How do people perceive organ donation? Using Q-methodology and post-Q

survey to examine views on deceased organ donation in the UK

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Publications and dissemination

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Abstract

There is a significant and chronically unmet need for donated organs from deceased donors. Despite generally positive views in the UK, donation rate remains low. It is imperative to understand what the public think about this issue if organ donation campaigns are to be effective and successful in addressing a particular group. This research investigates the public's views through a subjective perception of a network of barriers and motivators.

This research investigates the views on organ donation in the UK. This research is a mixed method research which consists of two studies: study one and two. Study one's objective is to identify distinctive views on organ donation in the UK using Q-methodology and interviews. Q-methodology uses qualitative and quantitative methods to explore the subjective perceptions of people in relation to a particular subject. Forty participants sorted 47 statements on organ donation on a Q grid. Factor analysis was then conducted using Centroid method and Varimax rotation. Six views were found but only four views were interpreted: The Realist, the Optimist Hesitant, the Convinced Pessimist and the Empathetic. Salient barriers to organ donation presented in each view suggest that perceived lack of knowledge, death anxiety, mistrust in the healthcare system and lack of cue to action are the main barriers to organ donation. Consensus statements suggest that religion and family agreement are inconsequential if attitude to organ donation is well formed.

Study two used post-Q survey method to identify the prevalence of each view in the UK. Self-categorisation to abbreviated factor descriptions (vignettes) method was used to transform Q-methodology views to four vignettes with 100-140 words each. A total of 385 participants were asked to rate and then rank four vignettes based on how much they reflect their view on organ donation. Results showed that the Empathetic view is the most common view in the UK, followed by the Realist, the Optimist Hesitant, and the Convinced Pessimist

successively. Results suggest no relationship between views and other demographic, social and organ donation attitude criteria.

This research demonstrated the importance of subjective perception in forming an attitude to organ donation. It suggests that 'one size does not fit all' when it comes to designing behavioural interventions, and subjective perception is an important variable in addressing low organ donation rate in the UK.

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1 Chapter one – Introduction

The UK's deceased organ donation rate in 2021 was 17.6 donors per million population, which is considered low compared to other countries such as Spain's 49.6 per million population (Statista, 2020). Donated organs are the only option for many patients with organ failure. Despite the widespread positive view on organ donation (Cox, 2015, NHSBT, 2019b, NHS, 2017) and the recent change in organ donation law in the UK from an opt-in to an opt-out system (Khiroya et al., 2021), donation rates remain low (as shown in Figure 1) (Statista, 2021), and especially since COVID-19 lockdown (Manara et al., 2020) as shown in Table 1.
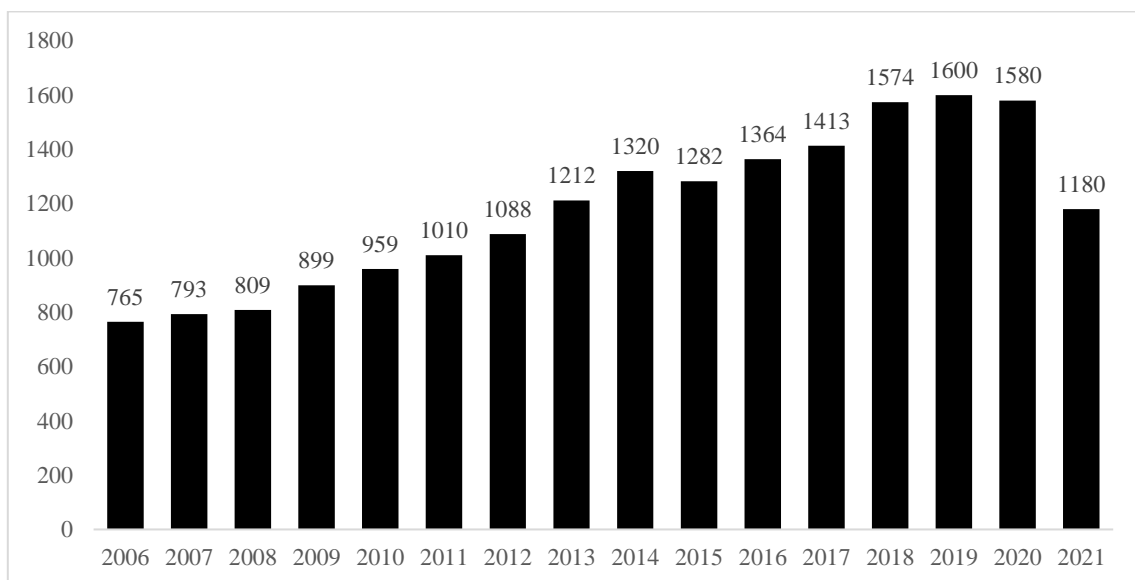
Figure 1 The number of deceased organ donors in the UK from 2005 to 2021 (Statista, 2021). The figure shows that despite the uptick in the number of deceased organ donors, the increase remains small, with a sudden decrease in 2020-2021 due to COVID-19 lockdown. Further information on that in Table 1.

COVID-19 had a determinantal effect on donation and transplantation rate. With the severe pressure on NHS resources and ICU beds, the healthcare system in the UK was overwhelmed. Furthermore, the pandemic heightened anxiety and caused major lifestyle changes across the world, which played a role in lower family approval rates as well,

donation rates were significantly lower in 2021 compared to previous years as demonstrated in Table 1.

Table 1 COVID-19 negative impact on organ donation rate and family approval (Manara et al., 2020). The table shows a nearly 66% decrease in the number of deceased organ donors in 2020 compared to the same period in the previous year.

Item	Lockdown (23.03.20-10.05.20)	Previous year (23.03.19-10.05.19)	% Change
Referrals to donation services (n)	585	963	-39·3
Total deceased donors (n)	71	208	-65·9

This research will review organ donation literature and identify limitations in the applications of theoretical models in behavioural interventions in the particular context of organ donation. The overall aim of this research is to advance theoretical frameworks in organ donation, in order to improve outcomes of behavioural interventions, hence addressing the empirical problem of low donation rates in the UK.

In this research, organ donation literature is discussed in four parts:

1. Literature on barriers to organ donation where main barriers and motivators are discussed and the impact of subjective perception of such barriers is explored. This is discussed in Section one – Barriers to organ donation.

Previous literature on organ donation found several barriers to organ donation, that includes religion, maintaining body integrity, death anxiety, mistrust in the healthcare system among other barriers. However, with a dominantly positive attitude towards organ donation (Cox, 2015, NHSBT, 2019b, NHS, 2017), it is vital to mobilise such a positive attitude towards relevant actions. To address that, it is necessary to explore new targeting strategies.

Organ donation actions may include registering as an organ donor (available for opt-out systems as well) and/or communicating a decision to be an organ donor to family and friends in order to improve family consent to organ donation, which is required to proceed with the donation. Research suggests that a barrier may be perceived differently, and it may

even act as a motivator sometimes. Subjective perceptions to barriers to donation have not been fully explored in organ donation.

2.   Literature on attitudes to organ donation are discussed in Section two - Attitude to organ donation. This section looks at models used to predict organ donation outcomes based on several factors such as demographic, psychological, and social characteristics. In this section, the relationship between cause and effect is not important, since the goal is to obtain good predictions. Predictive criteria are particularly important to support our understanding of relevant factors to organ donation decisions. Nonetheless, while predictive criteria can support small-scale interventions, organ donation is an important issue and requires further theoretical developments.

3.   In Section three – theoretical models used in behavioural interventions are discussed. Behavioural interventions aim at increasing the number of organ donors as well as increasing family approval rates to proceed with the donation. Using various models, they address several barriers to organ donation at community level. Changing attitudes towards organ donation for the potential donor themselves can positively influence post-mortem family approval as well (Liverman and Childress, 2006, NHSBT, 2021e).

4.   Section four – Evaluating implementation and reporting of interventions evaluates the conceptual and empirical issues in organ donation intervention studies. In this section, intention-behaviour gap will be discussed with its implications in organ donation context. Moreover, this section will evaluate the quality of evidence in intervention reporting.

Although empirically appealing, these models have several limitations in organ donation. Firstly, borrowed theories do not account for many variables specific to organ donation context. They describe general healthcare interventions and aim to understand the event with a small number of factors. These are not context-specific; they fail to explain why

and how different variables cause the behaviour. The borrowed models used in organ donation such as the Theory of Reasoned Action rationalise behaviour through social norms without taking into consideration the contextual behavioural barriers. Although borrowed theories may be effective in predicting organ donation behaviour, they fall short of explaining the behaviour and providing guidance for successful intervention.

Secondly, scholars found issues with model fit where small changes in one variable led to large changes in the outcome. To improve the fit of those models, scholars added various other variables guided by organ donation literature and created theoretical models that are specific to organ donation such as the IIFF and the Organ Donation Model. Those models have a better fit compared to the Theory of Reasoned Action and consider variables specific to organ donation context.

However, going back to the literature on barriers to organ donation (discussed in Section one), studies show a network of interrelating behavioural barriers and interacting motivators that shapes individual and social views on organ donation. They also show that one item can act as a barrier and a motivator depending on subjective perception. Yet, existing theories including the Theory of Reasoned Action, the Organ Donation Model, and the IIFF Model examine variables independently and fall short to investigate the pattern of overlap among different barriers and variables with no consideration to the role of subjective perception in shaping attitude to organ donation.

Consequently, the current literature is inadequate to produce effective interventions that have a significant and large impact in motivating people to donate their organs. Current models designed for organ donation context such as Organ Donation Model and IIFF continue to rely on social cognition and failed to fully explain the role of subjective perception in the decision-making process.

To develop more effective interventions in organ donation, this research aims to examine the subjective perception of behavioural barriers in organ donations. In Study one, Q-methodology is used to examine subjective views and elicit patterns of overlap among different barriers and motivators. It reveals different perspectives on organ donation based on assumptions derived from behavioural barriers perception, and further examines the similarities and differences between these perspectives. Thenceforth in Study two, in order to produce cost-effective interventions, a survey was conducted to examine the prevalence of each view in the UK. These results inform national interventions to target the most prevalent viewpoint.

1.1   Aim

Given the lack of research regarding subjective perception of barriers to organ donation in the UK, this study aims to identify how people in the UK perceive barriers to organ donation and how such a perception creates distinctive views. Views on organ donation further our understanding of barriers against organ donation and inform behavioural interventions to produce more targeted and effective approaches. Examining subjective perceptions on organ donation enhances our understanding of how people think about organ donation and offers insight into how they make the decision to be an organ donor. These insights inform policymakers and researchers to create strategic and meaningful interventions to increase organ donation and improve or save the lives of those in need of an organ.

1.2   Research questions

As is fully explored in the literature review chapter, there are several weaknesses in the existing literature. For example:

· There in an open problem in explaining the cause-and-effect relationship between behavioural barriers and motivators on one hand and attitude towards organ donation on the other hand.

· There is limited research to examine the patterns of overlap among barriers and motivators.

· There is limited research investigating the role of subjective perceptions of behavioural barriers in organ donation decision and attitude.

· There are a limited number of variables to account for non-cognitive variables in organ donation models.

This research will not address all these limitations, some are beyond the scope of this research. This research, however, will address two of these unexploited potentials. Accordingly, the research questions of the thesis are:

1. What are the subjective structures and perspectives on deceased organ donation of people residing in the UK?

2. How grouping people by subjective beliefs can inform behavioural interventions?

To answer these questions, several objectives guided this research:

· Research objective 1; to examine how people residing in the UK perceive deceased organ donation, and how people with similar points of views can be grouped together.

· Research objective 2; to examine the most influencing beliefs for each group.

· Research objective 3; to examine the prevalence of each view (group) in UK population.

· Research objective 4; to examine how views (groups) inform behavioural interventions.

These objectives will be addressed through the analysis of two studies; Study one; a Q-methodology study to explore behavioral barriers and motivators, their patterns in forming different views, and similarities and differences among these views. Ultimately, these views will be investigated in a large-scale survey in Study two to examine the prevalence of each view in UK population. These objectives allow for a thorough investigation of organ donation barriers and motivators and theoretically inform effective interventions at a national scale.

1.3   Contribution and limitation

The primary contribution of this research will be empirical. The outcomes of this research will assist in addressing the current limitations of research in this area and provide empirical real-world value to policymakers and researchers designing behavioural interventions in the UK.

Three specific barriers, namely, hesitancy, anxiety, and perceived lack of knowledge, were identified as main barriers to organ donation. Recommendations for intervention design will be addressing each of these barriers. Furthermore, this research will suggest that using motivators in intervention design might not be the most effective approach. The results of this research will be discussed to indicate why that is the case. This research will open the door to new research questions to be addressed in order to explore and enrich our current understanding of barriers to organ donation.

Associated with this, the research will make a theoretical contribution, conceptually, by integrating subjective perception with barriers to organ donation. A network view of attitude is theorised to be constructed through subjective perceptions and investigated in Study one. The research conceptualises subjectivity as an important component in shaping barriers to organ donation. It will enrich future theoretical frameworks in organ donation by introducing subjective perception as an important variable to investigate and change attitudes

to organ donation. Furthermore, this research contributes methodologically by using Q-methodology and post-Q survey. This research will be the first to use Q-methodology to examine attitudes to organ donation in the UK. Moreover, this research will develop post-Q survey to examine the prevalence of views on organ donation using vignettes.

Finally, this research focuses only on deceased organ donation in the UK. Moreover, there are several limitations related to Q-methodology context, sample, and factor interpretations. Post-Q survey limitations are also discussed in Chapter six – Discussion.

1.4 Chapter outline

This thesis comprises of six chapters. The first chapter is thesis introduction. Chapter two – Organ donation overview will introduce organ donation as a subject from a clinical and policy perspective. It explores the medical definition of death and introduces organ donation law in the UK.

In Chapter three – Literature review, existing literature on behavioural barriers, attitude prediction, theoretical models, and behavioural interventions in organ donation literature will be explored. Chapter three – Literature review is further divided into four sections:

- Section one – Barriers to organ donation where main barriers to organ donation is discussed.
- Section two - Attitude to organ donation further builds on barriers to incorporate barriers with demographic and social criteria to predict attitude to organ donation.
- Section three – introduces the theoretical models used to explain, predict and change organ donation behaviour.
- Section four – discusses behavioural interventions in organ donation.

This is then followed by

Chapter four – Methodology. It introduces two studies designed to answer the research questions: Study one - and Study two - Survey. In Study one, I propose Q-methodology to examine how behavioural barriers and motivators may be connected, and how people may hold a combination of positive and negative views at the same time. Q-methodology is commonly used to objectively examine subjectivity (Peritore, 1989, Zraick and Boone, 1991, Charmaz et al., 1995, Ho, 2017, Zabala et al., 2018). I show why Q-methodology can advance our understanding of organ donation views and how it can address some of the limitations in organ donation literature. I use Q-methodology to extract six views on organ donation in the UK, two views were excluded from further analysis for practical implications. Factor interpretation is supplemented by interviews to qualitatively enhance interpretation. In Study two, I use a survey method to investigate the prevalence of each view in the UK population.

Chapter five – Results discusses the main results of the two studies, and this is followed by Chapter six – Discussion in which I discuss the results of both studies and use the results to inform behavioural interventions. I show how such results can help identify cost-effective public campaigns and discuss further research opportunities. To the author's knowledge, this research is the first study on organ donation that aims to examine subjective views around organ donation using Q-methodology in the UK.

1.5   Chapter one summary

This chapter sets the underpinnings of this research by describing the outline of this research. The aims of the research have been defined. The structure of the literature review and the two studies are illustrated using a research overview diagram in Figure 2.

Chapter one: Introduction	Chapter two: Organ donation overview	Chapter three: Literature review	Chapter four: Methodology	Chapter five: Results	Chapter six: Discussion
Aim	Diagnosing death	Section one - Barriers	Study one: Q-methodology	Study one: Q-methodology	Main findings
Research questions	Organ donation process	Section two - Attitude			Study one findings
Thesis outline	Organ donation law	Section three - Theoretical models	Study two: Survey study	Study two: Survey study	Study two findings
		Section four - Interventions			Contribution
					Limitation

Figure 2 Thesis structure

2   Chapter two – Organ donation overview

Organ donation has been a success story in the history of medicine. It has created a new line of research and has brought new hope for hundreds of thousands of patients globally. It is the only option for many patients with organ failure with increasingly better survival rates (Smith et al., 2019, Rana and Godfrey, 2019, Kotecha et al., 2017). Organ donation can be medically divided into living and deceased organ donation. Deceased (or post-mortem) organ donation, which is the focus of this thesis, offers hope regarding critical organs such as the heart, brain, cornea and more. Whenever organ donation is mentioned in this thesis, it refers to deceased organ donation unless stated otherwise. Deceased organ donation occurs after circulatory or brain death. "Donation after Brainstem Death (DBD) is possible from patients whose death has been confirmed using neurological criteria" (ODT Clinical, 2021a) while "Donation after Circulatory Death (DCD) refers to the retrieval of organs for the purpose of transplantation from patients whose death is diagnosed and confirmed using cardio-respiratory criteria" (ODT Clinical, 2021b) which is the common way of diagnosing death.

A single deceased organ donor can donate up to seven organs, saving or improving the lives of up to seven recipients. Heart, lungs, liver, kidneys, pancreas, small bowel and tissue (such as skin, bone, tendons, eyes, heart valves and arteries) are organs that can be donated (ODT, 2021b). A single donor can add up to 55.8 additional life-years for recipients (Schnitzler et al., 2005). The total number of deceased organ donors in UK as of 9th April 2021 was 1,180 (766 donors after brain death and 414 donors after circulatory death) (ODT, 2021a). This is even lower than the previous year which was 1,580 donors (ODT, 2021a). The number of donors may seem like a large number until it is compared to the 5,937 people waiting for a transplant at the same time (NHS, 2021). People on the waiting list may never

receive an organ at all, as there is a chronic shortage of supplied organs. This shortage can be attributed to two reasons:

1. Shortage in organ supply:

    a. Low number of deceased organ donors.

    b. Poor harvesting procedures.

    c. Limited resources such as the number of available ICU beds or medical expertise.

2. Families of potential donors rejecting or blocking their loved ones' organ donation.

People hold different views on organ donation. Research found correlations to gender, age, religious beliefs, and many other criteria. Some may approve of living organ donation, but they might not accept deceased organ donation. Correlations between demographic criteria and organ donations views are discussed in Section two - Attitude to organ donation.

2.1   Diagnosing death

Death is defined as "irreversible loss of those essential characteristics which are necessary to the existence of a living human person" (Simpson et al., 2008). According to the Academy of Royal Colleges, death can be confirmed following either (Simpson et al., 2008):

1. The "irreversible cessation of brainstem function".

2. The "cessation of cardiorespiratory function".

For either situation, confirming death diagnosis must consider certain situations (Simpson et al., 2008):

1. "Aetiology of irreversible brain damage".

2. "Exclusion of potentially reversible causes of coma", such as:

    a. "There should be no evidence that this state is due to depressant drugs."

b. "Primary hypothermia as the cause of unconsciousness must have been excluded."

c. Potentially reversible circulatory, metabolic and endocrine disturbances must have been excluded as the cause of the continuation of unconsciousness.

3. Exclusion of potentially reversible causes of apnoea.

The cessation of cardiopulmonary function is accepted religiously and socially, and it represents the common diagnosis of death. Medically, criteria to confirm death by cessation cardiopulmonary functions are (Simpson et al., 2008):

· "The simultaneous and irreversible onset of apnoea and unconsciousness in the absence of the circulation.

· Full and extensive attempts at reversal of any contributing cause to the cardiorespiratory arrest have been made.

· One of the following is fulfilled:

   o the individual meets the criteria for not attempting cardiopulmonary resuscitation.

   o attempts at cardiopulmonary resuscitation have failed.

   o treatment aimed at sustaining life has been withdrawn because it has been decided to be of no further benefit to the patient and not in his/her best interest to continue and/or is in respect of the patient's wishes via an advance decision to refuse treatment.

· The individual should be observed by the person responsible for confirming death for a minimum of five minutes.

·   Any spontaneous return of cardiac or respiratory activity during this period of observation should prompt a further five minutes observation from the next point of cardiorespiratory arrest.

·   After five minutes of continued cardiorespiratory arrest the absence of the pupillary responses to light, of the corneal reflexes, and of any motor response to supra-orbital pressure should be confirmed."

Confirming death by brainstem death is a new and religiously and morally controversial area. The first country to accept brain death as a legal definition of death was Finland in 1975 (Kaste et al., 1979). The legal definition of death confirmed by brain death diagnosis differs among countries. In the UK, brain death is defined by cessation of brainstem functions. The brainstem is the lower part of the brain (as shown in Figure 3) and is responsible for breathing, heart beating, blood pressure and swallowing functions (Nicholls and Paton, 2009). In the USA, there have been several court cases rejecting brainstem death as a definition of brain death and necessitating the cessation of the entirety of brain functions (McGee and Gardiner, 2019).
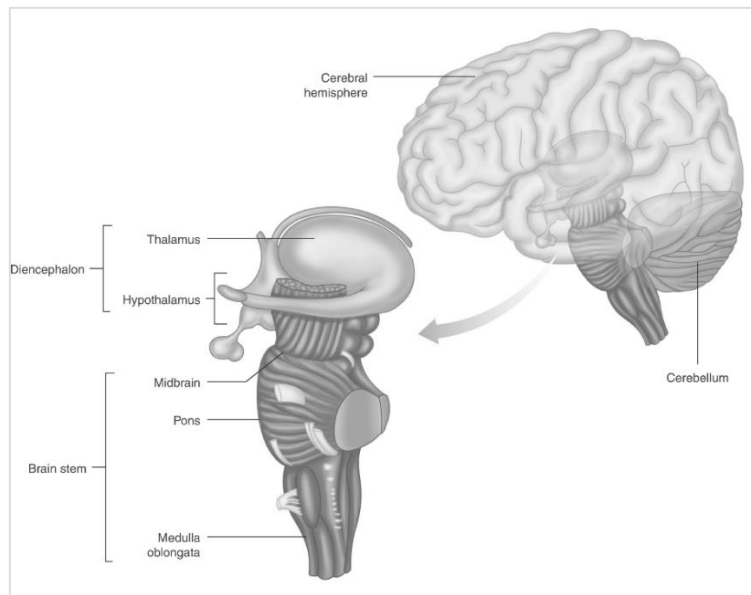
Figure 3 Brainstem (Malinowski, 2019). The figure shows the brainstem as the lower part of the brain. It consists of several parts and is responsible for vital body functions such as breathing and heart beating.

In the UK, confirming death following the irreversible cessation of brainstem death requires the following criteria (Simpson et al., 2008):

1. Absence of brainstem functions. This is confirmed by:

    a. "The pupils are fixed and do not respond to sharp changes in the intensity of incident light.

    b. There is no corneal reflex.

    c. No motor responses within the cranial nerve (providing motor and sensory supply mainly to the structures within the head and neck (Geibprasert et al., 2009)) distribution can be elicited by adequate stimulation of any somatic area.

    d. The oculo-vestibular reflexes are absent (this is a reflex that stabilises the gaze during head movement due to information from the inner ear (Simakurthy and Tripathy, 2021)).

e. There is no cough reflex response to bronchial stimulation by a suction catheter placed down the trachea to the carina, or gag response to stimulation of the posterior pharynx with a spatula.

f. The process for testing the respiratory response to hypercarbia (apnoea test) should be the last brainstem reflex to be tested and should not be performed if any of the preceding tests confirm the presence of brainstem reflexes.

2. When comprehensive neurological examination is not possible, a confirmatory neurophysiological or imaging investigation may be used.

3. The diagnosis of death by brainstem testing should be made by at least two medical practitioners who have been registered for more than five years and are competent in the conduct and interpretation of brainstem testing."

From the above criteria, we can conclude that brain death diagnosis requires detailed investigation by experts and has been reliable for 45 years so far. Brain death is irreversible and untreatable, and it can only survive on mechanical ventilation. Discontinuation of mechanical ventilation will result in complete cessation of all body function within minutes.

It is important to differentiate between brain death and other conditions that cause loss of consciousness such as vegetative state caused by various conditions such as hypothermia, intoxication, high spinal cord injury and locked-in neurological syndrome (Ronco et al., 2017). A person who is in a vegetative state is not dead and may or may not recover (Young et al., 1989).

There are several cases with reported "miraculous" recovery from brain death diagnosis such as the case reported in the USA of Zack Dunlap who had an accident in 2007 and was declared brain dead (Shewmon, 2021). The case was 'undocumented' hence it does

not represent a recovery from brain death but rather a negligible misdiagnosis. Another case

reported in the USA was that of Trenton McKinley, who recovered after a brain death

diagnosis (Wijdicks, 2015). It is unclear if he was merely thought to be brain injured or

actually brain dead, and by what criteria. Several similar cases represent poor reporting or

miscommunication. When all guidelines are followed, there have been no cases of recovery

or misdiagnosis of brain death ever reported (Starr et al., 2021).

2.2   Organ donation process

Before 2020, the organ donation law was an opt-in system in the UK. Those who

would like to donate can register online or can request a form from their GP, and a form for

organ donation registration is automatically posted when people apply for a driving licence in

the old opt-in system. The new opt-out system assumes that everyone is registered; however,

people can still register their decision on the NHS Blood and Transplant website. One would

register decision to donate in the opt-out to ensure that their decision is documented and to

help the deceased family to approve the donation with ease (Liverman and Childress, 2006,

NHSBT, 2021e). Once donors are registered for the first time, they receive a donation card

they can carry around with them (NHSBT, 2021f). Organ allocation is also managed by NHS

Blood and Transplant (NHSBT) through comprehensive allocation policies to ensure fair

allocation (Robinson, 2017). Race, ethnicity, and social status are not determinants of

allocation (NHSBT, 2021g). Recipients from all backgrounds have similar chances of

receiving an organ (Quick et al., 2016b).

BAME groups (Black, Asian and Minority Ethnics) represent 16% of the UK

population (ONS, 2011), yet they only make up 3.5% of organ donors (NHSBT, 2018).

"Black and Asian communities are more likely to develop conditions such as high blood

pressure" (NHSBT, 2021c), hypertensive nephropathy and certain forms of hepatitis than

white people (Hull et al., 2011). Type 2 diabetes is more prevalent in Asian and African groups compared to the white population (Riste et al., 2001, Forouhi et al., 2006). This makes them more likely to need a transplant. However, BAME groups represent 23% of recipients and 7% of donors (NHSBT, 2018, NHSBT, 2020b). Thus, it is important to discuss barriers to organ donation in BAME groups, especially as the perceived barriers to organ donation may vary according to ethnicity.

Families of BAME groups are more likely to veto organ donation of their loved ones (Barber et al., 2006), and while the consent rate in Black and Asian communities is improving, it remains considerably lower than that in the white group (NHSBT, 2020a). With the blood and tissue matching problems, it is easier to find a match from a donor from the same ethnicity (NHS, 2020b). It is more probable that a Black or Asian recipient receives an organ from a white donor than the other way around as "1,800 Black, Asian and minority ethnic patients are currently waiting for a transplant" (NHS, 2020b).

2.3   Organ donation law

"All it will do is increase the number of people on the organ donation register."

- *Yiling Lin (School of Biological and Chemical Sciences, 2018)*

The system for organ donation in UK used to be an opt-in system (Shepherd et al., 2014), which meant that donors had to register at NHS Organ Donor Register and share their decision with their families in order to be an organ donor. The Organ Donor Register (ODR) holds confidential records of decisions to donate (donors and non-donors who refuse to donate) (NHS, 2018b). Internationally, 23 countries operate with an opt-in consent system and 26 with an opt-out consent system (Shepherd et al., 2014).

2.3.1 Rationale for opt-out system

In 2014, only 58% of donations were approved by families in the UK, and 48% of all donations were blocked by the families' decision not to proceed; that is compared to rates of family approval exceeding 80% in some European countries (Council of Europe, 2014). If the person is registered as an organ donor, 91% of families agree to organ donation compared to 43% if their relative is not registered (BBC, 2018). Still, one in eight deceased *registered* donors get rejected by the family in the UK (Iacobucci, 2016), which led NHS Blood and Transplant to look for other ways to reduce the number of families unsupportive of their relatives' decision to be a donor. They did this by introducing the opt-out system.

A survey shows that 81% of the UK population supports organ donation, yet only 34% register (NHS, 2017). Other studies show similar results (Cox, 2015, NHSBT, 2019b). An opt-out system might close the disparity between intention and actual registration rates (Shepherd et al., 2014). It works by 'nudging' people through defaults into the desired action (Thaler, 2008), increasing loss aversion by sticking to the default option (Kahneman et al., 1991) and minimising cognitive effort (Johnson and Goldstein, 2003). People support defaults (Davidai et al., 2012) as they assume they are the recommendations of the policymakers and they address a certain problem (Mckenzie et al., 2006, Johnson and Goldstein, 2003).

The severe shortage in organ donation and the long waiting list where people die waiting for an organ led the UK government in February 2018 to pass the bill for an opt-out system nationally, and on 22 May 2020, organ donation law has been changed from opt-in to opt-out system. The opt-out system allows National Health Services, Blood and Transplant (NHSBT) to approach families for their consent and may nudge people into accepting the default option to be a donor. In this system, people can opt out (i.e., register their intention

NOT to donate), and adults will be presumed to be organ donors unless they have specifically recorded their decision not to be.

2.3.2   Soft opt-out system

In the soft opt-out system implemented in the UK, deceased donors' families are approached for consent. Although legally, they do not have the veto vote to stop the process, the NHS consider the donation to be inappropriate if it causes distress to grieving families, hence the process is stopped (NHS, 2018a). The 'soft' opt-out system was first implemented in Wales in December 2015 on a trial basis (Mc Laughlin et al., 2018). The soft system requires consultation with the patient's family, and according to the bill, the family is not required to give their own consent, rather they have to communicate and provide evidence that the patient's wishes would be not to donate, and in the absence of that evidence, donation lawfully proceeds. Evidence in Wales suggests that family authorisation increased between 2014 and 2018 from 44% to 65%, although this cannot be traced solely to the opt-out system (Young et al., 2017). In 2015/2016, 5% opted out, and in 2016/2017, 6% opted out (Young et al., 2017). Miller et al. (2018) found that around 10% of the UK population plan to opt out or are not sure about their decision once the opt-out system is implemented. In 2019, consent rates for white patients and patients from BAME communities were 77% and 44%, respectively (NHSBT, 2019a). Table 2 shows the consent and authorisation rate to donation rate across the four nations in the UK.

2.3.3   Family approval in the opt-out system

There is another body of research, although limited; examining the level of family authorisation for organ donation before and after changing the system, and it indicates that the opt-out system increases the family authorisation by around 20% (Bilgel, 2013). Evidence based on approaching families suggests that in order to decrease family rejection, we need to

improve awareness and encourage conversations with the family to record one's wishes to

donate (Young et al., 2017). Similarly, research suggests that families are more likely to

authorise donation if their loved one's wishes have been communicated and are well known

(Walker et al., 2013, Long et al., 2008).

Table 2 A four-nation comparison of Consent and Authorization Rate (1 April 2019 - 31 March 2020) – Source (NHSBT, 2021b). This table shows that donation rate remains the highest in Wales. The table further shows family's consent rate which indicates similar rates of consent in all four nations. Consent rate shows that an average of 35% of all organ donations are blocked by families. Interestingly, this table shows that, on average, consent rate after circulatory death is lower than that of donation after brain death, despite the organ donation literature showing great misconception when it comes to understanding and accepting brain death and putting brain death misinformation at the forefront of barriers to organ donation. This suggests further research should be conducted to explore the relationship between consent rate and death diagnosis.

Nation	Deceased Organ Donors (Per Million Population)	DBD* Consent Authorisation Rate (%)	DCD** Consent Authorisation Rate (%)	Overall Combined Consent Authorisation Rate (%)
England	23.5	72.3	65.2	68.3
Northern Ireland	26.1	65.4	62.5	64
Scotland	18.4	74.8	55.2	64.8
Wales	27.1	74.6	66.7	70.7

* Donation after brainstem death
** Donation after circulatory death

2.3.4 Nudging and Rationality

Carefully designed defaults could help trigger what is considered an ideal behaviour

by easing complication when it is difficult to make a choice, reducing analysis burden by

restricting the number of choices. Nudging is commonly used in policies through establishing

defaults. Nudging by defaults (or the Default effect) is defined as "change in likelihood that a

particular alternative is chosen when designated as the default versus a control condition

when no default is designated" (Brown and Krishna, 2004). Defaults increase the desired

behaviour through different mechanisms such as forming a preference towards the desired

behaviour. Defaults implicitly advise on the desired outcome and establish a habitual experience for the desired behaviour. Nudging by defaults works better when people share similar views, preferences, and environments. When they vary considerably in their opinions and views, it becomes difficult for default systems to achieve higher impact on public behaviour (Productivity Commission, 2015). Preferences in the organ donation context may vary, and that poses a significant challenge on the effectiveness of default nudges. Nudging by defaults might work for a certain group of people better than others. We do not fully understand how to group people based on their presences (views) on organ donation.

Nudging by defaults is driving motivation behind changing the donation law in the UK from an opt-in system to an opt-out system. Opt-out systems are often referred to as 'presumed consent' (English and Sommerville, 2003). In the opt-out system, everyone is an organ donor by default unless they opt out. Despite the potential of an opt-out system to increase donation rate, it is far from a magic solution. It suggests that organs will be harvested unless the person has registered an objection against that.

Ethically, nudging has significant implications on people's agency, which is most relevant to policymakers. Opt-out systems shift the responsibility of donation decision from those who want to register to those who don't want to register (Saunders, 2010), and from the individual to their families. By discouraging potential donors from documenting their donation decision, we are relying on confused and emotionally stressed family members to decide on their behalf in perhaps one of the most difficult times in their lives.

2.3.5 *Awareness and opt-out system*

There is a low level of awareness about organ shortage (Department of Health and Social Care, 2016). Evidence from Wales suggest that the opt-out system itself, and the publicity and campaigns associated with it (Young et al., 2017), might increase awareness of

organ donation especially at implementation phase, however, there is very limited research to support that conclusion (Niven and Chalmers, 2018). Studies show that there is a lack of awareness about the opt-out system as well (Johal et al., 2018, Shepherd et al., 2014, Organ Donation Taskforce, 2008b). A study by Johal et al (2018) shows that among the Sikh community, 58% had not even heard about the opt-out system. The lack of awareness and possible misunderstanding of the system might trigger negative attitudes towards organ donation.

Shepherd et al. (2014) found that if people are unaware of the nation's legislation, there is no change in willingness to donate between opt-in and opt-out systems. By contrast, people who are aware of the opt-out system are more willing to donate in an opt-out system (85.2%) than an opt-in system (81.7%) (Shepherd et al., 2014). There is a small body of research that suggests an opt-out system increases the public willingness to donate (Mossialos et al., 2008). However, there is limited evidence to examine intentions before and after opt-out system implementation (Niven and Chalmers, 2018, Steenaart et al., 2020).

2.3.6   *Opt-out efficacy*

There is contradictory evidence on the effectiveness of opt-out systems in increasing organ donation rates (Gill, 2004, Kennedy et al., 1998, Egan, 2017, Organ Donation Taskforce, 2008a, Parsons, 2019, Miller et al., 2020, Arshad et al., 2019, Costa-Font et al., 2020). In a systematic review by Rithalia et al (2009), they concluded that there was an increase in organ donation rate in all of the five included studies. Other studies show an increase in donation between 13-18% (Bilgel, 2013) and 25-30% (Abadie and Gay, 2006). However, there is limited evidence that an opt-out system, in isolation, can increase organ donation (Niven and Chalmers, 2018, Fan and Wang, 2019).

The current available research on opt-out systems is not specific. It does not differentiate between the organ donation rates from living versus deceased organ donors or have any specific figures for specific organ transplantation rates (Shepherd et al., 2014). There is also no research to examine the effect of the opt-out system on religious groups, with limited research examining the attitude of minority groups before and after the opt-out system is established (Johal et al., 2018). The research on the effect of opt-out system on donation rate is "inevitably observational" (Shepherd et al., 2014). The possible increase in organ donation might be for a variety of reasons associated with the implementation of the opt-out system such as improved donor identification criteria, surgical procedures and improving hospital capacity (Shepherd et al., 2014), the associated media coverage with the legislation change (Niven and Chalmers, 2018) and other changes in policy that might benefit from better examples such as Spanish model described below, such as creating team liaising across different trusts to help educate, improve and communicate better procedures and campaigns for organ donation.

There are several reasons why people might not opt out despite their objection to donate their organs (Saunders, 2010). The aforementioned lack of awareness might play a role in not opting out (Iacobucci, 2020). In addition, people might forget to register their option or simply change their mind (Saunders, 2010). Harvesting one's organ without explicit informed agreement might discourage genuine donation (Randall and Downie, 2012). The opt-out system might spur an avalanche of public contempt (McCartney, 2017), and brain death cases have caused similar negative public media as well (Dyer, 2018). This might directly push more people to opt out and register their intention not to donate (English and Sommerville, 2003). Moreover, a recent study showed that switching to an opt-out system increases the salience of emotional barriers despite informative attempts to bust the common myths associated with organ donation (Miller et al., 2018).

The relationship between the donation rate and the policy is far from being simple and straightforward. In Brazil and France, introducing the opt-out system had deteriorated the trust in the medical system, and led to a decreased transplantation rate (Shepherd et al., 2014). The Brazilian government had to withdraw the opt-out system due to public concern (Csillag, 1998). In Chile, switching to an opt-out system significantly lowered the family authorisation rates (Kottow Lang, 2016). Finally, countries like Bulgaria, Turkey, Cyprus, and Greece have all implemented an opt-out system, yet those countries are the lowest countries in organ donation rates in Europe.

Spain is currently leading the world in terms of rates of organ donation (Baraniuk, 2018, Scholz, 2020). The current system in Spain is an opt-out system; however, as Shepherd et al. (2014) put it, "it may be too simplistic to state that the introduction of opt-out consent will increase deceased donation rates". While Spain established the opt-out system in 1979, the new system did not have a significant impact on the organ donation registration rates for over 10 years (Fabre, 2014). It was not until 1989, when the Spanish Ministry of Health founded the Organización Nacional de Trasplantes (ONT), which is responsible for the management of donation and transplantation activities in Spain, when the registration rates started to increase to its current rates of 43.4 individual donors PMP in 2016 (Govan, 2017) compared to 23.9 PMP in the UK (NHS, 2018c). Spain's model combines organisation restructuring (Cuende et al., 2007, Govan, 2017), building trust in the medical system through restructuring and training (Matesanz, 1992, Matesanz, 2003, Tsai et al., 2019), and improving communications between the professionals and the public to improve registration rates (Domínguez-Gil et al., 2010).

There is a strong body of research urging to address the shortage of organs from different angles, highlighting that legislation alone cannot solve the whole problem (Niven and Chalmers, 2018, Sharif, 2015, Noyes et al., 2019). Other approaches might aim to

increase public awareness (Young et al., 2017), encourage conversations, increase hospital

capacity (Campbell, 2018), increase transplant coordinators (School of Biological and

Chemical Sciences, 2018) and improve health staff knowledge about organ donation.

2.4   Organ donation during COVID-19

The opt-out system in the UK has been active since 20 May 2020 (NHS, 2020d). In

the midst of an unprecedented pandemic, it is difficult and rather unfair to judge the impact of

the opt-out system on donation rate under the COVID-19 crisis that has swept the UK since

2020. NHS Blood and Transplant has planned an awareness campaign simultaneously, but

with the pandemic, it is understandable that the media prioritised news on the pandemic over

the new donation system. This resulted in many people in the UK who might be unaware of

the new legislation.

During the crisis, donors were checked for COVID-19 and were excluded if they

tested positive. NHS capacity affected the rate of transplantation, although transplantation

surgeries continued when it was safe and appropriate (NHS, 2020a). However, due to the

pressure on the healthcare system, transplantation procedures were significantly reduced and

donation rates dropped in the UK (Parsons and Moorlock, 2020). All these unprecedented

circumstances greatly affected the rate of donation and transplantation. Judgement on the

benefit of the opt-out system will have to take longer than expected.

3   Chapter three – Literature review

3.1   Chapter introduction

There is a chronic shortage of organ supply that will continue to be the case due to a continuously increased demand for several reasons including: organ transplants being an effective management of diseases, multiple transplantation sometimes being needed for a single person, and the long-term risk of rejection and eventually the need for another transplantation (Jox et al., 2015) and the fact that not all donors will have the opportunity to actually donate their organs after death as there are certain criteria to be met for donation to occur (Cheetham et al., 2016), as shown in Table 3. There are several social and religious barriers against organ donation, and there is a potential lack of awareness and a history of mistrust in the medical profession (Mekkodathil et al., 2019). Combined, they all form barriers against organ donation. This resulted in, among other reasons, similar patterns of shortage of organ donation not just in the UK but globally.

The aim of the literature review is to identify limitations in existing literature and areas not previously covered in order to develop appropriate research questions. A literature search was conducted using electronic databases including Web of Science, PubMed, Scopus, Ovid, and PychInfo using the term "organ donation" in the article title. These search terms were applied to articles only, published from 2000 onwards. Most of the research has been conducted in USA. With a significantly different demographic composition and a healthcare system compared to the UK, this may propose a certain limitation in generalising assumptions derived from such studies into this study which aims at investigating organ donation in the UK. However, most studies conducted in the UK share common outcomes with those conducted in other countries. In this study, results from studies conducted in other countries such as the US will be included with a keen consideration to the major differences

in demographic representation of the two countries and the differences in healthcare system.

For examples, concerns about the cost of surgical procedures related to donation will be

excluded.

Table 3 UK potential deceased organ donor population on 1 April 2018 – 31 March 2019 (NHSBT, 2019a). The table shows that only 0.27% of all deaths end in organ donation. Not all deaths can result in donation, only those that occur in hospitals (to ensure organs have blood supply). This is then filtered down by medical eligibility to donate. Finally, families of eligible donors are approached to consent to donation where some of them refuse to donate the organs of their loved ones.

Criteria	Number
UK population	66,000,000
UK deaths	600,000
Deaths in hospitals	290,000
Potential donors	6,991
Eligible donors	5,815
Donation requests	3,245
Consented donors	2,279
Actual donors	1,600

The literature review chapter will be divided into four sections. Section one – Barriers

to organ donation will discuss the behavioural barriers and motivators in organ donation. I

will show the complexity of barriers and motivators with; in certain situation; inconsistent

and unpredictable interactions among various barriers. I will also show that one item (such as

religion, or recipient criteria) may be perceived as a barrier by one person and a motivator by

another, depending on subjective perceptions.

This will be followed by Section two - Attitude to organ donation. This section will

describe the characteristics that are associated with positive attitudes towards organ donations

and may be used to predict attitude. I will describe several demographic, psychological, and

social criteria that can predict organ donation attitude, intention, and/or behaviour. I will

explore the impact of subjective perceptions in shaping attitudes to organ donation by showing how and why such criteria may be related to organ donation behaviour.

Section three – Behavioural models in organ donation will describe the theoretical models used in organ donation. I will describe three types of models:

1. Social cognitive models which are commonly used in healthcare and organ donation. Those models however have poor predictability in organ donation, therefore, scholars attempted to add various non-cognitive variables and other predictive criteria into social cognitive models to create models with better fit.

2. Organ donation models: scholars have incorporated barriers to organ donation (discussed in Section one), predictor to attitude (discussed in Section two) with social cognitive models (discussed in Section three) to create models that can better predict organ donation attitude and/or behaviour.

3. The third type of theoretical foundation discusses the application of Q-methodology in organ donation.

Section four – Evaluating implementation and reporting of interventions discusses behavioural interventions in organ donation. I will discuss the quality of evidence and the intention-behaviour gap that forms a significant issue in conducting effective interventions. I will discuss the reasons behind this gap and potential strategies to reduce it. I will also discuss the effectiveness of educationally based intervention and the impact of nudging in irrational and poorly formed decisions.

3.2   Section one – Barriers to organ donation

3.2.1   Introduction

In this section I will examine the behavioural barriers and motivators to organ donation. I will show that barriers to organ donation are "intractable" and complex (Irving et al., 2012b). Organ donation decision is under the influence of many barriers and motivators. Scholars identified several main themes that are commonly cited as barriers to organ donation: religion (Yoon, 2018, Rady, 2019, Rabinowich and Jotkowitz, 2018, Lim et al., 2020, Krupic et al., 2019, Krupic, 2019, Arisal and Atalar, 2020, Voyce, 2020), body integrity (Morgan et al., 2008a, Newton, 2011, Irving et al., 2012a, Mahat-Shamir et al., 2019), death anxiety (Wittig, 2001, Wang, 2020, Wu and Tang, 2008), knowledge (Çevik et al., 2018, Alsharidah et al., 2018a), medical profession (Fahrenwald and Stabnow, 2005, Bhengu and Uys, 2004, Molzahn et al., 2004, Williamson et al., 2017, Frates and Garcia Bohrer, 2002, Scott and Quick, 2012, Albright et al., 2005), and recipient (Molzahn et al., 2004, Frates and Garcia Bohrer, 2002, Molzahn et al., 2005b, Wang, 2020, Newton, 2011). Studies also show several variables that motivate organ donation; the most cited variable is altruism (Dixon and Abbey, 2000, Ryckman et al., 2004, Morgan et al., 2008a).

Barriers and motivators do not exist in isolation, they can be viewed as nodes, with dynamic interactions. The nodes and their interactions create a network that shapes attitude towards organ donation. While it is empirically helpful to examine barriers and motivators independently to ascertain each variable's influence on behaviour, research clearly shows a considerable intersection that lies within the network of barriers and motivators. Few studies have attempted to uncover this connection, and few have attempted a systematic approach to reveal its patterns.

Table 4 shows qualitative studies exploring barriers to organ donation and Table 5 shows the quantitative studies. Evidently, religion and body integrity concerns are the most

commonly cited barriers to organ donation. Within each theme, I will show the multifaceted nature of the barrier. For example, religion can be a strong barrier to organ donation; however, if someone believes their religion supports organ donation, religion becomes a motivator. To add another layer, I will show that people from the same religion might perceive religion's view on organ donation differently depending on their ethnicity, which suggests that historical health inequality may play a role in shaping normative beliefs.

This multi-layered and manifold nature of barriers to organ donation compels us to further explore barriers to donation as key to designing effective behavioural interventions. Later in this chapter, I will argue that interventions in organ donation must reflect the multifaceted nature of the barriers they aim to break. By the end of this chapter, I will argue that interventions in organ donation literature must be based on models that are relevant and theoretically informed.

Table 4 Overview of qualitative studies on barriers to organ donation. The table shows the barriers communicated in qualitative studies as barriers to organ donation. This list is by no means exhaustive, and other qualitative studies might not have been included in this table. I categorised it into five main themes and subcategorised each theme. The table shows that religion and body integrity concerns are most frequently expressed. Mistrust in the healthcare system appears to be a prominent barrier to organ donation as well. More importantly, this table shows that there are many barriers to organ donation and people can express many concerns; however, qualitative studies fail to show which barrier is more important to individuals and how these barriers co-exist and intersect with each other.

Author, Year	Themed Barriers																	
	Religion and Body						Death		Medical Profession			Recipient			Awareness and Knowledge			
	Body Integrity	Funeral	Jinxed	fatalism	Mutilation	Body and Soul Connected	Do not want to think about it	Too Young	Intentional Harm	Mistakes	System	Worthiness	Ethnicity and religion	Family and Friends	Unaware	Info	Need	My organs are damaged
Sanner, 2001	+						+							+				
Wittig, 2001	+			+			+							+				
Frates and Garcia Bohrer, 2002	+					+	+		+	+	+				+			
Kennedy, 2002	+			+			+					+			+			
Moloney and Walker, 2002	+	+							+	+	+							

Hayward and Madill, 2003	+	+		+			+		+	+	+	+	+	+			
Bhengu and Uys, 2004	+	+		+			+		+		+		+	+	+		
Davis and Randhawa, 2004	+			+			+		+		+	+		+	+		
Molzahn, Starzomski et al., 2004	+	+		+			+		+		+		+	+	+		
Albright, Glanz et al., 2005	+	+					+			+	+					+	
Alkhawari, Stimson et al., 2005	+	+		+			+		+	+	+	+	+				
Fahrenwald and Stabnow, 2005	+	+									+			+			
Molzahn, Starzomski et al., 2005		+		+			+		+		+		+	+			
Arriola, Perryman et al., 2007	+								+	+	+	+		+			
Lai, Dermody et al., 2007	+						+										

Morgan, Harrison et al., 2008	+	+		+			+		+	+	+	+			+			
Quick, LaVoie et al., 2012	+	+	+		+	+	+	+	+		+	+			+	+	+	+
Williamson, Reynolds-Tylus et al., 2017						+			+		+	+	+			+		+
Pfaller, Hansen et al., 2018					+	+			+	+	+				+	+	+	
Krupic, Westin et al., 2019														+		+		
Krupic, 2019	+															+		
Soon, Lim et al., 2019		+									+			+	+	+		
Wang, 2020	+	+			+		+		+		+	+						
Siminoff, Bolt et al., 2020	+		+			+	+		+		+							
Umair, Ho et al., 2020						+	+	+							+	+		

Table 5 Overview of quantitative studies on barrier to organ donation.The table shows the barriers communicated in quantitative studies as barriers to organ donation. Like Table 4, this list is not exhaustive. I categorised it into five main themes and subcategorised each theme. In a similar picture to Table 4, this table shows that religion and body integrity concerns are most frequently expressed. Quantitative studies also failed to explore patterns of barrier overlap.

Author, Year	Country	Sample	Recruitment	Barriers Themes					
				Religion and Body	Medical Profession	Death	Awareness and Knowledge		Recipient
Alden and Cheung, 2000	USA	752	Asian American and European American aged 16-60	+	+				
Morgan and Miller, 2002	USA	798	Random adult sample in a large corporation				+		
Bresnahan, Lee et al., 2007	Korea, Japan, and USA	426	19- to 29-year-old students						
Lam and McCullough, 2008	USA	150	Attendees of a non-denominational Chinese American church in the Houston, TX	+					+
Saleem, Ishaque et al., 2009	Pakistan	440	Convenience sampling	+			+		
O'Carroll, Foster et al., 2011	UK	151	Adult students and staff	+	+	+			

Author	Country	Sample	Population					
Tam, Suen et al., 2012	Hong Kong	362	Full-time nursing students of undergraduate and master programmes in a university	+				
Khalaila, 2013	Israel	563	College students	+			/	
Wu, Tang et al., 2013	Japan	667	Undergraduate students			+		
DuBay, Ivankova et al., 2014	USA	87	Registered donors and non-registered adults	+	+	+		
Chakradhar, Doshi et al., 2016	India	298	Dental students	+			+	
Ginossar, Benavidez et al., 2017	USA	200	American Indian, Hispanic, and Asian American	+				
Hinck, Naelitz et al., 2017	USA	326	Minority men	+	+		+	
Ríos, López-Navas et al., 2017	USA	1524	≥15 years Latin American immigrants	+			+	
Alsharidah, Al-Dossari et al., 2018	Saudi Arabia	643	Health professional and general public		+	+	+	
Katz, Blekher et al., 2019	UK and USA	777	Registered organ donors and unregistered adults		+		+	
Lim, Cheng et al., 2020	Malaysia	400	Patients who registered at an outpatient clinic (convenience sample)				+	
Arisal and Atalar, 2020	Turkey	724	University students	+			+	
Alsalem, Fry et al., 2020	Saudi Arabia	423	Adult users of social media	+		+		

+ Significant - / Not Significant

3.2.2   Themes of barriers to organ donation

3.2.2.1   Religion

Religiosity is defined as "society-based beliefs and practices relating to God or a higher power commonly associated with a church or organized group" (Egbert et al., 2004). The role of faith is recognised to play an important part in the decision to donate organs (Yoon, 2018, Thorson, 1991, Slabbert et al., 2011, Randhawa and Neuberger, 2016, Randhawa et al., 2012, Randhawa, 1998, Rady, 2019, Rabinowich and Jotkowitz, 2018, Lim et al., 2020, Krupic et al., 2019, Krupic, 2019, Khalaila, 2013, Güden et al., 2013, Frunză et al., 2010, Davis and Randhawa, 2006, Arisal and Atalar, 2020, Voyce, 2020). Despite the fact that most religions support organ donation (Randhawa et al., 2012, Cai, 2013, Slabbert et al., 2011, Joshi, 2020) and the concept of altruism is embodied by all religions (Neusner and Chilton, 2005, Barber, 2010), religion often materialises as a barrier to organ donation.

The relationship between religion and organ donation is evidently an intricate matter. Many variables can affect the perception of religion's view on organ donation (Yoon, 2018). Religious beliefs influence attitudes towards organ donation, positively or negatively (Demir and Kumkale, 2013). While religion can act as a strong barrier against donation, the belief that one's religion allows organ donation was significantly associated with the willingness to register as an organ donor (Khalaila, 2013, Saleem et al., 2009, Krupic, 2019). This suggests that religion may act as motivator to organ donation. However, studies show that the perception or religion to support organ donation may not be the best predictor to organ donation behaviour; sociodemographic features may play a significant role in determining behaviour (Ahmed et al., 2018). This suggests that while religion may play a strong and significant role in shaping views on organ donation, it is not dissociated from many other variables.

Religion may facilitate organ donation behaviour by advocating for altruistic behaviour. A few studies showed a positive relationship between religiosity and organ donation where religion may act as a direct facilitator to organ donation, or indirect by facilitating altruistic behaviour exemplified by organ donation (Dixon and Abbey, 2000, Ryckman et al., 2004, Morgan et al., 2008a). On a study on African American women, a participant said: "If you are a good person, you can pretty much do anything, 'cause you always got God there. To me, that is all life is worth. And if my child needed my kidney, my child got my kidney. It wouldn't be no hard decision for me, because I'm not going to use my parts so somebody living might well use them, child or not" (Wittig, 2001).

On the other side of religions' effect, most studies cite religion as a barrier to donation. The 'perceived' dismissal of religions to organ donation is negatively related to the decision to donate one's organs (Saleem et al., 2009, Ralph et al., 2016, Aksoy, 2001, LaFleur, 2002, Besser et al., 2004, Wu and Lu, 2011, Ríos et al., 2017, Ríos et al., 2018). However, people perceive religions' stance on organ donation differently depending on several demographic criteria. The influence of religion on organ donation decision varies considerably based on different sociodemographic features. For Christians, African Americans identify religion to be against organ donation significantly more than the white population (Morgan et al., 2003, Ginossar et al., 2017), and the same applies to the Hispanic population (McNamara et al., 1999, Alden and Cheung, 2000).

Generally, Muslims perceive Islam as a barrier for donation more than Christians (Khalaila, 2013). For Muslims, it is vital to know the Islamic standpoint (Randhawa, 1998, Hayward and Madill, 2003). In a study by Alkhawari (2005), a participant articulated: "Our local scholars are like the supervisors whom we cannot ignore" (Alkhawari et al., 2005). However, Islam scholars continue to hold conflicting views on organ donation (Ali and Maravia, 2020). Although Eduardo and Ferreira (2019) found that 85% of surveyed adults

stated that their decision to be a donor or not would be affected by their religion in the first place, religion remains a major barrier against organ donation (Tarabeih et al., 2020). Randhawa (2012) showed that not all Muslim leaders interviewed were against organ donation in principle.

Fatwa is an Arabic word which is translated into "a verdict or judicial" (Hossain, 2002). In Islam, it is considered as a ruling on a certain issue of Islamic law issued exclusively by "an authorised religious scholar" (Hosen, 2008). The work on issuing a *fatwa* first started in 1959 (Bårr, 1994), but since then, the work between the UK government and Islamic institutions has not stopped.

Knowledge and ethnicities combined with religion shape the perception of religion as a barrier to organ donation. Morgan et al. (2006) found that in the UK, knowledge and awareness are lower in ethnic minorities compared to white ethnic groups. Muslim groups may include Asians, Arabs, and other ethnicities. Randhawa (1998) showed that religion and cultural beliefs are perceived to be weak barriers to organ donation in contrast to previous beliefs regarding Asian groups; however, being aware of an individual's religious stance on organ donation for Muslim groups has been shown to be important (Hayward and Madill, 2003).

It is tricky to completely separate religion's effect and social norms (Platteau, 2015). Barriers to organ donation that are perceived to be related to religion may, in fact, reflect cultural attitudes that transcend religion (Truog, 2005). Studies with Chinese participants show firm beliefs that their religion would not allow it and a person must be buried with a whole body (LaFleur, 2002). In research on Chinese Canadians, a man stated: "Most of them [Chinese] are Buddhists, and even if they become a Christian, they still believe in old traditions and that's reincarnation. And if you lose part of your body, you're not a whole body so you can't go to heaven. And if you got part [of] your body, somebody who donate it

who is a bad person, you can't go to heaven either" (Molzahn et al., 2005a). It is important to examine the motive of following certain religious instructions in relation to organ donation to ascertain whether it is a genuine obedience to religion or out of respect to tradition and society (T Stephenson et al., 2008). The opposition of religions to organ donation may stem from concerns over body integrity, disrupted funeral procedures or brain death issues. "Religious obstacles to organ removal include fears that organ donation precludes an open casket funeral, that it delays funeral proceedings, and that the absence of particular organs at the end of this life will have ill-effects in the afterlife" (Radecki and Jaccard, 1997).

Different religions are perceived to oppose declaring death based on brain death (Rady, 2019, Verheijde et al., 2018, Yanke et al., 2016, Miller, 2016, Voyce, 2020). Christianity accepts the irreversibility of brain death (Tarabeih et al., 2020) but opposes declaring brain-dead people as dead, arguing that the body functions such as nutrients digestion, sexual maturity and other body functions can continue to work in brain-dead people (Nguyen, 2019). Other Christian groups argue that the continuation of body function was only made possible by medical instruments advancement and support and would not be possible otherwise. Hence, brain-dead people are, in fact, dead but their body functions are only supported by machines (Nguyen, 2019). Other religions such as Islam and Judaism continue debating brain death as a criterion for death. In Islam, some groups would consider brain death as an intermediate state between life and death while other groups accept it as an equivalent to death (Padela et al., 2013). The irreversibility of brain death supports the acceptance of brain death as dead in Judaism; however, Rabbis continue debating this issue (Tendler and Rosner, 1989). Religions vary in accepting brain death as reversible, hence, accepting brain death as a definition of death as shown in Figure 4.

Fundamentally, this raises two questions:

1. Is the patient really brain dead? Is brain death reversible?

2. Is the brain dead patient really dead? (Jox et al., 2015).

While the first question can be answered rather technically by updating and improving medical diagnosing techniques, the second question is concerned with beliefs that are rather tricky. Further details on brain death and body integrity as barriers will be discussed in the following sections.

Body integrity, religious funeral procedures (such as the myth that organ donors cannot have an open casket funeral), brain death definition in religions, cultural values and sociodemographic features are all related to the influence of religion on organ donation behaviour. This suggests that religion may affect even non-religious people by indirectly shaping normative beliefs on organ donation. It is concluded that the relationship between religion and organ donation behaviour is multidimensional, and it is difficult to disentangle that web of barriers and examine them independently. This proposes multi-collinearity issues, and it undermines the statistical significance of the independent variable in these studies.
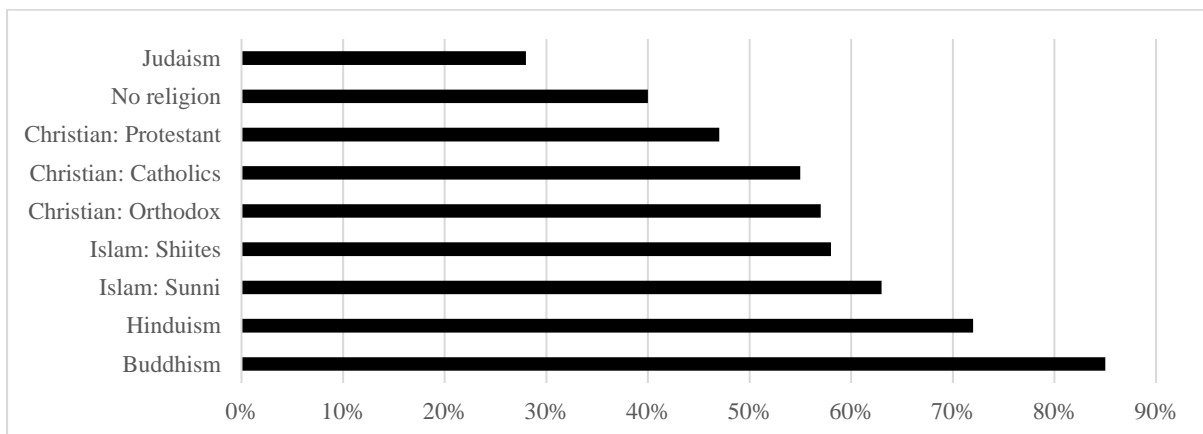
Figure 4 Percentage of people supporting the irreversibility of brain death grouped by religion. The figure shows that people from most religions reject the irreversibility of brain death. It is worth mentioning here that, medically speaking, irreversibility of brain death is not a matter of

debate. This figure shows that even medical 'facts' are perceived differently based on other criteria. This supports the argument that organ donation is irrational.

3.2.2.2   Body integrity

Ideas about the physical integrity of the body plays a major role in the decision-making process of potential donors and their families. Spigner et al. (2002) found that 29% of participants flagged "the body should remain whole!" as a reason not to donate. The body integrity concept may be examined directly (Quick et al., 2012, Arriola et al., 2007, Lai et al., 2007) or presented as fear of mutilation (Pfaller et al., 2018, Ríos et al., 2017). Body integrity concerns negatively affect the willingness to donate (Morgan et al., 2008a, Newton, 2011, Irving et al., 2012a, Mahat-Shamir et al., 2019), and this negative relationship extends to include family approval of donation even if it is against the will of the deceased (Mahat-Shamir et al., 2019).

People react negatively towards the idea of a 'defiled' body that may act as a significant factor against organ donation (Kopfman et al., 1998, McConnell, 1999, Skumanich and Kintsfather, 1996, Wang, 2020); for example, a woman described: "Well, I really don't know too much about the tradition but, you know, from the movies I've seen and all that I know, when you die, you want your whole body together, like everything buried together. Um, so, I think that's probably ingrained in my mind about not donating my body parts" (Molzahn et al., 2005a). In Chinese culture, the idea that "the body is a gift from one's parents and should be well cared for to show respect to one's parents" plays a significant role in organ donation decisions (Li et al., 2019).

Like religion, body perception may act as a barrier to or motivation for organ donation. Body perception metaphors cross many disciplines, including psychology, sociology, and gender studies. In medical ethics, body perception falls under two main categories: the body is *possessed* by us, or the body is *us* (Chirban, 1994). From the

possessive perception, two metaphors arise: body as a machine and body as a garden (Belk, 1992). Possession perception of the body reflects a positive attitude to organ donation. The perception of the body as a garden is reflected in the term 'organ harvesting' commonly used in transplantation literature. Contrary to this, perceiving the body as a central concept to 'self' is associated with a negative attitude towards organ donation. This view may consist of two main perceptions: the body as an identity and the body as a temple of God (Belk, 1992). This suggests that the subjective view of the body significantly affects the role it plays in organ donation behaviour. It is worth noting that body integrity act as a one-way barrier. Preserving body integrity acts as a barrier against donation, but there is no significant reference to it as a concern for receiving an organ, although body integrity is defiled on both ends, donating, and receiving. This demonstrates the moral hypocrisy behind this concept around organ donation.

Like most barriers in organ donation, body integrity is associated with other variables. The body integrity, defined as the need to have a whole body after death, is conceptually related to religions as the majority of body integrity concerns stem from fear of afterlife anguish brought about by the simple idea of an organ being cut (Sanner, 1994, Belk, 1992) or having to be reincarnated with missing organs (Braun and Nichols, 1997), or to be totally excluded from it (Parisi and Katz, 1986, Farsides, 2013). Body integrity concerns can also be related to misinformation on extra financial burdens to the family of the donor and its effect on burial process (DuBay et al., 2014b). However, we do not fully understand the "role of religiosity within a broader network of variables that include bodily integrity, religious norms, subjective norms, and attitudes toward donation" (Stephenson et al., 2008). Although it is fairly claimed that body integrity is connected to religious beliefs, Newton (2011) showed that it is maintained as a barrier against organ donation even in non-religious individuals, mostly related to the idea of cutting up the body or disgust (Sherman et al.,

2001). This suggests that, despite strong connections to religion, body integrity concerns are related to many other elements as well.

Body integrity can also be mirrored on other barriers such as disgust. Studies show that people who score high on the disgust scale and have negative attitudes towards all medical procedures are less likely to donate (Morgan et al., 2008a, O'Carroll et al., 2011, Sherman et al., 2001). However, the fear of body mutilation seems to be unrelated to the actual surgical procedure that is necessary in organ procurement, and it is more of a non-cognitive factor that does not respond to facts (Morgan et al., 2008b); a participant named Sophie said, "Even when I am dead…sounds really stupid but I still want my body to be me when I die. And I know it is going to disappear or whatever but I still, when I die, I want my body to stay as me" (Lai et al., 2007).

Body integrity as a concept may be related to social and cultural traditions. In Molzahn et al. (2005a), focus groups brought discussions about Chinese history where great emperors were preserved in their hometowns to be resurrected, demonstrating cultural tendency to bury rather than cremate. Rios et al. (2017) showed that people who prefer cremation over burial are more willing to donate. A female participant mentioned, "There's a saying in Chinese that in order to rest in peace, one needs to have everything intact in the body after one is dead. So, if you take away something and then it's considered to be something missing after death, then the person would not enjoy good after death or after life" (Molzahn et al., 2005a).

Research on organ donation and other related disciplines offer valuable insights into perceived barriers to organ donation in ethnic minority groups. For example, Chinese civilization has been the cradle for different religions, and it is hard to pinpoint which one has more effect on defending the concept of preserving body integrity. Chinese scholars agree that Confucianism has the most effect from which other religions stem from. Body integrity

has been showed to be one of the most significant barriers for Chinese minorities against organ donation (Cheung et al., 1998). Asians tend to form differentiated groups with individuals from similar backgrounds (Gao and Ting-Toomey, 1998). They are less willing to donate to other members of the public outside these differentiated groups (Lam and McCullough, 2008, Molzahn et al., 2005a). This suggests that social values and norms introduce different barriers to organ donation compared to the general population. It indicates that religion, social norms and body integrity are related to the recipient's ethnicity as well. All of this suggests a complex and unmapped relationships between body integrity and other barriers to organ donation.

3.2.2.3   Death anxiety

Thantophobia, or fear of death is defined as "the affective dimension of death attitudes and refers to the perceived amount of emotional distress provoked by the anticipated total nonexistence of the self" (Hui et al., 2007). Thantophobia consists of eight components: "fear of the dying process, fear of premature death, fear for significant others, phobic fear of death, fear of being destroyed, fear of the body after death, fear of the unknown, and fear of the dead" (Hoelter and Hoelter, 1978).

Anxiety is defined as "the physiological reactivity to events with uncertain but potentially aversive outcomes" (Friman et al., 1998). 'Death anxiety' (Sanner, 2001), or the fear of talking about death, can trigger a tremendous distress with certain individuals, and severe cases of death anxiety are portrayed as a strong barrier against organ donation (Wittig, 2001, Wang, 2020, Wu and Tang, 2008). Anxiety significantly affects the decision-making process. It increases the probability that an uncertain choice will be perceived as a negative choice, ultimately increasing risk and ambiguity aversion attitudes (Hartley and Phelps, 2012).

Death anxiety is related to disgust, jinx and sociodemographic features. Ethnicity, race, and religion play a significant role in death anxiety. Death studies show a significant difference in death anxiety among different ethnicity groups (Depaola et al., 2003, Cicirelli, 1999, Assari and Lankarani, 2016). Alden et al. (2000) found that White Americans have less death anxiety and body integrity issues than African and Hispanic Americans in the context of organ donation.

Sherman et al. (2001) found that people scoring high on the disgust scale have more death anxiety, indicating that death anxiety is not confined to organ donation conversation but rather induced by it. Some research indicates a severe fear of talking about death to avoid being 'jinxed' (O'Carroll et al., 2016), while in other research it was more related to cultural beliefs that indirectly impede the perception of self-ability to register (Wu et al., 2013).

Talking about death can bring bad luck according to Japanese culture and considered a taboo subject (Wu et al., 2013). Spigner et al. (2002) found that Asian-American families avoid talking about death. Miller et al. (2018) reaffirm that it is bad luck to talk about death, as if planning death will bring death. Non-donors usually do not plan death, they do not have a will, and sometimes even avoid recognising death (Cleveland, 1975, Molzahn et al., 2005b).

Research on death, dying and bereavement shows rather consistently higher death anxiety among women, old age and religious groups compared to male, young age and non-religious groups (Thorson and Powell, 1991, Russac et al., 2007, Thorson, 1991, Thorson and Powell, 1992, V. Fortner, 1999). However, research in organ donation shows that women have more positive attitude towards organ donation (Sherman et al., 2001, Reubsaet et al., 2001b, Weber et al., 2006, Ríos et al., 2017, Martínez-Alarcón et al., 2018, Ríos et al., 2018).

Anxiety is correlated with intolerance to uncertainty (i.e., the more uncertain a person is about a subject, the more anxious that person would be about it) (Lowe and Harris, 2019).

Although death anxiety has been studied as an independent variable, its behavioural consequences can extend its influence on other variables as well. It can prohibit individuals from seeking further information to relieve their uncertainty, which directly reflects on their lack of knowledge when it comes to organ donation, thus creating a vicious circle of anxiety and ignorance. Death anxiety would prevent individuals from discussing organ donation publicly, which eventually adds to more families refusing organ donation for their loved ones even if they are registered as organ donors.

3.2.2.4   Knowledge and medical profession

Knowledge in organ donation literature has been measured in different ways. It can be measured as awareness of organ donation and related to need and process, factual information that is answered by true or false, or general information on medical information, eligibility, success rate and other related areas. This section deals with several barriers: awareness, myths and knowledge, and trust in the medical system.

There is a general low level of awareness regarding the need and the process of organ donation and transplantation (Çevik et al., 2018, Alsharidah et al., 2018a), especially in minority groups (Davis and Randhawa, 2004). Studies have shown that African Americans have a knowledge level about organ donation that is significantly lower than the White population (Creecy et al., 1993, Morgan et al., 2003); however, there was no significant difference between African American and Asians (Edwards et al., 2007) or the Hispanic population (McNamara et al., 1999). This suggests that awareness and knowledge are significantly related to sociodemographic features.

Lack of knowledge about organ donation has been examined to have a negative impact on organ donor attitude. The concept of brain death is particularly prominent in studies examining the knowledge in the context of organ donation. Generally, people are

unaware or do not understand brain death (Ríos et al., 2017, Liu et al., 2019). However, the study conducted by Rabia Khalaila (2013) posited that people may be aware of organ donation but are unaware of brain death. Improvement in organ donation knowledge will improve willingness to register (Hu and Huang, 2015, Naçar et al., 2015, Çevik et al., 2018).

Trust has been defined as "the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party" (Mayer et al., 1995). Studies on trust show that trust at individual level is higher than trust in professional bodies (Nye et al., 1997). Diffused trust is crucial for modern complex societies (Luhmann, 2018, Zucker, 1986, Fukuyama, 1995) to facilitate vulnerable relationships without the need for extensive knowledge. The system-level trust influences the level of organ donation knowledge required by the public to alleviate anxiety in this area. Trust in the healthcare system is central to facilitating organ donation behaviour.

Distrust in the medical profession and system, on the other hand, has been frequently examined in the area of organ donation as a prominent barrier (Chan, 2019, Pfaller et al., 2018, Miller et al., 2018, Williamson et al., 2017, O'Carroll et al., 2011, Harrison et al., 2011b, Morgan and Miller, 2002a, Morgan et al., 2008a). The mistrust in the medical system results from either certain individual medical issue, historical scandals, or a general sense of suspicion about the profession. The issues surveyed can be categorised into intentional mistakes by the health care professionals or unintentional mistakes related to medical definition of brain and circulatory death; both eventually lead to distrust in the medical system and healthcare providers.

One of common concerns in this area is the deliberately premature announcement of death of the potential donor in order to proceed with the harvesting and transplantation process (Alkhawari et al., 2005, Stevens, 1998, Wang, 2020). Research has shown that

participants believe that doctors will deny the patients of their best care if they are organ donors (Siminoff and Sturm, 2000). Mistrust in the medical profession appears predominantly in research examining organ donation in minority groups, potentially reflecting historical mistrust with society as a whole and the possible racial discriminations against minorities (Fahrenwald and Stabnow, 2005, Bhengu and Uys, 2004, Molzahn et al., 2004, Williamson et al., 2017, Frates and Garcia Bohrer, 2002, Scott and Quick, 2012, Albright et al., 2005) and institutionalised racism (Townsend et al., 1990, Durand et al., 2002, Callender and Hall, 2001). A Pakistani woman put it simply: "they might not try as hard to keep me going" (Hayward and Madill, 2003).

Spigner et al. (2002) showed that White Americans correctly answered medical questions around organ donation like the need, the waiting list and the fairness of the allocation system (Weaver et al., 2000) significantly more often than Asian Americans. This might reflect back not only to emotionally driven trust (Morgan et al., 2008b) but rather an actual knowledge about hard facts related to the area of organ donation. The question that remains, of course, is why White Americans would know more than other groups, and whether this is related to an actual interest in organ donation that pushes White Americans to seek information compared to a culturally driven avoidance of dealing with death or culturally driven, emotionally approached distrust in the healthcare system from African American groups.

The distrust in doctors does not discriminate White doctors from minorities, there is a low level of trust in both non-minority and minority doctors (Hinck et al., 2017). This suggests that medical mistrust as a barrier to organ donation is presented differently at different demographic groups. Researchers may consider culturally informed message design for educational interventions aimed at ethnic minority groups that are different to that targeting ethic majorities or the general population.

Since the majority of organ donation research is based in the USA, it is worth noting that there is a major difference in the healthcare system between the USA and the UK that lies in the accessibility of minorities to healthcare in the USA that contributes to the gap even more. It is consistent that the most significant view in African Americans is their mistrust in the healthcare system (Kurz et al., 2007, Cull et al., 2016). This can be explained as fear of sub-optimal medical care as donors (Siminoff and Sturm, 2000, Sherman et al., 2001) or it could be extended to even bigger social issues reflecting the trust from African Americans to White Americans in general (Terrell et al., 2004). This suggests that further examination of perceived barriers to organ donation in ethnic minority groups residing in the UK is vital.

Medical mistrust is related to the dilemma of brain death, which has its connections in religious beliefs, awareness, and knowledge. Brain death is defined medically as the irreversible loss of all functions of the brain, including the brainstem (Goila and Pawar, 2009). Circulatory death, on the other hand, is the irreversible loss of function of the heart and lungs (Morrissey and Monaco, 2014). While it is medically well defined and diagnosed with accuracy, the widespread controversy lies in what 'death' means combined with lack of understanding of what is considered 'irreversible' loss and how it would be defined. Some would consider brain-dead patients to be still alive until non-beating heart death is diagnosed, thus the confusion around the brain death and organ donation. This demonstrates the connection between religion, brain death knowledge and organ donation behaviour.

The media plays a remarkable role in shaping public views about brain death. There has been a tremendous issue with the depiction of brain death in media. Systematic reviews found only a small percentage of media communications (between 4-6%) provided a definition of brain death (whether it is complete or not) and in the majority of the cases, there is no clear differentiation between brain death and a persistent vegetative state (Lewis et al., 2016, Daoust and Racine, 2014) which can be reversible and is not diagnosed as death.

There have been several reported cases of "miracles" where people have recovered after being allegedly diagnosed with brain death. Further investigation shows a lack of accurate reporting that resulted in spreading misinformation about organ donation to the public, such as the prominent cases of Zack Dunlap and Trenton McKinley as discussed in section 2.1 Diagnosing death. This suggests that media should be considered as an important source of information on organ donation, and it may significantly affect normative beliefs and subjective norms. Misinformation on organ donation key concepts may have a damaging effect on organ donation behaviour.

The topic of organ transplantation has been challenging to absorb, not only by the public but sometimes by medical professionals as well. The concept of brain death and its confusion with death by cessation of heartbeats has been ethically studied in the field of medical ethics and has been rather settled, but the jury is still out at the public court. The willingness to donate is linked closely to the acceptance of the current definition of brain death (Jox et al., 2015). The controversy about the validity of the brain death definition creates a huge obstacle to accept the 'new' definition of death.

From a biological, religious as well as philosophical perspective, there is no unified definition for death, rather it is a social normative construct transferred through social beliefs. The complexity of the concept makes it even harder for the mainstream public who lack professional medical training to understand and/or accept the concept without relying on a high level of trust in the medical system, adding more complexity to the spiderweb of barriers against organ donation. This raises another issue which is the ability of medical professionals to provide enough information for the public when needed. Several studies showed that medical professionals require more knowledge about organ donation, not only from the medical perspective, but from other issues such as ethics, laws, and donation procedures as

well to be able to educate the public or even promote organ donation (Lei et al., 2019, Ju et al., 2018, Hakeem et al., 2015, Fontana et al., 2017).

3.2.2.5 Recipient

Research revealed unease regarding the potential receiver, especially the social and medical worthiness of the receiver (Molzahn et al., 2004, Frates and Garcia Bohrer, 2002, Molzahn et al., 2005b, Wang, 2020, Newton, 2011); others signal, yet again, predominantly with minority groups, a concern about the economic status of the receiver (i.e. wealthy receivers have a priority) or being from the same religion and race (Williamson et al., 2017, Alkhawari et al., 2005, Park et al., 2020). This suggests that social values affect organ donation behaviour. These views can be strong and resistant to many behavioural interventions.

The worthiness of the recipient (Morgan et al., 2008a) can be related to wealth (potentially access to black market in some countries), being a family member, being from the same religion, having the same ethnicity or if the recipient will appreciate the organ and the opportunity he or she is receiving and stop the behaviour that possibly led to the organ failure in the first place (such as liver damage from alcoholism). A male participant said: "We want to do something good... but when you see how some people act, I would say no" (Alkhawari et al., 2005). Browning (2001) highlighted that recipient age and prognosis are the most influential factors for what is considered 'fair allocation', not their race or wealth.

Family is crucially important in certain cultures (Wittig, 2001) and there is a moral obligation towards family members (El-Shoubaki and Bener, 2005), especially for close family relationships (Saleem et al., 2009), where decisions are taken as a family rather than individually (Molzahn et al., 2005a). These family tights isolate individuals from the bigger society (Bhengu and Uys, 2004) with no sense of reasonability, reciprocity or obligation to

give back to society. This is reflected in two ways in Chinese groups, for example. Firstly, Chinse groups prefer to donate to family members (Li et al., 2019, Chung et al., 2008), and secondly and more prominently, Chinese groups are reluctant to disobey conservative parents by donating organs. This has a significant impact on donation from Chinese groups.

3.2.3   Conclusion

A plethora of barriers are identified in literature. Mapping behavioural barriers is a vital step in designing effective behavioural interventions. The main themes found in literature are religion, body integrity, death anxiety, knowledge, medial mistrust, and recipient worthiness. Behavioural interventions can enhance organ donation rates by systematically identifying behavioural barriers and how to best break them.

Behavioural barriers in organ donation interact with each other. The influence of one barrier may be related and even dependant on other barriers. Subjective perceptions play a role in how these barriers shape attitude to organ donation. Demographic and social criteria are important as well. It is necessary to consider the interrelated nature of behavioural barriers when designing behavioural interventions. The success of one-size-fits-all intervention design depends upon a complex and unmapped network of barriers and motivators. Recognising the interconnectedness of barriers to organ donation open new opportunities for organ donation interventions.

3.3   Section two - Attitude to organ donation

3.3.1   Introduction

Attitude plays a central role in determining human behaviour (DeFleur and Westie, 1963, Krosnick et al., 2005). It may play a valuable role in predicting behaviour (Ajzen, 2005). In this section, I will discuss the determinants of attitude and/or behaviour in organ

donation. A positive attitude towards organ donation can be predicted by several demographic, psychological and social criteria. This section aims at describing a profile for people with a positive attitude and assessing the quality of studies that describe these profiling criteria in order to assess the quality of available evidence.

3.3.2   Characteristics that are associated with attitude to organ donation

3.3.2.1   Demography characteristics

Several demographic criteria have been identified by the literature as associated with varied attitudes towards organ donation. Older age groups (at different cut-off points but mostly above 40 years old) have more of a negative attitude towards organ donation (Conesa et al., 2003) and younger individuals are more commonly associated with a positive attitude towards organ donation (Conesa et al., 2004, Conesa et al., 2006, Wu and Tang, 2008, Arriola et al., 2008). A similar conclusion was found in a systematic review conducted by Wakefield et al. (2010). However, some studies showed no significant relationship between age and attitude towards organ donation (Khalaila, 2013, Pham and Spigner, 2004). Gender also plays a role in predicting positive attitudes towards organ donation and it is commonly associated with the female gender (Sherman et al., 2001, Reubsaet et al., 2001b, Weber et al., 2006, Ríos et al., 2017, Martínez-Alarcón et al., 2018, Ríos et al., 2018). This relationship was also established in a systematic review conducted by Wakefield et al. (2010). However, several studies showed no significant relationship between gender and attitude towards organ donation (Conesa et al., 2003, Conesa et al., 2006, Wu and Tang, 2008). High education level is commonly correlated with positive attitude towards organ donation (Gimbel et al., 2003, Conesa et al., 2004, Conesa et al., 2006, Wu and Tang, 2008, Saleem et al., 2009, Khalaila, 2013, Ríos et al., 2017, Lim et al., 2020, Arriola et al., 2008, Morgan et al., 2002b). This correlation is supported by systematic reviews as well (Hollestelle et al., 2008, Wakefield et

al., 2010). However, some studies did not find a significant correlation (Reubsaet et al., 2001b).

Religion predicts attitude towards organ donation. Being an atheist (Ríos et al., 2017), Christian (Khalaila, 2013), or Catholic (Gimbel et al., 2003) can all be significantly correlated to a positive attitude towards organ donation. Some studies found that being highly religious is significantly correlated with a positive attitude towards organ donation (Demir and Kumkale, 2013), while others found that being less religious is also a predictor of positive attitude (Reubsaet et al., 2001a, Saleem et al., 2009, Ríos et al., 2018, Arisal and Atalar, 2020). Meta-analysis affirms the relationship between being less or un-religious and a positive attitude towards organ donation (Hollestelle et al., 2008) when some studies found no relationship between the two (Reubsaet et al., 2001b, Conesa et al., 2006, Wu and Tang, 2008). Some studies show certain religions are more correlated with positive attitude, some show a relationship between strong religious beliefs and attitude, and others suggest the opposite. This suggests that religious views are not abstract, and they fall under different subjective views. Like the findings in Section one – Barriers to organ donation, some perceive their religious views to be a motivator to organ donation, hence it is significantly correlated to positive views, whereas others perceive religious views to be a strong barrier.

It is evident that demographic criteria can play a valuable role in predicting attitude towards organ donation; however, we do not fully understand why such criteria are related to the attitude. Moreover, when it comes to criteria such as religion, the relationship to attitude becomes more complicated and sometimes even contradictory. Evidence is inconsistent on other demographic criteria, such as gender, age and education level. The reason for inconsistency in the relationship between demographic criteria and attitude to organ donation has not been investigated.

3.3.2.2　Psychological characteristics

Several psychological characteristics have been found to be correlated with positive attitude to organ donation. Different personality types have been found to differentiate donors from non-donors (Demir and Kumkale, 2013). Sidney Cleveland (1975) conducted different personality tests to examine personality characteristics that differentiate donors from non-donors. Cleveland concluded that donors are internally directed, with definitive body image. They accept their morality, but they display hostility, depression and guilt, and they perceive donation to be a humanitarian act (Cleveland, 1975). Non-donors, on the other hand, believe in luck and fate. They are concerned about body integrity, and they worry about death (Cleveland, 1975). Organ donors are shown to be more agreeable (Bekkers, 2006), compassionate (Demir and Kumkale, 2013), and hold politically liberal views (Chan, 2019). However, a study by Shianne Brackenbury (2019) found no relationship between personality type and organ donation attitude. Personality traits affect one's perception (Jafri, 2014), performance (Mendolia and Walker, 2014), assessment (Kortum and Oswald, 2018), subjective views (Atwood and Tomkins, 1976) and behaviour (Stangor and Walinga, 2010). Significantly different personality traits between donors and non-donors may be connected to how behavioural barriers are subjectively perceived, and thus how attitude is formed, suggesting a link between subjective views and attitude to organ donation.

There are several studies that have investigated the relationship between certain behavioural barriers and attitudes towards organ donation. The negative attitude towards medical procedures and high sensitivity to disgust are predictors for negative attitudes towards organ donation (O'Carroll et al., 2011, Sherman et al., 2001, Morgan et al., 2008a, Quick et al., 2014b, Ríos et al., 2017, Ríos et al., 2018, Arisal and Atalar, 2020). The perceived disgust can be influenced by media or wrong perceptions regarding the donation process (Miller et al., 2018). Related to disgust, Quick et al. (2014a) measured fear of

violating body integrity. Anxiety was also found to be significantly correlated to attitude towards organ donation (Reubsaet et al., 2001a, Demir and Kumkale, 2013, Wu and Tang, 2008). Death anxiety and body integrity are common barriers to organ donation, and they were found to be significant predictors to attitude towards organ donation. Research shows that knowledge about issues related to organ donation (Reubsaet et al., 2001b, Morgan and Miller, 2002b, Conesa et al., 2003, Saleem et al., 2009, Demir and Kumkale, 2013), the source of information (Conesa et al., 2004, Arisal and Atalar, 2020) and medical professionals have more positive attitudes (Khalaila, 2013). This probably stems from daily interaction with death and disease, reducing the anxiety and disgust level, in addition to having high trust in their own medical system.

Altruism has been found to be significantly related to organ donation behaviour (Alsalem et al., 2020b, Hollestelle et al., 2008, Morgan and Miller, 2002b, Conesa et al., 2003, Bekkers, 2006, Khalaila, 2013). This result was confirmed with systematic reviews and meta-analysis as well (Hollestelle et al., 2008, Wakefield et al., 2010). Moreover, people who have undertaken social work before (Conesa et al., 2006, Conesa et al., 2003, Conesa et al., 2004, Han and Wibral, 2020) and who hold a favourable attitude towards blood donation (Conesa et al., 2006) are more likely to have a positive attitude as well.

3.3.2.3 Social characteristics

Social influences play a significant role in altering beliefs, attitude, and behaviours (Duve and Jensen, 2011). Research has uncovered additional predictors, including familial support. Rios et al. (2018, 2017) showed that having a spouse who is in favour of organ donation can significantly predict positive attitude. Merely discussing the subject with friends can significantly improve attitude towards organ donation (Martínez-Alarcón et al., 2018). Friends, family, and role models can significantly affect the perceptions around organ

donation (Wong and Chow, 2017, Conesa et al., 2006, Conesa et al., 2003). Perceiving social norms to be supportive of organ donation (Morgan and Miller, 2002b) and having a prior experience with organ donation (Ríos et al., 2017) positively affect attitude to organ donation.

3.3.3   Conclusion

Demographic, psychological, and social criteria all predict attitude; however, it is not clear how and why such criteria are related to attitude; they may play a role in shaping the perception of barriers and indirectly affect attitude and organ donation behaviour. It is suggested by the literature that subjective views influence attitude and behaviour. Socio-demographic criteria shape the perception to organ donation and condition the likelihood that a person attributes a certain behavioural barrier to explain their behaviour. These findings suggest that we should pursue a better understanding of how these criteria influence perception, as they might affect behaviour towards organ donation.

3.4   Section three – Behavioural models in organ donation

3.4.1   Introduction

Organ donation has the potential to save the lives of thousands of patients and improve the quality of life of those who need organ transplantation. Choosing a theory to guide intervention design (Craig et al., 2008) leads to better outcomes by offering well informed and empirically tested assumptions. To maximise the efficacy of behavioural change interventions, it is necessary to understand organ donation behaviour.

This section offers a review of theories and models of behaviour and behaviour change in organ donation. I will describe the most prevalent models used to describe and change organ donation behaviour. Theory is important to identify causes of behaviour (Michie, 2008) and mechanisms of change (Michie and Abraham, 2004). Van der Linden

(2013) differentiates between models of behaviour that are used to understand the causes and influencers of behaviour, and behavioural change theories that are more cyclical and process oriented. In organ donation, there is a constant effort to develop theories that can better identity the underlying variables that influence organ donation behaviour, such as motivation and capabilities. Process-oriented interventions remain limited (Harrison et al., 2011a). Many of the models described in this section are drawn other from healthcare literature and offer a general description of healthcare behaviour. Attempts have been made to develop models specific to organ donation behaviour by isolating and then incorporating key variables that are related to organ donation behaviour.

In this section, I will discuss the benefits and limitations of theoretical models used in organ donation. Commonly, theoretical models fail to explain the mechanism of change. The causal link between antecedent variables and the behaviour remains insufficient to explain and implement behavioural change interventions. Furthermore, theoretical models in organ donation do not differentiate between people; they are mainly empirical, 'everyman' models (Darnton, 2008). I will follow with a reflection on the nature of organ donation decisions. I will argue that organ donation is not a healthcare decision, hence theoretical models from healthcare literature require significant modifications to be relevant to organ donation decisions.

I will end this section with a critical review of how attitude towards organ donation (and ultimately behaviour) is measured. I will highlight that not only are the current models oversimplified at the expense of individual context, but also consist of a systematic failure to connect reality between the individual and social levels. Using qualitative methods, scholars have accumulated many clues on how attitude is formed, how individuals perceive barriers as distinctly different from others, and how that may result in different views on organ donation at the individual level. Theoretical models described in this section fail to represent that

variation, by deliberately dissociating subjective perception naturally captured through interview methods.

3.4.2 *Important theories and their key variables*

Organ donation literature is dominated by the Theory of Reasoned Action/Theory of Planned Behaviour, while many other models in organ donation literature originate from TRA. Thus, we will start with social cognitive models, and describe the main variables and implementation limitation in organ donation. This will then be followed by organ donation models. Organ donation models attempt to explain organ donation behaviour using social cognitive models with the addition of variables that are specific to organ donation behaviour. These variables are derived from organ donation behaviour (discussed in Section one – Barriers to organ donation) and attitude (discussed in Section two - Attitude to organ donation). Following that, I will describe the few attempts to explain organ donation behaviour using Q-methodology. The last section will describe the few models infrequently used to *change* organ donation behaviour.

3.4.2.1 Social-cognitive models

These models examine "how people respond to and make sense of socially derived situations" (Albery and Munafò, 2008). It is evident that organ donation behaviour is related to socio-demographic variables, as discussed in Section two - Attitude to organ donation. However, such variables are not amenable to change. Hence, researchers turned their attention to social cognitive models to account for differences in behaviour relating to socio-demographic criteria (Rosenstock, 1974). Several social cognitive models have been proposed in organ donation. They intend to predict behaviours at single points in time. Typically, these models are designed with the aims of identifying the variables that bring about organ donation behaviour and evaluating their capacity to predict behaviour. That also

applies to organ donation models subsequently described in section 3.4.2.2 Models specific

for organ donation. The social-cognitive models reviewed in this section include Social

Cognitive Theory, Theory of Reasoned Action and the Health Belief Model.

There are several limitations to social cognitive models in organ donation:

·   They rely on cognitive functioning imparted through social relationships and minimise

the impact of emotional variables that are shown to be correlated to organ donation

behaviour.

·   They are broad-reaching models that are difficult to operationalise in specific contexts.

·   They do not explain or account for subjective perceptions or personality types, which

are shown to affect organ donation behaviour.

3.4.2.1.1   Social Cognitive Theory

Social Cognitive Theory (SCT) (shown in Figure 5) explains the effect of personal

experiences, and the activities of other people in social and environmental elements, on

behaviour (Schunk, 2012).
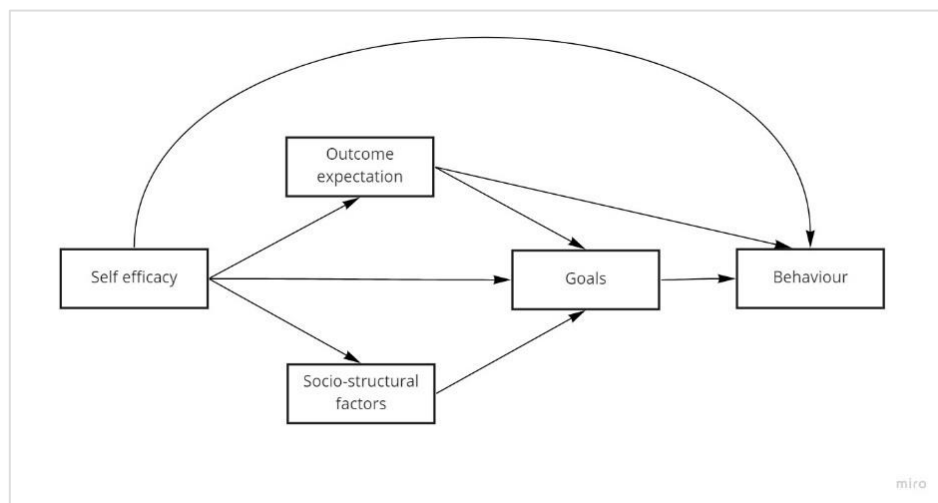
Figure 5 Social Cognitive Theory. It focuses on the role of cognitive processes in explaining behaviour. It posits that personal, environmental, and behavioural functions are reciprocal determinants of behaviour.

3.4.2.1.1.1   Strengths

SCT is used to describe and predict attitudes towards organ donation (Reubsaet et al., 2001a, Reubsaet et al., 2001b, Reubsaet et al., 2003, DuBay et al., 2017) and to change organ donation behaviour (Reubsaet et al., 2004b, Reese et al., 2020) but with mixed results. The theory has accumulated a wealth of previous research and is a valid theoretical representation for various behaviours. Its flexibility is often cited as a strength.

3.4.2.1.1.2   Limitations

The theory suggests cognitive decision-making and establishes the effect of social norms on behaviour. However, it tends to completely ignore non-cognitive variables, such as death anxiety and mistrust, which are shown to affect organ donation decisions.

Religion, mistrust in healthcare systems, body integrity beliefs and other barriers are all closely related to organ donation decisions and are tightly connected to social norms.

The theory acknowledges the necessity to overcome socio-structural impediments, but it establishes that as a mediator linking self-efficacy to goals and behaviour. While this may be the case in some healthcare activity, it certainly undermines the effect of social barriers on organ donation decisions.

3.4.2.1.2 The Theory of Reasoned Action / The Theory of Planned Behaviour

The Theory of Reasoned Action (TRA) is a social-cognition model. It is the most prevalent theory in organ donation literature. It seeks to predict outcomes based on existing attitude and intentions. It was first developed by Martin Fishbein and Icek Azjen (1975). There have been several modifications over the decades. Researchers who have used TRA have adopted modified configurations to the variables whilst preserving its main underlying assumptions.

TRA was specifically developed for behavioural interventions in healthcare. It has been used in several interventions in the areas of exercise (Ajzen and Driver, 1991, Godin, 1993, Blue, 1995, Downs and Hausenblas, 2005), weight gain (Godin and Kok, 1996, Baranowski et al., 2003), smoking (Godin and Kok, 1996, Hagger et al., 2018, Martinasek et al., 2017), alcohol consumption (Lorenzo-Blanco et al., 2016, Espada et al., 2015, Laflin et al., 1994), condom use (Jemmott and Jemmott, 1991, Sheeran and Taylor, 1999, Muñoz-Silva et al., 2007), breast self-examination (Lierman et al., 1990, Cooke and French, 2008, Montano and Taplin, 1991), flu vaccines (Brewer et al., 2007, Montano, 1986) and seatbelt interventions (Budd et al., 1984, Şimşekoğlu and Lajunen, 2008, Aarts et al., 1998).

3.4.2.1.2.1   Strengths

The TRA aims to explain a big proportion of the effect using a small set of variables (Fishbein, 2008) and it has been empirically supported (Albarracin et al., 2001, Godin and Kok, 1996, Conner et al., 2013). It is a widely used theory across multiple disciplines. TRA has been successfully and widely used for many reasons:

1. It is simple, with few variables. The TRA was able to predict 20–30% of behaviour with only small number of variables (Godin and Kok, 1996, Armitage and Conner, 2001, Hagger et al., 2002).

2. It is flexible: The weights of the variables in TRA are empirically determined to address different scenarios for different behaviours (for example, some behaviours are highly predicted by social norms, others are more predicted by normative beliefs)

3. It can provide insights on how to intervene.

3.4.2.1.2.2   Limitation

The TRA entails three main conditions to provide best predictive value (Madden et al., 1992). The first is to specify the level of intention (Madden et al., 1992). The more

specific the measurement of the intention, the more predictive the theory would be for the behaviour. In organ donation that may be a problem. As discussed in previous sections, attitude to organ donation is affected by a variety of barriers and is shaped by many demographics and social and psychological criteria, with subjectivity playing a role in shaping attitude as well. This shows how complicated the decision is, and how unlikely it is for people to form solid intentions. Furthermore, there is a general lack of awareness of organ donation as discussed earlier, and this hinders the formation of intention.

The second condition is to measure both intention and behaviour at specific times (Madden et al., 1992). This condition allows for time studies to explore the changes in behaviour in response to change in intention and its leading variables over time and allows for longitudinal studies to assess the causal relationships between the variables rather than cross-sectional studies, as these are commonly used in organ donation intervention studies.

The third condition is the ability of the individual to carry out the desired behaviour (Madden et al., 1992). In organ donation, studies suggest that improving the perceived ability to perform the behaviour improved the organ donation registration rate (Reubsaet et al., 2003, Wu and Tang, 2008, Anker et al., 2010, Wang and Zhao, 2018, Wang, 2020, Symvoulakis et al., 2019). However, the TRA does not take into consideration the required skills, conditions and resources required to enact the desired intended behaviour; it only acknowledges that as a barrier against the behaviour (Eagly and Chaiken, 1993, Sheppard et al., 1988). Perceived behavioural control was later added to the TRA to improve its predictive value and create the Theory of Planned Behaviour (Ajzen, 1991, Ajzen, 1985a), as shown in Figure 6.
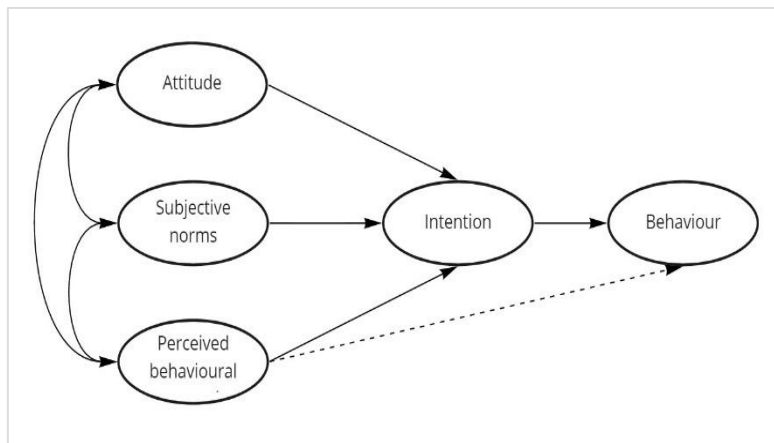
Figure 6 Theory of Planned Behaviour. It aims to explain voluntary behaviour by considering the primary motivation. It indicates that intention and perceived behavioural control determine behaviour. This suggests that behaviour must be preceded and determined by intention.

It is worth mentioning that the TRA cannot be used to design cost-effective interventions; rather, it is merely a predictive tool to help researchers achieve desired change (Taylor et al., 2006). This suggests that the TRA can be more valuable as an explanatory theory rather than as a behavioural change theory. In organ donation, it has been used mainly as an explanatory theory to predict attitude and behaviour. When the TRA has been used in interventions, it commonly acts as a foundation to investigate other different variables and techniques. Table 6 shows organ donation studies that were based on a theoretical framework, the variables that were added to the main model and whether it was used to describe and predict attitude and behaviour, or whether it was used to guide behavioural change interventions.

3.4.2.1.3 Health Belief Model

The Health Belief Model (HBM) is a social cognition model developed to explain and predict health-related behaviours (Janz and Becker, 1984). Figure 7 shows the Health Belief Model. It was created by social psychologists at the U.S. Public Health Service (Rosenstock, 1974). The HBM suggests that people will take a health-related action if:

1. The negative condition can be avoided.

2. The recommended action has positive expectation to relieve the negative condition.

3. The person feels capable of doing the recommended action.

3.4.2.1.3.1   Strengths

The interventions based on the HBM aim to increase the health-related behaviour by providing information to alter the perceived benefits, barriers and threats (Rosenstock et al., 1988). The HBM has been widely used to guide health interventions, like diet and obesity (Becker et al., 1977, Hanson and Benedict, 2002, Daddario, 2007), breast examinations (Lee Champion, 1985), osteoporosis (White, 2016), STDs (Hounton et al., 2005, Rosenstock et al., 1994) and many other areas (Yue et al., 2015, DelGiudice et al., 2018, Rezaei Jaberee et al., 2018, Livi et al., 2017, Struggs and Harris, 2016). The main strength of the HBM lies in its simplified view of health-related constructs, which facilitates its applications to many health related behaviour (Conner et al., 2010).
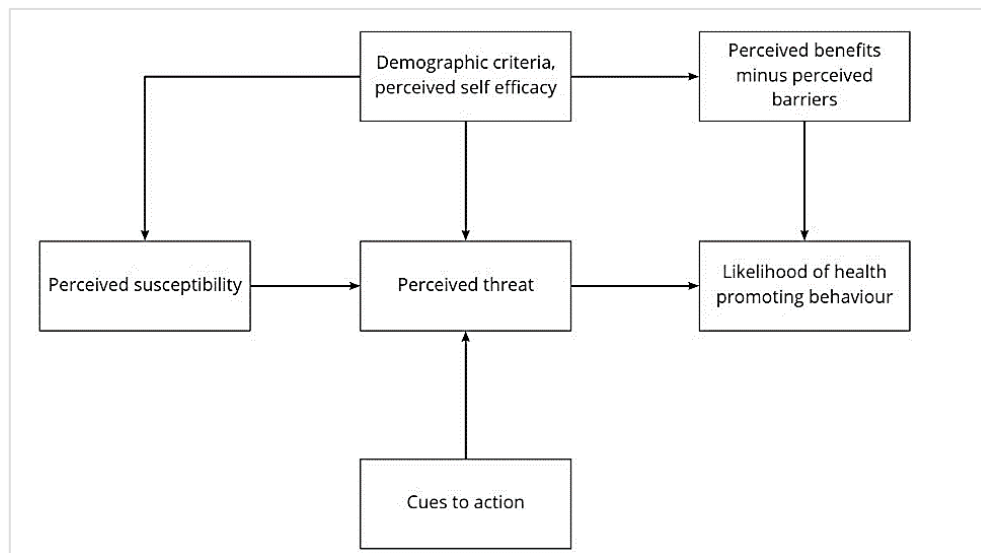
Figure 7 The Health Behaviour Model. Source: (Saunders et al., 2013). The HBM aims to explain health recommendations. The behaviour is predicted by an evaluation of perceived benefits, barriers and threats.

3.4.2.1.3.2   Limitations

The HBM specified a set of cognitive variables that mediate the effects of demographic variables amenable to health education (Conner and Norman, 2005). However, the HBM variables were broadly defined and flexibly used; researchers used various aspects of the model's key variables (Carpenter, 2010, Rosenstock et al., 1988). The operationalisation of the model has failed to measure all variables equally (Harrison et al., 1992). Harrison et al. (1992) also argued that while all variables showed statistical significance, the correlations account for a very small effect size, between 0.5–4% for the variance in behaviour. The HBM components showed different associations in cross-sectional versus longitudinal studies, and in prospective versus retrospective studies as well (Harrison et al., 1992).

The HBM assumes that there is a clear distinction between what is universally considered a positive or negative condition (Mimiaga et al., 2009); however, that distinction remains unclear in organ donation. Furthermore, it assumes rationality, despite research showing that non-cognitive factors such as unrealistic optimism are consistently broader than all elements of the HBM (Clarke et al., 2000), the model does not consider the effect of non-cognitive factors that are shown to affect organ donation behaviour (Glanz et al., 2008).

3.4.2.2   Models specific for organ donation

In response to the need to account for non-rational variables in organ donation, scholars have created and tested various organ donation models to address the fact that knowledge and attitude explain a small variance of change in registration rate (Feeley, 2007, Morgan and Miller, 2002b). Thus, organ donation models incorporate barriers to organ donations, as well as various demographic, social and psychological variables. However, like the TRA, they continue to theorise intention and attitude as precedents to behaviour, which

introduces an intention-behaviour gap (discussed in detail in section 3.5.2.3 Intention-behaviour gap). Organ donation models represent a further step towards understanding variables correlated with organ donation behaviour and a deeper understanding of the causal relationships with behaviour. However, they require further investigation of the interrelationships between non-cognitive variables. They are inadequate in describing the impact of subjective perception on non-cognitive variables and organ donation behaviour.

3.4.2.2.1 Organ Donation Model

The Organ Donation Model (ODM), developed by Morgan et al. (2002a), was the first model that aimed at being specific to organ donation. This was followed by several attempts to create different models and incorporating several variables to try and better predict organ donation behaviour. Figure 8 shows that the ODM first incorporated fear as a non-cognitive barrier to organ donation behaviour, accounted for by the knowledge variable.
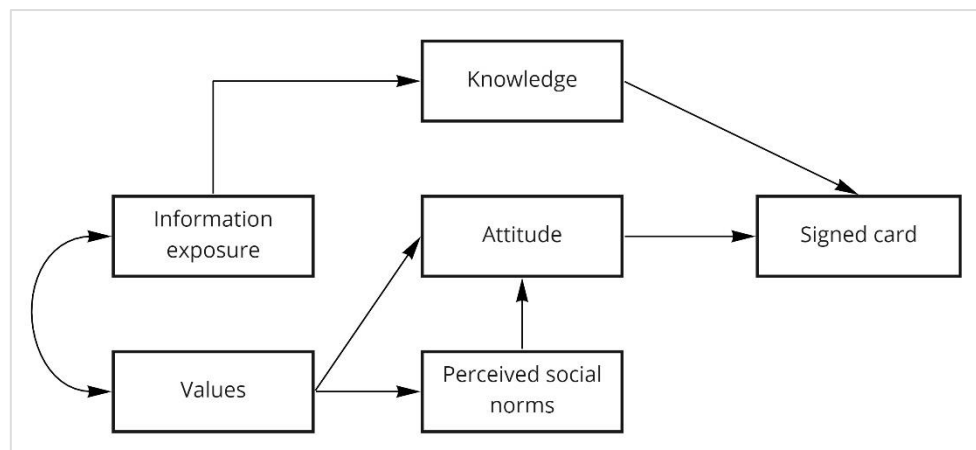
Figure 8 Organ Donation Model. (Source: (Morgan et al., 2002a). It aims to explain willingness to sign an organ donation card (in opt-in systems). It is based on models that are grounded on the TRA. The model considers fear to be part of the knowledge construct, wherein misinformation may create fear around organ donation, and it recommends emotional, non-cognitive variables to be further explored.

This model was further developed by Morgan et al. (2008b). It aimed at increasing the amount of explained variance by accounting for non-cognitive variables, such as

interpersonal information, media, and perceived benefits. Figure 9 shows the ODM further

developed, to include non-cognitive as a new variable.
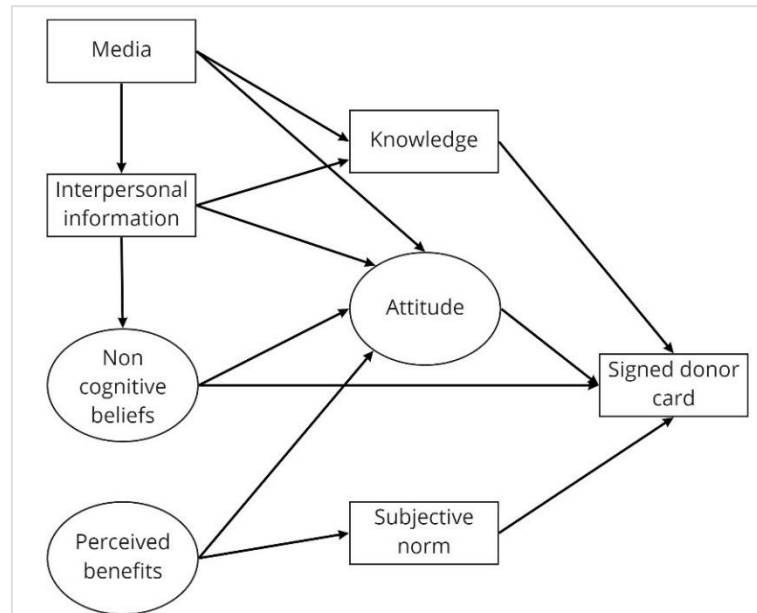
Figure 9 Organ Donation Model. (Source (Morgan et al., 2008b). This ODM further explored non-cognitive variables since knowledge and attitude (cognitive variables) were weak predictors of behaviour in the previous model (Morgan et al., 2002a). This model indicates that non-cognitive beliefs are the strongest predictor of behaviour, suggesting that the organ donation decision is irrational.

3.4.2.2.2 *The IIFF model*

The IIFF model, shown in Figure 10, is the result of theoretical integration of

psychological predictors of deceased organ donation. It suggests that four key factors are

central to the decision to donate: *i*mmediate opportunity to donate, *i*nformation on organ

donation, *f*ocused engagement, and *f*avourable activation (Siegel et al., 2010).

Falomir-Pichastor et al. (2013) endeavoured to ascertain the determinants of organ

donation behaviour, and the factors likely to increase the efficiency of donation promotion

campaigns. They identified two types of determinant factors: distal factors that are not

directly related to organ donation, and proximal factors that are directly related to organ

donation (as shown in Figure 10). This systematic review provides 14 determinants to organ

donation attitude and behaviours, and it acknowledge the absence of the specific contribution

of each factor; hence, it is difficult to ascertain which determinant contributes more (or even if it contributes significantly) to change in attitude around organ donation. Moreover, the simplistic 'list' design of determinants inhibits the examination of mediating effects. The long list of determinants, however, shows the complexity of organ donation behaviour and shows that simple isolated interventions may not have a strong impact on attitude.
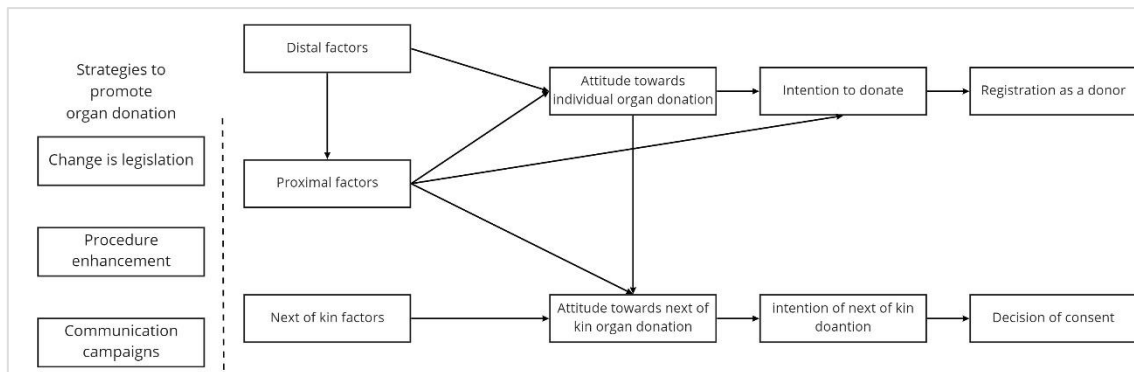
Figure 10 IIFF Model (Falomir-Pichastor et al., 2013). This model aims to integrate several theoretical models related to organ donation. It aims to explain organ donation behaviour from the perspective of donors and their next-of-kin. The model identifies proximal factors that directly predict attitude towards organ donation. Distal factors influence attitude directly and indirectly. The model also integrates strategies to promote organ donation, thus it represents the most comprehensive model in the organ donation literature.

3.4.2.2.3   Other organ donation models

Scholars have explored several other variables to understand organ-donation-related behaviour. O'Carroll et al. (2011) used the TRA and added four non-cognitive factors: disgust, , medical mistrust, body integrity and perceived benefits of donation as non-cognitive factors. O'Carroll et al. (2011) have also presented the non-cognitive ick factor and body integrity as main factors to differentiate between donors and non-donors when other cognitive factors such as knowledge, attitude and subjective norms failed to do so. On the other hand, Quick et al. (2014a) used the show *Grey's Anatomy* to investigate medical mistrust, disgust, bodily integrity, and superstition in three different groups: African Americans, Latinos and Caucasians (Figure 11 shows the structural model hypothesised by Quick et al.). They found

that the model was supported by data with differences among the three groups. Although not fully discussed by the authors, this brings an urgent question around the application of models across different ethnic groups and how behavioural barriers may be presented in different patterns across different ethnicities or perhaps religions too.
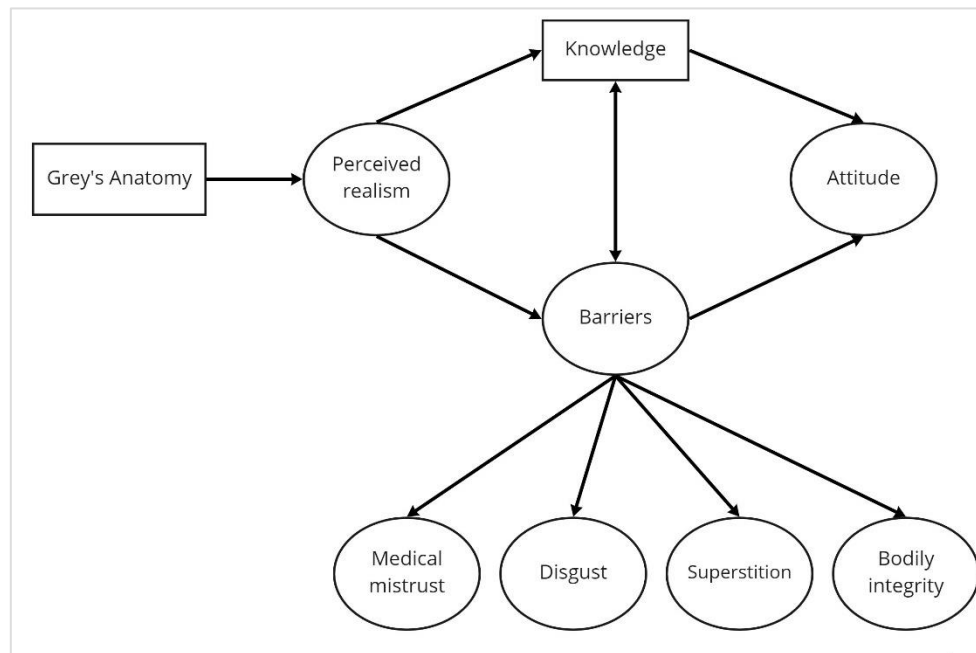
Figure 11 Hypothesized Structural Model (Quick et al., 2014b). This model aims to demonstrate how perceived realism of a TV show is positively related to misinformation and perceived barriers to organ donation. The study also showed that when non-cognitive variables are added, knowledge (a cognitive variable) failed to predict attitude to organ donation.

3.4.2.3   Q-methodology in organ donation

Q-methodology is a unique way to operationalise subjective views and is valuable for complicated issues. Q-methodology can be used for both theory building and theory testing (Yang, 2016, Molenveld, 2020). Q-methodology examines perspectives on the issue under examination to create theories that fall under the radical humanist paradigm (Gioia and Pitre, 1990).

We have discussed behavioural barriers to organ donation and the social, psychological, and demographic criteria related to organ donation in previous sections.

Moving on to theoretical frameworks, we described social cognitive theories such as the TRA and their limitations in organ donation. Theoretical models were further developed to produce the Organ Donation Model and IIFF that are more specific to organ donation and account for non-cognitive variables and barriers to organ donation. The IIFF model by Falomir-Pichastor (2013) was the first model that accounted for predictors of attitude being demographic, psychological or social characteristics. However, theoretical models fall short of investigating the effect of subjective perception on organ donation behaviour.

As discussed earlier in section 3.2 Section one – Barriers to organ donation, subjective perception plays a central role in shaping non-cognitive barriers to organ donation. There are several psychological criteria that can predict organ donation behaviour and differentiate between donors and non-donors, discussed in section 3.3.2.2 Psychological characteristics, which may be explained and predicted by differences in subjective perceptions. Moreover, with such a complicated network of variables and criteria, finding patterns can help develop interventions that can effectively target a specific pattern(s), thus reducing the long list of variables to take into consideration.

In its search for subjective perspectives, Q-methodology investigates how these different criteria, barriers and variables may interact to form distinctive patterns. I will describe three studies examining the views on organ donation using Q-methodology. I will follow that with a brief discussion of current Q-methodology studies in organ donation.

The first study is conducted by Truijens and Exel (2019) in the Netherlands with a sample of 30 participants. Participants were first interviewed, then asked to rank 43 statements on a grid (shown in Figure 12), based on how much each statement represented their own point of view. The results formed four views:

1. Not donating my organs would be a waste,

2. It does not go with my religion,

3. My family should decide,

4. It is a good deed, but I'm doubtful.

Figure 12 Q-methodology Grid (Truijens and Van Exel, 2019). The Q-methodology grid uses a rank-order scaling technique in a bell-shaped distribution. It allows participants to communicate their subjective views. It extends from one end to another, where one end represents statements that reflects the participant's views and the other end for statements that are opposite to the participant's views. There is no particular limit for the size of the Q-methodology grid or its numbering. It may consist of any number of columns (commonly 9 to 11 columns), and these columns consist of increasing number of rows towards the centre (commonly starting at 2 or 3 rows at each end).

The study showed a distinction in how people view organ donation, which was especially clear between the first and the second views. Most people who loaded in the first view exhibited a positive attitude towards organ donation and were either registered donors or individuals who intended to register. People who loaded on the second view had negative views towards organ donation. They had a low level of knowledge on organ donation and did not feel the need to acquire further knowledge on the subject. People with the third view were driven by their family's reaction to organ donation, while people with the fourth view had concerns about their family's approval, which resulted from lack of knowledge rather than religious or body integrity issues. The study clearly shows that there is no clear dichotomisation of views: people held both positive and negative views on organ donation.

All four views showed an understanding of the value of donating one's organs; however, different views showed different patterns of barriers to donation.

This study shows that people who have emotionally dealt with death anxiety and body integrity concerns and are holding a mechanistic view of the body; hold positive views towards organ donation as in the first view 'Not donating my organs would be a waste'. While the second view 'It does not go with my religion' shows that religion may play an important barrier to donation and may result in a negative attitude towards it. The third view 'My family should decide' falls under social cognitive theories, where attitude is shaped by one's social circle, and the fourth view 'It is a good deed, but I'm doubtful' suggests that personality characteristics may play a significant role in defining attitude towards organ donation.

The second study that implemented Q-methodology in the context of organ donation was conducted by Hammami et al. (2020) in Saudi Arabia with a sample of 120 participants. Participants were asked to rate 42 statements with responses ranging from 'strongly disagree' to 'strongly agree'. This study took a different approach to the first Q-methodology study (Truijens and Van Exel, 2019), which used ranking on a Q-methodology grid rather than rating.

In this study, 42 statements were divided into four areas:

1. Consequentialism

2. Justice

3. Rights

4. Virtue.

The authors analysed the rating for men and women separately. They found six models (views) for each gender (a total of 12). Each model represents a different pattern of

views across the four themes (Consequentialism, Justice, Rights, and Virtue). The study shows a heterogeneity in views even within similar demographic groups. It also indicates that Q-methodology analysis revealed interesting patterns that were masked by common survey-averaging methods. A third Q-methodology study was conducted by Jeon and Seo (2020), presenting four views on organ donation explaining 59% of variance. The study asked 33 participants to rank 32 statements on a grid from +4 to -4. The views are public-interest oriented, reluctant, passive and death-anxious.

Q-methodology studies in organ donation have some limitations. Organ donation is extremely context dependent. Studies' outcomes can only be applied to the country-specific context, and many variables contribute to that specificity, such as religion, social norms, the healthcare system, translation regulation, donation laws and the allocation system, among many others. Finally, despite the valuable contribution of Q-methodology studies to organ donation, they use statements from theoretical models, which account for certain barriers but certainly do not cover the breadth of potential barriers and motivators to organ donation. Further studies should further investigate patterns of behavioural barriers to organ donation, and how such patterns inform theoretical models.

3.4.2.4   Other theories used in organ donation literature

The Bystander Intervention Model (BIT) (Anker and Feeley, 2011) was used to predict the intention to donate and to compare donors with non-donors. It showed that situational factors play a role in *perceiving* organ donation need as an emergency. It reinforces the role of subjective perception in organ donation behaviour. Another theory that has been used organ donation is Immediacy Theory (King et al., 2012, Sharpe et al., 2017), to compare an immediate versus delayed registration opportunity. It was found that "in the immediate condition, 60% registered against 11.6% in the delayed condition despite

participants in both conditions having similar attitude profiles, suggesting that attitudes were facilitated or obstructed by the registration opportunity" (Sharpe et al., 2017). Finally, Self-Affirmation Theory considers how people adjust their behaviour in response to information or experiences that are perceived as a threat to their self-concept. Studies showed that self-affirmation reduced anxiety levels, individuals were more willing to acquire information about and have more of a positive attitude towards organ donation (Wang and Zhao, 2018, Wang, 2020). This also suggests that psychological factors influence attitude to organ donation. Immediacy of action and a sense of self-efficacy will eventually create the appropriate conditions to take action (Crano and Prislin, 1995), however, it is important to differentiate between task efficacy as in completing an organ donation form or decision-making efficacy, i.e., the ability to make the decision to donate (Williamson et al., 2017).

Anker et al. (2010) endeavoured to explain the attitude-registration discrepancy using the Vested Interest Theory (VIT). VIT suggests that the more an individual has vested their interest in a subject, the more correlated the behaviour will be to the attitude. The vested interest can be increased by increasing one's perception of gain, with salience of the environmental noise complemented with high certainty of the reward. Other social theories have also been used such as Social Representation Theory to examine the dissemination of message across an organisation (Morgan et al., 2010c, Harrison et al., 2011a), Prospect Theory, and Exemplification Theory (Message Framing) (Chien and Chang, 2015) to examine the difference between gain-framed and loss-framed messages and between narrative messages and statistical messages respectively.

There have been attempts to culturally tailor campaign messages to address certain ethnicities. Zaramo et al. (2008) found that culturally tailoring the message was effective to address the lack of trust within minority groups in the medical system and could improve the

registration rate. However, Dunkel et al. (2018) and Hansen et al. (2018) found no significant effect of culturally tailored messages.

3.4.3   Is organ donation a health problem?

After more than 15 years of social research on organ donation, research commonly falls under healthcare areas, hence; the theories, models and approaches seem to follow other healthcare-related theories as well. The decision to register or not register is extremely different to most other healthcare issues such as smoking, diet, and HIV protections, etc.

There are four main reasons that distinguish the organ donation decision-making process from other healthcare problems, and even from other altruistic decisions for that matter:

1. It is a one-time decision. Other healthcare problems feature repetitive decision-making. Smoking, condom use, exercise and health checks are all frequent events that one needs to do regularly. It is arguable that every time one abstains from a harmful behaviour, they are going through the decision-making process all over again.

2. Behaviour will not affect the quality of life, age, or prognosis of the actor. Deceased organ donation happens after the person dies.

3. Perceived risks, benefits and costs are irrelevant in organ donation. Although some factors might play a role, such as possible family disapproval of the person's decision to register as a donor, still; there is no perceived benefit to the decision maker, i.e., the deceased organ donor.

4. The beneficiaries are other people that the donor does not know, who cannot even be sure that the donated organ can or will save their lives, let alone improve it.

Based on the above four reasons, it is reasonable to argue that deceased organ donation is not a typical healthcare problem and theoretical models borrowed from healthcare

literature need to be modified to better fit the context. Scholars have added various variables to existing theories to better describe deceased-organ-donation decisions. However, further investigation is required to explore the complex network of barriers and motivators that influence these decisions.

Table 6 Explanatory and behavioural change theories in organ donation. The table shows the theories and models used to predict and change behaviour in organ donation literature. This list is by no means exhaustive, and other qualitative studies might have not been included in this table. The list shows a wide range of theories that have been used in organ donation, however, TRA (and TPB) are the most applied models. The third column represents variables that have been added to the original model to improve predictability. The last column indicates if the model was used to explain/predict organ donation behaviour or if it has been applied in an intervention study to change the behaviour.

Study	Theory or Model	Added Variables	Theoretical Use
Sherman, Sherman et al., 2001	Disgust Scale of Haidt, McCauley, and Rozin	-	Explanatory
Reubsaet, Brug et al., 2001	Social Cognitive Theory	-	Explanatory
Reubsaet, van den Borne et al., 2001	Social Cognitive Theory	-	Explanatory
Morgan, Miller et al., 2002	Model of Behavioral Willingness to Donate Organs	-	Intervention
Reubsaet, Brug et al., 2003	Social Cognitive Theory	-	Explanatory
Reubsaet, Brug et al., 2004	Social Cognitive Theory	-	Intervention
Quinn, Alexander et al., 2006	Transtheoretical Model	-	Intervention
Bekkers, 2006	Integrated theory of Volunteer work	-	Explanatory
Bresnahan, Lee et al., 2007	Theory of Reasoned Action (TRA)	Spiritual connection and concerns Family discussion Knowledge	Explanatory
McDonald, Ferreri et al., 2007	Communication Accommodation Theory	Knowledge level	Intervention
Park and Smith, 2007	Theory of Reasoned Action (TRA)	-	Explanatory
Weber, Martin et al., 2007	Theory of Reasoned Action (TRA)	-	Explanatory

Bresnahan, Lee et al., 2007	Theory of Reasoned Action (TRA)	Spiritual connection and concerns Family discussion Knowledge	Explanatory
Jeffres, Carroll et al., 2008	Theory of Reasoned Action (TRA)	-	Intervention
Morgan, Stephenson et al., 2008	Organ Donation Model (ODM)	-	Explanatory
Wu and Tang, 2008	Theory of Reasoned Action (TRA)	Death anxiety	Explanatory
Hyde and White, 2009a	Theory of Planned Behaviour (TPB)	Prototype/Willingness Model (PWM)	Explanatory
Hyde and White, 2009b	Theory of Planned Behaviour (TPB)	Prototype/Willingness Model (PWM)	Explanatory
Hyde and White, 2009c	Theory of Planned Behaviour (TPB)	Prototype/Willingness Model (PWM)	Explanatory
Yun and Park, 2010	Theory of Reasoned Action (TRA)	-	Explanatory
Morgan, Harrison et al., 2010	Theory of Reasoned Action (TRA)	Medical mistrust	Intervention
Anker, Feeley et al., 2010	Vested Interest Theory (VIT)	-	Explanatory
Morgan, King et al., 2010	Social Representations Theory (SRT)	-	Explanatory
Hyde and White, 2010	Theory of Planned Behaviour (TPB)	Prototype/Willingness Model (PWM)	Explanatory
Siegel, Alvaro et al., 2010	IIFF	-	Explanatory
O'Carroll, Foster et al., 2011	Theory of Reasoned Action (TRA)	Ick factor Anticipated regret	Intervention
Anker and Feeley, 2011	Bystander Intervention Theory (BIT)	-	Explanatory
Harrison, Morgan et al., 2011	Social Representations Theory (SRT)	Peer influence Number of conversations with co-workers Physical, Social and Information structures Industry type	Explanatory

King, Williams et al., 2012	Immediacy Theory	-	Intervention
Hyde and White, 2014	Theory of Planned Behaviour (TPB)	-	Intervention
Demir and Kumkale, 2013	CART – Classification and Regression Trees	-	Explanatory
Siegel, Navarro et al., 2014	Theory of Reasoned Action (TRA)	-	Explanatory
Hyde and White, 2013	Theory of Reasoned Action (TRA)	Prototype/Willingness Model (PWM)	Explanatory
Pradeep, 2015	Health Belief Model (HBM)	-	Intervention
Chien and Chang, 2015	The Theory of Exemplification	-	Intervention
Quick, Anker et al., 2016	Bystander Intervention Model (BIM), the Organ Donor Model (ODM), and Vested Interest Theory (VIT).	-	Explanatory
Siegel, Tan et al., 2016	IIFF	-	Intervention
Sukalla, Wagner et al., 2017	Theory of Reasoned Action (TRA)	Narrative engagement Ambivalence Perceived Behavioural Control	Intervention
Sharpe, Moloney et al., 2017	Immediacy Theory	Organ Donation Attitude Scale ODAS	Intervention
Wong and Chow, 2018	Theory of Reasoned Action (TRA)	-	Explanatory
Wang and Zhao, 2018	Self-Affirmation Theory	Tendency to consider future consequences The anticipated guilt	Explanatory
Alsalem, Fry et al., 2020	Theory of Reasoned Action (TRA)	-	Intervention
Wang, 2020	Self-Affirmation Theory and Terror Management Theory	Templer's death anxiety scale Organ donation misconceptions	Intervention

3.4.4 Individual perception in theoretical models

In all the theoretical models described in this section, attitude was considered a fundamental predictor of intention and behaviour. Within the studies mentioned in this chapter, attitude to organ donation has been operationalised by many researchers and several scales were developed, such as the Organ Donation Attitude Scale (ODAS) (Parisi and Katz, 1986), Morgan's scale (Morgan et al., 2010a), and Organ Donation Attitude (Morgan and Miller, 2002b). These are the scales that are used to measure attitude to organ donation.

These scales are commonly formed of subthemes combining questions about attitude towards the concept of organ donation (Morgan et al., 2008b) with few other barriers. First of all, it is worth mentioning that attitude to the concept of organ donation is not a valid measurement of the attitude of an individual concerning the donation of his/her own organs (Morgan et al., 2008b). Secondly, these scales, which consist of 24–44 questions, are useless in providing clues on how distinctive perception is formed. They adopt a bipolar measurement of attitude, either positive or negative, that is collected by averaging all different subthemes within the one scale. This will be further discussed in the next section.

Attitudes are immeasurably complex. They are shaped by many variables and formed through many processes. These components vary and fluctuate resulting in immense complexity. This picture seems to be applicable to the organ donation context. Attitude to organ donation has been shown to be complex and conflicting: positive and negative views coexist. This requires a significant amount of information to process one's attitude to organ donation. This necessitates a reflection on the definition of attitude in organ donation literature to examine the possibility of conceptualising attitude as a network rather than a scale. This then would suggest an examination of how these networks of barriers and motivators are formed. This conception of attitude may offer a new way to measure attitude

to organ donation that is meaningful and restores the link between attitude at the individual perception level to that at the society level.

3.4.5   Conclusion

Social cognitive models were insufficient to explain organ donation behaviour. They did not account for non-cognitive variables and did not include any demographic, psychological or social predictors to attitude. Later models were more specific to the organ donation context, taking into consideration various barriers to organ donation and attitude predictors as well. However, there is still a weakness in our understanding of organ donation behaviour. Studies shows a great degree of subjectivity in perceiving barriers to donation; however, this area remains poorly understood.

A great deal of our understanding of organ donation behaviour stems from the way we conceptualise its constructs. Combining barriers to organ donation with a network view of attitude to organ donation may offer a useful way to understand behaviour at various levels – at individual, group, and societal levels. Q-methodology studies attempted to uncover patterns of such variations and revealed different views that entail the need for different theoretical pathways. However, they remain limited in number: more studies are required to uncover patterns of subjective perception in specific contexts.

3.5   Section four – Evaluating implementation and reporting of interventions

3.5.1   Introduction

In previous sections, I highlighted the urgent need to increase the donation rate in the UK. I went on to discuss organ donation barriers and predictors. In the last section, I discussed the limitations of theoretical models used to explain and change organ donation behaviour. Now that I have identified several limitations and established a goal to increase

the organ donation rate, it is important to evaluate the implementation and reporting of organ donation intervention. Empirically, and in the UK, there seems to be a dissociation between academic work and NHS campaigns (this will be further discussed in section 6.4.1.1 Implications for policymakers). In this section however, I will examine the academic papers only. Many interventions discussed in this section are based on real-life interventions; however, none of them are based on an intervention designed by the NHS in the UK.

In this section, I will first discuss the conceptual issues with organ donation interventions. This will be followed by an evaluation of the quality of evidence in intervention reporting. From the literature search discussed in 3.1 – Chapter introduction, I have found 34 interventions in organ donation. Table 7 represents a list of interventions included in the discussion of this section. Conceptually, there is a significant intention-behaviour gap in organ donation interventions. I will discuss the gap between measured intentions and the intended behaviour, and its possible causes. I will also discuss ways to reduce the intention-behaviour gap in organ donation interventions. Furthermore, I will suggest that one of the issues contributing to this gap is unmeasured and unexplored subjectivity, in addition to the unexamined patterns of behavioural barriers to organ donation.

Discussion on the intention-behaviour gap will lead to an examination of the mechanism of change in interventions. I will discuss how an information deficit contributes to the intention-behaviour gap. I will also argue that decision salience plays a role in changing behaviour in educational interventions, which is the prevalent intervention design in organ donation. I will argue that while knowledge has been identified as a major barrier to organ donation and a main predictor to attitude towards organ donation, educational material impact is mediated by salience of the organ donation decision. Furthermore, when designing educational material for behavioural interventionism it is important to consider various types (areas) of knowledge and how these types may have different impact on behaviour.

By the end of this section, I will conclude that organ donation is not a rational (cognitive) decision and behavioural change models from a healthcare context are not sufficient in instigating behavioural change. Organ donation decisions are intricate and complex; hence, intervention must address such complexity and adopt a holistic approach to cover many of the barriers and predictors of organ donation behaviour.

3.5.2   Conceptual issues in organ donation interventions

The term 'intervention' refers to a combination of processes and strategies designed and implemented to produce a desirable behavioural outcome (Michie and Prestwich, 2010) at different target levels: individual, group and multi-level. Interventions are the embodiment of theories for two main reasons. First, theories set up a series of assumptions that underlie the intervention. These underlying assumptions dictate the process of the intervention, and it affects the choice of material, the message, the language, and the means of implementing the intervention. Second, theories guide the expectation for the intervention outcome. The outcome, i.e., the product of the intervention process, is mandated based on the theoretical foundation of the intervention. Thus, choosing the right theory and carefully implementing its variables in a coherent fashion is inherently crucial for any intervention. However, a systematic review on organ donation interventions shows that most do not report any atheoretical foundation (Feeley, 2007). That suggests that the intervention process, design and mechanism of change can be random and difficult to replicate.

There are two conceptual issues I will discuss here. First is the intention-behaviour gap. This gap applies not only in the organ donation context, but to intention-based theories in all contexts. The gap size varies from one context to another, but that gap is never non-existent. I will discuss the causes of the gap in the context of organ donation and suggest ways to reduce the gap. The second conceptual issue lies in interventions that rely on

educational material as a vehicle of change. It is worth mentioning that educational interventions do not target a knowledge deficit exclusively. Educational material is used around organ donation to target other barriers as well, such as mistrust in the healthcare system, and to improve self-efficacy. I will discuss the different barriers that educational material may target and argue that behavioural change is partly produced by decision salience rather than the content of the educational material. Hence, decision salience may be targeted to produce even more effective interventions.

3.5.2.1   Intention-behaviour gap

3.5.2.1.1   What is the intention-behaviour gap?

The intention-behaviour gap refers to the failure to translate intention into action. Most people have positive attitudes towards organ donation and have the intention to register to donate or to inform family and friends about wanting to donate their organs, but some never do (NHS, 2017). In organ donation, this gap is estimated at 27–46% (Armitage and Conner, 2001, Rhodes and de Bruijn, 2013). Simply said, nearly half of people with the intention to do the action never follow through. Studies on organ donation show that willingness to donate does not always reflect in the actual registration rate, and that there is a significant gap between the two (Park and Smith, 2007, Yang et al., 2015, Julka and Marsh, 2005, Johnson and Goldstein, 2003, Jacob Arriola et al., 2019).

The intention-behaviour gap jeopardises the effectiveness of intention-based theories, where intention directly precedes behaviour. Hence, it is important, though not always practical, to measure the intended behaviour in intervention rather than its antecedents. Research shows that behaviour is not always preceded by intention (Bagozzi et al., 1989, Rhodes and de Bruijn, 2013) and intentions are not always translated into behaviour (Yang et al., 2015, Manninen and Evans, 1985, Radecki and Jaccard, 1997, Siegel et al., 2014).

Evidence also suggests that behaviour might change without any change in attitude and vice versa (Jackson, 2005).

The intention-behaviour gap is especially important in organ donation interventions since the theoretical foundation commonly depends on behavioural antecedents. As discussed in section 3.4.4 - Individual perception in theoretical models, conceptualisation of attitude as a bipolar line is oversimplistic and as evident in qualitative research, views on organ donation vary significantly based on an individual's history, experiences, social environment, and personality. People hold both positive and negative views at the same time, which are potentially different from people with similar backgrounds.

3.5.2.1.2 *Is the intention-behaviour gap specific to organ donation?*

The intention-behaviour gap is not specific to organ donation. However, intention-based theories are commonly used in organ donation studies. For example, according to the TRA, the proximal antecedent of behaviour is the intention to perform that behaviour (Godin and Kok, 1996). The TRA indicates that adopting a behavioural change is preceded by a conscious plan to exercise the change in the targeted behaviour with a certain amount of effort measured in intention. Intention is affected by attitudes and shaped by personal perceptions and social norms. Other theoretical models, such as the Organ Donation Model and IIFF, theorise intention as a precedent to behaviour as well. This creates a problem in translating organ donation intentions into actions.

Although the TRA has been empirically validated in the context of organ donation, the theory still has limitations, and like any other theory needs constant refinement and revision (Sheppard et al., 1988). It creates a great deal of uncertainty when it comes to the translation of intention into actual behaviour (Sheppard et al., 1988). Ajzen (1985a) acknowledged that "some behaviours are more likely to present problems of controls than

others, but we can never be absolutely certain that we will be in a position to carry out our intentions. Viewed in this light, it becomes clear that strictly speaking every intention is a goal whose attainment is subject to some degree of uncertainty".

Additionally, the TRA acknowledges the impact of the time delay between the intention and the behaviour (Ajzen, 1985b), which might explain the success of interventions that apply Immediacy Theory to organ donation. This suggests that an immediately available opportunity to register may bridge the intention-behaviour gap by reducing the time delay between intention and behaviour, which may contribute to the gap between the two. There have been many attempts to introduce new variables to the TRA to moderate the intention-behaviour gap, such as personality and self-efficacy among others (Sniehotta et al., 2005, Reuter et al., 2008, Monds et al., 2016, MacCann et al., 2015, Adriaanse et al., 2011, Armitage and Conner, 2001, Wieber et al., 2015, Rhodes and de Bruijn, 2013).

3.5.2.1.3 *Properties of intention in organ donation*

Scholars have attempted to determine how well intentions predict behaviour by examining intention properties. Stable (Sheeran, 1999), well-formed (Trafimow et al., 2002), attitudinally controlled (versus intentions controlled by subjective norms) (Trafimow and Finlay, 1996), and certain types of intentions (Pieters and Verplanken, 1995) are correlated with a smaller intention-behaviour gap

An organ donation decision is a single action behaviour, not a goal that may require repetitive actions. According to Paschal (2002), this makes intention a superior predictor of behaviour. However, due to lack of awareness and lack of common discussion about organ donation, it is unlikely for intentions to be well formed. We do not fully understand how to differentiate between donors and non-donors, or stable, well-formed intentions from unstable, poorly formed intentions in organ donation. However, the literature review does suggest a

connection between personality types, subjective perceptions, and intention. Further research is necessary to explore this relationship.

3.5.2.2 Information deficit or decision salience

In this section, I will explore information deficit in organ donation. Knowledge, or lack thereof, is an established barrier to organ donation. Information deficits encompass a wide range of areas and may be related to awareness of shortages, information about brain death and the allocation process, information about registration, exclusion and the opt-out system, etc. Information deficit is one of the reasons for the intention-behaviour gap, which means that people's inaction happens because people are unaware of the necessity and importance of acting (Flynn et al., 2009). Most studies used various types of educational material, with the assumption that educational campaigns will lead to positive changes in the attitude towards donations, resulting in an increased donation rate (Morgan and Harrison, 2010, Salim et al., 2015, Bidigare and Ellis, 2000, Reubsaet et al., 2004a, Natt et al., 2017, Thornton et al., 2016, Pradeep, 2015).

Knowledge can be defined as facts, information, skills, experience or simply as awareness. In organ donation, there are several types of knowledge that have been addressed in literature. Educational materials designed to address certain types of knowledge may not be effective in improving other types of knowledge. In organ donation literature, several interventions used educational material to raise awareness (Thornton et al., 2016, Bidigare and Ellis, 2000, Harrison et al., 2011b), dispel myths (Sukalla et al., 2017), and improve procedural knowledge (Reubsaet et al., 2003, Anker and Feeley, 2011, Siegel et al., 2016).

Research shows that interventions that aim at raining awareness are effective in influencing organ donation behaviour (McGlade and Pierscionek, 2013). Unfortunately, there

remains a significant gap between the percentage of people with an awareness of organ donation and those who register as donors (NHSBT, 2018). I argue that this dichotomy between high awareness and low donation rate is principally due to a mix of other behavioural barriers that hinder donation besides a lack of knowledge.

Declarative knowledge, such as educational material that aims at dispelling myths, is explained by the TRA. It is important in shaping social norms (Aarts and Dijksterhuis, 2000). Myths in organ donation are common, and brain death can be confusing to non-medical professionals. Addressing myths and misbeliefs in organ donation is effective (Morgan et al., 2010a, Sukalla et al., 2017). This type of intervention responds to the medical mistrust serving as a significant barrier to organ donation. However, "addressing [myths and beliefs] to others previously unaware of these barriers could backfire and cause some to not join the organ donation registry" (Quick et al., 2014a). It is important to understand the overlap between medical mistrust as a barrier to organ donation and other barriers that may play a significant role in shaping the perception of such myth and lead to the formation of misbeliefs.

Procedural knowledge, on the other hand, applied in social cognitive theory (Reubsaet et al., 2003), bystander intervention theory (Anker and Feeley, 2011) and the self-affirmation principle (Siegel et al., 2016), is assumed to increase the self-efficacy perception that may trigger the desired action. This type of knowledge does not specifically respond to any common barrier to organ donation; it is related to other psychological barriers that are not systemically explored in qualitative studies but have been shown to be vital in organ donation behaviour. This suggests that there are many layers to this behaviour and there is a big gap yet to be explored in understanding the full decision-making process.

Building on the TRA or other theories discussed in the intervention literature, like the Health Belief Model (Pradeep, 2015) or Social Representation Theory (Harrison et al.,

2011b), knowledge is one construct that can directly or indirectly affect the outcome. However, Morgan et al. (2010b) stressed the fact that small changes in variables that lead to a robust change in the effect cannot be explained by the underlying theory alone. Furthermore, "educational interventions should not assume that increasing knowledge or simply encouraging individuals to declare a decision about donation will increase consent to donation" (Lawlor et al., 2007).

Martin Fishbein (2008) highlighted that the interventions that are based on improving the knowledge level of individuals do not usually work. The author ascribes that to a possible lack of skills or internal or external barriers that prevent the individual from performing the intended action. He emphasises the importance of focusing interventional efforts to improve skills or relieve barriers rather than to provide more information to change the attitude. This suggests that educational material aiming at improving knowledge may not be effective in bridging the intention-behaviour gap. Theory-based approaches that target a specific theoretical issue will be more effective and easily replicable.

The literature on barriers to organ donation consistently highlights knowledge as a barrier. Operationalising knowledge as a construct in organ donation studies has not been systematically validated. Studies used different scales to measure knowledge and did not always specify the type of knowledge or the part where information lies, whether it is in the need for donation, eligibility criteria, information on brain death or allocation system etc. Understandably, knowledge is a simple barrier to operationalise and measure, but that does not reflect its significance as stand-alone barrier and certainly does not justify the focus it has received from intervention studies. Most of the effect of educational material used in intervention is driven to a large extent by the salience of the decision they target (Bettinger et al., 2020). Using different theories to justify the same technique (i.e., educational material and knowledge positively affects attitude) is unwarranted: research here remains an art, rather

than a science. Salience may play a significant role in altering attention towards organ

donation, an unfamiliar topic. The intervention refocuses attention to the topic of organ

donation, thus it is argued that salience intervention that does not offer donation-specific

information may do equally well compared to informative interventions through salience

alone (Bettinger et al., 2020).

Table 7 Behavioural intervention in organ donation. This table represents a list of interventions. This list is not exhaustive. Most studies were not based on any theoretical modelling. The table shows location and sample size for each study. This is then followed by study outcome. Some studies used organ donation behaviour (registration or family discussion) as an outcome, others used indirect measures such as knowledge, attitude, and/or intention as an outcome. It is worth mentioning that these indirect measures may or may not be translated into the intended behaviour. The table also shows various material that has been used in each study. written educational materials are commonly used. The last column indicates the study design. It shows that Randomised Controlled Trial (RCT) design is not common in organ donation intervention studies.

Study	Theory or model	Location	Sample	Study outcome	Material	Design
Weaver, Spigner et al., 2000	NA	USA	36	Attitude + Knowledge	Educational written material + Educational sessions	Non-randomised CT
Bidigare and Ellis, 2000	NA	UK	300	Registration	Educational written material	Prospective, systematically randomized, cross-sectional study
Morgan, Miller et al., 2002	Organ Donation Model (ODM)	USA	798	Registration + Attitude + Knowledge	Educational written material + Educational sessions	Quasi-experiment
Reubsaet, Brug et al., 2004	Social Cognitive Theory	Netherlands	338	Intention	Video with group discussion + Educational computer program	Quasi-experiment
Quinn, Alexander et al., 2006	Transtheoretical Model	USA	754	Registration + Family discussion	Educational written material	RCT
Frates, Bohrer et al., 2006	NA	USA	500	Registration + Family discussion + Intention + Attitude	TV and radio advertisement	RCT

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Alvaro, Jones et al., 2006	NA	USA	600	Awareness + Intention + Beliefs	TV and radio advertisement	RCT
McDonald, Ferreri et al., 2007	Communication Accommodation Theory	USA	109	Intention to talk to family + Knowledge	Educational written material	RCT
Zaramo, Morton et al., 2008	NA	USA	NA	Registration	Educational program	One group cohort
Jeffres, Carroll et al., 2008	TRA	USA	420	Registration + Intention	TV and radio advertisement	Cohort study
Arriola, Robinson et al., 2010	NA	USA	425	Registration + Family discussion + Intention	Video + Educational written material	Cohort study
Morgan, Harrison et al., 2010	TRA	USA	9,477	Registration + Intention + attitude + Knowledge + Subjective norms	Education material	Quasi-experiment
Feeley, Anker et al., 2010	NA	USA	170	NA	Education material	Cohort study
O'Carroll, Foster et al., 2011	TRA	UK	482	Intention + Attitude + Knowledge + Subjective norms	Anticipated regret questions	RCT
Morgan, Stephenson et al., 2011	NA	UK	NA	Registration + Family discussion + Intention + Attitude + Knowledge	Mass media + interpersonal communication intervention	Cohort study
Andrews, Zhang et al., 2012	NA	USA	NA	Registration + Attitude	Conversation + Educational video	RCT

King, Williams et al., 2012	Immediacy Theory	USA	NA	Registration	Point-of-decision materials	Cohort study
Hyde and White, 2013	TPB	Australia	177	Registration + Family discussion	Motivational message or action plan	Cohort study
McGlade and Pierscionek, 2013	NA	Northern Ireland	100	Registration + Intention + Attitude + Knowledge	Formal training	Cohort study
Salim, Berry et al., 2015	NA	USA	59,181	Registration	Written material or written material + Verbal conversation	Interrupted time series
Pradeep, 2015	HBM	UK	907	Registration + Knowledge	Educational sessions for professionals + Peer education	Mixed method
Chien and Chang, 2015	The Theory of Exemplification	Taiwan	189	Registration + Family discussion	Message	Cohort study
Thornton, Sullivan et al., 2016	NA	USA	915	Registration	Educational video	RCT
Siegel, Tan et al., 2016	IIFF	USA	NA	Intention	Recall emotions	Cohort study
O'Carroll, Shepherd et al., 2016	NA	UK	14,509	Registration	Anticipated regret questions	Cohort study
Natt, Klar et al., 2017	NA	Canada	46	Registration	Educational written material	One group cohort

Sukalla, Wagner et al., 2017	TRA	Germany	308	Intention + Attitude	Narrative or narrative + Educational written material	RCT
Sharpe, Moloney et al., 2017	Immediacy Theory	Australia	200	Registration + Intention	Immediate or delayed opportunity to register	Cohort study
Dunkel, Nakamoto et al., 2018	NA	Switzerland	599	Registration + Family discussion + Intention	Educational, emotional or community oriented written material	RCT
Riley, Evans et al., 2019	NA	USA	120	Attitude	Educational videos then discussion	Quasi-experiment
Jacob Arriola, Redmond et al., 2019	NA	USA	1,585	Registration + Intention + Knowledge	Educational video + Booklet	Cohort study
Heitland, von Hirschhausen et al., 2020	NA	Germany	1,103	Registration + Intention + Attitude	Humorous video material	Quasi-experiment
Wang, 2020	Self-Affirmation Theory and Terror Management Theory	China	352	Intention + Death anxiety	Self-affirmation questionnaire	Cohort study
Robitaille, Mazar et al., 2021	NA	Canada	3,376	Registration	Educational printed material	Cohort study

3.5.2.3 Is organ donation a rational decision?

The TRA assumes rationality in that intention and behaviours follow beliefs (Ajzen, 2020). Cognitive processing is an indicator as to whether a decision is rational or irrational (Cacioppo et al., 1996). In organ donation, studies show that the prediction of the TRA is improved when non-cognitive variables are added, indicating that non-cognitive behaviour plays a role in the decision-making process. Incorporating non-cognitive variables to the TRA brought about the organ donation and IIFF models. Wong and Chow (2018, 2020) aimed at validating the measures generated based on the TPB. They argued that TPB assumed rational cognitive attitudes and ignored the affective nature of attitudes related to organ donation. They suggest that limitation may explain inconsistency between the general positive attitudes toward organ donation and the actual registration rate.

From an economic perspective, decisions that are inconsistent with technical and economic rationality are considered irrational. However, scholars in social-science fields ascertain that systematic analysis of input may also result in suboptimal decisions. Such decisions are the result of many biases that influence behaviour without individual awareness. According to behavioural science, people endeavour to make rational decisions but their ability to make optimal ones is usually restricted (March and Simon, 1958; Simon, 1957). Hence, people commonly adopt a simple approach by using cognitive heuristics that offer much more straightforward approach, accompanied by cognitive biases (Bazerman, 1998; Kahneman and Tversky, 1973, 1979).

Given the above argument, the TRA and related models in their current design are not useful in guiding interventions to change behaviour (Hardeman et al., 2002, Taylor et al., 2006, Webb et al., 2010). They focus on voluntary actions only to understand the rationale behind the action that guides the intervention. In fact, the theories rationalise irrational

behaviour by dictating that the process of rationalisation by the actor proceeds reasonably from the actor's beliefs (Fishbein, 2008). The non-challenged rationality of individuals delivers analytical truth rather than a synthetic one, which means that the conclusions resulting from the TRA and related models are true by definition and are unfalsifiable (Trafimow and Rice, 2012).

Although organ-donation intention is determined by non-cognitive affective barriers prohibiting individuals from registering (Morgan et al., 2002b), the TRA does not, on its own, account for the weight of these non-cognitive factors. In fact, the idea of affective behaviour itself goes against the basic underlying assumptions of the theory, despite the fact that Suzan Morgan and colleagues (2013, 2004, 2010, 2002b, 2002a) have relentlessly tried to incorporate non-cognitive variables, thus it seems only reasonable to move beyond the TRA for organ donation to explore and examine other theories that fit the situation with organ donation interventions.

Emotions affect subjective perception (Zadra and Clore, 2011). It is valuable to explore the effect of subjective perception (and emotions) in shaping non-cognitive variables. In turn, non-cognitive variables can be scrutinised through the lens of subjective perception to offer a new dimension to organ donation decisions.

3.5.3   Evidence on quality of interventions

It is vital to assess the quality of the evidence from interventions in organ donation to be confident with the estimates of the interventions. There is no specific system to evaluate the quality of evidence in organ donation. However, in healthcare literature, the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) (GRADE Working Group, 2021) offer insight on evaluation criteria that I will use in this research.

3.5.3.1 Study design

Few studies had randomised controlled trial design; the majority adopted cohort design. Cohort studies' participants commonly had shared characteristics, such as demographic or occupation criteria. Observational studies constituted a low quality of evidence compared to randomised controlled trials, which hold a stronger quality according to GRADE (see Table 7 for further details on study design in intervention studies). Although interventions reported successful results, limitations in the methodology cast doubts on the reliability of the evidence. For example, Pradeep (2015), Saleem et al. (2009), Natt et al. (2017) and Sukalla et al. (2017) reported limitations due to sample size or characteristic of the sample that might reflect biases.

In a systematic review conducted by Jones et al. (2017) on interventions in a primary-care setting, seven out of 10 studies were classified as methodologically weak, however all interventions reported an increase in the registration rate. The authors indicated that the small number of intervention studies and the generally weak quality of methodology suggests weak evidence for future replication.

3.5.3.2 Risk of bias

Li et al. (2015) examined the risk of bias in organ donation studies by implementing the Cochrane risk of bias tools and assessed confidence in the evidence using the GRADE framework. This tool assesses several biases in non-randomised studies such as confounding, selection, information, and reporting biases. It was concluded that there is a high risk of bias in intervention studies, and this could potentially result in overestimation of the intervention effect on individuals' willingness to be a deceased organ donor.

3.5.3.3 Change mechanism

Recognising the mechanism by which a change in behaviour has been achieved is critical for generalisation and replication of the intervention outcome. That entails a detailed description of all the techniques and tools used to implement the interventions, a part that is sometimes left unreported for different logistic reasons. This results in unexplained inconsistencies in intervention outcome data when replicated. Non-theoretically based interventions lack the means to create new knowledge.

Harrison et al. (2011b) and King et al. (2012) reported limitations regarding the underlying mechanism of change. Failure to identify a theory that explains the mechanism of change, which leads to the psychological change of perceptions and views, leads in turn to the desired outcome to be a merely random, chaotic, and unexplained phenomenon. Correspondingly, the adopted theory must explain the changes in the behaviour based on the combined effect of changes in its variables, providing a clear account of the chain of events that led to adaptation of the new behaviour.

3.5.3.4 Outcomes

There is a distinction between the intended behaviour and what precedes it. It is sometimes difficult to measure behaviour. This is especially the case with an opt-out system where everyone is presumed to be a donor. Various outcomes were used in intervention studies (see Table 7 for details on intervention outcomes). Intention, attitude, and knowledge are valuable predictors of organ donation behaviour, however, there is a gap between each of those variables and organ donation behaviour. This gap creates an issue in the quality of evidence of the intervention, since outcomes are indirect, and interventions do not investigate the behaviour itself.

3.5.3.5 Effectiveness

A clear challenge now exists for scholars to unpack the findings of interventions in organ donation in order to address their effectiveness. Behavioural intervention effectiveness constitutes a measurable outcome and a controlled experiment. Systematic reviews aim to identify, assess, and sum up the findings of all applicable individual studies over a specific issue, thus making the existing evidence more accessible to decision-makers (Aromataris and Pearson, 2014). A meta-analysis, on the other hand, is a quantitative study design that aims to systematically investigate previous individual research studies to present estimates of the effect that are more precise than any individual study (Rosenthal and DiMatteo, 2002).

Comparisons of effect sizes are becoming more frequent with the growing body of literature of systematic reviews and meta-analyses. Indicators of effect size allow comparison among interventions to determine those with highest potential to create a behaviour change when applied in practice. Not all interventions report on the effect size; instead, they report the P value. P value is merely "a conditional probability indicative of the probability of a result at least as extreme as the obtained difference assuming that the null hypothesis is true" (Volker, 2006). Effect-size indicators gauge the practical significance, i.e., the effect on the behaviour that we measure, being part of a broad assessment of the behaviour and the quality of life (Kaplan, 1990). Effect size is important for cost-effectiveness studies to determine the value of the intervention on the society, and it is a strong indicator to amend policies.

In organ donation, a meta-analysis conducted by Feeley and Moon (2009) showed a low effect size of only 5%. Another meta-analysis by Li et al. (2015) concluded interventions increase the registration rate by increasing the people with already positive intentions towards organ donation, and it has no causal effect on intention to donate. Interventions improve the commitment to behaviour rather than the intention to perform the behaviour. This suggests

that grouping people by certain criteria helps target different groups with various intervention designs.

3.5.4 Conclusion

A significant gap ails the intention-based models in organ donation studies. Interventions have suffered from a significant gap between attitudes towards organ donation intentions, and behaviour. This poses a significant limitation on intervention design in purely academic projects, as well as real-life campaigns. One of the main reasons for poor empirical results can be attributed to the linear theorisation of attitude and barriers to organ donation. Many connections between various barriers and motivators are lost on our linear view. Many other reasons may contribute to this gap, including delayed opportunity for conducting the behaviour, lacking necessary skills for the behaviour, and unstable intentions. This can be addressed by measuring necessary skills and offering an immediate opportunity to conduct the behaviour.

While educational interventions may address the information deficit issue, it is important to understand what type of information deficit is to be addressed, and that can only be done through careful contemplation of the intended outcomes of behavioural interventions. While educational material is valuable in improving knowledge about the need and the process of organ donation, informational interventions are only one of the corners of the behavioural change strategies. Multicomponent designs that reflect the intricate network of barriers to behaviour are necessary, especially given that even legislative interventions conducted at national level may not be enough to significantly change the behaviour over the long term.

3.6   Literature Review Discussion

Behavioural barriers towards organ donation influence donation rate. People may hold both negative and positive views on organ donation. Religious beliefs, maintaining body integrity after death, a lack of awareness on organ donation, misbeliefs, and lack of understanding around brain death, mistrust in the healthcare system, fear of death and a scepticism of the recipient's worthiness are commonly cited as barriers to organ donation.

My review suggests that barriers and motivators to organ donation cannot be isolated and should not be examined independently. A significant overlap exists between different barriers and motivators that form distinctive views on organ donation. We have little to no understanding around the extent to which these barriers and motivators interact, or on the nature of such overlap. Furthermore, behavioural barriers and motivators interact to shape attitude, which is a precedent to organ donation behaviour, as theorised by the TRA, ODM and IIFF models. Little is known, however, about how barriers and motivators interact to shape attitude toward organ donation especially given that organ donation attitude scales include questions about barriers and motivators as well.

There are several predictive factors to organ donation behaviour. Demographic factors such as age, gender and education may be useful in predicting organ donation behaviour. Other factors such as personality type, the disgust reaction, or political views were found to be valuable. Likewise, social factors such as the attitude of family, friends or spouse can be effective in predicting attitude towards organ donation. This can potentially provide a valuable insight to *explain* organ donation behaviour. However, we do not fully understand the contribution of these factors in predicting behaviour due to heterogeneity in the outcome variables used. Studies have not fully explored the mediating and moderating variables on the relationship between dependant and independent variables.

Several theoretical models have been used to predict, explain, and change organ donation behaviour. Commonly used theories include the Theory of Reasoned Action (and Theory of Planned Behaviour), Social Cognitive Theory and the Health Belief Model. These theories are primarily used to explain and change healthcare behaviours such as smoking, exercise, etc. These models have significant limitations when applied to organ donation. The organ donation decision is impeded by a network of barriers that are significantly different from other healthcare decisions. It is laden with non-cognitive emotional variables that, married with behavioural barriers, produce a multidimensional decision with many ties to religious and social norms at the societal level, and with psychological criteria and subjective perception on an individual level. Combining both non-cognitive barriers, predictive criteria to organ donation attitude with social cognitive models resulted in several models to explain organ donation behaviour such as the Organ Donation Model and the IIFF model.

Various models were adopted by behavioural interventions in organ donation. The Theory of Reasoned Action and other models derived from it were commonly used. The effect size remains small, and they have several methodological weaknesses, such as small sample size and a high risk of bias. Conceptually, they suffer from a significant intention-attitude-behaviour gap. Information deficit, discussed as a barrier to organ donation, may contribute to this gap. A poorly formed, unstable intention contributes to a large gap between intention and behaviour. In order to further understand the properties of intention in organ donation, more research is required. Organ donation is an unfamiliar subject, with poorly formed heterogenous preferences, widening the intention-behaviour gap when applying behavioural nudges. These, among other reason, may explain the generally positive attitude of the British public towards organ donation and the low donation rate. Legislative interventions implemented in the UK, where the law has been changed from an opt-in to an

opt-out system, may have a positive effect on donation rates, but such effect may require complementing behavioural interventions and systematic changes to the healthcare system.

Social cognitive and organ donation models were valuable in explaining and changing behaviour. They were able to establish the complex nature of organ donation behaviour and the complexity of relationships among its components. However, these models approach behaviour antecedents in a linear and oversimplified manner. Attitude is neither completely negative nor completely positive, and the measurement of any barrier loses quality data by using a linear assessment of independent questions. Moreover, there is no clear distinction between attitude towards organ donation as a concept, compared to the individual's decision. Current models de-contextualise the individual and collective voice; instead, they approach attitude and barriers as a set of numbers that were shown to offer little impact empirically.

It becomes clear that we need an entirely new view to attitude and barriers to organ donation. The new view must address the complex nature of the subject and the patterns that may arise from a network of barriers. Epistemically, the new view must emphasise "individual expression" (Robyn, 2000). To achieve that, I will used mixed-methods research and two studies. I will use Q-methodology in Study one - to explore the pattern of overlap among barriers and motivators. The interaction may result in distinctively different combinations, which may be useful in guiding interventions and theorising organ donation decisions. Q-methodology outcomes can re-conceptualise the concept of attitude from its classically linear view to a network view and elicit patterns within the network. To my knowledge, there has been no Q-methodology study that has been implemented on organ donation in the UK. Existing Q-methodology studies did not focus on barriers to organ donation. In Study two - Survey, I will discuss the survey method used to explore the prevalence of views (identified by the Q-methodology) in the UK and consider the recommendations for national campaigns on organ donation. Chapter five – Results will

present the results of two studies, and Chapter six – Discussion will discuss the findings of

this research along with its theoretical and practical contributions.

4   Chapter four – Methodology

4.1   Chapter introduction

Research methodology refers to the foundation, framework, or the strategy for the inquiry to collect and analyse data (Goddard and Melville, 2004). According to Creswell (2013), there are three main research methodologies, which are qualitative, quantitative, and mixed method. With each methodology, data collection, analysis, and interpretation are distinctively different.

Each methodology is appropriate to answer different kinds of questions. Qualitative research is concerned with in-depth analysis of social phenomenon. It is more appropriate to study how people perceive their reality and then interpret to describe how people perceive the world (Ritchie et al., 2013). Qualitative methodologies allow exploration of the data without a prior fixed framework (Antwi and Hamza, 2015), and it is important for exploratory studies. Whereas quantitative research is more concerned with quantification and verification (Firestone, 1987).

Mixed methodologies combine qualitative and quantitative methods to produce more holistic understanding of the social phenomenon by combining the strength of both methods (Johnson and Onwuegbuzie, 2004). Mixed method research design is a distinct process for gathering and investigating data by "mixing" both quantitative and qualitative research in together in the same research to address research questions. Mixed method studies combine qualitative and quantitative approaches to produce pragmatic results through different phases of the research process (Tashakkori and Teddlie, 2008).

This research aims to examine views to organ donation when attitude and barriers to behaviour imagined as a network. It is also important to emphasise the individual views to ascertain patterns within this network that are formed by subjective perceptions. For that

purpose, Q-methodology was chosen as an appropriate way to achieve that goal. The results of Q-methodology are not statistically generalisable, empirically, little can be done with Q-methodology results alone if one is to use this research to design a behavioural change campaign. For the purpose of empirical contribution, it was important to complement Q-methodology study with post-Q survey to examine the prevalence, and hence the potential effect size, of campaigns targeting each view independently.

This research is mixed method and conducted through two studies, Study one and two. In Study one, Q-methodology and interviews were used to unearth and interpret four different views on organ donation. Q-methodology is a research methodology used to study people's subjectivity. There is a great debate on whether Q-methodology is qualitative or quantitative. It is arguable that it combined both methods and maintain Q as a mixed method approach (Brown, 1997, Stephenson, 1953). Study two then set to examine the prevalence each view in the UK. These approaches can answer different questions, so combining them offers more in-depth findings.

4.2   Research Design

Research design refers to the strategy and process of research, it affects research choice, underlying assumptions, and data collection process (Creswell, 2014). It is the foundation on which research questions, data collection and analysis are based (Kroll and Neri, 2009). There are three categories of research design: exploratory, descriptive, and explanatory research (Saunders et al., 2009). In this research, the design is descriptive and exploratory. Study one in this research aims at exploring and describing the phenomena of organ donation through the lens of subjective views, to examine patterns of barriers and attitude that form distinctive views in organ donation, thus, Study one is an exploratory study (Sekaran and Bougie, 2003). Study two on the other hand, measure the prevalence of views

outlined by Study one, it serves as a guide for national behavioural change interventions, and it is guided by Study one outcomes. It provides estimation of views in populations and describe related characteristics to support and inform empirical research and campaign design. That is why Study two can be categorised as a descriptive study (Zikmund et al., 2003).

4.3　Methodology choice

This research adopted a mixed method approach by first conducting a Q-methodology study to illustrate views on organ donation, followed by a survey to identify the prevalence of these views in the UK. The choice of Q-methodology brought about by evident role of subjective perception in shaping barriers to organ donation. Literature review indicated there is another variable playing a role expressing various barriers to organ donation. It is clear that one barrier may play a different role, sometimes as a strong motivator or as a barrier depending on subjective perceptions. Q-methodology, designed specifically to examine subjectivity is the perfect choice to show how perceptions form distinctive patterns of barriers to organ donation. Theoretically, this is important to ascertain subjectivity as an important variable in organ donation decision.

The primary contribution of this research remains empirical; hence, it is important to be able to generalise the results from Q-methodology to the population in order to produce recommendations for cost-effective national campaigns by targeting the most prevalent of these views. Q-methodology data were collected to gather information on the patterns that formed views on organ donation. Further qualitative data was gathered through interviews to support factor interpretation in Q-methodology output. Q-methodology output were then incorporated into a survey design using post-Q technique. In short, both exploratory and descriptive design were necessary and complementary to answer this research's questions.

4.4 Study one - Q-methodology

This section will describe the Q-methodology used to answer the first research questions and the first two research objectives. The aim of Study one is to identify the views of a sample of UK residents and citizens on organ donation. Throughout this section, I will describe Q-methodology and post-Q Interviews conducted with some of the participants in Q-methodology study to achieve better understanding of their views.

4.4.1 Introduction to Q-methodology

Organ donation brings extensive emotional reactions the moment you start the conversation (Miller et al., 2018), these emotional reactions may affect information processing (Handley and Lassiter, 2002) as well as communications (Kret and Bocanegra, 2016, Taylor, 1984). It is not a common discussion subject and most people have never thought about it (NHS, 2017). Forming a clear opinion about a controversial subject with many ties to religion, social norms, morals and one's own death, and then being able to organise these thoughts and communicate it clearly and systematically to a researcher is tricky and challenging (Moussaïd et al., 2013, Stefanelli and Seidl, 2017). Naturally, participants will answer the first thing that comes to mind, things they are familiar with, things that are triggered intuitively (Greene and Haidt, 2002). Religion, fear of death and "I don't know much about it" are, unsurprisingly, the most common cited barriers.

Research examining attitudes, which uses questionnaires as the main method of inquiry, is the sequel of what research on barriers has concluded. The questionnaires on attitudes are designed and built over the barriers communicated by people "in their own words" (Morgan et al., 2008a). Attitude scales are formed of questions that combines attitude to organ donation concept mashed up with various categories of barriers. These scales measure attitude in a linear way. There have been few studies that conducted exploratory

factory analysis and found several factors within the scale (Güden et al., 2013, Wong and Chow, 2020). Examining patterns of barriers that form distinctive views on organ donation has not been fully explored yet.

Overall, there are many issues in investigating organ donation. To name a few, there are issues with emotional triggers that may affect perception and poorly formed intentions, both may play a role in affecting communication of views on organ donation and result in conflicting and even inconsistent outcomes when investigating behavioural barriers, weak interventions, and big intention-behaviour gap. Crucially, we do not fully understand how behavioural barriers interact with each other and what can such interactions inform future interventions. It is important to investigate the issue using a different method of inquiry. This new method may shed a light on undiscovered relationships and may hold the key to designing better interventions. In this research, I will be using Q-methodology to uncover new readings on barriers against organ donation.

4.4.1.1 What is Q-methodology?

Q-methodology is not uncommon, especially in healthcare literature (if we would accept organ donation as being one). It was invented by psychologist William Stephenson (1935). It has been primarily used in psychology and political studies (Brown, 1980). Q-methodology combines quantitative and qualitative analysis and it has been recently considered a mixed research method rather a distinctive methodology (Greene, 2008). Mixed methods research was introduced in 1989 (Schoonenboom and Johnson, 2017), at about the time of Stephenson's death (Barchak, 1991). There is ample evidence that Q-methodology is a mixed method research (Ramlo and Newman, 2011) that poses both qualitative and quantitative qualities as shown in Figure 13.

Quantitative methods	Q-methodology		Qualitative methods
Objective purpose		Q	Subjective purpose
Explanatory	Q		Exploratory
Numeric data	Q		Narrative data
Structured, close ended questions	Q		Open-ended questions
Statistical analysis	Q		Thematic analysis
Probability sample	Q (Sample is items)		Purposive sample
Deductive inference	Q (Uses abductive reasoning		Inductive inference
Value neutral	Q		Value rich

Figure 13 The multidimensional continuum of research projects (Teddlie and Tashakkori, 2009) with Q-methodology positions entered – Source (Ramlo and Newman, 2011). This figure shows Q-methodology in the middle of a continuum with quantitative methods on one end, and qualitative on the other. This shows Q-methodology to be a unique hybrid of both methods lies and can be used to develop and test theories as well.

Fundamentally, Q-methodology 'intensively analyses' subjectivity (Carlson and Hyde, 2003) in structured manner by recognising patterns in subjective point of view. It works by accounting all possible views around a subject or topic under 'finite diversity' (Barry and Proops, 1999), then assume patterns of similar views to emerge from that chaos. It is informed by subjective communicability as non-substantive, non-conscious, un-judged opinions (McKeown and Thomas, 2013). Q-methodology is one of the very few methods to study subjectivity in a self-referent manner, opening a room for 'pure behaviour' (Brown, 1980) to be examined in a systematic way.

4.4.1.2 My position

My own motivation in conducting this research using Q-methodology is personal. I am personally a registered organ donor (registered as a donor in the opt-out system). Furthermore, I donated my body for medical research. I believe in the mechanic view of body as a reservoir of spare parts. I understand this view can cause unease sometimes which I faced myself when I declared my decision, but I am personally motivated to play a role in convincing more people to donate their organs even if they do not share the same view.

As a researcher, I seek to break boundaries, and I sought a new methodology for this subject. Scholars mourning the fact that most published work is repeating the application of the same method (Bansal and Corley, 2011, Bansal et al., 2018), which led to "path of standardisation" reducing the research method diversity (Lê and Schmid, 2020). Looking for a career in academia, I would like to be part of a group of researchers who are working to push the limit of research conformity and face the difficulties in using innovative methods. Researching an uncommon subject and using a 'new' methodology has sparked interest in this research. I was constantly bombarded with questions and people show keen interest in Q-methodology from non-Q-methodology scholars and I perceived that as part of the wheel of change.

4.4.1.3 Background to Q-methodology

Q-methodology was created by William Stephenson (Stephenson, 1953, Stephenson, 1935). His methodology inverted prevalent R methodology by identifying correlations among people not variables. His analysis has "a very different, yet complementary purpose: its variables are persons, whilst its populations are groups of tests or estimates" (Stephenson, 1935).

In Fact, William Stephenson was a researcher assistant working with Charles Spearman on developing his analytic technique. Stephenson believed that R methodologies 'dissect' individual by studying 'bits' about people, with no effective way 'to put the person together again' (Stephenson, 1936). "The simple problem for R methodology … was that its focus on specific bits of people – variables, traits, abilities and so on – necessarily invoked a kind of methodological dissection" (Watts and Stenner, 2012). By using Q-methodology; we can solve this 'dissection' by correlating people rather than traits (Brown, 1980). The aim of Q-methodology is to examine these views structurally and highlight 'inner discursive

conflict' (Rogers and Kitzinger, 1995). Stephenson differentiated Q-methodology from what he called R methodologies (which is a generic name for all methodologies which aims at data reduction by identifying latent variables using Pearson's r correlation statistics) (Watts and Stenner, 2012) by analysing human expressivity and operant subjectivity (Stainton Rogers and Stainton Rogers, 2001).

Operant subjectivity is the foundation of Q-methodology (Wint, 2013). It is based on the idea that subjectivity can be operationalised. Subjectivity is "everywhere, from the loftiest philosophising and diplomatic negotiating to the street talk of the juvenile gang the self-talk of daydreamer, and it is the purpose of Q-methodology to enable the person to represent his or her vantage point for purposes of holding it constant for inspection and comparison" (Brown, 1997). It allows researchers to explore participants views in a "self-directed process" (Cross, 2004) while effectively minimising the researcher's own views (Ward, 2010). The 'flow of communicability' is called the concourse (Brown, 1993) which represent a collection of statements for various views on the subject of interest.

Q-methodology data is collected as Q sort, where a participant rank statements as it relates to that person's view, and by sorting those statements, participants are operationalising their subjective views. This operant subjectivity is the core or Q-methodology. This operationalisation is standardised by a new 'unit of measurement' called "self-significance" (McKeown and Thomas, 2013). Unlike the standardisation in R methodologies, the standardisation in Q-methodology aims at drawing attention to 'differences between persons' rather than 'differences between variables mapped at the population level' (Watts and Stenner, 2012). This unit of measurement allows a collection of individuals to scale a population of items or tests instead of the other way around (Watts and Stenner, 2012). This is followed by factor analysis, but in Q-methodology, the participants are the variables which is why is it sometimes called inverted factor analysis.

4.4.1.4   Using Q-methodology

Figure 15 shows the steps by which the Q-methodology study (Study one) was

conducted and Table 8 shows the glossary of Q-methodology terms. The first step in Q-

methodology is to create a concourse. A concourse refers to the collection of all discussions

around the topic (Stephenson, 1980). The concourse must initially account for all possible

views, statements and opinions around the topic (Stephenson, 1953). Different strategies can

be used to ensure this "stimulus representativeness" (Brunswik, 1947). The second step is to

reduce this comprehensive list to a manageable-sized list that still comprehensibly represent

discussions affiliated with the topic, forming Q sample. This Q sample is administered to

participants. Participants will 'sort' statement on a worksheet (Lien et al., 2018).

The participants sample in Q-methodology, the P set; has to be strategically and

systematically selected to reflect potential views (Brown, 1996). P set in Q-methodology does

not represent the population, but rather represents the variety of views in the sample. It is not

satisfactory to select participants based on demographic criteria only, the strategy of sample

selection must reflect 'subjective views' rather than objective factors such as age or education

only (Van Exel and De Graaf, 2005). However, there is no assumption that the sample will

exhaustively include all possible views.

Now that we have the Q sample (the statements that represent opinions on a subject),

the participants (P set) are asked to rank them on Q-methodology Grid. Figure 14 shows the

modelling process, where statements are placed on a gird when hardcopy version of

statements is used. The same process can also be done online. The resulting outcome is Q

sort, a genuine 'operationalised' representations of personal point of views (McKeown and

Thomas, 2013, Bridgman and Physicien, 1927).

Figure 14 Ranking Statements on Q-methodology Grid (Ellingsen et al., 2014). When done manually, the participant place statements on a bell-shaped grid based on how much each statement represents their point of view.

Once Q sorts are collected, they are analysed using correlation and by-person factor analysis. The final outcome are factor arrays that are contextualised to extract patterns of meaning. These patterns are generalizable in subjective ways (McKeown and Thomas, 2013) in the sense that it represents the variability of views in a population.

Q-methodology has been subjected to a great deal of misunderstanding, misconceptions, and poor applications. One of the major areas of confusion is the merging approach between quantitative and qualitative methods. These methods are used as necessary components within the umbrella of Q-methodology. It is not possible to apply Q-methodology 'properly', without applying both methods in a certain way. Hence, it is considered a quali-quantilogical method (Watts and Stenner, 2005).
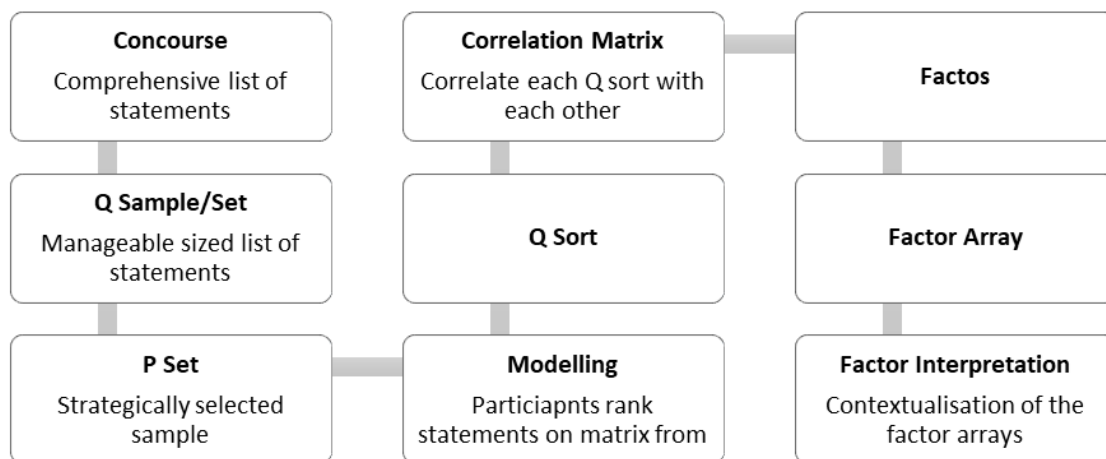
Figure 15 Q-methodology steps The Q-methodology starts with collecting the concourse, which represents a list of all possible statements on the subject, which then get reduced to a manageable size called the Q set. The study sample is strategically selected to represent the variety of views around the subject area. Participants are asked to place the Q set over a grid based on much each statement represents their views. The results in Q sorts. Q sorts then correlated, and factors are extracted, each factor with a factor array which is a representation of Q sort for someone who would load perfectly on the factor. Factor arrays are then qualitatively interpreted by the researcher.

4.4.1.5 Why Q-methodology for organ donation

Q-methodology is an alternative easy approach to understanding different views. Compared to commonly used methods such as interviews and Linkert-scales surveys, it offers an abundant and rich data by illustrating elements of a specific view and the distinctive pattern of how these elements interconnect simultaneously. It is clear from literature review, barriers to organ donation are numerous, they work together to shape attitude to organ donation. Q-methodology offers a new way to combine several barriers to organ donation to form one view instead of investigating them independently using questionnaires.

Q-methodology is able to systematically recognise and illustrate the distinct views; this offers a detailed insight into "who you are working with, how they see the problem in relation to other issues, and where barriers and levers are likely to exist" (Alderson et al., 2018). It can be of a great value to policymakers through thorough investigation of various perspectives in relation to intricate subjects such as organ donation.

There are many differences between Q and R methodologies that swayed the choice towards Q-methodology, these are:

· Primarily, the Q-methodology approach to study 'pure behaviour' (Brown, 1980) frees the participants from theories shaping the outcome. R methodologies stipulates a priori theory with established assumptions (Watts and Stenner, 2005). This influences the outcome of the study. Q-methodology on the other hand, exposes subjectivity without theoretical moulding and it is valuable in explorative research. The resulting factors (people with similar views) represent different patterns and connections between behavioural barriers that otherwise might be overlooked by R methods.

· Q-methodology is especially suitable for research with "many, potentially complex and contested answers" (Watts and Stenner, 2005) with multiple point of views (Stainton Rogers and Stainton Rogers, 1990) such as the case with organ donation. It allows for views about sensitive issues to be communicated using a "friendly tool" (Dudley et al., 2009).

· Q-methodology can shed a light on the interplay between affective and cognitive variables that eventually influence the decision. It compels participants to reflect upon their experiences and emotions, or what is known as 'mentalisation'. Mentalisation is defined as "the capacity to envision mental states in oneself and another, and to understand one's own and another's behavior in terms of underlying mental states and intentions" (Slade, 2008). Mentalisation brings emotions into the surface and allows analysis of emotional variables in combination with cognitive ones.

· Q-methodology provides opportunity to realise one's own views and communicate it safely and clearly without judgment. The nature of the statement provides a safe place to express opinions, as it refers to opinions such as 'I feel …' or 'to me, it feels like

….', it is ranked based on self-reference not a right and wrong scale (Stephenson, 1982).

· Communicating complexed feelings and ideas is not a straightforward process (Frick, 1985). Conscious strategic selection of concourse ensures a representation of prior literature in Q-methodology study. Concourse statements are collected from a variety of sources, one of which is previous literature such as studies on barriers against donation and intervention literature. The comprehensive concourse provides a new opportunity for participants to find their lost words in a new form of "utterance" (Brown, 1980). Thus, it provides a new way to turn subjectivity into objective construct away from the constraints of a ready-made theory.

· Surveys and questionnaire using yes-or-no or Likert scale might distort the actual picture that reflects a person's idea by scrutinizing his or her options to a limited scale only (Steelman and Maguire, 1999). In contrast, the comprehensive Q sort offers a wide range of potential views and statement tolerating even contradicting statements and thoughts to elicit deep thoughts and allow individuals to communicate in a new way beyond their own ability to formulise their own thoughts.

· Q-methodology resolves the problem of undecided people (Hagstrom et al., 1997). In fact, people might not be undecided in the subjective preference, but rather face the difficulty to voice their subjective view because they are unable to articulate those views or they are unaware of their own subjective views (Shemmings and Ellingsen, 2012). This is quite important in organ donation. Since the conversation is not usually part of daily discussions, opinions do not have enough time to formulate and mature. With ties to religion and cultural values, one might find him or herself on the horns of a dilemma between personal views and external ties.

· The statements on 0 does not mean insignificant, it means that this statement does not reflect that person's view, which is a different concept than what is used in survey questionnaires.

· The limited spots available in the matrix forces participants to prioritise the meaning for their statements providing a more solid representation of one's views (Goldman, 1999).

· Q-methodology reveals subjectivity and diversity beyond simple demographic factors. There is no prioritisations of opinions and marginalisation of others (Taylor et al., 1994). It applies beautifully to a subject like organ donation that touches different views with religion, culture and personal values (Brown, 2006). For all the above reasons, Q-methodology is relevant and valuable in examining views on organ donation.

Table 8 Glossary of Q-methodology terms – Adapted from (Bryant et al., 2006)

Item	Description
Concourse	The discourse or 'flow of communicability'; what is written and said about the topic of interest.
P-set	The participants of a Q study who complete the Q-sorting procedure.
Q-set	The sample items or statements on the topic under enquiry. These are transcribed onto a set of cards (physical or digital) and used in the Q-sorting procedure.
Modelling	The process whereby items are sorted and ranked on Q-methodology grid
Q-sort	The results of the ranking processes for each participant. Each item is allocated a score. A Q-sort represents the pattern of beliefs or opinions the individual holds about the topic.
Factor	Represents one understanding of the topic under enquiry. Operationalised by merging the exemplar Q sorts for each factor to produce a synthetic or standardised Q sort called the factor array.
Factor array	A synthetic or standardised Q sort that is used as a physical representation of a particular viewpoint or factor. Generated by amalgamating the exemplar Q sorts and averaging the scores (Z-scores) for each item. Arrays represents a 'best estimate' of the factor's viewpoint.

4.4.1.6   Methodology limitations

Q-methodology is not a common methodology and researchers are "forced to spend a lot of time and energy explaining and justifying their method" (Kitzinger, 1999). This lack of awareness about the methodology might raise as a challenge to publish it and/or interpret its outcome. The method is not statistically generalizable, it makes no assumptions that the points of views presented are fixed over time. The limitation of Q-methodology may also lie in the subject boundaries and the researcher ability to compile a comprehensive set of statement and to strategically select the participants. Additionally, it might not be suitable for illiterate people or participants with language barriers (Previte et al., 2007).

Q sorting can be time consuming (Peter et al., 2008). In this study, several participants showed concerns about Q sorting taking a very long time (one participant spent 2 hours for the Q sort) while other participants showed concerns about the credibility of the Q sort especially that someone might not have the patience to carefully examine each of the 47 statements used in this study and instead, arrange them haphazardly. Participants might also feel restricted by the available grid and the fixed distribution, although this does not affect the outcome (Brown, 1980). Moreover, the viewpoints from Q-methodology are not fixed, they might change over time. Finally, the non-generalisable nature of Q-methodology means that researcher would not know the prevalence of each view in population (Ellingsen et al., 2010).

4.4.2   Q-methodology in this research

In this section, I will discuss how Q-methodology was conducted in this study. I will go through the objectives of Study one, ethical approval, this will be followed by description of the concourse and Q set, followed by study sample, and focus group.

4.4.2.1 Objectives

Study one has several objectives. These objectives aim to address objective 1 and objective 2 of this research. Figure 16 shows the steps for conducting Q-methodology in this study. The Q-methodology investigation in this research has four main objectives:

1. To generate groups with distinctive views and inform future research in behavioural interventions in organ donation.

2. To have a holistic view of individuals' perspective on organ donation and identify similarities and differences in these perspectives.

3. To identify the relationship between different views (factors) and the demographic criteria and registration status.

4. To identify the most influential belief to be targeted in behavioural interventions.
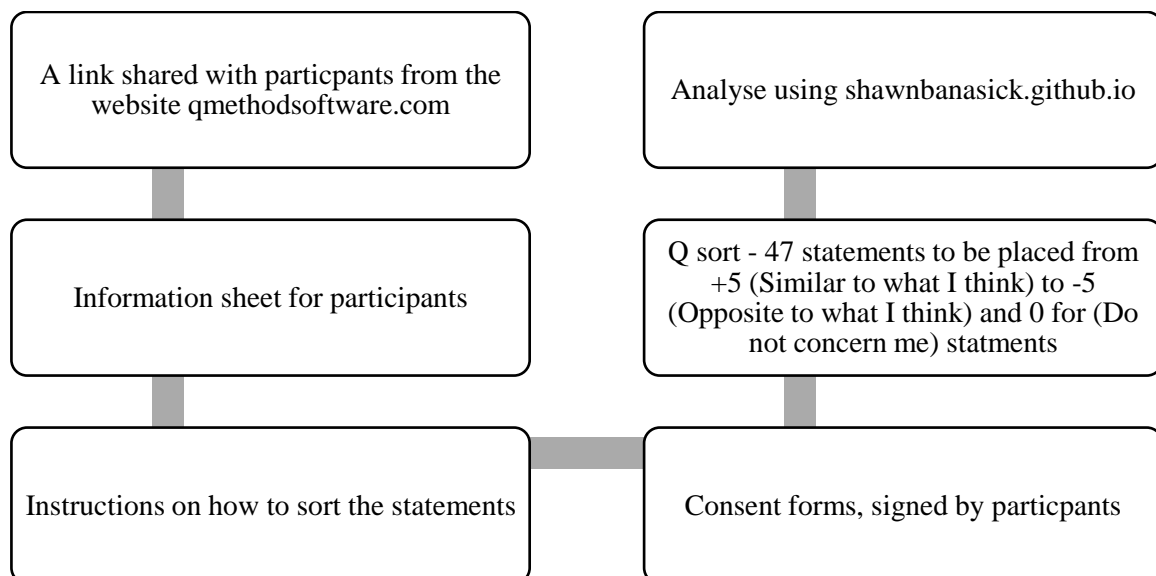
Figure 16 the Q steps. This figure represents the Q-methodology steps in this research. After collecting concourse, and then reducing it to 47 statements, the P set was strategically selected based on demographic and social criteria that are related to organ donation attitude. Participants received a link to complete the study. The link first present information sheet and instruction on how to complete the grid. After consent forms are signed, 40 participants were asked to place 47 statements on a grid. Once Q sorts are collected, they were analysed using a different website to find factors (view) related to organ donation. Factor interpretation was supported by interviews conducted separately from the Q study.

4.4.2.2   Ethical Approval

Ethical approval was obtained from the faculty of social sciences in the business school, University of Nottingham (ethical approval is shown in Appendix 1).

4.4.2.3   Concourse and Q set

The term concourse is originated from the Latin word 'concoursus' which means 'running together' (Brown, 1993). A concourse is a collection of statements that represents the range of views that different people have communicated about a topic. Concourse items might be anything communicable like art, painting, sounds pictures, or even smells (Stephenson, 1953), but they are usually represented by statements only (Watts and Stenner, 2012).

The concourse is collected from a variety of resources, for this research; concourse was collected from:

1. Comprehensive literature review.

2. Newspaper articles.

3. Social media posts (Facebook comments, YouTube videos, blogs, and NHS websites).

4. Informal conversations with people from different backgrounds.

The concourse should include salient statements, which means statements must be meaningful to participants. That does not necessarily mean concourse statements must be narrow, on the contrary, it is desirable for concourse statements to have "excess meaning" which allows for a range of perception; different people might perceive its meaning slightly differently than others (Webler et al., 2009).

When I started collecting the concourse, I decided to specifically collect statements on behavioural barriers, with a focus on interviews' snippets from qualitative research. I wanted to examine the pattern in behavioural barriers and limit the statements collected from theories

and models that are used in organ donation. I wanted to keep the participant voice and look for emerging patterns and connections.

Initially, 224 statements were collected. Most statements were collected through the literature review. Concourse statements were categorised into 8 themes: religion, body, death, healthcare, knowledge, awareness, recipient, and others (adopted from the themes found in the behavioural barrier section). Each theme was divided into 3-6 subthemes. I adopted an inductive approach to further divide the themes; I was guided by the statements in each theme to present new subthemes. If there are more than three statements that have a common subtheme, a new subtheme is created. Appendix 2 shows the initial list of concourse statements. Each theme has statements for behavioural barriers as well as few statements representing possible motivations for people to donate.

The following stage is reducing this list into a manageable list of statements for participants to sort, known as Q set. The statements in the Q set "cover all the ground within the relevant conceptual space" where "each individual item makes its own original contribution to the Q-set and that the items in their totality all sit neatly side by side without creating unsightly gaps or redundant overlaps" (Watts and Stenner, 2012). Watts and Stenner (2012) recommend the Q set to be between 40-80 statements. The Q set statements are not meant to be exhaustive of all possible 'sayable' things about organ donation (Akhtar-Danesh et al., 2008), but inclusive and contradictive enough to cover wide variety of interpretive meanings to different people (Stephenson, 1980).

The concourse has been categorised and Q set has been structurally chosen (Fisher, 1937) to avoid duplication and ambiguity (Akhtar-Danesh et al., 2008) with appropriate terminology (Darwin and Campbell, 2009) ensuring that statement contains one proposition (Watts and Stenner, 2012). One or two representative statements were chosen for each subtheme. The choice was informed by the author's background knowledge on the subject.

Statements were chosen if they are commonly cited in literature and/or if they are reasonably controversial. The reason for choosing controversial statements is to uncover potentially latent views on organ donation.

The final Q set has to be illustrative, clear, and simple (Cross, 2004) with salient and understandable statements (Webler et al., 2009). One to three statements were collected from each subtheme to form 60 statemented representing barriers and motivators that falls under all 6 themes. Those 60 statements were then reduced to 47 to make it easier for participants to rank and to keep the time-consumption and convenience in mind. Statements were mostly standardised, so they began with 'I think', 'I believe' and so on, except some statements reflecting a perceived understanding on the subject. The resulting Q set included 47 statements, 14 motivating statements and 33 barriers (shown in Appendix 3).

4.4.2.4 Focus group

A focus group was conducted with 3 people, all aged 26-27. The aim of the focus group is to discuss the concourse to ensure that the concourse is comprehensive and clear and that the instructions are understandable. The focus group lasted two hours. During which, participants reviewed the concourse and had discussions on the clarity statements and if there were any further statements they would wish to add. The Q sort was comprehensive for participants, and they did not suggest any further statements. The focus group found a minor grammatical error. They agreed on the clarity and inclusivity of the concourse with minor changes (for example clarify what minor groups include). Changes were made and the final Q set was produced. Table 9 shows the final Q set after modification recommended by the focus group were implemented.

Participants were asked to complete the Q study. Statements were printed at font size 11.5 and cut into equal size pieces of thick paper. The statement numbers were randomised. I

decided to keep random numbering on statements however for organisational purposes. Q-methodology girds were printed on cardboard measured 841 x 594 mm. 3 sets of statements and grids were printed. Participants were asked to rank statements on the grid based on how much it reflects their own point of view.

There were several issues with using paper/cardboard in the focus group. I first ran into an issue with the printing services having to print it on a large size paper and then cut the statements into equal size pieces to fit the grid, not to mention the cost of printing. In addition, one participant accidentally spilled a drink on the paper rendering the set unusable. The grid was large, and participants had problems finding a place to fix it. In addition, the cardboard was saved in a roller for transportation and the grid had to be fixed with heavy objects at all sides to fix it. All these problems encouraged me to collect data digitally to avoid all these handling problems.

One of the participants shared her anxiety in having to handle 47 statements all at once. I suggested creating three different piles, one for statements that reflect her own point of view, one that does not and one for statements that she would not consider. She grabbed three different boxes, labelled each one then started going through the statements. Once she categorised all statements onto three piles, she started ranking each pile on a side of the grid. The other two participants did not feel the need to do it on two stages.

Based on the feedback from the focus group:

· I corrected the grammatical error.

· Rephrased the statement on minority group.

· Decided to collect data digitally.

· Chose a digital platform that offers the option of a two-stage sorting, first into three piles of statements (a pile statements that reflects my view, a second pile for statements that do not reflect my view, and a third pile for statements I would not

consider), then allows sorting on the grid. I chose a platform where the two stages is

optional but not mandatory.

Table 9 Final Q Set after modification recommended by the focus group were implemented. Minor changes were made.

Statement
Religion
1 - I believe my religion does not allow it
10 - I believe I will be haunted if I donate
11 - I think it is non-religious to take organs
17 - If someone religious says it is not allowed, then I will not do it
43 - I think my religion encourages organ donation in order save other people's lives
Body
7 - I think giving out organs to save someone's life is a noble act
21 - I believe the human body is not a machine
38 - I don't mind donating some organs, but not my heart or eye
39 - I believe organs are a gift from God, we are not allowed to give them away
45 - I want to be cremated and if I donated organs, I cannot do that
Death
18 - I feel talking about death and after life is important to appreciate our lives
25 - When someone asks me to register to donate, it feels like he is waiting for my death to get my organs
46 - Talking about death is creepy
Awareness
3 - I don't think I have ever thought about it
6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups
12 - I don't know anyone who donated an organ
13 - I believe there is a great need for organs especially in minority groups
23 - I thought about registering as a donor but I never did
29 - I think people exaggerate on the importance of the whole organ donation subject
36 - I believe the present need for transplant organs is fully covered
Healthcare
8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register

14 - Brain death is confusing to me, but I think experts know better
19 - I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs
22 - I think brain dead people can regain consciousness
24 - I don't want doctors or the healthcare system to be in control of my organs
28 - I trust doctors and nurses to always provide the best care they can
47 - I think I am not dead if my heart is still beating
Knowledge
4 - I think the process of registration is complicated
5 - I think anyone can register and be a donor even if old or have a disease
9 - I think I am too old to donate
15 - I feel I cannot decide to donate because I don't know all the facts
16 - I believe transplantation results are successful and they are improving people's health
26 - I trust the donation system to be fair
30 - I think people who have medical conditions can't donate
34 - I believe donated organs can be bought and sold
Recipient
2 - I think rich or famous people can receive organs before the people with the most need
32 - I think transplant recipients don't live more than 10 years after a transplant operation
37 - I believe people wouldn't need transplants if they took better care of their health
Other
20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself
27 - I don't mind organ donation but my family disagree
31 - I feel I have no responsibility towards anyone else
33 - People on the waiting lists are ill and I believe they need my help
35 - I might feel easy to donate because my family encourages me to donate
40 - No matter how hard it is to think about organ donations, it makes me feel good about myself
41 - I don't think I have the courage to donate
42 - I think it is just easier to say no than to think about it
44 - I don't mind donating when I am alive, not when I am dead

4.4.2.5   P sample

P sample or P set refers to the participants who actively participated in the study by sorting out the statements to reflect their own views. Since the aim of Q-methodology is to explore variability of views rather than generalisation of results, a large sample group is not required (Stephenson, 1953). Brown (1996) suggests that no more than 50 participants is required to conduct a Q-methodology study. It is crucial, however, that the P sample is strategically selected to reflect the variety of views around a certain subject (Stephenson, 1935).

There is demographic, social and personality related criteria to predict attitude towards organ donation. Since it is difficult to select participants with different personality types, I strategically selected a sample based on demographic and social criteria. Demographic criteria were based on age, gender, socio-economic status, education, religion, and ethnicity. To create further variability within the small sample, I also examined the marital status, the attitude of the spouse, if the person had discussed organ donation with family and if the participant volunteer for charity work.

It is recommended that the number of participants to be lower than the number of the statement in a Q study (Watts and Stenner, 2012).The study was conducted on a sample of 40 participants. They aged between 19-64 years' old targeting a wide range of participants from different age groups with 45% female participants, as shown in Figure 17. There are more females in older age group which was not intentional, but given to the small sample size, small differences appear larger.

Participants were contacted directly in person, through emails or social media. A conscious effort was put to ensure that participants hold different religions and ethnicities. Four participants refused to declare their religious beliefs. Figure 18 shows the P set by religion and Figure 19 shows the P set by ethnicity.
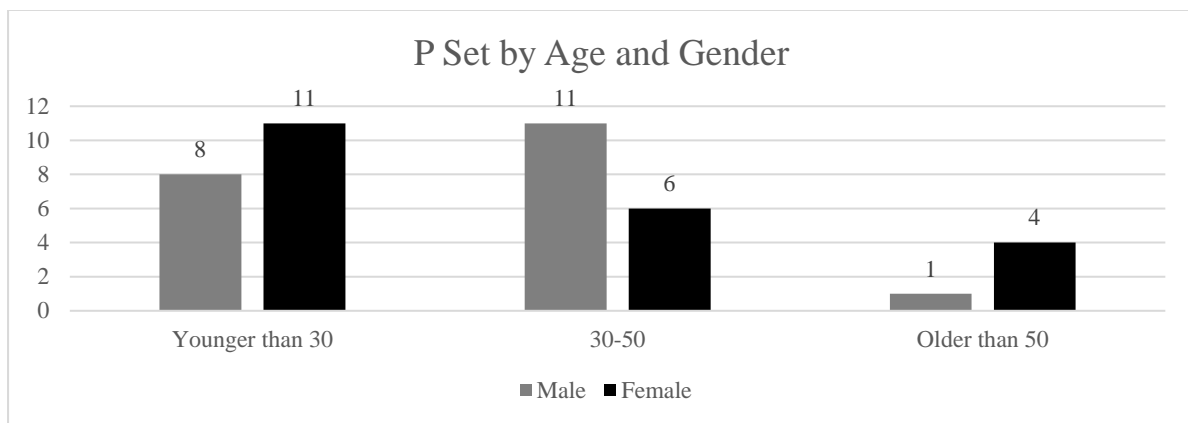
Figure 17 P set by age and gender. Gender was stratified by age group especially that literature suggests that female and young age group are related to more positive views on organ donation.
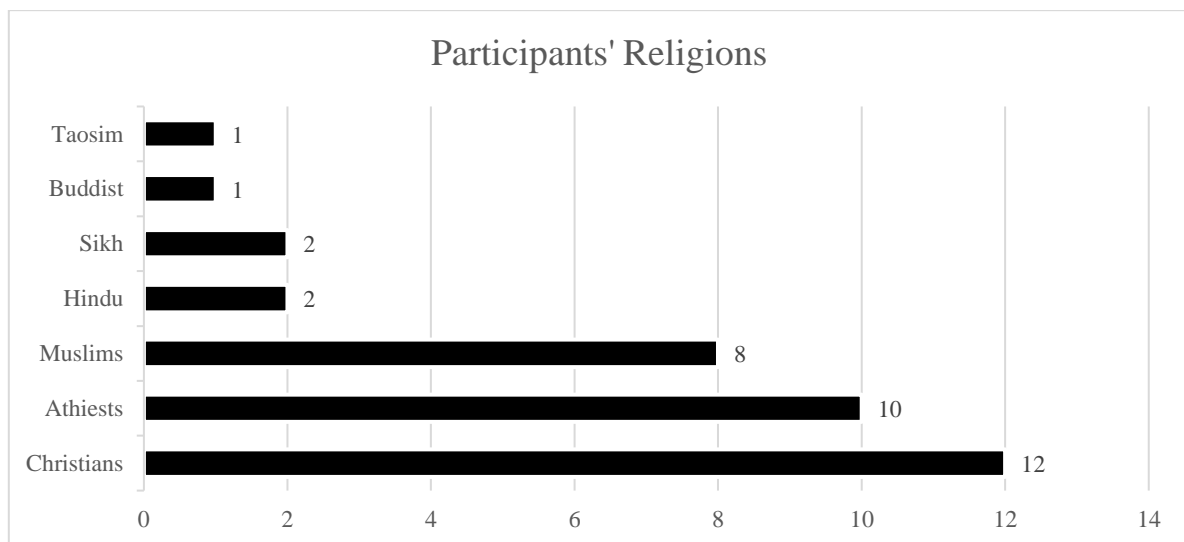
Figure 18 P set by religion. Literature suggest that religion is an important criterion to predict attitude to organ donation. Seven religious beliefs were included in the Q study. It is worth noting that Q-methodology is not statistically generalisable, hence representation of each religion in Q study is irrelevant however, it is important to include a variety of religious beliefs to explore variation in views.

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                                            ┌─────────────────────────────────────┐
                                            │         British (n=3)               │
                                            ├─────────────────────────────────────┤
                      ┌──────────────────┐  │         European (n=8)              │
                      │ White Ethnicity  │──┤                                     │
                      │     (n=14)       │  ├─────────────────────────────────────┤
                      └──────────────────┘  │         American (n=2)              │
┌──────────────┐                            ├─────────────────────────────────────┤
│              │                            │         Autralian (n=1)             │
│  All         │                            └─────────────────────────────────────┘
│ Participants │                            ┌─────────────────────────────────────┐
│  (n=40)      │                            │         African (n=3)               │
│              │                            ├─────────────────────────────────────┤
│              │                            │   Indian and Pakistani (n=8)        │
│              │  ┌──────────────────┐      ├─────────────────────────────────────┤
│              │  │ Non-White        │      │       Middle East (n=9)             │
│              │──│ Ethnicity (n=26) │──────┤                                     │
└──────────────┘  └──────────────────┘      ├─────────────────────────────────────┤
                                            │         Latino (n=1)                │
                                            ├─────────────────────────────────────┤
                                            │         Chinese (n=3)               │
                                            ├─────────────────────────────────────┤
                                            │       Other Asians (n=2)            │
                                            └─────────────────────────────────────┘
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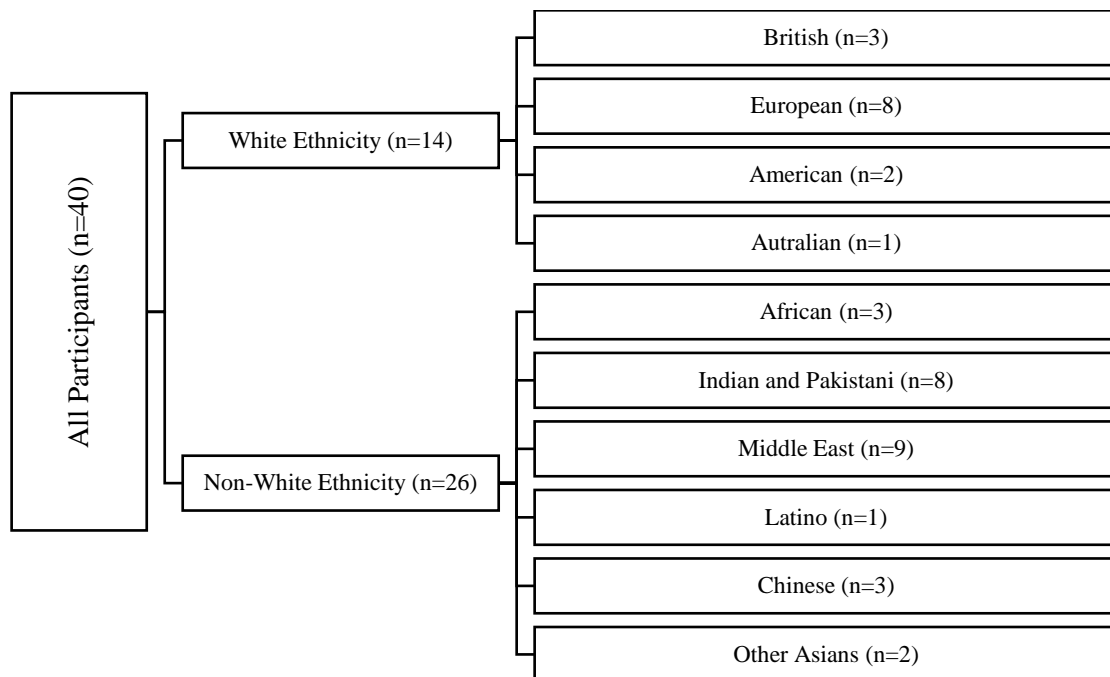
Figure 19 P Set by Ethnicity. Research (especially when conducted in the USA) suggests that non-white ethnic groups are correlated with negative views to organ donation. However, research also suggests that that social norm influences attitude to organ donation, hence, people living in western countries (such as western Europe, USA and Canada) where overall attitude to organ donation is positive, should show positive attitude to organ donation compared to middle eastern and east Asian countries.

4.4.2.6 Q sort

Participants were asked to arrange the statements from +5 (similar to what I think) to -5 (opposite to what I think) with the zero column for statements that (do not concern me), with no right or wrong answer (Brown, 1980). Figure 20 shows the **Q**-methodology grid used in this study. The grid distributions forces participants to rank statements from 2 statements on each end, till 7 statements per column at number zero. This is followed by a short survey for demographic details and four short questions.

The study was conducted online using the link qmethodsoftware.com/study/3202. Each participant was provided with an account, and invitations were shared via emails. Participants were provided with instruction to complete their Q sort (Appendix 4). Consent forms were signed, and short questions survey were requested after completion (Appendix 5).

Opposite to what I think					Do not concern me	Similar to What I think				
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5

Figure 20 Q-methodology grid used in this study. Participants were asked to place statements that are similar to what they think between +1 and +5, reserving statements on +5 column for statements that are strongly similar to what they think. The opposite goes for the negative side of the grid. Column zero is for statements that participants perceive to be irrelevant or non-concerning to them.

After completing the Q sort, participants were asked to complete two sets of questions. The first set asked for seven questions, mainly for demographic criteria. The second set of questions consists of four questions, inquiring of the participant feels there are any missing statement, if the grid allowed the participant to share their views, if there are any statements that they feel strongly about and why is that the case. The results of Study one will be presented in Chapter five – Results and discussed in Chapter six – Discussion.

4.5   Study two - Survey

This section will describe post-Q survey used to answer the second research questions and the last two research objectives. The aim of Study two is to examine the prevalence of views identified in Study one in UK residents and citizens. The rational for Study two is to inform policymakers (such as NHSBT) to address interventions to the most prevalent view. This will ascertain focus of efforts to the most influential barrier that may results in larger size effect when conducted nationally.

4.5.1 Introduction to post-Q survey

This section will describe the method used in Study two. Study one used Q-methodology to identify views on organ donation. The results of Study one (the views) were then used in Study two. Study two method depends on Study one result, one way to organise this thesis was to continue with the results from Study one before diving into Study two method. This structure would follow the timeline of the thesis; however, it dissects the thesis into two separate parts thus losing the bird's eye view on the research. As shown in Figure 21.

Q-methodology (in Study one) used inverted factor analysis technique by correlating people with similar "views" based on underlying "values" and "beliefs" set. Study one results is discussed in section 5.2 Study one results. The results of Study one are expected to be in the form of 3-5 views on organ donation. In Study one, as discussed in section 5.2 Study one results, four views were selected out of six views in total: the Realist, the Optimist Hesitant, the Convinced Pessimist and the Empathetic. Each view is represented by a factor array representing Q sort for someone who would load perfectly on the factor.
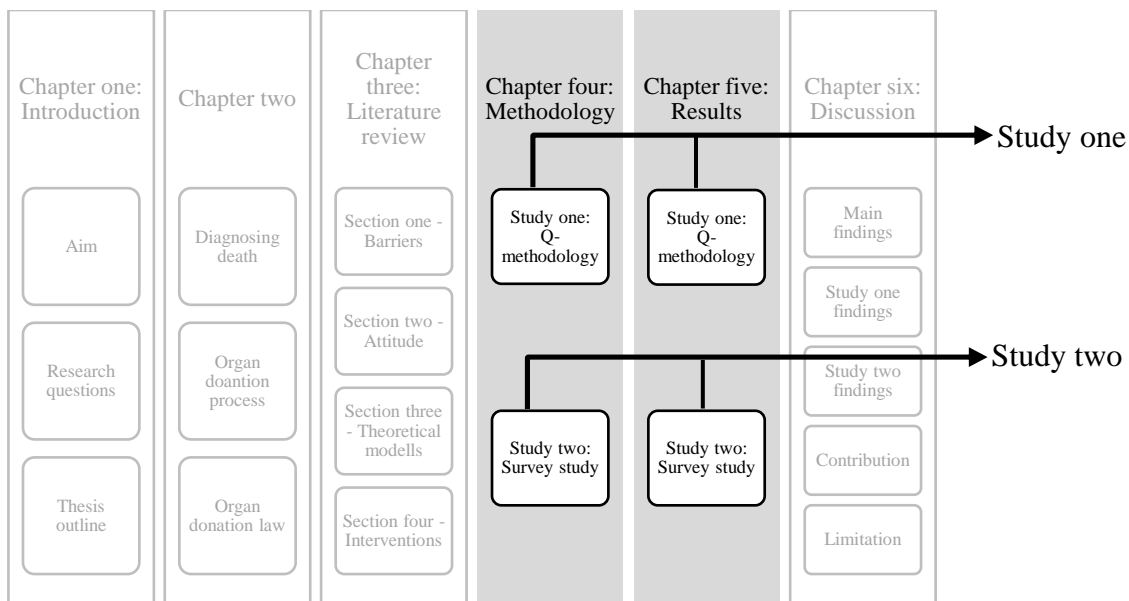
Figure 21 Thesis structure showing Study one and two. It shows that Study one and two are discussed in two chapters, methodology and results. Methodology chapter outlines methods used in both studies, and results chapter presents results for both studies as well. Some readers might prefer to go over the results from Study one before moving to Study two. All references to sections and chapters are hyperlinked, to facilitate thesis navigation.

The outcome of Q-methodology and the supplemental data from interviews provide a rich description of views around organ donation. However, factor interpretations used in Q-methodology studies describe the views of a very small sample of participants (40 participants in Study one), and while the results are generalisable in representing the different views around organ donation, it is not generalisable for the population in the prevalence of each view in the population. In other words, Q-methodology study result in distinctive views on organ donation, but it does not provide any indication to its prevalence in a population.

It is important to know the prevalence and the representation of each view in UK population to provide insight for the policymakers and intervention campaigns, especially those conducted at a national scale. This can provide a crucial insight onto selecting the most effective campaign design for nationwide interventions or campaigns by targeting the most common view. Even with the opt-out system recently implemented in the UK, the fact remains that the approval rate for donation among BAME (Black, Asian, and minority ethnic

groups) remains almost half of that of the White group, "families are simply not having these conversations and BAME people feel it's safer to say no in these moments of crisis" (Adebisi, 2020). Hence, campaigns must continue to support the current opt-out policy. Understanding views; especially for BAME groups, facilitates organ donation, and improves donation rates.

4.5.2   *Methods in post-Q survey*

The post-Q surveys have been conducted in health economics (Mokdad et al., 2016, Baker et al., 2014), however, methodologically; this has been experimental for the most part. There are several ways to conduct post-Q survey, here I discuss three main methods used to convert factor arrays to be used in a survey. It is not possible to represent any Q-methodology factor with one survey question, hence, several ways were used in attempts to provide a relevant and accurate method to do that, each way with different pros and cons. I will discuss three post-Q methods used by other researchers and explain rationale behind choosing the 'self-categorisation to abbreviated factor description' method I used in this research.

4.5.2.1   Talbot's Q blocks

This method presented by Albert Talbott in 1963 conference. This method is underdeveloped with the only reference known is for one conference paper (Talbott, 1963). Talbot's Q blocks presents an alternative to using Q-methodology and survey independently by combining both methods into one. This can be especially valuable in time series studies, follow up studies and in benchmarking two or more studies in a large population. Talbot presented "Q blocks", "which are comparable in one sense to a series of small individual Q sorts" (Talbott, 1963). Prior knowledge of Q factor structure is necessary, i.e., a prior Q study should have been conducted on the same subject before Q blocks can be constructed. The

study presented in his conference paper described the process of the study implemented at Michigan State University to examine views about fallout shelters.

As a first stage, a conventional Q-methodology study was conducted, four factors were presented. From that Q-methodology study, salient and distinguishing statements were identified by weighing persons and then applying those weights to item response followed by converting those scores into Z scores. This method identifies a small number of representative statements which are then combined onto "Q blocks" and participants were asked to rank statements per each block. There are no clear guidelines on how to block statements together or the criteria on which to determine which statements to use, however, Talbot did make a distinction between negative and positive statements and suggested statements blocks should be constructed with one or the other.

There are several issues encompassing this technique. Methodologically, there was no clear guidance on the method of selecting statements, blocking, or scoring and analysis. This can result in confusion and variation in conducting this technique. It is especially problematic for time series and benchmarking studies where consistency is key. Selecting one or two statements, even being distinguishing statements contradicts the holistic approach of Q-methodology and renders that into isolated blocks. Grouping the statements into blocks is another area which the technique failed to thoroughly describe. A difference or even small changes in the blocks formation and we might get different results that do not truly represent the view of the participants. Participants are asked to rank each block by what they agree with the most, then the next then the one they agree with the least. This might create an unclear situation in case the participant does not agree with any statement thus instruction would force participant to rank the one they disagree with the least as the one they agree with the most.

Talbot's Q blocks requires grouping negative and positive statements separately, this might require some statements to be rephrased in some studies, which adds another manipulation and distortion of the data. In the scoring and analysis stage, participants will load on one factor only which contradicts what Q-methodology shows (that people load on all factors at different loading scores), additionally, Talbot's technique assumes all statements contributes equally to each factor, another unrealistic assumption, and a distortion of reality. For all the above reasons, Talbot's Q blocks was not used in this study.

4.5.2.2 Brown's standardised factor index score

This method uses a short list of statements from a previous Q-methodology to be scored on a Likert-like scoring to identify prevalence of factors in representative sample. Like Talbot's blocks, there is no specific guidance on how to choose the statements and how many statements to be used. Researchers used different criteria based on their own experience. Statement selection starts with distinguishing and salient statements. Salient statements placed in the extreme two columns are chosen. Following that process, a set of around 12 statements are chosen from the original Q-methodology study. Participants were then asked to rate each statement independently. Statements index score and factor index scores are obtained. And finally, factor index scores can be standardised.

Brown's method seems easier than Talbot's blocks since surveys with questions scored independently are very common and easier for participants to complete. However, independent scoring of items contradicts the Q-methodology principle of relative scoring with limited spaces for each column to force meaning from participants, independent scoring allows participants to score subjectively. Statements might mean different things to different people with a great freedom of application. Moreover, the process of choosing statements is

not very clear which can create a variation of application even when using the same Q-methodology. For these reasons, this method was not used in this study either.

4.5.2.3   Self-categorisation to abbreviated factor descriptions

The above two methods were criticised mainly because they reduced factors to few statements only. Q-methodology approaches attitudes from a holistic view that is lost in the above two methods. In this study, self-categorisation to abbreviated factor descriptions, or may be called 'vignettes' were used. There were several attempts to maintain the entirety of the persona presented in each factor. One of the first attempts was conducted by Van Exel et al. (2011) who presented 2,000 adolescents aged 12-14 years with four short descriptions, each less than a 100 words. Each description represents a factor (view) that was the outcome of a prior Q-methodology study on adolescents' attitude (Van Exel et al., 2006b). The short descriptions were created using salient and distinguishing statements as well as insights from the post-Q interviews, thus; the 100 words or less descriptions can capture an insightful view of the attitude without having to rank statements independently or separately as in blocks. Survey participants were asked to choose the description that fits them the most, i.e., similar to their attitude. One of the limitations with this method include question order bias. In this research for example, abbreviated factor descriptions (vignette) were presented randomly to participants to avoid order bias.

Q-methodology studies show that people usually have overlapping loading on more than one factor. Factor loading is above zero and sometimes; participants have high factor loading on more than one factor at the same time (confounding sorts). Since there is no clear strategy on how to break the tie in confounding factors in case that happened in the survey, Van Exel et al. (2011) decided to simplify the process and ask for one best choice. In another study, Susan Jedeloo et al (2010) asked 1000 adolescents to rate each of the four descriptions

they are presented with from 1-5 independently depending on how much each description fits them. Almost 60% of all participants were assigned to one factor only since they assigned only one description with a high score. The remaining 40% either scored all four descriptions as low or assigned a high score to more than one description. While this might create a great deal of uncertainty about the outcome of the survey, it reflects the true nature of views and attitudes among population, especially when it comes to sensitive controversial subjects such as the ones where Q-methodology is used in the first place.

Both methods used here have advantages and disadvantages. Susan Jedeloo et al (2010) allow for more realistic representation of people views on organ donation. Views on organ donation are poorly formed and it is reasonable to expect some to have overlapping and may be even contradicting views on organ donation. When asked to rate all vignettes independently, some participants may feel confused or indeterminant for one reason or another, others may distinguish different views from each other while holding some agreement here and there.

Rating method may provide valuable insight into the level of overlapping and confusion exist in organ donation views. When all vignettes are rated highly by a significant proportion of participants, it indicates either non-distinctive representation of views or an overlapping and confusing views on organ donation. On the other hand, if all vignettes are rated low by a significant proportion of participants, it indicates a missing view that was not included in the study. The disadvantage of this method is the difficulty in allocating one factor to each participant. This will make it extremely difficult to examine the prevalence of views across various demographic and social criteria which might provide valuable insight for intervention studies. If there is a significant relationship between a factor and other criteria, that may help facilitate the identification of views using such criteria which is much easier in survey studies.

Van Exel et al. (2006a) study only allows participants to choose one view. This method may not reflect views on organ donation since people may hold overlapping views. Q-methodology study (Study one results discussed in section 5.2) shows that no single participant loaded perfectly on one factor only, some participants loaded highly on more than one factor as well. However, this method may be helpful in combination with rating method. It may help to break the tie when two or more vignettes were rated similarly and allows exploration of relationship between factors and other demographic and social criteria. For this reason, both rating and ranking methods were used in this study.

4.5.3   Survey in this research

Self-categorisation to abbreviated factor descriptions method was used in this study. The main reason for that is to maintain a holistic and rather overlapping views on organ donation. Rating and ranking were used sequentially to combine values of both methods.

4.5.3.1   The sample

A cross-sectional study was conducted to examine the prevalence of factors in population. Estimated sample size of 385 was calculated using Qualtrics sample size calculator[1] at 95% confidence level, margin error of 5% and a total population of 66,796,807 (UK population) (ONS, 2020).

The sample was divided into two parts. The first set of data was collected using social media platforms (Facebook, LinkedIn, and twitter). Using my personal profile and posting publicly on different public groups (business, students and news groups and pages). I was able to collect 70 surveys between 02/09/2020 and 06/01/2021. To collect further surveys,

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[1] Using the link https://www.qualtrics.com/blog/calculating-sample-size/

Qualtrics services collected a total of 310 participants. In the analysis section, results will be analysed for the total of 380 participants. Sample criteria are shown in Table 10.

Table 10 Survey sample criteria. Unlike Q study, this sample criteria represent UK population.

Item	n	Proportion%	Item	n	Proportion%
Gender			**Ethnicity**		
Female	188	49.50%	White	320	84.20%
Male	192	50.50%	Caribbean	4	1.10%
Age			African	8	2.10%
18-29	123	32.50%	Indian	6	1.60%
30-49	147	38.80%	Pakistani	5	1.30%
50 or older	109	28.80%	Bangladeshi	4	1.10%
Region			Chinese	5	1.30%
England	274	72.10%	Any other Asian background	5	1.30%
Scotland	25	6.60%	Latino	2	0.50%
Wales	9	2.40%	Arab	11	2.90%
Northern Ireland	2	0.50%	Middle eastern	3	0.80%
Non identified	70	18.40%	others	7	1.80%
Education			**Religion**		
Less than high school	33	8.80%	Christianity	162	42.60%
High school graduate	147	39.00%	No religion	178	46.80%
Bachelor's degree	119	31.60%	Islam	23	6.10%
Post-graduate degree	78	20.70%	Hinduism	4	1.10%
Income			Buddhism	4	1.10%
£30,000 and below	172	45.30%	Other Religions	8	2.10%
£30,001 - £45,000	86	22.60%			
£45,000 and above	122	32.10%			

4.5.3.2   The vignette

Vignette is "a set of systematically varied descriptions of subjects, objects, or situations in order to elicit respondents' beliefs, attitudes, or intended behaviors with respect to the presented vignettes" (Jedeloo et al., 2010). The vignettes were constructed for each factor using the statements on both extreme ends; two statements on +5 and two statements on -5. Statements located at the extremes are comparably more salient than those at the middle of the grid (Brown, 1980). Then all distinguishable statements were added. Distinguishable statements are those that are ranked significantly differently between a given factor and all other factors. Those statements represent motivators and barriers to organ donation. Vignettes were created from statements from the previous Q study, no further psychographic measures were added. Table 11 shows the statements collected for each factor, those statements were used to create the vignettes.

Factor 2 is a bipolar factor. The vignette for Factor 2A-Hesitant Optimist (participants who are positively loaded on this factor) was created from salient and distinguishing statements which are located on 0 to +5, salient and distinguishing statements which are located on -1 to -5 are used to create vignette for Factor 2B- Convinced Pessimist. There is no indication for any demographic criteria that might challenge internal validity such as gender, age, ethnicity, or socio-economic status, etc. Those vignettes composed of several statements each do not encapsulate a whole point of view; they simply represent part of the view that signals a reasonable likelihood for agreement with that view. Vignettes were between 99 and 200 words (Figure 22 shows the statements selected to create the vignettes for all factors).

Table 11 Statements selected for survey (by factor). To create vignettes that comprehensively represent a factor from Q study, firstly, two statements on each end (+5 and -5) were collected, secondly, most distinguishing statements were added. Thirdly, statements were excluded/included based on theoretical significance. Four paragraphs were then created for each factor from the statements in the list below

Statement	Rank	Dist.
F1 – The Realist		
11 - I think it is non-religious to take organs	-5	Yes
39 - I believe organs are a gift from God, we are not allowed to give them away	-5	
17 - If someone religious says it is not allowed, then I will not do it	-3	Yes
3 - I don't think I have ever thought about it	-2	Yes
18 - I feel talking about death and after life is important to appreciate our lives	0	
8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register	1	Yes
33 - People on the waiting lists are ill and I believe they need my help	1	Yes
28 - I trust doctors and nurses to always provide the best care they can	2	Yes
47 - I think I am not dead if my heart is still beating	3	Yes
16 - I believe transplantation results are successful and they are improving people's health	3	
30 - I think people who have medical conditions can't donate	4	Yes
37 - I believe people wouldn't need transplants if they took better care of their health	4	Yes
15 - I feel I cannot decide to donate because I don't know all the facts	5	Yes
12 - I don't know anyone who donated an organ	5	
F2A - The Optimist Hesitant		
17 - If someone religious says it is not allowed, then I will not do it	1	Yes
42 - I think it is just easier to say no than to think about it	1	Yes
38 - I don't mind donating some organs, but not my heart or eye	2	Yes
43 - I think my religion encourages organ donation in order save other people's lives	2	Yes
15 - I feel I cannot decide to donate because I don't know all the facts	3	Yes
20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself	3	Yes
41 - I don't think I have the courage to donate	3	Yes

26 - I trust the donation system to be fair	4	
28 - I trust doctors and nurses to always provide the best care they can	4	
23 - I thought about registering as a donor but I never did	5	Yes
16 - I believe transplantation results are successful and they are improving people's health	5	
F2B - The Convinced Pessimist		
24 - I don't want doctors or the healthcare system to be in control of my organs	-5	Yes
25 - When someone asks me to register to donate, it feels like he is waiting for my death to get my organs	-5	Yes
19 - I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs	-4	Yes
31 - I feel I have no responsibility towards anyone else	-4	
34 - I believe donated organs can be bought and sold	-3	Yes
2 - I think rich or famous people can receive organs before the people with the most need	-2	
30 - I think people who have medical conditions can't donate	-1	Yes
F3 - The Empathetic		
17 - If someone religious says it is not allowed, then I will not do it	-5	Yes
39 - I believe organs are a gift from God, we are not allowed to give them away	-5	
42 - I think it is just easier to say no than to think about it	-4	Yes
8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register	-4	
19 - I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs	-2	Yes
41 - I don't think I have the courage to donate	-2	Yes
15 - I feel I cannot decide to donate because I don't know all the facts	-1	Yes
30 - I think people who have medical conditions can't donate	1	Yes
5 - I think anyone can register and be a donor even if old or have a disease	2	
18 - I feel talking about death and after life is important to appreciate our lives	3	
33 - People on the waiting lists are ill and I believe they need my help	4	Yes
28 - I trust doctors and nurses to always provide the best care they can	4	
7 - I think giving out organs to save someone's life is a noble act	5	
16 - I believe transplantation results are successful and they are improving people's health	5	

How well does this profile fit you?

Factor 1, The Realist

- I believe people on the waiting lists are ill and they need my help no matter how little I know about it; I feel obliged to think about it. Death helps us appreciate life as long as I'm alive and my heart is still beating, and it feels like I have an opportunity to save someone's life, we all have a chance to be a donor even if ill or old. Transplantation results are successful, and doctors will do their best to improve our health. Religion should not prevent us from doing that, and if someone religious says it is not allowed then I believe it is my organs to gift. I can't decide to donate because do not know all the facts. I am not sure if brain death is really death, I believe I am not dead if my heart is still beating. I do not know anyone who donated an organ personally, but I believe transplantation results are generally successful. However, people would not need transplants if they took better care of their health to begin with and I think people who have medical conditions cannot even donate. I do not think it is against religion to donate organs, organs are yours to give.

Factor 2A, The Optimistic Hesitant

- I thought about registering as a donor, but I never did, I feel I cannot decide to donate because I do not know a lot about it, I think the allocation system is fair and I; of course, trust doctors and nurses to do their best to save people's life. However, I still find the idea of donating something like a heart or an eye is very uncomfortable. Maybe it is just easier to say no than to think about it. After all, if my religion is against it I will never do it no matter how successful transplantation surgeries are.

Factor 2B, Convinced Pessimist

- I do not want doctors or the healthcare system to be in control of my organs, when someone asks me to register to donate, it feels like he is waiting for my death to get my organs. I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs especially that donated organs can be bought and sold. I am not obliged to donate my organs, not everyone can, people who have medical conditions cannot donate. I think there is an exaggeration on the organ donation subject for potential financial gains.

Factor 3, The Empathetic

- I believe people on the waiting lists are ill and they need my help no matter how little I know about it; I feel obliged to think about it. Death helps us appreciate life as long as I'm alive and my heart is still beating, and it feels like I have an opportunity to save someone's life, we all have a chance to be a donor even if ill or old. Transplantation results are successful, and doctors will do their best to improve our health. Religion should not prevent us from doing that, and if someone religious says it is not allowed then I believe it is my organs to gift.

Figure 22 Abbreviated factor descriptions (vignettes). Four paragraphs, one for each statement created to comprehensively represent each factor from the Q study.

4.5.3.3 The survey process

The survey aims to describe the prevalence of views in UK population and how other criteria (demographic and social criteria) are mapped across the four views. The survey was delivered online using Qualtrics platform. First, a short description of the study context was introduced, followed by study aims stressing that all answers are socially comparable and there is no wrong or favourable answer. Then participants were presented with three stages; rating then ranking of vignettes followed by a questionnaire.

4.5.3.3.1 Pilot study

I conducted a pilot study prior to fully launching the full survey; its results are included in the analysis. I tested the survey with 30 participants, and I asked for their feedback. One participant indicated that two vignettes start with the same statement. Vignettes for Factor 1-The Realist and Factor 2A-The Optimistic Hesitant both started with the statement "I feel I cannot decide to donate because I do not know all the facts" which is a salient statement for Factor 1 and a distinguishing statement for Factor 2A. from that comment, I changed the sequence of statements in the vignettes and slightly changed the wording in some of the statement without affecting the meaning of the statement, I also changed the connecting words between statements. I also asked feedback on whether the vignettes are distinctive, participants indicated that it can be confusing especially with statements that exist in more than one vignette. However, I did not want to remove any salient or distinguishing statement from vignettes.

Based on the pilot study results, I also decided to:

- Allocate limited points to the rating question (15 credits).

- Assign minimum time for submission for both the rating and the ranking questions.

- Add region/area to the demographic questions.

4.5.3.3.2 Stage 1: vignette rating

At the first stage, participants were asked to read a short description of a view about organ donation and were asked to rate each view from 1-5 where 5 is extremely like my view and 1 is not similar to my view. Vignettes were randomly introduced to participants to avoid order bias. Participants were given a maximum of 15 credits (and a minimum of 4) in total to rate vignettes. This point allocation technique was used after the pilot study. They were asked to assign most credits to the vignette they most agree with. They were asked to rate each view from 1-5 where 1 is where the view does not fit them at all and 5 where the view fits them perfectly. They can rate all four views a minimum of 1 each, and they can distribute a total of 15 credits among four vignettes in the way that represents their own point of view. Two or more vignettes may be rated similarly.

This point-allocation technique is valuable. It was used to encourage participants to evaluate all items carefully and at the same time to determine the number of points that they need to allocate to each item. Forcing 15 credits as a maximum motivates the participant to consider which factor is worth "using" five credits for in comparison to other factors. Minimum rating was one for each factor, minimum total credit is four. Additionally, assigning 15 credits for four factors can help with differentiation problem associated with rating.

If participants decided to use all 15 credits, it will not be possible to rate all four factors at 5 and one or more factors must be favoured. If participants rate two or more factors the same way, then the second stage of the survey would break that tie. Furthermore, if a significant number of participants used less than five credits it indicates a potentially undiscovered factor where not a single factor is rated high.

Maximum sum questions require more efforts from participants compared to usual rating, but since participants are presented with four factors only, each with short description;

this should not cause significant respondent fatigue. Compared to ranking, rating with allocated points does not only provide an indication of preference of one factor over the other, but it also indicates how strong is that preference. Participants were able to change the rating of all views repeatedly until they feel the rating is reflective of how much each factor represents them. They were asked to take enough time to read each vignette. They were able to proceed to the next question once enough time has been spent reading the statements. Participants were able to submit their rating after at least 120 seconds.

The first stage aimed to reflect "factor loading" in the Q-methodology study where participants can have different loading on all factors. If a significant number of participants rate all vignette as 1, it indicates that there is a factor (a view) that was missing from the Q-methodology study. If a significant number of participants rank all vignettes on 5 and/or assign similar rating to all four vignettes, it indicates that the participants are confused and generally there is no significantly distinctive views in population.

4.5.3.3.3 *Stage 2: vignette ranking*

At the second stage, participants were randomly presented with the same four vignettes and were asked to rank the four views as to which fit them best, by dragging the view that fits them the best on the top, followed by the one that second fits them, then the third one that fits them, then the one that fits them the least on the bottom. Participants were able to submit their rating after at least 60 seconds, assuming they have read the vignettes in the previous question, and they need less time at the second stage.

This stage reflects the Q sorting in Q-methodology where participants were *forced* to place statements into the gird. Naturally, if participants have rated factors distinctively in the first stage, this would be a redundant part, however, this stage can be helpful if the participant has rated one or more profile similarly, this stage will help break the tie (Jedeloo et al., 2010). All participants completed this part, even with distinctive rating at first stage.

It is expected to find some inconsistencies in answers, if a significant number of participants show inconsistencies between stage 1 and 2, results from stage 2 will be considered. The ranking and rating of vignettes allows for more reliable results, it can also be used to break the tie between factors where two factors or more have similar rating.

4.5.3.3.4 *Stage 3: questionnaire*

Participants were asked to answer a series of questions to identify correlations between vignettes and other demographic, social and attitude variables. The literature on organ donation indicates that certain epidemiological factors are associated with varied attitudes towards organ donation. In the third part of the survey, I explored how these criteria that can be used as predictors to attitude would map across views. There are a selected number of questions from the literature were included. The first section is for demographic criteria, the second section is for attitude towards organ donation, and the third is for social interaction. The questionnaire was kept short and crisp to complement the Q study profiles and the prevalence section of the survey.

Studies have shown that younger individuals (Conesa et al., 2003, Zanuddin et al., 2017, Buthelezi and Ross, 2011) with high socioeconomic status (Conesa et al., 2003, Conesa et al., 2006, López et al., 2018, Qureshi et al., 2018, Bhengu and Uys, 2004, Lim et al., 2020) and favourable cultural history (Huang et al., 2015) are more likely to register as an organ donor. Female have been shown to have more favourable attitudes towards organ donation and they are more likely to communicate that attitude with their family (Reubsaet et al., 2001a, Gimbel et al., 2003, Smith et al., 2008, Martínez-Alarcón et al., 2018, Ríos et al., 2017). Other predictors include altruism. People who have undertaken social work before are more likely to have positive attitude as well (Conesa et al., 2006, Conesa et al., 2003, Conesa et al., 2004). Figure 23 shows survey stages and Appendix 8 shows the full survey questions.

Demographic questions Gender Age Region Education Income Ethnicity Religion	→	Rate vignettes (15 credit)	→	Rank vignettes	→	**Organ donation related questions** Donor status Attitude Marriage status Spouse attitude Know donor Discuss with family Volunteering
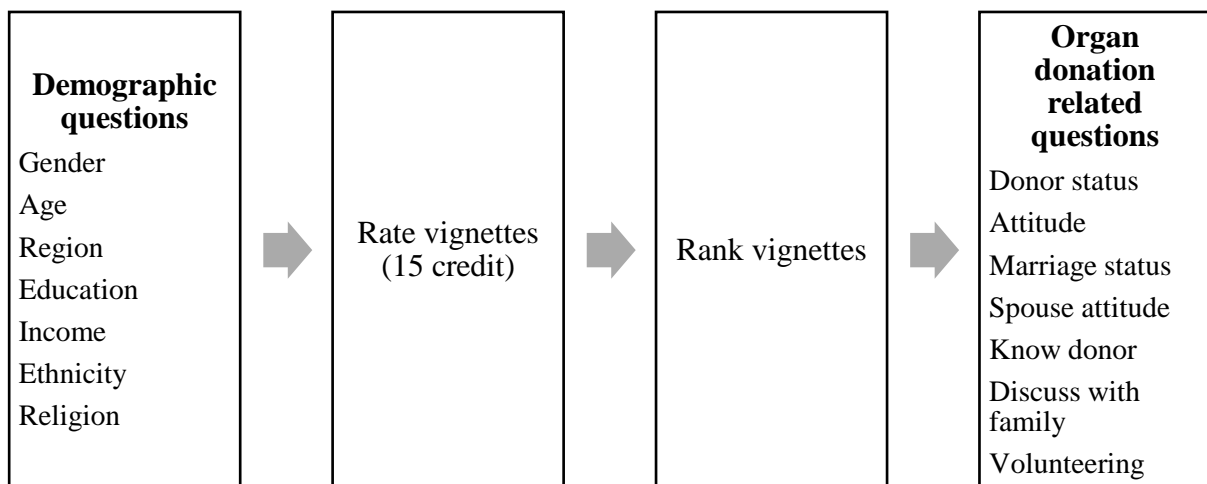
Figure 23 Survey stages. The survey was conducted online using Qualtrics platform. First participants were asked seven demographic questions. The second screen then presented four vignettes, participants were given 15 points' credit and were asked to rate each vignette independently based on how much it reflects their views on organ donation. A third screen presented the same vignettes, but this time participants were asked to rank four statements from the one that is closest to what they think to the least. The last screen presented seven questions related to organ donation.

4.6   Chapter four summary

This chapter discusses the methodology and design on this research. This research adopts mixed method design that combines qualitative and quantitative approaches. Two studies were conducted to answer research questions, Study one, and Study two. Study one used Q-methodology and interviews while Study two used survey method, each study seek to answer two of the research objectives. Next chapter will present the results of both studies.

5 Chapter five – Results

5.1 Chapter introduction

This chapter presents the results of two studies. The Study one results include factor analysis and interpretation followed by a discussion on the validity and reliability of the results. This is followed by Study two results, which include descriptive statistics for a survey followed by a discussion on validity of results.

5.2 Study one results

5.2.1 Introduction

In this section, I will describe in detail the analysis process as well as the results presented in factor interpretation. In the analysis process, using Pearson correlation, centroid factor extraction and Varimax rotation, three factors were extracted, one of which is a bipolar factor. The results of Study one show how subjective perception created three patterns (factors) of barriers to organ donation. These results will address Research Objective 1. Perceived lack of knowledge, anxiety and hesitancy are the most influencing beliefs. This is based on the most prominent barriers for each pattern, and it is the result of a holistic view and interpretation of factors. These results address Research Objective 2. These results are then complemented with recommendations on specific strategies to increase donation for each group, which addresses Research Objective 4. This is very important for the empirical contribution of this research since that is the primary contribution of this research.

Subjective perception plays an important role in how behavioural barriers are perceived and connected and eventually, how organ donation decisions are made. Subjectively, people perceive certain barriers to be strongly connected to others, the placement of statements (about a barrier or a motivator) on the extreme ends of the Q grid is

an indication on its salience. Attitudes towards the subject are formed through many connections between barriers and motivators. With Q-methodology, it is not only possible to find patterns within this relationship but also to ascertain the importance of these items. In Study one, salient barriers were extracted for each factor. It is not the one statement that has been placed on an extreme end, but rather a result of a holistic interpretation of factor arrays.

Since Q-methodology is not common in organ donation literature, I wanted to go into extreme detail in how analysis is conducted. In this research, I intend to contribute methodically to post-Q survey design. However, it is important to ensure clear understanding of Q-methodology beforehand. There were many challenges in data collection and analysis in Study one, and it is important to share these experiences in a clear easy-to-follow guide for Q-methodology-naïve researchers.

5.2.2   *Data analysis process*

5.2.2.1   **Study one analysis procedure**

Following data collection, a Q-methodology analysis was conducted using KenQ Analysis, a web application for Q-methodology (https://shawnbanasick.github.io/ken-q-analysis/). I attempted using several Q-methodology software, including the PQ Method. Most software packages use MS-DOS, which is not user-friendly. The website I used for data collection qmethodsoftware.com does offer data analysis but with limited analysis options. The KenQ Analysis, the web application I used, allows for data to be uploaded on an Excel sheet and offers a wide range of options such as:

- Choosing the number of factors to be extracted,

- Extracting method using either Principal Component Analysis (PCA) or Centroid method,

- Allowing direct download of the Scree plot,

- Offering Varimax or manual rotation options,

- Allowing easy management of confounding factors (participants who are loaded significantly on more than one factor) by manually selecting factors,

- Choosing the P value for analysis, and

- Downloading outputs on Microsoft Excel, with valuable data included.

Figure 24 shows the steps on analysis on the web application and the options chosen for the analysis at each step.

Data Input
- Data exported from qmethodsoftware.com
- Filled out an Excel template from KenQ Analysis web application

Correlation Matrix
- Pearson product moment correlation was used

Factor Extraction
- Seven factors were extracted, and they were all selected for further analysis.
- Centroid factors extraction was used (Instead of PCA)
- Download the Scree Plot.

Generate Output
- Exported as an Excel file

Factor Loadings
- A critical significance value of ±0.41 was chosen (manually chosen)
- P value = 0.01 (instead of 0.05)

Factors Rotation
- Three factors included in rotation.
- Varimax Rotation was used (Instead of judgemental (manual) rotation)

Figure 24 Q-methodology steps based on KenQ Web Application. This figure shows the analysis process using KenQ web application that was used to analyse Q study results. This figure will be used to signpost the analysis step by step and help follow the statistical choices made along the way.

5.2.2.2 Data input and correlation matrix

There are different correlations and rotations methods in Q-methodology. The resulted outcomes from different correlations vary minimally and make "virtually no difference" (McKeown and Thomas, 2013). The first step in analysis is to correlate the Q sorts with each other, creating a correlation matrix. I used the Pearson product moment correlation for this

study. It is common to use the "traditional orthogonal procedures" in Q-methodology (Watts and Stenner, 2012). Exploratory factor analysis was conducted resulting in seven factors.

5.2.2.3 Factor extraction

Factor analysis extracts groups "factors" from the correlation matrix. Factors in Q-methodology study represent a group of people with similar views on the examined subject. Before factor extraction, a decision had to be made regarding the method of extraction. Two options are available: centroid and Principal Component Analysis (PCA). The centroid (or simple summation method) is preferred by Q methodologists. It provides an infinite number of ways by which the factors can be rotated (Akhtar-Danesh, 2016). It provides an openness that makes it the preferred choice for Q methodologists (Watts and Stenner, 2005). The centroid method "is the only method which extracts nonorthogonal factors" (Akhtar-Danesh, 2016). "The uniqueness of the centroid method is its indeterminacy: There is no correct solution out of the infinite number of solutions" (Brown, 1980). In this research it was preferred to use centroid to maintain Stephenson vision in indeterminacy (Ramlo, 2016) rather than PCA's "one best solution" (Brown, 1980). Seven factors were extracted initially, which is the maximum number of factors that can be extracted as suggested by Watts and Stenner (2012). Table 12 shows the eigenvalues for seven unrotated factors found in this study.

"Eigenvalues are the sum of squared factor loadings for each factor" (Du Plessis, 2005). Extracted factors usually (but not always) have an eigenvalue of ≥1 or more (Watts and Stenner, 2005). Although six factors have eigenvalue of ≥1, the decision to rotate only three factors is twofold. First, the total number of loading Q sorts with the seven factors is 27 out of 40. The highest number of total loading Q sorts for Varimax rotation and the Pearson core method is three extracted factors. Thirty-one people loaded on a factor when three

factors were extracted, compared to 27 when seven factors were extracted. Secondly, I

considered the theoretical significance (McKeown and Thomas, 2013). The qualitative

analysis of three factors is far more significant and simpler than the interpretation of seven

factors. That entails quite a wide area of overlapping between the seven factors.

Table 12 Eigenvalues for seven unrotated factors. This table shows the eigenvalue of the seven
factors initially extracted. Eigenvalue is a measure of how much of the variance of the observed
variables a factor explains. The table shows that Factor 6 eigenvalue is below 1 and that of
Factor 7 is low as well. The table also shows the percentage of explained variance. It shows
that Factor 1 explains 27% of variance and then that goes sharply down to 7% and 5% for
Factor 2 and Factor 3, respectively. The table shows that if three or four factors are extracted,
they will explain 39% or 43% respectively.

	F1	**F2**	**F3**	**F4**	**F5**	**F6**	**F7**
Eigenvalues	10.849	2.757	1.993	1.4433	1.555	0.976	1.0142
% Explained Variance	27	7	5	4	4	2	3
Cumulative % of Explained Variance	27	34	39	43	47	49	52

Moreover, there are several criteria for choosing the number of extracted factors

described in Watts and Stenner (2012):

1. Kaiser-Guttman criteria: all extracted factors have eigenvalues of more than 1.00, thus

   satisfying Kaiser-Guttman criteria (Guttman, 1954, Kaiser, 1970).

2. Humphrey's Rule: this rule indicates that factors are extracted if "the cross-product of

   its two highest leadings exceeds twice the standard error" (Brown, 1980). Table 13

   shows that all three factors satisfy Humphrey's rule.

- Significant factor loading for this study = 2.58 × (1÷√no of Q sorts)

$$= 2.58 \times (1 \div \sqrt{40})$$
$$= 0.407 \text{ rounded up to } \pm 0.41$$

- Standard Error for this study = 1 ÷ (√no of Q set)

$$= 1 \div \sqrt{40}$$
$$= 0.158 \text{ rounded up to } 0.16$$

Table 13 Humphrey's Rule Calculation. The first row shows Q sorts that loaded the highest on that factor. The second row shows the loadings in the first row multiplied. To satisfy Humphrey's rule, the value in the second row must be higher that 0.316 (the standard error 0.158 multiplied by two)

	F1		**F2**		**F3**	
Highest Loading Q sorts	0.7237	0.5665	0.6667	0.5905	0.9284	0.6172
Cross product	0.40997605		0.39368635		0.57300848	

3. Scree Test: "the number of factors to extract is indicated by the point at which the line changes slope" (Watts and Stenner, 2012). The scree plot shows a long downward curve for the first factor, with smaller changes in the middle until it starts to level up between the last two factors. Although there are many behavioural barriers to organ donation, it is unlikely that five views with potential bipolar natures will be emerged. Empirically, it would be difficult to offer solutions for more than three or four view. For those reasons, only three factors were extracted. The decision to exclude several factors from further interpretation is made at the expense of full representation of views on organ donation.
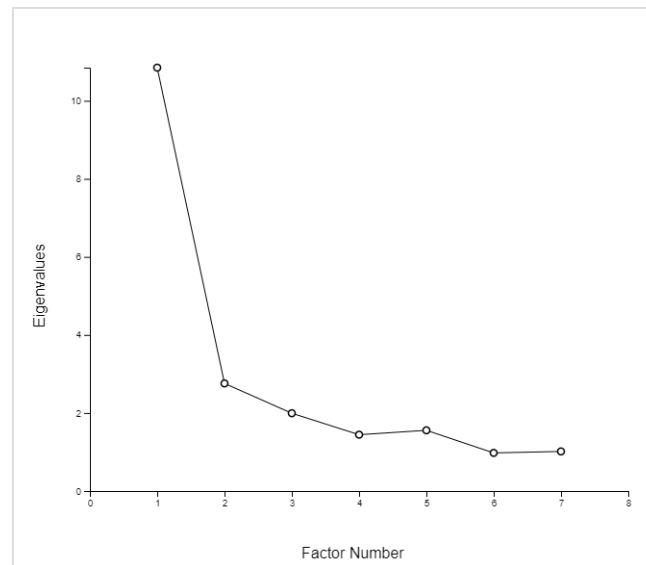
Figure 25 Factors' eigenvalues (Seven factors before rotation using Centroid for factor extraction).

5.2.2.4 Factor rotation and loading

I opted for Varimax rotation because it is "objective and reliable" (Watts and Stenner, 2012) and it is "routinely applied" in Q-methodology studies (Brown, 1980). It aims at "maximizing the purity of saturation of as many variates as possible" (McKeown and Thomas, 2013). Three factors were selected for rotation, F1, F2 and F3. The three extracted factors accounted for 31 participants out of 40, and explained 39% of total variance, which is under the recommendations to keep the total explained variance under 50% (Eghbalighazijahani et al., 2013).

A critical significance value of ±0.41 was chosen (the Q sort was included if it loaded with coefficient value of ±0.41 on any factor) at 0.01 level of significance (Correlations are statistically significant at the 0.01 level when they are more than 2.58 standard errors, irrespective of sign). Three participants were confounded (I4633, I4567 and I4586) (loading significantly on more than one factor). Furthermore, nine participants did not load significantly on any factor (Table 14 shows all participants and their loading scores).

Finally, the correlations between factors were low; this infers distinctive views amongst the three factors extracted. Following factor rotation, factor arrays were created (as shown in Table 15), factor arrays represent a hypothetical Q sort that loads perfectly onto a factor. These factor arrays then are subjected to qualitative interpretations.

Table 14 Factor Matrix with Defining Sorts Highlighted. The table shows the loading of each Q sort (participant) on factors. The flagging of Q sorts on factors is done automatically in the web application. However, some Q sorts were confounded (loaded highly on more than one factor). For these Q sorts it was manually flagged to the factor with strongest loading. Some Q sorts did not load on any factor.

Q sort*	Factor 1	Factor 2	Factor 3
I4526	0.3243	0.149	0.6024
I4527	0.2199	-0.0542	0.5009
I4565	0.1308	0.2506	0.5629
I4570	-0.0339	-0.3085	-0.4829
I4583	0.1673	0.0845	0.5476
I4606	-0.0205	0.2102	0.4413
I4607	0.3423	0.1217	0.4537
I4633*	0.4442	0.0037	0.5041
I4658	0.1692	0.3905	0.5632
I4725	0.088	0.0812	0.5988
I4726	0.2611	0.2083	0.6172
I5839	0.2415	0.2326	0.4911
I5850	-0.2087	0.3183	0.4653
I6271	0.2184	0.2095	0.9284
I6277	-0.0083	0.2159	0.5415
I4567*	0.1591	0.5492	0.4691
I4586*	-0.0752	-0.6897	-0.4092
I4616	0.1285	0.4705	0.1501
I4648	-0.0981	-0.7888	0.1268
I5897	0.3944	0.5905	0.2634
I6216	0.185	0.5791	0.2344
I6263	0.3676	0.6667	0.2828
I6291	0.0459	-0.7303	-0.354
I4572	-0.6301	0.0236	0.0119
I4584	0.5563	0.1373	0.3746
I4585	0.5665	-0.0684	-0.0206
I4609	0.4726	0.3321	0.4264

I4652	0.4722	0.2545	0.2257
I5931	0.4797	0.144	0.1398
I6018	0.4641	0.1612	0.399
I6205	0.7237	-0.2586	-0.0422
I4528	0.1823	0.1699	0.3597
I4576	0.3791	0.0558	-0.0061
I4577	0.3565	0.2814	0.2381
I4578	-0.3799	-0.1628	-0.2086
I4615	0.3454	0.172	0.1783
I4647	-0.039	0.3327	0.212
I4684	0.0191	0.1698	0.3459
I4714	0.2421	0.1009	0.1098
I4733	0.3791	0.2751	0.104

Confounding Q sorts

5.2.3 Factor interpretation

Factor interpretation aims to construct the different views. I used the factors arrays, crib sheet, distinguishing and consensus statements to interpret factors. The first step is to start with arrays of factors, to establish the first overview of the views, then establish a crib sheet for each factor to examine what people in each factor think relative to other factors. Factors arrays is how a "hypothetical respondent with 100% loading on that factor would have ordered all their statements within the Q-set" (Van Exel and De Graaf, 2005). Q sorts are used to calculate the factors arrays, excluding confounding and non-significant Q sorts.

Table 15 Factor arrays. Factors arrays are "no more or less than a single Q-sort configured to represent the view of a particular factor" (Watts and Stenner, 2012).

Statement	F1	F2	F3
1 - I believe my religion does not allow it.	-2	-1	0
2 - I think rich or famous people can receive organs before the people with the most need.	-1	-2	2
3 - I do not think I have ever thought about it.	-2	1	1
4 - I think the process of registration is complicated.	0	-2	-1

5 - I think anyone can register and be a donor even if old or have a disease.	0	1	2
6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups.	-3	-3	-2
7 - I think giving out organs to save someone's life is a noble act.	4	4	5
8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register.	1	-3	-4
9- I think I am too old to donate.	-4	-2	-3
10 - I believe I will be haunted if I donate.	-4	0	-2
11 - I think it is non-religious to take organs.	-5	-1	0
12 - I do not know anyone who donated an organ.	5	-2	4
13 - I believe there is a great need for organs, especially in minority groups.	2	1	3
14 - Brain death is confusing to me, but I think experts know better.	1	2	2
15 - I feel I cannot decide to donate because I do not know all the facts.	5	3	-1
16 - I believe transplantation results are successful and they are improving people's health.	3	5	5
17 - If someone religious says it is not allowed, then I will not do it.	-3	1	-5
18 - I feel talking about death and after life is important to appreciate our lives.	0	3	3
19 - I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs.	0	-4	-2
20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself.	1	3	2
21 - I believe the human body is not a machine.	-1	-1	0
22 - I think brain dead people can regain consciousness.	1	0	1
23 - I thought about registering as a donor but I never did.	2	5	1
24 - I do not want doctors or the healthcare system to be in control of my organs.	3	-5	0
25 - When someone asks me to register to donate, it feels like he is waiting for my death to get my organs.	-2	-5	-1
26 - I trust the donation system to be fair.	-1	4	3

27 - I do not mind organ donation but my family disagree.	0	0	0
28 - I trust doctors and nurses to always provide the best care they can.	2	4	4
29 - I think people exaggerate on the importance of the whole organ donation subject.	0	-3	-1
30 - I think people who have medical conditions cannot donate.	4	-1	1
31 - I feel I have no responsibility towards anyone else.	-1	-4	-3
32 - I think transplant recipients do not live more than 10 years after a transplant operation.	2	-1	0
33 - People on the waiting lists are ill and I believe they need my help.	1	2	4
34 - I believe donated organs can be bought and sold.	-1	-3	1
35 - I might feel easy to donate because my family encourages me to donate.	-2	1	2
36 - I believe the present need for transplant organs is fully covered.	-3	-2	-3
37 - I believe people would not need transplants if they took better care of their health.	4	-4	-4
38 - I do not mind donating some organs, but not my heart or eye.	-1	2	0
39 - I believe organs are a gift from God; we are not allowed to give them away.	-5	0	-5
40 - No matter how hard it is to think about organ donations, it makes me feel good about myself.	2	2	3
41 - I do not think I have the courage to donate.	0	3	-2
42 - I think it is just easier to say no than to think about it.	3	1	-4
43 - I think my religion encourages organ donation in order to save other people's lives.	-3	2	-1
44 - I do not mind donating when I am alive, not when I am dead.	-2	0	-3
45 - I want to be cremated and if I donated organs, I cannot do that.	-4	-1	-1
46 - Talking about death is creepy.	1	0	-2
47 - I think I am not dead if my heart is still beating.	3	0	1

Factor interpretation was carried out using the "crib sheet" method (Watts and Stenner, 2012) to ensure a systematic and holistic approach in the interpretation process, bearing in mind the researcher's own biases during interpretation brought about by the researcher's previous experiences and personal beliefs. The crib sheet method offers:

1. Rigorous and systematic process of interpretation.

2. Deep and detailed examination of each factor.

3. Shifted focus beyond factor distinguishing statements.

4. Holistic approach in interpretation for the emerging views.

The crib sheets start by listing the extreme scores for each factor (statements on +5 and -5 positions that represent the most important statements to the factors). Then by going through each statement, I compared the score for each factor, to elicit the factors that have been scored lowest or highest. For example, we can see statement 1 in

Table 15 is scored -2, -1, and 0 by F1, F2 and F3, respectively. Thus, statement 1 is scored the highest by F3 and lowest by F1. Thus, statement 1 is enlisted in the (higher) category of F3 in crib sheet and category (lower) of F1 crib sheet, and so on. Essentially, crib sheet allows us to compare the salience of items compared to other network patterns. If one imagines an item, for example statement 33 – "People on the waiting lists are ill and I believe they need my help", to be something that all views perceive to be true, this item will be positioned on the positive side of the grid for all factors. Crib sheet will offer a new insight by comparing its positioning compared to other views, so we can say for this particular item (statements) it is perceived as important and more salient for F3, compared to others. By doing so, we were able to compare the perceived salience of barriers among various patterns within the network view. Table 17, Table 22, and Table 27 show the crib sheet for Factor 1, Factor 2, and Factor 3, respectively.

Distinguishing statements were identified for each factor. The distinguishing statements show factors that have been ranked significantly (p<0.01). With a different rank for the factor, it accentuates the uniqueness of the factor. Distinguishing statements may expose a particular topic of interest for that factor to be further examined for theoretical significance. Its statistical significance indicates that, based on perception patterns, these items (statements) differentiate that pattern from others. Table 16, Table 21, Table 26 shows the distinguishing statements for Factor 1, Factor 2, and Factor 3, respectively.

5.2.3.1 Factor 1: The Realist

I always seek facts. My religion is personal, and I try to stay rational and shake out fear. I am confident and do well by others because I believe it is the right thing to do.

Factor 1 has an eigenvalue of 4.37 and explains 11% of variance in the study. Eight people loaded significantly on this factor (Table 14 shows the participants loaded on this factor). This factor consists of 50% male and 50% female, with an average age of 28 and they come from different ethnicities. Table 18 shows weights of sorts and demographic criteria for Factor 1. Only one of them is registered as an organ donor.

Figure 26 Factor 1 array

-5	-4	-3	-2	-1	0	1	2	3	4	5
11	9	6	1	2	4	8	13	16	7	12
39	10	17	3	21	5	14	23	24	30	15
	45	36	25	26	18	20	28	42	37	
		43	35	31	19	22	32	47		
			44	34	27	33	40			
				38	29	46				
					41					

People on this factor appreciate knowledge[2] (except for participant I4572 who located it negatively on this factor; ranked it at -5). They express their need to acquire more information to decide, and voice that as a significant barrier to organ donation. The call to provide (or acquire) more information does not necessarily correlate with their factual knowledge on organ donation. They are aware, for example, of the need for organ transplantation[3] (Figure 26 shows Factor 1 array). Commonly, organ donation attitude scales assess knowledge levels about the subject. Q-methodology is offering an insight on how the level of knowledge is subjectively perceived by individuals. From a network view of barriers and attitudes, Q-methodology shows that people in this group value social encounter with registered organ donors as much as they value information about the subject.

People loaded on this factor hold themselves responsible for seeking information to make better decisions for themselves, and they also upheld people to make sound decisions when it comes to their own health[4]. Hence, they show resistance to donating organs to people who do not take care of themselves. However, they do show compassion towards people in need, and if those people do get ill, they will consider helping[5]. The pattern of placement of statements shows that, for this group, perceiving the organ donation concept positively does not act in isolation of other consideration about recipient criteria. To the author's knowledge,

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[2] Statement 15 - I feel I cannot decide to donate because I do not know all the facts; is on +5 rank and it is a distinguishing statement for this factor and ranked the highest on F1 than on other factors.

[3] Statement 6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups, on -3 the lowest of the factors, and 13 - I believe there is a great need for organs especially in minority groups on +2

[4] Statement 37 - I believe people would not need transplants if they took better care of their health on +4, the highest amongst factors and it is a distinguishing statement for F1 and 31 - I feel I have no responsibility towards anyone else is on -1 which it the highest rank compared to other factors.

[5] Statement 7 - I think giving out organs to save someone's life is a noble act on +4, 40 - No matter how hard it is to think about organ donations, it makes me feel good about myself on +2, 33 - People on the waiting lists are ill and I believe they need my help on +1.

this connection has never been particularly made in any previous study. Examining attitude and barriers as a network and extracting patterns using Q-methodology indicate that the organ donation concept is perceived to be as important as potential recipients' worthiness. Combining desire for more information, the valued acquaintance with a registered donor and the positive perception to the organ donation concept, it can be deduced that, for this group, the considerations whether to help or not follow what they believe to be an analytical path. The analysis stems from an exploration of several issues related to the healthcare system and what constitute death.

Despite an interest in acquiring information on organ donation, they are bewildered with the brain death issue, and they do not seem to make up their mind about it[6]. It is important to mention here that these statements are factually wrong. However, the issue is subjectively perceived as reversible. Knowledge on organ donations scales would combine several questions on brain death without differentiating between statements' perception. For example, in this group, accepting brain death diagnosis as death is more salient than brain death reversibility. In fact, brain death as a diagnosis of death is rejected by this group more than others since it is ranked as the highest among other factors. During an interview (discussed below), participant 4586 mentioned in the interview: "I think when someone is brain dead, then they will not be conscious again, but I think it is hard or may be confusing to be 100% sure with the diagnosis; one can be diagnosed as brain dead, but they are not. I am not sure how that happens, but doctors can make mistakes and it happens".

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[6] Statement 47 - I think I am not dead if my heart is still beating on +3; a distinguishing statement and it is the highest rank compared to other factors, 22 - I think brain dead people can regain consciousness on +1.

When it comes to the healthcare system, they show a relatively positive view on the success of transplantation procedures[7]. They have good information on the registration process[8] but they show a misunderstanding on the donation criteria[9]. The placement of two statements related to donation criteria on +4 and -4 suggests that donation criteria is perceived to be a salient and important component of their view on organ donation. People loaded on this factor show a greater trust in the allocation process[10] while acknowledging some concerns on the donation process[11]. Placing two statements regarding organ allocation on -1, suggests that, despite the issues that might arise from allocation that might be sometimes unfair, it is not a prominent component of their view, while recipient worthiness from a health perspective is much more significant that it is placed on +4, a distinguishing statement and placed at a highest rank compared to other factors.

People in this group tend to stay rational and in control of their emotional attachments with their bodies; life is mechanistic despite our instinctive reaction of fear of death[12]. Several statements related to death anxiety are placed in the middle of the grid, indicating that death anxiety is not perceived as an important barrier to organ donation.

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[7] Statement 16 - I believe transplantation results are successful and they are improving people's health on +3 and 32 - I think transplant recipients do not live more than 10 years after a transplant operation on +1; a distinguishing statement.

[8] Statement 4 - I think the process of registration is complicated on 0 which is the highest ranking compared to other factors, 5 - I think anyone can register and be a donor even if old or have a disease on 0.

[9] Statement 30 - I think people who have medical conditions cannot donate on +4 and a distinguishing statement, while statement 9- I think I am too old to donate on -4.

[10] Statement 2 - I think rich or famous people can receive organs before the people with the most need on -1.

[11] Statement 26 - I trust the donation system to be fair on -1.

[12] Statement 46 - Talking about death is creepy on +1, 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself on +1 and the lowest compared to other factors, 18 - I feel talking about death and the afterlife is important to appreciate our lives on 0 as a distinguishing statement, 38 - I don't mind donating some organs, but not my heart or eye (which holds an emotional value) and 21 - I believe the human body is not a machine on -1 and the lowest compared to other factors.

This group tries to keep the religious influence on their decisions to the minimum, their religion is personal[13] reflecting a positive relationship with their religions; however, they do not tend to follow religious leaders[14]. The placement of these statements shows that religion is perceived as a motivator in this group (regardless of their religion), and that perception is not derived from religious leaders. There have been several campaigns introducing positive views from religious leaders on organ donation through texts or videos. It is suggested that this group would not respond well to religious messages on organ donation (positive or negative) introduced by religious leaders. Instead, it may be more effective to introduce positive religious messages from registered donors, especially if there is a social relationship between the donors and an individual from this group.

People in this group demonstrate a mechanistic view of the body and a distance from religion. Although some participants were atheists, others held religious beliefs, but their beliefs did not seem to interfere with their views on organ donation. However, people with religious beliefs did load relatively lower than atheists, Table 18 shows Q sorts weights and demographic criteria for Factor 1.

This pattern of barriers shows that both religious and non-religious people may share similar views. It also shows that the mechanistic view of the body is not exclusive to the non-religious; religious people may also share a more mechanistic view of the body. People in this group are aware of the need for organs and the process of donation, but they still hold myths on the donation criteria. And while they show concerns on the worthiness of the recipient, they generally hold positive views on organ donation. This pattern suggests that knowledge is not an abstract term, and educational campaigns targeting this view may prioritise targeting

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[13] Statement 11 - I think it is non-religious to take organs on -5 and a distinguishing statement.

[14] Statement 17 - If someone religious says it is not allowed, then I will not do it on -3.

certain themes (such as eligibility criteria, the reasons for organ failures and brain death diagnosis) over other aspects.

As a group, the Q sorts loading on this factor do not correlate highly with each other, despite the fact they load reasonably high on their factor (Table 18 shows the loading of participants on Factor 1 and Table 19 shows the correlations among participants loading on Factor 1). This indicates that participants loading on Factor 1 do not have a homogeneous view on organ donation. Moreover, Factor 1 is closer to Factor 3 than to Factor 2 (Table 20 shows the descending array of differences between Factor 1 and the other two factors).

The hallmark for this factor is a call for more information on the subject with perceived lack of satisfactory amount of knowledge to make a decision. For this factor, behavioural change campaigns should focus on providing detailed information about organ donation. However, information should not focus on need (S15 /+5), instead, it should include information about eligibility criteria and brain death. Eligibility criteria might exclude people suffering from certain diseases but not necessarily older people (S9/-4). For example, campaigns should focus on the fact that you can still register and even donate even if you have an illness (S30/+4). The eligibility criteria on the NHS website which lists very few diseases that exclude donation are: Creutzfeldt-Jakob Disease (CJD), Ebola virus disease, Active cancer and HIV (NHS, 2019d). One can donate organs even if they have had cancer (but not active) or even if they cannot donate blood (NHS, 2019e).

Another important part of information is brain death. Campaigns should focus on the fact that brain death is irreversible and the patient cannot regain consciousness (S22/+1) (NHS, 2019a) using preferably expert opinion (S14/+1). Campaigns should also focus on the diagnostic criteria of brain death and shows that strict measures for brain death diagnosis eliminates the risk of misdiagnosis.

The campaigns message for this group should refrain from religious messages, family agreement, and easy registration process (although this does not apply to the UK anymore with the opt-out system). With the opt-out system in place, it is important to highlight that despite the opt-out system, a potential donor will not be forced to donate organs. No organ will be harvested without the permission of the family; thus, the decision to donate still lies in the hands of the person (S24/+3), as participant 4586 explains in the interview: "If I die and then doctors ask my family for my organs, maybe my mother would be so sad she will say no. I want to give her that chance, to say no". Messages targeting this group should encourage to communicate the decision to the family if one wants to be a donor.

Q-methodology analysis for this factor shows that knowledge is categorical, and the level of knowledge is irrelevant to the perception of knowledge level. People may perceive their knowledge level to be low despite potentially scoring well in a survey for knowledge level. It is advisable to consider adding a category within knowledge to measure perceived level of knowledge to see if people feel comfortable to make a decision based on the level of information they have. It shows how perception shapes the expression of behavioural barrier to organ donation. That is a similar case for religion. People may hold different religions with similar views and vice versa. To address knowledge perception, interventions that are founded on Self-Efficacy Theory can be most relevant to this group.

Bipolar factors can be translated to "two diametrically opposed viewpoints" (Watts and Stenner, 2005). Bipolar factor interpretation requires reversal of factor array into a mirror image. For example, the mirror image for this factor's array will show that statements 11 and 39 are on +5 and statements 12 and 15 on -5 with reversal of all other statements in the grid. There is one participant who loaded negatively on this factor, which means that this factor is

bipolar. The mirror image shows an opposition to organ donation for religious reasons[15] while acknowledging the value of donated organs to save lives and a support of religion to the concept rather than the behaviour of donation[16]. The view shows various misconceptions and myths related to organ donation[17] and a lack of interest to learn more about it[18].

Over the past years, the NHS conducted a series of campaigns to address myths about organ donation, in addition to the campaigns associated with policy change in the UK. The average knowledge score on organ donation is adequate (Molina-Pérez et al., 2018). It is unlikely that this mirror image would be prevalent in the UK. Theoretically, it can be difficult to reject it as an existent view on organ donation. However, the main contribution for this thesis is empirical. It is inefficient and resource-intensive to address six different views on organ donation. Unlikely views will be excluded from further analysis and representation in Study two. A mirror image of factor will be excluded when only one person is loaded negatively on a factor for practical implication.

Table 16 List of distinguishing statements for Factor 1. A distinguishing statement is found on factors when it is placed in a position that is significantly different to other factors.

3 - I do not think I have ever thought about it.
4 - I think the process of registration is complicated.
8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register.
11 - I think it is non-religious to take organs.
15 - I feel I cannot decide to donate because I do not know all the facts.

[15] Statement 39- I believe organs are a gift from God, we are not allowed to give them away and 11 - I think it is non-religious to take organs on +5.

[16] Statement 43 - I think my religion encourages organ donation in order save other people's lives, and 44 - I don't mind donating when I am alive, not when I am dead on +2.

[17] Statement 9- I think I am too old to donate, 10 - I believe I will be haunted if I donate, 45 - I want to be cremated and if I donated organs, I cannot do that on +4, 16 - I believe transplantation results are successful and they are improving people's health on -3 and 6 - I think there is no special need for organs for Asian, African and Middle Eastern groups on +3.

[18] Statement 15 - I feel I cannot decide to donate because I don't know all the facts and 12 - I don't know anyone who donated an organ on -5.

17 - If someone religious says it is not allowed, then I will not do it.
18 - I feel talking about death and after life is important to appreciate our lives.
19 - I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs.
24 - I do not want doctors or the healthcare system to be in control of my organs.
26 - I trust the donation system to be fair.
28 - I trust doctors and nurses to always provide the best care they can.
30 - I think people who have medical conditions cannot donate.
33 - People on the waiting lists are ill and I believe they need my help.
34 - I believe donated organs can be bought and sold.
35 - I might feel easy to donate because my family encourages me to donate.
37 - I believe people would not need transplants if they took better care of their health.
41 - I do not think I have the courage to donate.
42 - I think it is just easier to say no than to think about it.
45 - I want to be cremated and if I donated organs, I cannot do that.
47 - I think I am not dead if my heart is still beating.

Table 17 Crib sheet for Factor 1. The crib sheets first list statements on columns +5 and -5. Then by going through each statement, the score for each factor is compared, to elicit the statements that have been scored lowest or highest.

F1	
-5	11 - I think it is non-religious to take organs.
	39 - I believe organs are a gift from God, we are not allowed to give them away.
Lower	1 - I believe my religion does not allow it.
	3 - I do not think I have ever thought about it.
	5 - I think anyone can register and be a donor even if old or have a disease.
	6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups.
	9- I think I am too old to donate.
	10 - I believe I will be haunted if I donate.
	11 - I think it is non-religious to take organs.
	14 - Brain death is confusing to me, but I think experts know better.
	16 - I believe transplantation results are successful and they are improving people's health.

	18 - I feel talking about death and after life is important to appreciate our lives.
	20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself.
	21 - I believe the human body is not a machine.
	26 - I trust the donation system to be fair.
	27 - I do not mind organ donation but my family disagree.
	28 - I trust doctors and nurses to always provide the best care they can.
	33 - People on the waiting lists are ill and I believe they need my help.
	35 - I might feel easy to donate because my family encourages me to donate.
	36 - I believe the present need for transplant organs is fully covered.
	38 - I do not mind donating some organs, but not my heart or eye.
	43 - I think my religion encourages organ donation in order to save other people's lives.
	45 - I want to be cremated and if I donated organs, I cannot do that.
Higher	4 - I think the process of registration is complicated.
	8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register.
	12 - I do not know anyone who donated an organ.
	19 - I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs.
	22 - I think brain dead people can regain consciousness.
	24 - I do not want doctors or the healthcare system to be in control of my organs.
	29 - I think people exaggerate on the importance of the whole organ donation subject.
	30 - I think people who have medical conditions cannot donate.
	31 - I feel I have no responsibility towards anyone else.
	32 - I think transplant recipients do not live more than 10 years after a transplant operation.
	37 - I believe people would not need transplants if they took better care of their health.
	42 - I think it is just easier to say no than to think about it.
	46 - Talking about death is creepy.
	47 - I think I am not dead if my heart is still beating.
5	12 - I do not know anyone who donated an organ.
	15 - I feel I cannot decide to donate because I do not know all the facts.

Table 18 Sorts weights and demographic criteria for Factor 1

Q Sort	Weight	Gender	Age	Education	Socio-Economic Class	Ethnicity	Religion	Years in UK	Are you a registered donor?	Do you have any intentions of registering as a donor?	Do you believe that you or someone else might need an organ?
I6205	10	M	27	Mid	Mid	Asian (Nepalese)	N/A	2	No	Maybe	Yes
I4585	5.48991	M	33	Mid	Mid	Middle East British	Atheist	3	No	Maybe	Yes
I4584	5.30164	F	26	Mid	Mid	Netherlands	Atheist	4	No	Maybe	No
I5931	4.10042	F	19	Low	Mid	White American	Christian	2	No	Yes	Yes
I4609	4.00454	M	25	Mid	Mid	White Ukrainian	Atheist	16	Yes	N/A	Yes
I4652	3.99921	F	36	Mid	Mid	Middle East	Muslim	2	No	no	Yes
I6018	3.8926	M	34	Mid	Mid	African	Christian	3	No	Maybe	Yes
I4572	-6.87697	M	22	Mid	Mid	Indian	Sikh	2	No	no	No

Table 19 Factor 1 sorts correlations

Q Sort	I6205	I4585	I4584	I5931	I4609	I4652	I6018	I4572
I6205	100	43	36	21	30	27	32	-37
I4585	43	100	67	14	15	15	17	-43
I4584	36	67	100	20	39	26	36	-41

I5931	21	14	20	100	29	31	36	-28
I4609	30	15	39	29	100	48	41	-23
I4652	27	15	26	31	48	100	48	-29
I6018	32	17	36	36	41	48	100	-13
I4572	-37	-43	-41	-28	-23	-29	-13	100

Table 20 Descending array of differences between factors (Factor 1). The table demonstrates how different factors are in relation to how statements are placed. The first column shows the statement number, then its Z- score on Factor 1. "The z-score is a weighted average of the values that the Q-sorts most closely related to the factor given to a statement" (Zabala and Pascual, 2016). This score then is compared to the other two factors. To do so, first, we list the Z score for that statement on Factor 2 and Factor 3. Extract the difference then square it. The sum of the squared differences in the last row shows that Factor 1 is closer to Factor 3 than it is to Factor 2

#	Factor 1	Descending array of differences between Factor 1 and Factor 3			Descending Array of Differences Between Factor 1 and Factor 2		
		Factor 3	Difference	Differences ^2	Factor 2	Difference	Differences ^2
1	-0.91	-0.14	-0.77	0.60	-0.52	-0.39	0.15
2	-0.60	0.73	-1.34	1.79	-0.73	0.13	0.02
3	-0.78	0.33	-1.11	1.24	0.34	-1.12	1.26
4	0.09	-0.67	0.76	0.57	-0.74	0.83	0.68
5	-0.11	0.86	-0.97	0.95	0.35	-0.46	0.21
6	-0.95	-0.75	-0.20	0.04	-1.00	0.05	0.00
7	1.69	2.07	-0.38	0.15	1.36	0.33	0.11
8	0.26	-1.38	1.64	2.70	-1.26	1.52	2.30
9	-1.47	-1.02	-0.45	0.20	-0.89	-0.58	0.34
10	-1.22	-0.88	-0.34	0.11	-0.30	-0.92	0.84
11	-1.71	-0.10	-1.62	2.62	-0.37	-1.34	1.80
12	1.83	1.52	0.31	0.09	-0.70	2.53	6.42
13	0.96	1.06	-0.10	0.01	0.58	0.38	0.14
14	0.21	0.62	-0.41	0.17	0.89	-0.68	0.47
15	2.11	-0.33	2.44	5.95	1.24	0.87	0.75
16	1.39	2.00	-0.61	0.37	1.88	-0.48	0.23
17	-1.01	-1.68	0.67	0.45	0.30	-1.31	1.72
18	-0.11	1.41	-1.52	2.30	1.10	-1.21	1.47
19	0.17	-0.89	1.06	1.12	-1.55	1.72	2.95
20	0.24	0.56	-0.32	0.10	1.28	-1.04	1.09
21	-0.44	0.00	-0.44	0.20	-0.64	0.20	0.04
22	0.31	0.40	-0.09	0.01	-0.32	0.63	0.40
23	0.82	0.29	0.53	0.28	1.75	-0.93	0.87
24	1.04	-0.11	1.15	1.32	-1.61	2.66	7.05
25	-0.68	-0.57	-0.11	0.01	-1.76	1.08	1.17
26	-0.40	1.35	-1.74	3.03	1.64	-2.03	4.14
27	-0.10	-0.21	0.12	0.01	0.09	-0.18	0.03
28	0.58	1.69	-1.11	1.24	1.51	-0.94	0.87
29	-0.25	-0.59	0.34	0.12	-1.00	0.75	0.57
30	1.42	0.36	1.06	1.12	-0.33	1.75	3.06

31	-0.58	-1.05	0.47	0.22	-1.36	0.78	0.61
32	0.43	0.00	0.43	0.19	-0.50	0.94	0.87
33	0.36	1.72	-1.37	1.87	1.06	-0.70	0.49
34	-0.63	0.09	-0.71	0.51	-1.29	0.66	0.43
35	-0.75	0.78	-1.53	2.34	0.42	-1.18	1.39
36	-1.17	-1.02	-0.15	0.02	-0.83	-0.34	0.12
37	1.61	-1.16	2.77	7.68	-1.45	3.06	9.37
38	-0.51	-0.13	-0.38	0.15	0.61	-1.12	1.25
39	-1.69	-1.84	0.15	0.02	-0.03	-1.66	2.76
40	0.91	1.06	-0.15	0.02	0.77	0.14	0.02
41	0.20	-0.67	0.86	0.74	1.22	-1.03	1.05
42	1.21	-1.28	2.49	6.22	0.56	0.65	0.42
43	-0.96	- 0.46	-0.50	0.25	0.78	-1.74	3.04
44	-0.87	-1.07	0.21	0.04	0.10	-0.97	0.94
45	-1.55	-0.60	-0.96	0.91	-0.63	-0.93	0.86
46	0.31	-0.67	0.98	0.96	0.07	0.24	0.06
47	1.30	0.35	0.95	0.90	-0.11	1.41	2.00
		Sum of Squared Differences		**51.90**	**Sum of Squared Differences**		**66.79**

5.2.3.2   Factor 2: The Optimistic Hesitant & Convinced Pessimist

Factor 2 has an eigenvalue of 4.69 and explains 12% of variance in the study. Eight people loaded significantly on this factor (Table 14 shows the participants loaded on this factor). Three out of eight (38%) were male and five were females (62%), with an average age of 37. Five out of eight are White (European, American, and Australian), two Chinese and one Latino. None of them is registered as an organ donor (Table 23 shows the sorts' weights and demographic criteria for Factor 2).

Three out of eight are loaded negatively on this factor (I4586 loaded -8.66, I6291 loaded -10.30 and I4648 loaded-13.74) for this factor. Thus, this is a bipolar factor. Interpretation will be divided into two views, one for the positively loaded participants (Optimist Hesitant) and then for the negatively loaded ones (Convinced Pessimist). Because all three sorts loaded negatively with similar strengths and at the same end, simply reversing the factors arrays will be enough for interpretation (Watts and Stenner, 2012). The mirror

image of this factor was selected for analysis and further representation in Study because it is common for mistrust in the healthcare system to be correlated with negative views on organ donation. The mistrust in the healthcare system may be extremely relevant to countries with significant health disparities such as the US (Bulatao and Anderson, 2004). However, even in the UK, there has been a decline in public satisfaction with the NHS due to limited funding and prolonged waiting lists (Robertson et al., 2019). This dissatisfaction is accompanied by an increasing distrust in the NHS (Serle, 2020), especially in minority ethnic groups (Agarwal, 2021). Because of this bipolar factor, the three-factor solution described four views on organ donation.

5.2.3.2.1 F2-A Optimist Hesitant

I see the glass half full; I trust people and systems and I feel responsible towards

them. Organ donation is noble and almost religious, but I am scared.

People who loaded positively on this factor show a high level of trust[19]. They trust the healthcare professionals[20] and extend this trust to the harvesting and allocation system as well[21] (Figure 27 shows the array for people loaded positively on Factor 2). This trust acts as the main motivator for people loading positively on this factor. It is evident that people loaded on this factor hold positive views on the organ donation process. Statements placement indicates the favourable attitude is supported with a trust in the healthcare system,

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[19] Statement 16 - I believe transplantation results are successful and they are improving people's health is on +5 rank, 26 - I trust the donation system to be fair and 28 - I trust doctors and nurses to always provide the best care they can on +4 highest among factors.

[20] Statements 24 - I don't want doctors or the healthcare system to be in control of my organs and 25 - When someone asks me to register to donate, it feels like he is waiting for my death to get my organs both on -5 and distinguishing statements for this factor, 19 - I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs on -4 and distinguishing factor as well and 8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register on -3 both are lowest among factors.

[21] Statement 34 - I believe donated organs can be bought and sold on -3 a distinguishing statement and 2 - I think rich or famous people can receive organs before the people with the most need on -2 rank and lowest among factors.

being harvesting, allocation and all in between extended to healthcare workers. Most statements that were prioritised to be on rank +,-4 and +,-5 are not related to factual or medical statements; they are mostly based on positive views towards healthcare as a system, suggesting that trust in healthcare system and providers as a core attitude for this group.

People loading on this factor show spiritual connections with religion[22] and with their body[23]. However, they do not perceive religion as a barrier to donation[24]. It is clear, however, that religion as a barrier does not hold a strong weight in the forming attitude to organ donation. Linear approaches using scales to measure attitude may or may not find correlations between religion and attitude to organ donation, and the network view of attitude suggests that people on this factor perceive trust in the healthcare system to be more salient than other barriers.

Figure 27 Factor 2 array – positively loaded sorts

-5	-4	-3	-2	-1	0	1	2	3	4	5
24	19	6	2	1	10	3	14	15	7	16
25	31	8	4	11	22	5	33	18	26	23
	37	29	9	21	27	13	38	20	28	
		34	12	30	39	17	40	41		
			36	32	44	35	43			
				45	46	42				
					47					

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[22] Statement 43 - I think my religion encourages organ donation in order to save other people's lives on +2 and 17 - If someone religious says it is not allowed, then I will not do it on +1, both are distinguishing statements.

[23] Statement 38 - I do not mind donating some organs, but not my heart or eye on +2 and distinguishing statement and 21 - I believe the human body is not a machine on -2 and the highest among factors.

[24] Statement 17 - If someone religious says it is not allowed, then I will not do it is on +1 and a distinguishing statement, statement 11 - I think it is non-religious to take organs and 1 - I believe my religion does not allow it on -1, and 39 - I believe organs are a gift from God, we are not allowed to give them away a distinguishing statement on 0.

They exhibit a significant fear of the process of organ donation[25]. Several statements show how consistent this group of people are in expressing their fear of donating organs and their hesitancy to register. That fear seems to be crippling, and it might be the main barrier against donation[26]. However, positive views from their family and friends may help alleviate such fear[27]. The anxiety expressed by people on this group is rather isolated from religion, mistrust, or family acceptance. The pattern formed by salient and distinguishing statements related to anxiety coupled with a general trust and positive views on the healthcare system and organ donation process suggests that fear is irrational, and it is not the result of certain issues related to organ donation. It is also noteworthy that statements on brain death and body integrity lie in the middle of the grid, implying that people on this factor might score positively on the anxiety and disgust scale. Observing patterns emerging from the network of barriers uncovered irrational and rather isolated anxiety to be a significant barrier to organ donation for this group.

Information related to brain death is of marginal position, for people loading on this factor (both positively and negatively), related statements lie in the middle region of the grid, indicating these statements are not salient to the decision to donate[28]. Most knowledge related

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[25] Statement 23 - I thought about registering as a donor but I never did is on +5 and a distinguishing statement for this factor, 41 - I don't think I have the courage to donate and 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself, and 15 - I feel I cannot decide to donate because I don't know all the facts, all on +3 and are distinguishing statements as well, and 40 - No matter how hard it is to think about organ donations, it makes me feel good about myself on +2 as well as 42 - I think it is just easier to say no than to think about it on +1 and a distinguishing statement.

[26] Statement 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself a distinguishing statement and scored the highest among factors and Statement 41 - I do not think I have the courage to donate scored the highest among factors and both statements are on +3.

[27] Statement 35 - I might feel easy to donate because my family encourages me to donate on +1.

[28] Statement 44 - I do not mind donating when I am alive, not when I am dead a distinguishing statement, 47 - I think I am not dead if my heart is still beating, the lowest among factors and 22 - I think brain dead people can regain consciousness, the lowest among factors, all on 0.

statements were ranked in the middle area of the grid (-2 to +2) indicating that this

knowledge is not a strong barrier to organ donation[29].

People loaded positively on this factor demonstrate a trustworthy view of the

healthcare system and healthcare providers. They also show brain death knowledge is not

relevant to them and religion may or may not hold negative views on organ donation but that

does not seem to be the main drive for their attitude. Fear and emotional distress play a major

role for people loaded positively on this factor. Despite a great trust in the healthcare system,

they appear to be hesitant to take a positive step towards organ donation. This pattern of

barriers shows that messages on religious views on organ donation or myth busting

campaigns on brain death may not be relevant. It is the irrational fear that plays the major role

regardless of any information they may hold about organ donation.

The hallmark of this factor is the hesitation and anxiety. For this factor, behavioural

change campaigns should focus on real-life stories that inspire others to become a donor.

However, campaigns messages should avoid evoking images of "wasted organs" (S38/+2)

but rather visuals and stories presenting positive views and appreciation for organ donors.

Examples of emotionally stimulating messages have been implemented globally and in the

UK (NHS, 2019c, Nicholas, 2017).

The campaigns message for this group should focus on emotionally attractive ideas to

encourage people to overcome their fear and decide to become an organ donor, especially

promoting organ donation as a selfless and noble act that will help save or improve people's

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[29] They ranked 13 - I believe there is a great need for organs especially in minority groups on +1, 36 - I believe the present need for transplant organs is fully covered on -2 and 6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups on -3. Regarding the registration process, transplantation results and eligibility criteria, they ranked statement 4 - I think the process of registration is complicated on -2, statement 32 - I think transplant recipients do not live more than 10 years after a transplant operation on -1 and statement 30 - I think people who have medical conditions cannot donate on -1 as a distinguishing statement and 9- I think I am too old to donate on -2.

lives. Messages that involve positive religious views and religious leaders advocating for organ donation might be effective too. Campaigns promoting sharing a person's decision with family might be helpful as well, especially if the family holds positive views, as that would help ease the tension when it comes to considering donating.

This group shows anxiety as the main barrier to donation. Consistently, they show a great emotional reaction throughout the array. For this group, Terror Management Theory may be the most effective theory to be used in behavioural interventions. This theory has been previously used by researchers to reduce anxiety and increase donation rate (Wang, 2020). Interventions to address the hesitancy and anxiety in this groups should promote organ donation as a selfless noble act that will help save or improve people's lives.

Table 21 List of distinguishing statements for Factor 2

| 10 - I believe I will be haunted if I donate. |
| 12 - I do not know anyone who donated an organ. |
| 15 - I feel I cannot decide to donate because I do not know all the facts. |
| 17 - If someone religious says it is not allowed, then I will not do it. |
| 19 - I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs. |
| 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself. |
| 23 - I thought about registering as a donor but I never did. |
| 24 - I do not want doctors or the healthcare system to be in control of my organs. |
| 25 - When someone asks me to register to donate, it feels like he is waiting for my death to get my organs. |
| 30 - I think people who have medical conditions cannot donate. |
| 33 - People on the waiting lists are ill and I believe they need my help. |
| 34 - I believe donated organs can be bought and sold. |
| 38 - I do not mind donating some organs, but not my heart or eye. |
| 39 - I believe organs are a gift from God, we are not allowed to give them away. |
| 41 - I do not think I have the courage to donate. |
| 42 - I think it is just easier to say no than to think about it. |
| 43 - I think my religion encourages organ donation in order to save other people's lives. |
| 44 - I do not mind donating when I am alive, not when I am dead. |

Table 22 Crib sheet for Factor 2. The crib sheets first list statements on columns +5 and -5. Then by going through each statement, score for each factor is compared, to elicit the statements that have been scored lowest or highest.

F2		
-5	24 - I do not want doctors or the healthcare system to be in control of my organs.	
	25 - When someone asks me to register to donate, it feels like he is waiting for my death to get my organs.	
Lower	2 - I think rich or famous people can receive organs before the people with the most need.	
	4 - I think the process of registration is complicated.	
	7 - I think giving out organs to save someone's life is a noble act.	
	12 - I do not know anyone who donated an organ.	
	13 - I believe there is a great need for organs especially in minority groups.	
	19 - I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs.	
	21 - I believe the human body is not a machine.	
	22 - I think brain dead people can regain consciousness.	
	29 - I think people exaggerate on the importance of the whole organ donation subject.	
	30 - I think people who have medical conditions cannot donate.	
	31 - I feel I have no responsibility towards anyone else.	
	32 - I think transplant recipients do not live more than 10 years after a transplant operation.	
	34 - I believe donated organs can be bought and sold.	
	37 - I believe people would not need transplants if they took better care of their health.	
	40 - No matter how hard it is to think about organ donations, it makes me feel good about myself.	
	47 - I think I am not dead if my heart is still beating.	
Higher	3 - I do not think I have ever thought about it.	
	9 - I think I am too old to donate.	
	10 - I believe I will be haunted if I donate.	
	14 - Brain death is confusing to me, but I think experts know better.	
	17 - If someone religious says it is not allowed, then I will not do it.	
	18 - I feel talking about death and after life is important to appreciate our lives.	
	20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself.	

	26 - I trust the donation system to be fair.
	28 - I trust doctors and nurses to always provide the best care they can.
	36 - I believe the present need for transplant organs is fully covered.
	38 - I do not mind donating some organs, but not my heart or eye.
	39 - I believe organs are a gift from God, we are not allowed to give them away.
	41 - I do not think I have the courage to donate.
	43 - I think my religion encourages organ donation in order to save other people's lives.
	44 - I do not mind donating when I am alive, not when I am dead.
	45 - I want to be cremated and if I donated organs, I cannot do that.
5	16 - I believe transplantation results are successful and they are improving people's health.
	23 - I thought about registering as a donor but I never did.

5.2.3.2.2 F2-B Convinced Pessimist

I see the glass half empty; I do not trust people and systems. I will not be an organ

donor and I set my mind on that.

This groups represent the people who loaded negatively in Factor 2 (Table 23 shows the sorts weights for F2). People in this groups show a great mistrust in the healthcare system[30], healthcare providers as well as allocation system [31]

Figure 28 shows the array for people loaded negatively on Factor 2). This mistrust acts as the main barrier to organ donation. As participant 6291 explains "If you participate in organ

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[30] Statement 16 - I believe transplantation results are successful and they are improving people's health is on -5 rank, 26 - I trust the donation system to be fair and 28 - I trust doctors and nurses to always provide the best care they can on -4.

[31] Statements 24 - I don't want doctors or the healthcare system to be in control of my organs and 25 - When someone asks me to register to donate, it feels like he is waiting for my death to get my organs both on +5 and distinguishing statements for this factor, 19 - I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs on +4 and distinguishing factor as well and 8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register on +3.

donation, you might have good intentions, but you are helping a great business become bigger and you are participating in murders of thousands of people".

People loading on this factor show a mundane connection with religion[32] with a view on their body that tends to be non-mechanistic[33]. However, they do not perceive religion as a major barrier to donation[34]. They exhibit a deterministic and negative view on organ donation[35]. Several statements show how consistent this group of people are in expressing their determination that donating organs is not an option for them. They indicate that fear does not play a role on forming their views[36]. Positive views from their family and friends will not budge that view[37]. As mentioned above, information on brain death is not the main concern for this factor. Statements related to knowledge and information on the organ donation process and brain death lie in the middle region of the grid, indicating these statements are irrelevant to the decision to donate[38].

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[32] Statement 43 - I think my religion encourages organ donation in order to save other people's lives on -2 and 17 - If someone religious says it is not allowed, then I will not do it on -1, both are distinguishing statements.

[33] Statement 38 - I do not mind donating some organs, but not my heart or eye on -2 and distinguishing statement and 21 - I believe the human body is not a machine on +2.

[34] Statement 17 - If someone religious says it is not allowed, then I will not do it is on -1 and a distinguishing statement, statement 11 - I think it is non-religious to take organs and 1 - I believe my religion does not allow it on +1, and 39 - I believe organs are a gift from God, we are not allowed to give them away a distinguishing statement on 0.

[35] Statement 23 - I thought about registering as a donor but I never did is on -5 and a distinguishing statement for this factor, 41 - I don't think I have the courage to donate and 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself, and 15 - I feel I cannot decide to donate because I don't know all the facts, all on -3 and are distinguishing statements as well, and 40 - No matter how hard it is to think about organ donations, it makes me feel good about myself on -2 as well as 42 - I think it is just easier to say no than to think about it on -1 and a distinguishing statement.

[36] Statement 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself a distinguishing statement and Statement 41 - I do not think I have the courage to donate both statements are on +3.

[37] Statement 35 - I might feel easy to donate because my family encourages me to donate on +1.

[38] Statement 44 - I do not mind donating when I am alive, not when I am dead a distinguishing statement, 47 - I think I am not dead if my heart is still beating and 22 - I think brain dead people can regain consciousness, the lowest among factors, all on 0. They ranked 13 - I believe there is a great need for organs

Figure 28 Factor 2 arrays - negatively loaded sorts

-5	-4	-3	-2	-1	0	1	2	3	4	5
16	7	15	14	3	10	1	2	6	19	24
23	26	18	33	5	22	11	4	8	31	25
	28	20	38	13	27	21	9	29	37	
		41	40	17	39	30	12	34		
			43	35	44	32	36			
				42	46	45				
					47					

People loaded negatively on this factor demonstrate a mistrust in the healthcare system and healthcare providers. They show an ordinary view of the body. They also show brain death knowledge is not relevant to them and religion may or may not hold negative to organ donation but that does not seem to be the main drive for their attitude. The mistrust in the healthcare system plays a major role for people loaded negatively on this factor. They seem confident with this view and with no great interest in information or family views, it seems challenging to change that view.

The hallmark of this factor is the determination. This group of people seems to be determined about their decision regarding organ donation. As participant 6291 iterates, "I do not want to change my view. I do not think there is anything specific you would say to change my mind. This opinion has been accumulated over years; you cannot change it that easily". Their mind is set potentially from death anxiety, poor knowledge or they might be affected directly or indirectly by organ donation scandals in different countries. It is hard to put a finger on a single issue, as participant 6291 explains, "I cannot put it in order, and it is not something that suddenly happened; organ donation has a negative thing about it. I think it is just over the years you hear stories here and there". Behavioural interventions for this

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especially in minority groups on -1, 36 - I believe the present need for transplant organs is fully covered on +2 and 6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups on +3. Regarding the registration process, transplantation results and eligibility criteria, they ranked statement 4 - I think the process of registration is complicated on +2, statement 32 - I think transplant recipients do not live more than 10 years after a transplant operation on +1 and statement 30 - I think people who have medical conditions can't donate on +1 as a distinguishing statement and 9- I think I am too old to donate on +2.

group of people seem futile. Further examinations of their views might uncover individual reasons for those views. Either way, behavioural changes on this group require individualised and long-term campaigns to alter the negative views which might exhaust the limited resources for such interventions.

As a group, they correlate reasonably high with each other (Table 23 shows that loading of participants on Factor 2 and Table 24 shows the correlations among participants' loading of Factor 2). That applies for the positively and negatively loading sorts. This indicates that participants loading on each pole (negative and positive) of Factor 1 have a homogenous view on organ donation. Moreover, Factor 2 is closer to Factor 3 than to Factor 1 (Table 25 shows the descending array of differences between Factor 2 and the other two factors).

Table 23 Sorts weights and demographic criteria for Factor 2

Q Sort	Weight	Gender	Age	Education	Socio-Economic Class	Ethnicity	Religion	Years in UK	Are you a registered donor?	Do you have any intentions of registering as a donor?	Do you believe that you or someone else might need an organ?
4567	5.18	F	46	Low	Low	White American	Christian	12	No	May be	Yes
4616	3.98	M	29	Mid	Mid	White European	Atheist	2	No	no	Yes
5897	5.97	F	22	Low	Low	White European	N/A	5	No	no	Yes
6263	5.73	F	52	Low	Mid	White Australian	Christian	25	No	yes	Yes
6291	7.9	F	56	Mid	Mid	Chinese	Taoism	7	No	no	Yes
4586	-8.66	F	26	Mid	Mid	Chinese Malaysian	Christian	7	No	no	No
6216	-10.3	M	40	Mid	Mid	Latino	Christian	3	No	May be	Yes
4648	-13.74	M	25	Mid	Mid	White European	Christian	10	No	no	Yes

Table 24 Factor 2 sorts correlations

Q Sort	I6263	I5897	I6216	I4567	I4616	I4586	I6291	I4648
I6263	100	59	60	64	47	-52	-49	-63
I5897	59	100	61	53	30	-47	-50	-50
I6216	60	61	100	51	29	-36	-39	-45

I4567	64	53	51	100	37	-46	-45	-47
I4616	47	30	29	37	100	-48	-44	-34
I4586	-52	-47	-36	-46	-48	100	94	54
I6291	-49	-50	-39	-45	-44	94	100	56
I4648	-63	-50	-45	-47	-34	54	56	100

Table 25 Descending array of differences between factors (Factor 2). The table demonstrates how different factors are in relation to how statements are placed. The first column shows the statement number, then its Z score on Factor 2. "The z-score is a weighted average of the values that the Q-sorts most closely related to the factor give to a statement" (Zabala and Pascual, 2016). This score then is compared to the other two factors. To do so, first, we list the Z score for that statement on Factor 1 and Factor 3. Extract the difference then square it. The sum of the squared differences in the last row shows that Factor 2 is closer to Factor 3 than it is to Factor 1.

#	Factor 2	Descending Array of Differences Between Factor 1 and Factor 2			Descending Array of Differences Between Factor 2 and Factor 3		
		Factor 1	Difference	Differences ^2	Factor 3	Difference	Differences ^2
1	-0.52	1.61	-0.39	0.15	-0.14	-0.39	0.15
2	-0.73	1.04	0.13	0.02	0.73	-1.46	2.14
3	0.34	1.83	-1.12	1.26	0.33	0.01	0.00
4	-0.74	1.42	0.83	0.68	-0.67	-0.07	0.00
5	0.35	0.17	-0.46	0.21	0.86	-0.52	0.27
6	-1.00	0.26	0.05	0.00	-0.75	-0.25	0.06
7	1.36	1.30	0.33	0.11	2.07	-0.71	0.51
8	-1.26	-0.68	1.52	2.30	-1.38	0.13	0.02
9	-0.89	0.43	-0.58	0.34	-1.02	0.13	0.02
10	-0.30	2.11	-0.92	0.84	-0.88	0.58	0.34
11	-0.37	0.09	-1.34	1.80	-0.10	-0.28	0.08
12	-0.70	-0.58	2.53	6.42	1.52	-2.23	4.96
13	0.58	-0.25	0.38	0.14	1.06	-0.48	0.23
14	0.89	-0.63	-0.68	0.47	0.62	0.27	0.07
15	1.24	1.21	0.87	0.75	-0.33	1.57	2.47
16	1.88	0.31	-0.48	0.23	2.00	-0.13	0.02
17	0.30	0.96	-1.31	1.72	-1.68	1.98	3.92
18	1.10	1.69	-1.21	1.47	1.41	-0.31	0.09
19	-1.55	0.31	1.72	2.95	-0.89	-0.66	0.44
20	1.28	-0.44	-1.04	1.09	0.56	0.72	0.52
21	-0.64	0.91	0.20	0.04	0.00	-0.64	0.41
22	-0.32	-0.60	0.63	0.40	0.40	-0.72	0.52
23	1.75	-0.95	-0.93	0.87	0.29	1.46	2.14

24	-1.61	-0.10	2.66	7.05	-0.11	-1.51	2.27
25	-1.76	-1.17	1.08	1.17	-0.57	-1.19	1.42
26	1.64	-0.91	-2.03	4.14	1.35	0.29	0.09
27	0.09	-0.11	-0.18	0.03	-0.21	0.30	0.09
28	1.51	1.39	-0.94	0.87	1.69	-0.18	0.03
29	-1.00	-1.47	0.75	0.57	-0.59	-0.41	0.17
30	-0.33	0.21	1.75	3.06	0.36	-0.69	0.47
31	-1.36	0.36	0.78	0.61	-1.05	-0.31	0.10
32	-0.50	-1.22	0.94	0.87	0.00	-0.50	0.25
33	1.06	-1.55	-0.70	0.49	1.72	-0.67	0.44
34	-1.29	0.82	0.66	0.43	0.09	-1.37	1.88
35	0.42	0.58	-1.18	1.39	0.78	-0.35	0.12
36	-0.83	-0.87	-0.34	0.12	-1.02	0.20	0.04
37	-1.45	0.20	3.06	9.37	-1.16	-0.29	0.08
38	0.61	0.24	-1.12	1.25	-0.13	0.73	0.54
39	-0.03	-0.51	-1.66	2.76	-1.84	1.81	3.28
40	0.77	-0.78	0.14	0.02	1.06	-0.29	0.08
41	1.22	-0.75	-1.03	1.05	-0.67	1.89	3.56
42	0.56	-0.11	0.65	0.42	-1.28	1.85	3.41
43	0.78	-1.01	-1.74	3.04	-0.46	1.24	1.55
44	0.10	-1.71	-0.97	0.94	-1.07	1.18	1.38
45	-0.63	-1.69	-0.93	0.86	-0.60	-0.03	0.00
46	0.07	-0.96	0.24	0.06	-0.67	0.74	0.55
47	-0.11	-0.40	1.41	2.00	0.35	-0.46	0.21
		Sum of Squared Differences		66.79	Sum of Squared Differences		41.41

5.2.3.3 Factor 3: The Empathetic

Organ donation is a selfless act. We must stand against any obstacles to help people

in need because we are fighting for a noble reason.

Factor 3 has an eigenvalue of 6.55 and explains 16% of variance in the study. Fifteen

people loaded significantly on this factor (Table 28 shows the participants loaded on this

factor). Seven out of fifteen are women and eight are men, average age is 37 and they come

from different cultures and religions. Four of them are registered as organ donors and only

one of them loaded negatively on this factor (Table 28 shows weights of sorts and also

demographic criteria for Factor 3).

Figure 29 Factor 3 arrays

-5	-4	-3	-2	-1	0	1	2	3	4	5
17	8	9	6	4	1	3	2	13	12	7
39	37	31	19	15	11	22	5	18	28	16
	42	36	10	25	21	23	14	26	33	
		44	46	29	24	30	20	40		
			41	43	27	34	35			
				45	32	47				
					38					

People on this factor view organ donation as a noble act[39], they are expressing a

certain degree of fear, which they are motivated to overcome in order to help those who are

ill and in need of those organs[40]. The pattern combining perception of organ donation as a

noble act with the effort to conquer fear suggests that empathy is a driving influence for this

group. Similar to F2 – A, Statement 16 is ranked at +5; however, given the placements of

Statement 33, which is on +4 position, a distinguishing statement and highest rank among

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[39] Statement 7 - I think giving out organs to save someone's life is a noble act on +5.

[40] Statement 33 - People on the waiting lists are ill and I believe they need my help on +4, a distinguishing statement for this factor and ranked the highest among factors, 40 - No matter how hard it is to think about organ donations, it makes me feel good about myself on +3 and the highest among all factors, and 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself on +2. Statement 46 - Talking about death is creepy on -2 a distinguishing statement and lowest among all factors and 42 - I think it is just easier to say no than to think about it on -4 as a distinguishing statement and the lowest among all factors as well.

factors, the Q-methodology holistic approach suggests that Statements 7, 33 and 42 are more closely related and more influential in shaping this group's view on organ donation. They show trust in healthcare providers[41], while recognising possible corruption in the allocation system[42]. They are motivated by their responsibility towards others without assigning any blame towards those who fall ill [43].

People loaded on this factor share a more mechanical view and they do not perceive religion to be a barrier to organ donation[44]. Both statements on -5 are related to body integrity and religion; this pattern reinforces the argument above that these two areas are perceived to be interrelated. People on this group believe their religion does not support organ donation (S43/-1 and a distinguishing statement), which suggests that using a linear view of attitude, religion would be a barrier to organ donation. Given the network view of attitude and barriers, the Q-methodology pattern shows that in this group the religious view on organ donation is not salient (S1/0 and S17, S39/-5).

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[41] Statement 28 - I trust doctors and nurses to always provide the best care they can on +4, 8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register on -4 and higher among all factors, 14 - Brain death is confusing to me, but I think experts know better on +2 and highest among all factors.

[42] Statement 2 - I think rich or famous people can receive organs before the people with the most need on +2, 34 - I believe donated organs can be bought and sold on +1 and 19 - I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs on -2 – all are distinguishing statements for this factor.

[43] Statement 31 - I feel I have no responsibility towards anyone else on -3 and the lowest among all factors and statement 37 - I believe people would not need transplants if they took better care of their health on -4.

[44] Statement 39 - I believe organs are a gift from God, we are not allowed to give them away and 17 - If someone religious says it is not allowed, then I will not do it which is distinguishing statement for this factor, both on -5, 11 - I think it is non-religious to take organs, 43 - I think my religion encourages organ donation in order to save other people's lives on -1 and a distinguishing statement and 1 - I believe my religion does not allow it on 0.

The awareness level in this group is high[45] with a considerable knowledge about organ donation registration criteria[46]. This awareness is mixed with a certain level of misinformation especially in information related to brain death[47]. However, they show some comfort with their knowledge level, and they do not perceive it as a barrier against becoming a donor[48].

As a group, the Q sorts loading on this factor correlate with each other, and they load reasonably high on their factor (Table 28 shows the loading of participants on Factor 3 and Table 29 shows the correlations among participants loading on Factor 3). This indicates that participants loading on Factor 3 have a homogenous view on organ donation. Moreover, Factor 3 is closer to Factor 1 than to Factor 2 (Table 20 and Table 25 show the descending array of differences between Factor 1 and Factor 2, respectively).

The hallmark of this factor is the need for a cue for action suggesting that interventions based on Immediacy Theory may be most effective for this group. For this factor, behavioural campaigns should focus on providing information about the allocation system and the laws that prevent unethical management of organs. This also includes highlighting whether there are financial rewards for the donors, and the nationality and race of the donors if possible. Complete transparency in the organ donation data on both ends;

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[45] Statement 13 - I believe there is a great need for organs especially in minority groups on +3, 6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups on -2 and 36 - I believe the present need for transplant organs is fully covered on -3.

[46] Statement 5 - I think anyone can register and be a donor even if old or have a disease on +2 a distinguishing statement for this group, 9- I think I am too old to donate on -3; registration process, 4 - I think the process of registration is complicated on -1 and transplantation results, 16 - I believe transplantation results are successful and they are improving people's health on +5.

[47] Statement 30 - I think people who have medical conditions cannot donate and 47 - I think I am not dead if my heart is still beating both on +1 and are distinguishing statements, and 22 - I think brain dead people can regain consciousness on +1.

[48] Statement 15 - I feel I cannot decide to donate because I do not know all the facts on -1 as a distinguishing statement.

donation and transplantation are essential for this factor (S2/+2 and S34/+1). Other medical

information regarding brain death definition is important too (S14/+2, S47/+1 and S30/+1).

The campaigns message for this group should maintain that the organ donation is a

selfless act (S7/+5) offering the gift of life (NHS, 2020c) and improving the lives of people in

need, picturing donors as heroes and asserting organ donation as the ultimate charitable act

especially at certain holidays like Christmas and Eid (NHS, 2019b). The pattern of barriers

for this factor also suggests that in addition to Immediacy Theory, Self-Affirmation Theory

can be effective by emphasising their roles as givers and their values such as selflessness to

be effective for this group. Campaigns, however, should avoid religiously motivated

messages and avoid awareness about the need for the organs as well (S13/+3 and S36/-3).

There is one participant who loaded negatively on this factor, which means that this

factor is bipolar. The mirror image shows a lack of empathy towards potential recipients[49],

with an opposition to organ donation due to religious reasons[50], and a mistrust in the

healthcare system[51]. Literature suggests that opposition to organ donation commonly

associated with death diagnosis, body integrity concerns and corruption in healthcare system.

There are several non-academic resources with extreme opposition to donation, however, it is

highly unlikely for that opposition to be attributed to complete disregard to the need of organs

to save and improves lives. As a concept, organ donation has been perceived positively, and it

is distinguished from attitude towards induvial organ donation behaviour (Morgan et al.,

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[49] Statement 7 - I think giving out organs to save someone's life is a noble act on -5, 33 - People on the waiting lists are ill and I believe they need my help on -4, a distinguishing statement for this factor, 40 - No matter how hard it is to think about organ donations, it makes me feel good about myself on -3, and 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself on -2.

[50] Statements 39 - I believe organs are a gift from God, we are not allowed to give them away and 17 - If someone religious says it is not allowed, then I will not do it on +5.

[51] Statement 8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register on +4, 16 - I believe transplantation results are successful and they are improving people's health on -5, 28 - I trust doctors and nurses to always provide the best care they can on -4, and 26 - I trust the donation system to be fair on -3.

2008b). The mirror image of this factor may represent a view on organ donation, but it is unlikely to represent a large proportion of population. For this reason and for empirical contribution concerns, this mirror image will not be represented in Study two.

Table 26 List of distinguishing statements for Factor 3

2 - I think rich or famous people can receive organs before the people with the most need.
15 - I feel I cannot decide to donate because I do not know all the facts.
17 - If someone religious says it is not allowed, then I will not do it.
19 - I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs.
24 - I do not want doctors or the healthcare system to be in control of my organs.
30 - I think people who have medical conditions cannot donate.
33 - People on the waiting lists are ill and I believe they need my help.
34 - I believe donated organs can be bought and sold.
41 - I do not think I have the courage to donate.
42 - I think it is just easier to say no than to think about it.
46 - Talking about death is creepy.

Table 27 Crib Sheet for Factor 3. The crib sheets first list statements on columns +5 and -5. Then by going through each statement, the score for each factor is compared, to elicit the statements that have been scored lowest or highest.

F3		
-5	17 - If someone religious says it is not allowed, then I will not do it.	
	39 - I believe organs are a gift from God, we are not allowed to give them away.	
Lower	7 - I think giving out organs to save someone's life is a noble act.	
	8 - I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register.	
	15 - I feel I cannot decide to donate because I do not know all the facts.	
	23 - I thought about registering as a donor but I never did.	
	37 - I believe people would not need transplants if they took better care of their health.	
	40 - No matter how hard it is to think about organ donations, it makes me feel good about myself.	

	41 - I do not think I have the courage to donate.
	42 - I think it is just easier to say no than to think about it.
	44 - I do not mind donating when I am alive, not when I am dead.
	46 - Talking about death is creepy.
Higher	1 - I believe my religion does not allow it.
	2 - I think rich or famous people can receive organs before the people with the most need.
	3 - I do not think I have ever thought about it.
	5 - I think anyone can register and be a donor even if old or have a disease.
	6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups.
	11 - I think it is non-religious to take organs.
	13 - I believe there is a great need for organs especially in minority groups.
	14 - Brain death is confusing to me, but I think experts know better.
	18 - I feel talking about death and after life is important to appreciate our lives.
	21 - I believe the human body is not a machine.
	22 - I think brain dead people can regain consciousness.
	25 - When someone asks me to register to donate, it feels like he is waiting for my death to get my organs.
	28 - I trust doctors and nurses to always provide the best care they can.
	33 - People on the waiting lists are ill and I believe they need my help.
	34 - I believe donated organs can be bought and sold.
	35 - I might feel easy to donate because my family encourages me to donate.
	40 - No matter how hard it is to think about organ donations, it makes me feel good about myself.
	45 - I want to be cremated and if I donated organs, I cannot do that.
5	7 - I think giving out organs to save someone's life is a noble act.
	16 - I believe transplantation results are successful and they are improving people's health.

Table 28 Sorts weights and demographic criteria for F3

Q Sort	Weight	Gender	Age	Education	Socio-Economic Class	Ethnicity	Religion	Years in UK	Are you a registered donor?	Do you have any intentions of registering as a	Do you believe that you or someone else might need an organ?
4526	6.22237	F	27	Mid	Mid	Middle East	Muslim	3	No	Yes	Yes
4527	4.40045	F	26	Mid	Mid	Middle East	Christian	1	No	Yes	Yes
4565	5.42259	F	34	Low	Low	African	Atheist	4	No	yes	No
4583	5.14718	M	38	Mid	Mid	Indian	Hindu	13	No	May be	Yes
4606	3.60653	M	46	low	High	Indian British	Sikh	46	No	no	Yes
4607	3.75967	F	56	Mid	Mid	White British	COE	56	No	Maybe	Yes
4633	4.4477	M	30	Mid	Low	Indian	Hindu	2	No	Maybe	Yes
4658	5.42812	F	37	Mid	Mid	White British	Christian	37	Yes	-	Yes
4725	6.1434	M	35	Mid	Mid	White European	Agnostic	11	Yes	-	Yes
4726	6.56115	M	25	Mid	Mid	White European	Atheist	7	No	Maybe	Yes
5839	4.25909	M	27	Mid	High	Middle East British	Muslim	12	No	no	No
5850	3.9082	F	53	Low	Mid	White British	CoE	53	Yes	-	Yes
6271	44.2508	F	24	Mid	Low	White European	Atheist	5	No	Maybe	Yes
6277	5.04195	M	47	Mid	Mid	Indian British	Buddhist	47	Yes	-	Yes
4570	-4.14432	M	47	Low	Mid	Middle East British	Atheist	20	No	Maybe	Yes

Table 29 Factor 3 sorts correlations

Q Sort	I6271	I4726	I4526	I4725	I4658	I4565	I4583	I6277	I4633	I4527	I5839	I5850	I4607	I4606	I4570
I6271	100	69	77	68	61	65	52	47	55	63	49	44	53	49	-56
I4726	69	100	60	26	32	57	31	34	48	32	48	41	41	36	-33
I4526	77	60	100	46	45	35	19	33	52	48	37	36	42	20	-48
I4725	68	26	46	100	39	28	42	35	48	51	20	28	40	25	-50
I4658	61	32	45	39	100	38	38	42	31	24	44	26	45	34	-48
I4565	65	57	35	28	38	100	28	29	26	38	51	28	30	50	-15
I4583	52	31	19	42	38	28	100	28	24	46	41	21	39	33	-25
I6277	47	34	33	35	42	29	28	100	42	20	39	30	25	35	-48
I4633	55	48	52	48	31	26	24	42	100	15	38	24	37	16	-33
I4527	63	32	48	51	24	38	46	20	15	100	26	11	38	22	-23
I5839	49	48	37	20	44	51	41	39	38	26	100	16	33	17	-16
I5850	44	41	36	28	26	28	21	30	24	11	16	100	22	45	-28
I4607	53	41	42	40	45	30	39	25	37	38	33	22	100	14	-21
I4606	49	36	20	25	34	50	33	35	16	22	17	45	14	100	-13
I4570	-56	-33	-48	-50	-48	-15	-25	-48	-33	-23	-16	-28	-21	-13	100

5.2.3.4 Consensus statements

Consensus statements are statements with similar Z[52] score across factors. They represent statements that do not differentiate between any pair of factors. In this study, there were six statements that were consensus among all three factors (Table 30 shows a list of consensus statements).

Three statements that are related to the need for donated organs are part of the consensus statements. This indicates that the need for organ donations is perceived equally by all factors. The rank of those statements indicates an awareness of such needs; thus, we recommend avoiding campaign designs that address the need for organ donation. Statement 9- I think I am too old to donate is another consensus statement. It implies that age as a criterion for organ donation is perceived similarly by all factors.

Statement 27 - I do not mind organ donation but my family disagree is a consensus statement on rank 0. This was an unexpected result, not only because family approval was perceived similarity among factors, but all factors perceived this statement to be a non-concerning issue. That goes against the assumptions of the Theory of Reasoned Action and Health Belief Model where subjective norm (a function of normative beliefs) is affected by perceptions of specific salient others' preferences about behaviour (Ryan and Carr, 2010). This result echoes what was discussed above in 3.4.2.1.2 The Theory of Reasoned Action / The Theory of Planned Behaviour that TRA is not suitable in interventions (Hardeman et al., 2002), certainly not in the case of organ donation.

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[52] The z-score is the weighted average of statements in a factor. It facilities comparison of statements' location between factors. Calculated by $z_1 = \frac{T - \bar{x}_l}{s_T}$ (BROWN, S. R. 1980. *Political subjectivity: Applications of Q methodology in political science*, Yale University Press.

Table 30 Consensus statements The table shows the Z score for all factors. It is clear from the table that Z scores for these consensus statements do not vary across factors.

Statement	F1		F2		F3	
	Rank	Z Score	Rank	Z Score	Rank	Z Score
6 - I think there is no special need for organs for Asian, African, and Middle Eastern groups	-3	-0.947	-3	-0.995	-2	-0.746
9- I think I am too old to donate	-4	-1.47	-2	-0.89	-3	-1.02
13 - I believe there is a great need for organs especially in minority groups	2	0.955	1	0.58	3	1.06
27 - I do not mind organ donation but my family disagree	0	-0.095	0	0.087	0	-0.211
36 - I believe the present need for transplant organs is fully covered	-3	-1.171	-2	-0.827	-3	-1.022
40 - No matter how hard it is to think about organ donations, it makes me feel good about myself	2	0.911	2	0.773	3	1.064

5.2.3.5 Interviews

The aim of the post-Q interview is to uncover the reasoning behind participants' ranking choices. It allows for the understanding of factor arrays based on participants' perceptions by exploring the values that led to the formation of the participant's view around organ donation. Calling participants to clarify their ranking choices especially at both ends of the grid (+5, +4 and -5, -4) is an important insight to understanding the underlying views and attitudes. It is critical to say that post-Q sort interviews do not aim at exploring participants' attitudes on organ donation, but rather to explore the underlying beliefs and values that may influence the formation of such attitudes and may explain the connections between organ donation barriers and motivators.

The interviews support factor array interpretation from participants' perception and provide a rich context for a new theory to be developed. It is important to highlight that interviews are not used to understand the views of the participants but rather the values and

experiences that underlines those views (Gallagher and Porock, 2010). Interviews are recommended to be conducted with open-ended questions (Wong et al., 2004). This allows for a wide space for the participants to diverge from the question to communicate their views freely.

Interviews in this research were done with participants who have completed Q sorts. All interviews were done separately from Q sorting, and the participants' Q sorts were presented to facilitate conversation. Participants are invited to comment on their ranking choices especially the ones at both ends of the grid, as well as questions about ranking of some statements that might indicate a conflicting or a confusing opinion allowing for further interpretation and clarification. The interviews were conducted after the Q sorts analysis was completed and interviews analyses were complementary to factor interpretations.

5.2.3.5.1 The Interview Process

Post-Q sort interviews should be based on open-ended questions to allow participants to express their rationale and to invite comments to diverge from a fixed restricting structure. In this research, interviews were conducted separately from Q sorting for two reasons. The first reason is to complete the analysis of Q sorts before conducting the interviews and the second one is because Q sorting was conducted online, while interviews were conducted later in person.

The Q grid was used to probe the conversation. Before the interview, the participant's Q sort was printed and handed to the participant at the beginning of the interview. Participants were allowed a few minutes to go over their Q sort before starting with the interview questions. Participants were invited to discuss the rationale behind their placement, especially for statements on the extreme ends of the grid on +5 and -5. I explored the ethical dilemmas that faced participants when choosing their placements for competing cards. For example, some participants indicated that they would like to put more cards on -5 ranking,

but they were limited to two places available on rank -5. One participant further explained

how she questioned which two statements to put on that rank. Some statements were

discussed collectively since they share a common theme, such as family approval or trust in

the healthcare system, etc. These discussions supported the factor interpretation process and

quotes from interviews were used to highlight interpretation.

5.2.4   Q-methodology validity and reliability

The assessment of validity includes three steps: measurement validity, internal and

external validity. Measurement validity is the degree to which the tool measures what it

intends to measure. Internal validity is concerned if the results within a sample can be trusted.

While external validity is concerned with generalising the results from sample to population.

Q-methodology does not claim external generalisability; thus, a survey (discussed in Study

two - Survey) can be conducted to generalise the Q-methodology results.

Q-methodology intends to measure participants' subjective view. In Q-methodology,

"each individual's set of rank ordered statements is deemed a valid expression of his or her

opinion." (Akhtar-Danesh et al., 2008). The Q-methodology grid extends from "*mostly* to

mostly" (McKeown and Thomas, 2013) allowing the view to be expressed at reasonable

range with available placement at the extremes to express strong views. Conceptualising

attitude as a network, the Q-methodology grid allows participants to express patterns of

attitudes to organ donation. The operant subjectivity (Stainton Rogers and Stainton Rogers,

2001) is central to communicate views on organ donation at individual level. Moreover, the

network view examined through operant subjectivity allowed distinctive patterns to emerge,

opening the door to innovative ways to conceptualise and change attitude and/or behaviour.

Several factors were excluded from further interpretation at the factor extraction stage.

Three factors were excluded out of six. All three factors had at least one participant loading

negatively resulting in a total of six view. Informed by organ donation literature, it is

unexpected to have more than three or four views. It would also be difficult for policymakers to translate a large number of views into campaigns' design. The patterns of views presented in Study one might not represent all possible views. Moreover, the variety of views in Study one may not be automatically generalised to population given the intentional sampling technique with certain criteria such as ethnicity, religion, age and gender are taken into consideration.

Using Q-methodology with a network view suggests that the salience of a barrier (or the size of the node) is perceived different. The node interaction with other nodes is also perceived differently. However, measurement validity of Q-methodology has been challenged due to the limited placement available for participants (in this study, two places are available at the extremes and then three places for ±4, etc). It is claimed that the limited placement available for participants violate measurement validity (Kampen and Tamás, 2014). However, Q methodologist claims that forced quasi-distribution on the Q-methodology grid forces participants to reveal their true preferences by comparing and then prioritising certain statements over others (McKeown and Thomas, 2013).

5.3   Study two results

5.3.1   Introduction

Study one resulted in four views (three factors). The results are presented as factor arrays and factor interpretations. These results were used in a survey to establish the prevalence of these views in the UK. Study two results address Research Question 3. Study two was designed to support the empirical and methodological contribution of this research. By examining the prevalence of the views, national health services will have an insight to direct the limited budget they may allocate to organ donation campaigns towards addressing

the most prevalent view. Designing the post-Q survey (sometimes referred to as Q2S technique) involved several judgment calls.

Study two contributes empirically by directing policymakers towards prevalent views on organ donation. Methodologically, conducting a post-Q survey has not been common. The technique remains largely underdeveloped. Throughout Study two, clear steps were identified and described that can be applied in another research study as well.

5.3.2   Sample

A total of 458 surveys were collected. However, only 380 completed the survey. Sample criteria are summarised in Table 10. The sample is representative of the UK population; thus, the results are generalisable.

Completion time was averaged at 75 minutes and ranging between 3 and 279 minutes. Figure 30 shows that the majority of participants (86 participants) completed the survey between 5 and 10 minutes. Only five people completed the survey in less than two minutes and those participants are from the pilot study because the time limit was introduced later where participants must spend at least 180 seconds on rating and ranking questions of the survey.

Figure 23 shows the survey stages and design. The survey consists of several stages; vignettes rating, vignettes ranking, followed by attitude questions. Survey design intend to maintain holistic view was adopted by Q-methodology. In the survey, it is expected to find overlapping patterns and conflicted results, which is a complex view brought about by the network approach to attitude and barriers.

Figure 30 Frequency of time category to complete the survey. The figure shows that most people took 5-10 minutes to complete the survey. Only five people took less than two minutes

to complete it. Their results were included in the analysis but after the pilot study, a minimum time was set to avoid such results.
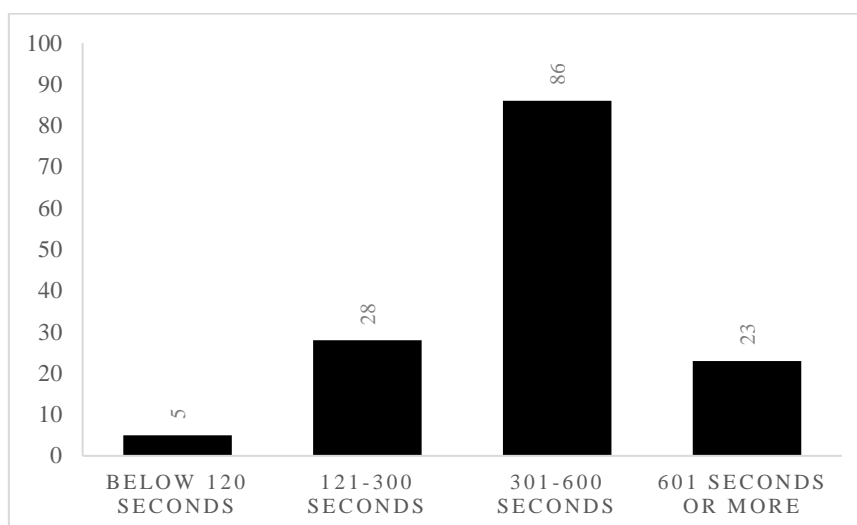
5.3.3 *Results of vignette rating*

5.3.3.1 Rating result

Table 31 shows the average rating and ranking per factor. Factor 3–The Empathetic has the highest average rating, followed by Factor 1-The Realist then Factor 2A–The Optimist Hesitant, with Factor 2B- The Convinced Pessimist at the lowest average rating. This indicates that most participants find Factor 3–The Empathetic the closest to their view. Further details on rating results are available in Appendix 9. Appendix 10 provides details on the demographic criteria for those who rated each factor at 5. The table in the appendix shows that there is no relationship between demographic criteria and rating a factor at 5.

Table 31 Average rating and ranking of factors

Factor	Average Rating	Average Ranking
Factor 1 - The Realist	3.35	2.97
Factor 2A – The Optimist Hesitant	2.37	2.17
Factor 2B- The Convinced Pessimist	2.17	1.82
Factor 3 – The Empathetic	3.84	3.06

5.3.3.2   Response time

The average time to complete the rating questions was 190 seconds (3 minutes and 10 seconds). Figure 31 shows the frequency of each total sum (the frequency by which participants used the 15 credits allocated for the rating question). At the pilot study, I did not use points allocation, which is why 10 participants have used more than 15 points for rating. Figure 31 shows that most people used more than seven credits; this shows that participants feel that the vignettes are close to their views. Using all 15 credits is the most common choice for credit use. This can either indicate that the 15 points credit is a reasonable cut off point, or it may indicate that vignettes overlap, and participants were conflicted, and they may have used more than 15 credits if they were allowed.
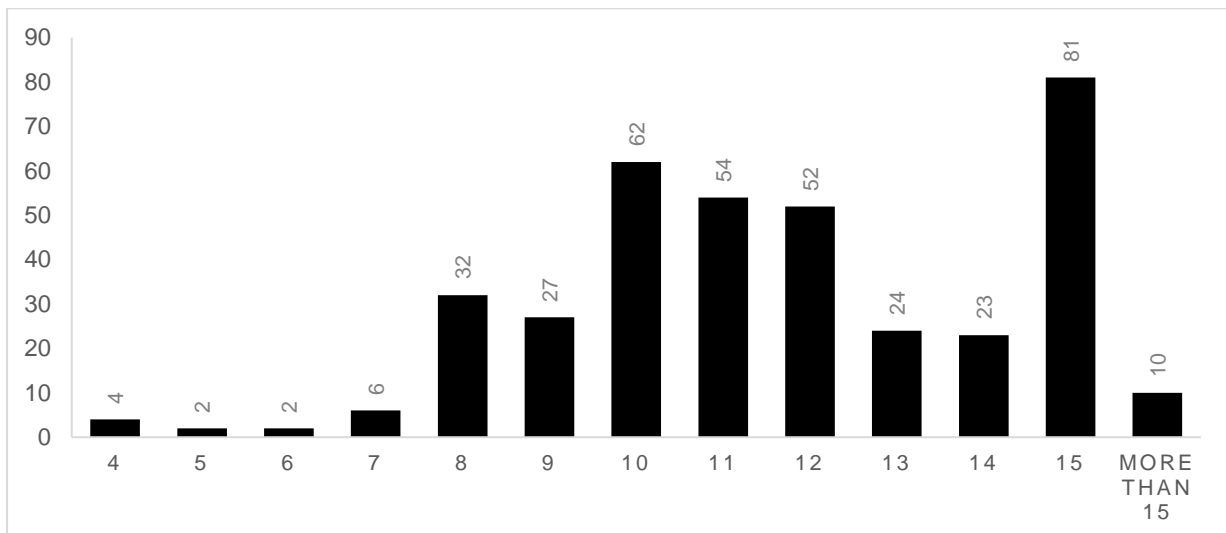
Figure 31 Frequency of total sum of rating. The figure shows that the majority of participants used 9-15 credits to rate the views. If a large number of participants used only a few credits, it indicates that the Q study missed a view, and it is not represented here. Only 10 participants used more than 15 credits. After the pilot study, a limit of 15 credits was put in place where participants can use 15 or less credits to rate all four views combined.

5.3.3.3   Conflicting rating

When I did the pilot study and the soft launch for the survey with Qualtrics, I received results with many contradictory scorings. This may include rating more than one factor at the same level, or even rating all of them at 5 in some cases. I also found contradictions between

the rating and the ranking questions. For example, a participant may rate one factor at 5, then rank it as the third closest factor to their view. I wanted to exclude that data from the survey for being invalid. I assumed that the only reason a person may give these answers is because participants did not carefully read all the vignettes and/or did not have enough time to reflect. However, I decided not to exclude any data because that may realistically reflect the poorly formed views in a population. Instead, a minimum submission time for each question was set, to encourage participants to read the vignettes and reflect on how much each vignette represented their own view. Going through the results, I realised these answers are not uncommon, and instead of excluding those results to create a "clean" survey result, I can analyse them and conclude that contradiction in answers reflect their own views on organ donation. I repeatedly indicated that organ donation is not a commonly discussed subject, and people may be confused. I argue here that their confusion is mirrored in these "contradictory" results.

Many participants rated more than one factor at 5. Table 32 shows the number of participants who rated one or more factors at 5. The table shows that most participants rated only one of the factors at 5 (301 participants rated one factor at 1; this represents 79.4% of all participants who rated one or more factors at 5). It also shows that 73 participants (19.3% of all participants who rated one factor or more at 5) have rated two factors at 5. It also shows that four participants rated all four factors at 5. While the 73 participants may feel two factors are close and overlapping and may be attributed to confusion and poorly formed views, I would argue that rating all factors at 5 is attributed to invalid answers. Having said that, I did not exclude those results since participants will have to use 60 seconds to rank those vignettes at the next stage and that will break the tie between factors with similar ratings. In fact, 78% of all participants gave similar rating (from 1-5) to two or more factors.

Table 32 The frequency of rating more factors at 5.This table shows that the majority of participants rated one of the factors at 5. This shows that views in the survey are distinct, since most participants indicated that only one of them is rated 5. 73 participants rated two views at 5 which supports the earlier claim that views on organ donation are complex and overlapping.

Number of Factor rated at 5	Number of factors at rating of 5	%
Rating one of the factors at 5	301	79.4%
Rating two factors at 5	73	19.3%
Rating three factors at 5	1	0.3%
Rating four factors at 5	4	1.1%

In order to further investigate vignettes that are rated similarly, Table 33 shows that 54 participants rated both Factor 1-The Realist and Factor 3-The Empathetic at 5. This is the highest overlap between any two factors. It shows that the two vignettes have more in common than any other set. The table also shows that the lowest overlap was between Factor 2A-The Optimist Hesitant and Factor 2B- The Convinced Pessimist, indicating that participants viewed those vignettes to be more contradictory/distinctive, as compared to others. This reflects the mirror effect of these factors being two contradictory views extracted from one factor.

Table 33 The frequency of participants rating any combination of factors at 5. This table shows that people who rated more than one view at 5 commonly rate Factor 1 and Factor 3. This reflects earlier results that these two views are closer to each other, and they are both popular views in the UK.

	Factor 1-The Realist	Factor 2A- The Optimist Hesitant	Factor 2B- The Convinced Pessimist	Factor 3-The Empathetic
Factor 1-The Realist	-	-	-	-
Factor 2A- The Optimist Hesitant	11	-	-	-
Factor 2B- The Convinced Pessimist	10	6	-	-
Factor 3-The Empathetic	54	11	-	-

5.3.4   Results of vignette ranking

In the rating question, participants were able to give similar rating to two or more factors. However, in this ranking question, that is not possible. The average time to complete the rating questions was 96 seconds (1 minutes and 36 seconds). Table 31 shows the average ranking per factor. Factor 3–The Empathetic has the highest average ranking followed by Factor 1-The Realist then Factor 2A–The Optimist Hesitant, with Factor 2B- The Convinced Pessimist at the lowest average rating. This a similar presentation to the rating question. This indicates that most participants find Factor 3–The Empathetic the closest to their view. Further details on ranking results are presented in Appendix 11 and the table in Appendix 12 shows there is no correlation between demographic criteria and factor ranking.

5.3.5   Attitude and social criteria

Study two shows that almost half of participants are registered organ donation. For those who are not registered, only 6.1% are against organ donation as shown in Table 34. To further explore attitude to organ donation across different factors, Appendix 13 shows attitude to organ donation per factor. It shows that most registered donors ranked either Factor 1 - The Realist or Factor 3 – The Empathetic as 1. On the other hand, it shows that none of those who are against organ donation ranked Factor 3 – The Empathetic as 1.

Table 34 The attitude for participants who are not registered as organ donors. These values indicate that most non-donors are not against organ donation, they are either in favour of organ donation or undecided. This suggests there is smaller leap towards registering and becoming a donor. This also supports the earlier results where Factors 1 and 3 were popular views while Factor 2B (holding negative views on organ donation) was the least common view.

Attitude	%
Against	6.1%
In favour	50.0%
Undecided	43.9%

The table in Appendix 14 shows that there is no relationship between knowing a donor in person and ranking any of the factors as 1, neither is discussion of organ donation with family and friends as shown in Appendix 15. The survey shows that 24% of participants know an organ donor and 60% have discussed it with their family and/or friends. This study also shows that discussing organ donation with family or friends results in a clearer attitude towards organ donation, either a registered donor or an unfavourable attitude. Those who have not discussed it with family or friends have favourable or unclear attitude towards organ donation. This supports previous research indicating that family discussion helps form mature opinions on organ donation as shown in Figure 32. Finally, Appendix 16 and Appendix 17 show there is no relationship between factor ranking and spouse attitude and doing volunteer work, respectively.

Figure 32 The relationship between attitude and family discussion. The figure shows that people who have discussed organ donation with their families are inclined to have a well-formed attitude to organ donation whether in favour or against. While those who have not discussed organ donation tend to be undecided and have less clear attitude to organ donation.
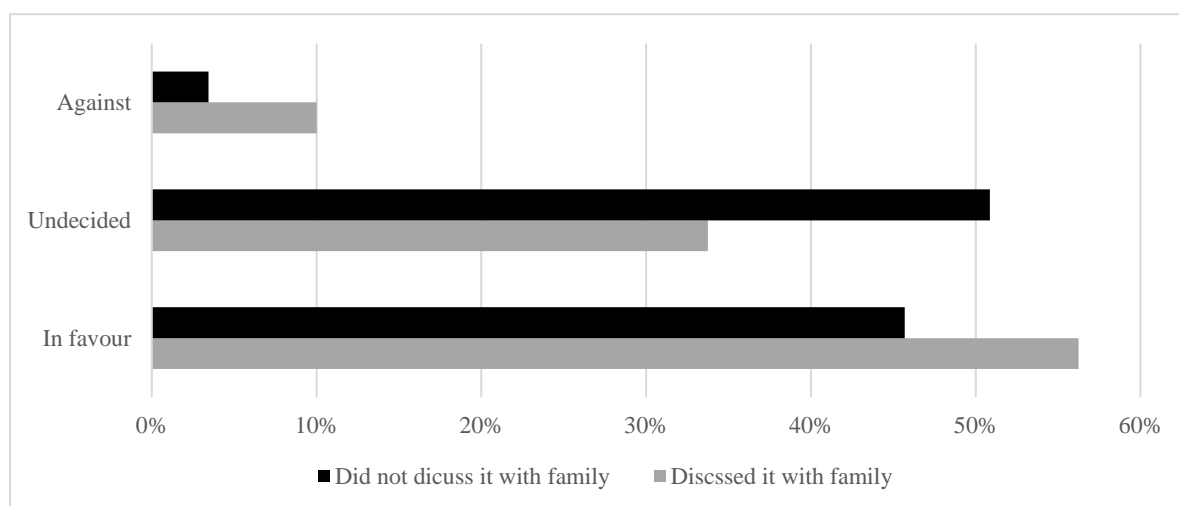
5.3.6   Survey validity

Face validity is defined as "the degree to which test respondents view the content of a test and its items as relevant to the context in which the test is being administered." (Holden, 2010). In the pilot study, feedback was asked from all participants. They were asked if they

feel vignettes are distinctive, meaningful, and valid to them. Participants confirmed vignettes are meaningful and valid. However, others did not comment on that. Participants indicated that the survey vignette forced them to examine their own view on organ donation and explore which vignette is closer to their attitude. One participant commented that he rated the vignette first and then he ranked them; he then realised that he rated one vignette the highest then he ranked it the second. He indicated that this situation forced him to reconsider which vignette is closer to what he thinks. Having done that, he was more aware of his own attitude towards organ donation, having considered different views.

Content validity, on the other hand, "refers to the extent to which the items on a test are fairly representative of the entire domain the test seeks to measure" (Salkind, 2010). The survey vignettes were an amalgamation of salient and distinguishing statements for the factor as per the result of Study one.

5.4   Chapter four summary

This chapter presented the results of Study one and Study two. In Study one, Q-methodology with interviews were used to identify patterns within a network of barriers and motivates. Six views were found. Two views were excluded, resulting in four view: The Realist, the Optimist Hesitant, the Convinced Pessimist and the Empathetic. Each view represents a distinctive pattern of barriers that form a unique view on deceased organ donation. The view holds a combination of positive and negative perceptions on the subject. The main barrier to organ donation was discussed for each view and potentially effective theories to address it.

Study one results shows that barriers to organ donation may be perceived differently by different groups, which reinforces the significance of examining attitude from the individual's subjective perspective. The study also shows that while many may share similar

negative views on organ donation, such as lack of knowledge or mistrust in the healthcare system; the main barrier that needs to be primarily addressed by behavioural interventions differs from one view to another. The most influential barrier to behaviour is determined on account of a holistic network view of barriers. Study one suggests that interventions targeting the Realist view should focus on providing information on organ donation, while interventions targeting the Optimist Hesitant should focus on overcoming anxiety by focusing on emotional story-telling material and cue for action for the Empathetic group.

In Study two, a post-Q survey was developed from the Q-methodology study by an amalgamation of salient and distinguishing statements to produce vignettes that reflect the theoretical assumptions of Study one. Study two results are beneficial in allocating the limited resources to address the most prevalent view. It was found that Factor 3 – the Empathetic is the most prevalent views in the UK. Furthermore, Study two showed there are no specific correlations between demographic and social criteria examined in relation to any view. The next chapter will discuss the results presented here and their implications.

6   Chapter six – Discussion

6.1   Chapter introduction

The aim of this research was to explore the public views on deceased organ donation to increase donation rate in the UK. Chapter five – Results outlined the analysis and interpretation of two studies conducted as part of this research. This chapter will discuss the main findings of this research. I will also discuss the theoretical, empirical, and methodological contributions. I will then discuss the limitations of this research and recommendations for future research. As a part of methodological contributions, I will also discuss my learnings as a researcher and things I would do differently for other researchers to consider.

This research examined views on organ donation for people residing in the UK. In Chapter three – Literature review, I argued that organ donation attitude is not linear and that we are losing valuable information without a network view of attitude connected to behavioural barriers, which may exist alongside motivators. Next, I will explore that argument with study findings.

6.2   Research Questions

6.2.1   *Subjective structures on organ donation in the UK*

To answer the first research question, Q-methodology was used to identify different subjective views on organ donation. Q-methodology study revealed three factors. All three factors were bipolar, however, the mirror image for the first and the third factor were unlikely to be prevalent in the UK, hence, they were excluded. The mirror image was included in the analysis because more than one person loaded negatively on that factor and it can be a reflection of declining trust in the NHS reported in the UK. The result was four views: the

Realist, the Pessimist Hesitant, the Convinced Pessimist and the Empathetic. Each factor is constructed by the same pool of behavioural barriers but with distinctively different pattern formation. All four views are formed of both barriers and motivators. The patterns of these barriers and motivators give rise to distinctively different views. These results reaffirm the network view of barriers and the distinctive patterns that emerge from subjective perception of barriers. It also suggests that behavioural interventions will not be equally effective. Empirically, strategies to increase donation rates must reflect the diversity in subjective perception of barriers to donation. The four views' solutions allowed for useful areas of differentiation to emerge among patterns. The use of Q-methodology has delivered more distinction among views found than would have been achievable if the data had exclusively been collected with surveys, or interview methods. The differentiation of views was enhanced by a minimum loading of Q sort of ±0.44.

Overall, three out of the four views have positive views towards organ donation. They had at least one motivator ranked between +1 to +5. Factor 2B- The Convinced Pessimist view did not have any motivator ranked between +1 to +5. The general positive view on organ donation found in the Q-methodology study was supported by the survey results in Study two exploring public views on organ donation on the UK, showing that the majority of the public are in favour of organ donation. This, in turn, is in agreement with the NHS public surveys in the UK showing that the majority of people hold positive views on organ donation (Cox, 2015, NHSBT, 2019b, NHS, 2017).

The Q-methodology study shows that most of the distinguishing statements represent behavioural barriers, and only a few of the distinguishing statements are motivators[53]. This

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[53] Factor 1: Statement 28 - I trust doctors and nurses to always provide the best care they can on +2 and 33 - People on the waiting lists are ill and I believe they need my help on +1 both are motivators and distinguishing statements for Factor 1.

suggests that people may generally agree on why organ donation is important and valuable for those who need it, but their views are differentiated by barriers to donation. This is a new insight offered by the network view of attitude and barriers that was not previously presented in the organ donation literature. It suggests that organ donation campaigns should target certain sets of barriers to organ donation rather than enhancing motivators.

Q-methodology shows that perceived lack of knowledge, anxiety, and lack of cue to action are the most prominent barriers to organ donation as perceived by Factor 1, Factor 2A, and Factor 3, respectively. Researchers can select various theories to design interventions that address specific views and their prominent concerns. Three theories suggested in the previous chapter that were previously used in organ donation interventions, Self-Efficacy Theory, Terror Management Theory, and Immediacy Theory, previously used in organ donation, are among many models that can be used to design interventions.

Statements used in Q-methodology are expected to be representative of opinions on a subject, a reflection of subjectively perceived views. Statements should not include factual information. However, as discussed in the literature review chapter, it was clear that myths about brain death and other related medical facts were persistent even when refuted by experts. In fact, people seem to reject the nature of certain bits of information as a factual information when it is in contrast to their existing beliefs, this is evident in the rejection of religions of accepting brain death as a diagnosis of death (as shown in Figure 4). This can be attributed to the need to reduce dissonance (Tavris and Aronson, 2007). For those reasons, I decided to include statements that include factual information in the Q-set, against the general

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Factor 2: Statement 43 - I think my religion encourages organ donation in order to save other people's lives and 33 - People on the waiting lists are ill and I believe they need my help on +2, and 20 - It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself on +3, all are motivators and distinguishing statements for Factor 2 – The Convinced Pessimist.

Factor 3: Statement 33 - People on the waiting lists are ill and I believe they need my help on +4, a motivator and a distinguishing statement for Factor 3.

consensus to avoid it. Results from Study one show that subjective perception of medical facts can indeed vary. However, this may limit its responses.

This study suggests that non-cognitive barriers are central to low donation rates. Three of the four views held positive views to organ donation, albeit different. The main barrier to donation is not related to factual knowledge, the healthcare system failings, or religious beliefs. Even for the first factor, the perception that the current information is not satisfactory to enable a decision is not entirely related to the objective level of knowledge held by this group. It is evident that the organ donation decision is a tug of war between motivators on the one hand and emotional hurdles on the other.

Q-methodology shows, however, that there is a great variation in views represented by relatively low correlations among Q sorts within each factor. Factor 2B is the exception to this where participants correlated highly with each other. That variation may be attributed to the complex nature of barriers' network configuration. Various unrelated variables may also affect individual subjective perception, such as personality, momentary emotions, and characteristics of the decision environment (Lerner et al., 2015). All extracted factors explain only 39% of variance. In a structured literature review, conducted with 52 studies on conservation biology, the average percentage of explained variance by all factors was around 58% (Zabala et al., 2018). The lower explained variance in this study may indicate variability in people's views on organ donation. However, sample size may affect the eigen values of the study and hence, the explained variance. The bigger the sample size, the more inflated eigen values can be (Herrington and Coogan, 2011). In the structured literature review study, sample size was averaged below 50 participants. Some studies had a big sample size at almost 200 participants.

6.2.1.1 Behavioural barriers

The most cited barrier to organ donation in the literature is religion. The literature review in Chapter two suggests that the relationship between religion and attitude to organ donation is complex and tied to various historical and cultural backgrounds. However, religion is commonly represented by a limited number of questions in quantitative research. For example, there is one question related to religion in Organ Donation Model which is "People who donate their organs risk displeasing God or nature" (Morgan et al., 2008a). Similarly, PCID-DTO-Ríos scale investigates religion with one statement only: "2. If you're against cadaveric organ donation, do you consider that it is for religious reasons?" (Martínez-Alarcón et al., 2018, Ríos et al., 2017, Ríos et al., 2018). This provides limited insight on the relationship between religion and attitude to organ donation. In Study one, this multifaceted relationship is investigated using multiple statements to examine the relationship between attitude to organ donation and various aspects related to religion. Study one also examines the relationship between the individual perception of religion's view on donation represented in statement 1 - I believe my religion does not allow it, and those offered by religious scholars represented in statement 17 - If someone religious says it is not allowed, then I will not do it. In F2A- The Optimist Hesitant, statement 1 is ranked as -1, and statement 17 is ranked on +1. This may suggest that following religious leaders may relieve their anxiety, even when they perceive their religion to be supportive of organ donation. This distinction can be important in certain groups such as Muslims, since studies suggest that they are keener on religious scholars compared to Christians (Randhawa, 1998, Hayward and Madill, 2003). However, Study one results cannot be generalised and Study two did not investigate this relationship, however, it would be interesting for future research to further investigate this relationship.

Study one investigates how religion may influence attitude from several perspectives, statement 11 - I think it is non-religious to take organs was intended for the increasing

number of individual beliefs and those who identify as deist; a person who hold spiritual beliefs about God in general with no specific religious context (Arnett and Jensen, 2002). Statement 43 - I think my religion encourages organ donation in order save other people's lives investigates the perception of religion's position on organ donation as a concept and this can be compared to the overall position on donation where opposition to donation may arise from accepting donation after brainstem death. Statement 39 - I believe organs are a gift from God, we are not allowed to give them away investigates the relationship between religion and body integrity concerns.

According to previous studies, religion is one of the main barriers to organ donation. In this study, religion seems to fall more into the negative side of the Q grid, indicating that religion's opposition to organ donation is not strongly perceived (people do not think their religion opposes organ donation), and some statements' placements show that even when people believe their religion opposes organ donation, they are still in favour of donation. This study suggests that religion's position on organ donation does not matter as highly as was suggested by previous research. This contradiction to previous studies arises from using Q-methodology for investigation of subjective views.

Q-methodology was conducted online, where unlike interviews, participants have virtually unlimited time to consider their response. They also can change their choices upon reflection before they submit their final answers. This flexibility and the ability to save the grid to return to it later enabled participants to reflect on their answers comfortably at their own pace. This may have contributed to the representation of religion's role in forming attitude towards organ donation in this study to be less central than that found in interviews.

Like religion, body integrity concerns fall mostly on the negative side of the grid. The statement that connected body integrity to religion (39 – I believe organs are a gift from God, we are not allowed to give them away) was ranked at -5 or at 0. There is no clear indication

that body integrity is a significant barrier to organ donation across all views. That is not to say that body integrity and sanctity are not important; however, it shows that body integrity concerns do not stem from the idea that the body is a "gift from God".

In this study, the awareness statements are concerned with organ donation shortages only. However, knowledge regarding the organ donation process and medical information is in different categories. The awareness fluctuated across factors. Three out of four views realise there is a need for organ donation, and the same views realise the special need for organs in minority ethnic groups. Factor 2B – the Convinced Pessimist is the only group that is not aware of the general shortages in organs and the greater need for organs in minority ethnic groups.

Knowledge statements include information on the donation system, eligibility to donate, registration process and transplantation success results. The ranking of this group of statement ranged from -5 to +5 with no clear pattern. This shows a variation in the knowledge level among factors. Surveys in organ donation literature examine the knowledge level frequently. However, there is no specific categorisation of organ donation knowledge, and studies often mix and match among many questions with no specific structure. For example, one study may focus on myths related to religion's position on organ donation, while others may focus on awareness, or eligibility criteria, but they are all labelled as knowledge on organ donation while disregarding the specific category by which people's knowledge level is examined. Such categories may include need, awareness, donation system, eligibility to donate, brain death, registration process, and transplantation success results. This suggests that future studies may benefit from establishing a systemic scale to examine knowledge related to organ donation, and that will facilitate comparison among various studies.

The healthcare statements consist of two parts; trust in healthcare professionals and brain death related statements. All factors agreed that the brain death concept is confusing,

and three out of four factors would rely on healthcare professionals to provide more information on brain death. This puts the burden on campaign-organisers to provide satisfactory information on brain death diagnosis and prognosis. To my knowledge, no campaign targeted brain death confusion as a standalone issue – myth busting campaigns usually simply reject certain myths related to brain death especially those depicted in the media. Another related and very important issue is the trust in healthcare professionals. Results show that even when people trust a doctor to explain what brain death is, that does not necessarily mean that trust will be extended to cover the full control of doctors on the donation process. This reveals a systematic and institutional mistrust in the healthcare system even in a country like the UK where healthcare is provided for free for everyone. It may also be an indication that people who have experienced health inequalities in other countries may extend that to the UK healthcare system as well.

The recipient played a role in shaping views on organ donation. While scholars emphasise the religion or ethnicity as an important criterion of the recipient, this study shows that people assign more importance to the accountability of organ recipients in their health situation. For example, statement 2 – I think rich or famous people can receive organs before the people with the most need, is ranked at -1 to +2, while statement 37 - I believe people would not need transplants if they took better care of their health is ranked either -4 or +4. This shows that participants, whether they agree or disagree with the statement, consider this as an important statement and prioritised it over others. It suggests that campaigns may focus on the fact that many causes of organ failures cannot be controlled by organ receivers.

Death anxiety as a barrier to organ donation was fluctuating, and there is no clear pattern. And finally, none of the motivators seems to have a powerful impact on any of the factors. This indicates that behavioural change campaigns should prioritise the removal of barriers to organ donation rather than motivating prospective donors.

6.2.1.2 Consensus statements

Consensus statements provide another insight into how people think about organ donation. Consensus statements as shown in Table 30 suggest that the general need for organs and the special need for minority groups are commonly agreed upon by all views. It is showed as a consensus statement acknowledging organ need. This result can be partially attributed to the national campaign that accompanied the changes in the organ donation law from opt-in to opt-out system. This result is in line with previous research showing that the publicity and campaigns associated with the change in the law might increase awareness about organ donation especially at the implementation phase (Young et al., 2017, Niven and Chalmers, 2018).

Family disagreement with organ donation was a consensus statement ranked at 0, which indicated that all factors agree that family approval is not considered during the decision to donate. It shows that, when considering all factors such as religion, anxiety and information, family approval falls behind. That does not necessarily mean that family and friends have no influence on their decisions, but it is a clear indication of the family approval position in the decision makers' priority list.

Consensus statements show that if an individual is willing to donate, family agreement to that decision is not extremely important. All factors (including Factor 2B- the Convinced Pessimist) agreed that family views on the organ donation decision would not be considered as part of the decision. That is not to say that social norms or family views on organ donation would not affect someone's decision. The statement used in Q study reads "27 - I do not mind organ donation but my family disagree" and it was ranked on 0. This suggests people who are in favour of organ donation would not seek family views to shape their views.

Studies show that almost half of organ donation gets blocked by families in the UK. It also shows that if a person is registered, most families are less inclined to block the donation (BBC, 2018). It is worth mentioning that even with the current opt-out system in the UK, people can still register their decision to be an organ donor, registration may act as a strong indication of donors' preferences towards organ donation and this, in turn, may convince their families to approve donation. There are several interventions aiming at increasing family approval level, when clearly, intervening at the individual level may produce better results, as supported by this and previous research.

6.2.1.3   Q-methodology for organ donation

Q-methodology offered many new insights to the barriers and motivators that influence organ donation decision. It is unrivalled in its emphasis on the study of subjectivity. The patterns it revealed advanced the conceptualisation of attitude to organ donation and presented a new and novel explanation for the intention-behaviour gap. It surpasses a network theory of attitude by epistemologically integrating subjectivity in attitude examination. This study supports existing literature to show that the decision to donate one's organs is not based on full or perfect information, and it does not follow fully cognitive or analytical processes. On the contrary, and in agreement with previous literature, this study shows a great variation not only in subjective views on organ donation but even in the perception of information. For example, statement 47 – I think I am not dead if my heart is still beating was placed at rank 0, 1 or 3. Medically speaking, a person can be dead with a beating heart, but this statement was not ranked at a negative place by all four views. This shows the extent of perception on decision-making process.

Q-methodology also offered a way for participants to reflect on their views and offered a safe place for them to express their views. No researcher was around them when Q grids were filled, and they had unlimited time to complete the Q sort. Finally, Q-methodology

offered a way to explore patterns of barriers and motivators. Surveys examine each barrier independently and does not offer a way for people to strategize their answers and communicate their preferences. Examining the patterns and overlap offered a new insight into the behavioural change campaign with a plethora of specific and detailed recommendations for campaign design.

6.2.2   Subjective perceptions and behavioural interventions

To answer this research's second question, a Q2S technique was conducted in Study two. The aim of the survey was to ascertain the prevalence of different views in order to design more cost-effective national campaigns. If the organisation is targeting a national audience, it is more cost-effective to target the most prevalent view. On the other hand, I wanted to explore whether certain views are prevalent in ethnic minority groups where the demand is higher, and the supply is short.

The most prevalent view was Factor 3- the Empathetic. This is in agreement with previous research showing that the UK population in in favour of organ donation. This is followed by Factor 1 – The Realist, then Factor 2A – The Optimistic Hesitant and the least prevalent views is Factor 2B – The Convinced Pessimist. This is in agreement with previous research showing that people have generally positive views towards organ donation in the UK. Demographically, there was no significant distribution across any of the demographic criteria; hence, the prevalence of views is presented randomly across ethnicity criteria.

The study shows that the number of participants who are registered as organ donors is higher than the UK average (48% compared to 39%), and only 6% are against organ donation. This suggests a small bias in the study results. This can be attributed to the fact that people who have considered organ donation are more likely to complete the survey. Previous studies have also recorded positive attitude that is higher than average (Patel et al., 2017, Surendrakumar et al., 2017).

There are several studies suggesting that family attitude towards organ donation (in favour or against) influences the participant's attitude towards organ donation. In this study, I did not measure the family attitude towards organ donation to compare with the participant's attitude. Instead, I compared the general attitude towards organ donation to whether the participant has discussed it with friends or family. This was not the main outcome of the survey, but it does show that discussing organ donation allows for the decision to form and mature. Participants who have discussed organ donation with family and friends are more likely to be registered organ donors while those who have not. They may fluctuate between favourable and undecided views. This suggests that campaigns encouraging people to discuss the matter, may result in reducing the gap between attitude and behaviour that is found in organ donation.

Contrary to previous research, this study did not find a significant relationship between attitude towards organ donation and whether the participant is engaged in volunteer work. However, the research connecting altruism/volunteer work is either qualitative (Wakefield et al., 2010) or contradictory reporting non-significant or positive effect sizes (Hollestelle et al., 2008).

6.3   Mind the gap

People's intentions are not always translated into action. Theoretically, there has been a great debate to moderate that gap by variables that are context specific. In organ donation, non-cognitive barriers, knowledge, media, etc, are attempts to explain and moderate donation behaviour. Constantly, ontological definition of attitude and behavioural barriers in organ donation has been avoided and had been replaced with borrowed concepts from other disciplines, such as healthcare. This research aims at improving the outcome of interventions outcome empirically by reducing the intention-behaviour gap.

This gap can be attributed to theoretical and epistemological issues. Theoretically, behavioural barriers are viewed as a network rather than independent actors. This network forms distinctive patterns or configurations. The second theoretical issue addressed in this research is conceptualising attitude as the configuration of the network formed by such barriers. Unlike the Theory of Reasoned Action, attitude to organ donation is not an independent entity that is measured separately from behavioural barriers. It is network modelling how barriers to donation are subjectively perceived by individuals.

Epistemologically, surveys and linear attitude scales will not be appropriate to examine attitudes and barriers in organ donation, and so it is imperative to use methods that address the subjective perception to elicit attitude patterns from the network of barriers. These patterns of attitude can then be examined using the Q2S technique to generalise findings and contribute empirically to intervention efforts.

6.3.1 Subjectivity in organ donation

In this research, subjectivity emerges as a fundamental influence that is central to configuration of attitude and/or behaviour. Failing to recognise the influential part subjectivity play in organ donation attitude, translates to a divergence between attitude as communicated and related behaviour.

In this research, the perceptual process is thoroughly examined as a determinant lens of organ donation behaviour. Subjective perception driven by various internal and external factors that are beyond the scope of this research, is that unique and contextual process that an individual uses to organise and interpret the environment, a process playing in the background of the behavioural barriers that are conceptualised in common theoretical models. In so doing, this research provides many opportunities to critically examine on the implications of the way we conceptualise subjectivity, and in the way we conduct/ design

behaviour, strive for social/personal wellbeing, make meaning, construct identities, and relate to others and ourselves.

Organ donation behaviour is often argued to be the results of social impact on individual belief. However, while that might often be the case, there is a rising individualism especially in the Western societies (Santos et al., 2017), suggesting that individual perceptions may be less engaged in social perceptions.

6.3.2   Research methods in organ donation

Theoretically, barriers to behaviour are divided into cognitive and non-cognitive barriers (fear, anxiety, disgust, and mistrust). Cognitive barriers are commonly rationalised through social acceptance of donation. Such barriers are frequently studied using continually developing scales. It is natural to simplify the way we measure and understand behaviour when we use mathematical modelling. Quantitative research methods yield limited insights into the elusive nature of connections between an individual and his/her environment as perceived by that individual.

However, there is a general tendency in existing literature to approach organ donation behaviour in a simplistic and fragmented manner. Consistently, scales are developed and validated to measure these concepts with a sheer focus on objective measures while somewhat overlooking rich data in qualitative studies. Quantitative research in organ donation is trending at the expense of qualitive methods. This may be attributed to marginalisation of qualitative data for being unreliable in healthcare.

This simplification of a rather delicate nature of a behaviour poses issues in the effectiveness of such a mathematical approach in behaviour design when we strip away the role played by how people perceive the world around them based on their personality, history, social environment, etc. Organ donation literature leans towards decontextualising

organ donation behaviour from personal traits. It tends to intentionally disregard subjectivity for the sake of simpler mathematical models despite strong signals from qualitative on the extensive impact of individual contexts in shaping and controlling organ donation behaviour. The Q-methodology purpose is to uncover subjective structures of attitude from individual perspectives (Brown, 1996). It is unmatched in its respect to the integrity of responses of individuals by combining both qualitative and quantitative qualities.

6.3.3 Attitude in organ donation

Existing literature ascertains that behavioural barriers and motivators act jointly as an antecedent of behaviour. In this research, attitude to organ donation is viewed as a pattern by which barriers are configured based on subjective perception. To measure the subjectively formed attitude patterns, we must use appropriate methodologies to account for these patterns of subjectivity.

Conceptualising attitude to organ donation as a network has implications on explaining organ donation behaviour. Conceptualising behavioural barriers as a network helps explain why attitude is not always translated into action. The strength of connections between barriers and inter-influence across the attitude network can explain weak intentions. The network view also supports the assumption that barriers and motivators do not work in isolation, whereas investigating attitude as a system offers valuable theoretical and empirical contributions to the study of organ donation behaviour. Unfortunately, attitudes toward donation in many studies has been operationalised as respondents' attitudes toward the abstract notion of organ donation rather than their attitudes toward becoming an organ donor. Examining patterns of behavioural barriers in organ donation gives us clues on how subjective perception positions some barriers in a more salient configuration than others.

6.4   Contributions

This research theorises attitude to organ donation to be subjective, where a set of barriers can be perceived in significantly different ways, and thus forms networks of distinctive patterns of views. Chapters one, two and three set the context by highlighting limitations in organ donation literature: 1) lack of systematic investigation to how subjective perceptions play a role in organ donation decision, and 2) overreliance on a borrowed theoretical framework that views barriers to behaviour to act in a linear and independent manner, which has resulted in a significant and unexplained intention-behaviour gap. Interventions in organ donation suffer from poor design and reporting, in addition to small effect size.

To develop effective behavioural change campaigns, it is important to meaningfully explore the barriers against organ donation. With the severe and chronic shortage of donated organs, the slow and small increases in the number of donated organs, and the incompatibility issues with ethnic minority groups, it is vital to support the change in legislative intervention with meaningful and targeted campaigns.

The contributions section provides highlights on the significance of research findings reported in Chapter five and subsequent discussion earlier in Chapter six. It also discusses the potential implications of this research for practitioners, policymakers as well as the communities. This chapter ends with a discussion of the research limitations and highlights areas for future research.

6.4.1   Empirical implications

Defining barriers to behaviour is the first step towards behavioural change. Using Q-methodology allows us to capture a holistic view of complex relationships among barriers that can be trimmed down to a set of the most influential barriers. The outcome is not necessarily the summation of all its parts. Research on barriers to organ donation explores

why people refrain from behaviour, and results are derived from barriers communicated by people on the spot. Q-methodology offers time for views and opinions to form, then from the factor array, provides an overall pattern of behaviour to be distilled to a few strong barriers that can be addressed in interventions. This offers insights to policymakers and researchers alike to design more effective interventions.

6.4.1.1   Implications for policymakers

This research was developed with the intention for implications to policymakers as the primary contribution. In this research, policymakers refer to the people responsible for formulating national campaigns to improve donation rates, namely NHS Blood and Transplant.

Currently, the NHSBT website promotes awareness on organ donation and advertises four campaigns (NHSBT, 2021d):

1. Talk to your loved ones.

2. Cooking up a conversation.

3. Organ donation law in England.

4. Own your decision (for under 18 years old)

While these campaigns are valuable and important, they fail to address behavioural barriers altogether. In fact, browsing the NHSBT website suggests awareness of and interest in the subject have not been specifically addressed by NHSBT. On the website, there is information on donation eligibility criteria, death diagnosing, religious views and other information related to donation. There are no specific pages to address misinformation, mistrust in the healthcare system, death anxiety and other barriers to organ donation. Family discussion is the core message for NHSBT (Figure 33 shows the landing page of NHSTBT website for organ donation).
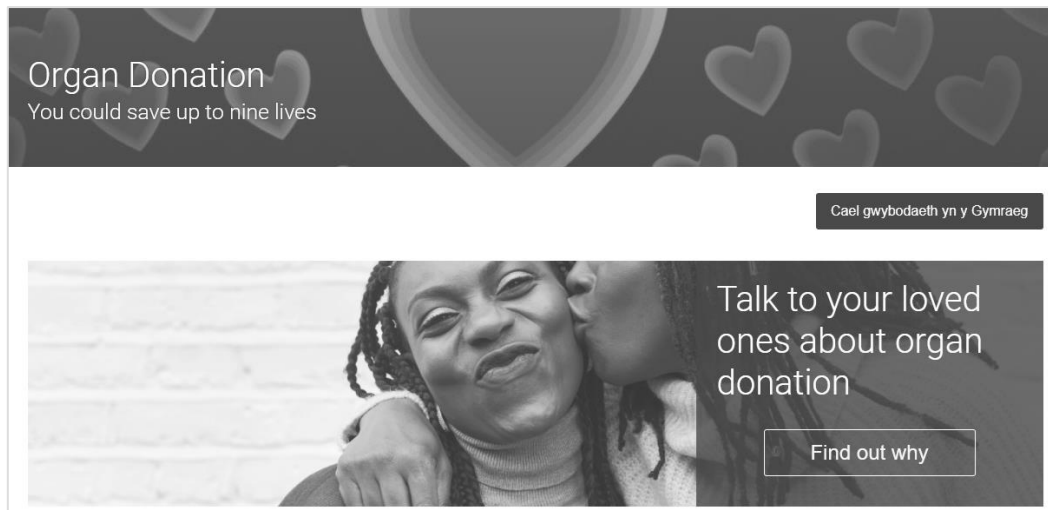
Figure 33 Landing page for NHSBT organ donation website Accessed 10/10/2021 from https://www.organdonation.nhs.uk/. It shows focus on communicating a decision to family and friends to donate organs. While this is an important step, it suggests a well-formed intention or even a decision that has already been made. It ignores most people who have not reached a decision regarding organ donation.

As a member of the public, I certainly urge NHSBT to consider expanding their campaigns to address organ donation shortages. Their business plan for 2021/2022 (NHSBT, 2021a) includes a campaign to engage Black donors and increase awareness.

Policymakers can benefit from this research output to design targeted interventions with a persistently low donation rate. Especially with COVID-19 and the extensive impact on donation and transplantation rate, it is now more important than ever to increase donation rates to meet the needs of people on the waiting list.

This research proposes distinctive intervention designed to address different views. Reflecting on patterns in behavioural barriers' perception, distinct intervention designs were recommended to address the main barrier for each view. A certain theory or intervention design that works effectively on one group may be less effective for another. For the Realist view, informative campaigns that are based on improving perceived level of knowledge using the Self-Efficacy Theory were recommended. For this view, the information campaign should mainly focus on raising awareness of the donation eligibility criteria, brain death diagnostic

criteria and the fact that the opt-out system in the UK does not mean that donation is obligatory. For the Optimist Hesitant, creating positive emotional real-life stories, exhibiting positive religious views and encouraging people to discuss it with their families to overcome that hesitancy using Terror Management Theory were recommended. While the Empathetic group may be targeted with cue-to-action campaigns and messages on the strict laws to prevent any unethical activities in organ donation, using Immediacy Theory.

The new insights brought by this research equip policymakers with yet another tool to best identify and target potential organ donors. This research offers an opportunity to show that hesitancy, anxiety, and *perceived* lack of knowledge are three main barriers to address. It also suggests that among these three, cue-to-action has the potential to produce better results and higher donation rates.

According to Study one findings, distinctive statements consist of behavioural barriers only. That indicates that people are not differentiated by what motivates them to become organ donors, but what prevent them from being one. Thus, the behavioural change campaigns suggested earlier are based on overcoming barriers. That does not necessarily mean that motivational campaigns are ineffective, but it is important to connect the motivational message to a potential barrier to create a stronger successful campaign such as the campaign messages recommended for the Optimist Hesitant, where real life stories can be designed to present positive messages about organ donation to alleviate hesitancy.

These specific message and theory recommendations were derived from the pattern of motivators and behavioural barriers represented in that view. It comes from a holistic analysis of the statements and not only on the statistical representations of the factor analysis conducted in Q-methodology. Previous campaigns conducted by the NHS target specific myths and religious groups and there is no clear analysis of its impact. Research papers adopt the Theory of Reasoned Action and other theories to analyse the impact. To my knowledge,

no other study provided a stratification of the campaign message to specifically target a group based on their attitude of belief. This study can have a unique and valuable impact on the effectiveness of a well-designed and well-implemented behavioural change campaign.

6.4.1.2 Implications for researchers

With the collection and analysis of data in this research, new insights into organ donation behaviour have emerged and ideas for further research to explore have surfaced. Future research can endeavour to map out the network of barriers and motivators by including all relevant nodes collected from existing literature. In Study one, only 47 statements were used. Further study can accumulate a larger number of barriers and use R methodologies to build attitude networks. In order to integrate subjectivity into network design, researchers may use innovative software packages where participants can virtually create networks that represent their views. Those networks can then be analysed using inverted factor analysis. This research can be conducted using the same statements used in this research. It would be beneficial to examine the differentiation of attitude network between non-donors and their families. This can uncover certain views that might be more susceptible to social influence. Moreover, a Q-Methodology study could be conducted using different Q-sort statements about family discussion. With the current focus on family discussions campaigns, statements could be designed to address elements of hesitancy in discussing the subject with family and friends. Using Q study statements, researchers could invite participants along with their family to complete Q sorts. Comparing the perspectives of the potential donors and their family members could assist in addressing specific concerns that are most meaningful to them.

Many other research ideas can help further understanding of organ donation behaviour, such as:

- Investigation of different views in certain ethnic minority groups. NHSBT focus on addressing organ donation shortages in BAME groups, Q-methodology study can help identify distinctive views within major BAME groups and provide insight to address them with campaigns.

- Time series study: Q-methodology is concerned with a snapshot of the subjective views at the time of the study. Views on organ donation may change over time, and thus Q-methodology studies over time series may be appropriate to investigate the change in views with the passing of time or before-and-after an intervention.

- To explore the divergence of networks when compared between donors' and non-donors' groups. This would provide valuable insight to the differences in perceptions of the two groups.

- To investigate how non-donors respond to interventions designed based on the recommendation in this research. Q-methodology study can be conducted before and after the intervention to understand how and why (or why not) the intervention influences organ donation behaviour.

- Future research can investigate criteria where a certain barrier is stronger. For example, the researcher can explore the relationship between the degree of intention maturation and family approval in organ donation.

- The researcher could attempt to construct and validate scales for knowledge and subjective perception in organ donation.

6.4.2 Theoretical contributions

The gap between the need for deceased organs and their supply is chronically unmet. Even with the opt-out system, organ donation rates continue to be low in the UK with the

added down curve brought by COVID-19. Organ donation literature is extensive. However, previous studies investigated the problem using borrowed theories with many attempts to improve their fit to organ donation. While this has been successful in producing the Organ Donation Model and IIFF with better fit, organ donation behaviour remains complex and intricate with many untapped questions. This research uses an in-depth mixed method analysis to investigate the determinants associated with the decision to donate.

The purpose of this research is to investigate ways to improve low organ donation rates in the UK. The literature review suggested that subjective perception of barriers plays a significant role in the communication of attitude to organ donation. While the Health Belief Model accounts for subjective perception of risk, this has not been fully explored. This research presents subjective perception as a lens or a filter by which barriers and motivators of organ donation are configured into complex patterns. This research presents attitude to organ donation as web or a grid where barriers and motivators lie. This view offers valuable theoretical and empirical outcomes. This research is the first to establish that subjective perception forms distinctively different views on organ donation in the UK and recommends further investigation to develop more appropriate methods to measure its effect on intention and/or behaviour.

Information collected from Study one allowed the opportunity to provide emerging barriers to organ donation. Perceived lack of knowledge, anxiety and hesitation emerged as main barriers to behaviour. This study contributes to organ donation literature by establishing that subjective perception is an important criterion in the decision-making process. Furthermore, Study two used the survey method to map the prevalence of each view that has contributed to the literature by establishing the most and the least dominant views in the UK. By demonstrating the effect of subjective perceptions attitude to organ donation, this research

provides a novel view on "polytextuality" (Stenner and Capdevila, 2020) of how attitude towards organ donation is formed.

6.4.3 *Methodological contribution*

Q-methodology is novel in organ donation literature. The process allows for greater involvement in a way that data cannot be manipulated by external sources. This method is particularly important in organ donation because of the heated controversy regarding after-death donation. This research evaluates approachable concepts, attitudes, and statements that may lead to better understanding of organ donor attitudes in the UK.

An innovative approach that is appropriate to the theoretical underpinning of this research is necessary to overcome the persistent gap between positive attitude and donation rates in the UK. Q-methodology offers a new way to examine patterns of attitude towards organ donation that is especially valuable for indeterminate, undecided participants. By limiting the sorting to a pre-determined normal distribution grid, they will have to provide different values for statements that may feel of equal value at the first moment.

Likert-type scales such as the organ donation attitude scale and the posthumous organ donation reasoned action scale (PODRAS) commonly used, offer statistically generalisable results, but their results may not be easy translated into campaign designs. Q-Methodology may be used as a precursor to the Likert-scale and may further our understanding of multidimensional, complicated, and highly individualised variables.

This research has also contributed methodologically to the development of the Q2S technique. It remains an under-used method in investigating views in larger samples. The method has been previously used but this research offers new and more detailed information that is easily duplicated. Study two used a combination of rating and ranking systems, which elicit the confused and overlapping nature of organ donation reflecting the Q-methodology approach.

6.5   Limitations and reflections for future research

In this section, I will discuss the study limitation for each study. I will also discuss what I have learned throughout the study to inform future studies in the context of organ donation.

6.5.1   Q-methodology limitations

6.5.1.1   Context

Because of the complexity of organ donation decisions, and quality of the data, the resulting factors depend on the degree of engagement by participants. Therefore, the study results (especially the Q-methodology factors which may be strongly affected by context, compared to survey results) are highly context specific.

6.5.1.2   The concourse / Q-set

The concourse may represent another limitation to the generalisability of the study. The study consists of 47 statements, significant effort was made to ensure those statements represent all subjective views. However, it may not completely represent all views. Post-Q questions and interviews were conducted to ensure that participants' voices are not lost and to highlight any significant views that may have been missed in the Q sorts. Participants were asked if there were any statements which they felt missing, and whether the statements allowed them to communicate their views. Most participants felt there were no statements missing. Furthermore, the post-Q survey shows that there are no missing views, as indicated by the high total sum of rating. If people rated all views low (this profile does not fit me), it would suggest there is a view that is not presented in the survey.

The choice of the statements in the study can affect the outcomes. Choosing more salient statements and fewer statements related to religion and healthcare may have provided further insights into the subjective views on organ donation. I conducted a focus group for the

Q study after the Q set was prepared, and only minor changes were needed for the Q study. However, conducting a focus group at the concourse stage might have been valuable in selecting the most salient statements; otherwise, a small survey might be valuable in identify the most salient statements. This may have had an impact on the total explained variable and could result in a higher value. Moreover, I could have examined possible resulting factors from the concourse I had and used that to guide the choice of the statements that can reveal deep views on organ donation.

I used many sources to collect the concourse; however, I tried to focus on statements that represent a barrier to organ donation and steered away from statements included in quantitative studies, since such studies assume that organ donation is a rational decision. However, reflecting on that, especially in the organ donation attitude scale, some statements might have been valuable to be added to the Q study. Effort was made to exclude any duplication in the Q-set; however, certain similarities remain between statements such as those regarding organ donation need and religious view on deceased organ donation.

Religion has often been cited as a major barrier to donation. Statements on body integrity and afterlife beliefs are also related to religious beliefs. In the UK, the number of people identified as non-religious is around 46% of population (ONS, 2018). This may cause a problem for the representativeness of the Q-set. However, only five out of 47 statements are concerned with religion. Studies show that even non-religious people may have a certain level of spiritual beliefs (Hyland et al., 2010) that can be predictive criteria of organ donation attitude (Bortz et al., 2015). For future research, statements on religious beliefs could be closer to spiritual connections and purpose of life to ensure that the Q-set is relevant to wider population.

6.5.1.3   P-set

The sample size in Q-methodology study is significantly smaller than a survey study. However, scholars who are unfamiliar with Q-methodology may argue that the sample size is small. Q-methodology results represent the "variety" of views in the sample; however, it is not concerned with generalising the results to the population. The smaller sample size allows for views to overlap for factors to emerge. The sample was recruited through snowballing, however, and that limits study generalisability.

Significant effort was put into recruiting participants with variation i strategically chosen criteria such as ethnicity, religion, and age. However, since snowballing sampling technique was used, representativeness of the sample is not guaranteed.

6.5.1.4   Factor interpretation

Several factors were excluded from further interpretation due to theoretical and empirical considerations. This means that views presented in this research does not represent all views on deceased organ donation in the UK.

Factor interpretations can be subjective to a certain extent. Although the grid is divided into agree-neutral-disagree areas, a participant may position a statement in a neutral area due to lack of available positions on the "agree side" and when other statements have been prioritised. This means, however, that for some participants, the distinction between the statements that reflect their own views and those that are irrelevant to them may vary.

For future research using Q-methodology in organ donation, I would recommend conducting the study in-person. Despite the convenience and time saving benefits of online platforms, in-person data collection may offer in-depth insights that may contribute to factor interpretation. I may be able to facilitate the study by immediately answering any questions or clarifying any issue. Additionally, conducting interviews immediately after the Q study to all participants may provide valuable information to aid interpretation.

6.5.2   Survey limitation

There are several limitations for the survey study. There is limited literature on Q-methodology studies in organ donation that may serve as vignettes for the survey. Post-Q surveys studies are also limited and there is little information on appropriate ways to conduct such surveys.

The limitations of Q-methodology study can be extended in post-Q survey such as the representativeness of views in Study one to all views on organ donation. limitations in sampling technique, Q-set, and interpretation from Study one can all be extended to Study two. Further down the process, there is an issue in interpreting the vignettes used in the study by the participant, which might differ among participants, and which poses issues of reliability.

The survey sample is aimed at representing the UK population; however, for future post-Q surveys, I would recommend collecting surveys for the BAME group as well as the general population.

Factor 1– the Realist and Factor 3- the Empathetic are closer to each other as indicated in Study one. There is an overlap between the two views where statements that are distinguishing for one factor are salient for the other. This means that similar statements are used in creating the vignettes for these views. However, the number of distinguishing statements for the first factor is more than other factors. As a result, the vignette for F1- the Realist is significantly longer (207 words for Factor 1 compared to 111 words for Factor 3). The similarities between the two views combined with the difference in lengths of the vignette may contributed to the fact that Factor 3 is the most common view due to its shorter vignette followed by Factor 1. This can be further suggested by the fact that people who rated more than one factor at 5 commonly gave these two factors similar rating. However, 79.4% of participants rated only one factor at 5, this suggests that the majority found views

distinctive and were able to distinguish between all four views. For future research, it is important to keep all vignettes at a similar length, this might come at the expense of excluding distinguishing and salient statements from the vignette. Exclusion of statements from vignette should be consistent across the entire survey and not exclusive to one view only. This might be difficult to achieve when the Q-methodology study produces factors with variable number of distinguishing statements, which is the case in this research.

6.6   Chapter six summary

This research examined views on organ donation in the UK. Q-methodology used in Study one explored the patterns of barriers and motivators to organ donation and brought new insights on how to address the low donation rate by targeting the most influencing perception. Study two used a survey method to examine the prevalence of views in the UK. This showed no specific correlation between views and the demographic and social criteria explored, investigating new ways to improve the organ donation rate. Conceptual, empirical, methodological, and practical limitations were discussed. This was then followed by study limitations and learnings.

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Appendices

Appendix 1 Ethical Committee Approval

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Social Sciences
Nottingham University Business School
University of Nottingham
Jubilee Campus
Nottingham
NG8 1BB

6 September 2019

To whom it may concern,

RE: **To donate or not to donate, Using Q-methodology to guide behavioural interventions on organ donation.**
Chief Investigator: Reem Mauid
Co-Investigators: Dr Thomas Chesney; Dr Robert Cluley
UoN Sponsor Reference: NUBS REC reference: Application No: 201819025
Ops Man & IS

I am writing as chair of the Nottingham University Business School Research Ethics Committee (NUBS REC) to confirm a favourable ethical opinion for the above research on the basis of the documentation submitted below. This opinion was given on 6 September 2019.

The School REC operates according to the University of Nottingham's *Code of Research Conduct and Research Ethics, and the Economic and Social Research Council (ESRC) Framework for Research Ethics.*

The documents reviewed and approved are:

Document Name:	Version No:	Date
Consent form – generic interviews	1.1	06.09.2019
Consent form – generic observation	1.0	06.09.2019
Email to chief operating officers	1.0	06.09.2019
Email to potential participants	1.0	06.09.2019
NUBS REC Ethics Review Checklist	1.0	06.09.2019
Participant Information Sheet - Generic	1.1	06.09.2019
Protocol	1.1	06.09.2019

The following conditions apply to this favourable opinion:
1. Management permission ("R&D approval") must be obtained from each host organisation prior to the start of the study at the site concerned.
2. The research must follow the protocol agreed and any changes will require prior NUBS REC approval.
3. The appropriate NUBS REC documentation must be completed at the end of the research project.

For further information about the School's Research Ethics Committee or approval process, please contact the Research Ethics Officer, Davide Pero at davide.pero@nottingham.ac.uk or +44 (0)115 84 67766.

Yours faithfully,

Dr Amanda Crompton
Chair of Nottingham University Business School Research Ethics Committee

Appendix 2 Concourse Themes

RELIGION		
I don't know / not sure	**I know for a fact**	**I feel**
• I think organ donation is against many religious beliefs • Someone (a friend or family) told me it is against my religion's beliefs • I think my religion does not allow it • I think my religion would not allow me to make such a decision • I think my religion is against organ donation because I am still alive when they take it, and they have to kill me • I do not know anything myself, but I would ask the scholars	• I know it's against my religion • I have never found my religion book (Quran, Bible) mention that it is allowed • I heard a religious leader saying it is against my religion • My religion is not against organ donation per se, but against disfiguring my body • According to my religion, this body is not mine • My religion is against it because I have to be buried with full organs • My religion is against it because no one should receive another person's organ • My religion is against it because it manipulates fate • My religion is against it because I might change the fate of the receiver • The deceased must not be harmed, and the body should be dealt with very gently • It is non-religious to take organs • Organs act as witnesses in afterlife	• Our bodies are like vessels, I don't want my body to mix with someone else's vessel • If I donate, I will be haunted

Positive:

- I think my religion allows organ donation
- I think my religion encourages organ donation in order to save other people's lives
- Donating organs is like an ongoing charitable act

BODY				
Whole Body	**Religion**	**Body Meaning and Value**	**Funeral**	**Fears**
• Organs should not be removed when someone dies • I think the body should remain whole after death	• The body should be kept whole for religious ceremonies that are important • Because the body, exactly as it is on earth, will be reunited with the spirit after • If an organ is removed from someone's body following death, the person will be devoid of that organ after life • Organs are a gift from God, we are not allowed to give them away • It is important for the body to remain whole between death and cremation • Spirit may be vengeful until the body is whole again	• The human body is not a machine • Our organs are not mere spare parts • Organ transplantation is abusing the body's dignity • Even though someone is dead, respect for the dead means not removing any organ • You come to life with your whole body, you need to go back with your whole body • Organs are a gift from God, we are not allowed to give them away	• The body should be kept whole for the funeral services • The body should be kept whole for burial • I want to be buried • I want to be cremated	• I am afraid of the surgery or procedure • For organs to be removed, the body will be "cut up," and that just isn't right • The idea of removing my organs is just horrifying • I worry about my body appearance • I invested in this body; I don't want to give it up to anyone

Positive:

- I think giving out organs to save someone's life is a noble act
- Donating my organs will not affect my burial plans

DEATH		
Feelings triggered by death	**Feelings triggered by organ donation**	**Superstitions**
• I feel shivering when someone mentions something about death • Talking about death is creepy • It is a very gross subject • I would never plan for death	• When someone asks me to register to donate, it feels like he is waiting for my death to get my organs • When someone talks about donations, it is like they are eager for me to die • I don't want to donate because I don't want to think about death	• People who donate will be disturbed when they die • I feel it is bad manners to talk with someone about his or her death • Talking about death will bring bad luck

Positive:

- Death is inevitable and it is ok to talk about it
- Talking about death and the afterlife is important to appreciate our lives

HEALTHCARE			
Intentional Harm	**Brain Death**	**Trust**	**Extra Cost**
• Doctors might not do their best to save someone's life if they know they are on the Organ Donor Register • If I am a donor, they will prematurely declare my death just so they can harvest my organs • Doctors might declare death prematurely to take organs from minorities and give them to whites • I believe that if someone is an organ donor, doctors will let them die in an emergency in order to get their organs • I worry that doctors may not try as hard to make me well if I carry a card saying that I want to be a donor • I don't trust doctors enough to donate organs or tissues • If I am a donor, everyone at the hospital will be waiting for me to die; that is not in my best interest	• People could still be alive when their organs are removed • I believe that it is possible to donate organs while you are alive • Brain dead people can regain consciousness • Brain death is not death • You have to be alive for them to collect your organs • They might misdiagnose brain death • Doctors might diagnose brain death just to take my organs • I am not dead if my heart is still pumping blood • The criteria for brain death sound confusing • Brain death is a medical hoax to collect organs • There are so many medical uncertainties these days • Even the professionals don't know what they're doing	• I only trust minority doctors • I don't trust non-minority doctors • There is an organ donation mafia • Doctors might do experiments on donors or their organs • The media reported that doctors stole organs from patients • I think donors are bad people • I don't want doctors or the system to be in control of my organs	• I believe that if you donate an organ, you are responsible for paying for the surgery • The family of the donor has to pay extra money for the donation

Positive:

- I trust doctors and nurses to always provide the best care they can
- Brain death is confusing to me, but I think experts know better

KNOWLEDGE			
Corruptions	**Donation Limits**	**Myths**	**General**
• Donated organs can be bought and sold • Sometimes, organs can be sold for money • Fairness of organ allocation system in the past 5 years, the local heart transplant programme has turned away about 30% of patients because of inability to pay	• There is an age limit for organ donation • I think I am too old to donate • People who have medical conditions can't donate • The NHS only need adult organ donors	• Organ donation leaves the body disfigured and afterwards, people won't be able to have an open-casket funeral • I get the information from insurance companies, I doubt their motives • I don't know what can go wrong, nobody talks about the negative part • It is not easy to register	• I don't know much about it • I do not know how to register • I do not understand how organ donation works • The information/news/stories I see on media is horrifying • I cannot decide to donate because I don't know all the facts • I do not have reliable sources of information to make a decision to donate

Positive:

• I trust the donation system to be fair
• I think registering process is easy
• I think anyone can register and be a donor

AWARENESS		
Aware	**Know someone**	**Need**
• I've never thought about it • I have never discussed that with anyone • I have not made up my mind about being a donor	• I don't know anyone who received an organ transplant • I don't know anyone who is on the waiting list • I don't know anyone who donated an organ • I don't know anyone who is signed up for donation	• There is not a special need for minority groups • Minority groups, like Africans, Caribbeans, Chinese, Indians and Arabs don't have to wait longer for an organ • More people die from automobile accidents and gunshot wounds than from heart disease. • The present need for transplant organs is fully covered • There are enough organs available for the people waiting for an organ transplant • I don't think it is important because my GP never mentioned it • Blood type doesn't make any difference when receiving a donated organ

Positive:

- I know there is a great need for organs, especially in minority groups
- I know someone who has registered as a donor, donated or received organs or is on the waiting list
- I thought about registering as a donor, but I never did

RECIPIENT			
Rich	**Unworthy**	**Outcome**	**Related**
• I am worried that if donated, my organs would only go to rich people • Rich or famous people can receive organs before the people with the most need • Transplant is not for minorities; it always goes to white people	• I cannot be sure the recipient is a good person • I would feel better if I can know who I am donating to • People wouldn't need transplants if they took better care of their health	• Transplant recipients don't live more than 10 years after a transplant operation • The patient's chance of surviving a transplant operation today is pretty low • A transplant operation has less than a 50/50 chance of allowing the recipient to return to normal activities	• The recipient is not family • The recipient is from another religion / Ethnicity

Positive:

- People on the waiting list are ill and need my help
- Transplantation results are successful, and they are improving people's health
- I am willing to donate to anyone, we are all human

OTHER				
Motive	**Emotional**	**Decision**	**Fate**	**Others**
• I don't think it is an altruistic act • I have no responsibility towards anyone else • I have no responsibility towards anyone except my family • They don't pay me money for that • God watches over us, it is not my job	• I want to be in control of my fate • I don't like the whole concept of organ donation • I feel pressured in organ donation campaigns to sign, I don't like that • I don't think I have the courage to donate • I feel that I'm scared	• I don't mind organ donation, but my family disagree • My family believes it is against our religion • I cannot decide • I have to ask permission from my husband • No one asked me to be a donor • I think it is just easier to say no than to think about it	• When your time is up, your time is up, no donation • Organ donation is not natural • If God wants someone to live longer, he will live without my organs • Life should come to an end when it needs to, we should not extend it • You die when the Creator thinks it's time for you to die	• I could not donate because I am taking care of children • I don't mind donating some organs, but not my heart or eye or – • I may get a different offspring from mixing organs • I would not receive an organ, so I would not give one • I don't mind donating when I am alive, not when I am dead

Positive:

- It is scary to donate, but once I pass that emotional hurdle, I feel better about myself
- My family encourages me to donate

Concourse List (Draft)

Barriers

1. I think my religion does not allow it
2. I have never found my religion book (Quran, Bible) mention that it is allowed
3. I think it is non-religious to take organs
4. I believe I will be haunted if I donate
5. I think the body should remain whole after death
6. I believe the person will be devoid of the organ that has been donated after life
7. I believe the human body is not a machine
8. I believe organs are a gift from God, we are not allowed to give them away
9. I want to be cremated
10. I think for organs to be removed, the body will be "cut up," and that just isn't right
11. Talking about death is creepy
12. I would never plan for death
13. When someone asks me to register to donate, it feels like he is waiting for my death to get my organs
14. I think talking about death will bring bad luck
15. I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register
16. I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs
17. I think people could still be alive when their organs are removed
18. I think brain-dead people can regain consciousness
19. I think I am not dead if my heart is still beating
20. I don't want doctors or the system to be in control of my organs
21. I think the family of the donor has to pay extra money for the donation
22. I believe donated organs can be bought and sold
23. I think I am too old to donate
24. I think people who have medical conditions can't donate
25. I think it is not easy to register
26. I cannot decide to donate because I don't know all the facts
27. I've never thought about it
28. I don't know anyone who donated an organ
29. I think there is not a special need for minority groups
30. I believe the present need for transplant organs is fully covered
31. I think rich or famous people can receive organs before the people with the most need
32. I believe people wouldn't need transplants if they took better care of their health
33. I think transplant recipients don't live more than 10 years after a transplant operation
34. I feel I have no responsibility towards anyone else
35. I don't think I have the courage to donate
36. I don't mind organ donation, but my family disagree
37. I think it is just easier to say no than to think about it
38. I believe organ donation is not natural
39. I don't mind donating some organs, but not my heart or eye or –
40. I don't mind donating when I am alive, not when I am dead

Motivators

41. I think my religion allows organ donation

42. I think my religion encourages organ donation in order save other people's lives
43. I believe donating organs is like an ongoing charitable act
44. I think giving out organs to save someone's life is a noble act
45. I believe donating my organs will not affect my burial plans
46. Death is inevitable and I feel it is ok to talk about it
47. I feel talking about death and the afterlife is important to appreciate our lives
48. I trust doctors and nurses to always provide the best care they can
49. Brain death is confusing to me, but I think experts know better
50. I trust the donation system to be fair
51. I think the registering process is easy
52. I think anyone can register and be a donor
53. I believe there is a great need for organs, especially in minority groups
54. I know someone who has registered as a donor, donated or received organs or is on the waiting list
55. I thought about registering as a donor, but I never did
56. People on the waiting list are ill and I believe they need my help
57. I believe transplantation results are successful and they are improving people's health
58. I am willing to donate to anyone, we are all human
59. It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself
60. I might feel easy to donate because my family encourages me to donate

Appendix 3 Final Concourse

Barriers

1. I believe my religion does not allow it.
2. I think it is non-religious to take organs.
3. If someone religious says it is not allowed, then I will not do it.
4. I believe I will be haunted if I donate.
5. I believe the human body is not a machine.
6. I believe organs are a gift from God, we are not allowed to give them away.
7. I want to be cremated and if I donated organs, I cannot do that.
8. Talking about death is creepy.
9. When someone asks me to register to donate, it feels like he is waiting for my death to get my organs.
10. I think doctors might not do their best to save someone's life if they know they are on the Organ Donor Register.
11. I think doctors will prematurely declare my death if I am a donor just so they can harvest my organs.
12. I think brain-dead people can regain consciousness.
13. I think I am not dead if my heart is still beating.

14. I do not want doctors or the healthcare system to be in control of my organs.
15. I believe donated organs can be bought and sold.
16. I think I am too old to donate.
17. I think people who have medical conditions cannot donate.
18. I think it is difficult to register.
19. I cannot decide to donate because I do not know all the facts.
20. I have never thought about it.
21. I think people exaggerate on the importance of the whole organ donation subject.
22. I do not know anyone who donated an organ.
23. I think there is no special need for minority groups.
24. I believe the present need for transplant organs is fully covered.
25. I think rich or famous people can receive organs before the people with the most need.
26. I believe people would not need transplants if they took better care of their health.
27. I think transplant recipients do not live more than 10 years after a transplant operation.

28. I feel I have no responsibility towards anyone else.
29. I do not think I have the courage to donate.
30. I do not mind organ donation, but my family disagrees.
31. I think it is just easier to say no than to think about it.
32. I do not mind donating some organs, but not my heart or eye or –.
33. I do not mind donating when I am alive, not when I am dead.

Motivators

34. I think my religion encourages organ donation in order save other people's lives.
35. I think giving out organs to save someone's life is a noble act.
36. I feel talking about death and the afterlife is important to appreciate our lives.
37. I trust doctors and nurses to always provide the best care they can.
38. Brain death is confusing to me, but I think experts know better.
39. I trust the donation system to be fair.
40. I think anyone can register and be a donor.
41. I believe there is a great need for organs especially in minority groups.
42. I thought about registering as a donor, but I never did.
43. People on the waiting lists are ill and I believe they need my help.
44. I believe transplantation results are successful and they are improving people's health.
45. It feels scary to donate, but once I pass that emotional hurdle, I feel better about myself.
46. I might feel easy to donate because my family encourages me to donate.
47. No matter how hard it is for me to think about organ donations, donating makes me feel good about myself.

Appendix 4 Q sort instructions

<u>Instructions</u>
To donate or not to donate: Using Q-methodology to guide behavioural interventions on organ donation
Thank you for partaking in this research. There are no right or wrong answers, and the statements are likely to mean different things to different people. The activity should take no more than 60 minutes. For each statement I am asking you to consider whether this represents something you would consider as a barrier or a reason for you not to register as an organ donor. The numbers on the cards do not mean anything; they are just to help record the result at the end regarding which statement you have placed where.

STAGE 1
You would complete a Q-sort activity which is where you are given some cards with statements on and asked to rate them on a line from 'I feel strongly about' to 'I don't feel strongly about'. The statements will refer to barriers against organ donation.

The statements that you answer 'I feel strongly about' with represent the statements that act as a strong barrier against organ donation, i.e., the main reason that prevents you from registering as an organ donor.

The stages that you say 'I don't feel strongly about' represent those statements that you *CONSIDER* as *NON* barriers, i.e., you consider these statements when taking a decision whether to donate or not and you believe these statements do not stop you from being an organ donor.

Neutral statements represent the statements that you do not consider as part of the decision to register or not, i.e., statements that you do not care about at all when it comes to whether to register or not.

I understand this method is not common and we usually rank things based on 'agree' and 'disagree' statements. To make sure that the statements reflect your perception, try to say loudly 'I feel strongly about' or 'I don't feel strongly about' followed by reading the statement. Check which side feels left to you.

<u>Part 1</u>
Arrange the statement in 3 piles without ranking, 'I feel strongly about' on the left, 'I don't feel strongly about' on the left and 'Neutral' in the middle.

<u>Part 2</u>
Rank statements of each pile on the board based on how strongly you feel about each statement.

1. From the pile on the left, choose two statements which are most like your view and put them in the far-left column (it doesn't matter which is on the top and which is on the bottom).
2. From the pile on the left, choose two statements which are least like your view and put them in the far-left column.
3. Back to the pile on the left, choose two statements which are more like your view than the others in the pile but not as much your view as the two you have already chosen. Put them in the second column from the left.
4. From the pile on the left, choose two statements to place in the second column from the left.

5. Keep doing this, working your way towards the middle with the statements you have left over.
6. Move statements around if you change your mind.
7. Check that you are happy with your arrangement and make any changes needed to make sure that the sort fits your view.

You will not be able to rank all statements; it is meant for you to prioritise some statements and choose to put them on the board over others. However, if you think that there is a statement that you think it is absolutely necessary to add, please let me know. Additionally, if you think there is any certain statements that you would like to add, the short interview following that stage will be a good place to communicate that.

STAGE 2

Following stage 1, you will be invited for a short interview to go over your views in a bit more detail. This interview is 10-15 minutes only and aims to make sure that the researcher understands your views and perspective clearly in reflection of what you did in stage 1.

Complete the 'Outcome Feedback sheet'; try to answer the questions as honestly as possible.

Opposite to what I think					Do not concern me	Similar to what I think				
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5

Appendix 5 Consent form and short survey questions

Participant Consent Form

To donate or not to donate: Using Q-methodology to guide behavioural interventions on organ donation

Researcher: **Reem Muaid**

Participant ID:

1. I have read and understood the 'Participant Information about the Research' sheet which explains the research. I understand that there are two stages of research that I am asked to participate in.
2. I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.
3. I understand that I will not benefit directly from participating in this research.
4. I understand that taking part is voluntary and that I am free to change my mind and withdraw at any time, without giving any reason. I also do not have to answer any

questions I do not want to. I understand that if I withdraw part way through the research, the data collected by this point may still be used.

5. I understand that my answers will be kept confidential, which means that only the researcher and research supervisors will know what I have said. I also understand that my name will not be linked to anything I have said.
6. I agree to have what I say audio recorded during the one-to-one interview.
7. I understand that signed consent forms will be retained in University of Nottingham secured office until March 2020.
8. I understand that a transcript of my interview in which all identifying information has been removed will be retained in the University of Nottingham cloud storage until March 2020.
9. I understand that under freedom of information legalisation I am entitled to access the information I have provided at any time while it is in storage as specified above.
10. I understand that I am free to contact any of the people involved in the research to seek further clarification and information.
11. I agree that what I say can be used in this research and may be used in future research.
12. I agree to participate in the research.

I believe the participant is giving informed consent to participate in this study.

1. Name / ID:
2. Gender:
3. Age:
4. Education:
5. Socio-Economic group:
6. Ethnicity:
7. Religion:
8. Years you lived in UK:

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1. Please write down any statements which you feel were missing from the cards (they do not have to represent your view):

2. Do you think that the way that you finally arranged the cards allowed you to give your view? If no, please explain why:

3. What do you think makes statements that you felt strongly about so important to you?

4. Are there any other cards that have stood out to you? This may be because it did not make sense to you or because you felt it should not belong in the card sort. Please state which card and why:

Appendix 6 Factors Arrays Highlighted by Barriers, Motivators, Cautions

Factor 1										
-5	-4	-3	-2	-1	0	1	2	3	4	5
39	9	17	44	31	19	8	32	42	37	15
11	10	36	25	38	41	46	23	24	30	12
	45	6	1	21	29	22	13	47	7	
		43	3	34	4	20	40	16		
			35	2	27	14	28			
				26	5	33				
					18					

Factor 2										
-5	-4	-3	-2	-1	0	1	2	3	4	5
25	31	6	9	11	39	17	43	41	26	23
24	19	34	36	45	10	3	38	18	28	16
	37	29	2	1	44	35	14	20	7	
		8	4	21	27	5	33	15		
			12	32	46	13	40			
				30	22	42				
					47					

Factor 3										
-5	-4	-3	-2	-1	0	1	2	3	4	5
39	37	31	19	25	24	34	2	13	12	7
17	8	9	6	29	11	30	35	40	33	16
	42	36	10	4	1	22	5	18	28	
		44	46	45	21	47	14	26		
			41	43	32	3	20			
				15	27	23				
					38					

Appendix 7 Interviews Transcripts

Interview-1

Code: 4633-Varun/F3
Date: 26/12/2019

- What do you think about organ donation?

It is not a bad thing, why would a person care, they will be dead anyway. I think for these kinds of decisions, you need to include your family, and that is where the disagreement comes from, because of the emotions and the orthodox attitude. My parents are too orthodox so I'm sure for them it will be a big problem, but I have never spoken to them about it before.

- Have you ever considered it?

Yes, of course, I first heard about organ donation when someone died of an accident back in India; they harvested his organs for donation, and it was all over the media. Organ donation is a worldwide activity, so you hear about it here and then.

- What would you say is the negative aspect of organ donation?

That would be something like consent. In some parts of the world, organs have been harvested without consent, which happened back in India. Another issue is the viability of their organs; how would that organ be healthy and beneficial if that person was medically ill before death? That would be the main concern I have about organ donation, not necessarily a bad view.

- S37/4, can you explain your view regarding this point?

This is not exactly what I think, that would be more of a zero rank. As you age, your immunity starts to worsen, and you would need an organ. It is not about taking care of your health; everyone tries to do that, but things sometimes just go wrong.

I took this statement in a different thought process. I thought about it in a positive way. If you take care of your health then you would reduce the possibility that you need an organ, but now that I am reading this again, especially with the recent event that happened with my father, that would certainly be on a 0 rank.

My father was recently in Australia, and he had a bad eye infection, and the doctor said that he needs to replace lenses in both eyes. Before this infection, my dad was careful about his health, and suddenly this infection happens and now he replaces lenses in both eyes, which nothing of his fault.

- S14/3, what is your view about brain death?

I do not know much about it; I do not really understand what it is. I think your brain continues to work even after you die, it out-lives your heart. I think I would trust doctors' diagnosis. If I do not know about a particular thing, then whatever I am being educated, that would be my view, so whatever the doctor says, people have to accept it.

- S26 and 34 on +3, that sounds a bit contradictory, can you explain it?

I do trust the allocation system to be fair, but it is also true that organs are being sold. There are two sides to the same story. Back in India, there have been many cases where organs have been bought and sold; it is a big black market, illegally. However, I haven't heard such cases in the UK. I tend to trust the system because it is managed by a governmental body in the first instance, but do I really believe nothing bad would happen? I hardly think so. If there is a rich person and they are influential enough they can even bribe and influence even governmental bodies to buy the organs, they needed.

- S4/1, what is your experience with the registration process?

I put it on 1 because I wasn't sure about it, I have never experienced any registration process and never looked for it.

- S24/1, could you expand on that?

As I mentioned before, the family's opinion is important in organ donation. If I would donate my organs, it would be my family's decision, they would decide whether my organs be donated or not. I put this on 1 because I am not sure about that either.

- S25/1, could you explain your view?

Similar to S24, it is on 1 because it is not very important to me. I do not consider that as part of my view in organ donation. This statement would be absurd to me. I'm pretty neutral to this and I do not really care, I put it there because I have limited spaces on rank 0.

Interview-2

Code: 6291-Hattie/F2
Date: 30/12/2019

- What do you think about organ donation?

I think organ donation suffered from several scandals over the years. It might help some people, but I think it has a big bad side to it.

- S7/-3, can you explain your view regarding this point?

If you participate in organ donation, you might have good intentions, but you are helping a great business becomes bigger and you are participating in murders of thousands of people. It is a lot worse than something like blood diamond or something. It is not a noble act; we need to stop those murders.

- S33/-3, can you explain your view regarding this point?

I know there are a lot of people on waiting lists; they are ill just like thousands of other ill patients. I am of course not talking about ignoring ill people, but I think there are lots of ways I can help with, but not my organs.

- Do you think there is a need for donated organs?

Yes, I think so, but we need to understand what happened to those organs and how we can help them. Medicine has improved a lot in the past few decades and there are millions of people getting help with advanced medical treatments. I am sure we can find medicines or surgeries to help those people. There is also research on creating organs for humans from animals or from 3D printers, that's great. There are a lot of ways we can help ill people without killing off others. It just does not make sense to me, killing one to save another.

- Do you think the allocation system in UK is better than the one in China?

I have heard terrible cases in China. I haven't heard that many cases in UK. But I still think there are big problems in the system. For example, in China, it is illegal now to take organs from people; does that mean it never happens? No. When you have enough money, you can do anything. You can go extremely legal and buy a kidney from someone for example. It is completely legal for someone to "volunteer" a kidney, and you can give them a "gift", but that does not mean it is ok. We don't know exactly how the system decides who will get the organ, there is a lot of things that can be manipulated.

- Do you know anyone received an organ?

No.

- Do you know anyone who is registered as an organ donor or has donated organ?

Not personally, no.

- What is the most negative event you ever felt against organ donation?

I cannot put it in order, and it is not something that suddenly happened. Organ donation has a negative thing about it, I think it is just over the years you hear stories here and there.

- Do you think there is any information that might help you develop a more positive view?

I do not want to change my view. I do not think there is anything specific you would say to change my mind. This opinion has been accumulated over years; you cannot change it that easily. Normally, I wouldn't hear about organs a lot, unless there is a disaster or in the UK when they changed it to a new system which reminds me of what happened in China too; they are basically forcing people to be organ donors even if they do not want to. Some of them might never have thought about it, and yet, we are still justifying that behaviour by saying there are people who need the organ. I just do not understand that.

Interview-3

Code: 4586-Sanara/F1
Date: 03/01/2020

- What do you think about organ donation?

I think it is great. It can save a lot of people from death, and it is not like we will use our organs after death.

- Have you tried to register before?
No. But I think I can do it online.

- Have you had any discussion about organ donations before?

Not personally, but you hear about it in the news, I think they wanted to change the system in UK, and I saw something about it and people were talking about their experience on how they received an organ and it saved them.

- S22/4 and S14/-2, could you expand on those statements? They look contradictory.

I think when someone is brain dead, then they will not be conscious again, but I think it is hard or may be confusing to be 100% with the diagnosis; one can be diagnosed as brain dead, but they are not. I am not sure how that happens, but doctors can make mistakes and it happens. So, when a doctor says for example, one of my family is brain dead, I would not just say ok then he is dead, let's bury him. I need to make sure the diagnosis is correct. I would take several opinions and ask for several tests just to make sure the diagnosis is correct. If we do a lot of things and they all agree it is brain death, then I will take it as brain dead, but I will not take the word of one person. I do not know how they do it actually, like what tests you do and how many people decide brain death, but apparently even when it is more than one doctor, mistakes still happen.

- S1/4, you mentioned religion, but you indicate that you are an atheist?

I am, but for example when someone asks me about my religion, my immediate response is still Islam; it is hard to just forget everything about it, when I get into troubles I still sometimes pray to God. I think in Islam only live donation is allowed. I know a lot of people who received kidney from their relative, for example, but I never heard anyone who donated or received any organ in my home country, I think because it is not allowed.

- S24/3 and S28/3, if you trust doctors, why don't you want them to be in control?

I trust the medical knowledge of doctors, to a certain level, but organ donation is an emotional subject. I mean imagine someone from my family gets in an accident and then a doctor who doesn't know me or my relative comes and says: hey, your relative is dead now and we want to take his organs. That would be a big shock to all of us. I cannot imagine the crying, the emotional state for everyone. It is not easy to hear that from a doctor, even if the doctor is simply doing his best to save everyone's life. I do not want anyone who is a complete stranger to me to decide for me. If I die and then doctors ask my family for my organs, may be my mother would be so sad she will say no, I want to give her that chance, to say no. I mean may be the doctor will say it in a very straight face, may be my mother or father will be hurt by this, that's why I will leave that decision to them.

Interview-4

Code: 6291-Deelan/F2
Date: 30/12/2019

- What do you think about organ donation?

I think organ donation suffered from several scandals over the years. It might help some people, but I think it has a big bad side to it.

- S7/-3, can you explain your view regarding this point?

If you participate in organ donation, you might have good intentions, but you are helping a great business become bigger and you are participating in murders of thousands of people. It is a lot worse than something like blood diamond or something. It is not a noble act; we need to stop those murders.

- S33/-3, can you explain your view regarding this point?

I know there are a lot of people on waiting list, they are ill just like thousands of other ill patients. I am of course not talking about ignoring ill people, but I think there are lots of ways I can help with, but not my organs.

- Do you think there is a need for donated organs?

Yes, I think so, but we need to understand what happened to those organs and how we can help them. Medicine has improved a lot in the past few decades, and there are millions of people getting help with advanced medical treatments. I am sure we can find medicines or surgeries to help those people. There is also research on creating organs for humans from animals or from 3D printers, that's great. There are a lot of ways we can help ill people without killing off others. It just does not make sense to me, killing one to save another.

- Do you think the allocation system in UK is better than the one in China?

I have heard terrible cases in China. I haven't heard that many cases in UK. But I still think there are big problems in the system. For example, in China, it is illegal now to take organs from people; does that mean it never happens? No. When you have enough money, you can do anything. You can go extremely legal and buy a kidney from someone for example. It is completely legal for someone to "volunteer" a kidney, and you can give them a "gift", but that does not mean it is ok. We don't know exactly how the system decides who will get the organ, there are a lot of things that can be manipulated.

- Do you know anyone received an organ?

No.

- Do you know anyone who is registered as an organ donor or has donated an organ?

Not personally, no.

- What is the most negative event you ever felt against organ donation?

I cannot put it in order, and it is not something that suddenly happened. Organ donation has a negative thing about it; I think it is just over the years you hear stories here and there.

- Do you think there is any information that might help you develop a more positive view?

I do not want to change my view. I do not think there is anything specific you would say to change my mind. This opinion has accumulated over years; you cannot change it that easily. Normally, I wouldn't hear about organs a lot, unless if there is a disaster or in the UK when they changed it to a new system which reminds me of what happened in China too, they are basically forcing people to be organ donors even if they do not want to. Some of them might never have thought about it, and yet, we are still justifying that behaviour by saying there are people who need the organ. I just do not understand that.

Interview-5

Code: 5931-Alison/F1
Date: 18/01/2020

- What do you think about organ donation?

I think it is wonderful. Generally, I like the idea of one human helping the other, but of course I have reservations on some issues.

- What issues are you referring to?

There are several things actually, and while I did your test it makes me think about some of them even more and I actually went and read few things about it. For example, I know someone who had received a kidney donation from his brother, which was truly inspiring; I have absolutely no issue with something like that, but I think we still have some issues with organ donation like some of the issues you mentioned in the test; things like brain death, for example, do we really know what it means? Are we really sure that people will never wake up after that? Can a doctor be mistaken and wrongly diagnose one? I mean people make mistakes.

- So, do you believe that brain death should be treated as death or not?

I am not sure, but it is a bit confusing. Even if the person is brain dead and diagnosed correctly, but the heart is still beating, why not keep it beating? I'm not saying that I am totally against considering brain death as death; I'm just saying it is confusing and hard to decide and be sure 100%.

- Would you say this situation is preventing you from considering becoming a donor?

It is certainly something of a mystery; the problem is, since I am not a doctor, the more I try to read about it, the more confusing it gets. I really don't understand.

- So, what do you think of the people who already received an organ? Do you think results are successful?

I think it is the best you can expect for now, I am sure it will be better in the future as we advance our knowledge and medicine and healthcare.

- You mentioned you would prefer live donation. Why is that?

I think it is better because you know quite a lot, you know you will donate, you know the person receiving it will benefit from it and you can see the person after they receive it. You also know the possible issues after you donate a kidney, for example, you know quite a lot of things, it feels much easier.

- Why do you think people need organs?

I don't know about that, but I think there might be a lot of reasons why their organs don't work anymore.

- You put 37 - I believe people wouldn't need transplants if they took better care of their health on +5; could you elaborate more?

Well, I think a lot of the health problems can be avoided, but we have a lot of bad eating habits; people don't exercise, they do not take care of their body, of course they will get ill.

- Does that mean you think all causes of illness that require organ transplant are preventable?

No, not like that, for example, the person I knew who had a kindly transplant had diabetes that led to damage to his kidney, he was overweight before he got diabetes. Correct me if I'm wrong, but if this person maintained healthy food diet and a good weight, even if he would have diabetes, it would be under control and may be not that bad, maybe then he wouldn't need a kidney.

- I understand this might be the case for a lot of people, but some of the cases happen for reasons one cannot control, some of them are genetic reasons, others are accidents, cancers or even infections, what do you think about that?

I guess that would be different.

- Do you think you would consider donating organs for those people?

(Long pause) if I'm dead, I cannot choose who gets my organ, I can only do that if I'm alive. To be honest, I think that would not be the main problem in donation; I think it is the general feeling of confusion, it is like you are lost in the details and it makes it so hard to make a decision and be 100% sure about it.

- What do you think would help you clear that confusion?

I am not sure, and I have to be honest here, I'm not going to say that I spent hours looking for answers. It is just a few ads I saw and some posts I read on the go. Maybe if I read more, I would not feel the same way.

- Why do you think you are not seeking more information about it?

Not really sure, probably because no one really made the effort to make me stop and think about it. It is not something you would discuss with your friends or anything. You just hear something and then you move on. I was interested in googling things myself after I did your test, but it is not like I stuck there looking for information for hours, nothing seemed interesting enough. Maybe it is the websites that seemed boring, not sure, but nothing caught my eye.

- How would you say your faith affect your view about organ donation?

I don't think religion has anything to do with that, I noticed there are quite a lot of statements about it, but I guess some people consult religion about it.

Interview-6

Code: 6216-Juan/F2
Date: 11/03/2020

- What do you think about organ donation?

It is good, it is nice to think that you can possibly save someone's life, offer them another chance in life, but I've never heard anyone say that. I mean, I do not think I ever had a conversation about it except sometimes you hear about it and see it on TV, but personally, I have not been in a conversation about it, and it never crosses my mind. Even when I watch it on TV, it is not like I would watch it and say: oh, I want to be that person, I might consider being the receiver but never the donor. In fact, I don't think they show it on TV, they always show the person who needs the organ and the happiness when they receive the organ last minute, but they never show the donor.

- Would you start a conversation about it?

I don't think so. I mean it is a sensitive subject, nothing you talk about in the pub or at dinner.

- What do you think people will think if you start this conversation?

I think they will feel very uncomfortable. Nobody wants to talk about illness and death, then you would picture blood and surgery and doctors and hospitals and people dying or in pain. Even if I push on the conversation past this stage, it is still not a comfortable conversation. For example, if I ask someone, ok, so what do you think about it, like what you just asked me, then he or she might be uncomfortable to tell me that he is against it, or that it is ridiculous to him, or that doctors are savages or something, he can't say good things about it because he might think that I'm against it, and he certainly can't say bad things because I might judge him. Either way, talking about death is not a subject anyone would like to start.

- What about you, how do you feel about the connection between organ donation and death?

They say death is the only truth, we all die, and I think the fact that our lives will end one day is what is giving our lives a meaning. It doesn't mean that I like to think about it. I mean I'm still young, I don't think about Alzheimer's or writing a will or even getting life insurance for that matter.

- You are not registered as an organ donor; can I ask why?

Well, as I mentioned in the form, I might consider it, I do not have a specific reason for not registering really, it is just, I never had the guts to do it, or maybe now that I'm thinking about it, I don't have the need to consider it. I mean, yeah, I know there is a need for transplants, but this is more of an abstract idea, I've never met someone who needs it, or someone that donated, dead or alive. (Smiling) It feels more like science fiction, you know, like those TV dramas. I do not have anything negative to say about it but for some reason, I don't want to register. I mean if I die, they might take it, but I don't want to make that decision now.

- Have you ever told your family about your view? Would they allow doctors to harvest your organs?

No, never. I guess I cannot guarantee they will donate my organs, they probably won't. But again, I'm not going to say anything and upset my old parents by talking about death.

- You mentioned that you feel responsible towards other people; doesn't it fall under your responsibility towards them?

I have a responsibility towards my parents too; they are more important than strangers and after all who said I will donate my organs? I might die normally, and they can't use my organs anyway; let it be when it is time, you never know what will happen.

- What about religion, how do you think this plays a role in your view and in your family view?

I don't think religion plays a significant role as far as I'm concerned. My parents might be more religious than I am, but I don't think this has anything to do with their opinion too. I don't even know their opinion about it, I've never asked, and it never happened to have a conversation about it. They might like it actually.

Appendix 8 Organ donation views survey

Start of Block: Introduction and Consent

A Participant Information

Aim of the Study My name is Reem Muaid, I am a Ph.D. student at the University of Nottingham, Operation Management and Information System department. I am conducting research for my Ph.D. on organ donation. Organ donation is a success story in the field of medicine since 1954 when the first kidney was transplanted. However, we still do not fully understand how people perceive organ donation. In this research, I want to examine subjective perceptions around organ donation. By understanding how people think about this subject, and how many people think in a certain way, we can use that knowledge to progress the research in this field and enrich our knowledge on the decision-making process. Participants in this project come from all different backgrounds, ethnicities, and cultures. You have to be residing in the UK (temporarily or permanently). The participants are a roughly equal mixture of gender, age groups, and education level.

Why have I been invited? We are inviting between 300-350 adults who live in the UK to participate in this research. Different people have different points of view about organ

donation. Hence, we want to understand the representation of each view in the representative sample from the UK population.

Do I have to take part? No, your participation is entirely voluntary. It is up to you to decide whether or not to take part. If you choose not to take part, you can dispose of the study information, and we will not contact you again.

What will I have to do if I choose to take part? You will need to read four different views about organ donation, each view is less than 150 words, then you will be asked to rate and rank those views, this will be followed by a short Questionnaire.

Will I get paid for my involvement? Participation in this research is voluntary, there is no payment or expenses available to people who participate.

What are the side effects of the study when taking part? There are no known side effects or adversities expected from this study.

What are the possible benefits of taking part? There are no benefits to you individually, but this may help people in the future. The results from this project will help to understand different views about organ donation, which will ultimately help to improve the campaigns to increase organ donation.

What will happen if I don't want to carry on with the study? You can withdraw from the study at any time without any effects on you. If you decide, at any point in time, that you no longer want your information to be used then you can contact the researcher. Your questionnaire will be removed, and your data will not be used.

What if there is a problem? If you have a problem with the research at any time you can report this to the researcher. If you have any concerns related to the way in which the research is being undertaken, you can report this to the researcher's supervisors (all contacts are listed below).

Will my taking part in this study be kept confidential? Yes. All information that is collected about you during the course of the research will remain strictly confidential and anonymous using a unique research code. This information will only be used for the research and will not be shared with anyone outside the research group which consists of me, my supervisors, and the research committee. You should not put your name on any sheet.

Will my GP be informed? No, your GP will not need to be informed regarding your participation in this study.

What will happen with the results of the study? Results will be published in scientific journals or presented at conferences. When the findings of the study are reported results will be discussed as a group with the identity of individual people being unidentified.

Who has paid for this research? The researcher has paid fully for this research

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Research participant privacy notice for tailoring privacy information for research participants

For information about the University's obligations with respect to your data, who you can get in touch with, and your rights as a data subject, please visit: https://www.nottingham.ac.uk/utilities/privacy.aspx.

Why we collect your personal data? We collect personal data under the terms of the University's Royal Charter in our capacity as a teaching and research body to advance education and learning. Specific purposes for data collection on this occasion are:
— Examine the prevalence of different viewpoints on organ donation in the UK population.
— Examine the relationship between different viewpoints and demographic criteria.

Legal basis for processing your personal data under GDPR The legal basis for processing your personal data on this occasion is Article 6(1e) processing is necessary for the performance of a task carried out in the public interest.
How long we keep your data? The University may store your data for up to 25 years and for a period of no less than 7 years after the research project finishes. The researchers who gathered or processed the data may also store the data indefinitely and reuse it in future research. Measures to safeguard your stored data include anonymisation of data.
Who we share your data with? Extracts of your data may be disclosed in published works that are posted online for use by the scientific community. Your data may also be stored indefinitely on external data repositories (e.g., the UK Data Archive) and be further processed for archiving purposes in the public interest, or for historical, scientific or

statistical purposes. It may also move with the researcher who collected your data to another institution in the future.

Participant Consent Form
— I have read and understood the 'Participant Information about the Research' which explains the research.
— I understand that there are two stages of research that I am asked to participate in.
— I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.
— I understand that I will not benefit directly from participating in this research.
— I understand that taking part is voluntary and that I am free to change my mind and withdraw at any time, without giving any reason. I also do not have to answer any questions I do not want to. I understand that if I withdraw part way through the research, the data collected by this point may still be used.
— I understand that my answers will be kept confidential, which means that only the researcher and research supervisors will know what I have said. I also understand that my name will not be linked to anything I have said.
— I understand that signed consent forms will be retained in the University of Nottingham secured office until March 2021.
— I understand that under freedom of information legalisation I am entitled to access the information I have provided at any time while it is in storage as specified above.
— I understand that I am free to contact any of the people involved in the research to seek further clarification and information.
— I agree that what I say can be used in this research and may be used in future research.

I agree to participate in the research.

I agree (1)

I do not agree (2)

Q3 What is your gender?

Male (1)

Female (2)

Q4 What is your age?

18-29 (1)

30-49 (2)

50 or older (3)

Q4 What is your region?

England (1)

Scotland (2)

Wales (3)

Northern Ireland (4)

Q5 What is your education?

Less than high school (1)

High school graduate (2)

Bachelor's degree (3)

Post-graduate degree (4)

Q6 What is your household income?

£30,000 and below (1)

£30,001 - £45,000 (2)

£45,000 and above (3)

Q7 What is your ethnicity?

White (1)

Caribbean (2)

African (3)

Indian (4)

Pakistani (5)

Bangladeshi (6)

Chinese (7)

Any other Asian background (8)

Latino (9)

Arab (10)

Middle Eastern (11)

Others (12)

Q8 What is your religion?

Christianity (1)

No Religion (2)

Islam (3)

Hinduism (4)

Sikhism (5)

Jewish (12)

Buddhism (7)

Jainism (8)

Neopaganism (9)

Bahá'í Faith (10)

Other Religions (11)

Q1 You will be presented with four different views about organ donation, each is around 100 words. They represent different views on organ donation and there is no right answer. You have a maximum of 15 credits (and a minimum of 4). Please assign credits to the accounts you most agree with. Rate each view from 1-5 where 1 is where the view does not fit you at all and 5 where the view fits you perfectly. You can change the rating of all views until you feel the rating is reflective of how much each factor represents you.

Please take enough time to read each statement. You will be able to proceed to the next question once enough time has been spent reading the statements.

I believe people on the waiting lists are ill and they need my help no matter how little I know about it; I feel obliged to think about it. Death helps us appreciate life as long as I'm alive and my heart is still beating, and it feels like I have an opportunity to save someone's life, we all have a chance to be a donor even if ill or old. Transplantation results are successful, and doctors will do their best to improve our health. Religion should not prevent us from doing that, and if someone religious says it is not allowed then I believe it is my organs to gift. I can't decide to donate because I do not know all the facts. I am not sure if brain death is really death, I believe I am not dead if my heart is still beating. I do not know anyone who donated an organ personally, but I believe transplantation results are generally successful. However, people would not need transplants if they took better care of their health

to begin with and I think people who have medical conditions cannot even donate. I do not think it is against religion to donate organs, organs are yours to give. : _____ (1)

I thought about registering as a donor, but I never did, I feel I cannot decide to donate because I do not know a lot about it, I think the allocation system is fair and I; of course, trust doctors and nurses to do their best to save people's life. However, I still find the idea of donating something like a heart or an eye is very uncomfortable. Maybe it is just easier to say no than to think about it. After all, if my religion is against it I will never do it no matter how successful transplantation surgeries are. : _____ (2)

I do not want doctors or the healthcare system to be in control of my organs, when someone asks me to register to donate, it feels like he is waiting for my death to get my organs. I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs especially that donated organs can be bought and sold. I am not obliged to donate my organs, not everyone can, people who have medical conditions cannot donate. I think there is an exaggeration on the organ donation subject for potential financial gains. : _____ (3)

I believe people on the waiting lists are ill and they need my help no matter how little I know about it; I feel obliged to think about it. Death helps us appreciate life as long as I'm alive and my heart is still beating, and it feels like I have an opportunity to save someone's life, we all have a chance to be a donor even if ill or old. Transplantation results are successful, and doctors will do their best to improve our health. Religion should not prevent us from doing that, and if someone religious says it is not allowed then I believe it is my organs to gift. : _____ (4)

Total : _____

Q2 Rank the four views as to which fits you best, put the view that fits you the best on the top, followed by the one that second fits you, then the third one that fits you, then the one that fits you the least on the bottom.
Please take enough time to read each statement. You will be able to proceed to the next question once enough time has been spent reading the statements.

_____ I believe people on the waiting lists are ill and they need my help no matter how little I know about it; I feel obliged to think about it. Death helps us appreciate life as long as I'm alive and my heart is still beating, and it feels like I have an opportunity to save someone's life, we all have a chance to be a donor even if ill or old. Transplantation results are successful, and doctors will do their best to improve our health. Religion should not prevent us from doing that, and if someone religious says it is not allowed then I believe it is my organs to gift. I can't decide to donate because do not know all the facts. I am not sure if brain death is really death, I believe I am not dead if my heart is still beating. I do not know anyone who donated an organ personally, but I believe transplantation results are generally successful. However, people would not need transplants if they took better care of their health to begin with and I think people who have medical conditions cannot even donate. I do not think it is against religion to donate organs, organs are yours to give. (1)

_____ I thought about registering as a donor, but I never did, I feel I cannot decide to donate because I do not know a lot about it, I think the allocation system is fair and I; of course, trust doctors and nurses to do their best to save people's life. However, I still find the

idea of donating something like a heart or an eye is very uncomfortable. Maybe it is just easier to say no than to think about it. After all, if my religion is against it I will never do it no matter how successful transplantation surgeries are. (2)

_____ I do not want doctors or the healthcare system to be in control of my organs, when someone asks me to register to donate, it feels like he is waiting for my death to get my organs. I think doctors will prematurely declare my death If I am a donor just so they can harvest my organs especially that donated organs can be bought and sold. I am not obliged to donate my organs, not everyone can, people who have medical conditions cannot donate. I think there is an exaggeration on the organ donation subject for potential financial gains. (3)

_____ Transplantation results are successful, and doctors will do their best to improve our health. Religion should not prevent us from doing that, and if someone religious says it is not allowed then I believe it is my organs to gift. I believe people on the waiting lists are ill and they need my help no matter how little I know about it; I feel obliged to think about it. Death helps us appreciate life as long as I'm alive and my heart is still beating, and it feels like I have an opportunity to save someone's life, we all have a chance to be a donor even if ill or old. (4)

Q9 Are you an organ donor? Have you registered your decision to donate organs?
    Yes (1)
    No (2)

Q10 What is your general attitude towards donating an organ?
    In favour (1)
    Undecided (2)
    Against (3)

Q11 Are you married?
    Yes (1)
    No (2)

Q12 What is your partner's opinion about donation?
    Favourable (1)
    I do not know (2)
    Against (3)

Q13 Do you know anyone who donated or received an organ?
    Yes (1)
    No (2)

Q14 Have you had a conversation about organ donation with family or friends?
    Yes (1)
    No (2)

Q15 Do you carry any volunteer work?
    Yes (1)
    No (2)

Appendix 9 The frequency of rating each factor from 1-5.The figure shows that 163 participants rated Factor 3 as 5 (close to what they think) and 100 for Factor 1. This indicates that Factor 3 and Factor 1 are popular views in organ donation. This is in contrast to Factor 2B where 194 people rated the view at 1 indicating that it is not similar to what they think.
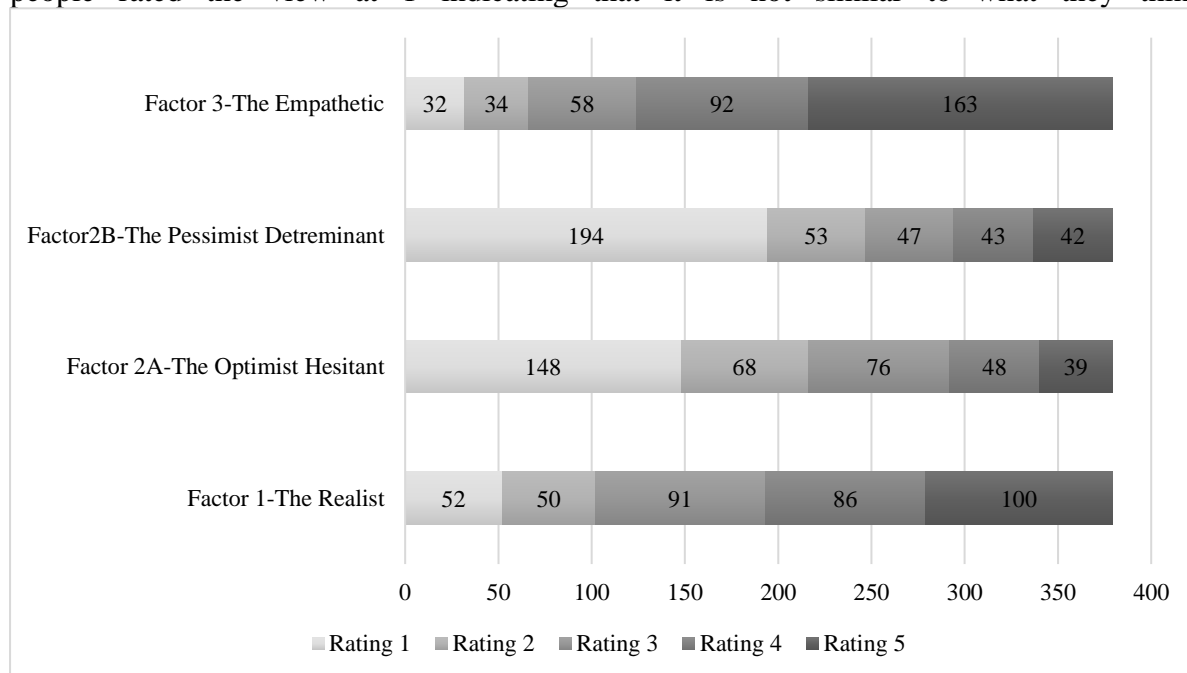
Appendix 10 Demographic criteria for participants who rated each factor 5. If one participant rated Factor 1 and Factor 3 at 5, his/her demographic criteria will be presented twice, once in Factor 1 column and again in Factor 3 column. The first column lists the demographic criteria, and that is then followed by two columns for each factor. The first column represents the number of people who rated that factor at 5 per criteria, the second column represents the percentage of that criteria for that factor. For example, for Factor 2A, 44% of those who rated the factor at 5 are female compared to 56% male. One extreme result was found at the income criteria. All participants who are earning £45,000 and above rated Factor 3-The Empathetic at 5 (if they have rated any factor at 5, it was factor 3). None of the participants with an income of £30,000 and below rated Factor 3-The Empathetic at 5, at all. Most minority Ethnicities such as Caribbean, Pakistani, Bangladeshi, any other Asian background, and Arab ethnicities seems to view Factor 2A-The Optimist Hesitant as the closest to their own view. Participants with African ethnicity seemed to view Factor 2B- The Convinced Pessimist as the closest to their view. This result resonates with the studies conducted in the US with African American communities showed a mistrust in the healthcare system which might have historical routes into health inequalities in the US. This is even though Factor 3-The Empathetic has the highest average rating. Christian's participants view Factor 2A- The Optimist Hesitant and Factor and 2B- The Convinced Pessimist as the closest to their views, while participants with no religion lean more towards Factor 1-The Realist and Factor 3-The Empathetic. Muslims view Factor 2A -The Optimist Hesitant as the closest view to theirs, as do ethnic minority groups

Criteria	Factor 1-The Realist		Factor 2A-The Optimist Hesitant		Factor 2B-The Convinced Pessimist		Factor 3-The Empathetic	
	N	%*	N	%	N	%	N	%
Gender								
Female	52	52%	17	44%	19	45%	85	52%
Male	48	48%	22	56%	23	55%	78	48%
Age								
18-29	34	34%	14	36%	13	31%	46	28%
30-49	38	38%	16	41%	18	43%	65	40%
50 or older	28	28%	9	23%	11	26%	52	32%
Region								
England	68	68%	28	72%	31	74%	110	67%
Scotland	10	10%	3	8%	2	5%	13	8%
Wales	2	2%	1	3%	1	2%	2	1%
Northern Ireland	0	0%	0	0%	0	0%	2	1%
Non-identified	20	20%	7	18%	8	19%	36	22%
Education								
Less than high school	10	10%	5	13%	3	7%	12	7%
High school graduate	37	37%	17	44%	22	52%	56	34%
Bachelor's degree	26	26%	2	5%	10	24%	53	33%
Post-graduate degree	27	27%	8	21%	7	17%	42	26%
Income								
£30,000 and below	67	67%	23	59%	23	55%	0	0%
£30,001 - £45,000	33	33%	12	31%	10	24%	108	66%
£45,000 and above	0	0%	0	0%	0	0%	55	34%
Ethnicity								
White	87	87%	27	69%	33	79%	147	90%
Caribbean	0	0%	2	5%	0	0%	2	1%
African	1	1%	1	3%	3	7%	3	2%
Indian	2	2%	0	0%	1	2%	1	1%
Pakistani	2	2%	3	8%	0	0%	0	0%
Bangladeshi	1	1%	2	5%	1	2%	1	1%
Chinese	0	0%	0	0%	1	2%	1	1%

Any other Asian background	1	1%	2	5%	0	0%	0	0%
Latino	0	0%	0	0%	0	0%	1	1%
Arab	3	3%	2	5%	0	0%	2	1%
Middle Eastern	2	2%	0	0%	0	0%	1	1%
others	1	1%	0	0%	3	7%	4	2%
Religion								
Christianity	38	38%	17	44%	19	45%	68	42%
No Religion	50	50%	14	36%	16	38%	85	52%
Islam	6	6%	7	18%	2	5%	3	2%
Hinduism	2	2%	0	0%	0	0%	1	1%
Buddhism	1	1%	0	0%	0	0%	1	1%
Other Religions	3	3%	1	3%	5	12%	5	3%
* Proportion of the total number of participants who rated that particular factor at 5								

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Appendix 11 The frequency of factors' ranking. This figure shows that 166 participants ranked Factor 3 at 1 (similar to what they think). This is followed by 121 participants ranking Factor 1 at 1. This is in contrast to Factor 2B where 207 participants ranked it at 4.
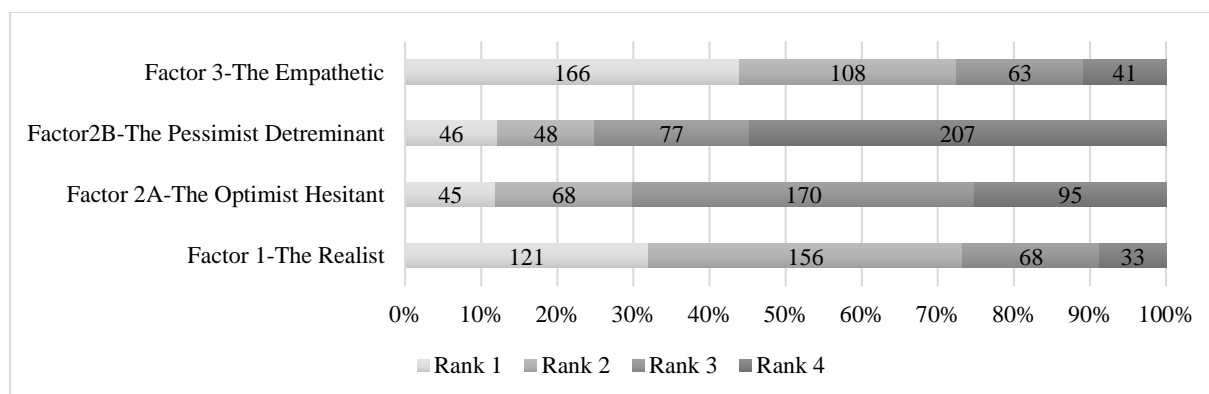
Appendix 12 Demographic criteria for participants who ranked each factor at 1. Since duplication is not possible in ranking question, this table shows the number of people who ranked each factor at 1, the next column shows the proportion of each criteria item per factor, then the total proportion column shows how much each criteria item represents out of the total survey sample. For example, in the first row, 56 female participants ranked Factor 1-The Realist on 1. Of all participants who ranked Factor 1-The Realist at 1, 46% of them were female. Moreover, 33% of all female participants ranked Factor 1-The Realist at 1. This table shows there is no relationship between any criteria and factor ranking.

Item	Factor 1 - The Realist			Factor 2A - The Optimist Hesitant			Factor 2B - The Convinced Pessimist			Factor 3 -The Empathetic		
	N	%*	Total %**	N	%*	Total %**	N	%*	Total %**	N	%*	Total %**
Gender												
Female	56	46%	30%	20	44%	11%	27	59%	14%	89	54%	47%
Male	65	54%	34%	25	56%	13%	19	41%	10%	77	46%	40%
Age												
18-29	34	28%	28%	18	40%	15%	16	35%	13%	54	33%	44%
30-49	49	40%	33%	20	44%	14%	18	39%	12%	59	36%	40%
50 or older	38	31%	35%	7	16%	6%	12	26%	11%	53	32%	49%
Region												
England	90	74%	33%	34	76%	12%	34	74%	12%	116	70%	42%
Scotland	9	7%	36%	0	0%	0%	5	11%	20%	11	7%	44%
Wales	3	2%	33%	1	2%	11%	0	0%	0%	5	3%	56%
Northern Ireland	0	0%	0%	1	2%	50%	0	0%	0%	1	1%	50%
Non-identified	19	16%	27%	9	20%	13%	7	15%	10%	33	20%	47%
Education												
Less than high school	12	10%	36%	2	4%	6%	8	17%	24%	10	6%	30%
High school graduate	45	37%	31%	15	33%	10%	18	39%	12%	69	42%	47%
Bachelor's degree	38	31%	32%	16	36%	13%	15	33%	13%	49	30%	41%
Post-graduate degree	26	21%	33%	12	27%	15%	5	11%	6%	38	23%	49%
Income												
£30,000 and below	25	21%	15%	14	31%	8%	27	59%	16%	77	46%	45%
£30,001 - £45,000	14	12%	16%	13	29%	15%	9	20%	10%	34	20%	40%
£45,000 and above	39	32%	32%	18	40%	15%	10	22%	8%	55	33%	45%
Ethnicity												
White	106	88%	33%	35	78%	11%	37	80%	12%	142	86%	44%
Caribbean	2	2%	50%	0	0%	0%	0	0%	0%	2	1%	50%
African	1	1%	13%	0	0%	0%	3	7%	38%	4	2%	50%

Indian	3	2%	50%	0	0%	0%	2	4%	33%	1	1%	17%
Pakistani	2	2%	40%	0	0%	0%	0	0%	0%	2	1%	40%
Bangladeshi	1	1%	25%	1	2%	25%	0	0%	0%	2	1%	50%
Chinese	2	2%	40%	2	4%	40%	1	2%	20%	0	0%	0%
Any other Asian background	1	1%	20%	2	4%	40%	0	0%	0%	2	1%	40%
Latino	0	0%	0%	1	2%	50%	0	0%	0%	1	1%	50%
Arab	0	0%	0%	3	7%	27%	0	0%	0%	7	4%	64%
Middle eastern	2	2%	67%	1	2%	33%	0	0%	0%	0	0%	0%
Others	1	1%	14%	0	0%	0%	3	7%	43%	3	2%	43%
Religion												
Buddhism	1	1%	25%	0	0%	0%	0	0%	0%	3	2%	75%
Christianity	55	45%	34%	18	40%	11%	21	46%	13%	67	40%	41%
Hinduism	4	3%	100%	0	0%	0%	0	0%	0%	0	0%	0%
Islam	4	3%	17%	8	18%	35%	3	7%	13%	11	7%	48%
No religion	53	44%	30%	22	49%	12%	19	41%	11%	85	51%	48%
Other Religions	4	3%	50%	0	0%	0%	3	7%	38%	1	1%	13%

* Proportion from the total number of participants who ranked that particular factor at 1
** Proportion of the total number of participants in the survey

Appendix 13 Organ donation attitude per factor. This table shows that that 88% of all registered donors in the study ranked either Factor 1 or Factor 3 at 1. Similarly, 75% of those who are against organ donation ranked Factor 2A and 2B at 1.

Factor	Attitude							
	Registered donors		In favour		Undecided		Against	
	N	%	N	%	N	%	N	%
Factor 1 - The Realist	59	32%	39	40%	20	23%	3	25%
Factor 2A - The Optimist Hesitant	11	6%	11	11%	22	26%	2	17%
Factor 2B - The Convinced Pessimist	11	6%	7	7%	21	24%	7	58%
Factor 3 - The Empathetic	102	56%	41	42%	23	27%	0	0%

Appendix 14 42 Knowing a donor per factor. The table shows no association between factors and knowing a donor.

Factor	Know donor			
	No		Yes	
	N	%	N	%
Factor 1 - The Realist	94	33%	27	30%
Factor 2A - The Optimist Hesitant	35	12%	11	12%
Factor 2B - The Convinced Pessimist	30	10%	16	18%
Factor 3 – The Empathetic	129	45%	37	41%

Appendix 15 Discussing organ donation with family and/or friends per factor. The table shows no association between factors and discussing organ donation with a friend or a family member.

Factor	Discuss			
	No		Yes	
	N	%	N	%
Factor 1 - The Realist	48	32%	73	32%

Factor 2A - The Optimist Hesitant	22	15%	24	11%
Factor 2B - The Convinced Pessimist	23	15%	23	10%
Factor 3 - The Empathetic	58	38%	108	47%

Appendix 16 Spouse attitude per factor. The table shows no association between factors and spouse's attitude.

	Spouse Attitude							
Factor	Unmarried		Favourable		Against		I do not know	
	N	%	N	%	N	%	N	%
Factor 1 - The Realist	63	30%	44	38%	2	29%	12	26%
Factor 2A - The Optimist Hesitant	28	13%	12	10%	0	0%	6	13%
Factor 2B - The Convinced Pessimist	29	14%	6	5%	3	43%	8	17%
Factor 3 - The Empathetic	89	43%	55	47%	2	29%	20	44%

Appendix 17 Volunteering per factor. The table shows no association between factors and doing volunteer work.

	Volunteer			
Factor	No		Ye	
	N	%	N	%
Factor 1 - The Realist	90	31%	30	35%
Factor 2A - The Optimist Hesitant	35	12%	11	13%
Factor 2B - The Convinced Pessimist	35	12%	11	13%
Factor 3 - The Empathetic	132	45%	34	40%