Behaviour theory-based correlates, barriers, and enablers to organ donation registration

JOHN BONNELL

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School of Epidemiology and Public Health

Faculty of Medicine

University of Ottawa

Abstract

Deceased organ donation is crucial to thousands of Canadians on transplant wait-lists, though many die waiting due to insufficient donation. Organ donation registration is key to increasing donation, but registration rates in Canada are low, necessitating the development of new, registration-promoting interventions. Behaviour theories could help to better understand registration behaviour, inform fit-for-purpose interventions, and assist in building cumulative evidence, but it is unclear how they have been applied to organ donation registration. Study 1 reports a systematic review identifying behaviour theories that have been applied to registration, and a meta-analysis of the amount of variance in registration intention and behaviour explained by behaviour theories. Study 2 reports a qualitative meta-synthesis of organ donation registration barriers and enablers, mapped to a behavioural framework. The resulting comprehensive set of factors helps to identify priorities for future research, and provide insights towards developing novel interventions to bolster registration rates in Canada.

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Abbreviations

TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
PBC	Perceived Behavioural Control
TGLN	Trillium Gift of Life Network
TDF	Theoretical Domains Framework
HAPA	Health Action Process Approach

Chapter 1: General Introduction

Currently in Canada, the demand for life-saving organs far outstrips the supply available for transplantation, a demand that is likely to continue to increase[1]. Approximately 4350 Canadians were on the transplant waitlist in 2018[2], up from nearly 3800 in 2009[3]. Once on the waitlist, the undersupply of organs often contributes to considerable transplant wait times. For example, kidney transplantation is the most common transplant performed worldwide, and Canadians requiring a kidney transplant can expect to wait an average of 20-56 months for a kidney[4]. Due in part to not meeting the demand for organs, nearly 225 Canadians died while waiting for a life-saving organ in 2018[2]. There is a clear need to address this issue.

Deceased Organ Donation

One source of organs for transplantation is deceased organ donation, where the viable organs of an individual who has passed away are collected and then used for transplant into an individual in need. Deceased organ donation is an important component in addressing the need for organs as each deceased individual can provide up to 8 organs for transplantation, including the heart, kidneys, liver, lungs, pancreas, and bowel[5]. In Canada, the majority of organ donors are deceased donors (58%), suggesting we primarily acquire organs for transplantation from deceased donors[6]. Tissues such as ocular tissue, bone tissue, cardiac tissue (e.g. heart valves), and skin can also be donated for transplantation upon death[7].

Deceased organ donation is only possible for 1.5% of all patient deaths[5] largely due to stringent eligibility requirements, this nevertheless represents approximately 4,250 Canadians each year (based on 2018 Canadian death data[8]), or up to 34,000 organs per year. Only patients who sustained a nonrecoverable injury and are on ventilation and other life-sustaining therapy at the time of notification to provincial organ donation authorities are eligible for donation[8]. This includes patients pronounced dead by neurological death criteria (NDD, or brain death), and in deaths after circulatory determination (DCD)[9]. However, all patients can donate tissues as these do not require blood flow at the time of recovery (i.e. patients do not require ventilation)[9]. Further exclusions are made as appropriate based on determination of increased risk donor status (e.g. patient tests positive for HIV, hepatitis B virus, and other infectious diseases), or based on disease pathology (e.g. cancerous organ, organ failure)[10].

Canadian deceased organ donation rates are low and variable across provinces and territories, lagging significantly behind the countries with the highest organ donation rates[11]. For example, Canada's deceased organ donation rate (21.91 donors per million population) in 2017 was less than half of that of the world leader, Spain (46.90 donors per million population), and was also significantly less than the USA's (31.96 donors per million)[11]. There is a need to understand what modifiable factors that may contribute to low deceased organ donation rates.

Factors Potentially Preventing Deceased Organ Donation

Barriers to successful deceased organ donation occur throughout the entire process, from identification of potential donors to the allocation of recovered organs to patients in need. Table 1 outlines several potential barriers along different junctures in the process.

Table 1. Clinical pathway of deceased organ donation process and the factors potentially preventing donation throughout the process[12].

Deceased Organ Donor Pathway	Potential Factors Preventing Donation
Hospital death cases (brain death and cardio-circulatory death)	-Failure to identify/refer potential donor -Brain death diagnosis not confirmed (e.g. does not meet criteria), or completed -Circulatory death not declared within the appropriate time window -Logistical issues (e.g. no recovery team)
Patient is on mechanical ventilation	-Logistical issues (e.g. lack of equipment or clinician resources) -Resources needed for higher priority patients (i.e. capacity issues)
Obtaining consent to recover organs	**-Deceased expressed intent to not be a donor** **-Deceased's intent to be a donor unclear (intent is not registered)** -Next-of-kin refusal for organ donation -Coroner or judicial authorities denied organ donation for forensic purposes
Donation exclusion criteria	-Medical unsuitability (e.g. cancers, infectious diseases, organ failure) -Hemodynamic instability/unanticipated cardiac arrest -Organ abnormalities (e.g. histological, anatomical, functional)
Organ procurement	-Organs are damaged during procedure -Inadequate perfusion to the organs -Thrombosis
Organ utilization	-No appropriate recipient for transplant

As so few deceased patients are eligible for organ donation[5], it is essential to streamline the process as much as possible, and target modifiable barriers. A key barrier to deceased organ donation lies in the patient's registration of their consent to deceased organ donation and the focus of this thesis is on better factors driving this modifiable barrier of organ donation.

Organ Donation Registration in Canada

As of 2020, all provinces in Canada operated an "opt-in" policy for organ donation registration. Every Canadian citizen is by default *not* an organ donor, but can choose to register their consent to be an organ donor once they are 18 years of age. However, Nova Scotia has passed legislation to enact "opt-out", where consent for organ donation is presumed unless residents register their opposition. This legislation is expected to take effect in mid-late 2020[13]. Registrations are managed by provincial organ procurement agencies, with most now operating organ donation registries. Depending on the province, organ donation registration can be performed online, by filling out and mailing paper forms, or in some cases, in-person in response to a prompt from a provincial agency representative such as a license and health card renewal service. For instance, in Ontario, citizens are able to register for organ donation online on beadonor.ca, in-person at any Ontario government service location (e.g. when renewing their driver's license), or by mailing consent forms (obtained online) to Ontario government service offices[14].

Across Canada, each province has its own official organ donor registry, with the exception of Saskatchewan which requires its residents to sign an organ donor card and/or place a sticker on their health card to indicate their intent to donate. However, Saskatchewan is currently developing an organ donor registry due to be implemented in 2020[15]. Among the Canadian territories, only Yukon has its own official organ donor registry[16]. Both the Northwest Territories' and Nunavut's organ donation systems are operated by Alberta, so any residents who wish to indicate their intent to donate can do so through Alberta's registry[17]. As of 2020, the only provinces that allow their residents to register online are: British Columbia, Alberta, Manitoba, Ontario, Quebec, and Prince Edward Island.

Regardless of the organ donation registration status of the individual, it is ultimately the next-of-kin of the deceased individual who is tasked with the final decision to donate organs. However, registering for organ donation provides an important opportunity for citizens to clarify their wishes, making the decision to donate organs easier on their next-of-kin ultimately tasked with this decision. Next-of-kin tend to follow the wish to donate of their deceased loved one when they have evidence that they desired to donate their organs, such as when their loved one is a registered organ donor[18]. In fact, in Ontario, approximately 90% of families will consent to donation when their loved one is registered, compared to 50% when they are not[19].

Over 90% of Canadians support organ donation and a further 51% intend to posthumously donate their organs[20], however this support is not being translated into actual organ donation registration rates, which stand at approximately 27% in Canada, based on public opinion surveys[20], and 34% in Ontario, based on registry data[21]. While registration rates are low among all Canadians, they are especially low in newcomers and first-generation Canadians[22]. There is a need to understand why this discrepancy between organ donation support and actual registration exists and what can be done to address it.

Increasing Organ Donation Registration

Policies have been introduced over the past 20 years to increase organ registration across all Canadian provinces and territories. For example, Ontario's online registration platform was introduced in 2011 to make registration more convenient. After its implementation, the registration rate has increased from 18% in 2011[23] to 30% in 2016[24]. Similarly, other provinces have recently implemented online platforms to increase their registration rates (e.g. PEI, Alberta). However, the effect of implementing a registry seems to have plateaued; as of 2020, organ donation registration rates have only increased to 34% in Ontario[21]. If organ donation registration rates are to improve further, additional interventions need to be developed.

Opt-Out Organ Donation Policies

Many believe enacting opt-out organ donation policies, as some European and South American countries have implemented, will increase the registration rate in Canada. Based on presumed consent, opt-out organ donation policies default all citizens as organ donors but can opt-out of becoming an organ donor at any time. It would stand to reason that since most Canadians support organ donation, automatically registering all citizens would increase the number of people consenting to donation. Only one province in Canada, Nova Scotia, has passed legislation to enact opt-out organ donation policies starting late in 2020. However, many other provinces have been actively considering opt-out organ donation policies as well, including Alberta, who has

submitted bills for opt-out organ donation. While some research has shown that opt-out organ donation registration policy is associated with increased donation rates[25-27], there have been concerns with its acceptability within the population[28-30].

The issue has been frequently debated in Canada, and with some provinces already enacting and proposing opt-out organ donation legislation, some have voiced their reservations for the new policies[31]. Most concerns are centered on the loss of autonomy and government ownership of the body from enacting opt-out legislation, especially for the cultures and religions who hold significant importance in post-mortem customs[31]. Given that presumed consent is the absence of an objection, it may not be appropriate to accept it as informed consent[30]. Furthermore, while over 90% of Canadians support organ donation, a much smaller proportion of Canadians (54%)[32] and Ontarians (34%)[33] support opt-out organ donation policies.

Opt-out organ donation is unlikely to be a feasible means of increasing organ donation rates across Canada at the present time, until a tipping point has been reached of a majority being registered, or until the success of the opt-out policies enacted in Canada can be observed. Until opt-out policies are enacted widely across Canada, patients remain on organ transplant waiting lists, and many die waiting for a life-saving organ. Therefore, we must continue to focus on developing effective interventions to optimize registration within the current opt-in system.

Importance of Theory in Developing Interventions

Organ donation registration is a health behaviour. To inform novel interventions to increase organ donation registration rates, there is a need for a better understanding of which modifiable factors associated with intention to register and actual organ donation registration. A common issue in intervention studies is a lack of clarity in the description and definition of the functional components that explain behaviour and behaviour change[34,35].

Behavioural theories provide a framework and standardized nomenclature for identifying modifiable factors associated with behaviour and to define and clarify the functional components of interventions[34-36]. By defining and clarifying the components of interventions responsible for behaviour change, theory also facilitates the reproducibility of interventions, resulting in the formation of a cumulative evidence base of agreed mechanisms of change. In addition to these benefits, some evidence suggests that applying theory as a basis for developing behaviour change interventions can yield a larger effect than interventions who do not use theory at all[37-41]. Therefore, interventions to improve organ donation registration may benefit from use of behaviour theories to inform their development. However, it remains unclear which theories and theory-informed factors are related to organ donation registration.

Selecting Behaviour Theories for Organ Donation Registration

One of the most frequently and widely applied behaviour theories across various health behaviours is the Theory of Planned Behaviour (TPB)[42] and its precursor, the Theory of Reasoned Action (TRA)[43]. The TPB posits a causal pathway wherein attitudes (positive or negative evaluation of behavioural performance), subjective norms (perception of social pressures to perform the behaviour or not), and perceived behavioural control (PBC, beliefs about one's ability to perform the behaviour) are mediated by one's intention to perform the behaviour, which in turn acts as the precursor to behaviour[42]. Since its conception, the TPB has been applied to understand factors associated with many different health behaviours such as

physical activity[44] and eating[45]. As well, a systematic review conducted in 2011 by McEachan et al. identified 206 articles in which the TPB was applied to predict various health behaviours[46], highlighting the prevalence of its use in behavioural science literature.

While among the most frequently used, the TPB is not the only theory of behaviour. Michie et al. developed a compendium of 83 theories of behaviour that span a wide variety of disciplines and behaviours[47]. Some can be applied across all behaviours (such as the TPB), while others were developed to understand specific behaviours (such as the Rational Addiction Model[48] for addictive behaviours). There is a variety of readily usable behaviour theories, however it is unclear which theories have been applied and which are the most relevant for organ donation registration.

A challenging aspect of selecting a theory to guide intervention development is identifying the constructs associated with the behaviour, and which theories incorporate those constructs. Further complicating this process, many contending theories have significant overlap in terms of the constructs used in behavioural prediction. For instance, the attitude, subjective norm, and PBC constructs from the TPB are all also incorporated into the Social Cognitive Theory[49], the Prototype Willingness Model[50] and the Integrative Model of Behavioural Prediction[51]. Most other behaviour theories will include at least one of these constructs, highlighting the significant overlap between theories, and the challenge of selecting the most appropriate theory for any given behaviour.

Some bespoke theories tailored specifically to the behaviour of organ donation registration have emerged in recent years to examine and understand variance in organ donation registration. One such theory includes the Organ Donation Model (shown in Figure 1) by Morgan et al.[52,53], which draws inspiration from both the TRA, and previous research on modelling organ donation registration behaviour[54,55]. This theory posits that in addition to attitude and subjective norm, knowledge, information exposure, and one's individual values influence one's registration behaviour. The values construct captures various religious and cultural beliefs, as well as altruistic attitude. In subsequent Organ Donation Model studies, the model was expanded to include constructs such as medical mistrust (belief that doctors will withhold care for patients to expedite death and obtain their organs), bodily integrity (belief that individuals must maintain the integrity of their body after death), "ick" factors (disgust related to the idea of organ procurement and transplantation), and "jinx" factors (belief that registering for organ donation will bring about a premature death)[56]. While still overlapping with traditional behaviour theories, these organ donation-specific constructs account for factors underlying positive and negative attitudes specifically towards organ donation, which may result in improved behavioural prediction compared to other theories of behaviour.

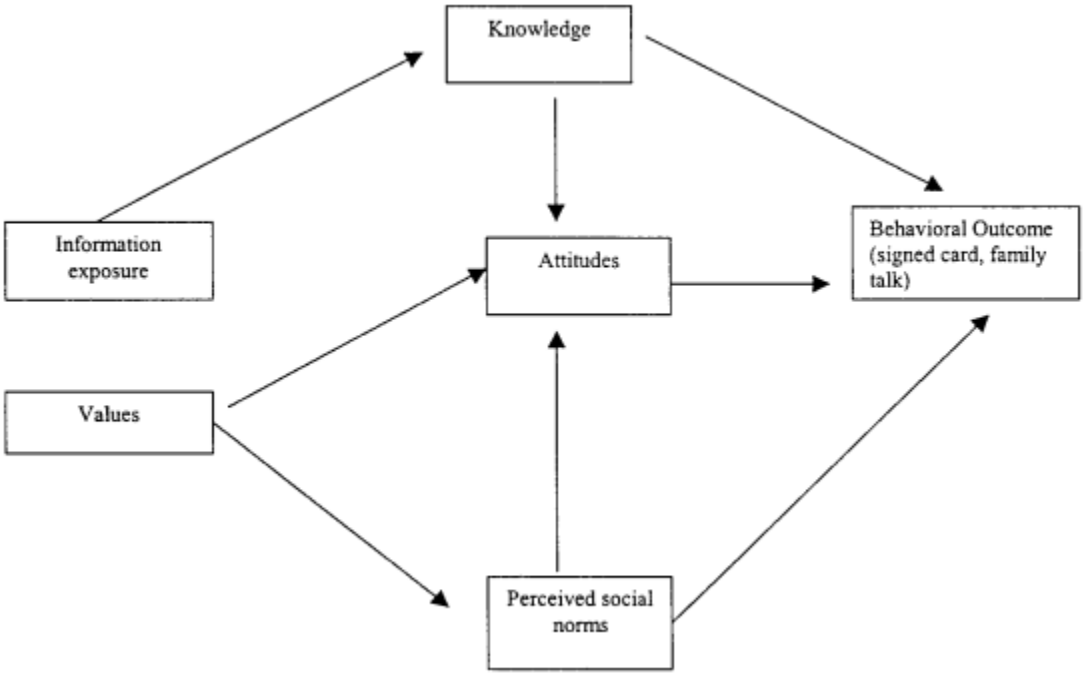

Figure 1. Organ Donation Model, as shown in original study[38].

Accounting for Overlap Between Theories

In response to the significant overlap of constructs in behaviour theories, Michie et al.[57] developed the Theoretical Domains Framework (TDF) that pooled together 33 theories (and 128 constructs included in those theories) into 12 domains to maximize the accessibility and utility of behaviour theories for implementation science. The TDF was later validated and refined in 2012 by Cane, O'Connor & Michie, and to include 14 domains to explain behaviour[58]. In the second version of the TDF[58], the *beliefs about capabilities, beliefs about consequences,* and *motivation & goals* domains were all split into two new domains while the *nature of the behavior* domain was removed. Both versions of the TDF are presented below in Table 2.

Table 2. Domains, descriptions, and examples of constructs included in the TDF[57-59].

Domain (TDF-V1)	Domain (TDF-V2)	Description	Constructs
Knowledge		An awareness of the existence of something	-Knowledge -Procedural knowledge
Skills		An ability or proficiency acquired through practice	-Skills -Competence
Social/Professional Roles & Identities		A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting	-Professional role/identity -Social/group identity -Leadership

Beliefs about Capabilities	Beliefs about Capabilities	Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use	-Self-confidence -Self-efficacy
	Optimism	The confidence that things will happen for the best or that desired goals will be attained	-Optimism -Pessimism
Beliefs about Consequences	Beliefs about Consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation	-Attitudes -Outcome expectancies -Anticipated regret
	Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between response and given stimuli	-Rewards -Punishment -Sanctions
Motivation & Goals	Intention	A conscious decision to perform a behaviour or resolve to act in a certain way	-Transtheoretical Model and Stages of Change -Stability of intentions
	Goals	Mental representations of outcomes or end states that an individual wants to achieve	-Goal priority -Goal/target setting
Memory, Attention, & Decision Processes		The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives	-Memory -Attention control -Decision making
Environmental Context & Resources		Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour	-Environmental stressors -Organizational culture/climate
Social Influences		Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours	-Social norms -Social pressure -Group conformity
Emotion		A complex reaction pattern, involving experiential, behavioural, and psychological elements, by which the individual attempts to deal with a personally significant matter or event	-Fear -Anxiety -Depression

Behavioural Regulation		Anything aimed at managing or changing objectively observed or measured actions	-Self-monitoring -Breaking Habit
Nature of the Behaviour		Relates to the history of the behaviour, and one's experience with said behaviour	-Past behaviour -Direct experience

Note. Definitions provided are exact wording from Cane et al.[58]

Although initially designed to facilitate the application of behavioural science principles to identify factors affecting health professional behaviour in the implementation of new innovations[59], the TDF has since been applied to health behaviours in patients and the public as well[60]. Its use has primarily been to inform qualitative studies by providing a framework to inform interview guides and analysis of qualitative data[59]. Since its conception, its application to health behaviours in patients and the public includes a range of settings such as diabetes prevention[61], medication adherence[60], and weight management during pregnancy[62]. It has been also useful in identifying enablers and barriers to certain behaviours such as pressure ulcer prevention[63], smoking cessation[64], and sexual health service use[65], among others. However, its application to understanding organ donation registration behaviour remains limited.

Existing Theory-Based Interventions to Increase Organ Donation Registration

Despite a lack of consensus of which theories can be most effectively applied organ donation registration, some studies, albeit few, have used behaviour theories to develop their interventions. A recent systematic review identified and narratively synthesized 24 studies that examined the effectiveness of psychological interventions in increasing organ donation registration rates[66]. Of these, only 6 studies explicitly reported using tested theories of behaviour (including bespoke theories) to inform their intervention development[66]. The theories of behaviour used in these interventions include the Organ Donation Model, IIFF Model (bespoke theory for organ donation registration; acronym for immediate and complete registration opportunity, information, focused engagement, and favourable action)[67], TPB/TRA, and Transtheoretical Model[68]. Five out of six (83%) of the studies reporting using tested theories of behaviour to inform their interventions observed increases in organ donation registration attributable to their interventions, compared to 13/18 (72%) that did not use explicit theory in their intervention development[66].

Based on this review, we cannot conclude whether or not the use of behaviour theories results in more effective interventions in this literature, nor which theories are most effective at changing registration behaviour. However, it does highlight how few interventions have actually incorporated behaviour theories in their development.

Lack of Quantitative Behaviour Theory-Based Understanding of Registration

Using theories of behaviour to inform which factors to focus upon in developing interventions to improving organ donation registration rates may help to develop novel registration interventions and contribute to a cumulative understanding of what does and does not work. Organ donation registration intervention research may not have entirely engaged in the behaviour change literature, and as a result, few have developed behaviour theory-based interventions and may not be drawing on from the most contemporary theories. Furthermore, it is unclear which theory, and which constructs from those theories, best predict organ donation registration. In order to

develop the most effective interventions, that are fit-for-purpose to increase organ donation registration, we need a better understanding of the association between behaviour theory-based constructs and organ donation registration.

Although previous systematic reviews have examined the effectiveness of several different types of interventions, including some behaviour theory-based interventions, none have systematically examined the theories that have been used to understand variability in organ donation registrations. Furthermore, no studies have systematically examined which constructs from those theories are associated with organ donation registration, and quantitively synthesized the magnitude of the associations, and the amount of variance in behaviour they explain. Study 1 (Chapter 2) aims to address this gap in the literature.

Lack of Qualitative Behaviour Theory-Based Understanding of Registration

While a quantitative understanding of how much variance theoretical constructs explain in registration behaviour is necessary to inform fit-for-purpose interventions, existing theories may not necessarily capture all key factors, or barriers and enablers, to registering for organ donation. Furthermore, quantitative data lacks the qualitative detail of drivers, barriers, and concerns towards organ donation registration, independent of the constructs suggested by behaviour theories. Therefore, a qualitative understanding of organ donation registration provides a complementary level of depth to further inform fit-for-purpose interventions and possibly help to enhance the selection of existing theories and/or suggest enhancements.

There have been two recent qualitative systematic reviews and meta-syntheses that pooled data from interviews and focus groups to elucidate themes related to views and perspectives on deceased organ donation[69,70]. Each of these reviews contribute to the body of knowledge on organ donation, however, they both developed their own themes/domains for their data synthesis, rather than using a predefined, validated set of themes/domains informed by theories of behaviour. Furthermore, these reviews were not conducted with a specific focus on organ donation registration. This means that all of the themes they elucidated relate primarily to the motivation (or lack thereof) to donate their organs after death, and not necessarily related to the actual process of registering their consent to donate their organs as well.

While a quantitative review will help to clarify which constructs explain variance in intention to register and registration behaviour, what specific beliefs and views within those constructs to target remains relatively unclear without contextualized qualitative perspectives on those views and beliefs. Thus to further inform fit-for-purpose interventions to increase organ donation registration, and identify constructs/beliefs impacting registration behaviour independent from those suggested in behaviour theories, it would be useful to conduct a thorough systematic review of qualitative studies (qualitative meta-synthesis) and identify how the themes generated in each qualitative study map to factors known to affect behaviour and behaviour change. Such mapping could be aided by using a comprehensive framework of factors known to be related to behaviour, such as the TDF.

Thesis Rationale

Organ donation registration intervention research may not have not entirely engaged in the contemporary behaviour change literature, as few intervention studies have incorporated tested theories of behaviour in their development or drawn on more recent advances in behavior

science. It is also unclear which theory, and which constructs from those theories, best predict organ donation registration. Furthermore, we lack a clear qualitative understanding of barriers/enablers specific to organ donation registration, and how they map to a comprehensive framework of behaviour theory-based factors. In order to develop better and novel interventions, that are fit-for-purpose to increase organ donation registration, we need a better understanding of the behaviour theory-based predictors, and qualitatively-reported barriers/enablers to organ donation registration.

Thesis Outline and Objectives

The overall aim of this thesis addresses the aforementioned research gaps. The remainder of this thesis is organized in a monograph format and divided into 3 chapters:

Chapter 2: In this chapter we present the findings of a quantitative systematic review and meta-analysis with the following objectives:

> **Objective 1:** Identify which theories of behaviour have been used to understand organ donation registration.
>
> **Objective 2:** Determine which modifiable constructs are associated with organ donation registration and the intention to register.
>
> **Objective 3:** Determine how much variability in organ donation registration behaviour and intention are accounted for by theories of behaviour.

Chapter 3: In this chapter we present the findings of a qualitative meta-synthesis with the following objectives:

> **Objective 1:** Elucidate the qualitatively-reported barriers and enablers to organ donation registration
>
> **Objective 2:** Use the TDF as a framework for the thematic synthesis of the data

Chapter 4: In this concluding chapter we integrate the results of Chapters 2 and 3, as well as discuss the implications and significance of these results.

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Chapter 2:

Behavioural Theory Factors Associated with Deceased Organ Donation Registration: A Systematic Review and Meta-Analysis

Bonnell J, Perkins I, Brehaut JC, Grimshaw J, Sikora L, Fakhraei R, Presseau J.

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Contributions: JB and JP were responsible for the conception and design of this project. JB wrote the manuscript. JP, JCB, and JG provided guidance and expertise throughout the entire project, and provided critical input and suggested revisions for the manuscript. LS assisted in search strategy development. JB and RF screened articles for inclusion. JB and IP completed data abstraction and risk of bias analysis.

Chapter 2 – Introduction

As established in Chapter 1, there is a great need for organs for transplantation in Canada that is currently not being met[1-3]. Deceased organ donation is the primary means through which organs for transplantation are obtained in Canada[4,5], however the Canadian deceased donation rates are far below the rates of world leaders (i.e. Spain)[6]. This is in part due to the low organ donation registration rates across Canada. Although the vast majority of Canadians support and intend to donate their organs upon death[7], relatively few have translated this support and willingness into actual registration[7,8]. Effective interventions to increase organ donation registration in Canada are therefore required.

As highlighted in Chapter 1, developing interventions using behavior theories leads to enhanced reproducibility[9-11], contributing to a cumulative knowledge base, and potentially increases the effect of the intervention[12-16]. However, it is currently unclear to what extent behavior theories have been applied to organ donation registration, and which constructs from those theories are associated with registration behavior and intention to register.

Aims and Objectives

Organ donation registration interventions are required to meet the growing need for organs for transplantation. Such interventions may benefit from the application of behavior theories; however, it is currently unclear to what extent behaviour theories have been used to understand variance in deceased organ donation registration behaviour and intention to register. Therefore, this systematic review and meta-analysis aims to answer the following questions:

1. Which behavior theories have been used to understand organ donation registration?
2. Which modifiable behaviour theory-based constructs are associated with intention to register and actual registration?
3. How much variance in registration behaviour and intention to register are accounted for by behaviour theories?

Methods

Protocol and Registration

The protocol was registered in PROSPERO on December 3rd, 2018 (CRD42018116654; http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018116654).

Eligibility Criteria

Study selection was based on the following criteria:

Participants: No restrictions.

Interventions: Not applicable.

Comparators: Not applicable.

Outcomes: The primary outcome of interest in this study was organ donation registration (behaviour). The secondary outcome was an indication of motivation to register for organ

donation (intention, desire, or willingness). For any study to be eligible, it must have included either the bivariate correlation between either the outcome and the theoretical constructs of an existing behaviour theory/model or organ donation registration theory/model, or the R^2 value of a model that predicts organ donation registration or motivation to register for organ donation.

Study Designs: Cross-sectional and prospective cohort designs were eligible for inclusion. The cross-sectional studies have only one point of measurement, wherein a theory-based survey may be administered at one time point and includes all study measures. Prospective cohort studies may have a similar baseline measurement along with a follow-up measurement at a different point in time. No other study designs were eligible.

Setting: No restrictions.

Language: Eligible studies were restricted to those published in English or French.

Publishing Details: No restrictions.

Exclusion Criteria: Studies focusing on living organ donation (e.g, kidney donation), consent to organ donation from family members of deceased loved ones, or *discussions* about organ donation registration were ineligible. Additionally, studies that developed a model either not informed by any specific theory or based on a theory that had not been previously tested (e.g. studies that were the first to develop and test a given theory) were ineligible for the review.

Information Sources

A search strategy was developed using MESH terms and title and abstract terms for both organ donation registration and behavior/psychological theories. MEDLINE, PsycINFO, EMBASE, and CINAHL were searched to identify eligible articles. To supplement these information sources, and to access grey literature, ERIC was also searched. Additionally, reference lists of eligible studies were scanned for eligibility.

Search Strategy

The search strategy was developed with a librarian (LS) with expertise in systematic reviews at the Health Sciences Library at the University of Ottawa. It was then independently peer-reviewed by another librarian, as per PRESS guidelines[17].

The ABC of Behaviour Change Theories[18] was used to identify a range of behaviour/psychological theories that are potentially relevant to include in the search. JB and JP assessed all 83 theories and models for eligibility based on their relevance to organ donation registration. Theories and models not relevant to organ donation registration (e.g theories on deviant behaviour, or AIDS prevention) were excluded. During preliminary work to calibrate the search strategy's sensitivity and specificity, we used the search term "(theory or theories)" to capture all theories present in the compendium, as well as capture any theories that may not be featured in the ABC of Behaviour Change Theories[18]. See Appendix A for model exclusion and inclusion and Appendix B for MEDLINE search strategy.

Study Selection

Two reviewers (JB and RF) independently screened the uploaded titles and abstracts for eligibility in duplicate. Full-text articles were then screened independently and in-duplicate for eligibility based on the previously described criteria. Any conflicts were resolved through

discussion between the two reviewers, and with a third reviewer if necessary. Study authors were contacted to provide any missing data.

Data Collection Process

Data abstraction forms were developed by JB, pilot tested with 5 included studies, then refined. Two reviewers (JB and IP) independently abstracted data from the included articles in duplicate. Disagreements were resolved through discussion, and if necessary, with a third reviewer.

Data Items

Data that was abstracted includes:

Study characteristics: year published, design, data collection method (eg mail, online), number of participants recruited, length of time for follow-up, country of conduct, behaviour theory used, additional constructs added.

Participant characteristics: Mean age, sex distribution, ethnicity distribution, type of population (eg, students, government employees), number of participants who dropped out, reasons for drop-out.

Outcome data: outcomes measured (intention, behaviour, willingness), method of measuring behaviour, actual registration rate, number of participants who intend on registering (or mean intention score), construct correlation coefficient, p-value of correlation coefficient, type of regression model, R^2 value from regression model, theoretical constructs/variables included in regression model.

Risk of Bias in Individual Studies

Risk of bias analysis was conducted using an adapted form of the NIH Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies[19]. Some items in the NIH tool were adapted to better fit the research question, others were omitted altogether, and some were added so as to better assess the risk of bias as it appears in the organ donation registration literature (see Appendix C for adapted form). Following calibration, several items were either further adapted, or added to the proposed form. The first adaptation involved presenting the risk of bias for each outcome, for studies that measured multiple outcomes (eg. intention and behaviour), to account for differences in outcome measurement. For example, one study may have had valid methods for measuring intention, but may have introduced bias in their measurement of behaviour. The other change involved adding an item that pertained to the operationalization of theory-based models (see item 12 in adapted form). This item assessed whether or not the theoretical models used by the studies accurately represented the theory. For example, if the theory cited the TPB/TRA as the theory that guided the development of the questionnaire and model, but only included attitude (e.g. excluded subjective norm and PBC from the model), then it would not accurately represent the TPB/TRA.

Each reviewer assessed the risk of bias for all studies independently and in-duplicate. Any disagreements were resolved through discussion, with a third reviewer if necessary. Study authors were contacted to provide any missing data.

Summary Measures

Bivariate correlations between theoretical constructs and behaviour served as a primary outcome, as did R^2 scores from theoretical models predicting organ donation registration behaviour. Bivariate correlations between theoretical constructs and intention, and R^2 scores from theoretical models predicting intention served as a secondary outcome. Bivariate correlations were pooled in random-effects models to determine which constructs are most strongly associated with organ donation registration behaviour and intention. Frequency-weighted mean R^2 scores were computed across theories as a primary analysis, and for each individual theory to determine the amount of explained variance in behaviour and motivation.

Synthesis of Bivariate Correlations

Data were pooled in Comprehensive Meta-Analysis using a random-effects model. Meta-analyses were computed separately for each theory, each outcome, and only for constructs reported by at least 2 studies. For example, bivariate associations between attitude and behaviour were pooled separately from associations between attitude and intention. Additionally, bivariate associations between attitude and behaviour were pooled separately for the TPB/TRA and the Prototype Willingness Model. Willingness was treated as an equivalent motivational construct as intention in all cases except for the studies testing theories that specifically differentiate willingness from intention (e.g. Prototype Willingness Model). In such cases, willingness was therefore meta-analyzed as a separate outcome variable from intention. Effect sizes are described in accordance with Cohen's[20] recommendations were $r = 0.10$ represents a small effect size, $r = 0.30$ represents a medium effect size, and $r = 0.50$ represents a large effect size. Analysis of heterogeneity was conducted and reported using Cochrane's Q statistic.

Multiple Measurements

Some studies reported correlations for separate subgroups in the same sample. In such events, we computed a frequency-weighted mean correlation to represent the whole sample, and entered it to the meta-analysis for that construct, as recommended by the Cochrane Handbook for Systematic Reviews of Interventions[21].

Subgroup and Additional Analyses

Subgroup analyses based on study population (student or general population) and study geographic region were only conducted on constructs with at least 10 measurements, as recommended by the Cochrane Handbook[21].

Sensitivity analyses were conducted where appropriate based on risk of bias and potential outliers in the data. Potential outliers were assessed using stem and leaf plots. Subgroup analyses were conducted both including studies with high risk of bias, to not restrict the available data, and excluding them to limit bias in the analyses.

Synthesis of Theoretical Model Testing (R^2)

Frequency-weighted mean R^2 for intention, behaviour, and willingness were computed across all theories using Excel. For studies that test multiple models for the same theory, we abstracted data for the test of the model with the most reported constructs and potential covariates (eg, age, gender, ethnicity), to represent the most complete model reported.

After the protocol was written, it was decided that any R^2 scores obtained from logistic regression models would not be eligible for inclusion in the meta-analysis. Logistic regression

models can only yield pseudo-R^2 scores[22], therefore, they were not pooled with true R^2 scores. Additionally, comparisons of pseudo-R^2 scores are not considered valid unless they are comparisons of different models, predicting the same outcome on the same dataset[22]. As such, pseudo-R^2 scores from logistic regression models were not pooled, but Nagelkerke R^2 scores were collected and reported in narrative synthesis.

Multiple Measurements

Some studies reported multiple, separate models all using different theories as a basis for the same sample. In such cases, we divided the sample size by the number of theoretical models tested, as per the recommendations of the Cochrane Handbook[21], so that each theoretical model was represented evenly within the study. Results reported by multiple subgroup levels was addressed as previously described in correlation-based meta-analyses.

Subgroup and Additional Analyses

Subgroup analyses based on study population (student vs general population), study geographic region, theory/model used, and type of regression model were only conducted on outcomes with at least 10 measurements, as recommended by the Cochrane Handbook[21]. Sensitivity analyses were conducted where appropriate based on risk of bias, and potential outliers (assessed using stem and leaf plots) in the data.

Results

Study Selection

A total of 2036 articles were screened for eligibility, and 1910 were excluded in level 1 screening. In level 2, 126 articles were screened with 98 exclusions. A total of 32 studies, published in 28 articles, were included in the review (see Figure 1 for PRISMA flowchart). All 32 studies were descriptively synthesized. One study used the Organ Donation Model as a basis for their survey, but did not report any bivariate correlations between constructs and intention/behaviour, and used logistic regression to predict behaviour[36]. Therefore, the study could not be included in the meta-analysis. Another study prospectively assessed registration behaviour through engagement in "preparatory behaviours" (e.g. discussing organ donation with family, signing an organ donor card)[45]. Although some of the "preparatory behaviours" were considered equivalent to registration (e.g. signing an organ donor card), the study did not report engagement in each individual "preparatory behaviour", therefore behaviour-based analyses from this study were not included in the meta-analysis. However, they were included in narrative synthesis and risk of bias analysis.

Study Characteristics

Database and reference list searches yielded 32 studies in 28 articles, with 16,289 participants in total. Table 1 describes the study and participant characteristics, while study outcome data is described in Table 2. Eleven studies measured behaviour[25,29,31,36,37,43,45,46,48], 26 studies measured intention[23-31,33-35,38-42,44-50], and 4 studies measured willingness[31,32,34]. All studies were survey-based, with only 3 studies including prospective follow-ups[29,31,45]. Only one study specifically measured corneal organ donation registration[35], rather than general deceased organ donation.

Of the 11 studies that measured behaviour, 3 measured it prospectively[29,31,45], and 8 measured it cross-sectionally[25,36,37,43,46,48]. None of the prospective studies obtained sufficient data (i.e.

observed a sufficient number of participant registrations) to conduct regression analyses to predict behaviour, but one conducted bivariate correlation analyses between theoretical constructs and behaviour[31]. Five studies measured behaviour cross-sectionally measurement by ascertaining their current organ donation registration status[25,36,37,43] and 3 measured registration immediately following completion of the survey[46,48].

A total of 9 different theories/models were used across the included studies, with some studies drawing from multiple theories for their design. The most commonly used theory/model was the TPB/TRA (k = 23)[23,27-31,33-35,38-42,44-46,48-50], followed by the Prototype Willingness Model (k = 3)[31,32]. Other theories/models used in the studies include the Triangle Model of Responsibility (k = 2)[25], Social Cognitive Theory (k = 1)[24], Metamotivational/Reversal Theory (k = 1)[26], Vested Interest Theory (k = 1)[43], the Bystander Intervention Model (k = 1)[43], and the Integrative Model of Behavioural Prediction (k = 1)[47]. The Organ Donation Model was the only organ donation-specific theory identified in the review, and was used by 3 studies[35,36,43].

The included studies were conducted in the USA (k = 14)[23,34,36,37,40,41,43-48], Australia (k = 9)[28-33,38,39], the UK (k = 3)[25,35], China (k = 1)[49], the Netherlands (k = 1)[24], Germany (k = 1)[27], France (k = 1)[26], Hong Kong (k = 1)[42]. One study recruited participants equally from both the USA and Korea[50]. Sample sizes ranged between 92 and 4426. Participants were primarily recruited from student-aged populations (k = 15)[23,24,30,33,35,38-40,42,44-48,50], while many other studies recruited general populations (k = 9)[25-27,34,36,41,45,46,49]. Some studies used a blended form of recruitment wherein students were primarily recruited with relatively fewer adult community members in the sample (k = 7)[25,28,29,31,32,37]. Only one study examined an older population of those 50-65 years[43]. Of the studies that reported participant sex (k = 30)[23-41,44-50], all but 3[41,46,48] recruited more females than males (range: 38.8%-96.7%). Only one study exclusively recruited participants from an ethnic minority population (African American)[36], but another study recruited participants who self-identified as religious (various religions recruited)[45].

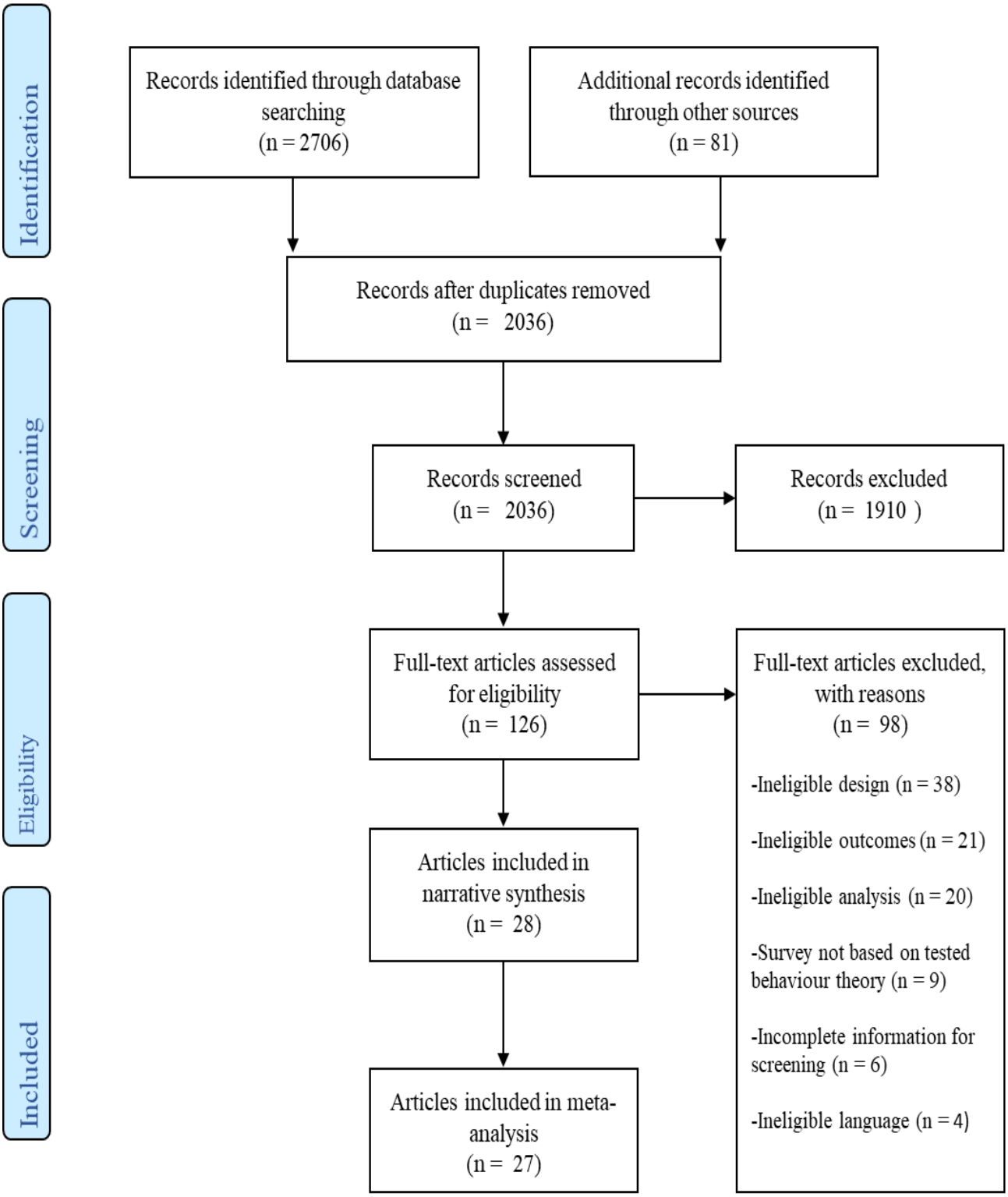

Figure 1. PRISMA flowchart for study selection. Thirty-two eligible studies were reported within 28 articles.

Table 1. Presentation of study and participant characteristics data

Author and Year	Study Design	Country of Conduct	Behaviour Theory/Model Used	Sample Size	Mean Age (standard deviation)	% Female	Type of Population
Britt, Britt & Anderson 2015[23]	Cross-sectional	USA	TPB/TRA	150	22.1 (1.5)	56.3	College students
Brug et al. 2000[24]	Cross-sectional	Netherlands	Social Cognitive Theory (extended)	145	16.2 (1.1)	51	High school students[1]
Farsides 2010 Study 1[25]	Cross-sectional	England	Triangle Model of Responsibility	154	38.5 (12.3)	54.5	General population
Farsides 2010 Study 2[25]	Cross-sectional	England	Triangle Model of Responsibility	497	29.4 (12.0)	66.9	University students and general population
Guedj, Sastre & Mullet 2011[26]	Cross-sectional	France	Metamotivational/Reversal Theory	102	36.7 (16.5)	69.6	General population
Hubner & Kaiser 2006[27]	Cross-sectional	Germany	TPB/TRA	639	35.2	67.7	General population
Hyde & White 2009a[28]	Cross-sectional	Australia	TPB/TRA	123 (107 for analysis)	24.7 (13.0)	64.2	University students and general population
Hyde & White 2009b[29]	Prospective cohort	Australia	TPB/TRA (extended)	359	29.0 (13.7)	73.8	University students and general population
Hyde & White 2009c[30]	Cross-sectional	Australia	TPB/TRA (extended)	303 (293 for analysis)	23.2 (7.8)	77	University students
Hyde & White 2010[31]	Prospective cohort	Australia	TPB/TRA and Prototype Willingness Model	339	24.6 (11.1)	65	University students and general population
Hyde & White 2014 Study 1[32]	Cross-sectional	Australia	Prototype Willingness Model	210	25.9 (13.4)	72	University students and general population
Hyde & White 2014 Study 2[32]	Cross-sectional	Australia	Prototype Willingness Model	307	25.0 (12.1)	65	University students and general population

Hyde, White, & Knowles 2013[33]	Cross-sectional	Australia	TPB/TRA (extended)	258 (238 for analysis)	21.9 (6.9)	81.3	University students
Jeffres et al. 2008[34]	Cross-sectional	USA	TPB/TRA (extended)	377	Not reported	59.9	General population
McGlade, McClenahan & Pierscionek 2012[35†]	Cross-sectional	Northern Ireland	TPB/TRA (extended)	92	24.0 (5.6)	96.7	University students
Morgan 2006[36]	Cross-sectional	USA	Organ Donation Model	310	45	59.4	General African American population
Morgan et al. 2008[37]	Cross-sectional	USA	Organ Donation Model	4426	Not reported	62	University students and general population
Newton et al. 2012[38]	Cross-sectional	Australia	TPB/TRA	309	19.4 (0.1)	58.9	Australian residents aged 18-24
Newton et al. 2013[39]	Cross-sectional	Australia	TPB /TRA (extended)	352	19.3 (1.7)	55.1	Australian residents aged 18-24
Park & Smith 2007[40]	Cross-sectional	USA	TPB/TRA (extended)	261	20.5 (2.5)	63.2	University students
Park, Smith & Yun 2009[41]	Cross-sectional	USA	TPB/TRA	2869	47.4 (14.1)	49.2	General population
Powpaka 1996[42]	Cross-sectional	Hong Kong	TPB/TRA (extended)	277	Not reported	Not reported	University students
Quick et al. 2015[43]	Cross-sectional	USA	Bystander Intervention Model, Organ Donation Model (extended), and Vested Interest Theory	688	54.9 (3.9)	Not reported	Americans aged 50-64
Reynolds-Tylus & Quick 2017[44]	Cross-sectional	USA	TPB/TRA (extended)	307	20.6 (2.2)	59	Non-registered Americans aged 18-24
Rocheleau 2013 Study 1[45]	Prospective Cohort	USA	TPB/TRA (extended)	157	19.1 (1.4)	70.1	University students
Rocheleau 2013 Study 2[45]	Cross-sectional	USA	TPB/TRA (extended)	201 (194 and 192	38.0	64.7	Self-identified religious adults

				for analysis)			
Siegel et al. 2014 Study 1[46]	Cross-sectional	USA	TPB/TRA	158	19.9 (2.9)	64.3	University students
Siegel et al. 2014 Study 2[46]	Cross-sectional	USA	TPB/TRA	358	30.7 (11.5)	38.8	General population
Wang 2011[47]	Cross-sectional	USA	Integrative Model of Behavioural Prediction	309	21.9 (5.9)	67.0	University students
Weber et al. 2007[48]	Cross-sectional	USA	TPB/TRA	370 (366 for analysis)	Not reported	50.0	University students
Wu & Lu 2011[49]	Cross-sectional	China	TPB/TRA (extended)	300	31.4	56.7	General population
Yun & Park 2010[50]	Cross-sectional	USA and Korea	TPB/TRA	American: 290 Korean: 292 (521 for analysis)	American: 20.3 (1.9) Korean: 21.8 (2.6)	Americans: 57 Koreans: 48	Unregistered American and Korean university students

Note. [†]Study specifically measured corneal donation registration rather than general organ donation registration

Table 2. Presentation of study outcome data

Author and Year	Outcome Measured	Registration Rate and Intention to Register Rate/Mean Intention Score	Measurement of Registration Behaviour (registration rate)	Constructs and Correlations	Type of Regression Model (outcome)	Variables Included in Regression Model	R^2 of Most Complete Model
Britt, Britt & Anderson 2015[23]	Intention	**Mean Intention Score:** 4.28/5	n/a	Attitude: 0.46*** Subjective norm: 0.24*** PBC: 0.22***	Hierarchical regression (intention)	Attitude, subjective norm, PBC, age, gender	0.49
Brug et al. 2000[24]	Intention	**Intention to Register Rate:** 51%	n/a	Knowledge: 0.27** Past behaviour: 0.60** Positive outcomes: 0.36** Negative outcomes: 0.65** Self-efficacy: 0.58** Social outcomes: 0.35**	Path analysis (intention)	Past behaviour, positive outcome expectancy, negative outcome expectancy, self-efficacy, social outcome expectancy	0.62
Farsides 2010 Study 1[25]	Intention and behaviour	**Mean Intention Score:** 5.79/9	Self-reported current registration status (38.3%)	**Correlations with Intention:** Obligation: 0.54*** Connection: 0.57*** Clarity: 0.31*** Opposition: -0.01 **Correlations with Behaviour:** Intention: 0.75***	Linear regression (behaviour)	Intention, obligation, connection, clarity, opposition	0.4

				Obligation: 0.47*** Connection: 0.55*** Clarity: 0.34*** Opposition: 0.00			
Farsides 2010 Study 2[25]	Intention and behaviour	**Mean Intention Score:** 5.23/9	Self-reported current registration status (28.6%)	**Correlations with Intention:** Obligation: 0.68*** Connection: 0.56*** Clarity: 0.22*** Opposition: 0.34*** Merit: 0.25*** **Correlations with Behaviour:** Intention: 0.77*** Obligation: 0.57*** Connection: 0.53*** Clarity: 0.27*** Opposition: 0.24*** Control: -0.03 Merit: 0.21***	Linear regression (behaviour)	Intention, obligation, connection, clarity, control	0.41
Guedj, Sastre & Mullet 2011[26]	Intention	Not reported	n/a	Financial incentives: -0.18 Humanistic or religious duty: 0.28** Positive consideration from others: -0.14 Gift of life: 0.32** Living on through receiver: 0.11 Close other: 0.04 Integrity of the corpus: -0.52**	Stepwise regression (intention)	Demographic information, personality measurements, motives (see constructs)	0.52

				Strict individualism: -0.28** Lack of control over organs: -0.31** Anonymity of the procedure: -0.11 Respecting family wishes: -0.30**			
Hubner & Kaiser 2006[27]	Intention	**Mean Intention Score:** 0.07 on scale from (-3)-3	n/a	Attitude: 0.62*** Subjective norm: 0.53*** PBC: 0.79*** Moral norm: 0.54***	Path analysis (intention)	Attitude, subjective norm, PBC, moral norm	0.72
Hyde & White 2009a[28]	Intention	**Mean Intention Score:** 4.37/7	n/a	Behavioural beliefs: 0.49*** Normative beliefs: 0.36*** Control beliefs: 0.42***	Path analysis (intention)	Behavioural beliefs for registering, normative beliefs for registering, control beliefs for registering, intention to discuss, behavioural beliefs for discussing, normative beliefs for discussing, control beliefs for discussing	0.33
Hyde & White 2009b[29]	Intention and behaviour	**Mean Intention Score:** 5.45/7	Self-reported prospective registration (6%)	**Correlations with Intention:** Respondent type (student = 1): 0.12** Attitude: 0.61***	Path analysis (intention)	Respondent type, past registration behaviour, donor prototype evaluation, attitude,	0.74

				Subjective norm: 0.74*** PBC: 0.70*** Moral norm: 0.68*** Self-identity: 0.64*** Past behaviour: 0.45*** Donor prototype evaluation: 0.22***		subjective norm, PBC, moral norm, self-identity	
Hyde & White 2009c[30]	Intention	**Mean Intention Score:** Registered: 6.49/7 Unregistered: 4.11/7	n/a	Attitude: 0.55*** Subjective norm: 0.44*** PBC: 0.59*** Moral norm: 0.51*** Self-identity: 0.65***	Linear regression	Attitude, subjective norm, PBC, moral norm, self-identity	0.63
Hyde & White 2010[31]	Intention, behaviour, and willingness	**Mean Intention Score:** 4.22/7	Self-reported prospective registration (10%)	**Correlations with Behaviour:** Respondent type (student = 1): 0.11 Attitude: 0.28*** Subjective norm: 0.29*** PBC: 0.35*** Moral norm: 0.38*** Self-identity: 0.18* Donor similarity: 0.36*** Donor favourability: 0.26*** Recipient similarity: -0.01	Path analysis (intention and willingness)	**Predicting Intention:** Respondent type, past behaviour, attitude, subjective norm, PBC, moral norm, self-identity, donor similarity, donor favourability, recipient similarity, recipient favourability, donor similarity x donor favourability interaction term,	**Predicting Intention:** 0.72 **Predicting Willingness:** 0.50 **Standard TPB (Int.):** 0.617 **Standard Prototype Willingness**

				Recipient favourability: 0.09 Past behaviour: 0.17* Intention: 0.41*** Willingness: 0.30*** **Correlations with Intention:** Respondent type (student = 1): 0.02 Attitude: 0.55*** Subjective norm: 0.70*** PBC: 0.67*** Moral norm: 0.80*** Self-identity: 0.57*** Donor similarity: 0.50*** Donor favourability: 0.37*** Recipient similarity: 0.25*** Recipient favourability: 0.26*** Past behaviour: 0.39*** **Correlations with Willingness:** Respondent type (student = 1): -0.06 Attitude: 0.54*** Subjective norm: 0.51*** PBC: 0.40***		recipient similarity x recipient favourability interaction term, willingness **Predicting Willingness:** Respondent type, past behaviour, attitude, subjective norm, PBC, moral norm, self-identity, donor similarity, donor favourability, recipient similarity, recipient favourability, donor similarity x donor favourability interaction term, recipient similarity x recipient favourability interaction term, intention	**Model (Will.):** 0.417

				Moral norm: 0.61*** Self-identity: 0.63*** Donor similarity: 0.48*** Donor favourability: 0.41*** Recipient similarity: 0.14** Recipient favourability: 0.26*** Past behaviour: 0.39*** Intention: 0.61***			
Hyde & White 2014 Study 1[32]	Willingness	**Mean Willingness Score:** 5.11/7	n/a	Attitude: 0.57*** Subjective norm: 0.58*** Prototype favourability: 0.30*** Prototype similarity: 0.50***	Hierarchical regression (willingness)	Attitude, subjective norm, prototype favourability, prototype similarity	0.49
Hyde & White 2014 Study 2[32]	Willingness	**Mean Willingness Score:** 5.26/7	n/a	Attitude: 0.53*** Subjective norm: 0.40*** Prototype favourability: 0.44*** Prototype similarity: 0.50***	Hierarchical regression (willingness)	Attitude, subjective norm, prototype favourability, prototype similarity	0.39
Hyde, White, & Knowles 2013[33]	Intention	**Mean Intention Score:** 4.11/7	n/a	Attitude: 0.74*** Subjective norm: 0.53*** Self-efficacy: 0.80*** Moral norm: 0.49*** Self-identity: 0.57***	Hierarchical regression (intention)	Age, sex, ethnicity, past blood donation, attitude, subjective norm, self-efficacy, moral norm, self-identity,	0.73

				In-group altruism (family/friend): -0.50*** In-group altruism (ethnic): -0.27*** Age: 0.04 Sex (1=male): 0.10 Ethnicity (1=Caucasian, 2=others): -0.20** Past blood donation (1=yes): -0.23**		in-group altruism (family/friend), in-group altruism (ethnic)	
Jeffres et al. 2008[34]	Intention and willingness	Not reported	n/a	**Correlations for Intention:** Communicating across channels: 0.21*** **Correlations for Willingness:** Communicating across channels: 0.43*** Negative beliefs: -0.24***	Hierarchical regression (willingness)	Age, education, sex, African American ethnicity, organ donation beliefs, communication channels, discussing organ donation with family/friends or doctor/clergy	0.26
McGlade, McClenahan & Pierscionek 2012[35*]	Intention	**Mean Intention Score:** 3.72/7	n/a	Attitude: 0.91** Subjective Norm: 0.67** PBC: 0.60** Behavioural beliefs: 0.45** Normative beliefs: 0.55** Control beliefs: 0.44*	Hierarchical regression (intention)	Religion, attitude, subjective norm, PBC	0.83

Morgan 2006[36]	Behaviour	N/A	Self-reported current registration status (not reported)	n/a	Logistic regression	Age, gender, education, income, knowledge, attitude, altruism, social norm, bodily integrity, medical mistrust, religiosity	0.32
Morgan et al. 2008[37]	Behaviour	N/A	Self-reported current registration status (not reported)	Media exposure: 0.03 Interpersonal information sources: 0.15 Medical mistrust: -0.23 Jinx factors: -0.29 Bodily integrity: -0.34 Ick factors: -0.31 Perceived benefits: 0.14 Knowledge: 0.15 Attitude: 0.23 Subjective norm: 0.05	Logistic block regression (behaviour), path analysis (behaviour)	**Logistic Regression Model:** Caucasian, African American, gender (1=male), medical mistrust, jinx factors, ick factors, knowledge, media exposure, interpersonal sources, benefits, attitude, subjective norm, constant **Path Analysis Model:** Media exposure, interpersonal information, noncognitive beliefs, perceived benefits, knowledge, attitude, subjective norm	**Logistic Regression Model:** 0.24 **Path Analysis Model:** 0.15

Newton et al. 2012[38]	Intention	**Intention to Register Rate:** 38.8%	n/a	Bipolar behavioural beliefs: 0.50*** Unipolar behavioural beliefs: 0.61*** Valanced behavioural beliefs: 0.48*** All outcome evaluations: 0.29*** Non-salient outcome evaluations: -0.07 Salient outcome evaluations: 0.48*** Attitude: 0.64***	Hierarchical regression (intention)	Salient outcome evaluations, non-salient outcome evaluations	0.21
Newton et al. 2013[39]	Intention	Not reported	n/a	Attitude: 0.60*** Subjective norm: 0.69*** PBC: 0.32*** Moral norm: 0.59*** Anticipated regret: 0.71*** Personal norm: 0.69***	Multiple regression (intention)	Attitude, subjective norm, PBC, moral norm, anticipated regret	0.65
Park & Smith 2007[40]	Intention	**Mean Intention Score:** 4.08/7	n/a	Attitude: 0.56** PBC: 0.32** Subjective norm: 0.53** Personal descriptive norm: 0.46** Personal injunctive norm: 0.48** Societal descriptive norm: 0.19**	Hierarchical regression (intention)	Attitude, PBC, subjective norm, personal descriptive norm, personal injunctive norm, societal descriptive norm, societal injunctive norm	0.44

				Societal injunctive norm: 0.42** Intention to discuss with family: 0.74** Attitude to discuss with family: 0.39** PBC to discuss with family: 0.27** Subjective norm to discuss with family: 0.39** Personal descriptive norm to discuss with family: 0.38** Personal injunctive norm to discuss with family: 0.37** Societal descriptive norm to discuss with family: 0.16* Societal injunctive norm to discuss with family: 0.30**			
Park, Smith & Yun 2009[41]	Intention	**Mean Intention Score:** 4.36/7	n/a	Attitude: 0.50*** Subjective norm: 0.56*** PBC: 0.35*** African American vs White: -0.03 Native American vs White: -0.05* Asian American vs White: 0.04*	Hierarchical regression (intention)	Attitude, PBC, subjective norm, African American, Native American, Asian American, Hispanic	0.4

				Hispanic vs White: -0.02			
Powpaka 1996[42]	Intention	Not reported	n/a	n/a	Path analysis (intention)	Subjective norm, attitude, belief measures	0.88
Quick et al. 2015[43]	Behaviour	N/A	Self-reported current registration status (not reported)	**Bystander Intervention Model:** Notice event: 0.17*** Interpret emergency: 0.38*** Accept responsibility: 0.35*** Know how to help: 0.17*** **Organ Donation Model:** TV dramas: 0.10** Medical mistrust: -0.14*** Ick factors: -0.29*** Jinx factors: -0.27*** Bodily integrity: -0.27*** Perceived benefits: 0.15*** Knowledge: 0.17*** Attitude: 0.25*** Subjective norm: 0.29*** **Vested Interest Theory:** Attitude: 0.25*** Self-efficacy: 0.46***	Path analysis (behaviour)	**Bystander Intervention Model:** Notice event, interpret emergency, accept responsibility, know how to help **Organ Donation Model:** Medical mistrust, ick factors, jinx factors, bodily integrity, medical drama, TV news, barriers, attitude, knowledge, perceived benefits, subjective norm **Vested Interest Theory:** Vested interest, self-efficacy, stake, salience, attitude	**Bystander Intervention Model:** 0.26 **Organ Donation Model:** 0.21 **Vested Interest Theory:** 0.34

				Salience: 0.07 Stake: 0.15***			
Reynolds-Tylus & Quick 2017[44]	Intention	**Mean Intention Score:** Caucasians: 4.38/7 African Americans: 4.04/7 Latin Americans: 4.38/7	n/a	Sex (0=female, 1=male): -0.14* Income: -0.06 Attitude: 0.54*** Subjective norm: 0.59*** PBC: 0.23*** Bodily integrity: -0.30*** Ick factors: -0.26*** Medical mistrust: -0.40*** Perceived realism: 0.19*** Total TV watched: 0.03	**TPB Model:** Hierarchical regression (intention) **Related Constructs Model:** Hierarchical regression (intention)	**TPB Model:** Attitude, subjective norm, PBC, income, sex, total TV watched, perceived realism **Related Constructs Model:** Income, sex, total TV watched, bodily integrity, ick factors, jinx factors, medical mistrust, perceived realism	**TPB Items:** 0.47 **Related Constructs:** 0.30
Rocheleau 2013 Study 1[45]	Intention and behaviour	**Mean Intention Score:** 5.41/7	Self-reported engagement in preparatory behaviours (33.1% engaged in 1 behaviour, 35.7% engaged in more than 1 behaviour)	**Correlations with Intention:** Past behaviour: 0.55*** Attitude: 0.41*** Subjective norm: 0.55*** PBC: 0.43***	Hierarchical regression (intention)	Past behaviour, attitude, subjective norm, PBC	0.48
Rocheleau 2013 Study 2[45]	Intention	**Mean Intention Score:** 5.06/7	n/a	Past behaviour: 0.62*** Outcome expectancies: 0.65*** Religious attitude: 0.68***	Hierarchical regression (intention)	Past behaviour, outcome expectancies, norm, PBC, religious attitude, positive	0.69

				Positive current affect: 0.35*** Negative current affect: 0.28*** Positive affect to donate: 0.40*** Negative affect to donate: 0.39*** Positive affect to not donate: 0.37*** Negative affect to not donate: 0.39*** Subjective norm: 0.62*** PBC: 0.46***		anticipatory effect, negative anticipatory effect, positive affect to donate, negative affect to donate, positive affect not to donate, negative affect not to donate	
Siegel et al. 2014 Study 1[46]	Behaviour	N/A	Organ donation registration form filled out after completing questionnaire (13.2%)	General attitude: 0.43 Specific attitude: 0.68**	Logistic regression (behaviour)	General attitude, specific attitude	Not reported
Siegel et al. 2014 Study 2[46]	Intention and behaviour	**Mean Intention Score:** 5.32/7	Clicking "yes" on option to "Would you like to register to be an organ donor at this time", which redirects survey respondent to website with more information (10.1%)	**Correlations with Intention:** General attitude: 0.55** Specific attitude: 0.75** Horton & Horton general attitude: 0.48** Godin et al. specific attitude: 0.63**	Logistic regression (behaviour), hierarchical regression (intention)	**Logistic Regression Model:** Sex, general attitude, specific attitude **Hierarchical Regression:** General attitude, specific attitude, Horton & Horton	**Logistic Regression Model:** Not reported **Hierarchical Regression Model:** 0.41

				Correlations with Behaviour: General attitude: 0.33 Specific attitude: 0.44 Horton & Horton general attitude: 0.31 Godin et al. specific attitude: 0.41		general attitude, Godin et al. specific attitude	
Wang 2011[47]	Intention	**Mean Intention Score:** 4.93/7	n/a	Empathy: 0.31** Attitude: 0.40** Subjective norm: 0.58** Self-efficacy: 0.41** Anticipated guilt: 0.61**	Path analysis	Empathetic concerns, attitude, subjective norm, self-efficacy, anticipated guilt	0.69
Weber et al. 2007[48]	Intention and Behaviour	**Mean Intention Score:** 7.24/10	Signing of organ donor card after completion of survey (17.8%)	**Correlation with Intention:** Attitude: 0.47** Normative beliefs: 0.51**	Logistic regression (behaviour)	Attitude, norm, intentions	0.23
Wu & Lu 2011[49]	Intention	**Mean Intention Score:** 3.33/5	n/a	Negative attitude: -0.41** Subjective norm: 0.50** Traditional beliefs: 0.27**	Hierarchical regression	Region, age, gender, education, negative attitude, subjective norm, traditional beliefs	0.38
Yun & Park 2010[50]	Intention	**Mean Intention Score:** 3.54/7	n/a	Attitude: 0.53** Subjective Norm: 0.54** PBC: 0.46** Intention to talk to family: 0.61**	Hierarchical regression (intention)	Culture, attitude, subjective norm, PBC	0.47

				Attitude to talk to family: 0.45** Subjective norm to talk to family: 0.50** PBC to talk to family: 0.50**			

Note. The related constructs model from Reynolds-Tylus & Quick (2017)[44] was not included in the meta-analysis since those factors act as an extension to formal theory and do not include any traditional constructs.

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Risk of Bias in Individual Studies

In total, 9 of the 11 (82%) measurements of registration behaviour were of poor quality[25,36,37,43,45,46,48], while the 2 other measurements were of fair quality[29,30]. With respect to the measurement of intention to register, 17 of 26 (65%) were of fair quality[24-28,30,33,38-40,45-49], 7 were of good quality (27%)[23,29,3135,41,44,50], and the remaining two studies were of poor quality (8%)[34,42]. Finally, for the measurement of willingness, 2 of 4 (50%) were of fair quality[33], 1 was of good quality (25%)[31], and the other was of poor quality (25%)[34]. The results of our risk of bias analysis are shown in Appendix D.

Most studies clearly defined their sample (94%)[23-33,35-41,43-50], their research questions (100%), their recruitment methodology (97%)[23-41,43-50], the validity and reliability of the constructs they measured (94%)[23-33,35-41,43-50], and the validity and reliability of outcome measurement (69%)[23,24,26-33,35,38-42,44,47,49,50]. Additionally, most studies measured registration status prior to intention/behaviour (69%)[23,25,27-38,41,44-46,48,50], used models that accurately represented the theory (84%) [23-33,35-37,39-41,43-45,47-50].

However, the majority of studies did not achieve or report a participation rate of ≥50% (75%)[23,25,26,28-30,33,34,36-40,42,43,45-48,50], report sample size calculations (100%), measure/adjust for confounding variables (53%)[24,25,27,28,30,32,38,40,42,43,45,47,48] or have a follow-up assessment of intention/behaviour (91%)[23-28,30,32-44,46-50].

Of the 11 studies examining registration behaviour, 9 (82%) studies had poor measurement of behaviour[25,36,37,43,45,46,48]. Most of these studies measured behaviour cross-sectionally, either through current self-reported registration status or registration immediately following the survey, both of which introduce bias into behavioural measurement. One prospective study measured registration behaviour as engagement in "preparatory behaviours" (e.g. discussing with family, signing an organ donor card) instead of actual registration[45], which we did not consider to be a valid measurement of registration behaviour. Among the 3 studies measuring behaviour prospectively[29,31,45], only 1 (33%) had a loss to follow up rate of 20% or less[45], but all 3 studies had sufficient time frames for follow-up.

Pooled Bivariate Correlations with Organ Donation Registration Behaviour

Table 3 describes the results for bivariate correlation meta-analyses (including sensitivity analyses) between theoretical constructs and behaviour/intention. Only the Organ Donation Model, the Triangle Model of Responsibility, and the TPB/TRA had sufficient data for meta-analysis with behaviour as the primary outcome. Data was limited for all construct-behaviour correlation meta-analyses, as there were only two studies that reported such correlations for each theory.

As shown in Table 3, meta-analyses were conducted for 8 constructs from the Organ Donation Model. Effect sizes for correlations ranged from r = -0.31 to 0.23. All of the organ donation-specific constructs were significantly and negatively correlated with behaviour, but the largest correlation was seen in the bodily integrity construct (r = -0.31). The smallest correlation with behaviour among organ donation-specific constructs was found in medical mistrust (r = -0.19). While the knowledge and attitude constructs from the Organ Donation Model were significantly correlated with behaviour, the subjective norm construct correlation was not statistically

significant. Significant heterogeneity was only found for the medical mistrust and subjective norm constructs.

Only 3 TPB/TRA studies conducted construct correlation analyses to predict behaviour[31,46]. As shown in Table 3, two of those studies only measured general attitudes and specific attitudes, and when those studies are pooled, specific attitude (r = 0.67) has a larger correlation with behaviour than general attitude (r = 0.50)[46]. The other TPB/TRA study (not included in meta-analyses, see Table 2 for study outcome data) found that the largest correlation with behaviour was intention (r = 0.41), while the lowest statistically significant correlation was past behaviour (r = 0.17)[31].

Finally, the correlation between 4 constructs from the Triangle Model of Responsibility and registration behaviour were meta-analyzed. The largest effect size was found in the intention-behaviour correlation (r = 0.77), while the lowest was found in the clarity-behaviour correlation (r = 0.29). Heterogeneity was not found for any Triangle Model of Responsibility construct-behaviour correlations.

Table 3. Summary of bivariate correlation meta-analyses.

Bivariate Associations	*n*	*k*	*r*	95% CI	*Q*
Organ Donation Model Constructs-Behaviour					
Knowledge	5114	2	0.15	0.13-0.18	0.25
Attitude	5114	2	0.23	0.21-0.26	0.27
Subjective Norm	5114	2	0.17	(-0.07)-0.39	36.64*
Bodily Integrity	5114	2	(-0.31)	(-0.38)-(-0.24)	3.54
"Ick" Factors	5114	2	(-0.31)	(-0.33)-(-0.28)	0.29
"Jinx" Factors	5114	2	(-0.29)	(-0.31)-(-0.26)	0.28
Medical Mistrust	5114	2	(-0.19)	(-0.28)-(-0.10)	5.16*
Perceived Benefits	5114	2	0.14	0.11-0.17	0.06
TPB/TRA Constructs-Behaviour					
General Attitude	516	2	0.50	0.38-0.61	2.71
Specific Attitude	516	2	0.67	0.47-0.81	10.40*
Triangle Model of Responsibility Constructs-Behaviour					
Intention	651	2	0.77	0.73-0.80	0.26
Clarity	651	2	0.29	0.21-0.36	0.69
Connection	651	2	0.54	0.48-0.59	0.09
Obligation	651	2	0.53	0.43-0.62	2.19
TPB/TRA Constructs-Intention					
Subjective Norm	7071	15	0.57	0.52-0.62	107.73*
Subjective Norm (Sensitivity Analysis)	6921	14	0.59	0.54-0.63	83.04*
Attitude	6943	14	0.59	0.53-0.64	134.15*
Attitude (Sensitivity Analysis)	6851	13	0.56	0.51-0.60	60.33*
PBC	6533	13	0.50	0.38-0.61	372.57*
Normative Beliefs	565	3	0.48	0.38-0.57	3.50
Behavioural Beliefs	508	3	0.47	0.40-0.55	0.13
Control Beliefs	199	2	0.43	0.31-0.54	0.03
Additional Constructs Added to Theory					
Moral Norm	2220	6	0.62	0.50-0.71	76.28*

Self-Identity	1229	4	0.61	0.57-0.65	4.04
Past Behaviour	1049	4	0.50	0.40-0.60	13.87*
Triangle Model of Responsibility Constructs-Intention					
Clarity	651	2	0.24	0.16-0.32	1.09
Connection	651	2	0.56	0.51-0.61	0.03
Obligation	651	2	0.62	0.47-0.74	5.85*
Prototype Willingness Model Constructs-Willingness					
Attitude	856	3	0.54	0.50-0.59	0.42
Subjective Norm	856	3	0.50	0.39-0.59	7.39*
Prototype Favourability	856	3	0.39	0.31-0.46	3.43
Prototype Similarity	856	3	0.49	0.44-0.54	0.14

Note. n = number of participants, k = number of studies, r = bivariate correlation coefficient, Q = Cochrane's Q statistic
*Statistically significant heterogeneity, $p \leq 0.05$

Subgroup and Sensitivity Analyses

There was insufficient data for subgroup analyses and sensitivity analyses for correlations with registration behaviour, as a maximum of 2 studies tested each construct.

Frequency-Weighted Mean R^2 Predicting Organ Donation Registration Behaviour

Results of all frequency-weighted mean R^2 meta-analyses (including subgroup and sensitivity analyses) are shown in Table 4. There were only 4 studies who reported R^2 scores from eligible regression models[25,37,43]. The theories that informed these models were the Organ Donation Model[37,43], the Triangle Model of Responsibility[25], the Bystander Intervention Model[43], and Vested Interest Theory[43].

Table 4. Summary of frequency-weighted mean R^2 meta-analyses, including subgroup and sensitivity analyses.

Outcome Predicted		*n*	*k*	R^2
Behaviour				
Overall Pooled Effect		5688	4	0.19
Intention				
Overall Pooled Effect		8597	22	0.51
By Theory/Model				
	TPB/TRA	8041	19	0.50
	TPB/TRA*	7413	16	0.50
	Other	556	3	0.64
By Regression Model				
	Path Analysis	2099	7	0.70

	Path Analysis*	1872	6	0.67
	Linear	6498	15	0.46
	Linear*	6097	13	0.46
By Study Population[†]				
	Student	3358	13	0.56
	Student*	2730	10	0.56
	General/Adult	4434	6	0.45
By Study Region[‡]				
	USA	4603	8	0.44
	Australia	1997	7	0.60
	Australia*	1688	6	0.68
	Europe	952	4	0.66
	Europe*	860	3	0.64
	Asia	527	2	0.60
	Asia*	300	1	0.38
Sensitivity Analyses				
	ROB and Outliers Removed	7969	19	0.51
	Park, Smith & Yun 2009[41] Removed	5728	21	0.57
	ROB, Outliers, and Park, Smith & Yun 2009[41] Removed	5100	18	0.57
Willingness				
Overall Pooled Effect		1233	4	0.39
	Sensitivity Analysis	856	3	0.44

Note. n = number of participants, k = number of studies, R^2 = frequency-weighted mean R^2 score, ROB = risk of bias
*results with poor-quality studies and outliers removed
[†]Some studies excluded since students and general population were sampled unequally
[‡]One study was excluded since participants were sampled from different regions, but reported together

The overall frequency-weighted mean R^2 for the prediction of behaviour was 0.19 (k = 4, n = 5688), with scores ranging from R^2 = 0.15 to 0.41. These results indicate that 19% of the variance in organ donation registration behaviour may be explained by the theoretical models included in this meta-analysis.

Five studies used logistic regression models to predict organ donation registration behaviour[36,37,46,48], and of those 5, only 3 reported Nagelkerke R^2 scores[36,37,48] (see Table 2). The largest Nagelkerke R^2 score was found in Morgan (2006)[36] ($R^2 = 0.32$), while the smallest was found in Weber et al. (2007)[48] ($R^2 = 0.23$). Both Siegel et al. (2014)[46] studies did not report Nagelkerke R^2 scores.

Sensitivity Analyses

All studies included in this meta-analysis posed significant risk of bias in their measurement of behaviour; therefore, sensitivity analyses were not warranted for frequency-weighted mean R^2 meta-analyses with behaviour.

Pooled Bivariate Correlations with Intention to Register for Organ Donation

As shown in Table 3, only the TPB/TRA and the Triangle Model of Responsibility had sufficient data for bivariate correlation meta-analysis with intention. The correlation between TPB/TRA subjective norm, attitude, and PBC constructs and intention were the most frequently tested within the studies, while the TPB/TRA belief-based constructs were tested considerably less within the studies. Several studies included other constructs in their TPB/TRA questionnaires such as moral norm, self-identity, and past behaviour. The forest plots for intention correlations with TPB/TRA subjective norm, attitude, and PBC are shown in Appendix E.

Effect sizes ranged from $r = 0.43$ to 0.59 for TPB/TRA constructs, with the attitude construct having the strongest bivariate correlation with intention. While all TPB/TRA results were statistically significant, heterogeneity was observed in the subjective norm, attitude, and PBC constructs, especially the latter construct. Correlations between the additional constructs added to the TPB/TRA (moral norm, self-identity and past behaviour) ranged form $r = 0.50$ to 0.61. Of these constructs, moral norm was the most tested ($k = 6$) and had the largest correlation ($r = 0.61$), while past behaviour had the lowest correlation ($r = 0.50$). Self-identity was the only additional TPB/TRA construct that did not have statistically significant heterogeneity.

For Triangle Model of Responsibility constructs, the effect sizes ranged from $r = 0.24$ to 0.62, with obligation having the largest bivariate correlation with intention ($r = 0.62$), and clarity having the smallest ($r = 0.24$). Significant heterogeneity was only found in the obligation-intention correlation.

Subgroup Analyses

Only the subjective norm, attitude, and PBC constructs' association with intention had sufficient data for subgroup analyses. For these constructs, subgroup analyses based on study region and type of study population were conducted, but did not suggest any meaningful differences between subgroups and are therefore not shown in this review. Although subgroup analyses based on ethnicity were planned, there was insufficient data to conduct them.

Sensitivity Analyses

No studies posed a high risk of bias based on measurement of construct correlations with intention, therefore, only potential outlier sensitivity analyses were conducted. Effect size data for bivariate correlation sensitivity analyses are presented in Table 3. Stem and leaf plots for all sensitivity analyses can be found in Appendix F.

Based on stem and leaf plots for the subjective norm-intention correlation (Figure 6, Appendix F), the correlation from Britt, Britt & Anderson's (2015)[23] study appeared to be a potential outlier ($r = 0.24$). Upon its exclusion, the overall correlation effect estimate increased to $r = 0.59$, and the heterogeneity decreased ($Q = 83.04$, $p < 0.05$), but was still statistically significant.

McGlade, McClenahan & Pierscionek's (2012)[35] study was excluded for the attitude-intention sensitivity analysis following stem and leaf plotting (Figure 7, Appendix F). Its bivariate correlation of $r = 0.91$ appeared to be a potential outlier in the data. Upon removing this study, the bivariate correlation decreased ($r = 0.56$) along with the heterogeneity, which decreased considerably ($Q = 60.33$, $p < 0.05$), but was still statistically significant.

Based on stem and leaf plotting for the PBC-intention correlation (Figure 8, Appendix F), the data appeared to be skewed but did not appear to contain any outliers. Therefore, sensitivity analyses were not conducted for this correlation.

Frequency-Weighted Mean R^2 Scores Predicting Intention to Register for Organ Donation

As shown in Table 4, total of 22 studies reported R^2 scores for eligible models predicting organ donation registration intention. The R^2 scores ranged from $R^2 = 0.21$ to 0.88. Overall, the frequency-weighted mean R^2 score for organ donation registration intention was $R^2 = 0.51$ ($k = 22$, $n = 8597$), meaning 51% of the variance in organ donation registration intention may be explained by the theoretical models included in this meta-analysis. Results from this meta-analysis are graphically visualized in Figure 2.

Subgroup Analyses

Subgroup analyses for R^2 meta-analyses predicting intention were conducted based on the theory used, type of regression model, study population (student vs. general population), and study region. Visualizations for all R^2 subgroup meta-analyses predicting intention can be found in Appendix G.

Theory subgroup analysis. The majority of the included studies used the TPB/TRA as the basis for their model ($k = 19$), while only 3 studies used other theories/models (e.g. Integrative Model of Behavioural Prediction, Social Cognitive Theory, and Metamotivational/Reversal Theory). Hyde & White (2010)[31] included a standard TPB regression model in addition to their combined model incorporating the TPB and the PWM. The standard TPB model was included exclusively in the TPB/TRA subgroup analysis (i.e. not in the main meta-analysis). Both models were treated as multiple measurements (see methods). The frequency-weighted mean R^2 scores for the TPB/TRA studies was $R^2 = 0.50$, while the frequency-weighted mean R^2 scores for the studies using other theories/models was $R^2 = 0.64$.

Type of regression model subgroup analysis. Most included studies used linear regression models ($k = 15$), while 7 studies used path analysis. The frequency-weighted mean R^2 score for path analysis models ($R^2 = 0.70$) was considerably higher than that of linear regression models ($R^2 = 0.46$). When poor-quality studies are removed from the path analysis subgroup, the adjusted frequency weighted mean R^2 score is relatively similar ($R^2 = 0.67$) to the unadjusted estimate.

Population subgroup analysis. Some studies were excluded from population-based subgroup analyses since their samples were constructed from unequal proportions of student and general populations[25,28,29,31]. Of the remaining studies, 13 recruited student populations while 7 recruited adult populations. The frequency-weighted mean R^2 score for student populations (R^2 = 0.56) was higher than that of general population studies (R^2 = 0.45).

Study region subgroup analysis. When grouped by study region, the frequency-weighted mean R^2 effect estimates ranged from R^2 = 0.48-0.66. Most studies were conducted in the USA (k = 8). The USA subgroup also had the lowest effect estimate (R^2 = 0.44). Conversely, the European studies were represented much less frequently (k = 4), but had a much larger effect estimate (R^2 = 0.66). Despite differing greatly in number of studies, the Australian studies (k = 7, R^2 = 0.60) have a very similar effect estimate to the Asian studies (k = 2, R^2 = 0.60). Overall, there does not seem to be much of an observable difference in effect sizes when the studies are grouped by study region, except for the USA studies, whose effect size is considerably lower than the others.

Ethnicity subgroup analysis. There was insufficient data for subgroup analyses based on ethnicity, however one study constructed separate TPB/TRA-based regression models for Caucasian, African American, and Latino participants[44]. The Caucasian model (n = 87) had the highest explained variance (R^2 = 0.61), while the African American model (n = 115) had the lowest explained variance (R^2 = 0.36). Finally, the Latino model (n = 105) explained 47% of the variance in organ donation registration intention.

Sensitivity Analyses

Powpaka's (1996)[42] study was the only study removed for sensitivity analyses due to its high risk of bias. With the removal of this study, the stem and leaf plot (Figure 9, Appendix F) seemed to indicate that R^2 scores from McClenahan & Pierscionek's (2012)[36] study (R^2 = 0.83) and Newton et al.'s (2012)[38] study (R^2 = 0.21) were outliers in the data. They were therefore excluded for the sensitivity analysis. Upon removing these 3 studies from the analysis, the adjusted effect estimate was $R^2_{adjusted}$ = 0.51, which was identical to the unadjusted estimate, suggesting a minimal impact of poor-quality and outlying studies on the overall effect estimate. Additional sensitivity analyses were conducted by excluding Park, Smith & Yun's study (2009)[41] as it had the largest sample size (n = 2869). Upon removing that study, the adjusted frequency-weighted mean R^2 increased to $R^2_{adjusted}$ = 0.57. When the studies with high risk of bias and outliers were removed in addition to Park, Smith, & Yun's study (2009)[41], the adjusted frequency-weighted mean R^2 score remained at $R^2_{adjusted}$ = 0.57.

Sensitivity analyses were also conducted for subgroup analyses by removing the aforementioned poor-quality study and outlier studies from their respective subgroups. Adjusted effect estimates for TPB/TRA-based studies, student samples, and studies conducting linear regression were identical to their unadjusted estimates. The frequency-weighted mean R^2 for Australian studies increased after sensitivity analyses ($R^2_{adjusted}$ = 0.68), while effect estimates decreased for studies conducting path analysis ($R^2_{adjusted}$ = 0.67) and Asian studies ($R^2_{adjusted}$ = 0.38).

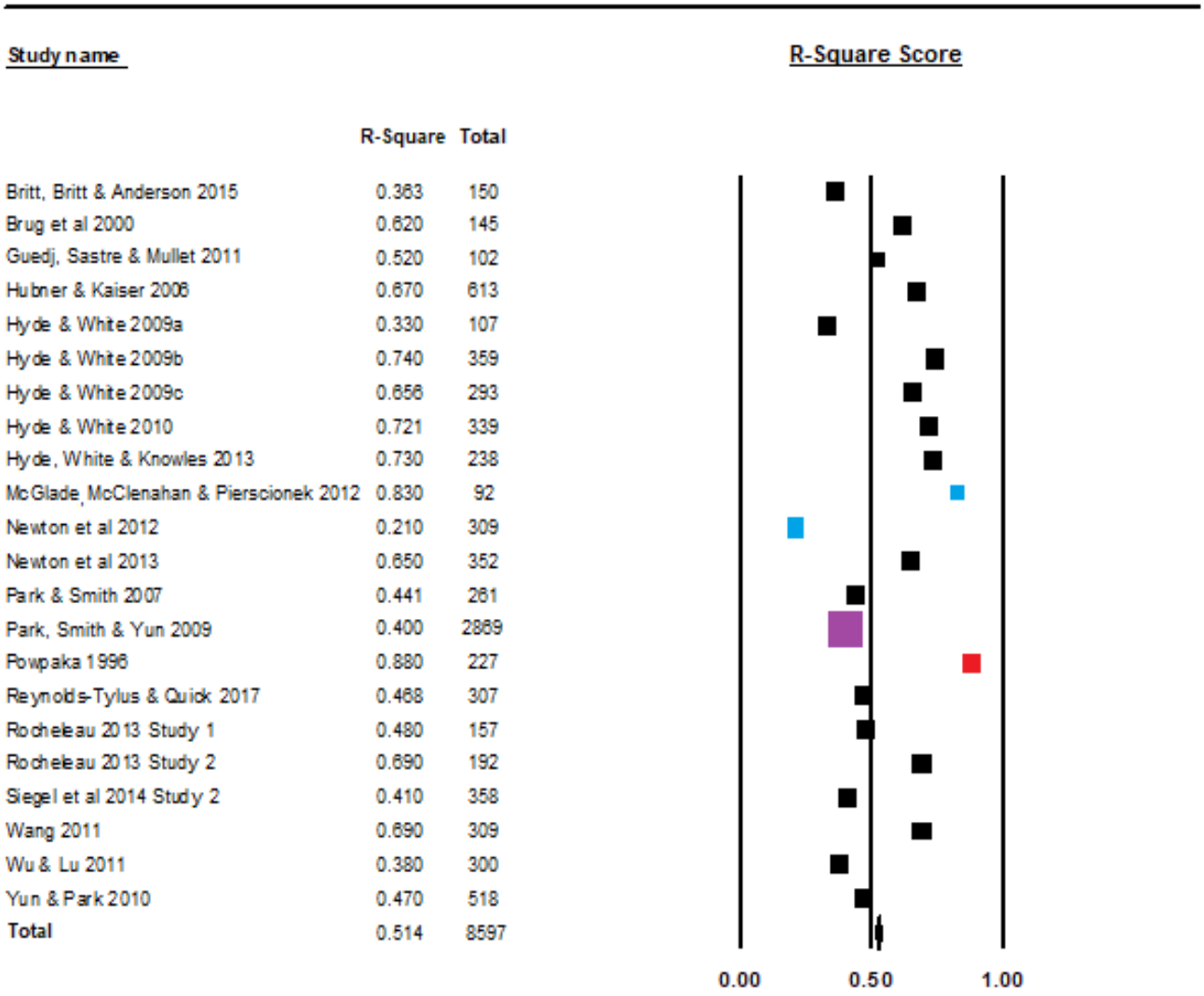

Figure 2. Visualization of frequency-weighted mean R^2 meta-analysis for the prediction of intention to register for organ donation.
Note. The size of the plots corresponds to the sample sizes of the studies. Studies removed in sensitivity analyses due to risk of bias are highlighted in red. Studies removed in sensitivity analyses due to potential outlier status are highlighted in blue. Park, Smith & Yun (2009)[53] is highlighted in purple as the study with the highest sample size.

Pooled Bivariate Correlations with Willingness to Register for Organ Donation

Only 4 studies measured willingness as a separate construct from intention, primarily because most of these studies used the Prototype Willingness Model as the basis for their surveys[31,32], a theory that explicitly distinguishes willingness from intention. The only other study that measured willingness was a TPB/TRA-based study[34], therefore its results were not meta-analyzed with the Prototype Willingness Model-based studies.

As shown in Table 3, the Prototype Willingness Model construct correlation with willingness effect sizes ranged from $r = 0.39$ to 0.54 and were all statistically significant. The construct with the largest correlation with willingness was attitude ($r = 0.54$), while prototype similarity had the smallest ($r = 0.39$). Significant heterogeneity was only found for the subjective norm construct.

Frequency-Weighted Mean R^2 Scores Predicting Willingness to Register for Organ Donation

As previously mentioned, there were 4 studies that used regression models to predict willingness to register for organ donation registration. Two of the studies used PWM-based regression models[32], one study used a TPB/TRA-based regression model[34], and the final study used a combined model incorporating the TPB/TRA and the PWM[31]. In addition to the combined TPB/TRA and PWM model, the final study also used a standard PWM regression model to predict willingness[31]. As such, the sample size was split equally among the two models, as per recommendations from the Cochrane Handbook[21].

As shown in Table 4, the overall frequency-weighted mean R^2 score for the prediction of organ donation willingness is 0.39. This means that 39% of the variance in organ donation registration willingness may be explained by the theoretical models included in this meta-analysis.

Sensitivity Analysis

Only one study by Jeffres et al. (2008)[34] was excluded for the sensitivity analysis for the prediction of willingness due to its high risk of bias. Once that study was excluded, the frequency-weighted mean R^2 score increased to $R^2_{adjusted} = 0.44$.

Discussion

This systematic review aimed to identify the theories of behaviour that have been used to understand organ donation registration, as well as the modifiable constructs associated with intention to register and actual registration. We also aimed to determine how much variability in organ donation registration intention and behaviour are accounted for by theoretical models pooled across this literature.

In line with these objectives, we identified 9 behaviour theories, and 82 constructs across those theories, that have been applied to understand variance in organ donation registration intention and behaviour. Bivariate associations between individual theoretical constructs and organ donation registration behaviour ranged in their effect sizes, but were mostly of small size, based on Cohen's guidelines[20]. Meanwhile, bivariate associations between theoretical constructs and organ donation registration intention tended to be of medium to large size. Furthermore, our review showed that when testing theoretical models as a whole (i.e. including all theoretical constructs specified by the model), constructs from behaviour theories explained a medium

amount variance in organ donation registration behaviour, and a large amount of variance in organ donation registration intention and willingness.

Theories/Models Applied to Organ Donation Registration

Across the 32 studies identified in this review, 9 different behaviour theories/models were identified in the review, with the TPB/TRA dominating this literature (72% of the included studies). It seems that this is a literature that has not engaged with more contemporary theories in behavioural science, seemingly instead focusing more on a few classic theories of behaviour or developing new, organ donation registration-specific theories. Indeed, of the 64 theories/models from the compendium ABC of Behaviour Change Theories[18] that were included in our search, only 3 were identified in this literature, with the TPB/TRA being predominant.

There is reason to consider this as an opportunity for this literature to engage with more contemporary theory. While the TPB/TRA has been one of the most important behaviour theories since its conception, and the most widely used in this (and other) literature[51-54], there have been concerns for its predictive validity and utility, and especially in its utility and sufficiency for informing behaviour change interventions[55]. The TPB only includes 4 constructs to explain behaviour (attitudes, subjective norms, PBC, and intention)[56]. Many cite that while these constructs predict intention well, they are insufficient to fully explain behaviour, and as a result, the TPB has limited predictive validity[55]. Further, some studies have shown that the theoretical constructs of the TPB better predict intention to engage in a behaviour rather than behaviour per se[57]. This is not new and is clearly also evidenced in our review. Contemporary theory has recognized this since the 1990s, including a focus on the gap between intention and behaviour[58]; however, the organ donation registration literature has largely not engaged with this. The aforementioned intention-behaviour gap arises when people form intentions, but do not translate them into behaviours[59]. This highlights the need for post-intentional processes to be better understood in behaviour change, especially given the number of Canadians who have not translated their intention to register into actual registration.

The Health Action Process Approach (HAPA)[60], is an example of a contemporary behaviour theory that elaborates on these post-intentional (volitional) processes in behaviour change. These volitional processes help to address the intention-behaviour gap by explaining the additional factors needed to understand how the intended behaviour change can be planned, initiated, and maintained once individuals are motivated (intend) to change[61]. Two processes comprising the volitional stage include action planning, where one plans how the behaviour will be performed, and coping planning, where one anticipates the barriers to the behaviour and plans how to address them[60]. Most applications of HAPA and action planning and coping planning mechanisms focus on recurring health behaviours such as participating in cardiac rehabilitation[61] and smoking cessation[62]. However, the application of the HAPA to organ donation registration to date remains minimal.

The only bespoke theory identified in the search, the Organ Donation Model, is grounded in the TPB/TRA and therefore contains similar constructs such as attitude and subjective norm. However, the Organ Donation Model expands on the TPB/TRA by adding constructs such as knowledge/exposure to information, bodily integrity (belief that the body should be kept whole after death), medical mistrust (belief that medical professionals will alter one's care based on registration status), "ick" factors (disgust related to organ donation), "jinx" factors (fear or superstition that registering for organ donation will curse one into a premature death) and

altruism to make it more applicable to the behaviour of organ donation registration[37]. However, the Organ Donation Model does not include intention as a construct mediating registration behaviour, despite intention acting as an important correlate of registration behaviour (as shown in our review). The only other study[44] to include the same organ donation-specific constructs (e.g. medical mistrust, bodily integrity, "ick" factors) was centred around the TPB/TRA, and found that each construct was significantly, and negatively, associated with intention, and altogether explain a large amount of variance in intention, albeit a lower amount than traditional TPB/TRA constructs[44].

Organ donation-specific constructs such as bodily integrity have a role in shaping attitudes towards organ donation registration. Most of the studies included in our review measured attitudes by assessing whether or not participants thought organ donation and/or registration was "good/bad" and whether or not they support it. While this does provide us with information on approval, it is limited in its ability to provide insight into why respondents think organ donation is right/wrong, and why they do or do not support it. Based on evidence from our review, organ donation-specific constructs are significantly associated with both intention and registration behaviour, and contribute to explaining a large amount of variance in intention and a medium amount of variance in behaviour. Therefore, future research should aim to test them in addition to traditional theoretical constructs, or use them to operationalize traditional constructs in the context of organ donation registration (e.g. medical mistrust belief items in measurement of attitude or behavioural beliefs) in order to provide a more complete understanding of the factors influencing registration motivation.

Measurement of Organ Donation Registration Behaviour

We considered the least biased measurement of organ donation registration behaviour as involving prospectively assessed (at a different time point than the theoretical constructs) and objectively measured (rather than self-reported). Examples of prospective and objective measurement of behaviour in this setting entailed verification of registration by checking an organ donor registry database 1 week to 2 months following administration of the survey.

Prospective assessment of behaviour ensures temporal distinction between the measurement of theoretical construct scores and registration behaviour. In contrast, studies testing associations between organ donation registration behaviour/intention and theoretical constructs using a cross-sectional measurement of past behaviour, does not ensure this temporality, and biases the results as theoretical construct scores for participants could have been different prior to registration.

Searching a registry of organ donors to determine whether or not participants have registered serves as more objective measurement of behaviour. Self-reported measurement of behaviour can be biased since it cannot be certain whether or not the participants have registered. Due to social desirability or memory bias, some participants may respond as being registered when they are actually not, because it may seem that is the option the researchers, or society as a whole, prefer. Further, some may assume they are already registered when they may not be, as some evidence suggests is the case for 15% of people[63]. This can lead to possible overestimation of registration.

All of the included studies in behaviour-based meta-analysis measured behaviour in a potentially biased manner. Several studies[46,48] asked participants to register for organ donation immediately following completion of the survey. Offering the chance to register following a survey

essentially acts as an intervention in these cases, as immediate registration opportunity has been highlighted as an important factor influencing registration[64]. The association between theoretical constructs and registration is then biased since the predictive study itself targets and addresses an important factor influencing registration. Although this measurement of behaviour is objective, it may introduce bias into the associations between theoretical constructs and behaviour. One study in particular measured behaviour in their online survey as clicking a link to a website where participants would be able to register for organ donation[46]. However, the researchers never verified that the participants had actually registered once they were redirected to the website. Although this measurement of behaviour is objective, as it is a proxy for actual registration behaviour, it likely overestimates the true registration rate. The other studies measured behaviour retrospectively, recruiting both registered organ donors and non-registered individuals, and determining the association between theoretical constructs and past registration behaviour[25,36,37].

Only the studies that measured registration cross-sectionally, either from past behaviour or immediate registration following the survey, obtained sufficient data to conduct regression analyses to predict organ donation registration behaviour. The fact that the cross-sectional studies with immediate measurement of behaviour following the survey had higher registration rates, as well as sufficient data for analysis compared to the prospective studies, suggests possible overestimation of registration.

Only 3 of 32 studies[29,31,45] conducted prospective measurement of organ donation registration behaviour, and of those, only one[31] obtained sufficient data to conduct any form of data analysis for the prediction of registration behaviour. Only bivariate correlation analysis could be conducted, while the other variables included in the study (intention and willingness) had sufficient data to conduct path analysis[31]. The prospective studies described organ donation registration as a low-performance behaviour, suggesting few of the participants actually registered after follow-up, which explained why they did not obtain sufficient data for analyses.

The RegisterNow-1 trial[65], which tested the effectiveness of an intervention in family physician waiting rooms to encourage registration, provides an example of how to measure organ donation registration behaviour both prospectively and objectively. In this trial, follow up occurred 7 days after the family physician visit to allow for family discussion of decision to register, and registration was verified through searching healthcare administrative databases[65].

Further research should seek to measure registration prospectively and objectively (when available). Although prospective studies in our review were unable to obtain sufficient registration data to run analyses, future research should assess whether or not prospective measurement of registration behaviour is feasible to analyze the association between theoretical constructs and registration behaviour.

Meta-Analyses

Perhaps predictably, the construct most strongly associated with organ donation registration behaviour was intention, which is consistent with other systematic reviews of other health behaviours where the TPB is the central theory under study[73,74]. There was only sufficient data for the intention-behaviour correlation to be pooled for the Triangle Model of Responsibility studies[37]. Only one TPB/TRA study by Hyde & White reported an intention-behaviour correlation, and it was the construct most associated with behaviour[43]. Although Hyde & White's intention-behaviour correlation was considerably smaller than those from Farsides's studies, this

is expected given they used prospective measurement of behaviour while Farsides measured behaviour cross-sectionally using current registration status[75,76].

While the TPB/TRA and the Organ Donation Model are inextricably linked in terms of their constructs, some organ donation-specific constructs included in meta-analyses had the largest correlation with registration behaviour, namely bodily integrity, "jinx" factors, and "ick" factors among all Organ Donation Model constructs. This further supports the potential utility for these constructs to be incorporated within behaviour theories applied to future organ donation registration studies.

In bivariate association meta-analyses testing correlations with intention, large correlations were found between each of the traditional TPB constructs (e.g. attitude, subjective norm, and PBC) and intention to register. Additionally, moral norm and self-identity, which were tested as additional constructs added to the TPB/TRA had larger correlations with intention than the traditional constructs, suggesting they are also important in explaining variance in intention. In fact, some have long advocated for the inclusion of moral norm and self-identity into the TPB/TRA[66-68], yet have been tested minimally in the organ donation registration literature.

Pooled R^2 meta-analyses showed that the behaviour theories identified in the review explain 51% of the variance in organ donation registration intention, and 19% of the variance in organ donation registration behaviour. These findings are consistent with a meta-analysis of the TPB by McEachan et al.(2011)[52] in which they concluded that across several different health behaviours (including physical activity, dietary changes, safer sex, and abstinence, though not organ donation registration), 44.3% of the variance in intention and 19.3% of the variance in behaviour is explained by the TPB/TRA. McEachan et al.'s meta-analysis showed that the TPB/TRA better predicts intention than behaviour for the health behaviours it included[52].

Although none of the studies that were included in the R^2 meta-analysis predicting behaviour used the TPB/TRA, the Organ Donation Model (most commonly tested theory in this meta-analysis) draws from the TPB/TRA in terms of its constructs and associations (although it excludes intention). Additionally, like the TPB/TRA, all of the theories included in this meta-analysis did not include any post-intentional constructs. Therefore, our results also suggest that the theories included in this review better predict intention than behaviour.

Subgroup Analyses

Each of the subgroup analyses for the frequency-weighted mean R^2 meta-analyses showed observable differences in R^2 scores between the subgroups, however we could not ascertain whether or not these differences were statistically significant. Due to the limited and heterogeneous data in our review, our subgroup analyses should only be treated potential variations in subgroups that may warrant further analysis in future research. In contrast, sensitivity analyses potentially offer the most accurate estimation of effect sizes, as they exclude the studies with higher risk of bias, outliers, and in some cases, the studies that exert the most influence on the rest of the dataset. However, the effect size of each sensitivity analysis is relatively similar to that of overall meta-analyses, but less heterogenous (for correlation-based meta-analyses)

Strengths and Limitations

Perhaps the greatest strength of this review is the comprehensive identification of theory-based factors associated with organ donation registration. In total, we have identified 9 behaviour theories tested in this literature. Many systematic reviews in behavioural science place the focus on the theory rather than the behaviour, meaning they search for the application of a single theory to multiple behaviours. While these are certainly helpful to inform ruling in or ruling out a theory when deciding which to select, our study has systematically identified all the theories applied to organ donation registration, how much variance in behaviour and intention they explain, as well as research gaps that should be addressed to improve our understanding of organ donation registration.

A few limitations in this review should also be mentioned. First, the search strategy was calibrated to retrieve as many relevant behaviour theories applied in the organ donation registration literature as possible, but it is possible we may have missed some. We were primarily anticipating the presence of theories/models from the ABC of Behaviour Change Theories[18] compendium of 83 theories (64 of which were included in our search strategy), but instead also identified a bespoke theory developed for organ donation registration specifically. It is difficult to predict the specific theories that may arise in the literature when bespoke theories are developed, and as a result we may have missed them in our search. However, the inclusion of the "(theory or theories)" search term (see Appendix B) allowed for a comprehensive search of any theories used in this literature.

As previously mentioned, we obtained few studies that measured behaviour and conducted eligible analyses (i.e. logistic regression not eligible for meta-analyses). Furthermore, all studies pooled in behaviour-based meta-analyses used methods that potentially introduced bias in their measurement of registration behaviour. These limitations suggest our results may not provide an accurate estimate of the explained variance in behaviour by theory. However, it is the most accurate estimate we can achieve based on the evidence currently available, further necessitating the need for future research to measure organ donation registration behaviour in addition to intention, and to measure it prospectively and objectively (where available).

Another limitation in this review involved the computation of the frequency-weighted mean R^2 score. It was clearly established in the correlation meta-analyses that the data was significantly heterogeneous, but it could not be accounted for in the computation of the R^2 score. This is due to the difficulty of calculating R^2 score variability, which is required for random effect meta-analyses. Upon consulting with statisticians, it was recommended to focus on computing frequency-weighted mean R^2 scores and reporting ranges. Although the data was heterogeneous, we took measures to try to explain this variance through subgroup and sensitivity analyses.

Conclusion

We identified 32 studies, published in 28 articles, testing theories of behaviour to predict organ donation registration intention and behaviour. The use of theories represented in this literature is varied, but dominated by the TPB/TRA. The constructs from the theories are shown to be significantly associated with organ donation registration behaviour/motivation, and also explain some variance in behaviour, but much more in intention. This review has shown that theory can be used to understand and predict organ donation registration motivation and behaviour. However, the substantial difference in explained variance between intention and behaviour

suggests that the theories retrieved in this study may be better in informing interventions targeting organ donation registration motivation, rather than behaviour. Furthermore, this review highlights the opportunity to test contemporary behaviour theories that incorporate post-intentional factors. Future research should therefore aim to test more contemporary theories of behaviour to understand and predict organ donation registration, and to strive to measure registration prospectively and objectively. Future interventions to increase organ donation registration rates should aim to incorporate behaviour theories into their design to maximize the potential for behaviour change by better targeting the factors that actually drive registration, while building cumulative knowledge of organ donation registration as a health behaviour.

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Appendix A: Behaviour Theory-Based Model Inclusion/Exclusion for Search Strategy

Table 5. Models from the ABC of Behaviour Change Theories[18] compendium that were excluded or included in the search strategy.

Theory/Model	Include or Exclude (reason)
Aids Risk Reduction Model	Exclude (not related to organ donation registration; AIDS prevention)
Behavioural-Ecological Model of Adolescent Aids Prevention	Exclude (not related to organ donation registration; AIDS prevention)
Classical Conditioning	Exclude (not related to organ donation registration)
COM-B System	Include
Consumptions as Social Practices	Exclude (not related to organ donation registration; consumer behaviour)
Differential Association	Exclude (not related to organ donation registration; deviant behaviour)
Diffusion of Innovations	Exclude (not related to organ donation registration; innovation adoption)
Ecological Model for Preventing Type 2 Diabetes in Minority Youth	Exclude (not related to organ donation registration; diabetes prevention)
Extended Information Processing Model	Include
Extended Parallel Processing Model	Exclude (not related to organ donation registration; fear)
Health Action Process Approach	Include
Health Behaviour Goal Model	Include
Health Behaviour Internalisation Model	Include
Health Belief Model	Include
Health Promotion Model	Include
I-change Model	Include
Information-motivation-behavioural skills model	Include
Information-motivation-behavioural Skills Model of Adherence	Exclude (not related to organ donation registration; adherence)
Integrative Model of Behavioural Prediction	Include
Integrative Model of Factors Influencing Smoking Behaviours	Exclude (not related to organ donation registration; smoking)
Integrative Model of Health Attitude and Behaviour Change	Include
Integrative Model of Factors Influencing Smoking and Attitude and Health Behaviour Change	Exclude (not related to organ donation registration; smoking)
Model of Pro-environmental Behaviour	Exclude (not related to organ donation registration; environmental behaviours)
Motivation-opportunities-abilities Model	Include

Needs-opportunities-abilities Model	Exclude (not related to organ donation registration; economics)
Precaution Adoption Process Model	Include
Pressure System Model	Include
Prototype Willingness Model	Include
Rational Addiction Model	Exclude (not related to organ donation registration; addictive behaviours)
Reflective Impulsive Model	Include
Relapse Prevention Model	Exclude (not related to organ donation registration; relapse/addiction)
Six Staged Model of Communication Effects	Include
Social Consensus Model of Health Education	Include
Social Development Model	Exclude (not related to organ donation registration; deviant behaviour)
Social Ecological Model of Behaviour Change	Include
Social Ecological Model of Walking	Exclude (not related to organ donation registration; walking)
Social Influence Model of Consumer Participation	Exclude (not related to organ donation registration; consumer behaviour)
Systems Model of Health Behaviour Change	Include
Technology Acceptance Model	Exclude (not related to organ donation registration; technology)
Terror Management Health Model	Include
Transcontextual Model of Motivation	Include
Transtheoretical Model of Behaviour Change	Include

Appendix B: MEDLINE Search Strategy

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to August 31, 2018>

Search Strategy:

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1 Tissue Donors/ (35736)

2 "Tissue and Organ Procurement"/ (16315)

3 Transplants/ (4584)

4 ((organ* or transplant*) adj5 don*).tw. (48995)

5 ((organ* or transplant*) adj5 regist*).tw. (6248)

6 (deceased adj5 don*).tw. (5802)

7 (organ adj5 designat*).tw. (102)

8 ((organ* or transplant*) adj5 consent*).tw. (974)

9 ((organ* or transplant*) adj5 recov*).tw. (9205)

10 (organ* adj5 transplant*).tw. (33491)

11 ((organ* or transplant*) adj5 procur*).tw. (3777)

12 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 (118370)

13 model of heath attitude behav* change.tw. (0)

14 health belief model.tw. (2018)

15 health action process approach.tw. (151)

16 transtheoretical model.tw. (1318)

17 prototype willingness model.tw. (64)

18 health behav* goal model.tw. (1)

19 I-change model.tw. (38)

20 COM-B System.tw. (8)

21 information processing model.tw. (241)

22 health behav* internalisation model.tw. (0)

23 health promotion model.tw. (280)

24 information-motivation-behav* skills model.tw. (116)

25 model of behav* prediction.tw. (59)

26 motivation-opportunities-abilities model.tw. (0)

27 precaution adoption process model.tw. (60)

28 pressure system model.tw. (2)

29 reflective impulsive model.tw. (9)

30 six staged model of communication effects.tw. (1)

31 social consensus model of health education.tw. (0)

32 social ecological model of behav* change.tw. (3)

33 systems model of health behav* change.tw. (1)

34 terror management health model.tw. (11)

35 transcontextual model of motivation.tw. (0)

36 transtheoretical model of behav* change.tw. (214)

37 (theory or theories).tw. (339126)

38 PSYCHOLOGICAL THEORY/ (12690)

39 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 (348139)

40 12 and 39 (641)

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Appendix C: Adapted Risk of Bias Assessment Form

Items for risk of bias assessment based on NIH guidelines for observational cohort and cross-sectional studies[19]

1. Was the research question or objective in this paper clearly stated?
2. Was the study population clearly specified and defined?
3. Was the participation rate of eligible persons at least 50%?
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?
5. Was a sample size justification, power description, or variance and effect estimates provided?
6. For the analyses in this paper, was organ donation registration status measured before behavior/intention?
7. Were the theory and its constructs clearly defined, valid, reliable, and implemented consistently across all study participants?
8. Did the study have any follow-up assessment of behaviour?
9. (If applicable) Was the timeframe sufficient so that one could reasonably expect to see an association between behaviour and theoretical constructs?
10. Were behavior and/or intention clearly defined, valid, reliable, and implemented consistently across all study participants?
11. (If applicable) Was loss to follow-up after baseline 20% or less?
12. Did the theoretical model accurately represent the theory?
13. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship?

Appendix D: Risk of Bias Analysis Results

Table 6. Summary of risk of bias analysis within individual studies

Author and Year	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	Overall Quality and Comments
Britt, Britt & Anderson 2015[23]	Y	Y	NR	Y	NR	Y	Y	N	N/A	Y	N/A	Y	Y	**Intention:** Good
Brug et al. 2000[24]	Y	Y	Y	Y	NR	N	Y	N	N/A	Y	N/A	Y	N	**Intention:** Fair
Farsides 2010 Study 1[25]	Y	Y	NR	Y	NR	Y	Y	N	N/A	N	N/A	Y	N	**Intention:** Fair **Behaviour:** Poor, cross-sectional and self-reported measurement of behavior may introduce bias
Farsides 2010 Study 2[25]	Y	Y	NR	Y	NR	Y	Y	N	N/A	N	N/A	Y	N	**Intention:** Fair **Behaviour:** Poor, cross-sectional and self-reported measurement of behavior may introduce bias
Guedj, Sastre & Mullet 2011[26]	Y	Y	NR	Y	NR	NR	Y	N	N/A	Y	N/A	N	Y	**Intention:** Fair
Hubner & Kaiser 2006[27]	Y	Y	Y	Y	NR	Y	Y	N	N/A	Y	N/A	Y	N	**Intention:** Fair
Hyde & White 2009a[28]	Y	Y	NR	Y	NR	Y	Y	N	N/A	Y	N/A	Y	N	**Intention:** Fair
Hyde & White 2009b[29]	Y	Y	NR	Y	NR	Y	Y	Y	Y	Y	N	Y	Y	**Intention:** Good **Behaviour:** Fair, prospective measurement with adequate follow-

														up length, self-reported measurement may introduce bias
Hyde & White 2009c[30]	Y	Y	NR	Y	NR	Y	Y	N	N/A	Y	N/A	Y	N	**Intention:** Fair
Hyde & White 2010[31]	Y	Y	Y	Y	NR	Y	Y	Y	Y	Y	N	Y	Y	**Intention:** Good **Behaviour:** Fair, prospective measurement with adequate follow-up length, self-reported measurement may introduce bias **Willingness:** Good
Hyde & White 2014 Study 1[32]	Y	Y	N	Y	NR	Y	Y	N	N/A	Y	N/A	Y	N	**Willingness:** Fair
Hyde & White 2014 Study 2[32]	Y	Y	Y	Y	NR	Y	Y	N	N/A	Y	N/A	Y	N	**Willingness:** Fair
Hyde, White, & Knowles 2013[33]	Y	Y	NR	Y	NR	Y	Y	N	N/A	Y	N/A	Y	Y	**Intention:** Fair
Jeffres et al. 2008[34]	Y	N	NR	Y	NR	Y	N	N	N/A	N	N/A	N	Y	**Intention:** Poor, survey designed for African Americans but applied to general population, varying levels of *n* for measurement of each variable, few TPB/TRA constructs clearly defined **Willingness:** Poor (see above)
McGlade, McClenahan & Pierscionek 2012[35*]	Y	Y	Y	Y	NR	Y	Y	N	N/A	Y	N/A	Y	Y	**Intention:** Good

Morgan 2006[36]	Y	Y	NR	Y	NR	N/A†	Y	N	N/A	N	N/A	Y	Y	**Behaviour:** Poor, cross-sectional and self-reported measurement of behavior may introduce bias
Morgan et al. 2008[37]	Y	Y	N	Y	NR	N/A†	Y	N	N/A	N	N/A	Y	Y	**Behaviour:** Poor, cross-sectional and self-reported measurement of behavior may introduce bias
Newton et al. 2012[38]	Y	Y	N	Y	NR	Y	Y	N	N/A	Y	N/A	N	N	**Intention:** Fair, only two constructs included in model
Newton et al. 2013[39]	Y	Y	N	Y	NR	NR	Y	N	N/A	Y	N/A	Y	N	**Intention:** Fair
Park & Smith 2007[40]	Y	Y	NR	Y	NR	NR	Y	N	N/A	Y	N/A	Y	N	**Intention:** Fair
Park, Smith & Yun 2009[41]	Y	Y	Y	Y	NR	Y	Y	N	N/A	Y	N/A	Y	Y	**Intention:** Good
Powpaka 1996[42]	Y	N	NR	U	NR	NR	N	N	N/A	Y	N/A	N	N	**Intention:** Poor, little reporting on study sample and methods
Quick et al. 2015[43]	Y	Y	NR	Y	NR	N/A†	Y	N	N/A	N	N/A	Y	N	**Behaviour:** Poor, cross-sectional measurement of behavior may introduce bias
Reynolds-Tylus & Quick 2017[44]	Y	Y	Y	Y	NR	Y	Y	N	N/A	Y	N/A	Y	Y	**Intention:** Good
Rocheleau 2013 Study 1[45]	Y	Y	NR	Y	NR	Y	Y	Y	Y	N	Y	Y	N	**Intention:** Fair **Behaviour:** Poor, prospective measurement with adequate follow-up length, behavioural measurement involves measuring preparatory behaviours instead of actual registration
Rocheleau 2013 Study 2[45]	Y	Y	NR	Y	NR	Y	Y	N	N/A	Y	N/A	Y	N	**Intention:** Fair

Siegel et al. 2014 Study 1[46]	Y	Y	NR	Y	NR	Y	Y	N	N	N	N/A	N	Y	**Behaviour:** Poor, registration after survey may bias measurement of behaviour, only measures one construct
Siegel et al. 2014 Study 2[46]	Y	Y	NR	Y	NR	Y	Y	N	N	N	N/A	N	Y	**Intention:** Fair **Behaviour:** Poor, registration after survey may bias measurement of behavior. Measurement of behavior does not guarantee registration was performed. Only measures one construct
Wang 2011[47]	Y	Y	NR	Y	NR	N	Y	N	N/A	Y	N/A	Y	N	**Intention:** Fair
Weber et al. 2007[48]	Y	Y	NR	Y	NR	NR	Y	N	N	N	N/A	Y	N	**Intention:** Fair **Behaviour:** Poor, registration after survey may bias measurement of behaviour
Wu & Lu 2011[49]	Y	Y	Y	Y	NR	NR	Y	N	N/A	Y	N/A	Y	Y	**Intention:** Fair
Yun & Park 2010[50]	Y	Y	NR	Y	NR	Y	Y	N	N/A	Y	N/A	Y	Y	**Intention:** Good

Note. Numbers at the top of each column represent their corresponding risk of bias assessment item (see Appendix C for risk of bias assessment form). Y= yes; N= no; NR= not reported; N/A = not applicable; U = unclear

[†]Registration status was measurement of behaviour, intention was not measured

Appendix E: Forest Plots for TPB/TRA Constructs and Intention to Register for Organ Donation

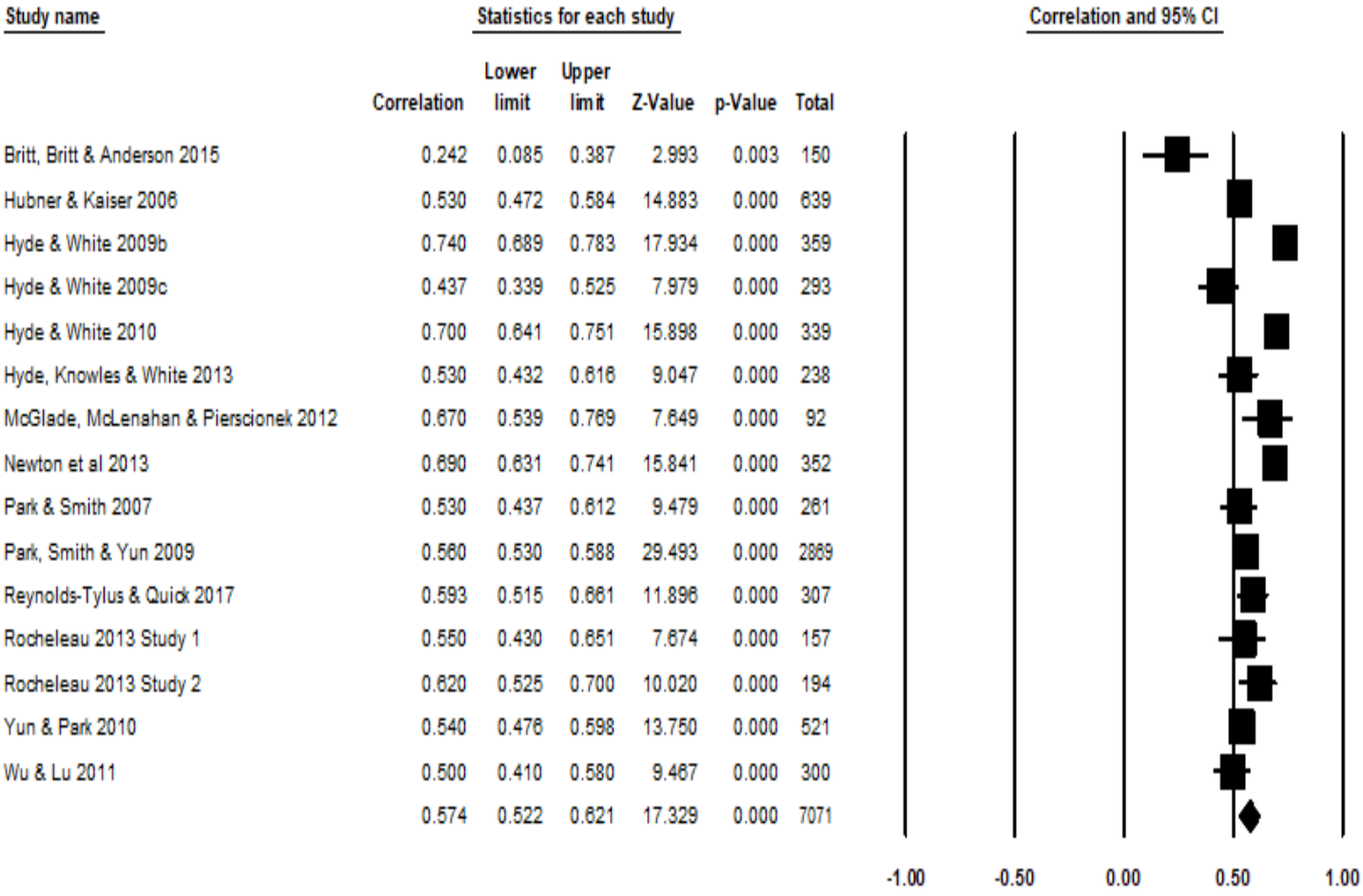

Figure 3. Forest plot of TPB/TRA subjective norm correlation with intention to register.

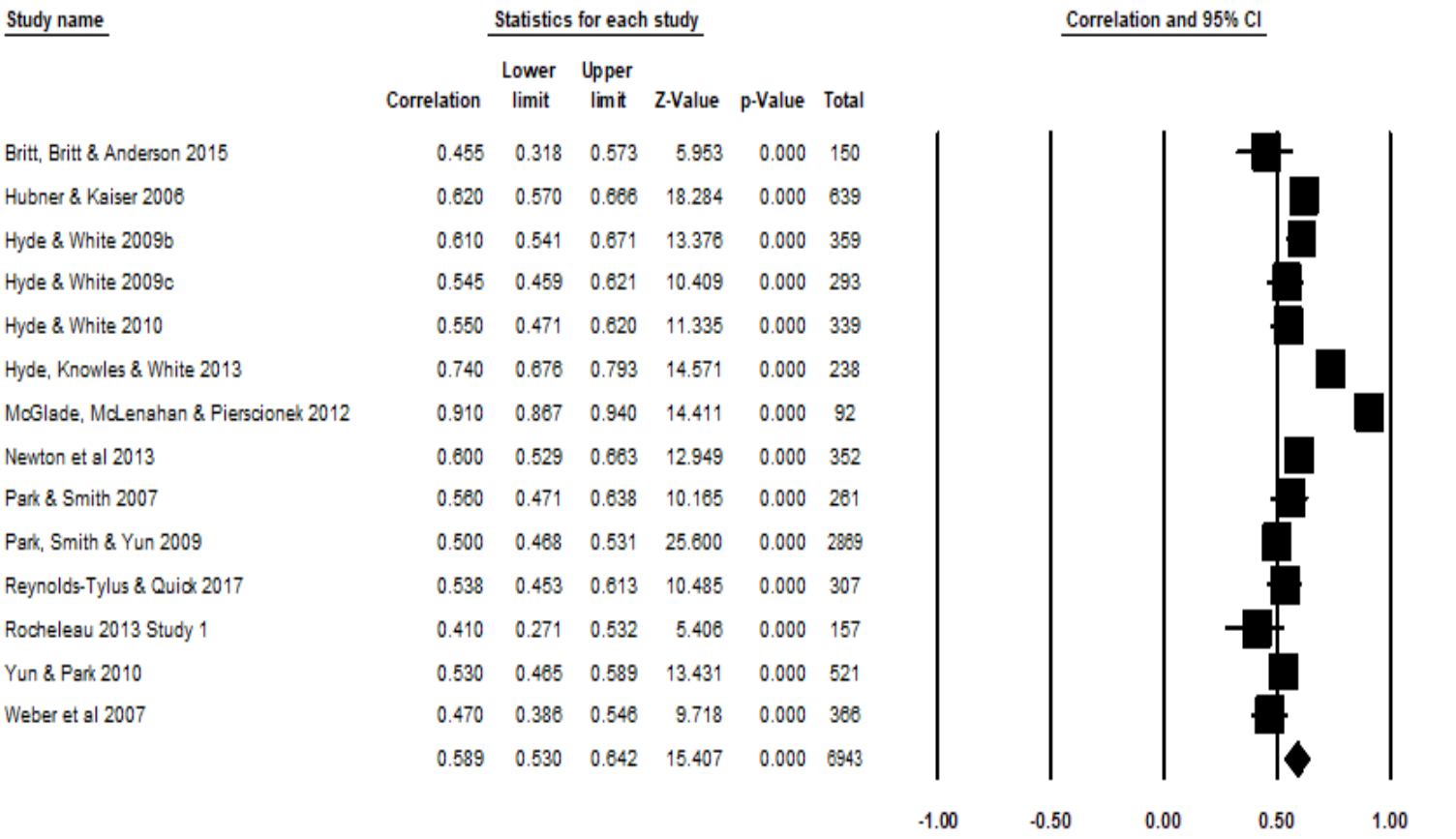

Figure 4. Forest plot of TPB/TRA attitude correlation with intention to register

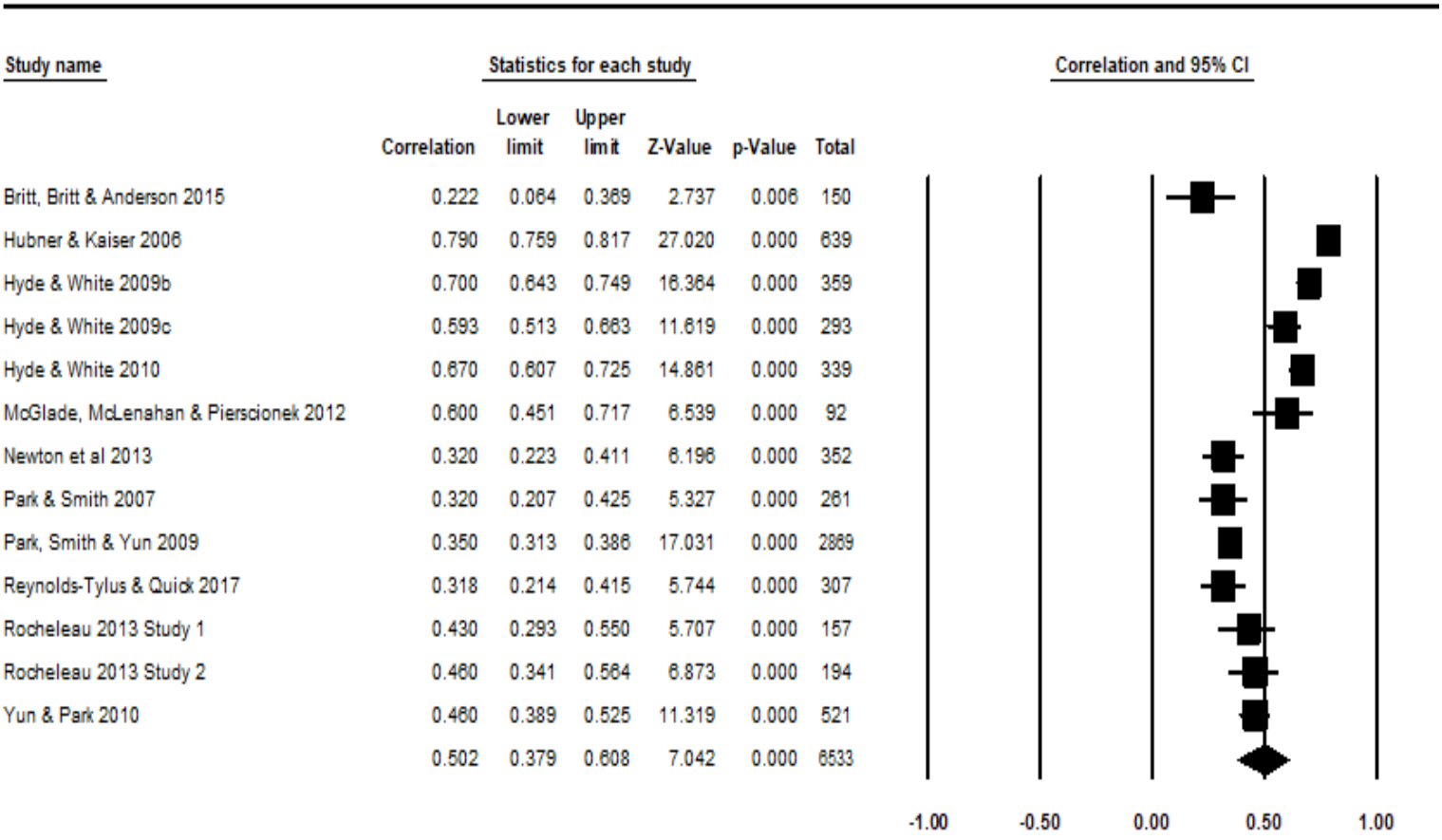

Figure 5. Forest plot of TPB/TRA PBC correlation with intention to register.

Appendix F: Stem and Leaf Plots

0.2	4
0.3	
0.4	4
0.5	0 3 3 3 4 5 6 9
0.6	2 7 9
0.7	0 4

Figure 6. Stem and leaf plot for TPB/TRA subjective norm correlation with intention to register.

0.4	1 6 7
0.5	0 3 4 5 5 6
0.6	0 1 2
0.7	4
0.8	
0.9	1

Figure 7. Stem and leaf plot for TPB/TRA attitude correlation with intention to register.

0.2	2
0.3	2 2 2 5
0.4	3 6 6
0.5	9
0.6	0 7
0.7	0 9

Figure 8. Stem and leaf plot for TPB/TRA PBC correlation with intention to register.

0.2	1
0.3	3 6 8
0.4	0 1 4 7 7 8
0.5	2
0.6	5 6 7 9
0.7	2 3 4
0.8	3

Figure 9. Stem and leaf plot for R^2 scores of models predicting intention to register.

Appendix G: Frequency-Weighted Mean R^2 Intention-Based Subgroup Analyses

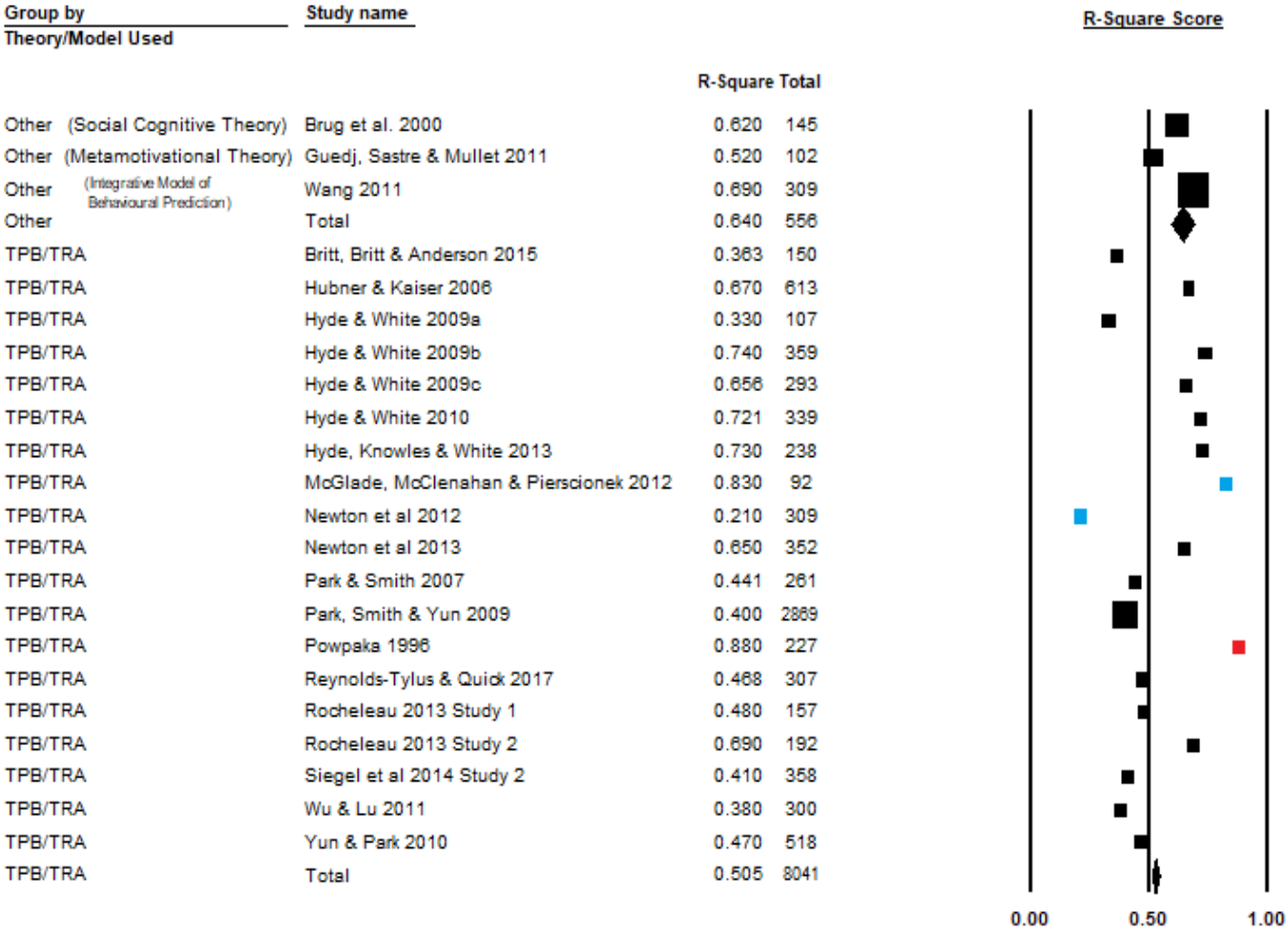

Figure 10. Visualization of frequency-weighted mean R^2 theory/model subgroup meta-analysis. *Note.* Studies removed in sensitivity analyses due to risk of bias are highlighted in red. Studies removed in sensitivity analyses due to potential outlier status are highlighted in blue.

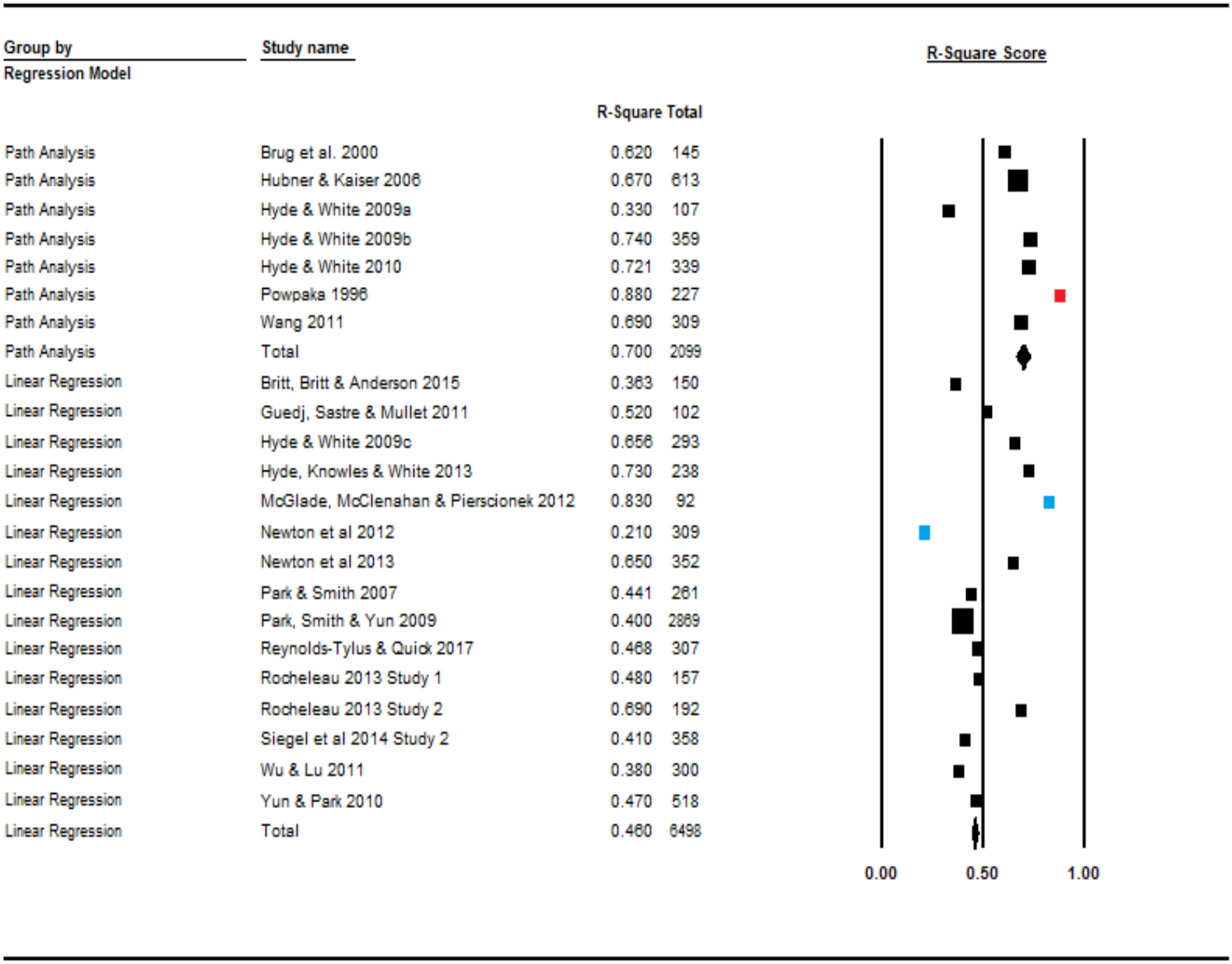

Figure 11. Visualization of frequency-weighted mean R^2 regression model subgroup meta-analysis.

Note. Studies removed in sensitivity analyses due to risk of bias are highlighted in red. Studies removed in sensitivity analyses due to potential outlier status are highlighted in blue.

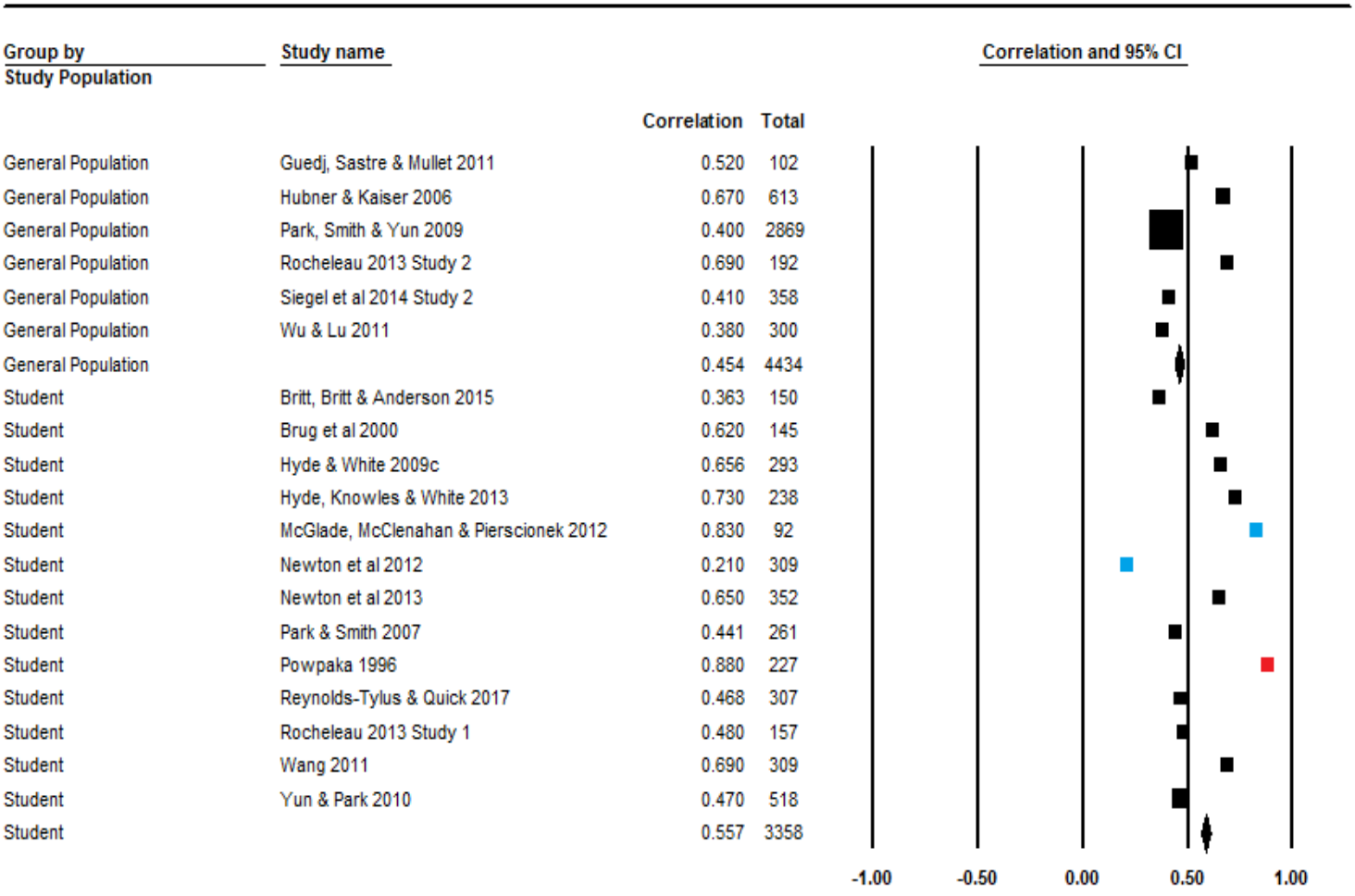

Figure 12. Visualization of frequency-weighted mean R^2 study population subgroup meta-analysis.

Note. Studies removed in sensitivity analyses due to risk of bias are highlighted in red. Studies removed in sensitivity analyses due to potential outlier status are highlighted in blue.

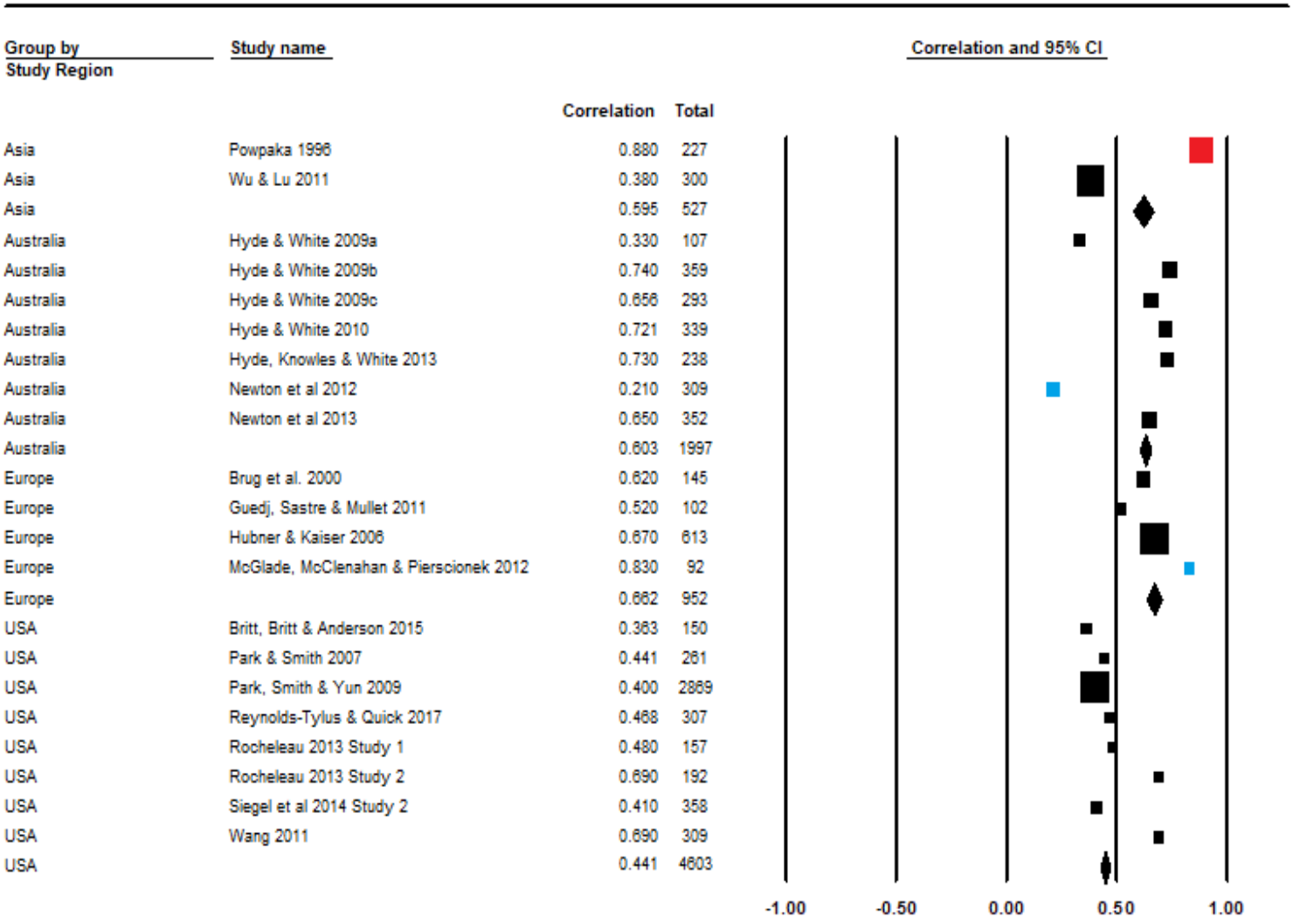

Figure 13. Visualization of frequency-weighted mean R^2 study region subgroup meta-analysis. *Note.* Studies removed in sensitivity analyses due to risk of bias are highlighted in red. Studies removed in sensitivity analyses due to potential outlier status are highlighted in blue.

Chapter 3:

Barriers and Enablers to Organ Donation Registration: A Theoretical Domains Framework-Based Qualitative Meta-Synthesis

Bonnell J, Perkins I, Brehaut J, Grimshaw J, Presseau J.

Protocol Registration: Bonnell J, Perkins I, Brehaut J, Grimshaw J, Presseau J. Barriers and enablers to organ donation registration: a theoretical domains framework-based qualitative meta-synthesis. PROSPERO 2019 CRD42019134093. Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019134093

Contributions: JB and JP were responsible for the conception and design of this project. JB wrote the manuscript. JP, JCB, and JG provided guidance and expertise throughout the entire project, and provided critical input and suggested revisions for the manuscript. JB and IP screened articles for inclusion, and completed data abstraction and risk of bias analysis.

Chapter 3 - Introduction

In Chapter 2 we conducted a systematic review and meta-analysis using survey data to examine the application of theories of behaviour to organ donation registration and provide a quantitative understanding of factors associated with organ donation registration. We identified a relatively restricted set of theories and theoretical constructs tested in this literature that focused primarily on factors associated with motivation to register, while relatively few focused on registration behaviour per se. While providing factors to focus on to inform future registration interventions, the identified theories in Chapter 2 may not necessarily sufficiently capture key factors, or barriers and enablers, to registering for organ donation. While the pooled findings from survey data in Chapter 2 provide generalizable and summative quantitative insight, the questionnaire-based approaches reviewed in Chapter 2 lack the qualitative detail on drivers, barriers, and concerns towards organ donation registration, and their justification. Summarizing these qualitative details may help supplement efforts to develop interventions to support registration.

To supplement our theory-based quantitative understanding of factors associated with organ donation registration, there is a need to understand which barriers and enablers have been identified in the qualitative literature. This broader literature likely identified more specific beliefs about registration. To our knowledge, few studies have systematically reviewed the qualitative literature to identify the barriers/enablers to organ donation registration, and none have taken a behaviour theory approach to meta-synthesizing these findings.

A qualitative meta-synthesis conducted in 2011 by Irving et al. identified six main factors affecting organ donation registration: religious beliefs, cultural factors, family/relational ties, body integrity, interaction with health systems, and knowledge[1]. The review elucidated how each factor positively and negatively affects organ donation registration[2]. Similarly, a meta-synthesis conducted in 2011 by Newton identified 8 broad themes influencing views towards organ donation (religion, death, altruism, personal relevance, the body, the family, the medical profession, and the transplants recipients), along with 41 subthemes between them[2]. However, both of these meta-syntheses did not specifically examine organ donation registration behaviour per se, and the review by Irving et al.[1] also included studies that examined living donation.

Although both reviews contribute to the body of knowledge on organ donation registration, they each developed their own coding scheme for their data synthesis, rather than using a predefined, validated set of domains informed by theories of behaviour. To inform fit-for-purpose interventions to increase organ donation registration and bring coherence to a disparate literature while building a cumulative knowledge base, it would be useful to conduct a thorough systematic review of qualitative studies (based on interviews or focus groups) and identify how the themes generated across studies map to factors known to affect behaviour and behaviour change; e.g. by using a comprehensive framework of factors known to be related to behaviour, such as the Theoretical Domains Framework (TDF).

Aims and Objectives

It is currently unclear to what extent behaviour frameworks have been used to understand factors influencing organ donation registration in qualitative studies. Such a review of the qualitative evidence of factors linked to organ donation registration may help to provide coherence in the

literature and directly inform efforts to encourage Canadians to register for organ donation. This chapter aims to systematically identify the barriers and enablers to organ donation registration and use the TDF as a framework for the thematic synthesis of the data.

Methods

Protocol and Registration

The protocol was registered in PROSPERO on the 18th of June, 2019 (PROSPERO ID: CRD42019134093). It can be accessed at the following URL: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019134093

Eligibility Criteria

Selection of the studies were based on the criteria outlined below.

Participants: No restrictions

Interventions: Not applicable.

Comparators: Not applicable.

Outcomes: Barriers and enablers to deceased organ donation or organ donation registration, informed by the perspectives/views/opinions of eligible participants.

Study Designs: Only studies involving the qualitative analysis of views, barriers, and/or enablers to personally registering for organ donation were eligible. Studies collecting qualitative data through interviews, focus groups, and survey-based methods (with open response option) that identify barriers and enablers to organ donation registration were considered eligible.

Timing: No restrictions.

Setting: No restrictions.

Language: Eligible studies were restricted to studies published in English and/or French.

Publishing Details: No restrictions.

Exclusion Criteria: If the study focused on living organ donation (e.g. kidney donation), body donation (e.g. for research), consent to organ donation from family members of deceased loved ones, or exclusively on organ donation registration *discussions* then the study was ineligible due to not focusing on the behaviour of interest. If the study focused on participants' opinions of why *other people* do or do not register for organ donation, it was ineligible as it did not provide participants' own experiences and perspectives about their own behaviour. Commentary articles in which no primary research was conducted were also ineligible.

Information Sources and Search Strategy

A search strategy was developed using MESH terms and words that relate to organ donation registration, enablers/barriers, and qualitative methodology. MEDLINE, PsycINFO, EMBASE, CINAHL, and ERIC databases were searched to identify eligible articles. Although we did not include any words relating to trials or interventions studies in our search strategy, we hand searched articles from a Cochrane review of interventions to increase organ donation

registration[3]. The search strategy was peer-reviewed by a librarian with expertise in systematic reviews, as per PRESS guidelines[4]. See Appendix A for the MEDLINE database search strategy.

Study Selection

All references were uploaded to Covidence for title and abstract screening, then full-text screening, based on eligibility criteria. Both levels of screening were conducted independently and in-duplicate by JB and IP. If there was any missing information pertaining to study eligibility, study authors were contacted for clarification. Any disagreement on eligibility was resolved through discussion between the two reviewers, and with a third reviewer if necessary.

Data Collection

All eligible articles were imported into NVivo (version 12) for further analysis. NVivo facilitates storing, organizing, categorizing, and analyzing of qualitative data[5]. Study and participant characteristic data were abstracted independently and in-duplicate by JB and IP. Abstracted study and participant characteristic data include data collection method, type of study population, number and mean age of study participants, ethnicity and sex distribution of participants, and themes identified in analysis. Study authors were contacted to provide missing data.

We identified and coded qualitative barriers and enablers to organ donation registration data from participant quotations reported in each paper regarding views, perspectives, experiences, and/or opinions on organ donation and organ donation registration. Barriers and enablers to deceased organ donation per se were also collected as they have a significant influence on the motivation to register and not including them would potentially miss key information on the factors hindering and enabling registration behaviour. To supplement participant quotations, interpretations and/or explanations offered by the study authors were abstracted as well, as recommended for qualitative meta-syntheses[6]. Quotations that were not abstracted included those where participants or organ donation experts explain their thoughts on why other people do or do not register for organ donation, and those in which participants/study authors describe barriers and enablers to having discussions about registration. We also collected data on actions suggested by the respondents to increase registration rates or improve views towards organ donation as a secondary outcome.

Risk of Bias in Individual Studies

Risk of bias was assessed using the CASP Qualitative checklist[7]. While there is no standard for qualitative critical appraisal tools, CASP is commonly employed in qualitative systematic reviews[7]. JB and IP assessed the risk of bias for each study independently, and resolved any disagreements through discussion, only discussing with a third reviewer if necessary.

Two review-specific items were added to the standard CASP checklist to better determine the risk of bias present in qualitative articles that examine organ donation registration. The additional items assessed the clarity with which the authors reported barriers and enablers to organ donation registration (i.e., is it clear that participants are speaking of their own barriers/enablers?; is it clear which form of organ donation participants are speaking of?). The CASP checklist and supplemental items are shown in Appendix B.

Synthesis of Results

Directed content analysis[8] using the TDF as a coding framework was initially conducted for data coding. Once data were sorted into TDF domains, we conducted inductive thematic analysis[9] to develop over-arching themes.

Data Coding

Using NVivo, and an iteratively-developed coding manual, all abstracted outcome data were coded line-by-line into their pertinent TDF domains by JB and IP independently and in-duplicate. Any quotations that matched more than one TDF domain were coded into each domain they matched, with decision rules on multiple domain coding captured in the coding manual. Any disagreements were resolved in conflict resolution between the two coders, discussing with a third reviewer if necessary.

The TDF coding manual was a living document, adapted to capture consensus decisions required to better suit the behaviour of organ donation registration. First, while we primarily used the second version of the TDF[10] as the basis for coding, we replaced the domain, b*ehavioural regulation*, with the *nature of the behaviour* domain from the first version of the TDF since, for the most part, organ donation registration is a one-time behaviour that does not require the on-going regulation inherent to behavioural regulation. The m*ature of the behaviour* domain served to represent explanations of having already performed the behaviour, as well as past experience with organ donation and organ donation registration. In addition, we added two placeholder categories to the TDF domains: *not a barrier/enabler*, and o*ther*. The *not a barrier/enabler* domain allowed for direct comparison between the articles that report the influence of specific barriers/enablers and the articles reporting their non-influence, while the *other* domain captures any barriers/enablers that were not deemed to be sufficiently accounted for by TDF domains.

Inductive Thematic Analysis

Following coding into TDF domains, data within domains were sorted to synthesize the themes in the literature. Similar data pooled within a TDF domain were grouped by JB based on similar barriers/enablers into subthemes. Subthemes within domains were the grouped into overarching themes within TDF domains, and across various domains. Both initial subthemes and overarching themes were then reviewed by other team members.

Planned Additional Analyses

Contingent on sufficient data, we planned to examine the difference in prevalence of domains, themes, and barriers/enablers between age/ethnic groups, when appropriate.

Results

Study Selection

A total of 10,162 articles were screened for eligibility, and 9409 were excluded in level 1 screening. In level 1,752 articles were screened with 682 exclusions. A total of 70 articles were deemed eligible for the review. All of the studies were descriptively synthesized and included in the qualitative meta-synthesis. See Figure 1 for the PRISMA flowchart for the study selection process.

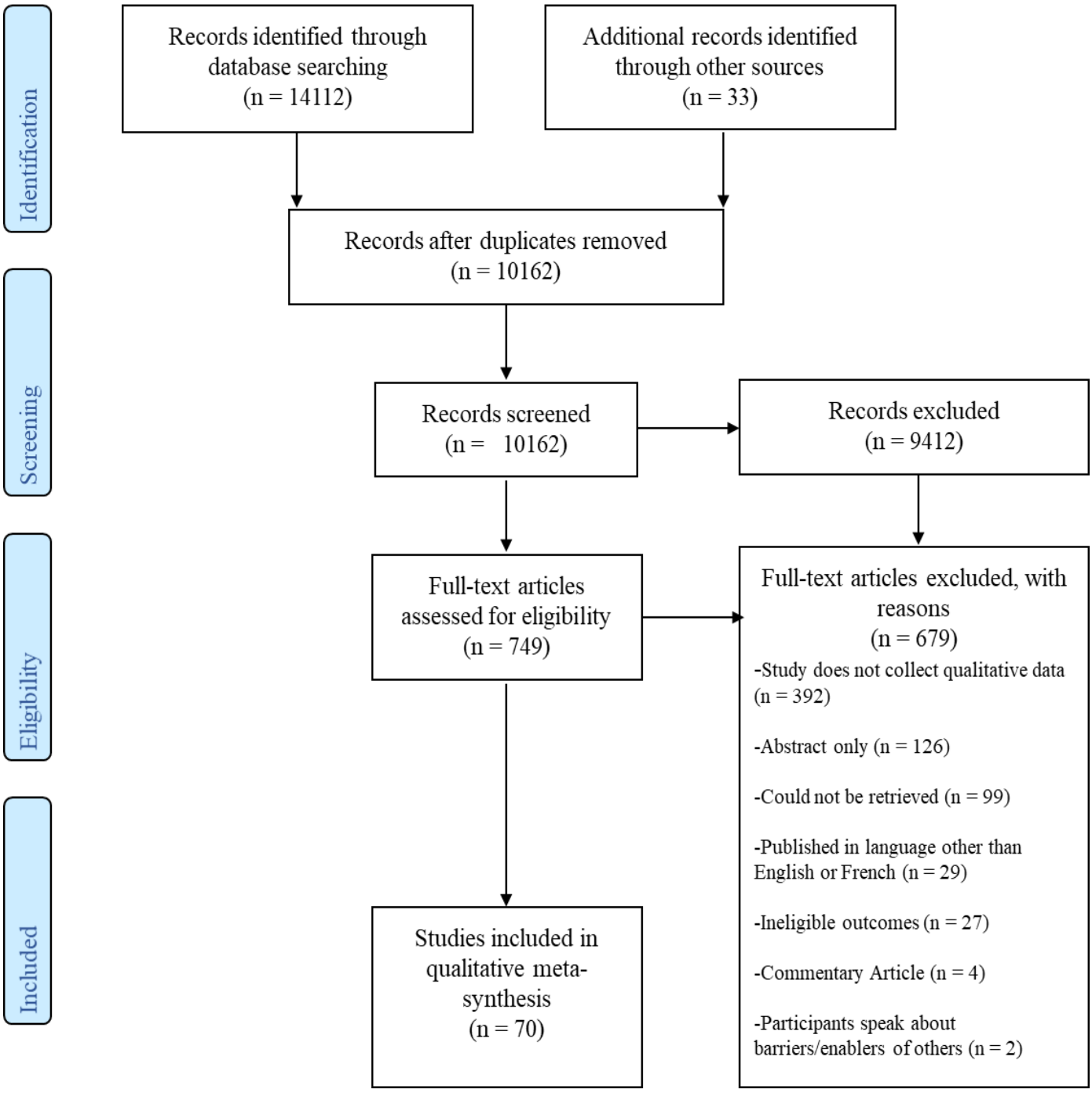

Figure 1. PRISMA flowchart for study selection.
Note. The 33 studies were identified from hand-searching articles from a Cochrane review of interventions to increase organ donation registration[3]

Study Characteristics

Database and hand-searching retrieved 70 eligible studies recruiting at least 9527 participants. Table 6 in Appendix F describes all studies in full. Forty-three studies (61%) contained questions or responses pertaining to organ donation registration, in addition to questions relating generally to organ donation and transplantation[11,12,14,16,18,21-27,29,30,33,34,37,38,43,45-47,50-53,55,58,60-65,67,68,70,74,76-80]. The remaining 27 studies (39%) only included questions and responses generally related to organ donation and transplantation[13,15,17,19,20,28,31,32,35,36,39-42,44,48,49,54,56,57,59,66,69,71-73,75]. There were 2 studies[57,72] that examined barriers and enablers exclusively to corneal donation, rather than general organ donation. All studies were cross-sectional, with only 9 exclusively survey-based studies[14,16,29,30,33,54,56,57,68]. All other studies (n = 61) conducted interviews or focus groups to collect qualitative data.

The studies retrieved in the searches were geographically diverse. Most of the studies were conducted in the USA (n = 28)[11,12,16,18,21-26,28-31,33,35,38-40,53,54,60,62,70,73-75] and the UK (n = 11)[13,19,27,32,34,53,55,64-66,72]. A handful studies were conducted in Canada (n = 7)[20,46,49-51,67,69], Australia (n = 5)[36,37,48,61,63], China (n = 3)[47,76,80], Sweden (n = 3)[42-44], India (n = 2)[25,56], Malaysia (n = 2)[77,78], and South Korea (n = 2)[41,79]. Only one study was conducted in each of the following regions: Brazil[60], Malta[45], the Netherlands[68], Poland[57], Turkey[58], South Africa[15], and Taiwan[17].

There was significant focus on ethnic/religious minority populations in this literature, especially in the studies conducted in Canada, America, the UK, Europe, and Australia. Of the all the studies conducted in America, 9 recruited African American populations[16,24,25,38,70,73-75], 2 recruited Indigenous populations[28,40], 2 recruited Filipino residents[11,12], 1 recruited Chinese American residents[35], 1 recruited Haitian immigrants[26], and 1 recruited Hispanic residents[31]. In total, of the 28 studies conducted in the USA, 16 studies (57%) recruited ethnic/religious minority populations. In the UK, 5 studies recruited Asian immigrants (including Middle-Eastern and Indian immigrants)[13,27,32,34,64], 2 studies recruited Caribbean immigrants[19,52], and 2 studies recruited Polish immigrants[65,66]. In total, of the 11 studies conducted in the UK, 9 studies (82%) examined ethnic/religious minority populations. Of the 6 studies conducted in Europe, 3 studies examined Asian immigrants (50%)[42-44], while the other 3 studies did not recruit any specific religious/ethnic minority[45,57,68]. For Australia-based studies, 1 study recruited Eastern European immigrants[61], and another study recruited Arabic-speaking immigrants[63]. In total, 2 out the of 5 studies (40%) conducted in Australia examined ethnic/religious minority populations. The only study conducted in Taiwan recruited participants from the Alishan-Tsou Indigenous tribe[17]. Finally, among the studies conducted in Canada, 2 recruited Indigenous populations[20,49], 2 recruited Chinese Canadians[50,69], 1 recruited Haitian immigrants[67], and 1 recruited Indian immigrants[51]. Of the 7 studies conducted in Canada, 6 recruited ethnic/religious minority populations (86%).

Some studies recruited participants based on age groups. For example, 10 studies recruited student or student-aged populations[13,18,29,32,47,57,58,62,68,76]. An additional 6 studies recruited student populations along with general community members or their family members[11,21,33,36,40,53]. Finally, there were two studies by Downing & Jones that exclusively recruited adults aged 50-70 years[22,23].

Four studies recruited patient-based populations[54,56,59,72]. Of those, 2 examined the barriers and enablers to corneal donation in those in need of corneal donation[56] and palliative care patients[72], respectively. The other 2 studies recruited patients with bipolar disorder[59] and HIV[54], respectively. Two studies recruited religious leaders (from various Christian religions)[38,71]. More females than males were recruited in 37 of the 49 studies (76%) reporting sex distribution, with 3 studies exclusively recruiting female populations[42,55,75].

Risk of Bias Within Studies

Table 5 in Appendix E presents the risk of bias analysis results for each individual study, while Figure 2 summarizes the risk of bias analysis across studies. Generally, reporting and clarity for the risk of bias items was fair. Only 10 studies or fewer did not report, or not clearly describe, the study's aims (item 1)[31,51,52], appropriateness of qualitative methods (item 2)[14,36], appropriateness of research design (item 5)[17,31,56], methods for data collection (item 7)[14,16,17,54,56,57,68,69], statement of findings (item 11)[16], and the value of the research (item 12)[16]. Reporting for the studies' data analysis methods (item 10)[13-17,21,22,27,31,35,45,36,54,56,57,60,68-70,77], ethical considerations (item 9)[14-17,19,21,27,31,35,45,46,48,54,56,57,60,70,74] and recruitment strategies (item 6)[15,17,18,40,42-44,46,55,57,58,60,64] were reported less frequently, with 20, 18, and 13 studies, respectively, not clearly describing/reporting them. The relationship between the researchers and the participants (item 8) was only described by 6 studies[12,20,28,37,72,75], making it the least reported item in this literature by a wide margin.

Among the items we added to the checklist, 14 studies were not clear about whose barriers/enablers participants were describing (item 4)[12,18,20,24,27,41,50,56,60,62-66], while 28 studies were not clear about which form of donation (e.g. live donation, deceased donation, next-of-kin donation) participants were discussing (item 3)[15,20,26,27,31,34,38-43,45,47,49-51,54,55,58-60,64,69,71,75,79,80].

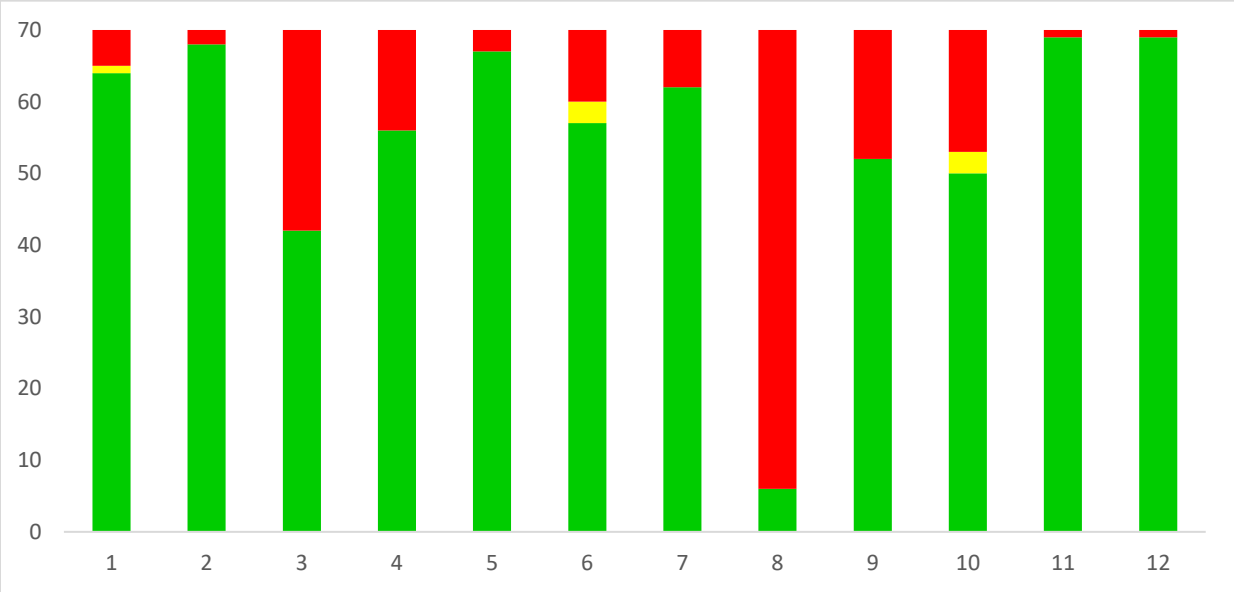

Figure 2. Visual summary of risk of bias analysis
Note. Numbers on x-axis correspond to items from adapted CASP Qualitative Checklist (Appendix D). Numbers on y-axis represent number of studies. Green = yes, yellow = unclear, red = no.

TDF Domain Representation

As shown in Table 1, TDF domain representation in this literature was varied. The most frequently reported domains included *beliefs about consequences* (100%), *social influences* (97%), *knowledge* (83%), *intentions* (73%), and *emotion* (70%) domains. Three domains were identified less frequently: goals (4%), skills (3%), and reinforcement (1%). Reliability for TDF domain coding was $\alpha = 0.69$, indicating acceptable levels of agreement, according to Krippendorff's criteria[81]. See Table 7 in Appendix G for TDF domain representation within individual studies.

Only 3 studies (4%) of the articles reported barriers/enablers coded into the *other* domain, indicating that few of the quotations could not be mapped to any TDF domains. Quotations coded to the *other* domain were often not specific enough to be coded into any of the TDF domains rather than not fitting into any of the domains per se (e.g. "[An] additional advantage to becoming an organ donor that [was] discussed by the participants [was] personal factors"[24]). We added a cross-cutting additional domain - *not a barrier/enabler* – which was represented in a majority of this literature (58.6%), and reflects the themes describing how participants felt unaffected by barriers/enablers typically reported by others.

Table 1. TDF domain representation across studies with explanations and examples.

Domain	Explanation	Example	Number of Studies
Knowledge	Includes any views pertaining to one's knowledge of the various aspects of organ donation and organ donation registration impact registration behaviour.	"People don't really know, maybe if they were informed and educated about it, they would be motivated to do it." [PQ][67] "I don't know much about donation or signing up to become a donor, which is the main reason why I'm not registered." [PQ][18]	58 (83%)
Skills	Includes views about skills required, or possessed, that enable or act as a barrier to organ donation registration.	"In some cases, people who had already registered felt that the process was too complicated, and that it relied too much on Internet access and computer literacy." [AI][40]	2 (3%)
Social/Professional Role & Identity	Includes views in which specific social or professional roles are	"I'm a Christian African American male and believe if my organs can help someone	31 (44%)

	expressed as contributing to barriers and/or enablers of organ donation registration.	else (regardless of race) after my passing, its Gods will and my blessing to pass along to that person." [PQ][16]	
Beliefs about Capabilities	Includes views expressing beliefs in how capable participants are to either donate their organs or register for organ donation, beliefs which either enable or act as a barrier to donation and/or registration.	"I think it is [easy], because I went to go get my license, and all you had to do was sign a paper and agree to it, and it gets done." [PQ][62] "At this point in my life it doesn't matter because I'm sure at my age they might not want most of me anyway. It doesn't really matter." [PQ][11]	35 (50%)
Optimism	Includes views expressing optimism or pessimism in response to questions about organ donation and registration.	"I don't think there's anything better that you can do in your life, than giving organs to…to some deserving person, someone whose life may be very important to his or her family…There is nothing more fulfilling than that." [PQ][53] "I want to be a donor. I don't think they would want any of my trash. Who wants to sell ugly arteries?" [PQ][28]	35 (50%)
Beliefs about Consequences	Includes views describing beliefs about possible outcomes of either organ donation or organ donation registration. Also includes attitudes towards organ donation and registration.	"Everything I got God gave it to me and if I can help somebody else, even after I'm gone I'm still helping someone else to live a more fruitful life." [PQ][39] "If I sign the donor card, I might not receive the right treatment. [The doctors] may cut me before I had died." [PQ][13]	70 (100%)
Reinforcement	Includes views explaining how reinforcement (e.g. monetary compensation) impacts the performance of organ donation registration.	"I know when I went with a group of my friends, everybody that she asked it was just, like 'organ donor? Everybody does that face like, 'hmmmm... well, it's money off so OK,' whereas, we 're still not thinking about it. We just know that we're getting	1 (1%)

		$10 off." [PQ][38]	
Intentions	Includes views specifically about intentions (or lack thereof) to register for organ donation, or to donate their organs.	"Eighty-nine participants explicitly stated that they were unwilling to donate their own organs." [AI][13] "If there's something and if I have it, I'll give it, with no obligation." [PQ][51]	51 (73%)
Goals	Includes views about goal and/or priority formation and planning with regards to organ donation registration are expressed.	"Maybe if it was something that personally impacts me or any of my family that needed something like that then of course that would be the first step I would want to educate myself and see if there was anything that I could do to help my family members, and when it personally affects you then that's going to be the number one trigger to go and learn more about it and to be more involved in something like that." [PQ][18]	3 (4%)
Memory, Attention & Decision Processes	Includes views about participants' beliefs about how the decision to donate should be made, the factors required to make a decision, and the amount of attention individuals have towards organ donation and registration.	"I never really thought about it at all… I just, you know, it's not anything I just really thought about." [PQ][25] "However, others emphasised personal choice in their decision about card carrying." [AI][34]	47 (67%)
Environmental Context & Resources	Includes views explaining the impact that institutions (e.g. hospitals, government), and other factors in their environment (e.g. laws, ambulance availability) have on organ donation registration behaviour.	"Only participants who chose to not become a registered organ donor expressed concerns about a lack of privacy at the DMV counter when making the decision" [AI][25] "Transport time to more regional healthcare systems was cited as a problem for both donors and recipients" [AI][28]	39 (56%)
Social Influences	Includes views describing the impact of other	"My mom had a great impact in that decision making because	68 (97%)

	people, or societal constructs like religion, tradition and culture on organ donation and registration.	she have always lived a Christian life. She have [sic] always went beyond her means for other people so she was a great example that I sought to follow." [PQ][25] "Islam does not support it... Nothing is mentioned in the Holy Qur'an" [PQ][13]	
Emotion	Includes views where participants expressed specific emotions towards organ donation or organ donation registration in their responses to interview questions.	''When I see ads for young children that need organs to keep them alive, I could happily donate an organ even alive.'' [PQ][36] "For me, I feel that I'm scared. I don't want to give, you know." [PQ][11]	49 (70%)
Nature of the Behaviour	Includes participants stating that they are already registered. Also describes participants' personal experience with organ donation, not related to experiences of loved ones.	"I'm an organ donor and it has been listed on my driver's license since I was 18 and I'm now 48. " [PQ][16] "A number of participants reported that personal experiences with donation prompted them to become donors." [AI][62]	11 (16%)
Not a Barrier/Enabler to Individual	Included as an extra domain to capture when participants express that barriers and enablers that impact others do not impact them.	"I don't care about what my religion says, I am not bothered. I am all for organ donation." [PQ][14] "My religion allows the donation of organs, but I'm not for it." [PQ][42]	41 (59%)
Other	Includes any quotations that do not fit any of the other domains.	"[An] additional advantage to becoming an organ donor that [was] discussed by the participants [was] personal factors" [AI][24]	3 (4%)

Note. PQ = participant quotation, AI = author interpretation

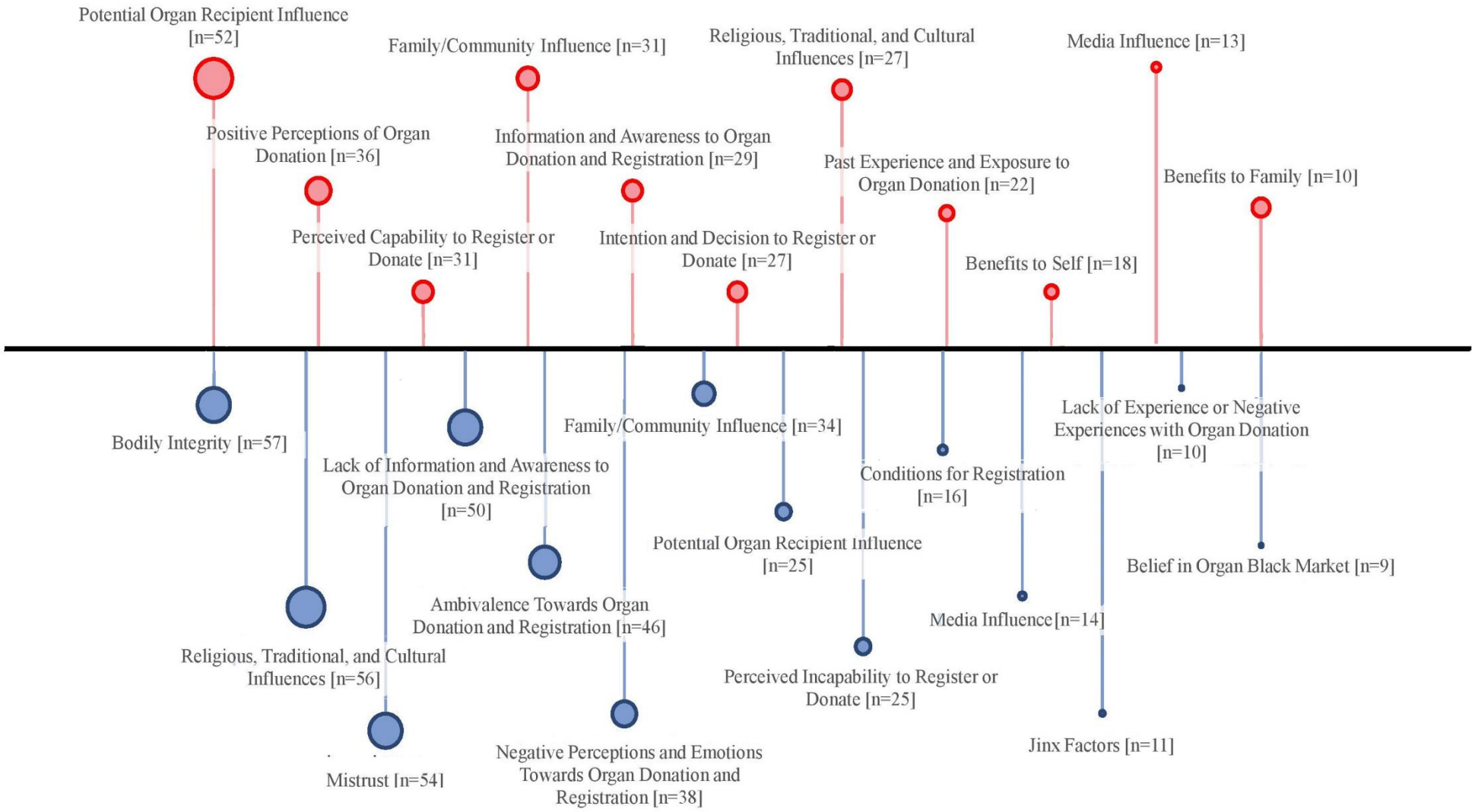

Figure 3. Summary of barriers (blue, below line) and enablers (red, above line) identified in meta-synthesis.
Note. Size of bubble represents the proportion of studies reporting the barrier/enabler.

Enablers

As shown in Figure 3, we identified 11 enablers to organ donation registration, with 24 subthemes within those enablers. There were 7 studies that did not report any enablers[22,29,41,56,57,60,68]. Table 3 in Appendix A presents a full summary of all enablers and subthemes, along with supplementary examples from articles reporting each enabler/subtheme

Enabler 1: Potential Organ Recipient Influence (n = 52)

Potential organ recipient influence was the most reported enabler in this literature, describing how the benefits of organ donation for the recipient, or how the characteristics of the recipient themselves enables them to register for organ donation. This enabler included 3 subthemes: benefits to recipient, family and friends, and deserving recipient.

Benefits to Recipient (n = 45; TDF domains: knowledge, social/professional role & identity, optimism, beliefs about consequences, social influences, emotion)

Most participants emphasized how organ donation helps to save the lives of the recipients, and described an altruistic desire to help those in need through organ donation. In one study, a participant tied this desire to help others to their Christian and African American identity[16]. Some felt good about themselves knowing that through organ donation, they could help recipients return to a normal life. Several studies commented that having knowledge of organ donation benefits for recipients enables participants to donate and register.

Counter views: There were two studies wherein participants reported not intending to donate their organs or register for organ donation despite knowing, or believing that organ donation helps save the lives of recipients[13,67].

Family and Friends (n = 15; intentions, social influences) and other Deserving Recipients (n = 9; intentions, social influences)

Some described an increased willingness to donate to family members and friends, or to other recipients they felt were "deserving" of their organs. Children, young parents, and those who are ill through no fault of their own were commonly reported as "deserving" recipients. Some participants voiced skepticism for the organ allocation process, believing that people from ethnic minorities and the financially disadvantaged have unequal access to organ transplants. Therefore, ethnic minority populations and the financially disparaged were also commonly deemed "deserving" recipients.

Enabler 2: Positive Perceptions of Organ Donation (n = 36; *optimism, beliefs about consequences, emotion*)

Many participants expressed positive perceptions, views, and attitudes towards organ donation and registration, including considering organ donation a "good" and "worthwhile" act, the "right" thing to do, and important. Some further felt that organ donation is "beautiful" and a "gift of life" that one human gives to another.

Counter views: In 3 studies, participants had positive perceptions of organ donation, but were still unwilling to donate or register[15,37,47].

Enabler 3: Perceived Capability to Register or Donate (n = 31)

Some expressed believing they were capable of donating organs and registering, relating to not needing organs when dead, and believing that registration is an easy process.

Do Not Need Organs When Dead (n = 30; beliefs about capabilities, beliefs about consequences, optimism, social influences)

Participants often believed that they will not need their organs when they die, and therefore are capable of donating them. Participants often rationalized deceased organ donation and registration through a simple, "why not?". Many described not donating organs as wasteful since potentially life-saving organs for another will be buried instead of given to those in need. Some related not needing their organs at death to their beliefs about the afterlife. Believing the afterlife to be a spiritual transformation, rather than physical, some believed that their organs would not be required in the afterlife, and could therefore be donated.

Registration is an Easy Process (n = 5; beliefs about capabilities, environmental context & resources)

Relatively few participants explicitly described the ease of the organ donation registration process. These participants equated organ donation registration to a simple "yes" or "no" decision. All studies reporting this subtheme were conducted in the USA or Canada, where convenient registration options such as online registries are common.

Enabler 4: Family/Community Influence (n = 31)

Some participants explained how members of their family and community positively influence their decision to donate or register for organ donation, primarily through discussion, supporting or inspiring registration, and feeling responsible to give back to the community.

Discussion (n = 17; memory, attention & decision processes; social influences)

Many participants expressed that discussion with family and community members assisted or would assist in their decision to donate or register for organ donation. Family members, friends, healthcare professionals, and donation authorities/experts were individuals that participants reported discussing (or desiring to discuss) organ donation with most. Discussion with parents was especially important for student populations. Many participants stated that they would not make a decision on registration before discussing with their family, stressing the importance of family in their culture. Some studies emphasized that discussions with family/community members leads to learning new information, having misunderstandings corrected, and having more support in donation and registration.

Family or Community Supports/Inspires Registration (n = 14; social influences)

Some participants felt supported or actually inspired to register by family/community members who have registered for organ donation. Others were inspired to register by family members' lifestyles and values (e.g. always helping others).

Responsibility to Give Back to Community (n = 12; social/professional role & identity, social influences)

Some participants felt a responsibility to the community, or a desire to give back to the community, which could be accomplished through organ donation. For example, in one study, a participant elaborates that they are grateful for everything the government and community has

done for them, so they want to give back through organ donation[80]. Many others framed their responsibility to give back in the context of the need for organs within their community. For instance, 5 studies in particular noted the need for organs in the African American and Indigenous community, and the responsibility that some felt to address this need[20,28,38,39,74].

Enabler 5: Information and Awareness to Organ Donation and Registration (n = 29)

This enabler reflects the importance of knowledge of the different facets of organ donation and registration in actually performing the behaviour. It also reflects participants displaying sufficient knowledge, and study authors describing participants as knowledgeable. Three main subthemes of knowledge emerged: knowledge of organ donation and registration process, awareness of need for organs, and knowledge addressing barriers.

Awareness of Need for Organs (n = 14; knowledge, social influences)

In 14 studies, participants displayed some awareness of the need for organs, which motivated them to donate and register. Many participants associated this need with the visible need within their community due to high rates of diseases that necessitate transplants (e.g. diabetes), and the high proportion of people on waiting lists.

Knowledge of Organ Donation Process (n = 12; knowledge)

In 12 studies, participants expressed having knowledge of the organ donation and registration processes. Study authors often assessed the knowledge of their participants, and then reported the proportion who displayed sufficient knowledge of the organ donation process. However, the information that actually enables organ donation registration was often unreported. One study detailed the following information as helpful in informing participants' decision to donate/register: the timing/length of procurement surgery, what the surgery entails, how the surgery affects the deceased body, as well as organ matching and success rates[63].

Knowledge Addressing Barriers (n = 5; knowledge)

Some participants explained that learning specific information allowed them to overcome their barriers to registration. One study in particular examined "aha" or turning moments where participants learned new information that helped change their opinion on organ donation and registration[23]. "Aha" moments occurred in response to information on donor eligibility (e.g. health status, age), religious support for organ donation, registration status not affecting hospital care, and treatment of the donor's body and family during the donation process[23].

Knowledge of Registration Process (n = 2; knowledge)

In only 2 studies, authors and/or participants reported having sufficient knowledge of the registration process, or detailed the information that enabled registration. In Wong's study[77], participants were described as knowledgeable about how to register. In Dubay et al.'s study (2017)[25], "getting more information" was highlighted as a factor associated with the decision to register, but the specific information this entails was left unclear.

Enabler 6: Intention and Decision to Register or Donate (n = 27)

Many participants expressed their intentions to register for organ donation, or explained how their perception of the decision to register enabled them to register, including personal choice and immediate registration opportunity.

Intent to Register or Donate (n = 22; intentions)

Several participants expressed their intent to donate their organs or register for donation. This subtheme was often reported as a descriptive characteristic for the study sample (e.g. x number of participants were willing to donate their organs upon death). One study in particular highlighted the disproportionate number of student-aged participants (73%) who were willing to register for organ donation compared to adult participants (35%)[70].

Personal Choice (n = 11; memory, attention & decision processes)

Some participants believed that organ donation and registration are personal choices that are not influenced by other factors such as family and religious considerations, therefore empowering them to register for themselves. Even some religious leaders in Vincent et al.'s study[71] described organ donation as a decision of "individual conscience", and "not relevant to religion". In one study, a participant described how their family may disapprove of organ donation, and highlighted the importance of registering themselves to ensure their wish is honored[25].

Immediate Registration Opportunity (n = 2; memory, attention & decision processes)

In a pair of studies[25,78], participants explained that they spontaneously decided to register simply because they were presented with the opportunity (e.g. in line at DMV).

Enabler 7: Religious, Traditional, and Cultural Influences (n = 27)

This enabler describes how the religious, traditional, and cultural influences in participants' lives enable them or register for organ donation, namely through religious/traditional/cultural permittance of organ donation and embracing a new culture as an immigrant.

Organ Donation is Permitted or Encouraged by Religion, Tradition, and/or Culture (n = 27; social/professional role & identity; social influences)

Several participants expressed that their religion, or interpretations of religious teachings permits, and even in some cases, encourages participants to register for organ donation. As many religions greatly emphasize helping and saving the lives of others, participants grounded their intent to donate in these teachings. Several participants considered donating their organs to an individual in need was more than just permitted in their religion, they considered it "God's will"[16] or a "responsibility to God"[39]. Some further elaborated that if they were to donate their organs, they would be rewarded in the afterlife, or sent straight to heaven.

Counter views: In 3 studies, participants reported that despite knowing that their religion supports organ donation, they are still not willing to posthumously donate their organs[42,58,60].

New Culture As an Immigrant (2 studies; social/professional role & identity, social influences)

Some explained how moving from their culture to a different one in a Westernized country changed their views on organ donation and as a result, were more accepting of organ donation. This enabler was especially prominent in young adult populations. The younger participants stated that while their older family members retain the traditional views in their country of origin, they are able to move away from tradition and form their own opinions on organ donation. This idea is corroborated by a study by Krupic et al. (2018a)[39] where older, Islamic adults reported retaining the views on organ donation that they had in their home country.

Enabler 8: Past Experience and Exposure to Organ Donation (n = 22)

Reported in 22 studies, this enabler describes how participants are more willing to donate or register for organ donation based on exposure to organ donation from their own personal experience, and the experience of family/community members.

Exposure to Organ Donation from Family/Community (n = 21; knowledge, social influences)

Participants described their exposure and experience with organ donation and transplantation through the experiences of family/community members. Knowing family/community members who have needed or received transplants had a significant influence for many participants, being more knowledgeable on the many facets of organ donation, including the quality of life before and after transplantation, and the need for organs in their community. The experiences of family/community members who died waiting for an organ were described as especially influential.

Personal Experience with Organ Donation (n = 4; social/professional role & identity, nature of the behavior)

Some participants expressed how personal experience with organ donation, including being on the transplant waiting list, and working in a medical setting where transplantation is performed, has enabled them to register.

Enabler 9: Benefits to Self (n = 18)

This enabler details the benefits participants believe they will receive from registering. These benefits include 5 subthemes: feeling good as a donor, living on in someone else, stimulus to take charge of own health, and monetary compensation.

Feeling Good As a Donor (n = 12; optimism, beliefs about consequences, social influences, emotion)

Some participants believed registering for organ donation is something that makes them feel good about themselves. Often, participants expressed feeling pride and happiness having done the "right" thing by registering to donate their organs to save the lives of others. Some further explained that they would be seen as "heroes" after donating their organs[62], or that even after just registering, they would be recognized as "somebody" by others[79].

Living on in Recipient (n = 7; optimism, beliefs about consequences, emotion, social influences)

Some participants described finding solace in death knowing part of them will continue to live on in the recipient, with one participant equating organ donation to a form of immortality[45].

Counter views: While most participants found comfort in this idea, some participants in one study found it disturbing[59].

Stimulus to Take Charge of Own Health (n = 2; beliefs about consequences)

Some participants felt registering for organ donation provides them with a stimulus to maintain a healthy lifestyle to ensure that their organs are in good shape since they will go to someone else upon their death.

Monetary Compensation (n = 1; reinforcement)

Only reported in one study, this enabler describes how receiving money (in this case, discount on license plate renewal) was the main driver to registering for organ donation for some participants.

Counter views: Participants from two other studies reported that monetary compensation would not act as an enabler for them to register[37,46].

Enabler 10: Media Influence (n = 13; *knowledge, optimism, beliefs about consequences, environmental context & resources, social influences, emotion*)

Several participants explained that stories and commercials found in various forms of media have positively influenced their decision to register for organ donation. Stories and commercials provided participants with relevant organ donation information. Some participants even stated that most of their information comes from media such as television, radio, and internet. The most influential stories showed sick patients in need of organ transplants, and recipients living healthy lives after their transplant. Other media such as fictional television shows and films enabled the participants to view organ donation more favourably.

Enabler 11: Benefits to Family (n = 10)

This enabler involves the participants' perceived benefits of organ donation and registration that extend to family members. This enabler includes 2 subthemes: onus of decision removed from family and family is comforted by decision to donate.

Onus of Decision Removed from Family (n = 6; beliefs about consequences, social influences)

In 6 studies, participants explained that by registering for organ donation, they would remove the family's burden of decision to donate their organs. Grieving with the loss of a loved one is very difficult, and participants expressed that having to make an organ donation decision during this time would add more stress and trauma to an already difficult time. Organ donation registration would then serve to clarify participants' wishes to their family, to ensure that families are not burdened with that decision.

Family Is Comforted by Decision to Donate (n = 5; beliefs about consequences, social influences)

Some participants believed that posthumous organ donation would bring comfort to their family, which enables them to donate. Such comfort included helping families cope with the loss of their loved one, as their death was not in vain and their life and memory would continue in the recipient. Some explained that organ donation may also bring honour to their family, and help them accumulate "blessings"[76]. A participant from one study stated that organ donation can further comfort family members by saving them money in the post-mortem process[80]. This subtheme prominently expressed by Chinese participants, as 3 of the 5 studies reporting this subtheme exclusively recruited Chinese participants[69,76,80].

Counter views: In one study, some participants expressed that organ donation does not help family cope with the death of their loved one[13].

Barriers

As shown in Figure 3, we identified 14 barriers to organ donation registration, with 34 subthemes within those barriers. There was only 1 study that did not report barriers to

registration[43]. See Table 4 in Appendix B for a full summary of all barriers and subthemes, along with supplementary examples from the articles reporting each barrier/subtheme.

Barrier 1: Bodily Integrity (n = 57)

Bodily integrity was the most frequently reported barrier, describing participants' reticence due to the effects the posthumous donation process would have on their bodies, or due to a desire to keep their body whole. This barrier involved 4 subthemes: preservation of body wholeness, mutilation, ownership of body after death, and will not donate certain organs. Many subthemes were driven by religious beliefs, and were double coded with subthemes from the 'religious, traditional, and cultural influences' barrier.

Preservation of Body Wholeness (n = 48; social/professional role & identity, beliefs about consequences, social influences, emotion)

Some participants' reluctance to donate their organs out of a desire to maintain the wholeness of their body after death. For some, this preservation belief was tied to an unspecific personal desire to their body whole after death. For the majority of participants, organ donation conflicted with their religious, traditional, or cultural beliefs that the body should remain intact after death, especially regarding beliefs about either living peacefully in the afterlife, or being able to transition to the afterlife. Most expressed that they would be unable to transition to the afterlife if they posthumously donate any organs. For studies that sampled participants from Korean and Coast Salish backgrounds[49,79], this inability to transition to the afterlife took the form of becoming a "wandering spirit that can never find peace"[49], with their family having to face various hardships as a result. However, some expressed that if they donate any organs, they would not have those organs in the afterlife, or in the next life (e.g. if kidney is donated, cannot urinate in afterlife; if eyes are donated, cannot see in afterlife). Some Hindu and Buddhist participants believing in reincarnation expressed that organ donation may impact how they are reincarnated in the next life (e.g. reincarnated as a dog or a mosquito instead of as a human).

Counter views: In 9 of the 48 studies reporting this barrier[19,32-34,38,39,53,58,71], and 1 other study[52], participants also expressed that they could still transition into the afterlife if they donated their organs[19,32-34,38,39,53,58,71].

Mutilation (n = 33; optimism, beliefs about consequences, intentions, social influences, emotion)

Participants expressed how the organ recovery process itself and its effects on their bodies drive their reticence to posthumously donate their organs. Most explained that donating would leave their bodies disfigured, abused, and mutilated. Some further stated that organ donation would impact the sacredness of their bodies and their identities. Participants often expressed fear, or even disgust at the thought of being "cut-up" during the donation process. Despite occurring after death, some participants expressed fear that they may still feel pain during the organ recovery procedure.

The mutilation concerns also extended to their families. Some worried their family would be distressed by seeing their body after organ donation, or not be able to recognize them. Others worried that the memory that their family has of them would be irreparably damaged due to the appearance of the corpse.

Ownership of Body After Death (n = 14; social/professional role & identity, beliefs about consequences, social influences)

Many participants expressed the belief that their organs belong to them, and only them, therefore they feel uncomfortable donating their organs to others, even after death.

Will Not Donate Certain Organs (n = 7; social/professional role & identity, beliefs about consequences, intentions, social influences, emotion)

Participants often expressed reticence to donate their heart in particular under the belief that it acts as the receptacle for their identity and ties them to their family. As such, if they were to donate their heart, the recipient may adopt their identity and/or other characteristics. Similarly, many expressed reservations in donating their eyes, as the eyes hold special meaning to them as they bear their memories.

Counter views: There were 3 studies in which participants expressed that this subtheme was not a barrier for them, as they would be willing to donate any organs, or any tissues upon death[38,51,70].

Barrier 2: Religious, Traditional, and Cultural Influences (n = 56)

This barrier captures perceptions of how religion, tradition, and/or culture precludes registering or donating, or are interfered with by organ donation. This barrier includes 3 subthemes: against beliefs; interferes with religious, traditional, or cultural processes; and uncertain religious permissibility.

Against Beliefs (n = 49; social/professional role & identity, social influences)

Many studies highlighted participants perceiving that organ donation is against their religious, traditional, or traditional beliefs, and they are therefore unwilling to register for organ donation. Many expressed that they wanted to die, "as God created them"[38], and believed that removing organs would go against religious teachings.

While most major religions actually support organ donation, there are nevertheless particular cultures that do not. However, some cultures have specific non-medical beliefs about donor eligibility. For example, in some cultures of included studies, organ donation in some bodies are not permitted by their cultural beliefs[17]. Bodies from "bad deaths" such as accidents or suicide should not be transplanted as it is believed by some that the recipient may be implanted with the same 'evils' as the deceased[17].

Some participants explained that in their ideology, the body of the deceased must be unharmed and dealt with very gently, therefore they cannot donate their organs. Others believed that their organs testify for their life and their actions and if they were to donate their organs, the organs would either be absent or would demand justice[13]. Other participants described fears about spiritual consequences such as being haunted by spirits and losing ancestral protection if they donated their organs.

Counter views: In 16 of the 49 studies reporting this barrier, participants also expressed that although their religion, tradition, or culture may disapprove of organ donation, they are still willing to register and donate their organs[11,28,32-34,38-40,50,53,58,59,61,63,69,70]. In 7 other studies, participants expressed that religious, traditional, and cultural beliefs of organ donation were not

barriers to them[14,23,51,52,71,75,80]. Some expressed that this belief was rooted in their beliefs in the afterlife (e.g. spiritual transformation rather than physical, therefore organs can be donated), while others simply expressed that their religion is unrelated to, or outweighed by other considerations in their organ donation decision. While participants expressed this belief irrespective of context, in one study, a participant expressed that religious beliefs should not prevent one from donating exclusively when they have loved ones or children in need[75]. This belief was often expressed by younger adults, especially those who have emigrated to Western countries, as they have broken away from their elders' traditional or cultural beliefs[32,33,58,63].

Interferes with Religious, Traditional, or Cultural Processes (n = 25; beliefs about consequences, environmental context & resources, social influences)

Post-mortem processes included funerals, burials, body washing, and other unspecific rituals were viewed as barriers to donation. Related to the 'mutilation' subtheme from the 'bodily integrity' barrier, some believed that donation would leave their bodies mutilated and therefore unfit for open-casket funerals. Other participants expressed the need for rapid burial, and that organ donation would lead to their bodies being detained in hospitals for too long. Some Muslim participants also described the need for body washing to be performed after death. It is important for the body to be handled with care, and by as few people as possible (often close family members). Participants therefore expressed that organ donation would interfere with their religious body washing ritual.

Uncertain Religious Permissibility (n = 18; knowledge, social influences)

In some studies, participants expressed being unaware of their religion's stance on organ donation, and as a result, erred on the side of caution to not act against their religion.

Barrier 3: Mistrust (n = 54)

Another barrier that was frequently reported in this literature concerns mistrust for the various institutions and individuals involved in organ donation. This barrier involved 4 subthemes: medical mistrust, organ procurement and allocation organization mistrust, government mistrust, societal mistrust.

Medical Mistrust (n = 49; knowledge, social/professional role & identity, optimism, beliefs about consequences, environmental context & resources, social influences, emotion)

In many studies, participants feared that if they registered for organ donation, care provided by medical professionals and institutions would act in the interest of recovering their organs. Some expressed this altered medical care as reduced or withdrawal of care leading to their death. Others worried that medical professionals and institutions would declare death prematurely if they were registered for organ donation, and subsequently recover their organs while they are still alive. Some expressed mistrust for the declaration and meaning of brain death. Pessimism and fear were often expressed alongside these beliefs. While physicians and hospitals were the most frequently reported source of mistrust, their mistrust sometimes extended to paramedics.

While this subtheme was expressed universally across religions, cultures, and ethnicities, African American participants often explained that their mistrust is rooted in their ethnic identity and history[19,24,52,62,73,74]. Some African American participants cited previous injustices such as the Tuskegee syphilis experiment, and general discrimination within society and medical

institutions, which have led to their general mistrust of medical professionals and institutions. Some of these participants also expressed that they believe medical professionals and institutions will prematurely recover their organs to save the lives of Caucasian patients. Some studies that sampled participants from immigrant populations also reported the fear that their organs will be prematurely recovered to save Caucasian non-migrants[13,61,65].

Some studies described views of participants' mistrust of medical professionals and/or hospitals to take care of their bodies during the recovery process, or to follow/respect their cultural customs during post-mortem care.

Counter views: In 7 of the 49 studies reporting medical mistrust participants also expressed a *trust* for medical professionals and institutions, or that their medical mistrust did not prevent them from registering[21,24,51,63,66,73,74]. In an additional 2 studies, participants reported that medical mistrust was not a barrier to organ donation registration[32,77]. Three of the 9 studies reporting that medical mistrust was not a barrier emphasized how students tended to have more trust for their country's medical professionals and systems compared to others in their community/culture[21,32,63]. African American participants from 2 studies expressed that they trusted medical professionals and the medical system[25,74]. One African American participant from another study expressed medical mistrust, but despite that, she had still registered for organ donation[73].

Organ Allocation and Procurement Organization Mistrust (n = 28; knowledge, optimism, beliefs about consequences, environmental context & resources, social influences, emotion)

This mistrust mainly lies in the fear/pessimism that their donated organs will not go to those who need it most, or the allocation will be influenced by prejudice/corruption. Most participants expressed a belief in an inequality in organ allocation driven by ethnic-based or class-based inequalities. For example, many participants expressed that Caucasian recipients are given priority by organ allocation organizations, and those of different ethnicities have limited access to organ transplants. This was especially expressed in studies recruiting African American/Caribbean participants, with 8 studies recruiting these populations having reported this belief[19,24,26,38,67,73,74]. Studies recruiting African American/Caribbean participants often describe their desire to donate to their community, but also a lack of trust in the allocation organization to equitably allocate organs for transplant. As such, participants often expressed themes relating to the deservingness of recipients and a need to give back to the community when describing their mistrust of organ allocation organizations. However, in these cases, mistrust for organ allocation organizations outweighed any considerations for "deserving" recipients or their community.

Participants also expressed mistrust in organ allocation due to a belief that the wealthiest are given priority for transplants. In one study, participants described the case of Alonzo Mourning, a famous basketball player who waited less than a month to receive a kidney transplant, to illustrate such inequal access to transplants[62] (it is worth noting that Alonzo Mourning received a living kidney donation from his cousin, not a deceased donor).

Participants expressed mistrust in organ procurement and allocation organizations out of a fear of their organs being misused. Some feared their organs would never be transplanted and would just rot. Others feared their organs would not go to those who needed them most, and that they would be misused on someone with the wealth or social status to access it. Finally, participants

expressed a mistrust for organ procurement organizations, fearing these organizations kept track of registered organ donors and would immediately come for their organs if they fell ill.

Counter views: In only one of the 28 studies reporting organ allocation and procurement mistrust[60], and one other study[46], participants trusted the allocation organizations, and believed that organs were allocated equitably.

Government Mistrust (n = 6; social/professional role & identity, environmental context & resources, emotion)

In some studies, participants expressed mistrust in government, and a reluctance to allow government involvement in their donation decision. Some expressed telling their family about their intentions to donate, but refused to register due to government mistrust. Others described their mistrust in the government's ability to regulate organ donation and allocation processes.

Government mistrust was often related to participants' perceptions of racial prejudice by the government towards Indigenous persons and African Americans. For example, in one study, African American participants believed that government institutions such as law enforcement were intentionally killing African American men to take their organs[74].

Societal Mistrust (n = 2; social/professional role & identity, social influences)

Some participants expressed a general mistrust for society that hinders them from registering. This subtheme was expressed solely by African American participants, and was expressed in the context of current and historical prejudice and discrimination towards them. One participant explained that African Americans have been traumatized for hundreds of years from their treatment in society, and that it is hard to give without ever receiving[74]. Others explained that due to the history of prejudice and discrimination towards them, African Americans have started to believe that they "would be disposable parts for people"[73].

Barrier 4: Lack of Information and Awareness to Organ Donation and Registration (n = 50)

Reported by most studies, this barrier describes a voiced or displayed lack of knowledge of the various facets of organ donation and registration by participant, often leading to perpetuation of fear, negative views, and misconceptions. This barrier includes 2 subthemes: lack of information about organ donation, and lack of information about organ donation registration.

Lack of Information About Organ Donation (n = 45; knowledge, emotion)

In this subtheme, participants expressed a lack of knowledge about the actual organ donation process, rather than the registration process per se. Many described a general lack of education or misinformation about the organ donation process. The most commonly reported knowledge gaps included how the organ donation/transplantation system operates, the organizations involved in donation and allocation, how transplants are performed, transplantation benefits and risks, organ donor eligibility, organs and tissues that can be donated, what happens to their body during and after donation, and the laws surrounding organ donation.

Some highlighted a lack of publicity and awareness of organ donation, and insufficient access to information. While some reported acquiring a limited amount of information from media such as television and radio, others reported being completely unaware of how to obtain any information

on organ donation. This lack of information, and lack of access to information, led to negative views, strong feelings of fear, and reluctance to donate for several participants.

Lack of Information About Organ Donation Registration (n = 17; knowledge)

Participants also expressed a lack of knowledge of how to register for organ donation. For many, the lack of knowledge and/or awareness of the organ donation registries in their region prevented them from registering. While some participants were unaware of alternatives to registering at physical locations such as the DMV (e.g. online registries), others were completely unaware of the methods for registration their region was operating at the time. For example, in one study[50] conducted in British Columbia, Canada, participants had reported signing an organ donation card, a method of designating consent that has not been in use since the British Columbia Transplant Organ Donation Registry was implemented in 1997[82].

Barrier 5: Ambivalence Towards Organ Donation and Registration (n = 46)

In many studies, participants described either not intending to register, not having decided yet/put much thought into making a decision, or how they intend to register but have not formally done so. This barrier includes 6 subthemes: have not thought about it, do not intend to register or donate, do not want to think about it, indecision or difficulty making decision, intention-behaviour gap, and deferral of decision to family.

Have Not Thought About It (n = 22; social/professional role & identity; beliefs about consequences; memory, attention & decision processes)

Some participants explained not having registered because they have never considered it or given organ donation much thought. Many expressed that they only ever think about organ donation when they are prompted at the DMV, and as such, have not put sufficient thought into their registration decision. Other participants related their lack of thinking of organ donation and registration to their professions. For example, one participant explained that as a nurse working in the medical field, the last thing she wants to think about, or talk about at home is organ donation/transplantation[8]. Some expressed that their lack of thought of organ donation registration is tied to their disinterest altogether.

Some studies placed emphasis on younger populations with this barrier, as several students-aged participants stated that given they are young, their death is not on their mind. Younger participants often expressed having time to make these decisions later, and that they are too young to be considering these decisions at this point in their life.

Do Not Intend to Register or Donate (n = 18; intention, emotion)

Some explicitly stated that they did not intend to register for organ donation or donate their organs. In some studies, reasons for this lack of intention were attributed by participants to fear, medical mistrust, and bodily integrity, whereas others just expressed a general lack of intention.

Do Not Want to Think About It (n = 14; beliefs about consequences; memory, attention & decision processes; goals; social influences; emotion)

Many participants explained that since thinking of organ donation requires thinking of their death, they do not want to think about organ donation whatsoever. In one study, a participant

elaborated that even invoking the topic of death is taboo in their culture, which prevents them from thinking about registration[33].

Counter views: In one of the studies reporting this subtheme, one participant expressed that not wanting to think about organ donation would not prevent them from registering[55]. This participant explained that she "would be happy to [register] and then just not think about it"[55].

Indecision or Difficulty Making Decision (n = 11; beliefs about capabilities; memory, attention & decision processes, intention)

Some expressed they have yet to decide whether to posthumously donate their organs. Some elaborated by acknowledging that while the registration process is easy to complete, the decision to register is difficult to make and they therefore remain undecided and unregistered.

Intention-Behaviour Gap (n = 7; intention)

In a few studies, participants had the intention to register for organ donation, but also explained that they have not done so yet. In some studies, this subtheme was reported by study authors as a descriptive characteristic for the sample. Of these studies, only two explicitly stated rates of occurrence for this subtheme, with 41.9%[71] and approximately 50%[51] of participants from these studies forming the intention to register, but not actually doing so.

Deferral of Decision to Family (n = 3; memory, attention & decision processes; social influences)

In a handful of studies, participants abstained from registering as they preferred to leave the decision to their family. In one study, a participant showed indifference towards organ donation registration, knowing their family can give consent[55].

Barrier 6: Negative Perceptions and Emotions Towards Organ Donation and Registration (n = 38)

This barrier pertains to negative perceptions and emotions about organ donation and registration, and includes 3 subthemes: does not apply or matter to individual, organ donation is wrong, and fear or discomfort.

Does Not Matter or Apply to Individual (n = 17; social/professional role & identity, optimism, beliefs about consequences)

Many participants stated organ donation and registration do not interest them, do not apply to them, and are not necessary for them. Some expressed that organ donation and/or registration were not relevant to them, or did not merit any consideration from them through statements like "it [is] not my job"[79] and "organ donation is not relevant to me"[76]. This belief was sometimes justified by participants' age, described as being young and still having more to accomplish, and therefore, organ donation and registration are not relevant to them. Others justified this lack of relevance through their religious or ethnic identity. For instance, in one study, a participant described organ donation as a "white man's issue"[67], while in another, a participant stated that since God cures illnesses among the righteous, organ donation is unnecessary for those who live "right"[72].

Organ Donation is Wrong (n = 15; optimism, beliefs about consequences, emotion)

Several participants believed that organ donation is simply not right. The expressions of this subtheme ranged from stating that organ donation "[challenges] fate"[34], "is a form of torture to the body and a bad deed"[56], and is equivalent to "tampering with nature"[45].

Fear or Discomfort (n = 14; beliefs about consequences, emotion)

Some participants expressed that organ donation scares them or makes them feel uncomfortable, without describing what drives this fear/discomfort. Some participants even expressed uneasiness related to not feeling safe in registering for organ donation.

Barrier 7: Family/Community Influence (n = 34)

Many participants described how their relationships and interactions with their family and community drive their reticence to donate and/or register, involving 2 subthemes: family and/or community disapproval, and interpersonal communication.

Family and/or Community Disapproval (n = 34; optimism; beliefs about consequences; memory, attention & decision processes; social influences; emotion)

Some worried that organ donation and registration would lead to disapproval and rejection from family/community members, most commonly from parents, spouses, friends, and elders.

For most, this disapproval impacted their intention to register. For instance, some participants were aware that their family members did not support organ donation, and therefore decided to remain unregistered out of consideration for their wishes. Going against their family's or community's wishes was seen as disrespectful, and participants feared it could lead to rejection. However, some explained that disapproval from family members actually reversed their registration behavior. For example, a participant in one study reported that their family forced them to reverse their registration once they found out[34].

This barrier proved especially strong for student-aged participants, as their parents filled out their applications for driver's licenses, which also contained section organ donation registration forms[12]. Other student-aged participants stated that their parents would not allow them to become donors, implying that their registration decision was not theirs to make. A young participant in Irving et al.'s study further elaborated on this, describing that since his family ultimately decides whether or not his organs are donated, he really does not have a choice in the matter[37].

Counter views: Of the 34 studies reporting this subtheme, 6 reported that family/community disapproval would *not* act as a barrier to donation or registration for some participants, as they would register even if it was against their family's wishes[11,32,51,63,72,77].

Interpersonal Communication (n = 7; intentions; memory, attention and decision processes; social influences; emotion)

In a smaller set of studies, participants explained that communication with people within the community propagated fear, and misconceptions regarding organ donation, particularly when telling stories centered on medical mistrust. In two studies conducted with student populations, participants expressed that communication between their classmates deterred them from registering and wanting to donate[18,21].

Counter views: In only one of the studies reporting this subtheme, a participant expressed that interpersonal communication was not a barrier for them[21]. This participant's faith in healthcare

professionals and the healthcare system prevented her from believing her friend's stories of reduced healthcare for registered organ donors[21].

Barrier 8: Potential Organ Recipient Influence (n = 25)

Some expressed concerns about who would receive their organs (subtheme: undeserving recipient) or adverse events their organs may cause (subtheme: harmful to recipient).

Undeserving Recipient (n = 19; optimism, beliefs about consequences, social influences, emotion)

Some participants worried that their donated organs would be allocated to someone that they deemed "undeserving" or "wrong". One type of potential recipient deemed "undeserving" by participants included "bad" people and criminals. Some rationalized this by explaining that if their organs were allocated to a criminal, they would be responsible for any future crimes that recipient may commit. One participant feared that if their organs were donated to a criminal, they themselves would be unable to transition to the afterlife[50]. Another type of potential recipient who was deemed 'undeserving' included people requiring a transplant due to unhealthy lifestyle factors such as alcohol abuse. Many equated donation to such recipients as waste, and worried their organ would be misused or damaged by the recipient. Participants from two studies expressed that they would be unwilling to donate to recipients outside their religion, though not because they deem them "undeserving" per se, but rather because they may not abide by the same traditional practices (e.g. abstaining from certain foods or alcohol)[13,77].

Counter views: In 3 of the 19 studies reporting this barrier[38,53,77], and 1 other study[75], participants expressed that the characteristics of the potential organ recipient were not a barrier to them, and were willing to donate to any person in need of organs, regardless of lifestyle and religious/ethnic identity.

Harmful to Recipient (n = 10; beliefs about consequences, social influences, emotion)

Some participants worried they may cause harm or death to the recipient if they were to donate their organs. In the majority of the studies reporting this subtheme, participants believed their characteristics or spirit may be transplanted in the recipient along with their organ, thereby changing the personality and identity of the recipient[12,17,34,45,49,64]. Some also feared that if transplanted, their organ could result in a lower quality of life or death for the recipients. For some, this fear was tied to perceptions of the quality of their organs.

Barrier 9: Perceived Incapability to Register or Donate (n = 25)

In 25 studies, participants described themselves as being incapable of posthumously donating their organs or registering for organ donation, specifically related to: perceived ineligibility, difficulty in registering, and registration being time-consuming.

Perceived Ineligibility (n = 18; beliefs about capabilities, optimism)

Some participants perceived that their age rendered them ineligible, often expressing pessimism about recipients not wanting their 'worn-out' organs. For others, this belief was driven by their health status, with participants with poor perceived health, diabetes, and other diseases believing that their organs are medically unsuitable for transplant, so they remained unregistered and did not intend to donate their organs.

Difficulty in Registering (n = 8; knowledge, skills, beliefs about capabilities, environmental context & resources)

Some expressed felt registration to be a difficult behaviour to perform, owing to the complexity of the registration paperwork at their local registration sites and other registration methods. For others, the process of even finding registration sites was difficult. Some expressed that finding and navigating organ donation registration sites relied too heavily on internet access, computer literacy, and English literacy.

Registration is Too Time-Consuming (n = 5; beliefs about consequences, beliefs about capabilities, environmental context & resources)

Some felt registration to be too time-consuming, and that they do not have the time to register. Many expressed that the factor making the process so time-consuming is having to go to a registration location (such as the DMV), and waiting to then register. As a result, D'Alessandro et al. commented that many participants would not want to take the time to register, unless they needed to renew their driver's license[18]. However, one participant from Dubay et al.'s study (2017)[25] expressed that even after waiting for 1-2 hours to renew their driver's license, they elected to remain unregistered for organ donation since they did not want to take the extra time to go through the registration process.

Barrier 10: Conditions for Registration (n = 16)

This barrier reflects the negative influence of physical, administrative, and legislative factors for registration in their region, including limited support from healthcare professionals and system, limited access to registry, uncertainty regarding registration laws and regulations, and physical registration environment.

Limited Support from Healthcare Professionals and System (n = 7; knowledge, environmental context & resources, social influences)

Some stated that their local hospitals and doctors do not provide them with enough information regarding organ donation and registration, or their inability/unwillingness discuss it with them. Others described their skepticism of the medical professionals' and institutions' ability to accommodate their religious, traditional, and cultural customs. Participants further elaborated that the hospitals and healthcare professionals would be unable to return their body to their family in time to accommodate their needs. This issue was especially problematic for participants from rural/remote regions, as the lengthy transport time to and from regional healthcare systems could cause delays in organ recovery and in returning the body to family[25].

Limited Access to Registry (n = 5; beliefs about capabilities, environmental context & resources)

Some described that limited or difficult access to organ donation registries hindered their ability to register. This was due to there being few registration locations, or that the existing locations were hard to find or conveniently access. Geographic isolation (e.g. living in rural/remote regions) contributed to some participants' ability to access registration locations.

Uncertainty Regarding Registration Laws and Regulations (n = 5; environmental context & resources)

Some were skeptical about laws and regulations for organ donation registration. For most, this was directed towards the organ donation registration process, or the system responsible for its regulation. Yin et al. commented that there were problems in the organ donation registration system that hindered actual deceased donation[80]. A participant in Liu et al.'s study corroborated this by expressing that are "not enough effective laws in [organ donation registration]" in China[47]. However, some expressed skepticism in the registration system due to the lack of an actual registry. These participants were primarily concerned with how the registration information was organized since the only option for registration was signing organ donor cards.

Physical Registration Environment (n = 2; environmental context & resources, social influences)

Two studies focused on the DMV as a primary registration location with inherent limitations[25,62]. Factors such as a lack of privacy when registering at the DMV, the crowded nature of the DMV, and the DMV staff deterred them from registering. Participants felt the staff was lacking in training and did not have the time or the desire to properly discuss organ donation registration with DMV patrons.

Barrier 11: Media Influence (n = 14; *knowledge, beliefs about consequences, social influences, emotion*)

Participants explained that either the information that the media provides is insufficient to actually learn about organ donation, or that hearing stories in the media have directly led to their reluctance to donate. These include stories such as those reporting on medical errors in organ recovery/transplantation, and stories of an international organ trade which may propagate misconceptions and myths around organ donation, and foster negative sentiment and fear towards it. One study commented that the more sensational and potentially inaccurate the story was, the better their participants seemed to remember it[60].

Barrier 12: "Jinx" Factors (n = 11; *beliefs about consequences; memory, attention, & decision processes; emotion*)

"Jinx" factors represent the fear that registration would lead to participants cursing, or "jinxing", themselves into an early death. Such views sometimes reflected a generalized avoidance of organ donation conversations. "Jinx" factors were reported across various cultures and religions.

Barrier 13: Lack of Experience or Negative Experiences with Organ Donation (n = 10; *knowledge, social influences, nature of the behaviour*)

Several studies have commented that participants lacking personal experience and exposure to organ donation often have less knowledge about organ donation, and have more negative feelings towards it. D'Alessandro et al.'s study emphasized the student population as less likely to know someone affected by organ donation or transplantation, and therefore are less likely to be knowledgeable about it[18]. In both Williamson et al. studies, participants expressed that both negative personal experiences, and the negative experiences of loved ones with transplantation and the medical system acted as barriers to registration and donation for them[73,74].

Barrier 14: Belief in Organ Black Market (n = 9*; knowledge, beliefs about consequences, environmental context & resources, social influences, emotion*)

Some feared the existence of an organ black market, and susceptibility to it by registering or donating. Some feared that by registering for organ donation, they could be killed prematurely,

or have their organs removed at death to be sold on the black market. This fear was often consistent with a mistrust for the medical institutions and the organ allocation and procurement organizations where the medical professionals harvest their organs for them to be sold to the rich and powerful by allocation organizations. While some were apprehensive about a black market for organs existing in the US, Europe, or Australia, other participants highlighted examples of organ trafficking occurring in countries such as China, India, Brazil, and various African countries. Meanwhile, others suggested the potential existence of an international organ trade, where individuals would be susceptible no matter where they are.

Participant-Suggested Strategies for Increasing Registration and Donation

In 41 studies, participants described policies, actions, or initiatives that they believed would increase organ donation and registration rates[11-15,17,18,22-28,31-33,35-39,42,45,47,49-51,53,60-65,67,69,70,72,74,77,78]. The vast majority of studies suggested actions focused on increased education and promotion of organ donation registration (n = 36)[11,12,14,15,17,18,22-28,31-33,35-37,39,42,47,50,51,60-63,65,67,69,70,72,74,77,78].

As with the knowledge-based barriers and enablers, many studies did not report the specific information that participants suggested to include in any educational initiatives. Only 7 studies specified the type of information participants suggested[11,22,24,27,28,62,78]. This information included the need for organ donors of all ages[11,22,78], how eligibility is determined for organ donation[22,24], respect for the body and religious practices during the procedure[22], how organ allocation is decided[27], the benefits of organ donation for recipients[28], how to register for organ donation[62], and frequently-asked-questions to address common barriers[24,62].

Many participants suggested settings and methods for delivering information about organ donation registration, placing special emphasis on making them culturally sensitive and age-appropriate. For example, many student-aged participants suggested the use of social media to promote organ donation and educate users[12,18,37,74], as well as school-based organ donation education[11,37,50]. Conversely, older adults preferred to have information delivered in brochures instead of over mass media channels[22]. Some participants also suggested that discussions with experts in organ donation, and physicians would also be effective means of educating the public[27,37,51,61,67,69,72].

Several participants also suggested using stories/testimonials from potential organ recipients about their experience with needing a transplant as well as their recovery thanks to organ donation (especially local, and culturally similar recipients) to inspire people to register/donate[18,26-28,35,36,50,61,63,74,78]. However, they discouraged displaying ‘gory’ images, or messages that remind people of death[22,33].

Culturally sensitive outlets such as cultural/language-specific radio/television programs/newspapers[26,31,50,69], Bollywood films[32,78], through which to deliver advertisements and information about organ donation were often suggested. Participants also stressed presenting or holding discussions at religious locations, and incorporating religious leaders into the delivery of any educational or awareness initiatives[14,15,17,26-28,50,51,61,67]. Additionally, participants also desired culturally relevant spokespersons to promote organ donation, such as local celebrities and community leaders[26,67,74]. These suggested actions point to the need for tailored interventions for certain populations to effectively increase organ donation rates.

In addition to suggestions for education, many studies had participants who suggested changes or improvements to the current registration system[35-38,45,47,49,53,60,63,74,77,78] (n = 12). Many stressed the importance of making registration more convenient and suggested adding registration sites that are easier (e.g. mall, public transit stations)[35,77,78]. Others suggested allowing the donors to know the recipient, or even to choose the recipient, or at least assure that it goes to someone who matches their desired recipient characteristics (e.g. same ethnicity)[36,38,45,49,74,77,78]. Increased government involvement to improve registration law and to take actions against the commercialization of organ donation was suggested by a handful of participants[47,53]. Other legislative changes suggested by participants included prevention of next-of-kin overriding of registered consent to donation[37,63] and making registration decisions mandatory (i.e. captured in census)[63]. While presumed consent was suggested by participants from one study[37], another study reported near-universal disapproval for presumed consent[60].

The final type of suggested actions proposed by participants was compensation or other rewards for organ donation (n = 7)[13,37,50,60,63,69,78]. The most commonly reported suggestion involved monetary compensation for organ donation and registration including: money for the family to cover funeral expenses[13,37,63] and reduction in insurance premiums or free health insurance for registered donors or families of donors[50,63]. Others suggested formal recognition for organ donation and registration (e.g. name engraved in memorial, certificates)[37,69,78]. Lastly, participants from 2 studies suggested that families of donors should receive preferential treatment for organ allocation should they ever require an organ[60,69].

Discussion

In this qualitative meta-synthesis, we aimed to synthesize the barriers and enablers to organ donation registration, and to map them to TDF domains. In line with this objective, we identified 70 studies in our literature search, and 14 barriers (with 34 subthemes) and 11 enablers (with 24 subthemes) to organ donation registration.

Previous meta-syntheses identified only 17[1] and 27[2] studies respectively; meanwhile, our review identified far more. Nevertheless, there is overlap in the studies identified. For instance, of the 17 studies identified in Irving et al.'s meta-synthesis[1], 14 were included in our review[13,15,19,27,28,45,48-52,64,75]. Additionally, of the 27 studies included in Newton's meta-synthesis[2], 20 were included in our review[11,13,14,19,27,28,34,38,39,48-53,60,64,70,75]. Furthermore, 49 of the 70 studies identified in our review, to our knowledge, have never been included in any previous qualitative meta-synthesis. Therefore, our review is likely the most comprehensive qualitative meta-synthesis examining the barriers and enablers to organ donation registration to date.

Populations Recruited

The studies identified in this review were conducted in a variety of countries, and recruited a variety of populations. There was considerable emphasis on recruiting ethnic/religious minority populations. Over half of the studies (54%) recruited ethnic/religious minorities in their region of study. For the Canadian studies included in the meta-synthesis, all but one (86%) recruited ethic/religious minority populations.

Examining the barriers to organ donation registration in ethnic minorities has allowed us to better understand the broad range of very specific beliefs underlying their reticence to donate/register, especially since registration and donation rates have been shown to be lower in these

populations[83]. For example, while a range of different populations expressed the 'medical mistrust' subtheme, ethnic minorities (especially African Americans) described how these beliefs are driven by perceived discrimination in healthcare and preferential treatment for Caucasian non-immigrants. Some barriers/enablers were unique to ethnic/religious minority populations, such as the 'societal mistrust' (expressed by African American participants) theme and 'new culture as an immigrant' enabler theme.

The range of barriers/enablers, and their associated beliefs, specifically affecting certain ethnic minority groups, as well as their suggested actions for culturally competent and sensitive interventions suggest a need for tailoring interventions towards these groups, and that all-purpose interventions may not be as effective for them. However, across Canada, registration rates remain low, which cannot be attributed solely to ethnic minorities. Clearly, there exist barriers to registration affecting the wider population as a whole, therefore, more research should examine general Canadian populations, and not just specific ethnic minorities.

While a relatively fewer amount of studies focused specifically on recruiting student-aged populations (23%), we were able to elucidate differences in barriers/enablers, as well as differences in beliefs driving barriers/enablers. For example, while participants of all age groups expressed the 'have not thought about it' subtheme from the 'ambivalence towards organ donation and registration' barrier theme, student-aged participants in particular tended to describe how they were too young to be thinking about their mortality.

Barriers/Enablers Identified

While there is overlap in terms of the barriers/enablers identified in our review compared to previous reviews, we have identified 15 novel barriers, and 6 novel enablers, not previously identified by any qualitative reviews, as shown in Table 2.

Table 2. Novel barriers and enablers to organ donation registration identified in meta-synthesis

Theme	Subtheme	Number of Studies (n=)
Enablers		
Perceived Capability to Register or Donate	Registration Is an Easy Process	8
Intention to Register/Donate	Immediate Registration Opportunity	2
Religious, Traditional, and Cultural Influences	New Culture As an Immigrant	2
Benefits to Self	Stimulus to Take Charge of Health	2

	Monetary Compensation	1
Media Influence	n/a	13
Barriers		
Mistrust		
	Government Mistrust	6
	Societal Mistrust	2
Ambivalence Towards Organ Donation Registration		
	Have Not Thought About It	22
	Indecision or Difficulty Making Decision	11
	Intention-Behaviour Gap	7
	Deferral of Decision to Family	3
Negative Perceptions and Emotions Towards Organ Donation and Registration		
	Does Not Matter or Apply to Individual	17
Family/Community Influence		
	Interpersonal Communication	7
Perceived Incapability to Register or Donate		
	Perceived Ineligibility	18
	Difficulty in Registering	8
	Registration is Too Time-Consuming	5
Media Influence	N/A	14
Conditions for Registration		
	Limited Access to Registry	5
	Uncertainty Regarding Registration Laws and Regulations	5
	Physical Registration Environment	2

Many of the novel barriers/enablers identified in our meta-synthesis describe factors that specifically influence organ donation registration, such as the 'limited access to registry' barrier subtheme. This is largely due to this meta-synthesis focusing specifically on identifying

barriers/enablers to *registration*, while most of the previously conducted reviews focused solely on views towards organ *donation* and transplantation[1,2]. This justifies the need for this review and highlights the significance of our findings.

Consistent with previous reviews[1,2], some of the most frequently reported barriers to organ donation registration involved religious, traditional, and cultural influences. Despite widespread religious approval for organ donation[84], organ donation and registration were often described as impermissible within participants' religions, and as interfering in their post-mortem customs. Our review assists in clarifying the specific beliefs driving religious objection (e.g. beliefs of afterlife), not to target them, but rather to be aware and respectful of them when developing interventions. Many participants were unsure of religious permissibility towards organ donation, and therefore abstained from registering, and often desired this information and for additional involvement of religious authorities in providing organ donation-related education. Religious beliefs also often acted as a strong enabler to registration, highlighting the potential for interventions to engage religious communities and their leaders to clarify and promote organ donation in the context of their religious teachings.

Recent research conducted in Ontario seems to point to the 'have not thought about it' barrier subtheme as the primary barrier to organ donation registration with 40% of Ontarians indicating it as their main barrier to registration[85]. While this barrier subtheme was reported by 31% of studies included in our review, far more studies reported barriers such as 'bodily integrity', 'mistrust', and 'religious, traditional, and cultural influences' in our review as well as previous meta-syntheses[1,2]. The 'have not thought about it' barrier was a novel barrier to our review and was not identified by any of the previous reviews[1,2]. Furthermore, the same Ontario-based research suggests that only 8% of Ontarians cite religious factors as barriers to their support of organ and tissue donation[85]. This discrepancy between the primary barriers cited by the qualitative literature, and those cited by wider-population level surveys is likely attributable to the populations recruited in qualitative studies.

This literature emphasized the recruitment and investigation of barriers/enablers within ethnic/religious minority populations, as evidenced by the proportion of studies in our review that recruited those populations. Elucidating religious/cultural beliefs surrounding organ donation was often the primary aim of these studies. This could have resulted in an overrepresentation of 'religious, traditional, and cultural influences' barrier themes, and some 'bodily integrity' subthemes, compared to other barriers that may be more widely reported in larger, general populations. That said, 'religious, traditional, and cultural influences' barriers were reported across all types of studies including those recruiting general populations, but were reported more frequently in studies recruiting ethnic/religious minority populations.

Focus on Organ Donation vs. Organ Donation Registration

Views towards organ donation and organ donation registration are inextricably linked, as views on the former directly impact those on the latter. Therefore, we elected to include the studies that did not include any questions or responses relating to registration in our review, so that we would not miss any key barriers/enablers that influence the registration process as well.

Of the 70 studies included in the review, 43 included questions or responses relating specifically to organ donation registration while the other 27 exclusively examined organ donation/transplantation. Despite this, all barriers/enablers that were not specific to the act of

registration were reported by both types of studies. This indicates that the studies that included questions or responses relating to registration also placed substantial emphasis on examining participants' views towards the organ donation process.

In most studies, including some that included registration questions or responses, posthumous organ donation is treated as the primary behaviour of interest. This highlights an issue in this literature, as posthumous organ donation is not a behaviour per se. It can only occur after death; therefore, it is not a behaviour, or an action, that an individual can perform. Only the intention to posthumously donate organs can be formed, with the registration of that intention to donate representing the only possible behaviour in organ donation. Therefore, the barriers and enablers to organ donation that are not specific to registration still impact registration behaviour, but only along the intentional pathway.

In our meta-synthesis, we identified 5 novel enabler subthemes related specifically to registration behaviour: 'registration is an easy process', 'knowledge of registration process', 'immediate registration opportunity', 'stimulus to take charge of own health', and 'monetary compensation'. Similarly, we identified 9 novel barrier subthemes related specifically to registration: 'government mistrust', 'lack of knowledge about registration', 'intention-behaviour gap', 'deferral of decision to family', 'difficulty in registering', 'registration is too time-consuming', 'uncertainty regarding registration laws and regulations', and 'physical registration environment'. However, these barriers/enablers to *registration* were reported and examined considerably less frequently than those related to organ *donation*. Forming the intention to posthumously donate organs is certainly important in organ donation registration, however there are unique barriers and enablers specific to registration that were largely uninvestigated in this literature, highlighting the need for increased examination of barriers/enablers to organ donation *registration*.

As most reported barriers/enablers relate to forming an intention to donate or register, very few actually relate to post-intentional factors that enable or hinder organ donation registration. Only the 'registration is an easy process', 'limited access to registry', and 'immediate registration opportunity' subthemes relate to barriers/enablers that occur after the formation of intention. There is therefore a clear need for future qualitative research to examine post-intentional enablers of organ donation registration.

Application of the TDF to Organ Donation Registration

Our results indicate that organ donation registration behaviour faces barriers/enablers related to all 14 TDF domains. Additionally, only a small proportion of data was coded into the *other* domain, demonstrating the diverse coverage of barriers/enablers by the TDF.

The TDF domains most relevant to organ donation registration were *knowledge, beliefs about consequences,* and *social influences*. The TDF domains least relevant to organ donation registration were: *skills, goals,* and *reinforcement*. Many barriers and enablers to organ donation registration cut across several TDF domains, such as the 'media influence' enabler theme, which was by the *knowledge, optimism, beliefs about consequences, environmental context & resources, social influences,* and *emotion* domains. Multiple TDF domain representation within barriers and enablers was common and highlights the complex range of factors that all exert influence on organ donation registration.

Using the TDF as a coding framework allowed us to identify new barriers and enablers to organ donation registration by sorting the data into domains known to influence behaviour. The two previous meta-syntheses by Irving et al.[1] and Newton[2] used grounded theory methodology for their meta-synthesis, leading to codes being developed based solely on the content that appears in the literature. While these synthesis methods are valid, the use of the TDF provides more direct knowledge translation to intervention development. Since each of the barriers/enablers are mapped to a framework of theory-based factors known to influence behaviour, this research provides a much clearer picture of which behavioural factors to target and how to operationalize those factors when developing interventions to effectively change organ donation registration in various diverse populations.

Another strength of using the TDF as a predefined coding framework lies in its ability highlight the domains that are examined less frequently in the literature. For instance, the *skills* and *goals* domains had minimal representation in this literature compared to the other domains. These two domains comprise constructs and factors related more closely to the post-intentional barriers and enablers to organ donation registration. For instance, the *goals* domain includes constructs such as goal formation, goal priority, and action planning, all important constructs assist in translating intention into behaviour. Similarly, the *skills* domain includes constructs that pertain to the skills and competencies required to actually perform the behaviour of registration after intention has been formed. These are both domains with potentially significant influences on organ donation registration behaviour that were minimally examined in this literature. Therefore, their influence on registration behaviour is still largely unknown.

Future Research

Based on the findings of this meta-synthesis, there are many avenues for future research. First, future research should focus more specifically on the factors influencing organ donation registration, rather than those relating to posthumous organ donation intention. Although forming the motivation to donate is an important step in organ donation registration, this literature has placed too much emphasis on this step at the expense of factors exclusively affecting registration behaviour. Therefore, in order to gain a better understanding of organ donation registration behaviour, future research should move beyond the motivation to donate.

Finally, future research should also move beyond the attitudinal and intentional factors influencing organ donation registration, and examine the post-intentional factors affecting registration. It is certainly important to address factors affecting motivation to register, but motivation is often not enough for organ donation registration behaviour change. This is best demonstrated by the low registration rates in Canada[86,87] despite widespread support for organ donation and willingness to posthumously donate organs[86]. This 'intention-behaviour gap' barrier was also identified by several studies in our review[29,37,46,50,51,63,71], but was never explored further within each study to identify the factors driving this barrier, or reasons for why it exists. Therefore, future qualitative research should examine the registration intention-behaviour gap, to better understand how we can develop interventions to bolster registration rates. It would be helpful to use TDF when conducting this qualitative research to build off the findings of this review, and to emphasize the *goals*, *environmental context & resources,* and *skills* domains, which incorporate post-intentional factors.

Strengths and Limitations

One of the primary strengths of our qualitative meta-synthesis is the use of the TDF as a coding framework. In addition to the aforementioned benefits, the TDF has allowed us to bring coherence to a disparate qualitative literature, and gain a deeper theory-based understanding of the factors influencing registration behaviour, as each barrier/enabler is mapped to domains known to influence behaviour.

Another strength of our meta-synthesis was its inclusiveness. We synthesized both studies that generally examine organ donation, and studies that are specific to registration. The barriers/enablers to organ donation directly influence motivation to register, therefore they are essential to understand in order to inform registration interventions. Although this literature largely focuses on factors driving the motivation to donate organs, neglecting the registration-specific factors influencing behaviour, this allowed us to identify this significant research gap and advocate for it to be addressed in future research.

Several studies were poorly described in terms of which form of donation participants/authors were discussing and in terms of whose barriers/enablers participants were describing. This may have hindered our ability to differentiate between the barriers/enablers to registration, and those to other behaviours that were not of interest in this meta-synthesis. One study included in our meta-synthesis examined living and deceased organ donation, but placed LD (living donation) or PD (posthumous donation) in parentheses after each barrier and enabler to clearly indicate which form of organ donation was being described[36]. Future research examining multiple forms of organ donation should consider using similar methods to mitigate this risk of bias within their studies.

Conclusion

Our qualitative meta-synthesis was the most comprehensive qualitative review examining organ donation registration to date, and we identified a large compilation of barriers and enablers to organ donation registration in the process, all of which were mapped to theoretical domains that can help inform interventions. We have also identified several important evidence gaps and priorities for future research, particularly in moving beyond general motivational barriers/enablers to organ donation.

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Appendix A: Summary of Enabler Themes and Subthemes

Table 3. Summary of enabler themes and subthemes, with explanations and representative quotations.

Theme (TDF Domains Represented)	Subtheme (TDF Domains Represented)	Explanation	Representative Quotation	Number of Studies
Potential Organ Recipient Influence		Describes the influence of who the recipient of their organs is and the effect their donation will have on that recipient has on participants' decision to register or donate.		52[11-18,20,23-26,28,30,32-39,42-54,58,59,61-63,65,66,69-72,74-77,80]
	Benefits to Recipient (*Knowledge* *Social/Professional Role & Identity* *Optimism* *Beliefs about Consequences* *Social Influences* *Emotion*)	For many, the benefits organ donation provides to recipients was the primary driver for registration.	"It would make other people live, you'd be saving somebody's life, they'd have their life back." [PQ][20] "My only benefit that I thought would benefit me is the satisfaction of somebody else being happy or somebody else living to see another day even when I'm gone, you know, that will still benefit me it was my organ that saved them" [PQ][25]	45[11,12,14,16-18,20,23-26,28,30,32-34,36-39,44-50,52-54,59,61-63,65,66,69-72,74-77,80]
	Family and Friends (*Intentions* *Social Influences*)	Some participants expressed stronger intention to register/donate when discussing or imagining donating to their family and/or close friends.	"In general, participants who were willing to donate an organ expressed a strong preference to donating to family members." [AI][75]	15[15,24,26,36,42-45,49,51,53,58,66,74,75]

	Deserving Recipient (*Intentions* *Social Influences*)	Some participants had a stronger willingness to register/donate when discussing donating to a "deserving" recipient (e.g. child, underserviced populations).	"I suppose the idea of children who haven't lived a life yet, having that second chance and that is what it is like, a second chance." [PQ][48]	9[13,35,36,38,48,53,58,63,74]
Positive Perceptions of Organ Donation (*Optimism* *Beliefs about Consequences* *Emotion*)	N/A	Describes participants' positive perceptions of organ donation and registration.	We need to preserve that spirit and [organ donation] gives a true understanding of what kindness is all about, the miracle of healing." [PQ][20]	36[11,14,15,18,20,25,26,28,30,34,37-40,43,45-48,50,51,55,59,61-63,65,66,71-74,76,77,79,80]
Perceived Capability to Register or Donate		Pertains to quotations in which participants expressed their capability to both donate organs and register for organ donation, as well as the factors that lead to those beliefs.		31[18,24,25,28,30,34,36-39,45-49,52,53,55,59,62-65,69,70,72,74-77,80]
	Do Not Need Organs When Dead (*Beliefs about Capabilities* *Beliefs about Consequences* *Optimism* *Social Influences*)	Several individuals expressed the belief that they will not need their organs after death, and that not donating them would be wasteful.	"If there's someone who needs my organs, sure, why not, my soul will be gone anyway. It is good to give something back to the people." [PQ][28] "I am not going to need them when I'm dead." [PQ][30]	30[18,24,25,28,30,34,36-39,45,47-49,52,53,55,59,62-65,69,70,72,74-77,80]
	Registration Is an Easy Process	Some individuals believed that registration is an easy	"I think it is [easy], because I went to go get my license, and all you had to do was sign a paper and agree to it,	5[18,25,46,62,74]

	(*Beliefs about Capabilities Environmental Context & Resources*)	behaviour to perform, which enabled them to register.	and it gets done." [PQ][62]	
Family/Community Influence		Details how participants' families and communities positively influenced their decision to register.		31[17,19-21,23-25,28,32,36,38,39,43,45-47,53,61,62,65-67,69,70,72,74-77,79,80]
	Discussion (*Memory, Attention & Decision Processes Social Influences*)	Discussion with family, healthcare professionals, religious leaders, and others in the community assisted or would assist in registration decision-making for some participants.	". . in the end, it's my choice, but I still think that it needs to be talked about" [PQ][67] "It is a very big decision, and I will ask my parents for their opinion and discuss it with my classmates." [PQ][47]	17[19,21,23-25,32,46,47,62,65-67,69,70,72,77,79]
	Family or Community Supports/Inspires Registration (*Social Influences*)	Some participants were supported in registering for organ donation by their family/community, or the decision to register was inspired by a family/community member who has registered.	"My mom had a great impact in that decision making because she have always lived a Christian life. She has always [sic] went beyond her means for other people so she was a great example that I sought to follow" [PQ][25]	14[17,19,24,25,32,36,53,61,62,66,72,76,79,80]
	Responsibility to Give Back to Community (*Social/Professional Role & Identity Social Influences*)	Some participants felt a responsibility to the community and a need to register for organ donation so that they can serve their community.	"Many respondents felt a sense of responsibility to helping the African-American community. This sense of group responsibility served as a strong motivation for agreeing to serve as a donor." [AI][38] "I chose donating my organs because	12[20,28,38,39,43,45,66,70,74-76,80]

			I really wanted to do good for the society." [PQ][80]	
Information and Awareness to Organ Donation and Registration		Specifies how sufficient knowledge of the different facets of organ donation and the actual process of registration itself influenced participants' registration.		29[11,13,18,20,21,23-25, 28,31-33,38,40,43,49,51, 59,62-64,67,69-71,74,77, 79,80]
	Awareness of Need for Organs (*Knowledge Social Influences*)	Some participants were aware of the great need for organs worldwide, or within their community, and therefore felt the need to contribute.	''Donating organs is very important. Because I can see everything going on around me. I can see the need to save lives'' [PQ][59]	14[11,13,18,20,28,33,38,40, 59,62,70,74,77,80]
	Knowledge of Organ Donation Process (*Knowledge*)	Participants had or showed sufficient knowledge of the organ donation process, including procurement, eligibility, and organs that can be donated.	"Information was the most common facilitator…to becoming a registered organ donor." [AI][24]	12[24,32,40,43,49,51,63, 67,69-71,80]
	Knowledge Addressing Barriers (*Knowledge*)	Participants stated that obtaining knowledge that helps them overcome their barriers enabled them to register.	"I always thought everything would be worn out by the time my time was up. So I probably will become a donor now since I know they just don't need the heart or the kidneys. They can use everything." [PQ][23]	5[21,23,31,64,79]
	Knowledge of Registration Process	Participants had or showed sufficient knowledge of the	"Many knew that people who wish to be organ donors needed to sign up to with the National Donor Registry and	2[25,77]

	(*Knowledge*)	organ donation registration process.	to carry a donor card in their wallets." [AI][77]	
Intention and Decision to Register or Donate		Describes the organ donation registration decision, and the factors related to the perception and timing of participants' organ donation registration decision		27[15,21,23-25,28,32,34,36, 38,42,43,46,49,51,55,63, 64, 66,69-72,75,77,78,80]
	Intend to Donate or Register (*Intentions*)	Participants declared their intent to donate their organs, and/or register for organ donation.	"If there's something and if I have it, I'll give it, with no obligation." [PQ][51] "Approximately half the participants said that they were willing to be organ donors upon death" [AI][51]	22[15,21,23,25,28,32,36,38, 42,43,49,51,55,63,64,66, 70-72,75,77,80]
	Personal Choice (*Memory, Attention & Decision Processes*)	Participants believed that organ donation registration is a personal choice that is not influenced by other factors such as family opinion, or religious considerations, which enabled them to register.	"…it was my choice, I don't need anybody's approval to just help… I didn't tell anybody, I didn't, I just went in an and did it." [PQ][25]	11[24,25,32,34,46,49,51, 63,69-72]
	Immediate Registration Opportunity (*Memory, Attention & Decision Processes*)	Participants stated they registered for organ donation spontaneously upon being presented with the opportunity to register.	"I didn't think about becoming an organ donor when I first got to the DMV, but after I was asked would I like to be one I decided yes." [PQ][25]	2[25,78]
Religious, Traditional, and Cultural Influences		Details how participants' religious, traditional, and cultural influences enabled		27[16,17,19,20,23,24,26-28, 32,34,35,38,39,45,46,50,51, 53,59,61,63,64,71,75,77, 78]

		them to register for organ donation.		
	Permitted or Encouraged by Religion, Tradition, and/or Culture (*Social/Professional Role & Identity* *Social Influences*)	Participants expressed that organ donation is in line with the values and/or teachings of their religion, tradition or culture, and therefore encourages them to register or donate.	"The Qur'an says if you save one life, you save humanity" [PQ][32] "From my belief, if you do something like that you would go straight to heaven. From my religion." [PQ][63]	27[16,17,19,20,23,24,26-28,32,34,35,38,39,45,46,50,51,53,59,61,63,64,71,75,77,78]
	New Culture as an Immigrant (*Social/Professional Role & Identity* *Social Influences*)	Participants expressed that moving to a new culture in a different country changed their views on organ donation, and allowed them to become more accepting of it.	"I think the older generation have this really old view, but I think a lot of us, younger Lebanese, have moved away, broken away from tradition and we've become our own individuals now and we're raising kids Australianised, totally different to what our parents raised us. We're not as strict. We still have Lebanese values, but we love this country so we're trying to embrace it. So in my opinion, family's opinion does not count." [PQ][63]	2[32,63]
Past Experience and Exposure to Organ Donation		Describes how participants were more inclined to donate/register based on their past experience, or from the experience of family/community members.		22[18,21,24,25,28,30,33,36-38,40,46,47,49,51,59,62,63,67,71,74,80]
	Exposure to Organ Donation from Family/Community	Participants acquired awareness and experience with organ donation through family	"The experience of knowing someone in the community who either needed or received a donation provided the	21[18,21,24,25,28,30,33,36-38,40,46,47,49,51,59,63,67,71,74,80]

	(*Knowledge* *Social Influences*)	members and community members who have received or needed organs for transplantation.	primary context for the knowledge base of participants who named individuals and families within their community who were affected by issues related to organ and tissue donation." [AI][28]	
	Personal Experience with Organ Donation (*Social/Professional Role & Identity* *Nature of the Behaviour*)	Participants described personal experience with organ donation that positively shaped their decision to register or donate.	"a number of participants reported that personal experiences with donation prompted them to become donors." [AI][62]	4[18,46,59,62]
Benefits to Self		Describes how participants believed organ donation and/or registration would benefit themselves.		18[11,14,17,24,25,36,38,45,46,53,59,61-63,72,76,79, 80]
	Feeling Good as A Donor (*Optimism* *Beliefs about Consequences* *Emotion*)	Participants felt good being an organ donor, knowing they have done something worthwhile.	"If I was to die tomorrow . . . it would make me the happiest person to know that I could save somebody's life." [PQ][61]	12[11,25,36,46,53,61-63,72,76,79,80]
	Living on in Recipient (*Optimism* *Beliefs about Consequences* *Emotion* *Social Influences*)	Participants felt some solace in their death knowing that part of them will continue to live on in the recipient.	'I think maybe I wouldn't die, that I'd live on, you know. A small part of me would live on'' [PQ][59]	7[14,45,53,59,62,76,80]

	Stimulus to Take Charge of Health (*Beliefs about Consequences*)	Participants described how registering for organ donation could act as a stimulus for them to maintain a healthy lifestyle since their organs will go to someone else upon their death.	"I'm told that if I decide to donate my organs, I should remain healthy until the day I die. If not, I won't be able to donate even if I want to. So it could give me an excuse to stay healthy" [PQ][79]	2[24,79]
	Monetary Compensation (*Reinforcement*)	Participants expressed that they decided to register for organ donation since they would receive monetary compensation for doing so.	"I know when I went with a group of my friends, everybody that she asked it was just, like 'organ donor? 'Everybody does that face like, 'hmmmm... well, it's money off so OK,' whereas, we 're still not thinking about it. We just know that we're getting $10 off [license renewal]." [PQ][38]	1[38]
Media Influence (*Knowledge* *Optimism* *Beliefs about Consequences* *Environmental Context & Resources* *Social Influences* *Emotion*)		Describes how stories or information provided in the media encouraged or enabled some participants to register for organ donation.	''When I see ads for young children that need organs to keep them alive, I could happily donate an organ even alive'' [PQ][36]	13[25,34,36,37,43,45,59,62,65,67,69,79,80]
Benefits to Family		Describes the benefits that participants stated organ donation and registration would bring to their family/community.		10[23,25,34,36,37,46,47,69,76,80]

	Onus of Decision Removed from Family (*Beliefs about Consequences Social Influences*)	By registering for organ donation, family is prevented from making a difficult decision, during a difficult time.	"Many felt leaving the final donation decision to next of kin was not ''fair,'' and the decision should be made well in advance to avoid this final ''trauma.''" [AI][37]	6[23,25,34,37,47,80]
	Family Is Comforted by Decision to Donate (*Beliefs about Consequences Social Influences*)	Some described how organ donation would help their family grieve with their death, since the benefits given to the recipient would give their death meaning.	''The family of the donor could feel some sense of worth, that the death of their loved one wasn't just a waste'' [PQ][36] "Some participants also mentioned that the donor's family might feel the existence of the deceased when meeting the organ recipient, and the family's pain could be reduced" [AI][76]	5[36,46,69,76,80]

Note. TDF domains represented by the subthemes are presented in parentheses. If a given theme does not have any subthemes, then the TDF domains represented by the theme are presented in parentheses. PQ = participant quotation, AI = author interpretation

Appendix B: Full Summary of Barrier Themes and Subthemes

Table 4. Summary of barrier themes and subthemes, with explanations, and representative quotations.

Theme (TDF Domains Represented)	Subtheme (TDF Domains Represented)	Explanation	Representative Quotation	Number of Studies
Bodily Integrity		Refers to how the effects organ donation would have on the deceased body caused a reluctance to donate/register, due to a desire to keep the body whole after death, or to prevent physical damage (mutilation), and/or negatively impact the transition to the afterlife.		57[11,13,15,17-20,24,26-42,44,45,47-53,55-65,67-72,74-79]
	Preservation of Body Wholeness (*Social/Professional Role & Identity* *Beliefs about Consequences* *Social Influences* *Emotion*)	Many participants described a desire to keep their body whole, with their organs unseparated from their body. For some, this was attributed to religious, traditional, and cultural reasons, such as requirements for the afterlife. Others described it as a personal desire.	"I still have to process because it was in-tuned in me when I was young that you are not supposed to separate your organs from your body." [PQ][11] ''I believe in the afterlife. When I go I want to be buried intact so that I can come back whole.'' [PQ][19]	48[11,15,17,19,20,26-29,31-34-42,44,45,47-51,53,55,58-65,67-71,74-77,79]
	Mutilation *(Optimism* *Beliefs about Consequences* *Intentions* *Social Influences* *Emotion*)	Participants described feelings of distress, fear, or disgust they and their families may feel when thinking of being "cut-up" (mutilated) or the general process of organ procurement. Beliefs about the effects on the body after organs are retrieved such as feeling	"The thought of having my body chopped up is not a nice thought for me or anybody" [PQ][32] "There were also concerns that the scars left behind may be upsetting for families at burial and cremation and would thus impact on	33[13,18,24,27,29,30,32,34-38,45, 47,48,50,52,53,55-58,61-65,69,72,76-79]

		pain, disfigurement, and desecration of one's identity or the sacredness of the body were also described.	willingness to donate" [AI][32]	
	Ownership of Body After Death (*Social/Professional Role & Identity* *Beliefs about Consequences* *Social Influences*)	Participants expressed ownership of their body after death, which precluded them from registering. They believed that their organs belonged to them alone, and therefore it would feel wrong for them to be in anyone else.	"I was made with the parts I have and that's the way I want to go and I wouldn't donate my parts either because they're mine not anybody else's. You come into this world with your own parts and you leave with your own parts." [PQ][20]	14[20,24,29,34,45,50,61,64,65,68,74-76,79]
	Will Not Donate Certain Organs (*Social/Professional Role & Identity* *Beliefs about Consequences* *Intentions* *Social Influences* *Emotion*)	Some described a belief that some organs can be donate while others cannot. Often tied to traditional beliefs of certain organs such as the heart.	"Some felt more uncomfortable with the notion of removing particular organs such as the heart and eyes." [AI][63] "Some parts may be donated but the heart attaches a person to his family". [PQ][15]	7[15,34,45,50,63,71,77]
Religious, Traditional, and Cultural Influences		Describes how participants' religion, tradition, and/or culture precludes them from registering, or would be interfered with by organ donation.		56[11-13,15,17-20,22,24,26-41,44,45,47-51,53,55-65,67-72,74,76-79]
	Against Beliefs	Participants believed that organ donation is against the beliefs of their religion, tradition, or culture	"Many also mentioned that organ donation was against their religion" [AI][12]	49[11-13,15,17,19,20,22,24,26-35,37-41,44,45,47,49,50,53,55,56,58-61,63-65,67-70,

	(*Social/Professional Role & Identity Social Influences*)	and therefore did not register for organ donation.	"Islam does not support it... Nothing is mentioned in the Holy Qur'an" [PQ][13]	72,74,76-79
	Interferes with Religious, Traditional, or Cultural Processes (*Beliefs about Consequences Environmental Context & Resources Social Influences*)	Several participants described how organ donation could interfere with traditional processes at death such as open casket funerals, washing the body after death, and immediate burial.	"If you are an organ donor you can't have a regular funeral" [PQ][12] "In Islam a body must be buried within two days, and only two people are allowed to touch the body after death." [PQ][32]	25[12,13,17,18,28,32-36,45, 48,49,51, 57-59,61-65,69,76, 77]
	Uncertain Religious Permissibility (*Knowledge Social Influences*)	Many participants were unsure whether or not organ donation is permitted within their religion/culture, and therefore did not register.	"Religion was often viewed as a barrier to organ donation, with some feeling unsure if their religion allowed them to become organ donors or whether it was ''right with God.''" [AI][19]	18[11,13,19,20,26,27,31,32, 34,51,53, 60,61,63,64,71,77, 78]
Mistrust		Describes participants' mistrust towards institutions involved in organ donation and its negative influence on registration behaviour.		54[11-16,18,19,21,24,26-31, 33-41,45, 47-53,55,57-68,70-74,76,79,80]
	Medical Mistrust (*Knowledge Social/Professional Role & Identity Optimism*	Participants feared that if they registered for organ donation, the medical professionals and system would alter the quality of care they provide, in order to extract their organs. Participants also expressed a general mistrust for medical	"If I sign the donor card, I might not receive the right treatment. [The doctors] may cut me before I had died." [PQ][13]	49[11-13,15,16,18,19,21,24, 26-31,33,34,36-41,45,48-53, 55,57-68,70,62-74,76,80]

Beliefs about Consequences *Environmental Context & Resources* *Social Influences* *Emotion*)	professionals and institutions which led to a reluctance to donate and register		
Organ Procurement and Allocation Organization Mistrust (*Knowledge* *Optimism* *Beliefs about Consequences* *Environmental Context & Resources* *Social Influences* *Emotions*)	Participants believed that the organ procurement and allocation organizations do not ensure equality in the distribution of organs and that organs only go to Caucasians, the rich or the powerful instead of ethnic minorities, or those without money or power.	"You want to give your organ? It will never reach the Black people.... They will give it to their own.'' [PQ][19] "…a wealthy person will get the kidney." [PQ][60]	28[14,19,24,26,29-31,34,35, 37-39, 47-49,53,60-63,66,67, 70,71,73,74, 79,80]
Government Mistrust (*Social/Professional Role & Identity* *Environmental Context & Resources* *Emotion*)	A mistrust of government led to mistrust of organ donation registration. Participants stated they did not want government involved in their decision to donate.	"I expressed my wishes to be a donor with my family. I don't want the government involved in my decision." [PQ][30]	6[30,49,60,67,73,74]
Societal Mistrust (*Social/Professional Role & Identity* *Social Influences*)	Participants expressed a general mistrust of society which drove reticence to register.	"Other participants expressed that they viewed the negative treatment of African-Americans in the United States, even outside the context of health, as a barrier to them	2[73,74]

			registering as potential organ donors." [AI][73]	
Lack of Information and Awareness to Organ Donation and Registration		Includes quotations in which participants stated and/or showed a lack of knowledge of the various aspects of organ donation, which often led to perpetuation of fear, negative attitudes, and misconceptions.		50[11,12,14,17-19,21,22,24-26,28-33,35-40,42,44,46,47, 49-51,53,54, 56,58,60-65,67, 69-72,74,76-79]
	Lack of Information About Organ Donation Process (*Knowledge Emotion*)	Participants expressed or showed a lack of knowledge of the organ donation process including donor eligibility, procurement, and organizations involved throughout the process.	"Personally, I don't know much about what organ donation entails.'' [PQ][33] "I haven't seen much about [organ donation] myself or heard about it or seen much publicity." [PQ][32]	45[11,12,14,17-19,21,22,24-27,28, 31-33,35-40,42,44,46, 47,53,54, 56,58,60-65,67,69-72,74,76-79]
	Lack of Information About Organ Donation Registration (*Knowledge*)	Participants expressed or showed a lack of knowledge of organ donation registration, including existence of registries, how to register, and how to access registries.	"I don 't know much about donation or signing up to become a donor, which is the main reason why I'm not registered." [PQ][18]	17[18,24,29-31,35,40,46,47,49-51, 58,61-63,77]
Ambivalence Towards Organ Donation Registration		Pertains to quotations in which participants expressed their decision to not register for organ donation or how they have not yet made a decision about registration due to not wanting to think about it, or simply never having thought of it.		46[11,13,16,18,19,20,23-25, 27,29-31,33,34,37,39-42,45-47,50,52,53,55, 56,58,60-64, 67,68,70-77,79]

Have Not Thought About It (*Social/Professional Role & Identity* *Beliefs about Consequences* *Memory, Attention & Decision Processes*)	Participants have not thought about organ donation. Often due to lack of attention to the issue, lack of knowledge, or belief that organ donation registration is something that does not necessitate an imminent decision, as there is time before they die.	"I never really thought about it at all… I just, you know, it's not anything I just really thought about." [PQ][25] "The biggest thing with many of us {students] is we don't understand our own mortality. We don't understand that it could be tomorrow. We believe that we've got time." [PQ][18]	22[11,18,20,23,25,27,29-31, 34,37,42, 46,47,51,52,61, 62-64,75,77]
Do Not Intend to Register or Donate (*Intentions* *Emotion)*	Participants expressed that they were not willing to donate their organs or register for organ donation.	"For me, I feel that I'm scared. I don't want to give, you know." [PQ][11]	18[11,14,24,29,30,34,39-41, 53,57,58,60,67,68,73,75,76]
Do Not Want to Think About It (*Beliefs about Consequences* *Memory, Attention & Decision Processes* *Goals* *Social Influences* *Emotion*)	Participants did not want to think about organ donation, often due to the implication of death, and therefore did not register for organ donation.	"Thinking about organ donation would involve invoking the topic of death which is taboo to Navajos.'' [AI][33] "X gave me that form and I read it I thought, 'ugh [y] I'd rather not go there at the moment'' (I: ''What kinds of thought did it bring up? What kind of worries?'') ''Just the death you know'' [PQ][34]	14[18,19,33,34,37,45,50,55, 61-63,72,76,79]
Indecision or Difficulty in Making Decision	Participants were forming their decision, or describe their difficulty	'I don't know yet.'' [PQ][29] "Like you said, the signing itself,	11[16,20,29,47,52,62,70,71, 74,76,79]

	(*Beliefs about Capabilities Memory, Attention & Decision Processes Intention*)	in reaching a decision regarding donation.	sure, but the process of getting to that point is not something I think would be easy for anyone." [PQ][62]	
	Intention-Behaviour Gap (*Intention*)	Some participants stated their intention or willingness to register, but did not actually register, implying a post-intentional barrier.	'…plan to, haven't gotten around to it.'' [PQ][29]	7[29,37,46,50,51,63,71]
	Deferral of Decision to Family (*Memory, Attention & Decision Processes Social Influences*)	Participants abstained from registering as their families could just make the decision for them upon death.	"One of the reasons why perhaps I've been blasé about it, perhaps assuming, you know, if something like that did happen, my next of kin could… give their consent or something." [PQ][55]	3[30,55,67]
Negative Perceptions and Emotions towards Organ Donation and Registration		Pertains to any expression of negative attitudes and emotions towards donation or registration.		38[13-16,20,24,29-32,34,37, 38,41,42,45-48,52,55-57,59-61,63-65,67,68, 70,71,73,75-77,79]
	Does Not Apply or Matter to Individual (*Social/Professional Role & Identity Optimism Beliefs about Consequences*)	Participants believed that organ donation registration is not something that they need to do, something that does not apply to them, or something that does not interest them.	"…the concept of organ donation [was] a distant and irrelevant issue." [AI][32] "Other women…were totally uninterested." [AI][42] "I think that organ donation is not related to me." [PQ][76]	17[13-15,20,29,30,32,37,42, 46,55,63, 67,75-77,79]
	Organ Donation Is Wrong	Participants believed that the act of organ donation and/or registration	"organ donation may be seen by some as challenging fate." [AI][34]	15[16,34,41,45,48,52,56,57, 59-61, 64,70,75,76]

	(*Optimism Beliefs about Consequences Emotion*)	is wrong, against the wishes of god, or against the laws of nature.		
	Fear or Discomfort (*Beliefs about Consequences Emotion*)	Participants expressed generalized fear and/or discomfort towards organ donation.	"Frankly speaking, I'm scared and anxious about it" [PQ][41]	14[24,29-31,34,38,41,46,56,63,65,68,71,73]
Family/Community Influence		Describes barriers related to their relationships and interactions with family and community members.		34[11-13,17-19,21,23,24,27-30,32-37,47,49-51,55,56,58,62,63,67,69, 72,74,76,77]
	Disapproval from Family and/or Community (*Optimism Beliefs about Consequences Memory, Attention & Decision Processes Social Influences Emotion*)	Family and/or community disapprove of organ donation and registration, therefore participants did not register. Some felt as though they have no say in their registration decision, as their family could override registration at death.	"Others mentioned the fear of family objection and rejection if they chose to become an organ donor, particularly in African families." [AI][19] "I have a free will to decide, but if it is gonna be hard for my family and they believe that they shouldn't, then it won't work." [PQ][28]	34[11-14,17-19,21,23,24,27-30,32-37,47,49-51,55,56,58,62,63,67,69, 72,74,76,77]
	Interpersonal Communication (*Intentions Memory, Attention & Decision Processes*	Communication with others led to a reticence to register for organ donation. Often due to the propagation of "myths" or "stories" through communities.	"Pakistanis described how myths and stories of bad experiences had filtered through Pakistani communities, making people unwilling to donate." [AI][32]	7[18,21,32,37,62,63,74]

	Social Influences *Emotion*)			
Potential Organ Recipient Influence		Describes the influence that the characteristics of the potential organ recipient has on their decision to register. Also includes quotations in which participants express that the negative effects that organ donation may have on the recipient.		25[11,13-15,17,30,32,34-38,45,49-51,53,58,62,64,69,71,74,76,77]
	Undeserving Recipient (*Optimism* *Beliefs about Consequences* *Social Influences* *Emotion*)	Participants believed, or feared, that their organs may go to someone who they believe is undeserving. Undeserving recipients included those who would misuse their organ and "bad" people (e.g. criminals).	"Say I had a liver to donate; I wouldn't want to give it to someone who was an…alcoholic." [PQ][32] "Two participants commented that they wanted organs to go to good people or young people, not "bad people," "criminals," "people who are selfish," or "a rich guy who could buy his organs."" [AI][35]	19[13-15,30,32,34-38,50,53,58,62,69,71,74,76,77]
	Harmful to Recipient (*Beliefs about Consequences* *Social Influences* *Emotion*)	Participants believed that if they were to donate their organs, they may cause harm or death to the recipient, or even cause their characteristics to be adopted by the recipient (brain-swapping).	"…recipients can assume the personality or preferences of the donor (as portrayed in popular movies and television shows where the recipient suddenly likes certain foods that the donor liked, or immediately falls in love with the boyfriend/girlfriend of the donor)." [AI][11]	10[11,17,34,36,45,49,51,54,62,63]

Perceived Incapability to Register or Donate		Describes participants' beliefs that they are unable to donate organs or to register for donation.		25[11,17,18,20,22-25,28,30,36,37,40,42,46,47,59,62,64,71,72,74,75,77,80]
	Perceived Ineligibility (*Beliefs about Capabilities Optimism*)	Participants believed that they were ineligible for organ donation, often due to health status and/or age.	"At this point in my life it doesn't matter because I'm sure at my age they might not want most of me anyway. It doesn't really matter." [PQ][11] "Because I have a lot of medical things and I don't think they would be worth it." [PQ][22]	18[11,17,20,22,24,28,30,36,37,40,46, 59,64,71,72,74,75]
	Difficulty in Registering (*Knowledge Skills Beliefs about Capabilities Environmental Context & Resources*)	Registering was challenging for some participants, and therefore they were unable to register.	"In some cases, people who had already registered felt that the process was too complicated, and that it relied too much on Internet access and computer literacy." [AI][40]	8[30,40,42,46,47,62,74,80]
	Registration is Too Time-Consuming (*Beliefs about Capabilities Beliefs about Consequences Environmental Context & Resources*)	Participants believed that registration is too time-consuming, and that they do not have the time to do it.	"However, even students who know about the sign-up process feel that the process is viewed as too time consuming." [AI][18]	5[18,25,30,46,77]

Conditions for Registration		Includes quotations commenting on the negative impact the physical, administrative, and legislative factors for registration in participants' regions have on their performance of registration.		16[13,24,25,28,30,33,34,40,44,47,61,62,63,77,80]
	Limited Support from Healthcare Professionals or System (*Knowledge Environmental Context & Resources Social Influences*)	Often, participants described a lack of support from healthcare professionals and the healthcare system that hinders their ability to register (not related to mistrust). A lack of information provided by healthcare professionals, and an inability to accommodate their cultural needs were commonly reported by participants.	"I go to the GP regularly. If it is important, why does he not inform us about it? I have been going to my GP for more than 30 years and he has never raised the subject with me." [PQ][13] "I have been to the hospital and did not see any posters or leaflets discussing organ donation." [PQ][13]	7[13,28,33,44,47,61,62]
	Limited Access to Registry (*Beliefs about Capabilities Environmental Context & Resources*)	Limited or difficult access to organ donation registries, prevented some participants from registering. Often described as due to a lack of convenient options for registrations.	"Many viewed the lack of opportunity to register due to a lack of easy access for people to conveniently register as an organ donor." [AI][77]	5[30,40,63,77,80]
	Uncertainty Regarding Registration Laws and Regulations (*Environmental Context & Resources*)	Participants were skeptical of the laws and regulations regarding organ donation registration, or the actual registries (or lack thereof) and therefore decided to abstain from registering.	"Some problems in the deceased organ donation registration system in China were revealed that hinder the deceased organ donation behaviors." [AI][80]	5[24,33,34,47,80]

	Physical Registration Environment (*Environmental Context & Resources Social Influences*)	Describes how factors within registration locations acted as barriers to registration for some participants.	"It wasn't, the way it was set up, it wasn't, you didn't have any privacy so it was a open conversation so when the clerk was asking questions to the person you could hear her asking you know and for the 3 or 4 people that were ahead of me when she asked me would you like to be an organ donor, 'no'." [PQ][25]	2[25,62]
Media Influence (*Knowledge Beliefs about Consequences Social Influences Emotion*)	N/A	Pertains to quotations explaining the influence the media has, primarily in the propagation of "myths", or promotion of stories that fuel fear and mistrust towards organ donation.	"College students are heavily influenced by Hollywood and media, which often convey information that shines a negative light on organ donation. The influence of movies, television programs, and other coverage that incorporate common myths and misconceptions only further cements these ideas." [AI][18]	14[13,15,18,30,38,44,47,50, 53,60-63, 73]
"Jinx" Factors (*Beliefs about Consequences Memory, Attention & Decision Processes Emotion*)	N/A	Describes the belief that if organ donation registration is considered, discussed, or performed then participants will bring about ("jinx") themselves into early death.	"When I catch myself thinking it, I think 'don't be an idiot'…it's madness to think that just because I've signed a piece of paper, or sent an email, then I'm likely to get, you know, dragged under a bus." [PQ][55]	11[15,25,41,45,25,61-63,70,76,77]
Lack of Experience or Negative Experiences with Organ Donation (*Knowledge*	N/A	Participants expressed that they have not had much personal experience with organ donation and/or transplantation, or have had or heard of negative experiences with organ	"College students are less likely to know someone affected by organ donation or transplantation and therefore tend to have less knowledge about the process and who benefits." [AI][18]	10[18,32,38,40,46,47,63,69, 74,75]

Social Influences *Nature of the Behaviour*)		donation/transplantation. Lack of personal experience led to less knowledge of organ donation.	"A number of participants cited negative personal experiences, or experiences of loved ones, as a barrier to organ donation." [AI][74]	
Belief in Organ Black Market (*Beliefs about Consequences* *Environmental Context and Resources* *Social Influences* *Emotion*)	N/A	Participants believed in, or feared, the existence of a black market for organs. This belief often extended to mistrust for the healthcare system and organ allocation organizations.	"For example, some feared that their organs could potentially be sold on the black market, that their organs could be removed before they were declared dead or that they could be killed for their organs." [AI][63]	9[31,35,41,53,58,59,61,63,74]

Note: TDF domains represented by the subthemes are presented in parentheses. If a given theme does not have any subthemes, then the TDF domains represented by the theme are presented in parentheses. PQ = participant quotation, AI = author interpretation

Appendix C: **MEDLINE Search Strategy**

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to October 10, 2018>

Search Strategy:

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1 Tissue Donors/ (35841)

2 "Tissue and Organ Procurement"/ (16380)

3 Transplants/ (4609)

4 ((organ or organs) adj don*).tw. (16452)

5 ((transplant* or tissue*) adj3 don*).tw. (42300)

6 ((organ or organs) adj3 regist*).tw. (1076)

7 ((transplant* or tissue*) adj3 regist*).tw. (4268)

8 (deceased adj3 don*).tw. (5840)

9 (cadav* adj3 don*).tw. (4925)

10 ((organ or organs) adj3 designat*).tw. (134)

11 (tissue* adj3 designat*).tw. (347)

12 ((organ or organs) adj3 consent*).tw. (699)

13 ((transplant* or tissue*) adj3 consent*).tw. (521)

14 ((organ or organs) adj3 recov*).tw. (1720)

15 ((transplant* or tissue*) adj3 recov*).tw. (9964)

16 ((organ or organs) adj3 procur*).tw. (3310)

17 ((transplant* or tissue*) adj3 procur*).tw. (2167)

18 ((organ or organs) adj3 transplant*).tw. (32852)

19 (tissue* adj3 transplant*).tw. (12367)

20 (factor or factors).tw. (2949792)

21 barrier*.tw. (248407)

22 enabl*.tw. (371748)

23 influenc*.tw. (1321633)

24 Motivation/ (61073)

25 motivat*.tw. (113415)

26 facilitat*.tw. (457317)

27 belief*.tw. (72443)

28 drive*.tw. (315978)

29 affect*.tw. (1640369)

30 determin*.tw. (3199404)

31 willingness.tw. (21064)

32 intent*.tw. (100870)

33 (attitude or attitudes).tw. (131285)

34 opinion*.tw. (89568)

35 view*.tw. (428253)

36 experience*.tw. (948320)

37 perspective*.tw. (268923)

38 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 (133365)

39 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 (9301608)

40 38 and 39 (57849)

41 interview*.tw. (312995)

42 (survey or surveys).tw. (519827)

43 questionnaire*.tw. (442360)

44 (focus group or focus groups).tw. (38093)

45 qualitative*.tw. (230973)

46 41 or 42 or 43 or 44 or 45 (1258526)

47 40 and 46 (3631)

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Appendix D: Adapted Risk of Bias Assessment Form

Adapted items for risk of bias assessment based on CASP Qualitative Checklist[7]

1. Was there a clear statement of the aims of the research?
2. Is qualitative methodology appropriate?
3. Were the authors clear about what form of organ donation they or participants were discussing (e.g. consent to organ donation for loved one, living donation or deceased donation)
4. Were the authors clear on whether or not participants are answering questions based on their perspectives, or based on their beliefs of others' perspectives?
5. Was the research design appropriate to address the aims of the research?
6. Was the recruitment strategy appropriate to the aims of the research?
7. Was the data collected in a way that addressed the research issue?
8. Has the relationship between researcher and participant been adequately considered?
9. Have ethical issues been taken into consideration?
10. Was the data analysis sufficiently rigorous?
11. Is there a clear statement of findings?
12. How valuable is the research?

Appendix E: Summary of Risk of Bias Analysis

Table 5. Summary of risk of bias analysis within individual studies.

Author and Year	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
Albright et al. 2005[11]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Albright et al. 2010[12]	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Alkhawari, Stimson & Warrens 2005[13]	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Bharambe et al. 2015[14†]	Y	N	Y	Y	Y	Y	N	N	N	N	Y	Y
Bhengu & Uys 2003[15]	Y	Y	N	Y	Y	N	Y	N	N	N	Y	Y
Brown 2012[16†]	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N
Chen et al. 2014[17]	Y	Y	Y	Y	N	N	N	N	N	N	Y	Y
D'Alessandro, Peltier, & Dahl 2012[18]	Y	Y	Y	N	Y	N	Y	N	Y	Y	Y	Y
Davis & Randhawa 2006[19]	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Davison & Jhangri 2014[20]	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y
Denvir & Pomerantz 2009[21]	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y
Downing & Jones 2010[22]	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Downing & Jones 2018[23]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
DuBay et al. 2014[24]	Y	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y

DuBay et al. 2017[25]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Dunleavy 2013[26]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Exley et al. 1996[27]	Y	Y	N	N	Y	Y	Y	N	N	N	Y	Y
Fahrenwald & Stabnow 2005[28]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Feeley & Servoss 2005[29†]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Feeley et al. 2014[30†]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Frates & Bohrer 2002[31]	U	Y	N	Y	N	Y	Y	N	N	U	Y	Y
Gauher et al. 2013[32]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Ginossar et al. 2016[33†]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hayward & Madill 2003[34]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Hebert et al. 2010[35]	Y	Y	Y	Y	Y	Y	Y	N	N	U	Y	Y
Hyde & White 2010[36]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Irving et al. 2012[37]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Jacob Arriola, Perryman & Doldren 2005[38]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Jacob Arriola et al. 2007[39]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Jernigan et al. 2013[40]	Y	Y	N	Y	Y	U	Y	N	Y	Y	Y	Y
Kim, Elliott & Hyde 2004[41]	Y	Y	N	N	Y	Y	Y	N	Y	Y	Y	Y
Krupic et al. 2018a[42]	Y	Y	N	Y	Y	N	Y	N	Y	Y	Y	Y

Krupic et al. 2018b[43]	Y	Y	N	Y	Y	N	Y	N	Y	Y	Y	Y
Krupic, Sayed-Noor & Fatahi 2017[44]	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Lauri 2009[45]	Y	Y	N	Y	Y	Y	Y	N	N	U	Y	Y
Li et al. 2018[46‡]	Y	Y	Y	Y	Y	U	Y	N	N	N	Y	Y
Liu et al. 2015[47]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Moloney & Walker 2002[48]	Y	Y	N	Y	Y	Y	Y	N	N	Y	Y	Y
Molzahn et al. 2004[49]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Molzahn et al. 2005a[50]	Y	Y	N	N	Y	Y	Y	N	Y	Y	Y	Y
Molzahn et al. 2005b[51]	N	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Morgan et al. 2008[52]	N	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Morgan, Mayblin & Jones 2008[53]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Nguyen et al. 2018[54†]	Y	Y	N	Y	Y	Y	N	N	N	N	Y	Y
Nizza, Britton, & Smith 2014[55]	Y	Y	N	Y	Y	N	Y	N	Y	Y	Y	Y
Noopur et al. 2018[56†]	Y	N	Y	N	N	Y	N	N	N	N	Y	Y
Olender et al. 2010[57†]	Y	Y	Y	Y	Y	U	N	N	N	N	Y	Y
Ozkan, Baykara-Acar, & Acar 2015[58]	Y	Y	N	Y	Y	N	Y	N	Y	Y	Y	Y
Padoan et al. 2016[59]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y

Peters et al. 1996[60]	Y	Y	N	N	Y	N	Y	N	N	N	Y	Y
Phillipson et al. 2015[61]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Quick et al. 2012[62]	Y	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y
Ralph et al. 2016[63]	Y	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y
Randhawa 1998[64]	Y	Y	N	N	Y	Y	Y	N	Y	Y	Y	Y
Sharp & Randhawa 2014[65]	Y	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y
Sharp & Randhawa 2016[66]	N	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y
Sherry, Tremblay, & Laizner 2013[67]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Sieblink et al. 2011[68†]	Y	Y	Y	Y	Y	Y	N	N	Y	N	Y	Y
Starzomski & Curtis 2011[69]	N	Y	N	Y	Y	N	N	N	Y	N	Y	Y
Thompson 1994[70]	N	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y
Vincent, Anker, & Feeley 2011[71]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Walker et al. 2018[72]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Williamson et al. 2017[74]	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Williamson, Bigman, & Quick 2018[73]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Wittig 2001[75]	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wong & Chow 2016[76]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Wong 2010a[77]	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Wong 2010b[78]	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Yeun, Kwan, & Yin 2014[79]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y

Yin et al. 2016[80]	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y

Note. The numbers in each column correspond to the items in the adapted CASP checklist (see Appendix D). Y = yes, N = no, U = unsure

[†]Survey-based study

[‡]Interview results were reported secondary to trial protocol

Appendix F: Presentation of Study Characteristics

Table 6. Summary of study characteristics

Author and Year	Outcomes Studied	Data Collection Method	Study Region	Study Population	Sample Size	% Female	Study Aims
Albright et al. 2005[11]	Registration and donation	Focus group	USA (Hawaii)	Filipino residents (student + adult populations)	57	73.7	Identify cultural/religious factors influencing their decision, willingness to discuss with family.
Albright et al. 2010[12]	Registration and donation	Focus group	USA (Hawaii)	Asian American or Pacific Island adolescents	68	43	Address research gap of ethnic minority youth's issues relating to designation of organ donor status and discussion with family.
Alkhawari, Stimson & Warrens 2005[13]	Donation	Interview and focus group	UK	Muslim Indo-Asians in UK	141	29.1	Understand the prevailing attitudes toward organ donation in the U.K. Indo-Asian Muslim community with a view to informing public policy initiatives.
Bharambe et al. 2015[14]	Registration and Donation	Survey	India	General population	41	34.1	Assess the knowledge and attitude of the people living in an urban city in India towards organ and body donation.
Bhengu & Uys 2003[15]	Donation	Interview	South Africa	Zulu religious leaders, traditional healers and community members	48	Not reported	Determine the extent to which the Zulu structural norms and social structure influence an individual's decision to donate an organ or to undergo a transplant.
Brown 2012[16]	Registration and Donation	Survey	USA	African Americans	55	Not reported	Test the theory of reluctance to explore if each of the five areas of reluctance remains the primary reasons why African Americans are hesitant to donate organs.

Chen et al. 2014[17]	Donation	Interview	Taiwan	Alishan Tsou tribe (Indigenous)	30	53.3	Explore hindering factors and suggestions related to organ donation for good dying from Taiwan Alishan Tsou's own perspective.
D'Alessandro, Peltier, & Dahl 2012[18]	Registration and donation	Interview and focus group	USA	Students	265	Not reported	Propose a conceptual model of how college students, and particularly those in student organizations, can be social media catalysts for viral communications designed to motivate others to learn about the need of organ donation and to become organ donors.
Davis & Randhawa 2006[19]	Donation	Focus group	UK	Black Caribbean and Black African population	120	Not reported	Examine the issues pertinent to organ donation, one of which was the influence of religion, in a cross-section of the Black African and Black Caribbean population of Lambeth, Southwark, and Lewisham.
Davison & Jhangri 2014[20]	Donation	Interview	Canada	Canadian First Nations	21	Not reported	Describe knowledge and attitudes toward organ donation and transplantation among First Nations people and explore beliefs that influence their decisions about organ donation and transplantation.
Denvir & Pomerantz 2009[21]	Registration and donation	Family discussion and interview	USA	Students and their families	117	Not reported	Describe and illustrate the varied understandings that people express and the assumptions that they appear to hold when they discuss the possibility of receiving less-than-optimal care, and to enumerate the kinds of reasoning and arguments with which people may counter or overcome a concern about receiving less-than-optimal care.

Downing & Jones 2010[22]	Registration and donation	Focus Group	USA	Adults aged 50-70 years	20	Not reported	Identify barriers to organ donation among older adults to inform educational strategies.
Downing & Jones 2018[23]	Registration and donation	Focus group	USA	Adults aged 50-70 years	198	67	Identify turning points (Aha! moments) wherein a change of opinion regarding organ donation and registration is expressed.
DuBay et al. 2014[24]	Registration and donation	Focus group	USA	African Americans	87	75	Identify factors associated with African Americans choosing to become registered organ donors.
DuBay et al. 2017[25]	Registration and donation	Focus group	USA	African Americans	100	Registered: 75 Unregistered : 66	Identify the personal, behavioral, and environmental factors that influence motivation and result in a decision to become or to not become a registered organ donor among African American adults who visited the Alabama DMV in the past 3 months.
Dunleavy 2013[26]	Registration and donation	Focus group	USA	Haitian immigrants	29	46	Identify culture-specific barriers to organ donation consent.
Exley et al. 1996[27]	Registration and donation	Interview and focus group	UK	Sikh population	22	59.1	Assess public opinion and perceptions within the Sikh community in Coventry regarding the issue of organ donation.
Fahrenwald & Stabnow 2005[28]	Donation	Interview	USA	Reservation-dwelling Indigenous Americans (Lakota tribe)	21	71.4	Discover the sociocultural patterns that influence intentions and decisions about organ and tissue donation among AI adults living on the Pine Ridge Reservation in South Dakota.
Feeley & Servoss 2005[29]	Registration and donation	Survey	USA	Students	502	Not reported	Gain a better understanding of college students' reasons for low signing rates and these same students' intentions to sign in the near future.

Feeley et al. 2014[30]	Registration and donation	Survey	USA	General population	1325	49.7	Provide a clear estimate of public sentiment toward donor registration by implementing a point-of-decision-making survey at DMV offices in New York state.
Frates & Bohrer 2002[31]	Donation	Family interview	USA	Hispanic families	21	57.1	Not clearly outlined.
Gauher et al. 2013[32]	Donation	Interview and focus group	UK	Indian and Pakistani youth aged 18-25 years	58	Not reported	Study the factors influencing the attitudes toward organ donation among a younger (age 18–25) generation of UK educated Indians and Pakistanis.
Ginossar et al. 2016[33]	Registration and donation	Survey	USA	Students and community members	602	55.8	Examine the relationship among ethnicity, religious affiliation, and demographic factors and self-reported status as a registered organ donor, as well as objections to deceased organ donation in a sample of young adults in New Mexico.
Hayward & Madill 2003[34]	Registration and donation	Interview	UK	Pakistani + Caucasian community members	27	51.9	Explore the meanings of organ donation, with particular emphasis on donating eyes and hearts, comparing people across gender and across two ethnic groups.
Hebert et al. 2010[35]	Donation	Focus group	USA	Chinese Americans	Not reported	Not reported	Assess the change, if any, in the number of Chinese Americans living in New York City choosing to join the New York State Organ and Tissue Registry, or expressing a desire to become an organ donor at their death and communicating these wishes to family members.

Hyde & White 2010[36]	Donation	Focus group	Australia	Students and community members	Students: 30 Community members: 24	59.3	Provide a current comparison of Australian beliefs about posthumous donation and living donation and preferences for the recipients of organ transplants. Explore organ recipient preferences and the perceived advantages and disadvantages of posthumous donation and living donation, consider whether the opinions of other people or groups may impact on individuals' donation beliefs, and examine the perceived factors that may prevent (i.e., barriers) and encourage (i.e., motivators) people's organ donation for both types of donation.
Irving et al. 2012[37]	Registration and donation	Focus group	Australia	General population	114	51	Elicit Australian community attitudes and perspectives on deceased organ donation, specifically the decision to donate and the current donation consent system, in order to better understand the organ donation decision process and inform strategies to improve organ donation awareness, thereby potentially increasing donation rates.
Jacob Arriola, Perryman & Doldren 2005[38]	Registration and donation	Focus group	USA	African American pastors/clergy and their families	Clergy: 26 Family: 42	Clergy: 54 Family: 81	Further the understanding of how respondents' experiences and values contribute to supportive attitudes toward organ and tissue donation.
Jacob Arriola et al. 2007[39]	Donation	Focus Group	USA	African American clergy	26	53.8	Understand attitudes and beliefs surrounding donation decision-

							making; messages that African American clergy deliver to their parishioners about donation decision-making; and how African American clergy perceive the role of the church and pastor in donation decision-making.
Jernigan et al. 2013[40]	Donation	Focus group	USA	Alaskan and other Native American citizens	99	Not reported	Characterize the knowledge, cultural beliefs, and behaviors of Native American college students that influence individual-level decisions to become an organ donor.
Kim, Elliott & Hyde 2004[41]	Donation	Interview	South Korea	Hospital Staff	9	Not reported	Identify the sociocultural factors that influence attitudes of Korean health professionals toward organ donation and transplantation from brain-dead patients.
Krupic et al. 2018a[42]	Donation	Interview	Sweden	Swedish female immigrants	39	100	Explore and elucidate women's knowledge about and willingness to take part in organ donation and to assess if their opinion was changed by coming to Sweden.
Krupic et al. 2018b[43]	Registration and donation	Interview	Sweden	Muslims in Sweden	27	44.4	Elucidate whether age, gender and religion influence decision-making about organ donation in religious Muslims living in Sweden.
Krupic, Sayed-Noor & Fatahi 2017[44]	Donation	Focus group	Sweden	Swedish Immgrant populations	32	50	Elucidate the factors that influence decision-making about organ donation in religious immigrants living in Sweden.
Lauri 2009[45]	Registration and donation	Focus group	Malta	General population	57	Not reported	Examine how one looks upon organ donation and how one looks upon one's own body.

Li et al. 2018[46]	Registration and donation	Interviews	Canada	General Population	20	Not reported	Inform the development of this intervention [RegisterNow-1 trial], and identify theory-based barriers and enablers to organ donation registration.
Liu et al. 2015[47]	Registration and donation	Interview	China	Students	9	55.6	Explore students' beliefs regarding posthumous organ donation in order to provide a basis for improving their awareness and to increase their willingness to donate organs.
Moloney & Walker 2002[48]	Donation	Focus group	Australia	General population	29	48.3	Investigate the meaning of organ donation and transplantation within society.
Molzahn et al. 2004[49]	Donation	Interview	Canada	Coast Salish peoples in Canada	14	57.1	Develop some understanding of the values and beliefs of Coast Salish people related to organ donation, in order to generate more questions and eventually equip nurses to provide more appropriate care.
Molzahn et al. 2005a[50]	Registration and donation	Interview	Canada	Chinese Canadians	Interview: 15 Focus group: 24	Interview: 66.7 Focus group: 66.7	Gain further understanding of values and beliefs to increase the likelihood that donor request processes are more culturally sensitive and that people who are willing to donate have the opportunity to do so.
Molzahn et al. 2005b[51]	Registration and donation	Interview and focus group	Canada	Indian Canadians	Interview: 15 Focus group: 25	Interview: 46.7 Focus group: 76	Not clearly outlined.
Morgan et al. 2008[52]	Registration and donation	Pair-dyad interview	USA	American families	156 (78 dyads)	62.6	Not clearly outlined.

Morgan, Mayblin & Jones 2008[53]	Registration and donation	Interview	UK	Carribean community members	14	64.3	Understand the ways in which the self-identity and experiences of a section of the Caribbean community living in a multi-cultural area of south London, shaped their perceptions and attitudes to kidney donor registration, and may explain low rates of deceased donation.
Nguyen et al. 2018[54]	Donation	Survey	USA	People living with HIV	114	47.8	Learn more from people living with HIV regarding knowledge, attitudes, and beliefs regarding HIV donor/receiver transplants, focusing primarily on their willingness to donate organs.
Nizza, Britton, & Smith 2014[55]	Registration and donation	Interview	UK	Caucasian females	4	100	Investigate the individual experience, motives and understandings of a small homogeneous group of non-donors, to shed more light on how cognitive and affective factors interact and relate to the experience and choices of individuals and how individuals make sense of, process and deal with the complex and tensile issues around organ donation.
Noopur et al. 2018[56]	Donation	Survey	India	People in need of corneal donation + matched controls	Cases: 442 Controls: 884	53.3	Determine the difference, if any, in the status of awareness about eye donation between cases needing corneal transplantation for corneal diseases and controls.
Olender et al. 2010[57]	Donation	Survey	Poland	Students	441	Not reported	Assess awareness of and approaches to tissue donation and transplantation among selected social groups and their

							possible needs for education in this respect.
Ozkan, Baykara-Acar, & Acar 2015[58]	Registration and donation	Focus group	Turkey	Students	29	61.5	Identify individual and social factors related to negative attitudes regarding organ donation and transplant of first- and second-year undergraduate students in midwifery, nursing, and social work.
Padoan et al. 2016[59]	Donation	Interview	Brazil	People treated for bipolar and their family	Bipolar patients: 12 Family: 6	66.7	Discover, through in-depth interviews, the opinions, attitudes, beliefs and feelings aroused in people with bipolar disorder and their families in relation to organ and tissue donation.
Peters et al. 1996[60]	Registration and donation	Focus group	USA	General population	102	Not reported	Explore the reasons that families give or refuse to give permission for organ recovery or participate in the societal endeavor of donation.
Phillipson et al. 2015[61]	Registration and donation	Focus group	Australia	Macedonian, Serbian, Greek orthodox community members in Australia	98	63	Understand current perspectives on organ and tissue donation as well as identifying barriers within the communities to seeking information, registering as a potential donor, and importantly, family discussion of organ and tissue donation wishes.
Quick et al. 2012[62]	Registration and donation	Focus group	USA	High school students	98	50	Understand 18-year-olds' awareness of the severity of the organ shortage and perceived susceptibility to this shortage; the benefits of and barriers to joining the first-person consent registry (FPCR); perceived confidence in their ability to join the Registry; and influential cues to action to promote the FPCR.

Ralph et al. 2016[63]	Registration and donation	Focus group	Australia	Arabic-speaking population in Australia	53	55	Describe the attitudes and beliefs of this population towards deceased organ donation and to assist development of education and other strategies and policies that might potentially lead to an overall increase in deceased organ donation rates.
Randhawa 1998[64]	Registration and donation	Interview and focus group	UK	Asian population (Hindu, Sikh, Muslim) in UK	64	Not reported	Examine the issues pertinent to organ donation, one of which was the influence of religion, in a cross-section of the Asian population in Luton.
Sharp & Randhawa 2014[65]	Registration and donation	Interview	UK	Polish immigrants in UK	31	71	Examine the knowledge and attitudes of the UK Polish population toward deceased organ donation.
Sharp & Randhawa 2016[66†]	Donation	Interview and focus group	UK	Polish immigrants in UK	31	Not reported	Not clearly outlined.
Sherry, Tremblay, & Laizner 2013[67]	Registration and donation	Focus group	Canada	Canadian Haitian immigrants	24	Not reported	Gain an understanding of the knowledge, attitudes and beliefs toward organ and tissue donation among the adult Haitian population in the greater Montreal area
Sieblink et al. 2011[68]	Registration and donation	Survey	Netherlands	Adolescents aged 12-15	2016	80.6	Investigate whether children had heard about organ donation, and what their opinions were on donation.
Starzomski & Curtis 2011[69]	Donation	Focus groups	Canada	Chinese Canadians	44	Not reported	Not clearly outlined.
Thompson 1994[70]	Registration and donation	Focus group	USA	African Americans	56	67.3	Not clearly outlined.
Vincent, Anker, & Feeley 2011[71]	Donation	Interview	USA	Religious leaders	59	Not reported	Supplement existing literature on religion and organ donation, as well as to determine if religious leaders (RLs)

							are adequately prepared to act as opinion leaders for donation, and answer the following research questions: 1. What do RLs report as their religious organization's position on organ donation? 2. What are RLs' personal perspectives and experiences with organ donation? 3. Where do RLs learn about organ donation and do they find such knowledge sufficient for communicating with others? 4. What are RLs' prior communication experiences with the topic of organ donation?
Walker et al. 2018[72]	Donation	Interviews	UK	Palliative care patients	9	55.6	Understand the views and feelings of patients in palliative care settings towards corneal donation, and to explore patients' opinions regarding the timing of discussions about corneal donation.
Williamson et al. 2017[74]	Registration and donation	Focus group	USA	African Americans	62	83.9	Understand the salient beliefs influencing African-Americans decision to (not) enroll in their state's organ donor registry..
Williamson, Bigman, & Quick 2018[73†]	Donation	Focus group	USA	African Americans	62	83.9	Examine African Americans' medical mistrust beliefs related to organ donation, identifying types of medical mistrust beliefs, and the role the

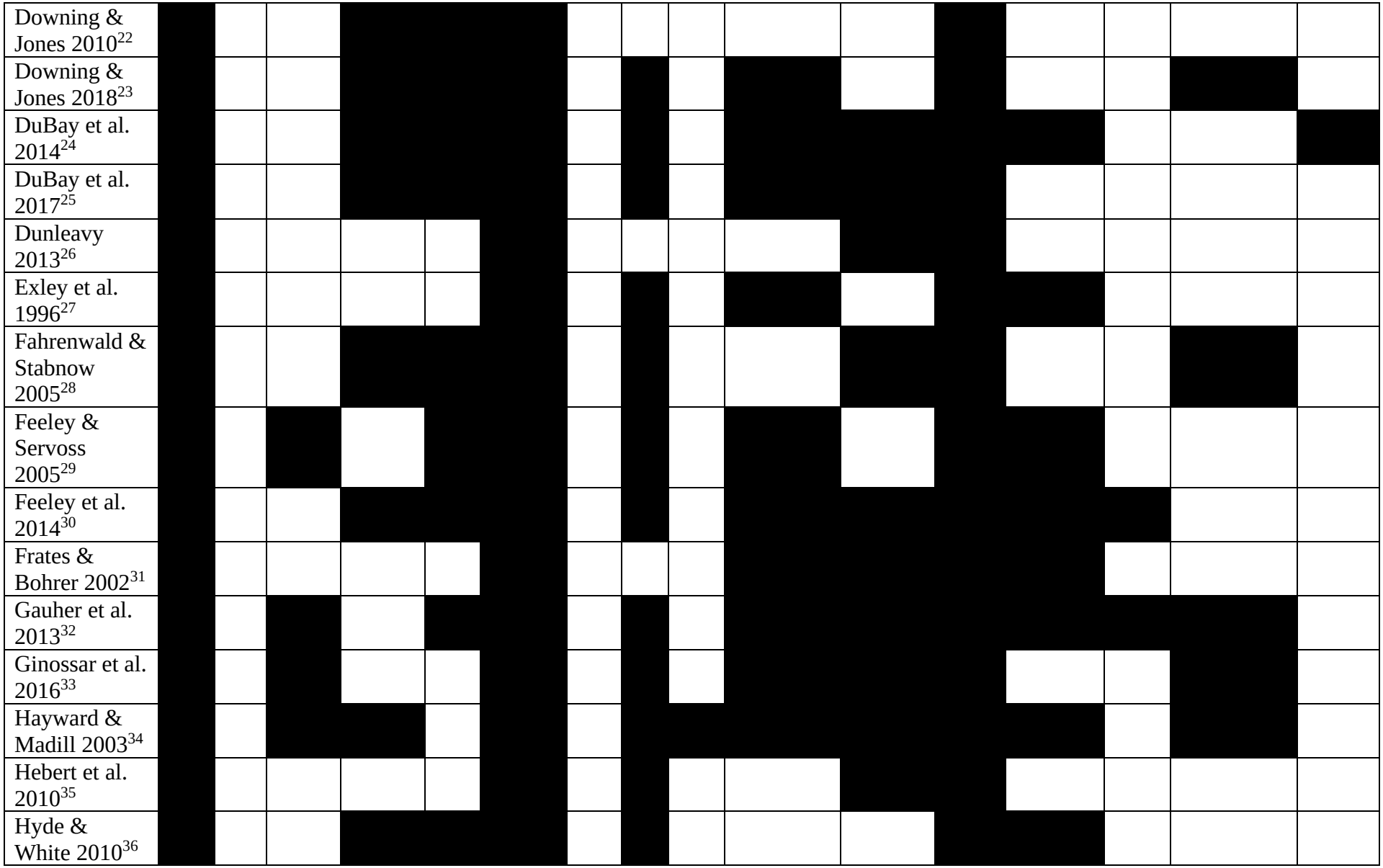
							communication environment plays in those beliefs.
Wittig 2001[75]	Donation	Interview	USA	African American women	10	100	Discover the culture care beliefs, meanings, and practices of selected African American women regarding organ donation.
Wong & Chow 2016[76]	Registration and donation	Focus group	China	Students	19	52.6	Explore the in-depth behavioral and normative beliefs among the students in Hong Kong through a qualitative approach.
Wong 2010a[77]	Registration and donation	Focus group	Malaysia	General population	105	55.2	Identify factors limiting organ donation among our diverse ethnic community to provide insights into culturally appropriate strategies to promote organ donation.
Wong 2010b[78†]	Registration and donation	Focus group	Malaysia	General population	105	55.2	Identify the areas of educational needs and to provide insight into how to generate a culturally sensitive public education campaign.
Yeun, Kwan, & Yin 2014[79]	Registration and donation	Interview	South Korea	General population	13	61.5	Identify the hidden patterns of behavior leading toward the decision to donate organs in the Korean cultural context
Yin et al. 2016[80]	Registration and donation	Interview	China	Chinese registered organ donors	34	50	Contribute to future interventions to promote the deceased organ donation in China.

Note. [†]Study uses same sample as previous study by same authors in previous years, but reports different barriers and enablers

Appendix G. TDF Domain Representation for Individual Studies

Table 7. Summary of TDF domain representation within individual studies.

Author and Year	1.K	2.S	3.SRI	4.BCa.	5.O	6.BCo.	7.R	8.I	9.G	10.MADP	11.ECR	12.SI	13.Emo.	14.N	15. NBNE	16.Ot.
Albright et al. 2005[11]	■		■	■	■	■		■		■		■	■		■	
Albright et al. 2010[12]	■					■						■				
Alkhawari, Stimson & Warrens 2005[13]	■		■		■	■		■		■	■	■			■	
Bharambe et al. 2015[14]				■	■	■							■		■	
Bhengu & Uys 2003[15]	■		■			■		■		■		■	■		■	■
Brown 2012[16]			■			■				■		■		■		
Chen et al. 2014[17]	■			■		■						■				
D'Alessandro, Peltier, & Dahl 2012[18]	■			■		■		■	■	■	■	■	■			
Davis & Randhawa 2006[19]	■					■				■	■	■	■		■	
Davison & Jhangri 2014[20]	■		■	■	■	■			■	■		■	■			
Denvir & Pomerantz 2009[21]	■		■			■		■		■	■	■	■		■	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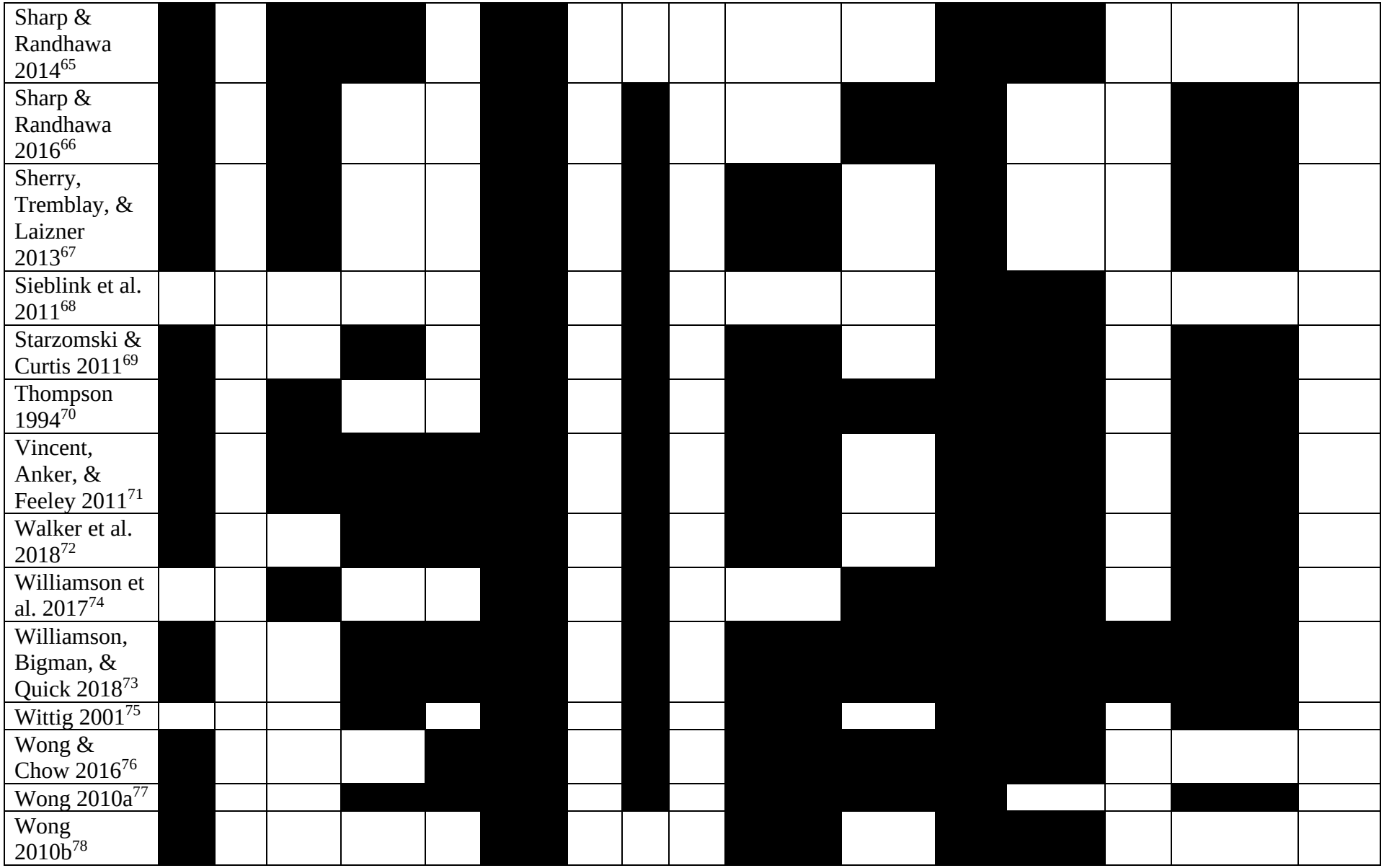
Downing & Jones 2018[23]
DuBay et al. 2014[24]
DuBay et al. 2017[25]
Dunleavy 2013[26]
Exley et al. 1996[27]
Fahrenwald & Stabnow 2005[28]
Feeley & Servoss 2005[29]
Feeley et al. 2014[30]
Frates & Bohrer 2002[31]
Gauher et al. 2013[32]
Ginossar et al. 2016[33]
Hayward & Madill 2003[34]
Hebert et al. 2010[35]
Hyde & White 2010[36]

Irving et al. 2012[37]	■			■	■	■		■		■	■	■	■	■	■		■	
Jacob Arriola, Perryman & Doldren 2005[38]	■		■	■	■	■	■		■	■	■	■	■	■	■	■	■	
Jacob Arriola et al. 2007[39]	■		■	■	■	■		■		■	■	■	■	■	■		■	
Jernigan et al. 2013[40]	■	■		■		■		■		■	■	■			■		■	
Kim, Elliott & Hyde 2004[41]						■						■		■				
Krupic et al. 2018a[42]	■		■			■		■		■	■	■	■		■		■	
Krupic et al. 2018b[43]	■		■			■		■		■		■		■				
Krupic, Sayed-Noor & Fatahi 2017[44]	■					■		■		■	■	■	■	■				
Lauri 2009[45]			■		■						■	■	■	■				
Li et al. 2018[46]	■	■	■	■	■	■		■		■	■	■	■	■				
Liu et al. 2015[47]	■		■	■	■	■		■		■	■	■	■				■	
Moloney & Walker 2002[48]				■	■	■		■				■	■	■			■	
Molzahn et al. 2004[49]	■					■		■		■	■	■	■	■			■	
Molzahn et al. 2005a[50]	■					■				■		■	■	■			■	

Molzahn et al. 2005b[51]																		
Morgan et al. 2008[52]																		
Morgan, Mayblin & Jones 2008[53]																		
Nguyen et al. 2018[54]																		
Nizza, Britton, & Smith 2014[55]																		
Noopur et al. 2018[56]																		
Olender et al. 2010[57]																		
Ozkan, Baykara-Acar, & Acar 2015[58]																		
Padoan et al. 2016[59]																		
Peters et al. 1996[60]																		
Phillipson et al. 2015[61]																		
Quick et al. 2012[62]																		
Ralph et al. 2016[63]																		
Randhawa 1998[64]																		


Sharp & Randhawa 2014[65]
Sharp & Randhawa 2016[66]
Sherry, Tremblay, & Laizner 2013[67]
Sieblink et al. 2011[68]
Starzomski & Curtis 2011[69]
Thompson 1994[70]
Vincent, Anker, & Feeley 2011[71]
Walker et al. 2018[72]
Williamson et al. 2017[74]
Williamson, Bigman, & Quick 2018[73]
Wittig 2001[75]
Wong & Chow 2016[76]
Wong 2010a[77]
Wong 2010b[78]

Yeun, Kwan, & Yin 2014[79]	■		■			■		■		■		■	■			
Yin et al. 2016[80]	■		■	■	■	■		■			■	■	■	■	■	■
Total n	58	2	31	35	35	70	1	51	3	47	39	68	49	11	41	3

Note. K = *knowledge*, S = *skills*, SRI = *social/professional role & identity*, BCa. = *beliefs about capabilities*, O = *optimism*, BCo. = *beliefs about consequences*, R = *reinforcement*, I = *intentions*, G = *goals*, MADP = *memory, attention & decision processes*, ECR = *environmental context and resources*, SI = *social influences*, Emo. = *emotion*, N = *nature of the behaviour*, NBNE = *not a barrier/enabler to individual*, Ot. = *other*

Chapter 4: General Discussion and Conclusions

The impetus for this thesis came from the substantial, unmet need for life-saving organ transplantation in Canada, and worldwide, and the potential that increased deceased organ donation registration has for addressing this need. Interventions to support increased registration may benefit from drawing upon what is known about factors related to organ donation registration, and from insights from theories of behaviour that explain how individuals do or do not engage in health behaviours. Given the broad survey-based quantitative literature and interview/focus group based qualitative literature on such factors, an organizing framework seemed necessary to bring coherence and clear actionable next steps for developing new interventions to support donation registration. I drew on theories of behaviour as they can provide the framework for synthesizing factors associated with organ donation registration, and help clarify the functional components of interventions so that a cumulative evidence base could be established and built upon. Therefore, organ donation registration interventions may benefit from the use of behaviour theories.

In this thesis, I first aimed to identify which behaviour theories have been applied to organ donation registration to date, and to determine the amount of variance in registration behaviour and intention that are explained by these theories and their constructs. I then aimed to systematically identify the barriers/enablers to organ donation registration reported in the qualitative literature, and then code them to Theoretical Domain Framework (TDF) domains.

In this chapter, I summarize key findings from each study and aim to triangulate the findings to highlight overlaps and gaps between both literatures, to further inform fit-for-purpose interventions, and to help support more Canadians to register their wishes for deceased organ donation.

Overall Summary of Findings from Study 1 (Chapter 2)

Chapter 2 reports a quantitative systematic review with meta-analysis that identified 32 studies with 16,289 participants in total. This review showed that to date, 9 theories of behaviour (and 82 constructs within them) have been applied to understand variance in organ donation registration intention and behaviour. This literature was dominated by use of the Theory of Planned Behaviour/Theory of Reasoned Action (TPB/TRA); however, we also identified a few instances of use of a more behaviour-specific theory – the Organ Donation Model – that incorporated constructs specific to organ donation registration such as bodily integrity, medical mistrust, and 'ick' factors. When all behaviour theories were pooled, their constructs explained a medium amount of variance in registration behaviour ($R^2 = 0.19$), and a large amount of variance in intention ($R^2 = 0.51$).

All constructs within the theories identified in the review focused more on understanding motivation (intention) to register than registration per se, and as a result, many did not account for post-intentional factors to understand how people act on their good intentions to register. This could explain why the behaviour theories accounted for much more variance in intention than behaviour. Furthermore, the majority of the studies that measured behaviour did so cross-sectionally (based on current registration status) or by providing the opportunity for registration

immediately after the survey, both of which may have introduced bias in their models predicting registration behaviour.

We gained a comprehensive understanding of the behaviour theories currently applied to organ donation registration, and the motivational constructs that are associated with intention to register and actual registration behaviour in our quantitative review.

Overall Summary of Findings from Study 2 (Chapter 3)

Chapter 3 reports a theory-based qualitative meta-synthesis to identify barriers and enablers to organ donation registration, drawing upon more in-depth data from studies involving interviews, focus groups or open text responses within surveys. To bring some theoretical coherence to the literature, we mapped the identified barriers/enablers to domains from the TDF. In this meta-synthesis, we identified a total of 70 studies involving at least 9527 participants, which focused heavily on ethnic/religious minority populations, as well as 14 barriers (with 34 subthemes) and 11 enablers (with 24 subthemes) to registration. The barriers/enablers were most commonly mapped to *beliefs about consequences, social influences,* and *knowledge* domains from the TDF. The most commonly reported barriers were 'bodily integrity', 'religious, traditional, and cultural influence', and 'mistrust', while the most commonly reported enablers were 'potential organ recipient influence', 'positive perceptions of organ donation and registration', and 'perceived capability to register'. This compilation of barriers/enablers is likely the most comprehensive meta-synthesis conducted on organ donation registration to date.

The vast majority of studies described barriers/enablers pertaining to beliefs about organ donation, rather than being specific to the act of registration though they are closely interrelated. Furthermore, similar to the quantitative review, the literature was primarily concerned with the motivational barriers to organ donation, rather than examining factors influencing registration after the formation of intention. There remain opportunities to better understand factors that may get in the way of translating motivation into action (i.e. the intention-behaviour gap).

Comparison of Findings between Reviews

Main Correlates of Registration Intention and Behaviour Identified by Quantitative Review

Based on the quantitative review, the constructs with the largest correlations with registration behaviour are intention (TPB/TRA; r = 0.41, Triangle Model of Responsibility; r = 0.77), connection (Triangle Model of Responsibility; r = 0.54), obligation (Triangle Model of Responsibility; r = 0.53), attitude (TBP/TRA; r = 0.50-0.67, Organ Donation Model; r = 0.23), and organ donation-specific constructs specified by the Organ Donation Model (e.g. "ick" factors; r = -0.31, and bodily integrity; r = -0.31). Evidence from a pair of TPB/TRA-based studies in the quantitative review point to specific attitudes to organ donation registration had larger correlations than general attitudes to organ donation[1].

There was much more data available for meta-analyses with organ donation registration intention than behaviour, and our meta-analyses highlighted the importance of attitude (TPB/TRA; r = 0.59), subjective norm (TPB/TRA; r = 0.57), perceived behavioural control (PBC) (TPB/TRA; r = 0.50), moral norm (expanded TPB/TRA; r = 0.62), self-identity (expanded TPB/TRA; r =

0.61), connection (Triangle Model of Responsibility; r = 0.56), and obligation (Triangle Model of Responsibility; r = 0.62).

There may be other important behaviour theory-based correlates of organ donation registration intention and behaviour, however, based on the available evidence synthesized in Chapter 2, we can conclude that these are the most consistently reported and strongest correlates of intention to register and actual registration.

Mapping Theoretical Constructs to TDF Domains

To determine to what extent qualitative factors described in context are captured in the theories of behaviour tested in the quantitative literature to date, two independent coders (JB and Dr. Jacob Crawshaw) mapped all 82 theoretical constructs identified in the meta-analysis from Chapter 2 to TDF domains, using the same coding scheme from the qualitative meta-synthesis in Chapter 3. Figure 1 shows the representation of TDF domains within each theory identified.

TDF Representation between Reviews

Upon mapping the theoretical constructs to the TDF, the behaviour theories identified in the quantitative review primarily captured the *social/professional role & identity, beliefs about capabilities, beliefs about consequences, intentions,* and *social influences domains.* The key (i.e. strongest) correlates of registration intention and behaviour were also captured by these domains. Similarly, the qualitative review had substantial representation for those domains as well. Both reviews had minimal representation for the *skills, goals,* and *reinforcement* domains. However, compared to the qualitative review, the *environmental context & resources; memory, attention & decision processes; emotion*; and *optimism* domains had less representation in the quantitative review.

When examining the quantitative review's coverage of TDF domains within constructs, it was clear that for the most part, many relevant beliefs identified in the qualitative review were not captured by the key correlates. For example, for constructs mapped to the *beliefs about capabilities* domain (e.g. PBC from the TPB/TRA), the beliefs surrounding the act of registration, from the difficulty in forming the decision to register, to the actual process of registration itself, were both well covered. However, beliefs surrounding one's ability to actually donate organs (e.g. 'perceived ineligibility' and 'do not need organs when dead'), which were frequently reported in the qualitative review were not covered within the quantitatively-tested constructs.

The *social influences* domain was captured by the subjective norm construct (TPB/TRA) in the quantitative review, any by many barriers/enablers in the qualitative review. The findings of both reviews point to the important influence of other people/parties in organ donation registration. For example, the subjective norm construct (TPB/TRA) primarily measured approval or disapproval towards organ donation from people close to the respondent (e.g. family, friends, religious groups), and if they would want them to register. The findings from the qualitative review supplement these measures by elucidating the specific beliefs underlying perceived approval/disapproval from these groups (e.g. 'preservation of body wholeness' barrier).

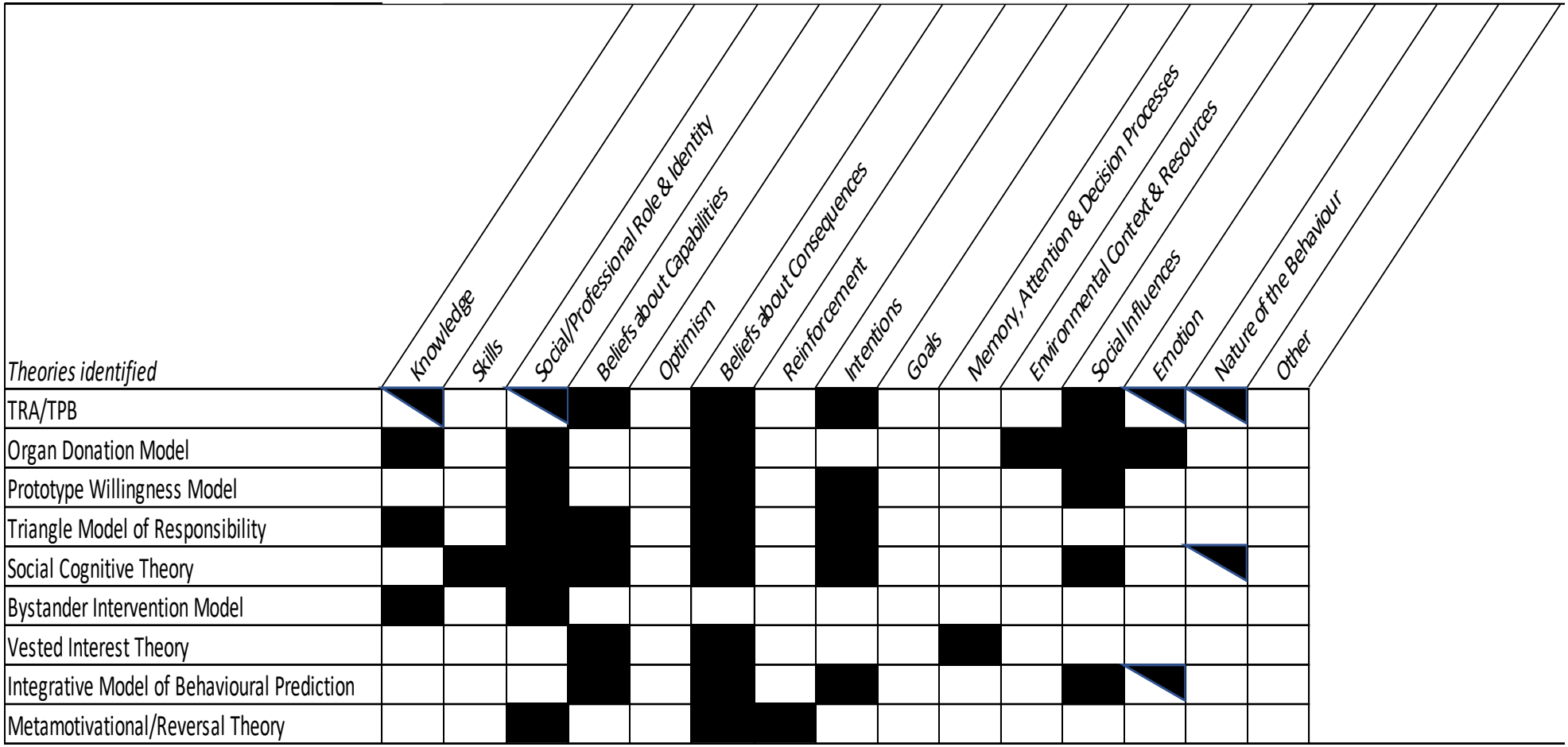


Figure 1. TDF domain representation within the behaviour theories identified in the quantitative review.
Note. Full shading indicates coverage of TDF domains by core constructs in each theory. Top-right shading indicates coverage due to additional constructs added to model.

Some of these religious beliefs were captured in the bodily integrity construct (Organ Donation Model), but the qualitative review also contributed additional barriers/enablers related to *social influences* that were not accounted for within key correlates, including the post-mortem customs that organ donation would interfere with, or the influence of the potential organ recipient (e.g. 'deserving/undeserving recipient').

Main correlates such as moral norm (expanded TPB/TRA), self-identity (expanded TPB/TRA), connection (Triangle Model of Responsibility), and obligation (Triangle Model of Responsibility) point to the influence of personal beliefs and feelings of association to/importance of organ donation registration. These constructs were all mapped to the *social/professional role & identity* domain. The themes captured by the *social/professional role & identity* domain in the qualitative review point to similar ideas. For example, the 'does not matter/apply to individual', 'against beliefs' barrier subthemes, 'personal experience with organ donation', 'benefits to recipient', and 'responsibility to give back to community' enabler subthemes all highlight the impact of one's personal beliefs, identity, and personal connection to organ donation on registration behaviour.

There were some differences in terms of the themes that each review contributed to the *social/professional role & identity* domain. The studies in the quantitative review measured these constructs by generally assessing whether participants felt "obligated to donate/register", or if "they were the type of person to donate/register"[2]. The findings from the qualitative review expand upon this by describing what specifically connects the person to organ donation, such as their identity/role within the community, through their own personal experience, and from their religious beliefs.

The attitude construct (TPB/TRA, Organ Donation Model) was one of the key correlates of both registration intention and behaviour, and was mapped to the *beliefs about consequences* domain. It measured participants' support for organ donation, and whether or not they thought organ donation was "good/bad", "worthless/worthwhile", among other attitudinal descriptions. The qualitative review contributed similar themes mapped to the *beliefs about consequences* domain with the 'positive perceptions of organ donation', and 'benefits to recipient' enabler themes, as well as the 'organ donation is wrong' barrier subtheme. However, the qualitative review elucidated many more themes related to *beliefs about consequences* that were not covered in the attitude construct. Some of these qualitatively-reported themes were covered by organ donation-specific constructs from the Organ Donation Model, such as medical mistrust, bodily integrity, "ick" factors, and "jinx" factors. However, the qualitative review added some additional depth to the *beliefs about consequences* domain, with themes describing the consequences to people other than the self such as 'harmful to recipient', 'onus of decision removed from family', and 'family comforted by decision to donate'. The key correlates were often operationalized to examine the consequences affecting the self, but many participants in the qualitative review emphasized the importance of consequences affecting others that enable/hinder their registration. Therefore, this is an opportunity for improvement in future quantitative studies.

Differences in Thematic Coverage between Quantitative and Qualitative Review

There were some barriers/enablers identified in the qualitative review that were minimally captured within the key correlates identified in the quantitative review, largely due to the lack of specificity with which the constructs were measured in the latter. While this may provide a more concise and summative measurement of attitudes towards organ donation registration, it provides limited information about the factors driving broad beliefs and attitudes towards organ donation that were identified in our qualitative review, such as bodily integrity, mistrust, religious beliefs/traditions, exposure to organ donation, and potential recipient factors.

Some constructs and theories had more coverage of barriers/enablers identified in the qualitative review, but were minimally tested in the quantitative literature. For example, the Organ Donation Model included various organ donation-specific constructs that readily covered more barriers/enablers than general measures of attitude or subjective norm. Additionally, the inclusion of behavioural beliefs (beliefs about the outcomes of the behaviour and evaluations of those outcomes), normative beliefs (beliefs about the expectations of others and motivation to adhere to these expectations), and control beliefs (beliefs about the factors that may enable or hinder performance of the behaviour, and how much power these factors are perceived to have) constructs allowed for some studies to investigate how various organ donation-specific beliefs were associated with intention to register within TPB/TRA-based studies. For example, in one study, the behavioural beliefs construct measured how likely participants thought certain disadvantages (e.g. receiving inadequate medical care) and advantages (prevent others from making difficult decision in place of self) were to occur if they registered for organ donation[3]. Although these belief-based measures allow for increased coverage of relevant barriers/enablers to registration, only 3 studies included them in their TPB/TRA-based studies[3-5].

General measures of constructs such as attitude, subjective norm, and PBC are certainly important in identifying key correlates of intention and behaviour to focus on for intervention development. The qualitative depth provides a helpful supplement to operationalize this key correlate when targeting it in future interventions. However, more specific measures, including belief-based measures, provide additional clarification of how relevant certain barriers/enablers to registration are to wider populations, and how much influence they actually have on registration behaviour and intention. Therefore, it is worthwhile to include general and specific measures of theoretical constructs in future quantitative research.

Additional Domains and Themes Identified in Qualitative Review

In addition to the *skills*, *goals*, and *reinforcement* TDF domains, the theories identified in the quantitative review had minimal representation of the *knowledge; environmental context & resources; memory, attention & decision processes; emotion;* and *optimism* TDF domains. The qualitative review highlighted various key barriers/enablers to registration mapped to these domains that could assist in identifying behaviour theories to test, enhance ones that have already been tested, and to inform factors to target in future registration-promoting interventions.

For example, it was clear in the qualitative review that factors mapped to the *environmental context & resources* domain such as ‘governmental mistrust’, ‘uncertainty regarding registration laws and regulation’, ‘limited access to registry’, and ‘physical registration environment’ were

important to participants in their consideration of organ donation registration. Similarly, the qualitative review highlighted the importance of barriers and enablers coded to the *memory, attention & decision processes* domain such as 'have not thought about it' (often unless prompted), and 'personal choice' in organ donation registration decisions.

One of the most important domains that was largely neglected by the quantitative literature was knowledge. Our qualitative review showed that knowledge and information about organ donation and registration is an important independent modifiable barrier to organ donation registration, from a behaviour change perspective, knowledge informs the attitudes and normative beliefs that people may hold. Knowledge and information were also the cornerstones of participants' suggested actions in the qualitative review, and are often the foundation of interventions to improve registration rates. Therefore, the lack of representation of *knowledge* and the other domains in the quantitative literature should be addressed in future studies.

Selecting Behaviour Theories for Organ Donation Registration

While 9 different theories have been quantitatively assessed for modifiable correlates of registration intention and behaviour in this literature to date, it is still not yet clear which theory is best applied to organ donation registration. As shown in Chapter 2, the behaviour theories (primarily the TPB/TRA) that have been applied to organ donation registration are able to explain a large amount of variance in intention, but may be limited in their ability to explain variance in behaviour, consistent with the wider literature examining the TPB/TRA[6,7]. These results suggest the presence of an intention-behaviour gap, where people form intentions, but do not translate them into behaviours[8]. The intention-behaviour gap in organ donation registration is not new, and is clear when the proportion of Canadians willing to register is compared to the proportion who are actually registered[9]. Some research examining organ donation registration has acknowledged this intention-behaviour gap, but opted to focus on constructs mediated by intention (e.g. attitude), rather than testing constructs that influence behaviour after the formation of intention[1,10]. As such, the literature should test more contemporary theories of behaviour that incorporate post-intentional factors.

Health Action Process Approach

While there are several different theories that account for post-intentional factors in behavioural prediction[11], the theory that is most often cited when discussing post-intentional processes in behaviour change is the Health Action Process Approach (HAPA)[12]. The HAPA proposes two separate phases of behaviour: motivational and volitional. The volitional phase includes action planning (planning how the behaviour will be performed) and coping planning (one anticipates barriers to behaviour and plans how to address them) as post-intentional constructs, while the motivational phase includes constructs such as outcome expectancies (beliefs about whether engaging in a given behaviour will result in desired outcomes), risk perception (beliefs regarding personal risk or susceptibility).

In other health behaviours such as cardiac rehabilitation[14] and smoking cessation[15], the HAPA's post-intentional constructs have explained additional variance in behaviour to its motivational constructs, and has mediated the relationship between intention and behaviour. According to results from a recent meta-analysis, across various health behaviours, the use of the HAPA has explained as much as 28% of variance in behaviour[16]. Even adding post-intentional constructs like action planning to the TPB/TRA has been shown to explain additional, unique variance in behaviour[17]. Suffice to say, there is evidence to suggest that the use of theories that include post-intentional factors may result in increased behavioural prediction, compared to theories that focus only on motivational factors.

The HAPA is also the only theory incorporating post-intentional factors, to our knowledge, that has been applied to organ donation registration. A randomized controlled trial (RCT) by Hyde & White used the HAPA to develop a volitional intervention using action planning and coping planning[18]. The volitional intervention was tested alongside a motivational intervention (using a TPB-based framework to target intention), a control intervention, and a combined motivational-volitional intervention[18]. The volitional intervention resulted in higher registration rates (25%) than the motivational (14%) and control (16%) interventions[18]. However, the greatest effect was seen in the motivational-volitional intervention group (42%)[18], suggesting that targeting both motivation and volition is the most effective strategy for increasing registration rates. Although this study was unable to examine the effects of action planning and coping planning separately, and was underpowered, it points to the potential of targeting post-intentional factors in addition to motivational factors in research and intervention development.

Use of Bespoke Theories

Although use of bespoke theories such as the Organ Donation Model allows for the inclusion of factors specific to the behaviour of organ donation registration, it does not necessarily allow for progression alongside the contemporary behaviour change literature. The inherent strengths of bespoke theories lie in its specificity to the behaviour, and its ability to provide information that is readily translatable to intervention development (e.g. which attitudes/fears to specifically focus on improving or addressing). However, it is important that these bespoke theories do not remain static, and keep pace with contemporary literature. Adopting a process of creating different versions of bespoke theories that evolve over time and update the theory based on new evidence, similar to the TDF, could prevent bespoke theories from stagnating.

Implications for Future Research

Specificity to the Behaviour of Interest

It was clear in the findings of both reviews that the organ donation registration literature tends to focus more on intention to donate organs and intention to register, rather than organ donation registration behaviour. This is especially true for the qualitative review, where we identified few barriers or enablers exclusively applicable to organ donation registration per se. The majority of barriers/enablers to organ donation act as motivational barriers and enablers to registration. For example, fears of possible mutilation in the organ donation process directly affect one's motivation, as shown in our qualitative review. Although inherently tied to organ donation,

registration itself has unique barriers/enablers influencing it. These unique barriers and enablers, unfortunately, have largely been neglected by researchers in the qualitative literature, because the focus has been on generally understanding the factors related to organ donation, rather than those specific to registration.

Meanwhile in the quantitative review, the theoretical constructs were often applied specifically to registration, however, the majority of the studies focused on cross-sectional measurement of intention to register. Relatively few studies focused on registration behaviour, consistent with the wider literature systematically examining the application of the TPB/TRA to health behaviour[19,20]. The wider behaviour science literature has long called for fewer cross-sectional studies that only examine intention, since it provides a limited understanding of the behaviour[6], further illustrating how the organ donation registration literature has not evolved with contemporary behavioural science.

Among the studies included in the quantitative review that measured behaviour, none measured registration behaviour with the methods we considered to be the least biased (e.g. prospective, objective through checking registry). A small proportion of these studies measured registration behaviour prospectively, but all of them used self-reported registration, and one of them measured 'preparatory behaviours' (e.g discussing with family member) rather than actual registration. The remaining studies measured registration behaviour cross-sectionally either through self-reported past registration behaviour, or objectively through registration immediately following the survey. The methods employed by all studies measuring behaviour introduced bias and highlights a significant opportunity for improved behavioural assessment.

Future Research

To advance our understanding of organ donation registration behaviour, we need to move beyond exclusively focusing on motivational factors related to organ donation. From the findings of this thesis, we have a comprehensive understanding of the motivational barriers/enablers to organ donation registration, as well as the amount of variance in intention explained by certain theories of behaviour. Future research should seek to utilize more contemporary theories of behaviour that include post-intentional processes (e.g. HAPA), to further our understanding of the intention-behaviour gap present in organ donation registration. Furthermore, these studies should aim to measure registration prospectively and objectively (if possible) to ensure validity in behavioral assessment.

In synthesizing of the qualitative literature, we determined that some barriers/enablers are unique to some subgroups, as are some beliefs driving barriers/enablers that are common to all groups. As such, future qualitative research should continue to examine ethnic/religious minority groups that have not previously been researched. However, as mentioned in Chapter 3, there are barriers/enablers specific to organ donation registration that are common to all people that have not yet been, or minimally, examined to date. Therefore, future qualitative research should also aim to recruit general populations to examine registration-specific barriers/enablers.

Future qualitative studies should also aim to contribute to our understanding of the intention-behaviour gap in organ donation registration by examining post-intentional factors, while

incorporating the TDF domains that capture post-intentional factors and have low representation in the existing literature.

Implications for Future Interventions and Policies

Opt-Out Organ Donation Policies

Many point to opt-out organ donation policies as options to increase organ donation registration and deceased organ donation rates overall. Although support for organ donation is high among Canadians[9], support for opt-out organ donation policies is far lower, even as low as 33% in Ontario[21]. Furthermore, the findings from both of our reviews point to specific motivational barriers that opt-out policies would not address, or in some cases, could worsen.

Concerns related to 'mistrust' barriers (e.g. medical mistrust, allocation mistrust) may only be exacerbated by opt-out policies. With every resident consenting to organ donation by default, concerns of medical mistrust would extend beyond just registered donors, thereby likely increasing perceived susceptibility to reduced medical care, among other consequences. Furthermore, some studies from the qualitative review reported several participants' reluctance to register was attributable to concerns over government involvement, which would only increase with opt-out policies.

The consequences of not adequately addressing these concerns and educating the public on opt-out legislation is highlighted by Chile's implementation of opt-out policies to increase deceased organ donation rates. In the first year of implementation, organ donation rates reached a 15-year low, and within 2 years nearly 3 million Chileans opted out[22]. Surveys of the Chilean public revealed that over 70% of people were unaware of the scope of the opt-out policies, with many people also expressing fears related to medical mistrust and organ procurement and allocation mistrust[23]. Therefore, implementation of opt-out organ donation policies must be accompanied by widespread education and awareness campaigns to resolve relevant motivational barriers, and ensure that opt-out policies effectively increase the number of deceased organ donors.

Opt-out organ donation is unlikely to be a feasible means of increasing organ donation rates across Canada at the present time, until the success of opt-out policies that have been enacted in Canada have been observed and have led to significant changes in public perceptions and acceptance towards it. In the interim, our findings can help support provinces who have enacted opt-out policies (e.g. Nova Scotia) to develop successful educational/awareness initiatives by highlighting important barriers to target (e.g. mistrust, knowledge gaps), in addition to informing the development of novel interventions to optimize registration within the current opt-in system.

Current Interventions in Canada

There are a wide range of interventions that have been tested worldwide to increase registration rates, however, relatively few of these interventions have been conducted in Canada. Across 6 different systematic reviews examining interventions to increase registration rates[24-29] only 2 Canadian studies were identified[30,31], highlighting a lack of organ donation registration intervention research being conducted in Canada. Furthermore, both of these studies[30,31] did not fully describe their interventions, and did not use randomized controlled trial methodology to test

the effectiveness of their interventions, suggesting that the limited Canadian evidence may be of low quality.

Nevertheless, provincial organ and tissue donation authorities in Canada routinely implement interventions aiming to increase registration rates. The organ and tissue donation registry in Ontario, the Trillium Gift of Life Network (TGLN), encourages various different community engagement initiatives to increase registration rates. For instance, their Spread the Word initiative encourages Ontario residents/organizations to create organ donation registration drives to promote registration within their community via social media[32]. Additionally, TGLN offers the opportunity for residents to schedule information sessions and set up registration booths at their workplace, school, places of worship, and local shopping malls[32].

These interventions tend to be poorly described, making replication in other jurisdictions a challenge. It is also unclear how such interventions are evaluated, making it challenging to know what specifically leads to increased registration rates. Without clearly evaluating and clarifying each specific intervention component, our ability to develop a cumulative knowledge base from which to enhance existing interventions and develop novel ones is hindered. There is therefore a need for transparency in intervention description, and improved evaluation of interventions aimed at increasing organ donation registration rates in Canada.

The recent RegisterNow-1 intervention by Li et al.[33] is an example of transparency and rigorous design for other organ donation registration intervention studies. In addition to measuring registration behaviour prospectively and objectively (by confirming registration in registry), this trial conducted TDF-based interviews to inform which barriers/enablers to target in intervention development[33]. Furthermore, the trial was clear about which behaviour change techniques were used to increase registration and how they were operationalized. Despite finding no effect on registration[33], this trial has helped contribute to a cumulative evidence, and makes it clear what future steps can be taken to address its limitations, and advance research in this field.

Scalable Settings for Intervention

Our research also points to the potential of various scalable settings in which to implement interventions, especially to assist in tailoring interventions to ethnic/religious minority groups. Many participants from the qualitative review highlighted the importance of engaging religious groups and authorities in order to promote organ donation registration. With increased communication and clarification about organ donation with religious authorities/leaders, participants described that they would feel more capable to register. This highlights the potential for places of worship to be engaged as a scalable setting for interventions. As mentioned previously, some regional organ donation and transplantation authorities offer opportunities for information sessions to be held in places of worship, but they do not specify how they are tailored to specific religions, or the barriers/enablers they address, suggesting improved opportunities for testing and evaluating such interventions in Canada.

A small number of RCTs have shown that church-based interventions can be effective at increasing self-reported registration in African American populations in the US[34,35]. However, there is limited research testing the effectiveness interventions delivered in other places of

worship such as mosques, despite recent calls for such interventions[36]. The barriers/enablers, underlying beliefs, and suggested actions identified in our qualitative review could also be used to inform how to both tailor interventions for ethnic/religious minority populations and engage the religious community prior to implementation.

Motivational-Volitional Interventions

Hyde & White's RCT[18] highlighted the potential of volitional interventions (e.g. action/coping planning) being used in tandem with motivational interventions to increase organ donation registration rates. Although this study was published in 2013, to our knowledge, there have been no other organ donation registration interventions incorporating volitional interventions (as of 2020), highlighting the need for more motivational-volitional intervention research to increase registration.

The Role of Knowledge

While knowledge is certainly necessary for behaviour change, it may not be sufficient to change behaviour. Across health behaviours, there is a general consensus that knowledge is important in behaviour change, but the provision of knowledge alone does not ensure behaviour change[37,38]. For example, in healthy eating behaviour change, individuals are often knowledgeable about what types of food are healthy and unhealthy, but cite various other factors that prevent them from engaging in health eating habits[39,40]. This is corroborated by findings from our quantitative review where constructs that were captured by the *knowledge* domain, including knowledge (Organ Donation Model) and clarity (Triangle Model of Responsibility), had the smallest correlations with registration behaviour among constructs tested within their respective theories.

Nevertheless, there are clear knowledge gaps that affect organ donation registration and should be addressed as part of a broader overall strategy. Some of these knowledge gaps were elucidated in our qualitative review. For example, our review identified many studies reporting participants who were reluctant to register due to uncertainty over religious permissibility, but the vast majority of major religions either support or encourage organ donation[41]. Our findings could serve to inform which specific knowledge gaps should be targeted in educational components within comprehensive interventions.

Contribution of Thesis to Future Intervention Development

The need for effective interventions to increase organ donation registration in Canada is clear, however, there are few intervention studies that have been conducted in Canada. Many of the Canadian-based interventions that have been conducted are poorly described, poorly evaluated, and may be of low quality.

Our research contributes to intervention development by identifying the key behaviour theory-based correlates of registration behaviour and intention, as well as which TDF domains they map to. This can serve to inform which strategies and behaviour change techniques to use in developing interventions. The comprehensive list of barriers/enablers to organ donation registration identified in the qualitative review can serve to inform how to operationalize each construct. For example, an intervention using the PBC construct or *beliefs about capabilities*

domain can use the 'do not need organs when dead' enabler, or target the 'perceived ineligibility' barrier to operationalize the construct/domain. Furthermore, our findings also systematically identified which barriers/enablers are relevant to certain subgroups (e.g. ethnic/religious minorities, student-aged populations), and can be used to inform how to tailor interventions to those populations. Therefore, our findings can inform a diverse range of future interventions to increase organ donation registration rates.

In addition to directly informing which constructs to address and how to operationalize these constructs within intervention, our findings support, encourage, and facilitate the use of behaviour theory in developing interventions to increase organ donation registration. Organ donation registration literature may not have engaged in contemporary behavioural science literature, but our reviews provide an accessible means through which researchers can begin to use behaviour theories to develop novel interventions, or enhance existing ones. As such, our findings also facilitate better clarification of components within interventions (through the use of theory) and the formation of cumulative evidence within this field, as constructs and intervention components are tested and evaluated in the future.

Strengths and Limitations

A strength of this thesis is the application of a wide range of behaviour theories and behavioural science to organ donation registration. Many reviews focus on a single theory, and determine how much variance that theory can explain in a single, or, multiple behaviours, thereby keeping the focus on the theory itself, rather than the behaviours. Systematically identifying theories that have been applied to organ donation registration, and systematically mapping qualitatively-reported barriers/enablers to the TDF confers several benefits to our research. First, it allowed us to identify a vast array of theory-based factors associated with registration intention and to assist in intervention development. It also allowed us to bring theoretical coherence to the disparate qualitative literature. Finally, it allowed us to identify several key research gaps in terms of behaviour theory application in this literature, and opportunities for testing new theories or enhancing existing ones.

Despite identifying all theories that have been applied to organ donation registration, we are limited by the small number of studies that use theories other than the TPB/TRA. We have discussed the potential shortcomings in using the TPB/TRA to explain variance in behaviour, but we have limited evidence of other theories that have been tested in this literature. Similarly, although our primary outcome of interest was organ donation registration behaviour, a considerable amount of studies in both reviews primarily examined intention to donate and intention to register. While we may have been limited in our ability to investigate the factors associated with organ donation registration behaviour, especially those beyond the formation of motivation, both of these limitations allowed us to highlight a significant research gap that this literature has largely neglected.

Arguably the greatest strength of this research is the combination of qualitative and quantitative methodologies to synthesize all available data to understand organ donation registration. In Chapter 2, we identified the associations between theoretical constructs and registration

behaviour/intention among typically general populations to inform prioritization of factors to target in interventions. Meanwhile, in Chapter 3, the factors influencing registration were contextualized within the lived experience of participants. We gained insight into how it is difficult to apply general measurements of theoretical constructs to all participants, as there exist many interindividual differences in societal, personal, cultural, and environmental factors affecting organ donation registration. This insight was obtained from also conducting qualitative analyses to support and further contextualize the findings from the quantitative review.

Conclusion

Acting as a foundation for promoting a behaviour theory-based understanding of organ donation registration to build a cumulative evidence base, this thesis has highlighted priorities for future research and will contribute to developing novel, fit-for-purpose interventions to increase registration rates worldwide. Our work suggests that theories of behaviour and their related constructs are associated with organ donation registration, and explain variance in registration behaviour and motivation. Our findings also highlight a substantial opportunity to test new theories of behaviour, and explore factors beyond the motivation to register. Our research has also created the most comprehensive compilation of barriers/enablers to organ donation registration to date. With further research into the intention-behaviour gap in organ donation registration, our findings could inform development of motivational components of motivational-volitional interventions to support increased organ donation registration.

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