Understanding the Barriers to Organ Donation Under Opt-out Legislation

Jordan Miller

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Division of Psychology
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Abstract

Background: Although transplantation rates around the world have increased by 7% since 2015, existing rates of transplantation fulfil less than 10% of global need. In the United Kingdom, approximately three people die every day as a result of the donor shortage. To increase the donor pool, England, Scotland and Wales have reformed donor legislation by implementing opt-out consent. Emotional barriers are key organ donation deterrents under opt-in consent, however, limited research has explored barriers under opt-out consent. The aim of this thesis was to conduct an in-depth, mixed-methods investigation into the barriers to organ donation under opt-out legislation.

Methods: This thesis encompassed five studies: (Study 1) a questionnaire study (*n* =1202) measuring opt-out intentions, emotional barriers and testing the efficacy of an NHS "myth-busting" intervention, (Study 2) a thematic analysis of free-text responses from the above study (*n* =923) which explored the reasons behind donor choices under opt-out consent, (Study 3) a qualitative interview study (*n* =15) which explored attitudes to opt-out consent with individuals who intend to opt-out and, (Study 4) an online study (*n* =1352) which investigated language and message framing used in opt-out campaigns on the development of reactance and its impact on donor intentions. Lastly, Study 5 encompassed a systematic review of the factors influencing family decision-making for organ donation.

Findings and Conclusions: Emotional barriers, namely a desire to preserve bodily integrity and medical mistrust are key deterrents under an opt-out donation system. Psychological reactance and perceptions of unwarranted government control represented unique barriers influencing donor-relevant decisions. Subtle language and framing manipulations within opt-out communication campaigns influenced the development of psychological reactance and one's donor intentions. Consideration of the most effective ways of communicating this sensitive legislative change is critical to mitigate reactance and reduce the number of opt-out respondents.

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List of Publications Arising from This thesis

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Miller, J., Currie, S., & O'Carroll, R. E. (2019). *‘If I donate my organs it’s a gift, if you take them it’s theft’*: A qualitative study of planned donor decisions under opt-out legislation. *BMC Public Health*, 19(1), 1463. https://doi.org/10.1186/s12889-019-7774-1

Miller, J., Currie, S., McGregor, L. M., & O'Carroll, R. E. (2020). *'It's like being conscripted, one volunteer is better than 10 pressed men'*: A qualitative study into the views of people who plan to opt-out of organ donation. *British Journal of Health Psychology*, 25, 257-274. https://doi.org/10.1111/bjhp.12406

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Other Dissemination

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Conference Presentations

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Declaration

I declare that, except where explicit reference is made to the contribution of others, the thesis embodies the results of my own research and was composed by me.

This thesis has not been submitted for any other degree at the University of Stirling or any other institution.

Signature: Jordan Miller

Printed name: Jordan Miller

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List of Acronyms and Abbreviations

ANOVA – Analysis of Variance

AR – Anticipated Regret

BAME – Black Asian and Minority Ethnic

BIT – Behavioural Insights Team

CASP – Critical Appraisal Skills Programme

DBD – Donation after Brainstem Death

DCD – Donation after Circulatory Death

DVLA – Driver and Vehicle Licensing Authority

EC – Elizabeth Collins

ENTREQ – Enhancing Transparency in Reporting the Synthesis of Qualitative Research

HBM – Health Belief Model

HTA – Human Tissue Authority

JM – Jordan Miller

LM – Lesley McGregor

MANOVA – Multivariate Analysis of Variance

NHBD – Non-Heart-Beating Donation

NHS – National Health Service

NHSBT – National Health Service Blood and Transplant

ODR – Organ Donor Register

ODT – Organ Donation Taskforce

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROSPERO – International Prospective Register of Systematic Reviews

ROC – Ronan O’Carroll

SC – Sinéad Currie

SN-OD – Specialist Nurse Organ Donation

SPIDER – Sample, Phenomenon of Interest, Design, Evaluation and Research Type

TPB – Theory of Planned Behaviour

TRA – Theory of Reasoned Action

UK – United Kingdom

USA – United States of America

YHEC – York Health Economics Consortium

Chapter 1: Introduction

Preface

The original aim of this research, which began in October 2017, was to explore the barriers to organ donation in the United Kingdom (UK) and to investigate interventions to increase the number of donor registrations. However, in June 2017, shortly before the start of this PhD, the Scottish Government announced plans to introduce an opt-out system of organ and tissue donation. In October 2017, the UK Government also announced plans to change legislation and introduce an opt-out consent system in England. In short, this legislative change eliminates the need for active registration on the National Health Service (NHS) organ donor register to indicate one's consent for organ donation. Rather, an opt-out system follows deemed consent; meaning that if no donor decision has been registered, eligible adults are automatically considered to have agreed to donate their organs when they die. If an individual does not want to be an organ donor, they are required to actively record this by opting out of the organ donor register. This landmark change in legislation presented a unique and timely opportunity to focus this PhD project on the transition to opt-out consent in England and Scotland. The overarching aim of this thesis was to provide an in-depth examination of the barriers to organ donation, with a specific focus on the barriers influencing donor decision-making under an opt-out consent system, given the scarcity of empirical evidence in this area.

1.1 Organ Donation in the United Kingdom

Organ Transplantation is the most effective treatment for end-stage organ disease. This complex procedure involves surgically removing donor organs or tissue from an individual's body and transplanting them into a compatible recipient (NHS Blood and Transplant, 2019b). Organs can be transplanted posthumously from an individual who has died (deceased organ donation), or in the case of specific organs, for example, a kidney or a lobe of the liver, while an individual is alive (living organ donation). This thesis focuses exclusively on deceased organ donation. Throughout the main body of Chapter 1, an overview of organ donation in the United Kingdom, and the literature on barriers to organ donation will be presented. Within the second half of this chapter, an outline of the transition to opt-out consent legislation, the evidence in support of its implementation, and a rationale for the thesis will be provided.

Organ Donation and Transplantation services in the United Kingdom are managed by a specific subsection and special health authority of the NHS, known as NHS Blood and Transplant (NHSBT). This specialist operational body maintains the national Organ Donor Register (ODR) the UK transplant registry, coordinates the allocation of organs between donors and recipients across the UK (and occasionally Europe) and leads the training and employment of specialist clinical staff involved in the organ donation process.

In the UK, the lives of almost 5,000 people are either saved or transformed by an organ transplant each year (NHS Blood and Transplant, 2020a). However, across the world, there is a serious discrepancy between the number of people waiting for an organ transplant and the number of organ donors (Global Observatory on Donation and Transplantation, 2020). This shortage is echoed in the UK, where, as of February 2020, a total of 6,138 individuals were on the active waiting list for a potentially lifesaving, or life-improving organ transplant[1]. A substantial proportion of these individuals will die before they receive a transplant; with the most recent data from NHSBT reporting that between 2019 - 2020, a total of 372 people died while on the active transplant waiting list (NHS Blood and Transplant, 2020a). This figure does not include the 746 individuals who were removed from the active waiting list during

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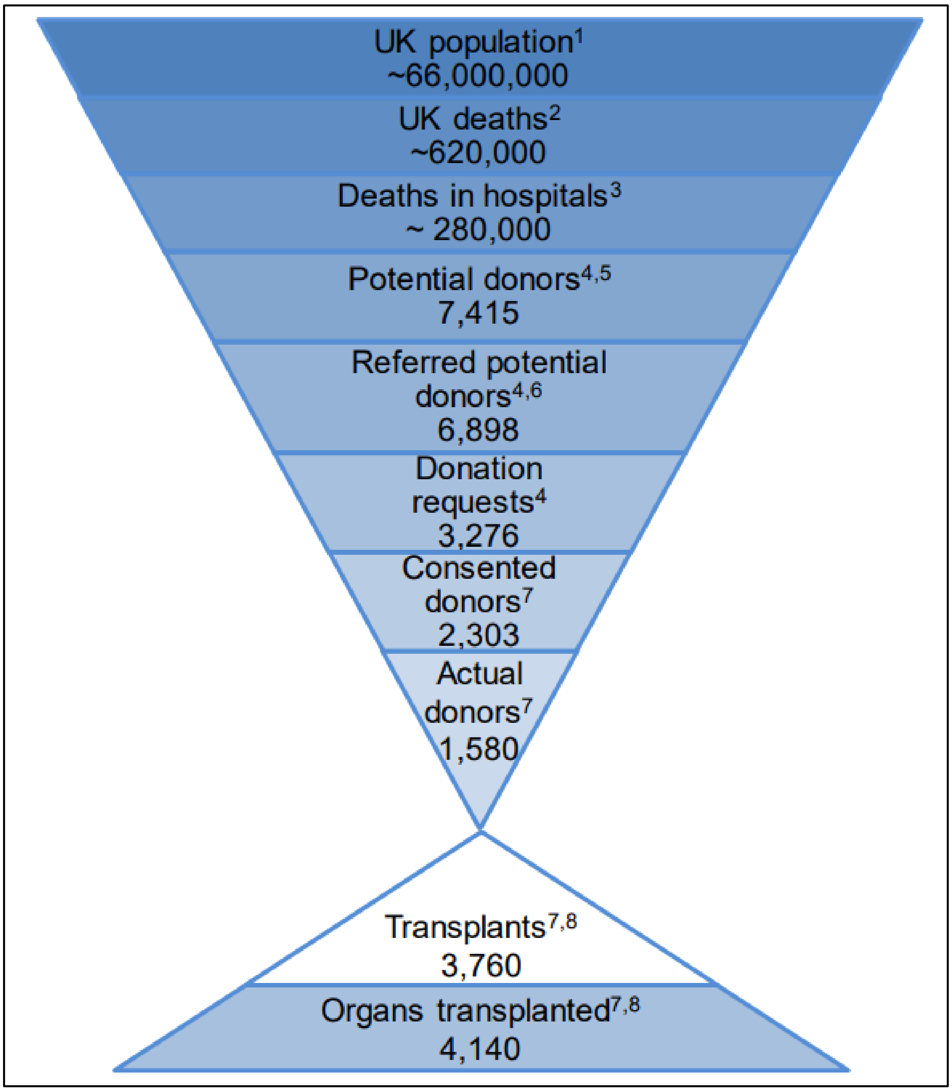
[1] Waiting list data is presented from February 2020. Figures beyond March 2020 do not accurately reflect the need for organ transplantation due to the Covid-19 pandemic.

this period as a result of deteriorating physical health. Many of these individuals were deemed too unwell to survive transplant surgery and will have died shortly afterwards. Taken together, this suggests that over 1,000 people die needlessly every year in the UK due to the lack of available organ donors. Given that just one per cent of annual deaths in the UK occur in circumstances whereby organ donation is a viable option, exploration of factors that deter potential donors is of critical importance (NHS Blood and Transplant, 2020a). Figure 1.1, taken from the annual NHSBT donor activity report demonstrates this pathway, from the proportion of annual deaths to the number of eventual organ donors. This illustrates that of the 7,415 potentially eligible donors, just 1,580 became actual organ donors.

Figure 1. 1. Diagram of UK Organ Donation Activity from 1 April 2019 – 31 March 2020



Note. [1] Mid 2018 estimate: www.ons.gov.uk

[2] 2018 data: England & Wales: www.ons.gov.uk; Scotland: www.gro-scotland.gov.uk; Northern Ireland; www.nisra.gov.uk

[3] 2018 data: England & Wales www.ons.gov.uk; Scotland www.isdscotland.org; Northern Ireland www.nisra.gov.uk

[4] 2019/2020 data, NHSBT, Potential Donor Audit - 8 June 2020.

[5] Potential donor - patients for whom death was confirmed following neurological tests or patients who had treatment withdrawn and death was anticipated within four hours.

[6] Referred potential donor – Potential donor who was discussed with a SN-OD.

[7] 2019/2020 deceased donor data: NHSBT, UK Transplant Registry.

[8] Using organs from actual donors in the UK.

1.1.2 Pathways of Donation

The two principal pathways of posthumous organ donation in the UK are, donation after brainstem death (DBD), which occurs following clinical confirmation of brainstem death, and donation after circulatory death (DCD), which takes place within the eligible time frame following cessation of cardiac activity, known as cardio-respiratory death. Historically, organ retrieval exclusively occurred following circulatory death, formerly, non-heart-beating donation (NHBD). However, in 1976, after the introduction of neurological diagnostic criteria to confirm irreversible brainstem death in the UK, organ retrieval from brain dead patients acted to substantially increase the supply of donor organs (Academy of Medical Royal Colleges, 1976; NHS Blood and Transplant, 2010, 2020a).

The timely identification and referral of potentially eligible DBD or DCD donors is a key factor in optimising the number of organ donors (NHS Blood and Transplant, 2012). Therefore, in accordance with the UK Timely Identification and Referral of Potential Organ Donors Strategy, if an individual in hospital is identified as satisfying criteria for brainstem death, or is anticipated to undergo brainstem death testing, a referral for potential organ donation is made to a team of specialist nurses who coordinate the donation process. In probable donation after cardiac death cases, a referral is advised as soon as the intention to withdraw life-sustaining treatments has been authorised (NHS Blood and Transplant, 2012). The timely referral of potential donors enables the prompt involvement of specialist nurses in organ donation (SN-OD) who navigate the discussion around end-of-life care and the potential for organ donation with a donor family.

A number of factors are taken into consideration when discussing the possibility of organ donation with a donor family. This primarily includes evidence of a recorded donation decision on the national organ donor register (ODR). In cases where the deceased had registered as a donor, a specialist nurse will discuss this with the donor's family and encourage them to support their loved one's recorded decision. For individuals who had not registered a donor decision, a specialist nurse will raise the possibility of donation and will ask family members to make a surrogate decision on the patient's behalf. In the UK, family members or appropriate close friends of the deceased are required to provide authorisation for organ donation, irrespective of whether the deceased had registered as an organ donor. In instances where no appropriate individual can be contacted, the retrieval of donor organs would not proceed (Human Tissue Authority, 2017). This excludes Wales, whereby donation can proceed in the absence of family members, though organs retrieved under these circumstances are considered high-risk (Shaw, 2016). The rate of consent varies substantially between those who have formally registered or shared their donation decision with family, in comparison to non-registered potential donors, with consent authorised in just 50% of instances where the deceased's choice was not known by the family. This compares to a rate of 91% for patients with a recorded or expressed donation decision (NHS Blood and Transplant, 2020a).

In the context of this thesis, it is important to acknowledge that the architecture of consent for organ donation varies across the four nations of the UK, in line with the implementation of opt-out legislation. The research in this thesis, focuses primarily on participants from England and Scotland, with a small number of participants from Northern Ireland included in Study 1 and Study 2. Throughout the duration of this research, all three of these nations operated in accordance with an opt-in or express consent policy of organ and tissue donation, although opt-out legislation was introduced in England in May 2020 and is scheduled in Scotland for March 2021. A detailed account of the transition to opt-out consent throughout the UK will be provided in the second half of this chapter.

1.2 A Brief Examination of Health-Related Decision-Making and Organ Donation

A substantial body of evidence reinforces the contributing role of affective attitudes and emotions at guiding health-related decision-making. A brief overview of the evidence to support this interpretation in the context of decision-making about organ donation will be provided throughout the following section.

Across the literature in health-related decision-making, it is well-established that decisions pertaining to one's health are principally driven by rational-cognitive processes, which rely on a combination of deliberative informational processing and reasoning to inform decision-making (Conner & Norman, 2015). Accordingly, a number of theoretical models support the view that health-related decisions are principally determined by rational, reasoned actions. These models include, but are not limited to, Social Cognitive Theory (SCT) (Bandura, 1986), The Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975) and The Theory of Planned Behaviour (TPB), (Ajzen, 1991). Each of these models are alike in that they propose decision-making to arise following a systematic sequence of cognitive evaluations and reasoning. However, the application of social cognition models is somewhat challenging in the context of organ donation. Consistently, when asked, approximately 80-90% of the UK population report favourable attitudes and intentions towards organ donation (NHS Blood and Transplant, 2017a; Webb et al., 2015). Yet, just 40% of the UK population are registered as organ donors. This is a clear example of an intention-behaviour gap. Thus, the discrepancy between an individuals' favourable attitudes, intentions and their subsequent behaviour suggests that rational-cognitive factors do not exclusively drive donor-relevant decisions.

Although social cognition models such as the TPB are widely recognised as being strong predictors of intentions and behaviour across a number of health-related behaviours, this varies substantially across different categories of behaviour. For example, an extensive meta-analysis of 206 studies by McEachan and colleagues (2011) found that the specific type of behaviour moderated the predictive power of the TPB. Overall, the findings indicated that while the TPB demonstrated high predictive validity for physical activity and dietary behaviours, comparably less predictive validity was reported for sex, health-detection, risk, and abstinence behaviours (McEachan et al., 2011). A plausible reason for this discrepancy suggested by the authors is that the TPB focuses on rational cognitive influences, yet, factors such as affective attitudes may have superior predictive validity under some circumstances. This seems to be particularly important when considering health-related decisions that evoke an emotional response.

Indeed, there is now mounting criticism of the predictive validity of such social cognitive models, in acknowledgement of their problematic lack of consideration into the role of affective attitudes and emotions in predicting intentions and behaviour (Sheeran et al., 2013; Sniehotta et al., 2014; Williams et al., 2018). Existing research supports this view, reporting affective attitudes to supersede the contribution of cognitive variables in predicting one's behavioural intentions (Kraft et al., 2005; Lawton et al., 2009). For example, in Lawton et al.'s (2009) study, the predictive validity of both affective and cognitive attitudes were evaluated in order to differentiate the predictive value of each attitudinal construct across various categories of health behaviours. In total, *n* = 390 participants completed self-report measures of cognitive and affective attitudes in relation to 14 health behaviours. These included, self-examination, alcohol consumption and physical activity behaviours, selected in accordance with UK Government targets for health. One month later, self-report measures of intention and behaviour were obtained. The findings indicated that affective attitudes were significant predictors of intention and self-reported behaviour for all 14 health behaviours. Cognitive attitudes, however, were significant predictors of intention for 11 of the behaviours, and significant predictors of behaviour for just seven behaviours. Importantly, affective attitudes demonstrated substantially stronger and more consistent predictive validity than cognitive attitudes. These findings, therefore, endorse the powerful role of emotions and affective attitudes in driving one's intentions and behaviour. As such, the authors called for further research to disentangle the role of affective attitudes as independent predictive factors in guiding health behaviours. A number of researchers have echoed this viewpoint, acknowledging that across the literature, comparably less attention has been dedicated to investigating affective attitudes and emotions as key determinants of health behaviours (Conner et al., 2015; Lawton et al., 2009; O'Carroll, 2020; Williams et al., 2019).

1.2.1 Determinants of Organ Donor Behaviour

In the context of organ donation, historically, researchers investigating the predictive factors and deterrents to organ donor registration have modelled donor-relevant behaviours in accordance with traditional social-cognitive based theories including, the Theory of Reasoned Action, Theory of Planned Behaviour, and the Health Belief Model. With reference to the TPB, one of the most frequently used models of donor behaviour, intention to engage in a specific behaviour is thought to be a function of one's attitude towards that behaviour, subjective norms, and perceived behavioural control. Existing research has endorsed the TPB as being predictive of people’s donor intentions (Godin et al., 2008; Hyde & White, 2009b; Park & Smith, 2007).

However, as described previously, despite public awareness of the need for organ donors, positive attitudes and intentions towards organ donation, the vast majority of the public have not registered as organ donors in the UK (NHS Blood and Transplant, 2020a; Webb et al., 2015). In 2008, Morgan, Stephenson and colleagues described similar findings in the context of the United States (US) in their paper entitled *“Facts versus ‘Feelings’: How rational is the decision to become an organ donor?”.* In this seminal research article, the authors explained that social-cognitive approaches which assume donor-decisions to be driven by rational-cognitive factors are ineffective at understanding the complex factors that predict donor behaviour (Morgan, Stephenson, et al., 2008). Instead, the authors advocated for the examination of “non-cognitive” variables as potential factors influencing donor relevant decisions. These were subsequently defined as the ick factor, the jinx factor, medical mistrust and bodily integrity. Although forms of “non-cognitive” variables have been acknowledged within existing literature (e.g., Brug et al., 2000) the authors state that such variables have, in most occasions, been regarded as an “*important afterthought*” (Morgan, Stephenson, et al., 2008, p.648) rather than the primary predictive factors of donor intentions and behaviour. As such, a systematic examination of visceral, “non-cognitive” variables and their utility in determining donor behaviour was deemed imperative.

1.3 ‘Non-Cognitive’ Determinants of Organ Donor Behaviour

1.3.1 Conceptualising ‘Non-Cognitive’ Determinants of Donor Behaviour

Before proceeding with an overview of research from Morgan, Stephenson and colleagues (2008), it is important to first define the “non-cognitive” variables described. Reference to the term “non-cognitive” beliefs throughout this thesis will largely follow the conceptualisations provided by Morgan, Stephenson, et al. (2008) and will therefore be used to describe deep-seated beliefs regarding organ donation that are associated with emotion or affect. These beliefs can arise independent from direct experience and may represent an automatic negative response to the notion of organ donation. Such beliefs are reported to be difficult to articulate and inherently problematic to objectively refute. For example, concerns relating to the physical integrity of the body being damaged as a consequence of organ donation and the negative repercussions of this on the afterlife, cannot be disproved. There are, however, existing debates regarding the utility of the term “non-cognitive” as representative of beliefs that are formed in the absence of conscious thought or awareness (O'Carroll, Foster, et al., 2011; Williams et al., 2019). Whilst some of these beliefs, for example, the ick factor, which represents an instinctual feeling of disgust, may arise as an immediate subconscious gut response to the thought of organ donation, others such as medical mistrust, involve a degree of conscious reasoning. In particular, given that Morgan, Stephenson, et al. (2008) stated that non-cognitive beliefs were related to reasoning, use of the term “non-cognitive” may be somewhat misleading. Therefore, in line with recommendations from O’Carroll, Foster, et al. (2011) the term “non-cognitive” variables will be referred to interchangeably throughout this thesis as ‘affective attitudes’ or ‘emotional barriers’. Each of the four barriers identified by Morgan, Stephenson, et al. (2008) are defined below and an example item from their emotional barriers scale is presented for interpretation.

Bodily Integrity: *Removing organs from the body just isn’t right.*

Bodily integrity concerns relate to fears of the physical integrity of the body being irreparably compromised as a result of organ donation (Morgan, Stephenson, et al., 2008). Rooted in the principles of bioethics, a central feature of bodily integrity and autonomy is the belief that the body represents an ‘untouchable core’ (Rendtorff, 2008). With reference to organ donation, this encompasses the belief that the human body should remain whole and undamaged after death and ultimately, the fear that removing organs may violate the integrity and dignity of the deceased person. For some people, this relates to uncertainties relating to the physical appearance of the body in the afterlife if one’s organs were to be removed. It is primarily for this reason that beliefs surrounding the maintenance of bodily integrity are inherently attributed to religious barriers, although fears surrounding bodily integrity are not wholly conditional upon one’s subscription to a particular faith (Morgan et al., 2003).

Medical Mistrust: *If I register as an organ donor, doctors might take my organs before I’m actually dead.*

Medical mistrust is defined as an overarching mistrust of medical professionals or health care institutions. Evidence has primarily considered medical mistrust to encompass fears of a premature declaration of death to procure donor organs, and subsequent fears of one being alive during the organ retrieval process (Morgan, Stephenson, et al., 2008). In addition, medical mistrust may also encompass concerns of general medical malpractice and poorer quality of care in such instances where medical staff are aware that an injured or unwell person is a potential organ donor.

The Ick Factor: *The idea of organ donation is somewhat disgusting.*

The ick factor represents an instinctual aversion to the thought of organ donation. Although associated with fears of mutilation of the body, which may to some degree overlap with bodily integrity concerns, the ick factor is distinct in that it manifests as a strong, visceral, gut response to the overall notion of organ donation (Morgan, Stephenson, et al., 2008). Such beliefs have been evidenced to encompass both an aversion to the thought of donating and receiving donor organs (Sanner, 2001).

The Jinx Factor: *The surest way to bring about my own death is to make plans for it like signing an organ donor card.*

The jinx factor is characterised as superstitious beliefs relating to the potential misfortune that may arise as a consequence of registering as an organ donor (Morgan, Stephenson, et al., 2008). This primarily concerns the belief that the act of registering as an organ donor is bad luck and may increase the likelihood of death itself.

1.3.2 The Role of Emotional Barriers at Influencing Donor Behaviour

As previously described, Morgan, Stephenson, et al. (2008) noted that models of rational decision-making provide comparatively weak predictive utility of donor-relevant behaviours. Therefore, in their seminal study, which included over 4,000 adults across six US states, a model test of both traditional rational-cognitive and “non-cognitive” emotional variables was conducted. As such, participants completed measures assessing cognitive-based determinants of donor behaviour in accordance with the TPB and the TRA (attitudes, knowledge, and subjective norms) and non-cognitive emotional variables defined as the ick factor, the jinx factor, medical mistrust and bodily integrity. Measures of self-reported donor behaviour (registration on the US donor register or consent specified on a driver’s licence) were also obtained. The data then underwent structural equation modelling (SEM) with the four non-cognitive emotional domains (ick, jinx, medical mistrust and bodily integrity) specified as latent variables which collectively loaded onto the construct of non-cognitive beliefs. The findings indicated that rational-cognitive factors were comparably weak predictors of donor behaviour. Instead, the strongest direct determinants of donor registration were non-cognitive or negative affective beliefs towards organ donation (Morgan, Stephenson, et al., 2008). Of the four variables, upholding the physical integrity of the body was the strongest negative predictor of behaviour.

Subsequent research from O’Carroll, Foster, et al. (2011) offers support for these findings in a UK context, reporting that affective attitudes play a principal role in influencing donor relevant behaviours. Each stage of this three-part study will be discussed in turn. The first study, which involved 151 participants, tested whether the emotional barriers identified by Morgan, Stephenson, et al. (2008) would discriminate between self-reported registered donors and non-donors. The findings indicated that emotional barriers significantly differentiated donors from non-donors, with non-donors reporting significantly higher negative emotional barriers. Each of these barriers demonstrated a medium between-group effect size, with the strongest effect observed for the ick factor (r = .44), followed by bodily integrity concerns (r = .37), the jinx factor (r = .31) and medical mistrust (r = .30). This evidence replicated the findings of Morgan, Stephenson, et al. (2008) amongst a sample of UK adults.

The second stage involved 138 participants, and further assessed the discriminant utility of emotional barriers between donors and non-donors, but importantly, included traditional measures of rational-cognitive variables (attitudes, knowledge and subjective norms). In further support of Morgan, Stephenson, et al’s. (2008) findings, rational-cognitive factors of donor behaviour did not differ between donors and non-donors (O'Carroll, Foster, et al., 2011). Regarding non-cognitive variables, only two of the emotional barriers, the ick factor and bodily integrity concerns significantly differentiated donors versus non-donors. The final study, which included a larger representative sample of the UK general adult population (n = 342) again found non-donors to exhibit significantly higher negative emotional barriers towards organ donation. Collectively, the evidence from all three stages of this research provides important insights into the role of affective attitudes in guiding donor behaviours. Further research has also revealed that emotional barriers not only discriminate between current donor behaviour, but play a predictive role in discerning future decisions about organ donation (Shepherd & O’Carroll, 2014). In this prospective study, participants who were not registered as organ donors first completed measures of emotional barriers towards organ donation. Following completion of the questionnaire, participants were presented with an electronic link to the UK organ transplant website with the instructions "*If you would like to register as an organ donor, please click here to be redirected to the UK Organ Transplant website. It only takes a few minutes to register as an organ donor*". This served as a proxy measure of future donor behaviour. The results indicated that only bodily integrity concerns reduced the likelihood of participants selecting the link to register as an organ donor. This evidence, taken together with the findings from Morgan, Stephenson, et al. (2008) and stage two of the previously discussed study from O'Carroll, Foster, et al. (2011), indicate that bodily integrity concerns may act as one of the most salient barriers towards organ donation.

To summarise, the above studies provide compelling evidence that the determinants of donor behaviour are not exclusively rational, and instead highlight the principal role of emotions in driving donor-relevant decisions (Morgan, Stephenson, et al., 2008; O'Carroll, Foster, et al., 2011; Shepherd & O'Carroll, 2014). Collectively, this represents a growing evidence base which supports the view that negative affective attitudes towards organ donation are key predictors of donor behaviour (Cohen & Hoffner, 2013; Resnicow et al., 2012), over and above that observed for traditional rational-cognitive models of decision-making (Brug et al., 2000; Quick et al., 2014).

1.3.3 Interventions to Increase Donor Registration

In recognition of the important role emotions play in donor-relevant behaviours, several studies have tested interventions to reduce or bypass emotional barriers and encourage donor registration. One of the most well-documented approaches is by manipulating anticipated regret (AR). Regret is defined as an aversive emotion that arises when one believes the outcome of a situation may have been more favourable if their behaviour (action or inaction) had been different (Zeelenberg & Pieters, 2007). Anticipated regret theory, therefore posits that reflecting on potential future regret (in this context, one may later regret not registering as an organ donor) can act to increase positive health behaviours as a means to avoid the aversive emotion of regret (Zeelenberg & Pieters, 2007). Robust evidence has validated the use of AR manipulations in strengthening intentions and the prospective enactment of a number of health behaviours, including vaccination, screening and physical activity behaviours (for reviews, see Brewer et al., 2016; Sandberg & Conner, 2008).

With reference to organ donation, a pilot study from O'Carroll, Dryden and colleagues (2011) tested whether a brief anticipated regret intervention would increase rates of registration on the organ donor register (measured 1-month following the study) versus a TPB questionnaire and a control questionnaire. It was found that simply asking participants to consider the future regret they would feel if they did not register as an organ donor, significantly increased self-reported registration behaviour. In total, 21% of those in the intervention group reported registering as a donor after the study, compared to 13% for participants who received the TPB questionnaire and 8.5% for the control group (O'Carroll, Dryden, et al., 2011). Further research has also shown AR to increase one's intentions to posthumously donate their organs (O'Carroll, Foster, et al., 2011). Taken together, these findings suggest that encouraging non-donors to reflect on the anticipatory regret of their inaction towards organ donation, may increase donor-relevant behaviour.

Though both studies were limited in that they relied upon self-report measures of intention and behaviour, a recent large-scale study has examined the effect of AR using verified measures of donor behaviour (O'Carroll et al., 2016). In this large randomised controlled trial, over 14,500 members of the Scottish general public were allocated to one of four experimental questionnaire arms: a no questionnaire control, a questionnaire control, a TPB questionnaire, and in the intervention arm, a questionnaire containing measures of anticipated regret. Donor behaviour was measured in the form of verified registration on the UK donor register six months later. Contrary to previous studies, the authors found the manipulation of anticipated regret to significantly reduce verified donor registration in comparison to the control conditions (O'Carroll et al., 2016). A potential explanation for this unexpected result was that participants in the AR group also completed questions assessing negative emotional beliefs towards organ donation (e.g., bodily integrity and medical mistrust). The authors suggested that measurement of negative affective attitudes in the intervention arm may have elicited an unintended emotional response, actively encouraging participants to consider emotional barriers towards organ donation and thus, may have amplified harmful donation attitudes. This finding ultimately reinforces the powerful influence of emotions in decision-making regarding organ donation.

This interpretation was later investigated by Doherty et al. (2017). In this study, participants were allocated to one of three questionnaire intervention arms. The first, included items assessing both affective and cognitive attitudes towards organ donation, the second omitted measures of affective attitudes, and the third, omitted only negatively worded affective attitudes (e.g., "*The idea of organ donation is somewhat disgusting"*). Self-report measures of intention and a proxy measure of behaviour (accepting an organ donor card immediately following the study) were obtained. The results indicated that participants allocated to group two, where all affective attitudes were omitted, demonstrated significantly higher intentions towards organ donation (Doherty et al., 2017). This group were also more likely to accept an organ donor card, although this was not a statistically significant outcome. In sum, these findings reaffirm the importance of affective attitudes in donor decisions, and advocate for the careful consideration of such measures in health interventions designed to promote donor behaviour.

1.3.4 Choice Architecture and Behavioural Nudging

Although research has explored interventions to promote active donor registration, the most effective method of translating the publics' positive attitudes and intentions into actual donor behaviour, remains largely unclear. As such, in recent years, efforts have transitioned from directly attempting to overcome barriers to organ donation to encourage registration, to influencing the context or environment in which donor decisions are made. This concept, known as choice architecture, has been central to recent approaches designed to increase the number of organ donors (Thaler & Sunstein, 2008). This is because evidence suggests that manipulating the environment within which people make choices, can act to increase engagement with health-related behaviours, namely physical activity, alcohol and eating behaviours (for reviews, see Hollands et al., 2013; Skov et al., 2013).

Manipulating choice architecture draws upon the principles of behavioural 'nudging', defined as "*any aspect of the choice architecture that alters people's behaviour in a predictable way without forbidding any options or significantly changing their economic incentives*" (Thaler & Sunstein, 2008, p.6). In its simplest form, nudging entails presenting information in a certain way to influence decision-making (Hollands et al., 2013). Behavioural nudging, in the context of donor behaviour, is designed to target the longstanding problem of choice deferral observed across the UK. This occurs in part because making decisions about organ donation by nature requires active contemplation of mortality. In further support of this interpretation, literature has shown that when faced with a challenging or emotive decision, people are more likely to revert to choice deferral to relieve a perceived affective burden (Luce, 1998).

1.3.5 Reflective and Impulsive Determinants of Behaviour

Nudge-based interventions draw on the principles of dual-processing models of decision-making (Vlaev et al., 2016). Notably, the reflective impulsive model of decision-making is particularly relevant when exploring the mechanisms behind behavioural nudges (Strack & Deutsch, 2004). This model postulates two distinct systems of information processing, known as reflective and impulsive systems, to underpin decision-making and subsequent behaviour. The reflective system involves a sophisticated sequence of higher order cognitive processing that facilitates the controlled evaluation of knowledge and evidence before a decision is made. Activation of higher order processes such as executive functioning within the reflective system, enables the formulation of rational goal-directed judgements about a particular behaviour. This system subsequently requires a considerable degree of cognitive capacity and is a comparably time-intensive process. In contrast, the impulsive system acts almost independently from conscious reasoning, and is instead driven by automatic impulsive actions. As such, this system is considerably faster, requires little to no cognitive capacity and has a low threshold for informational processing. Of both the reflective and impulsive system, the former is particularly sensitive to choice architecture. Evidence therefore suggests that ‘nudging’ could be applied to promote health-related decision-making via the impulsive route (Vlaev et al., 2016). In the context of organ donation, this may bypass and reduce the detrimental impact of negative affect on one’s donor behaviour.

1.3.6 Behavioural Nudging and Organ Donation

One of the most well-known examples of a successful behavioural nudge strategy has been applied to organ donation. The intervention, which was implemented by the Behavioural Insights Team (BIT), established in 2010 by the UK Government, altered the traditional choice architecture for donor registration via the UK national donor registry (UK Government, 2011). This involved collaboration with the Driver and Vehicle Licensing Agency (DVLA) and made it compulsory for members of the public who were applying for or renewing a UK driver’s license to first answer a question about joining the organ donor register. While the option to register as an organ donor through the DVLA had previously been available since 1994, responses to this question and the proportion of webpage users subsequently registering as donors remained low. This nudge-based strategy actively prompted webpage users to respond to mandatory questions about joining the donor register before completing their application (UK Government, 2011). An experimental study later built on this registration route by testing the effect of incorporating theoretically informed prompted messages on rates of registration (Sallis et al., 2018). In this quasi-randomised controlled trial, over one million individuals were randomised to receive one of seven messages while renewing their road tax on the GOV.UK webpage. The message which applied the principles of reciprocity, e.g., "*I would accept an organ from a deceased donor in order to save my own life*" was most effective at encouraging registrations and is now in use across several end-of-transaction government websites. Registration via the DVLA is now the most frequently used sign-up method, accounting for 57% of total organ donor registrations between 2019-2020 (NHS Blood and Transplant, 2020a). Overall, this indicates the powerful influence of a simple modification to choice architecture, at enhancing donor registration rates. A recent manipulation of choice architecture intended to bypass emotional decision-making, which forms a fundamental part of this thesis, relates to the implementation of opt-out consent legislation.

1.4 The Implementation of Opt-out Consent Legislation in the UK

This thesis is focused on understanding the barriers to organ donation under an opt-out consent system.[2] It is therefore necessary to first contextualise the transition to opt-out consent legislation within the wider context of UK organ donation.

1.4.1 Organ Donation in the United Kingdom

Organ transplantation across the four nations of the UK is governed by the Human Tissue Authority (HTA). The HTA acts to regulate and manage compliance of the ethical removal, storage and use of human organs for transplantation purposes. The primary legislative framework which underpins this across England, Northern Ireland and Wales is the Human Tissue Act (2004). Scotland operates under a similar legislative framework, known as the Human Tissue (Scotland) Act (2006).

Both the Human Tissue Act (2004) and the Human Tissue (Scotland) Act (2006), set out the legal requirements for the consent and authorisation procedures for posthumous organ and

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[2] Throughout this thesis, the opt-out system may be referred to interchangeably as an opt-out, deemed consent or presumed consent system.

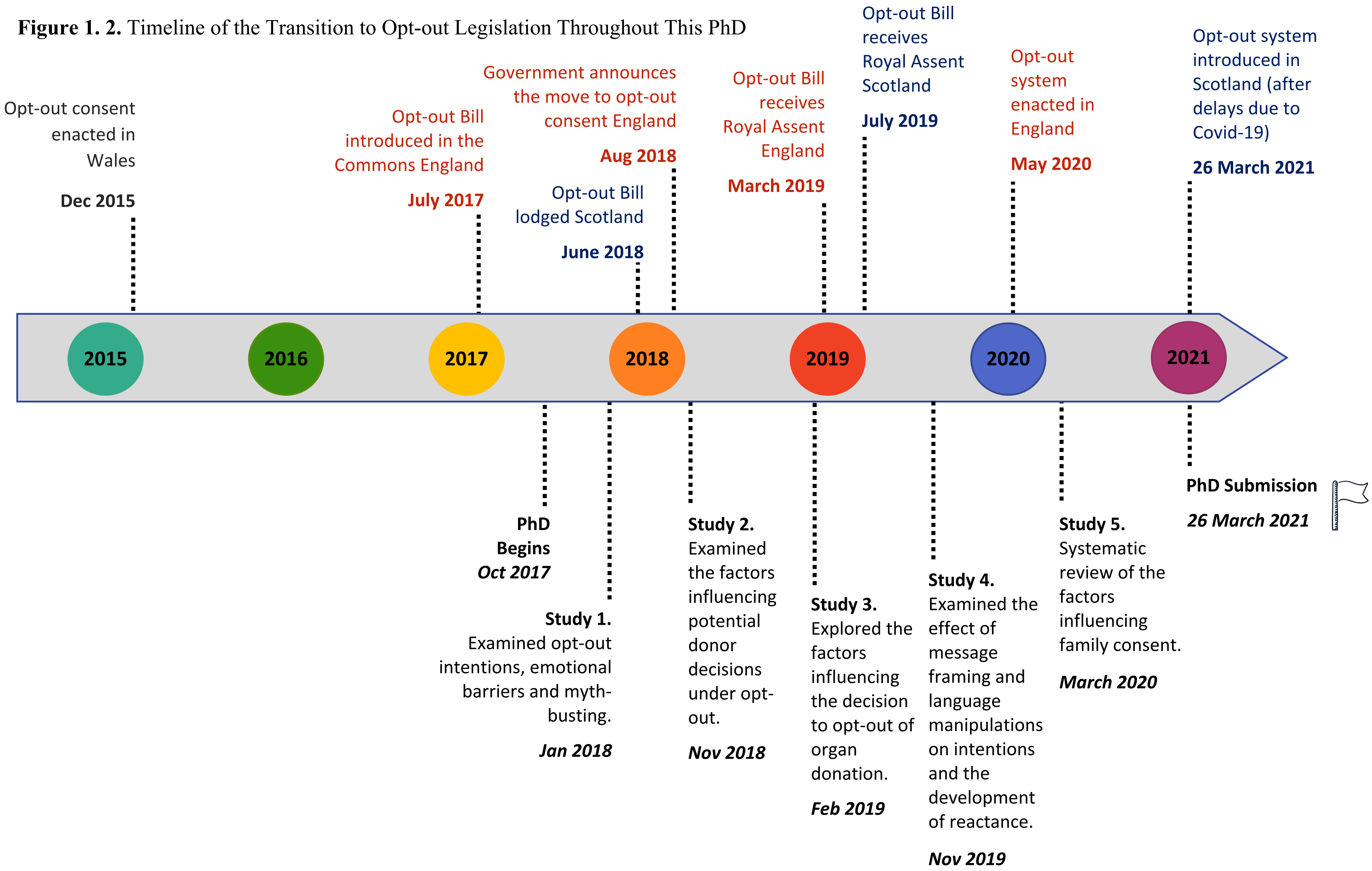
tissue donation. Before the implementation of opt-out consent, both acts were alike in that they operated under the principles of express consent for organ donation. This is also referred to as an ‘opt-in’ policy of consent. Therefore, in England, Northern Ireland, Scotland and Wales, consent for organ donation could previously be authorised following an expression during one’s lifetime of their intention to donate their organs. The principal pathway of expressing donor-relevant decisions involved actively registering consent on the national organ donor register. Authorisation could also be achieved by appointing a nominated representative or by verbally expressing a donation decision to family or appropriate longstanding friends who may act to represent an individual’s wishes in the event of their death (Human Tissue Authority, 2017). In Scotland, children can self-authorise their donor decision from the age of 12, elsewhere in the UK the age of authorisation is 18 years.

It is important to briefly note that while the UK Parliament is the principal legislative body responsible for passing legislation in the UK, Northern Ireland, Scotland and Wales are devolved nations. While the UK Parliament retains the responsibility to legislate on reserved matters, such as foreign policy, devolved matters that concern those living in each respective nation are legislated by that nation’s authoritative body. Legislation concerning organ donation is a devolved power, therefore, the procedure for the passage of donor legislation is independent across each respective nation.

1.4.2 Opt-out Legislation

In 2017, shortly before the commencement of this PhD, the English and Scottish Parliaments announced plans to change the opt-in or express consent donation policy, to an opt-out system. These legislative changes follow that enacted in Wales, the first UK nation to introduce opt-out consent for organ and tissue donation in December 2015. A diagram of the transition to opt-out consent throughout the duration of this thesis is presented in Figure 1.2.

Figure 1. 2. Timeline of the Transition to Opt-out Legislation Throughout This PhD



Opt-out consent enacted in Wales

Dec 2015

Opt-out Bill introduced in the Commons England

July 2017

PhD Begins
Oct 2017

Study 1. Examined opt-out intentions, emotional barriers and myth-busting.

Jan 2018

Opt-out Bill lodged Scotland

June 2018

Government announces the move to opt-out consent England

Aug 2018

Study 2. Examined the factors influencing potential donor decisions under opt-out.

Nov 2018

Study 3. Explored the factors influencing the decision to opt-out of organ donation.

Feb 2019

Opt-out Bill receives Royal Assent England

March 2019

Opt-out Bill receives Royal Assent Scotland

July 2019

Study 4. Examined the effect of message framing and language manipulations on intentions and the development of reactance.

Nov 2019

Study 5. Systematic review of the factors influencing family consent.

March 2020

Opt-out system enacted in England

May 2020

Opt-out system introduced in Scotland (after delays due to Covid-19)

26 March 2021

PhD Submission
26 March 2021

The implementation of opt-out legislation represents a substantial overhaul in traditional organ donation consent procedures. Under an opt-out system, active registration on the national donor register is no longer required to indicate consent for organ donation. Rather, an opt-out system follows the principles of deemed consent or authorisation; meaning that if no decision has been registered, individuals are automatically 'deemed' to consent for organ donation. If an individual does not want to be an organ donor, they are now required to actively record an opt-out decision on the donor register. As such, an opt-out system will enable consent to be passively deemed without the need for people to action an intention to donate. The primary rationale behind this system is that altering the automatic default (the passive option) to consent rather than refusal, should align with the majority of the publics' support and positive intentions towards organ donation. This should, theoretically, act to bridge the gap between the publics' favourable intentions towards organ donation and inaction, thus increasing the pool of potential donors. This is important, as although the vast majority of the UK public are reported to support organ donation, in practice, less than half are registered as donors (NHS Blood and Transplant, 2020a; Webb et al., 2015). Table 1.1 provides an overview of the donation decisions available in the UK under the previous opt-in or express consent donor system, and those now available under an opt-out system.

Table 1. 1. Summary of Donor Decisions Under Opt-in and Opt-out Donation Systems

Donor decision	Actively register as an organ donor	Do nothing (do not register as an organ donor)	Opt-out	Withdraw your details from the organ donor register
Opt-in system (also referred to as an express consent system)	Indicative of consent for organ donation.	Remain as a non-donor.	Indicative of refusal for organ donation.	Remain as a non-donor.
Opt-out system (also referred to as, deemed consent, deemed authorisation, or presumed consent system)	Indicative of consent for organ donation.	Deemed consent applies, therefore taking no action is now indicative of consent for organ donation.	Indicative of refusal for organ donation.	Deemed consent applies, therefore in the absence of any recorded donor decision, this would be indicative of consent for organ donation.

There are two main variants of opt-out legislation; a 'hard' and 'soft' opt-out. The factor distinguishing both forms of legislation concerns the degree of family involvement during the donation decision-making process. In nations with hard opt-out legislation such as Austria, family members are not routinely consulted to authorise organ donation. However, very few nations utilise a hard opt-out system, with most operating under a 'soft' opt-out policy. Under 'soft' opt-out policies, family members or appropriate close friends of the deceased are consulted to authorise donation (Rosenblum et al., 2012). In England, Scotland and Wales, a 'soft' opt-out policy is applied, whereby family members play a principal role in the decision-making process. Notably, while a potential donor's family does not have the legal jurisdiction to override or veto a loved one's express decision for organ donation in the UK, in practice, donation would not proceed if family members opposed the decision (NHS Blood and Transplant, 2013a).

1.4.3 The Transition Towards Opt-out Legislation

The legislative change to opt-out consent has been debated at considerable length in the UK since 2008, after Gordon Brown, the former UK Prime Minister (2007 - 2010), published a newspaper report in January of 2008 in The Telegraph, calling for urgent reforms to existing organ donation legislation (Brown, 2008). Within the newspaper article, entitled *'Organ donations help us make a difference*', the then Prime Minister publicly signalled, for the first time, support for an opt-out organ donation system as a way of improving the comparatively poor rates of organ donation in the UK.

This newspaper article was published just three days before the Organ Donation Taskforce released their first report, which provided recommendations on ways to improve UK organ donation. The Taskforce was established by the UK Government in late 2006, when, with just 12.9 donors per-million people in the population (pmp), the UK was described to have *"one of the worst records for organ donation in Western Europe"* (Organ Donation Taskforce, 2008a). This compared poorly to rates of donation in other western nations at that time, including: Belgium (29.1 donors pmp), France (23.2 donors pmp), Germany (15.3 donors pmp), Italy (21.7 donors pmp), Spain (35.5 donors pmp) and the US (26.9 donors pmp) (International Registry in Organ Donation and Transplantation, 2007). This figure is also considerably lower than the 23.2 donors pmp identified in the 2006 audit of potentially eligible organ donors in the UK (Barber et al., 2006). In sum, this indicated that the potential for organ transplantation in the UK was not being met.

1.4.4 Organ Donation Taskforce Report 1: Organs for Transplants

On the 16th of January 2008, the Taskforce published its first report which entailed 14 recommendations on ways to increase the number of organ donors (Organ Donation Taskforce, 2008a). The recommendations aimed to improve the previously unsystematic and localised approach to organ donation throughout the UK and focused on one central facet: organ donation should be managed as a co-ordinated UK-wide service. A summary of the Taskforce's primary recommendations adapted from the report: Organs for Transplants, are provided below in Figure 1.3. In addition, each of the 14 recommendations are also presented in Appendix 1. It was estimated that, if implemented successfully, a 50% increase in rates of transplantation would be achievable by 2013.

Figure 1. 3. Primary Taskforce Recommendations

The recommendations cover **five** broad aspects of donation, based on one overriding principle – that there should be a **UK-wide Organ Donation Organisation** established by NHS Blood and Transplant.

The five aspects are:

i. Legal and ethical issues surrounding consent for donation.
ii. The role of the NHS in ensuring organ donation is considered as a usual, not an unusual event.
iii. Organisational aspects of co-ordination and retrieval – the expansion and development of systematic network of donor transplant co-ordinators and retrieval teams centrally employed by a UK-wide Organ Donation Organisation.
iv. Organ donation training for critical care and other relevant clinical staff involved in the donation process.
v. Public recognition of donors and their families and public promotion of donation.

1.4.5 Organ Donation Taskforce Report 2: The Potential Impact of an Opt-out System for Organ Donation in the UK.

Following public endorsement of opt-out legislation from the UK Prime Minister Gordon Brown, a second report was commissioned from the Taskforce. The objectives of this report were to explore the requirements for the implementation of an opt-out system in the UK and to assess the potential implications of opt-out legislation on public attitudes and donation rates (Organ Donation Taskforce, 2008b). Several key points from the report are discussed below.

As part of the reports' core evidence base, the Taskforce commissioned an international review on the impact of opt-out policies on rates of donation (Rithalia et al., 2009). The review reported that donation rates in countries with opt-out systems were, on average, higher than countries with opt-in legislation. However, variance in rates of donation were noted, with some opt-in countries reporting higher donation rates than those with opt-out. The authors also explained that it may be difficult to disentangle the role of other causative factors, including transplantation infrastructure, health care provision, public awareness and underlying public attitudes. Taken together, the review concluded that the introduction of presumed consent alone does not explain the variation in rates of donation.

In addition, public views and attitudes towards opt-out consent were sought from over 350 representative members of the UK public. While most endorsed a potential move to opt-out consent, 22% opposed the potential change. Among this group, many had concerns relating to the perceived elimination of choice under opt-out consent and reported reservations around increased state control of organs. Specifically, a key concern was of diminished trust in the government and the health care system, a factor the Taskforce endorsed as being pivotal to the success of such a legislative change. This was of particular concern to the Taskforce, who made reference to recent reports of a substantial decline in perceptions of trust in the government (Duffy et al., 2005).

Legislative implications were also taken into consideration. With the Taskforce noting that following consultation with the Human Tissue Authorities (HTA), implementing a system of presumed consent would be incongruent with the existing legislation on express consent and authorisation for organ donation in England and Scotland (The Human Tissue Act, 2004 and the Human Tissue (Scotland) Act, 2006). In turn, both relatively new legislative frameworks would require considerable revision. Concerns were also raised that subsequent revisions to the above-named legislation, may in turn, cause confusion and destabilise the provision of informed consent within other sensitive activities involving human tissues.

1.4.6 Taskforce Conclusions

In November 2008, the Taskforce concluded that an opt-out system would be exceedingly costly to implement, would distract from much needed system infrastructure improvements, and from campaigns to increase public awareness and understanding of organ donation, as recommended in the first Taskforce report published in January of that year. Moreover, the Taskforce identified key concerns that opt-out legislation may incur a loss of trust and undermine public confidence in the NHS and the government, which would be detrimental to public support and rates of registration. The overall conclusion was that "*no convincing evidence*" was available to suggest that implementing an opt-out system would act to increase rates of donation and transplantation. Taken together, the Taskforce recommended against the introduction of opt-out consent legislation in the UK (Organ Donation Taskforce, 2008b). It was advised that a potential move to opt-out consent be reassessed in 2013, only if, following application of the initial Taskforce recommendations, donation rates had not improved. It should be acknowledged that the Taskforce's 14 recommendations (presented in Appendix 1) were successfully implemented throughout the UK, and by April 2013, an impressive 50% increase in the number of deceased donors and over a 30% increase in transplantation rates were observed (NHS Blood and Transplant, 2013c).

However, before the Taskforce's report which unanimously rejected the move to opt-out legislation in the UK was published in November 2008, the Welsh Assembly had, in October of that year initiated a series of public debates regarding the move to an opt-out system (Welsh Government, 2009). After being granted additional legislative powers in late 2011, the Welsh Assembly almost immediately initiated the process of changing donor legislation. Thus, the implementation of opt-out consent in Wales was already well underway by the time the success of the Taskforce's initial recommendations had been assessed in 2013. Despite the Welsh Assembly's move towards opt-out legislation, in 2013, NHS Blood and Transplant made clear its intention to continue with an opt-in system, although it aimed to build upon the success of the 2008 Taskforce report to achieve a family consent rate for organ donation of 80% by 2020 (NHS Blood and Transplant, 2013c). This ambitious target was never achieved (latest data as of May 2020 reports a consent rate of 68%), and amidst heightened national debate in England and Scotland, both nations began to review the impact of the change in Wales. By the end of 2017, both Westminster and Holyrood had publicly expressed enthusiasm to follow the Welsh example. In England, the Organ Donation (Deemed Consent) Bill was introduced in the Commons in July 2017, received Royal Assent on the 15th of March 2019, and was enacted in May 2020. In Scotland, the Human Tissue (Authorisation) (Scotland) Bill was lodged in June 2018 and became law on the 18th of July 2019. The legislation was scheduled for implementation in Autumn of 2020; however, was later postponed until March 2021 due to the Covid-19 pandemic.

1.5 Default Policy and Organ Donation

This section will first outline the evidence of the effect of default polices on health behaviours, and the application of defaults in the context of organ donation. Following this, the main evidence base used to endorse opt-out consent as a method of increasing rates of donation and the criticisms and controversy surrounding the legislative change will be discussed. Finally, an overview of the impact of opt-out consent on rates of transplantation in Wales, the first UK nation to introduce opt-out legislation, will be provided.

1.5.1 Altering Default Policy and Health Behaviour

As discussed previously, existing evidence has endorsed modifications in choice architecture as a powerful mechanism in which to increase engagement in a number of health-related behaviours (Aysola et al., 2018; Hollands et al., 2013; Skov et al., 2013). In the context of organ donation, the application of a default policy is intended to guide public behaviour by altering the default position to consent for organ donation. The impact of default polices at guiding public behaviour has been empirically examined within a recent meta-analysis of 58 studies (Jachimowicz et al., 2019). Overall, while default policies are associated with increased compliance with the default option, considerable divergence in the efficacy of default legislation was reported. Notably, the authors found policy endorsement to be a key factor in implementation efficacy, with defaults found to be less effective when members of the public perceive lower trust in the policy ‘architect’ (i.e. the persons accountable for the implementation of the default policy) (Tannenbaum et al., 2017). This finding is important in the context of opt-out organ donation.

Moreover, opt-out interventions have been found to incur negative consequences under some conditions. For example, the use of an opt-out scheduling appointment letter for preventative colonoscopy screening was shown to have a significant detrimental effect on screening attendance in comparison to a standard opt-in letter (Narula et al., 2014). The authors speculated that an opt-out default may have appeared outwardly forceful and controlling which, in turn, deterred individuals from engaging with screening. In sum, though often endorsed as an effective method of increasing compliance with positive health behaviours, default interventions may have unintended consequences, particularly when applied to sensitive topics, as in the context of organ donation.

1.5.2 Donation Rates in Opt-out Versus Opt-in Countries

A number of reviews have examined donation rates across nations with opt-in versus opt-out consent. On the whole, the evidence base is somewhat mixed. For example, Abadie & Gay (2006) examined donation rates in 22 nations over a 10-year period. Overall, the supply of donor organs in nations with presumed consent legislation was found to be approximately 25-30% higher than nations which follow an opt-in donation policy. The authors reasoned that if this increase was applied in the context of the UK, it would be sufficient to reduce the discrepancy between the demand and supply for donor organs (Abadie & Gay, 2006). More recent reviews support this finding, reporting rates of donation to be on average, higher in countries with opt-out legislation (Rithalia et al., 2009; Shepherd et al., 2014; Ugur, 2015). However, there is substantial variance found in donation rates, indeed some opt-out countries have much lower rates of donation than nations with opt-in systems. These reviews also emphasised that other factors, including transplantation infrastructure, health care provision, public awareness and underlying attitudes may play a key role in increasing rates of donation and transplantation. Therefore, the success of opt-out legislation is dependent on a multitude of complex factors and should not be attributed to opt-out consent in isolation.

Spain is a notable example of this and is often presented as evidence of the success of opt-out legislation. The Spanish organ donation system is recognised as being the finest in the world, with the latest global data illustrating Spain to have the highest rate of deceased donors per million population (49.61 donors pmp), a figure almost double that recorded in the UK, at 24.88 donors pmp (International Registry in Organ Donation and Transplantation, 2020). Therefore, the Spanish model of organ donation is recurrently used as a benchmark for the potential donor system in the UK. Spain, in principle, enacted opt-out legislation in 1979 and has recurrently been used as supportive evidence for introducing opt-out legislation in the UK (English, 2007). While Spain seems to be a clear example of the success of presumed consent, it was not until 1989, 10 years after the change in legislation, that increased rates of donation and transplantation were observed. This occurred only after the Spanish transplantation infrastructure and donation system underwent a systematic overhaul, which included changes in end of life practices in line with the early identification and referral of potential donors, and the introduction of specialist donor co-ordination teams within intensive care units (Matesanz et al., 2017). Thus, Spain's success cannot solely be attributed to opt-out consent. Indeed, there is no active opt-out register in Spain. This view is endorsed by the president of the Organización Nacional de Trasplantes (The Spanish National Transplant Organisation) who has co-authored articles dissuading policy makers from the assumption that presumed consent would alone increase donation rates (Fabre et al., 2010; Matesanz et al., 2017).

The most up-to-date review published in 2019 by Arshad and colleagues (2019), compared cross sectional donation and transplantation data from the years 2012-2016 across 35 developed nations; encompassing 18 countries with opt-out consent legislation and 17 countries with opt-in (Arshad et al., 2019). Importantly, Spain was considered an opt-in nation within this study. The data was analysed using a linear regression model to measure the impact of consent legislation on donation rates. The analysis also controlled for confounding factors that may influence rates of donation (e.g., road traffic accidents, number of hospital beds, hospital expenditure). No significant differences in overall rates of organ transplantation between nations with opt-in (61.7 pmp) or opt-out systems (63.6 pmp) were found. In sum, the authors concluded that implementing a system of presumed consent, should not be considered as a 'quick fix' for the worldwide donor shortage. Instead, continued exploration into the potential barriers towards organ donation is warranted, irrespective of a nations consent system (Arshad et al., 2019). These findings were also supported by a recent review from the Scottish Government designed to inform the development of the planned opt-out system. The review ultimately reported limited evidence that in isolation, an opt-out system would increase transplantation rates (Scottish Government, 2018).

While opt-out consent was reported to have no impact on overall rates of transplantation in the most recent review from Arshad and colleagues (2019), significantly fewer rates of living donation were recorded, at a rate of 4.8 donors pmp, in comparison to 15.7 donors pmp in countries with opt-in systems. This finding is supported by existing research (Abadie & Gay, 2006) and appears to be prominent in relation to rates of living kidney donation (Bendorf et al., 2013; Shepherd et al., 2014). This is concerning, given that of the 6,000 people on the UK transplant waiting list almost 5,000 require a kidney (NHS Blood and Transplant, 2020a).

1.5.3 Attitudes Towards Opt-out Legislation in England and Scotland

Overall, public attitudes to opt-out consent in England and Scotland have been largely positive. The public consultation on the move to opt-out consent in England received a substantial 17,047 responses. When asked if the legislative change would impact upon current donor decisions, the majority of respondents (72%) reported that the opt-out system would have no impact on current donor decisions and 13% reported intentions to actively register as a donor. In total, 15% of respondents reported the intention to opt-out. Although there was no question which measured support for opt-out consent, question nine of the consultation asked respondents to *"tell us about any opinions or evidence you have about opting out of organ donation".* While 10,500 people contributed a free-text response to this question, the governments analysis of responses was deemed not to "*uncover any new issues that had not already been covered in previous responses*" (UK Government, 2018a, p.19) and as such, no responses to this question were reported.

In Scotland, the government consultation on the move to opt-out consent received just 824 responses (from 778 individuals and 45 organisation). Support from individual respondents was high, at 84%. However, support from organisations (health boards, charities and faith groups) differed considerably, with almost half (47%) against the change in system. While voluntary organisations were largely supportive of the proposed move, faith groups, NHS boards and local authorities predominately opposed the change (Scottish Government, 2018). This view is supported by research from Randhawa et al. (2010) who found the majority of UK faith and belief leaders to favour the existing opt-in system. A number of concerns with the proposed opt-out system were raised in this interview study; namely, fears of public backlash, reservations regarding government control and loss of personal freedom (Randhawa et al., 2010). A measure of donor intentions under opt-out consent was not provided within the Scottish Government consultation. This was later assessed in a follow-up consultation from the Scottish Parliament's Health and Sport Committee; of the 747 total respondents to this survey, over one in five (22.5%) reported the intention to opt-out if the proposed opt-out system became law (Scottish Government, 2018).

1.5.4 Controversy Surrounding the Move to Opt-out Consent

Though public support for opt-out consent is generally high, the proposals have been met with considerable controversy. Indeed, recent research has criticised plans to change the UK donor system due to a "*fundamental lack of convincing evidence to support its efficacy*" (Sharif, 2018, p. 251). A number of researchers have echoed this view, reporting a lack of substantiated evidence that opt-out consent will, in isolation, increase the number of donors (Bramhall, 2011; Scottish Government, 2018; Willis & Quigley, 2014). As a result, concerns that the introduction of opt-out laws may divert attention and efforts away from other evidence-based approaches of increasing donor activity have been raised (Fabre et al., 2010). Indeed, some critics have expressed concerns that the law may incur a detrimental impact on public support and trust for organ donation, and may threaten the altruistic 'gift-like' nature of organ donation (Bramhall, 2011; McCartney, 2017). Other fierce critics regard a system of presumed consent to be "*morally problematic*", with the application of a default policy of this nature seen to threaten one's autonomy, which may result in a proportion of the population inadvertently being considered donors against their will (MacKay & Robinson, 2016, p.4)

Given the relatively recent transition to opt-out consent in the UK, very few studies have empirically investigated the factors that may deter potential donors under these laws. However, evidence from other opt-out nations has endorsed the view that the legislative change may incur a negative public response which, in turn, may increase the number of opt-out respondents. For example, following the implementation of opt-out legislation in Brazil, support for organ donation considerably declined (Bailey, 1999; Csillag, 1998). Similarly, in Chile, a substantial decrease in rates of transplantation and an increase in instances of family refusal to just over 50% were recorded in the year following the legislative change (Csillag, 1998; Domínguez & Rojas, 2013). These findings were attributed to heightened concerns of mistrust in the medical professionals and general distrust in the government (Bailey, 1999; Csillag, 1998; Domínguez & Rojas, 2013). As a result, the opt-out policy was overturned in Brazil and later revised in Chile. Notably, it was concerns over these factors that contributed towards the UK Organ Donation Taskforce advising against the introduction of opt-out consent in 2008 (Organ Donation Taskforce, 2008b). More recently, adverse public responses to opt-out consent were also observed in the Netherlands, where opt-out legislation was enacted in July of 2020. It was found that, in the month following the initial passage of the Dutch opt-out bill in February 2018, the number of residents registering their refusal for organ donation markedly increased to over 40 times higher than those recorded in the preceding months (Krijnen et al., 2017).

Ultimately, although the above evidence may suggest opt-out legislation to have heightened salient deterrents towards organ donation, the absence of empirical evaluation into negative affective attitudes, specifically their relative importance under opt-out legislation, limits the interpretation of such evidence. Indeed, several of the main factors used to reject the opt-out system in 2008, namely, medical mistrust, diminished trust in the NHS and concerns of heightened government control have not been investigated. Therefore, there is a pressing and timely need to address this gap.

1.5.5 The Strength of Donor Decision-Making Under Opt-out Consent

Although an opt-out system will unquestionably increase the pool of potential organ donors, a number of studies have questioned the efficacy of opt-out legislation at increasing the number of eventual organ donors (Fabre, 2014; Lin et al., 2018; Rosenblum et al., 2012). This is principally attributed to differences in the strength of donor decisions across opt-out and opt-in systems. Recent research from Lin et al. (2018) has tested this interpretation. In this sophisticated study, participants acted as a ‘third-party judge’ and, after reading a hypothetical vignette regarding ‘Mark’ a registered organ donor, were required to discern the underlying preference and strength of Mark’s donor decisions under an opt-in or opt-out system. Consistently, participants perceived active registration under opt-in system to provide a stronger indicator of the deceased’s preferences to donate and a greater signal of donor intentions, in comparison to an opt-out system. This suggests that when an individual is automatically deemed to consent for donation, the underlying preference and strength of their donation intentions are considered to be substantially weaker. Existing literature supports this finding, reporting that comparably lower value is assigned to being an organ donor under an opt-out system in comparison to active registration in opt-in systems (Davidai et al., 2012).

The discrepancy in underlying preference and strength of donor intentions may also have important implications for family consent. Throughout, participants in the above-described study from Lin et al. (2018) reliably perceived family members to be more likely to refuse consent for organ donation under an opt-out system in comparison to instances where consent for donation was actively registered (an opt-in system). This may suggest that opt-out legislation will do little to reduce the rate of family refusal as passive donation decisions remain comparably weak and unclear under opt-out consent (Lin et al., 2018; Rosenblum et al., 2012). This reinforces the view that sustained investigation into both the barriers to organ donation and the factors influencing family decision-making is critical.

There is limited in-depth, before and after donor data across other nations following the implementation of opt-out consent. As such, figures from Wales, the first UK nation to introduce an opt-out system in December of 2015, may provide a reasonable estimation of the potential impact of opt-out legislation across other UK nations.

1.5.6 Donor Behaviour Under Opt-out Consent in Wales

Initially, a nine per cent reduction in the number of deceased donors was recorded in the year following the transition to opt-out consent in Wales. This reflected a subsequent reduction in the proportion of organ transplants, from 168 transplants recorded in 2015/16 to 135 recorded between 2016/17 (NHS Blood and Transplant, 2016, 2017b). The opt-out system has now been in operation in Wales for over five years. Donation rates during that period have fluctuated, although the latest data has indicated a recovery from the initial post-implementation decline. With the figures from 2019/20 reporting there were 85 deceased donors in Wales and 155 recorded transplants (NHS Blood and Transplant, 2020a). To date, just six percent of the population in Wales have recorded the decision to opt-out of organ donation. This figure has remained stable since 2016 and is less than originally recorded in pre-implementation analyses (Welsh Government, 2012a).

1.5.7 Family Consent in Wales

Increasing the comparatively low rate of family consent was recognised as the single most important objective of the seven-year UK-wide organ donation strategy, *Taking Organ Transplantation to 2020* (NHS Blood and Transplant, 2013c). The implementation of an opt-out system has been endorsed as a means of improving family consent (UK Government, 2018b) therefore, the following section will provide an overview of consent rates in Wales in comparison to the UK, and the proportion of family refusals following the enactment of opt-out legislation.

First, in an initial 18-month post-implementation analysis, Welsh rates of consent were compared against the remaining three opt-in UK nations (Noyes, McLaughlin, Morgan, Walton, et al., 2019). Overall, rates of consent were found to have significantly increased in Wales, from 48.5% between 2014/15 to 61% in the 18-months following the legislative change. However, this increase was not unique to Wales, and a significant increase in consent from 58.6% to 63.1% was also reported across the remaining UK nations during that time. Therefore, it was considered too early to determine whether a sustained increase in consent rates in Wales would be observed beyond that reported elsewhere in the UK.

An important recent study from Madden et al. (2020) has extended the above findings, by providing a detailed sequential analysis of consent rates across England and Wales between January 2016 and December 2018. The analysis also controlled for population differences between England and Wales. In short, the results indicated an overall upwards trend of consent rates in Wales following the enactment of opt-out legislation in comparison to England. Breaking this down in terms of types of donation (DBD and DCD), a significant increase in consent for donation after brain death in Wales was observed. No such effect was reported for donation after cardiac death (Madden et al., 2020). The second stage of analysis applied a logistic regression model to predict the likelihood of consent being ascertained within each nation after controlling for factors recognised to influence consent rates, including knowledge of a patient’s donation decision, ethnicity, and the presence of a SN-OD. The results indicated that in the year following the introduction of opt-out legislation, family consent rates in Wales were significantly lower than that recorded in England. In the second year, equivalent rates of family consent were observed for England and Wales. However, three years following the legislative change, the likelihood of consent in Wales was found to be double that observed in England. Taken together, these findings indicate that consent rates for deceased organ donation have improved over time in Wales. Though, this should not be solely attributed to the introduction of opt-out laws. Instead, the authors noted that accessory measures implemented alongside the opt-out system may have played a role. For example, in the two years following the legislative change, two million pounds was allocated to media campaigns promoting organ donation. Arguably this sustained level of population-wide promotion may have acted to increase awareness and support for organ donation.

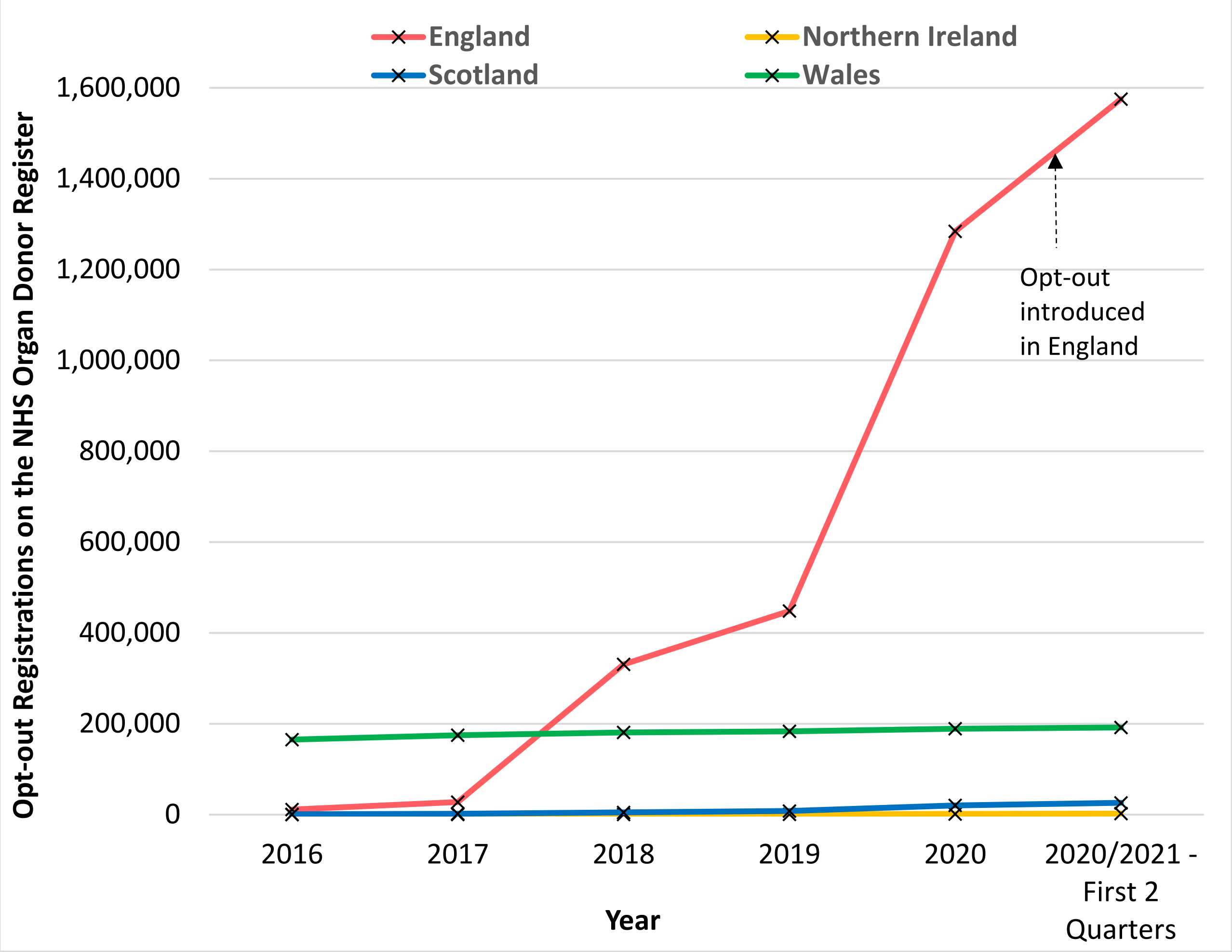
It is also important to consider that, initially, an increase in the proportion of family members overriding a loved ones' recorded donation decision was reported (Noyes, McLaughlin, Morgan, Walton, et al., 2019). In this before and after study, family overrides in Wales significantly increased from just 5-7.2% in the three years preceding the legislative change, to almost 30% in 2016/17. This increase was attributed to confusion regarding the role of the family under the opt-out system (Welsh Government, 2017b). In response, the Welsh communication campaign was altered to encourage families to share their donor decisions. This may have played a role in the subsequent recovery in rates of consent. The most recent data from NHS Blood and Transplant now indicate Wales to have the highest overall rate of consent for organ donation in the UK at 69%, this compares to 68% observed in England, 62% in Northern Ireland and 65% in Scotland (NHS Blood and Transplant, 2020a). To summarise, while consent rates in Wales are now the highest in the UK, the findings reiterate the crucial role of the family under opt-out legislation.

1.5.8 Data on Opt-out Respondents in England, Northern Ireland and Scotland

While the introduction of opt-out consent was implemented in England in 2020 and is planned for Scotland in March 2021, the option to register not to be a donor has been available since late 2015, although this is not actively promoted. Data on the number of opt-out registrants across the UK is provided within the annual activity report produced by NHSBT; figures recorded within the last five years across the four UK nations are graphically represented in Figure 1.4. This indicates that since 2016, a slight increase in the number of opt-out registrations have been recorded across Northern Ireland, Scotland and Wales. However, with reference to England, the data indicates an initial surge in opt-out registrations in 2017 following the UK governments announcement regarding the intention to move to an opt-out system. A considerable increase in opt-out registrations was then also observed in

2019, the year opt-out legislation was formally passed and received Royal Assent. In summary, the most recent data from October 2020 indicates that within the last three years, opt-out registrations have increased from 27,569 in 2017, to almost 1.6 million opt-out registrations in October 2020 (NHS Blood and Transplant, 2017b, 2020a). This figure represents 2.8% of the population in England. Whilst opt-out registrations have also increased across Scotland, from 1,834 opt-out registrations in March 2017, to 25,939 in October 2020 (representative of 0.47% of the Scottish population), the magnitude of opt-out registrations is markedly higher in England. Ultimately, this finding strengthens the need for rigorous investigation into the factors influencing opt-out decisions in the UK.

Figure 1. 4. Opt-out Registrations on the UK Organ Donor Register



To summarise, although extensive research has shown that emotional barriers towards organ donation consistently differentiate donors and non-donors under the longstanding opt-in system (Morgan, Stephenson, et al., 2008; O'Carroll, Foster, et al., 2011; Shepherd &

O'Carroll, 2014), limited empirical research has investigated the factors that may deter potential donors under opt-out legislation. A number of review articles have concluded that opt-out legislation does not, in isolation, increase rates of donation and transplantation. Instead, research has advocated for the key role of other factors including public perceptions and attitudes towards the change in legislation. Strikingly, the most recent figures from NHS Blood and Transplant now report that a higher proportion of the UK population actively opted out of organ donation between March 2019 and March 2020 than those who actively registered as organ donors, with 744,687 donor registrations in comparison to 856,290 opt-out registrations (NHS Blood and Transplant, 2020a). In sum, there are concerns that the legislative change to opt-out consent may exacerbate salient emotional barriers and detrimentally impact public support for organ donation. Therefore, given the intrinsically emotive and complex nature of organ donation, and the scarcity of research in this area, before the implementation of opt-out legislation in England and Scotland, rigorous evaluation of factors that may lead people to opt-out of the donor register is essential.

1.5.9 Thesis Objectives

This thesis has four objectives:

1. To develop a greater understanding of barriers to organ donation, in particular of factors that lead to individuals removing themselves (opting-out) from the organ donor register following the implementation of opt-out legislation.

2. To explore key differences between potential donor decisions under an opt-out system; namely, differences in the decision to actively opt-in, or to take no action and follow deemed consent.

3. To develop an understanding of the factors influencing family consent and refusal for posthumous organ donation.

4. To investigate methods of overcoming barriers to organ donation, including currently used NHS campaigns (e.g., myth-busting).

1.5.10 Overview of the Thesis Structure

To achieve the aforementioned aims, the studies reported in this thesis followed a mixed-methods approach and encompassed seven chapters, as outlined below. Each chapter will begin with a brief preface to situate each study in relation to either the transition to opt-out legislation or within the context of the preceding chapter. A visual representation of the main empirical chapters is also presented in Figure 1.5.

Chapter 2 provides an online quantitative questionnaire study which examined donor intentions regarding opt-out consent, and included an embedded experimental manipulation assessing whether donor intentions could be changed following exposure to an NHS myth-busting intervention.

Chapter 3 presents a qualitative study which examined the free-text responses collected within Chapter 2 and explored the reasons behind participants intended donor decision-making under opt-out consent (opt-in, opt-out, take no action and consent for organ donation indicated via deemed consent and those who are unsure).

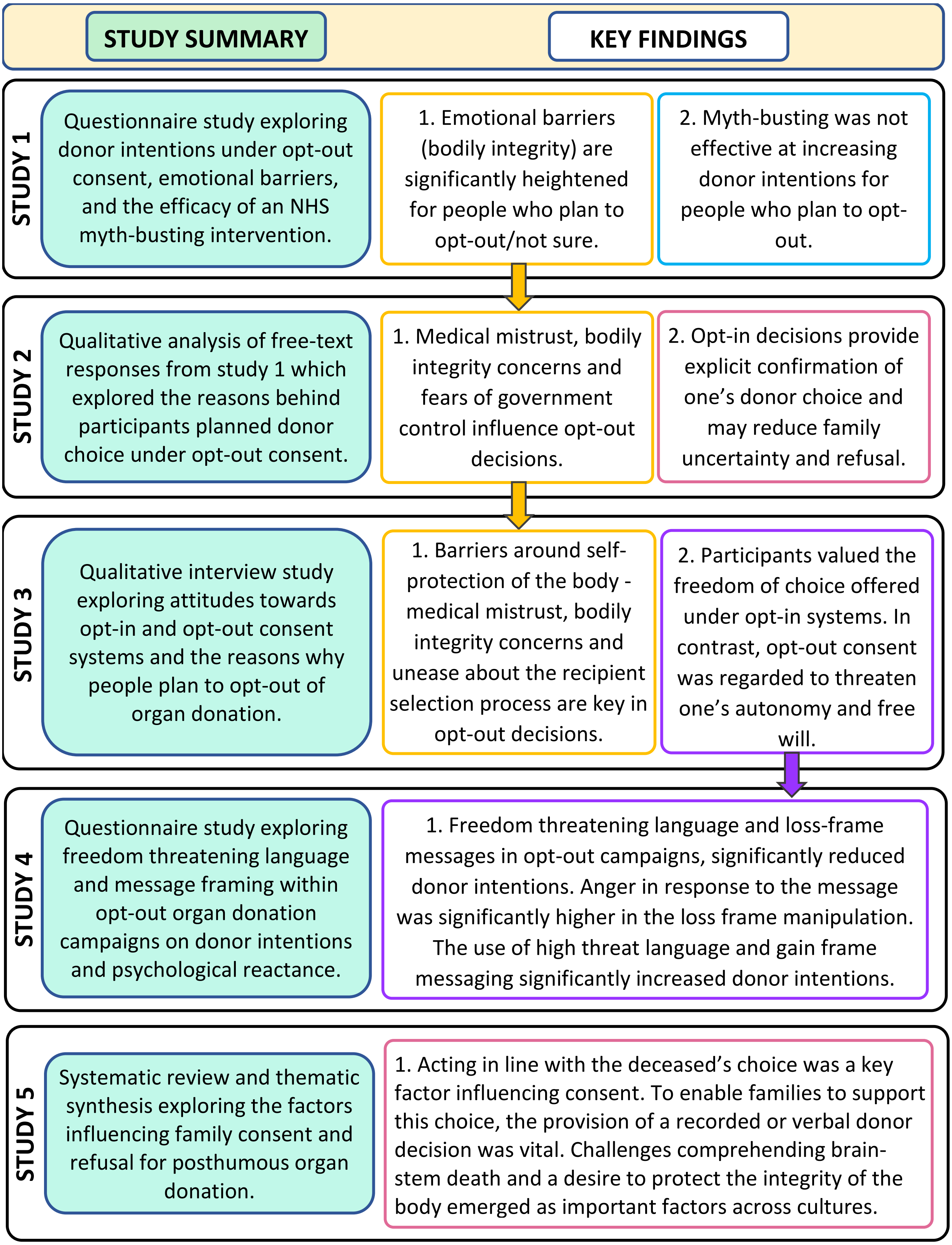
Chapter 4 presents an in-depth qualitative interview study with individuals who self-reported the intention to opt-out of organ donation following the implementation of opt-out laws in Scotland and England. Thematic analysis was used to investigate attitudes towards the opt-in system, the planned opt-out system, and to gain an in-depth understanding of why people plan to opt-out of the donor register.

Chapter 5 provides an online experimental study which examined the role of freedom threatening language and message framing within opt-out organ donation campaigns on the development of psychological reactance and the influence of this on donor intentions.

Chapter 6 provides a systematic review and thematic synthesis of the literature on family decision-making for posthumous organ donation and explored the factors influencing consent and refusal.

Chapter 7 presents an overall discussion of the thesis findings, including consideration of the implications, potential applications and future directions of the research. Acknowledgement of the study limitations and the final conclusions are provided.

Figure 1. 5. Visual Representation of the Empirical Chapters Within This Thesis



	STUDY SUMMARY	KEY FINDINGS	
STUDY 1	Questionnaire study exploring donor intentions under opt-out consent, emotional barriers, and the efficacy of an NHS myth-busting intervention.	1. Emotional barriers (bodily integrity) are significantly heightened for people who plan to opt-out/not sure.	2. Myth-busting was not effective at increasing donor intentions for people who plan to opt-out.
STUDY 2	Qualitative analysis of free-text responses from study 1 which explored the reasons behind participants planned donor choice under opt-out consent.	1. Medical mistrust, bodily integrity concerns and fears of government control influence opt-out decisions.	2. Opt-in decisions provide explicit confirmation of one's donor choice and may reduce family uncertainty and refusal.
STUDY 3	Qualitative interview study exploring attitudes towards opt-in and opt-out consent systems and the reasons why people plan to opt-out of organ donation.	1. Barriers around self-protection of the body - medical mistrust, bodily integrity concerns and unease about the recipient selection process are key in opt-out decisions.	2. Participants valued the freedom of choice offered under opt-in systems. In contrast, opt-out consent was regarded to threaten one's autonomy and free will.
STUDY 4	Questionnaire study exploring freedom threatening language and message framing within opt-out organ donation campaigns on donor intentions and psychological reactance.	1. Freedom threatening language and loss-frame messages in opt-out campaigns, significantly reduced donor intentions. Anger in response to the message was significantly higher in the loss frame manipulation. The use of high threat language and gain frame messaging significantly increased donor intentions.	
STUDY 5	Systematic review and thematic synthesis exploring the factors influencing family consent and refusal for posthumous organ donation.	1. Acting in line with the deceased's choice was a key factor influencing consent. To enable families to support this choice, the provision of a recorded or verbal donor decision was vital. Challenges comprehending brain-stem death and a desire to protect the integrity of the body emerged as important factors across cultures.	

Chapter 2: '*What if I'm not dead*?': Myth-busting and organ donation

Preface

This study commenced at the beginning of this PhD research in January 2018. At this preliminary stage in the transition to opt-out legislation, both England and Scotland had publicly signalled the intention to follow Wales and introduce opt-out consent. However, only England had formally introduced the Organ Donation (Deemed Consent) Bill for consideration in the Commons. As such, this initial study was conducted to assess the number of people who plan to opt-out of organ donation, and to investigate emotional barriers under the proposed opt-out legislative change in the UK.

Sections of this chapter also appear in: Miller, J., Currie, S., & O'Carroll, R. E. (2019). '*What if I'm not dead?*'– Myth-busting and organ donation. *British Journal of Health Psychology*, *24*(1), 141-158. https://doi.org/10.1111/bjhp.12344

2.1 Abstract

Background: In the UK, three people die every day awaiting an organ transplant. To address this, England and Scotland plan to follow Wales and introduce opt-out consent. However, emotional barriers, myths and misconceptions may deter potential registrants. The objectives of this study were primarily to estimate the number of people who plan to opt-out of the donor register, and to test if emotional barriers were higher in this group. Finally, in an experimental manipulation, this study examined whether donor intentions (a) decreased by making emotional barriers more salient and (b) increased following a widely used NHS myth-busting intervention.

Methods: UK residents (*n* = 1202) were asked if donor legislation changes to an opt-out system, whether they would choose to; opt-in, follow deemed consent, opt-out or were currently unsure of their decision. Participants also completed measures of donor intentions at baseline, following a 12-item emotional barriers questionnaire and again, following a 9-item myth-busting intervention.

Results: The findings indicated that 66.1% of participants plan to opt-in to the donor register, 24.3% plan to follow deemed consent, 5.2% selected not sure and 4.2% of participants plan to opt-out. Emotional barriers, notably, fears surrounding bodily integrity and the jinx factor were significantly elevated in participants who plan to opt-out. Increasing the salience of emotional barriers reduced donor intentions in the opt-out group. However, an NHS myth-busting intervention had no effect on donor intentions in those who plan to opt-out.

Conclusions: If opt-out legislation is introduced in England and Scotland, approximately 10% of participants plan to opt-out or are not sure of their donation decision. Dispelling organ donation myths with facts may not be the best method of overcoming deep-seated emotional barriers and increasing donor intentions for those planning to opt-out.

2.2 Introduction

Despite widespread support for organ donation around the world, there is a critical shortage of available organs for transplantation. Approximately 6,000 people in the UK are on the waiting list for an organ transplant. However, the insufficient supply of available organs means that a substantial proportion of people on the waiting list will die before receiving a lifesaving transplant (NHS Blood and Transplant, 2020a). This illustrates the pressing need to explore factors that both, promote and deter organ donor intentions and behaviours, in order to encourage donation and save lives.

At the time of conducting this study, the UK Government and the Scottish Parliament had recently proposed to change donor legislation from an opt-in registration system, to an opt-out system. This change in legislation means that individuals are automatically considered to consent for organ donation unless they actively record an opt-out decision on the organ donor register. As described in Chapter 1, the proposals for opt-out legislation were met with some controversy. In short, there were concerns that adopting an opt-out system could detrimentally impact public support for organ donation and increase mistrust in the medical system; a pivotal factor in the abolishment and revision of opt-out consent laws in other nations (Domínguez & Rojas, 2013).

Preceding the enactment of opt-out consent in Wales in December 2015, an extensive 24-month nationwide communications campaign was implemented to increase public awareness for opt-out legislation (Welsh Government, 2017a). This was accompanied by comprehensive research into opt-out consent, which assessed public attitudes, awareness and provided baseline assessments of donor intentions. This revealed that less than half of respondents supported proposals for opt-out consent and 19% reported intentions to opt-out (Welsh Government, 2012a). However, following a widespread communications campaign and enactment of the law, support for opt-out consent increased to 71%, and to date, just 6% of the Welsh population have actively opted-out (Young et al., 2017). Importantly, at the time of conducting this study, very little research had investigated public attitudes and intentions regarding opt-out consent laws in England and Scotland. Therefore, given the intrinsically sensitive nature of opt-out consent, exploration of these factors was critical.

2.2.1 Emotional Barriers Under Opt-out Legislation

As described in the previous chapter, a considerable body of literature has shown that emotional barriers towards organ donation consistently differentiate donors and non-donors under opt-in legislation (Morgan, Stephenson, et al., 2008; O'Carroll, Foster, et al., 2011; Shepherd & O’Carroll, 2014). However, as far as the author is aware, no research has investigated the aforementioned barriers in relation to opt-out legislation. Given that the Organ Donation Taskforce advised against the implementation of opt-out legislation due to concerns the legislation may increase medical mistrust, and lead to diminished trust in the NHS and the government, empirical examination of such factors was urgently required (Organ Donation Taskforce, 2008b). Therefore, this preliminary study examined whether emotional barriers differentiate those who plan to opt-out of organ donation.

2.2.2 Interventions to Increase Organ Donor Behaviour

This study also aimed to extend the findings of recent research from O’Carroll and colleagues (2016). Within this large-scale intervention study discussed in Chapter 1, section 1.3.3, the authors attempted to increase donor registration by manipulating anticipated regret (AR). However, counter to expectation, pilot studies and existing evidence, (O'Carroll, Dryden, et al., 2011; O'Carroll, Foster, et al., 2011) an AR manipulation which encouraged readers to reflect on future regret they may experience by not registering as an organ donor, led to a decrease in verified organ donor registrations (O'Carroll et al., 2016). Participants in the intervention group also completed questions assessing emotional barriers towards organ donation (e.g., medical mistrust). The authors speculated that completion of these measures may have led to a negative contextual cuing effect and unintentionally amplified negative attitudes towards organ donation. Investigating this effect may have important implications when designing subsequent interventions to promote donor intentions and registration behaviours. Therefore, to test this interpretation, the present study also examined whether making emotional barriers salient reduced organ donor intentions.

2.2.3 Myths and Misconceptions

Other factors found to play a role in organ donor behaviour, relate to people’s knowledge and beliefs (Falomir-Pichastor et al., 2013; Feeley, 2007; Morgan et al., 2003). Although public awareness of organ donation and the donor shortage is generally high, studies have shown pervasive gaps in knowledge or misunderstandings surrounding organ donation, in particular, regarding the concept of brainstem death (Horton & Horton, 1990; Morgan, Harrison, et al., 2008). This in turn, may contribute to the development and maintenance of erroneous beliefs and myths which deter potential donors; for example, the belief that organs are removed from the body while a person is alive. Myths and misconceptions are often exacerbated by harmful representations of organ donation, often through sensationalist media misrepresentations within popular entertainment TV programmes such as Grey's Anatomy (Morgan et al., 2005; Quick et al., 2014). Collectively, these factors may intensify negative representations of organ donation, reduce trust in medical staff and contribute to the development and maintenance of misconceptions and myths that deter potential registrants.

The primary mechanism by which individuals acquire knowledge and information regarding organ donation is through the media, and in particular, internet-based sources and social networking websites (Aykas et al., 2015). Ultimately, the media contributes towards positive and negative representations of organ donation. However, as a growing number of the population are regular media users, negative information is disseminated rapidly and reaches a wider audience than ever before. A compelling example of this concerns the German organ donation scandal of 2012, whereby reports emerged that doctors had manipulated the transplant allocation system, by intentionally falsifying patient information to reduce transplant waiting times for specific patients (BBC News, 2013). Reports of the scandal were widespread and, consequently, public support for organ donation in Germany considerably declined. At the time of writing, donation rates in Germany had yet to recover (Global Observatory on Donation and Transplantation, 2012, 2019). Although, largely isolated incidents, the negative implications can be enduring and widespread.

The importance of dispelling harmful myths has also been endorsed by The UK Organ Donation Taskforce. Within the second taskforce report, which advised against the introduction of opt-out legislation, harmful donation myths were reported to have arisen during a series of events assessing public attitudes towards the potential opt-out system. As such, the taskforce advocated for increased publicity and education to reduce salient myths and misconceptions about organ donation (Organ Donation Taskforce, 2008b). Following this, the NHS implemented a 'myth-busting' feature on their webpage (https://www.organdonation.nhs.uk/supporting-my-decision/myth-busting/). The webpage, which has since been updated, presents readers with a series of common organ donation myths and misconceptions, and then provides corrective information and evidence to dispel each myth. To date, very limited research has explored this approach as a way of increasing donor intentions or registrations (Sukalla et al., 2017). Similar methods have recently been used to dispel vaccine-related myths, improve vaccination attitudes and increase immunisation rates for communicable diseases such as measles, mumps and influenza (Hornsey et al., 2018). However, studies have found that exposure to corrective information intended to dispel vaccination myths had a differential effect and significantly reduced intention to vaccinate in individuals with highest levels of vaccination concerns (Nyhan & Reifler, 2015). This finding supports the testing of the efficacy of similar public health interventions.

2.2.4 Study Objectives and Hypotheses

The objectives of this preliminary study were: (1) to estimate the percentage of the English and Scottish population planning to opt-out of organ donation following the implementation of proposed opt-out legislation, (2) to test if emotional barriers (e.g., medical mistrust) differentiate those who plan to opt-out, (3) to extend the findings of previous research (O'Carroll et al., 2016) and test if making emotional barriers salient following exposure to an emotional barriers questionnaire, reduces organ donor intentions, and finally (4) to test the efficacy of a current NHS strategy to reduce organ donation myths, by assessing the impact of a myth-busting intervention on organ donor intentions. As a secondary objective, the study also examined the impact of a myth-busting intervention on emotional barriers.

Hypothesis 1. Participants who plan to opt-out of the organ donor register will exhibit higher emotional barriers towards organ donation.

Hypothesis 2. Increasing the salience of emotional barriers will result in decreased donor intentions.

Hypothesis 3. Dispelling harmful organ donation myths will act to increase donor intentions.

Secondary Hypothesis 4. Dispelling harmful organ donation myths will act to decrease emotional barriers.

2.3 Methodology

2.3.1 Power Analysis

A G*Power calculation indicated that using ANOVA with 3 groups, a total sample of 969 participants would be sufficient to detect a small effect size of $f = .01$ at an alpha level of .05 and a power of .80 (Cohen, 1988). The target sample size was achieved, and a preliminary examination of the first 100 responses was conducted to determine the proportion that satisfied basic criteria for data inclusion. Inclusion was defined as completion of the three primary donor intention measures. Of this sample, 14 responses did not satisfy the inclusion criterion. Therefore, it was necessary to continue recruitment until a final sample of 1202 responses was obtained to ensure sufficient responses to achieve adequate statistical power.

2.3.2 Ethical Approval, Participant Eligibility Criteria and Recruitment

This study received ethical approval from The University of Stirling's General University Ethics Panel. The ethical approval email is available in Appendix 2. Recruitment took place between January and March 2018. Participants were opportunistically recruited after responding to online advertisements posted on the social media websites, Facebook, Twitter and Reddit. The online advertisement was also placed on the University of Stirling Portal page, used for advertising research opportunities to students and staff. The advert contained a URL link to the study questionnaire which was delivered via Qualtrics, a web-based research platform (Qualtrics, 2005) (https://www.qualtrics.com/uk/). The advertisement text is available in Appendix 3. The study inclusion criteria were as follows, aged over 18 years and currently resident in either England, Northern Ireland or Scotland.

2.3.3 Procedure and Measures

Following the presentation of participant information and eligibility criteria, informed consent was obtained via an electronic check box. The participant information sheet is provided in Appendix 4. Participants first completed questions measuring demographic characteristics, followed by measures assessing current organ donor status (registered organ donor, not registered and not sure). Measures of anticipated donor status were then obtained. Participants were initially presented with information regarding the proposed legislative change (presented in Figure 2.1) and asked, '*If the organ donation laws in your country change to an opt-out system, what would your choice be*?' The potential responses were as follows: (1) I would opt-in (I want to be an organ donor), (2) I have no objection to donating my organs (deemed consent to be an organ donor), (3) I would opt-out (I do not want to be an organ donor) and (4) not sure. After selecting a response, participants were then presented with a free-text entry box and asked to '*Please briefly provide the reason behind your choice'*. The free-text data acquired from this question will be the focus of Chapter 3.

Figure 2. 1. Information Presented to Participants Describing the Planned Opt-out System

The following information describes 2 organ donation systems

Opt-in system = anyone wishing to donate their organs in the event of death must provide consent by signing up to the organ donor register.

Opt-out system = you are automatically assumed to give consent for the donation of your organs in the event of death unless you remove yourself from the organ donor register.

The Scottish and English Governments are planning to change the process of registering as an organ donor. Currently, anyone in Scotland, England and Northern Ireland wishing to donate their organs in the event of their death must opt-in and join the organ donor register.

Scotland and England may change to an opt-out system of organ and tissue donation. This means that if you have not registered a decision regarding organ donation, you will be treated as having no objection to being an organ donor.

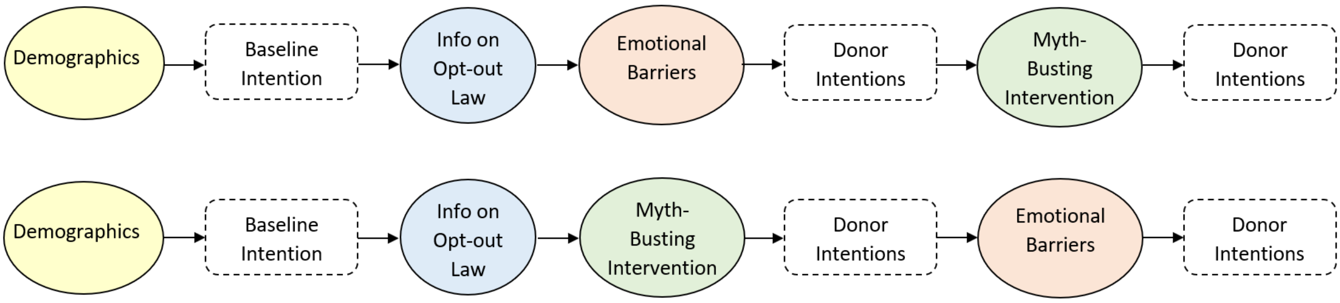
If the opt-out system is introduced it means you will have 3 options:

Option 1. Join the Organ Donor Register (ODR) if you want to be a donor (opt-in).
Option 2. Record that you do not wish to be a donor (opt-out).
Option 3. If you select neither option 1 or 2, you will be treated as having no objection to donating your organs (deemed consent).

2.3.4 Experimental Manipulation

The order of the experimental manipulation was counterbalanced to control for potential order effects. Participants were randomly allocated using a randomiser feature within Qualtrics to receive, the emotional barriers questionnaire followed by the myth-busting intervention, or alternatively, first completed the myth-busting intervention followed by measures of emotional barriers. The study procedure is illustrated in Figure 2.2.

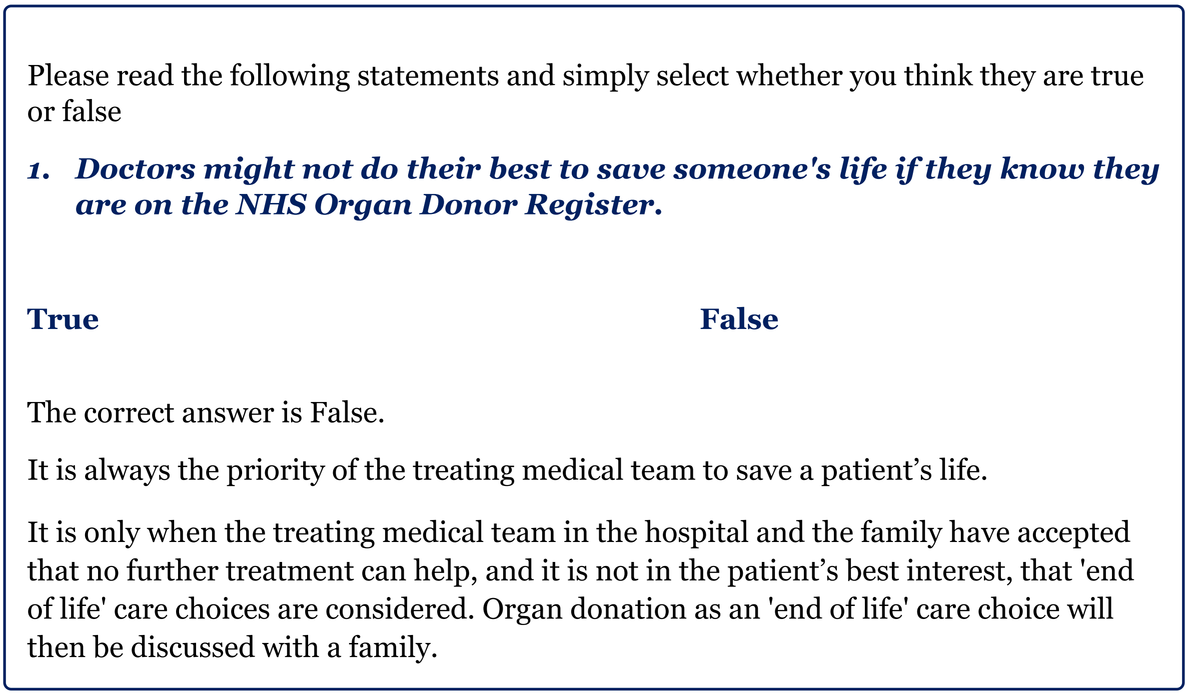
Figure 2. 2. Study Procedure Diagram



2.3.5 Organ Donation Myth-Busting Intervention

The myths used in the myth-correcting intervention were adapted from an NHS myth-busting webpage (the webpage has since been updated following completion of this study) https://www.organdonation.nhs.uk/supporting-my-decision/myth-busting/. The webpage presented common myths and misconceptions surrounding organ donation alongside corrective information designed to refute and dispel each myth. Nine myths were reviewed and selected for the intervention. Calls to action presented within some of the corrective information that may have primed a response from participants, for example, appeals for readers to '*leave a lasting legacy and join the donor register*' were omitted. Within this study, participants were presented with each of the nine statements and asked to select whether they believed the statement to be '*true*', or '*false*'. Regardless of the response, participants were then presented with the correct answer and corrective information to serve as a myth-busting intervention. In addition, participants responses to each of the true or false statements were also used as a measure of organ donation knowledge, with higher scores indicating greater organ donation knowledge (lower belief in myths). The nine myths and counter-evidence used in the intervention are available in Appendix 5. An example is provided in Figure 2.3.

Figure 2. 3. Myth and Corrective Information Presented in the Myth-Busting Intervention



Please read the following statements and simply select whether you think they are true or false

1. ***Doctors might not do their best to save someone's life if they know they are on the NHS Organ Donor Register.***

True **False**

The correct answer is False.

It is always the priority of the treating medical team to save a patient's life.

It is only when the treating medical team in the hospital and the family have accepted that no further treatment can help, and it is not in the patient's best interest, that 'end of life' care choices are considered. Organ donation as an 'end of life' care choice will then be discussed with a family.

2.3.6 Dependent Variables

Organ Donor Intentions. Donor intentions were measured at three time-points throughout this study (baseline, post myth-busting and post emotional barriers) using the following question, '*I intend to donate my organs after death*'. Responses were scored on a 7-point Likert scale ranging from 1 '*strongly disagree*' to 7 '*strongly agree*'. Higher scores are indicative of greater intentions to donate.

Emotional Barriers. Emotional barriers towards organ donation were measured using an adapted version of the attitudes towards organ donation scale (Morgan, Stephenson, et al., 2008). The present study used a 12-item scale, which measured four affective attitudes towards organ donation, bodily integrity, the ick factor, the jinx factor and medical mistrust. The items from this measure are presented in Appendix 6. All responses were scored on a 7-point Likert scale ranging from 1 '*strongly disagree*' to 7 '*strongly agree*'. As the process of registering as an organ donor is now predominantly completed online without the requirement to physically sign a donor card, the wording in three of the questions was modified. The phrase '*signing an organ donor card*' was amended to '*register as an organ donor'*.

Bodily Integrity. This concerns the belief that the body should remain whole after death. Bodily integrity was measured by two items (α = .74). An example item is, '*Removing organs from the body just isn't right'*. Higher scores are indicative of greater bodily integrity concerns.

Ick Factor. This represents an aversion to the concept of organ donation. The ick factor was measured by three items (α = .78). An example item is, '*The idea of organ donation is somewhat disgusting'*. Higher scores indicate greater feelings of revulsion towards the idea of organ donation.

Jinx Factor. This relates to fears and superstitions that misfortune will arise following organ donor registration. The jinx factor was measured by three items. An example item is, '*Organ donors may not be resurrected because they don't have all of their parts'*. Higher scores indicate a stronger feeling that it is bad luck to talk about death or to register as an organ donor. The reliability of the 3-item jinx factor scale was low (α = .50). Deletion of question 2 from this scale, '*The surest way to bring about my own death is to make plans for it like registering as an organ donor'* increased the reliability of the scale to α = .60.[3]

Medical Mistrust. This represents fears regarding the medical profession in relation to organ donation. Medical mistrust was measured by four items (α = .70). An example item is, *'If I register as an organ donor, doctors might take my organs before I'm actually dead'*. Higher scores indicate stronger medical mistrust.

2.3.7 Data Preparation

The study analyses were conducted using SPSS Version 25. Participants were initially grouped based on their response to the following question, '*If the organ donation laws in your country change to an opt-out system, what would your choice be*'? Available responses were as follows: *opt-in, deemed consent*, *not sure* and *opt-out.* Of the total sample*,* 1199 participants answered this question*.* A preliminary scope of the data indicated substantial differences between the anticipated donor groups, with only a small number of respondents

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[3] Data analysis was repeated with question 2 of the jinx factor subscale removed. The same results were obtained; therefore, all 3 items from the jinx subscales were retained.

reporting the intention to opt-out of the organ donor register (*n* =50). As such, analysis of group-level differences may be limited as a consequence of low statistical power. Within the publication arising from this chapter, (Miller et al., 2019) the response variables *opt-out* and *not sure* were collapsed and the analysis conducted with a three-group comparison (*opt-in, deemed consent* and *opt-out/not sure)* to ensure adequate power for analysis. For the purpose of this chapter, the opportunity was taken to further test the differences between the *not sure* and active *opt-out* respondents, therefore analysis was conducted with all four response variables (*opt-in, deemed consent*, *not sure* and *opt-out).*

2.3.8 Data Analysis

Differences in demographic characteristics between the donor groups was assessed using chi-squared tests and one-way analysis of variance (ANOVA). To test the first hypothesis and examine whether individuals who plan to opt-out of organ donation, experience heightened emotional barriers, a multivariate analysis of variance (MANOVA) was conducted. The four emotional barriers (bodily integrity, ick, jinx and medical mistrust) were entered as the dependant variable, with anticipated donor choice under opt-out consent (opt-in, deemed consent, not sure and opt-out) as the independent variable. The multivariate statistic Pillai's trace was applied to account for unequal sample sizes between the donor groups. A series of follow-up univariate ANOVAs were performed on each emotional barrier. Group-level differences were then explored using a Games-Howell *post-hoc* test, used to correct for a violation of the assumption of homogeneity. To test the second and third hypotheses, a repeated measures ANOVA was conducted to compare differences in donor intentions across the experimental conditions (baseline, following exposure to the myth-busting intervention and the emotional barriers questionnaires). A series of *post-hoc* paired samples *t*-tests were run to further explore these results. Finally, to explore differences in scores across the myth-busting intervention (which also served as a measure of organ donation knowledge), a one-way ANOVA was conducted. A Games-Howell *post-hoc* test was applied to assess differences across the donor groups.

A secondary objective of this study, given the use of a counterbalanced design was to examine whether participants who first completed the myth-busting intervention demonstrated lower emotional barriers scores. A Hotelling's T^2 (an extension of the univariate *t*-test which encompasses two or more dependant variables) was conducted with order (1.

myth-busting then emotional barriers or 2. emotional barriers then myth-busting) and the four emotional barriers (bodily integrity, ick, jinx and medical mistrust) entered as the dependant variables. A series of pairwise comparisons were conducted to further interpret these results.

Partial η^2 effect sizes were generated throughout the analysis; for interpretation, the square root of these values was calculated to enable interpretation of effect size *r*. According to Cohen (1988), an *r* of 0.1 represents criteria for a 'small' effect size, 0.3 represents a 'medium' effect size and 0.5 represents a 'large' effect size. There was a small amount of missing data for study dependent variables, anticipated organ donor status (0.25%), organ donation myths (0.23%) and the emotional barriers questionnaire (0.55%). As a result, *listwise* deletion was implemented throughout the analysis.

2.4 Results

2.4.1 Participant Demographics

A total of 1202 members of the adult general public from England, Northern Ireland and Scotland participated in this online study. The overall sample largely consisted of white (97.92%) female participants (80.95%), with a mean age of 39.86 years (*SD* = 12.47). Most participants, 87.77% (*n* = 1055) were resident in Scotland, with 10.98% (*n* = 132) resident in England, and just 1.25% (*n* = 15) resident in Northern Ireland. The demographic characteristics of the sample (grouped in accordance with participants' anticipated donor choice under opt-out consent) are provided in Table 2.1.

2.4.2 Demographic Comparisons

A series of one-way ANOVAs and chi-squared tests were conducted to assess demographic differences between the donor groups (opt-in, deemed consent, not sure and opt-out). For this purpose, participants' ethnicity was dichotomised into White or Other minority ethnic group, education into Higher (completion of a bachelor's degree) or Lower education, and gender dichotomised into Male or Female. Religious beliefs were also categorised into, No religion, Christian or Minority religion (categorised as 10 different religious beliefs all with less than 5

cases). Prefer not to say responses were handled as missing data. For each significant chi-squared test, Cramer's V (ϕ_c) was used to represent the strength of association.
The analysis revealed significant differences in; age, F (3,1130) = 18.86, p <.001, and gender (3, n = 1186) = 15.60, p = <.01; ϕ_c =.12. Significant group-level differences were also observed in education (3, n = 1197) = 9.97, p = .02; ϕ_c =.09 and ethnicity (3, n = 1192) = 8.12, p = .04; ϕ_c =.08[4]. No differences in religion were found, p =.20.

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[4] Significant demographic differences were found between the participant groups. These reflect demographic differences in participants' anticipated donor decisions (e.g., those who plan to opt-out were slightly older). Participants were not randomly assigned to experimental arms. However, the analysis was repeated with age, gender, ethnicity, and education entered as covariates. The principal findings remain unchanged. i.e., dispelling organ donation myths did not increase intentions in those who plan to opt-out. This supplementary analysis is reported in Appendix 7.

Table 2. 1. Demographic Characteristics of the Participant Groups

	Opt-in (*n* = 794)	Deemed consent (*n* = 292)	Not sure (*n* = 63)	Opt-out (*n* = 50)
Age (*SD*)	37.90 (11.90)	43.17 (12.47)	44.00 (11.90)	45.59 (15.37)
Gender N (%)				
Female	665 (83.75%)	217 (74.32%)	48 (76.19%)	40 (80.00%)
Male	119 (14.99%)	73 (25.00%)	15 (23.81%)	9 (18.00%)
Transgender	4 (0.50%)	0	0	0
Prefer not to say	6 (0.75%)	2 (0.68%)	0	1 (2.00%)
Education Level N (%)				
Lower Education	349 (43.95%)	135 (46.39%)	37 (59.68%)	30 (60.00%)
Higher Education[a]	445 (56.05%)	156 (53.61%)	25 (40.32%)	20 (40.00%)
Religion Beliefs N (%)				
No Religion	432 (54.41%)	150 (51.37%)	28 (44.47%)	20 (40.00%)
Christian	334 (42.07%)	129 (44.18%)	32 (53.33%)	28 (56.00%)
Agnostic	1 (0.13%)	1 (0.34%)	1 (1.61%)	0
Buddhist	1 (0.13%)	0	0	0
Hindu	0	1 (0.34%)	0	0
Muslim	0	2 (0.68%)	0	0
Jewish	2 (0.25%)	1 (0.34%)	0	0
Prefer not to say/other	24 (3.02%)	8 (2.74%)	3 (4.76%)	1 (2.00%)
Ethnicity N (%)				
White	782 (98.99%)	282 (96.91%)	61 (98.39%)	50 (100%)
Asian or Asian British	1 (0.13%)	6 (2.05%)	1 (1.61%)	0
Black, African or Caribbean	0	1 (0.34%)	0	0
Mixed/multiple ethnic groups	6 (0.80%)	2 (0.68%)	0	0
Prefer not to say	1 (0.13%)	0	0	0
Organ Donor Status N (%)				
Yes	691 (87.03%)	137 (46.92%)	8 (12.70%)	7 (14.00%)
No	53 (6.68%)	115 (39.38%)	49 (77.77%)	43 (86.00%)
Not Sure	50 (6.30%)	40 (13.70%)	6 (9.52%)	0

Note. [a] Higher education was categorised as completion of a Bachelor’s degree.

2.4.3 Anticipated Donor Decisions Following the Introduction of Opt-out Consent

Frequency counts indicated that, 66.06% (*n* = 794) of participants selected to '*opt-in*' to the organ donor register following the proposed legislative change. Just less than a quarter of participants, 24.29% (*n* = 292) plan to follow '*deemed consent',* 4.16% (*n* = 50) of participants selected to '*opt-out*' and 5.24% (*n* = 63) of participants selected '*not sure*'. Table 2.2 presents a breakdown of participants anticipated donor decisions across England, Northern Ireland and Scotland.

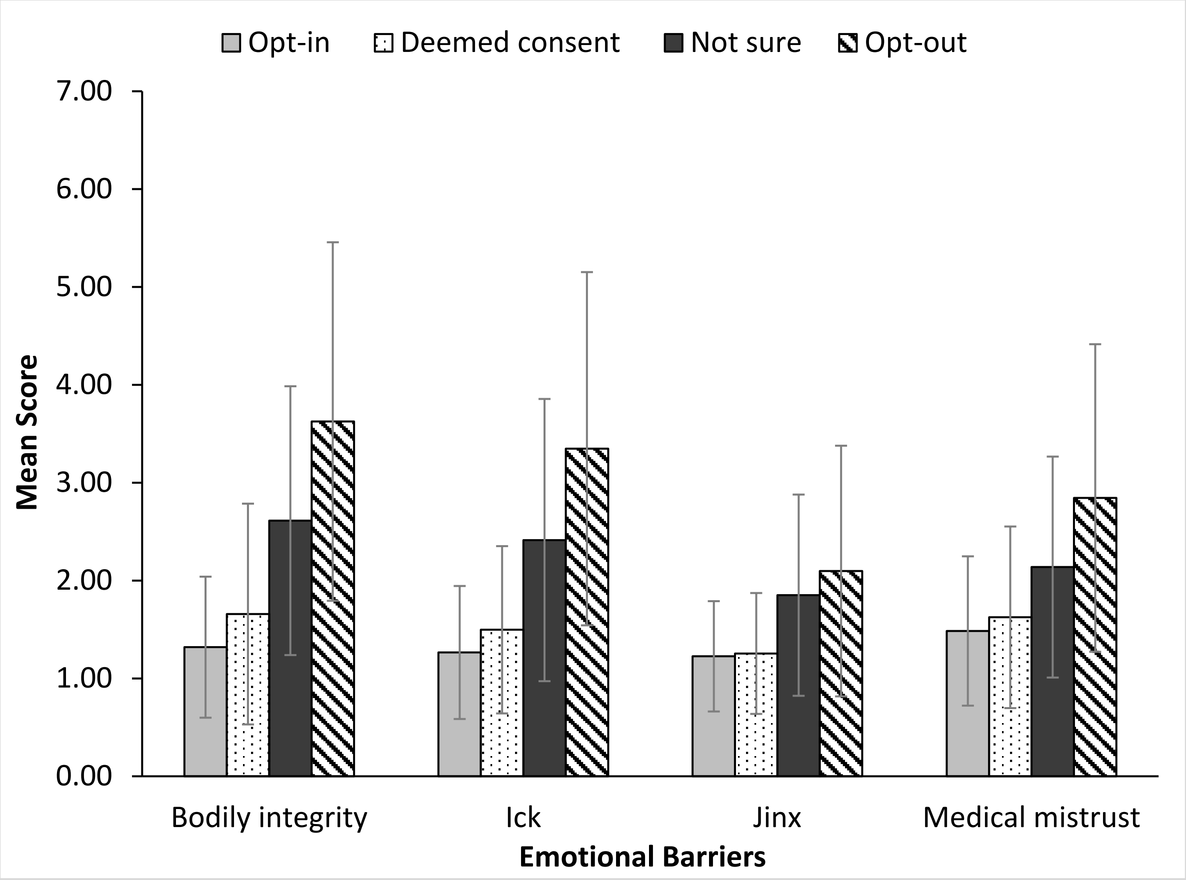
Table 2. 2. Anticipated Donor Decisions Across England, Northern Ireland and Scotland

	Opt-in (*n* = 794)	Deemed consent (*n* = 292)	Not sure (*n* = 63)	Opt-out (*n* = 50)
England *N* (%)	92 (69.70%)	29 (21.97%)	6 (4.55%)	5 (3.79%)
Northern Ireland *N* (%)	10 (66.67%)	5 (33.33%)	0 -	0 -
Scotland *N* (%)	692 (65.78%)	258 (24.52%)	57 (5.42%)	45 (4.28%)

2.4.4 Emotional Barriers: Hypothesis 1

A MANOVA was conducted to investigate differences in emotional barriers towards organ donation (bodily integrity, medical mistrust, ick and jinx) across the anticipated donor choice groups (opt-in, deemed consent, not sure and opt-out). A statistically significant difference between the groups on the combined dependent variables was found, F (12, 3456) = 35.27, p <.001; Pillai's V = .327; r = .33. Mean emotional barriers scores for each of the groups are graphically represented in Figure 2.4.

Figure 2. 4. Mean Emotional Barriers Scores Across the Four Donor Choice Groups.



Note. Error bars represent standard deviation.

To ascertain which of the outcome variables contributed to the significant MANOVA, a series of univariate ANOVAs on each of the emotional barriers were conducted. To differentiate group-level differences, a Games-Howell *post-hoc* test was conducted. This was selected to correct for a violation of homogeneity of variances.

Bodily integrity. ANOVAs revealed a statistically significant difference in bodily integrity scores between the groups, F (3, 1153) = 118.63, p <.001; r = .49. *Post-hoc* analysis indicated significant differences across all group comparisons. Bodily integrity scores were highest in respondents who plan to opt-out, in comparison to the opt-in, deemed consent and not sure group. These differences were significant at p <.001 for participants who plan to opt-in or follow deemed consent, and at p =.01 for the not sure group. Higher scores are indicative of greater bodily integrity concerns.

Ick Factor. A statistically significant difference in ick factor scores between the groups was found F (3, 1153) = 116.92, p <.001; r = .48. *Post-hoc* analysis revealed significant differences across all group comparisons. Ick factor scores were highest in the opt-out group, in comparison to the opt-in, deemed consent and not sure group. These differences were significant at p <.001 for participants who plan to opt-in or follow deemed consent, and at p =.02 for the not sure group. Higher scores indicate greater feelings of revulsion at the idea of organ donation.

Jinx Factor. Significant differences in jinx factor scores were also found, F (3, 1153) = 41.58, p <.001; r = .31. *Post-hoc* analysis revealed that participants in the opt-out group had significantly higher jinx factor scores than both, those who plan to opt-in and those who would follow deemed consent; at p <.001. Higher scores indicate stronger feelings that it is bad luck to talk about death or becoming an organ donor. No differences were found between those who plan to opt-in and those who plan to follow deemed consent, p = .90. There were also no differences in jinx factor scores between those in the opt-out versus those in the not sure response group, p = .70.

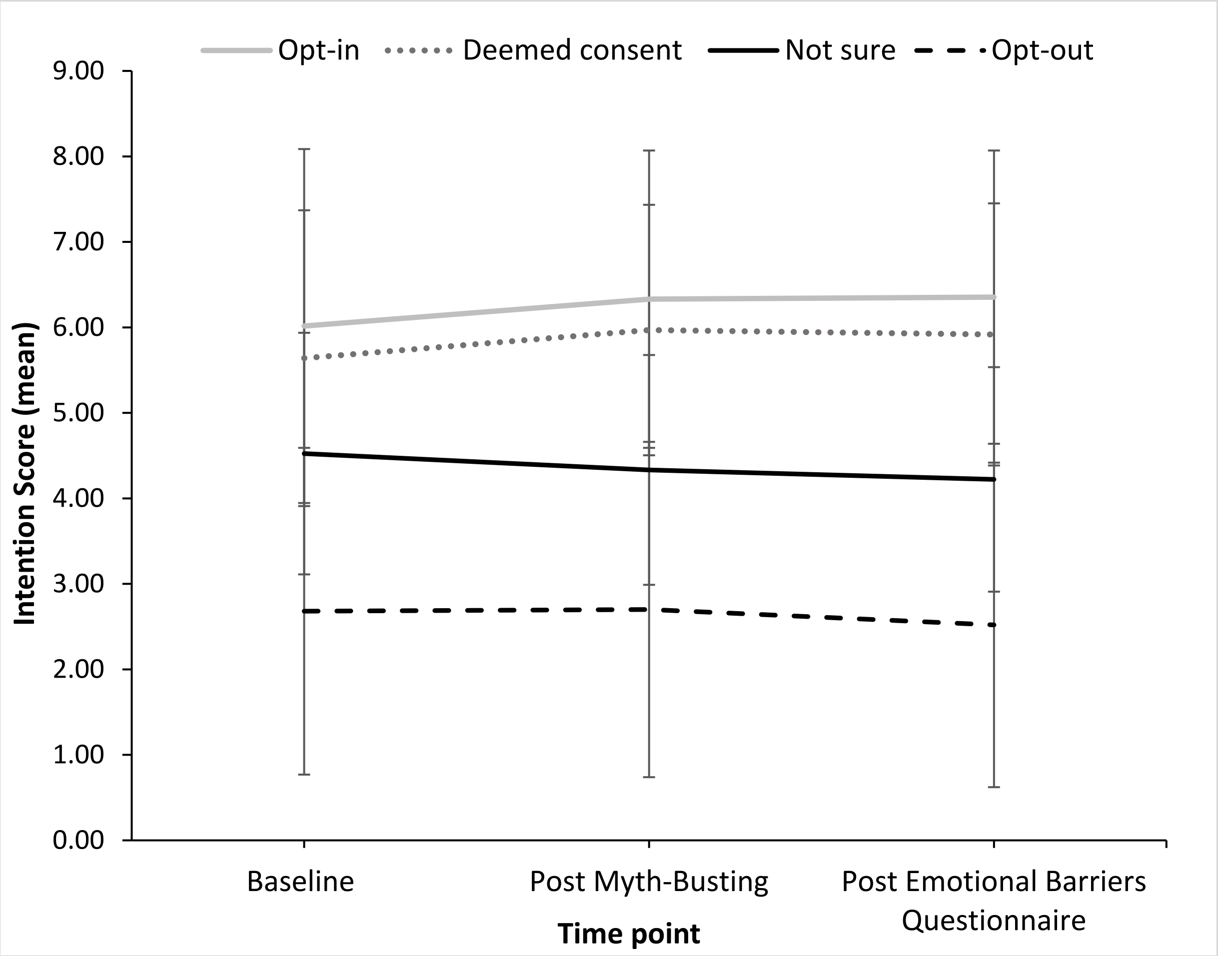
Medical Mistrust. ANOVAs revealed a statistically significant difference in medical mistrust scores between the donor response groups, F (3, 1153) = 44.33, p <.001; r = .32. *Post-hoc* analysis indicated that participants in the opt-out group had significantly higher medical mistrust scores than the opt-in and the deemed consent group, at p <.001 and the not sure response group, at p =.052. Higher scores indicate stronger medical mistrust. No differences between the opt-in and the deemed consent group were found p = .11.

2.4.5 Experimental Manipulation: Hypothesis 2 and 3

A repeated measures ANOVA was run to investigate differences in donor intentions as a function of time-point (baseline, post myth-busting and post emotional barriers questionnaire) and group (opt-in, deemed consent, not sure and opt-out). Mauchly's test of sphericity indicated that the assumption of sphericity was violated, χ^2 (2) = 96.30, p <.001. As estimated epsilion was greater than 0.75, a Huynh-Feldt correction was applied. A main effect of group was found, F (3, 1195) = 123.27, p <.001; r = .49. Donor intentions significantly differed between the participant groups.

As described in the methodology, to ensure adequate cell sizes for analysis, the publication arising from this chapter, (Miller et al., 2019) reported a three-group comparison (opt-in, deemed consent and opt-out/not sure). Within the four-group comparison conducted for this chapter (opt-in, deemed consent, not sure and opt-out), there was no significant main effect of time, *F* (1.86, 2227.01) = .921, *p* = .39; *r* = .03. There was also no significant interaction between time point and donor group, *F* (5.59, 2227.01) = 2.00, *p* = .07; *r* = .07, ε =.93. It should be noted that the main effect of time and the interaction effect were significant in the three-group comparison. However, the interaction effect reported in the current chapter was close to statistical significance (*p* =.07) and the effect size for both, the three-group and four-group comparison, identical *r* = .07. As such, the change in significance is likely due to low statistical power. A graph illustrating changes in intention over time for each donor group is presented in Figure 2.5.

Figure 2. 5. Mean Donor Intentions Across Study Time-Points, Within the Four Anticipated Donor Groups.



Note. Error bars represent standard deviation.

2.4.6 Increasing the Salience of Emotional Barriers and Organ Donor Intentions: Hypothesis 2

A *post-hoc* paired samples *t-test* was conducted to examine differences in donor intentions between baseline, and after exposure to an emotional barriers questionnaire. For the donor group, that is individuals who plan to actively opt-in or follow deemed consent, exposure to the emotional barriers questionnaire significantly increased intention in comparison to baseline at p <.001 and p =.01 respectively. However, for both, participants in the not sure group and those who plan to opt-out, exposure to the emotional barriers questionnaire decreased intention, although this did not emerge as a significant finding (p =.07 and p =.47).

Table 2. 3. Donor Intention Between Baseline and After Exposure to Emotional Barriers

		M	*SD*	*t*	*p*	95% CI	
						Lower	Upper
Opt-in	Baseline	6.02	2.07	4.47	.000	.189	.486
	Post emotional barriers	6.35	1.72				
Deemed Consent	Baseline	5.64	1.73	2.77	.006	.080	.475
	Post emotional barriers	5.92	1.53				
Not Sure	Baseline	4.52	1.41	-1.87	.066	-.623	.020
	Post emotional barriers	4.22	1.31				
Opt-out	Baseline	2.68	1.91	-.727	.471	-.602	.282
	Post emotional barriers	2.52	1.90				

2.4.7 Myth-Busting and Organ Donor Intentions: Hypothesis 3

To investigate whether correcting harmful organ donation myths would increase donor intentions, *post-hoc* paired samples *t*-tests were conducted between baseline and post myth-busting. For both, participants who plan to actively opt-in to the donor register and those who plan to follow deemed consent, dispelling myths significantly increased intention in comparison to baseline, both at p <.001. However, for both participants in the not sure group and participants who plan to opt-out, dispelling myths had no effect on intention, at p =.21 and p =.94.

Table 2. 4. Donor Intention Between Baseline and After Exposure to the Myth-Busting Intervention.

		M	*SD*	*t*	*p*	95% CI	
						Lower	Upper
Opt-in	Baseline	6.02	2.07	4.86	.000	.187	.440
	Post myth-busting	6.33	1.74				
Deemed Consent	Baseline	5.64	1.73	3.65	.000	.151	.506
	Post myth-busting	5.97	1.47				
Not Sure	Baseline	4.52	1.41	-1.26	.21	-.493	.112
	Post myth-busting	4.33	1.34				
Opt-out	Baseline	2.68	1.91	.081	.94	-.476	.516
	Post myth-busting	2.70	1.96				

2.4.8 Secondary Objective: The Effect of Myth-Busting on Emotional Barriers

To explore differences in emotional barrier scores, represented as multivariate data (bodily integrity, medical mistrust, ick and jinx) as a function of the intervention order (1. myth-busting then emotional barriers or 2. emotional barriers then myth-busting) Hotelling's T^2 was conducted. A significant difference between the intervention order (myth busting vs emotional barriers) on the combined dependant variables was found, $F(4, 1155) = 20.69$, $p < .001$; Pillai's V = .067; $r = .26$. To follow-up the significant Hotelling's T^2, a series of independent samples t-tests for each dependant variable were conducted. A Bonferroni adjusted α level of .025 with a 95% confidence level was applied. Medical mistrust scores were significantly lower for participants who completed the myth-busting intervention before measures of emotional barriers ($M = 1.38$, $SD = .73$) in comparison to participants who had not received the myth-busting intervention before completing measures of emotional barriers ($M = 1.84$, $SD = 1.03$); 95% CI [-.58, -.34], $p < .001$. Differences between the remaining emotional barriers (ick, jinx and bodily integrity) were not significant.

2.4.9 Organ Donation Myths

Participant responses from the organ donation myth-busting intervention, which also served as an assessment of organ donation knowledge are displayed in Table 2.5. To examine potential differences in organ donation knowledge scores between the donor groups, a one-way ANOVA was conducted. A Welch ANOVA was implemented to control for a violation of homogeneity of variances. Significant differences in knowledge scores were found between the opt-in *(M* = 7.61, *SD* = 1.02) deemed consent, *(M* = 7.52, *SD* = 1.04) not sure, (*M* = 7.33, *SD* = 1.40) and the opt-out group (*M* = 6.70, *SD* = 1.23), Welch's *F*(3, 135.11) = 9.40, *p* <.001. A Games-Howell *post-hoc* analysis revealed that participants in the donor group, that is, both participants who plan to opt-in and those who plan to follow deemed consent, demonstrated significantly higher knowledge scores in comparison to participants who plan to opt-out, at *p* <.001. No differences were observed between the opt-out and the not sure response group. Higher scores indicate greater knowledge of organ donation (lower belief in myths).

Table 2. 5. Responses for the Myth-Busting Intervention Across the Donor Choice Groups (Cell Shading is Used to Indicate Incorrect Answers)

			Response %	
Statement/Myth	**Group**	***N***	True	False
1. Doctors might not do their best to save someone's life if they know they are on the NHS[a] Organ Donor Register.	Opt-in	793	2.65%	97.35%
	Deemed consent	292	4.11%	95.89%
	Not sure	62	17.74%	82.26%
	Opt-out	50	26.00%	74.00%
2. People could still be alive when their organs are removed.[b]	Opt-in	793	44.01%	55.99%
	Deemed consent	291	42.61%	57.39%
	Not sure	63	36.51%	63.49%
	Opt-out	50	62.00%	38.00%
3. Organ donation is against many religious beliefs.	Opt-in	793	59.27%	40.73%
	Deemed consent	291	63.23%	36.77%
	Not sure	63	60.32%	39.68%
	Opt-out	50	78.00%	22.00%
4. Organ Donation leaves the body disfigured and afterwards, people won't be able to have an open-casket funeral.	Opt-in	791	1.52%	98.48%
	Deemed consent	291	1.72%	98.28%
	Not sure	63	9.52%	90.48%
	Opt-out	50	4.00%	96.00%

Table 2.5 (*Continued*) Cell Shading is Used to Indicate Incorrect Answers

Statement/Myth	**Group**	***N***	Response % True	 False
5. There is an age limit for organ donation.	Opt-in	793	18.41%	81.59%
	Deemed consent	290	21.03%	78.97%
	Not sure	63	14.29%	85.71%
	Opt-out	50	24.00%	76.00%
6. The NHS only need adult organ donors.	Opt-in	791	0.13%	99.87%
	Deemed consent	292	0.34%	99.66%
	Not sure	63	0%	100%
	Opt-out	50	0%	100%
7. There are enough organs available for the people waiting for an organ transplant.	Opt-in	791	1.01%	98.99%
	Deemed consent	292	1.03%	98.97%
	Not sure	63	0.0%	100%
	Opt-out	50	0.0%	100%
8. People who have medical conditions can't donate.	Opt-in	790	6.71%	93.29%
	Deemed consent	292	8.90%	91.10%
	Not sure	62	17.74%	82.26%
	Opt-out	50	20.00%	80.00%

Table 2.5 (*Continued*) Cell Shading is Used to Indicate Incorrect Answers

			Response %	
Statement/Myth	**Group**	***N***	True	False
9. Donated organs can be bought and sold.	Opt-in	790	5.04%	94.96%
	Deemed consent	292	5.14%	94.86%
	Not sure	63	9.52%	90.48%
	Opt-out	50	16.00%	84.00%

Note. [a] NHS = National Health Service. [b] The high percentage of incorrect responses may result from ambiguity in this question regarding the potential to donate organs as a living donor.

2.5 Discussion

2.5.1 Intention to Opt-out

This study investigated the percentage of the population planning to opt-out of the organ donor register if opt-out legislation is implemented in England and Scotland. Approximately 10% of respondents plan to actively opt-out of the donor register or, are unsure of their decision if the law changes to an opt-out system. Notably, this figure is considerably less than baseline assessments recorded in England, Scotland and Wales during pre-implementation analyses, whereby 15% of the English population, 22.5% of the Scottish population and 19% of the Welsh population indicated intentions to actively opt-out of the donor register (Scottish Parliament, 2018; UK Government, 2018a; Welsh Government, 2012a). These findings may suggest greater preliminary support for opt-out legislation in Scotland and England among this sample. However, it should be noted, that support may be overinflated among the study respondents as over 70% reported being registered as donors, in comparison to the 38% UK average reported at the time of conducting this study (NHS Blood and Transplant, 2018). Therefore, these findings should be interpreted within the context of a selection bias.

2.5.2 Do Emotional Barriers Differentiate Participants Who Plan to Opt-out?

The findings from this chapter indicate that both individuals who plan to opt-out of organ donation and individuals who are unsure of their donor decision, had significantly higher negative emotional barriers, in comparison to participants who plan to opt-in or follow deemed consent. In particular, bodily integrity concerns were most prominent within these groups, closely followed by the ick factor. Fears that the physical integrity of the body may be violated as a consequence of organ donation have recurrently emerged within both quantitative and qualitative literature as a key barrier to organ donor registration in countries with opt-in donor systems (Morgan, Stephenson, et al., 2008; Newton, 2011; Shepherd & O'Carroll, 2014). The findings from this research have confirmed that emotional barriers are also important in the context of opt-out legislation.

While this is, as far as the author is aware, the first quantitative study to examine emotional barriers in relation to opt-out legislation, existing qualitative literature supports these findings (Lauri, 2009). In this study, metaphors used to describe organ donation and opt-out consent were explored in relation to Maltese participants' social representations of the body. Throughout, a number of metaphors of organ donation that align with bodily integrity concerns were expressed, including fears of desecration and dismemberment of the body after organ retrieval, and subsequent negative implications for the afterlife. The following excerpt from this study epitomizes these concerns, '*So if they will take away my kidneys, will I be resurrected with them missing*'? (Lauri, 2009). These metaphors were then conceptualised in the overarching social representation of ownership of the body (*I am my body*). Participants who reported these beliefs were described to hold a monistic view of their body, believing that the mind and the body function as a single entity that cannot operate independent from one another. For these participants, organ donation was seen to irreparably damage the integrity of the body. Importantly, the author reported that almost every participant who opposed the opt-out system expressed these views.

2.5.3 Experimental Manipulation

This study also examined the effect of increasing the salience of emotional barriers, and a brief NHS myth-busting intervention on participants' intention to donate organs. Based on previous research (Doherty et al., 2017; O'Carroll et al., 2016), it was hypothesised that increasing the salience of emotional barriers towards organ donation, by completing an emotional barriers questionnaire, would decrease intention to donate organs. However, counter to expectation, a differential effect was observed, and exposure to emotional barriers significantly increased intention for both, the opt-in and deemed consent groups. However, for participants who plan to opt-out, and those who are unsure of their donor decision, increasing the salience of emotional barriers slightly reduced intention, although this was not a significant outcome. Therefore, for participants inclined to opt-out of the donor register, increasing the salience of emotional barriers may have acted to amplify negative barriers towards organ donation.

2.5.4 Myth-busting

A brief NHS myth-busting intervention was found to significantly increase intention to donate for participants who plan to opt-in or select deemed consent. However, for participants who plan to opt-out and those who are unsure of their donor decision, the group one would be most hoping to influence, dispelling myths had no effect on intention to donate.

This finding is consistent with extant literature on the use of corrective factual information to dispel anti-vaccination myths. Such interventions are reported in the literature to be either, ineffective or detrimental towards vaccination intentions (Hornsey et al., 2018; Nyhan & Reifler, 2015). Moreover, this effect is reported to be amplified for individuals with more negative attitudes and heightened vaccination concerns (Nyhan et al., 2014).

A supplementary examination of the intervention order, indicated that participants who first received the myth-busting intervention, reported significantly lower medical mistrust scores. However, no differences in the remaining emotional barriers were found. Ultimately, while corrective information provides the reader with rational evidence to refute harmful myths, information provision was not sufficiently powerful to change donor intentions for those inclined to opt-out. Notably, participants who plan to opt-out exhibited significantly higher negative emotional barriers towards organ donation. Extensive research has shown that emotions and affective attitudes play the greatest role in predicting donor behaviours (Morgan, Stephenson, et al., 2008; O'Carroll, Foster, et al., 2011). However, the myth-busting intervention targeted facts rather than feelings. Adopting a dual-process perspective (Strack & Deutsch, 2004), interventions that target ‘facts’ may have a limited impact on donor intentions that are driven by ‘feelings’ (emotional barriers). This may explain why, the act of presenting corrective rational evidence was not sufficient to dispel deep-set myths and subsequently, influence intention. Moreover, the potential persuasiveness of information increases following readers perceptions of credibility (Henkel & Mattson, 2011). Although the myths and counter-evidence within this manipulation were derived from the NHS, participants were not explicitly made aware of this. Consequently, the credibility and thus the effectiveness of the intervention may have been undermined.

2.5.5 Implications and Future Directions

As media campaigns designed to dispel harmful myths about organ donation are common within organ donation awareness campaigns, rigorous evaluations of their efficacy and mechanisms of effect are essential. This is crucial, as such campaigns could potentially have deleterious effects on intentions towards health-related behaviours for those with heightened negative attitudes (Nyhan et al., 2014). Research has shown that emotions play a major role in predicting organ donor behaviours (Morgan, Stephenson, et al., 2008). However, the myth-busting intervention used by the NHS at the time of conducting this study targeted facts rather than feelings. Previous research has found narrative communication campaigns that employ fictional testimonies to refute organ donation myths, to be more effective at increasing donor consent in comparison to corrective statistical based information (Weber et al., 2006). This may suggest that interventions designed to target feelings and emotions could be more effective at overcoming deep-set emotional beliefs and increasing donor intentions. Future studies are required to test this.

2.5.6 Limitations

Potential limitations of this research concern the generalisability of the findings to the UK general public. While the use of volunteer sampling enabled the recruitment of a large sample, there was likely a selection bias, as over 70% of participants self-reported being registered as organ donors. This is significantly higher than the 38% of the UK population registered as donors at the time of conducting this study (NHS Blood and Transplant, 2018). Therefore, support for organ donation and opt-out legislation may have been overrepresented in this sample. Additionally, the study primarily consisted of people living in Scotland, and only a small percentage of adults living in England and Northern Ireland. This limits the generalisability of the findings to populations outside of Scotland. Moreover, this study relied on a self-report measure of donor intentions. This was essential, as opt-out legislation had not yet been introduced in Scotland and England. Therefore, the use of self-report intention measure provided an important preliminary estimate of the nation’s probable behaviour. It should also be recognised that there was considerable heterogeneity between the group sizes, with a very low number of respondents reporting the intention to opt-out. Following the introduction of opt-out consent legislation, future studies with a more representative, balanced sample of donor groups should test whether these findings are replicated in between-group analyses using verified measures of organ donor behaviour.

2.6 Conclusions

Approximately 10% of participants plan to either, actively opt-out of the organ donor register or, are currently unsure of their decision if opt-out consent legislation is introduced. Emotional barriers towards organ donation were significantly higher in participants inclined to opt-out of the register. Therefore, before the implementation of planned opt-out legislation, examination of interventions to counter these potential barriers are imperative. However, dispelling organ donation myths using corrective factual information may not be the best means of increasing donor intentions for those most likely to opt-out, as it is using facts to challenge feelings. The development of public health campaigns designed to target affective attitudes require rigorous evaluation.

Chapter 3: ‘*If I donate my organs it’s a gift, if you take them it’s theft*’: a qualitative study of planned donor decisions under opt-out legislation

Preface

In Chapter 2, anticipated donor decisions and emotional barriers were explored in relation to the proposed opt-out system. To do so, emotional barriers were examined using a validated and extensively used quantitative measure of affective attitudes towards organ donation. This approach provided an important preliminary measure of emotional barriers, although it is acknowledged that a quantitative measure of emotions may limit the depth of understanding into such complex factors. At the time of conducting the study in Chapter 2, very little was known about why people may opt-out or, indeed, why individuals may choose to actively register as an organ donor or take no action and follow deemed consent. Therefore, to provide more in-depth insights into the reasons underpinning participants’ anticipated donor choices following the transition to opt-out legislation, the current chapter provides a qualitative analysis of free-text response data collected within the questionnaire study reported in Chapter 2.

Sections of this chapter also appear in Miller, J., Currie, S., & O’Carroll, R. E. (2019). *‘If I donate my organs it’s a gift, if you take them it’s theft’*: a qualitative study of planned donor decisions under opt-out legislation. *BMC Public Health*, 19(1), 1463.
https://doi.org/10.1186/s12889-019-7774-1

3.1 Abstract

Background: There is a worldwide shortage of donor organs for transplantation. To overcome this, several countries have introduced an opt-out consent system. However, the factors driving donor decisions under opt-out legislation (opt-in, deemed consent and opt-out) remain unclear. This study explored the reasons influencing donor choices for people who plan to actively opt-in to the register, take no action and follow deemed consent, opt-out, and those who are unsure of their decision.

Methods: This study reports a thematic analysis of free-text responses obtained from the preliminary study described in Chapter 2, and explores the reasons behind participants intended donor decisions should opt-out legislation be introduced in England, Northern Ireland and Scotland. Of the n = 1202 participants who completed the questionnaire in Chapter 2, n = 923 provided a free-text response explaining their views. Thematic analysis was used to explore the reasons why participants plan to: opt-in (n = 646), follow deemed consent (n = 205), opt-out (n = 32) and those who were not sure (n = 40).

Results: A key theme for those planning to actively opt-in was that it ensures one's donor choice is explicitly clear and unequivocal. Some respondents viewed deemed consent as "*wishy washy*" and open to ambiguity, thus actively registering consent was seen as a way of protecting one's decision from family interference. Taking no action and following deemed consent was considered to represent a simple effortless choice. This was important from a pragmatic point of view and because it protects ambivalent participants from making a challenging emotive choice about organ donation. Key themes for those planning to opt-out relate to fears around medical mistrust and bodily integrity. Moreover, participants who plan to opt-out perceived presumed consent as "*authoritarian*" and a method of increasing government control of organs. In response, opting out protected their freedom of choice.

Conclusions: These findings highlight the importance of registering deliberate active consent for people who choose opt-in, due to concerns over possible family refusal under deemed consent. These findings could inform the development of communication campaigns that encourage family communication before the implementation of opt-out legislation.

3.2 Introduction

Although transplant activity has increased globally by 7.2% since 2015, there remains an insufficient supply of organs to satisfy demand (Global Observatory on Donation and Transplantation, 2020). The introduction of the proposed opt-out legislation has been endorsed as a strategy to overcome this discrepancy. This is because an opt-out system will enable consent for donation to be passively indicated without the need for people to actively register as a donor (Johnson & Goldstein, 2003). This is key in the context of UK organ donation, whereby despite high public support, less than 50% of the population have acted upon their intentions and registered as donors (NHS Blood and Transplant, 2020a). Therefore, altering the default policy is intended to bridge this longstanding intention-behaviour gap observed in relation to organ donation.

Existing literature has reported that emotional ambivalence towards organ donation contributes to the established intention-behaviour gap by reducing one's 'readiness' to engage in donor-relevant behaviours (Parisi & Katz, 1986). As discussed in Chapter 1, this may arise because actively registering as a donor, by nature involves contemplation of mortality. Indeed, when faced with decisions that incur a degree of emotive reasoning, people may be more likely to defer from making an active decision to avoid confronting aversive emotions (Luce, 1998). Arguably, the introduction of a default deemed consent system, may act to bypass negative evaluations of organ donation that previously prevented ambivalent individuals from actively registering as donors. This interpretation will be investigated in the current chapter.

3.2.1 Attitudes Towards Opt-out Consent

Within the last 40 years, there has been a shift in attitudes towards opt-out consent laws. Evidence from a well-known systematic review of survey data from 1976 - 2007 reported levels of support for opt-out legislation in the UK to vary between 34% - 64% (Rithalia et al., 2009). Notably, greatest support was recorded in studies conducted after the year 2000. A European update of this review from 2008 to 2017 has again reported variable findings (Molina-Pérez et al., 2018). With regards to views on different models of consent, an analysis of 48 studies indicated that most respondents express greater overall support for an express consent (opt-in) system. This was found even for studies conducted in nations who currently operate under an opt-out system. However, in terms of attitudes and support towards changing to a system of presumed consent in respondents' countries, data from 19 studies indicated generally high levels of support, ranging from 48% recorded in Ireland in 2008, to 80% reported in Iceland in 2014. However, the authors note that the majority of included studies consisted of government reports, which can vary substantially in the way questions are framed. Indeed, methodological inconsistencies within the included surveys were described in both reviews to have limited the conclusions to some degree.

While the above reviews may suggest public support for opt-out laws to have increased, as discussed in Chapter 1, the proposals for opt-out legislation in the UK were initially met with some contention. In fact, the Organ Donation Taskforce advocated against opt-out legislation in 2008 over a lack of efficacy, and concerns that the system may incur a loss of faith in the health service and the government (Organ Donation Taskforce, 2008b). Indeed, a recent review designed to inform the development of the opt-out system in Scotland reported limited robust evidence that in isolation, opt-out legislation would increase transplantation rates (Scottish Government, 2018). Instead, the review reinforced the importance of public awareness and attitudes, such as medical mistrust. This is critical, and reinforces the extensive evidence base which has shown emotional beliefs and attitudes to be key determinants of donor behaviour in countries with opt-in legislation (Morgan, Harrison, et al., 2008; Morgan, Stephenson, et al., 2008; O'Carroll, Foster, et al., 2011; Shepherd & O'Carroll, 2014). The results from Chapter 2 strengthen these findings in the context of opt-out legislation, confirming that negative emotional beliefs are significantly heightened for participants who *plan* to opt-out of the donor register (Miller et al., 2019).

At the time of conducting this study, the Bill for opt-out legislation had been passed in England and Scotland and was planned for implementation in mid-2020. However, with the exception of government reports on levels of public support for opt-out consent, limited research has explored the factors influencing donor decisions under this novel donation system. As such, a timely investigation of these factors was required. Given the emotive nature of the topic of organ donation, the application of qualitative methodology may provide deeper insights into the factors driving participant's decisions under opt-out legislation. Therefore, using free-text qualitative responses collected within the questionnaire study described in Chapter 2, the current study builds on these preliminary quantitative findings by exploring the reasons *why* people plan to make a particular donor choice (opt-in, deemed consent, not sure and opt-out) if opt-out legislation is introduced in the UK.

3.2.2 Study Objectives

The overall aim of this study was to explore the differences between donor choices under the planned opt-out consent system. Specifically, the study aimed to:

(1) Investigate the key differences between participants who plan to actively opt-in and opt-out of the donor register.

(2) To examine the key differences and similarities between people who provide consent for donation by actively opting-in to the register and those who plan to take no action and follow deemed consent.

3.3 Methodology

3.3.1 Study Procedure

The qualitative data reported in this study was acquired from free-text responses obtained from the questionnaire study reported in Chapter 2. Detailed information about the questionnaire content is available within Chapter 2, section 2.3.3. Ethical approval and recruitment procedures for this study are also outlined within the above section in Chapter 2. The qualitative data describes the reasons behind participants' donor decisions (opt-in, deemed consent, not sure or opt-out) following the proposed introduction of opt-out legislation. This was acquired in two stages. First, to obtain a measure of anticipated donor status following the introduction of opt-out consent, participants were presented with information describing the existing opt-in and the proposed opt-out system. The information presented to participants is shown in Figure 2.1 in Chapter 2. After being informed of the proposed legislative changes, participants were asked to respond to the following question, '*If the organ donation laws in your country change to an opt-out system, what would your choice be*?' The potential responses were as follows; I would opt-in (I want to be an organ donor), I have no objection to donating my organs (deemed consent to be an organ donor), not sure, and I would opt-out (I do not want to be an organ donor). After selecting one of these responses, participants were then presented with a free-text entry box and asked to '*Please briefly provide the reason behind your choice'*. The free-text data acquired from this question is the focus of the current chapter.

It should be acknowledged that the responses to this question from participants who plan to opt-out were initially intended to inform the development of the qualitative interview study reported in Chapter 4. However, when evaluating the data across all four donor choice groups, it became apparent that the responses had generated suitably rich and potentially new insights into the factors influencing decision-making under the opt-out system. There is currently no research exploring these factors, therefore, it was deemed appropriate to conduct a qualitative analysis of the data from each response group.

3.3.2 Qualitative Free-Text Responses

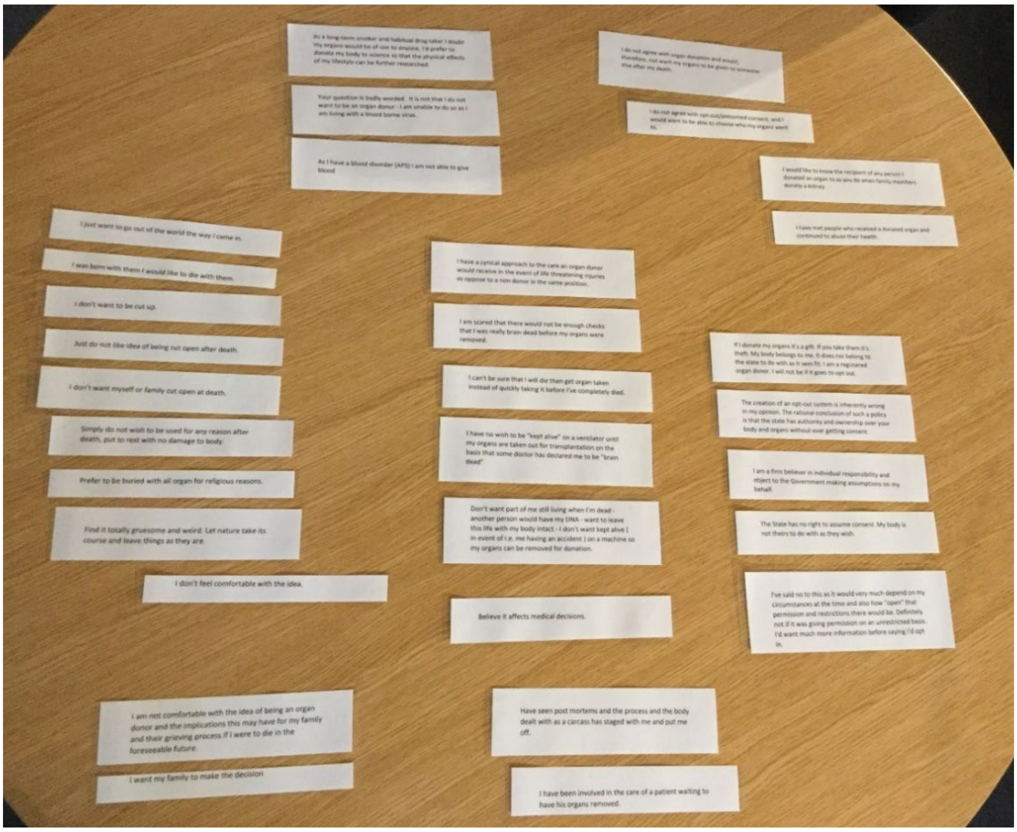
In total, 1202 participants completed the full online questionnaire described in Chapter 2. Of the total sample of questionnaire respondents, 76.79% (n = 923) provided a free-text written response explaining the reasons behind their planned donor decision. Of these responses, n = 646 were obtained from participants who plan to opt-in, n = 205 from participants who would follow deemed consent, n = 40 from participants who selected not sure, and n = 32 from respondents who plan to opt-out.

3.3.3 Data Preparation and Analysis

The data was analysed using Braun & Clarke's approach to thematic analysis (Braun & Clarke, 2006). This analytic approach was largely selected due to its flexibility and suitability for identifying patterns and themes within large, heterogenous datasets. In relation to the topic of opt-out organ donation, thematic analysis was also considered an appropriate approach to enable the generation of new perspectives and actionable implications in relation to decision-making under opt-out consent (Braun & Clarke, 2020). At this initial stage of the PhD, the thesis author also had limited experience of qualitative analysis, therefore the application of thematic analysis was selected due to its accessibility and appropriateness for new qualitative researchers.

The analysis was conducted based on the four respective donor groups (opt-in, deemed consent, not sure and opt-out). To encourage familiarisation with the data, each response was read multiple times and potential features of interest and preliminary notes were systematically recorded on either printed copies of the responses, or within Microsoft word for the largest response group (opt-in, *n* = 646). Following this, the data within each donor choice group was then indexed into respective groups or categories based on their similarities, interpreted meaning and content. To facilitate the identification of initial codes during this stage, the responses from the deemed consent, opt-out and not sure group were printed and indexed manually before respective codes were assigned in Microsoft word. An image of this process for the opt-out response group in shown in Figure 3.1. Following this, the codes were organised, and consideration given to their underlying meaning with regards to the research question in order to enable refinement into themes and subthemes. To increase the trustworthiness and level of consistency within the analysis, the primary themes and subthemes were independently reviewed by two members of the research team (JM and SC). Members of the research team (JM, SC, ROC) then met to discuss the resulting themes and subthemes and to select the illustrative excerpts presented throughout this chapter.

Figure 3. 1. Indexing of Opt-out Responses During the Initial Coding Stage



As a long-term smoker and habitual drug taker I doubt my organs would be of use to anyone. I'd prefer to donate my body to science so that the physical effects of my lifestyle can be further researched.

Your question is badly worded. It is not that I do not want to be an organ donor - I am unable to do so as I am living with a blood borne virus.

As I have a blood disorder (APS) I am not able to give blood

I do not agree with organ donation and would, therefore, not want my organs to be given to someone else after my death.

I do not agree with opt-out/presumed consent, and I would want to be able to choose who my organs went to.

I would like to know the recipient of any person I donated an organ to as you do when family members donate a kidney.

I have met people who received a donated organ and continued to abuse their health.

I just want to go out of the world the way I came in.

I was born with them I would like to die with them.

I don't want to be cut up.

Just do not like idea of being cut open after death.

I don't want myself or family cut open at death.

Simply do not wish to be used for any reason after death, put to rest with no damage to body.

Prefer to be buried with all organ for religious reasons.

Find it totally gruesome and weird. Let nature take its course and leave things as they are.

I don't feel comfortable with the idea.

I have a cynical approach to the care an organ donor would receive in the event of life threatening injuries as oppose to a non donor in the same position.

I am scared that there would not be enough checks that I was really brain dead before my organs were removed.

I can't be sure that I will die then get organ taken instead of quickly taking it before I've completely died.

I have no wish to be "kept alive" on a ventilator until my organs are taken out for transplantation on the basis that some doctor has declared me to be "brain dead"

Don't want part of me still living when I'm dead - another person would have my DNA - want to leave this life with my body intact - I don't want kept alive (in event of i.e. me having an accident) on a machine so my organs can be removed for donation.

Believe it affects medical decisions.

If I donate my organs it's a gift. If you take them it's theft. My body belongs to me. It does not belong to the state to do with as it sees fit. I am a registered organ donor. I will not be if it goes to opt out.

The creation of an opt-out system is inherently wrong in my opinion. The rational conclusion of such a policy is that the state has authority and ownership over your body and organs without ever getting consent.

I am a firm believer in individual responsibility and object to the Government making assumptions on my behalf.

The State has no right to assume consent. My body is not theirs to do with as they wish.

I've said no to this as it would very much depend on my circumstances at the time and also how "open" that permission and restrictions there would be. Definitely not if it was giving permission on an unrestricted basis. I'd want much more information before saying I'd opt in.

I am not comfortable with the idea of being an organ donor and the implications this may have for my family and their grieving process if I were to die in the foreseeable future.

I want my family to make the decision

Have seen post mortems and the process and the body dealt with as a carcass has staged with me and put me off.

I have been involved in the care of a patient waiting to have his organs removed.

3.4 Findings

3.4.1 Participant Demographics

The age of respondents who provided free-text comments (*n* = 923) ranged from 18 to 82 (*M* = 40.34, *SD* = 12.68). The majority of respondents 80.50% (*n* = 743) identified as female, 18.31% (*n* = 169) as male, four participants identified as transgender and seven declined to state their gender. The majority of respondents, 87.32% (*n* = 806) reported to be living in Scotland, 11.59% (*n* = 107) in England and 1.08% (*n* = 10) in Northern Ireland. The demographic information for each response group (opt-in, deemed consent, not sure and opt-out) is presented in Table 3.1.

3.4.2 Theme Summary

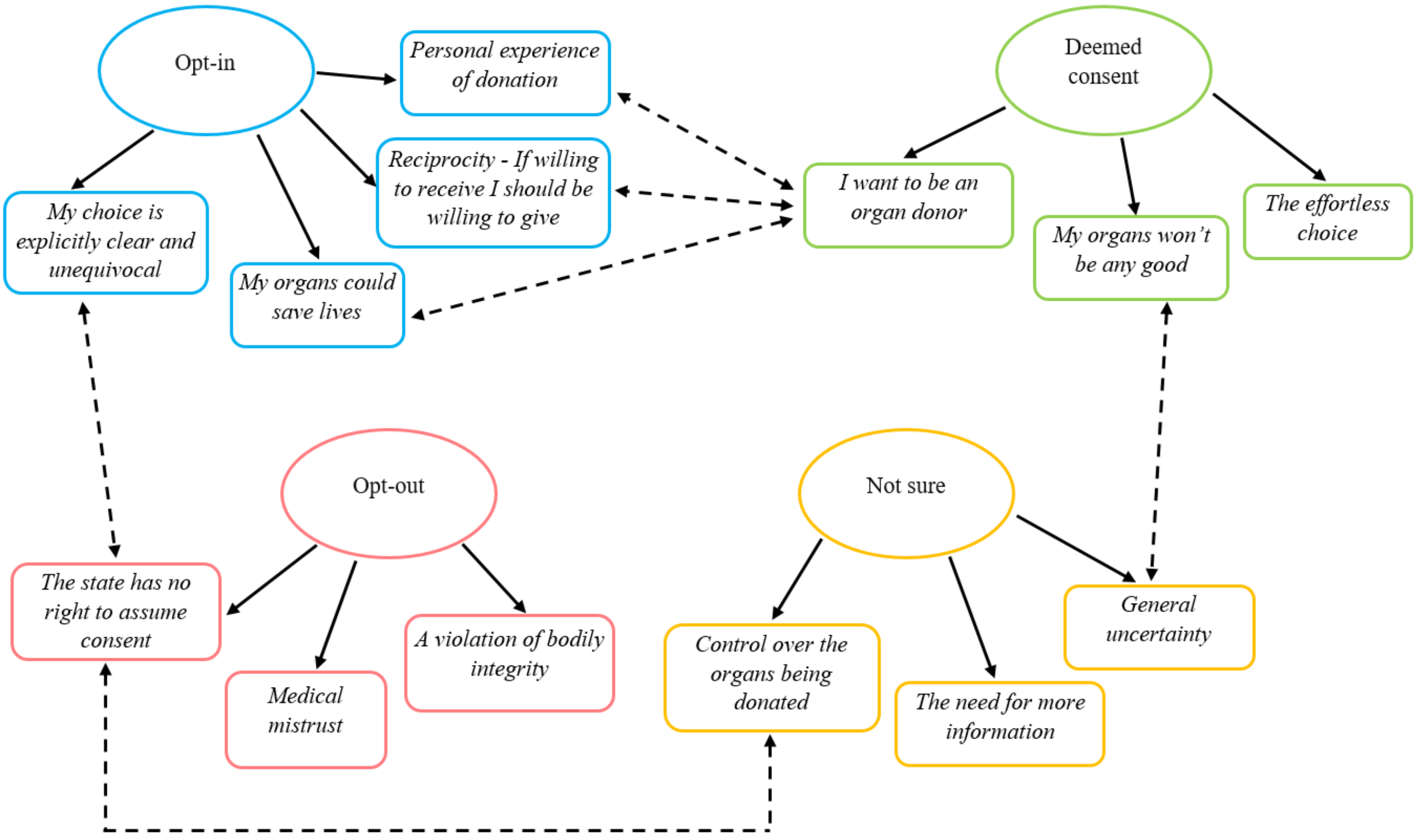
Across the four donor response groups, 13 themes were identified. A diagram of the key themes is presented in Figure 3.2. Each donor group (opt-in, opt-out, deemed consent and not sure) provided free-text comments related to three or four unique themes. For example, the four themes identified for participants who plan to actively opt-in were: (1) my choice is explicitly clear and unequivocal, (2) my organs could save lives, (3) reciprocity and, (4) personal donation experience. The key themes and sub-themes for each response group are provided in Table 3.2 (opt-in group), Table 3.3 (deemed consent group), Table 3.4 (not sure group) and Table 3.5 (opt-out group). The illustrative quotes are identified by the corresponding participants' sex and age, e.g., Female, 24 years. Some participants expressed multiple reasons for their choice, therefore some quotes can be assigned to more than one theme.

Table 3. 1. Demographic Characteristics of the Free-Text Respondents

	Opt-in (*n* = 646)	Deemed consent (*n* = 205)	Not sure (*n* = 40)	Opt-out (*n* = 32)
Age (*SD*)	38.38 (12.04)	43.97 (12.76)	46.47 (12.46)	47.47 (16.22)
Gender N (%)				
Male	98 (15.17%)	53 (25.85%)	11 (27.50%)	7 (21.88%)
Female	540 (83.59%)	150 (73.17%)	29 (72.50%)	24 (75.00%)
Transgender	4 (0.62%)	0	0	0
Prefer not to say	4 (0.62%)	2 (0.98%)	0	1 (3.13%)
Education Level N (%)				
Lower Education	277 (42.88%)	90 (43.90%)	20 (51.28%)	16 (50.00%)
Higher Education[a]	369 (57.12%)	115 (56.10%)	19 (48.72%)	16 (50.00%)
Religious Beliefs[b] N (%)				
No Religion	350 (54.18%)	107 (52.20%)	18 (45.00%)	14 (43.75%)
Christian	269 (41.64%)	87 (42.44%)	21 (52.50%)	16 (50.00%)
Jewish	2 (0.31%)	1 (0.49%)	0	0
Prefer not to say/other	25 (3.87%)	10 (4.88%)	1 (2.50%)	2 (6.26%)
Ethnicity N (%)				
White	636 (98.91%)	198 (97.06%)	38 (97.44%)	32 (100%)
Asian or Asian British	0	1 (0.49%)	1 (2.50%)	0
Mixed/multiple ethnic groups	6 (0.93%)	3 (1.46%)	0	0
Prefer not to say/other	1 (0.15%)	2 (0.98%)	0	0
Organ Donor Status N (%)				
Yes	571 (88.39%)	107 (52.20%)	6 (15.00%)	4 (12.50%)
No	35 (5.42%)	72 (35.12%)	31 (77.50%)	28 (87.50%)
Not Sure	40 (6.19%)	26 (12.68%)	3 (7.50%)	0

Note. [a] Higher education was categorised as completion of a bachelor's degree. [b] Muslim, Hindu and Sikh were included as independent categories however, no respondents reported to follow these beliefs.

Figure 3. 2. Key Themes for the Opt-in, Deemed Consent, Opt-out and Not Sure Groups



3.5 Themes from Opt-in Respondents

Table 3. 2. Themes and Respective Sub-themes from the Opt-in Group

Donor Choice	Themes	Sub-themes
Opt-in	1. My choice is explicitly clear and unequivocal	- *My wishes are set in stone* - *Reduces family distress* - *Protection against family interference*
	2. My organs could save lives	- *Dead people don't need organs* - *It's just the "right thing to do"*
	3. Reciprocity - If willing to receive I should be willing to give	(No sub-theme)
	4. Personal experience of donation	(No sub-theme)

3.5.1 Theme 1: My Choice is Explicitly Clear and Unequivocal

This theme represents the view that actively opting-in to the donor register, provides a stronger indication of participants' wishes to be an organ donor. This theme encompasses three sub-themes, (1) my wishes are set in stone, (2) reduces family distress and, (3) protection against family interference. Throughout, the act of opting-in was reported to provide explicit verified evidence of participants' donor intentions, in contrast to passively taking no action and following deemed consent. Participants in this group described the notion of deemed consent as ambiguous and open to uncertainty. Therefore, actively registering as a donor was perceived as a way of ensuring their intentions to donate were explicitly clear and unambiguous (sub-theme 1).

> *I wouldn't want any confusion about my intentions to donate my organs after I die so I would opt-in so it was conclusive proof.* (Female 28 years)
>
> *Providing no objection is not actually consenting to donating especially if people are unaware of the system, I think it's safer to opt-in so it is definitely my choice.* (Female 20 years)

A few participants who plan to actively opt-in perceived opt-out legislation as a threat to their individual responsibility and choice. In the following excerpt, automatically presuming consent for organ donation was thought to indicate the state's ownership of the body after death. Therefore, exerting a degree of control over this decision by actively registering as a donor was viewed as a way of protecting one's autonomy.

> *I do not believe that my body belongs to the state and as such I want to decide what happens after death.* (Male 39 years)

Before organ donation can proceed, the potentially eligible donors' next of kin are approached and consulted during the donation decision-making process. A number of participants expressed that by actively registering as a donor and thereby unmistakeably indicating a preference to donate, potential uncertainty and confusion regarding their wishes would be minimised. It was hoped that in turn, this would ameliorate distress when newly bereaved families are confronted with the emotive decision to donate their loved ones' organs (sub-theme 2).

> *I would prefer this to be a conscience* [conscious] *decision on my part and not something left to the state. Making arrangements myself would also grant some comfort to my family to know that the harvesting of my organs was something I wanted and not something which was decided for me.* (Male 30 years)

> *I would still like to be perceived as an active organ donor, indicating it was my own choice so that my family does not have to make any difficult decision in such difficult time.* (Female 32 years)

Some participants expressed concerns that members of their family, who "*don't like the idea"* of organ donation*,* may potentially disregard their wishes and overturn their donor decision. Therefore, actively registering as a donor was a method of safeguarding their choice and preventing family interference after their death (sub-theme 3).

> *I want there to be no confusion on my death, and I do not want my family (some who do not hold my views) to be upset by, or interfere in my decision after death.* (Female 53 years)

> *I want to donate and think the option of "deemed to give consent" is wishy washy and family members could argue against it, saying you didn't know. I want my choice to be clear.* (Female 41 years)

3.5.2 Theme 2: My Organs Could Save Lives

Throughout, participants in the opt-in group described a strong desire to save lives after their death as an important reason for registering as a donor. This theme encompasses two distinct subthemes (1) dead people don't need organs, and (2) it's just the "*right thing to do*". Many participants described simple pragmatic reasons for donating their organs after death and questioned why others did not share the same view. To these participants, their organs were described as personally useless for them, but potentially lifesaving for others (sub-theme 1).

As such, the act of discarding functional organs was labelled as "*wasteful"* and "*selfish"*. Often, participants in this response group displayed limited psychological attachment to their organs and likened the act of organ donation to everyday activities such as recycling or donating unwanted items to charity.

> *What is the point in letting perfectly good organs rot away inside a dead body when they could be used to save lives? I see it as the same principle as taking things you don't need to the charity shop. Why keep it if you don't need it but it could really benefit someone else?* (Female 33 years)
>
> *Personally, I just think that it makes sense to donate healthy organs when you can no longer use them yourself. We make a conscious effort to recycle paper etc. so why should it not make sense to recycle valuable organs?* (Female 20 years)

Some participants also expressed the view that ethically, agreeing to donate their organs after death was simply "*the right thing to do*" (sub-theme 2). This manifested in some participants considering organ donation to represent their last act of kindness, which was somewhat expected as part of their civic and societal duty.

> *I believe it would be the most ethical choice, as I would be maximizing my utility to my society through allowing my organs to be given to those who need them most.* (Male 24 years)
>
> *I would like to be able to help someone after my death if I can. Organs are obviously not needed after death it seems like the obvious socially responsible action to take.* (Female 52 years)

Others, viewed the act of organ donation as a method of compensating for any negative actions that may have occurred during their lifetime.

> *You're doing a good thing when you're dead. It balances the bad things you've done when alive. A bit.* (Male 44 years)

3.5.3 Theme 3: Reciprocity - If Willing to Receive I Should be Willing to Give

Participants who plan to actively opt-in to the donor register also described the principles of reciprocity as key factors influencing their decision. Participants explained that if they ever required an organ transplant, a donor organ would be gratefully accepted; therefore, many felt it would be hypocritical not to offer the same opportunity to others. For some participants, the donor system was likened to a banking system; as such, it was believed that one should only receive what they put in. In this instance, if a person is unwilling to donate their organs, they should not be eligible to receive an organ if they ever needed one.

> *If I or one of my children needed an organ I would hope there would be a donor for us, therefore, I expect any of us to be a donor for any other human being in need or an organ. It’s an equalities issue as well as a humanity and compassionate issue.* (Female 47 years)

> *I think it should work like a bank if you don't put anything in then you shouldn't be allowed to take anything out. I believe every person who is ABLE to opt in should and those who simply don't fancy it should not be allowed an organ if they find themselves in need of one.* (Female 39 years)

3.5.4 Theme 4: Personal Experience of Donation

Some respondents shared personal experiences of organ donation as the influential factor in their decision to register as a donor. In the following extracts, participants described how the lives of family and friends had been completely transformed through organ donation. Others, described the experience of losing a loved one during the wait for a lifesaving transplant as their motivation for registering as a donor. Whilst for some participants, knowing that their loved ones had saved multiple lives by donating their organs upon their death, cemented the importance of organ donation.

> *My mum, uncles and papa have all had or having a kidney transplant! My mum had hers 8 years ago and seeing how it's not only changed my life and my dads, but also hers and it's amazing to see her healthy again!* (Female 23 years)

> *My dad needed a liver transplant and I was going to be a "live donor" We had to wait till he was strong enough for the operation but unfortunately he died before we could complete it. Organ donation is giving someone a second chance.* (Male 36 years)

> *When my Grandfather passed away, he helped 5 different people from donating organs. This has made me aware of the importance of donating organs and the great difference that it can make for others.* (Female 21 years)

3.6 Themes from Deemed Consent Respondents

Table 3. 3. Themes and Respective Sub-Themes from the Deemed Consent Group

Donor Choice	Themes	Sub-themes
Deemed Consent	1. The effortless choice	*- I'm lazy, and this means less hassle* *- It saves me a difficult choice*
	2. My organs won't be any good	(No sub-theme)
	3. I want to be an organ donor	*- No need for organs when you're dead* *- Reciprocity* *- Personal experience of donation*

3.6.1 Theme 1: The Effortless Choice

This theme encompasses the view that following deemed consent (taking no action and thereby indicating consent for organ donation by default) serves as the easiest way of indicating a donor choice. This theme consists of two sub-themes, (1) I'm lazy, and this means less hassle, and (2) It saves me a difficult choice. Participants explained that a system of deemed consent was favourable as becoming an organ donor will now require no conscious action or unwarranted paperwork to be completed on their part. Many participants in this group expressed underlying support for organ donation and described intentions to donate yet, had not actively registered as a result of "*laziness*". For these participants, taking no action and following deemed consent was favourable due to its pragmatic and effortless nature (sub-theme 1).

> *I'm happy to be opted in without having to fill out any paper work. I hate paperwork so the less I have to do, the better!* (Female 43 years)
>
> *I'm rather lazy and so wouldn't want to have to 'do' anything! Besides which I'm happy to donate my organs or whatever's left of them.* (Female 28 years)

Deemed consent was also regarded by some participants as a way of indicating a desire to be an organ donor without the need to make a challenging or emotive decision (sub-theme 2). At times, participants in this group described general support for organ donation yet, reported the thought of organ donation to evoke unease and stated fears of "*being cut open after death*". For these participants, deemed consent may be considered as a way of indicating their underlying preference to donate whilst, avoiding barriers that may have previously prevented these participants from registering an active opt-in decision.

> *I'm not against them using my organs after I die but I don't really want to volunteer for it or anything.* (Female 20 years)
>
> *Opting in means confronting your own mortality, general support for the principal of organ donation and not wishing to confront your own mortality means option 3* [deemed consent] *satisfies both.* (Male 55 years)
>
> *Whilst I don't want to think about my organs being used or being cut open after death I also think if my organs could be used to save someone that's acceptable.* (Female 50 years)

3.6.2 Theme 2: My Organs Won't be Any Good

Some participants who plan to follow deemed consent, expressed a desire to donate their organs, however, were unsure if they were medically suitable due to physical illnesses and poor lifestyle choices. For these participants, taking no action and following deemed consent will enable them to maintain a positive stance regarding organ donation, whilst allowing medical professionals to assess their suitability for donation in the event of their death.

> *I would happily opt in but due to a medical condition, I understand they cannot be accepted. I won't actively opt-out & leave it to the doctors to decide whether they can use anything.* (Male 57 years)
>
> *Due to being a smoker and overweight I have thought that most of my organs would be of no use. I have no objection to my organs being used if required.* (Female 35 years)

3.6.3 Theme 3: I Want to be an Organ Donor

While the aforementioned themes describe the specific reasons why participants made a choice of deemed consent, the following theme describes participant's motivations for becoming an organ donor. This is because these participants, satisfied that deemed consent signalled their consent for donation, described general reasons why they would donate their organs after death. This theme is comprised of three sub-themes: (1) no need for organs when you're dead, (2) reciprocity, and (3) personal experience of donation. For many, motivations to become an organ donor centred on helping others and giving life after death. Participants frequently stated that after death they would have no requirement for their organs and expressed frustration at the thought of their valuable organs "*rotting in a coffin or being incinerated*". Organ donation was subsequently seen as a way of utilising otherwise useless organs to give life to people in desperate need (sub-theme 1).

> *I choose it as I have no longer any need for these organs when I'm dead so someone else should benefit from my life - goodness knows I've done bugger all else with it, this is my tiny contribution to humanity.* (Female 42 years)
>
> *Why should we take valuable organs with us when we die, when there are still people who are fighting to live, needing an organ? Organ donation is an amazing thing.* (Female 25 years)

For some, the decision to become an organ donor was driven by the concept of reciprocity. These participants, similar to those in the opt-in group, described feeling duty bound to agree to be an organ donor as they would accept an organ if they or someone close to them ever required a transplant. Therefore, participants felt it would otherwise be "*selfish*" not to agree to donate (sub-theme 2).

> *I'd want an organ if I needed it, so would have to agree with donation.* (Female 39 years)
>
> *I would hope an organ would be available if myself or any friend or family needed. I therefore feel I should be prepared to donate my own organs.* (Female 36 years)

In a similar way to the opt-in group, some participants reflected on their own personal experience of family members whose lives had been transformed through organ donation as their motivation (sub-theme 3).

> *My dad waited 3 years for a kidney transplant it transformed his life when he received it. Another friend's husband had a heart transplant over 20 years ago and he's still living a full life- it is an honor to help others live full lives once mine ends.* (Female 43 years)
>
> *My father had a heart transplant and would not have survived without the selflessness of organ donors.* (Female 33 years)

3.7 Themes from Not Sure Respondents

Table 3. 4. Themes and Respective Sub-Themes from the Not Sure Group

Donor Choice	Themes	Sub-themes
Not Sure	General uncertainty	*- I'm still not sure I want to be a donor* *- Medical uncertainty*
	The need for more information	(No sub-theme)
	Control over the organs being donated	(No sub-theme)

3.7.1 Theme 1: General Uncertainty

This theme encapsulates feelings of uncertainty around the decision to become an organ donor and encompasses two sub-themes, (1) I'm still not sure I want to be a donor and, (2) medical uncertainty. Throughout, participants in this group described the enormity of the decision to become an organ donor. Although several participants explained that they had been contemplating organ donation for a long period of time, they remained undecided and uncertain (sub-theme 1).

> *I have been thinking about this for many years and am yet to decide what route I'd like to take.* (Female 29 years)
>
> *It's a big decision and not one that I have ever been confident about making ...* (Female 51 years)
>
> *Still really unsure as to whether or not I'm 100% committed to donating organs.* (Male 40 years)

For some participants, pre-existing medical conditions or episodes of physical illness contributed towards uncertainty around the suitability of their organs for use in transplantation. This led to some individuals reporting concerns about transmitting illness' or poor-quality organs to the recipient (sub-theme 2).

> *I do not think I am able to donate as I previously had skin cancer. If it would be permitted I would be happy to select opt-out system.* (Female 53 years)

> *I have experienced a 2-year period of illness diagnosed as Chronic fatigue syndrome, as I do not know the cause I would not wish others to experience this due to any donation of my organs or blood. Until such times as I can be assured that such would not be the case I would not be happy to donate.* (Male 57 years)

3.7.2 Theme 2: The Need for More Information

Some participants felt that they lacked the appropriate information about organ donation in general, and in relation to the proposals for opt-out consent. As this legislation has not yet been enacted in Scotland, England and Northern Ireland, many were uninformed of the proposals. For some, more information was required in order to make an informed decision.

> *Don't know enough about organ donation.* (Male 49 years)

> *Really don't have enough information, but would like to have more information about this.* (Female 42 years)

3.7.3 Theme 3: Control Over the Organs Being Donated

Participants who were unsure of their decision also described a desire to choose which of their organs would be donated. Some expressed unease at the thought of donating particular organs and tissue, for these participants, a perceived lack of control over the donation process was an important factor in their decision.

> *I think not sure covers it. I think there are certain organs I wouldn't want to donate.* (Male 43 years)

> *I would like control of which organs are used.* (Female 42 years)

3.8 Themes from Opt-out Respondents

Table 3. 5. Themes and Respective Sub-Themes from the Opt-out Group

Donor Choice	Themes	Sub-themes
Opt-out	Medical mistrust	*- What if I'm not dead?* *- Reduced lifesaving care*
	A violation of bodily integrity	*- A desire to remain whole* *- Organ donation damages the body* *- A barrier to a peaceful passing*
	The State has no right to assume consent	(No sub-theme)

3.8.1 Theme 1: Medical Mistrust

Participants in this group expressed feelings of distrust in the medical profession in the event of life-threatening injuries as a key reason in their decision to opt-out. This theme comprised of two sub-themes, (1) what if I'm not dead?, and (2) reduced lifesaving care. In particular, some participants expressed concerns regarding the validity of a brainstem death diagnosis and described fears that doctors would hastily harvest their organs before they were really dead. As a result, participants expressed fears that they would be alive and aware of their organs being removed (sub-theme 1).

> *I am scared that there would not be enough checks that I was really brain dead before my organs were removed.* (Female 61 years)
>
> *I have no wish to be "kept alive" on a ventilator until my organs are taken out for transplantation on the basis that some doctor has declared me to be "brain dead".* (Female 65 years)

Participants also voiced concerns regarding the degree of life-saving treatment they would receive if doctors were aware they were organ donors. Throughout participants' accounts, there appeared to be a dichotomy between donor care and non-donor care. As such, there were concerns that registered donors would receive a reduced lifesaving effort in lieu of saving a potential recipient's life with viable donor organs (sub-theme 2).

> *I have a cynical approach to the care an organ donor would receive in the event of life threatening injuries as oppose to a non-donor in the same position.* (Female 44 years)

3.8.2 Theme 2: A Violation of Bodily Integrity

This theme broadly represents concerns expressed by participants that organ donation would violate the physical integrity of their body after death. This theme encompassed three sub-themes, (1) a desire to remain whole after death, (2) organ donation damages the body, and (3) a barrier to a peaceful passing. Participants recurrently expressed concerns that removing organs after death would jeopardise the completeness of their body. It was important for these participants to remain bodily intact after death (sub-theme 1).

> *I was born with them I would like to die with them.* (Male 29 years)
>
> *I just want to go out of the world the way I came in.* (Female 47 years)

Participants also reported fears that organ donation would cause unnecessary, additional physical damage to their body after death (sub-theme 2). This was frequently epitomised through powerful word choice that represents harm, e.g., "*cut open*" when describing the process of organ donation.

> *Just do not like the idea of being cut open after death.* (Female 24 years)
>
> *I simply do not wish to be used for any reason after death, put to rest with no damage to body.* (Male 57 years)

Some individuals who plan to opt-out regarded organ donation to be incongruous to a peaceful death (sub-theme 3). Throughout, participants reported distress at the thought of unnecessary medical interventions, such as the use of mechanical ventilation during their death. Overall, some participants expressed the desire for their death to be a peaceful and natural process; organ donation, however, was believed to needlessly delay and interfere with death's natural course.

> *I find it totally gruesome and weird. Let nature take its course and leave things as they are.* (Female 21 years)
>
> *I have no wish to be "kept alive" on a ventilator until my organs are taken out for transplantation on the basis that some doctor has declared me to be "brain dead".* (Female 65 years)

3.8.3 Theme 3: The State Has No Right to Assume Consent

Participants held strong views concerning the ownership of their own body. Therefore, this theme encompasses the belief that opt-out consent laws give the government unwarranted control over the body after death. Participants expressed concerns that following the enactment of deemed consent laws, the absence of a clear objection will now be regarded as consent for organ donation. The importance of individual responsibility and informed consent was marked within participants' responses; notably, this was believed to be threatened under the opt-out system.

> *I am a firm believer in individual responsibility and object to the Government making assumptions on my behalf.* (Female 82 years)
>
> *The creation of an opt-out system is inherently wrong in my opinion. The rational conclusion of such a policy is that the state has authority and ownership over your body and organs without ever getting consent.* (Male 22 years)

For some participants, this was considered to criminalise the act of organ donation. In the following excerpt, organ donation under the current opt-in system is viewed as an altruistic gift, yet, under a system which automatically presumes the absence of a recorded decision to indicate consent, it is theft.

> *If I donate my organs it's a gift. If you take them it's theft. My body belongs to me. It does not belong to the state to do with as it sees fit. I am a registered organ donor. I will not be if it goes to opt out.* (Female 60 years)

3.9 Discussion

Following the introduction of opt-out legislation, if an individual has not registered an active donor decision, consent for organ donation is automatically presumed through deemed consent. This qualitative study prospectively explored the reasons underpinning the planned choice to either, opt-in, take no action and follow deemed consent, or opt-out of the donor register if opt-out legislation was later implemented in England, Northern Ireland and Scotland.

3.9.1 Key Similarities Between Opt-in and Deemed Consent Responses

For participants who want to be an organ donor, either by actively opting-in to the register or by taking no action and following deemed consent, personal experiences of organ donation were important factors that cemented their decision. Throughout, participants shared emotive anecdotal stories of loved ones whose lives had been "transformed" after receiving an organ transplant. Others shared experiences of losing a loved one during the wait for a transplant. For many, this personal insight increased their awareness of the importance of organ donation and motivated them to register. These findings are consistent with previous literature, which found personal organ donation experience to be a powerful influence on one's willingness to become an organ donor (Feeley et al., 2014; Irving et al., 2014).

Participants in the opt-in and deemed consent group shared a largely pragmatic view of their body after death. These respondents expressed limited psychological attachment to their organs and viewed donation as akin to recycling. Therefore, the prospect of reusing potentially lifesaving organs was an influential factor for both groups. Another important factor shared by both those who plan to opt-in and follow deemed consent, centred on the concept of reciprocity. Participants in both groups reflected on the impact a donated organ would have if they, or someone they loved required a transplant. This in turn, elicited a sense of obligation to offer the same opportunity to another person. For some, willingly accepting an organ without being willing to register as a donor was considered "*hypocritical*". These findings support existing research into the use of reciprocity primes as a method of increasing donor intentions (O'Carroll et al., 2017; O'Carroll et al., 2018). Moreover, research from the Behavioural Insights Team found campaigns that focus on reciprocity to increase active donor registration. In this study, approximately one million participants were exposed to one of eight organ donation campaigns during the process of renewing vehicle tax or registering for a driving licence on the GOV.UK webpage. The campaign that focused on reciprocity by asking, "*If you needed an organ transplant, would you have one? If so please help others*" was most successful at increasing verified donor registrations (Behavioural Insights Team, 2013; Sallis et al., 2018). An example of a NHS reciprocity campaign is shown in Figure 3.3.

Figure 3. 3. NHS Reciprocity Communication Campaign

Although people who plan to opt-in and those who plan to follow deemed consent are both indicating a choice to be an organ donor, their reasoning for selecting either an active opt-in or a passive deemed consent decision revealed important distinctions; these are discussed in more detail below.

3.9.2 Key Differences Between Opt-in and Deemed Consent Responses

One of the principal reasons' participants plan to actively opt-in and register as a donor following the implementation of opt-out consent, is that it represents a robust and unambiguous intention to donate organs after death. Conversely, the notion of deemed consent, while supported in principle by this group, was perceived as being unclear ("*wishy washy*") and susceptible to ambiguity. Throughout participants' responses, the decision to opt-in was influenced by two key factors; for some, this was viewed as a way of safeguarding their donor decision against family interference, while for others it was hoped that explicitly providing consent would relieve a grieving family of an incredibly difficult choice.

The decision to become an organ donor was considered by participants to be an autonomous conscious choice. Therefore, the notion of family members interfering with this personal decision evoked unease. To reduce the likelihood of family interference, an active opt-in donor decision was believed to represent a substantially stronger indication of participants' wishes. This interpretation is reliably supported by annual donor data from NHS Blood and Transplant. Consistently, donor families are noticeably more likely to provide consent for organ donation in instances where the deceased had actively registered as a donor (NHS Blood and Transplant, 2020a).

Participants in the opt-in group also acknowledged the enormity and emotive nature of the donation decision-making process faced by grieving families. As a result, many expressed concerns that taking no action and following deemed consent was not a sufficiently clear way of communicating their consent for organ donation. As such, participants in this group raised concerns that their grieving family may be left feeling confused. In turn, opting-in was regarded as an unambiguous way of cementing one's donor decision in order to reduce uncertainty and relieve family members from making an incredibly difficult choice. Existing literature supports this finding, reporting family confusion regarding the deceased's wishes to be a principal factor behind family refusal for organ donation (Anker & Feeley, 2010). This is particularly important as rates of family refusal substantially increased in Wales following the implementation of deemed consent laws (Welsh Government, 2018). Therefore, during the transition to opt-out legislation in England and Scotland, the development of campaigns designed to encourage families to discuss their donor choices should be a priority.

The enormity and emotive nature of a donor decision was also a recurrent theme expressed by participants who plan to follow deemed consent. Hence, for some participants taking no action and thereby passively indicating consent for donation was viewed as a way of circumventing this difficult choice. The findings indicated that participants who plan to follow deemed consent, at times, expressed fears of being "*cut open after death*" or general discomfort "*confronting your own mortality*" when contemplating donor-relevant decisions. However, this was also accompanied by affirmations of support for the principle of organ donation. This implies that participants who plan to follow deemed consent may experience ambivalence when considering organ donation; simultaneously describing support for organ donation whilst citing emotional barriers as a deterrent to an active donor choice. Indeed, ambivalence and affect are acknowledged to play a role in donor-relevant decisions (van den Berg et al., 2005).

The findings of this chapter are in line with evidence from previous research conducted by Siegel and colleagues (2010). This study examined reasons for non-registration in passive-positive individuals (adults who hold positive attitudes towards organ donation, yet have not registered as donors). The main component of the study encompassed a focus group discussion following which, participants were provided an immediate opportunity to join the organ donor register. While 46.6% of passive-positive adults subsequently registered as donors, retrospective examination of reasons for non-registration revealed compelling differences. Of the passive-positive individuals who attributed their non-registration to arise from lack of knowledge of organ donation, lack of opportunity, or awareness on how to register, 63.3% signed-up after the focus group. Interestingly, for passive-positives who attributed their lack of active registration to have arisen from more emotive factors, including general discomfort about death and medical mistrust, the registration rate was just 5.8% (Siegel et al., 2010). This provides compelling evidence on the role of affective attitudes and suggests that a system of deemed consent may provide a useful pathway of consent for ambivalent, 'passive-positive' individuals.

The effortless nature of deemed consent may also increase the pool of donors; by including people with favorable viewpoints towards organ donation who have not registered an active opt-in decision as a result of "*laziness*". Throughout, participants in this group favored the simplistic nature of a deemed consent system as, unlike the current opt-in system, consent can be recorded without any required action. Consistently, research has shown that one's positive intentions do not exclusively predict behaviour (Ajzen, 1991). Organ donation is a particularly powerful example of this tendency; as although the majority of the UK public support organ donation, only 40% are registered as donors (NHS Blood and Transplant, 2020a). Thus, a default system that removes the requirement for active registration may reduce this discrepancy by capturing those who have not yet actioned their intentions.

3.9.3 Key Differences Between Opt-in and Opt-out Responses

For the participants who plan to actively opt-out of the donor register, fears surrounding the medical profession were salient factors influencing this decision. Notably, this concerned the validity of using brainstem death criteria as a method of defining irreversible total-body death. The complex and misunderstood nature of brainstem death has been recognised in previous qualitative research in organ donation (Morgan, Harrison, et al., 2008). Participants who plan to opt-out often did not equate brainstem death as a "real" death; this manifested as fears of premature withdrawal of care and donation occurring while patients were still alive. To ensure potential donor organs are in optimal condition, they require an adequate supply of oxygen. As the patient's breathing is maintained using mechanical support, it can be challenging for families to comprehend that their loved one is no longer alive. These views may also be compounded by misleading depictions of brainstem death and organ donation portrayed within the media (Lewis et al., 2017). As the main source of information and knowledge regarding organ donation, damaging media misrepresentations rapidly propagate and influence the development of harmful beliefs (Aykas et al., 2015).

Concerns that organ donation would violate the physical integrity of the body were also prominent within participants' reasons for planning to actively opt-out. Bodily integrity concerns manifested as fears of a loss of completeness without organs, disfigurement and concerns over unnecessary intervention to prevent a peaceful death. Moreover, some participants expressed worries that organ donation would involve "*cutting-up*" the body for organs to be "*harvested*". Such concerns have consistently emerged as key factors that deter potential registrants (Morgan, Harrison, et al., 2008; O'Carroll, Foster, et al., 2011; Shepherd & O'Carroll, 2014). The concept of bodily integrity is rooted in morality and personal autonomy (Viens, 2016). As these beliefs centre around transgressions of the body after death and are believed to have consequences for the afterlife, they are intrinsically challenging to falsify and overcome. These may also be exacerbated by conflicting viewpoints of organ donation and religion. Although the major religions in the UK support organ donation, the findings from Chapter 2 indicated that over 50% of respondents believed organ donation was against most religious beliefs (Miller et al., 2019).

Another reason for choosing to opt-out focused on perceptions of heightened government control of organs after death. The importance of free choice and autonomy were central reasons for opting-out; signifying that participants' choice was perceived to be threatened under the proposed opt-out system. This may reflect the wider psychological concept of reactance, an unpleasant emotional response experienced following a perceived threat to one's freedom (Steindl et al., 2015). Consequently, perceptions of presumed consent as an impingement of rights may result in the public taking action to protect their free choice (*opting-out*). Indeed, critics of opt-out legislation have reported that accepting the absence of objection as permission for donation, to undermine the ethical principles of informed consent (Truog, 2008). Moreover, the absence of active informed consent was perceived as reducing the altruistic nature of organ donation to an act synonymous with theft. Although concerns over government control were reported in Wales prior to the introduction of opt-out consent laws, limited research has investigated these issues. Given such concerns have contributed to the reversal of opt-out laws in other countries an exploration of these factors features as the focus of Chapter 4 and Chapter 5.

3.9.4 Implications for Future Research

This study has important implications that may inform future research and practice. In particular, the findings demonstrate the importance of encouraging clear unambiguous consent for people who would opt-in and illustrate the potential for family refusal under deemed consent. This finding could inform the development of communication campaigns in England and Scotland that focus on explaining the role of the family before the implementation of opt-out laws. This is important, as after the enactment of opt-out legislation in Wales, instances of family refusal doubled (Welsh Government, 2018). Now, following extensive campaigns designed to encourage family communication and to prevent families from overturning their loved one's wishes, Wales has the highest rate of consent for organ donation in the UK (NHS Blood and Transplant, 2018). This is particularly important for individuals within Black Asian and Minority Ethnic groups, where family refusal rates are markedly higher. Given that 21% of individuals who died while waiting for a transplant last year were from BAME communities, there is an urgent need to increase consent and rates of donation among minority ethnic groups (NHS Blood and Transplant, 2019a).

3.9.5 Strengths and Limitations

It is important to first acknowledge some limitations of this study. As is common in this field, there was a recruitment bias, in that the majority of free-text responses were obtained from female participants and individuals living in Scotland. There was also a limited number of respondents from ethnic minority groups who participated in this study.

As survey methods do not permit exploration or probing of salient response topics, the use of a questionnaire will have to some degree limited the depth of participants' responses. However, an open-ended free-text response option, enabled participants to explain in their own words, the reasons important to them. As such, the data was deemed suitably rich to provide a breadth of information and insights into donor decisions under opt-out consent. It should be acknowledged that some themes represent a manifest reflection of participants responses. For example, within the 'not sure' group, there was a lower-level interpretation provided as the data was generally brief and the analysis more surface level. Although interview-based methods are preferred in qualitative research, the number of studies collecting data using questionnaire-based methods are increasing, particularly when exploring potentially sensitive topics (Halley et al., 2018; Opperman et al., 2014).

This study had a number of strengths. Importantly, the use of an online survey was effective at obtaining a large sample of over 900 respondents across different donor choices (opt-in, opt-out and deemed consent). This is, to the authors' knowledge, the largest qualitative study to examine donor decisions under the new opt-out system. A particular strength of this method is that the application of an anonymous questionnaire may reduce socially desirable responding often found when investigating potentially emotive topics (Tourangeau & Yan, 2007). Moreover, these methods offer participants anonymity to express potentially complex and contentious viewpoints. This is important for people who plan to opt-out of the donor register who may be hesitant to express their decision not to donate within a face to face or group interview setting. Before the introduction of opt-out laws in England and Scotland, future research using qualitative interview methodology is warranted to obtain a comprehensive understanding of the factors influencing donor decisions under opt-out consent. This will be addressed in the next chapter.

3.10 Conclusions

This chapter provides deeper insights into donor-relevant decisions under an opt-out system in England and Scotland. The findings highlight the importance of an active indisputable choice for individuals in the opt-in group, to ensure their wishes are safeguarded and not overridden by distressed families at the time of death. The introduction of deemed consent is advantageous primarily for those who have not actioned intentions to be an organ donor due to “laziness”, and for those with psychological ambivalence as it protects them from making a difficult choice. The themes from participants who plan to opt-out, strengthen the existing opt-in organ donation literature around concerns of medical mistrust and violations of bodily integrity, and highlight a novel deterrent for the opt-out system, namely concerns of heightened government control and loss of freedom of choice. While implementing a system of deemed consent may increase the pool of eligible organ donors, the potential for confusion should not be overlooked. Two primary concerns with deemed consent; family interference and reactance due to perceptions of unwarranted government control have emerged from this study. Before the introduction of deemed consent laws, further investigation into these barriers is required.

Chapter 4: ‘*It’s like being conscripted, one volunteer is better than 10 pressed men*’: A qualitative study into the views of people who plan to opt-out of organ donation

Preface

The qualitative analysis of free-text responses described in Chapter 3 generated preliminary insights into the factors influencing planned donation decisions under opt-out legislation. The importance of emotional barriers, specifically medical mistrust and concerns of upholding the integrity of the body are now well-documented factors influencing donor-relevant decisions under an opt-in and opt-out donation system. However, perceptions of unwarranted government control and a perceived threat to freedom were also identified and represent unique barriers under opt-out legislation. No research to date has explored these factors. The current chapter directly builds on the novel findings of Chapter 3 and, using qualitative interview methodology, provides an in-depth examination of these deterrents.

Sections of this chapter also feature in Miller, J., Currie, S., McGregor, L. M., & O'Carroll, R. E. (2020). *'It's like being conscripted, one volunteer is better than 10 pressed men'*: A qualitative study into the views of people who plan to opt-out of organ donation. *British Journal of Health Psychology*, 25: 257-274. https://doi.org/10.1111/bjhp.12406

4.1 Abstract

Background: Studies have demonstrated that emotional barriers play a key role in donor decisions under opt-in legislation, yet little is known about the specific factors that influence donor decision-making under opt-out consent. The objectives of this qualitative interview study were to investigate attitudes towards organ donation and opt-out legislation from individuals who plan to opt-out, and to explore the reasons *why* they plan to do so.

Methods: Semi-structured interviews were conducted with 15 individuals from Scotland (n = 14) and England (n = 1) who self-reported the intention to opt-out of organ donation following the legislative change to opt-out consent. The interviews were transcribed verbatim and analysed using thematic analysis.

Results: Three main themes were identified; (1) consent versus coercion, which describes the perception of freedom of choice under an opt-in system and fears of "*government interference*" and threatened autonomy under opt-out, (2) self-protection, encompassing fears of medical mistrust, bodily integrity concerns and apprehension regarding the recipient selection process. Lastly, (3) 'riddled with pitfalls', which includes the notion that opt-out consent may increase susceptibility of stigma and reproach when registering an opt-out decision.

Conclusions: This study reinforces existing opt-in literature surrounding medical mistrust and bodily integrity concerns. A threat to one's autonomous choice and heightened reactance arising from perceptions of unwarranted government control have emerged as novel barriers under opt-out legislation.

4.2 Introduction

At the time of conducting this study, opt-out legislation had been in operation in Wales for over four years. The latest figures from 2019/20 have shown an increase in the number of organ donors and rates of transplantation (NHS Blood and Transplant, 2020a). The current figures also indicate that 6% of the Welsh population have recorded an opt-out decision on the organ donor register. While this figure has remained stable since the year after the introduction of deemed consent laws in 2016, and is considerably less than the initial anticipated 19% reported in pre-implementation studies in 2012, no research to date has explored the attitudes and views of this particular group (NHS Blood and Transplant, 2017b; Welsh Government, 2012a).

It is also noteworthy that a recent 18-month post-implementation analysis of NHSBT donation figures reported that of the 205 potentially eligible organ donors in Wales, 16.5% had expressed an opt-out decision (Noyes, McLaughlin, Morgan, Walton, et al., 2019). Only a very small proportion of these individuals had actively recorded this decision on the organ donor register, with the vast majority (76%) of individuals verbally expressing their opt-out decision to family members. Irrespective of a verbally expressed or recorded opt-out decision, all surrogate decision makers acted in accordance with their loved one's opt-out decision and refused consent for donation. This finding is concerning and ultimately may suggest that although recorded opt-out registrations in Wales are low, the number of verbally expressed opt-out decisions may be markedly higher.

4.2.1 Barriers to Organ Donation

A substantial body of international evidence has shown that feelings and emotional beliefs (e.g., the desire to remain whole after death) are crucial factors that influence donor-relevant decisions under opt-in legislation (Morgan, Harrison, et al., 2008; O'Carroll, Foster, et al., 2011; Shepherd & O'Carroll, 2014). Although the above studies used quantifiable measures of emotions, qualitative literature has also reinforced these findings (Irving et al., 2011; Newton, 2011). Given the relatively novel nature of opt-out legislation in the UK, few studies have investigated the factors deterring potential donors under these laws. As previously described, evidence from other nations has suggested there may be specific factors associated with the legislative change that drive opt-out decisions. For example, the opt-out policies in

Brazil and Chile were revised following a considerable decline in transplantation rates and an increase in family refusal (Bailey, 1999; Csillag, 1998; Domínguez & Rojas, 2013). This was attributed to heightened concerns of medical mistrust and general distrust in the government. Notions of unwarranted government control were also reported among members of the Welsh population preceding the introduction of opt-out laws (Welsh Government, 2012b).

As highlighted in Chapter 1, the number of people actively recording the decision not to donate their organs and registering an opt-out decision in England and Scotland has markedly increased ahead of the implementation of opt-out legislation (NHS Blood and Transplant, 2020a). Minimising the number of opt-out respondents is critically important to maintain rates of transplantation, therefore, research that focuses on understanding why participants plan to opt-out of the donor register was urgently required.

While the findings from Chapter 2 indicated that emotional barriers were significantly heightened for individuals who signal an intention to opt-out, this study utilised a quantitative measure of emotional barriers, which may limit the degree of understanding into these complex emotive factors. Moreover, the level of depth and interpretation of the barriers identified within the free-text analysis of Chapter 3 are limited to some degree by the relatively fixed nature of the methodology. This study aimed to build upon these findings. In sum, obtaining a rich and more nuanced understanding of these factors using qualitative interview methodology, from a prospective point of view, may enable researchers to identify modifiable barriers that could be targeted before the introduction of opt-out consent. This has the potential to reduce the number of opt-out registrations. This was particularly important in light of recent research from the Scottish Parliament which reported 22% of individuals plan to opt-out of the new donor system (Scottish Parliament, 2018).

4.2.2 Study Objectives

The present study had three aims:

(1) To examine attitudes towards, the current opt-in system and the planned opt-out system from the perspective of individuals who plan to opt-out.

(2) To gain an in-depth understanding of why people plan to opt-out of the donor register.

(3) To explore participants’ specific concerns in relation to the planned opt-out system.

4.3 Methodology

4.3.1 Design

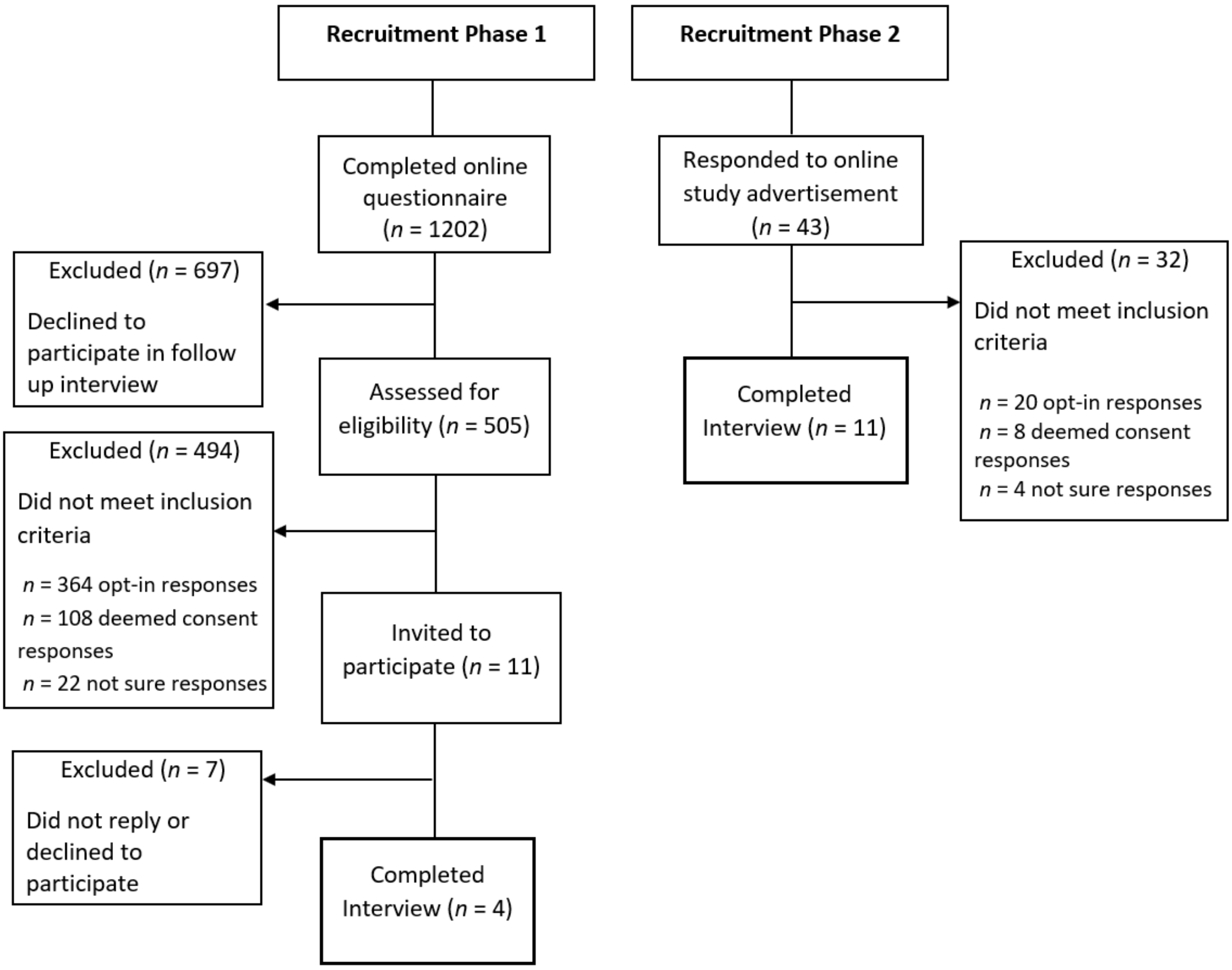
This study involved one to one, semi-structured telephone interviews. Telephone interviews were primarily selected due to the potentially diverse geographic location of interviewees, as such, this was a cost-effective and timely method of interviewing individuals across Scotland and England. Moreover, evidence suggests that telephone interviews are effective mediums when exploring potentially sensitive topics, a particularly important consideration within the current study (Block & Erskine, 2012). Guidelines on sample sizes in qualitative research were applied to inform the recruitment target. As the study aims are relatively narrow and concern the views of a specific, small sample of individuals who plan to opt-out of the organ donor register, recruitment of approximately 15 participants was considered to provide sufficient 'information power' to obtain new knowledge regarding attitudes towards opt-out consent legislation (Malterud et al., 2016).

4.3.2 Eligibility and Recruitment

Individuals aged over 18 years, who lived in Scotland or England and who plan to opt-out of the organ donor register following the introduction of deemed consent legislation were eligible to participate. Recruitment for this study occurred in two phases (see Figure 4.1). Phase 1 involved purposive sampling of participants who had: (1) completed the study reported in Chapter 2, (2) indicated they would opt-out of the donor register if laws change to an opt-out system, and (3) gave consent to participate in a follow-up interview study. Approximately six months later, these participants (*n* =11) were sent an email with information on the study. The email text is available in Appendix 10. The email also contained a URL link to a Qualtrics survey (Qualtrics, 2005). This was used to present participants with the study information, to collect informed consent and basic demographic characteristics (age, gender, country of residence and registered donor decision). The participant information sheet is also available in Appendix 11. Participants were also asked to select a suitable date and time and to provide a contact telephone number. Of the (*n* =11) participants who were invited to participate, four completed the interview, the remaining seven, did not reply or declined to participate.

Phase 2 involved opportunistic sampling via advertisements presented on the social media websites, Facebook and Twitter. The study advert was also posted on the University of Stirling Portal announcement page. The advertisement, which is available in Appendix 12, presented information on the study and a link to the same Qualtrics survey used in Phase 1. To ensure that only people who plan to opt-out of the donor register were recruited, a measure of anticipated donor status was obtained. As part of the Qualtrics survey, participants were presented with details on the planned opt-out system (presented in Figure 2.1 of Chapter 2) and were asked, '*If the organ donation laws in your country change to an opt-out system, what would your choice be*?'. Participants were presented with the following response choices; I would opt-in (I want to be an organ donor), I have no objection to donating my organs (deemed consent to be an organ donor), I would opt-out (I do not want to be an organ donor) and not sure. In total, a further 11 opt-out respondents were recruited and completed the interview. As an incentive, all participants were offered a £5 Amazon voucher.

Figure 4. 1. Participant Recruitment Diagram



4.3.3 Participants

Fifteen individuals who self-reported the intention to opt-out of the organ donor register participated in this study. Of the 15 participants, nine (60%) were female and six (40%) were male. Participants mean age was 45.13 (*SD* = 19.43, range 19-83), 14 participants were resident in Scotland and one participant was resident in England. Demographic information is provided in Table 4.1.

Table 4. 1. Participants' Demographic Characteristics

Name	Age (years)	Gender	Resident	Current Donor Status
Anna	49	Female	Scotland	Registered Donor
Emily	45	Female	Scotland	Not registered
Olivia	83	Female	Scotland	Not registered
Victoria	60	Female	Scotland	Not registered
Andrew	19	Male	Scotland	Not registered
Robert	41	Male	Scotland	Not registered
Madison	54	Female	Scotland	Not registered
Lauren	42	Female	Scotland	Not registered[a]
Robyn	20	Female	Scotland	Not registered
Erin	33	Female	Scotland	Not registered
Charlotte	28	Female	Scotland	Not registered
James	57	Male	Scotland	Not registered
Luke	22	Male	England	Opted-out[b]
Mason	46	Male	Scotland	Not registered
William	78	Male	Scotland	Not registered

Note. Participants names have been replaced with a pseudonym. [a]Participant was a registered donor in Australia but was not registered in the UK. [b] Participant had recorded the decision not to donate their organs. This option was made available under the opt-in donor system in late 2015.

4.3.4 Procedure

Ethical approval for this study was provided by The University of Stirling's General University Ethics Panel. The interviews were conducted via the telephone between August 2018 and February 2019 by the author (JM) and lasted on average, 32 minutes (range = 18 - 46 minutes). A semi-structured interview guide was used flexibly throughout the interviews (available in Figure 4.2). The interview schedule encompassed open questions regarding participants' attitudes towards the current opt-in and planned opt-out system. In recognition of the potential sensitivity of the topic, the researcher initially explained the purpose of the study and affirmed there to be no right or wrong answers to any of the questions being asked. When exploring participants' views towards the forthcoming changes to organ donation legislation, a clear verbal definition of the present opt-in donor system and the planned opt-out system was provided to each participant. The interview initially commenced with a broad, non-directive question which inquired about participants' personal views on organ donation. The core questions within the topic guide were designed to function as opening questions to facilitate a fluid interview, and to promote the exploration of individual factors of importance. Throughout, standardised prompts and follow-up questions were used to elaborate on salient responses. Before recruitment commenced, pre-testing of the interview schedule was conducted between members of the research team in a pilot interview.

A number of recommended techniques for effective telephone-based data collection were applied throughout the interviews (Drabble et al., 2016). This involved expressing regard for participants' contributions and providing non-judgemental affirmations when participants shared sensitive viewpoints. In addition, time orientating statements were used to promote continued engagement towards the end of the interview *"We're just about finished so thanks for your patience, I've just got a few more questions left*". At points during the interview, participants' responses were summarised to enhance accuracy and to enable the elaboration of potentially ambiguous points of discussion. At the end of the interview, participants were thanked for their contribution and verbally debriefed. An electronic copy of the debrief form and a £5 Amazon voucher was then sent to participants email addresses. The debrief is available in Appendix 13.

Figure 4. 2. Semi-Structured Interview Schedule

Semi-structured interview schedule

1. (Opening question) To begin, could you tell me more about your personal views on organ donation in general?

Definition of the current opt-in donor system*: Currently in Scotland, England and Northern Ireland if you want to be an organ donor you must actively sign-up and join the organ donor register.*

2. What do you think about the current opt-in donor system?
3. Do you think there are any particular good points to the current opt-in system?
4. Do you think there are any particular negative points to the current opt-in system?

Definition of the proposed opt-out donor system*: The organ donation laws are planning to change. At the moment, in Scotland, England and Northern Ireland if you want to be an organ donor you must actively sign-up and join the donor register.*

Recently, the Scottish and English Governments have announced plans to change organ donor laws to an opt-out system. This would remove the requirement to sign up and instead follows presumed consent. This means that if you take no action, you will become an organ donor by default. If you don't want to be an organ donor you must actively remove yourself from the donor register, thereby opt-ing out.

5. What do you think about the plans to move to opt-out?
6. Can you describe any positives of an opt-out consent system?
7. Can you describe any negatives of an opt-out consent system?

Orienting participants to time: So, we're just about finished so thanks for your patience. I've just got a few more questions left.

8. Do you feel that you have any worries or fears about organ donation?
9. Do you think your view on organ donation would be different if the law changes to an opt-out system?
10. Do you have any suggestions for us as researchers on things that may make a difference?
11. (Closing question) I think that's everything I wanted to ask, is there anything else you'd like to say or any final thoughts you have?

4.3.5 Data Management and Analysis

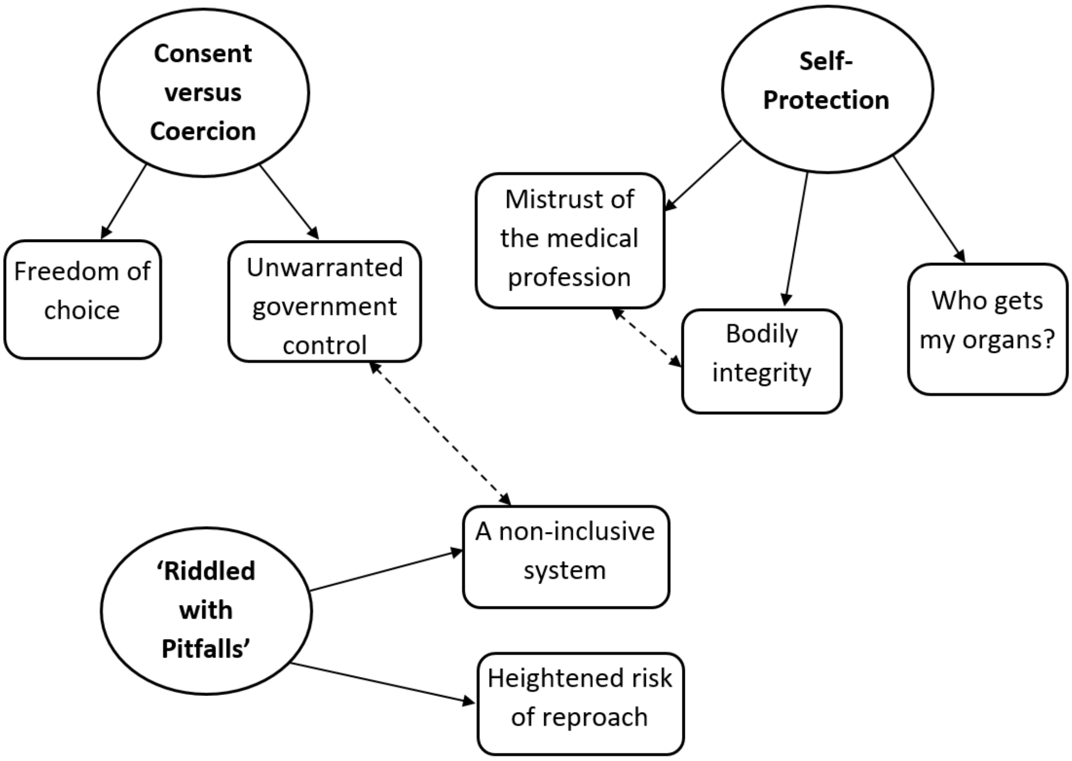
The interviews were audio-recorded using a telephone pickup microphone connected to both the author's (JM) telephone and an Olympus voice recorder. As existing qualitative literature has acknowledged that transcription should be considered a "*key phase of data analysis within interpretive qualitative methodology"* (Bird, 2005, p.227) the interviews were transcribed verbatim by the author to facilitate immersion with the data. During the transcription process, each interview was listened to on multiple occasions to ensure accuracy and anonymised by allocating each participant a pseudonym.

The data was analysed using a thematic analysis, as described by Braun & Clarke (2006). Throughout, a largely essentialist/realist approach was adopted, which communicates experiences, language and meaning from the participants perspective (Braun & Clarke, 2006). The qualitative software Quirkos was used to manage the data (Quirkos, 2020) https://www.quirkos.com/index.html. During the coding process, interesting features throughout the data were highlighted and assigned a preliminary code or "quirk". These preliminary codes were then reviewed and organised into respective themes and sub-themes by the first author (JM). The themes were identified in accordance with their salience and prevalence to the research questions using an inductive, data-driven approach. In acknowledgement of the primary authors support for organ donation, existing knowledge of the organ donation literature and the potential influence of this on the interpretation of the data, a second researcher (SC) reviewed the themes and sub-themes to ensure these were represented within the data and to enhance the 'trustworthiness' of the analytic process (Shenton, 2004). The resulting themes and illustrative excerpts were then presented and discussed openly with all members of the research team to ensure there was sufficient evidence to substantiate each theme. Further refinements to themes were made during this process until a consensus was reached.

4.4 Findings

Three overarching themes were identified within the transcripts: (1) consent versus coercion, (2) self-protection, and (3) 'riddled with pitfalls'. A diagram of the themes and respective sub-themes is presented in Figure 4.3.

Figure 4. 3. Thematic Diagram of Key Themes and Sub-Themes



Note. Single directional arrows represent the respective sub-themes; bi-directional dotted arrows indicate a relationship between themes.

4.5 Theme one: Consent Versus Coercion

This theme encompasses participants' attitudes towards the changing representation of choice and consent between the current donor system and the future opt-out system. The non-intrusive nature and freedom of choice offered within the opt-in system was considerably favoured (sub-theme 1.1). In contrast, the planned opt-out system, where consent is deemed automatically in the absence of a recorded decision, was perceived as forceful and intrusive (sub-theme 1.2).

4.5.1 Freedom of Choice (sub-theme 1.1)

The current opt-in registration system was viewed as facilitating freedom of choice regarding the decision to register as an organ donor. This decision was described by Andrew as one of great importance "*you can't make that decision lightly*". As such, actively seeking out the means to register, demonstrates consent to have been informed and the decision, a voluntary choice. Throughout participants' narratives, freedom of choice was conceptualised as being one's lawful right. This was juxtaposed with the proposals for opt-out consent, considered as invasive and a threat to one's individual responsibility. This is highlighted by Luke, who describes his experience as a nurse to emphasise the importance of informed consent:

> *As a nurse before I do anything I ask for consent so I don't just like go and take somebody's blood and then go "is that okay that I've just taken your blood?" so in my opinion, you need to ask for consent and that's what it [an opt-in system] does, it asks for consent.* (Luke)

Moreover, registering under an opt-in system was reported to act as irrefutable confirmation of one's donor wishes. As such, participants felt this may reduce uncertainty and distress when next of kin are confronted with the emotive decision to donate their loved one's organs.

> *I mean an opt-in I guess then you've definitely got people saying I'm happy for you to take my organs and maybe that makes it easier for people or parents or people in the position where they're unsure of that person, that persons' wishes so maybe it makes it easier as part of a grieving process if somebody's made that decision to give their organs.* (Madison)

4.5.2 Unwarranted Government Control (sub-theme 1.2)

For some participants, the opt-out system was viewed as forceful, and as Victoria states "*like being conscripted*" into organ donation. For many, this signified unwarranted government interference into a highly personal decision. As such, the opt-out system was perceived to give the government illegitimate control and ownership over an individual's body after death. Anna expands on her concerns below:

> *I would feel like erm because I said earlier that erm my body was y'know it was like presumed part of the state rather than my own, because if I don't*

> *have that written down somewhere then that can be taken away from me, my opinion my decision can be taken away from me by the state and overruled by the state.* (Anna)

Many participants also felt that the opt-out system will force them to take action [register an opt-out decision] to safeguard their body from donation. While some participants acknowledged the choice to opt-out of organ donation, implicit throughout the data was a sense of injustice that such protective action was now necessary.

> *Even though there is y'know that erm… you can go and make the decision to get your name taken off the register it's still well why should I have to go and take my name off a register? I don't want to do this why are you saying that I do? Don't make a decision for me.* (Victoria)

Some participants viewed the basic principles of consent to be disregarded by the opt-out system. Consent was epitomised as something informed and unambiguous. As Robyn states "*assumed consent can't really be considered consent*". Andrew expands on this below, and describes why a system that automatically deems consent for organ donation is concerning:

> *I mean it comes down to those two words doesn't it? At the end of the day presumed consent what a slippery slope that is, because y'know presumed consent you could absolutely never get away with presumed consent in damn near every other area of life there's not a chance you could go to court and say "actually well y'know I had presumed consent" it doesn't work like that* (Andrew)

These comments seem to suggest that deemed consent is viewed by some participants as an oxymoron. The reference to a court of law highlights the magnitude of informed consent in society. In turn, presuming consent for something as important as organ donation was deemed unlawful. Reflecting on the sensitive nature of consent, Robert felt it was inappropriate "*for the government to overrule ethics*" and presume that individuals who have not opted-out automatically consent to organ donation. Below, Andrew uses an example of consent within society to highlight its delicate nature:

> *If you take what it comes down to judicial reviews of things like consent when it comes to sexual interaction, consent is massive within the terms of sexual language, it is because consent is more in the mind of somebody explicitly saying yes and if they do not say yes then it is not considered consent, you must physically say yes.* (Andrew)

Table 4. 2. Additional Illustrative Quotes for Theme 1: Consent versus Coercion

Sub-themes	Illustrative excerpts
Freedom of choice (sub-theme 1.1)	*It just comes down to people being able to make that choice, not being coerced into anything or presumed, it's if you want to do it you go you actively seek out the means to do that.* (Robert) *Well it's not mandatory, it's not compulsory and it's not legal to do otherwise and I then have a free choice and it is up to me to make that choice.* (William)
Unwarranted government control (sub-theme 1.2)	*Being told that your body belongs to the government to decide what to do with it, I just that's anathema to me basically it's probably not logical it's just a gut feeling.* (Olivia) *I don't need the government trying to make me into a good person I'm quite capable of doing that myself.* (Robert)

4.6 Theme two: Self-Protection

Participants conveyed a number of fears around organ donation that played an influential role in their donor decision. These were predominantly expressed around the overarching notion of protection, which manifested into three distinct sub-themes concerning the protection of one's life, body, and organs. This encompassed: mistrust of the medical profession (sub-theme 2.1) which symbolised fears over protection of life, preserving bodily integrity (sub-theme 2.2) which represented the importance of protecting the body during and after the time of death, and finally, concerns of the organ allocation process (sub-theme 2.3) which represented the desire to protect ones organs from potential misuse.

4.6.1 Mistrust of the Medical Profession (sub-theme 2.1)

Negative attitudes and suspicions towards the healthcare system and medical staff were an important factor in the decision to opt-out. Throughout, participants voiced reservations about the quality of care provided by medical professionals in the event of life-threatening illness or injury. As such, a sense of uncertainty regarding lifesaving decisions was implicit within participants' narratives. Below, Emily highlights her fears that doctors may place greater value on procuring organs rather than saving an individual's life:

> *I have the fear that if somebody needs an organ and somebody's sitting there you know kinda in deaths door and somebody else needs an organ then they might make a call that well y'know rather than save this 45-year-old's life then we could let this person just go gently and this young 18-year-old who's desperate for a heart here could get it.* (Emily)

There were also concerns that doctors may initiate the process of organ retrieval prematurely. As a result, some participants expressed fears that they would be alive while their organs were being removed.

> *If you were in hospital and they think you're dead but you're not and they start whipping parts out, that's a fear whether it's rational or not I don't know.* (James)

At times, there appeared to be a conflict between participants' emotional and rational evaluations of these beliefs. The following extract from Madison illustrates the dual role of facts versus feelings in her donor decision:

> *I guess it's the "what ifs", it's the y'know what if you aren't really dead and all this sort of nonsense and the sensible side of me is telling me not to be stupid but the not so sensible side y'know is still questioning it...* (Madison)

4.6.2 Preserving Bodily Integrity (sub-theme 2.2)

This sub-theme represents the belief that the integrity of the body is irreparably jeopardised as a consequence of organ donation. Throughout participants' narratives, the desire to remain whole in life and in death appeared to be an influential factor in the decision to opt-out. Victoria, for example, felt that if her organs were donated, her body would no longer be whole, and the finality of her death would be endangered:

> *When I die I want all of me to die, not a bit of me living on here, I think erm it's not like erm… it sort of feels like as if you wouldn't be properly dead do y'know what I mean and then you think well…I want all of me, I want to leave the world the way I came with all the bits that I came with.* (Victoria)

Participants also voiced worries over the envisioned brutality of organ donation and described fears that their body would remain in a damaged and disfigured state. As such, many participants expressed a desire to protect their body from further harm after death. These fears appeared to be compounded by the belief that as the donor is no longer alive, doctors may not display the necessary respect to the body after death. In the following extract, Anna compares organ donation to a surgical procedure to highlight her fears:

> *I mean it's not going to be like surgery if you're going in for surgery, they're not going to take their time to go in and mend an organ or mend a part of your body they're going to go in for the organ they need to then save someone's life. So erm for me I would be scared they just went in an(d) made a mess of my dead body to take the organ that they needed without having any respect for me.* (Anna)

For others, the preservation of bodily integrity was both, personally important and represented a value shared among family members. This manifested for some participants, into feelings of unease at the thought of their loved one's body being used for donation and the repercussions of this decision on their grieving process. Below, Charlotte explains that following her father's sudden death, knowing that his body remained intact was comforting:

> *I think being able to go to somewhere, where I know that he is there and that he is whole and I can speak to him erm it really just like puts my mind at ease and it's just quite nice [...] he is there in his entirety and that's really important to me.* (Charlotte)

4.6.3 Who Gets My Organs? (sub-theme 2.3)

Participants also reported misgivings about the organ-allocation process as an influential factor in their decision. Many voiced a desire for their organs to be gifted to someone who would make a positive contribution to their life and the wider community. The absence of control over this process led to apprehension that one's organs would be allocated to a recipient who was undeserving of such a precious gift. James expands on this view below:

> *I would want to know that the people receiving the organs were deserved and no self-abusers i.e. alcoholics erm I don't want to tell anybody else how to run their life but if they are going to be given the gift of an organ by somebody they have to accept it with some humility and look after themselves.* (James)

Table 4. 3. Additional Illustrative Quotes for Theme 2: Self-Protection

Sub-themes	Illustrative excerpts
Mistrust of the medical profession (sub-theme 2.1)	*I worry that if something happens to someone that I love will the doctors work as hard to save them if they think they can get good body parts?* (Erin) *There was always an old fear if you're dying in hospital and they thought oh we'd have a bit of him, they wouldn't bother saving you or they might just pull the plug a bit premature.* (James)

Preserving bodily integrity (sub-theme 2.2)	*I want to go intact. I don't want anybody to be messing about with me erm once I'm dead erm I want to be that perfect package going wherever I'm going because at the end of the day we dunno really what happens until we get there.* (Anna) *y'know wee boys used to raise their school hats when a hearse went past and it was just.. although the soul if you believe in a soul wasn't there anymore it was still a body of somebody and eh you just didn't tamper with it.* (Olivia)
Who gets my organs? (sub-theme 2.3)	*It just seems to be taking a bit of control away especially sort of in terms of like where your body goes as well and who your donating it to, I think there should be more sort of say really about that.* (Lauren) *they've got no choice where they are going to y'know I wouldn't want my organs going to a murderer for example and it's theoretically possible that could happen.* (Robert)

4.7 Theme three: 'Riddled with pitfalls'

Specific concerns regarding the implementation, management and inclusivity of the opt-out system were an important feature within participants' narratives. Two prominent concerns were identified: heightened risk of reproach when registering to opt-out (sub-theme 3.1) and a non-inclusive system (sub-theme 3.2).

4.7.1 Heightened Risk of Reproach (sub-theme 3.1)

Many participants described stigma associated with the decision not to be an organ donor. Charlotte, for example, recounted personal experiences of judgement from family or friends "*four people said I was like y'know a bit of a mean person".* As the majority of people are seen to be supportive of organ donation, under the new system, the act of recording an opt-out decision was anticipated to increase the likelihood of harmful judgements and ridicule from other people.

> *If you're going in to opt-out of something that traditionally people don't really opt-out of you're opening yourself up to a lot of judgement and a lot of um just remarks from possibly the people who are part of the kind of system[...]people don't necessarily want all of their dirty laundry aired out in public and it's seen as quite a taboo thing at least in my generation to not want to donate your organs.* (Robyn)

Considering concerns of negative appraisals, the introduction of deemed consent was perceived to make registering or voicing an opt-out decision significantly more challenging. For example, Victoria felt that "*people are being coerced into being organ donors*" and they may "*feel afraid to say that's not what they want"*. Other participants were worried about heightened pressure when making donor decisions for next of kin. Below, Erin explains her worries about making a donor decision on her husband's behalf following the introduction of opt-out consent:

> *To have to y'know stand against all the doctors and all the nurses because the image that we always get is that they're always for it and y'know morally in the media it's something that you should do because it's the* <u>*right thing to do*</u>*, so to then stand up and say "no I disagree I don't want it to happen" and y'know everyone's waiting and lives are y'know on the brink and you've decided no when it's always been assumed because he didn't opt-out. I think that would be a really hard decision to make y'know in that situation that's when things really fall apart and people don't recover from that kind of thing.* (Erin)

4.7.2 A Non-Inclusive System (sub-theme 3.2)

Participants also criticised the inclusivity of the opt-out system, in particular for vulnerable groups; namely, those with poor health literacy, older adults, immigrants without a comprehensive command of the language, and individuals with limited capacity to comprehend the implications of the new system. As such, concerns were raised that individuals "*that don't actually have a voice for themselves*" would be automatically registered as organ donors against their wishes.

> *To opt-out that requires action, many many people are really inactive it's the road to hell is littered with good intentions and whilst there would be many people and let's be blunt about it there are people who are maybe not as well read or maybe not as erudite as they possibly could be who will have been deceived by this, there's also many many people who may be unable to make a really conscious considered decision* (William)

This was further compounded by the envisaged practical challenges to registering an opt-out decision. As Olivia states *"it's easier to sign-up than to sign-out of something"*. Consequently, participants described worries that an online system would be challenging to operate and that it would be purposely difficult to opt-out.

> *Where's the system to go an(d) opt-out, is it easy to navigate? If it's like any of the other government based websites it's horrendous erm they'll have no call centres because it will cost you one pound fifty a minute and people will think "oh heck I'm not paying that to go an talk to somebody". They will make it as awkward as possible to opt-out in my opinion.* (James)

Table 4. 4. Additional Illustrative Quotes for Theme 3: 'Riddled with pitfalls'

Sub-themes	Illustrative excerpts
Heightened risk of reproach (sub-theme 3.1)	*I think people are actually more likely to get ostracised if they opt-out cause people will just think oh right well that's a bit selfish[..] erm I think yeah that might stigmatise opting out a lot more.* (Charlotte) *People might feel like oh I want to phone up to say I don't want to be an organ donor and they might be frightened that they might be questioned about why, y'know "why are you making this decision oh y'know people could live on with your organs" or whatever y'know trying to talk you out of it.* (Victoria)

A non-inclusive system (sub-theme 3.2)	*I strongly believe in democracy and they're coming out with a blanket law that would affect everybody okay there's an opt-out clause but the thing is not everybody would have the capacity to work through mentally the fact that they could opt-out.* (Andrew) *I think people that aren't as kind of socially aware or community aware or whatever might not understand the implications and might be mistakenly signed into something that they don't want to be signed in to.* (Emily)

4.8 Discussion

This research contributes to the existing literature by investigating attitudes towards the opt-in system and the planned opt-out donor system from the unique perspective of individuals who plan to opt-out of organ donation. The findings emphasise the importance of autonomy and individual responsibility over one's donor decision and suggest this to be threatened under opt-out consent. The study also offers important insights into factors that may influence the decision to opt-out of organ donation. Notably, perceptions of government control and emotional factors around mistrust of medical professionals, preservation of bodily integrity and worries regarding the allocation of donor organs appear to play a considerable role.

4.8.1 Consent Versus Coercion

Under the long-established opt-in system in Scotland and England, consent for donation is recorded following an individual's decision to sign-up and join the donor register. As this requires one to "*actively seek out the means*" to register, this was reported to signify that consent was a considered and conscientious decision. This was important for two main reasons; primarily, it enables participants to exercise their autonomy regarding the decision not to register as a donor. This is because under the opt-in system "*no presumptions"* are made regarding the absence of an active donor decision. However, under opt-out consent, the absence of a recorded decision [opt-in or opt-out] will now be used to indicate consent for donation via deemed consent. Secondly, actively registering as a donor under an opt-in system was considered to provide explicit and unambiguous evidence of one's donor intentions. This was believed to reduce uncertainty when family members are approached regarding donation. As the donor register represents clear evidence of one's intentions, participants felt this may, in turn, make it "*easier*" for grieving family members to proceed with organ donation. This finding is consistent with recent consent figures from countries with opt-in laws, which reports that families are considerably more likely to agree to organ donation if their loved one had registered as a donor. However, in instances where no decision has been recorded, a 42% increase in family or next-of-kin refusal is observed and consent is authorised in just over 50% of such cases (NHS Blood and Transplant, 2020a).

Though participants favoured the opt-in system due to its non-invasive nature, when talking about the proposed opt-out system, the word choice of "*conscripted*", and "*enforced*" suggests that participants consider opt-out legislation as a forceful method of obtaining consent for organ donation. As consent will be deemed automatically for those who have not registered a donor decision, some believed this would "*remove their choice and their voice*". The concept of autonomous choice fundamentally concerns the right for an individual to exercise control over their lives and decisions (Deci & Ryan, 1987). A principal component of autonomy is the provision of informed consent and the capacity for an individual to make choices and take action without coercion from external factors (Rendtorff, 2008). This may explain why those who plan to opt-out, view the Government as a coercive, external factor that constrains their autonomous choice.

This finding may be associated with the concept of reactance, an unpleasant motivational response that arises following a perceived threat to one's freedom (Brehm & Brehm, 1981). In response, individuals are driven to take action to protect the notion they perceive as being under threat (Rosenberg & Siegel, 2018). As such, people who perceive the opt-out system to threaten their freedom of choice may be driven to opt-out to preserve their autonomy. Perceptions of reactance can be exacerbated by language that is perceived as being particularly controlling and forceful (Miller et al., 2007). Within the current study, it is interesting that participants made frequent reference to the word 'presumed' and appeared vexed at the idea of consent for organ donation being nonchalantly presumed by default. This was particularly apparent during Andrew's example of consent for sexual interaction; *"there's not a chance you could go to court and say actually well y'know I had presumed consent".* This suggests that participants view the notion of deemed consent as paradoxical and incompatible with the delicate nature of consent. As such, cautious use of language may be required when promoting opt-out consent. This interpretation will be investigated within the next Chapter.

4.8.2 Self-Protection

Emotional barriers associated with the preservation of one's life, body and organs were found to be influential factors in the planned decision to opt-out. Throughout, unease regarding the medical and healthcare system was predominantly associated with the notion that doctors may hasten death to procure organs for those on the waiting list. Such comments illustrate that recipients on the waiting list are viewed more favourably than potential donors in the event of life-threatening injuries. The findings also suggest unease regarding the organ allocation process. Often, participants conveyed fears that they had no control over the allocation of donor organs and could not guarantee their organs would be donated to individuals who "*deserved*" such a gift. Similar factors have emerged in existing qualitative studies as key deterrents for individuals registering as a donor under an opt-in system (Irving et al., 2011; Newton, 2011). Notably, some participants in this study attributed these fears to depictions of organ donation in films and television programmes. Previous literature supports this and suggests that barriers towards donation may be fuelled by harmful misrepresentations of organ donation in the media (Morgan et al., 2005). Given the alarming rate at which misinformation is now disseminated, careful consideration of future organ donation depictions should be encouraged (Lewandowsky et al., 2012).

In recognition of this, NHSBT currently provide a 'myth-busting' feature on their webpage as a method of dispelling myths and correcting misinformation surrounding organ donation. The study in Chapter 2 of this thesis investigated the impact of this campaign on self-reported organ donor intentions. While dispelling myths increased intentions for those with favourable attitudes towards organ donation, namely participants who plan to opt-in and those who plan to follow deemed consent, for those who plan to opt-out, the myth-busting intervention had no effect on intentions. At present, the most effective components of organ donation campaigns remain unclear, though emergent evidence suggests that emotive campaigns may be more effective (Feeley & Moon, 2009; Rodrigue et al., 2014). Given the powerful role of feelings and emotions in relation to organ donor decisions, future research evaluating such campaigns would be beneficial.

The preservation of bodily integrity after death was also a crucial factor driving the decision to opt-out of organ donation. Participants described fears that proceeding with donation would "*make a mess*" of their dead body. Throughout, word choices of "*mutilated*" and "*tampered*", suggest participants view donation to inflict unwarranted physical harm. As such, this led to fears that the body would be left damaged and disfigured during the afterlife, whilst for others, it signified death to be somewhat incomplete. Interestingly, although this concept is often attributed to religion, with the exception of one participant (Anna), all interviewees in this study stated that they held no religious beliefs.

A core principle of bodily integrity is the notion that one's body signifies an "*untouchable core*" (Rendtorff, 2008). Adopting a bioethics perspective, a fundamental factor in the maintenance of these values is the provision of autonomy and informed consent. Importantly, these factors are also crucial for the preservation of harmonious relationships between individuals and healthcare professionals (Delgado, 2019). Given that bodily autonomy and informed consent were perceived as being threatened under an opt-out system, concerns regarding bodily integrity and medical mistrust may be exacerbated following the enactment of new donor laws. In sum, although these factors have emerged as pivotal deterrents towards donor relevant decisions for nations with opt-in donation systems (Morgan, Harrison, et al., 2008; O'Carroll, Foster, et al., 2011; Shepherd & O'Carroll, 2014), the current study suggests that emotional barriers are also important factors for people who intend to opt-out of organ donation.

4.8.3 'Riddled with pitfalls'

A number of key concerns regarding the implementation and management of the opt-out system arose. In particular, the act of registering an opt-out decision was envisaged to heighten vulnerability to reproach. Participants described occasions in which they had experienced judgement and stigma from friends and family regarding their donor decision. In turn, such negative experiences may have perpetuated the anticipation of reproach when communicating donor decision under an opt-out system. These findings are similar to that of (Breitkopf, 2006) in which, anticipated negative experiences decreased the intention and willingness of individuals to discuss their donor decisions with family. Although this study measured communication of donor wishes under an opt-in system, it highlights the importance of perceived negative expectations during face-to-face donor discussions on one's donor behaviour. Under an opt-in system, the decision not to be an organ donor was regarded by participants as one "*you can kinda avoid*". As individuals will now have to take action to opt-out of the donor register, further examination of these factors is required.

4.8.4 Limitations

There are limitations to this study that should be acknowledged. Although the study aimed to recruit participants from England and Scotland, the sample consisted almost exclusively of individuals living in Scotland and only one interviewee from England. Therefore, these findings may largely reflect the experiences of individuals living in Scotland. However, there were a number of shared themes between our interviewee from England (Luke) and the cohort from Scotland, namely the importance of informed consent and concerns over violation of bodily integrity. In future, a more geographically representative sample would enable the exploration of factors that may be unique to Scottish and English residents. Moreover, participants' ethnicity was not explicitly recorded, therefore, inferences regarding cultural variations in attitudes towards organ donation and opt-out consent policies cannot be made. Existing research has found specific barriers in relation to maintaining bodily integrity after death as an important deterrent for individuals of different ethnic and faith groups (Morgan et al., 2013). As such, future research that explores attitudes towards opt-out consent with a more diverse sample of individuals from different ethnicities, faith, and belief groups is required. A potential limitation also pertains to the use of telephone interviews. Although selected due to the potential widespread geographic location of participants, telephone interviews have been criticised due to the absence of visual and nonverbal cues (Novick, 2008). This predominantly concerns the loss of nonverbal data including gestures and facial expressions which can incur challenges in establishing rapport and may limit the depth of responding. To mitigate this, the author employed various techniques including, active listening, expressing appreciation of participants' dialogue through non-judgemental affirmations and time orienting statements. Collectively, use of these approaches have been found to facilitate the development of trust and rapport between participants (Drabble et al., 2016; Weger Jr et al., 2014).

4.8.5 Implications and Future Directions

This study has a number of potential implications for policymakers and healthcare professionals in England and Scotland. The findings highlight the importance of a clear and active opt-in donor decision in reducing family uncertainty and refusal for donation. As family refusal remains a significant problem under opt-out legislation, future studies investigating this are required. A perceived threat to one's autonomy and freedom of choice emerged as key barriers under opt-out consent. The development and evaluation of targeted campaigns to reduce these concerns are important. Specifically, given its role in perceptions of reactance, evaluation of the word 'presumed' may be a useful next step. Lastly, to reduce fears of reproach and reduced inclusivity, it is essential that individuals planning to opt-out are able to register that choice in a discreet, simple and efficient manner. In light of these concerns, when communicating the transition opt-out consent in England and Scotland, clear guidance on the procedure for registering an opt-out decision is required.

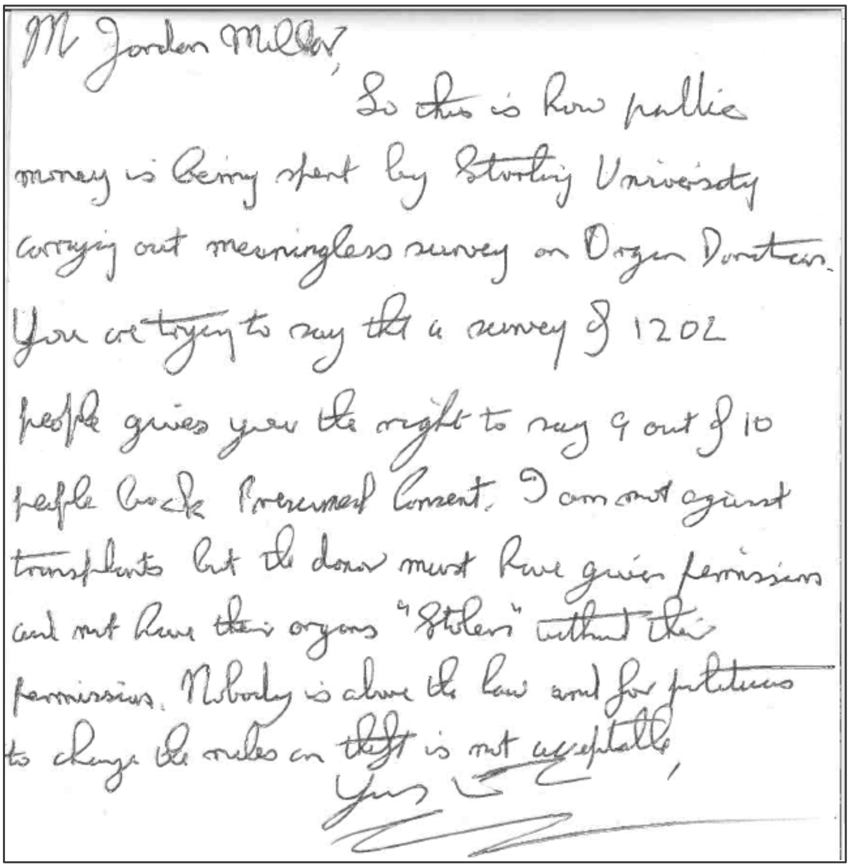
4.9 Conclusions

The findings of this chapter confirm that as in the existing opt-in organ donation literature, medical mistrust and concerns over preserving bodily integrity are also important barriers under the opt-out legislation. Barriers and concerns specific to opt-out legislation include heightened government control, loss of autonomy and fears of stigma when registering or voicing an opt-out decision. To reduce the number of people planning to opt-out of the organ donor register, attempts to better understand and address these barriers before the introduction of opt-out consent is vital.

Chapter 5: Investigating the effects of threatening language, message framing and reactance in opt-out organ donation campaigns

Preface

The decision to focus a component of this PhD on the role of psychological reactance first arose following receipt of the letter (presented below), received in response to a press release following the publication of Study 1. This letter gave the first inclination of the role of reactance-based responses in influencing the decision to opt-out. The subsequent findings of the interview study in Chapter 4 were instrumental in supporting this interpretation, with a number of participants who plan to opt-out reporting the donor system to threaten their free will. As such, the decision was made to focus this chapter on investigating this novel barrier.



Mr Jordan Miller,
So this is how public
money is being spent by Stirling University
carrying out meaningless survey on Organ Donation.
You are trying to say that a survey of 1202
people gives you the right to say 9 out of 10
people back Presumed Consent. I am not against
transplants but the donor must have given permission
and not have their organs "Stolen" without their
permission. Nobody is above the law and for politicians
to change the rules on theft is not acceptable,
Yours

Transcription: *"So this is how public money is being spent by Stirling University carrying out meaningless survey on Organ Donation. You are trying to say that a survey of 1202 people gives you the right to say 9 out of 10 people back Presumed Consent. I am not against transplants but the donor must have given permission and not have their organs "stolen" without their permission. Nobody is above the law and for politicians to change the rules on theft is not acceptable".*

Sections of this chapter also feature in Miller, J., McGregor, L. M., Currie, S., & O'Carroll, R. E. (2021). Investigating the effects of threatening language, message framing and reactance in opt-out organ donation campaigns. *Annals of Behavioral Medicine,* 1-14. https://doi.org/10.1093/abm/kaab017

5.1 Abstract

Background: At the time of conducting this study, awareness campaigns to promote opt-out legislation in England and Scotland were ongoing. Growing evidence suggests that the language used within organ donation campaigns influences donor intentions and decision-making and may play a role in the development of psychological reactance (arising following a perceived threat to one's freedom). The objectives of this study were to investigate the effect of threatening language and message framing used in organ donation campaigns on donor intentions and psychological reactance.

Methods: Individuals from Scotland and England (*n* =1350) completed this online experiment. Participants were randomised to view one of four messages designed in the format of a newspaper article, which described the upcoming opt-out system. This followed a 2 x 2 design whereby the degree of threatening language (high threat vs. low threat) and message framing (loss vs. gain) of the newspaper article was experimentally manipulated. Measures of intention (pre and post message exposure), and post-message reactance (threat to freedom, anger and counter-arguing) were obtained.

Results: A mixed ANOVA revealed a significant group x time interaction on donor intentions; *post-hoc* analysis revealed intentions significantly decreased for individuals exposed to the high threat x loss frame article, but significantly increased for those exposed to high threat x gain frame article.

Conclusions: In campaigns to promote opt-out legislation, the results suggest that high threat language combined with loss frame messages should be avoided. If high threat language is used, gain frame messaging which highlights the benefits of organ donation, should also be incorporated.

5.2 Introduction

Across the world, there is a disparity between the limited number of organ donors and the growing demand for transplantation (Global Observatory on Donation and Transplantation, 2020). In an effort to increase the number of donors, nations across the world are implementing opt-out consent legislation. At the time of conducting this study in late 2019, opt-out legislation had been implemented in Wales in 2015, was planned for England in May 2020, and Scotland in March 2021.

5.2.1 The Factors Influencing Opt-out Decisions

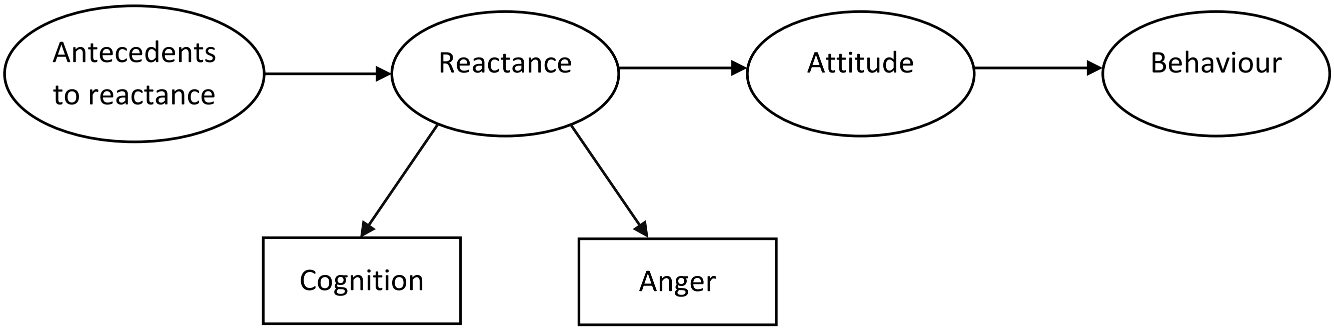
Consistently, evidence has emphasised the important role of affective beliefs (e.g., medical mistrust) in influencing donor decision-making among nations with opt-in policies (Morgan, Stephenson, et al., 2008; O'Carroll, Foster, et al., 2011; Shepherd & O'Carroll, 2014). However, few studies have investigated the possible factors influencing donor decision-making under opt-out consent. Within the context of this thesis, barriers specific to the nature of opt-out legislation have emerged within the qualitative findings of Chapters 3 and 4. In particular, the findings of the qualitative interview study of Chapter 4, demonstrated that participants who plan to opt-out considered the new donor system as giving the government "*ownership*" over their body and their donor choice. Indeed, a number of participants remarked that under opt-out consent, people may be "*coerced*" into consenting for organ donation. Throughout, participants emphasized the value and importance of autonomy regarding the personal decision <u>not</u> to be an organ donor. In particular, voicing frustrations at the notion of presumed consent, and suggested this would threaten their "*free will to make their own decisions*". Therefore, for this group, opting out of organ donation was viewed as a way of protecting one's freedom of choice. Accordingly, the concept of psychological reactance may contribute to our understanding of these deterrents.

5.2.2 Psychological Reactance

Psychological reactance is an aversive motivational response arising when an individual perceives their behavioural freedoms or autonomous choice to be under threat (Brehm & Brehm, 1981). In response to perceived threats or restrictions, psychological reactance theory posits that individuals will be driven to take action to safeguard or reinstate control over the notion they perceive as being under threat (Brehm, 1966; Brehm & Brehm, 1981). In broad terms, behavioural freedoms are a set of actions, values, or attitudes a person expects they should be able to enact without restriction or coercion from external sources (Brehm, 1966; Clee & Wicklund, 1980). Accordingly, within the context of health decision-making, the choice to register or indeed, not to register as an organ donor can be categorised as a free behaviour. This free behaviour subsequently becomes more desirable when it is believed to be restricted or threatened (Brehm & Brehm, 1981).

The concept of reactance had been, until recently, poorly demarcated. Whilst it was generally acknowledged that affective responses, including anger and hostility, were important elements needed to understand the nature of reactance, the conceptualisation of reactance was unclear, and it was formerly deemed to be unmeasurable (Brehm, 1966). However, developing a robust understanding of the way reactance manifests and optimising its measurement, is central to our understanding of the way reactance influences attitudes and behaviour. In recognition of this, Dillard and Shen (2005) sought to operationalise reactance, and thus evaluated four possible models. The results indicated that reactance was optimally conceptualised within an intertwined process cognitive-affective model (As shown in Figure 5.1). This means, that following exposure to a stimulus perceived to threaten one's behavioural freedom, reactance, which encompasses a combination of negative cognitions and anger will ensue. It is a consequence of both, negative cognitive responses, that often manifest as counterarguments, source derogation and anger, which drive action to promote restoration of freedom by influencing attitudes and behavioural intentions.

Figure 5. 1. Dillard and Shen's Intertwined Process Cognitive-Affective Model



A number of studies have since provided empirical support for the intertwined model (Kim et al., 2013; Quick & Considine, 2008; Quick & Stephenson, 2007; Rains, 2013; Rains & Turner, 2007). In line with this, reactance is defined throughout this chapter in accordance with Dillard & Shen's conceptualisation: a combination of anger and counterarguing which arises following exposure to a stimulus perceived to threaten one's behavioural freedom (Dillard & Shen, 2005). This threat-based response drives restoration of freedom by influencing one's attitudes and behavioural intentions. Within the context of health communication, restoration of freedom often manifests in the form of an unintended 'boomerang effect', whereby reactant readers will engage in oppositional behaviours in response to health warnings, for example, increased alcohol consumption following exposure to alcohol warning messages (Byrne & Hart, 2009; Shorey-Fennell & Magnan, 2019; Wechsler et al., 2003). Taken together, if information regarding opt-out consent arouses a sense of threat to one's freedom, reactance, which manifests as a composite of anger and counterarguments towards the source, may occur. This in turn, may induce negative attitudes and adversely impact behavioural intentions towards organ donation.

5.2.3 The Role of Reactance in Health Decision-Making

Reactance is particularly important in the context of change situations, including political and healthcare reforms. This is partly attributable to the use of language within such communications, for example, persuasive terminology, such as 'you must', 'you have to' and 'you need', are often perceived as being more threatening and restrictive than autonomy-supportive language, such as 'you may', 'you could', and 'consider' (Miller et al., 2007; Quick & Considine, 2008). Given their often direct and persuasive nature, this may explain why public health campaigns and interventions to change health behaviours can incur undesirable consequences.

Research across a variety of public health domains has investigated this, reporting the application of persuasive and high threat language to induce perceptions of threat to freedom, negative cognitive responses and anger in comparison to low threat messages (Dillard & Shen, 2005; Grandpre et al., 2003; Miller et al., 2007; Quick & Considine, 2008; Quick & Stephenson, 2008). For example, in Dillard and Shen's well-known study (2005), the threat level of language applied to promotional health materials used to endorse dental flossing and reduced alcohol consumption was experimentally manipulated. Exposure to the high threat condition induced perceptions of threat to freedom, negative cognitive responses and anger in comparison to low threat messages. Notably, reactance, which manifests as a combination of anger and negative cognitions, mediated the relationship between the freedom-threatening message and negative attitudes toward the message. These attitudes then adversely impacted behavioural intentions towards the promoted behaviour within the dental flossing campaign.

A small number of studies have applied this to the context of organ donation campaigns and reliably report the use of high threat language to increase perceptions of freedom threat which, in turn, induced state reactance (Quick, 2012; Quick et al., 2011). For example, research from Quick et al. (2011) found high threat language within messages encouraging organ donor registration to increase psychological reactance which, in turn was associated with negative attitudes and behavioural towards organ donation. One concern about this study relates to the lack of ecological validity, given the strength of the high threat language manipulation e.g., "*Stop the denial! Given the need for organ donors, a reasonable person would consent to be an organ donor*". Therefore, it is somewhat unsurprising that those exposed to the high threat condition reported perceptions of restricted freedom and experienced reactance-related negative cognitions and anger. The application of such overtly forceful language is unlikely to be used in 'real-world' health communication campaigns. As such, it is important to investigate whether more subtle, realistic manipulations, using language that is routinely used within the public domain, can induce a sense of restricted freedom and elicit reactance.

5.2.4 Message Framing

In addition to the degree of language threat, the way in which messages are framed (loss vs. gain) can also impact behavioural intentions. This effect is attributed to prospect theory and the concept of risk perception (Kahneman & Tversky, 2013). In short, when making decisions, an individual considers the degree of risk and certainty associated with each choice. Specifically, the way a message is framed, for example, presenting the benefits of a particular decision (*gain frame*) influences one's risk-related preferences and decision-making.

Applying prospect theory to health-related decision-making, 'risk' refers to the likelihood of an individual experiencing unpleasant outcomes as a consequence of a particular action. A considerable body of literature has examined message framing and reports a differential effect of framing manipulations for specific categories of health behaviours (Detweiler et al., 1999; Gallagher & Updegraff, 2012; Rothman et al., 2006; Rothman & Salovey, 1997). Accordingly, gain frame messages, which emphasise the benefits of engaging in certain behaviours, are effective at promoting protective or preventative behaviours (Detweiler et al., 1999). Loss frame appeals, which highlight the adverse consequences of not engaging in certain behaviours, are most effective at encouraging health detection or diagnostic behaviours (Rothman et al., 2006). However, the application of these findings is somewhat challenging within the domain of organ donation, as the implications of the behaviour (registering as an organ donor), do not personally benefit the individual who enacts the decision. In line with this, the following loss frame manipulation (*Last year, 400 people died waiting for a potentially lifesaving transplant*), or gain frame manipulation (*Last year, 4990 people received a potentially lifesaving transplant*) presents the reader with costs and benefits pertaining to other people.

A number of studies have explored framing effects in the context of organ donation (Cohen, 2010; McGregor et al., 2012; Reinhart et al., 2007; Sallis et al., 2018). However, the evidence base appears inconsistent, with some studies reporting no differential effect of framing on attitudes or behaviour (Cohen, 2010; Sallis et al., 2018). Conversely, research from McGregor et al. (2012) found gain frame messages to increase one’s willingness to become a living kidney donor (McGregor et al., 2012). Evidence from Reinhart et al. (2007) within the domain of posthumous organ donation offers support for these findings, reporting that gain frame messages were perceived as more favourable and resulted in greater intentions towards deceased organ donation than loss frame counterparts (Reinhart et al., 2007). The impact of message framing on psychological reactance was also considered within this study. Interestingly, loss frame messages (e.g., illustrating how many people die because of the donor shortage) were found to increase reactance, which in turn adversely affected attitudes and donor intentions. Reactance was found to mediate the relationship between message frame and subsequent message response. The authors reasoned that presenting organ donation messages within a loss frame may have elicited a sense of guilt among readers and led to the perception of the message as being covertly forcible. These findings warrant further testing of message framing within organ donation literature.

5.2.5 The Current Study

A considerable body of evidence has shown that the content of communication campaigns plays an important role in the attitudes and behavioural intentions of the public. Research to date has focused on message content and language within campaigns designed to encourage donor registration. However, evaluating language and message framing arguably becomes more important in the context of opt-out legislation, as those who have not registered a donor decision are now presumed to consent for organ donation. At the time of conducting this study, opt-out consent had been enacted in Wales and was scheduled for implementation in England and Scotland in mid-2020 (opt-out consent was later postponed in Scotland due to the Covid-19 pandemic). As far as the author is aware, no previous research has investigated the role of threatening language and message framing in relation to opt-out organ donation campaigns. The present study, therefore, employed a between-group design to examine the role of language (high vs. low threat) and message framing (loss vs. gain) used within opt-out organ donation campaigns on donor intentions and the development of reactance.

Although there remains considerable debate as to the best ways of measuring reactance, a review of the literature has shown threat to freedom, negative cognitive responses and anger to be important components (Rains, 2013). For the purpose of this study, reactance was measured using two of Dillard and Shen's (2005) measures of threat to freedom and anger. From a practical perspective, it was not feasible to implement Dillard and Shen's method of measuring negative cognitive responses via a thought-listing task within this online study. However, a number of studies consider reactance-related negative cognitions to encompass counter-arguing or source derogation (Dillard & Shen, 2005; Rains & Turner, 2007). Therefore, a 4-item counter-arguing measure adapted from Nabi et al. (2007) was used to represent the final component of reactance in response to the organ donation narrative.

In addition, perceptions of unwarranted government control under opt-out legislation have emerged throughout Chapters 3 and 4 as important factors influencing planned opt-out decisions. No research to date has empirically examined these potential predictive factors. Therefore, a secondary objective of this study was to assess the influence of government trust and NHS trust at predicting anticipated opt-out decisions.

5.2.6 Hypotheses

Hypothesis 1. The opt-out organ donation campaign which contains high threat language and a loss frame component will decrease donor intentions in comparison to the low threat and gain frame campaign.

Hypothesis 2. High threat language will induce greater threat to freedom than campaigns which use low threat language.

Hypothesis 3. Participants who plan to opt-out will exhibit higher levels of state reactance (manifesting as greater threat to freedom, anger and counter-arguing) when exposed to campaigns describing the transition to opt-out consent.

Hypothesis 4. Participants who plan to opt-out of organ donation will have heightened levels of dispositional trait reactance (heightened reactance sensitivity).

5.3 Methodology

5.3.1 Power Analysis

A G*Power calculation was conducted to determine the number of participants required to detect a small effect size of f =.10 (Cohen, 1988). This indicated that using a between-group comparison with 4 groups at an alpha level of .05 and a power of .80, a sample size of 1292 was required (approximately 320 in each of the 4 arms).

5.3.2 Ethical Approval

Ethical approval for this study was obtained from The University of Stirling's General University Ethics Panel. As special categories of personal data were collected within this study including; racial and ethnic origin, religious beliefs and organ donor status, a Data Protection Impact Assessment (DPIA) was completed and approved by the University Data Protection Officer during the study design phase.

5.3.3 Participant Eligibility Criteria and Recruitment

Recruitment took place between November 2019 and February 2020. At the time of recruitment, neither England nor Scotland had introduced opt-out consent legislation, though wide-spread communication campaigns to promote the legislative change were underway. As such, only adults aged over 18 years living in England and Scotland were eligible to participate. Participants were opportunistically recruited for this study through UK-wide mailing lists and via social networking sites (Twitter, Facebook). The study link was also shared with academic colleagues across the UK. Advertisements were also placed on the University of Stirling Portal announcement page, used for publicising research studies to students and staff. Lastly, recruitment posters with a study URL link and a QR code were displayed in various shops, bus stops and faith centres around Central Scotland. As an incentive, participants had the opportunity to enter a prize draw for a £25 Amazon voucher.

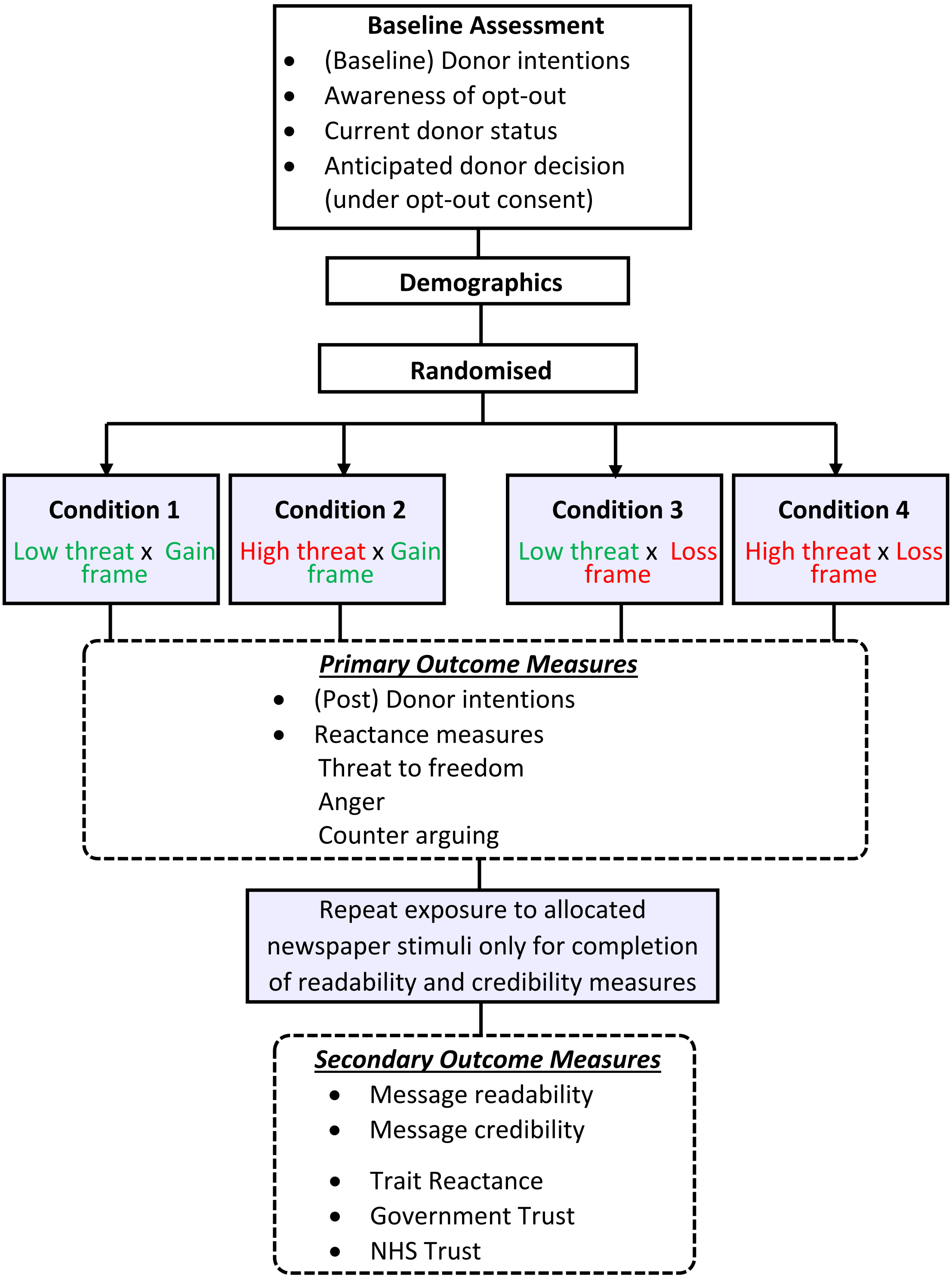
5.3.4 Design

This study employed a 2x2 between-groups design. To examine the effect of threat level and framing on donor intentions and perceptions of reactance, the language threat level (high vs. low) and message framing (loss vs. gain) of opt-out organ donation campaign messages were experimentally manipulated. Newspaper and electronic articles are a key communication medium for information regarding organ donation, therefore, to enhance ecological validity, each message was designed in the format of a newspaper article. Participants were therefore, randomly assigned to view one of four message conditions: Condition 1: low threat x gain frame, Condition 2: high threat x gain frame, Condition 3: low threat x loss frame, Condition 4: high threat x loss frame.

5.3.5 Procedure

This study involved the completion of an online questionnaire using Qualtrics, a web-based questionnaire platform (Qualtrics, 2005). A diagram of the study procedure is available in Figure 5.2. Participants accessed the survey via an anonymous URL link or QR code affixed to the study advertisements and recruitment posters.

Figure 5. 2. Study Procedure Diagram



5.3.6 Baseline Assessment

After informed consent was collected via an electronic checkbox at the beginning of the questionnaire, participants were presented with brief information describing the opt-in donor system that was, at the time of recruitment, active in England and Scotland (see Figure 5.3).

Figure 5. 3. Information Presented to Describe the Existing Opt-in System.

The following information describes the current donor system in Scotland and England.

At the moment, anyone who wants to be an organ donor after they die can provide consent by actively signing up and joining the organ donor register. This is often referred to as an opt-in system.

Participants were then asked to record their baseline donor intentions in response to the following statement '*I intend to donate my organs after death'*. To assess current unprompted awareness of the upcoming legislative changes, participants were initially asked if they were aware of any planned changes to the organ donor register in their country. Only participants who selected '*yes'* or '*not sure'* to this question were presented with a free-text response option and asked '*briefly, what do you think the change is?'*. All participants were then asked to report whether they were currently registered as an organ donor. The response options: (1) Yes - I am registered an organ donor, (2) No - I am not currently registered as an organ donor, (3) I am unsure if I am a registered as an organ donor, and (4) No - I have opted out of the organ donor register, were presented. To assess planned donor status following the change in legislation, participants were presented with a description of the opt-out system (See Figure 5.4) and asked to indicate their anticipated donor decision by selecting from one of the following response options: (1) opt-in, (2) take no action and follow deemed consent, (3) undecided and (4) opt-out.

Figure 5. 4. Information Presented to Describe the Forthcoming Opt-out System.

The following information describes the new donor system planned for Scotland and England next year.

If an individual does not want to be an organ donor, they are required to opt-out of the donor register. If an adult has not registered a donor decision, they will be treated as having no objection to being an organ donor.

Following this, demographic information was collected. The presentation of demographic questions in this order was used to serve as a buffer between the exposure to information about organ donation used at the beginning of the questionnaire, and the presentation of the experimental manipulation.

To encourage continued engagement with the study, directly before presentation of the experimental conditions, participants were presented with a message stating "*In the next section you will be asked to read an article about organ donation. Please read this carefully, you'll be asked a few questions afterwards.*". Upon selecting to proceed, participants were randomly allocated to view one of four messages: Condition 1: low threat x gain frame, Condition 2: high threat x gain frame, Condition 3: low threat x loss frame, Condition 4: high threat x loss frame. In an effort to ensure participants read the information within the allocated message, a timer function was embedded into the survey which delayed progression onto the next stage of the study until 50 seconds had elapsed, approximately the time required to read each message. The duration was calculated using an estimated reading time generator for the four conditions (Read-o-Meter; http://www.niram.org/read/).

5.3.7 Opt-out Organ Donation Message Content

As communication campaigns are underway in England and Scotland to ensure public awareness and understanding of the legislative change, each message was designed using Adobe Acrobat software to mimic a newspaper article. The newspaper conditions were matched in content and contained a similar number of words (range: 164 – 180 words). The readability of the conditions was assessed using the Flesch-Kincaid Readability statistics, the message manipulations were deemed suitable to be read from approximately grade level 7 and 8 (Kincaid et al., 1975). Each message broadly contained information describing the current opt-in donor system, UK organ donation figures, the introduction of opt-out legislation, and the main donor decisions offered under opt-out consent. An example of Condition 2 (high threat x gain frame) and Condition 4 (high threat x loss frame) are shown in Figure 5.5 and 5.6. Each of the conditions are also provided in Appendix 17.

Figure 5. 5. Example of Condition 2: High Threat x Gain Frame Message.

Local Inquirer

Wednesday
21 June 2019

The Government have decided to change the organ donation laws in Scotland and England

Currently, anyone in Scotland and England who wants to donate their organs in the event of their death can choose to opt-in and join the organ donor register.

Last year, 4990 people received a potentially lifesaving transplant.

Under the Governments' new law, adults will now be presumed to be in favour of donating their organs. This is known as presumed consent.

If you do not want to donate your organs, you must now opt-out of the donor register.

The Welsh Government changed the donor law and introduced presumed consent in 2015. The latest figures have now shown a promising increase in the number of transplants.

When the Government introduces the new law, you will now have to:

- Opt-in if you want to donate your organs.
- Opt-out if you do not want to be a donor.
- If you do nothing, it will now be assumed that you are willing to donate your organs when you die.

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Figure 5. 6. Example of Condition 4: High Threat x Loss Frame Message.

Local Inquirer

Wednesday
21 June 2019

The Government have decided to change the organ donation laws in Scotland and England

Currently, anyone in Scotland and England who wants to donate their organs in the event of their death can choose to opt-in and join the organ donor register.

Last year, 400 people died while waiting for a potentially lifesaving transplant.

Under the Governments' new law, adults will now be presumed to be in favour of donating their organs. This is known as presumed consent.

If you do not want to donate your organs, you must now opt-out of the donor register.

The Welsh Government changed the donor law and introduced presumed consent in 2015. The latest figures have now shown a small increase in the number of transplants.

When the Government introduces the new law, you will have to:

- Opt-in if you want to donate your organs.
- Opt-out if you do not want to be a donor.
- If you do nothing, it will now be assumed that you are willing to donate your organs when you die.

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The language threat manipulations were informed by existing reactance literature (Dillard & Shen, 2005; Miller et al., 2007; Quick & Considine, 2008). In addition, the manipulations were also informed by the qualitative findings from Chapter 4 of this thesis, which showed heightened reactance to arise following reference to opt-out legislation as a system of presumed consent (Miller et al., 2020). Overall, the aim of the manipulations was to create important but realistic and subtle differences. Within the low-threat condition, neutral word choice and autonomy-supportive language was used throughout. For example, when describing donor decision-making under the opt-out system, the following phrase was used "*If you decide you don't want to donate your organs, you can always choose to opt-out of the donor register*". Conversely, within the high threat condition, the threat level was manipulated by the inclusion of more direct language, overtly forceful adverbs and imperatives. Thus, when describing donor decision-making under opt-out consent, the reader was presented with a command which may restrict choice "*If you do not want to donate your organs, you must now opt-out of the donor register*".

Two framing manipulations (loss vs. gain) were used. The first, presented figures on the number of people who had died on the waiting list (loss): "*Last year, 400 people died while waiting for a potentially lifesaving transplant",* and how many people's lives had potentially been saved by an organ transplant (gain): *"Last year, 4990 people received a potentially lifesaving transplant"*. The second manipulation centred around a description of the opt-out system in Wales. As Wales was the first UK nation to introduce opt-out consent, information on Welsh rates of donation following the legislative change feature heavily within UK opt-out media campaigns. Therefore, the gain frame manipulation described the opt-out system in Wales to have resulted in, "*a promising increase in the number of transplants"* and in the loss/neutral frame manipulation *"a small increase in the number of transplants".* The specific message variants used in each of the language and framing manipulations are available in Table 5.1.

Immediately after presentation of the experimental conditions, participants completed a post-intervention measure of donor intentions and three scales measuring the key aspects of reactance in response to the message: threat to freedom, anger and counter-arguing. Following completion of the main outcome measures, participants then completed two further scales measuring the readability and credibility of the messages. For this purpose, the newspaper condition each participant had been allocated during randomisation was displayed again for completion of the readability and credibility scales.

5.3.8 Secondary Outcomes

Finally, participants completed measures of trait reactance, government trust and NHS trust. Although the trait reactance measure was intended to assess dispositional levels of reactance, there were concerns that administering these measures before the main experimental conditions may induce a priming effect. Therefore, each of these measures were administered at the end of the experiment, after exposure to the newspaper conditions. To examine potential measurement reactivity effects across the experimental groups, a series of one-way ANOVAs were conducted.

Table 5. 1. Message Variants Used Within Each of the Four Conditions

<table>
<tr><th>Low Threat Message Components</th><th>High Threat Message Components</th></tr>
<tr><td>The way that people choose to register as an organ donor in Scotland and England is changing.

Currently, anyone in Scotland and England wishing to donate their organs in the event of their death can choose to opt-in and join the organ donor register.</td><td>The Government have decided to change the organ donation laws in Scotland and England.

Currently, anyone in Scotland and England who wants to donate their organs in the event of their death can choose to opt-in and join the organ donor register.</td></tr>
<tr><td colspan="2">Gain Frame OR Loss Frame Message Components
Gain - Last year, 4990 people received a potentially lifesaving transplant.
OR
Loss - Last year, 400 people died while waiting for a potentially lifesaving transplant.</td></tr>
<tr><td>Under the new system, if an adult hasn't registered a donor decision, they will be considered to have no objections to becoming an organ donor. This is known as deemed consent.

If you decide you don't want to donate your organs you can always choose to opt-out of the donor register.</td><td>Under the Governments' new law, adults will now be presumed to be in favour of donating their organs. This is known as presumed consent.

If you do not want to donate your organs, you must now opt-out of the donor register.</td></tr>
<tr><td colspan="2">Gain Frame OR Loss Frame Message Components
Gain - Wales introduced a deemed consent system in 2015. The latest figures have now shown a promising increase in the number of transplants.
OR
Loss - The Welsh Government changed the donor law and introduced presumed consent in 2015. The latest figures have now shown a small increase in the number of transplants.</td></tr>
<tr><td>When the system changes, you have the opportunity to make the following choice:
• Opt-in if you want to donate your organs.
• Opt-out if you do not want to be a donor.
• Do nothing and you will be considered as having no objections to being a donor.</td><td>When the Government introduces the new law, you will now have to:
• Opt-in if you want to donate your organs.
• Opt-out if you do not want to be a donor.
• If you do nothing, it will now be assumed that you are willing to donate your organs when you die.</td></tr>
</table>

5.3.9 Primary Outcome Measures

Each of the primary outcome measures were scored using a 7-point Likert scale, ranging from 1 (*strongly disagree*) to 7 (*strongly agree*).

Donor Intentions. The primary outcome measure, change in donor intentions, was measured at two time-points (baseline and post message exposure). Participants were asked to respond to the following statement '*I intend to donate my organs after death'.* Higher scores indicate greater intentions to donate organs.

Threat to Freedom. Participants completed a 4-item validated measure of threat to freedom used extensively within reactance research (Dillard & Shen, 2005). An example statement is '*The message tried to make a decision for me'.* Higher scores indicate the message has caused a greater threat to freedom. This scale had excellent reliability α =.91.

Anger. Anger was measured using a 4-item scale (Dillard & Peck, 2000). Participants were presented with a series of statements and asked to respond in accordance with how the newspaper article made them feel. An example item is '*I felt angry while reading the article*'. Higher scores represent greater anger in response to the message. To reduce the potential impact of negative priming, an additional, 3-item positive emotions scale, designed by the same authors was interspersed within this measure. Scale items were therefore categorised as positive cognitions (happy, content and cheerful) and anger (angry, irritated, annoyed and aggravated). Only the 4-item anger scale was used in the analysis. The anger scale demonstrated excellent reliability α =.91.

Counter-arguing. To measure counter-arguing in response to the message, participants completed a 4-item measure adapted from previous research (Nabi et al., 2007). An example item is '*I found myself actively disagreeing with the content of the article'.* Higher scores are indicative of greater counter-arguing in response to the message. The scale had acceptable internal consistency α = .75.

5.3.10 Readability and Credibility Measures

Readability. Readability was assessed by means of a 3-item scale used previously within existing framing literature (McGregor et al., 2012). The scale demonstrated good reliability (α = .84). Participants were presented with the sentence stem '*How easy or difficult was the article to…*' and asked to respond using the following criteria (*read, understand and remember*). Scores were measured on a 7-point scale from 1 (*very difficult) to* 7 (*very easy*) with higher average scores indicative of greater message readability.

Credibility. A three-item scale was used to measure credibility (Appelman & Sundar, 2016). Participants were presented with the statement '*The article was…*' and asked to score the message on the following adjectives (*accurate, authentic and believable*). Responses were scored on a 7-point scale 1 (*strongly disagree) to* 7 (*strongly agree*). Higher scores represent greater message credibility. The scale demonstrated good internal consistency (α = .81).

5.3.11 Secondary Outcome Measures

5.3.11.1 Trait Reactance

Trait Reactance. Participants' trait reactance was measured using the 11-item Hong Psychological Reactance Scale (Hong & Faedda, 1996). Participants were presented with 11 statements and asked to respond via a 5-point scale, from 1 (*strongly disagree*) to 5 (*strongly agree*). Higher scores are indicative of higher trait reactance. An example item is '*I become frustrated when I am unable to make free and independent decisions'.* The internal consistency of the scale was α = .84.

5.3.11.2 NHS and Government Trust

A nine-item modified version of the Citizen Trust in Government Organizations scale was administered to measure trust in the NHS and government (Grimmelikhuijsen & Knies, 2017). The scale uses nine criteria found to represent dimensions of trust (e.g., *capable, expert, and honest*). For completion of the measure, participants are presented with each of the nine trust criteria within the following template: When it concerns [domain A], [organisation B] is [insert trust criteria]. The template is then populated with the name of the domain and organisation being assessed. In this study, the domain of health and social care was used. Therefore, an example item in the scale measuring NHS trust is '*When it concerns* [*health and social care*]*,* [*the NHS*] *is* [*capable*]. Participants were presented with each item and asked to rate on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*) how much they agreed or disagreed with each statement. Higher scores indicate greater trust in the respective organisation. Both scales demonstrated excellent reliability, NHS trust α = .92 and government trust α = .94.

5.3.12 Statistical Analysis

The data was analysed using IBM SPSS 25. Initially, one-way ANOVAs and chi-square tests were conducted to assess demographic differences across the experimental conditions. To test the primary hypothesis and examine whether donor intentions differed over time as a function of the experimental conditions, a 2 x 4 mixed-measures ANOVA was conducted, with time (baseline and post-message exposure) as the within-subjects factor and condition (1, 2, 3 and 4) as the between-subjects factor. Differences in intention across the four conditions were then explored using simple main effects. To test our second hypothesis and investigate whether components of the experimental manipulation (high vs. low threat language and loss vs. gain frame messaging) induced reactance, a series of 2 x 2 ANOVAs were conducted. To test the third hypothesis and examine whether individuals who plan to opt-out of organ donation, experience heightened reactance in response to the message conditions, a 3 x 4 MANOVA was conducted. The reactance outcome variables (threat to freedom, anger and counter-arguing) were entered as the dependent variable, and the anticipated donor groups (opt-in, deemed consent, not sure and opt-out) as the independent variable. The multivariate statistic Pillai's trace was adopted to account for unequal sizes between the anticipated donor choice groups. Univariate ANOVAs on each of the three reactance measures were conducted and a series of Games-Howell *post-hoc* tests were used to investigate group-level differences.

5.3.13 Secondary Objective Analysis

A secondary objective of this study was to explore the predictive utility of the factors identified in the preceding chapters of this thesis at discerning participants who plan to opt-out of organ donation. To test this fourth hypothesis, a binary logistic regression was conducted with age, gender, religion, political views, registered donor status, trait reactance, NHS trust and government trust entered as predictor variables. Within the anticipated donor choice group (opt-in, deemed consent, not sure and opt-out), a dummy variable was generated to dichotomise participants' planned donor choice into donor (opt-in and deemed consent) or non-donor (opt-out).

5.4 Results

5.4.1 Participant Demographics

A total of 1350 adults from Scotland (78.3%; *n* = 1057) and England (21.7%; *n* = 293) participated in this study. Participants' mean age was 36.52 years, *SD* = 13.55; range = 18-95. The majority of participants 78.7% (*n* = 1063) were female, 19.8% (*n* = 267) were male and 0.7% (*n* = 10) identified as non-binary. Of the total sample, 78.3% (*n* = 1057) lived in Scotland and 21.7% (*n* = 293) in England. Most participants 71.6% (*n* = 967) were registered organ donors, 17.8% (*n* = 240) were not registered as donors and 10% (*n* = 135) of the sample were unsure of their donor status. A small percentage of respondents 0.6% (*n* =8) had actively registered not to donate their organs and opted-out of the organ donor register. Participants' demographic information and additional baseline donor characteristics are provided in Table 5.2 and Table 5.3.

5.4.2 Demographic Comparisons

A series of one-way ANOVAs and chi-squared tests were used to investigate differences in participants' baseline donor intentions, current donor registration status and anticipated donor choice under opt-out consent (opt-in, deemed consent, not sure and opt-out) between the four experimental arms: no significant differences were found, $p > 0.05$.

To further examine differences in demographic characteristics, ethnicity was first dichotomised into White or Other minority ethnic group, education into Higher (completion of a bachelor's degree) or Lower education, and gender dichotomised into Male or Female. Due to the inclusion of a prefer to self-describe response option within the question assessing religious beliefs, 51 respondents used the free-text entry box to self-describe their religion. Therefore, religious beliefs were categorised into, No religion, Christian, Dharmic (Buddhist, Hindu and Sikh) or Minority religion (e.g., Wiccan, Pagan, Druid). Prefer not to say responses were handled as missing data. No significant differences in gender, age, education, ethnicity, political or religious beliefs were found (p =.74, p =.80, p =.84, p = .39, p = .96, p = .06 respectively).

The secondary objective of this study was to investigate factors predictive of opt-out intentions, including government trust, NHS trust and trait reactance. However, the studies primary objective was to examine the impact of the experimentally manipulated messages on donor intentions and reactance. Therefore, exposure to these measure before the main experimental conditions may have had a priming effect. To avoid this, the measures were presented at the end of the study, after exposure to the newspaper conditions. To investigate potential measurement reactivity effects, a series of one-way ANOVAs were conducted to assess differences in participants trait reactance, NHS and government trust scores between the four experimental arms. No significant differences in all three measures across the groups were found (trait reactance $p = .24$, NHS trust $p = .78$, or government trust $p = .61$).

Table 5. 2. Participants' Demographic Characteristics

	Experimental Condition			
	1: Low Threat x Gain Frame (*n* = 335)	2: High Threat x Gain Frame (*n* = 336)	3: Low Threat x Loss Frame (*n* = 342)	4: High Threat x Loss Frame (*n* = 337)
Age M (*SD*)	36.65 (13.63)	35.89 (13.41)	36.66 (13.89)	36.87 (13.29)
Gender N (%)				
Female	263 (78.74%)	266 (79.17%)	274 (80.59%)	260 (77.38%)
Male	69 (20.66%)	69 (20.53%)	60 (17.65%)	69 (20.53%)
Non-binary	1 (0.30%)	0	3 (0.88%)	6 (1.79%)
Other[a]	1 (0.30%)	1 (0.30%)	3 (0.88%)	1 (0.30%)
Education N (%)				
Lower education	119 (35.52%)	128 (38.21%)	121 (35.38%)	126 (37.39%)
Higher education[b]	216 (64.47%)	207 (61.79%)	221 (64.62%)	211 (62.61%)
Religious Beliefs N (%)				
No religion	239 (71.34%)	205 (61.01%)	208 (60.82%)	192 (56.97%)
Agnostic	2 (0.60%)	1 (0.30%)	3 (0.88%)	2 (0.59%)
Christian	78 (23.28%)	103 (30.65%)	111 (32.46%)	113 (33.53%)
Buddhist	0	2 (0.60%)	3 (0.88%)	3 (0.89%)
Hindu	1 (0.30%)	2 (0.60%)	1 (0.29%)	3 (0.89%)
Muslim	2 (0.60%)	3 (0.89%)	1 (0.29%)	3 (0.89%)
Jewish	1 (0.30%)	2 (0.60%)	3 (0.88%)	2 (0.59%)
Prefer not to say/other	11 (3.28%)	16 (4.76%)	11 (3.22%)	16 (4.75%)
Ethnicity N (%)				
White	316 (94.33%)	320 (95.24%)	330 (96.77%)	319 (94.66%)
Asian or Asian British	8 (2.39%)	5 (1.49%)	3 (0.88%)	8 (2.37%)
Black, African or Caribbean	2 (0.60%)	2 (0.60%)	2 (0.59%)	2 (0.59%)
Mixed/multiple ethnic groups	7 (2.09%)	3 (0.89%)	2 (0.59%)	1 (0.30%)
Hispanic or Latino	0	1 (0.30%)	1 (0.29%)	5 (1.48%)
Prefer not to say/other	2 (0.60%)	5 (1.49%)	3 (0.88%)	2 (0.59%)

Note. [a] 4 participants preferred not to state their gender, the remaining 2 identified as female to male transgender and genderqueer. [b] Higher education was categorised as completion of a bachelor's degree.

Table 5. 3. Additional Baseline Donor Assessment

	Experimental Condition			
	1: Low Threat x Gain Frame (*n* = 335)	2: High Threat x Gain Frame (*n* = 336)	3: Low Threat x Loss Frame (*n* = 342)	4: High Threat x Loss Frame (*n* = 337)
Organ donor status N				
Registered donor	238 (71.04%)	245 (72.92%)	237 (69.30%)	247 (73.29%)
Not registered	61 (18.21%)	52 (15.48%)	68 (19.88%)	59 (17.51%)
Unsure	35 (10.45%)	36 (10.71%)	36 (10.55%)	28 (8.31%)
Opted-out[c]	1 (0.30%)	3 (0.89%)	1 (0.29%)	3 (0.89%)
Awareness of change N				
Yes	190 (56.72%)	171 (50.89%)	171 (50%)	172 (51.04%)
No	98 (29.25%)	117 (34.82%)	123 (35.96%)	129 (38.28%)
Not sure	47 (14.03%)	48 (14.28%)	48 (14.03%)	36 (10.68&)
Planned donor choice N				
Opt-in	252 (75.22%)	256 (76.19%)	254 (74.27%)	259 (77.31%)
Deemed consent	52 (15.52%)	46 (13.69%)	44 (12.86%)	39 (11.64%)
Not sure	20 (5.97%)	25 (7.44%)	27 (7.89%)	22 (6.57%)
Opt-out	11 (3.28%)	9 (2.68%)	17 (4.97%)	15 (4.48%)

Note. [c] The option to record your wishes not to be an organ donor has been offered under the current opt-in system since late 2015.

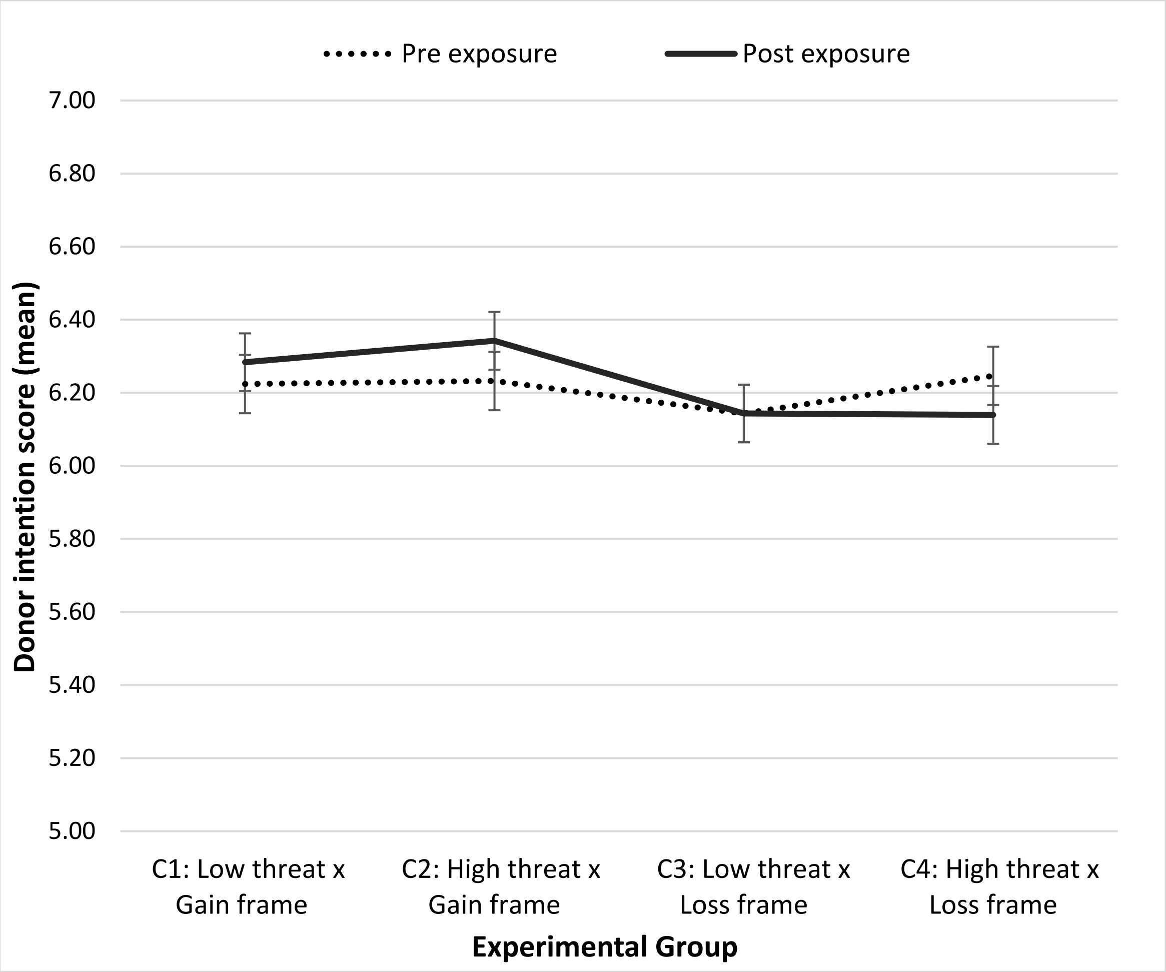
5.4.3 Planned Donor Decisions Following the Introduction of Opt-out Consent

Frequency counts were conducted to assess anticipated donor choice under the upcoming opt-out system. Most respondents plan to opt-in, 75.63% (*n* = 1021). Four response options were combined to represent the opt-in group: (1) participants who had formerly completed the opt-in process and plan to uphold this decision (*n* = 802), (2) individuals who had completed the opt-in process and plan to repeat this after the legislative change to reaffirm their views (*n* = 155), (3) participants who had not yet registered and plan to opt-in (*n* = 25) and lastly, those who were unsure if they were registered and plan to opt-in (*n* = 39). In total, 13.41% (*n* = 181) of participants plan to take no action and follow deemed consent, 3.85% (*n* = 52) plan to opt-out and 6.96% (*n* = 94) were unsure of their donor decision.

5.4.4 Hypothesis 1: The Effect of Language and Message Framing on Donor Intentions

To test for differences in donor intentions (pre and post) as a function of the four conditions, a 2 x 4 mixed-measures ANOVA was conducted. There was no significant main effect of group: *F*(3, 1346) = .726, *p* =.54; *r* = .04, or time: *F*(1, 1346) = .408, *p* =.52; *r* = .02. However, a significant group x time interaction was observed, *F*(3, 1346) = 3.57, *p* = .01; *r* =.09. Changes in intention over time and condition are shown in Figure 5.7.

Figure 5. 7. Mean Pre and Post Donor Intentions Across the Four Experimental Groups



Note. The y-axis has been inflated in order to better illustrate the group by time interaction. Error bars represent standard error.

The significant group x time interaction was then explored using simple main effects. This revealed differences in intention scores over time for participants exposed to Condition 2 and Condition 4. For participants who received Condition 2 (high threat x gain frame) intention significantly increased between baseline (*M* = 6.23, *SE* = .08) and post message exposure (*M* = 6.34, *SE* = .79), *F*(1,336) = 5.00, *p* = .03; *r* =.12. For participants exposed to Condition 4 (high threat x loss frame), donor intentions significantly decreased between baseline (*M* = 6.25, *SE* = .08) and post message exposure (*M* = 6.14, *SE* = .79), *F*(1, 336) = 4.22, *p* = .041; *r* =.11. No differences were found for participants exposed to Condition 1 (low threat x gain frame) or Condition 3 (low threat x loss frame).

5.4.5 Hypothesis 2: The Effect of Language and Message Framing on Reactance

To assess whether components of the language and framing manipulation influenced perceptions of threat to freedom, anger and counter-arguing, a series of 2-way between-group ANOVAs were conducted. Accordingly, the four conditions were grouped in relation to their respective language threat level (Condition 1 and 3: low threat) and (Condition 2 and 4: high threat) and framing variants (Condition 1 and 2: gain frame) and (Condition 3 and 4: loss frame). For all three reactance outcome measures, Levene's test indicated that homogeneity of variances was met, *p* >.05. Mean threat to freedom, anger and counter-arguing scores for each condition are provided in Table 5.4.

Threat to freedom: No interaction was found between threat level and framing on threat to freedom scores, *F*(1, 1346) = .37, *ns*. There was a significant main effect of threat level, in that participants reported significantly higher threat to freedom scores in response to the high threat language conditions (*M* = 2.26, *SD* = 1.34) in comparison to those who received the low threat conditions (*M* = 2.09, *SD* = 1.29), *F*(1, 1346) = 5.68, *p* = .02; *r* =.06.

Anger: No significant interaction effect was found between threat level and framing on anger scores, *F*(1, 1334) = .04, *ns*. A significant main effect of framing was found. This indicated that participants who received the loss frame conditions reported significantly higher anger scores (*M* = 1.99, *SD* = 1.22) in comparison to those who received the gain frame conditions (*M* = 1.82, *SD* = 1.13), *F*(1, 1334) = 7.01, *p* <.01; *r* =.10.

Counter-arguing: No significant interaction effect was found between threat level and framing on counter arguing scores, *F*(1, 1306) = .03, *ns*. There was also no significant main effect of threat level or framing manipulation.

Table 5. 4. Mean Reactance, Credibility and Readability Scores Across Each Condition

	1: Low Threat x Gain Frame (*n* = 335)	2: High Threat x Gain Frame (*n* = 336)	3: Low Threat x Loss Frame (*n* = 342)	4: High Threat x Loss Frame (*n* = 337)
Threat to Freedom M *(SD)*	2.03 (1.28)	2.25 (1.33)	2.15 (1.31)	2.28 (1.36)
Anger M *(SD)*	1.81 (1.10)	1.82 (1.16)	2.00 (1.22)	1.98 (1.22)
Counter-arguing M *(SD)*	2.44 (1.00)	2.41 (1.07)	2.53 (1.07)	2.52 (1.10)
Message Readability M *(SD)*	6.16 (.85)	6.11 (.92)	6.19 (.76)	6.06 (.84)
Message Credibility M *(SD)*	5.71 (.90)	5.57 (.90)	5.60 (.94)	5.48 (.94)

5.4.6 Message Readability and Credibility

To investigate differences in message readability and credibility, a series of 2-way between-group ANOVAs were conducted. As described above, the four conditions were grouped in relation to their respective language threat and framing manipulation. Means and standard deviations of credibility and readability scores are provided in Table 5.4.

Readability: No interaction effect was found between language threat level and message framing on readability scores, *F*(1, 1285) = .71, *ns*. There was also no main effect of threat level or framing manipulation. On average, the conditions were considered *easy* to read (*M* = 6.13, *SD* = 0.84).

Credibility: No interaction between language threat level and framing on message credibility was found, *F*(1, 1285) = .03, *ns.* There was a significant main effect of threat manipulation, in that participants exposed to the high threat conditions reported the message to be significantly less credible (*M* = 5.52, *SD* = .92) than those who received the low threat conditions (*M* = 5.65, *SD* = .92), *F*(1, 1285) = 6.5, *p* =.01; *r* =.10

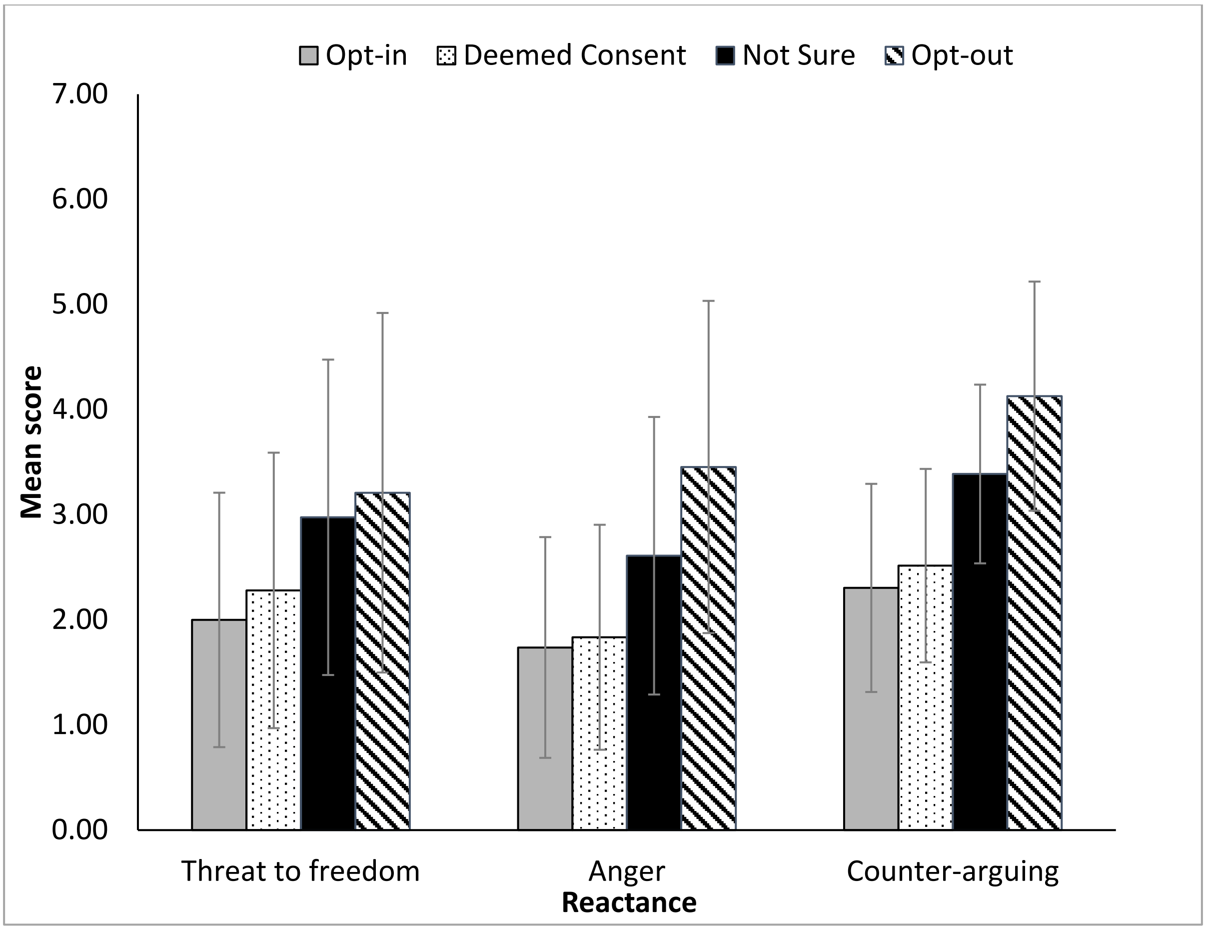
5.4.7 Hypothesis 3: Reactance in Individuals Who Plan to Opt-out of Organ Donation

Previous findings within this thesis have found that people who plan to opt-out demonstrate heightened negative emotional barriers towards organ donation. Therefore, it was hypothesised that opt-out respondents would report heightened psychological reactance in response to the message conditions. To test this, a 4 x 3 MANOVA was conducted. Planned donor choice under opt-out consent (opt-in, deemed consent, unsure and opt-out) was entered as the independent variable, and in line with reactance literature, threat to freedom, anger and counter-arguing scores were entered as dependent variables. A significant difference was found between the groups on the combined dependent variables $F(9, 3912) = 28.35, p < .001$; Pillai's V = .184; $r = .25$. Mean reactance scores across the groups are graphically represented in Figure 5.8. Means and standard deviations for each donor choice are available in Table 5.5.

Table 5. 5. Means Reactance Scores Across the Four Anticipated Donor Groups

	Opt-in (*n* = 993)	Deemed consent (*n* = 175)	Not sure (*n* = 91)	Opt-out (*n* = 49)
Treat to freedom M *(SD)*	2.00 (*1.21*)	2.28 (*1.31*)	2.98 (*1.50*)	3.21 (*1.71*)
Anger M *(SD)*	1.74 (*1.05*)	1.83 (*1.07*)	2.61 (*1.32*)	3.45 (*1.58*)
Counter-arguing M *(SD)*	2.30 (*0.99*)	2.52 (*0.92*)	3.39 (*0.85*)	4.13 (*1.09*)

Figure 5. 8. Mean Reactance Scores Across the Four Anticipated Donor Choice Groups.



Note. Error bars represent standard deviation.

Follow-up univariate ANOVAs were conducted to determine the contributing role of each reactance component. Group-level differences between each donor choice were examined using a Games-Howell *post-hoc* test, used to correct a violation of homogeneity of variances within two of the dependent variables.

Threat to freedom: A significant difference in threat to freedom scores between the donor groups was found, F (3, 1344) = 30.88, p <.001; r =.24. *Post-hoc* analysis revealed that participants who plan to opt-out and those who are unsure of their planned donor decision, reported significantly higher threat to freedom scores in response to the message than those who plan to opt-in or follow deemed consent, at p <.01. No difference in scores between the opt-out and not sure group were found. Higher scores indicate the message to have evoked a greater sense of threat to one's freedom.

Anger: A one-way ANOVA revealed significant differences in anger scores between the four donor groups *F* (3, 1332) = 52.55, *p* <.001; *r* =.33. *Post-hoc* exploration indicated significant differences across all group comparisons. Both, respondents who plan to opt-out and those who are not sure, reported significantly higher anger in response to the message than people who plan to opt-in or follow deemed consent, at *p* <.001. In addition, the opt-out group also reported significantly higher anger scores than those in the not sure group, *p* = .01.

Counter-arguing: Significant differences in counter-arguing scores were found between the donor groups *F* (3, 1304) = 84.33, *p* <.001; *r* =.40. *Post-hoc* analysis revealed differences across all group comparisons. Highest counter-arguing in response to the message was found in those who plan to opt-out, in comparison to those who plan to actively opt-in, follow deemed consent and those who are unsure. These differences were significant at *p* <.001.

5.4.8 Reactance and Awareness of Opt-out Legislation

As almost half of our sample (*n* = 622) were unaware of the legislative change, a supplementary one-way MANOVA was conducted to investigate differences in reactance based on respondents self-reported awareness of the move to opt-out legislation. Awareness of the legislative change (yes and no/unsure) was entered as the independent variable, with the reactance variables, threat to freedom, anger and counter-arguing entered as dependent variables. A significant difference between the groups on the combined dependent variables was observed *F* (3, 1306) = 3.96, *p* =.01; Pillai's V = .009; *r* =.09. Univariate ANOVAs revealed significantly higher scores within each reactance component for individuals who reported being either not aware or unsure of the legislative change, all at *p* <.01. Mean reactance scores across the groups are available in Table 5.6.

Table 5. 6. Mean Reactance Scores Across Participants Self-Reported Awareness of Opt-out Legislation

	Awareness of legislation		Results
	Yes ($n = 688$)	No/unsure ($n = 622$)	
Treat to freedom M *(SD)*	2.05 (*1.27*)	2.26 (*1.34*)	$F(1, 1308) = 8.46, p = .004; r = .09$
Anger M *(SD)*	1.79 (*1.13*)	1.98 (*1.20*)	$F(1, 1308) = 8.83, p = .003; r = .09$
Counter-arguing M *(SD)*	2.40 (*1.08*)	2.57 (*1.03*)	$F(1, 1308) = 7.94, p = .005; r = .09$

5.4.9 Secondary Objective - Hypothesis 4: Trait Reactance in Opt-out Respondents

To assess whether individuals who plan to opt-out of organ donation, had higher dispositional reactance, a one-way ANOVA with (trait reactance) x (anticipated donor choice) was conducted. This revealed a significant difference in levels of trait reactance between the groups $F(3, 1271) = 9.91, p < .001; r = .14$. Follow up Tukey *post-hoc* tests indicated that trait reactance scores (an increased predisposition to reactance-based responses) were significantly higher in people who plan to opt-out, in comparison to participants who plan to opt-in or follow deemed consent, at $p < .01$.

5.4.10 Predictors of Donor Status Under Opt-out Consent.

A binomial logistic regression was conducted to determine the effect of age, gender, political views, religious beliefs, registered donor status, trait reactance, NHS trust and government trust on the likelihood of participants opting out of organ donation when opt-out legislation is introduced. Within the anticipated donor choice group (opt-in, deemed consent, not sure and opt-out), a dummy variable was generated to dichotomise participants planned donor choice into donor (opt-in and deemed consent) or non-donor (opt-out). The Hosmer-Lemeshow goodness-of-fit was not significant ($p = .89$) indicating the model to be a good fit. The logistic regression model was statistically significant, $\chi 2$ (10) = 109.25, $p < .001$. The model explained 53% (Nagelkerke R^2) of the variance in the decision to opt-out of organ donation and correctly classified 96.7% of overall cases. The positive predictive value (the percentage of correctly predicted opt-out respondents) was 42.86%, and the negative predictive value (the percentage of correct predicted donor respondents) was 97.16%. Of the eight predictor variables, two were statistically significant (current donor status, and government trust). The likelihood of opting-out of organ donation under the new donor system was predicted by lower trust in the government, and by participants current donor registration status (those who are not currently registered as organ donors are more likely to opt-out).

Table 5. 7. Regression Coefficients.

	B	*p*	Odds Ratio	95% CI for Odds Ratio	
				Lower	Upper
Age	.01	.52	1.01	.98	1.04
Gender	-.95	.12	.39	.12	1.26
Political Scale	.42	.057	1.52	.99	2.33
Religion*		.49			
Religion 1	.03	.96	1.03	.33	3.21
Religion 2	1.39	.36	4.02	.21	77.42
Religion 3	1.02	.20	2.76	.58	13.06
Registered Donor	5.25	.00	191.12	24.55	1487.66
NHS Trust	.08	.82	1.09	.53	2.27
Government Trust	-.73	.04	.48	.24	.96
Trait Reactance	.72	.11	2.06	.85	5.04

Note. Ethnicity was not included in the regression analysis as just 32 cases identified as being of non-white ethnicity (non-white ethnicities were represented across 11 different categories). *Religion variable entered as nominal data across four categories: No religion, Christian, Dharmic (Buddhist, Hindu and Sikh) or Other minority religion.

5.5 Discussion

Existing health communication literature has predominantly focused on evaluating the utility of message variants and framing manipulations within appeals designed to increase the number of organ donor registrants (Quick, 2012; Quick et al., 2011; Reinhart et al., 2007). However, many nations across the world are now implementing opt-out consent. Thus, the act of registering as a donor is no longer essential to indicate consent for organ donation, as accordingly, all eligible adults will be automatically considered to have agreed to be a potential organ donor in the event of their death. If an individual does not want to be an organ donor, they should record this by opting out of organ donation.

In the UK, opt-out legislation is currently operational in England and Wales, and is, following postponement due to the Covid-19 pandemic, scheduled for implementation in Scotland on 26 March 2021. In line with this substantial change in policy, national awareness campaigns are ongoing to ensure widespread public awareness of opt-out consent. Although evidence demonstrates the content of organ donation campaigns to play an important role in donor attitudes, intentions and decision-making, there is currently no research investigating this in the context of opt-out legislation. This study is novel and builds on the existing opt-in evidence base by exploring the contribution of language and framing manipulations within opt-out campaigns on both, intention to donate organs and on the development of reactance.

5.5.1 The Effect of Language and Message Framing on Donor Intentions

Within the current study, the impact of two message features, language threat level and message framing were explored. It was predicted that the organ donation campaign containing high threat language and loss frame component would act to reduce intention to donate, in comparison to messages containing low threat, autonomy-supportive language and gain frame components. The findings provide support for this hypothesis, in that the application of freedom threatening language and loss-frame components significantly reduced organ donor intentions. These findings are consistent with existing health communication research which reports the use of high controlling language within promotional health messages to decrease intentions towards the advocated behaviour (Dillard & Shen, 2005; Miller et al., 2007).

Notably, these results highlight the particularly potent combination of high threat language and loss frame components on one’s donor intentions. Indeed, exploration of the language and framing manipulations and their impact on participants’ responses to the message, revealed that the two high threat language conditions induced significantly higher perceptions of threat to freedom than the messages which used low threat language. With regards to framing, participants exposed to the loss frame manipulation, which detailed the lives lost annually as a consequence of the donor shortage, reported significantly higher levels of anger compared to those who received the gain frame manipulation. Therefore, this may have induced an unintended negative emotional response. Existing evidence offers support for this interpretation, reporting loss frame messages to evoke guilt and increased perceptions of freedom threat due to their implicitly forceful nature (Quick et al., 2015; Reinhart et al., 2007). It is also interesting to note that within this study, high threat messages were perceived to be significantly less credible than low threat, autonomy-supportive messages. This effect has also been described within extant literature on physical activity campaigns, whereby the use of high controlling language was reported to significantly lower perceptions of credibility, characterised as decreased message expertise, trustworthiness and sociability (Miller et al., 2007). As credibility plays an important role in message acceptance, particularly within campaigns related to health decision-making, careful consideration into the use of high threat language is warranted (Hocevar et al., 2017). Collectively, these results advocate for the avoidance of overtly high threat language and loss frame statements, in order to minimise the number of potential opt-out registrations.

Though the high threat and loss frame condition acted to significantly reduce intentions to donate, the application of high threat language coupled with gain frame messaging was found to significantly increase donor intentions. Gain frame manipulations, which highlight the positive impact of organ donation, may serve to buffer the negative effects of high threat language. Further studies testing the utility of such framing manipulations are warranted. Across the aforementioned results, it is challenging to determine why the low threat autonomy-supportive messages had no impact on donor intentions. There is some evidence to suggest that low-threat messages can be interpreted as somewhat ambiguous and difficult to understand in comparison to more explicit messages which use high-threat or high-controlling language (Miller et al., 2007). Therefore, a plausible explanation for this finding may be that the low threat messages were comparatively unclear. Future research is required to investigate this.

It is important to acknowledge that the degree of threat manipulation employed in the present study was relatively subtle in comparison to existing health communication research (Dillard & Shen, 2005; Quick et al., 2011). The following excerpts depict high threat language that successfully induced perceptions of threat to freedom within experimental manipulations. In both examples, the use of language could be considered as overtly authoritarian, and somewhat accusatory; "*No other conclusion makes any sense. Stop the denial. There is a problem and you have to be part of the solution.*" and "*Stop the denial! Given the need for organ donors, a reasonable person would consent to be an organ donor*" (Dillard & Shen, 2005; Quick et al., 2011). The application of such language would not be appropriate for routine use in public health campaigns as they run the risk of eliciting reactance. Comparatively, the high threat manipulation within the current study was developed to realistically reflect the type of language used in existing organ donation press releases, for example, "*Don't want your organs to be donated? You WILL have to opt out as ministers back law change to help transplant patients*" https://www.dailymail.co.uk/news/article-5428997/You-opt-ministers-law-change.html (Brown, 2018). This has important implications for health communication literature and indicates that even subtle manipulations in language, designed in line with existing communication campaigns has the potential to induce a freedom threat and psychological reactance.

5.5.2 Reactance in Individuals Who Plan to Opt-out of Organ Donation

Within this study, reactance was explored in the context of both, a state response to persuasive messaging and as a trait construct. The findings demonstrate that participants who plan to opt-out, and those who are unsure of their anticipated donor decision, are at risk of experiencing a heightened reactant response to opt-out organ donation campaigns. In sum, both groups appraised the opt-out messages to cause a significantly greater threat to their freedom and reported heightened anger and counter-arguing that those who plan to donate their organs by opting in or via deemed consent. The results also confirm that individuals with higher trait reactance, who have an inflated desire for self-determination and are sensitive to impingements on their freedom, are more inclined to opt-out of organ donation. Previous literature supports this view, reporting high trait reactance to be an important factor in health-related decision making within the context of vaccination hesitancy (Hornsey et al., 2018). These results ultimately reinforce and triangulate the existing qualitative findings within Chapters 3 and 4 of this thesis, whereby participants perceived the upcoming legislative change as a threat to their individual responsibility.

5.5.3 Restoration of Freedom

In acknowledgement of the harmful impact of reactance within communication campaigns, a number of studies have explored the utility of restoration postscript messages as a method of freedom restoration (Bessarabova et al., 2013; Bessarabova et al., 2017; Miller et al., 2007; Quick et al., 2015). In short, restoration postscripts are designed to mitigate the effects of reactance by reaffirming the reader's autonomy following exposure to a freedom threatening message (Miller et al., 2007). Within the context of the current chapter, an appropriate restoration postscript would be to emphasise that readers still have a choice regarding the decision to be, or not to be an organ donor. However, research examining restoration postscripts within health communication literature have reported inconsistent results. For example, though the application of restoration postscript messages within exercise campaigns was found to reduce perceptions of threat to freedom (Miller et al., 2007), no such effect was reported when applying postscript messages to campaigns promoting organ donation registration (Quick et al., 2015). In the context of recycling communication campaigns, restoration postscripts have been effective at reducing reactance, increasing positive attitudes and intentions (Bessarabova et al., 2013). Notably, this effect was only evident within the high threat language condition. Thus, the inclusion of a restoration postscript message may present a relatively straightforward method of reducing reactance and increasing intentions within campaigns for opt-out consent.

5.5.4 The Factors Influencing Opt-out Decisions

The present study also investigated the factors predictive of the decision to opt-out of organ donation. A number of review articles have identified proximal predictive factors that influence both, donor intentions and verified organ donor registrations in countries with opt-in policies, namely; higher education, altruism, religious beliefs, and increased knowledge of organ donation (Falomir-Pichastor et al., 2013; Nijkamp et al., 2008). However, few have investigated the profile of non-donors. In the current study, the likelihood of opting out of organ donation was predicted by lower trust in the government and by participants' current donor registration status, in that, those who are not currently registered as organ donors are more likely to opt-out. Although the demographic and psychological profile of recorded opt-out respondents in England and Wales is as yet unknown, the current findings provide meaningful insights into the characteristics of individuals who report the behavioural intention to opt-out of organ donation.

5.5.5 Implications and Future Directions

This study demonstrates the detrimental impact of a relatively subtle language and framing manipulation applied to opt-out organ donation messages, on perceived threat to freedom, anger, credibility and donor intentions. Future research investigating the most effective way of communicating this legislative change to the public, is critical to mitigate reactance and promote informed decision-making. When communicating the change in legislation, collaboration with UK newspapers and news sources is important to ensure sensationalist representations of opt-out consent are avoided, and the legislation is communicated in an appropriate way. Ideally, this could be achieved through engagement between the government and the press to facilitate the development of specific practices to apply when promoting this sensitive legislative change. In line with this, future studies examining existing newspaper articles describing the transition to opt-out consent, and their role in eliciting reactance-based responses is warranted. Existing research has also endorsed the use of restoration postscript messages as a method of alleviating psychological reactance and/or increasing behavioural intentions within the communication literature (Bessarabova et al., 2013; Bessarabova et al., 2017; Miller et al., 2007). Future studies examining these approaches within the context of opt-out organ donation campaigns are required.

5.5.6 Limitations

A number of limitations should be considered. First, the newspaper conditions were designed by the author of this thesis, and though informed by existing organ donation press releases, this may to some degree limit the ecological validity of the study. However, designing the messages to emulate a newspaper article, rather than presenting print messages alone, may go some way towards mitigating this. Moreover, this enabled the examination of multiple message variants. A further limitation concerns the second framing manipulation applied to the description of the Welsh opt-out system. Accordingly, in the loss frame manipulation, opt-out consent was described to have *"a small increase in the number of transplants"* and the gain frame, *"a promising increase in the number of transplants."*. It may be argued that this does not align fully with traditional loss framing interventions, whereby readers are presented with overtly negative outcomes e.g., "*400 people died waiting for a lifesaving transplant*". The second framing manipulation in the current chapter could therefore be classified as more of a neutral framing manipulation. However, this decision was made in accordance with existing descriptors of opt-out consent that feature within the public domain.

In addition, a component of the study outcome measures involved participants' completing a measure of trust in the NHS and the government. The lack of specificity in the wording of the government trust measure for Scottish participants', may have led to ambiguity with regards to which specific governing body the outcome measure referred to. This makes it challenging to determine whether the findings denote trust in the Scottish Government or the UK Government. It is also important to note that participants completed trait measures of reactance, NHS and government trust after exposure to the experimentally manipulated messages. As the primary focus of this study was to examine the impact of the message manipulations, this decision was taken in an attempt to minimise a priming effect following completion of the trait reactance measure, e.g., *"I become angry when my freedom of choice is restricted"* and for economy of time. While the analysis indicated no evidence of measurement reactivity, the study would benefit from replication as two independent studies. Finally, a large proportion of our respondents were university educated, white, females. As such, this may limit the generalisability of the findings.

5.6 Conclusions

This chapter has evidenced the detrimental impact of high threat language and loss frame messaging applied within opt-out organ donation campaigns, on donor intentions. Emphasising the benefits of organ donation via gain frame messaging within campaigns that use high threat language, increased intentions towards organ donation. Further studies are required to examine if this is a robust and replicable finding. If it is, this type of message framing could be considered for use in future organ donation public health campaigns. In sum, careful consideration into the way this sensitive legislative change is communicated is imperative to minimise perceived threats to freedom, anger, and to reduce the number of opt-out respondents.

Chapter 6: The factors influencing family consent for organ donation: A systematic review and thematic synthesis

Preface

At the beginning of this PhD, a scoping search identified the opportunity to conduct an update of a well-known systematic review, commissioned by the UK Organ Donation Taskforce which investigated public attitudes towards opt-out consent legislation (Rithalia et al., 2009). However, shortly before the Protocol for this proposed review was submitted to PROSPERO in autumn 2018, an update of the Rithalia et al. (2009) review was published (Molina-Pérez et al., 2018). At this stage of the PhD, emergent evidence had highlighted a concerning reduction in rates of family consent following the implementation of the opt-out system in Wales. This, coupled with evidence that the efficiency of opt-out legislation is contingent upon high rates of family consent, emphasised the importance of systematically examining the factors that influence family decision-making (Bilgel, 2012). Altering the focus of the review to family consent also complements the findings from Chapter 3, which indicated that the decision to actively register as a donor under the proposed opt-out system was considered as a method of preventing unwarranted family interference in one’s donor decisions.

6.1 Abstract

Background: Family or next of kin refusal for organ donation is a central factor that limits the potential for organ transplantation across the world. The primary aim of this qualitative systematic review was to provide an updated overview of the factors that influence family or next of kin decision-making in nations with both opt-in and opt-out consent systems.

Methods: Following systematic searching of electronic databases (Medline, Embase, CINAHL, PsycINFO and Web of Science), 22 qualitative articles which explored the factors influencing consent and authorisation for posthumous organ donation, published between 2012-2020, were identified. The articles were quality assessed using The Critical Appraisal Skills Programme (CASP) tool and analysed using thematic synthesis.

Results: Across 22 studies, the perspectives of over 600 bereaved family members were synthesised to provide insights into the factors influencing family decision-making for posthumous organ donation. Six overarching themes were found to play a key role in consent-related outcomes: (1) The will of the deceased; (2) the meaning attributed to death; (3) the paradox of brain death; (4) preservation of bodily integrity; (5) an intricate balance of time, and (6) the need for compassionate care.

Discussion: Acting in accordance with the deceased's donor decision emerged as the most salient factor influencing consent-related outcomes. Irrespective of donation policy, the development of evidenced based strategies to encourage members of the public to share their donor decisions are crucial. Future research would also benefit from examining the optimal ways of communicating the nebulous concept of brainstem death to donor families in order to minimise uncertainty and optimise rates of consent. The complex relationship between religion and organ donation emerged as an important finding. Given the serious shortage of donors for individuals within minority ethnic groups, developing a clearer understanding of religious deterrents and encouraging engagement from faith leaders is a critically important area for future study.

6.2 Introduction

Despite a steady increase in global transplant activity, there remains a serious shortage of organ donors to satisfy the need for organ transplantation (Global Observatory on Donation and Transplantation, 2020). A key contributing factor in this shortage is family refusal to provide consent for organ donation. In most nations around the world, an individual can formally express the decision to donate their organs after death by either, recording this on a national register (for example, the UK organ donor register) or verbally expressing their donor decision to an appointed individual. A growing number of nations have implemented, or plan to implement opt-out legislation, whereby consent for donation is automatically considered for eligible adults unless an active opt-out decision is recorded. As discussed in Chapter 1, section 1.4.2, two variants of opt-out consent systems exist: a 'hard' or 'soft' opt-out system. From an international perspective, the degree of decision-making power that family members or next of kin hold differs in line with each nation's organ donor policy (Shaw et al., 2017). Broadly, under 'soft' opt-out policies, bereaved families play an active role in the decision-making process and are consulted to approve the request for organ donation. It is during this incredibly distressing time that a considerable number of families refuse to consent for the donation of their loved one's organs (Domínguez-Gil & Matesanz, 2018). It should be acknowledged that, while bereaved families do not have the legal authority to override a loved one's donor decision, organ retrieval would not proceed if family members refused (NHS Blood and Transplant, 2013a). The importance of family consent is echoed internationally, with 21 of the 25 nations with opt-out policies in this study reported to allow family members to override their loved one's recorded decision (Rosenblum et al., 2012).

6.2.1 Rates of Family Consent Across the World

Improving the rate of family consent is of particular importance in the context of UK organ donation, where such rates are relatively low at 67% (NHS Blood and Transplant, 2020a). This is significantly lower than rates of consent in other European nations including, Belgium with 76% and Hungary, Malta, Poland, Spain and Slovakia all recording upwards of an 86% consent for organ donation (Domínguez-Gil & Matesanz, 2018). Accordingly, increasing family consent was identified as the core objective of the seven-year UK wide organ donation strategy, ‘Taking Organ Transplantation to 2020’ (NHS Blood and Transplant, 2013c). Whilst overall family consent rates have moderately improved since the strategies recommendations were implemented, rising from 57% in 2013, to 68% in 2019/20; the strategies principal objective of increasing consent rates to 80% by 2020 has not been achieved (NHS Blood and Transplant, 2013b, 2020a). In sum, the UK continues to have one of the highest instances of family refusal in the Western world (Domínguez-Gil & Matesanz, 2018).

A particular challenge to obtaining family consent appears to be uncertainty regarding the deceased’s donor wishes before death (Anker & Feeley, 2010; Vincent & Logan, 2012). Indeed, figures from the UK potential donor audit confirm this finding, with families refusing consent for organ donation in almost 50% of instances where the deceased’s donor decision was not known by the family. When the deceased’s donor wishes are known, typically via a recorded decision on the UK donor register, consent markedly increases to 91% (NHS Blood and Transplant, 2020a). While encouraging individuals to actively record their donor wishes goes some way towards increasing rates of consent, between 2019 and 2020, despite knowing their loved one was a registered donor, 109 families actively overruled the deceased’s decision and refused consent for organ donation.(NHS Blood and Transplant, 2020a) Concerningly, the proportion of family members overriding their loved one’s donor decision have increased by 38% in the last year. Given that each donor has the potential to save or transform the lives of up to nine others, family refusals and overrides represent a substantial number of missed transplant opportunities (NHS Blood and Transplant, 2019c, 2020a).

6.2.2 Existing Research on Family Consent

Several studies have sought to investigate the factors that contribute towards family refusals. The request to donate a loved one’s organs comes at an incredibly emotional and distressing time, therefore, it is understandable that emotional conflict over the decision has been described throughout the existing literature as a key barrier to securing consent (Sque et al., 2008; Vincent & Logan, 2012). Practical limitations during the donation request have also been identified to influence rates of consent, including the availability of specialist organ donation clinical staff, and the timing, delivery and setting of the donation request (Simpkin et al., 2009; Vincent & Logan, 2012).

Although a number of reviews have previously examined family consent for organ donation, a search of the existing literature identified the opportunity to contribute new knowledge. For example, existing reviews have focused on quantitative literature to identify modifiable factors associated with refusal (Simpkin et al., 2009). Other studies have provided a mixed methods integrative review of both, the empirical qualitative and quantitative literature (Walker et al., 2013). A similar review from de Groot and colleagues (2012) also synthesised quantitative and qualitative literature, however, their review included empirical, practical and theoretical literature (de Groot et al., 2012). A small number of exclusively qualitative review articles have been published, including a recent critical literature review from Miller & Breakwell (2018) which focused on primary qualitative literature from 1996-2008 within a UK context, and an international synthesis of the qualitative literature which aimed to provide a broad understanding of donor families experiences and attitudes towards organ donation (Miller & Breakwell, 2018; Ralph et al., 2014). However, of the aforesaid qualitative reviews, the most up to date search included literature published between 1987 and 2012. Therefore, this presented an opportunity to provide a contemporary international, qualitative review from the year 2012 onwards.

6.2.3 The Impact of Opt-out Legislation on Family Consent Rates

It is important to acknowledge that a number of nations have recently implemented opt-out consent legislation as an approach to increase the supply of organs for transplantation. This change in policy to opt-out consent has also been endorsed as a means of improving rates of family consent (UK Government, 2018b). The reasoning behind this is that most adults report favourable attitudes and intentions towards organ donation, yet only the minority actively register this decision. Given that a crucial deterrent for families is uncertainty concerning the deceased’s donor wishes, an opt-out system alters one’s default donor decision to consent. In turn, the absence of a recorded opt-out decision should now be indicative of support for organ donation and thus, may make it easier for family members to proceed with donation.

However, obtaining family consent remains a substantial challenge in nations with opt-out policies. Indeed, a number of countries with opt-out systems report substantially higher instances of family refusal and lower rates of donation than those who operate under explicit consent or ‘opt-in’ systems (Domínguez-Gil & Matesanz, 2018). There is also evidence to suggest that sustaining rates of family consent is particularly challenging immediately after the implementation of opt-out laws. For example, the rate of family refusal following the enactment of opt-out legislation in Wales increased by 50%. Though recent evidence has shown improvements in consent and rates of donation, it has been acknowledged that this cannot be credited to opt-out legislation alone, and that it may be due to a collective effect of other interventions applied during the transition (for example, a nationwide communications campaign focused on encouraging family consent) (Madden et al., 2020). Existing research supports this interpretation, reporting the success of opt-out legislation to be highly dependent on rates of family consent (Bilgel, 2012). In sum, this suggests that irrespective of donor consent policy (opt-in or opt-out), family refusal plays a critical role in the worldwide organ donor shortage. As such, investigating the factors influencing decision-making during this highly emotive time is crucial.

6.2.4 The Current Review

The current review will contribute to the existing evidence base by providing an up to date, international perspective of the factors that influence family decision-making in nations with both opt-in and opt-out consent systems. Given the emotive nature of the review topic, the decision was made to focus solely on synthesising qualitative research articles. A qualitative synthesis was deemed more appropriate to facilitate in-depth interpretations into the factors influencing consent-related decisions, whilst remaining grounded in the authentic perspectives of bereaved family members. To that end, the objective of this systematic review was to examine the factors that play a role in the decision-making of families and next of kin who were approached to authorise consent for posthumous organ donation.

Review question: What are the factors that influence family or next of kin decisions to consent or refuse to consent for organ donation?

6.3 Methodology

The protocol for this review was registered in June 2020 on the International Prospective Register of Systematic Reviews (PROSPERO), ID: CRD42020185848. Protocol available at: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020185848

In May 2019, prior to beginning this review, the primary author undertook a series of systematic review training courses facilitated by the York Health Economics Consortium (YHEC).

6.3.1 Reporting Guidelines

This systematic review and thematic synthesis is reported in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (Tong et al., 2012). The ENTREQ guidelines were developed in 2012 to promote comprehensive and transparent reporting of qualitative systematic reviews. The ENTREQ comprises of a 21-item checklist grouped in accordance with five core domains: introduction, methodology, literature search and selection, appraisal, and synthesis of findings (for the completed 21-item checklist, see Appendix 22).

6.3.2 Eligibility Criteria

Broadly, the review included studies that explored the factors influencing consent and authorisation for posthumous organ donation among families of potential organ donors. The SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation and Research Type) was used for the formulation of the review question and search parameters (see Table 6.1) (Cooke et al., 2012). This tool was selected due to its suitability for use in qualitative reviews that largely encompass no intervention or comparison as stipulated within existing quantitative search tools, e.g., the PICO tool (population/problem, intervention/exposure, comparison, and outcome).

Sample - The population of interest includes family members who were approached to give consent or authorisation for the posthumous donation of a loved one's organs. Family members in this context will include bereaved relatives, next of kin and any appointed individual with the appropriate authority, who were approached to make a decision regarding the posthumous donation of organs from an individual identified as a potential organ donor.

Phenomenon of Interest - The factors influencing organ donor decisions (consent or refusal) from family members who were approached to provide consent for the posthumous donation of a deceased loved one's organs.

Design - Studies conducted using any qualitative methodological approach, including qualitative interviews, focus groups, observations or qualitative questionnaires were eligible for inclusion. To ensure relevant information was not omitted from this review, all analytic methods were eligible for inclusion, provided descriptive qualitative data pertaining to family decision-making for organ donation was included.

Evaluation - Studies with a core focus on exploring the factors that influence consent outcomes for organ donation were included in this review. Qualitative studies which did not directly address this research question, but which focused on the overall experience, beliefs, perceptions or attitudes of family members in relation to the organ donation experience, were also considered for inclusion if data on consent-related factors were included as part of the study findings.

Research Type - Peer-reviewed qualitative studies. Mixed-methods research that included qualitative data on family decision-making for organ donation were also considered for inclusion.

Table 6. 1. SPIDER Criteria Used for Inclusion and Exclusion

	Inclusion	**Exclusion**
Sample	Bereaved relatives, next of kin, and/or any appointed individuals who were approached to provide consent or authorisation for the posthumous donation of a relevant other's organs (regardless of consent outcome).	Studies focusing on the perspective of healthcare professionals, for example, nurses, doctors and organ procurement coordinators.
Phenomenon of Interest	Family consent or refusal to consent for posthumous organ donation.	Family consent or refusal to consent for paediatric organ donation, or corneal donation.
Design	Studies using any qualitative data collection methodology, for example: interviews, focus group discussions, observations and qualitative questionnaires. Any qualitative analytic method will be eligible for inclusion, for example thematic analysis, content analysis, interpretative phenomenological analysis (IPA), grounded theory, discourse analysis. Studies without a recognised qualitative analytic method but which report data in a qualitative manner may be included.	Hypothetical studies, for example, studies which use vignettes or simulations about organ donation decision making and ask people to imagine they had lost a family member.
Evaluation	The factors influencing family decision making in relation to consent/authorisation or refusal for posthumous organ donation.	
Research Type	Peer-reviewed qualitative research articles or mixed-methods research articles with a qualitative component in relation to family decision making. Articles published in English from the year 2012 onwards.	Quantitative research articles, RCT's, policy documents, audits, editorials, opinion pieces, case studies, theses, and review articles (meta-analysis, systematic review, narrative reviews).

6.3.3 Data Sources

A specialist health sciences subject librarian was consulted to advise on the appropriate databases to be searched and on the development and refinement of the review search strategy. The following electronic databases were systematically searched on 27 April 2020; Medline on Ovid (1946 - present), EMBASE on Ovid (1947- present), Cumulative Index of

Nursing and Allied Health Literature (CINAHL) on EBSCO, (1982 - present), PsycINFO on EBSCO (1887 - present) and Web of Science Core Collection (1900 - present). The databases Medline, EMBASE and CINAHL were selected due to their breadth and comprehensive coverage of allied healthcare, medical and nursing literature. PsycINFO and Web of Science were selected as general cross disciplinary psychological and scientific literature databases. In addition to electronic database searching, a series of supplementary manual searches were conducted to identify additional eligible articles. A literature search was conducted using Google Scholar and the reference lists of existing reviews which broadly examined organ donation consent-related factors, or the family experiences of organ donation, were reviewed. Lastly, the reference lists of all eligible full-text articles were manually searched.

6.3.4 Search Strategy

A preliminary scoping search of organ donation literature within each electronic bibliographic database was conducted to identify the appropriate medical subject headings (MeSH), keywords and additional free-text search terms to implement within the search strategy. This iterative process was conducted to ensure optimal search terms were included within each of the five databases. A three-concept search strategy which included the domains of: (1) organ donation, (2) family members and, (3) decision-making was subsequently designed. The search strategy for Medline Ovid is presented in Table 6.2. Search lines 1-10 were used to identify records pertaining to the phenomenon of interest, posthumous organ donation. Lines 12-15 of the search strategy were applied to capture the review sample of bereaved family members or next of kin. Lines 17-22 were then used to capture the concept of decision-making.

Following a conversation with Julie Glanville (a specialist information retrieval researcher) while attending systematic review training from the York Health Economics Consortium, the decision was made to omit concepts within the search strategy pertaining to specific qualitative study designs (e.g., qualitative interviews, focus groups). Given the niche topic area, a four-concept search strategy was considered too restrictive and may have resulted in the omission of potentially relevant studies. Rather, a more inclusive search strategy which targeted the three core domains of (1) organ donation, (2) family or next of kin, and (3) decision-making was applied. The primary search was restricted to studies published from the year 2012 onwards, and to full-text articles published in English due to limited translation resources.

Table 6. 2. Search Strategy for Medline Ovid: 2012 - 27 April 2020

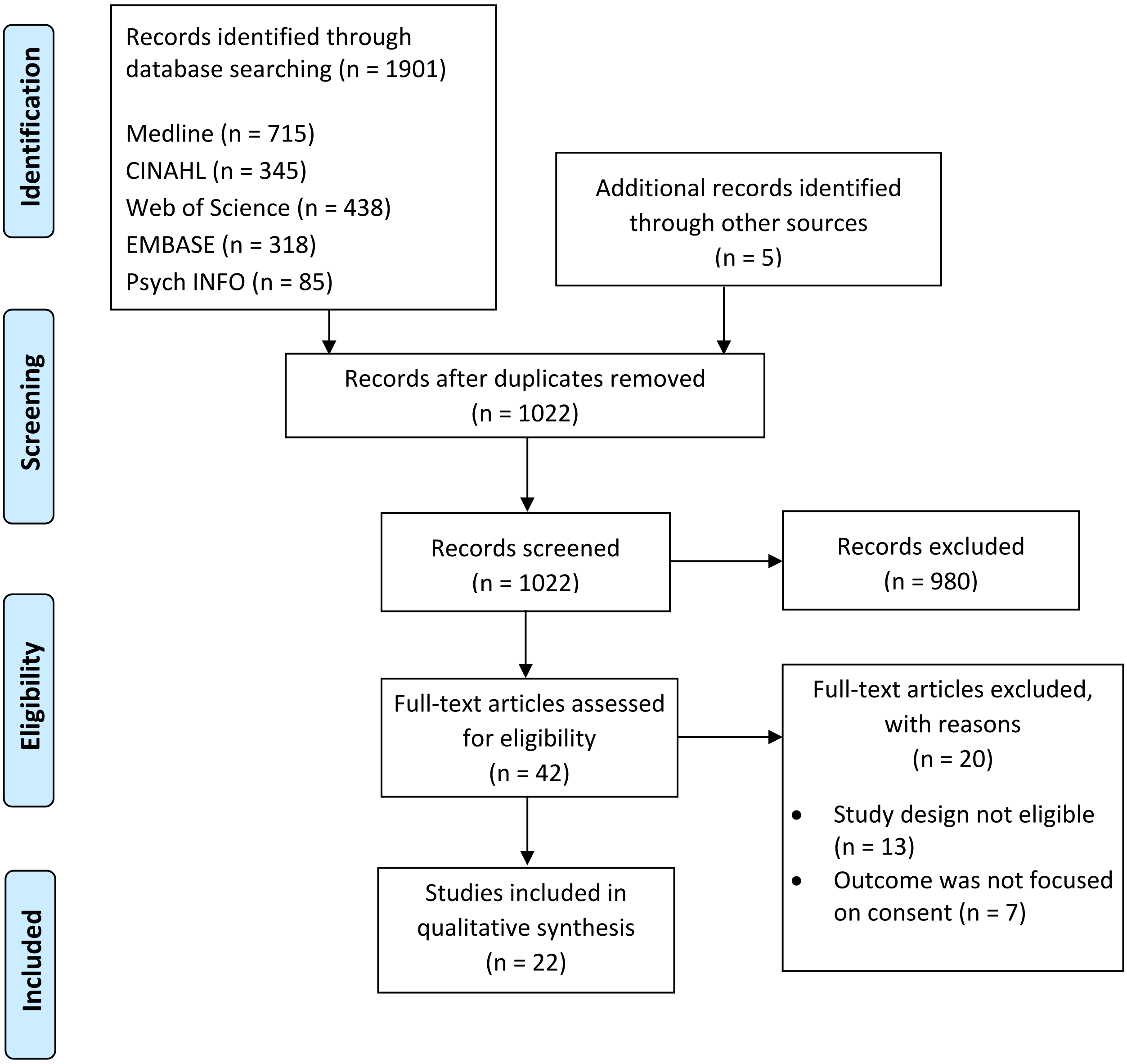
#	**Search Terms**
1	Exp Organ Transplantation/
2	Exp “Tissue and Organ Procurement”/
3	Exp “Tissue and Organ Harvesting”/
4	Exp Transplants/
5	(“Organ Transplant$” or “Organ Don$”).ti,ab.
6	((organ or organs or tissue) adj4 (transplant or transplantation)).ti,ab.
7	Tissue Donors/
8	((organ or organs or tissue) adj4 (donat$ or procure$ or harvest$)).ti,ab.
9	("potential organ don$" or “potential don$” or “non don$”).ti,ab.
10	((cadaver* or deceased or “post mortem” or post-mortem or posthumous) adj4 (donat$ or donor)).ti,ab.
11	or/1-10
12	Family/
13	Exp Family/ px [Psychology]
14	((grieving or bereaved or donor) adj2 (famil$ or relatives)).ti,ab.
15	(“next of kin” or “family members” or “loved ones”).ti,ab.
16	Or/12-15
17	Exp Decision Making/
18	(decision$ or discussion$ or approach$ or experience$).ti,ab.
19	Exp Choice Behavior/
20	("request process" or "donation request$" or "care process").ti,ab.
21	(consent or accept or agree$ or proceed or approval or permission or authori#ation).ti,ab.
22	(refusal or decline or deny or object or objection or override or overrule or oppose).ti,ab.
23	Or/17-22
24	11 and 16 and 23
25	Limit 24 to (English language and yr = "2012 -Current" and journal article)

6.3.5 Screening and Data Extraction Process

Electronic database searching was conducted on 27 April 2020. All potentially relevant records identified from the search strategy were exported to the reference managing software EndNote X9. Following de-duplication, the remaining records were imported to Rayyan QCRI to facilitate screening against eligibility criteria (Ouzzani et al., 2016). One reviewer (JM) conducted the initial screening of all articles by their titles and abstracts. A random 10% of this sample (n =101) was screened for eligibility by a second reviewer (LM). The full text of articles identified to be potentially eligible for inclusion were then obtained and independently appraised by two researchers (JM and LM) to determine those that satisfied the study inclusion criteria. The proportion of agreement between both reviewers was substantial K = .795, p <.001. Papers found not to satisfy eligibility criteria by both researchers were removed and the reason recorded (n = 20). Any discrepancies were resolved through discussion with both reviewers until a consensus was reached. A total of four articles were assessed by a third reviewer (ROC), which resulted in one additional article being included. One study which initially satisfied inclusion criteria was later excluded from this review (Marck et al., 2016). The decision was made to exclude this article as it reported the same primary data from article already included in this review conducted by the same authors. The included article from Neate and colleagues, (2015) reported the reasons for Australian families' organ donation decisions, while the excluded article published by the same group of authors re-analysed this data to provide insights into donor family communication (Marck et al., 2016). A PRISMA flow diagram was used to record the progression of searches from identification to inclusion (available in Figure 6.1).

Data extraction was conducted independently by one reviewer and appraised for appropriateness by both LM and ROC. Eligible articles were retrieved, and the following data extracted into a Microsoft Excel spreadsheet: study bibliographic details (study title, author details and publication date), and information on the study characteristics (location, research aims, participant details, potential donor details, study methodology and design, analytic method, and the study findings). In accordance with guidelines on data analysis from Thomas and Harden (2008), verbatim text containing the study findings, discussions and conclusions, including participants' quotes where available, pertaining to the factors influencing decision-making were extracted into Microsoft Word for preliminary formatting. Following this, the data was imported into Quirkos, a qualitative data analysis software used for data management and coding (Quirkos, 2020) https://www.quirkos.com/index.html.

Figure 6. 1. PRISMA Flow Diagram



6.3.6 Quality Assessment

The quality of the included studies was assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist. The CASP checklist is recognised within Cochrane qualitative reviewing guidelines as an appropriate tool for health-based qualitative appraisal (Noyes et al., 2018). The checklist includes 10 core questions designed to measure methodological quality within the following domains; clarity of aims, appropriateness of the methodological approach, design and recruitment strategy, data collection, researcher and participant relationship, ethical considerations, data analysis, findings and research value (for the CASP checklist, see Appendix 23). Nine of the questions follow a checklist-based format using the response options (*yes, can't tell,* and *no*) and question 10 presents an open-ended response option to the question: "*How valuable is the research?"* Although the CASP is a well-recognised tool for appraising health-based qualitative studies, recent research has reflected on both, the lack of guidance when administering the tool and limitations in the scoring criteria (Long et al., 2020). In response, Long and colleagues (2020) proposed a number of modifications to improve the value of the tool, which have been adopted within this thesis. This included, modifying the scoring criteria to include a fourth '*somewhat*' response option in acknowledgement that there is often more complexity and nuance warranted when assessing methodological quality than a 'yes', 'no' or 'can't tell' response option. For this review, the response option '*somewhat*' was defined in line with the description from Long et al. (2020): meaning 'to some extent' or 'partly' and used when it was determined that the primary authors had reported a reasonable attempt at fulfilling a particular quality domain. The authors also proposed an additional question "*Are the study's theoretical underpinnings (e.g., ontological and epistemological assumptions; guiding theoretical framework) clear, consistent and conceptually coherent?*"

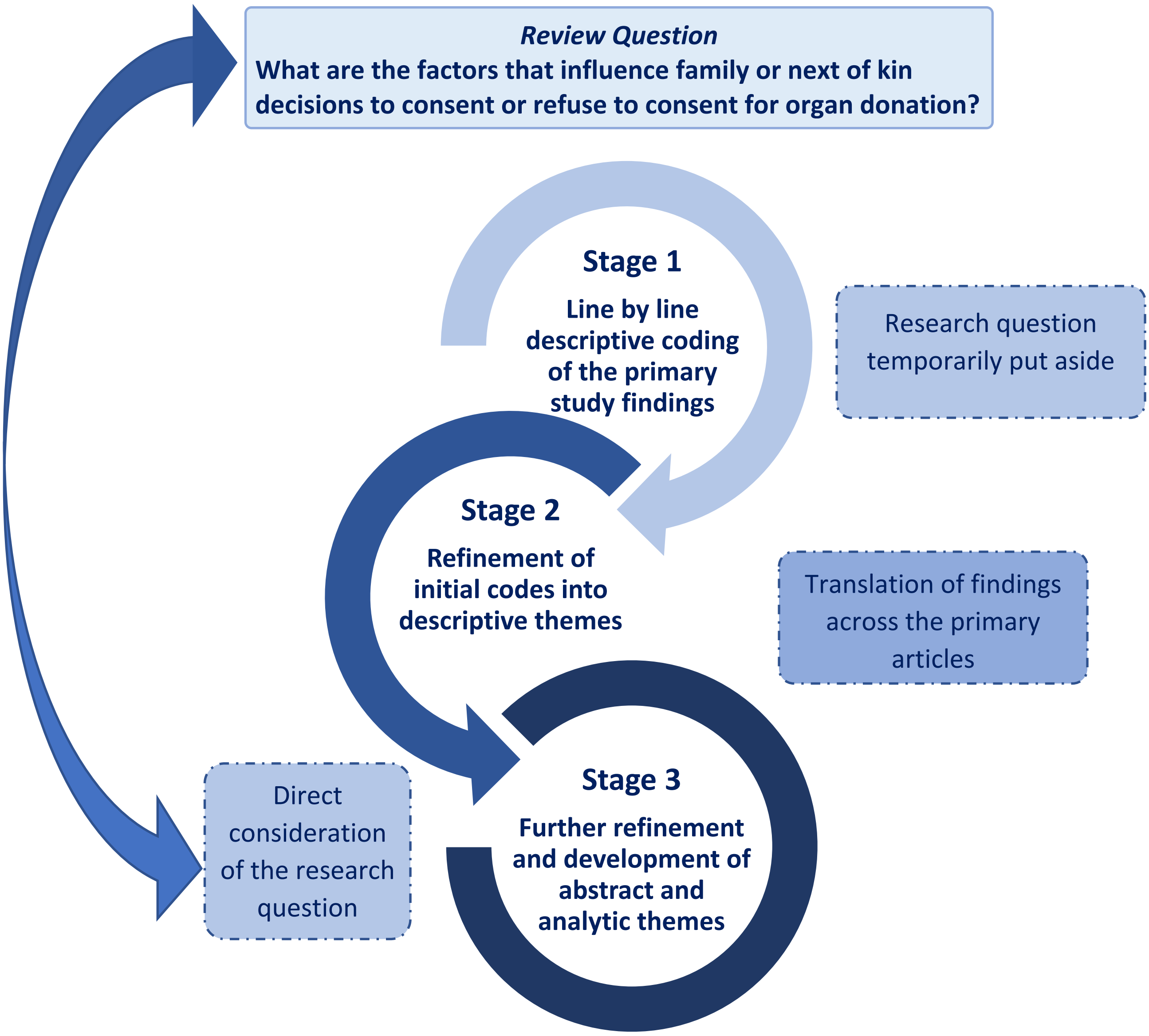
6.3.7 Appraisal Process

One reviewer (JM) independently evaluated the quality of the included studies using the CASP criteria. A second reviewer (LM) appraised one-third of the included articles, ($n = 7$) No substantial discrepancies between reviewer appraisals were noted (for example, reviewer one (JM) appraising a particular quality criterion as '*Yes*' and reviewer two (LM) appraising the criterion as '*No*'). Minor discrepancies were resolved through discussion and further consultation sought from a third reviewer (ROC) when required. In line with CASP recommendations, numerical values were not assigned to the quality criterion. Papers were not excluded based on the critical appraisal results, rather, this was used to inform the weight of discussion from the included articles, with higher quality articles, lending more weight to the review findings.

6.3.8 Data Synthesis

A thematic synthesis using the guidelines described by Thomas and Harden was conducted on the findings from the included articles (Thomas & Harden, 2008). This method enables researchers to potentially go beyond the findings of primary studies and facilitates the development of analytic themes which may enhance our understanding of the factors that influence family decision-making for organ donation. This approach was also selected as it facilitated the synthesis of findings from across different analytic approaches, which was particularly important in the context of the current review. Thematic synthesis encompasses three stages (as demonstrated in Figure 6.2), 1) line-by-line coding of verbatim text, 2) development of descriptive themes, and 3) the development of abstract and analytic themes. Each stage is discussed in detail below.

Figure 6. 2. Diagram Representing the Stages of Thematic Synthesis



During stage 1, the findings and interpretations from the included articles were printed, read on multiple occasions and both, initial impressions and preliminary codes handwritten within the paper margins. Although coding was conducted using the qualitative software Quirkos, this preliminary process was used to support familiarity and immersion with the articles. After the verbatim data (findings, discussion and conclusions) from each article was imported into Quirkos, the study findings underwent line-by-line inductive descriptive coding in accordance with their meaning and content. Within the coding software Quirkos, this involved assigning a code or 'quirk' to a respective line of text, as shown in Figure 6.3.

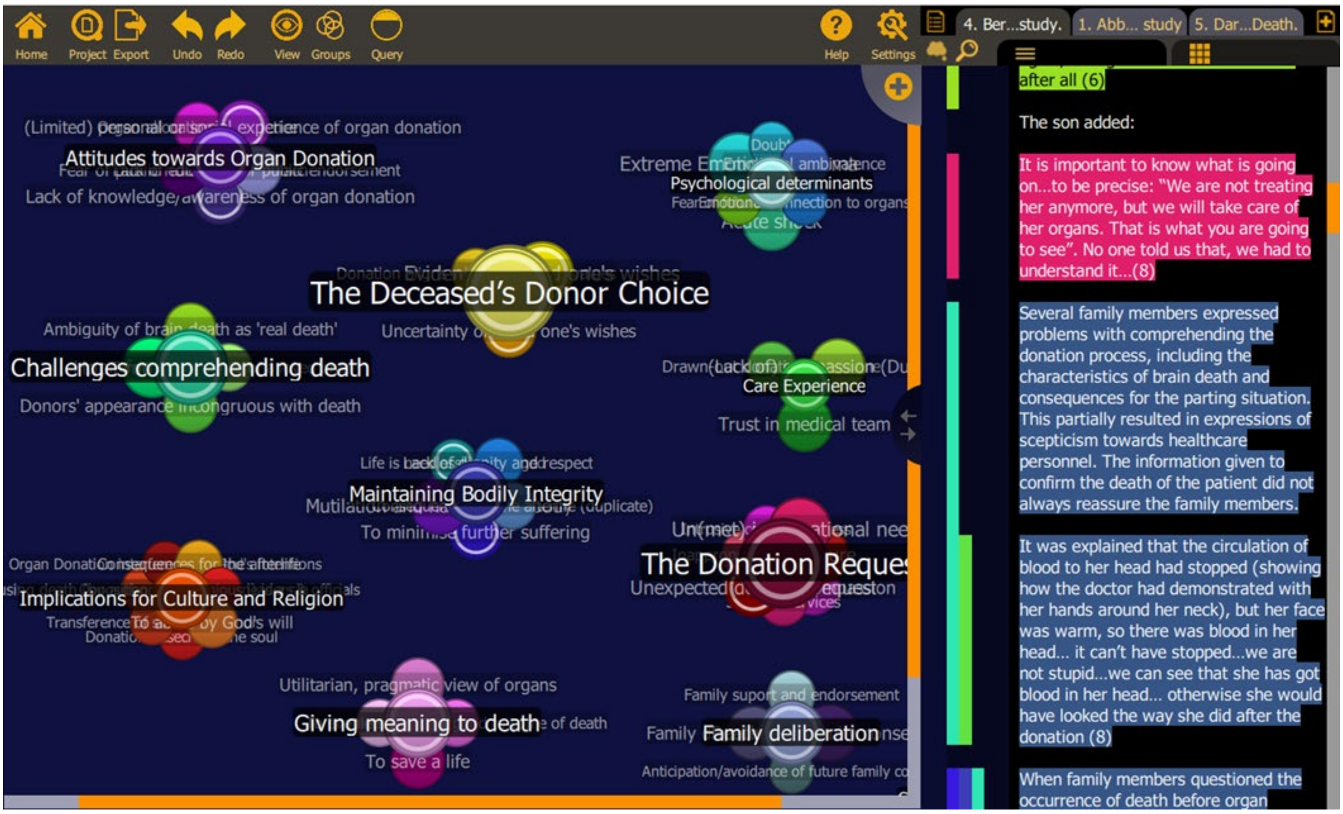
This preliminary coding process contributed towards stage 2, which involved reviewing the line-by-line coding and using this to develop an initial 'bank' of descriptive codes. It should be noted, that during stage one and two, it is recommended to provisionally "put aside" the review question to avoid restricting the potential findings with the application of a priori framework. These codes were then refined and developed into descriptive themes by the author and reviewed by all members of the research team. This stage also involved the examination of overlapping similarities and differences across the data within each code to enable refinement. Collectively, this is acknowledged as a core component of thematic synthesis which facilitates the 'translation' of central findings across the primary studies.

The third and final stage of synthesis involved "going beyond" the primary study findings to develop themes that answer the overarching review question. During this stage, the descriptive themes were grouped and further refined in order to optimally represent the complex factors influencing family consent and refusal for organ donation. The resulting themes were discussed across a series of meetings with all members of the research team. This iterative process facilitated the development of overarching analytic themes which answer the review question.

The notion of "going beyond" the findings of the included articles is hallmarked as a defining feature of thematic synthesis. While it is important to ensure the review findings are not limited to a simple summary of the findings from the primary articles, the level of abstract theme development is dependent on the similarities in the aims of the included articles. As Thomas and Harden (2008) note in their guide on thematic synthesis: *"In situations in which the primary studies are concerned directly with the review question, it may not be necessary to go beyond the contents of the original studies in order to produce a satisfactory synthesis"*

(Thomas & Harden, 2008, p.9). The findings from this review are largely in line with that found within the primary studies. This may be because the majority of the articles included in this review directly aimed to explore the factors influencing consent-related outcomes for organ donation.

Figure 6. 3. Example of Line-by-Line Coding in Quirkos



after all (6)

The son added:

It is important to know what is going on...to be precise: "We are not treating her anymore, but we will take care of her organs. That is what you are going to see". No one told us that, we had to understand it...(8)

Several family members expressed problems with comprehending the donation process, including the characteristics of brain death and consequences for the parting situation. This partially resulted in expressions of scepticism towards healthcare personnel. The information given to confirm the death of the patient did not always reassure the family members.

It was explained that the circulation of blood to her head had stopped (showing how the doctor had demonstrated with her hands around her neck), but her face was warm, so there was blood in her head... it can't have stopped...we are not stupid...we can see that she has got blood in her head... otherwise she would have looked the way she did after the donation (8)

When family members questioned the occurrence of death before organ

6.3.9 Peer Debriefing

It is important also to critically reflect on the authors' role during the analytic process, and to carefully consider the impact of this on the validity and rigour of the analysis (Palaganas et al., 2017). Inevitably, the primary authors' position as a somewhat novice qualitative researcher, familiarity with the organ donation literature and personal beliefs may have, to some degree, influenced the subsequent assumptions and interpretation of the data. In acknowledgement of the impact this may incur, particularly during the development of themes, peer-debriefing was conducted. This technique is endorsed as a method of increasing the rigour and trustworthiness of the findings by encouraging the researcher to reflect on how their perspectives have influenced the analytic process (Henry, 2015; Spall, 1998). For the purpose of the current review, this involved inviting a researcher (EC) with prior qualitative experience, who works outside of the discipline of Health Psychology, and who had no involvement in the research project to appraise the review findings. Together, during a meeting hosted on Microsoft Teams with the thesis author, EC reviewed the initial codes, descriptive and analytic themes, illustrative quotes and engaged in discussion to explore the development of descriptive to analytic themes. As a result of this meeting, two previously separate themes were refined and developed into an overarching analytic theme.

6.4 Findings

6.4.1 Description of Studies

The characteristics of the included studies are detailed in Table 6.3. For the purpose of this chapter, each of the included articles was assigned a number (1-22), which will be used when referring to specific studies throughout the findings and discussion section. The included articles will be represented by an Asterix within the thesis reference list.

Of the 1022 articles identified, a total of 22 studies published between 2012-2020 met the review inclusion criteria. In total, the experiences of 623 bereaved family members were included in this review. This represents approximately 231 family members who gave consent for the donation of a loved one's organs (DCD or DBD), 144 family members who did not provide consent for organ donation and 168 family members from three studies that included donor and non-donor families, but omitted details on the cases of consent or refusal. The consent and refusal figures do not include reference 12, which included 80 bereaved families yet only reported the number of cases of donation (50 donation and 1 refusal). This figure also excludes participant numbers from one study (reference 20) which applied a secondary data analysis to one of the articles (reference 21) included within this review. Most studies were explicitly aimed at understanding the factors influencing family decision-making; however, a small number of studies examined the overall family experience of deceased organ donation. Within these articles, data on consent-related aspects of the family experience were elicited throughout participants' discourse and consequently feature in the study findings.

Regarding data analysis, most studies applied forms of content analysis (*n* = 10), or thematic analysis (*n* = 5). The remaining methods included grounded theory (*n* = 2), discourse analysis (*n* = 1), framework approach (*n* = 1), phenomenological approach (*n* = 2) and one study that provided a general description of an analytic method but no specification.

6.4.2 Study Setting

The included studies were conducted across 12 different countries: Australia, Brazil, Canada, China, Denmark, France, Greece, Iran, Netherlands, Norway, the UK and the US. In terms of donor legislation, four studies were conducted in nations governed under an opt-out donor system (France, Greece, Norway and Wales (UK)). Eighteen studies were conducted across eight nations with an opt-in system, defined as a nation whereby members of the public pre-register or record intentions to donate their organs. Of the four UK studies, three were conducted in England, which, at that time followed an opt-in system, and one in Wales which follows an opt-out system.

Table 6. 3. Characteristics of the Included Studies

#	Authors Country	Study details					Participant details		
		Consent system^{a}	Research Aim(s)	Recruitment & Data collection	Theoretical framework	Analytic Method	Participants	Time from bereavement^{b}	Consent or refusal for donation
1	(Abbasi et al., 2020) Iran	Opt-in	To explore family obstacles to organ donation consent.	Purposive and snowball sampling. Semi-structured interviews	Not specified	Content analysis	20 non-donor family members	Not specified	Refused
2	(Ahmadian, Khaghanizadeh, et al., 2019) Iran	Opt-in	To explore stressors experienced by family members during the process of organ donation.	Purposive sampling. Semi-structured interviews	Not specified	Content analysis	17 donor family members	Range: 6-16 months	Consented
3	(Ahmadian, Rahimi, et al., 2019) Iran	Opt-in	To explore the outcomes of organ donation for the families of brain-dead patients.	Purposive sampling. Semi-structured interviews	Not specified	Content analysis	19 donor family members	Range: 6-22 months	Consented

4	(Berntzen & Bjørk, 2014) Norway	Opt-out	To investigate the experience of donor families during organ donation after brain death.	Purposive (criterion) sampling. Semi-structured interviews	Not specified	Content analysis	20 donor family members	Range: 16-22 months	Consented
5	(da Silva Knihs et al., 2015) Brazil	Opt-in	To understand the experience of families in the process of hospitalization, brain-death and the request for organ donation	Purposive (criterion) sampling.	Phenomenological approach	Phenomenological approach	18 non-donor families	Mean: 14 months	Refused
6	(Darnell et al., 2020) US	Opt-in	To understand goals and tensions experienced by families during organ donation discussions that may have influenced refusal.	Purposive sampling. Semi-structured interviews.	Multiple goals framework	Thematic analysis	14 non-donor family members	Range: 3-21 months	Refused

7	(de Groot et al., 2016) Netherlands	Opt-in	To determine the factors that influence family decision-making of un-registered eligible, brain dead donors.	Purposive sampling. Secondary analysis of semi-structured interviews.	Not specified	Content analysis	24 family members	Approx. 3.5 months	6 Consented 18 Refused
8	(de Groot et al., 2015) Netherlands	Opt-in	To gain insight into family decision-making of potential brain-dead donors.	Purposive sampling. Semi-structured interviews	Not specified	Content analysis	39 family members	Median 85 days	22 Consented 17 Refused
9	(de Moraes et al., 2019) Brazil	Opt-in	To understand the experience of family members of potential donors in deciding to refuse donation.	Face to face interviews	Social phenomenology	Schutz's phenomenological approach	8 non-donor family members	At least 12 months	Refused
10	(Fernandes et al., 2015) Brazil	Opt-in	To identify relatives experiences and feelings of the donation process.	Face to face interviews	Not specified	Content analysis	7 donor family members	Range: 5-15 months	Consented

11	(Huang et al., 2019) China	Voluntary register (resembles an opt-in system)	To explore factors that influence the family decision-making for organ donation	Semi-structured interview	Not specified	Not specified	30 donor family members	Not specified	Consented
12	(Jensen, 2016) Denmark	Opt-in	To understand how families use hope to accept organ donation decisions and make sense of tragic deaths.	Face to face interviews and observations with potential donor families.	Social anthropology	Thematic analysis	80 family members (51 cases of eligible donation)	At least 6 months	50 Consented 1 Refused
13	(Kentish-Barnes et al., 2019) France	Opt-out	To understand what it means for family members to make a donation decision.	Semi-structured telephone interviews	Not specified	Grounded theory	24 family members	Range: 11-14 months	16 Consented 8 Refused
14	(Manzari et al., 2012) Iran	Opt-in	To explore the needs of family members of brain-dead individuals during the organ donation process.	Purposive sampling Semi-structured interviews	Not specified	Content analysis	53 family members	Consenting relatives - at least 3 months Non-consenting relatives - at least 6 months	No data on specific number of consent/refusal cases

15	(Neate et al., 2015) Australia	Opt-in	To determine reasons underpinning consent decisions made by families of potential organ donors.	Purposive sampling Semi-structured interviews	Not specified	Thematic analysis	49 family members from 40 families	Median 89 days	23 Consented 17 Refused
16	(Noyes, Mclaughlin, Morgan, Roberts, et al., 2019) Wales	Opt-out	To assess the specialist nurse (SN-OD) enactment of opt-out consent and to explore the family experience.	Semi-structured interviews	Not specified	Framework approach	88 family members of 60 potential organ donors	Initial contact to engage in the study was received at least 4 weeks after bereavement	No data on specific number of consent/refusal cases
17	(Podara et al., 2019) Greece	Opt-out	To explore the experiences of donor family involved in donation decision-making.	Semi-structured interviews	Grounded theory approach, guided by the principles of Charmaz, (2006)	Grounded theory	11 donor family members	Range: 6 months - 11 years	Consented
18	(Sarti et al., 2018) Canada	Opt-in	To explore next of kin experiences throughout their donation journey.	Semi-structured interviews	Not specified	Inductive thematic analysis	27 family members	Range: 6 - 36 months	No data on specific number of consent/refusal cases

19	(Sque & Galasinski, 2013) England, UK	Opt-in[c]	To explore family members accounts of refusing to consent for the donation of a loved one's organs.	Interviews (face-to-face & telephone)	Social construction-ist perspective	Critically oriented discourse analysis	25 non donor family members	> 3 months - 19 years	Refused
20	(Sque et al., 2018) England, UK	Opt-in[c]	To determine families' perceptions of how their experiences influenced donation decision-making.	Semi-structured interviews	Not specified	Content analysis-combined inductive and deductive approach.	43 donor family members	Range: 4-12 months	Consented
21	(Walker & Sque, 2016) England, UK	Opt-in[c]	To provide insight into the benefits of organ and tissue donation for grieving families.	Semi-structured interviews	Not specified	Content analysis	43 donor family members	Range: 4-12 months	Consented
22	(Yousefi et al., 2014) Iran	Opt-in	To investigate the donation decision-making process of families with brain dead relatives.	Unstructured interviews (face-to-face)	Not specified	Thematic analysis	16 donor family members	Range: 40 days - 1 year	Consented

Note. [a]Consent system in place at the time of the study data collection. [b]timeframe as specified by each paper. [c]England now follows an opt-out consent system, at the time of recruitment for the three articles from England an opt-in system of organ and tissue donation was in operation.

6.4.3 Quality Appraisal

Responses to the quality appraisal tool are detailed below in Table 6.4. All of the included articles were appraised to have a clear statement of aims. In almost all of the studies, both the application of a qualitative methodology and the study design were appraised as being appropriate to address the aims of the research. This excludes one study (11), in which both reviewers (JM and LM) were unable to determine whether qualitative methodology was appropriate (*can't tell*) and appraised the design as being unsuitable for the study aim. The study recruitment strategy and data collection method were considered as being appropriate or somewhat appropriate in all but three studies (1,11 and 14). The study theoretical underpinnings were considered in less than half of the included articles. Similarly, the relationship between researcher and participant was not considered within most studies. Ethical issues were considered in some degree in all but one study (11). Regarding data analysis, with the exception of three studies (9,10,11), analysis was deemed to be sufficiently rigorous and a clear statement of findings was available in all but two studies (10,11). As described previously, studies were not excluded on the basis of quality, however, this was used to inform the weight of discussion from respective articles, with lower weight assigned to lower quality articles.

Table 6. 4. CASP Criteria Applied to Assess the Quality of the Included Articles

	A: Are the results valid?							**B: What are the results?**		
Study no.	Is there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been considered?	Was data analysis suitably rigorous?	Is there a clear statement of findings?
1.	Yes	Yes	Somewhat	Can't tell	Can't tell	Yes	Can't tell	Somewhat	Somewhat	Yes
2.	Yes	Yes	Yes	Can't tell	Somewhat	Yes	Can't tell	Yes	Yes	Yes
3.	Yes	Yes	Yes	Somewhat	Yes	Yes	Can't tell	Yes	Somewhat	Somewhat
4.	Yes	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Yes	Somewhat	Yes
5.	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Can't tell	Somewhat	Somewhat	Yes
6.	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Somewhat	Yes	Yes
7.	Yes	Yes	Yes	Can't tell	Somewhat	Yes	Somewhat	Yes	Somewhat	Somewhat
8.	Yes	Yes	Yes	Can't tell	Somewhat	Yes	Somewhat	Yes	Somewhat	Somewhat

A: Are the results valid?								B: What are the results?		
Study no.	Is there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been considered?	Was the data analysis suitably rigorous?	Is there a clear statement of findings?
9.	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Can't tell	Somewhat	No	Yes
10.	Yes	Yes	Somewhat	Can't tell	Somewhat	Somewhat	Can't tell	Somewhat	No	No
11.	Yes	Can't tell	No	Can't tell	Can't tell	Somewhat	Somewhat	No	No	No
12.	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Yes
13.	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	Yes	Yes
14.	Yes	Yes	Yes	Can't tell	Somewhat	Can't tell	Can't tell	Yes	Somewhat	Somewhat
15.	Yes	Yes	Yes	Can't tell	Yes	Yes	Somewhat	Yes	Yes	Yes
16.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

A: Are the results valid?								B: What are the results?		
Study no.	Is there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been considered?	Was the data analysis suitably rigorous?	Is there a clear statement of findings?
17.	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Somewhat	Yes	Yes
18.	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Somewhat	Yes	Yes
19.	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
20.	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
21.	Yes	Yes	Yes	Can't tell	Somewhat	Somewhat	Can't tell	Yes	Yes	Yes
22.	Yes	Yes	Yes	Can't tell	Yes	Somewhat	Can't tell	Yes	Somewhat	Somewhat

6.4.4 Thematic Synthesis Findings

This synthesis identified six overarching themes used to represent the central factors influencing the donation decision-making of families and next of kin. These include: (1) The will of the deceased; (2) the meaning attributed to death; (3) the paradox of brain death; (4) preservation of bodily integrity; (5) an intricate balance of time, and (6) the need for compassionate care. Theme 1 (the will of the deceased) and theme 2 (the meaning attributed to death) were observed to play a dual role in influencing both consent and refusal.

In the following section, a description of each theme is provided. A table detailing the transition from the initial descriptive themes generated during stage two, to the analytic themes generated in stage three is available in Table 6.5. Brief representative quotations are presented alongside each theme description to support interpretation. Full illustrative extracts for each theme are provided in Table 6.6.

Table 6.5. The Transition from Descriptive to Analytic Themes

Descriptive Theme[a]	**Analytic Theme**	**Sub-themes**	**Description**
The Deceased's Donation Choice	**1. The Will of the Deceased**	No sub-theme	The decision to provide consent or refusal for organ donation is driven by a family's duty to uphold their loved one's choice.
Challenges Comprehending Brain Death	**2. The Paradox of Brain-Death**	Patients appearance incongruous with death	Incongruence between the appearance of an individual diagnosed as satisfying brainstem death criteria (breathing and heartbeat are mechanically supported) and their clinical condition.
		Chance of recovery	The belief and hope that the patient will recover. This may arise as a consequence of the potential donors' appearance.
		Bearing the responsibility of death	The belief that by providing consent for organ donation, the family are responsible for terminating the life of their family member.

Protecting the Body After Death	**3. Preservation of Bodily Integrity**	To protect the deceased from harm and suffering	Refusing to consent for organ donation protects the deceased from unnecessary suffering and harm.
		To preserve the dignity of the deceased	Refusing to consent for organ donation enables family members to protect the dignity and physical integrity of the deceased's body.
Cultural and Religious Factors Utilitarian, Pragmatic View of the Body	**4. The Meaning Attributed to Death and the Body**	The body as a resource	The body holds little symbolic embodiment and donation is considered by families as a utilitarian way of utilising valuable organs.
		The body as "*God's gift*"	Death is considered to embody God's will. Organ donation acts in accordance with God's will.
		The body and the soul as one	The body and the soul were considered to be connected in life and death. The decision to refuse was viewed as a way of protecting the deceased's soul.
The Donation Request Process	**5. An Intricate Balance of Time**	No sub-theme	The timing of the donation request is an important factor in the decision to provide consent or refusal.
Care Experiences	**6. The Need for Compassionate Care**	No sub-theme	A perceived lack of compassion from the treating medical team influenced perceptions of care and consent related outcomes.

Note. [a] Within theme 4 (The Meaning Attributed to Death), multiple initial descriptive themes were grouped and refined in order to facilitate the development of the overarching analytic theme.

6.4.5 Theme 1: The Will of the Deceased

The most compelling factor influencing both, the decision to provide consent or refusal for organ donation, was a sense of duty for family members to uphold the will of the deceased. In almost all of the included articles, family members stated that explicit evidence their loved one had wanted to donate their organs substantially increased the family's self-assurance in supporting their decision to proceed with organ donation. In such instances, families often described themselves as vessels responsible for upholding their loved one's decision. As such, the agency of decision to consent was often redirected and attributed as being the donor's and not the family's decision: "*It wasn't my decision, it was M.'s"* (13) and *"It's very straightforward. She wished it and we did it. As simple as that"* (20).

Similarly, in instances of refusal, family members stated that knowingly consenting for organ donation against their loved one's wishes would constitute a betrayal. Therefore, upholding the deceased's beliefs, even in instances where family members supported organ donation themselves, was recurrently described as a way of ensuring the families retained "*peace of mind*" with the decision.

The Will of the Deceased Under Opt-Out Consent

Although an important component of this review was to explore the factors influencing consent-related decisions across different donation systems, just one study made specific reference to the influence of donation policy on donor-relevant decisions. In this study, conducted shortly after the implementation of deemed consent in Wales, families who were unaware of their loved one's donation preferences, expressed different viewpoints on the opt-out system (16). While, under opt-out consent, doing nothing (not registering a donation decision) is intended to indicate consent for organ donation, some families expressed concerns that under such circumstances, if a loved one had not registered a donor decision, in the absence of prior discussion with the family, their donation preference ultimately remains unclear. As such, families reported doubts as to whether their surrogate decision aligned with the will and values of their loved one. The absence of a recorded donor decision under these circumstances perpetuated family uncertainty: "*how is your family going to know what you want to do, they would always worry if you really wanted (or didn't) want it*" and "*Families are not supporting wishes either way as they didn't know*" (16). However, another family in this position described the opt-out system as a useful framework which aided their decision to proceed with donation: "*…It helped us because none of us knew at the time what Mammy wanted*" (16).

Upholding the will of the deceased was found to influence both consent and refusal for organ donation. As such, the illustrative excerpts in Table 6.6 are grouped and presented by consent and refusal related outcomes to aid interpretation. This theme was found to be the most salient factor influencing consent-related decisions and was observed irrespective of a nation's donation policy (opt-in or opt-out).

6.4.6 Theme 2: The Paradox of Brain Death

Across several studies, family members reported challenges understanding and accepting a diagnosis of brain-death as being representative of a 'real death'. As such, this led to conflict and uncertainty surrounding the decision to provide consent for organ donation. The paradoxical nature of brain death was recurrently expressed throughout family members' accounts, with two principal factors found to influence these beliefs: [1] the loved one's appearance being incongruous with death and [2] chance of recovery.

A number of family members emphasised their decisional conflict by describing the signs of life their loved one had presented despite receiving a brain-death diagnosis: "*He had a pulse, was warm to touch, his chest moving up and down*" (4). Therefore, for many families, their loved one's physical presentation acted to directly contradict their prognosis. As such, this contributed towards family members believing that their loved one was alive and that they may recover. In line with this, some families expressed fears that, if they consented for organ donation under these circumstances, they would in turn be held accountable for sanctioning their loved one's death. Hence, refusing to consent for organ donation was viewed as a way of relieving the family of this burden. This factor was particularly salient within two studies conducted in Iran and appeared to emanate from religious beliefs "*She said that it is a sin to be the cause of someone's death…*" (1,3).

6.4.7 Theme 3: Preservation of Bodily Integrity

The decision to refuse consent for organ donation was often attributed by family members as a need to preserve the integrity of the deceased's body. Throughout family's descriptions, this manifested in a desire to: (1) protect the deceased from undue harm and suffering and (2) to preserving the dignity of the deceased. Often, family members expressed the view that their loved ones had been through considerable suffering "*our mom had been through hell her whole life"* (6) and sought to protect them from further harm during their most vulnerable moments. For some families, the concept of organ donation evoked fears of inflicting unnecessary physical harm to their loved one. Notably, several families used language with connotations of disfigurement and damage "*they would cut his body into pieces"* (9) and "*I didn't want him mutilated*" (19) to emphasise this.

Families also expressed concerns relating to a lack of dignity and respect for the donor during the transition from end-of-life care to organ retrieval. This was often expressed in relation to the interventions or invasive procedures (mechanical ventilation) required to sustain the organs prior to transplantation "*just being kept alive on the ventilator. There seemed no dignity…*" (19). Therefore, the act of refusing was viewed by family members as a way of preserving the dignity of their loved ones. Notably, within a number of studies, families reported considerable distress as a direct consequence of the perceived lengthy process of organ donation. This culminated in some families, who originally intended to proceed with donation, withdrawing their consent: "*At the start we thought yes of course, but it all went on too long. In the end we all thought this isn't dignified"* (16).

6.5.8 Theme 4: The Meaning Attributed to Death and the Body

A salient factor influencing donor-relevant decisions was the meaning family members ascribed to death, the body and the potential donation of their loved one's organs. This was broadly categorised in the form of three overarching representations: [1] The body as a resource, [2] The body as "*God's gift*" and [3] The body and soul as one.

For some families, the body retained little symbolic meaning after death and the decision to donate was considered to be a largely pragmatic, utilitarian way of using valuable organs. For families with this viewpoint, upon their loved one's death, the body was described to represent a separate entity from that of the soul, the mind, or the self: "*what's left behind is just a shell"* (20). As such, the decision to donate their loved one's organs was considered a way of making use of organs that otherwise serve no further purpose: "*there's no way you can get them back, why wouldn't you recycle what you can*?" (15).

Throughout the primary studies, religious beliefs were expressed as both a facilitating and prohibitive factor in family's decision-making. This divergence largely centred on the family's interpretation of death and the body. For example, within two Iranian studies in particular, the body was often conceptualised by family members as being "*God's gift*" (3, 22). Therefore, this signified God to have a sense of agency over their loved one's body. As such, families attributed the death of their loved one to embody God's will: *"He was a gift from God and the Lord wanted to get him back"* (3, 22). Therefore, providing consent for donation was seen as acting in accordance with a higher power. However, not all families who expressed religious beliefs shared this view, with families in one study from Iran reporting the act of organ donation to signify a direct interference of God's will (1). More generally, religious and spiritual beliefs were expressed throughout a number of other the primary studies to play a role in consent-related decisions. This was primarily expressed in all five of the studies conducted in Iran, one study from Brazil and one from Australia (15), although in this latter example the donor family came from a Hindu background. These beliefs also aligned with existing themes, namely, challenges contemplating the paradoxical nature of brain death or a desire to preserve the integrity of the body: *"I have heard, if the whole body is not buried in one place, the soul will suffer badly in the other world* (1).

6.5.9 Theme 5: An Intricate Balance of Time

The request to donate a loved one's organs comes at an incredibly difficult time. As such, throughout almost half of the studies in this review, family members reflected on the timing of the request for organ donation as an influential factor in their donation decision. Several families felt the donation conversation had occurred "*too quickly*" following notification of their loved one's death. As such, a number of families described feeling "*shocked"* and emotionally unable to process the request at a time when they should have been focused on comprehending the imminent death of their loved one: "*(It was) too early. Let us… hold on to the fact that he's dying"* (15). For some families, the perceived intrusive and ill-timed nature of the request was described as a source of stress when making the decision to proceed with organ donation. Whilst for others, the inappropriate timing of the donation request played a key role in the decision to refuse: "*Maybe if we had more time, we would have agreed…"* (1).

6.5.10 Theme 6: The Need for Compassionate Care

In a fifth of the included studies, family members described shortcomings in the care their loved one had received to have a negative impact on their decision to support organ donation. This largely manifested throughout the primary articles as perceptions of poor quality of care, and a lack of compassion from the treating medical team. Notably, throughout some studies, medical personnel were described as being "*indifferent*" or "*cold*" (2, 7,14, 17). This, in turn, may have perpetuated the belief that the treating medical team were prioritising organ procurement over the life and dignified death of their loved one: "*The only thing they wanted from us was to donate organs*" (1). The findings from two studies also described that the manner in which the deceased had been treated to have an adverse effect on families trust in the doctors. These viewpoints were not sufficiently salient across the data to warrant representation as an overarching theme of medical mistrust.

It should also be acknowledged that families within three studies in particular (6,19, 20), reflected on the high quality and compassionate care their loved one received throughout their time in hospital to have had a positive impact on their donation experience: *"... They knew that [A] had died. They still treated him as if he was a living person."* (20).

Table 6. 6. Illustrative Extracts from Included Studies

Theme	**Illustrative Excerpts** ***Italicised text* = participant quotes, Non-italicised text = author interpretations**	**Evidenced in Source**
1. The Will of the Deceased Consent	*"We knew that was her wish and that's why we went through with it, if there had've been any doubt we would've said well that's okay I'm out of here".* **(15)** *"He said if I die before you I'll donate whatever, and I went, fair enough… I was just doing it because he wanted to. Because I can assure you I wouldn't have done it... But I thought that what he wanted to do was lovely".* **(15)** *"I didn't want to be wrong about saying no … I'm going against her wishes. Because I said to [A, husband]; 'if I go against her wishes, she's not doing what she wanted and that was to help people'. And so, thinking that way … That made me agree to it".* **(20)** Many participants acknowledged their deceased relative as the decision-maker and portrayed themselves as the person responsible for fulfilling their wishes. **(20)**	3, 11, 12, 13, 15, 18, 20, 22
1. The Will of the Deceased Refusal	When faced with the decision to consent to organ donation, family members actively looked for reasonable evidence to validate their decisions. For some participants, the unsigned driver's license served as a credible indicator of the patient's feelings about organ donation. **(6)** *"I said to her, I don't know, I am going to look at his driver's license.' He clearly did not have the organ donor marked on his driver's license, so I said, He has made his decision. I'm sorry".* **(6)** *"We were 99.9 % sure that he did not want that [donation]. Despite our idea that you should help people when you can, it's still his body".* **(8)** *"To have peace of mind, we have to honor the person's wish in life. I did this so I could lie down at night and sleep in peace, to be at peace with myself and my son. If I had authorized donation of my son's organs, I couldn't live with my own conscience".* **(9)**	6, 8, 9, 13, 15

	"*So I would have loved to have said yes, but it would be so against his wishes that I just couldn't do it*". **(15)**	
2. The Paradox of Brain-Death Patients' appearance incongruous with death	"*We were told she had passed away and I called my children and told them grandma had died. Then we got into her room at the ICU and saw her with all the machines…I remember calling them again, telling them she was not dead after all*". **(4)** "*The doctor showed a lot of exams; he said that his brain had stopped working. His heart was beating. The doctor explained that it was all because of the machine, but it was hard for us to believe. For us, the important thing was that his heart was beating*". **(5)** *"My daughter… well for me she was just sleeping, she was still there really. I didn't have a sense of loss at the time. I was like floating. We didn't realize at the time—it came later"*. **(13)** Some families felt unclear about the true meaning of brain death and did not seem to have clearly received the message that their loved one had died. Others indicated that while they knew and understood their family member had technically died, it did not feel this way until their heart stopped beating. (15)	1, 2, 4, 5, 7, 10, 13, 14, 15, 17, 18, 20, 22
Chance of recovery	*"I had pangs of conscience and said to myself that if I did not consent to donate, he might show some degree of recovery"*. **(3)** *"… They told me the machine was breathing for her, but the machine was breathing for her yesterday, and she's still breathing, and that stupid bit of hope and you think someone made a mistake and she'll be okay and she'll wake up"*. **(20)** "*We kept on touching her, all the time, she was warm … so she was there. And frankly, when I think about it now, I know that during all that time we believed that she would come back. Even if we knew it wasn't possible*" **(13)**	1, 2, 3, 5, 7 10, 13, 14, 17, 20, 22

Bearing the responsibility of death	*"My mother is very religious and we could not convince her to donate my brother's organ. She said that it is a sin to be the cause of someone's death…".* **(1)** *"I felt guilty. I thought that he may be dissatisfied. Many instances of "maybe" hit my mind. At the first days, I thought that we did not have the permission to terminate the life of a person whose heart was still beating".* **(3)** *"You take a human life in your hands … I decide about another's life and death, I decide about another's body … what if I'm the one who took her life? … It was the most difficult decision of my life".* **(17)**	1, 3, 8, 17
3. The Preservation of Bodily Integrity To protect the deceased from undue suffering	*"We thought that they would cut his body into pieces if we gave our consent for organ donation. If so, how we could wash his body and hold a proper funeral…".* **(1)** *"I looked at her and I knew I couldn't do it. I knew that the doctors thought that we were bad people because we wouldn't do it because S had received a kidney and I tried to explain to him, because she had cancer, because she had so many operations and so many things done that I just couldn't bear the thought of her being touched again".* **(19)** *"It was more the thought of keeping her whole, keeping her as she was and I guess that was the only thing".***(20)**	1, 2, 4, 6, 8, 11, 13, 17, 19, 20
To preserve the dignity of the deceased	*"They said it was going to take between six and eight hours and that's where it fell over because the kids couldn't do another six or eight hours of [him] on the ventilator. They just went no, no, no and so I had to pull the pin".* **(15)** *"At the start we thought yes of course, but it all went on too long. In the end we all thought this isn't dignified. We don't regret saying no, we held on as long as we could".* **(16)** *"Seeing L laid there imagining her being cut up for the sake of an eye or something like this just being kept alive on the ventilator. There seemed no dignity if you see what I mean, and uhh it's funny because when he [the doctor] first asked both my wife and I said well yeah, we would be interested".* **(19)**	8, 15, 16, 19

4. The meaning attributed to death The body as a resource	*"It is like a washing machine where the control system is broken, but the spare parts are still in good shape".* **(12)** Some families were very practical about organs being put to good use and were not preoccupied by themes of body invasion or desecration. **(15)** *"Why would anyone not donate, even though you've lost a loved one… there's no way you can get them back, why wouldn't you recycle what you can?"* **(15)** *"You have a spirit within you and when you die that spirit transcends to another dimension and what's left behind is just a shell. You take your personality and your character with you".* **(20)**	12, 13, 15, 20
The body as God's gift	*"Undergoing such a fate was God's will. A child is God's best gift for parents. He gave a child to us as a deposit and reclaimed it again".* **(3)** *Meaning can be hard to find in the midst of tragedy. Meaning for me was that God took Sam to spare him and his family from something worse than death. He was a haunted child. And in order to spare him from being a vegetable or something, "We better get him now to save him and his family from further pain."* **(12)** *"God wanted us to give back his gift. We are happy, we finished it, and thank God, he (the deceased) had a glorious death and got immortal like a martyr".* **(22)** *"He was a gift from God and the Lord wanted to get him back. We dealt with God".* **(22)**	1, 3, 12, 22

The body and the soul as one	*"I have heard, if the whole body is not buried in one place, the soul will suffer badly in the other world. Of course, we did not want this for our patient…"* **(1)** *"If my husband's organs were transplanted into another body, all the sins done by the receiver of the organ would be counted as my husband's sins. That is why I did not give my consent to organ donation…"* **(1)** Some participants had experienced difficulties in making donation-related decisions due to their misconceptions about the presence of the spirit in the braindead cadaver, their concerns over life in afterlife without the donated organs, and concerns over the oppositions of religious authorities **(2)**	1, 2, 9
5. An intricate balance of time	*"He asked if we wanted to donate his organs. You ARE there losing a son, his heart IS beating, and they ARE already asking for his organs".* **(5)** *"It was very fast, because the person receives the news of the brain death, I think the physician should not talk right away about organ donation. At that time, I had no strength, I would not listen more, I began to scream ... then the physician stopped talking".* **(10)** *"[It was] too early. Let us… hold on to the fact that he's dying... I'm never going to hold my husband ever again and you're asking me for his kidneys".* **(15)** *"I do remember thinking that this was happening all too quickly … and I think that was part of the grieving process in that; 'wait a minute. Hang on a second. She's not dead and we're whipping bits out of her."* **(20)**	2, 5, 8, 10, 15, 20, 22

6. The need for compassionate care	*"The medical personnel treated us badly as if they had no idea what we were going through. The only thing they wanted from us was to donate organs. They were not able to feel our condition…".* **(1)** *"It is just, I have a bad feeling about the intensivist that we were dealing with. I think she was a real cool and cold lady and she…She was hardly humane. Just a medical…".* **(7)** *"I needed their understanding and attention. I needed them to communicate with me during that hard situation. But their cold and inspirited way of treating me had a negative effect on my morale and belief system. I didn't trust them…".* **(14)** *"In the back of my mind is the poor treatment that she had and the thoughts keep coming through did she have the best care? ….. I lost all my trust with the doctors in the hospital because they treated her absolutely diabolical".* **(16)**	1, 2, 7, 14, 16

6.5 Discussion

Family refusal is a key factor limiting the potential for deceased organ donation across the world, irrespective of a nations donor consent policy (Domínguez-Gil & Matesanz, 2018). Despite opt-out legislation being heralded as a method of increasing family consent, the substantial increase in rates of family refusal after the introduction of opt-out laws in other nations highlights the complex and delicate nature of family decision-making. In this qualitative systematic review, the factors influencing family consent and refusal for posthumous organ donation were thematically synthesised across 22 studies from 12 countries. This synthesis provides an up to date understanding of family decision-making, represented across six overarching themes. In the following section, each of these themes will be discussed in relation to the existing literature. Implications and recommendations arising from each of the core findings will then be provided.

6.5.1 The Will of the Deceased

Irrespective of consent-related outcome, awareness of the deceased's donation preferences represents a crucial factor guiding family decision-making. This finding was represented across nine countries within this review (Australia, Brazil, Canada, China, Denmark, France, Iran, the UK and the US). For families with explicit knowledge of their loved one's donor choice, supporting the deceased's end-of-life decisions was considered to represent a family's duty. Notably, this knowledge guided decision-making, regardless of families own beliefs. Thus, the deceased's agency over their donation decision was safeguarded for both, the decision to provide consent: "*I was just doing it because he wanted to*" (15) and refusal: "*it would have meant betraying him… because that was his choice*" (13). In these circumstances, some families described their decision as being "*straightforward*" and "*simple*". Though still fraught with challenges, this appeared to ease the emotional burden and uncertainty surrounding the decision. Conversely, when the deceased's donor decision was not known, family members recurrently expressed conflict and decisional uncertainty. These factors consistently appear throughout the literature to be a principal reason for family refusal (Barber et al., 2006; Hulme et al., 2016; Miller & Breakwell, 2018; Walker et al., 2013). The importance of these factors is further supported by the annual UK donation figures provided by NHSBT. Reliably, family members of potential organ donors are almost twice as likely to support organ donation if they know this aligned with their loved one's decision (NHS Blood and Transplant, 2020a).

While an important component of this review was to explore differences in the factors influencing donor decisions across nations with different models of consent, the findings were not sufficiently heterogenous to enable such comparisons. However, this may be interpreted as an indication that irrespective of consent-system, family decision-making across nations with opt-in or opt-out systems remains comparable. While four nations operated under an opt-out system (France, Greece, Norway and Wales (UK)), just one study made explicit reference to the impact of the newly implemented opt-out system on family decision-making (16). In this Welsh study, while one family described deemed consent to have been helpful in guiding their decision to proceed with organ donation, others explained that under deemed consent, if the deceased had not registered as a donor, their decision remained incredibly difficult: "*Families are not supporting wishes either way as they didn't know*" (16). This aligns with the findings of theme one and suggests that under an opt-out system, while no recorded decision should now infer support for organ donation, family members require more concrete evidence of a loved one's intentions to ease their uncertainty with the decision.

A number of studies have echoed this interpretation, reliably reporting the perceived strength of ones' donor intentions under a deemed consent system to be comparably weaker than those made under an active opt-in system (Davidai et al., 2012; Lin et al., 2018). Recent figures on family consent in Wales strengthen these findings; with families refusing consent for organ donation in 41.7% of cases where deemed consent applied due to the absence of an opt-in or opt-out decision (NHS Blood and Transplant, 2020a). Concerningly, this figure is only slightly below that recorded in opt-in countries where the deceased had not registered, and their decision was not known (48.5%). This compares poorly to the overall UK consent rate observed when the deceased had actively registered as a donor (91.4%). Taken together, this may suggest that the factors influencing family decision-making under an opt-out system, are almost indistinguishable to those in an opt-in system. To that end, these findings highlight the need for sustained campaigns encouraging members of the public to communicate their donor decision with eligible family.

6.5.2 The Paradox of Brain Death

The families of potential donors are predominately approached regarding organ donation in instances where their loved one has satisfied criteria for brainstem death. A core finding of this review is that families experience considerable challenges comprehending the implications of this diagnosis. A large body of evidence has echoed these findings, describing challenges understanding brain-death to be a crucial factor influencing family decisions (Long et al., 2008; Morgan, Harrison, et al., 2008; Ralph et al., 2014; Simpkin et al., 2009). However, this synthesis offers new insights into families decisional conflict, by conceptualising these challenges to arise as a consequence of the nebulous and perceived paradoxical nature of brain-death. These findings may be understood in relation to Sque & Payne's (1996) theory of Dissonant Loss, whereby, donor relatives' decisional conflict was characterised by a sense of "*psychological inconsistency*" similar to that observed in the present review. In the above-mentioned study, conflict was recurrently expressed in relation to the confirmation of brainstem death (Sque & Payne, 1996), which, in line with the findings of the current synthesis, arose due to contradictory evidence that their loved one had died.

To ease this decisional conflict, some families within the current synthesis explicitly requested evidence to validate the death of their loved one: "*Just let me see that scan, we only wanted something…*" (7). Therefore, where appropriate, allowing family members to witness formal brainstem death testing may act to alleviate family uncertainty. Previous mixed-methods research offers support for this recommendation, with relatives who observed brainstem death testing recounting the experience to have been beneficial in providing tangible confirmation of death (Ormrod et al., 2005). With specific reference to consent related outcomes, a number of relatives who did not consent for organ donation and later expressed regret regarding their decision, directly attributed this to not being present during brainstem death testing (Ormrod et al., 2005). This suggests that observing this procedure may alleviate family's residual uncertainty and decisional conflict. A small amount of evidence strengthens these findings, reporting that the while family's presence during brainstem death testing is not routine practice, witnessing the procedure was found to aid the understanding and acceptance of brain-death (Reid, 2013). Given the lack of empirical research in this area, future studies examining the acceptability of observing brainstem death testing from the perspective of donor families are needed.

6.5.3 Preservation of Bodily Integrity

For many families, the decision to refuse consent for organ donation was considered as a way of preserving and protecting the physical integrity of their loved one's body. Bodily integrity concerns, in their simplest form, comprise the view that the body should remain whole after death. These beliefs play a principal role in donor decision-making from both an individual and a family perspective (O'Carroll, Foster, et al., 2011; Stephenson et al., 2008). The concept of bodily integrity is fundamentally complex; manifesting in different ways according to one's interpretation of the body and one's beliefs around the factors that constitute a violation of integrity (Viens, 2016). The multifaceted nature of bodily integrity concerns was echoed within the current synthesis, with families expressing their refusal to have arisen from the belief that organ donation would inflict needless harm or damage to their family member's body. For others, maintaining bodily integrity was grounded in the principles of dignity and respect, to which organ donation was considered to threaten. Given the complex nature of bodily integrity concerns, there is little consensus throughout the literature on the optimal ways of overcoming such beliefs. However, improving family knowledge and understanding, particularly of the process and time frame of organ donation may be an important consideration. This is crucial, as several families who initially gave consent for organ donation, later withdrew this as a consequence of the perceived drawn-out and undignified time frame for organ retrieval. Although few studies have examined this, a report from NHSBT has acknowledged that substantial lengthening of the donation after cardiac death pathway between 2007-2012 was associated with a decrease in family consent (NHS Blood and Transplant, 2012).

6.5.4 The Meaning Attributed to Death and the Body

The findings have also demonstrated that families appear to rationalise donor decisions in relation to their interpretations of death and of the body. For some, the decision to consent for organ donation was interpreted as a pragmatic way of utilising the body's valuable resources. Existing qualitative literature on beliefs surrounding death and organ donation reinforce these findings, with family members who perceived their loved one's body as being distinct from the soul, reported to experience less conflict with the decision to donate (Haddow, 2005).

For other families, death and the body were interpreted in accordance with firm religious and cultural beliefs. This was particularly noticeable throughout the studies conducted in Iran (1, 2, 3, 14, 22). Iran is a developing Islamic country, and although religion was not explicitly categorised within four of the Iranian articles, the vast majority of Iranians are members of the Muslim community who follow the Islamic faith. While a fatwah (Islamic legal pronouncement) was issued in 1989 which formally acknowledged brain-death and approved deceased donation, and formal donation legislation was passed in Iran in 2000, support for organ donation from religious leaders remains conflicted (Ghods, 2014; Randhawa et al., 2012).

The findings of the current synthesis support this interpretation. For example, a number of families attributed their refusal to arise from concerns associated with religious beliefs. This predominantly encompassed concerns relating to desecration of the deceased's soul and transference of sin from donor to the deceased: "*all the sins done by the receiver of the organ would be counted as my husband's sins*" (1). Thus, for these families, the act of refusal was considered as a way of safeguarding the deceased's soul in the afterlife. Understandably, in instances where families hold such beliefs, agreeing to organ donation is almost inconceivable. Whilst these experiences may also align with a desire to preserve bodily integrity, they are distinct in that they relate to the lasting connection between the body and the soul. However, for other families, religion was described as an outlet for making sense of their loved one's death. Throughout, the body was interpreted as being "*a gift from God*" (22). In line with these beliefs, death and the decision to provide consent for organ donation was considered as a way of acting in accordance with God's will. These findings suggest that families seek to make sense of their loss in the context of a higher power.

Taken together, the findings of this review highlight the multifaceted nature of religious beliefs and their (positive and negative) influence on family decision-making. The complexity of this relationship is well-established. Indeed, an existing review of social psychological factors influencing organ donation has echoed these findings, reporting religious beliefs to play both, a facilitating and hindering role in the decision to support organ donation (Falomir-Pichastor et al., 2013). Notably, in the current synthesis, the multifaceted nature of religious interpretations of organ donation may have been compounded by a lack of consensus and disagreement from religious leaders. These findings are supported by qualitative literature from Randhawa et al. (2012). This interview study with UK faith leaders, commissioned by the Organ Donation Taskforce, reported that while no faith groups were against the principles of organ donation, all reported ambiguity and a lack of consensus surrounding their support. One interpretation for this finding is that organ donation represents a fairly new medical procedure, to which there is largely no mention of within religious writings (Randhawa et al., 2012; Stephenson et al., 2008). As a result, the decision to endorse organ donation is often made at an individual level and may arise from subjective interpretations of death, organ donation and religion.

Discrepancies in the supply of organs and waiting times to transplant for minority ethnic groups are well-documented (NHS Blood and Transplant, 2020b). While the various factors contributing to these discrepancies remain somewhat indistinct, ambiguity from religious groups appears to play an important role (Davis & Randhawa, 2006; Falomir-Pichastor et al., 2013). To counter this, awareness campaigns to promote engagement from faith groups, and to increase public and healthcare professionals understanding of religion and organ donation are urgently required. As literature reports a divergence of opinion to arise on occasion within the same faith groups (Randhawa et al., 2010), engagement with faith communities at grassroots levels is needed.

6.5.5 An Intricate Balance of Time and The Need for Compassionate Care

The request to donate a loved one's organs occurs during incredibly difficult and complex circumstances. Within this review, the need for compassionate care and sensitively timed end-of-life conversations were recurrently expressed throughout participants' accounts to have influenced donor decisions. For many families, the donation request was deemed to have arisen too soon following their loved one's death. In such circumstances, families described the unexpected nature of the request to induce severe emotional distress and shock. A key finding within this review is that unexpected donation requests have a detrimental impact on family members' capacity to comprehend the imminent death of their loved one: "*She's not dead and we're whipping bits out of her*" (20). This, in turn, detrimentally impacted the decision to provide consent. Accordingly, the timing of the donation request has been reported across a number of studies as a barrier to obtaining family consent (Chandler et al., 2017; Simpkin et al., 2009). This synthesis demonstrates the importance of ensuring families have sufficient time and support to process and accept the imminent death of their loved one before a request for organ donation should be considered. This concept has broadly been referred to throughout the literature as 'decoupling', defined as a separation in time between the announcement of death and the subsequent request for organ donation (Siminoff et al., 2002). The notion of 'sufficient time' to process the unexpected death of a loved one is inherently difficult to definitively label. In these circumstances, the provision of specialist donation staff plays an important role in supporting families through this process. Both factors are central to the UK best practice guidelines on approaching the families of potential donors (NHS Blood and Transplant, 2013a). In short, the guidelines emphasise the importance of confirming that relatives understand and demonstrate a degree of acceptance of their loss with senior trained medical staff before the donation request is initiated by a specialist nurse in organ donation (SN-OD).

6.5.6 Strengths and Limitations

This study contributes to the existing literature by providing a contemporary synthesis, using an established analytic method, of the factors influencing family decision-making for posthumous organ donation from the perspectives of over 600 bereaved family members. While the views of family decision-makers across 12 nations provide a valuable international context to this review, there were discrepancies in the reporting of contextual factors, such as variations in cultural and health-care provisions within the primary articles. In addition, the review excluded articles not published in English. As such, this may limit the transferability of the findings to different contexts. Moreover, there were substantial differences in the methodological quality of the included articles. This predominantly related to the principles required for rigorous qualitative research, including consideration of reflexivity and of the overall role the authors played during data collection, analysis and interpretation. Consequently, this may limit the interpretations and trustworthiness of the findings. It is important to also acknowledge that, as the study synthesis was conducted primarily by one independent researcher, there may be a degree of bias within the analysis and interpretation of the study findings. However, steps were taken to mitigate this, including a series of iterative meetings with members of the research team throughout the theme development stages, and peer-debriefing, which led to a slight revision of themes. Finally, there is an inherent selection bias among the included participants, as ultimately, only family members willing or able to verbally express the factors influencing their decisions were included.

6.6 Conclusions

The request to donate a loved one’s organs arises in the midst of an untimely and unexpected tragedy. This review has demonstrated that irrespective of consent-related outcome, family decision-making about organ donation is fraught with challenges. The provision of specialist staff trained to deliver compassionate and sensitively timed donation discussions appears to have an important positive influence on the family’s experience and their consent-related decisions. A particular challenge during the donation process is the perceived paradoxical nature of a brain-death diagnosis and the subsequent burden of responsibility this may impose on potential donor families. Future research examining the optimal ways of communicating this difficult diagnosis is warranted. This synthesis also reinforces the complex nature of the relationship between religion and organ donation. As such, future research aimed at understanding religious deterrents and widespread communication strategies designed to encourage engagement from members of faith and belief groups is essential.

Acting in accordance with the deceased’s donor decision emerged as the most salient factor influencing consent-related outcomes. For family members, an actively recorded or verbally expressed donor decision was an important way of alleviating family uncertainty and ensuring “*peace of mind*”. However, multiple nations across the world are now considering altering the model of consent for organ donation to an opt-out system in the hopes of improving rates of transplantation. In the UK, deemed consent legislation has been heralded as a method of improving the persistently low rates of family consent for organ donation. However, this review has emphasised the complexities of consent-related decisions to persist irrespective of donation policy. In sum, continued efforts to enhance family communication and support for relatives involved in end-of-life decisions remains of the utmost importance

Chapter 7: General Discussion

This thesis was submitted on 26 March 2021, the day Scotland legally transitioned to an opt-out system of organ and tissue donation. The implementation of opt-out legislation across England, Scotland and Wales signifies a landmark change from the longstanding 'opt-in' policy of consent. From the onset of this research in October 2017, it was clear that while extensive literature had advocated for the key role of affective attitudes in guiding donor-relevant decisions under opt-in systems, no empirical research had explored the barriers to organ donation under an opt-out consent system. The latest figures from NHS Blood and Transplant indicate that more people had actively recorded the decision not to donate their organs between March 2019-2020 than those who joined the organ donor register. As such, a timely investigation into the factors influencing the decision to opt-out was of the utmost importance. The research presented in this thesis, conducted during the transition to opt-out consent in England and Scotland, addresses this important gap by providing the first in-depth examination of the barriers to organ donation under opt-out legislation.

7. 1 Chapter Overview

This chapter first provides an overview of the primary objectives of this research and addresses how each of the studies presented within this thesis achieved these aims. The principal findings from each study will be outlined and interpreted within the context of evidence from existing literature. A detailed discussion of the unique contributions of this research, the potential implications for policy and practice and key directions for potential future research will be provided. Finally, consideration of the study's strengths and limitations, and the final conclusions will be presented.

7.2 Thesis Objectives

1. To develop a greater understanding of the barriers to organ donation under opt-out legislation, with a particular focus on the factors influencing the decision to opt-out of organ donation.

2. To explore the differences between donor decision-making under an opt-out system, namely the factors influencing the decision to actively opt-in, or to take no action and follow deemed consent.

3. To explore the factors influencing family consent and refusal for posthumous organ donation.

4. To investigate methods of overcoming barriers to organ donation (e.g., myth-busting).

7.2.1. Objective 1: The Emotional Barriers to Organ Donation Under Opt-out Legislation

Objective one represents the principal aim of this thesis, which was collectively fulfilled throughout four studies, presented in Chapters 2, 3, 4 and 5. The findings from the preliminary questionnaire (*n* = 1202) in Chapter 2 confirmed, for the first time, that emotional barriers towards organ donation are critical factors influencing anticipated donor decisions under the proposed opt-out system. All four emotional barriers (bodily integrity, medical mistrust, the ick factor, and the jinx factor) were significantly elevated for both participants who report the intention to opt-out and for participants who were at that time, unsure of their donor decision. These findings subsequently enhance the extant opt-in donation literature (Morgan, Stephenson, et al., 2008; O'Carroll, Foster, et al., 2011) by providing the first empirical examination of emotional barriers to organ donation under opt-out legislation.

The qualitative studies presented in Chapters 3 and 4 fulfil objective one, by emphasising the prominent role of two emotional barriers, medical mistrust and bodily integrity concerns, as influential factors in the planned decision to opt-out. Across both chapters, medical mistrust was represented by a deep-rooted unease with the prospect that, in the event of life-threatening injury or illness, health care providers may not act in a patient's best interests. This manifested as beliefs about the inequity of care for registered donors and fears that doctors, inherently motivated to utilise valuable organs, may provide lesser life-saving treatment to patients identified as potential donors. Fears that doctors may hasten or prematurely declare a patient's death and remove organs while a patient is alive also arose. These findings align with existing qualitative literature on the public perceptions of organ donation, and on the factors influencing the decision to register as a donor (Irving et al., 2011; Newton, 2011). A particular strength of this thesis, specifically related to objective one, is in the application of qualitative methodology within the studies reported in Chapter 3 (qualitative analysis of free-text responses) and Chapter 4 (qualitative interview study). This mixed-methods approach acted to triangulate the preliminary quantitative results and provide a rich and more nuanced understanding of these complex emotive factors. The study in Chapter 3 provided, to date, the largest qualitative study (*n* =923) of anticipated donor decision-making under the new opt-out system. Moreover, the qualitative interview study of Chapter 4 was also the first to examine the perspectives of individuals who plan to opt-out of organ donation.

The concept of "fact versus feelings" in relation to these barriers features as a central component of this thesis. Collectively the powerful role of emotional beliefs is perhaps best represented within the following quote arising from the interview study in Chapter 4, section 4.6.1:

> *"I guess it's the "what ifs", it's the what if you aren't really dead and all this sort of nonsense, and the sensible side of me is telling me not to be stupid but the not so sensible side is still questioning it..."*

Bodily integrity concerns represent one of the most powerful deterrents to donor registration (Morgan, Harrison, et al., 2008; Shepherd & O'Carroll, 2014; Stephenson et al., 2008; Viens, 2016). Throughout Chapters 3 and 4, the concept of bodily integrity represented a desire to uphold a sense of respect and dignity for the body, which arose from fears that removing organs leaves the body in a damaged and undignified state. For others, integrity was characterised by a need to maintain a sense of wholeness after death. In this sense, organ donation was considered to disrupt the finality of death: "*I want all of me to die, not a bit of me living on"* (Chapter 4, section 4.6.2).

Existing literature has acknowledged the complexity of such beliefs, describing bodily integrity to be rooted in an individual's subjective interpretation of their body and its sense of physical integrity (Viens, 2016). Hence, the factors that constitute a transgression and violation of bodily integrity may differ substantially amongst individuals and across situations. This was apparent within the interview study of Chapter 4, whereby organ donation was explicitly juxtaposed with a surgical procedure. While surgery was conceptualised as a procedure to "*mend*" the body, organ donation was interpreted as a way of causing harm or making a "*mess*" of the body. Taken together, these findings emphasise the multidimensional and interconnected nature of these barriers. Acknowledging the complexity of these beliefs, it is not surprising there is little consensus on how best to overcome these barriers. While the implementation of opt-out consent may circumvent these factors as active contemplation of emotional barriers can be avoided under a default policy, sustained research is required in order to fully understand the long-term implications of this legislation.

Furthermore, from a bioethics perspective, the principles of integrity and dignity are also considered to be fundamental in the provision of patient autonomy (Rendtorff, 2008). This is important within the context of opt-out consent legislation which now assumes that an individual is willing to be an organ donor in the absence of an explicitly recorded donor decision. Indeed, a unique finding within both studies is that one's individual responsibility and autonomy were perceived as being threatened under an opt-out system. It is plausible that given the relationship between autonomy and integrity in the maintenance of trust between members of the public and healthcare professionals (Delgado, 2019), that the implementation of opt-out consent has the potential to exacerbate these barriers.

When exploring attitudes towards the, then proposed opt-out system within the interview study of Chapter 4, it became clear that the novel barriers in relation to autonomous choice, which are arguably specific to the nature of default policy, may play a role in the decision to opt-out. Aside from government reports, limited research had examined these factors in relation to opt-out legislation. As the Organ Donation Taskforce rejected the proposals for opt-out legislation over concerns the law would destabilise the nature of consent, a detailed exploration of these factors was urgently required (Organ Donation Taskforce, 2008b). In short, Chapter 4 gave the first indication that the decision to opt-out may be driven by a desire to preserve one’s autonomy. Ultimately, these findings culminated in the development of Chapter 5, which represented the first empirical examination of psychological reactance theory and opt-out organ donation. Collectively these findings embody the principal unique contribution of this thesis to the wider literature and will be explored within section 7.3.

7.2.2. Objective 2: Differences Between Opt-In and Deemed Consent Decisions

The free-text qualitative analysis in Chapter 3 fulfilled objective 2 by providing new insights into the factors underpinning an active opt-in or passive deemed consent decision. Altering the default position to consent for organ donation now means that an active opt-in decision is no longer compulsory to indicate one’s consent. However, the unambiguous nature of a registered opt-in donor decision was favoured by some, as it serves as irrefutable evidence of one’s resolve to donate and may eliminate the likelihood of family interference. The results also provided important evidence in support of deemed consent legislation as a way of reducing the longstanding intention-behaviour gap. It was found that those who plan to follow deemed consent often expressed underlying willingness to be an organ donor, yet a lack of motivation or “*laziness*” had prohibited these positive intentions from being translated into action. Most notably, these findings strengthen literature on default donation policies and suggest that deemed consent may broaden the pool of potential donors by automatically including ambivalent, ‘passive-positive’ individuals who expressed positive donation attitudes but were reluctant to confront aversive emotional barriers during the active registration process (see Chapter 3, section 3.9.2 for further exploration of this) (Johnson & Goldstein, 2003; Siegel et al., 2010). While these findings are promising, it is important to reflect on the crucial role of family consent in this context.

It is well-known that families are almost twice as likely to provide consent for organ donation in instances where the deceased had registered or discussed their decisions with significant others (NHS Blood and Transplant, 2020a). For individuals who are ambivalent towards organ donation, it is plausible that the barriers which prevented this group from actively registering: “*I don't want to think about dying*” (Chapter 3, section 3.6.1) may also reduce the likelihood of this group actively discussing their donor decisions with family. Previous research, which almost exclusively focused on the student population, has described perceived negative experiences, lack of motivation, uncertainty and discomfort at discussing one’s death to impede family discussions (Breitkopf, 2006; Hyde & White, 2007, 2009a).

While the role of ambivalence and family communication is as yet unclear, future research examining the barriers to initiating donation discussions are, in light of the legislative change, an important avenue for future research.

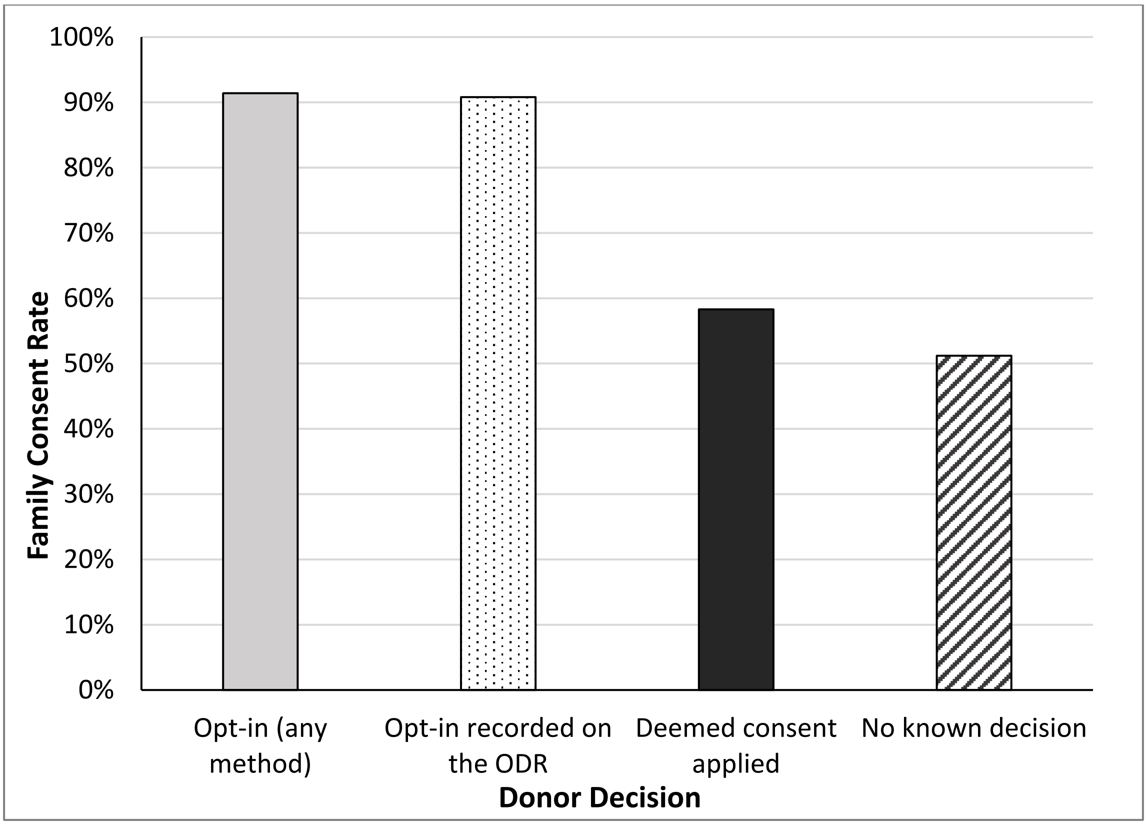
7.2.3. Objective 3: Family Consent and Refusal for Organ Donation.

To fulfil objective 3, Chapter 6 presented a contemporary, international, qualitative systematic review of 22 studies, which synthesised the perspectives of over 600 bereaved family members to provide insights into family decision-making. The decision to focus on family consent evolved in response to the novel findings of Chapter 3, which indicated that while active donor registration is no longer necessary to indicate consent under an opt-out system, it was considered by some as a way of protecting one's decision from family interference or uncertainty. Through the application of a thematic synthesis, it became apparent that upholding the will of the deceased is an integral factor influencing next of kin donor decisions. Given the central implications of this theme in the context of opt-out legislation, the following section will focus only on this principal review finding. In support of the findings from Chapter 3, the provision of a recorded or verbally expressed donor decision signified to donor families that their surrogate decision aligned with their loved one's choice. In fact, even in instances where families were themselves not personally supportive of organ donation, this knowledge acted to protect the deceased's autonomy over their donor decision: "*... I was just doing it because he wanted to. Because I can assure you I wouldn't have done it"* (Chapter 6, section 6.4.5.). This clearly demonstrates the powerful influence of a recorded or expressed donor decision in increasing the rate of family consent. An extensive body of international literature strengthens this finding, reporting uncertainty regarding the deceased's views to be a primary reason for family refusal (Barber et al., 2006; de Groot et al., 2012; Hulme et al., 2016; Miller & Breakwell, 2018; Walker et al., 2013).

7.2.3.1 Maintaining Family Consent Under Opt-out Legislation

It is imperative also to consider the implications of the review findings in relation to opt-out legislation, where the absence of a recorded donor decision should now be used to imply consent for donation. The findings from Chapter 6 highlight that in nations with an opt-out system, families experience the same degree of decisional uncertainty: "*they would always worry if you really wanted (or didn't) want it*" (Chapter 6, section 6.4.5.). Indeed, a number of experimental studies have echoed this interpretation, reporting that opt-out legislation will do little to improve the rate of family consent, as passive donation decisions (taking no action and consent being deemed automatically) renders one's true donor intentions indistinct (Davidai et al., 2012; Lin et al., 2018; Rosenblum et al., 2012). Figure 7.1 highlights this discrepancy in relation to the annual consent figures published by NHS Blood and Transplant (NHS Blood and Transplant, 2020a). This illustrates that between 2019-2020 on occasions where deemed consent applied in Wales, the rate of family consent or authorisation was only slightly above that recorded when families were unaware of their loved one's decision. Taken together, while a deemed consent system may go some way towards increasing the rate of family consent, by far the most important factor remains the provision of a documented or verbally expressed organ donor decision.

Figure 7. 1. Family Consent Between 2019 to 2020 by Active or Passive Donor Decision



Note. Any method includes, consent recorded on the Organ Donor Register (ODR), those expressed verbally, or via an appointed representative.

To that end, the above findings provide evidence to suggest that deemed consent alone may not increase the number of deceased organ donors and rates of transplantation. Instead, sustained research focused on developing strategies that continue to encourage individuals to register as a donor, and to share their decisions with family members is of critical importance. Reflecting on the Welsh example, whereby family overrides initially increased by 50% following the introduction of opt-out consent, it may also be important to pre-empt an initial surge in family refusal in England and Scotland (Noyes, McLaughlin, Morgan, Walton, et al., 2019). The increase in family overrides in Wales was later attributed to two factors, first that the introduction of deemed consent had provided an additional route for family members to override donor-decisions and secondly, heightened uncertainty regarding the families' position under the new donor system. In response, the Welsh Government reformed the nationwide communications campaign to one which focused on promoting family discussions to reduce the proportion of family overrides: https://www.youtube.com/watch?v=iXPknPeUQMc. This emotive campaign which encouraged families to "*talk about organ donation, or someone else may speak for you"* may have contributed towards the subsequent recovery in overall rates of family consent. In light of this, the introduction of a similar campaign in England and Scotland which both prompts families to share their views and emphasises the family's role in honouring their loved one's choice may mitigate the risk of heightened family refusal. Tailoring of these campaigns is a critical area in which future research should target.

7.2.4. Objective 4: Strategies to Overcome the Barriers to Organ Donation

The findings of the experimental manipulation described in Chapter 2 indicated that a myth-busting intervention used by the NHS, significantly reduced levels of medical mistrust. However, this effect did not translate into an increase in donor intentions for the groups this intervention was intended to impact, those who plan to opt-out and those who are undecided. These findings may be attributed to a 'backfire' or 'boomerang' effect, which, in the context of this thesis, represents increased beliefs in harmful donation myths following exposure to corrective information (Swire-Thompson et al., 2020). This is thought to occur as a result of counterarguing, whereby an individual will generate counterarguments that align with their negative beliefs to challenge corrective information (Nyhan & Reifler, 2010). This effect, which is strongest in those with negative beliefs or worldviews towards a particular topic, may explain why the intervention was not effective for the opt-out and not sure group.

Findings from existing studies support this interpretation, reporting similar interventions in the context of vaccination myths to have a detrimental impact on those with heightened negative attitudes towards the targeted behaviour (Hornsey et al., 2018; Nyhan & Reifler, 2015). In line with dual-processing models of decision-making, these findings suggest that interventions targeting emotions rather than facts, may be more effective (Strack & Deutsch, 2004). Overall, countering misinformation is a particularly difficult challenge, as the Covid-19 pandemic has demonstrated. In light of the transition to opt-out consent in Scotland and the potential for myths and misinformation to proliferate rapidly[5], regular monitoring, and correction of harmful information, specifically from credible sources is of key importance (Guillory & Geraci, 2013).

The qualitative findings in Chapter 3 also provide anecdotal evidence in support of reciprocity interventions, e.g., "*I would accept an organ from a deceased donor in order to save my own life*" at increasing donor-relevant behaviours. For both, individuals who plan to actively register as a donor, and those who plan to follow deemed consent, the concept of reciprocal altruism was an influential factor in their decision. This finding provides additional support for existing literature on the efficacy of reciprocity priming as a strategy to increase active registrations (O'Carroll et al., 2018; Sallis et al., 2018).

7.3 Unique Contributions of This Thesis

More than a decade has passed since the Organ Donation Taskforce unanimously rejected the proposal for an opt-out system in the UK. However, several of the primary factors used to inform this decision have received limited investigation. This thesis addresses this paucity by providing the first detailed examination of autonomy, government trust, and perceived threat to freedom as unique deterrents under an opt-out system.

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[5] NHS correction of misinformation circulating in England ahead of the transition to opt-out consent https://www.organdonation.nhs.uk/get-involved/news/fake-news/

7.3.1 Consent Versus Coercion

Within the interview study of Chapter 4, the notion of 'consent versus coercion' highlights that the presumptive nature of assumed consent was considered as a way of constraining one's autonomy. As previously defined, the provision of informed consent and the capacity for an individual to make decisions free from the influence of external factors, embodies the core principles of autonomy (Rendtorff, 2008). Under the former opt-in system, whereby only active registration signalled consent for donation, members of the public were able to exercise their freedom of choice in the decision not to be an organ donor: "*if they do nothing, then nothing happens and I think that's their right, it's their body*" (Chapter 4, section 4.5.1). However, the transition to opt-out consent alters this position, and the absence of an explicitly recorded objection now indicates consent for donation. To that end, the implementation of opt-out legislation may, in principle, result in an individual being considered as an organ donor against their will. Notably, this interpretation draws an interesting parallel to the excerpt presented from the Organ Donation Taskforce, who made explicit reference to the value and importance of active registration as a clear signal of informed consent for organ donation (Organ Donation Taskforce, 2008a, p.34)

> *If we take registration as a donor to be a valid instance of consent, and further interpret it as a clear statement of an important wish on the part of the patient, we might argue that anything we do to facilitate the patient having that wish fulfilled is in his or her best interests. However, if we are unclear about the value of the consent, or where no wishes have been stated, we would have to concede that some of the actions taken to facilitate donation may not necessarily be in the interests of the donor* (Organ Donation Taskforce, 2008)

Accordingly, in anticipation of the legislative change, the act of opting out of organ donation was considered to defend one's fundamental right to autonomy. It should also be noted that within Chapter 3, perceptions of constrained autonomy were also shared by individuals who had previously registered as an organ donor:

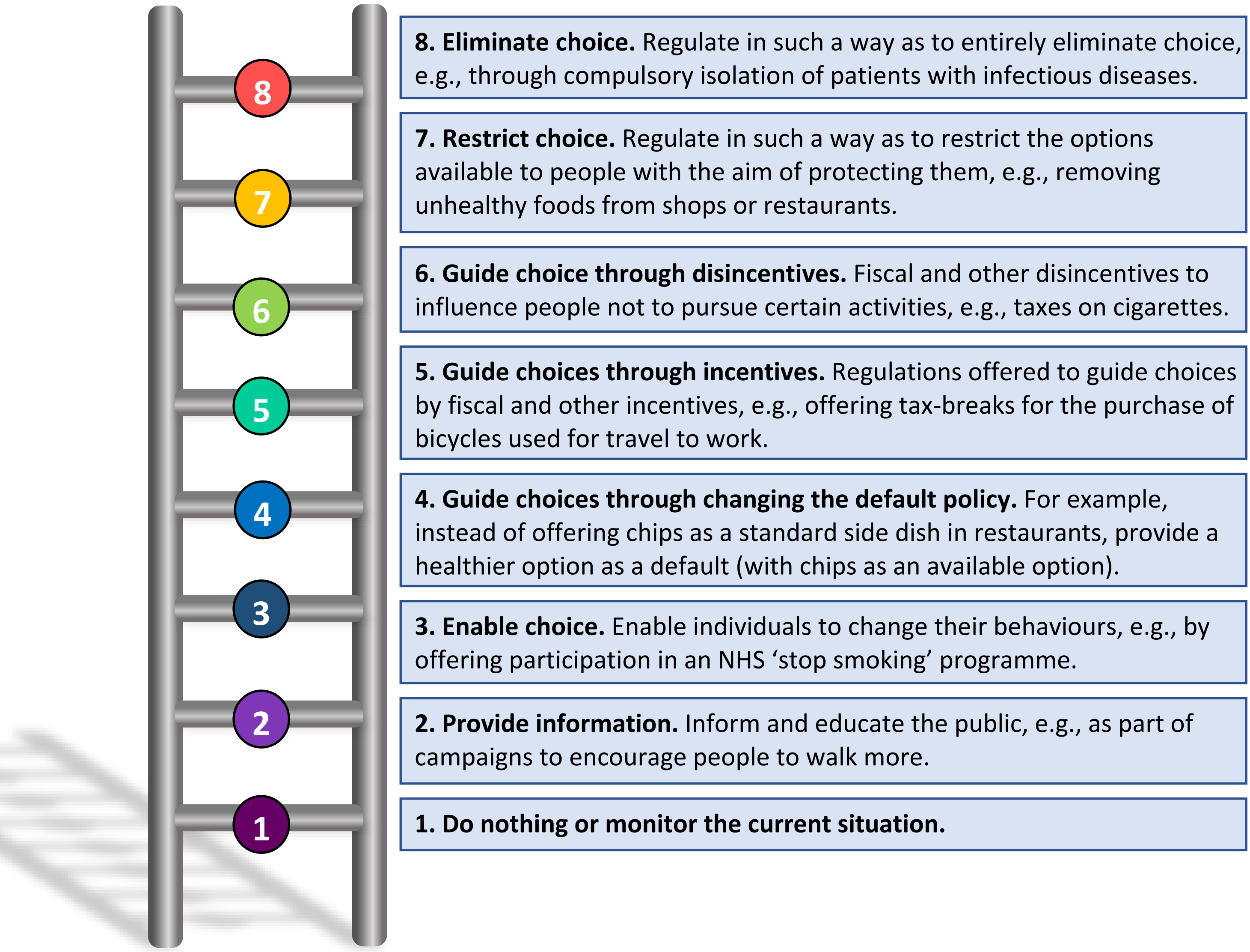
> *If I donate my organs it's a gift. If you take them it's theft. My body belongs to me. It does not belong to the state to do with as it sees fit. I am a registered organ donor. I will not be if it goes to opt-out.* (Chapter 3, section 3.8.3)

While few expressed this interpretation, this finding affirms the deep-rooted, intrinsic value of autonomy and may suggest that members of the public who have previously chosen to register as a donor, may opt-out in principle to protect their autonomy. This barrier is somewhat specific to the nature of the legislative change and not in relation to organ donation *per se*. While the importance of autonomy and freedom of choice, particularly within the context of healthcare and bioethics is well documented (Deci & Ryan, 1987; Rendtorff, 2008), this thesis provides important evidence to reinforce the role of autonomy as an central factor under opt-out legislation.

7.3.2 Autonomy and Policy Intrusiveness

Evidence from a review of the public acceptability of government health-related policy interventions provides important insights in relation to these findings (Diepeveen et al., 2013). In this review study, the authors reported that the level of policy 'intrusiveness', defined in this context as the degree of restriction a government policy incurs on ones' freedom of choice, to be a fundamental predictor of legislative acceptability and support. Policy intrusiveness was characterised in accordance with the intervention ladder, proposed by Nuffield Council of Bioethics (Nuffield Council on Bioethics, 2007). A diagram of the intervention ladder adapted from a Nuffield report on ethical issues in public health is presented in Figure 7.2. This model proposes eight levels of legislative change with varying degree of intrusiveness; from level one, which constitutes taking no action (least intrusive), to level eight which involves implementing a policy that explicitly eliminates choice (most intrusive). Arguably, altering the default position to consent for organ donation, optimally aligns with level four of the intervention ladder; 'guide choices through changing the default policy'. However, the findings of the previous chapters of this thesis (Chapter 3, Chapter 4, and Chapter 5) demonstrates that an opt-out policy for organ donation was appraised by some as restrictive and a coercive method of procuring donor organs. This heightened perception of policy intrusiveness may subsequently align with level seven or eight of the intervention ladder, 'restrict' or 'eliminate choice'; *"if it's opt-out you remove their choice and their voice"*.

Figure 7. 2. The Intervention Ladder, Adapted from Nuffield Council of Bioethics



8. Eliminate choice. Regulate in such a way as to entirely eliminate choice, e.g., through compulsory isolation of patients with infectious diseases.

7. Restrict choice. Regulate in such a way as to restrict the options available to people with the aim of protecting them, e.g., removing unhealthy foods from shops or restaurants.

6. Guide choice through disincentives. Fiscal and other disincentives to influence people not to pursue certain activities, e.g., taxes on cigarettes.

5. Guide choices through incentives. Regulations offered to guide choices by fiscal and other incentives, e.g., offering tax-breaks for the purchase of bicycles used for travel to work.

4. Guide choices through changing the default policy. For example, instead of offering chips as a standard side dish in restaurants, provide a healthier option as a default (with chips as an available option).

3. Enable choice. Enable individuals to change their behaviours, e.g., by offering participation in an NHS ‘stop smoking’ programme.

2. Provide information. Inform and educate the public, e.g., as part of campaigns to encourage people to walk more.

1. Do nothing or monitor the current situation.

7.3.3 Psychological Reactance and Opt-out Organ Donation

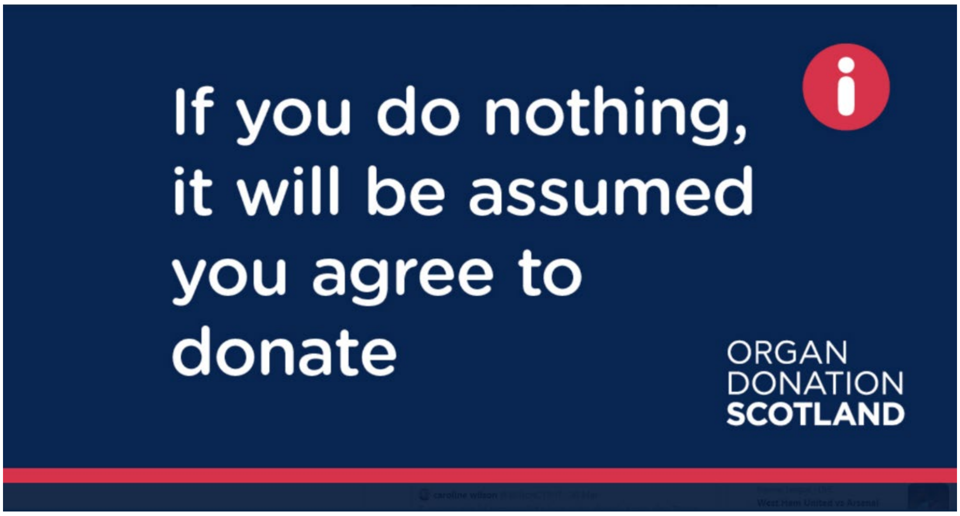
The findings of Chapter 4 affirmed the intrinsic value of autonomy when making donor-relevant decisions and highlighted perceptions of coercion and constrained freedom of choice to be an important factor driving the decision to opt-out. As such, the theory of psychological reactance (Brehm & Brehm, 1981), which posits that following a perceived threat to one’s behavioural freedom, an individual will experience resistance and may be driven to take action to restore their autonomy, was applied to enhance our understanding of these important deterrents.

Reactance is crucial in the context of political change and is distinctly sensitive to message features and language, owing to the often-direct nature of public health communication. Given the requirement for a nationwide communications campaign to promote opt-out legislation, Chapter 5 focused on examining, for the first time, the role of a language and framing manipulation within opt-out organ donation campaigns on the development of reactance. The principal finding arising from this chapter was that subtle, 'real-world' language and framing manipulations applied to opt-out organ donation campaigns can have a harmful impact on perceptions of threat to freedom, anger, credibility and donor intentions. In particular, when publicising the change in legislation in England and Scotland, it is imperative that overtly high threat language and loss frame messaging, which emphasises the number of lives lost due to the donor shortage, are avoided. These findings are consistent with extant health communication literature (Quick et al., 2015; Reinhart et al., 2007).

A key consideration is that the strength of manipulations in this study, as shown in Table 5.1, section 5.3.7, are likely to be considerably less direct and less overtly persuasive than campaigns disseminated by the media. Accordingly, there is a risk that, if not communicated sensitively, media reports of opt-out legislation could increase the number of opt-out registrants. While evidence highlights the impact of negative sensationalist representations of organ donation in the media on rates of donation, few studies into the relationship between the media, dissemination of political change and subsequent public attitudes has been conducted. In partial acknowledgement of this gap, a recent study has, using a "summative" content analysis reviewed the media coverage of opt-out legislation in Wales between 2015-2017 (Dallimore et al., 2019). In sum, the valence or 'tone' of the media coverage varied; 55% of sources were reported to have a positive tone, 30% had a neutral tone and 15% were coded as having a negative tone, e.g., '*Organs can be taken from the dead without prior consent: Landmark law change in Wales*.' The valence of media coverage and subsequent media endorsement for opt-out legislation was also found to improve over time, from just 3% positive coverage in 2015, to 60% in 2017 following enactment of the law. A replication of this study in England and Scotland and further research investigating the impact of opt-out media coverage on attitudes and intentions towards organ donation would provide key actionable insights to inform future organ donation campaigns.

While the findings of Chapter 5 did not support the use of autonomy supportive language as a method of increasing donor intentions, this should not be considered to reflect the inefficacy of autonomy supportive language. Indeed, those exposed to the low threat, autonomy supportive condition, reported significantly less perceptions of threat to freedom that those in the high threat condition; a finding supported by existing evidence in this area, (Miller, 2015; Rosenberg & Siegel, 2018). Reflecting on the findings discussed in Chapter 4, participants demonstrated a marked reactant response to the word ‘presumed’ when describing the opt-out system; *“you could absolutely never get away with presumed consent in damn near every other area of life”* (Chapter 4, section 4.5.2). To that end, the evidence presented in this thesis advocates for the avoidance of similar presumptive word choice (as illustrated in Figure 7.3) and suggests the application of more autonomy supportive language or phrasing – for example, ‘if you do nothing, you may be considered as a donor’ – is an important application of this research.

Figure 7. 3. Opt-out Advertisement Shared by Organ Donation Scotland



If you do nothing, it will be assumed you agree to donate

ORGAN
DONATION
SCOTLAND

The findings of Chapter 5 also reported individuals with higher trait reactance, who have an inflated desire for autonomy and are more susceptible to impingements on their freedom, were more inclined to opt-out of organ donation. Evidence in the domain of vaccine hesitancy reinforces this finding (Hornsey et al., 2018). Taken together, these results bolster and triangulate the qualitative findings within Chapters 3 and 4 of this thesis, whereby the upcoming legislative change was considered as a coercive system described to threaten participants’ sense of individual responsibility: *“I don’t want to do this…why are you saying that I do? Don’t make a decision for me”* (Chapter 4, section 4.5.2). In relation to these novel findings, several principal recommendations when communicating the legislative change will be discussed in section 7.4: Implications for Policy and Practice.

7.3.4 Anticipated Donor Decisions Under Opt-out Consent

A further contribution of this thesis is in relation to public intentions regarding organ donation. At the time of conducting the research presented in Chapter 2, an evaluation of public intentions regarding the proposed legislative change in Scotland had not been formally assessed. These findings therefore provided the first indication of the nation's probable behaviour and indicated that approximately 10% of the population plan to either opt-out of organ donation or, were at that time, unsure of their anticipated donor decision in the event of opt-out legislation being introduced in England, Northern Ireland and Scotland. As discussed in Chapter 2, section 2.5.1 the opt-out intentions reported in this thesis are substantially lower than those recorded in other nations. While this could be understood to indicate greater support for opt-out legislation among the study sample, over 70% of respondents in Chapter 2 were registered as organ donors and thus, the findings should be interpreted in the context of a probable selection bias.

7.3.5 The Efficacy of Opt-out Defaults

This thesis provides important insights into the public perception of opt-out policies and the role of autonomy and psychological reactance in the decision to opt-out of organ donation. At this preliminary stage, there is limited evidence to enable a comprehensive assessment of the efficacy of opt-out legislation in the UK. However, the findings of an extensive meta-analysis on the effectiveness of default policies has important implications in relation to the thesis findings (Jachimowicz et al., 2019). In terms of policy efficacy, across 58 studies, opt-out default policies were observed to have a substantial influence on decision-making, resulting in a significant increased uptake of the default option, with a medium effect size ($d = 0.68$). Despite this, the authors noted substantial variability in efficacy, with default policies found to be most effective in consumer choice domains, in comparison to environmental and health-related domains.

7.3.5.1 The Efficacy of Opt-out Defaults: Government Trust and Endorsement

The authors of the above review then applied the theoretical framework used by Dinner and colleagues (2011) to examine the impact of three factors, recognised to influence the acceptability and efficacy of default policy: endowment, endorsement, and ease (Dinner et al., 2011). The findings indicated that public attitudes towards the choice architect (e.g., the person accountable for implementing the default policy) play a key role in policy efficacy. Specifically, lower endorsement or trust in the choice architect was a key mechanism in reduced compliance with the default option (Jachimowicz et al., 2019; Tannenbaum et al., 2017). Indeed, endorsement has a particularly powerful effect in the context of sensitive interventions (McKenzie et al., 2006). In this US study, participants were required to judge policymakers implied endorsement across default and non-default donation policies. Under a hypothetical default policy for organ donation, participants were more likely to infer the policy to represent an implicit recommendation from policymakers in terms of desired behaviour. Applying this evidence in the context of this thesis, suggests that members of the public are more likely to attribute a default donation system as a signal or implicit recommendation from the government that one ought to be an organ donor. As such, maintaining levels of trust in the policy architect arguably becomes more important under an opt-out policy. Compelling evidence of diminished government trust described by some participants throughout the qualitative studies in Chapter 3 and 4 subsequently provides support for this interpretation: *"it's very very sneaky on the part of the government to kinda try to force people into doing something they may not necessarily want to do".* The role of policy endorsement was further strengthened by the quantitative findings of Chapter 5, whereby reduced trust in the government emerged, for the first time, as a significant predictor of anticipated opt-out decisions. Taken together, these findings reinforce the importance of maintaining government trust in the context of a sensitive population-wide health policy.

7.4 Implications for Policy and Practice

While implications have been discussed throughout this chapter in relation to the core thesis objectives, a number of key implications have arisen from unique findings of loss of autonomy, reactance and government trust in relation to opt-out consent.

A core implication of this research is the need for sustained evidence-based communication campaigns to ensure awareness and understanding of the legislative change. This is critical, as Chapter 5 illustrated heightened reactant responses to occur in those who were unaware of the legislative change. Indeed, existing evidence reports awareness of a nation's legislative framework to be an important factor in willingness to donate (Shepherd & O'Carroll, 2013). Drawing on the Welsh experience, awareness of opt-out legislation decreased to 70% almost two years post-implementation. This coincided with a reduction in spending allocated for promotion. A subsequent increase in campaign activity focused on family consent and the re-introduction of television and radio advertising between September 2017 and March 2018 acted to increase awareness to 82%. This highlights the importance of a prolonged communication campaigns in England and Scotland.

When communicating the opt-out system, the role of the family should not be understated. In sum, as the evidence in this thesis has reinforced the considerable challenges families face when making donor-relevant decisions, the transition to opt-out consent and the sustained level of population-wide promotion would be a useful opportunity to prompt family members to discuss their wishes.

Further actionable implications in relation to the interview findings of Chapter 4, section 4.7 – '*Riddled with pitfalls*' – should be noted. Throughout, participants expressed concerns that recording an opt-out decision would be purposely challenging and prohibitive: *"they will make it as awkward as possible to opt-out in my opinion*". Anticipated impediments when recording the decision to opt-out may contribute towards perceptions of coercion, reduced trust in the government and the subsequent risk of reactance under opt-out legislation. In particular, the preservation of trust in the government during this sensitive legislation change represents a particularly formidable challenge with no easy or obvious solution. However, a potential means of minimising these barriers when communicating opt-out consent in the media, is to ensure the pathway for registering an opt-out decision is clearly communicated, and the opportunity to register an opt-out decision as straightforward and accessible as possible. This may act to reduce implicit perceptions of coercion.

7.5 Key Directions for Future Research

The implementation of opt-out legislation signals a critically important period for further research. This thesis has identified a number of avenues which future research should investigate. As previously acknowledged, the absence of an objective verified measure of donor behaviour, though necessary, is a limitation of this thesis. As opt-out legislation has now been introduced in England and Scotland, a natural progression of this research would be to examine the discriminant utility of emotional barriers between verified donors and those who have actively registered an opt-out decision.

Collectively, this research provides preliminary evidence on the mechanisms behind opt-out decisions, and emphasises the contributing role of autonomy, government trust and psychological reactance. There is an urgent need to develop a comprehensive model of donor behaviour incorporating these variables within the context of opt-out legislation. Therefore, further examination of these variables, specifically in a trait capacity, and their contribution towards verified opt-out decisions would be an essential addition to the evidence base.

Chapter 5 provides important evidence to suggest that subtle manipulations in language and message framing can heighten reactance and impact one's donor intentions. Two primary avenues for future study have been identified. Firstly, the media play a principal role in disseminating awareness of political change. Therefore, future studies examining the media coverage throughout the transition to opt-out consent, and the role this plays in the development of reactance, public attitudes and intentions towards opt-out consent is an important area for future study. Secondly, identifying the most appropriate components for future organ donation campaigns is of critical importance. In particular, the systematic examination of evidence-based techniques to mitigate reactance and increase positive behavioural intentions, including restoration postscript messaging and inoculation messaging, would provide key actionable insights.

Finally, the findings of Chapter 6, emphasise the complex and emotive nature of donation decision-making faced by the family of potential organ donors. Given the importance donor families placed on protecting the deceased's agency and honouring their donation choice, future research should explore the development and acceptability of strategies to sensitively emphasise this during the donation request process. This is vital in the context of opt-out legislation, whereby confusion over the families' role under the new donor system in Wales contributed towards an increase in the number of families overriding their loved ones recorded donor decision.

7.6 Limitations of This Thesis

There are a number of limitations to this research which should be acknowledged. Primarily, as the barriers to organ donation were investigated in the context of a self-report measure of planned behaviour, the findings within studies 1, 2, 3 and 4 are limited by the absence of an objective measure of actual donor behaviour. It is well-acknowledged that behavioural intentions do not wholly translate into actual behaviour (Webb & Sheeran, 2006). However, the decision to rely on self-report measures was essential, as opt-out legislation had not yet been enacted in either England or Scotland throughout the duration of this research. Therefore, future studies using objective measures of donor behaviour are essential.

A core limitation across the quantitative studies presented in Chapter 2 and 5, is that the study samples were not representative of the general population. As is common in this field, a recruitment bias was evident in both studies, in that the majority of respondents were female participants (Chapter 2 - 80%) and (Chapter 5 - 78%). A selection bias was also evident within both studies, as over 70% of respondents were registered as organ donors. At present, just 40% of the UK population are registered as organ donors, therefore support for organ donation was inflated across both experimental studies (NHS Blood and Transplant, 2020a). Moreover, there was also a limited number of individuals from ethnic minority backgrounds who participated in both studies. However, advertisements for the study in Chapter 5 were distributed across faith centres throughout Central Scotland and may have acted to increase engagement from minority ethnic groups (increasing from just 1.4% in Chapter 2 to 3.8% in Chapter 5). Indeed, Scottish census data indicates that 4% of individuals in Scotland are from minority ethnic groups. In recognition of the serious discrepancies in the supply of organs and transplant waiting times for minority ethnic groups, sustained research and efforts to engage individuals across cultural and faith groups in the UK is warranted.

This research also did not consider the role of traditional rational-cognitive variables (attitudes, knowledge and subjective norms) in driving donor-relevant decisions. While extensive evidence has confirmed the superior role of affective attitudes in distinguishing between donors and non-donors (Brug et al., 2000; Morgan, Stephenson, et al., 2008; O'Carroll, Foster, et al., 2011; Quick et al., 2014), future research should, using an objective measure of verified donor behaviour, evaluate the role of both affective attitudes and “rational” cognitive factors in predicting opt-out behaviour.

7.7 Conclusions

On 26 March 2021 an opt-out consent system for organ and tissue donation commenced in Scotland. This research, conducted throughout the passage of opt-out legislative in England and Scotland, represents the first investigation into the role of emotional barriers in guiding decision-making under an opt-out system. In support of existing opt-in literature, maintaining a sense of bodily integrity after death and fears of medical mistrust were particularly notable factors in the planned decision to opt-out of organ donation. While support for opt-out legislation is generally high, this thesis advocates for the powerful role of autonomy, reactance and government trust as influential factors in the decision to opt-out. The evidence presented in this thesis affirms the risk that, if not managed sensitively, the opt-out system could have detrimental impact on attitudes, intentions, and may increase the number of opt-out respondents. In sum, it is crucial that the implementation of opt-out legislation is not considered as a simple solution for the critical shortage of organ donors in the UK.

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Appendices

Appendix 1: Organ Donation Taskforce Recommendations 1-9

1. A UK-wide Organ Donation Organisation should be established.

2. The establishment of the Organ Donation Organisation should be the responsibility of NHSBT.

3. Urgent attention is required to resolve outstanding legal, ethical, and professional issues to ensure that all clinicians are supported and able to work within a clear and unambiguous framework of good practice. An independent UK-wide Donation Ethics Group should be established.

4. The NHS must embrace organ donation as a usual, not an unusual event. Local policies, constructed around national guidelines, should be put in place. Donation discussions should be part of end-of-life care when appropriate. Each Trust should have a clinical donation champion and a Trust donation committee to help achieve this.

5. Minimum notification criteria for potential donors should be introduced on a UK-wide basis.

6. Donation activity in all Trusts should be monitored. Rates of potential donor identification, referral, approach to the family and consent should be reported.

7. Brain Stem Death (BSD) testing should be carried out in all patients where BSD is a likely diagnosis, even if organ donation is an unlikely outcome.

8. Financial disincentives to Trusts facilitating donation should be removed through the development and introduction of appropriate reimbursement.

9. The current network of DTCs should be expanded through central employment by a UK-wide Organ Donation Organisation. Additional co-ordinators, embedded in critical care areas, should be employed to ensure a comprehensive, specialised and robust service. There should be collaboration between DTCs, clinical staff and Trust donation champions. Electronic donor registration and organ offering systems should be developed.

Appendix 1 (Cont.): Organ Donation Taskforce Recommendations 10-14

10. A UK-wide network of dedicated organ retrieval teams should be established to ensure timely, high-quality organ removal from all heart beating and nonheart beating donors.

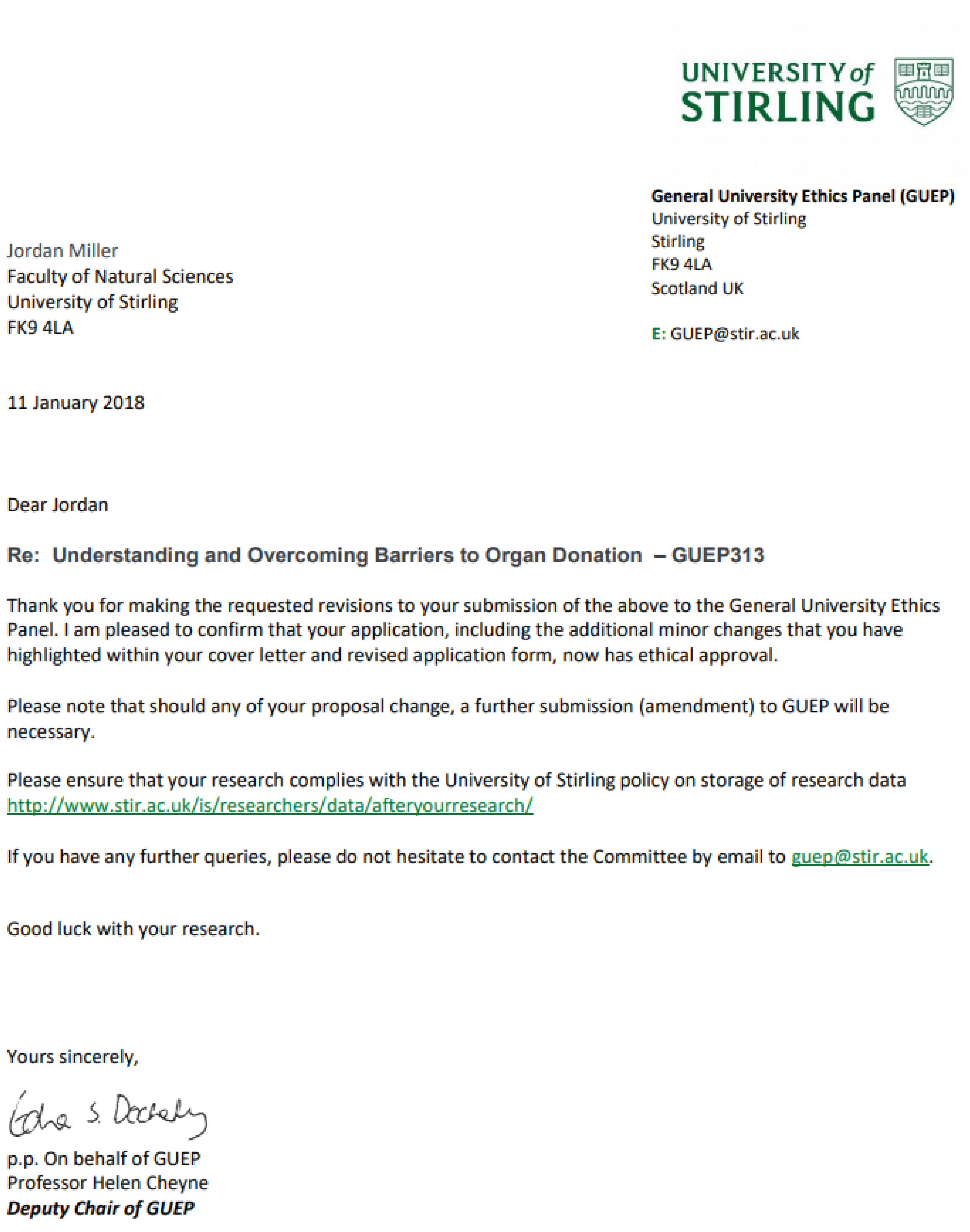
11. All clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation.

12. Appropriate ways should be identified of personally and publicly recognising individual organ donors, where desired. This may include national memorials, local initiatives and personal follow-up to donor families.

13. There is an urgent need to identify and implement the most effective methods through which organ donation and the ‘gift of life’ can be promoted to the general public, and specifically to the BME population.

14. The Department of Health and the Ministry of Justice should develop formal guidelines for coroners concerning organ donation.

Appendix 2: Ethical Approval for Study 1 (Chapter 2)



UNIVERSITY of STIRLING

General University Ethics Panel (GUEP)
University of Stirling
Stirling
FK9 4LA
Scotland UK

E: GUEP@stir.ac.uk

Jordan Miller
Faculty of Natural Sciences
University of Stirling
FK9 4LA

11 January 2018

Dear Jordan

Re: Understanding and Overcoming Barriers to Organ Donation – GUEP313

Thank you for making the requested revisions to your submission of the above to the General University Ethics Panel. I am pleased to confirm that your application, including the additional minor changes that you have highlighted within your cover letter and revised application form, now has ethical approval.

Please note that should any of your proposal change, a further submission (amendment) to GUEP will be necessary.

Please ensure that your research complies with the University of Stirling policy on storage of research data http://www.stir.ac.uk/is/researchers/data/afteryourresearch/

If you have any further queries, please do not hesitate to contact the Committee by email to guep@stir.ac.uk.

Good luck with your research.

Yours sincerely,

p.p. On behalf of GUEP
Professor Helen Cheyne
Deputy Chair of GUEP

Appendix 3: Recruitment Advert for Study 1 (Chapter 2)

Title: Participants needed for short study on Organ Donation

Understanding and Overcoming Barriers to Organ Donation

We are inviting people over the age of 18 who live in Scotland, England and Northern Ireland to complete a short web-based questionnaire about attitudes and awareness of organ donation.

This project has been approved by The University of Stirling General University Ethics Panel.

In this study, you will be asked to read a short piece of information regarding organ donation in your country. You will then be asked to answer a series of questions about organ donation. This study will take approximately 15-20 minutes to complete.

If you are interested in taking part in this important research, please follow the questionnaire link below:

https://stirlingpsych.eu.qualtrics.com/jfe/form/SV_0NDivtzS8Pse5mZ

For further information, please contact: jordan.miller1@stir.ac.uk

Appendix 4: Participant Information Sheet for Study 1 (Chapter 2)

Understanding and Overcoming Barriers to Organ Donation

Background We are inviting people over the age of 18 who live in Scotland, England and Northern Ireland to complete a short web-based questionnaire about attitudes and awareness of organ donation. This project has been approved by The University of Stirling General University Ethics Panel.

What will this study involve? Before the study begins, you will be asked to confirm you have read and understood the study information. You will then be asked to provide consent to participate in this study by selecting either, Yes or No on an electronic tick box. You will then be provided with a unique 6-digit number in case you wish to withdraw your data. The questionnaire will take approximately 15-20 minutes to complete.

In this study, you will be asked to read a short piece of information regarding organ donation laws in your country. You will then be asked to answer questions about organ donation. **Some of the questions in this study will be repeated, i.e. you will be asked the same question more than once. This is deliberate.**

Some of the questions included in this questionnaire are of a sensitive nature and may make some participants feel uncomfortable. We recognise that organ donation can be an emotive and sensitive subject, but are interested in your honest opinions and views on this important topic. Therefore, you may leave an empty response to any question you feel unable to answer. You are also free to withdraw your participation at any time, without explanation or penalty by closing down your internet browser.

What happens to the data I provide? This research will be used to form part of a PhD thesis and may be published in a journal article. The data obtained from this research will be stored in The University of Stirling's secure database for 10 years. All answers will be completely anonymous.

At the beginning of the questionnaire, we will ask for your postcode. All postcodes will be replaced with an anonymous number to represent the general area in which you live.

At the end of this questionnaire, you will be asked if you would be interested in receiving information about taking part in two follow-up studies. If you consent to receive information about these studies, you will be asked to provide your email address and may be contacted at a later date with more information. All email addresses received by participants interested in taking part in these studies will be stored separately from questionnaire responses. You are under no obligation to participate in any further research.

Can I withdraw my data? Your participation in this research is voluntary and if after participating in this study you decide that you would like to withdraw your data, you are free to do so up to 2 weeks after participating in this study without providing a reason.

To withdraw your data, please contact either Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk, or Jordan Miller jordan.miller1@stir.ac.uk at the University of Stirling up to 2 weeks after participating in this study. If emailing to withdraw your data, please include your 6-digit unique identifier number as a method of identifying which participant information to remove. All data from participants who choose to withdraw from the study will be destroyed and will not be used in the analyses.

Also, if you have any questions, concerns or complaints about the study, please contact either Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk, or Jordan Miller jordan.miller1@stir.ac.uk at the University of Stirling. Should you wish to speak to someone independent of the study, you may contact Dr Stephan Dombrowski s.u.dombrowski@stir.ac.uk.

Thank you for your participation.

Appendix 5: Myths and Counter-Evidence Used in the Myth-Busting Intervention for Study 1 (Chapter 2)

Statement 1. Doctors might not do their best to save someone's life if they know they are on the NHS Organ Donor Register.

It is always the priority of the treating medical team to save a patient’s life.

It is only when the treating medical team in the hospital and the family have accepted that no further treatment can help, and it is not in the patient’s best interest, that 'end of life' care choices are considered. Organ donation as an 'end of life' care choice will then be discussed with a family.

Statement 2. People could still be alive when their organs are removed.

Organs can be donated as a living donor but this is not the type of organ donation being discussed here. Organ donation from a person who has died is called deceased organ donation. There are strict criteria in place in the United Kingdom for the diagnosis of death. Organs are never removed until the patient’s death has been confirmed in line with these criteria.

In the United Kingdom, we determine death in two ways – either confirmation of brain stem death or circulatory death. Brain stem death is confirmed and diagnosed by a series of clinical tests performed twice by two senior doctors.

Statement 3. Organ donation is against many religious beliefs.

The major religions in the UK support the idea of organ donation and transplantation. These include:

- **Christianity**
- **Islam**
- **Judaism**
- **Buddhism**
- **Hinduism**
- **Sikhism**

Statement 4. Organ Donation leaves the body disfigured and afterwards, people won’t be able to have an open-casket funeral.

The donor is treated with the utmost care during the removal of organs and/or tissue for donation. Specialist healthcare professionals will make sure the donor is treated with dignity and respect. We carefully close and cover the surgical incision after donation as in any other surgical procedure. The arrangements for a viewing of a loved one’s body after donation are the same as after a death where donation doesn’t take place.

Organ and tissue donation doesn't stop people from having an open-casket funeral. The body is clothed for burial, so there are no visible signs of organ or tissue donation.

Statement 5. There is an age limit for organ donation.

People of all ages can be organ donors. Patients who die in circumstances where they may be able to donate their organs, irrespective of age are considered individually. Whether or not someone’s organs can be safely used to help others is assessed at the time through a number of assessments. Information from the patient’s clinical and social history is also considered from medical records and the person’s next of kin.

Statement 6. The NHS only need adult organ donors.

Organs from children are needed too.

None of us want to contemplate the death of a loved one, least of all a child. Sadly, some children do die and the decision to donate has provided some comfort to whole families, knowing their child went on to help others. While some organs from adult donors can be transplanted to children, organs such as heart and lungs need to be matched on size. This may mean babies and young children can have a prolonged wait for heart or lung transplants.

Statement 7. There are enough organs available for the people waiting for an organ transplant.

Around three people die every day across the United Kingdom in need of a life-saving organ transplant.

Only 1 in 100 people across the UK die in circumstances where their organs can be considered for transplantation. This means every potential donor is of vital importance.

Statement 8. People who have medical conditions can’t donate.

Very few medical conditions automatically disqualify people from donating.

Medical professionals will determine if the donor's organs and/or tissue could be transplanted based on clinical and medical criteria. Certain organs and/or tissue may not be suitable for transplantation, but others may save or transform lives.

Statement 9. Donated organs can be bought and sold.

This is not true in the United Kingdom. Organ donation is a highly controlled area and is regulated by the Human Tissue Authority. Selling human organs or tissue is illegal.

Appendix 6: Emotional Barriers Measure used in Study 1 (Chapter 2)

	Strongly disagree	**Moderately disagree**	**Slightly disagree**	**Neither agree nor disagree**	**Slightly agree**	**Moderately agree**	**Strongly agree**
1. Removing organs from the body just isn't right.	☐	☐	☐	☐	☐	☐	☐
2. The body should be kept whole for burial.	☐	☐	☐	☐	☐	☐	☐
3. Hospitals sometimes prescribe medication as a way of experimenting on people without their knowledge or consent.	☐	☐	☐	☐	☐	☐	☐
4. If I register as an organ donor, doctors might take my organs before I'm actually dead.	☐	☐	☐	☐	☐	☐	☐
5. Sometimes medical procedures are done on people without their knowledge or consent.	☐	☐	☐	☐	☐	☐	☐
6. If I register as an organ donor, doctors might not try so hard to save my life.	☐	☐	☐	☐	☐	☐	☐
7. The idea of organ donation is somewhat disgusting.	☐	☐	☐	☐	☐	☐	☐
8. I wouldn't like the idea of having another person's organs inside of me, even if I needed an organ transplant.	☐	☐	☐	☐	☐	☐	☐
9. The thought of organ donation makes me uncomfortable.	☐	☐	☐	☐	☐	☐	☐
10. People who donate their organs risk displeasing God or nature.	☐	☐	☐	☐	☐	☐	☐
11. The surest way to bring about my own death is to make plans for it like signing an organ donor card.	☐	☐	☐	☐	☐	☐	☐
12. Organ donors may not be resurrected because they don't have all of their "parts".	☐	☐	☐	☐	☐	☐	☐

Appendix 7: Chapter 2 Analysis Including Covariates

The demographic comparisons between the donor choice groups reported in Chapter 2 (section 2.4.2) indicated significant differences in age, gender, education and ethnicity. The following analysis controls for these variables.

Emotional Barriers: Hypothesis 1

A MANCOVA was conducted to investigate differences in emotional barriers across the planned donor choice groups (opt-in, deemed consent, not sure and opt-out). After controlling for age, gender, education and ethnicity a significant adjusted mean difference between the groups on the combined dependent variables was found, $F(12, 3201) = 33.85$, p <.001; Pillai's V = .338; $r = .34$. Of the four covariates, both age $F(4, 1065) = 9.12$, $p = <.001$, $r = .18$ and education $F(4, 1065) = 4.36$, $p = <.01$, $r = .13$ emerged as significant within the model. To determine which outcome variables contributed towards the significant MANCOVA, a series of univariate ANCOVAs on each of the four emotional barriers were conducted. Group-level differences were explored using a Bonferroni *post-hoc* test. The findings from this analysis are the same as those reported in Chapter 2, pg. 54.

The Impact of Age and Education on Emotional Barriers

To explore the relationship between age on each of the four emotional barriers (bodily integrity, medical mistrust, ick and jinx), a series of Pearson's product-moment correlations were conducted. There was a significant, weak negative correlation between age and jinx factor scores, $r(1119) = -.10$, $p <.01$. The square root of the correlation coefficient was calculated to provide the coefficient of determination, with age found to explain 1% of the variability in jinx factor scores. No significant relationships between the remaining three emotional barriers was found.

To assess the impact of education, grouped as higher education (completion of a bachelor's degree) or lower education on emotional barriers, a series of independent-samples t-test were conducted. Mean bodily integrity knowledge scores were significantly greater for participants with lower education ($M = 1.70$, $SD = 1.21$) in comparison to higher educated participants ($M = 1.47$, $SD = .97$), $t(1032.09) = 3.70$, $p = <.001$. Mean jinx factor scores were significantly greater for participants with lower education ($M = 1.39$, $SD = .79$) in comparison to higher educated participants (*M* = 1.24, *SD* = .60), *t*(1003.57) = 3.78, *p* = <.001. No significant differences between the remaining emotional barriers were found.

Experimental Manipulation: Hypothesis 2 and 3

A 2-way repeated measures ANOVA was conducted to investigate differences in donor intentions across the three time-points (baseline, post emotional barriers and post myth-busting) as a function of group (opt-in, deemed consent, not sure and opt-out). Mauchly's test indicated that the assumption of sphericity was violated, χ^2 (2) = 105.51, *p* <.001. As estimated epsilion was greater than 0.75, a Huynh-Feldt correction was applied.

After controlling for age, gender, education and ethnicity, a significant main effect of group was found, *F*(3, 1104) = 108.39, *p* <.001, *r* = .48. There was no significant main effect of time, *F*(1.85, 2039.42) = .41, *p* = .65, *r* = .02, and no significant interaction found between time point and group, *F*(5.54, 2039.42) = 1.32, *p* = .25, *r* = .06, ε =.92. Of the four covariates, only gender emerged as significant within the model, *F*(1,1104) = 6.53, *p* =.01 *r* =.08.

To determine whether increasing the salience of emotional barriers decreased intentions (Hypothesis 2) and whether exposure to a myth-busting campaign increased donor intentions (Hypothesis 3) a series of *post-hoc* paired samples *t-tests* were conducted. The analysis was conducted individually for each of the four donor choice groups, as such, there was no requirement to control for covariates. Accordingly, the findings are identical to that reported within in the main results of Chapter 2.

The Effect of Gender on Donor Intentions

As gender emerged within the model as a significant covariate, a one-way ANOVA was conducted to further investigate differences in baseline donor intentions between male and female participants. Significant differences were observed, *F*(1, 1187) = 6.34, *p* = .01, *r* = .07. Baseline intention was significantly higher in female participants (*M* = 5.77, *SD* = 2.08) in comparison to males (*M* = 5.37, *SD* = 2.13).

Organ Donation Myths

To examine differences in organ donation knowledge between the groups, a one-way ANCOVA, was conducted. This revealed, after adjustment for age, gender, education and ethnicity, significant differences in knowledge scores between the donor groups *F*(3, 1100) = 17.13, *p* <.001, *r* =.21. Of the four covariates, both age and education demonstrated a significant covariate effect.

To explore differences in the adjusted means between the groups, a Bonferroni *post-hoc* test was conducted. This revealed that both participants who plan to opt-in and those who plan to follow deemed consent, demonstrated significantly higher knowledge scores in comparison to participants who plan to opt-out at *p* <.001. No differences were observed between the opt-in and deemed consent group. Participants in the opt-out group, demonstrated significantly lower knowledge scores than those in the not sure group at *p* =.001. Higher scores indicate greater knowledge of organ donation (lower belief in myths).

The Impact of Age and Gender on Organ Donation Knowledge

A Pearson's product-moment correlation was run to further explore the relationship between age and scores on the organ donation knowledge test. There was a significant, weak positive correlation between age and knowledge scores, *r*(1122) = .17, *p* <.001. The square root of the correlation coefficient was calculated to provide the coefficient of determination, with age found to explain 3% of the variability in knowledge scores.

To assess the impact of education, grouped as higher education (completion of a bachelor's degree) or lower education on organ donation knowledge scores, an independent-samples t-test was conducted. Mean knowledge scores were significantly greater for participants with higher education (*M* = 7.59, *SD* = 1.03) in comparison to lower educated participants (*M* = 7.47, *SD* = 1.11), *t*(1186) = -1.93, *p* =.05.

Appendix 8: Participant Debrief for Study 1 (Chapter 2)

Thank you for giving up your time to take part in this important research project.

The aim of this study was to explore the UK public's knowledge of organ donation, and to explore whether people's intentions to donate their organs after death could be increased following a myth-busting quiz.

This research will be used to form part of a PhD thesis. The data collected from this study will be stored in a secure database and your answers will be completely anonymous. If this research is later published in a journal article, you will not be identifiable in any manner.

Can I withdraw my data? If you decide that you would like to withdraw your data, you are free to do so without providing a reason. To withdraw your data, please contact either Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk, or Jordan Miller jordan.miller1@stir.ac.uk at the University of Stirling up to 2 weeks after participating in this study. If emailing to withdraw your data, please include your 6-digit unique identifier number as a method of identifying which participant information to remove. All data from participants who choose to withdraw from the study will be destroyed and will not be used in the analyses.

Once again, I would like to thank you for your participation and remind you that if you have any questions about the research or any queries you wish to raise, please feel free to contact either Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk, or Jordan Miller jordan.miller1@stir.ac.uk at the University of Stirling.

Should you wish to speak to someone independent of the study, you may contact Dr Stephan Dombrowski s.u.dombrowski@stir.ac.uk.

If you would like to find out more information on organ donation, please visit

https://www.organdonation.nhs.uk/

Appendix 9: Ethical Approval for Study 3 (Chapter 4)

UNIVERSITY of
STIRLING

Jordan Miller
Natural Sciences
University of Stirling
FK9 4LA

jordan.miller1@stir.ac.uk

General University Ethics Panel (GUEP)
University of Stirling
Stirling
FK9 4LA
Scotland UK

E: GUEP@stir.ac.uk

26 June 2018

Dear Jordan

Re: Ethics Application: Understanding and Overcoming Barriers to Organ Donation (formerly GUEP313) - GUEP431

Thank you for making the requested revisions to your submission of the above to the General University Ethics Panel. I am pleased to confirm that your application now has ethical approval.

Please note that should any of your proposal change, a further submission (amendment) to GUEP will be necessary.

Please ensure that your research complies with Stirling University policy on storage of research data which is available at:
https://www.stir.ac.uk/about/faculties-and-services/information-services-and-library/researchers/research-data/before-you-start-your-research/our-policy/

If you have not already done so, I would also strongly encourage you to complete the Research Integrity training which is available at: https://canvas.stir.ac.uk/enroll/CJ43KW

If you have any further queries, please do not hesitate to contact the Committee by email to guep@stir.ac.uk.

Good luck with your research.

Yours sincerely,

p.p. On behalf of GUEP
Professor Helen Cheyne
Deputy Chair of GUEP

Appendix 10: Recruitment Email for Interview Study 3 (Chapter 4)

Dear participant,

You recently took part in a study about organ donation. Thank you very much for taking part. In this study, you indicated that you would be willing to take part in a follow-up interview.

Therefore, we would like to invite you to take part in a telephone interview about organ donation. The interview will last approximately half an hour.

Your views on organ donation are important and it is hoped that this research will help generate a greater understanding of public attitudes towards opt-out organ donor consent. By taking part in this study, the information you provide will be important in shaping future research into organ donation.

If you are interested in taking part, please follow the secure link below. This will allow you to read more information before you decide if you want to take part. If you would like to take part, please follow the instructions to provide consent and to arrange a suitable time for the interview.

You will also be offered a £5 amazon voucher as a thank you for taking part in this important research. This will be emailed to you after the study has finished.

URL link to Qualtrics: https://stirlingpsych.eu.qualtrics.com/jfe/form/SV_55pyEzapG4pZY2x

Appendix 11: Participant Information Sheet for Interview Study 3 (Chapter 4)

Understanding and Overcoming Barriers to Organ Donation

We would like you to consider taking part in a research study. Before you decide, it is important for you to understand what the research will involve and why it is being done. Please read the information below.

Background We are inviting people over the age of 18 who live in Scotland, England and Northern Ireland to complete a short telephone interview about organ donation. Recently the Scottish and English governments have proposed changing the organ donation laws to an opt-out system. This means that when the law changes, instead of signing up to be an organ donor, you are automatically put onto the register unless you decide to remove yourself and opt-out. We would like to know more about what the public think about this decision.

Who has reviewed this research project? This project has been reviewed and approved by The University of Stirling General University Ethics Panel.

Do I have to take part? No, you do not have to take part. If you decide not to take part, simply close down the internet browser. You do not have to reply to the email, and you are under no obligation to take part.

What will this study involve? This study will involve a telephone interview about organ donation, expected to last approximately half an hour. Before the interview, you will be asked to confirm you have read and understood the study information. You will then be asked to provide consent to participate in this study by selecting either, Yes or No on an electronic tick box. You will then be provided with a unique 6-digit number to ensure you remain anonymous. This number can also be used in case you wish to withdraw your data.

To arrange the interview, you can choose a date and time that is suitable for you. The researcher will then email you to confirm a suitable date and time.
Some of the topics covered are of a potentially sensitive nature and may make some participants feel uncomfortable. We recognise that organ donation can be an emotional and sensitive subject but are interested in your honest opinions and views on this important topic. Therefore, you do not have to answer any questions you don’t want to. If at any point, you feel uncomfortable, you may end the interview at any time.

What happens to the data I provide? The interviews will be recorded and then typed up by a professional transcriber. The transcriber has signed a confidentiality agreement to protect your identity and the data. Everything you say will remain confidential. You will be allocated

an anonymous 6-digit number which will be assigned to your data. Any potentially identifiable information will be removed from the transcript and we will ensure that no-one is able to identify you as a participant in this study.
This research will be used to form part of a PhD thesis and may be published in a journal article. Again, if this research is later published, you will not be identifiable in any manner. For example, if any quotes from the interview are used in the publication, a pseudonym or false name will be used. The data obtained from this research will be stored in The University of Stirling's secure database for a minimum of 10 years. This will only be accessible by the research team within a password-protected folder.

What are the benefits of taking part? The study may not benefit you directly, however this information will contribute towards research into organ donation and will help generate a greater understanding of public attitudes towards opt-out organ donor consent. By taking part in this study, the information you provide will be important in shaping future research into organ donation. You will also be offered a £5 amazon voucher as a thank you for taking part. This will be emailed to you after the study has finished.

Can I withdraw my data? Your participation in this research is voluntary and if after the interview you decide that you would like to withdraw your data, you are free to do so up to 4 weeks after participating in this study without providing a reason. To withdraw your data, please contact either Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk, or Jordan Miller jordan.miller1@stir.ac.uk at the University of Stirling up to 4 weeks after participating in this study. If emailing to withdraw your data, please include your 6-digit unique identifier number as a method of identifying which participant information to remove. All data from participants who choose to withdraw from the study will be destroyed and will not be used in the analyses.

Also, if you have any questions, concerns or complaints about the study, please contact either Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk, or Jordan Miller jordan.miller1@stir.ac.uk at the University of Stirling. Alternatively, should you wish to speak to someone independent of this study you may email the psychology office psych-enquiries@stir.ac.uk.

Thank you for your participation.

Appendix 12: Recruitment Advert for Interview Study 3 (Chapter 4)

Would you be willing to have a short chat about organ donation?

Organ donation laws are planning to change in Scotland and England. Currently, if you want to be an organ donor you must sign-up and join the organ donor register.

Scotland and England are planning to follow Wales and change to an ***opt-out*** system. This means you will be automatically presumed to consent for organ donation unless you remove yourself from the register and opt-out.

If the **opt-out** system is introduced it means you will have **3 options:**

Option 1. Join the Organ Donor Register (ODR) if you want to be a donor.
Option 2. If you select neither option 1 or 2, you will be presumed to have no objection to donating your organs (**deemed consent**).
Option 3. Record that you do not wish to be a donor (**opt-out**).

If you think you would choose to ***opt-out*** of the register I would really like to hear your views!

I am a PhD researcher from the University of Stirling interested in hearing about what you think about this change. Would you be willing to take part in a short telephone interview? (about 20-30 minutes long)

If you are potentially interested in taking part, please follow the secure link below for some more information.

After the interview, you will be offered a £5 Amazon voucher as a thank you for helping with my PhD research.

https://stirlingpsych.eu.qualtrics.com/jfe/form/SV_81vaU4onf6oRMzz

Appendix 13: Participant Debrief for Interview Study 3 (Chapter 4)

Thank you for giving up your time to take part in this important research project.

The aim of this study was to gain a deeper understanding into the public views of opt-out organ donor laws. By taking part, the information you have provided will help shape future research into organ donation.

This research will be used to form part of a PhD thesis. The data collected from this study will be stored in a secure database and your responses will be completely anonymous. If this research is later published in a journal article, you will not be identifiable in any manner. For example, if any quotes from the interview are used in the publication, a pseudonym or false name will be used.

Can I withdraw my data? If you decide that you would like to withdraw your data, you are free to do so without providing a reason. To withdraw your data, please contact either Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk, or Jordan Miller jordan.miller1@stir.ac.uk at the University of Stirling up to 4 weeks after participating in this study. If emailing to withdraw your data, please include your 6-digit unique identifier number as a method of identifying which participant information to remove. All data from participants who choose to withdraw from the study will be destroyed and will not be used in the analyses.

As a thank you for giving up your time to take part in this research, we would like to offer you a £5 amazon voucher. The link to the voucher will be emailed to you shortly.

Once again, I would like to thank you for your participation and remind you that if you have any questions about the research or any queries you wish to raise, please feel free to contact either Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk, or Jordan Miller jordan.miller1@stir.ac.uk at the University of Stirling. Alternatively, should you wish to speak to someone independent of this study you may email the psychology office psych-enquiries@stir.ac.uk.

If you would like to find out more information on organ donation, please visit

https://www.organdonation.nhs.uk/

Your unique 6-digit number is: [NUMBER LINKED FROM QUALTRICS QUESTION A1]

Appendix 14: Ethical Approval for Study 4 (Chapter 5)

UNIVERSITY of
STIRLING

Jordan Miller
Faculty of Natural Sciences
University of Stirling
FK9 4LA

18 November 2019

General University Ethics Panel (GUEP)
University of Stirling
Stirling
FK9 4LA
Scotland UK

E: GUEP@stir.ac.uk

Dear Jordan,

Re: Understanding and Overcoming Barriers to Organ Donation – GUEP 722A

Thank you for submitting revisions to your submission of the above to the General University Ethics Panel. The ethical approaches of this project have now been approved by Chair's Action.

Please note that should any of your proposal change, a further submission (amendment) to GUEP will be necessary.

Please ensure that your research complies with the University of Stirling policy on storage of research data which is available at:
https://www.stir.ac.uk/about/faculties-and-services/information-services-and-library/current-students-and-staff/researchers/research-data/plan-and-design/our-policy/

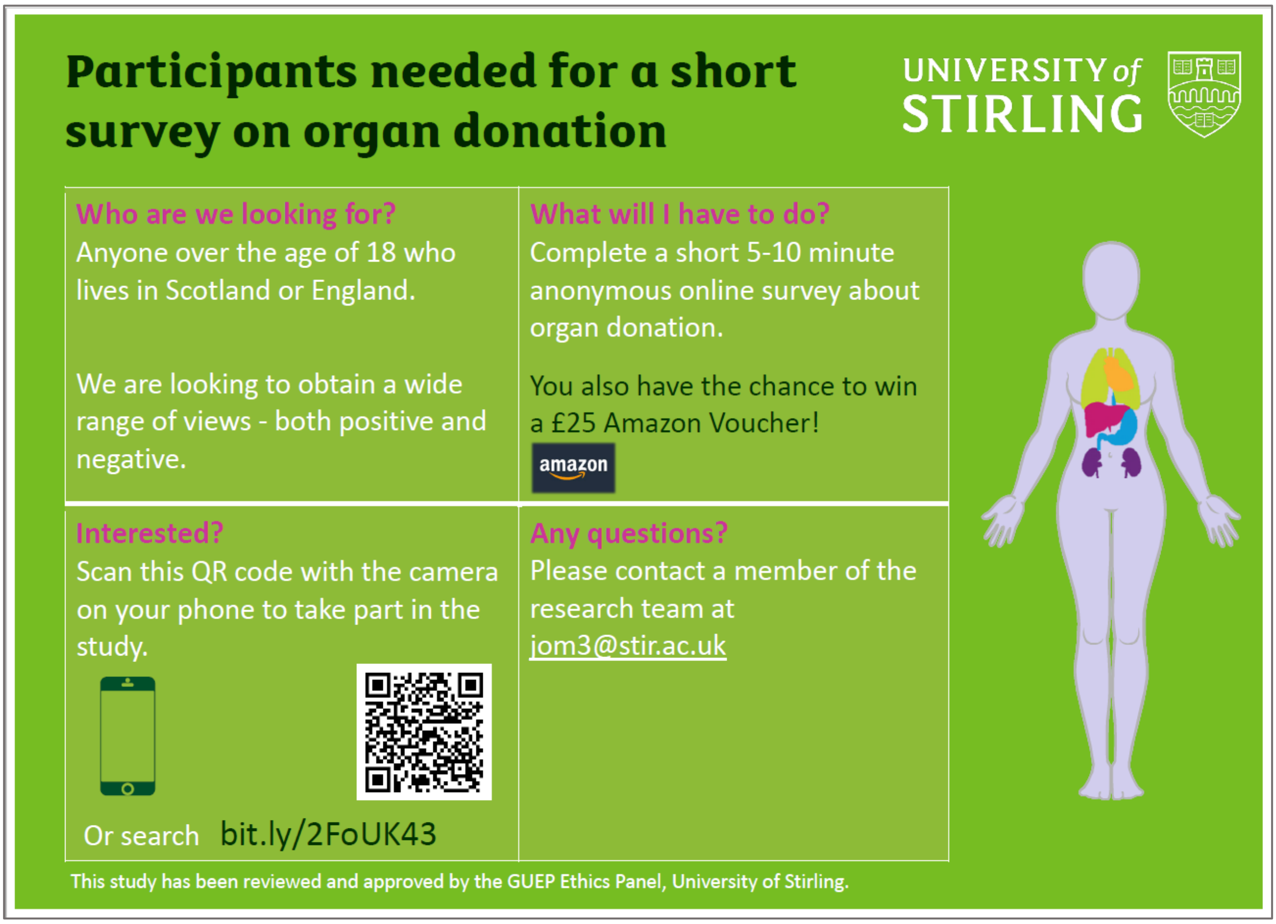
If you have not already done so, I would also strongly encourage you to complete the Research Integrity training which is available at: https://canvas.stir.ac.uk/enroll/CJ43KW

If you have any further queries, please do not hesitate to contact the Panel by email to guep@stir.ac.uk.

Good luck with your research.

Yours sincerely,
Pp.
Claire Exley
On behalf of GUEP
Professor Catherine Hennessy
Deputy Chair of GUEP

Appendix 15: Recruitment Poster Advert for Study 4 (Chapter 5)



Participants needed for a short survey on organ donation

UNIVERSITY of STIRLING

Who are we looking for?
Anyone over the age of 18 who lives in Scotland or England.

We are looking to obtain a wide range of views - both positive and negative.

What will I have to do?
Complete a short 5-10 minute anonymous online survey about organ donation.

You also have the chance to win a £25 Amazon Voucher!

amazon

Interested?
Scan this QR code with the camera on your phone to take part in the study.

Or search bit.ly/2FoUK43

Any questions?
Please contact a member of the research team at jom3@stir.ac.uk

This study has been reviewed and approved by the GUEP Ethics Panel, University of Stirling.

Appendix 16: Participant Information Sheet for Study 4 (Chapter 5)

We would like you to consider taking part in a research study. Before you decide if you would like to take part, please read the information below.

Background We are inviting people over the age of 18 who live in Scotland and England to complete a short web-based questionnaire about organ donation.

Who has reviewed this research project? This project has been reviewed and approved by The University of Stirling General University Ethics Panel.

Do I have to take part? No, you do not have to take part. If you decide not to take part, simply close down the internet browser.

What will this study involve? If you participate in this study, you will be asked to read a short piece of information regarding organ donation. You will then be asked to answer some questions about organ donation. Some of the questions in this study will be repeated, i.e. you will be asked the same question more than once. This is deliberate. The questionnaire should take approximately 15 minutes to complete.

Some of the questions in this questionnaire are of a sensitive nature. We recognise that organ donation can be an emotive and sensitive subject, but are interested in your honest views on this important topic. Therefore, you do not have to answer any questions you don't want to. You are also free to stop participating at any time, by closing down your internet browser. If you choose to close down the survey, your responses will not be used in the analyses.

Before the questionnaire begins, you will be asked to confirm you have read and understood the study information. You will then be asked to provide consent by selecting either, Yes or No on an electronic tick box. You will then be provided with a unique 6-digit number to ensure you remain anonymous. This number can also be used in case you wish to withdraw your data.

At the end of the questionnaire, you will be asked if you would be willing to take part in a short follow up questionnaire in approximately 6 – 12 months' time. If you agree, you will receive an invitation email with more information at a later date. All email addresses will be stored securely and separately from questionnaire responses. You are under no obligation to participate in any further research.

What happens to my data? This research will be used within a PhD thesis and may be published in a journal article. All data will be kept anonymous through the use of a code. Your IP address will not be collected and you will not be identifiable in any way.

What are the benefits of taking part? Although the study may not benefit you directly, this information will help generate a greater understanding of attitudes towards organ donation.

You will also have the opportunity to enter into a prize draw for a £25 pound Amazon voucher at the end of the questionnaire.

Can I withdraw my data? Yes, you can withdraw your data up to 2 weeks after taking part in this study. If you decide that you would like to withdraw your data, you can do so by emailing Professor Ronan O'Carroll ronan.ocarroll@stir.ac.uk or Jordan Miller jordan.miller1@stir.ac.uk with a copy of your 6-digit identifier number as a way of identifying the data to remove. All data from people who withdraw from the study will be deleted and not used in the analyses.

If you have any questions, concerns or complaints about the study, please contact either Professor Ronan O'Carroll or Jordan Miller (contact details above). Should you wish to speak to someone independent of this study you may email the psychology office: psych-enquiries@stir.ac.uk.

GDPR Statement As part of the project we will be recording personal data relating to you. This will be processed in accordance with the General Data Protection Regulation (GDPR). Under GDPR the legal basis for processing your personal data will be public interest of the University. We will also be processing special categories of personal information relating to your health (organ donor status) political and religious beliefs.

The data obtained from this research will be stored in the University of Stirling's secure database for a minimum of 10 years. This will only be accessible by the research team within a password-protected folder.

Your rights You have the right to request to see a copy of the information we hold about you and to request corrections or deletions of the information that is no longer required. You have the right to withdraw from this project at any time without giving reasons and without consequences to you. You also have the right to object to us processing relevant personal data, however, please note that once the data are being analysed and/or results published it may not be possible to remove your data from the study.

Thank you very much for your participation.

Appendix 17: Newspaper Conditions for Study 4 (Chapter 5)

Condition 1: Low Threat x Gain Frame

Local Inquirer

Wednesday
21 June 2019

The way that people choose to register as an organ donor in Scotland and England is changing

Currently, anyone in Scotland and England wishing to donate their organs in the event of their death can choose to opt-in and join the organ donor register.

Last year, 4990 people received a potentially lifesaving transplant.

Under the new system, if an adult hasn't registered a donor decision they will be considered to have no objections to becoming an organ donor. This is known as deemed consent.

If you decide you don't want to donate your organs you can always choose to opt-out of the donor register.

Wales introduced a deemed consent system in 2015. The latest figures have now shown a promising increase in the number of transplants.

When the system changes, you have the opportunity to make the following choice:

- Opt-in if you want to donate your organs.
- Opt-out if you do not want to be a donor.
- Do nothing and you will be considered as having no objections to being a donor.

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Condition 2: High Threat x Gain Frame

Local Inquirer

Wednesday
21 June 2019

The Government have decided to change the organ donation laws in Scotland and England

Currently, anyone in Scotland and England who wants to donate their organs in the event of their death can choose to opt-in and join the organ donor register.

Last year, 4990 people received a potentially lifesaving transplant.

Under the Governments' new law, adults will now be presumed to be in favour of donating their organs. This is known as presumed consent.

If you do not want to donate your organs, you must now opt-out of the donor register.

The Welsh Government changed the donor law and introduced presumed consent in 2015. The latest figures have now shown a promising increase in the number of transplants.

When the Government introduces the new law, you will have to:

- Opt-in if you want to donate your organs.
- Opt-out if you do not want to be a donor.
- If you do nothing, it will now be assumed that you are willing to donate your organs when you die.

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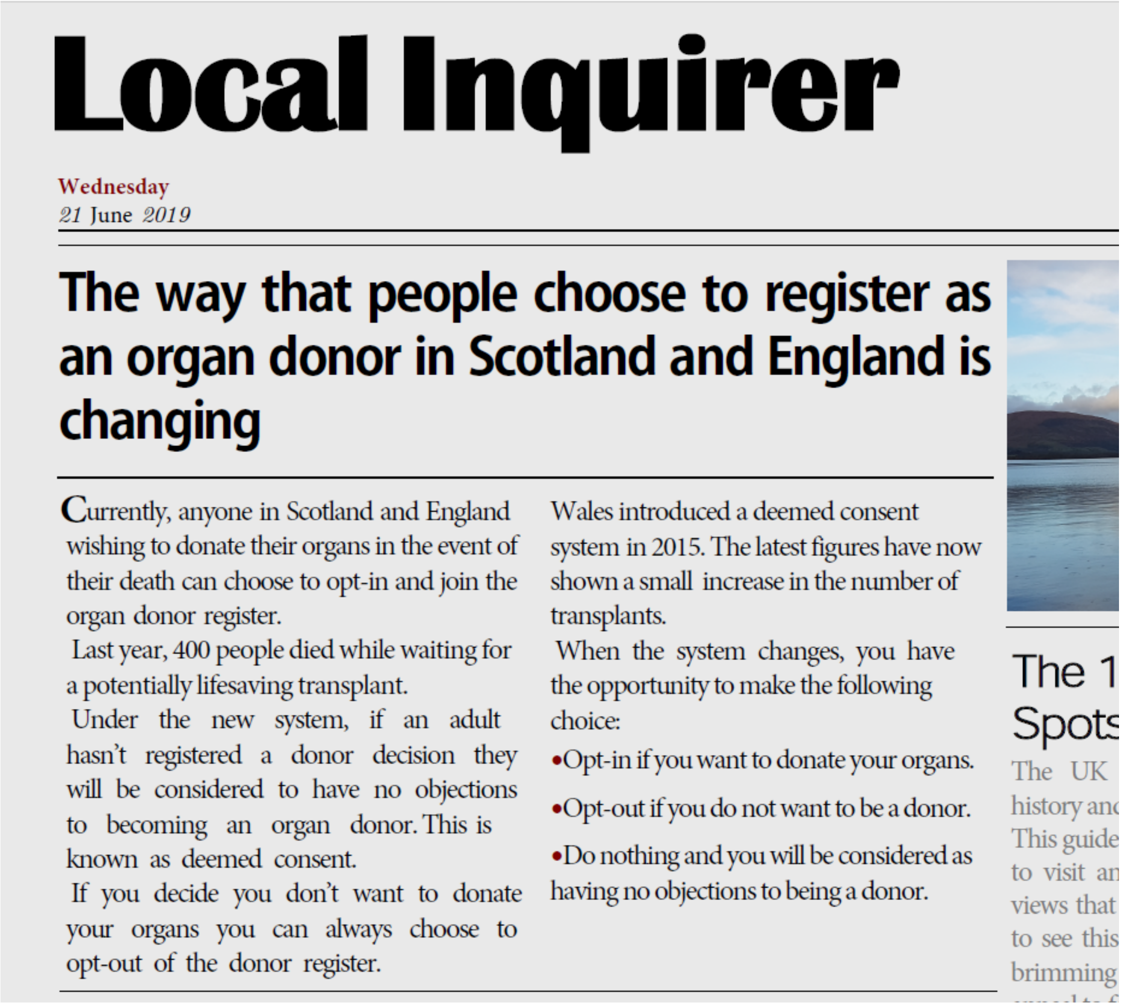
Condition 3: Low Threat x Loss Frame



Local Inquirer

Wednesday
21 June 2019

The way that people choose to register as an organ donor in Scotland and England is changing

Currently, anyone in Scotland and England wishing to donate their organs in the event of their death can choose to opt-in and join the organ donor register.

Last year, 400 people died while waiting for a potentially lifesaving transplant.

Under the new system, if an adult hasn't registered a donor decision they will be considered to have no objections to becoming an organ donor. This is known as deemed consent.

If you decide you don't want to donate your organs you can always choose to opt-out of the donor register.

Wales introduced a deemed consent system in 2015. The latest figures have now shown a small increase in the number of transplants.

When the system changes, you have the opportunity to make the following choice:

- Opt-in if you want to donate your organs.
- Opt-out if you do not want to be a donor.
- Do nothing and you will be considered as having no objections to being a donor.

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Condition 4: High Threat x Loss Frame

Local Inquirer

Wednesday
21 June 2019

The Government have decided to change the organ donation laws in Scotland and England

Currently, anyone in Scotland and England who wants to donate their organs in the event of their death can choose to opt-in and join the organ donor register.

Last year, 400 people died while waiting for a potentially lifesaving transplant.

Under the Governments' new law, adults will now be presumed to be in favour of donating their organs. This is known as presumed consent.

If you do not want to donate your organs, you must now opt-out of the donor register.

The Welsh Government changed the donor law and introduced presumed consent in 2015. The latest figures have now shown a small increase in the number of transplants.

When the Government introduces the new law, you will have to:

- Opt-in if you want to donate your organs.
- Opt-out if you do not want to be a donor.
- If you do nothing, it will now be assumed that you are willing to donate your organs when you die.

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Appendix 18: Threat to Freedom, Anger and Counterarguing Measures for Study 4 (Chapter 5)

1. Threat to Freedom Measure

The following statements relate to the newspaper article you just read. Please rate how much you agree or disagree with the following statements.

	Strongly disagree	**Moderately disagree**	**Slightly disagree**	**Neither agree nor disagree**	**Slightly agree**	**Moderately agree**	**Strongly agree**
1. The article tried to make a decision for me.	☐	☐	☐	☐	☐	☐	☐
2. The article tried to pressure me.	☐	☐	☐	☐	☐	☐	☐
3. The article threatened my freedom to choose.	☐	☐	☐	☐	☐	☐	☐
4. The article tried to manipulate me.	☐	☐	☐	☐	☐	☐	☐

2. Anger Measure

The following statements relate to how the newspaper article made you feel. Please rate how much you agree or disagree with the following statements.

	Strongly disagree	**Moderately disagree**	**Slightly disagree**	**Neither agree nor disagree**	**Slightly agree**	**Moderately agree**	**Strongly agree**
1. I felt angry while reading the article	☐	☐	☐	☐	☐	☐	☐
2. I felt happy while reading the article	☐	☐	☐	☐	☐	☐	☐
3. I felt annoyed while reading the article	☐	☐	☐	☐	☐	☐	☐
4. I felt content while reading the article	☐	☐	☐	☐	☐	☐	☐
5. I felt irritated while reading the article	☐	☐	☐	☐	☐	☐	☐
6. I felt cheerful while reading the article	☐	☐	☐	☐	☐	☐	☐
7. I felt aggravated while reading the article	☐	☐	☐	☐	☐	☐	☐

Note. Items 2, 4 and 6 are filler items only. They were not scored as part of the anger scale.

3. Counterarguing measure

The following statements relate to the newspaper article you just read. Please rate how much you agree or disagree with the following statements.

	Strongly disagree	**Moderately disagree**	**Slightly disagree**	**Neither agree nor disagree**	**Slightly agree**	**Moderately agree**	**Strongly agree**
1. I found myself actively agreeing with the content of the article (*reversed*)	☐	☐	☐	☐	☐	☐	☐
2. I found myself actively disagreeing with the content of the article	☐	☐	☐	☐	☐	☐	☐
3. I was looking for flaws in the content of the article	☐	☐	☐	☐	☐	☐	☐
4. It was easy to agree with the arguments made in the article (*reversed*)	☐	☐	☐	☐	☐	☐	☐

Appendix 19: Readability and Credibility Measures for Study 4 (Chapter 5)

1. Readability Measure

	Very difficult	**Difficult**	**Somewhat difficult**	**Neither easy nor difficult**	**Somewhat easy**	**Easy**	**Very easy**
1. How easy or difficult was the article to read?	☐	☐	☐	☐	☐	☐	☐
2. How easy or difficult was the article to understand?	☐	☐	☐	☐	☐	☐	☐
3. How easy or difficult was the article to remember?	☐	☐	☐	☐	☐	☐	☐

2. Credibility Measure

	Strongly disagree	**Moderately disagree**	**Slightly disagree**	**Neither agree nor disagree**	**Slightly agree**	**Moderately agree**	**Strongly agree**
1. The article was accurate.	☐	☐	☐	☐	☐	☐	☐
2. The article was authentic.	☐	☐	☐	☐	☐	☐	☐
3. The article was believable.	☐	☐	☐	☐	☐	☐	☐

Appendix 20: Trait Reactance Measure for Study 4 (Chapter 5)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. Regulations trigger a sense of resistance in me.	☐	☐	☐	☐	☐
2. I find contradicting others stimulating.	☐	☐	☐	☐	☐
3. When something is prohibited, I usually think, “That’s exactly what I am going to do.”	☐	☐	☐	☐	☐
4. I consider advice from others to be an intrusion.	☐	☐	☐	☐	☐
5. I become frustrated when I am unable to make free and independent decisions.	☐	☐	☐	☐	☐
6. It irritates me when someone points out things which are obvious to me.	☐	☐	☐	☐	☐
7. I become angry when my freedom of choice is restricted.	☐	☐	☐	☐	☐
8. Advice and recommendations usually induce me to do just the opposite.	☐	☐	☐	☐	☐
9. I resist the attempts of others to influence me.	☐	☐	☐	☐	☐
10. It makes me angry when another person is held up as a role model for me to follow.	☐	☐	☐	☐	☐
11. When someone forces me to do something, I feel like doing the opposite.	☐	☐	☐	☐	☐

Appendix 21: NHS and Government Trust Measure for Study 4 (Chapter 5)

1. NHS Trust Measure

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. When it concerns health and social care the NHS is capable.	☐	☐	☐	☐	☐
2. When it concerns health and social care the NHS is expert	☐	☐	☐	☐	☐
3. When it concerns health and social care the NHS carries out its duty very well.	☐	☐	☐	☐	☐
4. If citizens need help, the NHS will do its best to help them.	☐	☐	☐	☐	☐
5. The NHS acts in the interest of citizens.	☐	☐	☐	☐	☐
6. The NHS is genuinely interested in the well-being of citizens.	☐	☐	☐	☐	☐
7. The NHS approaches citizens in a sincere way.	☐	☐	☐	☐	☐
8. The NHS is sincere.	☐	☐	☐	☐	☐
9. The NHS is honest.	☐	☐	☐	☐	☐

2. Government Trust Measure

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. When it concerns health and social care the government is capable.	☐	☐	☐	☐	☐
2. When it concerns health and social care the government is expert	☐	☐	☐	☐	☐
3. When it concerns health and social care the government carries out its duty very well.	☐	☐	☐	☐	☐
4. If citizens need help, the government will do its best to help them.	☐	☐	☐	☐	☐
5. The government acts in the interest of citizens.	☐	☐	☐	☐	☐
6. The government is genuinely interested in the well-being of citizens.	☐	☐	☐	☐	☐
7. The government approaches citizens in a sincere way.	☐	☐	☐	☐	☐
8. The government is sincere.	☐	☐	☐	☐	☐
9. The government is honest.	☐	☐	☐	☐	☐

Appendix 22: Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (Chapter 6)

No	Checklist Item	Guide and Description	Reported on section
1	Aim	State the research question the synthesis addresses.	6.2.4
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory, synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	6.3.8
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	6.3.3
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	6.3.2
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches were conducted; provide the rationale for using the data sources.	6.3.3
6	Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	6.3.4
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	6.3.5
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	6.4.1, Table 6.3
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion	6.3.5, Figure 6.1

		based on modifications to the research question and/or contribution to theory development).	
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	6.3.6
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	6.3.6
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	6.3.7
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	6.4.3, Table 6.4
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	6.3.8
15	Software	State the computer software used, if any.	6.3.8
16	Number of reviewers	Identify who was involved in coding and analysis.	6.3.8
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	6.3.8
18	Study comparison	Describe how comparisons were made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	6.3.8
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	6.3.8
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	6.4.4, Table 6.6
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g., new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	6.4.4

Appendix 23: Critical Appraisal Skills Programme (CASP) Checklist (Chapter 6)

Section	**Screening Questions**	**Yes**	**Somewhat**	**Can't Tell**	**No**
A: Are the results valid?	1. Was there a clear statement of the aims of the research?				
	2. Is a qualitative methodology appropriate?				
	3. Was the research design appropriate to address the aims of the research?				
	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?				
	5. Was the recruitment strategy appropriate to the aims of the research?				
	6. Was the data collected in a way that addressed the research issue?				
	7. Has the relationship between researcher and participants been adequately considered?				
B: What are the results?	8. Have ethical issues been taken into consideration?				
	9. Was the data analysis sufficiently rigorous?				
	10. Is there a clear statement of findings?				
C: Will the results help locally?	11. How valuable is the research?				