well as kidney and liver disease.

Impact on the Donor: Both positive and negative health effects have been reported for donors. There is increasing evidence that whole blood donation may

result in long-term iron deficiency (Brittenham, 2011; Di Angelantonio et al., 2017). Whether or not this is of clinical significance and its effects on long-term health are yet fully determined. There are also reported health benefits of donating blood with respect to: (1) reduced mortality (Ullum et al., 2015; Vahidnia et al., 2013), (2) better mental health in young donors and physical health in older donors (Rigas et al., 2017), and (3) reduced risk of myocardial infarction (Salonen, Tuomainnen, Salonen, Lakka & Nyyssonen, 1998). However, there is a potential *selection bias* (the '*healthy*' donor effect) in operation as blood donors are a self-selected healthier group (Atsma, Veldhuizen, Verbeek, de Kort & de Vegt, 2011). Yet even after controlling for the 'healthy donor effect,' there is still evidence of reduced morality (Ullum et al., 2015) and better self-reported health (Atsma et al., 2011) in blood donors, which may reflect healthier lifestyles amongst blood donors (Atsma et al., 2011).

# **Organ Donation**

Impact on the Recipient: Advances in transplant surgery and post-surgical medical care mean that post-transplant outcomes for patients are usually very good (National Health Service Blood and Transplant [NHSBT], 2017). However, there

currently exists a global shortage of organs for transplant, significantly impairing the health and well-being of those awaiting donated organs. In 2018 in the US more than 114,000 people were awaiting an organ transplant, around 20 of whom died every day (organdonor.gov), and in the UK, more than 6,000 people were on the transplant waiting list, approximately three of whom died every day (NHSBT;

Impact on the Donor: For the posthumous donor there is no direct impact, but there is impact for the relatives of the donor, who will be approached (both under opt-in and soft opt-out defaults) by a specialist nurse for organ donation (SNOD) to consent to their relatives' organs being used for transplant. This can be a very distressing time for family members who are coming to terms with the death of a relative and are then asked for consent for their relatives' organs to be removed and donated.

For living donation there are significant health impacts on the donor that arise from the removal of the organ, not just in terms of the surgery and immediate recovery, but also in terms of long-term health consequences. For example, persistent post-surgical pain is reported by over one quarter of living liver donors 12-months later (Holtzman et al., 2014).

# Prevalence of Blood and Organ Donation

#### **Blood Donation**

How many donate blood? Across Europe about 40% of people say that they have donated whole blood at some point in their lives

(<a href="http://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs\_333b\_en.pdf">http://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs\_333b\_en.pdf</a>).

However, while blood and blood products are available to all, at any one time only 3-4% of the eligible UK population donate blood. This figure is consistent across western style donation systems. At present, in the UK, whole blood donors can donate up to 4 times a year if male, and 3 times if female, while apheresis donors can donate up to 24 times a year.

How many donors are needed? Whole blood has a shelf life of 35 days and the UK National Health Service (NHS) requires 31 units of blood per 1000 of the population, per annum, to provide the efficient and safe delivery of health care (Blood 2020, NHSBT Annual Review 2012-13). To meet these healthcare demands, recruiting new donors, especially young donors, is an ongoing issue, with nearly 200,000 new donors required by the UK NHS yearly. New donors, compared to repeat donors, have a higher risk of fainting and higher incidence of red cell antibodies for transfusion-transmittable-infections (TTIs) (Lucky et al., 2013; Zou et al., 2012). Thus, converting 'new donors' into 'repeat donors' constitutes a significant saving in terms of recruitment costs, improved donor safety, and reduce waste in terms blood that cannot be subsequently used. However, the conversion rate from 1st to repeat donations is low, with only 7.2% making three subsequent donations (Schreiber et al., 2005), thus interventions to enhance conversion rates are needed.

While there has been a steady reduction in the demand for red cells across the world, due to better cell-salvage or operative procedures, this does not mean that recruiting new

donors and retaining repeat donors is not an on-going issue. Future shortfalls in blood supplies are predicted as the population ages (requiring more transfusions), the current donor pool ages out, and younger donors not being recruited to replace lost donors (Carter et al., 2011; Greinacher & Fendrich, 2010; Greinacher, Fendrich, Alpen, & Hoffman, 2007; Greinacher, Fendrich, & Hoffman, 2010).

Who is needed? With the genomic revolution, more detailed blood typing and matching offers the possibility of improved treatment options that require matching specific donors with particular blood types and antigens to specific recipients. Thus, recruitment becomes targeted on specifically needed donors, rather than an 'all-comers model'. This is exemplified by a world-wide need to recruit donors from minority groups (van Dongen, Mews, de Kort, & Wagenmans, 2016). A particular need is to encourage donors from Black, Asian and Minority Ethnic (BAME) backgrounds to improve the treatment of certain conditions (e.g., sickle cell disease: SCD), that have a higher prevalence in BAME communities (Shaz, Zimring, Demmons, & Hillyer, 2008). SCD requires repeat transfusions and are most effectively delivered with phenotype-matched red blood cells for the Ro Kell antigen to reduce haemolytic transfusion reactions (Shaz et al., 2008). The Ro Kell type has a much higher prevalence in BAME communities at approximately 55% in black Africans, 43% in black Caribbean, 17-24% in mixed race and 2% in white Caucasians, making phenotypic matching easier if the number of BAME donors increases. However, of the 4% of the UK population who donate, only 4% are from BAME groups (NHSBT Annual Review 2012-13). The UK NHSBT needs to recruit 40,000 BAME donors per year, with the current number approximately 15,000 (https://nhsbtdbe.blob.core.windows.net/umbraco-assetscorp/4481/nhsbt-strategic-plan-2017-2022.pdf.). Thus, interventions to encourage BAME donors is a pressing clinical need.

#### **Organ Donation**

How many donate? Currently, approximately 38% of the population are registered posthumous donors on the UK opt-in ODR. Furthermore, families/next of kin refuse to consent in 34% of requests for organs, often over-riding the wishes of potential donors (http://www.organdonation.nhs.uk/ statistics, NHSBT 2017-2018). This, and other factors (e.g., health of the donor's organs) means that only a very small proportion of deaths convert to organs donated. For example, in the UK in 2017-2018 from 600,000 deaths there were 7,281 potential donors which then reduced to 6,038 eligible donors. Of these, only 2,233 had actively opted-in and this eventually resulted in 1,574 actual donors (NHSBT, 2017-2018).

**Who are needed?** Ethnic minority groups represent 11% of the UK population, but only 7% of deceased organ donors (NHSBT, 2017-2018), and rates of consent from family members are lower than for white family members. As with blood donation there is an urgent need to engage BAME communities and explore reasons for the lower consent rates.

# Correlates of Blood and Organ Donation

#### **Blood Donation**

Theory of Planned Behaviour (TPB): TPB is the theoretical model most often applied to blood donor behaviour (Bednall, Bove, Cheetham & Murray, 2013; Ferguson, 1996). Within the TPB, intentions are the proximal predictor of behaviour, with intentions predicted by (1) attitudes, (2) subjective norms (i.e., people who are important to the donor approve of blood donation), and (3) perceived behavioural control (PBC: i.e., feeling able to donate despite possible barriers). Attitudes can be further split in to affective (i.e., anticipated and current positive or negative emotional

responses) and cognitive (i.e., pros and cons) (Trafimow & Sheeran, 1998). With respect to blood donation, the TPB has been extended to include descriptive norms (i.e. the perception of how many others perform the behaviour), self-efficacy, and donor role identity. Prosocial factors including *pure altruism*, *personal moral norms* (i.e. donors' beliefs that they *ought to help*), and *warm-glow* (termed 'satisfaction with self' by Bednall et al., 2013) have also been added. Bednall et al.'s (2013) metaanalytic review showed that intentions are the strongest predictor of blood donor behaviour (r = .362), followed by PBC (r = .311), attitudes (r = .216) and subjective norms (r= .165). Self-efficacy (r= .352) and role identity (r= .232) were also significant predictors of behaviour from the extended TPB. In terms of prosocial factors, personal moral norms (r = .188) and warm-glow (r = .097) both predicted actual donations, but pure altruism did not (r = -0.015) (Bednall et al., 2013; see also Ferguson, 1996).

Transtheoretical Model (TTM): Blood donors potentially progress through a 'donor career,' cycling through repeat donations (Ferguson, 1996; James & Matthews, 1993). Starting as non-donors, they then become 1st time/novice donors,

and if not deferred<sup>3</sup>, return to become repeat donors. This career structure makes the TTM a promising theoretical framework to describe the donor career and the types of intervention that may be appropriate at each stage (Ferguson & Chandler, 2005). The TTM consists of two main factors: stages and processes of change (Prochaska, DiClemente & Norcross, 1992). The model outlines five stages to progress through: (1) 'pre-contemplation' where individuals have no intention to change, (2) 'contemplation' where individuals are aware of the reasons to change and may weigh up the pros and cons, (3) 'preparation' where individuals are intending to take action in the next month, (4) 'action' where individuals have successfully achieved the desired behaviour, and (5) 'maintenance' where the desired behaviour is maintained for at least six months. Ten basic processes of change (e.g., consciousness raising) are proposed to facilitate the transition from one stage to the next (Prochaska & DiClemente, 1982), and can be explained by two higher order factors with respect to blood donation (Ferguson & Chandler, 2005): (1) experiential processes (e.g., cognitive and emotional strategies including dramatic

<sup>&</sup>lt;sup>3</sup> A person may be *permanently* (can never give blood) or *temporally* (can give blood after a designed time window) deferred from blood donation. Permanent deferrals occur if, for example, the person has had a blood transfusion (or blood products) since 1st January 1980. Temporary deferrals can be on grounds of anaemia, travel abroad, sexual behaviour, tattoos, or intravenous drug taking.

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relief i.e. "Dramatic portrayals about the consequences of a lack of blood donors upset me", social liberation i.e. "I know I'd feel better about myself if I was a blood donor"), and (2) behavioural processes (e.g., activity based strategies including stimulus control i.e. "I leave stickers / letters about blood donation in prominent places around my home" and counter-conditioning i.e. "When giving blood I try to think of something else"). Ferguson and Chandler (2005) further showed that the number of previous donations was positively predicted by behavioural processes and negatively predicted by experiential processes. Stage and process factors became uncorrelated as donors became more experienced, suggesting that helping donors develop behavioural strategies would be beneficial. Further support for the psychometric validity of the TTM with respect to blood donation has been reported (Amoyal et al., 2013; Burditt, et al., 2009).

Prosocial Emotions: Ferguson and Masser (2018) suggested that prosocial emotions are central to understanding blood donor behaviour, and used Haidt's (2003) concept of 'families of moral emotions' to categorize these. They argued that warm-glow (i.e. happiness) and pride (within the family of self-conscious emotions), are key emotions, with warm-glow predicting donor return (Bednall et al., 2013;

Ferguson et al., 2008; Piliavin & Callero, 1991), and more likely to be reported by experienced donors (Ferguson et al., 2012b). Ferguson and Flynn (2016) have shown, theoretically, that warm-glow can also be anticipated, making it equivalent to the concept of an anticipated affective reaction in the prosocial context. This is important as anticipated positive affective reactions have been shown to be significant predictors of blood donor behaviour (Conner, Godin, Sheeran & Germain, 2013).

*Pride* can be divided into *hubristic* (linked to arrogance and conceit), and *authentic* (linked to achievement) (Tracy & Robins, 2007). Authentic pride is linked to both prosociality (Tracy & Robins, 2007; Weiner, 1985) and warm-glow (Saito, 2015) generally, and recent evidence shows that plasma donors report authentic pride as a function of giving 'more' than whole blood donors (Bove, Bednall, Masser & Buzza, 2011).

Shame and guilt are also self-conscious emotions referring to the self-representation of personal wrong-doing. Guilt is private and behaviour-focused and shame public and self-focused (Amodio, Devine & Harmon-Jones, 2007). People are motivated to avoid the guilt of not acting prosocially or the shame of acting selfishly

(Saito, 2015), and both emotions lead to increased prosociality (Allpress, Brown, Giner-Sorolla, Deonna, & Teroni, 2014). Guilt has been identified as a key blood donor motivation (France, Kawalsky, France, Himawan, Kessler, & Shaz, 2014), and one that is linked to donating blood in emergency contexts (Chliaoutakis, Trakas, Socrataki, Lemonidou, & Papaioannou, 1994). The concept of *anticipated regret* at not donating is clearly linked to guilt and shame, with evidence showing that anticipated regret is a strong, positive predictor of both intentions to donate (Godin, et al., 2005) and actual donation (Godin, Conner, Sheeran, Bélanger-Gravel, & Germain, 2007).

The 'other-praising emotions' of *gratitude*, *awe* and *elevation* are all potential important predictors of blood donation. Of these, gratitude is likely to be significant.

There is extensive evidence that gratitude is linked to prosociality and both direct and indirect reciprocity (Ma, Tunney & Ferguson, 2017). Indeed, reciprocity towards the blood service and the donor, is a frequently cited motivation by blood donors (Bendall & Bove, 2011).

Fear and Anxiety: The emotions of fear and anxiety associated with donating blood have been shown to impact negatively on return rates by increasing the

chances of the donor fainting (Chell, Waller & Messer, 2016; Meade, France, & Peterson, 1996; Viar, Etzel, Ciesielski& Olatunji, 2010), or directly by fear and anxiety making people less willing to donate in the first place (Bednall & Bove, 2011).

Vasovagal Reactions: A consistent strong predictor of a donor not returning is the experience of feeling faint, or actually fainting (Ditto & France, 2006; France et al., 2014a; France et al., 2013; France, Rader & Carlson, 2005), which results in a 20% and 33% reduction in return rates amongst first time and experienced donors respectively (France et al., 2005 see also Bednall et al., 2013). Effects of fainting on return rates are not just confined to those fainting, but are also seen in those observing others faint (Ferguson & Bibby, 2002).

The Functional Model of Volunteer Behaviour: Omoto and Snyder (1995) and Clary et al. (1998) identified six functional motivations for volunteerism (Table 2).

Applied to blood donation more experienced donors express motivations that reflect avoidance of guilt at not donating, and strengthening of social bonds (Alfieri, Paolo, Marta, & Saturni, 2016; Paolo, 2013; Paolo, Alfieri, Marta, & Saturni, 2015),

**Self Determination Theory (SDT)**: Self-determination theory describes people as motivated along a continuum from extrinsic to intrinsic motivation (Ryan & Deci,

2000). Extrinsic motivation has four components that increase in personal autonomy from 'external regulation' (motivated by rewards), to 'introjected regulation' (avoidance of guilt), to 'identified regulation' (personally valued behaviour) to 'integrated regulation' (behaviours consistent with a person's life goals). Pure intrinsic motivations concern behaviours that are enjoyable and satisfying. France, Kawalsky and colleagues (2014) developed the Donor Identity Survey that assesses the fundamental motivation of SDT for blood donation. Table 2 shows how the motivations from SDT, the Functional Model of Volunteer Behaviour and MOA align with respect to prosociality. For example, intrinsic motivation from SDT and the enhancement motivation from the functional approach all assess warm-glow, as do affective attitudes. To avoid a 'jangle fallacy' (where by the same construct is given different names) in the area of prosociality, we propose that they should all be termed warm-glow as this is a fundamental MOA.

Personality: Bekkers (2006) showed that while trait helpfulness (i.e., being helpful and cooperative) predicted blood donation, traits of warmth (akin to agreeableness) and empathy did not. The lack of significant association between both traits of agreeableness and empathy with blood donation has also been

reported by others (Ferguson, 2008; Ferguson et al., 2008; Steele, et al., 2008). This lack of association with prosocial traits, in conjunction with the observation that repeat blood donation follows a career path, led Ferguson (2008) to reason that trait conscientiousness (linked to being organized) should predicted repeat donation.

However, while Ferguson (2008) shows that conscientiousness predicts the frequency and rate of past donations, the link between conscientiousness and reported future blood donation has not be established (see White, Poulsen & Hyde, 2017).

Deferrals: A person may be *permanently* (can never give blood) or *temporally* (can give blood after a designed time window) deferred from blood donation.

Temporary deferrals have a medium sized negative effect on return rates (Bednall et al., 2013).

**Donation Context**: The experience the donor has while donating blood may greatly influence subsequent donor behaviour. Ferguson (1996) showed that longer waiting times have a large negative effect on return rates (r = .417), while satisfaction with the quality of services has a positive effect on both return rates (r = .092) and intentions to return (r = .290) (Bednall et al., 2013).

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**Donor Experience (past behaviour)**: The number of previous donations has an important influence on donor return rates, intentions and motivations. More experienced donors, especially those who have made five or more donations, exhibit higher return rates (Bednall et al., 2013; Ferguson, 1996; Ferguson & Chandler, 2006). However, the link between past and future blood donor behaviour is complex and best represented by a quadratic inverted U shaped function, which is positive up to 60 previous donations, and then levels off and becomes negative (Ferguson & Bibby, 2002). Similarly, past behaviour influences the effects of intentions on future behaviour, such that the intentions-behaviour link is significant and positive for novice donors (4 or less donations), and not significant for experienced donors (5+ donations: Ferguson & Bibby, 2002; Sheeran et al., 2017). Indeed, an inverted U shaped quadratic function also explains this link between donor intentions and behaviour, with intention predictive up to a certain point of experience, and then dropping off (Sheeran et al., 2017). Experienced donors are also less likely to be adversely affected by temporary deferrals and more positively motivated by anticipated regret (Bednall et al., 2013).

# **Organ Donation**

Models of Organ Donation: A variety of models have been proposed to explain organ donor behaviour. Many focus on social cognition models (e.g. TPB) and have been recently reviewed by Falomir-Pichastor, Berent and Pereira (2013). The authors conclude that in addition to attitude and intention, 14 additional determinants of organ donation can be identified. Distal predictors of attitude and intention included demographic factors, cultural differences, religiosity, social insertion and personality factors. Proximal predictors of organ donation included behavioural beliefs, normative beliefs, self-efficacy, past behaviour, direct experience, affective reactions, social representations, identity and moral norms. Hyde, Knowles and White (2013) tested the utility of an extended TPB model and found that it explained 75% of the variance in organ donation intentions. Significant predictors in the final model included attitude, subjective norm, self-efficacy, selfidentity and in-group altruism. They concluded that future donation strategies should foster a perception of self as the type of person who donates and address preferences to donate organs to in-group members only.

The IIFF model (Siegel et al., 2010) propose that four factors are key to donation: (1) an *immediate* and complete registration opportunity ('ICRO' "a card in the hand"), (2) *information*, (3) *focused* engagement and (4) *favourable* activation.

Alvaro, Siegel and Jones (2011) tested one component of the IIFF, the ICRO, and found that simply providing an ICRO significantly increased organ donor registrations (see section below on community-based interventions).

Quick, Anker, Feeley and Morgan (2015) compared three models of organ donation behaviour – (1) Bystander Intervention Model (BIM) which emphasises bystanders' situational interpretation with respect to intervening to help others in need, (2) Vested Interest Theory (VIT) which positions vested interest as a moderator of the attitude-behaviour relationship, and (3) The Organ Donation Model (ODM) which was developed to take into account affective attitudes. They found that VIT accounted for most variance in organ donation registration intentions.

Attitudes of Potential Donors: Negative affective attitudes have been identified as important barriers to organ donation (Morgan et al., 2008; O'Carroll, Dryden, Hamilton-Barclay, & Ferguson, 2011, O'Carroll, Foster, McGeechan, Sandford, &

Ferguson, 2011) and shown to be stronger predictors than TPB variables (Morgan et al., 2008; O'Carroll, Dryden, et al., 2011; O'Carroll, Foster, et al., 2011) or knowledge (Morgan et al., 2008). These affective barriers include concerns that clinicians may not try as hard to save the potential donor ("medical mistrust"), disgust at the thought of donation ("ick factor"), that registering in some way hastens one's death ("jinx factor"), and discomfort at the thought of one's body being operated on for organ retrieval ("body integrity").

Personality: Relationships between the 'Big Five personality traits' (Costa, & McCrae, 1992; Goldberg, 1993) and organ donation behaviour have been explored, and the prosocial trait of agreeableness and its facets (e.g., cooperation, trust, empathy) have been linked to organ donor behaviour and intentions. For example, individuals registered to donate some specific, but not all organs, have been found to have higher warmth (agreeableness) (Bekkers, 2006), and higher agreeableness scores have been associated with positive organ donation attitudes and intentions (Hill, 2016). Altruism (a facet of agreeableness) has been associated with possession of a signed organ donor card (Kopfman & Smith, 1996), but was not

directly associated with Singapore residents' willingness to donate (Lwin, Williams & Lan, 2002)<sup>4</sup>, or the organ donor registration status of American students (Hill, 2016). In a meta-analysis, altruism (measured using generic scales that asses low cost unconditional altruism towards strangers) was associated with an increased likelihood of organ donor registration (Nijkamp, Hollestelle, Zeegers, van den Borne, & Reubsaet, 2008). Compassion and empathy (facets of agreeableness) have also been linked to intentions to donate (Demir & Kumkale, 2013). Thus, unlike blood donation there seems to be some linkage between unconditional altruism, empathy/compassion and organ donor registration.

Clinicians' Attitudes Towards Living Donation: Twenty-eight percent of UK kidney donations currently come from living donors (NHSBT, 2017/2018). There exists wide variation in non-directed living donation rates across transplant centres which may reflect clinicians' attitudes to non-directed donors, which are polarized between seeing them as extremely altruistic or psychiatrically disturbed (Henderson et al., 2003). However, comparisons of directed versus non-directed UK kidney

<sup>&</sup>lt;sup>4</sup> Singapore operates a priority system, with those on the organ donation register given greater priority to organs if needed. This powerful default is likely to over-ride other factors.

donors have found no difference in psychiatric history, personality, or current depression, anxiety, stress, self-esteem, or well-being. Importantly, no differences in donors' physical outcomes were found and non-directed donors recovered from the operation slightly quicker (Maple et al., 2014).

#### **Intervention to Promote Blood and Organ Donation**

#### **Blood Donation**

As there is a clear blood donor career, we explore interventions targeted prior to donation (to recruit and retain donors), as well as during donation (donor safety and satisfaction) (Ferguson, et al., 2007; van Dongen, 2015).

Interventions for Recruitment and Retention: A number of techniques have been used to enhance both recruitment and retention such as use of reminders (letters, texts, emails), social motivational interventions to enhance positive attitudes of altruism (usually messages and slogans such as 'do something amazing, save a life'), and techniques such as 'foot-in-the-door' (i.e. asking for a small commitment to donate initially, then for a subsequent larger one). A meta-analysis of these interventions undertaken by Godin et al. (2012) showed that, overall, reminders were quite effective (OR = 1.91, r = .69), as were foot-in-the-door techniques (OR = 1.86, r

= .68) and cognitive based social motivations (OR = 2.47, r = .77). Godin et al. showed that altruism-based interventions had the largest effect size (OR = 3.89, r = .89). However, while coded as altruism, Ferguson et al. (2007) had previously argued that these 'altruism' based interventions are in fact tapping 'impure' rather than 'pure' altruism.

Evidence suggests that feedback on the success of a prosocial act increases the likelihood of subsequent prosocial acts (Smith, Keating & Stotland, 1989). In blood donation, providing text messages to donors saying that their blood has been used, increases return rates by approximately 8% (Gemeilli, Carver, Garnm, Wright & Davison, 2018).

Making a plan after donating, indicating when and where the donor's next donation will be ('implementation intention') increases the likelihood of return donations (Godin et al., 2013 & 2014; Wevers, Wigboldus, van den Hurk K, van Baaren, & Veldhuizen, 2015). However, with appointment systems becoming more common, additional interventions are needed to enhance the motivation to return once an appointment has been made. Motivational interviewing is one promising possibility with evidence that a motivational interview increased personal autonomy

and intrinsic motivation, with both linked to increased likelihood of making a subsequent donation (France & France, 2018; France, France, Carlson, Frye, et al., 2017; France, France, Carlson, Himawan, et al., 2017). Finally, a recent feasibility study on the use of TTM stages and process tool to recruit blood donor has shown that such an approach would be acceptable and increase intentions to donate blood (Robbins et al., 2015).

While showing promise, all these interventions focus on "cold" cognition, while the above review suggests that affect is important. Furthermore, they are all based on an assumption that blood donors are pure rather than impure altruists. Below, therefore, we consider some promising avenues for interventions based on affect and the impure altruistic donor.

Evidence shows that *anticipatory* guilt (guilt arising in advance of a future transgression, which can be avoided), rather than *reactive* guilt (guilt experienced when a transgression takes place), predicts intentions to donate blood (Renner, Lindenmeier, Tscheulin, & Drevs, 2013). However, if the activation of guilt is perceived as manipulative ("if people like you do not donate then there will be shortages") it can lead to anger and reactance (Cotte, Coulter, & Moore, 2005). To

avoid this problem, Ferguson (2015a) and Ferguson and Lawrence (2015) suggested a form of message to engender prosocial guilt based on the models of inequality aversion (Fehr & Schmidt, 1999). Such a message would state: "As someone in good health, you can help someone whose health is not as good as yours by donating blood". There is some initial evidence that this form of message may be effective (Ferguson, 2015b).

As experiencing warm-glow becomes a more salient motivation in experienced donors, Ferguson (2015a) has argued that promoting warm-glow should be a more effective intervention for donor retention. Consistent with this, Ferguson et al. (2008) contrasted a warm-glow appeal with a pure-altruism appeal and showed that the warm-glow appeal increased willingness to donate in those who committed to donate blood. Further, interventions that reactivate the feelings of 'warm-glow' after donating are also a promising avenue to pursue (Ferguson, 2015). Currently an RCT is underway with the Australian Red Cross to test this (pre-registered with OSF: https://osf.io/r8dca/).

Similarly, a simple 'thank-you' that likely engenders feelings of *gratitude* should be an effective intervention (Ma et al., 2017) and there is some evidence, in

women, that this is the case compared to an implementation intention or reward (Myhal, Godin & Dubuc, 2017).

As blood donors can be characterised as impure altruists, financial incentives could be beneficial (Ferguson, 2015). While it has been argued that financial incentives (i.e., 'blood money') may de-motivate ("crowd-out") intrinsically experienced donors (Titmuss, 1970), framing the transaction as a 'social exchange' (i.e., the donor provides a 'gift of life' and the blood service thanks them with a gift), may be effective (Mauss, 1990; Sharp & Randhawa, 2014). This approach has been explored in two ways, either as a (1) 'gift voucher' in return for donation ('Gift Exchange: Lacetera, Macis, & Slonim, 2013, 2014) or (2) financial gift that can be donated to another health charity ('Charity Option': Mellstrom & Johannesson, 2008; Sass, 2013). The opportunity to help another charity in exchange for donating blood should provide the opportunity to gain extra warm-glow. When incentives were given for a pre-donation health check, evidence to-date suggests that a charity option has a neutral effect, while a financial exchange leads to crowding-out in female donors (Mellstrom & Johannesson, 2008). In contrast, when focusing explicitly on a financial 'gift exchange' there is empirical support that donor attendance is proportional to the

value of the gift card (Lacetera et al., 2013, 2014). While the financial 'gift exchange' seems promising, there is no real evidence for any systematic effects of other financial (e.g., tax relief) and non-financial (including time off work, cholesterol testing) incentives to donate blood (Chell, Davison, Masser & Jensen, 2018).

## Interventions During Donation to Enhance Donor Experiences and Health:

How the donor feels or reacts (vasovagal reactions) while donating blood influences both their intentions and actual return (Bendall et al., 2013). Vasovagal reactions also have implications for the donor's health at their time of donation. Diverting attention away from anxiety provoking stimuli can have significant benefits (Anderson, Baron & Logan, 1991). In the context of blood donation, donors who prefer avoidant coping strategies were less likely to experience negative reactions when watching a movie while donating blood, and those who preferred vigilant coping were neither helped nor harmed by watching the movie (Bonk, France & Taylor, 2001). Similarly, mixed detrimental and beneficial findings have been reported for the presence of "easy listening" background music as a function of donation experience and vigilance coping (Ferguson, Singh, & Cunningham-Snell, 1997).

Repeated, rhythmic contraction of major muscle groups of the arms and legs applied muscle tension (AMT) – has been used successfully to treat fainting reactions in blood and injury phobia (e.g., Ost & Sterner, 1987). AMT has been applied to prevent negative reactions in blood donors (e.g., Ditto, France, Lavoie, Roussos & Adler, 2003). Meta-analytic evidence shows that while AMT did not reduce vasovagal reactions as reported by the phlebotomist, it did result in a reduction in vasovagal symptoms (*Mean Difference* = -0.07, p = .02) (Fisher et al., 2016). Furthermore, AMT is effective when performed at key points across the donation process (when the needle is inserted, the needle is removed, and getting up from the chair) (Thijsen et al., 2018). There is some evidence that AMT increases intentions to return (*Mean Difference* = 2.87, p = .004), but not actual return behaviour (RR = 1.02, p = .64).

Based on evidence that healthy individuals show increased vascular constriction and arterial constriction after consuming water (Scott, Greenwood, Gilbey, Stoker & Mary, 2001), the effect of pre-donation hydration on the experience of vasovagal reactions has been examined in blood donors (e.g., Newman et al., 2006). Meta-analysis results show that pre-loading significantly reduces blood donor

vasovagal reactions as reported by the phlebotomist ( $RR \, 0.79$ , p < .0001), as well as vasovagal type symptoms (MD = -0.32, p = .001) (Fisher et al., 2016). There are no data at present linking water consumption directly to return rates. However, these techniques may have indirect effects on return rates via vasovagal symptoms and intentions (France et al., 2013).

Interventions Targeted at Specific Groups: Blood donation agencies face the need for increased specialization in donor recruitment to meet clinical needs. This is exemplified, as described above, by the need for increased donations from the BAME community. In terms of developing targeted recruitment campaigns for BAME donors, no unique cultural specific motivating factor that differentiates BAME donors/non-donors from non-BAME donors/non-donors has been identified (e.g., Burzynski, Nam, & Le Vior, 2016; Tran, Charbonneau, & Valderrama-Benitez, 2013). Altruism emerges as a motivator across all communities and may offer critical insights when considered within a cross-cultural perspective. First, BAME communities conceptualize altruism that focuses on reciprocity within the community rather than helping strangers, which is common in western cultures (Tran et al., 2013). Second, evidence shows that *lack of trust* in healthcare provision/medical

mistrust (Guerrero, Mendes de Leon, Evans, & Jacobs, 2015; Kimberly et al., 2013), and in transfusion services (e.g., Boenigk, Mews & de Kort, 2015; Boulware, Ratner, Cooper et al., 2002), is an important demotivating factor within BAME communities.

A focus on reducing medical mistrust would, therefore, appear to be a fruitful avenue to pursue for interventions in this context.

#### **Organ Donation**

Interventions for posthumous donation to-date have largely focused around legislative change (e.g., changing to an opt-out policy or prioritising transplant candidates who have shown commitment to organ donation: Sallis, Harper, & Sanders, 2018).

Legislative Approaches - "Opt-In Versus Opt-Out": Many governments have moved to an 'opt-out' default (i.e., presumed consent to organ donation, unless an individual actively opts out) from an 'opt-in default' (i.e., the default is to be a non-donor unless one actively registers). Some countries (e.g., Austria) have a "hard-opt-out system" where the registration will be followed, regardless of the families' wishes, whereas other countries (e.g., Spain) offer a "soft opt-out" system whereby families

of potential donors are given the chance to refuse (Reinders, van Kooten, Rabelink, & de Fijter, 2018).

It has been shown that, on average, changing the default to an opt-out system leads to an increase in donation rates (Bilgel, 2012; Johnson & Goldstein, 2003; Rithalia, Myers & Snowden, 2009; Ugur, 2015) and this change is supported by public opinion (Moseley & Stoker, 2015; Rockloff & Hanley, 2014; van Dalen & Henkens, 2014). However, while, on average, opt-out is associated with higher deceased donations, compared to opt-in, it is also associated with lower living donations (Shepherd, O'Carroll & Ferguson, 2014). Indeed, there are a number of other concerns about moving to an opt-out default that detract from its actualized effectiveness (see McCartney, 2017; Wellesley, 2011; Willis & Quigley, 2014). The main concerns (Table 3) with an opt-out system include: (1) an epidemiological focus on the average that obscures important cross-country variance, with many opt-out countries performing less well than opt-in countries, (2) reduced living donation rates, (3) difficulty interpreting what passively not opting-out means in terms of the donor's true preference to be a donor, (4) moral objections relating to 'state'

ownership of organs and lack of autonomy, (5) potential negative consequences of the 'lone wolf effect' whereby people are more likely to follow the lead of others deregistering, as signalled by posts on social media for example, and opt-out and (6) inability to establish causality. Furthermore, while the Spanish system is widely heralded as a great illustration of the success of an opt-out system, having now achieved 40 deceased donors per million (Matesanz, Gil, Coll, Mahíllo & Marazuela, 2017), Spain does **not** have an opt-out register for those who do not wish to become organ donors. The presumed consent law in Spain is thus dormant. In these circumstances, Spain's world-leading deceased organ donor rate cannot be attributed an opt-out system (Fabre, Murphy & Matesanz, 2010). Instead, the pioneers of the "Spanish model" attribute its success to three main features: (1) promoting early referral of donors from outside intensive care unit and incorporating the option of organ donation into end-of-life care, (2) expanding the criteria for organ use (e.g., from older donors), and (3) developing donation after circulatory death (Matesanz et al. 2017).

Many countries have implemented a soft opt-out system where removal of organs goes ahead only with family agreement. Indeed, under an opt-in system, the UK has one of the highest family refusal rates for organ donation in the world, with 34% of families currently refusing. This will possibly be higher under an opt-out system where it may be impossible for relatives to infer the true preference of the potential donor. While Vincent and Logan (2012) suggested a set of potentially modifiable factors relating to the family approach, the uncertainty that deemed consent brings is hard to overcome. Importantly, family members often later regret not giving consent (see Burroughs, Hong, Kappel & Freedman, 1998; Rodrigue, Cornell & Howard, 2008).

Increasing Registrations Within an Opt-in System: If an opt-out system does not solve the organ shortage problem, it could be argued that the focus should be to improve registration and donation rates under an opt-in system. Since 2009 under the UK opt-in system, there has been a steady annual increase in the number of registered donors, increasing from 16.1 million in 2009 to 24.9 million in 2018 (NHSBT, 2017-2018).

One option to further enhance this growth is by using *social media* (e.g., WhatsApp, Facebook, Twitter). Social media, as well as web-based and print media opinion and comment, play an important role in organ donor recruitment that can be capitalized on (Aykas, Uslu & Simsek, 2015; Bail, 2016; Bramstedt & Cameron, 2017; Brzezinski & Klikowicz, 2015; Cameron et al., 2013). A good example of this is a *Facebook* campaign that gave individuals the opportunity to post status updates with respect to their organ donor registration which resulted in increased registrations (Cameron et al., 2013). Thus, rather than an expensive change to an opt-out system, resources are perhaps better spend enhancing the opt-in system with social media used to increase registrations under an opt-in system.

Reciprocal altruism is another potential effective mechanism to increase organ donor registration under an opt-in system (Landry, 2006). Reciprocal altruism (direct and indirect) has a selfish component (Ma et al., 2017; Nowak, 2006), thus Landry proposed that campaigns should appeal to individuals' self-interest but balance this against their desire to do what is fair and just. He termed this voluntary reciprocal altruism (VRA). This is achieved by asking people to consider if they

would 'accept' an organ if they needed one, highlighting self-interest ('you may need an organ') and reciprocity and fairness ('if we do not register to give there may not be a sufficient supply for us all'). These ideas gained some support in a pilot study which showed that medical students' intentions to donate were higher following exposure to a VRA message (Landry, 2006). Developing on this, O'Carroll, Haddow, Foley, and Quigley (2017) and O'Carroll, Quigley and Miller (2018) showed that nonregistered participants exposed to a VRA message, compared to controls, reported greater intentions to register. The effect of VRA on behaviour (donor registration) was demonstrated by the results from a large scale (1 million participants) trial comparing nine different messages on UK driving license application web pages. A VRA message ("If you needed an organ transplant, would you have one? If so, please help others") was the most successful, followed by a loss framed message ("Three people die every day because there are not enough organs") (Sallis et al., 2018). Norm based strategies ("Every day thousands of people who see this page decide to register") were the least successful, and when combined with an image of people, norm-based strategies had a detrimental effect, resulting in a reduction in donor registrations (Sallis et al., 2018). The UK NHSBT advertising campaign currently

uses VRA, asking "If you needed an organ transplant would you have one?" (NHSBT, 2016).

Anticipated regret (AR) is an example of an anticipated affective reaction. Asking people to anticipate possible future regret is a potentially powerful behaviour change technique (Brewer, DeFrank & Gilkey, 2016). O'Carroll, Dryden, et al. (2011) and O'Carroll, Foster, et al. (2011) assessed the impact of a simple AR intervention, showing that intention to join the UK ODR was significantly higher for participants asked to rate possible AR compared with a control condition. However, a subsequent large-scale trial with 14,509 members of the Scottish public which measured actual registrations, found significantly *lower* registrations in the AR arm compared to a pure control (O'Carroll, Shepherd, Hayes, & Ferguson, 2016). In attempting to understand why the brief AR intervention led to a significant decrease in registrations, the authors speculated that as those in the active arms completed items assessing affective responses in relation to organ donation (e.g., jinx) and control participants did not, they were 'primed' to consider negative beliefs about organ donation. To test this possibility, Doherty, Dolan, Flynn, O'Carroll, and Doyle (2017) found that omitting negative affective items resulted in higher intention to

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donate organs and marginally higher rates of acceptance of organ donor cards (proxy measure of behaviour). These findings suggest that questions about negative affective responses require careful consideration and should probably be omitted in public health campaigns attempting to increase organ donor registration (Doherty et al., 2017).

Community Based Interventions: Golding and Cropley (2017) conducted a narrative systematic review of psychological interventions designed to increase the number of individuals in the community who register as organ donors. They identified 24 studies, 19 of which found a positive intervention effect, but only 8 were rated as being methodologically robust. The previously cited study by Alvaro et al. (2011), which provided an immediate registration opportunity (ICRO), was found to be the most effective with an OR of 5.9.

Primary Care Interventions: Pedder-Jones, Papadopoulos and Randhawa (2017) showed that successful interventions in primary care were characterised by active participant engagement and those that encouraged donation at the point of patient contact (ICRO).

"Myth-Busting": Myths or incorrect beliefs (e.g., "Doctors may not try their best to save my life if I am registered as an organ donor") are common deterrents of organ donation registration. Miller, Currie and O'Carroll (2018) recently evaluated the effectiveness of myth correcting interventions. They found that for participants who plan to opt-in to the organ donor register or passively register (deemed consent), dispelling myths acted to increase donor intentions. However, for the group the intervention is aimed at (i.e., those who plan to opt-out or are unsure), dispelling myths had no effect on intention.

Xenotransplantation: A very different intervention to reduce the organ shortage is to move to a source of organs other than humans: *Xenotransplantation* (Denner, 2014). Recent advances in engineering pig (the most suitable organism for xenotransplantation) organs have overcome many innate immune rejection problems (Denner, 2014). This combined with the promise of mixed-chimerism, a technique to reduce the burden of anti-rejection medication, means that xenotransplantation is becoming a real possibility (Sykes & Sachs, 2001; Yamada, Sykes, & Sachs, 2017). The potential endless supply of organs offers a real solution to the organ shortage

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(Harris et al., 2014; Hryhorowicvz, Zeyland, Slomski, & Lipinski, 2017). However, there is an urgent need to assess acceptability to patients and relatives.

Correlated Behaviours: Blood and organ donation behaviours are consistently correlated across countries (Ferguson et al., in press). This implies that recruiting organ donors from blood donors, or vice-versa, is a distinct possibility. Indeed, in some countries (e.g., Australia) blood donors are encouraged to become organ donors (https://www.donateblood.com.au/learn/organ-tissue-donation).

## **Common Themes**

While blood and organ donation are both health-based voluntary philanthropic acts, they are different in a number of ways (Table 1), have different predictors, and require unique interventions. There are, however, a number of communalities that can be identified across the two that suggest common themes.

Emotions and Empathy Gaps. A key emerging theme from the review on blood and organ donation is the role of emotional experiences. Such processes tend to be dynamic – blood donors cycle through a number of donations, and people consider registering as an organ donor and then register or not. Thus, we need to consider

this dynamic emotional journey and empathy gaps offer one theoretical tool to do this. An empathy gap emerges when people have difficulty in predicting how they will act in an emotional state different to their current one (Loewenstein, 2000). Important to this discussion are *prospective hot-cold* and *cold-hot* empathy gaps. Prospective gaps refer to how well people predict their future behaviour, when in a different emotional state to their current one. Hot-cold gaps are experienced when people in an aroused emotional state underestimate how their current emotions influence their decisions. In cold-hot gaps, people in a cold emotional state under-estimate how their emotions in an aroused state will influence their behaviour. There are cold-hot prospective empathy gaps in both blood and organ donation behaviour. For blood donation this focuses on people's prospective prediction that they may faint when donating blood. Indeed, the potential blood donor's emotional responses are very different depending on whether or not they can observe images and equipment associated with blood donation (Clowes & Masser, 2012; Masser, France, Himawan, Hyde, & Smith, in press), with anxiety being higher when blood donation paraphernalia are present. Similarly, cold-hot prospective empathy gaps are likely to be present in relation to deceased organ donation registration. That is, while people

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express a positive attitude towards organ donation (70% or more) in the UK, only approximately 38% register. Reflecting a possible cold-hot prospective empathy gap, people may feel more negative emotions when it comes to signing up on the organ donor register than they anticipated, and this is sufficient to prevent them from registering.

There are also hot-cold retrospective empathy-gaps in both blood and decease organ donation. The blood donor in the hot after-glow of donation, may over estimate their likelihood of return, but as they emotionally cool-off they may recall the donation less positively. Thus, interventions to enhance blood donors' recall of post-donation positive affect would be a useful avenue to pursue. Ferguson and Masser (2018) provide a detailed theoretical account of the application of empathy gaps to blood donor research. Applying hot-cold retrospective empathy-gaps may also explain why many family members express regret for earlier decisions not to consent to organ donation from their relatives (Rodrigue et al. 2008), as their decision was made in a hot emotional state and later reflected on in a cold emotional state.

Reciprocity. Another common theme is the role of reciprocity. Voluntary

Reciprocal Altruism (VRA) has been shown to be effective with respect to increasing registrations in deceased organ donor intentions (Sallis et al., 2018). The same approach is equally applicable to blood donation, with recent evidence showing that a VRA manipulation enhanced trust and reciprocity (Ferguson & Lawrence, 2018) and increased both donor and non-donors intentions to return (Ferguson, 2018).

## **Conclusions**

Clearly this review has clearly highlighted the central importance of both blood and organ donation for the effective provision of health care. We have argued that neither act is purely altruistic, and that affective responses (jinx factor, warm-glow) and reciprocity (VRA, reluctant altruism) are key to understanding both organ and blood donation, and are thus important components to consider in the development of effective interventions. We have highlighted that financial incentives (when appropriately framed) can be effective in the domain of blood donation as are warm-glow interventions. We further highlight that a move to an opt-out default may not increase the number of available organs for donation, but that focusing on

mechanisms to boost organ donor registrations under an opt-in default may be more successful, especially if combined with a VRA manipulation or social media updates.

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Table 1. Behavioural characteristics of Blood and Organ Donation

|                              |              | Organ Donation                        |              |                       |
|------------------------------|--------------|---------------------------------------|--------------|-----------------------|
|                              | Whole Blood  | Posthumou                             | Living-      | Living – stranger     |
|                              | Donation     | s                                     | familial     | (non-                 |
|                              |              |                                       | (directed)   | directive/altruistic) |
| Voluntary                    | $\checkmark$ | √                                     | $\checkmark$ | $\checkmark$          |
| Anonymous                    | $\checkmark$ | √                                     |              | $\checkmark$          |
|                              |              |                                       |              |                       |
| Single Act                   | $\checkmark$ | √                                     | $\checkmark$ | $\checkmark$          |
| Repeat Act                   | $\checkmark$ | √                                     |              | $\checkmark$          |
| Costly: Self                 | $\checkmark$ |                                       | $\checkmark$ | $\checkmark$          |
| Costless: Self               |              | √                                     |              |                       |
|                              |              |                                       |              |                       |
| Benefit: Stranger            | $\checkmark$ | √                                     |              | $\checkmark$          |
| Benefit: Relative            |              |                                       | $\checkmark$ |                       |
| O a marking Oissailla with a | I            |                                       | I            |                       |
| Genetic Similarity           | $\checkmark$ | \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ | $\sqrt{}$    | √                     |
| Phenotypic                   |              | √                                     | $\checkmark$ | $\checkmark$          |
| Similarity                   |              |                                       |              |                       |
| Feedback                     | $\checkmark$ |                                       | $\checkmark$ |                       |
| i eedback                    | V            |                                       | ·V           |                       |
| Free-riding                  | $\sqrt{}$    | $$                                    |              |                       |
|                              | ·            | ,                                     |              |                       |
| Obligation felt by           |              |                                       | $\checkmark$ |                       |
| recipient                    |              |                                       |              |                       |
| ·                            |              |                                       |              |                       |
| Surrogate                    |              |                                       |              |                       |
| Decisions                    |              |                                       |              |                       |

**Table 2**. Links Between Volunteer Function, Self-Determination Theory-motivations and Mechanisms of Altruism (see also Ferguson & Lawrence 2015)

| Volunteer     | Definition   | Self-Determination Theory         | Link to MOA                     |
|---------------|--|-----------------------------------|---------------------------------|
| Functions     |  | (SDT)                             |                                 |
|               |  | Motivations                       |                                 |
| Values        | Volunteers can express values of                   | Extrinsic: Identified regulation  | Pure Altruism                   |
|               | altruism/humanitarianism                           |                                   |                                 |
| Understanding | Volunteer can learn new skills that they would not |                                   | Self-Interest                   |
|               | normally have the chance to exercise               |                                   |                                 |
| Social        | Volunteer in activities that important others view |                                   | Reputation Building & Gratitude |
|               | favourably and strengthen social bonds             |                                   |                                 |
| Career        | Volunteering enhances career related goals         | Extrinsic: external regulation    | Self-Interest                   |
| Protective    | Volunteering is ego protecting by reducing         | Extrinsic: Introjected regulation | Inequality Aversion             |
|               | feelings of guilt from being better off            |                                   |                                 |
| Enhancement   | Volunteers grow personally and emotionally         | Intrinsic regulation              | Warm-Glow                       |

Table 3. Advantages and Disadvantages of an opt-out deceased organ donor registration system.

|                                   | Evidence  | Reference                                   |
|-----------------------------------|---|---|
| Advantages                        |   |   |
| Under opt-out more organs for     | Epidemiological evidence that countries with opt-out defaults, on     | Bilgel, 2012; Johnson & Goldstein, 2003;    |
| transplantation are available     | average, to have higher transplantation rates than opt-in             | Rithalia, Myers & Snowden, 2009; Ugur, 2015 |
|                                   | countries   | Shepherd, O'Carroll & Ferguson, 2014        |
| Power of defaults                 | The default option is on average selected by the majority             | Thaler & Sunstein, 2009                     |
| Positive public attitude          | Members of the general public are positively disposed to an opt-      |   |
|                                   | out system  |   |
| Disadvantages                     | _   |   |
| High donation variance: The       | For example, Sweden, Luxembourg and Bulgaria have opt-out             | Shepherd, O'Carroll & Ferguson, 2014        |
| range of donation/transplantation | default since 1996 yet remain lowly-ranked countries for organ        |   |
| rate varies widely by opt-out and | donation within Europe, and lower than many opt-in countries          |   |
| opt-in countries                  | such as England   |   |
| Negative impact on living         | Under opt-out default the number of living donations goes down.       | Fernandez, Howard & Krose, 2013; Shephero   |
| donations                         | This is especially the case for non-directed living donations         | O'Carroll & Ferguson, 2014                  |
| Individual presumed content is    | Passively not opting-out (deemed consent) does not provide any        | Beshears, Choi, Laibson & Madrian, 2008     |
| not interpretable                 | information about a person's true preferences to be a                 |   |
|                                   | posthumous organ donor. People may not opt-out because; they          |   |
|                                   | want to be a donor, they forgot to, inertia, or lack of effort. Thus, |   |
|                                   | there may be people who do not want to be a donor who are on          |   |
|                                   | the register by 'default'. This lack of certainty is problematic      |   |

|                                    | when it comes to asking for relatives' consent and this group will |  |  |
|------------------------------------|--|--|--|
|                                    | reflect a large percentage of donors registered under an opt-out   |  |  |
|                                    | system   |  |  |
| Moral concerns                     | There are public concerns around medical mistrust and              | Csillag, 1998 ; MacKay & Robinson, 2016    |  |
|                                    | reactance to State "ownership" of organs and lack of personal      |  |  |
|                                    | autonomy   |  |  |
| 'Lone wolf effects' – a reciprocal | In the world of social media there is evidence that updating       | Ferguson, Shichman & Tan, 2018             |  |
| effect where by people follow the  | Facebook status about being an organ donor greatly enhances        |  |  |
| lead of a person opting-out and    | registration under an opt-in system. Game theoretic analyses       |  |  |
| follow suit and this is a stronger | and data shows that an opposite and more powerful 'lone wolf       |  |  |
| effect than following the lead of  | effect' emerges under opt-out. Here when people share              |  |  |
| someone opting in ('A good         | information that they have decided to opt-out, it acts as a strong |  |  |
| Shepherd Effect')                  | social force resulting in others rapidly following suit            |  |  |
| Causal Status                      | The cross-sectional nature of the epidemiological evidence         | McCartney, 2017; Wellesley, 2011; Willis & |  |
|                                    | means that it is not possible to infer any real causal role to a   | Quigley, 2014                              |  |
|                                    | change to opt-out. While Shepherd et al. (2014) used               |  |  |
|                                    | instrumental variable to infer a causal role of an opt-out system, |  |  |
|                                    | this does not allow for an estimate the direct causal role the     |  |  |
|                                    | dynamic change from opt-in to opt-out and visa-versa.              |  |  |